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UNIVERSITY OF SOUTHAMPTON

FACULTY OF LAW, ARTS & SOCIAL SCIENCES

School of Education

**Biography from Childhood to Adulthood:
Mirroring as an Educative and Therapeutic Strategy in Caring for Carers**

by

Catherine M Gardner

Thesis for the degree of Doctor of Philosophy

October 2010

"... all things noble are as difficult as they are rare."

Baruch de Spinoza 1632-77

UNIVERSITY OF SOUTHAMPTON

ABSTRACT

FACULTY OF LAW, ARTS & SOCIAL SCIENCES

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Doctor of Philosophy

**BIOGRAPHY FROM CHILDHOOD TO ADULthood:
MIRRORING AS AN EDUCATIVE AND THERAPEUTIC STRATEGY IN
CARING FOR CARERS**

by Catherine May Gardner

The Assert programme (Gardner 2006) is A Semi-Structured Empowering Reflective Therapy for unpaid carers. It is based on Butler's (1963; 1974) life review therapy and incorporates Pennebaker's (1990) narrative writing paradigm. This single-subject study (Sinclair 1962; MacIntyre 1985; Erben 2000) sought to determine whether Assert was safe and effective in an individual setting and whether mirroring (Winnicott 1971) was effective as an educative and therapeutic strategy for a carer on a one-to-one basis.

Underpinned by humanistic, person-centred principles (Rogers 1951; 1961), fortnightly life review sessions alternated with opportunities for narrative writing during the six-month programme. 'John', the participant, aimed to reduce his stress and 'put the past in the past'. An additional aim of the study was to ascertain whether engaging in the Assert life review process improved John's childhood autobiographical memory recall.

Qualitative data analysis employed *verstehen* hermeneutics (Dilthey 1976) with grounded theory (Glaser and Strauss 1967; Patton 2002) and biographical research methods (Erben 1998). The most noticeable outcome was a positive shift in John's biographical reflective focus indicating increased psychological congruence together with some startling improvements in his sense of selfhood. Conversation analysis (Sacks, *et al.* 1974) also revealed a change in John's interaction style. John achieved his personal aims but retrieved no 'new' memories; however his narrative assumed greater coherence.

It was concluded that the Assert programme was safe and effective and that mirroring was effective as an educative and therapeutic strategy on a one-to-one basis with a carer. To compare the programme's long-term effectiveness with other conventional therapies a randomised control trial is recommended with pre- and post-programme brain-scanning of participants to detect any change in neural activity. Potential applications for the Assert programme are more wide-ranging than originally envisaged, including the amelioration of burnout in what is termed in this study as the 'unpaid carer's syndrome'.

**Biography from Childhood to Adulthood:
Mirroring as an Educative and Therapeutic Strategy in Caring for Carers**

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Biography from Childhood to Adulthood: Mirroring as an Educative and Therapeutic Strategy in Caring for Carers

Chapter 1

Introduction and Context

Introduction

Those looking after the frail, sick and disabled can experience inordinate amounts of stress according to findings from a small local survey of unpaid carers conducted over ten years ago (Gardner 2002). Many other surveys and studies carried out since have confirmed this but what published research tends not to highlight and which this small survey did, is the reluctance carers have of speaking openly to officialdom about their concerns for fear of retribution. In a recent survey of 1,941 unpaid carers for example, seventy-four per cent (1,436) felt that they had reached breaking point (Carers UK, *et al.* 2009) and forty-one per cent (796) stated that it was frustration with bureaucracy (not fear) that had pushed them to it, often because of the complex and lengthy procedures for welfare benefits, health care and social services. 'Having someone to talk to' came second to practical support in making a difference for them according to the survey but to improve the 'lot' of Britain's six million unpaid carers a radical change in social policy is required (Carers UK, *et al.* 2009; Carers UK 2004; Carers UK 2007). Meanwhile people's increasing longevity, diminishing affordable domiciliary support services and the continuing reduction in residential care placements (CareAware 2005) increases the demand for unpaid carers and places ever-greater demands upon them. As a consequence, the voice of Britain's so-called "Secret Service" (Carers UK, *et al.* 2009) continues to be largely unheard and their needs unmet.

Advocare – Caring for Carers is a small, independent charity run by unpaid carers and former carers of the frail, sick and disabled to support fellow-unpaid carers. People generally contact Advocare or are referred when they are stressed due to the demands of their caregiving role, or distressed by the standard of care those for whom they are responsible are receiving from others. In enabling them to voice their concerns without fear of retribution from officialdom Advocare seeks to empower unpaid carers to champion their own rights and the rights of those for whom they advocate. In order to strengthen this endeavour, I developed the Assert programme, A Semi-Structured Empowering Reflective Therapy, drawing

on my own insights as a long-term unpaid carer, my counselling skills and psychotherapy training (Gardner 2006). Originally devised for groupwork, the programme is based on Butler's (1963; 1974) life review therapy and incorporates Pennebaker's (1990) narrative writing paradigm to provide individuals with an opportunity for private reflection. Outcomes for the four participants in the Assert development group included positive changes in outlook, greater sense of self-fulfilment, improved sense of selfhood and an increased sense of empowerment, Advocare's primary aim for carers (Gardner 2006). These encouraging results prompted this research.

Research Aims

The aim of this research was to determine whether the Assert programme was safe and effective in an individual setting, and whether mirroring was effective as an educative and therapeutic strategy for 'John', a middle-aged former carer. John's personal aims were 'to discover a way of being more relaxed' and 'to put the past in the past'. An additional aim of this study was to ascertain whether John's retrieval of his autobiographical memories of childhood improved.

The Structure of Thesis

Embedded within this thesis is a literature review which conveys the justification for this research by exposing some of the gaps in service provision for unpaid carers, vividly illustrating the manner in which officialdom frequently pays lip-service to their needs and highlighting how institutional systems and inflexible bureaucratic processes prevent their altruistically-motivated concerns from being actively addressed (Foucault 1980). 'John's Story' at the end of this opening chapter epitomises the 'lot' of the long-term unpaid carer. John's endeavour to safeguard his late father's wellbeing provides insight into some of the challenges he encountered and overcame as the sole advocate of a vulnerable person.

In chapter 2, 'The Ties and Tolls of Caring', a microcosm of the carer/advocate role is portrayed in 'Cameo of a Carer: Dave's Story'. Written as ethnographic fiction which provides a voice for silenced groups (Sparkes 1997), Dave's acute "nightmare" experience before and after his foster-father died strengthens the rationale for empowering unpaid carers. 'In Retrospect' contrasts Dave's situation with that of John and highlights some of the commonalities in their experience.

Part II entitled 'The Unpaid Carer's Syndrome' considers the need for reform and the case of 'Jenny', who was her mother's sole advocate, illustrates how the voice of unpaid carers is silenced. After exploring some of the motivations to care, some of the stress and distress, often the hidden toll of caregiving, is outlined, aided by eight vignettes of casework examples. Along with John's and Dave's stories, Jenny's case and these vignettes lend credence to the existence of the unpaid carer's syndrome. That professional care workers suffer from burnout (Maslach 2001) is generally acknowledged but similar suffering endured by unpaid carers is not recognised in the same way. What is generally recognised is that looking after someone with dementia takes a heavy toll on their carer (Briggs and Askham 1999; Brashares and Catanzaro 1994). Conventional therapeutic support of long-lasting benefit is not easily accessed by carers (Dawson 2004) and it can take a heavy toll on the therapist (John 2000; Figley 2002; Pennebaker 1990) for whom clinical supervision is expensive. Life review on the other hand is a natural healing process as defined by Butler (1963; 1974) who pioneered employing this phenomenon therapeutically. As most of the 'work' in life review and narrative writing therapy is done by the individual's personality (Butler 1974; Pennebaker 1990) the toll on the Assert programme facilitator is minimal and fees for clinical supervision are low making it a more accessible, cost-effective therapy.

As chapter 3, 'Methodology and Methods', describes, Butler's (1963; 1974) methodological principles form the framework for the Assert programme which is underpinned by humanistic therapeutic principles (Rogers 1951; 1961) and has semi-structured protocols that are sufficiently flexible to accommodate the needs of unpaid carers. This chapter also outlines Pennebaker's (1990) narrative writing paradigm, the effectiveness of which has been validated not only by his own extensive research (Pennebaker 1990; 1995; 1997; 2004), but also by that of others, including psychiatrists Baikie and Wilhelm (2005) whose overview of the paradigm suggests how expressive writing can be used as a therapeutic tool for survivors of trauma, and Gidron, *et al.* (2002), upon whose Guided Disclosure Protocol the Assert Narrative Writing Opportunity protocol (Gardner 2006) is based. These two different but compatible methodologies I combined into one, potentially unique, iterative model, namely the Assert programme, to provide individuals with an opportunity to gently reminisce and then to safely reflect upon different stages and various aspects of their life. Protocols for the Assert life

review process broadly align with Erikson's (1950, p222) "Eight Ages of Man" and were devised to enable participants to share their fears, anxieties and pain with others in a group, and to confront painful or disturbing feelings or traumatic "epiphanies" (Denzin 1989, p70) in private, if and when they feel it appropriate, with the knowledge and confidence that in either setting they would be supported. Participants in the Assert development group (Gardner 2006) reported that any painful memories or disturbing emotions which surfaced during their semi-structured life review process had been dealt with safely and effectively; they were able to forget them or let them go, and move beyond the experience (Butler 1974; Pennebaker 1990; Gardner 2006).

The same protocols devised for the Assert development group (Gardner 2006) were deemed suitable for John's individual life review process, which was conducted in a safe, relaxed setting conducive to self-disclosure. His Assert programme, which forms the basis for this single-subject study, comprised sixteen Life Review Sessions (where appropriate these are abbreviated to 'LRS'), the majority of which were tape-recorded, and fourteen Narrative Writing Opportunities (these are abbreviated where appropriate to 'NWO') scheduled for the non-session weeks. To contextualise his caregiving role John was asked to complete a questionnaire during the Introductory Session. At Mid-term, post-programme and Follow-up four months later, John made an appraisal of his life review process. Qualitative data analysis employed *verstehen* hermeneutics (Dilthey 1976), comparative content and comparative thematic analysis (Patton 2002), and grounded theory (Glaser and Strauss 1967), with Erben's (1998) biographical research methods providing a temporal dimension. Using a simple measuring tool based on the Likert scale 1-5, with 5 indicating most satisfaction, John rated his life satisfaction before starting, at intervals during, and on completing, his Assert programme.

The findings from this study are described in chapter 4, 'Findings, Interpretation and Discussion' and in part I, 'Results', it may be seen that almost all of John's low satisfaction ratings for his chosen aspects of life increased by the end of his programme when he rated his quality of life as completely satisfactory. This and other outcomes are consistent with Butler's (1974) 'benchmarks', key indicators selected from desired goals and recommendations for his group and individual life review psychotherapies (Gardner 2006). By the end of his Assert programme John

saw himself less as a victim of circumstance and felt less bitter about giving up his career and losing financial status to care for his father. He valued himself more not only as a carer, but also as a person, as a father, and most important of all, as a son. For the first time he started planning for his future which, after gaining new insight into his style of attachment, he began to nurture. Although he retrieved no 'new' childhood autobiographical memories, John reported that those he did have had been "sharpened up" and he could now see where he "sits in things".

An interesting phenomenon came to light during the content analysis when (as researcher) I noticed that John began to mirror not only the words of my responses as facilitator - this term is used interchangeably with researcher - but also my tone, meaning and emotion. Though not tracked in the Assert development group (Gardner 2006), the camaraderie and emotional resonance experienced at various times by its members, the group mirroring reaction phenomenon (Brown and Pedder 1979), appeared to be linked to the positive shift in their biographical reflective focus which was indicative of their increased psychological congruence over time. As both facilitator and researcher I had a 'hunch' that the change in John's interaction style might be significant and decided to listen again to the audio tape recordings of life review sessions in which he reflected at length on his Caring Phase, employing the principles of conversation analysis (Sacks, *et al.* 1974) and paying particular attention to what I termed his 'mirroring responses'.

In a disquisition on the concept of mirroring from the Winnicottian (Winnicott 1971) perspective in part II of chapter 4, entitled 'No Reflection on Erikson', John's interactions during his life review sessions are paralleled with mother-infant¹ attunement and turn-taking (Ainsworth, *et al.* 1971; Trevarthen 1977; Stern 1984). Drawing on a comparative thematic interpretation of the data (Patton 2002), John's epiphanies (Denzin 1989) underpin the main theme of 'Starting Again ... Significant Ends and Significant Beginnings'. The possible consequences for an individual for whom the first four of Erikson's (1950, p222) "Eight Ages of Man" may have been lost are explored in 'The Nurture of Nature', in terms of having no "lived experience" (van Manen 1990, p36) of their early psychosocial development. Lastly, there are some 'Further Reflections'.

¹ Throughout this thesis 'mother', 'mother-figure' and 'parent' are referred to as 'she' and 'infant' and 'child' as 'he' in keeping with the original texts.

Part III of chapter 4, 'In Absence of Oedipus' discusses 'John's "Completely Missing Phase"' and the possible impact that missing autobiographical memories (Fonagy 2003) and poor prospective memory (Young and Saver 2001; Fleming, *et al.* 2005) may have on an individual's coherent narrative and identity (Brockmeier 1997). The main interpretive theme of 'Finding the Lost Child' focuses on some of the effects John's accident may have had on his emotional and psychological self, and discusses his change in attitude towards his relationship with his late father after completing the Assert programme, testimony of which is his 'Letter to Dad'. Taken from John's last life review session is 'The Penknife Scenario', which is interpreted as a transference epiphany (Denzin 1989) and illustrates the benefit of my being both facilitator and researcher. Lastly, in "'A Genius or An Idiot?": Knowing How To Be or Not To Be', John's sense of selfhood is explored and the process of formulating his Outlook/Inlook Action Plan for Change is described.

The findings from this study show that John was able to "put the past in the past" as he had hoped and move beyond his experience towards feeling more comfortable with and within himself. Besides ameliorating some of John's suffering (Butler 1974) the Assert programme improved his sense of selfhood and 'sharpened up' his existing memories. As a therapeutic strategy, mirroring was therefore effective for John and may have been instrumental in 're-educating' him in aspects of his social interaction - including mirroring. This being the case, the training of future Assert facilitators is given consideration in 'Conclusions and Recommendations' in chapter 5, which begins by examining the methodological strengths and weaknesses of the study followed by an appraisal of John's life review process. Some of the issues this study raises that are pertinent to caring are then considered including the unpaid carer's syndrome. Potential applications for the Assert programme are far wider than originally envisaged and include the amelioration or prevention of burnout in order to safeguard the physical and mental wellbeing of both paid and unpaid carers. It is also suggested that the Assert programme could be beneficial to people with memory loss including those suffering post traumatic stress disorder and those with social interaction problems including quasi-autism. Finally, recommendations are made for further research in order to ascertain the Assert programme's effectiveness compared with that of conventional therapies.

To set the scene for 'John's Story', a brief overview is provided of some of the less visible aspects of the unpaid caregiver's role.

The Hidden Cost of Care

The true financial cost of disability is hidden, according to Evandrou and Glaser (2003). Hidden costs include having to pay for extra heating, cleaning, gardening, odd jobs, extra bedding, extra travelling and buying convenience food because there is no time or transport for excursions to outlying supermarkets; indeed some older carers have to cut back on food to make ends meet (Carers UK 2004). Nolan, *et al.* (1994) identified three factors that are crucial to maintaining the quality of life of the carer and the person they care for, namely: adequate financial resources, reliable domestic support and regular respite breaks. Carers are still struggling in all three areas despite a recent YouGov survey (Carers UK, *et al.* 2009) showing that of the 2,000 participants, seventy-six per cent (1,520) felt the Carers Allowance (currently £53.10, the lowest benefit of its kind) is unreasonable. Other research (Carers UK 2004; 2007) shows that resources for domiciliary support are ever-diminishing, and fewer services to help older people maintain their independence are routinely available, or remain within their financial reach (Carers UK 2007). The presence (or not) of reliable, appropriate practical support, not just quantity but quality and flexibility, affects carers' physical and mental health according to Carers UK (2004).

The more care a person provides, the greater the cost to their own health. For those providing over fifty hours a week the picture is particularly gloomy since according to Carers UK (2004; 2007) social exclusion is known to herald mental illness and poverty. They give no figures for those living with people with dementia who provide care twenty-four hours a day, seven days per week (168 hours a week), but point out that despite a positive obligation on the UK under the Human Rights Act to address the causes of this social exclusion:

... no meaningful and consistently applied measures seem to have been put in place to compel local authorities and health authorities to provide services and support that could minimise the impact of caring on social exclusion ... and (in later life) consequent poverty (Carers UK 2007, p23).

Despite the fact that carers save the UK approximately £87 billion a year (The Princess Royal Trust for Carers 2010), as Neuberger (2005) observes, the

so-called 'experts' who inform government policy-makers do not deem caregiving to be an economic activity. Indeed, by ascribing a low priority to caring (Tier 3) the Government allows money allocated for improving the carer's 'lot' to be spent elsewhere. Although Primary Care Trusts (PCTs) were allocated £50 million in 2009 for implementing the Government's Carers' Strategy, none of the funding was used for this purpose and The Princess Royal Trust for Carers (2010) anticipate PCTs will do the same with their £100 million allocation in 2010.

With utilitarian cost and benefit principles driving government policy-making which "countenances sacrificing the good of one or a few for the many" (Ross 2002, p10), the social contract is being broken as the state and the authority of the law lets vulnerable people down according to Neuberger (2005) who, whilst recognising that support is being withheld from family carers, fails to mention their suffering. Similarly, in an article which stemmed from a paper on abuse, Forbat (2002) suggests that much of the stress in caregiving may be attributed to the emotions involved in carer/caree relationships. Whilst Forbat's study is insightful, it does not consider carer stress adequately in terms of the care burden² and specifically the carer's level of responsibility, the presence or lack of social capital in the form of reliable practical and emotional support, and the degree of social exclusion and poverty experienced. Had it done so, some of the hidden emotional cost of caring would have been made visible. Having said this, Forbat (2002) acknowledges that whilst UK policy documents place carers centre stage, it is a barely disguised bid to ensure the burden of care remains with the family, thereby preventing a drain on NHS and social services resources. People with dementia, for example, are deemed by the NHS to need primarily social care, and the responsibility for providing this falls mainly on the family. Currently there are 821,884 people suffering from dementia in the UK, which is more than previously estimated, rising to over a million by 2025 (Alzheimer's Research Trust 2010)³.

² Care burden is conceptualised here according to the Burden Interview (Zarit, *et al.* 1980, cited in Brashares and Catanzaro 1994). It is described by Wagner, *et al.* (1997) as a 22-item inventory that assesses caregivers' subjective reports of the negative impact of caregiving on their emotional and physical health, social life and financial status.

³ Alzheimer's disease and other forms of dementia have a much lower priority for research funding than cancer and heart disease, the burden of care for which falls mainly on the NHS, not on the family (Alzheimer's Research Trust 2010). Given every person suffering from dementia has an unpaid carer at some stage, the health of not one but two million people could be affected by the condition in 2025.

As 'John's Story' will show, he was a resilient carer; he needed to be in the face of an increasingly fragmenting society where family values are being destroyed by a modern welfare state that is "actively discouraging private efforts to help others" (Bell 2005, p14). With its "universalising logic of rights and entitlements" the state is eroding altruism and dissipating social ties by "rendering superfluous obligations to communities" and "providing incentives that encourage the break-up of families" (Bell 2005, p14). John felt under obligation to prevent his late father from entering residential care. His story is drawn from his Assert life review process: quotations from his life review sessions end with a 'J' reference and extracts from his narrative writing texts end with an 'NWO' reference.

John's Story

John can remember the moment his life changed one fateful January morning in 19xx. He recalled in his narrative writing that at around 8.00 a.m. as he was alighting from the train after his usual two-hour journey commuting to London:

... I heard my name being announced over the public address system. I was being told to go to the Information Office. Naturally I was worried about this and imagined something had happened to my mother who had always suffered with bad health. Imagine my shock to be told that my father had been taken into hospital and would I go to St Mary's Hospital as soon as possible (NWO/11/1).

On arriving at St Mary's in the south east of England, John found his mother in "an awful state", having discovered his father collapsed in the bathroom first thing that morning. After calling an ambulance she had tried to contact John but he had already left for the office. It transpired that John's seventy-five year old father had suffered a major stroke which had rendered him virtually helpless. His right side had been affected; he was unable to speak or swallow and could not recognise his family. He was also left partially sighted. Reflecting on the situation John recalled:

We were told not to expect too much ... [the prognosis was six months]. We were also told that he was probably never going to get home. This made coming to long term plans very painful for both myself and my mother. More so for my mother, of course (NWO/11/2).

John visited the hospital almost daily for the next couple of months during which time his father made painfully slow but steady progress. Eventually he was transferred to a stroke rehabilitation unit nearer home to help him adjust to having

become paralysed and being confined to a wheelchair. It made visiting easier for John's mother but it was still a long way for John to travel to see his father and as the only child it was difficult for him to support both parents:

My father was also in a very low state, although he was less aware of the long-term situation. Some time later, when he had regained the ability to write, he slipped me a sheet of paper on which he had written out the 'order of service' which he wanted for his funeral (NWO/11/3).

On visiting his father one day, John found he had been left in a sun-drenched conservatory for four hours, unable to summon help to prevent the sun burning the top of his head and side of his face. Until that time John had assumed the best was being done for his father; he then became aware of the need to be vigilant in order to protect him. Thereafter, whenever his father was in the care of others John questioned the beneficence of the "clinical gaze" (Foucault 1991), a mechanism of power that was purposefully developed by early physicians to dehumanise the patient in the face of their 'expert' knowledge when exposing a hidden truth (Foucault 1991; Pryce, undated). After six months' rehabilitation John's father was discharged. John explained:

Both he and my mother had many times said that they didn't want him to go into a home and I decided to retire from work to assist my mother as his full time carer (NWO/11/4).

"Lambs to the Slaughter"

It was in good faith and not without some optimism that John and his then partner, Margaret, found a suitable property large enough for two families. John made all the necessary adaptations for his father's dedicated room, including installing a toilet, hand basin, bath and fitting an electric overhead hoist. Once the adaptations were completed, John made preparation for his father's homecoming, which included advising the local social services department by letter, fax and telephone three weeks before the date his father was due to be discharged from hospital. John recalled:

Little did we know! Like lambs to the slaughter! Talk about going into something with your eyes closed! (NWO/11/9). After a couple of days we were getting into a very difficult state trying to cope ... and got in touch with the local social services office. They had no records of us we were told. No letters. No records of 'phone messages, nothing! It took a couple of weeks to sort out a care package (NWO/11/10).

Hospital staff had given John only the most basic information on how to care for his father, a newly-disabled elderly person unable to do things for himself:

One of the things you don't know when you decide to become a carer is ... (small sigh) ... that you don't know what you don't know. ... You don't know what you're going to be up against. You don't know what you're going to be facing. ... there was my father, he couldn't have got up out of a chair on his own when we first started caring for him. And lifted to his feet he could just about manage to stand up on one leg. Because he only had one leg that was working. We had absolutely no preparation whatsoever. The only thing I'd been shown by ... the OT [Occupational Therapist] who was there was if he slid down in his chair, in his wheelchair, how to get hold of him from behind and just lift him and place his bottom back into the right sort of place in the chair. ... Now, he couldn't go to the toilet on his own, ... blow his nose, ... get himself a drink, ... pick up a glass ... maybe for three or four months if his dinner was cut up he could actually sit at the table in his wheelchair and have a meal just by picking up food on a fork but you know you're totally unprepared ... Nobody actually tells you the truth about how difficult it's going to be and before you start caring you don't get in touch with any caring organisations because you either don't know they exist – you don't know that you'll ever need them – and we were told by those people in positions of authority, 'oh, you'll have no problems at all, you can call on people to do this and people to do that' ... (J11(b)/11/5).

As well as taking on his father's physical care, John took on most of the household chores and prepared three meals a day, including for Margaret who worked full-time from home. He described himself as being "very hard-up" and found caring arduous as it involved his being 'on duty' for an average of 156 hours a week. For John "doing the physical bit" was the easier option. His mother did "the emotional side" which he would have found difficult. He recalled:

We had a baby alarm intercom system fitted, but of course sometimes my father didn't realise that he would call out for something every ten minutes or so. One night there were 23 calls between midnight and 7.00 am. Hence my exhaustion (NWO/11/10). You don't have a life that anybody else would consider to be normal and you come to appreciate ... sitting out in the garden doing nothing for half an hour (J11(b)/8/1).

The "drudge was made easier" for John when his father went into the local respite hospital:

He spent six weeks at home and two weeks in hospital ... without that it would have been worse (J11(b)/6/3) ... though things did go wrong he was generally reasonably well cared for so I used to get time off ... there would probably be three or four days to wind down and acknowledge the fact that there was nothing to do, though I couldn't relax completely (NWO/11/11) ... It's the switching off which you can't normally do ... but that didn't mean that you stopped being concerned because you had to keep an eye on things that went on ... (J11(b)/8/1).

John recalled that he had to be “completely ready” for whatever problems were going to be presented by virtue of what might have gone wrong whilst his father was in hospital:

...you might find he went into hospital without any pressure sores and comes out with pressure sores all over his back which means he can't sit up in bed for two months, which means a completely different regime would apply for him. Baths become additional problems, extra pad on hoist seat and so on and so on. Everything becomes that much more difficult. Hospital couldn't care less because they've got rid of him. The next time he goes in he would just have been cured (NWO/11/11).

As John explained: “You get to screaming pitch eventually” (J1/10/1). “You just get used to being normal” during the respite period and “then went back to being dehumanised again” (J1/10/7).

“For ‘Care in the Community’ read ‘Care *by* the Community’”

John reflected that he had found it “very easy to get angry, not with my father or my mother or with immediate family but with the system” (J13/15/4).

I felt there were lots of people getting lots of money and they achieved nothing. Achieving far less than I achieved with no money and no training ... Professional background and so on ... I really, honestly felt I was far more capable of deciding what was better for my father than ... people who specialise in older people ... (J13/15/6). I distanced myself from listening to people who I thought were idiots. One or two [his GP and consultant] who actually came and did things for him were excellent. They really were superb, dedicated ... one consultant ... actually came to my father's bedside and treated him for hours and hours and hours trying to do the best he could rather than my father having to be admitted to hospital to be treated (J13/15/10).

Some of the disputes with social services and hospitals drained him; they were “very difficult, complicated and time-consuming”.

There were lots of different battles ... Once a month something happened, something went wrong. Once I knew the right people to go to or the right approach to take ... you learn which is the right way to do it. And the right way, I found, was to get somebody senior, fairly near the beginning to say: ‘No matter what you say to us, your father will receive excellent care and it won't affect the care your father receives’, as a consultant said to me, probably without thinking of the implications. ...I used that as the opening phrase in every subsequent argument I had, particularly with [health care workers], to improve my father's care: ‘Here are my current criticisms, do something about it’ (J1/2/5).

John remembered finding “a damned great pressure sore” at the bottom of his father's spine:

A district nurse looked at him after he came out of hospital once and couldn't believe the pressure sore that was on his backside. And her first words were: 'Oh my God, what have they done to him this time?' (J13/17/9).

John requested a hospital case conference and expected the district nurse to support the argument for improving his father's care but in front of her fellow-healthcare workers she denied having been shocked by the pressure sore and John was viewed as 'misrepresenting the truth' by those present at the meeting. He realised he had to fight this battle alone and "fight dirty". With his father's permission John took 'before' and 'after' photographs and got the district nurse to sign a brief witness statement to verify the absence of pressure sores prior to each respite period and, if necessary, the presence of them when he came home. John later presented the photographs and statements to his father's GP and consultant and eventually he succeeded in getting the standard of respite care improved.

John's partner Margaret found the strain too much and left him "to go her own way" after the second year. Almost four years into his caregiving role there was a radical change in Government policy with regard to funding care at home. John observed cynically "You can't be forced into doing it" and envisaged people "dying pretty quickly and in discomfort and illness". He believed that "officialdom relies on the fact that family members are not usually as callous as social services" and that the phrase: 'care in the community' is a misnomer because it implies care is already there. "It should have been called 'care *by* the community'" he suggested (J11(b)/18/9).

John recalled that following "a fiasco of a review" carried out by social services:

... ninety per cent of my father's care package was cancelled. I was told by the care manager that I would have to accept the situation and that there was nothing I could do about it. I refused to accept the fact that he was suddenly not entitled to social services care and started to fight the system. (NWO/11/13). I wrote and telephoned various help organisations and my MP, all to no avail. Eventually I went to [the media]. After unsuccessfully trying to contact the local head of social services ... he 'phoned me following a broadcast and on the 'phone we eventually managed to bargain a mutually acceptable care programme. The power of the media! (NWO/11/14) I didn't manage to get the whole of my father's care package reinstated, but at least the night-sitting service was put back into place. This meant that my mother and I were at least still able to get some sleep (NWO/11/15). ... if we hadn't got night sitting and I'd done it we would have coped somehow but his life would have been worse for it (J11(b)/1/6).

John's father deteriorated rapidly over the next few months and he died of pneumonia in the following spring. By this time John had diligently cared for his father for almost four and a half years. He recalled:

My father died on a Sunday in hospital. On the Monday I had lots of things to do, register his death, etc, etc. But I also went to the Job Centre ... to inform them that I was no longer a carer. I spent half an hour talking to a young girl from the office ... we went through all the paperwork and then I said to her: 'Well, when do I get some unemployment money?' And she said: 'It takes about six to eight weeks.' So my question, obviously, was: 'What do I do in the meantime? Do I starve?' She said: 'Well, can't you live off any savings from the job you've just done?' And I said: 'Have you been listening to a word I've said to you? What is the job I've just done?' And she couldn't remember the fact that minutes before I had told her that I'd been living on [Carers Allowance] for the previous four years caring for my dying father (J11(b)/14/5).

By now in his mid-fifties, John described how difficult it had been for him having to find employment and how he "still felt like a carer":

It takes some doing because it's another complete lifestyle change. Though caring is quite difficult obviously at times (J12/1/5) ... there wasn't the same sort of regimented structure because every day could be totally different ... it wasn't the get up at six thirty, shower and shave, get on the train, travel to London, two hours on the train etc. (J12/2/1). The first thing is you realise you don't have to care any more and the second thing is you think; 'But what am I going to do about me?' (J12/3/3).

John had become a carer in the belief that his father had not long to live and that he would be making the time he had left more bearable for both his parents. He had not planned on being in a caregiving role for the next four years and in hindsight wondered if he had done 'the right thing' in prolonging his father's life. With regard to himself, in giving up his career as a relatively high-earner in middle management, not only did he lose his five-figure income but also the five-figure pension that would have provided him with a comfortable retirement. John was nevertheless philosophical about his four plus years of caring:

... either caring can destroy you completely so that you can't face the future or it can make you stronger so that at least you know you can cope with the worst things that life can throw at you (J12/11/8). ... you're emotionally drained but at least you know what you've got ahead. With caring you didn't even know what was going to happen in ten minutes' time, let alone the next day, or the following week or a year in the future (J12/10/10).

John's attitude towards the system remained cynical and he continued to feel angry about the "careless approach" of some of the well-paid health and social care workers:

The excuses put forward by the well-heeled owners of some care agencies had to be heard to be believed. Bad punctuality - or not bothering to turn up - was an ongoing problem with care agency staff. Not so much the social services people, though I did have to get rid of one vicious woman (NWO/11/25). ... I hope that one day some of them will find themselves in the same position as myself. Then they may learn something (NWO/11/29).

Initially John made the decision to leave work out of a sense of obligation to both his parents' wishes to prevent his father being admitted into residential care but this sense of duty was overtaken by a need and determination to do his utmost to protect his father from harm at the hands of others. His methods may have been unusually drastic, but for him, as an assertive individual, they worked. John's situation and his encounters with the system were by no means unique, however, as the next section 'Cameo of a Carer: Dave's Story' illustrates.

At times, having someone to talk to was crucial for Dave and various aspects of his "nightmare" highlight his need for empowerment. The demands of caring full-time precluded him from an Assert programme which further strengthens the justification for this study.

Chapter 2

The Ties and Tolls of Caring

Part I

Cameo of a Carer: Dave's Story

Preface to Dave's Story

As I waited near the nurses' station in 'Ward 10' of the 'Wilson Memorial Hospital' for 'Dave' to arrive, a couple of elderly female patients ambled across the area in front of me, gazing straight ahead as they walked without acknowledging my smile or each other. Then a tall, dishevelled, unshaven man in his mid-seventies wearing an ill-fitting sports jacket emerged from a doorway, seemingly bewildered. A nurse broke away from what she was doing at the nurses' station and went over to him. With a wide smile she took his arm and inclining her head appealingly, nodded in my direction. Slowly the man's gaze shifted towards me. Was this man Wilf? I had yet to meet him but remembered Dave telling me he needed assistance when walking. I noticed the man was wearing pyjamas under his sports jacket. His gaunt, haunted stare – not quite in my direction as far as I could discern - seemed at odds with the bright, cheery chatter of the nurses nearby as they dealt with what seemed to be clerical work, namely the perpetual ringing of 'phones, form-filling and fielding enquiries. I felt a growing sense of foreboding and the whole scenario took me back fifteen years, when I used to visit my mother who had Alzheimer's disease. Her dementia had prompted her admission to hospital as an emergency one day after her home care worker discovered she had left the gas oven on without lighting it. That was only the second time in my life I had seen my mother cry; she pleaded with me to get her out of that hospital, so unhappy was she there. For a few moments I became mindful of the strain of finding a forced cheerfulness for her and a false friendliness towards the nurses who were kind but lacked understanding of her condition. It was happening again. My heart sank. I knew Wilf was in the early stages of dementia, but why was he in a ward like this ...?

Introduction

It was just over two years ago that Age Concern had referred Dave to Advocare – Caring for Carers because he felt stressed and isolated. Having cared diligently for ‘Wilf’ for many years, Dave was at breaking point, finding it difficult to cope with the recent loss of his foster brother of whom he had been very fond, as well as the increasing demands of his caregiving role. In what he describes as his “nightmare”, ‘Dave’s Story’ depicts some of the events that occurred before Wilf died and what happened to Dave himself in the months that followed. It was in the hope of preventing similar things happening to other carers that Dave agreed to recount his experiences to me.

Sparkes (1997) recommends ethnographic fiction as an effective means of speaking to and for the interests of silenced groups and absent others and I felt this style of writing would best illustrate Dave’s story. Fictional ethnography is a method increasingly being used by researchers to convey lived experience (Byrne 2008), unlike creative fiction where the writer invents people and places and includes things that never happened (Sparkes 2002). Using ethnographic fiction or creative non-fiction an author can recount real events and draw on actual data gathered in the field to produce an evocative story whilst at the same time protecting those involved (Sparkes 2002). As Byrne (2008, pp194-5) points out, in creative fiction a story unravels as if told “through the eyes of another” and distances those involved from real painful or disturbing experiences which can then be told “with greater force” and engage the reader emotionally “without accusations of bias or lack of transparency”. Fiction can therefore be used as a vehicle for revealing some of the more traumatic and difficult issues that might otherwise seem absurd or unbelievable in a factual account (Byrne 2008). In her ethnographic narrative Petersen (2007) describes her protagonist as “a factual fiction or a fictional fact, a bodied figure ... not ‘real’, not ‘there’”, an actor created from a “conglomerate” of people with whom she has spent her time. Whilst acknowledging there is risk in engaging the reader “on planes other than the rational one alone” (Sparkes 2002, p18), this reader sensed Petersen’s (2007) story was fictionalised to the extent that it was orchestrated to engender sympathy for a protagonist whose ‘created’ characteristics tend to weaken the “plot” (Sparkes 2002, p5). Using similar fictional techniques, Byrne (2008, p194-5) on the other hand “weaves” a convincing “humanised” story about institutional

“moral bankruptcy”, and succeeds without manipulation in evoking sympathy for and empathy with a protagonist who ‘feels’ like a real person.

The people involved in ‘Dave’s Story’ and their characteristics *are* real; events are recounted with integrity to leave the reader free to resonate with them - or not – according to their personal interpretation. Where appropriate, reference is made to communications I had with the hospital and social services department concerned and apart from changing some of the details and the names of the establishments involved and the employees within them to preserve anonymity, Dave’s story is authentic. Excerpts from several hours of our tape-recorded conversations, together with extracts from Dave’s daily record of events (his carer’s log), and the notes I made during our numerous telephone calls, form the basis of this cameo of Dave’s story which began when Wilf was admitted to Ward 10 at the Wilson Memorial Hospital in southern England.

Setting the Scene

Dave’s story is not dissimilar to that of John’s in chapter 1; both men were middle-aged when they gave up work to look after their father or father-figure; both felt exploited by the establishment; both battled with bureaucracy; both had to fight for financial survival and both felt they had little to lose in their struggle. The struggle was perhaps harder for Dave than for John who, as an only child, had more material and educational advantage, greater familial security and support. After having been separated from his three siblings and adopted when a baby Dave was then fostered as a small child. It was on learning that his foster father was dying, Dave once told me, that he ran away from home because his foster mother treated him harshly. She had several children of her own and at times “couldn’t cope”. He explained that:

She looked after me well enough in the physical sense and gave me some worthwhile values ... but she used to beat me with a poker when I didn’t do as I was told ... Wilf took me in when I was fifteen and gave me a home when no-one else would.

Dave had come to regard Wilf as a second foster father and feeling indebted to him, had given up work about twelve years ago when in his late forties to become his full-time carer. By this time Wilf was approaching eighty and showing signs of physical and mental frailty. There was a frailty about Dave, too, but I also found

him to be kind, compassionate and straightforward with a boyish, almost childlike naivety, which on occasions had led to his being misunderstood and vulnerable to exploitation. Twenty or so years earlier, Dave told me, his spine had been damaged in a vicious, unprovoked attack which had resulted in his prolonged hospitalisation for a nervous breakdown. At this point whilst recounting the incident Dave wept, and asked me to turn off the tape recorder until he had regained his composure. The attack had continued to be a source of psychological pain for Dave, not least because an unsuccessful operation had left him in chronic physical pain. Despite this Dave was an extremely diligent carer, according to Wilf's GP. By the time Dave was referred to Advocare Wilf had limited mobility, was receiving medication for prostate cancer and had started to become doubly incontinent, all of which added to Dave's care burden, already compounded by existing on the cusp of poverty.

"He's in Our Care Now"

Wilf, by this time in his nineties, had developed pain in his knee which made it difficult for him to keep his balance. He was admitted to hospital but soon after was diagnosed with leukaemia. It was on finding Wilf "all packed and ready to go home" when visiting him one afternoon that Dave was prompted to make contact with Advocare again. Wilf had been in hospital for exactly twenty-eight days and as far as Dave knew he had received no treatment for his knee, which he told me was "still as painful as it was before 'e went into 'ospital an' 'is walkin's no better". He was anxious about how Wilf was going to manage the stairs at home. When he asked ward staff what support there would be to help him to look after Wilf when he returned home Dave was met with stony silence. There was much hurt and indignation in his voice as he told me:

They put on 'is new trousers that I took in and some new shirts and I was amazed to see Wilf looking so well, but this was deceivin' because, even though 'e was well dressed, the next day 'e was seriously ill. Why was the 'ospital dressing him up smart ... obviously all ready for discharge, without givin' me a discharge plan?

"Were you consulted about Wilf coming home?" I asked.

No. No-one told me anything ... Why was 'e prepared to be sent 'ome when the next day 'e was seriously ill? I think this was an unwise decision on the 'ospital's behalf. There was no way Wilf was fit to be discharged, 'e was in no state to be discharged.

Having already been primed by Advocare, Dave knew a discharge plan should have been prepared for Wilf which, with enduring power of attorney, he was entitled to see even though he was not next of kin. I asked him if he felt that having enduring power of attorney helped with the situation.

Yes, they was flummoxed but eventually I got round to proving in writing that I did have the enduring power of attorney and they did accept it. They kept saying that I wasn't his next of kin and this was the problem I had. In the end I had to explain everything to them and they were reluctant but they accepted it in the end.

Wilf thus remained in hospital and Dave remained in continual contact with me. The notes I made during our many long telephone conversations form a formidable log on the shortfalls in Wilf's care but never once did Dave criticise the nurses. "They're always short-staffed ... there's one friendly one but the others never smile ... they seem so cold. It's the system that's wrong", he insisted, "not the nurses ...".

In an endeavour to forestall any further deterioration in Wilf, and desperate to get him out of Ward 10 which he described as "a cold, uncaring dungeon", Dave asked a young duty doctor for information on his condition. She gave him a leaflet describing leukaemia which alarmed Dave. (Indeed, it alarmed me when I read it.) The leaflet described the pathology but failed to give the reader any idea of how a patient with the disease might be feeling and the care they needed. It did mention, however, that people with leukaemia are prone to infection which added to Dave's concerns and heightened the intensity of his protest:

What I needed to know as the carer was the relevant treatments to get Wilf better. I wasn't really concerned about the actual leukaemia. All I was interested in was his treatment and if it's a positive sort of attitude that would get Wilf better. I wasn't even warned about him having leukaemia. Wilf's doctor [the consultant] said 'I can't stay long, I'm going on holiday tomorrow' and he saw me for two minutes. It wasn't a very good two minutes. It wasn't really right to do what he did to me. All he said was that Wilf's got leukaemia and we don't think he got long to live. That's the only two minutes he could give me of his life. I didn't see him for six weeks after that. He's meant to be Wilf's doctor. He never had the decency to come and see me or ring me. He never bothered with Wilf and he never bothered with me. I don't think really as the doctor he did his job properly and I feel rather bitter over that. They give up hope with Wilf because he's ninety years old and they didn't seem to be interested in helping him get better. The feeling I got is because he's got leukaemia he's just got to live with it. I'm sure they could have done something to make his life a bit more comfortable. They gave Wilf blood transfusions – I had to be there to stop him from pulling the needle out and blood going all over the place. I was there for three or four hours sometimes and didn't even get a cup of tea. I always thought a hospital was a caring place.

While Dave understood how ill Wilf was, it was unclear whether he appreciated the significance of the condition in terms of its possible time limitation. Despite my gently reminding Dave about Wilf's great age and that he had had a 'good innings', he seemed fixed on the idea that Wilf's leukaemia was treatable. He had recently read about some successful stem cell research and sought out hospital staff he thought could "do something to cure Wilf". Dave tried to 'button-hole' doctors to find out more about Wilf's treatment and asked to see the haematologist so he could tell him about the stem cell research. He expressed concern that someone with leukaemia and susceptible to infection should be put in a ward with people who had chest infections and commented: "They should never have put him into a ward with six people with chest infections ... I think the hospital was irresponsible". Dave was upset further when he learned from someone visiting the person in the bed next to Wilf's that another patient apparently suffering from dementia had poured a jug of water over Wilf, soaking his hair and pyjamas. Convinced this had exacerbated a chest infection, Dave became angry when the ward doctor refused to prescribe something to help ease Wilf's laboured breathing, and asked the nurses if he could bring in some linctus to help clear his cough.

Soon after Wilf's admission Dave discovered he was not routinely given his dentures to wear when eating his meals, and choked on food because he could not chew it properly. "There's a notice up in the ward" he told me "that says relatives can come in and feed patients". He got permission from Wilf's consultant to come in every day to help feed him. He frequently found Wilf sitting in soiled and wet clothes and bedding, a preventable precursor to bedsores. Furthermore, on occasions he found Wilf eating with blood and excrement on his hands and took it upon himself to clean him up. Wilf had had several falls; Dave believed one was probably due to the wrong zimmer frame being left alongside his bed. As he pointed out: "The man in the bed opposite had a small walking frame beside 'is bed and 'e's over six feet tall!"

Exasperated, Dave explained how he brought some of these events to the attention of Wilf's young duty doctor. "Do you know what she said?" he asked me rhetorically:

She said: 'he's in our care now', but they don't care! ... She told me I'm no longer his carer and that his care is nothing to do with me!

In Dave's view, Wilf was not being cared for properly and he needed to be vigilant lest he lose him. He went on to exclaim:

She said I should have a break! How ridiculous is that when I'm coming every day to feed him, making sure he's got his dentures in, cleaning him up, washing his dirty pants? ... I even found poo under his chair!

I ventured to suggest that perhaps the doctor was right, that he should take a break, his response was:

There are two nurses looking after forty patients in that ward. If he was getting good care, I wouldn't be stressed ... I mean, they give him pyjamas that are too long and he trips and falls over! ... I brought in three pairs for 'im which got lost and 'e never even wore.

Wilf's life-long friend Maurice telephoned me one morning to tell me how disturbed he had been on finding him with butterfly stitches in his forehead and how shocked to see blood still on the floor around his bed from a fall the day before. In his late seventies and a sick man himself, Maurice had struggled to make the four-hour journey to see Wilf. He had telephoned the Wilson Memorial Hospital two weeks before to find out how his friend was but was told he would only be given information face-to-face by the person in charge of Ward 10. Maurice sought out the duty doctor (the same one who had stressed to Dave that Wilf was "in our care now") but she refused to tell him anything. When Maurice pressed her further on how Wilf had cut his head and why there was still blood on the floor around his bed the doctor laughed. An incensed Maurice exclaimed: "You do realise this is not a laughing matter?" Without apology she retorted: "We have neither the time nor the staff to look after these patients properly!" Maurice said: "Then you and your staff should go to the Chief Executive and tell him to close the ward!" "Don't you think we haven't?" she snapped and walked off.

The doctor must have reported this incident because a few days later I received an E-mail from the hospital's chief administrator advising me that some "unacceptable behaviour bordering on aggression" had been exhibited by one of Wilf's visitors towards ward staff. It felt as if Advocare was being blamed for this and I asked Maurice to recount events in an E-mail to me for possible future reference. In my response to the administrator I made it clear that my colleagues

and I had no knowledge of Wilf's friends and indeed had never met any of them. I suggested that their behaviour was an indication of their being worried about him and concerned about the care he was receiving, and decided to put all Dave's concerns in writing to the hospital's Chief Executive. As a former governor of the hospital I thought he might remember me favourably, and sent him an E-mail saying how shocked and disappointed I was to learn of what had been happening to Wilf. He thanked me for my comments and arranged for Dave and myself to meet with some of his staff. Spurred on by the hope of the hospital making improvements in Wilf's care, Dave enthusiastically prepared a list of eleven shortfalls and I produced a resumé of events for ease of reference. We met before the meeting to go through Dave's 'agenda' and went together to the hospital to be received courteously at the entrance by the hospital's chief administrator.

Keeping a polite, professional distance as he led us upstairs and along the corridors into the directorate, we were greeted respectfully by two ward staff and another administrator already in the meeting room. Once everyone was settled I handed round copies of the papers Dave and I had prepared. The senior administrator took the chair for the meeting and took me by surprise by launching an attack in my direction about the "unacceptable behaviour" of some of Wilf's visitors towards ward staff. Mindful of Maurice's version of events I told him that, according to my sources, in the duty doctor's opinion the patients in Wilf's ward were not being looked after properly because they were short-staffed, that the Chief Executive knew about this but chose to ignore it. His face froze; after a moment he shook his head and the ready, reassuring professional smile reappeared assuring me the ward was not in any way short-staffed. There was no mistaking the squaring of shoulders and shifting on seats as others present closed ranks and in unison claimed unconvincingly that the ward "has a full complement of staff". Interestingly when the doctor's comments were later brought to the attention of the hospital's Chief Executive via Dave's MP, he would acknowledge only that: "... this doctor no longer works for the NHS".

Throughout the meeting Dave spoke with passion; all eleven points on his 'agenda' were acknowledged with nods and smiles. It was possible Wilf *might* get excrement on his hands, we were told, if he did not make it to the toilet in

time and tried to take off his pad. "Couldn't you put wipes on the ward?" asked Dave who, a few days afterwards, was delighted to tell me he had "some good news" - that wipes were now available to cleanse Wilf's hands - "so they have taken notice". With regard to putting up Wilf's bed rails to prevent him from having falls, these were thought to be dangerous, we were told, because Wilf might try to climb out and hurt himself. "'E'd probably do that lookin' for me ... I shouldn't be 'ere I should be wiv 'im", Dave said tearfully.

Upset at her ward being criticised for its standard of care for Wilf whom we were assured was "a delight to nurse", the manager of Ward 10 was also reduced to tears at one point. The problems around Wilf's delayed discharge, she and the ward sister informed us, were due to "poor communication" between the hospital and social services, mostly by social services, and we were assured that communication procedures would be altered to prevent this happening again. I was heartened by this and ventured to suggest that the leaflet given to Dave on leukaemia should be made carer-friendly as it even alarmed me when I read it. I suggested to them that for most people the very word 'leukaemia' is synonymous with death and that such a leaflet fails to reassure but instils fear into the reader's heart. I also appealed for someone to sit down with Dave and write out for him the information he was seeking about Wilf's condition and the care he needed, in order to better understand his situation ahead of his discharge from hospital. As if to redeem herself the ward manager promised to meet with Dave at 3.00 pm later that afternoon and the meeting ended on a very positive note. Dave felt his voice had been heard and strode off with a lighter heart to see Wilf, convinced he had made his stand under difficult circumstances.

At about 9.30 pm that same evening, however, having just arrived home from the hospital, a forlorn Dave telephoned me to say he had waited hours for the ward manager to come to see him as arranged on Ward 10, but she had sent a message saying she was too busy.

Hospital Revisited

Almost a month after this meeting Wilf was *again* prepared for discharge, *again* with no discharge plan detailing the home support that would be provided for him. There was no mistaking the intense frustration in Dave's voice as he told me:

“And then we went through the whole performance again ... there was no discharge plan because they couldn’t get the care”. As a consequence Wilf remained in hospital for a further ten days.

Realising our efforts had been wasted I contacted the Chief Executive again who thanked me for my comments and suggested another meeting with hospital staff. With a heavy heart I resigned myself to potentially wasting more time in preparation and discussion. Then a nurse from Wilf’s ward ‘phoned me. The conversation was confusing. I found myself irked by its lack of clarity and expressed my feeling about the futility of having another meeting in view of the last one, referring to the promise made to Dave for written information that had still not been kept. In a later, and again vague and confusing ‘phone call I was told a meeting had been arranged between hospital staff and Dave but he would only attend if I was present. Sensing some form of manipulation I reluctantly agreed to support Dave and was then told this meeting would be taking place on the ward.

After affably acknowledging me and a moment’s good-natured banter with one of the nurses, Dave hustled eagerly towards the entrance of a bay directly opposite the nurses’ station where I was standing. Following somewhat more soberly, I realised as I looked back that none of the patients in this bay could be observed from the nurses’ station. I peered into the gloom, watching Dave as he strode towards a bed on which a small form lay sleeping peacefully. Even though it was a sunny summer’s day outside, the bay seemed sombre, dull and dingy. The unmade beds seemed uncomfortably close together giving the area a cramped, crumpled appearance. Visitors sitting beside their loved ones seemed still, silent and sad; one or two glanced up, others kept their heads bowed. One woman was crying. ““Er Dad’s dyin”” Dave whispered confidentially. “She was told yesterday, on ‘is birfday. That’ll make four now since Wilf’s bin in ‘ere”. I found myself tip-toeing reverently past the end of the first bed to Wilf’s, where I stood waiting to be introduced. In sharp relief was a momentary reflection from years ago, of sitting by my son’s bed in the cheerful, colourful, caring paediatric ward waiting for him to wake up after he had his tonsils removed. My attention returned to the drabness of my present surroundings and I noticed how shallow Wilf’s breathing was. After pausing for a moment, Dave bent over Wilf to rouse

him. "Oh, please don't wake him", I said quietly. "It's all right, 'e wants to meet you", Dave grinned up at me boyishly. Looking back at Wilf again he bent lower, his stage-whisper in Wilf's ear cutting through the silence : "Wilf, Caffy's 'ere to see you!" I could feel all eyes upon me as Wilf struggled to open his. He blinked and then closed them again. "Caffy's here!" Dave persisted. Wilf opened his eyes wider this time, and with a cherub-like beam he gazed up at Dave, his expression radiating love in the absolute certainty of being loved. Dave's reciprocal gaze conveyed utmost compassion and genuine warmth, such was the bond between them. The image of Wilf smiling up at Dave without guile was imprinted on my memory in that moment for all time. I feel privileged to have witnessed such an exchange. It transcended the sad surroundings. A moment or two later, when Wilf realised I was there, he swept his smile over me, too, and said with a twinkle in his brilliantly blue eyes: "Would you like to give me a bath?" I just smiled and was about to move forward to shake his hand but remembered just in time what he might have on it. "I'd like it" he chuckled to himself with an impish glance at Dave. "Pleased to meet you at last, Wilf", I said softly and with the greetings over Dave plumped up some pillows to make the elderly man comfortable and helped him sip at a drink. Relieved for my sake as much as his, I noticed Wilf was wearing a pad; I could see he was wearing one because his pyjamas were tied around the waist but gaping open completely at the front.

The Bombshell

After ten or so minutes a nurse appeared and briskly shepherded Dave and myself out of Wilf's bay, led us past the nurses' station and into a small side room where a young doctor sat waiting. He looked up disinterestedly as we came in, said "hello" without eye contact and, as we sat down, introduced us cursorily to the occupational therapist, the hospital discharge co-ordinator, the hospital social worker and the ward sister ("the one friendly one"). The introductions over, instead of listening to Dave's concerns as I had anticipated, without a hint of emotion the young doctor explained how Wilf's leukaemia was taking a hold, that he had only weeks rather than months to live and may not make it home. For Dave it was a bombshell: he was unable to take in the news at first but as he endeavoured to do so his tears flowed. He was totally unprepared for this (as was I), unable to imagine life without Wilf, the man to whom he was so indebted

for giving him a home when no-one else would. As Dave struggled to grasp what he had been told, the possibilities and options for Wilf's remaining days were more gently considered. Uppermost in Dave's mind was Wilf's welfare. He dearly wanted him home but if this was not possible, Dave wanted an assurance that Wilf would be well looked after in his remaining days. He wanted to spend quality time with him. "We both enjoy listening to classical music", he said bleakly. Dave did not want Wilf to know how little time he had left and his overriding concern was that he should not suffer. The one friendly ward sister had put her arm around Dave's shoulders as he wept, and kept it there. Several moments passed in silence; gradually Dave gathered his strength and bravely began to grapple with the reality of losing Wilf.

Mobility assessments would have to be made, we were told, and depending on whether Wilf could manage the stairs, he might just be able to return home. If there was still a chance for Wilf to go home, I thought, we needed to head off any hitches and I sought confirmation that the hospital social worker and discharge co-ordinator would liaise on the discharge plan to ensure Dave had something in writing. I also made a mental note to contact the social services team manager in any case to make sure domiciliary support would be in place if needed to help Dave by the time Wilf was discharged.

With his duty done, the doctor and the rest of the team quietly filed out of the room, each saying how sorry they were to Dave as they went. When Dave had regained sufficient composure I suggested we had a few moments together - I wanted to be sure he was all right before I left him to go home. The friendly ward sister found another room with a kettle and made three mugs of tea.

Devastated at the thought of Wilf possibly never coming home again, Dave had been somewhat reassured when he heard that he would not be allowed to suffer. He would get all the palliative care he needed; his end of life care we were assured would be paid for by the NHS. I already knew that the hospital social worker had had to fight hard to get fast-track agreement for Wilf's Continuing Health Care to be funded but found it reassuring to learn that he would receive this whether he was at home or in a care home. As Dave clutched his mug of tea, I wondered why the funding for Wilf's care could not have been obtained

weeks ago when it first became apparent he was terminally ill so he could have gone home then. I said nothing to Dave about this. What I did not know then was that an earlier application had been made for NHS-funded Continuing Health Care for Wilf which had failed. Had I known, I would have wanted to know the grounds on which it had been refused.

After that day Dave spent more time than previously at the hospital in order to be with Wilf. The regular telephone calls kept me up to date until one day he rang to tell me that a discharge plan had been prepared and after two and a half months in hospital, Wilf was able to come home, albeit in a much weakened state. The palliative care workers visited at regular intervals but Wilf's chest infection had worsened. Dave told me later:

'E was 'ome wiv me for four days an' I took 'im to see Dr Shackleton [his GP] as an emergency because 'e was persistently coughin' and chokin' on 'is food. Dr Shackleton ... was reluctant to give him antibiotics because in his opinion he was still in hospital care even though he was discharged. But he did give me some linctus which he said would help him with his cough. He was re-admitted to hospital four days later because he came over ill again.

This time Dave had insisted Wilf went to a different hospital ward, not the cold, uncaring dungeon.

The hospital staff had done all they could to get Wilf home but he had become too ill by now to stay there. Wilf was deteriorating fast and each day I expected to hear the worst. So that he could be made as comfortable as possible it was decided he should go into a nursing home. Dave chose the home for Wilf with the support of a social worker who helped him to get Wilf settled. "It's got amenities", he said. "It's got a cinema, a swimming pool, and a snooker table" he told me. "It's a pity Wilf's too ill to enjoy all these amenities". It soon became apparent to Dave that Wilf was not being encouraged to eat or drink and when he learned that the treatment for his prostate cancer had been stopped, Dave asked me to visit the home one afternoon. He told me "the girl in the office got me to sign a form" but she "whipped it away" before he had had time to read the small print. Three times he had tried unsuccessfully to obtain a copy but she had evaded him. He felt he had been tricked into signing it so as to secure his agreement for Wilf not to be resuscitated if the need arose. On visiting Wilf we

found him sitting in a chair in his room and although not asleep he barely stirred as we entered. Even at this late stage and despite the doctor's 'bombshell', Dave urged me to find out more about the stem cell research from a London clinic he had heard about and desperately considered ways of getting Wilf there. I remembered noticing how pale Wilf was and thinking that, with his breathing so shallow, I would be surprised if he made it through the night. But he did. I was glad afterwards that I had kept my thoughts to myself. I promised Dave that I would telephone the clinic for him, and did so, guessing that he may have to face the brutal truth sooner rather than later.

The Cost of Benefits

Late one evening about two weeks after Wilf's admission to the nursing home, Dave left a brief, anxiety-filled message on my answerphone. When I rang him back the next morning he sounded beside himself. Highly agitated and without waiting to ask who was on the line, he started talking straight away, his voice thin and reedy, as if in panic and frightened for his life. I had difficulty in following what he said, thinking that at any moment I would hear the news I'd been expecting; yet I was puzzled because I detected no sorrow in his voice. Dave started sobbing and I thought I heard him say the word "fraud". After several minutes he stopped and stuttered slowly: "Wh-wh-who am I speaking to?" "It's Cathey", I told him. "Oh, thank God!", he said and his agitation began to recede. "I-I've been awake all night, *all night* ... I haven't slept because of this letter they sent me".

It transpired he had received a letter from "the benefits people" (the Department of Work and Pensions, the DWP) stating that all his benefits had been suspended with immediate effect and worse still, it inferred that he may have committed fraud in his not having notified them that Wilf had been in hospital more than 28 days.

Dave's panic began to mount again as he read out the bit about "fraud". My mind was racing as I endeavoured to get the story straight and find some reassuring words for him. As we ran through what had happened the only 'out of the ordinary' event appeared to be a visit from a new social worker, Ms West. It transpired that once it had been decided that Wilf should go into a nursing home, Ms West had asked to visit Dave and it was in the belief that she would act in his

best interests that he had agreed to meet her. On enquiring about Dave's financial situation she promised he would receive full Housing Benefit. (Dave had 'phoned me after she left, delighted and relieved to be able to tell me this as he had been worrying about how he was going to pay the rent on the flat in the event of Wilf's death.) However, on learning that Wilf was still receiving Attendance Allowance, Ms West had spoken to an Age Concern adviser who told her she should notify the DWP that Dave was technically no longer a carer and therefore no longer entitled to his weekly Carers Allowance. Ms West took it upon herself to telephone the DWP straight away. This was the "possible fraud" that had so panicked Dave. The result was that with immediate effect his weekly Carers Allowance of approximately £50 was stopped, as were all his other benefit entitlements, including Income Support. I asked him why Ms West 'phoned Age Concern in the first place.

She asked for my permission to ring up Age Concern ... They say in their leaflets they help carers ... what they don't tell you is they only help you if you're over sixty I did suggest to her that Age Concern do help carers but they disagreed with that. They said that I wasn't old enough ... they said they only deal with claimants at sixty or over.

I asked him to tell me again what happened after the conversation Ms West had with Age Concern.

... they injudiciously, wrongly stopped my benefits which I've since found out that they shouldn't have stopped it because carers are allowed an additional 12 weeks' breathing space. We are allowed, even though the Carers Allowance stops, we are allowed 12 weeks of Income Support. A breathing space to get our life back together again.

Still not clear about Ms West's actions, slowly and carefully I rephrased the question to Dave: "Once Ms West got the information from Age Concern, what did she do?" Patiently he explained that she rang up the Benefits Department and told them that Wilf had been in hospital for approximately 12-13 weeks. At some length he continued:

They said that they would have to stop my benefits, which they did, but I've since found out that they shouldn't have stopped my Income Support. They were right to stop the Carers Allowance but they were breaking the law by stopping my Income Support ... because they stopped my Income Support, they made a suspension on my Housing Benefits, made a suspension on my Council Tax benefit ... and ... I had to go to the Town Hall and fill in more forms which needn't have happened. Up to now I've had 250 pages, 5 booklets, all each containing 50 pages, that's 250 pages of forms to fill in. ... It's been a nightmare, believe me, it's a nightmare. All I've been doing all the last two weeks is filling in forms, making 'phone calls, on a wild goose chase going from one department to the other; being told different things from different departments; being given wrong information and wrong advice; given 4 or 5 different addresses to send forms back; being told that my forms could be handled over the 'phone then being told by the Job Centre "no, that's incorrect, they have to be done in written form". Given all this bad and wrong advice, all the maladministration ... And also, it cost me a lot of money in 'phone calls ... they broke the law and didn't pay the benefits that according to the law I was entitled to. They gave me more hassle and harassment which was the last thing I needed at a time when I got somebody dying

Dave wept again at this point. I deemed him to be on the edge of another breakdown and resolved to telephone the Director of Social Services who happened to be a former colleague of mine. It transpired he was on sick leave. I tried the social work team manager. He was on leave. Considering the matter to be a priority I tried telephoning the Chief Executive of the local authority concerned. She was away at a conference and not reachable by telephone. Her PA suggested E-mailing her deputy, which I did, pointing out that, had Ms West used a moment's common sense or forethought, or better still exercised Aristotelian 'practical wisdom' she could have ensured that at least Dave would have continued receiving Income Support until the end of his three months "breathing space" so he had *some* income during such a critical time whilst his other benefits were being sorted out. "Money can be repaid", I wrote, "reparation of a person's sanity when a loved one is dying is not so easy...".

The somewhat tardy response from the acting Chief Executive was sympathetic but accepted no responsibility for Dave's inordinate level of distress. I learned from the social services team manager that Ms West could face "a disciplinary" but Dave was unwilling to pursue the matter because she "did her best" to help him and after an internal investigation the matter was dropped. Dave was immediately assigned another new senior social worker (the seventh in two years - he went to Wilf's funeral, as I did). "He still visits me but he doesn't *do* anything to help me", Dave commented to me recently, "... only you do that".

At Dave's suggestion I wrote to his MP on his behalf telling him about Wilf's hospital treatment and the suspension of all the benefits. The MP responded immediately and was proactive in arranging for Dave to be back-paid the Income Support he should have had. It was through no fault of their own that Wilf and Dave had 'broken' social security rules; preoccupied with the poor standard of care Wilf was receiving, Dave's only 'crime' was failing to notify the DWP of Wilf's continued hospitalisation in the light of his stop-start discharge. Had Ms West taken the trouble to consider Dave's situation thoroughly she could have perhaps explained to the DWP that Dave had not intentionally avoided making any declarations, that any oversight was due to the twice-delayed discharge of a dying man and coping with impending bereavement, and saved him the trauma of being accused of fraud which caused him such an inordinate amount of distress. Ironically, however, had Dave notified the Department of Work and Pensions he would have been summoned to visit the Job Centre and been forced to start looking for work while Wilf was dying! Dave reflected incredulously:

I can't see how you can be seeking work and still be available for the person when they are discharged from hospital. If you're out looking for jobs, seeking work or even getting a job, how can you be at home waiting for the person to come home and have your home ready and look after them? You can't do both. This is another reason why the rules are wrong. You can't be a full time carer and be out looking for jobs as a prerequisite to Job Seekers Allowance. If I thought Wilf was getting the appropriate treatment I would have gone to see him, yes, to keep him company, but I wouldn't have had to be there 8 to 10 hours a day. I was told one patient got smacked in the face by a mental patient. I was protecting Wilf and being reassuring and also he was crying when I wasn't there and he used to get up out of bed looking for me and fall over. Once he tripped on his pyjamas ... that were too big for him. He was anxious of where I was. The point the system doesn't seem to understand is, when they stop all your benefits, my landlord still has to have his rent ... even if Wilf's not living here. Where am I going to get the money to pay my Council Tax? ... Obviously, if my benefits stop I haven't got the money to pay the Council Tax. It's just wrong to treat a carer like this because the person is seriously ill it's not the fault of the carer. If he's been in hospital for 28 days, 4 weeks, his Attendance Allowance stops. When the Attendance Allowance stops, the Carers Allowance stops. Because the Carers Allowance stops, the Income Support stops. Because the Income Support stops, the Housing Benefit stops. When the Housing Benefit stops, the Council Tax Benefit stops. It puts the carer in a very awkward position. ... It's just not fair on the carer ... Seeing someone who I live with and cared for, for nearly 12 years ...

His voice trailed off and we both reflected ruefully upon how Ms West had promised him full Housing Benefit which was suspended once the council

learned of the joint bank account giving him access to Wilf's savings of £6,000. Wilf's funeral cost just over £2,000 and once Dave had paid this and reduced the account to below the qualifying threshold, his Housing Benefit had been reinstated. I wondered why Ms West had not considered this but Dave defended her good intentions, bitterly blaming the system:

The rules are draconian, they are old-fashioned and they need to be brought up to date with care and compassion, empathy and to help the carer when the carer goes through a difficult time. After all said and done, I've spent 12 years doing everything a carer could possibly do, working seven days a week without a break, 24/7, making sure he's got his teeth in because the hospital was feeding him without his teeth in; assisting him with his food; taking new clothes to him; cleaning his glasses for him; making sure he's having his tablets; assisting him when he was having his blood transfusions to make sure he didn't pull the cords out because the blood goes everywhere. The hospital demanded I was there. They didn't even offer to pay me my bus fare. They demanded me to be there. I was there 13 weeks, 7 days a week without a day off. Now I come to a crisis and now with the bureaucracy and red tape and all the injudicious forms I've had to fill in, it's just grossly unfair to treat me like this. All I can say is, because of all this upset has affected my health, it's made me ill and it's just not fair. It's just an injustice, I just feel very upset. I really feel deep inside of me that it's my duty to help other carers not having to go through what I've been through ... I will do everything in my being to make sure that other carers don't have to go through what I've been through. It's grossly unfair on the person that's dying. It's not fair on Wilf ... he's crying every day because I'm not there. The system is draconian, old fashioned, needs to be brought up to date and when carers go through a difficult time like I've been through, there should be somebody there that they can turn to from the state to help them. I was always told that if I was a carer, when things went wrong, the system would help.

No longer entitled to his Carers Allowance, Dave also lost the Carers Premium (around £27 per week) and his Income Support (around £24 per week), which entitled him to free medication for his chronic back pain and free dental treatment. The new social worker endeavoured to get Dave's Housing Benefit reinstated together with his Council Tax relief (which happened eventually but not without some pressure from Advocare). Dave has also since found that being on a low income he is still entitled to free prescriptions and dental treatment. "Why", he asked me, "didn't the benefits people tell me about this?" However at the time of writing Dave's only income is his Incapacity Benefit of £63.75 per week, approximately £3 a week of which goes towards his Housing Benefit and Council Tax. An application for Disabled Living Allowance has been turned down and currently he faces potential homelessness and possibly destitution.

In the hope of finding a solution to Dave's situation I contacted various organisations, including charities, that purport to help people in adversity, only to hear from courteous if somewhat curt administrators that Dave does not meet their eligibility criteria and to be signposted to other similar organisations whose eligibility criteria also screen out people like Dave. I even telephoned the solicitor who had suggested that Dave should set up the joint bank account when Wilf's prognosis became known. On hearing the sorry social security saga his response was: "Oh, he won't starve and he won't become destitute! ... he's just got to get used to living on a reduced income. And anyway, he's got access to Wilf's savings (now around £3,000)". "But they won't last for ever" I said, wondering how *he* would cope with living on £63.75 a week.

Later, as Dave reflected upon all that had happened to him he told me:

The system has just chucked me onto the rubbish heap ... I really feel deep inside of me that it's my duty to help other carers ... I'll do everything in my being to make sure that other carers don't have to go through the nightmare I've been through.

Dave's story is not an isolated case but it is perhaps more disturbing than most because in his being forced to fight for financial survival, Dave was not at the nursing home when according to the manager Wilf was "calling for him to hold his hand when he wanted to 'go to sleep'".

Discussion on 'Cameo of a Carer': A Microcosm of the Caregiving Role

Research suggests that unpaid caregivers experience greater levels of emotional distress than the general population (Nelis and Quinn, *et al.* 2007, cited in Cochrane Review 2008). Still grieving over the loss of his foster brother and already vulnerable because of his background, Dave's level of stress and distress intensified after Wilf was admitted into hospital. From the outset Dave was worried about the sub-standard treatment and care his foster father was receiving; he had to deal with the shock of Wilf's alarming diagnosis and prognosis and cope with the continuous uncertainty surrounding his twice-delayed discharge; Dave then had thrust upon him the responsibility of finding Wilf a suitable nursing home. With regard to his financial situation, Dave was misled by a social worker promising him entitlement to full housing benefit that was subsequently suspended by local council clerks until he had paid for Wilf's funeral and could prove he had sufficiently reduced Wilf's meagre savings; Dave

suffered from the inexperience or ineptitude of this same social worker who, having learnt from Age Concern that they did not help carers under sixty years of age, nevertheless acted upon their advice and took it upon herself to tell the Department of Work and Pensions about Wilf's protracted hospitalisation without explaining why; in consequence Wilf's Attendance Allowance ceased and, literally overnight, a social security system that claims to help people maintain financial independence stopped Dave's Carers Allowance along with all his other benefits through a 'domino effect'. Only after the intervention of Dave's MP was his Income Support reinstated until its legitimate expiry date. Added to this, Dave now faces the prospect of losing his home because he cannot pay his utilities and feed himself on £63 a week.

Dave's story spans a period of just over six months yet it depicts critical episodes or epiphanies (Denzin 1989) in one unpaid carer's life. As such it represents a vivid microcosm of the demands and vicissitudes of the caregiving role which six million or more other people in the UK (Carers UK 2007) may also experience.

In Wilf's Wake

This cameo raises many unanswered questions: some of the most significant relate to Wilf's discharge from hospital. Wilf was first prepared for discharge precisely twenty-eight days after being admitted; his knee was no better than before admission and although he had been diagnosed with a terminal illness no consideration was given to arrangements for his care at home until Dave asked to see his discharge plan. This begs the question as to why NHS funding for Wilf's end of life care was not applied for and obtained at the point of diagnosis, which would have ensured his safe discharge home and maximised his comfort there.

Apparently preoccupied with going on holiday, Wilf's consultant showed a total lack of sensitivity towards Dave when telling him about the elderly man's terminal condition. His apparent indifference about the leaflet on leukaemia so alarming Dave highlights the need for greater consideration for carers when producing such leaflets. The wall of silence experienced by Dave when exercising his right to have home support is also symptomatic of poor communication as is the indifference shown towards him by the doctor who dropped the 'bombshell' about Wilf's prognosis, the dialogue Wilf's life-long friend Maurice had with the duty

doctor which was later dismissed by the Chief Executive and the nurse who failed to keep her promise to explain things to Dave. Each 'epiphany' (Denzin 1989), not least the manipulation to get Dave and myself to a meeting on the ward, epitomises the oppressive culture within this medicalised arena, and the systemic failure of its management. Interestingly, a lack of communication and involvement with relatives and carers about hospital care and treatment plans was highlighted in a recent report *Spotlight on complaints* published by the Healthcare Commission (2008). However, Wilf being left in his own excrement cannot be attributed to poor communication. About 140,000 complaints are made against the NHS in England each year but merely 7,500-10,000 are referred to the Healthcare Commission for 'independent' review. Further, it is difficult to quantify the number of complaints about hospital or nursing care because of the way this report is worded and its convoluted references to trends and percentages. Indeed, a colleague recently contacted this government-funded Commission to find out how many complaints about the NHS are upheld and the administrators themselves did not know. Some indication of the scale of the problem may be drawn from a report by the Joint Committee on Human Rights (JCHR) (2007) which is based on "a considerable volume" of evidence on the quality of treatment older people receive in hospitals and residential care homes in the UK. The Committee defines abuse as:

A single or repeated act or lack of appropriate action occurring within any relationship where there is an expectation of trust, which causes harm or distress to an older person ... At any one time in the UK it is estimated that 500,000 older people are subject to abuse (JCHR 2007 p10).

The report estimates that thirty-four per cent of abusers are paid care workers and of the one third of abuse perpetrated by two or more people acting together, sixty-two per cent is perpetrated by paid staff through abusive practices that are institutional and passed from one worker to another (JCHR 2007, p9). The report also highlights people being roughly treated and the 'revolving door syndrome', readmission due to inadequate assessment of their needs and too hasty discharge from hospital. It cannot be coincidence that Dave's concerns about malnourishment, low hydration, lack of dignity, poor hygiene, carelessness and neglect are reflected in the report (JCHR 2007, p9). Neglect is one aspect of elder abuse which the Committee regards as a violation of older people's human rights; treatment that is less severe than neglect but which implies a lack of

thought by staff about the effect of their actions on patients such as lack of hygiene is defined as “carelessness” (JCHR 2007, p11). According to this report ‘carelessness’ has led to individuals developing bedsores through being left in their own waste matter, and also to avoidable deaths: the difficulty unpaid carers have is proving what is happening and finding out who is responsible for it. The seventy-four per cent of Britain’s carers who are at breaking point and the forty-one per cent who say it is bureaucracy that pushes them to it according to Carers UK, *et al.* (2009) are, in effect, caught up in a never-ending struggle against submission to power - “the force that says ‘No’” (Foucault 1980, p90). Few therefore ever get into a position where they can gather sufficient evidence to persuade policy-makers to implement change. Dave is an exception. He has obtained Wilf’s medical notes with the intention of bringing a case of inhumanity towards a vulnerable person to the attention of the highest authority.

Voicing the Need for Revelation and Reformation

It could be argued that some of Dave’s problems were self-made, arising from his unassertiveness, poor communication skills and possibly a compulsive element of overdeterminism (Smith 1984). His vigilance over Wilf’s care seemed to border on obsession, perhaps prompted by the fear of losing him, and his need for a continual presence at the hospital was possibly driven by his own need for care – his comment that he always thought “a hospital was a caring place” may have stemmed from a deep-rooted wish to be looked after himself. Dave’s reluctance to ‘let Wilf go’ could be seen as indicating fear of abandonment and his frenetic activity in attempting to sort out his benefit entitlements could be seen as a displacement activity (Gross 1987). However since Dave’s experiences parallel those of others, for example John’s, as described in chapter 1, this counters the notion that his nightmare was of his own making, as does Wenger’s (2007) personal account of her six days of “hell in hospital”. Wenger (2007) provides graphic detail of sub-standard care, but her article contains some interesting contradictions. Firstly, whilst she made formal complaints about the “poor and dirty facilities” and “lack of thought in procedures in place” she made no specific complaint about her treatment and care. Secondly, like Dave, she refrains from openly denouncing the nurses yet criticises their condescending, patronising manner and blames the unhygienic conditions and lack of privacy on

their being short-staffed. Thirdly, she decries the doctors' detached, elitist attitude yet claims they and the nurses were kind and sympathetic to her when she felt suicidal and sought to discharge herself - from a situation they had helped to bring about, namely her depersonalisation and the dehumanising conditions in which they kept her. Some of her formal complaints brought about change. The shower cubicles for example, one of which was described by nursing management as a "horror", were refurbished and now provide patients with some privacy. Given the circumstances and the power of the organisation, it is not surprising that Wenger (2007) tacitly defends the perpetrators by generalisation. This is not to deny the risk she took in revealing her truth and the attention it attracted. For example, she comments that she is no longer confident that doctors have the freedom to make the best clinical decision; she suggests budgetary constraints may be forcing them to make money-saving clinical decisions. This may have been the case for Wilf.

Dave was given no warning by hospital staff of their first attempt to discharge Wilf on the twenty-eighth day and it is interesting that this coincided with the cut-off date for his Attendance Allowance. Sometimes local authorities are fined for bed-blocking if a person remains in hospital when they are not receiving medical treatment. On the hospital's second attempt to send Wilf home Dave commented that "there was no discharge plan because they couldn't get the care". The absence of a discharge plan legitimised social services' exemption from providing support; Wilf would have had to commission it himself and pay for it out of his Attendance Allowance. This could explain the hospital's haste to get him discharged on the twenty-eighth day. That the hospital social worker had to contest so strongly the (clinical) decision for the NHS not to fund Wilf's end-of-life health care before she could get this decision rescinded and get the NHS funding in place, implies a clinical expectation of Wilf dying at home unsupported, solely in Dave's care. Had this been the case the NHS could also have 'legitimately' sidestepped or evaded involvement in providing Wilf's (expensive) palliative care.

In not calling to account those responsible for the neglect and carelessness she herself experienced and witnessed Wenger (2007) mutes her own voice and dilutes an otherwise powerful argument for radical change. As Cummins (2002, p7) astutely observes, the audit culture is characterised by the desire to know in

order to evaluate but it masks a deeper desire *not* to know things that are uncomfortable:

... the imperatives of auditability create a series of institutional dysfunctionalities, iatrogenic effects, and counter-productive effects or ironies. ... Quality assurance processes and the auditing which supports them are internally corrupted. [But] official definitions of quality assurance conceal this. What counts is ... the production of organisational legitimacy. Accounts are produced to defend against more meaningful accountability. [Thus] Assurance can be provided that the system works well, even if the performance is poor.

This evasion or sidestepping is recognised by the Joint Committee on Human Rights (JCHR 2007, p10) as a tactic used to hide the truth at the highest level for in its report the Committee states that:

The Department of Health in its written evidence to the Committee's Enquiry does not explicitly acknowledge any of the problems identified by other witnesses but instead focuses rather defensively on the financial investments made into the NHS and the many initiatives launched by government in relation to older people.

In his written explanation to Dave's MP, the hospital chief executive sidesteps the issues Dave brought to his attention including sub-standard hygiene and the ward doctor's remarks about being short-staffed and unable to look after patients properly. Instead he focuses on defending his staff with regard to Wilf's dignity, insisting his pyjamas had poppers, not ties! He also fails to acknowledge there was no discharge plan for Wilf on the first two occasions he was about to be sent home as a dying man.

Opening Death's Door

Proponents of government doctrine as evidenced by these examples also strive to hide the truth with false dogma and rhetoric. Such a lack of transparency would not exist in an educated public, described by MacIntyre, *et al.* (1985, p18) as:

... a large body of individuals, educated into both the habit and the opportunity of active rational debate, to whose verdict appeal is being made by the intellectual protagonists. These individuals must understand the questions being debated as having practical import for ... important aspects of their shared social existence.

MacIntyre, *et al.* (1985, pp18-19) contrasts an educated public with exclusive specialist groups whose debates often fail to reach "an effective terminus" and with the "passive mass public of readers and listeners who merely provide an audience for the debates of others". In other words, an educated public is a community that

abides by generally agreed beliefs and principles and one that is underpinned by rational scrutiny of the standards it itself decrees and upholds. An educated public cannot exist, according to MacIntyre, *et al.* (1985, pp18-19) without such “shared assent” or where there is no “tradition of interpretive understanding” of its doctrines. Indeed, the possibility of an educated public is destroyed where there is “undue prevalence of a certain kind of scepticism ... or dogmatism”, and even in a completely literate society, such conditions are more likely to produce “public mindlessness” suggests MacIntyre, *et al.* (1985, p18).

Bearing MacIntyre, *et al.*’s. (1985) conceptualisations in mind, it could be argued that instead of seeking to foster an educated public the government avoids opportunities for ‘active rational debate’. For example, in ascribing dominion to the British Medical Association (BMA) over western society’s moral ethics and the dying patient, undeniably an important aspect of Britain’s shared social existence, the government has authorised this exclusive specialist group to bring credence to hastening the deaths of vulnerable older people. In guidelines for what is known as the Liverpool Care Pathway (BMA 2006, p2) the BMA classifies food and water as ‘medical treatment’ and decrees that:

Medical treatment can legally and ethically be withdrawn when it is futile in that it cannot accomplish any improvement, when it would not be in the patient’s best interest to continue treatment (because for example it is simply prolonging the dying process) or when the patient has refused further treatment.

In a letter to Dr Michael Wilks, Chairman of the BMA Ethics Committee, Cardinal Winning (Scottish Media Catholic Office 1999) expresses both dismay and concern:

... the new guidelines are both sinister and worrying. There can be no justification for starving and dehydrating people to death, even when they are not terminally ill and when the move goes against the wishes of their relatives. The best interests of the patient risk being replaced by economic criteria and as a result situations could arise where lives are deemed too costly to support. That this should happen in NHS hospitals with the full approval of the BMA is almost beyond belief (Scottish Media Catholic Office 1999).

What is more alarming, is the recent amendment to the Mental Capacity Act (2005) (see Appendix A2.1) which came into force in October 2007. This legislation purports to protect people who lack the mental capacity to make their own decisions since it presumes a person has capacity unless proven otherwise.

Those responsible for giving treatment and care must now follow a statutory checklist of best interests (see Appendix A2.1) in order to ascertain what *is* in the person's best interest but, in truth, if the person is deemed not to meet the eligibility criteria of the agencies involved or if there is no money available for the care that person needs, the checklist is rendered redundant. In practice the legislation serves mainly to confound and weaken carers' powers of attorney for it leaves the vulnerable person at the mercy of medical personnel who have the right to withhold all treatment including food and water from patients whom they judge to be incapable of making decisions for themselves according to ALERT, (Against Legalised Euthanasia Research and Teaching, 2008). Combined with withdrawal of fluids, deep sedation leads quickly to death and doctors are in essence selecting patients for death and arranging what could be seen as a lethal cocktail for those who are too costly to keep alive and care for according to Dr Treloar, a psycho-geriatrician and senior lecturer at Guys', King's and St Thomas's hospitals in London (ALERT 2008). Once this judgement has been made, according to Treloar (ALERT 2008), withdrawal is ordered on the grounds that it is in the patient's "best interests" to die and if families try to protect their loved ones, social services and police can be, and have been, called to intervene.

Treloar warns of "involuntary euthanasia" by deep sedation and dehydration in chronic diseases such as dementia, where dying may take years, and that such patients may be deemed eligible for the Liverpool Care Pathway, a trend which has increased over the last ten years and which is now becoming regarded as Britain's pathway to euthanasia according to ALERT (2008). If Wilf took longer to die than anticipated this would explain why Dave felt he was perceived as a nuisance and given short shrift by some hospital staff.

Even though the Mental Capacity Act (2005) makes it a criminal offence of neglect or ill-treatment of a person who lacks capacity, before a criminal investigation can be mounted hard evidence of gross negligence is required. In spite of Treloar's warnings about doctors selecting older people for death and despite the amount of evidence it has gathered on the treatment of older people in hospital, the Joint Committee on Human Rights has in effect determined that preventable hospital deaths, if brought about through carelessness, are excusable. On the one hand the Committee accepts that it is a criminal offence to neglect those who lack

mental capacity but on the other appears to ignore the avoidable misery and death brought about in older people who *do* have capacity. A situation that may indeed be happening because, in 2006, Age Concern reported that sixty per cent of older people in hospital were at risk of malnourishment or of their situation getting worse during their hospital stay and insufficient help given with eating and drinking has, on occasion, led to preventable deaths (JCHR 2007). Not providing food and water is a dereliction of basic care which is defined by Randall and Downie (1996, p134 cited in Open Learn 2008) as:

... those medical treatments and nursing measures essential to provide comfort and alleviate pain or distress. It includes the provision of warmth, shelter, hygiene measures, and management of distressing symptoms such as pain and breathlessness, and provision of oral food and fluids (but not artificial feeding by nasogastric tube ...).

In his talk to Advocare members recently on the Mental Capacity Act (2005), a senior social worker supported the new legislation wholeheartedly in the belief that it was drawn up to prevent fraud. It appeared that he failed to realise that under this law doctors, rather than the family or the patient, have the authority to judge if a patient is deemed mentally capable. In essence, the act gives two doctors the right to authorise the withdrawal of medical treatment, including food and water, for those they deem to lack mental capacity and gives them the authority to bring about the death of those who (like Wilf) cannot speak up for their right to life (ALERT 2008). This may explain why the hospital doctor encouraged Dave to “have a break” and perhaps the form which was “whipped away” from him after he signed it gave the nursing home his agreement to all but stop giving Wilf food and fluids to speed up his death.

Members of Advocare did not tell the speaker that a small group of doctors and carers is gathering evidence to support an amendment to this legislation which will remove “food” and “water” from the “medical treatment” element of the Mental Capacity Act (2005) and thereby prevent doctors from withdrawing these and condemning vulnerable older people to what could be and, to my certain knowledge, has been for some, a horrible death. This, the group believes, will prevent legalised inhumanity and allow people like Dave to provide basic care, including food and water, to their loved ones, to enable them to die naturally, and in the peace and dignity they deserve. Wilf appears to have been a clinical

inconvenience in taking so long to die. Nonetheless Dave can take some comfort in knowing that his interventions prevented his beloved 'second foster father' from suffering greater misery due to other people's 'carelessness'. The fact that carelessness resulting in a vulnerable older person's death in hospital is not regarded by the Joint Committee on Human Rights as a violation of their human rights brings into question this Committee's powers, its remit and its definition of neglect. Two years ago Dave felt he was a victim without a voice. Having found his voice he wants his story to be heard. Not satisfied with the evasive explanations from the hospital and "the benefits people", Dave resolved to get answers to key questions that cannot be sidestepped and to challenge the mechanisms that allow legalised inhumanity towards vulnerable older people. In the end radical reform for carers and those they care for may depend upon the humanity of those engaged in responding to stalwarts like Dave and whether those individuals or their organisations have sufficient openness and integrity to be educated by and act upon their stories.

In Retrospect

Unlike John, in chapter 1, Dave was not a naturally assertive individual from a stable middle class background yet both experienced exploitation by 'the system', each having cared full-time - Dave for ten years, John for four some years before - for different reasons in different circumstances but both had similar motivations. Their battles with health and social care service providers and practitioners were also similar. They each sought to obtain an adequate standard of hospital care for a dying person. John's anger and frustration with bureaucracy in trying to do his best for his helpless father was no less intense than the desperation Dave felt about doing his best for Wilf to whom he felt indebted. Despite being assertive, having more social support and greater social advantage, the toll on John was similar to that on Dave and it is suggested here that both may have been suffering from burnout. In John's case, being physically and psychologically stronger may have protected his mental health. Dave on the other hand was still grieving over the loss of his foster brother when Wilf died.

In publishing her story of hospital neglect and carelessness Wenger (2007) goes some way towards educating a section of the public but she fails to challenge the elitist culture that subordinates patients and subjugates their carers. In contrast, 'Jenny' in part II of this chapter used one of the establishment's mechanisms of

power against itself. By creating an 'audit trail' of truth she strengthened her own voice as well as that of other carers and vulnerable older people. However, having had to retain her anger and frustration for so long took its toll on her physical and possibly her mental health. It was in the course of gathering qualitative data to deepen and extend an appreciation of the lives and dispositions of unpaid carers that I noticed there were commonalities in other cases, particularly in those who were long-term sole advocates of vulnerable loved ones and whose emotions were thwarted. During a literature search, I alighted upon the "burnout" phenomenon defined by Maslach (2001, p1415) as "a psychological syndrome that develops in response to chronic emotional and interpersonal job stressors". This prompted enquiry into the possible existence of the 'unpaid carer's syndrome' which, aided by eight vignettes of casework examples, is also explored further in the next section.

Addendum to Dave's Story:

Subsequent to Wilf's death Advocare persuaded Dave to apply for Disabled Living Allowance (DLA), a state benefit. A supporting letter was required from his GP but it mentioned only his physical conditions. His application failed. Advocare urged him to appeal against the decision and asked his GP to write a supporting letter that would strengthen Dave's case on psychological grounds. The GP refused to comply with our request saying that Dave's emotional and mental state was not sufficiently disabling. Dave broke down completely during his recent interview with the DLA appeal panel. A doctor on the panel instantly recognised Dave's diminished mental state and his appeal was successful. With the underlying entitlements his income has virtually doubled. His DLA has been backdated to the date of his first application - almost a year before. Had his GP recognised and accepted the seriousness of his psychological state at that time, Dave may not have suffered as he did for so long. He could have afforded to heat his flat during the winter following Wilf's death.

Chapter 2

The Ties and Tolls of Caring

Part II

The 'Unpaid Carer's Syndrome'

Introduction

Most people recognise that Britain's six million unpaid carers who look after the frail, sick and disabled make an invaluable contribution to society, however the general public greatly underestimates how many carers there are (Carers UK, *et al.* 2009) and is unaware that they are frequently left helpless, unsupported and alienated, and are exploited by the very organisations upon which they should be able to rely. Health and social care departments often fail to work together and carers are forced to subjugate their needs to the demands of these services which leaves them few opportunities to speak freely about needing more help; indeed some regard a needs assessment as pointless because, according to their social workers, the resources are not available to meet their needs anyway (Carers UK 2007). Recent surveys show that eight out of ten carers feel their role is overlooked or ignored by social workers, GPs and hospital staff and three-quarters that it is not recognised by family members and friends, all of which has a significant negative impact on their lives (Carers UK, *et al.* 2009).

The need for change in today's society is considered first in this chapter, making reference to the communitarian agenda and drawing on the case of 'Jenny', who for most of her life has looked after her mother. Family ties generally motivate human beings to care about each other notwithstanding the difficulties and dilemmas, the stress and distress, which the caregiving role frequently entails and these aspects are considered next, making reference to situations described in 'John's Story' but illustrated mainly by Jenny's case and eight other casework examples in the form of vignettes. It is widely recognised that the stress of caregiving can take its toll in the form of burnout syndrome (Maslach 2001) in paid care workers and affect their motivation and capacity to care, yet the possibility of this phenomenon affecting unpaid carers is not acknowledged in the same way. At the end of this chapter the existence of the 'unpaid carer's syndrome' is considered along with some suggestions on how to prevent it.

The Need for Change

In what Bell (2005, p14) describes as “our current malaise”, society is reaping what was sown in the Thatcher/Reagan era in terms of individualism and the valorisation of greed: moral codes previously underpinned by civil obligation and a sense of “uncalculated reciprocity” (Smith 2001, p14) have been pushed aside by the state to make way for the dictates of the international market place. The older generation, formerly venerated as caretaking role models, seems to have been relegated to redundancy. Western society is losing, indeed may have already lost, its sense of community and be experiencing Durkheim's “anomie” (Giddens 1989, p127). In addition, according to Smith (2001), Western society has lost the sense of working together to make change and in response to the potential threat of total nihilism the communitarian agenda was proposed by Etzioni (1995) as an alternative to greed-inducing instrumentalism (Bell 2005). The agenda draws on the traditional moral values which bind society together, and in a climate of “moral panic” in the mid-nineties (Rikowski 2008, p1), communitarianism offered a form of liberal democracy that would fit different contexts and enable individuals to be self-determining, albeit within a moral framework that may itself be “unchosen” (Bell 2005, p11). In the view of Smith (2001, p8) there is an inclination for political communitarians to “plough a fairly authoritarian furrow”. However, others see in communitarianism an egalitarian philosophy that emphasises community without swamping the individual (Etzioni 1995). The communitarian debate now centres on the theory and practice of human rights (Bell 2005) to which the voice of unpaid carers could contribute much on reform but, unless the agenda is inclusive, their voice will not be heard.

Applying Etzioni's model of organisational involvement to carers (Penley and Gould 1988, p45), they could be said to have a “moral, affective attachment” to their work of caring, but an “alienative commitment” to statutory organisations and residential care and nursing homes which render their voice silent. The case of ‘Jenny’ illustrates this. She was just sixteen when her father died and so traumatised was her mother in being suddenly widowed two weeks before the birth of her sixth child that she became clinically depressed. As the eldest daughter, it fell to Jenny to look after her mother and baby brother whilst working to support her family financially. Now that her mother is in the last stages of Alzheimer's disease, totally helpless and unable to communicate, Jenny is her

sole advocate. One blazingly hot afternoon, when visiting her mother in her care home she discovered that:

Two new care home workers had put her mother to bed two hours earlier than usual “because she seemed sleepy”. When Jenny realised how hot her mother’s bedroom was she sought out the manager and suggested to her that her mother had symptoms of dehydration and needed a drink, not sleep. The manager retorted sharply to Jenny that she should “have more respect for the opinion of university-trained nurses!”

As Neuberger (2005) points out nurses are expensive to train and in her view too expensive a resource to be allowed to feed patients, make beds, plump up pillows. According to Etzioni’s criteria for professionalism (Evetts 2006, p519) they are regarded as “semi-professionals” along with teachers and public sector administrators. All have lower status than highly-paid lawyers or doctors, for example, whose longer training, specialist knowledge, occupational culture and autonomy is socially sanctioned and authorised (Evetts 2006). As her mother’s lifelong carer and sole advocate Jenny has specialised knowledge and had hitherto carried greater scope of responsibility and commitment than any highly-educated ‘professional’. Nevertheless Jenny was perceived by the care home manager as an unwelcome *unprofessional* deserving of disdain. Like many carers, Jenny did not invite her situation in but became ensnared by a system which alienates and fails to value her wisdom and experience or to honour universal ethical principles regarding human rights.

Commenting on the need for health care reform Etzioni, *et al.* (1993, p19) call for paid (American) health care professionals to:

... speak out about health and health care, and act in ways that promote and ensure the provision of all levels of health care ... including special attention to ... preventative services.

The same needs to be done in the UK – and by carers, too – but with privatisation of the NHS anticipated within the next twenty years (Pollock 2008), those doing the speaking may unwittingly be ‘gifting’ the NHS as we know it to extinction and clinching with haste the government’s health-as-a-business deal. Given the “coercive culture” of the NHS and similar organisations which “nurture dysfunction” according to Etzioni (Penley and Gould 1988, p45), it is understandable why so few professionals speak out for change and why so few articles in the literature highlight the unpaid carer’s perspective. What is not understandable, indeed

unacceptable, is the corporate sociopathy operating within these organisations which impacts on those who are saving the establishment around £87 billion a year (The Princess Royal Trust for Carers 2010). In Turner, *et al.*'s (2000) study for example, nurses were given an opportunity to learn about carers' experiences. As was anticipated, some carers became upset when recounting their stories. However, the study was not aimed directly at improving things for the carers but at using their experiences to educate the nurses. Although the nurses were sympathetic to the carers, they did not (or could not) themselves provide skilled therapeutic support for those in distress. As Baker (2007) points out, ruminating about unhappy experiences without adequate support can adversely affect an individual's sense of wellbeing and as Pennebaker (1995) discovered, when cultural values of whole communities are distorted, those living in the shadow of catastrophe become inhibited about self-disclosure, which adversely affects the society's general health.

Enduring unhappy circumstances without adequate support, as many unpaid carers do, is stressful in itself but the fear of retribution renders most of them silent. It is suggested here that in consequence not only is the health of a community of six million unpaid carers at risk, but also their willingness and ability to care. If the social ties and networks that promote solidarity (Putnam 2000) have been eroded, if the quality and values of commitment, mutuality, fellowship, trust and fair play have degenerated (Bell 2005; Rikowski 2008), then family life *is* in meltdown as Justice Coleridge observes (BBC News 2005).

In a society that is losing - or has already lost - the will, if not the ability, to care for itself, the question arises of how its motivation to care can be rekindled. A deceptively simple answer may lie in Maslow's humanistic hierarchy of needs theory which holds that man is inherently good but subject to two different sets of motivational states or forces, namely: those which ensure survival (such as fear of abandonment) and those which promote self-fulfilment, what Maslow terms "self-actualisation" (Gross 1987, p651). "Mature man needs to be needed" (Erikson 1950, p240) and caring does bring intrinsic reward for some whilst for others, like Dave, it becomes a nightmare. Motivations are mixed and vary from person to person (Billington 1988). According to Kantian ethics negating self-interest in doing one's duty, as John did, is synonymous with 'doing the right thing' (Billington 1988).

Family Ties and Tolls in 'Doing the Right Thing'

John felt he had little choice but to do 'the right thing' and negated self-interest:

... you've got to ... convince yourself that you're doing the right thing ... and the right thing has always got to be ... what is to the benefit of the person you're caring for. ... Sometimes the right thing has got to be 'I need a night's sleep' ... you don't exactly ignore what's going on but you have to put yourself first on occasions but not very often (J1/2/3).

In hindsight, however, John wondered if he *had* done 'the right thing' in prolonging his father's life and, as it transpired, his suffering. As Billington (1988) asks: How can a person be sure where their duty lies? The dilemmas faced by carers have some parallels with those faced by professionals in public service who are required (ideally) to consider their duty above their own feelings and resolve conflict rationally using Aristotelian wisdom:

... Practical wisdom is the quality of mind concerned with things just and noble and good for man ... these are the things which it is the mark of a *good* man to do ... (Aristotle, translated 1980, p154, cited in Martinez, 1998).

Thirteenth century theologian Aquinas modified Aristotelian 'practical wisdom' in expounding that nothing is in an individual's intellect that is not first in their senses, and that "Man insofar as he acts wilfully, acts according to some imagined good" (Yalom 1980, p292). The Hobbesian view holds that man's natural state is war-like, selfish, power-hungry, quarrelsome, cruel, perverse, with everyone against everyone, which inspired the conceptualisation of social contract theory, namely that the state should check man's innate, destructive tendencies (Hobbes 1651). It is upon this philosophy that Western political philosophy is based. Schopenhauer shares the Hobbesian, deterministic view of man but regards the body as an extension of the will, and maintains that acts of will, including the will to live and the drive to love, are caused by a combination of unalterable character and motives which are representations of the individual's outside world (Janaway 1998). For Schopenhauer man's motivations and behaviour represent his struggle in a hostile environment (Janaway 1998), which reflects the situation for John who described himself as being "at war" with the system.

Yalom holds that all human beings ultimately choose how they behave and to explain behaviour on the basis of motivation is to absolve an individual of responsibility for their actions. For Yalom (1980, p290) the will is not "an illusory

subjective state” as perceived by Hobbes but the “seat of volition” which can influence motivation but not replace it. ‘Acting wilfully’, according to Yalom, is inextricably linked with freedom of choice but he concedes that whilst “creative” individuals with access to their emotions can will what they want, there are those who cannot. For example, in antisocial individuals the will is suppressed and dominated by impulse; in the neurotic whose emotional life is inhibited, the will is “ensnarled with guilt” (Yalom 1980, p296). There are also those whose will is immiserated by unformed narrative capacity (Erben 2004). However, neither the psychological nor the sociological case holds for many carers: whilst freedom of will to choose may exist in theory, in reality for most unpaid caregivers, ‘creative’ or not, it is Hobson’s choice¹. Jenny, for example, had little choice but to care for her mother and siblings to whom she was very close, but she was also motivated by fear of her family being separated.

At a basic level, without strong mechanisms to keep infants close to adults and motivate adults to care for and protect their infants, human beings would not have survived (Maccoby 1980). The quality of emotional ties between parent or caregiver and child (Bowlby 1969; 1973) is crucial to a child’s sense of security; it sets the scene for his upbringing, has a profound effect upon his feelings and character, and provides a blueprint for later relationships (Maccoby 1980; Gross 1987; Livingstone 2005). Attachment theory is explored in more depth in chapter 4, ‘Findings, Interpretation and Discussion’ but suffice to say here that generally the emotional ties of childhood eventually loosen to enable individuals to *detach* from their parents (Gross 1987). For many unpaid adult carers, however, a form of *reattachment* may take place such as in the case of dementia where there may be role reversal. Having strong family ties is associated with wellbeing in older people whose adult offspring are more likely to provide emotional rather than instrumental support but increased longevity may result in the elderly having to rely increasingly on family networks as key sources of support (Merz and Consedine 2009). Were caregiving to become obligatory and choice denied there could be a huge toll for society in losing the altruism of six million ‘good’ people doing the ‘right thing’, with or without close family ties.

¹ Thomas Hobson (1545-1631) ran a thriving carrier and horse rental business in Cambridge and refused to rent them out other than in the correct order. The choice his customers were given was “this or none”, hence Hobson’s choice (Martin 2008).

Guilt or Altruism

Experiencing guilt according to Winnicott (1965) is part of the human condition, he maintains that it is guilt that gives rise to the capacity for concern for others and the sense of responsibility. Guilt, he suggests, stems from childhood anger prompted by the pressures of the socialisation process. When an infant's needs and wants are thwarted he is permitted to express feelings of frustration and hostility. Through socialisation he learns to control these destructive impulses, contain his 'antisocial' ideas and eventually develops a sense of responsibility for them (Winnicott 1965).

According to psychodynamic theory², individuals experience anxiety about feeling anger towards their parents: they fear punishment, but, fearing the loss of their parents' love even more, they turn their angry feelings inwards and punish themselves (Maccoby 1980). This repression forms the basis for guilt which, in Winnicott's view, is "related to the idea of destruction where love is also operating" (Winnicott 1965, p103). Guilt, when 'mixed' with fear of abandonment, becomes a powerful motivating force in an individual's social development and fundamental to their having a conscience; their "harsh, internalised parent" (Maccoby 1980, p338), an imaginary psychological construct which both punishes and rewards according to Freudian theory (Gross 1987; Yalom 1980). According to the Winnicottian view, a person's conscience can evoke a strong sense of duty (Maccoby 1980). A mixture of guilt, fear and sense of duty may motivate many to care for vulnerable parents or parent figures but for John, Dave and Jenny, in opting to do so, their "volition" (Yalom 1980, p290) was also influenced by altruistic motives, since, according to Maccoby's (1980, p344) definition, each had:

... a willingness to take positive action (i.e., helping, comforting, rescuing, defending, or sharing with others) to further the interests of other people, even if the action requires sacrifice of time or immediate self-interested goals.

Altruism is a question of *degree* of sacrifice, namely the extent to which motives are, or should be selfless or how far they are inescapably selfish, according to Billington (1988, p24) who, with the Christian ethic of 'loving one's neighbour as oneself' in mind, observes that:

² The very expression 'dynamic' was borrowed by Freud from nineteenth century physics to convey the idea of two conflicting forces producing a resultant third force acting in another direction. Central to psychodynamic theory is the idea of conflict over unacceptable aspects of the self (Brown and Pedder 1979, p11).

I am unlikely to make much of a contribution to my neighbour's wellbeing if I am indifferent to my own. ... Perhaps the most charitable actions are those which don't leave the recipient with a sense of being beholden to the agent.

A newborn baby would not have this sense of being beholden and therefore a mother who gives up her career to look after offspring could be seen as a good example of altruism. In a study of perceived commitment to motherhood and communality of working mothers, Gorman and Fritzsche (2002) found the behaviour rated as most selfless and altruistic was that accompanied by the greatest sacrifice, echoing Billington's notion of degree. The ratings were made by undergraduates, however, whose own career aspirations may have influenced their view of mothers who opt to give up their careers. It is not clear if the study allowed for the possible changes in attitude of mothers who give up work. For example, the greater the sacrifice or hardship associated with their choice, the greater would be the pressure towards 'making the best of it' according to Gross (1987), who observes that as a species, much of our behaviour is altruistic. He includes here activities of whole professions and occupations that help other unrelated people, recognises that such 'altruism' also provides these people with monetary reward, yet fails to mention *unpaid* family caregivers who behave selflessly in situations they did not invite in. A spouse suffering from Alzheimer's disease may become uncharacteristically dependent upon their partner and eventually 'lost' to them (Wagner, *et al.* 1997); a stroke may suddenly disable a parent who then becomes physically dependent upon a grown-up son or daughter, as in John's case; there may also be a complete role reversal for a child who cares: Jenny now cares for an ageing parent who no longer recognises her but were she caring for a parent with mental illness at sixteen in today's society she would probably be regarded as a 'young carer'.

Most carers care without the prospect of reward; many become poorer as a result; the majority would probably rather not be doing it but few carers continue to care because they think they may need help themselves one day. Some may fear "community's rebuke" were it known they were acting selfishly but most probably continue caring out of a sense of duty because they feel it is 'the right thing to do', as John did, (Billington 1988, p25) or, like Dave and Jenny because they feel compassion for the person they love.

Love and Compassion

In her fascinating paper analysing the concept of compassion, Schantz (2007) subscribes to the distinction made by Dietze and Orb (2000, cited in Schantz 2007) between pity, which they argue conveys condescension and dissociation, and compassion, where any sense of differentiation is removed. For Rousseau, however, there is no such distinction; it is through feeling compassion or pity that man recognises the vulnerability he shares with all human beings and appreciates the pain of others (Janaway 1998, 2002). Compassion (or sympathy) is our one genuine moral impulse, according to Shopenhauer (Janaway 1998, 2002) however, Schantz (2007) does not regard compassion (and by implication altruism) as an inherent quality in mankind, inferring instead that it is learned and (perhaps like Yalom, 1980) ultimately a matter of choice. Schantz (2007), an assistant professor at an American school of nursing, attempts to persuade her reader that the caring, compassionate behaviour required of trained nurses (who after all choose their profession and get paid for what they do) is altruistic. She refers to man's selfishness and links self/essness with pain, highlighting the paradox of the "altruistic ... and noble ideals" which the nursing profession fosters in its novices who then encounter the "real world" of the hospital ward. This for Schantz (2007, p49) was painful; for Kramer (1974) it was a "reality shock".

As Yalom (1980, p300) points out, choice is made "only after wishing occurs", and is part of a process which requires effort involving commitment and volition. However Koenig, *et al.*'s (2007) study on twins found that altruistic (and therefore compassionate) behaviour was in fact genetically programmed and not environmentally influenced. According to Dawkins (1976, p36), human beings are born as selfish survival machines with the gene as "the basic unit of selfishness", but he concedes that "whilst our genes may instruct us to be selfish we are not necessarily compelled to obey them all our lives" (Dawkins 1976, p3). In subscribing at least in part to the notion of free will (Yalom 1980), Dawkins appears to concur with Maslow's humanistic theory of motivation (Gross 1987) but claims that even "reciprocal altruism" (Dawkins 1976, p166) – you scratch my back and I'll scratch yours – is really long-term selfish interest (Dawkins 1976, p200). In the case of unpaid carers, their resilience in the face of alienation and exploitation suggests they are motivated to care because "[a greater] love is operating" Winnicott (1965, p103). Caring about the welfare of others is

synonymous with love, according to psychologist Farsides (2007), and fundamental for promoting a truly caring society. He suggests that the greater people's ability to empathise with others and appreciate the world from their perspective, the greater their potential to be altruistic. Appreciating the pain of others echoes Rousseau's philosophy (Janaway 1998, 2002) and as Farsides (2007) observes, altruism tends to thrive when people are not prevented from developing and expressing the nobler of their natural inclinations. Yalom (1980, p434) appears equally optimistic about everyone's "latent nobility" and potential for good. On altruism Brown (1986, cited in Gross 1987, p330) concludes:

... cultural evolution, not biological, (i.e., kinship) has produced moral principles that can powerfully reward actions that are in accord with them.

Higher Moral Principles

Unlike Hobbes and Schopenhauer, for whom character and motives are unalterable, Kant expresses the hope of individuals developing (or evolving) into "mature moral agents" (Billington 1988, p112), which aligns with Kohlberg's theory of moral development (Gross 1987). According to Kohlberg, our morality is partly under the control of maturation and in this sense it has biological roots in that we are predisposed to acquire a particular form of thinking in relation to our social experience (Gross 1987). However, educational and other socio-cultural factors can influence the rate of our moral development and how far it will actually progress. New and challenging situations (such as adversity) are important to a person's 'moral evolution', according to Kohlberg, who began developing his theory over fifty years ago (Gross 1987). Interestingly, Kohlberg's theory embraces the human rights of vulnerable people and their carers since the predominant themes are: the sacredness of human life; understanding of equality; respect for the dignity of human beings as individuals, and justice, which for him is the most fundamental moral principle.

Critics of Kohlberg maintain that all morality is culturally relative and that it is ethnocentric to regard one kind of moral thought as "higher" or "more mature" than another (Gross 1987, p552). However, Kohlberg's critics have not addressed the epistemological problems of relativism. For example, moral relativism rejects the idea of an objective morality and there are no absolute rights or wrongs, only different situations. In cultural relativism moral values are

applicable only within certain cultural boundaries – torture is an extreme example where the predominant principles of Kohlberg's theory are ignored. There are six levels to Kohlberg's theory of moral reasoning, the highest of which is attained by only a few exceptional, resilient individuals who devote their lives to humanistic causes that are guided by universal ethical principles (Gross 1987). According to Janaway (1998, 2002), Schopenhauer observed that individuals governed by compassion apprehend the world and their place in it in a superior way, and they and their actions are good. Whether John, Dave and Jenny heeded their head or their heart to care for others, whether motivated by guilt or altruism; duty and 'practical wisdom'; whether they were driven by self-punishment or self-fulfilment, or cared because it was the right thing to do; whether they had Hobson's choice or acted wilfully according to higher moral principles, they are regarded here as exceptionally altruistic human beings highly resilient to the hidden toll of caring.

The Hidden Toll of Caregiving

In broad terms, stress is a 'fight or flight' state that occurs when someone is faced with events they perceive as endangering their physical or psychological wellbeing, and they are unsure of their ability to deal with these events (Atkinson, *et al.* 1990). According to Baker (2007) there is a strong interaction between emotions and wellbeing and accumulating evidence shows that continuous stress increases the risk of an individual developing many different physical conditions and diseases; stress lowers immune function, slows wound healing, induces damage to DNA and affects its repair. Unpaid carers, who often do not have the time (or the money) to eat or sleep properly, frequently feel depressed and often suffer from viral infections and feel 'low' (Dawson 2004). This was the case for Jenny, scorned by a care home manager who subsequently accused her of seriously abusing her mother. With unwavering tenacity during two traumatic years, but at high cost to her own health which some might regard as heroic, Jenny refuted the allegations of abuse made against her and found the strength to withstand subjugation by social workers and vulnerable adult protection officers. Despite strong opposition by the care home staff she took photographs of her mother's bruised face, kept a contemporaneous log of her concerns and with Advocate's support eventually cleared her name. It transpired that to cover up their own poor practice the care workers had blamed Jenny who received a

full written apology from the head of the social services department concerned and won the right to care again for her mother at home, thereby creating a precedent for other carers. The independent investigator commissioned by the local authority to conduct an internal review of her case recommended that “Jenny’s status as a sole advocate for her mother be recognised, noted and respected”. He also strongly recommended that:

... a note be placed prominently on ‘Mrs Smith’s’ file to the effect that evidence shows that care in ‘Castle Court’ [nursing home] was not always adequate at the time of the incidents and that her daughter Jenny was not an abusive perpetrator towards her mother ... that the actions she took were undertaken in good faith for the relief of her mother’s pain and distress.

Fortunately for Jenny, the senior administrator to whom the independent investigator reported accepted his recommendations; were he a person lacking in integrity he could have instead utilised the investigation as an audit trail to hide the truth rather than to reveal it. A complete list of the independent investigator’s recommendations may be found in Appendix A2.2.

When carers contact Advocare or are referred they are usually at their wits’ end, stressed and distressed with no ‘fight’ in them to improve their situation or opportunity to take ‘flight’ from it. Most fear backlash from officialdom; indeed, subjugation, feeling helpless and not being in control of what is happening, seems central to their distress (Atkinson *et al.* 1990). In the following eight anonymised casework vignettes all the carers are older people and all except ‘Clive’ in the first vignette (V1) are, like Jenny, sole advocates for vulnerable adults. With the exception of Clive and ‘Geraldine’ (V5), none is in particularly good health or has much social capital (Putnam 2000) insofar as they are isolated and lack social support networks such as extended family, friends, neighbours and reciprocal connections with other problem-solving agencies.

Vignettes of Grief, Anger, Fear and Anxiety

(V1) The case of ‘Clive’

After a hip operation Laura (80+) was admitted to a rehabilitation unit where she contracted infections, developed (preventable) bedsores, was left to lie in urine-soaked bedding and died two weeks later. Shocked and grief-stricken Clive wanted to “get to the truth” about the demise of his neighbour and friend of thirty years. Laura’s medical notes, to which Clive was denied access for over twelve months, showed ten derelictions of basic nursing care.

Clive was very angry about the neglect and pain his neighbour suffered before she died and reported his case to the police. It is being investigated as a 'low priority' but so far not enough evidence has been found to mount a case of clinical negligence.

(V2) The case of 'Wendy'

Full-time carer and sole advocate Wendy, who has reasonably good social support, regretted having to "put her mother in a home" when she herself went into hospital for a major operation. Angered by the home's substandard care, Wendy approached staff and social workers about moving her mother. The care home manager claimed Wendy was being over-vigilant and made an official complaint against her. Wendy was then bullied and intimidated by social services staff and became afraid to move her mother. Suffering from dizziness, headaches, tummy ache, chronic fatigue and confusion, Wendy wondered if she herself had Alzheimer's disease.

After working with Advocare for over a year Wendy found the courage to challenge the care system, showed that it was inadequate in her mother's case and won the right to bring her mother home again. In the meantime one wing of the home was closed down after an official inspection and since then it has had three different managers. Wendy's health has since slightly improved.

(V3) The case of 'Sally'

Always in a 'low' state Sally, who has little social support, left an official envelope unopened for three weeks, scared of its potential contents concerning the care of her father for whom she is sole advocate.

Other carers intimidated by bureaucracy have also asked for official letters to be sent to them via Advocare.

(V4) The case of 'Ray'

Extremely kind but anxious and unassertive, Ray has a stress-related illness and feels he is fighting against time: his frail, elderly father, to whom he is devoted, has moderate dementia. Like many carers Ray lives on the cusp of poverty (Carers UK 2007) and is worried his father will have to go into a home due to his progressively worsening mobility. Advocare helped Ray's father to become the beneficiary of a charity through which he received vouchers for clothes and bedding and subsistence towards food and transportation costs.

It is worth posing the question here why caring for a vulnerable person at home to prevent their institutionalisation does not warrant financial consideration equal to that for fostering a child, and equal human rights. Fostering someone else's sixteen-year-old, for example, attracts a minimum weekly allowance at the time of writing of £204 (The Fostering Network 2007) plus possible additional allowances

for clothing, school uniform, travelling, birthdays and holidays, compared with the Carers Allowance which is just over £50 a week.

Apart from the prospect of 'losing' a loved one to dementia, being separated from them is perhaps the most anxiety-provoking scenario for carers.

Vignettes of Separation and Loss

Geraldine found separation difficult:

(V5) The case of 'Geraldine'

Geraldine's husband has Alzheimer's disease and is in a nursing home. She cared for him at home for several years until she could cope no more. She visits her husband every day but so distressed is she because he no longer recognises her that her doctor told her to visit only once a week. Geraldine feels guilty about not visiting him every day. Advocare suggested tailing off the visits and seeing her husband on alternate days but Geraldine insisted on doing as her doctor told her. "But it breaks my heart!" she said.

Despite strong social support Geraldine is suffering a 'living bereavement' and grieving for the man she once knew. Grief is both an expression of distress and a cry for help which if unrecognised can put mental health at risk (Parkes 1998).

(V6) The case of 'Marlene'

Marlene, a sixty-plus year-old, travelled over fifty miles each day for a year to see her husband in a psychiatric hospital. The separation did neither of them any good. So worried and upset was Marlene about the drugs and treatment her husband was receiving she came near to collapse. Once Marlene realised she could move her husband to a more appropriate unit nearer home she began to rally. Now he is "being treated like a human being" and "safe and happy", no longer on the powerful anti-psychotic drugs that had changed his behaviour.

Interestingly, once Marlene was assured her husband was being properly cared for she visited him less, even though he was much nearer home. She began to pick up the threads of normal life again but stress eventually took its toll and Marlene 'caved in' with severe depression for six weeks.

Loss, according to Parkes (1998), may go unrecognised when the imperceptible progression of an illness, such as Alzheimer's disease, is ignored. Social pressures from families and allegiance to a spouse, he points out, force them to pretend that the gross change in personality that has resulted from the disease has not impaired their relationship. The failure to acknowledge the truth may cause them to blame the spouse for failing to be the person he or she always

was (Parkes 1998). Parkes, however, fails to acknowledge that 'professional' insensitivity can intensify living bereavement, as for Geraldine and Marlene.

Vignettes of Institutional Abuse of Older People - and their Carers

Some 22,000 older people are being given drugs to sedate them, to make them easier to manage by paid care workers (Neuberger 2005; Action on Elder Abuse 2003), over a third of whom are the perpetrators of abuse (JCHR 2007). Nurses have been found to sleep through night shifts and unnecessarily dress patients in incontinence pads so they are not disturbed; some older people come near to starvation in care homes, others are left to die because call buttons are placed out of reach (Neuberger 2005).

(V7) The case of 'Janet'

Janet is in poor health and has little reliable social support. Her mother Lily has a serious mental illness and lived in sheltered housing where the personal care she received was inadequate. Lily was often left for hours in her own excreta, afraid to admit this, and to being maltreated and bullied by her paid care workers, to anyone except her daughter and Advocare. Lily is over-awed by and over-compliant with authority figures. Janet worked tremendously hard to keep her mother clean and comfortable. With Advocare's support she found the courage to confront the health and social services departments. Health care professionals chose not to believe her and social workers accused Janet of lying about the dehumanising conditions her mother was living in. After reporting Lily's plight to every relevant organisation, including the Healthcare Commission and the police, to no avail, Advocare prompted a local authority Protection of Vulnerable Adults (PoVA) investigation. This turned out to be a fruitless, time-wasting exercise as Lily's over-compliance was not appreciated and "no evidence was found to substantiate Janet's allegations".

It took Janet almost another year to get her mother into a suitable nursing home.

'Mary' could not assert herself with care workers and was treated cruelly.

(V8) The case of 'Mary'

When Mary, who always feels 'low', complained about the staff and the standard of care in her father's care home the manager restricted her visiting rights. Despite strong support from her partner Mary could not assert herself. She felt heartbroken at not being able to stay long enough in the evening to make sure her father was comfortable in bed and say 'good night' to him.

Mary's health deteriorated further but with Advocare's support she found the strength to 'take on the system' and won back her visiting rights.

These eight vignettes were selected to illustrate typical situations. It is interesting that the only two carers in good health had strong social support: Clive (V1) who

was prepared to 'fight' to get to the bottom of his neighbour's demise and Geraldine (V5) who was in 'flight', unable to come to terms with her husband's illness. The other vignettes illustrate how fearful, anxious, angry, grief-stricken and guilt-ridden carers may become, and as yet the Human Rights Act has failed to address this (Carers UK 2007). In the case of Wendy (V2) and Marlene (V6), both were intensely concerned for vulnerable loved ones at risk, but felt too oppressed to fight for their rights. Wendy's 'over-vigilance' closely parallels Erikson's (1950, p122) "worried devotion" for a newborn, and any guilt seems to resonate with a role-reversed attachment – or reattachment (Bowlby 1969; 1973) – for there is no doubt that "love was operating" here (Winnicott 1965, p103). For over a year Wendy felt intimidated; fear checked her anger, which adversely affected her health (Baker 2007). There is an irony here: as infants we are encouraged to keep our hostile feelings in check (Maccoby 1980; Winnicott 1965), but doing so in adulthood can put our health at risk (Baker 2007). Moreover, it is suggested here that chronic fear is more harmful. The way Mary (V8) was victimised and Jenny was undermined by care home workers illustrates how unpaid carers are perceived at best as a resource and at worst as a nuisance and Janet's case (V7) is an example of how the system sanctions the appalling abuse of vulnerable older people and exploits their carers.

If not cruelty *per se*, insensitive and uncaring attitudes that lead to abuse in institutions is something Neuberger (2005, p45) predicts will increase with each "layer upon layer of regulation and inspection". What is needed, she suggests, is the "opening up" (Neuberger 2005, p45) of institutions so that ordinary people can come and go frequently as part of daily life. Openness, she believes, is far more likely to breed an atmosphere of trust than any system of regulation and inspection. These open institutions, it is suggested, would have to tolerate their visitors to be open too, as for too long they have been suffering in silence and subjugated (Carers UK 2007). Showing concern for a loved one in a culture where corporate sociopathy is operating rather than love and compassion puts carers at a huge psychological disadvantage. Neuberger (2005) suggests that callous attitudes stem from poor planning, and that inadequate training and the low status and pay of care workers are the cause of institutional abuse. "Callous or even dehumanised perceptions of others" are seen by Maslach, *et al.* (1996, p4) as symptoms of burnout which can foster a blame culture. This highlights the need

for change not only in the attitudes of those responsible for planning and training but also in the policy-makers responsible for the low status and pay of staff. However, since the guiding principles of 'practical wisdom' (Martinez 1998) are incompatible with utilitarianism, it is difficult to see how this aspect of care could actually improve.

In the following two sections, the effect of burnout on the health of professional caregivers is discussed and the possibility of this syndrome affecting unpaid carers is considered along with some strategies for prevention.

The Burnout Syndrome

Those who work with the suffering suffer from the work they do, according to Figley (2002). Therapists caring for others in emotional pain are at risk of developing a clinical disorder which Figley (2002, p2) terms "compassion fatigue", a form of emotional burnout. Burnout was first recognised more than forty years ago according to Maslach (2001) who describes it as a process, a psychological syndrome associated with chronic emotional and job-related stress (Maslach and Goldberg 1998). Maslach's ground-breaking work with Jackson produced the Maslach Burnout Inventory or MBI (Maslach and Jackson 1986). The MBI comprises a twenty-two-item questionnaire employing a seven-point rating scale. In Appendix A2.3 is a modified extract highlighting key aspects of demotivation. The MBI can be self-administered in ten to fifteen minutes but cannot (yet) be used as a diagnostic tool (Maslach, Jackson and Leiter 1996).

Years of service is a predictor of burnout according to Maslach (2001), the hallmark of which is (1) emotional exhaustion; the other defining components are (2) cynicism and detachment from the job, and (3) a sense of inefficacy and reduced accomplishment. Sufferers of burnout are, in effect, demotivated. They have a sense of wasting, no energy and feel drained of their resources; symptoms include negative self-concept and low self-esteem; they experience personal conflict at work, have a diminished interest in their job due to a lack of resources, and a sense of powerlessness over their work situation; their contact with colleagues is cold and impersonal (Benevides-Pereira and Das Neves Alves 2007; Schutte, *et al.* 2000; Maslach 2001; Maslach and Goldberg 1998; Embriaco, *et al.* 2007). Conversely, in their study of non-professional

counsellors in South Africa, Fourie, *et al.* (2008) found those who were 'at one' with themselves and their work, had a stable set of life experiences after the age of thirty and a strong sense of coherence experienced less burnout, more work engagement and more professional efficacy.

Since women are in the majority in the caring professions, burnout affects more women than men, according to Benevides-Pereira and Das Neves Alves (2007), but interestingly they found women had lower burnout scores than men. They suggest this is because women tend to have more opportunity to cry and share their worries, whereas men tend not to express their emotionality. Again this supports the link between health and emotion (Baker 2007). However, burnout scores also tend to be higher in those with a less "hardy" personality, and those with an external locus of control (Maslach 2001, p1417; Gross 1987), which implies that the syndrome affects people who are weak or "flawed" in some way (Maslach and Goldberg 1998, p1417). Impaired cognitive functioning is also associated with chronic burnout, according to Sandström, *et al.* (2005). However the idea that it is the result of over-achievement, almost virtuous and noble, and a consequence of going above and beyond the call of duty helps to counter this notion (Maslach and Goldberg 1998), and it is suggested here that carers who 'walk the extra mile' can and *do* suffer from burnout. Whilst Figley (1997), for example, recognises emotional burnout can affect members of a family traumatised by tragedy, such as a life-changing disaster or serious injury to a child, there seems to be a general failing to appreciate the suffering and possible burnout in unpaid family carers like John, Dave and Jenny.

According to Schutte, *et al.* (2000), a modified version of Maslach's Burnout Inventory, the MBI-General Survey, is a suitable instrument for measuring burnout across nations and various occupations including blue collar workers. A study by de Souza Barros, *et al.* (2007) found that high levels of burnout were related to lower quality of life in four domains: physical, psychological, social relationships and environment, which ties in with the situations of unpaid carers. There are, however, some important differences to consider. Those working in the caring professions, for example, have trained and entered them of their own volition and in theory are free to leave or to give up their job altogether, whereas carers do not choose their family circumstances and often feel trapped. The nominal eight

hour working day ends for the professional whereas it does not for carers living with someone with dementia; they are 'on duty' twenty-four hours per day, seven days per week, which is a 168 working-hour week. Professionals can have therapy as supervision, take a holiday or sick leave whereas carers cannot and they have to fight for meagre respite which is not free of charge. Stress at work, according to Maslach, *et al.* (1996, p42), results from a "mismatch" in areas such as workload, control, reward, community, fairness and values, which highlights the fact that whilst paid care workers may choose to stay in the 'wrong' job, unpaid carers have to tolerate such 'mismatch' and further, that those nurses who have to 'learn' compassion (Schantz 2007) may be 'wrong' for their job.

Maslach (2001) describes professionals with burnout as being indifferent to their clients and Bauer, *et al.* (2005) found there was an emotional distancing from work colleagues. Carers cannot distance themselves from their loved one and still continue caring for them, any more than they can distance themselves physically from their situation. Instead, Gardner (2006) suggests, they distance themselves from themselves. An interesting concept put forward by Juthberg, *et al.* (2008, p1905) is the "deadening of conscience" which can cause "profound loss of wholeness, integrity and harmony in the self", and is strongly associated with burnout. Most participants in Juthberg, *et al.*'s (2008) study were nurses in an old people's home, and the few who kept silent about organisational practices which they knew were wrong in order to keep their jobs suffered a 'deadening of conscience'. Juthberg, *et al.* (2008) do not specify the events that troubled the participants' conscience, but it is worth noting that the study has some resonance with the cases of Jenny, Wendy (V2) and Janet (V7) and the diminished sense of selfhood suggested by Gardner (2006) in carers who are psychologically disempowered. The findings of Juthberg, *et al.* (2008) reveal that most nurses told someone about practises they knew were wrong and supports the notion of Benevides-Periera and Das Neves Alves (2007) that sharing worries can ameliorate the effects of burnout.

The Unpaid Carer's Syndrome

With regard to preventing burnout, some years ago Maslach and Goldberg (1998) recommended a positive approach that is situation-centred rather than person-centred, and one which promotes an individual's engagement and motivation

rather than disengagement from the work they do. In other words, focusing on the main stressors and removing these as opposed to treating the 'flawed' sufferer for a clinical disorder or a cognitive impairment. This would seem a sensible approach since it puts the onus of prevention on the organisation, not the individual, although, having said this, the notion of mismatch has to be considered. Not only might this prevent burnout *per se*, but also prevent the syndrome being medicalised as a psychological disorder in a patient needing treatment. More recent studies show that organisations are failing to recognise that burnout prevention strategies are urgently needed in health care, social care and education. Interpersonal strategies are needed to increase social capital for the individual which provides a buffer; further, reduced working hours and strategies to foster a better sense of community within the organisation are needed so that individuals are supported, have a sense of belonging and feel valued by each other (Embriaco, *et al.* 2007; de Souza Barros, *et al.* 2007; Putnam 2000; Maslach 2001; Bauer, *et al.* 2005; IMCARES 2008; Fourie, *et al.* 2008).

Echoed here is the theme of the communitarian agenda for political reform referred to earlier in the section 'The Need for Change'. It is worth mentioning that when asked if he thought he was suffering from emotional exhaustion, John, the participant in the current study, affirmed this without hesitation and without knowing it was a defining component of burnout. Reflecting on the toll his caring role took on him, John commented that he still had difficulty sleeping³. He also described a sense of depersonalisation and remains cynical about the system that consistently let him down. With regard to inefficacy however, he answered without hesitation: "I couldn't do less otherwise my father would have suffered".

In making the choice they do most carers 'act wilfully' and mature into 'moral agents' with 'practical wisdom' of what is just, noble and good (Billington 1988; Martinez 1998). However, would the carers in the vignettes have taken on their caregiving role had they been aware of the dynamics that would be operating against them and which would exhaustively exploit their altruism? Most would probably not have done things differently, even though caring was (self-)punishing psychologically (Maccoby 1980; Winnicott 1965; Gardner 2006).

³ Sleep strengthens memory and promotes mental structuring (Sandström, *et al.* 2005) which highlights the need for respite for those caring 24 hours x 7 days a week = 168 hours a week for people with dementia.

Much research has been carried out to ascertain carers' unmet needs but it has consistently failed to address them and merely affirms what is known already: that carers sacrifice their time and energy, some their careers, aspirations, even autonomy, to look after the frail, sick or disabled and that their future is grim in a society that has traded its generosity of spirit and compassion for liberalism and individualism. In the face of potential nihilism and 'meltdown', the drive for communitarianism is shifting political focus onto the need for a better sense of community, but unless the rules of engagement are fair, the situation will only be improved for those of sufficiently high status to be heard, not for carers who, like Jenny, are seen as unprofessional, deserving of scorn, and have no voice. Perhaps the communitarianists in their new debate on human rights could widen their 'authoritarian furrow' sufficiently to replace short-sighted dogma with collective practical wisdom and usher in true transparency for carers. Then, when the era of openness arrives, instead of having to 'put up and shut up' about appalling standards of care and a bureaucracy that apparently concerns itself only with process and defending its utilitarian masters, carers like Jenny, no longer alienated, could make an impact on their intransigence. Today, particularly in the caring professions within and without this 'corporate bubble' is a common theme conspicuous by its absence, namely: the sense of belonging (Smith 2001). Addressing this theme alone might ameliorate the symptoms of society's 'current malaise' but not root out the cause of its 'deadened conscience'; people not feeling valued, not being valued and not valuing others.

In order to restore the sense of belonging to a society that is out of kilter and 'ellipsing', if harmony is to be brought to coercive organisations and to society at large, it is suggested here that attitudes of policy-makers need to change. Since utilitarianism seems impervious to 'practical wisdom' and hardship not "countenanced" (Ross 2002, p10), perhaps the answer is to persuade policy-makers not of what is right, but of what is *wrong*. For example, it is *wrong* for unpaid carers to suffer from the stress of subjugation and exploitation; *wrong* for older people to be neglected and abused by those paid to look after them; it is *wrong* for families to be expected to bear the financial cost of care that fails abysmally to meet the needs of their loved ones. However, caution is needed, for the broadcasting of such evidence as mentioned may unwittingly strengthen the case for the government's health-as-a-business deal to be clinched sooner rather

than later. It is not intended to make political comment here but rather to show by contextualising the stress which caregivers, paid and unpaid, experience how contemporary society, not guided by higher moral principles and fostering a blame culture, engenders corporate sociopathy which is burning out good people.

Whilst burnout in professionals has long been recognised (Kramer 1974), it has yet to be accepted that the onus is on organisations to implement prevention strategies. Meanwhile for those being paid for doing 'people work' the suffering goes on and the presence of burnout in unpaid carers and the toll it takes on them continues to go unrecognised. Unable to 'fight' alienation and subjugation by the establishment or to 'take flight' from situational stressors which may include a race against time with respect to a loved one's progressive condition, unpaid carers experience emotional exhaustion and may distance themselves psychologically from themselves (Gardner 2006). The conclusion drawn from this study is that the stress and distress they experience can lead to a condition termed here as 'the unpaid carer's syndrome' which is similar to, but not the same as, burnout in paid care workers. The physiological and psychological symptoms, including emotional burnout and distancing, do not manifest themselves in individuals before they take on the responsibilities and demands of caring for a frail, sick or disabled loved one but tend to persist even when these dynamics are no longer operating. Thus it is argued that the unpaid carer's syndrome is the hidden toll of caregiving and may be seen as a symptom of a compassionless society which appears itself to be burning out.

According to communitarians, society is in need of a moral revolution to redeem its conscience regarding human rights and restore its guiding principles for equity. Based on the belief that everyone has noble inclinations (Yalom 1980) and is capable of altruism, the voice of carers, if heard, could bring revelation and contribute much to moral evolution.

Chapter 3

Methodology and Methods

Introduction

As explained in chapter 1, Advocate – Caring for Carers is a small, independent charity which seeks to support unpaid carers of the frail, sick and disabled and enable them to champion their own rights and those of their vulnerable loved ones without fear of retribution from officialdom. In order to strengthen this endeavour the Assert programme (Gardner 2006) was devised as A Semi-Structured Empowering Reflective Therapy based on Butler's (1963; 1974) concept of life review therapy and incorporating Pennebaker's (1990) narrative writing paradigm. The first stage in the Assert development programme (Gardner 2006) involved four middle-aged participants, two long-term carers and two former life-long carers. Positive outcomes from the initial development work prompted this single-subject study to be undertaken in order to discover whether the Assert programme would be safe and effective on a one-to-one basis. If so, future Assert programme participants could then be offered the choice of a life review process in either a group or an individual setting with confidence.

Before describing the methodology and methods for data collection and analysis for this study, some background on the Assert programme is provided, beginning with a brief outline of the concept of life review as a natural process and as a form of psychotherapy (Butler 1963; 1974). The rationale for life review therapy for unpaid carers is then outlined after which some of the theoretical principles underpinning the methodology for the Assert programme are described. This is followed by the rationale for adopting an iterative protocol for the Assert life review process. Some of the potential risks, costs and benefits of life review therapy and narrative writing therapy are then considered after which the therapeutic stance of the Assert programme facilitator is described. Next some background on the development of the methodology for identifying key outcomes of the Assert programme is given together with an explanation of how some of the associated problems were surmounted. The aims of this study; the participant, 'John'; and the setting, with myself as facilitator, are then briefly described, followed by the ethical considerations. Lastly the methods for data collection and analysis of the data are detailed.

Background to the Assert Programme: The Concept of Life Review

Some years ago, whilst working as a reviewer of mental health services for the Health Advisory Service¹, I visited a hospital ward for older people with severe and enduring mental illness and was inspired by the vitality and effectiveness of a therapy group facilitated by the young ward manager who had started running such groups there after alighting upon the concept of life review almost by chance. He directed me to the work of Butler (1963; 1974); Lewis and Butler (1974) and Sable (1984) from which I learned that research psychiatrist and gerontologist Dr Robert Butler had identified the concept of life review as a spontaneous healing process. He defines it as:

... a naturally occurring universal mental process characterised by the progressive return to consciousness of past experiences, and, particularly, the resurgence of unresolved conflicts; simultaneously, and normally, these revived experiences and conflicts can be surveyed and reintegrated (Butler 1963, p487).

People of all ages “look back to comprehend the forces and experiences that have shaped their lives” (Butler 1963, p492) but the process assumes more intensity in older age when it is “essential to the final reorganisation ... of the personality” (Butler 2002, p5). In Butler’s (1963; 1974) view, the personality can change across the lifespan and on perceiving a connection between the inner experience of reviewing the past in order to understand the present, and the occurrence of later-life disorders such as depression, he pioneered life review therapy for older people.

Butler’s (1963; 1974) life review therapy was based upon the premise that with an empathic listener older people, particularly those nearing death, can re-examine their life, make sense of the life they have lived, resolve loss, address unresolved conflicts (Butler 1963; 1974) and “forge new means of adaptation” (Butler 1982, p355). According to Butler (1974) older people experience the full range of emotions and, contrary to popular myth, they also experience more stresses than any other age group. He comments at length on their “remarkable resilience” to “external stressors” which “often are devastating” and bring about “internal reactions” such as depression, anxiety and psychosomatic illnesses (Butler 1974, p532). Butler, however, fails to acknowledge that many unpaid carers are themselves older people who experience high stress levels in their caregiving role.

¹ The Health Advisory Service, now the Health and Social Care Advisory Service, is a registered charity which assesses standards and makes recommendations to the Department of Health.

The Rationale for Life Review Therapy for Unpaid Carers

Butler (1974) recognises that grief, either for one's own losses or for the ultimate loss of oneself, is a frequent companion of old age and it is suggested here this can apply to carers, too, whatever their age, but with one difference. Butler (1974, p532) sees loss of oneself as "ultimate loss" and synonymous with a person contemplating their own mortality but in the context of caregiving, 'loss of oneself' may be interpreted as a diminished sense of selfhood, what Charmaz (1983) describes in the chronically sick as a "fundamental form of suffering".

Some carers distance themselves psychologically from themselves (Gardner 2006) as a defence mechanism when, for example, their resources are outstripped by the demands placed upon them, what Mirowsky and Ross (1989, p85) term "role overload", or when they are experiencing prolonged stress which, as suggested in chapter 2, can induce "burnout" (Maslach 2001), or when they are in constant crisis which they cannot resolve or from which they feel there is no escape. According to Butler (1963, p493) it is generally when 'in the face of a life crisis' that people consider their past and re-examine their identity; indeed, one of the criteria for joining a life-cycle therapy group is being in acute, sub-acute or chronic crisis (Butler 1974). Since many unpaid carers, in particular long-term sole advocates of vulnerable people, are in 'chronic crisis', it seemed pertinent to consider: why not life review therapy for carers? For if, as Lewis and Butler (1974, p168) claim, during the process of re-examining their life a person's identity is "restructured" and their "sense of selfhood stabilised", then this form of therapy could re-empower disempowered carers.

Although life review therapy was developed originally for those approaching the end of their journey through life (Butler 1963; 1974; Lewis and Butler 1974), in an effective group both old and young can "re-experience the past through each others' lives and unite against the vicissitudes of the life-cycle" (Lewis and Butler 1974, p173). Drawing on my own insights and experience as a long-term carer, my counselling skills and integrative psychotherapy training, I set about developing the Assert programme (Gardner 2006) based on Butler's (1963; 1974) concept of life review therapy, and incorporating Pennebaker's (1990) narrative writing paradigm, envisaging that a gentle, non-directive therapy could help carers, whatever their age, to deal effectively with the 'vicissitudes' of caregiving.

The Therapeutic Principles Underpinning the Developing Methodology for the Assert Programme

Haight (1988) sees life review as a naturally-occurring adaptive process whereby older people can achieve *reintegration* and parallels this with *integration*, Erikson's (1950, p222) last stage in his "Eight Ages of Man" theory of psychosocial development, the opposite of which is despair. Sable (1984) also sees the concept of life review as a developmental process and describes it as a journey towards self-acceptance initiated by structured recall or reminiscence. Negative memories according to Haight (1988) are as important as, if not more than, positive ones. However, whereas she regards reminiscence as a communal 'feel good' activity, Butler (1980, p53) describes reminiscence as the process of "recollecting past experiences without evaluation". In the view of Bender, *et al.* (1999, p240), Erikson (1950) may have identified integration but Butler "reframed reminiscence" as the method for achieving it. Each act of recall is a re-creation, a "narrative framing" which is a "dynamic, variable and vulnerable process"; but not all past experiences are shared, some are hidden (Lewis and Butler 1974; Young and Saver 2001, pp72-79). The facilitator's role in life review therapy is to make the process for the individual concerned "more conscious, deliberate and efficient" (Lewis and Butler 1974, p166).

In formulating the original proposal for the initial Assert development work I consulted Professor Roger Baker, Head of the NHS Research and Development Support Unit in Poole, who suggested that incorporating psychologist Professor James W Pennebaker's (1990) narrative writing paradigm into the methodology would strengthen the therapeutic process. People tend to avoid discussing topics that are too upsetting, too painful or psychologically threatening for them according to Pennebaker (1990), and for those who find it difficult to express their feelings, who keep a "stiff upper lip" or somatise their emotions (Baker 2007, p109) Pennebaker's (1990) narrative writing therapy is particularly effective. Writing externalises what is internal and allows for reflection and within the context of therapy it can be "a useful accompaniment" (Pennebaker and Seagal 1999, p1251). However there is a clear distinction between this type of narrative writing and narrative writing *therapy* where individuals write emotively, expressing emotion, for a short time on different occasions about disturbing or painful episodes in their lives.

Pennebaker (1990) 'discovered' the narrative writing paradigm almost by chance when charged with reducing psychology clinic waiting times but has yet to discover a convincing explanation for its effectiveness (Pennebaker 2004). He found that once a complex event is put into a story format it is simplified; the mind does not then have to "work so hard" to inhibit thoughts and feelings or constrain behaviours associated with an "emotional upheaval" (Pennebaker 1997, p164) thus the very act of writing can be therapeutic. According to Pennebaker (1997, p167) it "organises traumas"; it brings a sense of resolution to the person and allows them to "move beyond the experience" and forget it (Pennebaker and Seagal, 1999, p1251). Sincere self-disclosure is "unequivocally at the core of therapy" for Pennebaker (Pennebaker and Seagal 1999, p1243) whose paradigm has been validated not only by his own experiments but by those of others such as psychiatrists Baikie and Wilhelm (2005) who suggest how expressive writing can be used as a therapeutic tool for survivors of trauma. Research by Gidron, *et al.* (2002) showed that after guided expressive writing frequent clinic attenders made fewer visits to the clinic and their psychological wellbeing improved. The protocol for the Assert Narrative Writing Opportunity (Gardner 2006) is based upon the Guided Disclosure Protocol used by Gidron, *et al.* (2002).

Thus two quite different but compatible therapeutic principles were built into the Assert development programme (Gardner 2006). Combining Butler's (1963; 1974) concept of life review and Pennebaker's (1990) narrative writing paradigm created a potentially unique methodology whereby individuals have the opportunity to organise their memories and integrate their emotions about past events in two different ways (Gardner 2006). First they are invited by the facilitator to focus broadly on a particular phase of their life and then to choose certain memories for their reminiscence 'slot', revisiting both positive and negative experiences and recapturing both happy and unhappy memories (Butler 1963; 1974). Then in their narrative writing opportunity they can focus on significant events or "epiphanies" (Denzin 1989, p70) within that phase if they wish, process any associated emotions and 'move on' (Pennebaker 1990) having 'let go' of the associated painful memories (Butler 1974). Assert programme participants choose whether to have feedback on their writing from the facilitator and before starting their programme they are given contact details of a fully qualified, independent counsellor should they feel the need to talk to them in confidence.

The Rationale for an Iterative Element in the Assert Life Review Process

In Haight's (1988) protocol for life review therapy which comprises eight one-hour sessions using questionnaires, not until the last session does the elderly person have the opportunity for integrating their reminiscences and evaluating their life story. Bender, *et al.* (1999, p240) contend that with a time-limited check-list the practitioner runs the risk of reducing the person's life review to a "march-past" because people vary in how much time they need to spend exploring different phases of their lives. The protocol for their Life Stages Assessment and Treatment Group (Bender, *et al.* 1999, p242) includes time for individuals to discuss any "disagreements in understanding" before moving from one stage to the next. That 'disagreements in understanding' may arise during 'treatment' implies that participants may have unwanted perspectives imposed upon them by clinical practitioners, which Butler (2002) cautions against. An iterative protocol was therefore adopted for the Assert programme (Gardner 2006) so that during a life review session a participant can share chosen memories from a particular age phase in their reminiscence 'slot' knowing they have time to reflect upon these later at the end of the session, and again if they wish in their narrative writing opportunity. In being able to reflect upon and work through any painful or disturbing emotions that may surface for that phase before moving on to review the next, participants have an emotional 'safety net'.

Butler's (1963; 1974) concept of life review therapy focuses mainly on the past and tends to be somewhat sombre: he describes the process for most people as being "a combination of hard truths and the softer lens with which they remember their less noble deeds" (Butler 2002, p4). The iterative element in the Assert programme offers the opportunity for individuals to use their past "to create a new lens through which to see hope for change in the future" (Gardner 2006, p8).

Potential Risks, Costs and Benefits of Life Review Therapy

As Sable (1984, p53) points out, not all aspects of the life review process are positive: "past events cannot be changed, only understood and accepted" and to prevent any existing depression deepening, the person needs to know they will be supported through a crisis. Butler (2002, p4) cautions that if a person decides that his or her life was a total waste which he describes as a "tragic" outcome of a life review, they may become severely depressed and there are three groups of

people for whom Butler (1963) would not recommend life review therapy at all. Firstly, those who always look to the future in order to avoid the past or present: for these individuals the future holds promise until old age when there is only the prospect of death. Secondly, he advises against life review for those who have consciously injured others, because there is no way they can reverse the harm they have done and their guilt is real. Interestingly, Butler (1963) initially felt these people could never achieve a positive life review outcome, however in his later work (Lewis and Butler 1974, p168) he concedes that people can take responsibility and atone for acts that caused “true harm”, so long as they can differentiate between “real” and neurotic guilt (Butler 1963). Thirdly, Butler suggests that life review for the “arrogant and prideful” may result in extreme depression as these narcissistic individuals tend to prefer living in the present; for them the threat of death in the future is insurmountable (Butler 1963, p491).

These risks must of course be borne in mind along with issues that could impede group compatibility and cohesion but they are not likely to be of great significance in the Assert programme as firstly, carers would not normally be under pressure from facing the threat of imminent death. Indeed the aim is to bring about a change in outlook (Yalom 1980) so that they come to value themselves as individuals with a future. Secondly, when invited to take part in the Assert development group (Gardner 2006) some carers with narcissistic personality traits similar to those Butler (1963) describes declined to participate, so such risks may be offset through ‘natural selection’ (Gardner 2006). It is worth emphasising here that whilst there may be elements in the Assert programme that could help people who are depressed, it is not intended for carers who have been diagnosed with mental illness unless referred by their GP.

A successful life review, then, whether in an individual or group setting, depends on the outcome of the struggle the person has in dealing with “old issues of resentment, guilt, bitterness, mistrust, dependence and nihilism” (Lewis and Butler 1974, p169), which can be particularly painful for someone facing death. For these individuals the desired outcome according to Butler (1963; 1974) is a philosophical acceptance of their past and their mortality. There is comfort for those older people “whose dreams of youth may be relived through memory” (Lewis and Butler 1974, p168). Some like to “set the record straight” and “restore

harmony through atonement” (Butler 2002, p3). For others there may be a renewal of “ideals of citizenship” or a “transmission of knowledge and values to those who follow” in writing an autobiography (Butler 1974, p532); indeed, sometimes memoirs are written to “get back at an adversary” (Butler 2002, p3). Whatever the method, the age of the person or their situation, the very nature of life review “evokes a sense of regret and sadness” within them when they come to realise how short life is and reflect upon choices made that “turned out badly” and “the missed opportunities and wrongs they have done to others” (Lewis and Butler 1974, p169). These possible costs are among the ethical issues raised with participants in the Introductory Session before they begin their Assert programme. For those who dare to reflect honestly upon their lives the potential risks and short-term costs are off-set by longer-term benefits such as “a maturing of the ability to tolerate conflict and uncertainty” (Lewis and Butler 1974, p168). According to Butler (2002, pp2-3) the therapeutic strength of life review:

... lies in its ability to help promote life satisfaction, psychological well-being and self-esteem. ...The overall benefit ... is that it can engender hard-won serenity, a philosophical acceptance of what has occurred in the past, and wisdom.

Potential Risks, Costs and Benefits of Narrative Writing Therapy

Research on emotive, expressive writing shows that a coherent narrative is a good indicator of an individual’s mental and physical wellbeing (Pennebaker 1990); conversely, when a person’s narrational ability is impaired there is a risk of psychological suffering according to MacIntyre (1985). Narrative writing studies have been replicated across age, gender, culture, social class and personality type, and have been shown to bring numerous benefits; however there is some evidence that the paradigm may not be effective for people with severe depression, post-traumatic stress disorder or those with “disordered cognitive processing” (Pennebaker and Seagal 1999, p1243).

In an early experimental study in laboratory conditions, 130 American college students randomly assigned to two groups were asked to write about one of two topics on three consecutive days (Pennebaker, Colder and Sharp 1990). In four ‘waves’ the students wrote once at intervals of several months. The experimental group described their deepest thoughts and feelings about coming to college whilst the control group wrote about non-emotional topics such as their

plans for the day. The preliminary findings showed that in the first few months of being at college, students who wrote about upsetting experiences visited their doctor less after writing than those in the control group. They were also better adjusted to being away from home than the control group.

In another study Pennebaker (1990, p56) found when participants were “letting go” and disclosing deeply personal experiences there were immediate changes in their brain-wave patterns and skin conductance levels; there were also correlates in behaviour. Post disclosure, participants experienced significant drops in blood pressure and heart rate, there were improvements in immune function and improvements in both their physical and psychological health in the months that followed (Pennebaker 1990). Extensive later research has shown that there are many overlapping processes involved in narrative writing therapy, all of which bring about cognitive, emotional and biological improvements in health (Pennebaker 2004). When self-disclosing emotively about an upsetting or disturbing event, the person is “forced to change the way they think about it” according to Pennebaker (2004, pp138-140), both in the short and longer-term. After writing for example they are more likely to talk about a trauma, they gradually alter the way they talk with others and laugh more, and may subtly change their friendship networks (Pennebaker 2004, pp138-140).

Findings from Pennebaker’s (1990; 1997) USA ‘confession studies’ showed the greatest risk was to the experimenters who were shocked and depressed on reading what the subjects had disclosed. Accordingly, to forestall the possibility of this happening to an Assert facilitator, regular supervision (one hour every sixth therapeutic hour) with a UKCP-registered, psychotherapist whose practice is eclectic, drawing from various schools of psychotherapy, is incorporated in the methodology for the Assert programme.

The Assert Programme Facilitator’s Therapeutic Orientation

Haight (1988) claims that life review therapy is most effective when conducted on an individual basis, stressing that elderly people should ‘examine’ their lives only in the presence of a suitably trained clinician. Like Sable (1984), Butler (1963; 1974) and Bender, *et al.* (1999), Haight (1988) refers to life review therapy as a ‘treatment’ for ‘patients’ whereas Butler places less importance on professional

elitism. He recommends instead that health professionals approach the “patient” with “an open mind” (Butler 2002, p4), maintaining that life review therapy can be conducted successfully by “non-professionals”, that it “need not be expensive”, and that people benefit more if an “empathic listener”, someone who is receptive and not judgemental with a compassionate listening ear shares in the process (Butler 1974, p355). Lewis and Butler (1974, p166) recommend the psychotherapist “taps into” a patient’s life review rather than leading or directing the process (Butler 1963; 1974) and in an endeavour to reduce any perceived elitism, the Assert programme ‘facilitator’ works with ‘participants’ and does not treat ‘patients’.

Butler’s life-cycle group therapy is not psychoanalytic, dealing mainly with the past and unconscious conflict, nor is it “strictly encounter” (Butler 1974, p535), where the expression of feelings and thoughts in the “here and now” are encouraged (Brown and Pedder 1979, p166), yet it has a humanistic, phenomenological, anti-deterministic orientation (Yalom 1980). This approach is based on the premise that human beings have within themselves an inherent capacity for self-understanding and self-actualisation (Gross 1987) which can be brought about by reflecting upon the phenomena of “lived experience” (van Manen 1990), as these phenomena come into conscious awareness (Holloway and Wheeler 1996). This non-directional approach is particularly effective for individuals whose self-concept does not match their experience, whose feelings are “masked” and incongruent with their behaviour (Rogers 1951; 1961). Individuals can learn to put aside their masks and discover their “hidden selves” (Brown and Pedder 1979, p166) through the therapeutic relationship (Gross 1987; Clarkson 1995), but this requires a facilitator who themselves is psychologically congruent (whose feelings match their behaviour), capable of working in the here and now, is non-judgemental and empathic and able to express genuine warmth, tender, unconditional, positive regard for their client, as in person-centred therapy (Rogers 1951; 1961; Gross 1987). Hence the therapeutic orientation of the Assert programme facilitator is based on these principles and is termed ‘carer-centred’.

The Methodology for Identifying Key Outcomes from the Assert Programme

A good indicator of a successful life review is life satisfaction (Butler 2002; Haight 1988) and a simple diagrammatic measuring tool devised for the Assert development programme (Gardner 2006), the Aspects of Life Log, was used in

this study. John, the participant, was invited to rate his satisfaction with chosen aspects of his life prior to starting his Assert programme, during the Introductory Session, the Mid-term appraisal and at Closure. An example of the Aspects of Life Log may be found in Appendix A3.1.

Reminiscence and nostalgia play a part in the life review process (Butler 2002), but it is the recovery of memories, the making of the unconscious conscious, that is generally regarded as fundamental to the “curative process” (Butler 1963, p495), which is itself an “elusive” concept, the characteristics of which “are difficult to demonstrate and even harder to measure” (Butler 1982, p355). For someone undergoing therapy a significant turning point or a step towards change may be a change in outlook (Yalom 1980) but it is difficult to determine whether this is long-lasting. For outcomes such as increased self-fulfilment for example the Assert development programme (Gardner 2006) (which was not conducted in laboratory conditions) relied on subjective self-reports which were adequate for the scope and purpose of that research project. To evaluate an outcome such as ‘getting back at an adversary’ (Butler 2002, p3) would be problematic for this study and in any case is not deemed by the researcher as an appropriate or desirable outcome indicator for carers, although in some circumstances, acquiring the assertiveness to take such action could be regarded as empowering by some.

In order to surmount the methodological difficulties of measuring subtle changes in selfhood, each of Butler’s (1963; 1974; 1982; 2002) recommendations and desired characteristics for individual and group life review therapy were identified, and those judged to be the most appropriate indicators of outcomes for participants in the Assert development programme (Gardner 2006) were then extracted. Butler (1974, pp534-5) recommends, for example, that a group life review process should be preventive (1) and remedial (2); he highlights as a desired outcome the creating of new opportunities for achieving a greater sense of self-fulfilment (3), with the amelioration of suffering as the main goal (4). Among the beneficial outcome characteristics for an individual life review process Butler (1974, pp534-5) highlights the expiation of guilt (5); the exorcism of problematic childhood identifications (6); the resolution of intra-psychic conflicts (7), and the reconciliation of family relationships (8). To these eight indicators, which are termed Butler’s ‘benchmarks’ (Gardner 2006), a ninth was added: empowerment, Advocare’s

primary aim for carers (see chapter 1). Set beside these nine indicators were the key changes reported by and observed in the development group participants. A detailed list of the nine outcome indicators selected for the Assert life review process may be found in Appendix A3.2. Findings from this earlier development work (Gardner 2006) indicated that the four participants, all long-term carers or former carers and sole advocates of vulnerable people, had attained greater psychological congruence (they felt more positive and more comfortable with and within themselves), and their sense of selfhood had improved. Evidence from self-reports including life satisfaction ratings using the Aspects of Life Log, (see Appendix A3.1), indicated a positive shift in all four participants' biographical reflective focus, insofar as they felt less distanced from themselves. Moreover, at the end of the Assert development programme (Gardner 2006) all participants reported increased sense of self-fulfilment and greater sense of empowerment.

Spurred on by these findings the next step in the development work was to determine whether the Assert programme (Gardner 2006) would be effective for carers on a one-to-one basis and the decision to employ mirroring to facilitate an individual life review process was in order to compensate for the absence of group mirroring reaction (Brown and Pedder 1979) for the participant. With the level of governance and scrutiny this research receives, carers will potentially have the choice of a group or an individual setting for their Assert life review process and Advocare will have the assurance that it is safe and effective in both.

The Aims, the Participant and the Setting

There were two primary aims for this research. Firstly, it sought to determine whether the Assert programme (Gardner 2006) was safe and effective in an individual setting and secondly whether mirroring was effective as an educative and therapeutic strategy when employed in facilitating the programme on a one-to-one basis with an unpaid carer. The participant in this single-subject study was 'John', who, as explained in chapter 1, was a middle-aged former long-term carer. His two personal aims were firstly 'to discover a way of being more relaxed' and secondly 'to put the past in the past'. Following a road accident in his youth, John had virtually no childhood memories. An additional aim of this study was to ascertain from self-reports whether John's recall of his childhood autobiographical memory had improved after completing his Assert life review

process. John was invited to review his life with myself as facilitator in a relaxed setting conducive to self-disclosure. Each of the fortnightly life review sessions lasted between one and two hours and during the non-session weeks John was invited to undertake some narrative writing at home.

Ethical Considerations

The ethics of the interview contract are built on a true regard for the most obvious of protocols, i.e., freely given participant agreement, but beyond that they are not sanctioned by a positivist ethics but by a dispositional ethics where what is at stake is a mutual flourishing between participant and research characteristic of virtue ethics (Sinclair 1962; MacIntyre 1985). As it was John's wish to take part in an Assert programme, his agreement to participate in this study was freely given and in moving from contract ethics to virtue ethics, formal obligation based on law-like provisos gives way to a dispositional mastery of the self. Biographical research methods regard the individual as a complex social identity (Erben 2000) and a microcosm of society (Dilthey 1976) and it was deemed this single-subject study would provide a rich resource for *verstehen* hermeneutic analysis.

Before commencing this research certain ethical and governance protocols had to be followed according to the 'do no harm' ethics policy of the University of Southampton's School of Education Research Ethics Committee (Research Governance Office 2007). For example, a participant information sheet was required to be produced explaining there could a slight risk of emotional distress and giving contact details of the independent counsellor on 'stand-by' should John wish to consult him. This information sheet was handed to John at the start of his first (Introductory) session, and a copy of it may be found in Appendix A3.3. This information sheet also explained that his life review sessions would be tape-recorded and that the transcriptions, together with his narrative writing texts, would form the basis of his biography which he would have at the end of his programme. It also assured him that all data relating to his Assert programme would be kept securely in strict confidence and that in the report to be written afterwards, the names, places and establishments would be changed to preserve his anonymity. Once the report was produced the data would become his property. A copy of the consent form which John then signed is in Appendix A3.4.

Data Collection and Data Analysis

In order to move away from an elitist, medicalised model of therapy, the semi-structured, iterative protocols devised for the Assert development programme (Gardner 2006) were designed to be invitational and thereby enable the facilitator to work collaboratively *with* carers from a carer-centred stance rather than providing a 'treatment' for them as 'patients'. As these protocols proved effective for the development group participants, they were therefore included in the methodology for the current study virtually unchanged. The protocols were designed to be flexible and allow for absence due to constraints of caregiving.

Before starting his life review process, to contextualise his caregiving role, John was asked to complete an Advocare casework questionnaire, a copy of which is in Appendix A3.5. There were six departures from the Assert development programme (Gardner 2006) methodology which are discussed in 'Results', Part I of chapter 4, which is entitled 'Findings, Interpretation and Discussion'.

A list of the age phases for the Assert programme life review process (Gardner 2006) may be found in Appendix A3.6. The standard Assert programme protocol for the life review process may be found in Appendix A3.7 showing how the age phases align with Erikson's (1950) psychosocial stages of development, and a flow chart shows how the life review sessions and the narrative writing opportunities dovetail into the life review process.

John's (sixteen) life review sessions were held fortnightly and are shown in purple on his session schedule in Appendix A3.8 included in which are his narrative writing 'slots' (shown in blue), scheduled alternately for the non-session weeks. In John's first session the facilitator outlined the rationale for the study, described the format for the Assert programme and invited him to choose a phase of his life to review. Having virtually no recollection of events in his childhood, John chose to focus on his Caring Phase (50-55 years) which was a departure from the Assert development programme methodology (Gardner 2006). Thereafter John reviewed each age phase chronologically.

At the beginning of each life review session John was handed a reminiscence prompt sheet as devised for the Assert development programme (Gardner 2006). This was to aid his recall. An example of this semi-structured protocol may be

found in Appendix A3.9(1), on the reverse of which (A3.9(2)) space was available for jotting down the selection of memories upon which he wanted to reflect.

John was invited to complete a simple evaluation sheet at the end of each life review session to indicate whether he had found it helpful (or not) and why. Similarly, he was invited to evaluate and comment on his latest narrative writing opportunity. An example of the sessional evaluation sheet for the Assert programme (Gardner 2006) may be found in Appendix A3.10. At the end of each life review session, in preparation for his narrative writing opportunity during the next (non-session) week, John was also handed an information sheet on the reverse of which was the semi-guided narrative writing protocol based on Gidron, *et al.*'s (2002) Guided Disclosure Protocol (GDP). A copy of this information sheet and guidelines may be found in Appendix A3.11(1) and (2). John was asked to bring any narrative writing texts to the next life review session. On occasions when he found writing physically difficult John used a word-processor. The texts were kept in confidence by the facilitator who read them at the end of the programme and typed out those that were handwritten.

Half-way through the programme both John and the facilitator appraised the life review process thus far. A copy of the format for the Assert Mid-term Appraisal may be found in Appendix A3.12. During this mid-programme appraisal John was invited to take part in an experiential mindfulness exercise known as "The 'Observer Self' exercise" (Hayes, Strosahl and Wilson 2003, pp193-5) during which the person observes their 'self'. John was asked by the facilitator to close his eyes while she read aloud the passage which may be found in Appendix A3.13. Once relaxed, his attention was gradually directed to different domains of the self and body. On completing this mindfulness exercise John was invited to review and reflect upon his past, consider his present and make an action plan for change in the future and to help him with his introspection he was shown four 'spider' diagrams (see overleaf) which had been devised for the Assert development programme (Gardner 2006).

Weber maintained that man cannot escape the influence of his culture but is suspended in webs of significance he himself has spun (Geertz 1973). Yalom (1980, p19) is more optimistic: "Man creates his own experience ... [therefore] ...

man has choice". Ahead of his time, Schopenhauer recognised autonomy and contextualised man's behaviour within his environment (Janaway 1998). Unusually, Schopenhauer gave loving kindness precedence over reason and saw life as a contest of personal desire with a world that is inimical to it. His philosophy perhaps best reflects the carer's 'lot'.

The matchstick figures inside the spiders' webs in the diagrams below represented aspects of the participants' inner selves (inlook) in relation to their outside world (outlook) and helped them in identifying an aspect of themselves with which they felt uncomfortable and wanted to change:

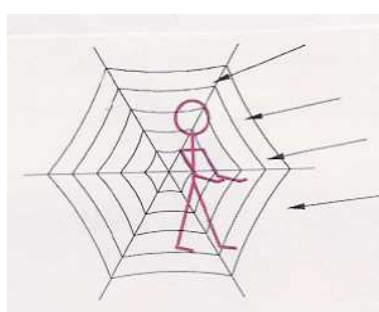


Fig F3.1: An Aspect of Self

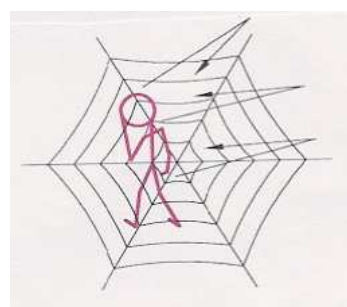


Fig F3.2: An Aspect of Self

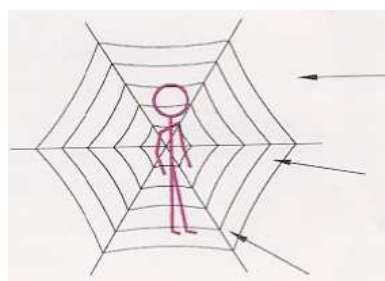


Fig F3.3: An Aspect of Self

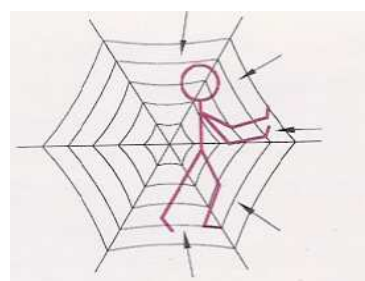


Fig F3.4: An Aspect of Self

The format for the Assert programme Action Plan for Change (Gardner 2006) may be found in Appendix A3.14. Feedback from John on his Action Plan for Change was invited in the Closure Session. The formats for the Assert Closure Session and the Action Plan for Change feedback may be found in Appendix A3.15(1) and (2) respectively.

Towards the end of the programme John expressed the wish to review his Caring Phase (50-55 years) again in an extra session, a second departure from the methodology used in the Assert development programme (Gardner 2006).

In his final narrative writing opportunity (NWO.14) John wrote a letter to his late father. This had been suggested to the facilitator by her psychotherapy supervisor as a way of helping John to address any unresolved grief. It was the third departure from the methodology used for the Assert development programme (Gardner 2006). An extra session was requested by John so that he and the facilitator could read and reflect upon the letter together. This was the fourth departure from the methodology for the Assert development programme (Gardner 2006). The rest of John's narrative writing texts were read by the facilitator after he had completed his Assert programme.

Twelve transcriptions from the life review sessions, each averaging fifteen pages, formed the basis of John's biography along with fourteen narrative writing texts, each averaging three pages. Assert development group participants were asked to read the transcripts from their last session at the beginning of the next but John opted to read his transcripts after completing the Assert programme. This presented an opportunity in the Follow-up Session four months after John's Assert programme had ended, to ascertain whether his memory had improved. This was the fifth departure from the methodology for the Assert development programme (Gardner 2006). Having read the transcriptions and his narrative writing texts, John was invited to appraise these in the Follow-up Session when he was asked again if he had recalled any new memories of his childhood. (See Appendix A3.16 for an example of the Follow-up Session evaluation sheet).

According to Doud (1999, p7) "all of human communication is a hermeneutic struggle ... with fits and starts of ... valid and invalid interpretation" and qualitative interpretation begins with elucidating meanings (Patton 2002). John's life review session transcriptions and narrative writing texts were analysed using *verstehen* hermeneutics (Patton 2002). According to Bleicher (2006, p344) Dilthey "re-defined *verstehen*" (which is German for "everyday understanding") and central to his theory is the relationship of an historical event to its interpretation (Doud 1999), where the researcher compares it to his or her self-understanding in their own time and place. Thus *verstehen* is an act of interpretation where the whole interprets the parts and the parts interpret the overarching whole according to Bleicher (2006). This is known as the "hermeneutic circle" (Doud 1999, p7). It was with "imaginative fidelity" and "aesthetic reasoning" (Erben 1998, p11) that

John's meanings were made explicit within the context of his background (Patton 2002). Biographical research methods endeavour to reconcile the positivistic (the quantitative), and the interpretive (hermeneutic), the structural and the phenomenological (qualitative) and include the temporal dimension. The circularity and universality of *verstehen* hermeneutics may be likened to "a series of dolls that fit one inside the other" according to Erben and Martin (2008, p28). Every interpretation is layered in and dependent upon other interpretations, and the actual meaning embedded within the utterance or text is uncovered layer by layer, rather like the elusive revelations of a palimpsest. With utmost objectivity, the interpreter eventually comes to something approximating a complete and correct understanding of the meaning of a text in which whole and parts are related in perfect harmony (Erben and Martin 2008).

In preparation for comparative content analysis of the qualitative data each statement in the verbatim transcriptions of John's life review sessions was allocated a reference: 'J' (for John) or 'C' (for Cathey) and similarly, each paragraph of his narrative writing was given an 'NWO' reference. Through line-by-line examination of each statement, termed a texttract, seventeen phenomena including 'mirroring' emerged as dominant and are listed in Appendix A3.17. These phenomena were then coded using various symbols, the key for which is also shown in Appendix A3.17. Patterns in the data were then sought which provided a link between a new or emergent pattern and any and all patterns observed and considered previously (Patton 2002, p463). According to their initial coding each texttract was then assigned to relevant pattern categories. For example, positive mirroring texttracts were assigned to the category 'Attitudinal' and 'Style of interaction'. Next, 'Accordant' and 'Discordant' statements were encoded as were phases of the participant's life that were deemed significant, such as Post-accident. The key for the symbols in this secondary coding is also provided in Appendix A3.17. Examples of texttracts with initial and secondary coding symbols (the latter are shown in blue) may be found in Appendix A4.3.

In preparation for the comparative thematic data analysis, a synopsis of all the texttracts appertaining to each of the dominant phenomena was produced. For ease of reference an extract from a synopsis of the texttracts relating to the phenomenon of 'Gaining new insight' (shown in red) is provided in Appendix A4.3.

The results of the comparative content analysis are described in 'Results', part I, of chapter 4 which is entitled 'Findings, Interpretation and Discussion' and discussed in part III 'In Absence of Oedipus'.

Comparative thematic analysis and grounded theory (Glaser and Strauss 1967) helps to build theory rather than test it and leads the researcher to objective generation of explanatory propositions that correspond to real-world phenomena (Patton 2002). This method of analysis was deemed most compatible with *verstehen* hermeneutics and most suitable for the intense level of biographical analysis that was required for deepening and extending appreciation and understanding of the participant's life story from the emic perspective, the insider's view (Holloway and Wheeler 1996). A parallel may be drawn here with the advice that James (2008, p118) gives to those caring for people with dementia: by "getting alongside" them, becoming "a fully paid up member of the club ... (of which sufferer and carer are the only members) ... and analysing the (sufferer's) biographical context of their concerns within their terms of reference", the carer (or the researcher) can, with sincerity, validate the other person's meaning.

Using the elaborate classification system which emerged in the initial and secondary encoding, reciprocal reflection upon and interpretation of the data revealed connections and elucidated deeper meanings of John's lived experience (Patton 2002; Bleicher 2006). Data were sorted for internal homogeneity (similarities) and external homogeneity (differences), meanings were extracted and comparisons made, significances were determined, common themes identified and collapsed into fresh categories (Braun and Clarke, 2006; Patton 2002; van Manen 1990). Interpretation of the results of this analysis is described in chapter 4 part II, 'No Reflection on Erikson', and discussed in part III, 'In Absence of Oedipus'. As may be seen from Table T4.6 three main themes were identified, namely: (1) John's caregiving role; (2) his sense of selfhood and (3) his childhood from which four categories emerged of John's reflections on key changes due to the Assert programme, namely, in his self-concept, autonomy, self-awareness and sense of agency. As a result of this analysis creative frameworks for interpretation were constructed (Patton 2002) and theories developed giving rise to 'hunches' which were verified by deduction back into the field (Glaser and Strauss 1967; van Manen 1990; Patton 2002).

An interesting phenomenon came to light during analysis of the transcript from John's specifically-requested session on his Caring Phase (50-55 years), which proved to be an especially enlightening part of the thesis. Bearing in mind John had already reviewed this phase in his first life review session, it became apparent that his mode of interaction with the facilitator was different during the later session. On examining the data more closely, small but significant changes in John's response style and conversational turn-taking were identified. Starting with the two sessions that focused on John's Caring Phase (50-55 years) and his Whole Life Review Session, the audio tapes were re-analysed in order to ascertain whether this change in his conversational style was significant, this time using the principles of conversation analysis (Sacks, *et al.* 1974; Woodruff and Aoki 2004). The definitions for the terms used in this method of re-analysis are loosely based on the conventions of transcript analysis (Sacks, *et al.* 1974; Woodruff and Aoki 2004), and may be found in Appendix A3.18. This was the sixth and most significant departure from the methodology developed for the Assert development programme (Gardner 2006) and using this method the phenomena that occurred in the dialogue between the participant and the facilitator were identified. For example, the 'normal' turn-taking was encoded thus: '☺'; pausing between responses was encoded thus: '// ' and 'cutting in' before the other person had finished speaking thus: '≠ '.

This method was not, however, sufficiently robust to identify the nature of responses made by the participant and added nothing new to this aspect of the analysis. It did not, for example, indicate when accordant statements such as "Of course!" or "Oh absolutely!" were followed by a discordant statement which created dissonance. This phenomenon, termed an 'accordant-discordant response', and encoded thus: '👍👎', was absent altogether from the participant's later life review sessions according to comparative content analysis of the data and gave rise to a 'hunch' that this change in interactive style could be linked to a turning point for John. In order to discover more about these phenomena the data were re-analysed employing a new term 'opposing', encoded thus: '⊕', for an accordant-discordant, contradictory response. The template devised for the analysis of the audio tapes of John's life review sessions may be found in Appendix A3.19. Since the Introductory Session (LRS.1), John's Caring Phase

(LRS.11(b)) and his Whole Life Review (LRS.13), focused on John's caring role the audio tapes from these three sessions were analysed first as a 'trial run', the outcome of which is documented in 'Results', part I of chapter 4, 'Findings, Interpretation and Discussion'. On further analysis a subtle shift in John's interaction style along a dissonance-concurrence-resonance continuum was detected and contradictions in meaning which were encoded thus: ' ⊗ '. A full coding key for what is termed a comparative content and (interpretive) conversation analysis may be found in Appendix A3.20. The significance of the changes and contradictions in John's dialogue with the Assert facilitator is discussed in 'No Reflection on Erikson' in part II of chapter 4.

Chapter 4

Findings, Interpretation and Discussion

Introduction

This single-subject study (Sinclair 1962; MacIntyre 1985; Erben 2000) sought to determine whether the Assert programme (Gardner 2006) was safe and effective in an individual setting and whether mirroring (Winnicott 1971) was effective as an educative and therapeutic strategy in facilitating the programme on a one-to-one basis with 'John', whose caregiving experience was described in 'John's Story' in chapter 1. John's aims were to become more relaxed and to "put the past in the past" (see Appendix A4.1). An additional aim of the study was to ascertain whether after engaging in an Assert life review process John's retrieval of autobiographical memory of childhood improved.

Results of the data analysis are documented in this chapter which has three parts. In part I, after outlining John's Assert programme, the results of the comparative content analysis (Patton 2002) in respect of John's life review process are described, and the subtleties of his dialogue with the facilitator examined from the perspective of a dissonance-concurrence-resonance continuum, with a particular focus on mirroring (Winnicott 1971). Following this are brief appraisals by John and the facilitator of his life review process, including his narrative writing. The key changes in John's interaction style are then described with observations on when his biographical reflective focus, an indicator of his increased psychological congruence, may have shifted. Set beside outcome indicators termed Butler's (1963; 1974) 'benchmarks', are key changes in John's attitudes attributed to his Assert programme (Gardner 2006). Prompted by a 'hunch', which gave rise to further methodological development, subtle changes in John's interaction style were identified. The overall effectiveness of John's individual life review process was affirmed by his life satisfaction ratings.

Part II of this chapter, 'No Reflection on Erikson', draws on a comparative thematic interpretation of the data (Patton 2002). 'Starting Again ... Significant Ends and Significant Beginnings', the main interpretive theme for this section, highlights John's reflections on his epiphanies (Denzin 1989). Also discussed are the possible consequences for an individual without a "lived experience" (van Manen 1990) of all

Erikson's "Eight Ages of Man" (1950). 'The Nurture of Nature' provides a disquisition on the concept of mirroring from the Winnicottian (Winnicott 1971) perspective where the significance of "turn-taking" as an "organisational device" in conversation (Sacks, *et al.* 1974, p700) is discussed in respect of John's life review sessions along with its role in infant attachment (Trevarthen 1977; Stern 1984; Ainsworth, *et al.* 1971). Lastly some 'Further Reflections' are offered.

Part III of this chapter, 'In Absence of Oedipus', focuses on the possible impact the loss of autobiographical memory (Fonagy 2003) may have on an individual's coherent narrative and sense of identity (Brockmeier 1997) which is discussed in 'John's "Completely Missing Phase"'. In 'Finding the Lost Child', some of the emotional and psychological after-effects of traumatic head injury (Young and Saver 2001; Fleming, *et al.* 2005) are considered, drawing on interpretation of data employing *verstehen* hermeneutics (Dilthey 1976; Patton 2002). Powerfully depicted in 'Letter to Dad', John's last piece of narrative writing, is his change in attitude towards his late father as a result of his Assert programme (Gardner 2006). The possibility of transference having occurred during John's last life review session and contributing to this change is considered in 'The Penknife Scenario'. Finally, the changes in John's self-concept are discussed in "A Genius or An Idiot?": Knowing How To Be Or Not To Be', where also featured is the process for formulating his action plan for bringing about some of his desired changes in sense of selfhood and attitudes towards his outside world.

Part I

Results

John's Assert Programme

John's individual Assert programme comprised sixteen life review sessions (LRS.1-16), twelve of which were devoted to reminiscence, reflection and review of various phases of his life. All except the Follow-up Session (LRS.16) were tape-recorded with his permission, the verbatim transcriptions of which, together with John's narrative writing formed his biography which he opted to read on completion of his programme. The schedule for John's life review process in Table T4.1 overleaf notes the five minor departures as previously described from the standard Assert programme protocol which may be found in Appendix A3.7.

Table T4.1
John's Assert Life Review Schedule

Life Review Session	Age Phase or focus for John's Life Review Session (scheduled fortnightly)	Narrative Writing Opportunity	Age Phase or focus for John's Narrative Writing Opportunity (scheduled for non-session weeks)
LRS.1	Introduction. John chose to review his Caring Phase (50-55 yrs) (see note 1)	NWO.1	Infancy Phase (0-5 yrs)
LRS.2	Childhood Phase (5-10 yrs)	NWO.2	Childhood Phase (5-10 yrs)
LRS.3	Early Teen Phase (10-15 yrs)	NWO.3	Early Teen Phase (10-15 yrs)
LRS.4	Late Teen Phase (15-20 yrs)	NWO.4	Late Teen Phase (15-20 yrs)
LRS.5	Early Twenties Phase (20-25 yrs)	NWO.5	Early Twenties Phase (20-25 yrs)
LRS.6	Late Twenties Phase (25-30 yrs)	NWO.6	Late Twenties Phase (25-30 yrs)
LRS.7	John's Mid-term appraisal of his life review	NWO.7	John considered aspects of his life and aspects of himself he wanted to change.
LRS.8	(a) Mid-term appraisal continued (b) Thirty-something Phase (30+ yrs)	NWO.8	Thirty-something Phase (30+ yrs)
LRS.9	(a) Reflected on aspects of life and self. Considered an Action Plan for Change (b) Early Middle Age Phase (40+ yrs)	NWO.9	Forty-something Phase (40+ yrs)
LRS.10	John formulated his Action Plan for Change	NWO.10	John used this NWO for further reflection upon his Action Plan for Change
Four-month break (2)			
LRS.11	(a) Reviewed Action Plan for Change (b) Caring Phase (50-55 yrs) (3)	NWO.11	Caring Phase (50-55 yrs)
LRS.12	Later Middle Age Phase (55+ yrs)	NWO.12	Later Middle Age Phase (55 + yrs)
LRS.13	Whole Life Review	NWO.13	Whole Life
LRS.14	Closure. Revisited Action Plan. 'Letter to Dad' suggested	NWO.14	'Letter to Dad'
LRS.15	Reflected upon John's 'Letter to Dad' (4)	-	John invited to read his biography (5)
LRS.16	Follow-up four months after LRS.15. (This session was not tape-recorded.)	-	-

The five minor departures from the standard Assert programme protocol:

- (1) Findings from the Assert development programme (Gardner 2006) suggest that some participants may prefer to start with an age phase other than infancy, which was the case for John, who has virtually no recollection of his early childhood.
- (2) John reported that he felt too 'low' and fatigued to make the next session.
- (3) This was an extra session specifically requested by John for reviewing his Caring Phase.
- (4) John requested this session specifically to reflect upon his 'Letter to Dad' with the facilitator.
- (5) John opted to read his biography, which comprised the transcripts of his life review sessions and his narrative writing, at the end of his Assert programme (Gardner 2006), unlike the participants in the development group, who read their transcripts at the beginning of each session.

As can be seen from Table T4.1, John opted to start with his Caring Phase (50-55 years) and reviewed subsequent Age Phases chronologically. Correspondingly he produced a total of fourteen narrative writing texts (NWO.1-14) which as facilitator I read at the end of his programme to offset any 'writing for effect'. The narrative writing produced in non-session weeks John either E-mailed to the facilitator or brought it to the sessions which, as can be seen from Table T4.1 and the Assert programme protocol in Appendix A3.7, were arranged fortnightly.

Session seven (LRS.7) was John's Mid-term appraisal of his life review and in session nine (LRS.9) he had an opportunity to reflect upon aspects of himself and his situation with which he felt uncomfortable and wanted to change. According to Yalom (1980, p346) "Psychotherapy is successful to the extent that it allows the person to alter his or her future". Change, he argues, comes about through liberation of the "stifled will" (p338). John found it difficult to accept that every individual has the power to change (Yalom 1980) and had difficulty in conceptualising his inner and outer realities. It was with some scepticism that John produced an action plan for change in session ten (LRS.10), an extract of which is in Appendix A4.2. Although a protracted process, the data suggest that this may have contributed to bringing about some of the changes in John.

John requested an extra session (LRS.11(b)) to focus specifically on his Caring Phase (50-55 yrs) which was included without difficulty in his flexible Assert programme schedule. After formulating his Action Plan for Change in session LRS.10 (see Table T4.1 note (2)), John took a four-month break, claiming work commitments prevented him from keeping the arrangement. He also reported feeling fatigued and 'low' and made several visits to his doctor with symptoms of unspecified illness during this period. At one point (as facilitator) I wondered if John would opt out of the programme altogether. Data from the Assert development programme (Gardner 2006) analysed using biographical research methods (Erben 1998) revealed that sometimes participants who 'forgot' to attend a session or who reported illness prior to it and postponed were intending to reflect upon a phase of their lives that was particularly painful. Interestingly, in contextualising John's attendance record it transpired that he had arranged his extra session on a date three days before the anniversary of his father's stroke and had reinstated it during the week following the anniversary of his death.

According to the evaluations John made at the end of each session (see Table T4.2 below), he found all of his life review sessions helpful, particularly his Whole Life Review (session LRS.13), and most opportunities for narrative writing worthwhile, especially for his Early Teen Phase (10-15 years) and his Whole Life Review. Interestingly John produced some narrative writing for his Late Teen Phase (15-20 years) but forgot to bring this text to the following session and cannot remember if it was worthwhile for him. This was the phase in which John sustained a serious head injury in a road accident which affected his autobiographical memory of childhood.

At Closure (session LRS.14) it was suggested to John that to help address any unresolved issues with regard to the relationship he had had with his late father he might write a letter to him. As can be seen from Table T4.1 his 'Letter to Dad' was his last piece of narrative writing (NWO.14), the significance of which is explored in depth in Part III of this chapter, 'In Absence of Oedipus'. At John's request he and I as the facilitator read and reflected upon his letter together in a separate session, (LRS.15).

Table T4.2

John's Evaluations of his Life Review Sessions and Narrative Writing Opportunities

Age Phase or focus	Evaluation of Life Review Session				Evaluation of Narrative Writing Opportunity			
	Session No.	Helpful	Un-helpful	Not sure	Text No.	Worthwhile	Not worthwhile	Not sure
Introduction/Caring Phase (50-55 yrs)	LRS.1	✓	-	-	NWO.1	✓	-	-
Childhood (5-10 yrs)	LRS.2	✓	-	-	NWO.2	✓	-	-
Early Teen (10-15 yrs)	LRS.3	✓	-	-	NWO.3	Definitely	-	-
Late Teen (15-20 yrs)	LRS.4	✓	-	-	NWO.4	Cannot remember if worthwhile		
Early Twenties (20-25 yrs)	LRS.5	✓	-	-	NWO.5	✓	-	-
Late Twenties (25-30 yrs)	LRS.6	✓	-	-	NWO.6	✓	-	-
Mid-term appraisal of life review	LRS.7	✓	-	-	NWO.7	-	-	-
Mid-term appraisal continued	LRS.8(a)	N/A	N/A	N/A	NWO.8	N/A	N/A	N/A
Thirty-something (30+ yrs)	LRS.8(b)	✓	-	-				
Reflected on aspects of life and self	LRS.9(a)	N/A	N/A	N/A	NWO.9	✓	-	-
Considered Action Plan for Change	LRS.9(b)	✓	-	-				
Early Middle Age (40+ yrs)	LRS.10	N/A	N/A	N/A	NWO.10	N/A	N/A	N/A
Formulated Action Plan for Change	LRS.11(a)	N/A	N/A	N/A	NWO.11	✓	-	-
Reviewed Action Plan for Change	LRS.11(b)	✓	-	-				
Caring Phase (50-55 yrs)	LRS.12	✓	-	-	NWO.12	✓	-	-
Later Middle Age (55+ yrs)	LRS.13	Very	-	-	NWO.13	Very	-	-
Whole Life Review	LRS.14	N/A	N/A	N/A	NWO.14	✓	-	-
Closure	LRS.15	-	-	-	-	-	-	-
Letter to Dad								

(N/A = Not Applicable)

After completing his Assert programme (Gardner 2006) John was given the transcriptions of his life review sessions along with his narrative writing texts which formed his biography. He was asked to write down brief observations as he read each phase of his biography in preparation for the Follow-up Session (LRS.16) which was held four months after Closure. Interestingly, some of the observations in 'John's Perspective on his Life Review Process' (see page 105) echo those of the facilitator (see page 107).

Extracts from the verbatim transcriptions were termed 'textracts'. The location of John's quotations is indicated by the textract's 'J' reference. Those with a 'C' refer to responses made by the facilitator. A textract followed by 'J', for example '(J1/2/3)', shows that the quotation is from John's Assert programme, the number '1' shows that it is from session 1. The '2' shows the quotation is on page two of the transcript, and the '3' that it is the third response on that page. Phenomena from the transcriptions of John's life review sessions deemed dominant (by myself as researcher) in terms of his expression and interaction with myself as facilitator¹ were given the initial coding symbols listed in Appendix A3.17. The initial coding system was applied to John's narrative writing which was dovetailed with other qualitative data for analysis. A secondary coding system (also shown in Appendix A3.17) was assigned to what were termed John's 'discordant responses', 'accordant responses', and 'accordant-discordant responses'. Examples of textracts containing these responses follow but for ease of reference some are given in Appendix A4.3.

In the Assert development group (Gardner 2006) each participant had a timed reminiscence 'slot' in which they could reflect upon some of their chosen experiences. Sometimes there was a resonance of emotion, prompting a warm camaraderie within the group which engendered close emotional bonds between participants (Brown and Pedder 1979; Bateman and Holmes 1995). The findings from this work suggest that the group mirroring reaction (Brown and Pedder 1979) had helped to shift the participants' biographical reflective focus and increase their psychological congruence (Gardner 2006). Not ascribed

¹ Telling a story from the point of view of "subordinates" as opposed to "superordinates" provokes suspicion of bias since credibility and the right to be heard are differentially distributed through the ranks of the system. Since superordinates are the ones held responsible, they "usually have to lie" (Becker 1967, p242). It is to interpret meaning of both sides of the story authentically and objectively that this author moves between 'I' as facilitator and 'I' as researcher whilst maximising sensitivity to the tensions created by the dual role and distance as 'insider' and 'outsider'.

significance then and therefore not 'logged', mirroring was tracked in this study. A response, spoken or unspoken, which copied, echoed or resonated with the other's words, tone, emotion or meaning, was termed a 'mirroring response'. Definitions of this and other responses are provided in Appendix A3.17.

In Dialogue with John

In essence, the life review sessions were two-way conversations between John and the facilitator focusing primarily on his experience. Each tape-recorded dialogue lasted one to two hours, during which time John had the opportunity to review and reflect upon some of his chosen memories about a particular phase in his life. By taking a non-directional stance and asking open-ended questions the facilitator gently "tapped into" John's life story (Lewis and Butler 1974, p166) as it gradually unfolded in the "shared space" (Brown and Pedder 1979, p67) of the therapeutic encounter. The facilitator reflected back to John the essence of what he said by mirroring and was thus able to convey understanding and appreciation of his meaning without patronising him or interrupting his train of thought.

According to the facilitator's observations John had appeared eager to take part in the Assert programme yet almost from the outset he seemed reluctant to reflect upon his feelings. Referring somewhat cursorily to the notes he had jotted down on his reminiscence prompt sheet for the first session in which he focused on his Caring Phase, John ('J') was evasive when the facilitator ('C') asked:

C: How did you feel about thinking about aspects of your life that maybe you hadn't thought of for a while? (J1/6/4).
J: Mmmm. I wrote down that I was ... that I was pleased when I no longer needed to get up halfway through the night to care for my father. (J1/6/5).

John's defensiveness increased when he reflected upon "the completely missing phase" of his childhood.

Dismissing the 'Missing Phase'

During his second session (LRS.2) in which he focused on his Childhood Phase (5-10 years) John referred to his jottings as if they were of no more importance to him than items on a shopping list, mentally ticking off each memory or impression after mentioning it. He searched for words as he described matter-of-factly:

J: ... I see the incidents as if I was looking at them on video ... looking at a moving photograph ... of the incident rather than as actually being part of it. (J2/2/7). I look at myself doing the things rather than ... rather than experiencing them (J2/2/8).

In the following (third) session John stressed:

J: ... I can't remember the first *school* I went to. Let alone the names of any of the kids or the teachers or anything. And it's very disconcerting (J3/12./6).

The facilitator wanted to understand how John felt about his lack of autobiographical memory but again he did not expand on this in his answer to her question:

C: Do you feel you've missed something quite significant? (J3/12/9).
J: I don't know (J3/12/10).
C: But there's something, if it's disconcerting – (J3/12/11).
J: [Cutting in] No, I don't feel as if I've got anything missing but then I wouldn't know if it was (J3/12/12). ... It's like saying to somebody 'Do you regret the fact that you're not rich?' Well if you're not, you'll never know what it would have been like so ... (J3/12/14).

The facilitator persisted:

C: But you say 'disconcerting' – (J3/12/15).
J: You can't regret the fact that you were – disconcerting in as much as I suppose in later years when I had kids I couldn't think when they were eight what it was like to be an eight year old or a ten year old or a twelve year old or a two year old. (J3/12/16).
C: (Nodding) Right. ... That's quite significant, isn't it? (J3/13/1).
J: (Dismissively) So it was a missing – it would be a completely missing phase (J3/13/2).

Sensing that John did not want to discuss the gap in his memory the facilitator simply agreed with John's last statement without pursuing the matter any further. However he continued with this theme by saying flatly:

J: So there wasn't an experience on which one could establish the future. Whether it's done any harm or not, I'm sure it probably has. But ... but that's another matter (laughs wryly) (J3/13/4).
C: That's quite an interesting notion though ... (J3/13/5).
J: I don't know, if you miss something yourself. The things that I've missed might not have been ... of any value anyway, even if I did remember them. (J3/13/6).

When talking about his memory problems in the fourth session (LRS.4) John observed somewhat resignedly:

J: Things get jumbled, just jumbled up, that's the trouble (J4/2/7).

Throughout his programme John gave little detail about the catastrophic accident that kept him in a coma for months and robbed him of his childhood. He learned that his parents - "it was more of a heartache for them" - had visited him every

day in hospital for months. His mother's hair "went white overnight" with the strain of not knowing if he would ever regain consciousness. When he did he had to learn to walk, speak and write again. John appeared indifferent to it all. Dismissively he described how it had left him with a constant sense that time was running out for him and that he was about to die. It became apparent that John contemplated the future and his retirement with dread. The facilitator suggested there could be an element of adventure:

J: The unknown isn't necessarily an adventure. Terror could be a better description. I don't know. I *don't* know! (J1/9/4).
C: But you look forward to it ... (J1/9/5).
J: I think so. I look forward to the last day of work (J1/9/6).
C: Mmm. You look forward to the chances that you may have ... (J1/9/7).
J: Oh, absolutely (J1/9/8).
C: And the freedom ... ? (J1/9/9).
J: That would be the worst part for me – that would be the biggest enemy (J1/9/10).

In the fourth session I ventured to comment that John had still not said much about his accident:

C: You haven't mentioned what caused the accident (J4/3/3).
J: ... I can only recount what I've been told ... the corner of the kerbstone and the back of my head came into collision. ... (J4/3/6). ... It's as if it's somebody else because it means nothing to me, I've got no recollection of it happening ... no memory of the incident. No memory of anything months afterwards (J4/4/6). ... the recovery hospital I was in, not the neurosurgery hospital, was the same one as I had had my appendix out in the year before and it was almost like a continuation of that appendix visit (J4/5/8).

It was around this time that I had become aware that underlying John's ready concurrence was a subtle dismissiveness which seemed to be an enduring characteristic of his style of interaction.

Concurrence with a Cutting Edge

Sometimes I detected an edge to his voice which in itself created dissonance. In the first session, for example, whilst reflecting on his Caring Phase John concluded quietly:

J: ...all you achieved was ... was ... keeping someone alive and reducing their suffering. And I suppose that was the be all and end all of what one's existence was (J1/10/5).
C: (Reverently) It's a very selfless task ... I would say a noble task, actually. (J1/10/6).

John seemed to evade the prospect of any warm camaraderie by blocking, rebuffing or ‘cutting off’ the facilitator’s warmth. John’s frustration surfaced and there was an edge of sarcasm in his voice as he explained:

J: It’s a bit like being a guide dog. I’ve heard that when guide dogs aren’t actually doing their job when they’re not actually guiding somebody they’re wild and uncontrolled (J1/10/7).

Such responses caused momentary dissonance which (as researcher) I termed as ‘discordant responses’. A harder edge came into John’s voice when he reflected upon the demise of his beloved pet dog Amber, his ‘best friend’:

J: That dog died when I was probably – can’t remember now – may be eleven or twelve. She got run over. (J3/5/13) ... Survived being run over but never really got better. Um ... (J3/5/16).
C: (Softly) Were you sorry about that? (J3/6/1).
J: Oh yes. ... Oh yes. (Yawns) She was my best friend. It’s always annoying when your best friend dies. (Chuckles) Well not annoying, but – I don’t know. Yes. Probably I should think. And probably because she was my best friend. Because you can talk to a dog and it doesn’t argue back (J3/6/2).

John’s: “Oh yes. ... Oh yes”, an example of his ready concurrence, an ‘accordant response’, followed by the ‘cutting edge’. Another example had occurred in John’s first session when he was talking about the end of his caregiving role.

Sympathetically the facilitator summed up what John had been describing:

C: It was a relief when it was over ... (J1/7/11)
J: Oh, absolutely (J1/7/12).

John’s accordant responses such as “Oh absolutely” were frequently followed by negative statements, flippant comments or sarcastic remarks that momentarily jarred in the “shared space” (Brown and Pedder 1979, p67) and created dissonance. For example, continuing on from the last textextract:

J: Oh, absolutely. And I can’t even think in saying that it was a relief when it was over sounds a bit callous, you know, ‘Thank goodness he’s dead and I can get on with my life’. But it didn’t exactly mean that. It didn’t mean that at all.....but you don’t recover immediately (J1/7/12).

This type of response was termed an ‘accordant-discordant response’ by the researcher, a further example of which had occurred in John’s second session.

Obviously pleased that he could remember clearly “the first night for the first time” he had “managed to swim a few strokes without sinking” John animatedly told the facilitator:

J: ... after I learned to swim, I used to *love* going to swimming pools ... I was terrified of water to start with. And then ... (J2/7/3).

John’s animation suddenly vanished. He looked serious and fell silent. The facilitator wondered if he had been reminded of a sad or painful experience and continued encouragingly:

C: But you conquered it (J2/7/4).
J: (Dismissively) I just kept flapping my arms around and one moment I didn’t sink and it was called swimming. It probably wasn’t very elegant and nobody would have recognised it as actually being swimming but I didn’t sink and go downwards (J2/7/5).

John’s initial pleasure in recapturing the experience of learning to swim seemed suddenly to be wiped out. He became distant and his sense of achievement faded. It was as if he was reflecting negatively on how he had appeared to others. In his third session John was reflecting on family holidays:

J: I used to enjoy going on holiday ... (J3/6/4).
C: What did you used to enjoy most about it?
J: (Thinks for a moment) Splashing around on the beach. It was always somewhere like that, generally ... (J3/6/6).

Remembering John’s enthusiasm in the previous session when describing how he “used to *love* going to swimming pools” the facilitator continued warmly:

C: (Smiling broadly) You were a water baby – [by the sound of it] (J3/6/7).

Before the facilitator could finish her sentence John cut in flatly with:

J: - No, I wouldn’t go that far, but I just – I quite enjoyed it. It was a change. (Yawns) If I wasn’t on holiday during the summer, the school summer holidays, I always had a season ticket for the local swimming pool and just used to spend all my time in the swimming pool ... (J3/6/8).

As well as interrupting the flow of dialogue it seemed John ‘warded off’ the facilitator’s warmth by opposing and cutting off what she was about to say. Sometimes John’s tone was more discordant than what he actually said.

He appeared dismissive, even indifferent about having closed a two-year gap in his schooling and succeeding in higher education; a sense of triumph in this and at having overcome terrible injuries after his accident was completely lacking:

C: ... you stayed on at college and got your degree ... (J5/3/12).
J: Mmm. Oh, long while later (J5/3/13).
C: How many years were you at college, then? (J5/3/14).
J: (Long pause) Four and a half years altogether (J5/3/15).
C: Not that long really. And were they funded by your – ? (J5/3/16).
J: [Cutting in] First one was, the second one wasn't. They were funded by me. By me (J5/3/17). ... but there were grants (J5/3/19) ... I can't remember now. I can't remember what it cost, I've got no idea (J5/4/2).

The facilitator focused on the positive side and continued gently:

C: Mmm. But even so, to stick at it for four and a half years takes some self-discipline doesn't it, under the circumstances? (J5/4/3).
J: Maybe. I don't – I don't know if self-discipline was the thing. It was just ... I just ... couldn't think of anything else, I mean it had become a part of life (J5/4/4).
C: Mmm. So notwithstanding that, you've still shown a commitment and honoured the work ethic if you like (J5/10/1).
J: Yeah. Only for the money. Not for any other reason. No, I suppose two things. Money and fear (J5/10/2).

Mirroring Moments

In the third session when John was focusing on his early teens, he made his first mirroring response which fleetingly resonated with the facilitator's emotion. Animatedly, he described the "thrill and excitement" of Amber, his pet dog, pulling him along on his roller skates behind her at high speed. John remembered how two hours after their "usual charging around the streets one morning Amber surprised everyone with a litter of puppies in the afternoon". He continued heartily:

J: ... It must have helped. It was an easy birth! (J3/4/7).
C: (Mirroring) Stirred things up a bit! (J3/4/8).
J: (Flatly) Certainly did stir things up a bit (J3/4/9).

John's animation receded as he said "Certainly did stir things up a bit". In the next session (LRS.4), John's Later Teen Phase (15-20 years) he was recounting unexpressively what he regarded as a lowly means of transportation in his teenage years:

J: ... So you got a motor bike. Which was a fairly grotty old thing. That was a year later. Then a car (J4/8/4).

Disinterestedly he then went on to talk about how he did in his 'O' and 'A' levels and in an appropriate pause the facilitator reminded him about his different modes of transport. There was a subtle change in the nature of his next mirroring response:

C: (Encouragingly) So you got your grotty motor bike ... (J4/10/3).
J: So I got my grotty motor bike which made me slightly more mobile, then I got a grotty car which made me even more mobile. (J4/10/4).

As he echoed the words "so I got my grotty motor bike", John's inflection mirrored the facilitator's. Some months later when reflecting on his Caring Phase in session LRS.11(b) John was reflecting somewhat bitterly about his lack of money in his four-year "drudge". The facilitator reflected back to him his notion about the drudge. As John repeated the facilitator's words he echoed her inflection but this time without bitterness in his voice:

C: (Quietly) And the drudge ... (J11(b)/2/3).
J: And the drudge. (Yawns, small sigh) Yes, but then a lot of going to work is a drudge. Just swap one for another. Would I rather drudge and get paid for it? I suppose the answer's 'Yes'. (Long pause) Hmmm ... Would I do it again? I don't know. If I was suddenly transported back in time? ... Would I do it again? Probably ... Yes, I'm sure I would (J11(b)/1/6).

Later in the same session John was describing the ties of the caregiving role and remembered having the rare opportunity of going to a millennium party. Someone he knew happened to be there and when they questioned why he was not at home looking after his father John had told them:

J: "Well, it's December 1999. The last time I went out for an evening was the 15th of July 1995 and I'm sorry if I'm making a habit of it." (J11(b)/5/4).
C: Did that make you feel angry? (J11(b)/7/1).
J: Well, if it had been a fella I'd have hit him but it wasn't, it was a woman. (Pause) But ... once a drudge, always a drudge. If you've decided to become a carer you've gotta do it a hundred per cent of the time. Otherwise you're only cheating, was her attitude (J11(b)/7/2). ... She was a care manager or something ... But I didn't allow it to spoil the evening (J11(b)/7/4) .

In recounting the party scenario John echoed the theme of "drudge" without emotion, but in the following exchange there was sadness in his voice which echoed the facilitator's tone, unlike his characteristic quick-fire follow-up remarks:

C: (Softly) And that just about sums it up, really (J11(b)/7/5).
J: Just about ... (J11(b)/9/6).

Later still in the same session the facilitator asked John how he felt about having to radically change his lifestyle to look after his father. In his affirming response John matched the facilitator's tone thoughtfully. I sensed that John was comfortable for the first time with silence:

J: No, I don't think ... I don't think I thought about it. Something happened in January that was going to have, as the year progressed, ... this big effect come August. And that's what happened. That's what we did (J11(b)/11/1).
C: (Softly) And you got on with it. ... (J11(b)/11/2).
J: (Nods) ... We got on with it. ... (J11(b)/11/4).

Reflecting upon the impact caring had had on him in session 12, John's Post Caring Phase (55+ years) I asked him if he had integrated quite well into society. I sensed this was an extremely painful reflection for John as he struggled for words:

J: No. Because there were things that I couldn't ... couldn't ... that I hadn't done for years (J12/5/2).

John hesitated in framing his emphatic response to my next question. It was as if he was taking time to register his feelings before answering:

C: You felt ... (J12/5/3).
J: I felt ... I was a pauper! I mean I was nothing like the sort of person I had previously been (J12/5/4).

There was also another indication of change in John in this session: as he reflected upon his life before he became a carer he looked away thoughtfully before responding:

J: ... the only thing I still had ... was a very old expensive car that was falling apart anyway. It's always been falling apart. Well, it hasn't always been falling apart but it's always been old (J12/5/8).
C: (Softly) So that was your link with a previous life ... (J12/5/7).
J: (Softly) A previous life (J12/5/8).

It was as if John was acknowledging, albeit gloomily, that his 'previous life' was now in the past. After a few moments his expression brightened as he contemplated his retirement in the near future. For the first time his response mirrored the facilitator's words, tone, meaning *and* emotion as he cheerfully mentalised being on a journey and in 'the driving seat':

C: That's a very good way of putting it, actually, that you're on a journey (J12/8/1).
 J: Somebody else is controlling the journey and you don't know the destination (J12/8/4).
 C: It's a good way of putting it. But you feel now you're in the driving seat ... (J12/8/5).
 J: Well, in the driving seat. ... I'm struggling ever forward towards the point where I can actually stop, being retired (J12/8/6). ... I've seen my destiny. I know where my destination is (J12/8/8).
 C: So in a way it's helping you to tolerate the journey (J12/8/9).
 J: Oh, knowing my destination is not just helping me to tolerate the journey it's the only thing that's getting me through it. Not that the journey is difficult, ... I'd sooner not be doing it. But if I've got to do it at least I can look ahead and see at the end of the journey what there is waiting at the end of it is glorious compared to what things have been. ... (J12/8/10).

There was a comfortable resonance between John and the facilitator for the first time. Thereafter the pace of dialogue slowed and flowed more smoothly.

Listed in Table T4.3 overleaf are the instances of John's 'discordant', 'accordant-discordant', 'accordant' and 'mirroring' responses. As can be seen from the Table, in session LRS.12, his Post-Caring Phase, John made twenty-three accordant responses compared to twelve in the previous session, LRS.11(b), his Caring Phase, twenty-two of which mirrored those of the facilitator. This suggests a subtle change had occurred in John; possibly even a turning point.

“A Discovery!” and a Turning Point for John

In his Whole Life Review Session (LRS.13), John was more relaxed but there was also a new vitality in him, too. As usual the facilitator invited him to jot down some memories on his reminiscence prompt sheet:

J: ... as I started to jot things down ... it sort of ... made me overwhelmed and put out of my mind any of the little things that went on in between but each ... this situation when you understand what it is ... when I show you ... it brings out all the bits and pieces that have happened in my life (J13/1/2).

John needed no encouragement to expand on this. Eagerly he continued:

J: (Animatedly) A discovery! And it's odd, it's not something I thought about before I sat down and just looked at a blank sheet of paper. And I'll tell you what I've written down. I can't remember much before [the accident]. The occasional snapshot incidents. I don't know if I missed these memories or not and I think to myself ... what sort of threads have run through my life? ... it seems that my life seems to go in phases which match who's in my life at any one time. It tends to have been how my life has been has been reflected or is ... to an extent a reflection of the person who's been in my life! (J13/1/4).

Table T4.3
John's Key Responses

<u>Key to secondary coding symbols to indicate phases of John's life:</u>					
←	= pre-accident	↖	= post-accident	↷	= pre-caring
↻	= caring	↶	= post-caring		

LRS No.	Age Phase or focus for Life Review Session	Coding Symbol	Key responses			
			No. of Discordant responses	No. of Accordant-Discordant responses	No. of Accordant responses	No. of Mirroring responses
1	Introduction. John chose to review his Caring Phase (50-55 yrs)	↻	3	11	3	3
2	Childhood Phase (5-10 yrs)		4	6	2	2
3	Early Teen Phase (10-15 yrs)	←	3	14	1	1
4	Later Teen Phase (15-20 yrs)	↖	2	6	5	5
5	Early Twenties Phase (20-25 yrs)		1	6	5	4
6	Late Twenties Phase (25-30 yrs)		0	0	0	0
Total No. of responses made by John prior to Mid-term appraisal of his life review:			13	43	16	15
7	John's Mid-term appraisal of his life review		N/A	N/A	N/A	N/A
8	(a) Completion of Mid-term appraisal (b) Thirty-something Phase (30+ yrs)		0	2	0	0
9	(a) Inlook/Outlook + Action Plan (b) Early Middle Age Phase (40+ yrs)	↷	0	5	9	9
10	John's Action Plan for Change formulated		N/A	N/A	N/A	N/A
11	(a) Reviewed Action Plan for Change (b) Caring Phase (50-55 yrs)	↻	1	3	12	13
12	Later Middle Age (55+ yrs) (Post-Caring Phase)	↶	0	3	23	22
13	Whole Life Review		1	11	18	22
14	Closure session Revisited Action Plan for Change		N/A	N/A	N/A	N/A
15	Reflected upon 'Letter to Dad'		2	3	17	10
Total No. of responses made by John post Mid-term appraisal of his life review:			4	27	79	76
Total No. of responses made by John:			17	70	85	91

John, perhaps for the first time, had drawn together the “threads” that ran through his life and ‘come alive’. He was ecstatic about his discovery and talked non-stop with positive feeling throughout the session as he had not done in any previously, reflecting on his whole life and making sense of it:

J: ... a person came into my life ... who's made more difference to it than anybody I've ever known. Who is more important in my life than anybody else I've ever known. And that's changed my life completely. I've probably contributed a bit ... but I've been helped, encouraged, nagged, loved, back into being a person. Rather than just being an empty sort of nothing. ... And it's oddly enough the only time in my life when I've found myself making plans (J13/1/4).

It was as if John had suddenly come to see a longstanding relationship in a different light, not only realising the value of it but also how he was valued in it.

Later in the session he was reflecting on the toll caring had taken on him and as the session concluded his next response was without bitterness or dissonance:

C: Did you feel cynical about the ‘system’? (J13/15/5).
J: ... (Thoughtfully) Cynical ... (long pause) I felt there were lots of people getting lots of money and they achieved nothing. Achieving far less than I achieved with no money and no training and no anything (J13/15/6).

John appeared to be giving himself time to consider the wider implications of what he had heard the facilitator say and what he was about to say himself.

Analysis of the data suggests that the Mid-term appraisal session (LRS.7), shown in blue in Table T4.3 on the previous page, may indeed have been a turning point (Yalom 1980) for John, who made only four discordant responses in total after formulating his Action Plan for Change (LRS.10). In the six sessions prior to the Mid-term appraisal (LRS.1-6) John made thirteen discordant responses altogether, whereas he made only four over a similar number of sessions post Mid-term. Interestingly, he made only one discordant response during the session he had requested on his Caring Phase (LRS.11(b)), despite focusing at length on a painful and stressful time; there had been three in the first session which had focused on this phase relatively briefly. The number of accordant-discordant responses post Mid-term was twenty-seven compared with forty-three prior to Mid-term and there were seventy-nine accordant responses after Mid-term compared with sixteen prior to Mid-term. Most significant of all were John's mirroring responses: fifteen prior to Mid-term compared to seventy-six post Mid-term, a total of ninety-one.

John's Narrative Writing

John chose not to follow the semi-guided protocol for the Narrative Writing Opportunity which may be found in Appendix A3.11(2). It suggests to the participant that they write expressively about a chosen episode in their life on three consecutive days in order to deal with disturbing or painful memories and 'move on' (Pennebaker 1990). To counter any writing 'for effect' as the facilitator I read John's narrative writing texts at the end of his life review programme when his texts were returned to him with the transcripts of his life review sessions. His writing texts were mainly summaries of the happy memories he had reflected upon in his life review sessions. They had little emotional content and most he found "easy to write" and "not painful" according to his evaluation sheets. On his evaluation sheet from the Closure Session (LRS.14) which may be found in Appendix A4.3, John comments on his Whole Life Review (NWO.13):

Writing this brief 'whole life review' has given me reason to believe that I'm not entirely the 'waste of time' I've always considered myself to be (NWO.13).

A change in John's self-concept had occurred by this time: the most significant aspect of this text is that at no time in his life review sessions had John voiced feeling this way about himself to the facilitator which suggests that although he chose not to follow the guidelines his own style of narrative writing was therapeutic for him. John's last piece of narrative writing, 'Letter to Dad' (NWO.14), was emotive, written "straight off" in the moment he was moved to do so. This letter to his late father portrays a microcosm of John's life story and is discussed in more depth in part III, 'In Absence of Oedipus' where with John's permission it is reproduced, unedited but anonymised (see page 165).

John's Perspective on his Life Review Process

At the beginning of his Assert programme John's aim was "to be able to discover a way to relax and put the past in the past" (see penultimate line of Appendix A4.1). In part at least, he has succeeded in doing this because in writing about his Caring Phase (50-55 years) he noted it had helped him to "close the book on this chapter of his life". John's 'Letter to Dad' (NWO.14) suggests that he has also put some of his greatest sadness in the past: during his Whole Life Review

Session (LRS.13) prior to writing his letter, the facilitator asked John if the Assert programme had changed him in any way:

J: It's completely changed the way I look at things (J13/18/2).
C: Has it? (J13/18/3).
J: Mmm. Absolutely (J13/18/4).

The facilitator asked John if he had more sense of permanency:

J: Well, this is – this is, now – the first time in my life when I've thought - I mean ... I'm actually thinking about well, I'll save some money now so that I can do something in eight or ten months' time so that in a year's time I can have a particular thing. And I've not ever been a person to do that (J13/18/6). ... If I have it [the money], let's spend it and let's do it now (J13/18/8).

The facilitator reflected this back to John:

C: Complete change around then ... (J13/18/9).
J: Total change (J13/18/10).
C: Do you put that down to the Assert programme? (J13/18/11).
J: I don't know, but I didn't feel like it before (J13/18/12).
J: Now I've been doing the Assert programme for ... six months? ... and other things in my life haven't changed in that time. I can't think of anything else that has changed that would have changed me (J13/19/1).

The facilitator commented on John's sense of time running out and that the first change she noticed in him was when he started thinking about his health:

C: ... Now that was a change because before ... you just thought oh well, I'm going to die – [anyway] (J13/19/2).
J: Well, I still think that (J13/19/3).
C: But you're doing something to prevent it (J13/19/4).

John explained that “strangely enough” he had visited his doctor four or five times in the last few months which was more than for the last ten or twenty years and had been found to be in good health.

During the interval between Closure (LRS.14) and Follow-up (LRS.16) John was asked to read the transcripts of his life review sessions and his narrative writing. Together these formed his biography and reflected back to him his own perceptions of his life which is another form of mirroring. As facilitator I asked John to write down his impressions, thoughts and feelings as he read his biography phase by phase, explaining that his comments would feature in their discussion at Follow-up. He noted that although the Assert programme (Gardner

2006) had not brought back any new memories it had “sharpened up” those he does have and he can see where he “sits in things”.

On reading the transcript for his Early Twenties Phase (20-25 years) John commented that he could:

... look back on painful interludes with unemotional clarity – maybe it’s just the length of time, or maybe it’s ... because I feel safe and comfortable.

On re-reading his narrative writing for this phase he commented that:

... it was quite painful to do so. I think that I have exorcised a bad memory!

Reflecting on his life review process he admitted that he had “unintentionally tried to lead the sessions” and realised that he changed towards the end of the programme but did not know why. His comments on his Post Caring Session (LRS.12) include: “I even seem to be less argumentative ... maybe Assert has allowed me to relax more”. And in the following session (LRS.13), his Whole Life Review, John observed: “I felt much more positive about myself. ... Again, I felt less argumentative in the session. Instead of one-liners it was long statements ... not batting backwards and forwards” and “I think before I was trying to lead the sessions”.

The Facilitator’s Perspective on John’s Life Review Process

In the early sessions indifference, dismissiveness and negativity seemed to pervade John’s conversation, particularly when talking about himself. At one point even he acknowledged the emptiness and bleakness in his tone and as facilitator I found it rewarding when our dialogue became naturally interactive in session 12 and was particularly pleased about John’s “discovery” and his spontaneity during his Whole Life Review (LRS.13).

The mirroring aspect of John’s life review process will be discussed in more depth in Part II of this chapter, ‘No reflection on Erikson’ but there was one exchange which may have been significant in the last life review session (LRS.15). When recalling that he was always being punished for “getting into trouble” as a child, with comic licence John described the scenario of being given a penknife to play with by a grandparent.

J: ... on the understanding I would be sensible with it ... but two minutes later I'd opened it up and was running around like cowboys and Indians (grins and waves hands in the air). It got taken away from me and I don't think I ever saw it again (J15/6/1).
C: (Softly) That's understandable, isn't it, really? (J15/6/1).
J: (Slowly and thoughtfully) ... Yes, understandable (J15/6/2).

John's last response "Yes, understandable" resonated with the facilitator's inflection and as he said this he looked away and was thoughtful for the next few moments, as if reflecting upon the scenario. I searched his face for an indication of disappointment in my not having shared in his humour but if there was any, he hid it well. In the (unusually extended) silence I wondered if perhaps for the first time John was seeing himself as a child through 'different' eyes, through kindly, parental eyes, and with new meaning. If so, this could have been indicative of a shift in John's biographical reflective focus. This notion is explored in 'Finding the Lost Child' in part III, 'In Absence of Oedipus'. In the meantime other key changes in John's outlook are considered below in terms of the shift in his biographical focus.

The Shift in John's Biographical Reflective Focus

The key outcomes of John's life review process are listed in Table T4.4 overleaf. Set beside selected criteria, i.e., Butler's (1963; 1974) 'benchmarks' and a sense of empowerment, Advocate's primary aim for carers (Gardner 2006), they also show the positive shift in his biographical reflective focus indicative of his increased psychological congruence over time. Midway through his programme in session eight, LRS.8(b), for example, John was still somewhat harsh on himself about the upbringing of his children and felt he had not appreciated them:

J: I don't know if I ever even said you know, well done or I'm proud of what you've done and so on (J8(b)/1/6). ... I know I was much too hard on them in lots of other ways (J8(b)/2/1).
C: But you were also very good to them ... (J8(b)/2/2).
J: I provided for them. Which doesn't necessarily mean good *for* somebody (J8(b)/2/3).

In his last session (LRS.15), there was no edge to John's voice when he reiterated the same thoughts and feelings about himself as a parent:

J: ... I didn't make a very good job of bringing up my children (J15/10/2).
C: But you still supported them (J15/11/1).
J: Oh, absolutely. I was about to say but I supported them. They didn't go without things ... (J15/11/2).

Table T4.4

The Key Changes in John's Attitudes Attributed to the Assert Programme

Psychological Incongruence		Positive Shift in Biographical Reflective Focus															Psychological Congruence	
Outcome Indicator *	John's Attitudes Prior to the Assert Programme	Life Review Session and Age Phase in Years Reviewed															John's Attitudes After the Assert Programme	
		Session 1 Infancy (0-5 yrs)	Session 2 Childhood (5-10 yrs)	Session 3 Early Teen (10-15 yrs)	Session 4 Later Teen (15-20 yrs)	Session 5 Early Twenties (20-25 yrs)	Session 6 Late Twenties (25-30 yrs)	Session 7 Mid-term Appraisal	Session 8 Thirty-something (30+ yrs)	Session 9 Early Middle-age (40+ yrs)	Session 10 Action Plan for Change	Session 11(b) Caring Phase (50-55 yrs)	Session 12 Later Middle-age (55+ yrs)	Session 13 Whole Life Review	Session 14 Closure & Evaluation	Session 15 Letter to Dad		
1 Amelioration of suffering		John feels bitter about having given up his career and status to look after his father.										"I feel less bitter. I would say I did a wonderful job."						
2 Preventive		John feels time is running out and that he is going to die.										"I might live forever!"						
		After starting the Assert programme John visited his doctor five times – "more than in the last 10 years".										For the first time in his life John starts to plan ahead which was "a total change".						
3 Remedial		John's memory loss is "disconcerting". He regrets his lack of knowing what it's like to be a child ... "it's as if I'm talking about someone else".																
		Although no new memories have surfaced John feels the Assert programme has "sharpened up those I do have" and "I can see where I sit in things".																
4 Increased sense of self-fulfilment		John feels his life "is a waste".										"The Assert programme has made me appreciate how much I did for my father."						
		"I value myself more ... and I'm a better person in my eyes."																
5 Reconciliation of family relationships		John was estranged from his son and daughter after his divorce. After starting the Assert programme he contacted his daughter who had been seriously ill for a number of years and met up with his son again shortly after he got married.																
6 Expiation of guilt		John feels he was "much too hard" on his children.					John thinks he "must have done something right!"					John concedes that he did a "reasonable job" of parenting.						
7 Exorcism of problematic childhood identifications		John believes his father never loved him.															"I suppose he must have loved me."	
8 Resolution of intra-psychic conflicts		The pain of separation and loss feels "like a death" for John.										John realises his attachment style is the cause of his unhappiness.						
9 Increased sense of empowerment*		John feels he is a victim of circumstance.					John realises his problems are "all my own fault".											
← Start of the Assert Programme — Mid-term — Follow-up →																		

← Start of the Assert Programme — Mid-term ————— Follow-up →

*Butler's 'benchmarks' (Butler 1963; 1974) and Advocare's primary aim for carers (Gardner 2006)

Reflecting in session LRS.11(b) upon his caregiving role and his irrevocable drop in living standards John's tone was bleak. I asked him:

C: Does it depress you? (J11(b)/4/3).
J: No. No, it doesn't depress me (J11(b)/4/4).
C: Does it make you feel bitter? (J11(b)/4/5).
J: Against whom? (J11(b)/4/6).
C: That such a thing had happened. And you were caught up in it (J11(b)/4/7).
J: Mmm. No, because it was my own decision. I didn't have to get caught up in it. I made the decision, I wasn't forced into it. I didn't have to do it (J11(b)/4/8).

John mirrored my phrase "caught up in it" and later in the same session admitted that he used to feel bitter. I then asked John if he thought the Assert programme (Gardner 2006) had changed his perception of his Caring Phase:

C: Do you think your perception of those caring years has changed in doing the Assert programme? (J11(b)/13/1).
J: Yes, I should think so. (J11(b)/13/2) ... I used to be fairly bitter about things whether it's the Assert programme, whether it's just time but I think the Assert programme as well. I'm not as bitter about things as I used to be ... (J11(b)/13/4).

I also asked John what he thought it was about the Assert programme that possibly made him less bitter:

J: (Sighs) I'm not very good at analysing those sort of things. ... maybe it's made me appreciate how much I did. But then I've always known that I did as much as I could (J11(b)/13/6).
C: So are you not giving yourself a hard time over it now? (J11(b)/13/7).
J: Probably not. And I don't know that I was giving myself a hard time. I can't remember. Don't know (J11(b)/14/1).

Two sessions later (LRS.13) in his Whole Life Review I asked John if there were any changes which he would attribute to the Assert programme:

C: Well, looking back over things ... is there anything you see differently about your life now, having done the Assert programme? (J13/6/4).
J: Oh, well, it's probably clarified more than anything, clarified the things of caring. ... If I was somebody else assessing what I did whilst caring for my father I would say that I did a wonderful job (J13/6/4).

During his last life review session, LRS.15, the extra one John had requested to reflect upon his Letter to Dad (NWO.14), John's mirroring was evident in tone, meaning and emotion. He spoke more kindly of himself and was less intense when speaking about his relationship with his late father:

J: Yes. I always did well, or all right, at school, never any problems at school. Never any social problems. You know, police or anything like that ... (J15/5/1).
C: (Softly) But you still had this sense that he was hard on you ... (J15/5/2).
J: (Softly) But there's a sense that he was hard on me (J15/5/3).

As John reflected upon his caregiving role later in the session his sense of achievement was apparent:

J: ... I'd probably think to myself that really, throughout most of my life I haven't done that many things which anybody outside would look at and say well, didn't he do well there, (clears throat) ... for all the amount that it cost me, financially ... It is definite that, giving up work to look after my father was the ... probably the only really good thing I have done in my life (J15/10/2).

In Further Conversation with John

The subtle change in John's interaction style I had noticed as facilitator was puzzling to me as researcher; I had anticipated there would be a similar rate of discordance running throughout similar data. It could be argued that John's discordant responses were due to missed verbal or non-verbal cues, that having reviewed his Caring Phase in the first session (LRS.1) this provided a rehearsal (Erben 1998) for this part of his narrative so that in the later session (LRS.11(b)) he recognised those cues. Perhaps by this stage of his life review process John had begun to value himself and felt less negative about this phase. However none of these notions explained the apparent shift in the dissonance-concurrence-resonance continuum, why his mirroring responses increased, why his turn-taking style changed and what had made him (by his own admission) less argumentative.

In an endeavour to discover more about these phenomena, (as researcher) I re-listened to and re-analysed the audio tapes of John's life review sessions using the principles of conversation analysis (Sacks, *et al.* 1974; Prevignano and Thibault 2003; Woodruff and Aoki 2004), with particular focus on John's turn-taking in conversation and his mirroring responses.

Taking Turns on the Contrary

Conversation is "a vehicle for interaction between parties with any potential identity and any potential familiarity" according to Sacks, *et al.* (1974, p700) who conclude that turn-taking is "an organisational device" which is both "context-free and context-sensitive" and has "an appropriate sort of general abstractedness and a local particularisation potential". Schegloff (Prevignano and Thibault 2003, p166)

suggests that in analysing conversation “the issue is how best to get at what is going on ...”, and to discover “... how it comes to be going on”. The initial analysis of John’s life review session transcripts was concerned with content, the ‘what was going on’. Re-listening to the tapes provided an opportunity to ‘get at’ the phenomena occurring in the dialogue between John and myself as facilitator.

As mentioned in the last chapter, ‘Methodology and Methods’, the terms devised for conversation analysis in this study defined in Appendix A3.18 are based loosely on the conventions of transcript analysis developed by conversation analysts Sacks, *et al.* (1974, p731). For example ‘normal’ turn-taking is encoded thus: ‘☞’ in this study and the small or imperceptible amount of time between turns of speaking is what Sacks, *et al.* (1974) term ‘latching’, which in this study is encoded thus: ‘=’. The symbol ‘○’ indicates a response by John that missed or ignored what the facilitator had said and these symbols were added to text extract references where appropriate, for example: ‘J1/2/3/○’. In this way the turn-taking phenomena in the life review sessions were re-analysed taking into account, where appropriate, some of my observations as facilitator. As mentioned earlier, I had noticed how quickly John responded after I had finished my ‘turn’ of speaking, indeed, even before I had finished speaking, sometimes emphatically agreeing and then contradicting what I had said which in some cases was reflecting what *he* had just said! As can be seen from the example on page 99 when, as facilitator, I asked John about the funding for his four and a half years in higher education: “... And were they funded by your –” John cut in sharply with: “First one was, the second one wasn’t. They were funded by me. By me” (J5/3/17/#). This is similar to what Sacks, *et al.* (1974) term ‘cutting in’. Sometimes John cut across the meaning of what I was saying, for example:

C: You were a water baby – (J3/6/7).

Before I could finish saying “by the sound of it” John cut in with: “No, I wouldn’t go that far” (J3/6/8/#). Below is an example of John continuing on a theme as if he had not heard me, for example:

J: I had to say how nice it [an old-fashioned, second hand, black bicycle] was ... and ‘thank you very much’ – and I’m sure I did (J3/3/3).
C: You were a polite child ... (J3/3/4).
J: I’m sure I did but I’ve got no idea at all whether or not I did ... (J3/3/5/○).

As can be seen from Table T4.3 (page 103) and the instances given earlier, John's mirroring responses (' Φ ') increased to thirteen in LRS.11(b), and towards the end of the Assert programme he began to resonate with the facilitator's words, tone, meanings and emotion. For example when I pressed him gently to say more about his relationship with his father (see the first textextract box on p111) enquiring softly: "But you still had this sense that he was hard on you?" he reiterated equally softly, mirroring my inflection: "But there's a sense that he was hard on me" (J15/5/3/ Φ).

In what I described in my facilitator's notes as 'the most meaningful mirroring moment', the most significant change in his interaction style became evident:

Reflecting upon the scenario of saying goodbye to his father just before he died, John was moved to tears. When he noticed there were tears in my eyes he indicated for the tape to be paused until we had both regained our composure. Afterwards he explained he was concerned not for his own sake but for mine in case what he had just described had upset me. There was a resonance of emotion in that moment when John empathised with me (LRS.15).

As researcher I decided to compare the analysed conversation data from the three sessions I felt were most significant, namely the introductory session LRS.1, in which John reviewed his Caring Phase; LRS.11(b), the extra session on his Caring Phase and his Whole Life Review, LRS.13, paying special attention to the turn-taking phenomena therein.

The re-analysis revealed nothing new and merely reinforced the results that had already been obtained; a method was needed that could cope with the dynamics of interaction style, content *and* meaning. Having already identified John's accordant-discordant responses and encoded them thus: ' Φ ', I found in some cases that John had eventually returned to the accordant position. In order to track initially accordant statements that were followed by statements that seemed to oppose the *meaning* of what had been said, another term was introduced, 'opposing/contradictory responses' and encoded thus: ' \otimes '. Re-analysis of the data from the same three sessions, namely, LRS.1, John's Caring Phase; session LRS.11(b), the extra session on John's Caring Phase; and session LRS.13, his Whole Life Review, showed, as might be expected, that most of his opposing/contradictory statements (nine in total) occurred in the first session which

focused on his Caring Phase. Interestingly he made no opposing responses about caring in the extra session on his Caring Phase (LRS.11(b)) or in his Whole Life Review (LRS.13). As more subtle contradictions gradually emerged from the data it became evident that John made more contradictions when reflecting on himself negatively as a person as distinct from a carer or as a child. This analysis and the significance of turn-taking is discussed in part II of this chapter, 'No Reflection on Erikson' where Table T4.8 on page 128 lists the occurrence of his opposing/contradictory responses. Suffice to say here that as facilitator and researcher and a former carer myself, I felt able to 'tune into' the meaning behind such statements. Had this not been the case, they may have been accepted at face value and without *verstehen* hermeneutics going beyond the superficial, their deeper significance may have been missed. Discussed next are the more obvious shifts towards positivity in John's 'Aspects of Life' and 'Aspects of Self'.

John's Outlook – Aspects of Life

The Aspects of Life Log is a simple diagrammatic life satisfaction measuring tool (see Appendix A3.1) which was devised for the Assert programme development group (Gardner 2006). Ratings for life satisfaction are based on the Likert scale from 1, the lowest, to 5 the highest. In the Introductory Session prior to starting their programme, development group participants were invited to select and reflect upon six aspects of their life, such as 'work', 'home' or 'health', which were currently significant to them and then asked to rate them for life satisfaction by completing an Aspects of Life Log, similarly at Mid-term and again at Closure. They were also asked at Closure to include and rate again all previously selected aspects of life. As well as providing a means for the facilitator (myself) to monitor participants' progress throughout the programme, by reflecting upon their log ratings, the participants themselves were able to determine current levels of life satisfaction in various aspects of their lives and by comparing their first ratings with those made at Mid-term they could identify areas of *dissatisfaction* and explore avenues for change. Listed in Table T4.5 overleaf are the ratings John gave his chosen aspects of life in order of first rating to show the change. As can be seen from this table John was invited to provide an extra set of ratings in Life Review Session 11(a) (LRS.11(a)) after his four-month gap.

Table T4.5**John's Chosen Aspects of Life Satisfaction Ratings in Order of First Rating**

Selected aspect of life	Rating given in Introductory Session LRS.1	Rating given at Mid-term Session LRS.7	Rating given in Session LRS.11(a)	Rating given at Closure Session LRS.14
Leisure	-	2.0	-	4.5
Future	2.5	-	4.5	5.0*
Relaxation	2.5	-	-	4.5
Health	3.0	3.5	4.5	4.0**
Home	3.5	4.0	3.5	4.0
Security	-	-	4.0	4.5
Money/Security	-	4.5	-	4.0
Romance	-	3.5	-	5.0
Love	4.0	-	4.5	5.0
Work	4.0	4.0	4.0	5.0
Quality of Life	-	-	-	5.0***

*John added the comment: 'Loads of it!'

** John added the comment: 'Could be better and will be!'

*** John added the comment: 'Excellent'.

As can be seen from Table T4.5, the most significant change was in the 'Future' aspect of John's life, rated 2.5 prior to starting the Assert programme. It was increased to 4.5 in Session 11(a), and by Closure it was completely satisfactory at 5.0. John's satisfaction ratings for 'Romance' and 'Love' were also completely satisfactory at Closure, each rated at 5.0, which reflects John's comments in his Whole Life Review (session LRS.13) about looking forward to his retirement and feeling more positive about a long-standing, relatively stable relationship (J13/1/4).

It is interesting to see from Table T4.5 that a stable relationship did not appear to feature in John's sense of security, since this aspect of his life appeared to be linked with money. The 'Money/Security' aspect first came into significance for John at Mid-term when he rated it 4.5, and decreased this to 4.0 at Closure. In Session 11(a) John selected 'Security' as a separate aspect and rated this 4.0, increasing it to 4.5 at Closure. Except for 'Health' and 'Money/Security', both of which decreased in satisfaction and were reduced to 4.0 at Closure, all John's life satisfaction ratings were at their highest. That John did not select 'Money' as a separate aspect of life suggests that, despite his hitherto impoverished circumstances as a carer, its significance was diminishing as his overall satisfaction in other aspects of his life increased. This may have been due to his

'Work' aspect which remained constant at 4.0 throughout the programme until Closure, when he rated it as completely satisfactory at 5.0.

Owing to the loss of his childhood memories, John had chosen to reflect upon his Caring Phase in the first life review session. Noticing his low ratings for 'Future', 'Relaxation', 'Health' and 'Home' as facilitator I became mindful that John may be rendered at risk of becoming depressed. I was somewhat reassured, however, when 'Home' which he had rated 3.5 prior to starting the programme, increased to 4.0 at Mid-term, but this rating dropped back to 3.5 in Session 11(a). It rose again to 4.0 at Closure. John's rating for his 'Health' aspect of life was 3.0 prior to starting the programme, 3.5 at Mid-term and rose to 4.5 in Session 11(a).

The aspects of life John had chosen to rate prior to starting his Assert programme and at Mid-term were 'Leisure', 'Future', 'Relaxation', 'Health', 'Home', 'Money/Security', 'Romance', 'Love' and 'Work'. His reflections on his ratings for these aspects helped him to identify areas of *dissatisfaction* in his life and to formulate an action plan defining what actions he might consider taking to make changes. His Aspects of Life Log ratings at Mid-term, and the attitudes he held at that time towards his current situation, helped to form part of the framework for his 'Outlook' Action Plan for Change. One of John's desired changes for example involved making plans for his retirement. He decided he would start saving money (interestingly an aspect which was not selected separately) and visited his GP for a health check up. The small but nevertheless positive increases in John's 'Home' and 'Health' ratings at Mid-term reflected these decisions and were among those which encouraged him to trust in his own endeavours to self-determine his fate. John's developing autonomy indicated a shift from external to internal locus of control and this, together with a positive perspective about his future, indicated a significant change in his attitudes.

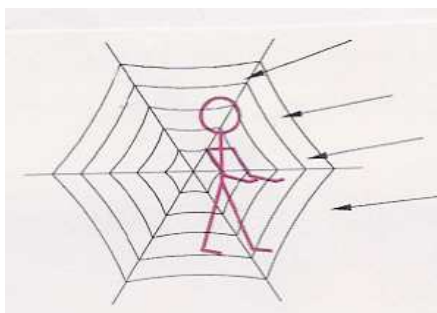
As can be seen from Table T4.5, prior to starting the programme 'Relaxation' was one of John's lowest ratings at 2.5. He wanted the Assert programme to enable him to discover a way of being more relaxed and it is interesting that this aspect was not selected for rating again until Closure (session LRS.14) when it scored 4.5, indicating a significant improvement. 'Leisure', an aspect featured at Mid-term and rated 2.0, is also interesting because although John's work/home

balance and activities had not changed, his *perception* had, as his rating at Closure of 4.5 shows. Perhaps the most interesting aspect of all, however, was 'Quality of Life', an aspect which John introduced at Closure and rated as completely satisfactory at 5.0, adding the comment: 'Excellent'. Quality of life for John meant having a stress-free lifestyle and the self-introspective process of formulating his 'Inlook' Action Plan for Change may itself have helped to reduce his level of stress.

John's Inlook - Aspects of Self

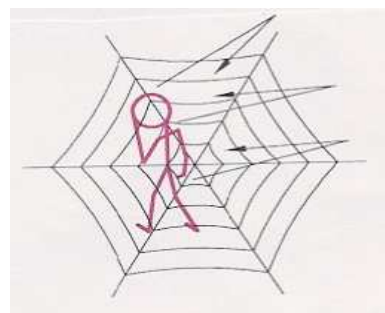
To help with the formulation of John's 'Inlook' Action Plan for Change, he was shown four untitled diagrams depicting emotional and psychological states, termed 'Aspects of Self', from a carer's perspective, (see chapter 3, p82) which had been devised for the Assert development group (Gardner 2006). He was invited to select the one he felt best symbolised his attitude towards himself in relation to his outside world at that time. The four diagrams below were shown without captions to John for whom they symbolised the following aspects of himself:

Diagram 1:



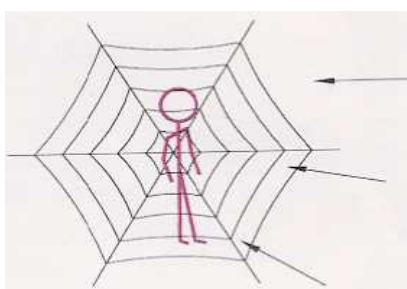
For John Diagram 1 represented 'Acceptance – having to work'.

Diagram 2:



For John Diagram 2 represented 'Beaten – it's beaten me'.

Diagram 3:



For John Diagram 3 represented 'Facing up to things – coming to terms'

Diagram 4:



For John Diagram 4 represented 'Fighting – challenging something that is wrong'

John identified immediately with the diagrams but had difficulty in conceptualising his inner and outer realities and asked if he could “take the Action Plan home to do”. Those with an extremely fragile sense of selfhood may perceive their inner world as reality (Gerhardt 2004, p150). Ever mindful of John’s mental welfare and aware that the ‘debris’ that had surfaced in reviewing his life thus far could render John at risk of depression, before embarking on more introspection with John to further explore his sense of selfhood, I sought guidance from my psychotherapy supervisor. From my reports he judged the boundaries of the therapeutic relationship to be ‘holding’ John securely and that the programme’s semi-structured protocols were sufficiently robust in providing him with a balance between reflections on past sadnesses and those of happier episodes in his life. The Aspects of Life Log provided a means for detecting a participant’s mood change and in John’s case this was indicated by a slight shift from external to internal locus of control at Mid-term. My psychotherapy supervisor deemed that John was becoming more trusting of his own endeavours in determining his own fate which in itself created a ‘springboard of hope’ for his greater life satisfaction in the future.

Session 10 was devoted to discussing John’s action plan which may have helped him create a new lens through which to see hope for the future and start a process of change. As can be seen from the extract of John’s Outlook/Inlook Action Plan for Change in Appendix A4.2, included in desired changes in himself were: ‘being more relaxed’ and being ‘less guarded’ which meant risking being ‘more true to himself’. A four-month gap followed session 10 after which in session 11 John was noticeably more relaxed. Having first reviewed his Action Plan for Change (in LRS.11(a)), as his reminiscence prompt sheet for reviewing his Caring Phase (in LRS.11(b)) shows he had begun to question why he took on his caring role (see Appendix A4.5) which infers greater objectivity. Perhaps in being able to distance himself from thinking as a carer he was able to be more true to himself. He made fewer discordant statements; one in session LRS.11(b), one in LRS.13 and two in LRS.15, four in total as shown in Table T4.3 on page 103. John also followed the protocols with more ease and sought less to control the session. He said he appreciated the opportunity of being listened to and, after reading the transcript of session 10, had commented at Follow-up: “I realised I was no longer trying to lead the sessions”, “I am less argumentative” and “most

of my problems are of my own making". More significantly, perhaps, he commented that he felt himself to be "a better person".

According to Gerhardt (2004, p89), if a person has not been securely 'held' in infancy, in their adult life their "baby within" continues to seek what they missed. This is partly why adequate boundaries in the therapeutic setting are crucial. Gerhardt (2004) also points out that as dependent behaviour is not easily tolerated by others in adulthood the person may be unable to attain true autonomy. Interestingly, when asked how he might consider making his desired changes in outlook it was with thoughtful insight that John had commented: "I don't know if the young person is in there trying to get out", referring to his missing autobiographical memories of childhood (see Appendix A4.2).

Although a resilient individual in many ways, John's sense of selfhood may have been rendered fragile due to his lost memory. However, according to his life satisfaction ratings at Closure and his comment about being a better person, he was gaining in autonomy and his sense of selfhood, too, had strengthened.

In Summary

Initially John had seemed defensive; his guardedness could have been due to feeling like a 'guinea pig' and he may have been anxious about not being 'held' securely in the therapeutic arena (Clulow 1982; Bateman and Holmes 1995). Having said this, the extract from the facilitator's notes indicating that John empathised with her in the last session indicates that he did feel secure then. These findings suggest that the subtle shift towards resonance on the dissonance-concurrence-resonance continuum is an indicator of change in John and that in particular mirroring was instrumental in bringing about change within him.

Initially his exchanges with the facilitator may have caused dissonance - and by his own admission he was argumentative. [Secure or not, it is perhaps pertinent to note that outside of the therapeutic setting John's dissonance may have been interpreted by some sensitive souls as a painful rebuff.] By the end of the programme, however, his style of interaction had become more relaxed and natural and his cutting edge less obvious yet interestingly, he did not select 'Relaxation' as an aspect for life satisfaction rating in the evaluation exercise in

session 11 (LRS.11(a)). Previously “jumbled” memories appear to have been “sorted” and John “sees where he sits in things” now. That a sense of achievement arose within him with regard to caring for his late father indicated a significant improvement in John’s self-concept. Perhaps the most therapeutic aspect of John’s life review process lies in his follow-up session in which he reveals that he no longer thought of himself as “a waste of time” as he had always done hitherto. Interestingly, when asked if he thought changes in perception of his relationship with his late father were linked to his improved self-concept he said:

J: (Long pause) Don't know. Don't know ... if there's a link. (Clears throat) ... the probability is 'no' (J15/10/2).

One clear example of the positive shift in John’s biographical reflective focus is his increased psychological congruence with regard to parenting his children. By the end of the programme John had a more realistic perception of what he had done for them and was less harsh on himself about the way he had treated them. Perhaps he had begun to forgive himself for having no knowledge of being a child himself. John felt he had “no experience on which to establish the future” and for most of his life had lived for ‘now’. The Assert programme enabled him to “discover a way to relax” and “put the past in the past”, including his caregiving role. As his life satisfaction ratings for ‘Leisure’ and ‘Quality of Life’ indicate, it was his *perception* that his way of life was much more positive that had changed.

By the end of his Assert programme John was relaxed enough to release some control in the present and start facing freedom, formerly his “biggest enemy”, and planning his journey towards the future without “terror”.

Chapter 4

Findings, Interpretation and Discussion

Part II

No Reflection on Erikson

Introduction

It was anticipated that John would benefit from his Assert programme (Gardner 2006) however the degree of change was much greater than expected. Changes in John's interaction style prompted re-analysis of the life review session audio tapes after completing the comparative thematic interpretation of the data with grounded theory and *verstehen* hermeneutics (Patton 2002; Glaser and Strauss 1967; Holloway and Wheeler 1996; Dilthey 1976). Most key changes in John's attitudes became apparent after his Mid-term appraisal of his life review, the outcome of which informed an action plan for his wished-for changes in the future.

On Reflection

When formulating his Outlook/Inlook Action Plan for Change in session ten (LRS.10), John described himself as a 'glass half-empty' person but by the end of the programme his sense of selfhood was more positive. The first sign of change in his self-concept was in session LRS.6, John's Late Twenties Phase (25-30 years) when his attitude towards himself as a parent softened. In session LRS.9, his Early Middle-age Phase (40+ years) John saw how he had contributed to his problems and a shift from "external" to "internal locus of control" was discernible (Rotter 1966, cited in Gross 1987, p428) with an increase in his autonomy. By session LRS.11(b) his Caring Phase (50-55 years), John had begun to appreciate all that he had done for his late father and was less bitter about the cost to him. During his Whole Life Review (session LRS.13) he became aware that it was a loss in self-confidence that had probably made 'starting again' more difficult for him when his caregiving role ended. As his attitudes towards himself improved, John's intentionality (Fonagy, *et al.* 2004; Fine, *et al.* 2001) increased, and he started making plans for the first time. His reflections on these and other key changes which he attributes to the Assert programme such as improved self-concept and (growing) sense of autonomy, increasing self-awareness and sense of agency are set out in Table T4.6 overleaf according to three main themes: (1) caregiving role, (2) sense of selfhood and (3) childhood.




Table T4.6

John's Reflections on Key Changes due to the Assert Programme

Key:		Comments relating to positive changes in self-concept
		Comments relating to increased sense of autonomy
		Comments relating to increased sense of self-awareness
		Comments relating to increased sense of agency

Theme (1) John's reflections on changes relating to his caregiving role	Theme (2) John's reflections on changes relating to his sense of selfhood	Theme (3) John's reflections on changes relating to his childhood
Reflecting on his Caring Phase John said he used to be fairly bitter but later in the same session he felt "less bitter ... about things than I used to be" (J11(b)/13/4).	At the beginning of his Assert programme John regarded the unknown with "terror" and freedom as "the biggest enemy" (J1/9/4). By the end of his programme he contemplated his "destiny" with eagerness (J12/8/10).	John described his missing memories as "disconcerting" (J3/12/6). Although no new memories surfaced for John, he felt after reading his biography the Assert programme "sharpened up those I do have" and "I can see where I sit in things" (Follow-up).
The Assert programme made John "appreciate how much I did for my father. - I would say I did a wonderful job" (J11(b)/13/6).	Reflecting on his Late Twenties Phase John felt he should "never have been a parent" (J8(b)/1/2) and was "much too hard on my children" (J8(b)/1/4). In his Whole Life Review John conceded that he did "a reasonable job" of parenting (J13/10/10).	Before starting the Assert programme ending a personal relationship felt "like a death" for John (J9(b)/11/11). Then "A discovery! ... one thread [his attachment style] stands out more than anything else" in his life (J13/1/2).
John thought maybe he "didn't try hard enough" to get a job after his caregiving role ended (J11(b)/1/6). Loss of confidence was the reason why "it was very difficult starting again at the end of caring ... I don't know that I was aware of it" (J13/14/8).	For a number of years since his divorce John had been estranged from his son and daughter. After starting the Assert programme he made contact with them.	Whilst reflecting on a particular childhood event – 'The Penknife Scenario' – John, who was "always being punished for getting into trouble" may for the first time have seen himself as a child through kindly, non-punishing parental eyes (J15/6/1).
"Even though the caring phase was the worst time of my life, I can reflect on what I did with the pleasure of knowing I did the best I could at the time ... when I was the best person" (Follow-up).	"Six months ago I may not have been able to sit and think with relatively calm detachment about the person I am ... and talk so easily about painful episodes" (J12/12/14).	Having firmly believed all his life that his father did not love him John supposed "he must have loved me for the number of things he did for me" (J15/9/7).
Reading his biography made John feel "very sad and unhappy for the loss of my father ... I feel more comfortable now" (Follow-up).	Instead of feeling that time is running out and that he is going to die John said "I might live forever!" (J12/16/2).	
	Instead of feeling "an empty sort of nothing" (J13/1/4) "I do feel a lot more positive about myself" (J13/19/3).	
	For the first time ever in his life John is able to plan ahead and save money which has "Totally changed ... I didn't feel like it before" (J13/18/10-12).	
	John feels he is less argumentative. (Follow-up)	
	Since starting the Assert programme John visited his doctor "four or five times which is more than in the last ten or twenty years" (J13/19/4).	
	Instead of feeling that his life is "a waste" and he is a "waste of time ... I value myself more and I'm a better person in my eyes" (Follow-up).	
	Instead of feeling a victim of circumstance John realised after reading his biography "my problems are all my own fault" (Follow-up).	

John's enlightened and more positive attitude towards himself and others is reflected in his interactions during his life review sessions which were analysed on the basis of a dissonance-concurrence-resonance continuum. As was seen in Table T4.3 in chapter I (page 103) for example, during the six sessions prior to Mid-term, John made a total of thirteen discordant and forty-three accordant-discordant responses whereas during the eight sessions after Mid-term he made only four and twenty-seven respectively. John's accordant responses also reflect this trend since before mid-term he made a total of sixteen accordant responses compared to seventy-nine post Mid-term. The definitions for John's accordant, discordant and accordant-discordant responses are listed in Appendix A3.17 but for ease of reference they are given below along with some examples:

Definition of response	Examples
Accordant Responses Those which were emphatically harmonious were encoded thus: 	<p>"Of course!" "Of course!" "Exactly!" "Precisely!"</p>
Discordant Responses Statements which seemed to create dissonance were encoded thus: 	<p>When, as facilitator, I suggested to John that he could forgive himself for being too hard on his children because no-one is perfect John said after a long pause:</p> <p>J: ... But some of us try to be ... I've never appreciated the failings of others with tolerance ... I hope that I try not to make too many excuses for my own failings ... (J13/10/12-J13/11/6).</p>
Accordant-Discordant Responses Statements which expressed harmony followed by disagreement or by a statement which created dissonance were encoded thus: 	<p>"Absolutely! But ..."</p> <p>When asked if he was sorry when his pet dog Amber had died John said:</p> <p>J: Oh yes. Oh yes. [Yawns] She was my best friend. It's always annoying when your best friend dies [chuckles]. Well not annoying, but – I don't know. Yes. Probably I should think (J3/6/2).</p>

Data from the Assert development groupwork suggest that the participants' emotional resonance contributed to changes in their outlook. For this reason all mirroring responses were tracked specifically in the analysis of the transcribed data from John's life review sessions as was shown in Table T4.3 on page 103.

The definition for the mirroring phenomenon may be found in Appendix A3.17, but again for ease of reference it is given below with examples shown in red.

Definition of response	Examples
<p style="text-align: center;">Mirroring</p> <p>Statements by John that repeated the facilitator's words, echoed her tone, mirrored her meaning or resonated with her emotional expression were encoded thus:</p> <p style="text-align: center;">Φ</p>	<p>Repeating the facilitator's words:</p> <p>C: So the uncertainty of being a carer is harder to deal with than – (J12/11/1).</p> <p>J: Is harder to deal with than the certainty of having to recover from being a carer (J12/11/2/Φ).</p>
	<p>Echoing the facilitator's tone:</p> <p>C: So that's quite a positive perspective ...? (J12/12/7).</p> <p>J: There was a positive outcome. I'm probably a better person (J12/12/8/Φ).</p>
	<p>Mirroring the facilitator's meaning:</p> <p>C: ... to climb out of a soul-destroying situation into being a 'pauper' [John's term] and then having to climb your way out of that as well, I mean that's a tremendous uphill struggle (J12/10/8/Φ).</p> <p>J: ... Because you see the one advantage is you've then got this well-defined uphill struggle ... (J12/10/10/Φ).</p>
	<p>Resonating with the facilitator's emotion:</p> <p>C: ... I mean, once you're retired and enjoying life you'll go on with your life (J12/16/1).</p> <p>J: Oh, absolutely! I might live forever! (J12/16/2/Φ).</p>

It was with a carer-centred, humanistic stance based on Rogers' (1951; 1961) client-centred therapy, that in my role as the Assert facilitator I mirrored John's responses in his life review sessions, reflecting back to him the essence of his reminiscences in a non-patronising way. At times John mirrored my responses; as shown in Table T4.3 (page 103) he made fifteen mirroring responses in the sessions up to Mid-term and a total of seventy-six post Mid-term which, it is suggested here, reflects his improving self-concept. He made thirteen mirroring responses in session LRS.11(b) and twenty-two in LRS.12 and, as explained in part I of this chapter, it was this sudden increase in mirroring responses which prompted me (as researcher) to re-listen to the audio tapes. The three sessions with most data relating to John's Caring Phase (50-55 years), namely sessions LRS.1, LRS.11(b) and LRS.13, were selected for analysis first as a trial. The methodology used for this re-analysis was loosely based on Conversation Analysis (Sacks, *et al.* 1974). Definitions for the phenomena in question with full coding key and the template used are provided in Appendices A3.17-A3.20. The number of times these phenomena occurred is shown in Table T4.7 overleaf.

Table T4.7

John's Responses According to Topic and Conversation Analysis (CA)

[Loosely based on the methodology of Sacks, Schegloff and Jefferson (1974)]

Coding key for nature of response according to CA:

☉ = 'Normal' turn-taking = = Latching ≠ = Cutting in # = Cutting across // = Pausing

Coding key for type of response:

👍 = Accordant response 👍👎 = Accordant-Discordant response 👎 = Discordant response

Coding key for significant Age Phases:

← = Pre-accident ↩ = Post-accident ↶ = Pre-caring ↷ = Caring ↷ = Post-caring

LRS No.	Topic Age Phase or focus	Coding	Nature of Response according to CA					Type of Response (See Table T4.3, p103)		
			☉	=	≠	#	//	👍	👍👎	👎
1	Introductory/Caring Phase	↷	32	0	6	0	11	3	11	3
2	Childhood (5-10 yrs)	←	26	1	0	0	3	2	6	4
3	Early Teen (10-15 yrs)	←	42	0	5	3	0	1	14	3
4	Later Teen (15-20 yrs)	↩	66	1	0	0	2	5	6	2
5	Early Twenties (20-25 yrs)		45	0	3	0	7	5	6	1
6	Late Twenties (25-30 yrs)		25	0	1	0	0	0	0	0
Total responses prior to Mid-term:			236	2	5	3	23	6	43	3
8(b)	Thirty-something (30+ yrs)		13	0	0	0	0	0	2	0
9(b)	Forty Plus (40+ yrs)	↶	50	0	2	0	4	9	5	0
11(b)	Caring Phase (50-55 yrs)	↷	31	0	11	2	9	2	3	1
12	Later Middle Age (55+ yrs)	↷	41	0	1	3	1	3	3	0
13	Whole Life Review		40	5	11	8	3	8	11	1
15	Letter to Dad		40	1	6	0	9	17	3	2
Total responses post Mid-term:			215	6	31	13	26	69	27	4
Total at end of programme:			451	6	46	6	49	85	70	17

Whilst re-examination of the data using Conversation Analysis (CA) methodology (Sacks, *et al.* 1974) added nothing further to thematic interpretation, it was evident that some of John's accordant responses were followed by contradiction. At times he even contradicted himself as the following example shows:

C: So the world didn't seem to be a frightening or anxious place for you? (J2/6/11).
J: I don't think of it like that. No. ... There wasn't anything that I couldn't contemplate doing. That I wasn't happy to do (J2/6/12) ... I was terrified of the water to start with (J2/7/3).

As explained in chapter 4 part I, such responses were already assigned to the accordant-discordant category, encoded thus: '⊕', but of these some responses appeared to oppose the facilitator as if John was arguing 'for the sake of arguing' whilst others seemed to contradict his own or the facilitator's meaning. These were termed 'opposing/contradictory responses' and encoded thus: '⊗'. An example of his opposing stance occurred in session LRS.3, John's Early Teen Phase (10-15 years). When he was describing how his 'missing phase' was disconcerting for him he cut across the facilitator's attempt to understand:

J: ... - disconcerting in as much as I suppose in later years when I had kids I couldn't think when they were eight I couldn't think what it was like to be an eight year old or a ten year old or a twelve year old or a two year old (J3/12/11).
C: ... you're talking now about how you might have felt as an eight year-old and you could have identified with your own son or daughter - (J3/13/5).
J: [Countering tone] But the circumstances would have been different! (J3/13/8/#⊗).

In order to be clear about what his missing memory meant to him as facilitator I summed up what I thought John had described. He quickly countered it and then reverted to an accordant position:

C: But most of us don't have proper memories until about after the age of four or five so don't let that concern you - (J2/1/3).
J: But everything still comes back as facts and pictures rather than emotions ... like a photographic album starting at nought - (J2/2/5/⊗).
C: So you're more of an observer of yourself rather than actually participating. Is that what you're saying? (J2/2/6).
J: Mmm ... not so much as maybe I see the incidents as if I was looking at them on video. As if I was looking at a photograph. A moving photograph, a video of the incident rather than as actually being part of it. So I suppose, yes (J2/2/7/⊗↗).

The subtleties of John's opposing/contradictory responses were most apparent when reviewing his caregiving role and some examples of these are given in

Appendix A4.6 with some of the researcher's observations. Using this modified methodology, detailed conversation analysis of John's contradictions in meaning revealed some positive shifts in his biographical reflective focus not only across the duration of the programme but also during individual sessions, one of which was illustrated in 'The Penknife Scenario' in part III of this chapter.

Listed in Table T4.8 overleaf are John's accordant, accordant-discordant and discordant responses according to the focus of his reflections, i.e., theme (1) Caregiving, theme (2) Selfhood and theme (3) Childhood. Mirroring responses are shaded and session six (LRS.6), John's Late Twenties Phase (25-30 years), is also shaded because he made no accordant, no discordant and no accordant-discordant responses. John appeared relaxed throughout this session, and as can be seen from Table T4.7 there were only twenty-five interactions during this session and apart from cutting in once on what I was saying all were 'normal' turn-taking responses. It was during his late twenties that he met and fell in love with his future wife and he described this phase of his life as 'happy', 'settled' and 'rewarding', despite the hard work involved and he seemed to thoroughly enjoy reflecting anecdotally about his young family's activities. As can also be seen from Table T4.8 John's discordant responses included continuing on his own theme or notion 'As if not hearing' the facilitator. Most of these responses (a total of five) occurred during his third session, his Early Teen Phase (10-15 years). Another particularly interesting phenomenon is shown in Table T4.8 in session twelve (LRS.12), when John was reflecting on his Later Middle Age Phase (55+ years) which was his Post Caring Phase. He had been describing the difficulties he had experienced:

J: ... After caring ... the first thing you have to get used to was being normal again. Just how long it takes ... even something as mundane as going back to work (J12/1/3). Getting back into a 'normal' routine (J12/4/5). ... I was just in the situation where I was going to lose my home (J12/5/10).
 C: So that must have been quite catastrophic. Because – (J12/6/1)
 J: I don't know if cata ... (pause) Because I knew it was happening all the time I was caring. Knew it was coming (J12/6/2).

John paused as if to stop himself from opposing the facilitator and considered his response before making it. This changed style of interaction, encoded thus: 'Θ' occurred seventeen times in the following session, his Whole Life Review (LRS.13), as can be seen in the shaded box in Table T4.8 overleaf.

Table T4.8

John's Responses According to Focus of Reflection

Coding key for type of response:															
☺ = Accordant response			☺☹ = Accordant-discordant response			☹☹ = Discordant response									
☺☹ = Mirroring			☺☹☹ = Accordant-discordant/Agree but			☹☹☹ = As if not hearing			☹☹☹☹ = Opposing/contradictory			☹☹☹☹☹ = Considered			
Coding key for significant Age Phases:															
☹☹☹ = Pre-accident			☹☹☹☹ = Post Accident			☹☹☹☹☹ = Pre-caring			☹☹☹☹☹☹ = Caring			☹☹☹☹☹☹☹ = Post Caring			
LRS No.	Focus of Reflection	Coding	Theme (1) Caregiving				Theme (2) Selfhood				Theme (3) Childhood				
			☺☹☹												

= 17

In having the opportunity to reflect upon his caring experience during the last twelve sessions John had begun to think afresh about some of the themes and notions he had raised. It was as if a shift had occurred from dissonance towards concurrence which prompted his recall of the lighter side of some of his experiences in his Post Caring Phase. In session twelve (LRS.12) he reflected:

J: ... I can't say that all the time I spent as a carer was mind-blowingly awful. There were some dreadful times. There were some pleasant times. There were some times when there wasn't a lot to do when I could relax. I could go out riding a horse, albeit my father would have been in respite at the time, but I actually went on one occasion when he was in respite which was only a mile by road from where we lived, that actually backed onto the bottom of our paddock, with about a quarter of a mile of fields and forest in between. I actually went visiting him in hospital by horse once! [Puts on accent] I tied my 'orse up in the car park! [laughs] No I didn't, I tied it to a tree in the lawn ...right outside his bedroom window. (J12/14/1).
C: Did he see it? (J12/14/2).
J: Yes. (J12/14/3).
C: Wow, that's nice! (J12/14/4)
J: I walked in – and I said 'I didn't drive in today I rode here and there it is!' And there it was at 17 hands standing outside tied to a tree in the middle of the lawn! ... On another occasion I actually went shopping into the local town by 'orse ... (J14/14/6).
... I went to a little supermarket by 'orse. [Laughs] And tied it up outside to a dog-ring on the wall. Did my shopping. Came out with two carrier bags tied to each other which I put across the front of the saddle and rode home again. Which was quite pleasant. It was easier than the car 'cos they can't nick you for parking a horse on the pavement. They were the sort of fun things. I mean it only happened because my father was in respite. (J12/14/7).

Having reflected on the nature of John's response phenomena, their meaning is discussed in the next section of this chapter, 'The Nurture of Nature', a disquisition on mirroring from the Winnicottian (Winnicott 1971) perspective. This holds that the nature of an individual's attachment¹ style and their capacity for emotional regulation is dependent upon the quality of maternal resonance or 'mirroring' in early infancy (Bowlby 1969; 1973; Solomon 2004; Fonagy, *et al.* 2004; Gerhardt 2004). Reference is also made to sensitive mothering (Ainsworth, *et al.* 1971; Stern 1984), mother-infant attunement and turn-taking (Trevarthen 1977; Murray and Trevarthen 1985).

¹ Attachment theory (Bowlby 1969; 1973) postulates a universal human need to form close emotional bonds. At its core is the reciprocity of early relationships which is a precondition of normal development. An infant's attachment behaviours, (e.g., proximity-seeking, smiling, clinging) are reciprocated by adult attachment behaviours (touching, holding, soothing) and these responses strengthen the attachment behaviour of the infant toward that particular adult. The infant learns that emotional arousal in the presence of the caregiver will not lead to disorganisation beyond his coping capabilities. The infant's past experiences with the caregiver are aggregated into representational systems termed by Bowlby (1973) "internal working models" (IWMs). Thus the attachment system is an open emotional regulatory system (Fonagy, *et al.* 2004, p37), which is not about control or lack of it, but about alerting the individual to the need for action (Gerhardt 2004).

To 'set the scene' for 'The Nurture of Nature', some of John's life-changing events or 'epiphanies' (Denzin 1989) are discussed in terms of Erikson's (1950) theory of psychosocial development under the main interpretive theme(s) of 'Starting Again ... Significant Ends and Significant Beginnings'. The possible consequences for an individual without a lived experience (van Manen 1990) of the first four or five stages in Erikson's (1950) "Eight Ages of Man" are then explored drawing on the comparative thematic interpretation of the data from John's life review process.

"Starting Again ... Significant Ends and Significant Beginnings"

The most positive reminiscences for John were those of his late twenties. He recalled that he was "very happy" because "I had somebody in my life who I loved" and "for all the hard work and long hours it was very rewarding as well" (J6/9/16). Married life with family responsibilities suited John - at first. However, reflecting on his Thirty-something Phase (LRS.8(b)), he regretted being "much too hard" on his children, that he had not appreciated them "as much as I could have done" and admitted somewhat ruefully that there were "a few problems other than me ... but I was always the problem, I s'pose" (J8(b)/1/4). In his Whole Life Review (LRS.13) John's reflections about his career were also tinged with regret. For several years after he qualified in his field John had been "trying to fight ever onwards and upwards, never getting anywhere because there was never anywhere to get to" (J13/1/14). There was mild irony and an element of pride in his voice when John reflected that in his Thirty-something Phase (LRS.8):

J: There I am, I struggle all my life, work hard and so on and get nowhere ... and she [ex-wife Louise] just turns up to work and gets promotion [grins]. ... I've struggled all my life and all I get is money ... it would have been nice if I'd had a position as well. But you know, in saying that, [resignedly] I probably only wanted the money (J8(b)/2/11).

As a highly qualified, capable individual with relatively unfulfilled potential, John (understandably perhaps) had felt "a bit cheesed off" (J8(b)/5/6) by his ex-wife's 'overnight' success. After his divorce in his forties there were "turbulent times", his life was then dominated by "significant ends and significant beginnings" (J9/1/3). Some 'significant ends' were "immensely painful"; one "was like a death" (J9(a)/3/8). When his late father was rendered virtually helpless with only six months to live after a massive stroke, John, by now in his fifties, took time off work to help his mother care for him at home. As recounted in 'John's Story' in chapter 1, when promised support services did not materialise he did "the right thing" (J1/2/3) and

gave up his job to help his mother care full time. John did all the “practical bits” whilst his mother “did the emotional side” (J11(b)/8/9) yet he still found caring “emotionally draining” (J13/17/1). For John it was “four years’ worth of battles, basically” (J1/2/5), during which time he lost his home and his pension. This John sacrificed “for his mother’s sake” since his father was someone he had been “afraid of” (J15/6/4); “I had the sense he was hard on me” (J15/4/7), and to whom he had “never felt emotionally close” (J15/7/11). Reflecting on his father’s “four and half years of absolute hell” (J15/2/6) moved John to tears. In his first session (LRS.1) he had described the start of caring as “the end of everything” (J9/12/5) and caregiving itself as “dehumanising” (J1/10/7). In his Whole Life Review (LRS.13) he recalled how the frustration of dealing with officialdom:

J: ...was like trying to fight a battle whilst struggling up a steep hill with your feet in a bucket of molasses (J13/1/4).

As facilitator I asked John in the session on his Post Caring Phase (LRS.12), if he had felt confident about getting a job after caring?

J: [Softly] No, not at all ... You’ve got to start again (J12/3/4). ... The office environment was completely different. ... totally electronic. And you had to be fairly sharp indeed to be able to understand office computers and so on ... (J12/3/5). I just adjusted to it (J12/4/1) ... I didn’t have any training (J12/4/1).

In his Whole Life Review (LRS.13) John recalled:

J: It was starting again; but it was starting again from a very low position. A lower position than you’d ever started from before (J13/14/4). ... I thought to myself: ‘Who’s going to employ me now that I’ve been a carer for four years?’ (J13/14/6).

Eight years after giving up his career to become his father’s carer John did in fact succeed in obtaining highly-paid employment in his field. However he had no sense of achievement in this and saw himself as:

J: ... struggling ever forward to the point where I can actually stop. Being retired (J12/8/6). ... compared to what things have been ... It’s a glorious ending (J12/8/10).

Throughout this glimpse of John’s biography runs incongruence: he appeared to know the strength of his resilience yet did not regard his strength of will to ‘start again’ (J13/1/4) after his most adverse epiphanies (Denzin 1989) or disjunctures (Charmaz 1983) as a strength. Instead he seemed to allow his personal autonomy and professional confidence to be undermined. Paradoxically, in ‘doing the right thing’,

John sacrificed all he valued to prolong the life of a parent he believed did not value *him* - that is until he had completed his Assert programme – for the sake of one who did. “Starting again after caring” was “very difficult” for John yet he regarded finding employment and somewhere to live as “major but insignificant compared with the things you’ve just been fighting for in the previous four years” (J12/11/6). To aid discussion on the theme of ‘Starting Again ... Significant Ends and Significant Beginnings’ (J9/1/3) some of John’s epiphanies (Denzin 1989), are set out in Table T4.9 below, again with some of his reflections.

Table T4.9

John’s Reflections on some of his ‘Significant Ends and Significant Beginnings’

Assert Age Phase	John’s Epiphanies (Denzin 1989) Significant End/Significant Beginning	Textract Ref	John’s Reflection
Infancy (0-5 yrs)	---	---	Virtually no recollections “Bits and pieces” “Like snapshots” No unhappy memories
Childhood (5-10 yrs)	Started school. Remembers his first school friend.	J2/4/5	
	Knows he could service his father’s car by age 6 or 7 but has no memory of ever doing so.	J15/7/11	
	Found Amber, the stray dog who became his best friend.	J3/4/1	“Casual light-hearted”
Early teens (10-15 yrs)	Repeated school year after appendicitis. Loses friends.	J4/6/4	
	After his accident he had to learn to speak, walk and write again. Left with a sense of time running out and going to die. Thinks his personality changed. Started same school year again for the second time. Loses friends again. No experience on which to build the future.	J4/3/2 J13/1/4	
Later teens (15-20 yrs)	Started first long-term relationship (aged 17).	J13/1/4	“Almost destroyed me”. “No sense of achievement” “Very happy”
Early twenties (20-25 yrs)	End of first long-term relationship (aged 20).	J5/1/2 J9(b)/2/6	
	End of four years’ study. Started well paid career.	J5/3/15	
	Started courting Louise, his future wife.	J5/7/1	Took responsibilities seriously; “happy, settled down”
Late twenties (25-30 yrs)	Started married life.	J6/1/4	
Thirty-something (30+ yrs)	Found family life difficult. “I was always the problem”.	J8(b)/1/4	
Early Middle Age (40+ yrs)	Ended his marriage. “Regretted it afterwards”.	J9(b)/11/11	“Turbulent times some good, some bad”
	End of a meaningful relationship was “crushing”.	J13/1/4	
	End of another meaningful relationship felt “like a death”.	J9(b)/11/11	
Caring (50-55 yrs)	The start of caring was the end of everything; he felt “like a pauper” and “dehumanised”.	J1/10/7 J12/14/1	“All pretty b..... awful”
Post Caring Later Middle Age (55+ yrs)	Felt he was going to die.	J12/19/3	
	Starting again “very difficult”. Took 2 years to recover.	J13/1/4	
	A new relationship started prior to starting the Assert programme seen in a new, more meaningful light.	J13/1/4	“Being normal again” “Being a person”
	Started the Assert programme; reconciled with children; new insight about attachment style; comes to believe he is not ‘a waste of time’ and that his father loved him.	J12/1/5 J13/1/4	

As can be seen from Table T4.9, despite the disruption to his education and having to 'start again' in many other aspects of his life, John's positive reflection on the 'significant ends and significant beginnings' in his teenage phase seems dismissive of his fortitude. Less positive are the reflections about his emotional attachments, including to his children. The ending of a relationship at twenty "almost destroyed" John; in his forties another significant ending "was like a death". He was aware that his memory loss left him with "no experience on which to build the future" (J3/13/4) and it is suggested here that this could partially explain why some of his emotional attachments and his family life were problematic. John felt he was too hard on his children and did not appreciate them enough; however, without a lived experience (van Manen 1990) of his own childhood he may have little insight into that of others. Furthermore, if his accident 'wiped out' crucial stages in his psychosocial development, this may have rendered John not only unable to (mind-) 'read' his children accurately, but adults as well (Livingstone 2005). To help explore this notion further in 'The Nurture of Nature', set out in Table T4.10 are Erikson's (1950) "Eight Ages of Man" with John's potentially 'lost' or partially 'lost' stages highlighted. It can be seen from Table T4.10 that, according to Erikson's (1950) theory of psychosocial development, if an individual succeeds in navigating their way through each stage, they acquire the desirable 'basic virtues': if not, they are left with the proposed less desirable alternatives which, it is suggested here, may have been outcomes for John if the first four stages, and possibly fifth, were indeed lost to him.

The fact that as a child John was afraid of his father and that in adulthood he regarded the unknown with "terror" fits with the proposed alternative outcome in the first stage of Erikson's theory, namely, a 'distrust' of the world. Towards the end of his Assert programme (Gardner 2006) John was able to save money and plan ahead for the first time in his life. This former lack of autonomy ties in with the proposed alternative outcome in Erikson's second stage. John commented in his Whole Life Review Session (LRS.13) that his life was "a reflection of whoever's in it" (J13/1/4) and that prior to his Assert programme he felt his life was a waste which would fit with Erikson's proposed alternative outcome in the third stage, 'lack of direction and purpose'. As a student John had excelled without a sense of achievement; he also felt his potential was unrealised career-wise which

Table T4.10

Erikson's "Eight Ages of Man"
[Based on Erikson (1950) and Pennington (1986)]

Key: Stages of psychosocial development that may have been 'lost' to John
 Stages of psychosocial development that may have been partially lost to John

Approx age	Stage	Brief description of stage	Outcome attitude (Basic virtue)
0-1	I	Baby learns to feel comfortable and trust parent's care <u>or develops distrust of the world.</u>	Trust (Drive & Hope) or Mistrust
1-3	II	Infant learns sense of competency <u>or feels ashamed and doubts own abilities.</u>	Autonomy (Self-control & Willingness) or Shame
3-5	III	Young child learns to use own initiative <u>or develops sense of guilt over misbehaviour</u>	Initiative (Direction & Purpose) or Guilt
5-11	IV	Child learns to meet demands imposed by school and home responsibility <u>or comes to believe he is inferior to other people</u>	Industry (Method & Competence) or Inferiority
11-18	V	Teenager acquires sense of identity in terms of beliefs, vocation, etc <u>or fails to achieve identity</u>	Identity (Devotion & Fidelity) or Identity diffusion
18-40	VI	Young adult engages in successful intimate relationship, joint identity with partner <u>or becomes isolated</u>	Intimacy (Affiliation & Love) or Isolation
40-65	VII	Individual focuses on helping others, allowing independence to children <u>or becomes self-centred and stagnant.</u>	Generativity (Production & Care) or Stagnation
65-70 (N/A)	VIII	Older person reaps benefits of earlier stages, develops acceptance of temporary nature of life <u>or despairs over ever being able to find meaning in life.</u>	Integrity (Renunciation & Wisdom) or Despair

reflects the proposed alternative outcome, inferiority, in the fourth stage of Erikson's theory. John's accident occurred during his teens, Erikson's fifth stage, after which he suffered no further major memory loss but was without a strong sense of vocation so this may have been a partially lost stage. Having 'lost' the lived experience of his mother's love as a child and feeling unloved by his father, it seems John was without a sense of belonging as a teenager and without the insight or experience fundamental to his lifelong socialisation process and identity formation (Erikson 1950). The Assert programme (Gardner 2006) provided John with an opportunity to re-navigate some of the earlier stages that may have been lost to him. This aspect of 'starting again' is discussed in the next section, 'The Nurture of Nature'. To aid this discussion, emplotted chronologically overleaf in 'Starting Again', are John's epiphanies (Denzin 1989) according to Assert programme Age Phases, and Erikson's (1950) "Eight Ages" of psychosocial development.

‘Starting Again’

A Chart Showing John’s Epiphanies

Key: John’s potentially lost and partially lost stages are in red.



It is suggested here that John’s accident may have robbed him of his childhood narrative² and with it aspects of nurturing that are crucial to the formulation of an individual’s identity and sense of selfhood, which most people can take for granted. As can be seen from the above chart, it was from depleted resources that John ‘started again’ after his accident and his caring phase, which shows the strength of his resilience. This concept features in the next section, ‘The Nurture of Nature’ which first examines the Winnicottian (1971) approach to mirroring.

² John’s amnesia was possibly due to his inability to retrieve the information rather than a true loss of that information (Atkinson, *et al.* 1990).

The Nurture of Nature

Whilst narrative writing opportunities, especially his 'Letter to Dad', contributed to the positive outcomes for John, it was the anomalous 'cluster' of his twenty-two mirroring responses (see Table T4.3, p103) during the life review session on his Post Caring Phase (LRS.12) which heralded a changing trend in his style of interaction with myself as facilitator (see Tables T4.7 and 8, pp125 and 128) and then to the possibility of a significant or even fundamental change in John himself.

Activated by the brain's mirror neuron system³ (Tettamanti, *et al.* 2005), mirroring is never outgrown and in adulthood it is a healthy form of self-love according to Bateman and Holmes (1995). Some aspects of therapist-patient interaction are analogous to the parent-infant relationship (Fonagy, *et al.* 2004, p240), and this disquisition begins by outlining the concept of mirroring from Winnicott's (1971) perspective. Consideration is then given to the role and significance of mirroring in John's life and in his life review process with reference to maternal attachment theory (Bowlby 1969; 1973); sensitive mothering and mother-infant attunement and intersubjectivity (Ainsworth, *et al.* 1971; Stern 1984; Reddy and Trevarthen 2009; Fonagy, *et al.* 2004). Unlike Lacan (1977), who posits that mirroring in infancy is a form of mimicry, Winnicott's (1971) theory holds that in her "mirror-role" a mother gives back to her infant the infant's own self. When she looks at her baby, according to Winnicott (1971), what the mother looks like is related to what she sees there and a (sighted) baby sees himself when he looks at his mother's face. Underpinning the concept of mirroring is Winnicott's (1971, p47) "theory of play" which embraces the notion of an infant 'starting again' after being traumatised. As can be seen from Table T4.9 (p132) and the chart of John's epiphanies on page 135, this is symbolically relevant not only to John's accident but to almost all phases of his life. According to Winnicott (1971, p96) the space created by the intrapsychic 'to and fro' process between mother and infant is a "playground" where a "state of confidence ... grows up" (Winnicott 1971, p47). Here the baby

³ Mirror neurons were first discovered in Macaque monkeys in the 1990s. While primates engage in imitation, human social cognition requires a more highly developed system and the brain's mirror neurons are thought to play an important role in empathy, the understanding of others' actions, language acquisition, abstract or metaphorical thinking and even consciousness itself. It is now known that several different types of mirror neuron not previously seen in primates are more widely distributed in the human brain. They 'fire' when they are involved in performing an action but are suppressed when one is observed. This could help to explain why people do not mimic observed behaviours all the time and why they do not perceive someone else's behaviour as their own (Tettamanti, *et al.* 2005; Slack 2007; Viale, *et al.* 2008).

enjoys experiences of “omnipotence” based on “the interplay of personal psychic reality and control of actual objects” according to Winnicott (1971, p81 and p96) who suggests that:

... the object is a symbol of the union of the baby and the mother ... located ... at the place in space and time where and when the mother is in transition from being (in the baby's mind) merged in with the infant and alternatively being experienced as an object to be perceived rather than conceived of. The use of an object symbolises the union of two now separate things, baby and mother, *at the point in time and space of the initiation of their state of separateness*. [Winnicott's emphasis] ... The mental representation in the [infant's] inner world is kept significant ... by the reinforcement given through the availability of the external separated-off and actual mother, along with her technique of childcare ...

With respect to ‘technique of childcare’, Winnicott (1971, p81) maintains that this determines at a very early age an individual's “pattern of defences” and creates “blueprints for later sublimation”. Adequate parenting includes “acceptable levels of parental failure” (Clulow 1982, p28) which allows for a mother sometimes leaving her baby whose distress is soon “mended” upon her return since “babies are constantly being cured by the mother's localised spoiling” according to Winnicott (1971, p97) who further explains that:

This mending ... re-establishes the baby's capacity to use a symbol of union; the baby then comes once more to allow and even benefit from separation ... that is not a separation but a form of union.

However, if the mother is away from her baby for too long, this can traumatise the infant whose “imago” of her fades, and “along with this the baby's capacity to use the symbol of the union ceases” (Winnicott 1971, p97). In this case:

... the mother's return does not mend the baby's altered state. Trauma implies that the baby has experienced a break in life's continuity [serious deprivation], so that primitive defences now become organised to defend against a repetition of ‘unthinkable anxiety’ or a return of the acute confusional state. (Winnicott 1971, p97).

John's accident was a ‘break in his life's continuity’ which can be seen as analogous to a traumatised infant who:

After ‘recovery’ from ... [serious] deprivation ... has to start again permanently deprived of the root which could provide *continuity with the personal beginning* [Winnicott's emphasis]. ... This implies the existence of a memory system and an organisation of memories (Winnicott 1971, p97).

As can be seen from Table T4.9 (p132), and the chart on p135, John ‘started again’ many times in different aspects of his life; indeed, it could be said he ‘struggled all his life’ *with* life. Continuing with the traumatised infant analogy,

when John's accident brought his childhood 'memory system' to a 'significant end', the 'imago' of his early experience would have faded, and he would have been left without 'symbolic union' with his past wherein lay 'blueprints' for 'continuity with his beginning'. Any reflection on his blueprint of psychosocial stages (Erikson 1950) navigated thus far would have no experiential, symbolic or subliminal referent and his 'primitive defences' may then have become organised in an endeavour to protect him from 'a repetition of unthinkable anxiety' (Winnicott 1971). According to Gerhardt (2004) the essential aspect of trauma is that it not only generates doubts in a person about surviving as a body but it also generates doubts in them about surviving as a psychological self. Living with this level of constant threat to his corporal and psychological being could account for John's dissonance when reflecting on his life in the life review sessions and may explain his lack of resonance with the facilitator. According to the findings of Reinholdt-Dunne, *et al.* (2009), high levels of attention control may serve as a protective function for anxious individuals. This could account for a response by John which sometimes caused dissonance, 'as if not hearing' (see Table T4.8 p128). For example, when recounting his disappointment about a bicycle he had been given for passing his eleven-plus examination John was dismissive:

J: [The bicycle] ... was black, old, something probably about the same age as my father would have ridden in the 1920s (J3/3/3) ...

He recalled wryly that he had to say how nice it was and "thank you very much – and I'm sure I did". I asked rhetorically: "you were a polite child ...?" but, as if he had not heard this, John mused:

J: I'm sure I did but I've got no idea at all whether or not I did. I hated it! (J3/3/5/O).

If John was anxious or insecure he hid it well in the sessions except when contemplating the future. He regarded the unknown with "terror" (J1/9/4) and the prospect of freedom in his forthcoming retirement was the "biggest enemy" (J1/9/10). However by his twelfth session, his Whole Life Review, John was more optimistic: "I might live forever!" (J12/16/2) he exclaimed. His long-held belief that time was running out, that he would "never have enough time to do things" (J13/7/8) and that he was "going to die" (J13/19/3), though still apparent, was less marked as his ability to tolerate uncertainty matured (Lewis and Butler 1974).

Insecurity is not itself an indication of disorder or even maladjustment (Rutter, *et al.* 2009) but a child needs the satisfaction that comes with the “interest, encouragement and admiration” of those to whom they feel emotionally attached otherwise “life with all others can lose its energy and pleasure” (Trevarthen and Reddy 2006, p13). As can be seen from the ‘Starting Again’ chart, for example, John had no memory of the ‘interest, encouragement and admiration’ he may have received for his precocious mechanical engineering ability or any other childhood accomplishments during Erikson’s (1950) development stage IV where the proposed outcomes are either ‘Industry or Inferiority’. This might explain why he had “achieved without a sense of achievement” as a student: “I’ve always been better at most things than I thought I was” (J4/9/2) and why he felt his life had been a “waste of time” and he “a waste” (Follow-up).

In terms of maternal attachment theory (Bowlby 1969; 1973) authoritarian parenting is commonly associated with maltreatment (Fonagy, *et al.* 1994, p233) and in the extreme, a child who ‘reads’ the hatred or murderousness implied by their parent’s acts of abuse is forced to see himself as worthless or unlovable according to Fonagy, *et al.* (2004). Two striking examples of dissonance in the life review sessions occurred whilst John was reflecting on his love of being in the water. The first was during his Childhood Phase (5-10 years) when he was recalling with obvious pleasure his sense of achievement in learning to swim. His voice had ‘flattened’; his enthusiasm faded, and as facilitator I had sensed that John was reflecting how he might then have appeared to others:

J: I was terrified of the water to start with. And then ... [long pause] (J2/7/3). ... [flattened tone] I just kept flapping my arms around and one moment I didn’t sink and it was called swimming. It probably wasn’t very elegant ... but I didn’t ... go downwards (J2/7/5/⊕).

The second instance of dissonance occurred in the next session, his Early Teen Phase (10-15 years), when John was reflecting on how much he used to enjoy “splashing around on the beach” (J3/6/6). Empathically attuned to John’s positive mood, as facilitator I remarked warmly on his being a water baby but before I could finish speaking John said: “- No. I wouldn’t go that far ...” (J3/6/7/⊕).

Being able to engage and respond to someone is entering a shared reality, what Tirassa, *et al.* (2006, p208) term “sharedness”, where the behaviour of one

individual can be shared by another (Reddy and Trevarthen 2009) but John appeared not to want to share his reality – at least not at that point in his programme. His somewhat dismissive response conveyed a negative self-concept but in blocking the facilitator's warmth he had shut himself out of the therapeutic 'playground' where, at a deeper level, in the "overlap" of the two areas of 'playing' [between therapist and patient], trust develops and "psychotherapy takes place" (Winnicott 1971, p38).

The focus of the Assert programme (Gardner 2006) is on reminiscence and life review (Butler 1963; 1974) and whilst, unlike some conventional psychotherapies, it is not a re-parenting process, the facilitator's empathic mirroring responses can be likened to those of a nurturing parent (or carer) who resonates sensitively with their offspring's mood (Winnicott 1971; Ainsworth, *et al.* 1971). Empathy elicits the altruistic motivation in a mother to reduce her baby's needs according to Psychogiou, *et al.* (2008, p221) who define empathy as "the understanding and sharing in another's emotional state ... [and that it] combines both affective and cognitive dimensions". The cognitive component, or perspective-taking involves the understanding of another's point of view and the affective component involves the "vicarious experience of emotions consistent with those of others including compassion" (Psychogiou, *et al.* 2008, p221). In her 'mirror-role' (Winnicott 1971) a sensitive, empathic mother (Ainsworth, *et al.* 1971) who handles her baby well soothes his emotional states by reflecting them back to him in an appropriately modulated form and in so doing fosters a sense of security in the child (Fonagy, *et al.* 2004; Gerhardt 2004; Winnicott 1971; Solomon 2004; Bateman and Holmes 1995, p61). Thus a mother's emotional resonance or affect attunement (Stern 1984) provides a "creative social mirror" (Fonagy, *et al.* 1994, p247) for her developing infant where aspects of this "primary intersubjective relationship" (Trevarthen 2004, pp7-9) are "captured" with an organising perspective gradually being added to explain past behaviour and predict future actions (Fonagy, *et al.* 1994, p247).

According to Fonagy, *et al.* (2004), no matter how well attuned the mother is to the baby's state, her facial and vocal mirroring behaviour will never perfectly match the temporal, spatial and sensory intensity parameters of the infant's emotional expressions. This, they suggest, provides the opportunity for the

mother to “decouple” from the infant’s physical reality when appropriate which “marks” certain emotional expressions as “non-consequential” or “pretend play” (Fonagy, *et al.* 2004, p298). This symbolic externalisation or “referential anchoring” (Fonagy, *et al.* 2004, p178) occurs in what Psychogiou, *et al.* (2008, p229) describe as “mature empathy” where an individual is required to “maintain boundaries between the self and the environment without the merger of the self with the other” and according to Trevarthen (2004, p26) “in tune and in *time* with another” [my emphasis]. Such is the nature of mirroring by the facilitator in the Assert life review process.

In the primary intersubjective relationship mother and baby take turns in asserting or showing and apprehending or receiving human will and interest (Trevarthen and Reddy 2006, p6). The mother “picks up on the beat” of her infant’s expressions, reflecting their intonation and emphasis (Trevarthen 2004, pp7-9). These “empathic emotion-reflective displays” tend to be brief communicative acts or gestures rather than more continuous state expressions which Fonagy, *et al.* (2004, p172) term “time out in mirroring” and it is crucial interpersonal *timing* which provides a cue (Henning and Striano 2005, p146) to the contingent mother-infant relatedness (Tirassa, *et al.* 2006, p204). It was the *slowing* of John’s responses, which became evident when he began to reflect before speaking that alerted the researcher to a possible fundamental change in him (Henning and Striano 2005). John’s first Considered Response encoded ‘ Θ ’ occurred in his twelfth session (LRS.12) (boxed and shaded in Table T4.8 (p128) for ease of reference). The rhythms of adults and infants appear the same according to Trevarthen and Reddy (2006) since from birth infants have flexible parameters of timing and regulation of expression that match those of adults. It is possible that John’s rhythm was re-set during his life review process. The ability to share another’s mental state is innate according to Tirassa, *et al.* (2006) and whilst John may have taken part in what they term “sharedness” as most infants do, in his life review sessions generally he seemed to miss or avoid the facilitator’s ‘empathy cues’. In his fifth session (Early Twenties Phase) whilst reflecting on family life John commented:

J: Maybe that’s what maturity is. Maturity might be considering the consequences of your actions and deeds and putting other people first (J5/11/14).

Interestingly John was uncertain about what maturity is and what it meant to him and did not include other people's feelings or wishes. However, after reflecting on saying "goodbye" to his father just before he died, John had been moved to tears in his 'Letter to Dad' session (LRS.15). In what I described as "the most meaningful mirroring moment" for John, I commented in my notes that on his noticing tears in *my* eyes John asked for the tape to be paused. I wrote:

... he explained he was concerned not for his own sake but for mine in case what he had just described had upset me. There was a resonance of emotion in that moment when John empathised with *me*.

Not only was he able to express his emotion but he showed apt (if not needed) consideration for the facilitator's feelings. This was an indication that John was capable of 'sharedness' and that he may have 'moved on' from what had appeared throughout the programme to be a deficit in mature empathy.

As Fonagy, *et al.* (1994, p233) point out, "history is not destiny" and resilient individuals can develop normally under difficult conditions. A critical test of maturity is competent parenting and according to Psychogiou, *et al.* (2008) fundamental to sensitive and compassionate parenting is the capacity to perceive things from the child's point of view. Parents with deficits in empathy may be less sensitive to their child's cues and less responsive and warm (Psychogiou *et al.* 2008, p222). In some ways competent parenting parallels caring for a sick, frail or disabled loved one: with depleted resources John worked hard as a sensitive and compassionate carer to meet his late father's physical needs (and possibly his mother's) and although he maintained that few emotional demands were made of him he nevertheless found caring "emotionally and financially crippling" (see Appendix A4.5). In his first session he explained he wanted to help other carers because he had been unsupported himself:

J: I had to create all the care for myself (J1/1/6) ... trying to foresee difficulties and hopefully do something that prevents the problems from occurring (J1/2/3). ... it was his helplessness, his inability to help himself which was the spur to make me fight harder for his rights (J11(b)/1/6) ... I was resilient and strong enough to take it (J11(b)/8/5).

By the end of his life review process John came to acknowledge that he had done "a wonderful job" (J13/6/4) in caring for his father and had been a reasonable parent to his children. He had worked hard to provide for his family and despite

being “much too hard” on his children he acknowledged that he “must have done something right” because they were “decent, hardworking human beings” (J13/5/8). Not being able to identify with his young children or understand their behaviour was “disconcerting” for John but as he gained in self-understanding his attitude towards himself softened with regard to being too harsh a parent:

J: Maybe I just didn't take into account that they were only five or six years old (J6/1/4).

At the level of inner realities according to Clulow (1982), parents have also been children with needs, experiences, feelings, which are liable to re-surface in adult life and influence their behaviours and relationships. On his lost childhood experience John commented matter-of-factly:

J: I don't feel as if I've got anything missing but then I wouldn't know if it was (J3/12/11). So it was - it would be - a completely missing phase (J3/13/2) ... there wasn't an experience on which one could establish the future. Whether it's done any harm or not, I'm sure it probably has (J3/13/4). ... I don't know if you miss something yourself. The things that I've missed might not have been ... of any value anyway, even if I did remember them (J3/13/7).

Being lovingly held is the greatest spur to a baby's development (Gerhardt 2004) but parents with a history of deprivation, neglect or abuse are themselves more likely to encounter problems at all stages of family life (Fonagy, *et al.* 1994). However, as John could not remember being a child this may not have applied to him. Psychogiou, *et al.* (2008) have found that mothers of insecurely attached children seem less able to 'read' their behaviour and depressed mothers tend to focus on their own feelings and treat their children more harshly. John may have had difficulty 'reading' his children yet as far as can be ascertained they were not insecure, nor was he depressed. It is more likely that John's difficulty was due to his not being able to derive support from his “internal parent” since individuals who have had little opportunity to internalise models of competent parenting are themselves more likely to find parenting difficult (Clulow 1982). Insecurity in children comes about because parents find it hard to respond adequately to them as babies, mostly because they have not had their own “baby needs” fulfilled and so are unable to provide this for their offspring (Gerhardt 2004, p88). After his accident most of John's memories were “wiped out” (J2/9/10); he could remember his past only as “snapshots”, “bits and pieces”, “... things get jumbled up, that's the trouble ...” (J4/2/7) and the only lived experience he had of being

parented was as a teenager. Despite knowing his mother “was always there” (J2/2/10) for him, if virtually all of his childhood narrative was lost he may also have lost all sense of her nurture which means his early attachment process may have been ruptured leaving him with no sense of security.

At the heart of attachment, and at the core of a child’s emotional security and self confidence, is for him to know that a parent will not let him suffer for too long (Gerhardt 2004). Having possibly lost the lived experience of being lovingly held and nurtured by his mother in his infancy and early childhood phases, John may also have lost his ‘blueprint’ for parenting.

An insecurely attached child is less likely to develop the ability to manage his own emotions and to control his impulses later on (Bateman and Holmes 1995; Gerhardt 2004; Fonagy, *et al.* 2004). Children who are securely attached tend to be resilient and learn to survive loss (Bateman and Holmes 1995) whereas those whose loss is unresolved may become disorganised in their attachment behaviour. According to Rutter, *et al.* (2009), this tends to occur in children who have been subjected to threatening and dissociative parental behaviour. When a baby’s emotional displays are not ‘contained’ by maternal mirroring, particularly their negative raw emotions, they can suffer narcissistic damage (Solomon 2004; Fonagy, *et al.* 2004) which can “bring a threat of chaos” to a child (Winnicott 1971, p113). If an infant does not feel good enough to be held, his sense of ‘I’ is not affirmed and the disapproval of self can become internalised; an unloved self then exists in a state of emotional coldness and feeling subject to external scrutiny (Batmanghelidjh 2000). The individual has no sense of remorse for, feeling no pain themselves, they imagine others feel no pain (Batmanghelidjh 2000). Gifted individuals who suffer such early narcissistic trauma may compensate through creative achievement which fills their internal void for a time ‘as if’ they were undamaged but eventually they collapse (Solomon 2004). A disorganised attachment style in adulthood is characterised by an incoherent narrative, inconsistencies, contradictions, unexplained shifts in voice or point of view and incomplete sentences (Fonagy, *et al.* 1994, p240). This could describe some of John’s contradictory and opposing responses and it is suggested here that such characteristics can be present in a secure individual who has suffered loss of autobiographical memory. For example, as facilitator I suggested in the

first session that sometimes it was good for people to reflect on the past and contemplate the future but that this may not always be possible because they are so bogged down with their situations. John seemed to miss the point:

J: I did, sort of [coughs]. By the end of caring there was this big gap with lots of time available. And that's probably just as difficult to cope with as having no gap with no time available (J1/9/16/⊕).

Wondering how John's mother would have been coping after losing her husband I asked him:

C: ... Was there an essence of being or feeling needed once you no longer had your caregiving role ...? (J1/9/17).

J: You mean wanting to be needed or – (J1/10/1).

C: Just an element in you of being needed ... Did that feature at all? (J1/10/2).

J: Not consciously I don't think. ... it [caring] was more of a toil than being needed (J1/10/3/⊕).

John did not seem to intuit his mother's grief which perhaps indicates the nature of his maternal attachment.

The aim of therapy is to restore healthy psychosocial life (Trevarthen 2004) and according to Winnicott (1971, p117) psychotherapy is “not making clever and apt interpretations, ... it is a giving back to the individual what the individual brings”. In other words an individual's internal world is mirrored back to them by the therapist (Brown and Pedder 1979). The Assert programme (Gardner 2006) also provides the opportunity for an individual to reflect upon their inner world *themselves* and on the premise that the mirroring interactions between John and the Assert facilitator are analogous with Winnicott's (1971) maternal mirror-role, it is proposed that the mirroring interaction *per se* facilitated a 'mending' for John and in the intersubjective 'playground' some of the lost stages of his psychosocial development were revisited and remnants of others possibly recovered.

In his “Discovery!” at the very beginning of his Whole Life Review (LRS.13) when he was writing down key reminiscences, John suddenly realised for the first time that there was a common thread running through all the different phases of his life. He saw that his life tended to be “a reflection of the person who's in it” (J13/1/4). In other words, he let whoever was in his life 'steer' it, which is characteristic of a person with an external locus of control (Gross 1987) who feels a victim of circumstance. Part of John's 'recovery' was this “discovery!” When he became aware of his

dependent attachment style and how this may have contributed to his problems, John's orientation to the world began to change, as was observed at Follow-up, he could see where he "sits in things" (J13/1/4). With increasing autonomy and seeing the different phases of his life as part of the whole, he may also have begun to interpret his own hermeneutic circle (Patton 2002): "I don't know whether it's one's because of the other or the other's because of one ... cause and effect ..." (J13/1/4).

Further Reflections

On the assumption that the changes in John were due to the Assert programme (Gardner 2006), his life review process may have strengthened his mentalising ability (Fonagy, *et al.* 2004). His perception of himself and his relationships as a child, as a parent, a partner and as a grown-up son all improved, which suggests that the 'nurture of nature' can bring about psychosocial development according to Erikson's (1950) theory at later, non-age-specific phases in a person's life. This being the case, although resilient, it follows that had John had the opportunity soon after his accident to reflect on his lived experience (van Manen 1990) such as he had during his Assert programme (Gardner 2009), he might have found life less of a struggle, perhaps with fewer adverse epiphanies (Denzin 1989). This also prompts the question 'is resilience inborn or learned'? Perhaps the answer is: it depends on the 'nurture of nature'.

In the early sessions John's discordant responses created dissonance; gradually the quality and timing of his responses improved until eventually he empathised with myself as the facilitator. He may have had the capacity for intersubjectivity but chose not to mirror the facilitator or, for various reasons, was unable to express emotion until his last session. An individual's emotional life is largely a matter of co-ordinating with others through participating in their states of mind (mentalising) and thereby predicting what they will do and say (Gerhardt 2004). As Gerhardt (2004) also points out, the attachment system is activated when a child is afraid and needs comfort, reassurance, safety and it is traumatic when these needs are not met. This has important parallels for adult carers in crisis. Assuming John's childhood attachment(s) had been secure until 'lost' to him, perhaps it was in being able to trust and feel secure within the therapeutic relationship that some of John's earlier-met but disrupted "baby needs" (Gerhardt 2004, p88) were met afresh, enabling him to let go or detach more comfortably.

There is strong evidence to confirm an intergenerational transmission of insecurity, the propensity for which lies in the parent's internal working model of their own relationships (Fonagy, *et al.* 1994) but having said this, Fonagy, *et al.* (2004) maintain that psychology is moving away from the idea that early mother-infant interaction is the generator of a template for later relationships. They also argue that insecurity in attachment relationships is a signal of limited ability to mentalise and since early developmental experiences, including those at a neuropsychological level, determine the depth to which the social environment may be processed, the traditional classification of attachment patterns (Bowlby 1969; 1973) needs to be reinterpreted. This may be good news for those labelled as having personality disorders thought to be due to dysfunctional maternal attachment, depressed or anxious mothers whom society has hitherto tended to blame for poor parenting skills and mothers who blame themselves for their offspring's inadequacies. Taking Fonagy, *et al.*'s (2004) notion further, given John's positive 'Assert experience' perhaps more significance should be ascribed to dysfunctional attachment styles in adulthood: here the Assert programme (Gardner 2006) could perhaps contribute to proactive and cost-effective modification.

When a person pays close attention to someone else the same neurons are activated in their brain (Gerhardt 2004) and, as described by Trevarthen (2004, p5) act as a "mechanism of sympathy" which mirrors emotions and reflects states of awareness and intention, further, the mirror neuron system is thought to play an important role in mind-reading, the understanding of other people's feelings and behaviour (Viale, *et al.* 2008). On the assumption that John's mirror neuron system had been operating normally prior to his accident the changes in him suggest that this neuron activity may have been halted, but not damaged beyond repair. A study by Dapretto, *et al.* (2005) shows that in normal development there is increased mirror neuron system activity when an individual observes another's emotional expression and they argue that the mirroring mechanism may underlie the ability to read others' emotional states from a mere glance at their faces. Their findings support the hypothesis that early dysfunction in the mirror neuron system may be at the core of the social deficits observed in autism. Colvert, *et al.*'s. (2008) research involving Romanian adoptees shows that profoundly deprived children tend to display disinhibited attachment behaviours

and suffer from quasi-autism. According to Tirassa, *et al.* (2006, p208) all that is needed for “sharedness” in infancy is a primitive, innate recognition of agency in the people with whom mental states are shared. If this innate, neural mechanism is damaged, as John’s may have been, although it appeared to work well enough to prompt altruism when he was a carer, perhaps remnants of the mirror neuron system can be salvaged and regenerated. If the mechanism is impeded, as John’s empathy deficit in his life review sessions appeared to indicate, perhaps halted neuron activity can be reactivated. If so, as well as empowering carers, a suitably modified Assert programme (Gardner 2006) may be of benefit to those with autistic behaviours.

As John’s outcomes according to Butler’s ‘benchmarks’ (Butler 1963; 1974) set out in Appendix A3.2 show, the Assert programme (Gardner 2006) increased his psychological congruence without medication, stigmatisation or apportioning blame for inadequacy as the conventional medical/psychiatric model of psychological therapy tends to do. In psychosocial terms, the programme opened or re-opened a means for John to visit or re-visit developmental stages (Erikson 1950) that may have been lost to him after his accident. What the Assert programme (Gardner 2006) did for John is only part of the story however: part III of this chapter entitled ‘In Absence of Oedipus’ explores what John did for himself. Under the main theme of ‘Finding the Lost Child’, John’s ‘Letter to Dad’ is discussed with regard to the change in his perception of his relationship with his late father. In ‘The Penknife Scenario’ some transference issues that may have had a bearing on this change are considered. The possible impact that missing autobiographical memories (Fonagy 2003) and poor prospective memory (Young and Saver 2001; Fleming, *et al.* 2005; Wilson 2009) may have on an individual’s narrative and identity (Brockmeier 1997) is explored in “‘A Genius or An Idiot?’ Knowing How To Be or Not To Be’, drawing from John’s narrative writing, his Aspects of Life Log and his Action Plan for Change.

Chapter 4

Findings, Interpretation and Discussion

Part III

In Absence of Oedipus

Introduction

The autobiographical self emerges around the age of six years (Fonagy, *et al.* 2003, p422). The autobiographical memory embodies sequential stories and creates a narrative which enables an individual to make sense of who they are (Allen and Fonagy, *et al.* 2002). Ricoeur (1980, p169) holds that the narrative is fundamental in the construction of an individual's identity, and that time is its "ultimate referent". However, whilst recognising the narrative is fundamental to identity, Brockmeier (1997, p15) points out that "no such thing as immediate experience of time exists" but linear, material, and psychic temporalities are "combined and recalibrated" in the person's re-telling of a story. He maintains that it is the person's "time-self", the genre of their narrative and the positing of "possible pasts and possible beginnings in the light of the end" which generates possible meanings for their life in time. Brockmeier (1997, p2) also suggests that the construction of a text telling the story about the lived life of a real person is not merely an exercise for "documenting the 'data' of past events", but rather the autobiographical process may itself be a form of narrative psychology which plays an essential role in various psychological functions such as memory, problem solving, and ultimately in the understanding and development of the self. Brockmeier's perspective fits John's life review process for, despite having been left with virtually no narrative of his childhood after a road accident, as described earlier in this chapter, he was able to 'recalibrate' his temporalities whilst 'held' in time during his Assert life review programme, and 'posit possible pasts' and discover some 'significant ends and significant beginnings'.

The focus for the previous discussion in this chapter was the impact that John's lost childhood narrative may have had on his psychosocial development. Underpinning the discussion here is the possible impact John's memory deficit may have had on his sense of self. In 'John's "Completely Missing Phase"',

John's missing autobiographical memories are considered in terms of a diminished sense of selfhood and missing selves. Under the main theme of 'Finding The Lost Child', some emotional and psychological aspects that may be associated with John's missing autobiographical memories are explored. 'Letter to Dad' depicts the dramatic change in John's attitude towards his late father and, in 'The Penknife Scenario', this positive shift in his biographical reflective focus is discussed in terms of the transference that may have occurred during his life review sessions. The discussion draws, in the main, on an exposition by Bateman and Holmes (1995) of psychodynamic theory. The process for formulating John's Outlook/Inlook Action Plan for Change is discussed in "A Genius or Idiot?": Knowing How To Be or Not To Be'.

That John did not retrieve any 'new' memories during his Assert programme was disappointing although not surprising, but it 'sharpened up' those he did have and, as will be seen later, he was able to reclaim some lost aspects of selfhood. To set the scene, some of the factors that may be associated with John's "completely missing phase" are now outlined.

John's "Completely Missing Phase"

Autobiographical memory comes into being at around four years (Young and Saver 2001), when the generic memory system that helps a young child to distinguish the unfamiliar against the norm combines with episodic memory, the system by which a significant, specific event is tied to its own time and place. The combination of the generic and episodic memory systems enables a person to construct their life story through recollection and re-telling, each act of recall drawing upon multiple, dynamically changing modular fragments that shape a new mosaic (Young and Saver 2001). According to Jung (1968), a person's narrative is a continuation of awareness of the conscious world through the succession of conscious moments. For an item of autobiographical memory to be recalled, the memory representation of a specific event that a person has experienced must specify the event itself and represent the fact that the memory has been caused by that event (Fonagy, *et al.* 2004). Due to an accident which "wiped out most of them" (J2/9/10) (retrograde amnesia, see Appendix A4.7, Memory Deficit), John had virtually no recall of memories from childhood.

In his third life review session (LRS.3), he observed that he was without “an experience on which one could establish a future” (J3/13/1), but contended that the memories from his “completely missing phase ... might not have been of any value anyway” (J3/13/6). Thus his capacity for “narrative framing” of the past to make predictions for the future (Young and Saver 2001, pp78-9) was also ‘wiped out’.

Restoration of autobiographic memory lost through head trauma is unlikely in the majority of cases, and rehabilitation tends to focus on strategies to compensate (Wilson 2009). All memories are suspect at the neural level due to what Young and Saver (2001, p79) term the “inescapable subjectivity” of the brain’s narrative and memory system. To be without memories, they suggest, is to be without stories, which means “something like being without a self” (Young and Saver 2001, p74) and in psychosocial terms (Erikson 1950), life for John may have been ‘something like being without a self’, not only as a child but also as a son, a husband and a father; it could be said that he had several ‘missing selves’.

Like John, most memory-impaired people have problems with explicit memory tasks (see Appendix A4.7) where they try to consciously recollect specific incidents and episodes from the past (Wilson 2009; Kopelman 2002). Oldest memories are most resistant to disruption, according to Wilson (2009), but this was not so in John’s case; he lost almost all his “remote memory” (Wilson 2009, pp4-5) for the years prior to a road accident. However, despite this retrograde amnesia (Atkinson, *et al.* 1990), John did recall feeling “proud and a bit scared” when chosen at the age of eleven to read a lesson during a church service:

J: I was chosen because of my good clear reading ability ... to read a passage from the Bible to some huge congregation of kids in a church. The teachers were supportive and I don’t recollect any problems with the kids (J3/1/2). ... I’ve always known I did it but ... the picture I’ve got is *me* looking down at *me* doing it (J3/2/4).

Having no sense of familiarity or ‘real’ subjective feeling about the experience, John ‘knew’ rather than ‘remembered’ that the event happened (Hirano, *et al.* 2002; Kopelman 2002), possibly having been told about it after his accident. It is widely accepted that autobiographical episodic remembering is naturally accompanied by subjective feelings of an experience, and if these are lacking it cannot be considered episodic memory (Hirano, *et al.* 2002). Only a few

studies have been made on amnesic patients involving ‘remembering’ and ‘knowing’ autobiographical memory and such studies have focused on new learning (Hirano, *et al.* 2002). However, the amnesic patient in Hirano *et al.*’s (2002) study could recall specific episodes about his accident but he had no real feelings associated with it, suggesting that autobiographical episodic remembering may be independent of remembering accompanied by real feeling. At first this seemed also to be the case for John, whose mental “time travel” (Wilson 2009, p5) in his second life review session (LRS.2) evoked childhood memories about Amber, the stray dog who became his ‘best friend’:

J: ... I don’t have that many memories and what I do have tend to be like little snapshots from a photograph album (J2/1/2). Everything still comes back as facts and pictures rather than emotions (J2/2/5). I look at myself doing the things rather than experiencing them (J2/2/8). ... I don’t get inside and re-experience the pleasure of it again (J2/4/2). ... I used to go out a lot. Roller skates and bike. I think. Yes, just about, yes, bike as well. But roller skates more than anything (J2/5/5).
C: On your own or with your friends? (J2/5/6).
J: With friends or with the dog. With a pet dog that used to pull me about a lot on roller skates but I can’t remember ... (sighs) ... (J2/5/7).

In the next session (LRS.3) John’s hitherto muted tone became louder and it was with some animation that he described his roller skating excursions with Amber:

J: [Louder voice] And the dog used to take me out on roller skates. I was on roller skates, the dog wasn’t! And it used to run around pulling me all over the place on roller skates. Absolutely wonderfully exciting it was. We’d go faster than any of my friends but not necessarily in the same direction! (J3/4/1).
C: And you can actually remember that ...? (J3/4/2)
J: I can remember it, yes! ... (J3/4/3).
C: The thrill of it ...? (J3/4/4).
J: Because it happened so many dozens and dozens of times. It’s not like having to remember one incident (J3/4/5).

Yet there was a lack of feeling when John talked about losing Amber:

J: ... That dog died ... She got run over ... survived being run over but never really got better. Um ... (J3/5/16).
C: Were you sorry about that? (J3/6/1).
J: Oh yes. Oh yes. [Yawns]. She was my best friend. It’s always annoying when your best friend dies [chuckles]. Well not annoying, but – I don’t know. Yes. Probably I should think. And probably because she was my best friend. Because you can talk to a dog and it doesn’t argue back (J3/6/2). And it always looks sympathetic and wags its tail. ... So what else ... ? (J3/6/4).

As facilitator I asked John how he perceived his roller skating memories. He explained:

J: ... I'm seeing it happen to me ... But I'm also, and if I close my eyes I can imagine I am actually behind the dog being pulled along with the lead. But I can also as it were stand on the roof of a building and look down at myself being pulled along. And that's probably the stronger memory (J3/16/11) ... Rather than being in it (J3/16/14).

This recall of the roller skating scenario was factual rehearsal (Erben 1998) without any zeal; a fortnight later John 'zoomed' in on the reminiscence, momentarily recapturing the fun and excitement associated with the experience. This suggests that the special kind of conscious awareness Hirano, *et al.* (2002) refer to may have been available, but not accessible to John at that time. This may have been due to what Bower (1995, pp1-2) describes as "mood-dependent retrieval". He suggests that:

... a person's emotional state can become associated with ongoing events, so that the events and the emotion are stored in memory together. Later those memories can be best retrieved if the person returns to an emotional state similar to that experienced during the original event. Thus, when made happy, people should do better recalling events experienced earlier when they were happy. When sad, they should more easily recall events they experienced when they were sad.

John's mood was low during the first recall of the roller skating scenario and it is suggested here that he may have kept sad feelings at bay by "cognitive avoidance", by adopting a less specific, over-generalised memory retrieval style of factual recollections in order to limit the amount of negative emotion experienced (Raes, *et al.* 2005, p134). In his third session John's mood was brighter and when reminiscing about the same experience, he could 'connect' with the positive feeling associated with the fun he had with Amber.

Not only had John's ability to retrieve memories of things that had already happened been affected by his accident, his retrospective memory, but also his prospective memory, the ability to remember to do things in the future which require an element of motivation and strategy (see Appendix A4.7). This seemed to interfere with his ability to create and monitor goal-related behaviour, his intentionality, which is a necessary precursor of self awareness and the development of concepts of mental states (Fine, *et al.* 2001).

John enjoyed reflecting upon the often humorous activities of his young family but for some reason he decided to keep a second 'instalment' of an anecdote about 'Droopy', his daughter Charlotte's pet rabbit, for a later session:

J: We used to eat rabbit. Then she had a pet rabbit called Droopy ... she kept it in a cage outside. She only had it for a week and it chewed its way out of the bottom of the cage and escaped! She would never eat rabbit again because it might be Droopy (J6/6/6). And how could we eat rabbit? Then she went to stay with cousin Jacques [who kept rabbits for food] ... many years later (J6/7/2).
 C: Shall we keep that for later ...? Or does that come into this? (J6/7/3).
 J: No. ... (J6/7/4).
 C: Shall we make a note of that then? (J6/7/5).
 J: I won't remember – I mean I won't forget ... (J6/7/6)
 C: You won't forget - ? (J6/7/7).
 J: I won't forget rabbits and Charlotte (J6/7/8). It was an enlightening moment in her life (J6/7/10).
 C: Uh-huh, I see. All right. As long as you won't forget (J6/7/11).

John did not remember the second 'instalment' of the anecdote in his next life review session, nor did he write about it in his next narrative writing opportunity.

According to Fleming, *et al.* (2005) a person whose retrospective memory lets them down is seen as having an unreliable memory; if their prospective memory fails them, however, they are regarded as an unreliable person. Only recently has the prevalence and ecological significance of prospective memory impairments following traumatic brain injury (TBI)¹ been recognised, yet according to Fleming, *et al.* (2005), little attempt has been made to extend research beyond assessment of the problem to evaluate effectiveness of rehabilitation. This memory deficit exasperated John: at the end of each session he duly took away his reminiscence prompt sheet but if he mislaid it at home or forgot to bring narrative writing texts to the following life review session he would apologise profusely and reproach himself for "being so stupid". When this pattern became evident to me as facilitator I gave John the option of sending his writing to me electronically. This he did only once, but the strategy seemed to succeed in allaying his anxiety about his forgetfulness. I asked if he had ever had any rehabilitation for his memory deficit. John commented matter-of-factly:

J: I didn't have any therapy. I don't remember going to the hospital after I came out but possibly. But I can't honestly remember (J3/10/4). ... I smashed open the base of the skull. I think it's called a basal fracture. It usually kills. But it didn't. I smashed, breaking the bone at the point where the spinal cord enters the skull and usually if that piece of bone breaks it punctures the spinal cord. But luckily it didn't. So I have a plate in there (J3/10/6).

¹ Dawodu (2009) defines TBI as a non-degenerative, non-congenital insult to the brain from an external mechanical force, possibly leading to permanent or temporary impairment of cognitive, physical and psychosocial function, with an associated diminished or altered state of consciousness.

Cognitive behaviour therapy is now very much part of TBI rehabilitation (Wilson 2009), but at the time of John's accident over forty years ago, support and rehabilitation services were scarce and inadequate. In their large, prospective cohort study of head injured survivors aged fourteen and over, Thornhill, *et al.* (2000, p1633) found the number of patients followed up after one year who had visited hospital after discharge was less than half. Three quarters of those severely injured were disabled after one year, as were just over half who had sustained mild or moderate injuries. In total just over a quarter of the survivors had received input from rehabilitation services, the most commonly provided service being physiotherapy "despite the predominance of mental sequelae" (Thornhill, *et al.* 2000, p1633). People with more education and higher intelligence have larger brains and a greater number of neurons; they may show less impairment than those with poor education and low intelligence (Wilson 2009). The greater the cognitive reserve, the more severe the damage has to be to cause functional impairment, and other neural networks sometimes compensate for the disrupted ones (Wilson 2009). Perhaps John's "cognitive reserve" (Wilson 2009, p28) aided his recovery.

It is assumed that young people who sustain a TBI fare better than older people, but in fact they tend to do worse in terms of social deficits and behaviour problems (Wilson 2009). One factor may be that apart from support from parents, in times of adversity children and young people have had less opportunity to develop effective social support networks, and thereby establish their own social capital (Putnam 2000). John's parents were devoted: "Whenever I was awake they were there with me ... they came to the hospital twice a day every day ... it was far worse for them than it was for me" (J4/5/2). After being in a coma for three months, John made a good physical recovery; he regained his speech, learned to walk and write again but felt no sense of triumph or joy at having 'cheated death'. The fact that John's accident occurred in his teens may partly account for this, since this is when, according to Harris (2009, p268):

...[individuals] acquire the patterns of behaviour, and the inner thoughts and feelings that accompany these patterns, that will serve them for the rest of their lives. The adult personality is quite resistant to change. The personality we acquire in our childhood and adolescence is the one that accompanies us through the rest of our lives. It is the "me" that continues to look out of our eyes even when our eyes require bifocals

As an alternative to “the nurture assumption” (Harris 2009, p14), the notion that parents are the most important part of a child’s environment and can determine how they ‘turn out’, Harris (2009, p297) posits that “If you’re lucky enough to inherit good genes you will turn out ok”. She suggests that teenagers have far greater influence on each other than their parents do and that, to some extent, they are attracted to different teenage ‘tribes’ according to their genes. Harris (2009, p256) maintains that teen “groupness”, which evolved in the 1960s, can be a source of visible hostility when ‘tribal’ differences are most salient pointing out that:

In societies like ours where parents and peers are kept in separate compartments of a child’s life the parents’ status no longer serves as a shield. Dislocation and money disadvantages are key to lack of success (Harris 2009, p276).

This adds an interesting perspective to John’s case insofar as he commented that his mother mentioned “a couple of times” that the accident changed him “a little”, that he was “shorter and sharper with people ... very impatient” (J13/7/8). A sudden, salient change in personality, no memory of anything he had learned at school and the consequent ‘dislocation’ of having to repeat a year, may have led to misunderstandings and isolation for John for whom being at school “was not the happiest time of my life” (J4/9/6). Also, with a disrupted narrative and an unreliable prospective memory, John may have come to regard *himself* as an unreliable person. Indeed, when reflecting upon a relationship, the significant ending of which ‘felt like death’, John had commented: “I think I was probably not reliable enough” (J9(b)/6/12).

John’s genes and intelligence may have saved his physiological self, but his psychological recovery may have been hampered by his being left with a less tolerant personality - combativeness had featured in his life review sessions. This characteristic may in turn have prompted hostility in his new peers who, unlike stray dog and best friend Amber, would no doubt have argued back. If so, ostracised and decompartmentalised, John may have missed out on a lived experience (van Manen 1990) of ‘tribal groupness’ in his teens (Harris 2009), and may even have suffered peer abuse. Too old in any case perhaps, to be ‘shielded’ by (intelligent, middle class) parents, offered no therapy - not even physiotherapy - to deal with possible mental sequelae after his accident, and virtually friendless, it is small wonder that he had low self-esteem. After reading the transcript of his

biography for his Forty-plus Phase (session LRS.9), the Closure Session, John wrote: “I felt sad about the waste of time my life represents”. His narrative writing (see Appendix A4.4) echoed this:

Writing this brief ‘whole life review’ has given me reason to believe that I’m not entirely the waste of time I’ve always considered myself to be ... (NWO.13).

It seemed that part of John’s “interpreter of experience”, his “ageless self”, (Kaufman 1986, p14) was missing for in his opinion the self that had survived the accident was a waste of time. This could be seen as a disjuncture which mirrors the fundamental form of suffering Charmaz (1983) describes for people whose sense of identity changes significantly on becoming physically disabled.

The following section entitled ‘Finding the Lost Child’ considers some of the effects John’s accident may have had on him emotionally and psychologically, and discusses the change in his attitude towards his late father.

Finding the Lost Child

As Erben and Martin (2008, p25) point out:

It seems ... little short of a miracle that the ... utterly dependent child oscillating between need and satiation is transformed by five years into someone with an articulate social life ... with relationships, structured pleasures and who can feel for and with others. ... an amnesia covers our earliest, crucial years. ... [when] early dependency begins to form part of who we are ... and goes toward laying down our psychic selfhood.

The psychological self, the thinking and feeling self (Gerhardt 2004), holds the key to the self as a mental agent, yet is a relatively neglected area of study (Fonagy, *et al.* 2004). Part of the “laying down of our psychic selfhood” involves infant-carer intersubjectivity, although a newborn is unaware that he is seeing another’s subjective state, and does not know other people have internal feelings (Fonagy, *et al.* 1994). A child’s development is not a succession of events left behind in history but a continuing process which is constantly updated and revised in the light of present experience (Stern 1984). The newborn is certainly self-centred (Bateman and Holmes 1995), but they are able to create mental representations (Internal Working Models or IWMs) of attachment relationships (Bowlby 1969; 1973) and towards the end of the first year as the child begins to become aware of the onlooker, he can incorporate the mental states of others

(Fonagy, *et al.* 1994). The infant begins to understand that other people may not see what they themselves see (Tirassa, *et al.* 2006). This happens through a process known as “mentalising” whereby a child makes mental representations of their own and others’ emotional states (Fonagy, *et al.* 2003, p420; Fonagy, *et al.* 2004, p3). Mentalisation² is rooted in a child’s relationship with their attachment figures and enables them to form a ‘theory of mind’ by which they can learn to ‘read’ other people’s minds and predict their behaviour (Tirassa, *et al.* 2006, p197; Fonagy, *et al.* 2004, p24; Livingstone 2005). In assuming an “intentional stance” (Fonagy, *et al.* 2003, p420) the child can potentially mediate psychological risk by changing the other person’s state of mind (Fonagy, *et al.* 2004). By the end of their first year the child has a “common-sense theory” of what their own mental states are, of what other people’s mental states are, and how the two differ from each other, and in being able to make these distinctions they can update, revise and apply their theory to an actual situation in which they find themselves in the here and now (Tirassa, *et al.* 2006).

The ‘here and now’ in which John found himself on waking from his coma was devoid of any temporal referents:

J: One morning I woke up in hospital ... but I couldn’t actually remember why I was in there ... (J3/8/4). ... I’ve got no memory of any lead up to it ... No memory of the incident. No memory of anything afterwards – months afterwards. It is just as if it happened to somebody else ... (J4/4/6).

When a person attributes an emotional state to someone they must be able to generate at least some conditional states of affairs in their mind otherwise they would not be able to infer anything about the other person’s future behaviour (Fonagy, *et al.* 2004). At first, if he had no ‘common-sense theory’ to call upon, John may have had to interpret his world as an infant and make new mental representations (IWMs) of his relationships, including those with his parents, from ‘scratch’ in order to learn afresh how to predict other people’s behaviour (Fine, *et al.* 2001). Unable to reflect upon his own reactions or fully represent his own mental context he would only be able to resonate with, but possibly not entirely comprehend, another person’s emotional state (Fonagy, *et al.* 1994).

² Mentalisation is an unconscious reflective function that ideally provides an individual with a capacity to distinguish inner from outer reality. It is quite different from conscious introspection or self-reflection where their theory of mind is applied to their own mental states (Fonagy, *et al.* 2004).

Fonagy *et al.* (2003, p442) observe that a “collapse” of mentalisation in the face of trauma entails a loss of awareness of the person’s relationship between their internal and external reality. These authors are referring to psychological trauma, but it is suggested here that something similar may have occurred in John if, due to his extensive amnesia amidst his lost childhood memories was his representational world, likened by some to a “proscenium stage” upon which scenes and dramas of our inner life are enacted (Bateman and Holmes 1995, p41). Therein would have been his ‘store’ of mental representations of relationships including those of his parents. In the mental representational world there is no distinction between opposites or time and space; past, present and future no longer hold, and the relationships between the person’s internal representations or mentalised ‘objects’ act as templates for subsequent relationships, including close attachments. Mental representations of relationships are not inborn; individuals identify with and internalise the relationships to which they are exposed (Bateman and Holmes 1995).

According to Gerhardt (2004), if a person took the view that they had had a wonderful relationship with their mother yet could recall no memories of enjoying good moments with her, their narrative would be regarded as internally inconsistent (dismissing), and they would be regarded as insecure. With his lived experience of childhood security ‘wiped out’ in the crisis of his accident and his capacity to cope “overtaxed”, John may have experienced “personal disorganisation” in which old conflicts symbolically linked with the present problem would be revived, according to Winnicott (1971, p42).

The attachment hypothesis according to Harris (2009, p4), owes its popularity to a “tired notion bequeathed to us by Freud”, which blames mothers for almost everyone’s psychological ills. Whilst this ‘tired notion’ does not appear to apply to John’s mother, indeed, ‘knowing’ (Hirano, *et al.* 2002) that his mother was “always there” (J2/2/10) may have been his only buffer between order and chaos (Winnicott 1971) in both his inner and outer worlds, Freudian theory may nevertheless help to explain John’s ambivalence towards his late father. The psychological construct Freud termed the ‘Oedipal complex’ symbolises a child’s wish to destroy their same-sex parent in order to claim exclusivity of the other one. Theoretically the child achieves resolution of this conflict by

subconsciously suppressing their murderous impulses and identifying with the same-sex parent. It is suggested here that with no memory of any symbolic representations of his relationship with his parents, John may have lost his theoretical resolution to this conflict, and the John who emerged from the coma was 'in absence of Oedipus'.

According to Bateman and Holmes (1995) the Oedipal phase arises out of the exclusive, two-person (usually mother and baby) pre-Oedipal stage when emotional attachments are formed to provide a secure base from which the child can explore their inner and outer worlds:

... the 'good' oedipal parent is simply 'there', neither present nor absent, not too close nor too far away; like Goldilocks' three bears, neither too hot nor too cold, too hard nor too soft, but a transformational object grounded in reality, able to be incorporated into phantasy (Bateman and Holmes 1995, p69).

Under normal circumstances, by about five years of age a child can tolerate separation and absence and respond with "healthy protest" rather than repressing their hatred and envy (Bateman and Holmes 1995, p69). During the Oedipal phase a child learns how to be close enough to their parents so as to feel special and loveable, but not so close as to be engulfed; how to respect limits and boundaries without feeling unbearably excluded; how to tolerate envy without being overwhelmed by it, or using it to destroy (Bateman and Holmes 1995). With the Oedipal conflict resolved, potential "biographical and societal disaster" is avoided (Erben and Martin 2008, p27). The non-Freudian view holds that difference can exist in tension with likeness and the other recognised in the self; loving someone need not involve power and domination and provoke rivalry. Boys acquire an appreciation of the security and "innerness" of the mother; girls the difference and "exploratory possibilities" of the father, and they learn to tolerate the separate relationship their parents have without anxiety and develop a stable sense of self and others (Bateman and Holmes 1995, pp67-9).

According to Clarkson (1995, p65), people who cannot use memory in preparation for present or future coping are "severely handicapped" because they cannot learn from experience, therefore they cannot update and revise their mentalised representations of relationships (Tirassa, *et al.* 2006). When an infant experiences the loss of a meaningful symbol, according to Winnicott (1971, p102),

the potential space becomes filled with the products of their own creative imagination in favourable circumstances, but in unfavourable circumstances the creative use of objects is missing. In this case the “false self” appears (Winnicott 1971), which can bring about better behaviour but the person has no genuine empathy; they may imitate these postures but cannot draw on inner experience (Gerhardt 2004). The “true self”, with its potential for creating new mentalised representations, is then hidden (Winnicott 1971, p102) and the individual can become “cluttered up with persecutory elements of which he has no means of ridding himself” (Winnicott 1971, p103).

Plotted on page 135 in ‘Starting Again’, in part II of this chapter, are some of John’s significant endings and significant beginnings. If John’s loss of autobiographical memory included the loss of past mental representations he may have regressed to a pre-Oedipal state, and ‘in absence of Oedipus’ old conflicts may have been revived. Experiences and feelings may have re-surfaced in John’s father who had also been a child with needs, which may then have influenced *his* behaviour and *his* relationship with John (Winnicott 1971). Seeing his teenage son as ‘neither fish nor fowl’, for example, and perhaps as a stranger after his accident, rivalrous tensions may have arisen in him as if for the first time. It is possible that John had to ‘start again’ in forming a ‘commonsense theory of everything’, gathering new ‘data’ across all temporalities (Brockmeier 1997) and experiences relating to his beliefs, his sharedness with others, his expectancies, desires, intentions, hopes and fears (Tirassa, *et al.* 2006). As van Manen (1990, p37) points out:

We assign meaning to the phenomena of lived life by giving memory to them through interpretation, for example in conversation. Only by later reflecting on the experience can we apprehend what it was like.

As van Manen (1990, p125) further observes:

Writing fixes thought on paper. It externalises what in some sense is internal; it distances us from our immediate lived involvements with the things of our world.

John’s narrative writing was generally in the form of an abridged version of his reminiscences during his life review sessions. He commented that he described situations rather than experiences in his narrative writing and it is suggested here

that since his narrative writing texts were not expressive, John's data-gathering on an emotional level may have been limited. Analysis showed that the texts written after appraising his life review at Mid-term were more expressive than those John had written earlier. In his first life review session (LRS.1) for example, in which he chose to reminisce about his caregiving phase, John seemed to speak in a generalised way about events rather than express emotion about them. After his Mid-term appraisal, however, there was a noticeable change in his narrative writing style.

In his eleventh piece of narrative writing John specifically mentions the two emotions which he experienced the most during his Caring Phase and which had the greatest effect on him. About his desperation John wrote:

Desperation was brought on by the never ending, grinding struggle to get the best of whatever was necessary for my father. Whether this was medical care, domestic care or just the everyday bits and pieces of life. What do you do when a bed-bound person has toothache? Phone around for a wheelchair-friendly dentist on a ground floor. Struggle to get him into the dentist's chair and so on and so on. (NWO/11/22).

Desperation when I needed to go into hospital (just for one night) finding a local nursing home which could take him just for the night. And then discovering the next day that they had left him on a bedpan for hours, laying flat on his back and causing blisters in the worst possible places! I didn't pay them!! (NWO/11/23).

and about his anger:

And anger. So many of the paid professionals seemed to be incapable of doing anything like a caring job. From nursing home staff (see above) to hospital staff who allowed a paralysed man's fingers to fall into the spokes of his wheelchair and then pushed [wheeled] him off. 'He must have put his fingers in the spokes' I was told. He couldn't *'put'* his hand anywhere. Nursing staff seemed to feel that the normal state of affairs for a doubly incontinent person was to be soaking wet and filthy (NWO/11/24).

An individual's emotional life is a mirror image of their impulse life, according to Yalom (1980), and in some individuals unacceptable feelings are converted into physical symptoms, for example bottling up anger may lead to migraines (Brown and Pedder 1979). John alludes to his emotional 'flatness' when describing his unhappiness during his Caring Phase, simply not having the strength or energy to feel. In his narrative writing he revealed:

Towards the end, of course, seeing my father decline so rapidly, I did occasionally have the time to be overcome with sorrow. Strangely, his death came not so much as a moment of shock, but almost like the end of a chapter in a book. I suppose that he had died as a person four years before (NWO11/27). I don't think that there were any times when I didn't think that I would win the day, but sometimes the way of winning was almost impossible to find. Maybe it was all the problems encountered during my time of caring which prevented my descending into too much unhappiness and emotion. Fighting uses up a lot of the emotion. Another problem was that I didn't have anyone around to whom I could talk openly about any emotional problems. ... In truth though, maybe I just didn't feel emotionally strongly about anything! (NWO11/28).

According to Gerhardt (2004), an individual's sense of selfhood is reflected in the way they deal with their emotions, and the way they manage stress is at the heart of their mental health. It is not passing periods of stress for a few hours or days but persistent powerlessness and unrelieved chronic stress that does the damage, and a willingness to confide in others is important for good health both physically and mentally in later life (Gerhardt 2004). In this way the Assert programme can benefit isolated carers who, like John, do not have the opportunity to talk to someone on an emotional level.

John's coping with isolation as a carer is indicative of his resilience, despite possibly having been "stuck in a constant appraisal of threat" (Gerhardt 2004, p142) as a child. John did not mention during either of his first two life review sessions when reflecting on his childhood that his father had been "hard on him", but mentioned it at the end of his first piece of narrative writing:

It's strange, but I have some feelings of happy things, but I can also remember being scared of getting into trouble with my father. He was rather hard on me. My mother was just always there to love me (NWO1/10).

John could not 'give memory to and interpret' his experience of childhood but in his last life review session (LRS.15) he recalled:

J: I know ... that as a small child he was very hard on me. ... but I can't remember I just know it's there. I know it's there. I know it as a fact. But I don't remember. I don't remember *an* incident (J15/4/3). ... I could rack my brains for another ten years and it wouldn't be there. ... I'm just aware of the fact that there's something. (J15/5/7-8).

John understood that his narrative writing was for him, not for me as facilitator, and that I would read the texts only after the end of his programme. Having read

through the guidelines for the narrative writing opportunities, John said in his second life review session (LRS.2) that he thought about them before starting to write, but then did it a completely different way. He found it easier to write in bullet points, as he did for his reminiscence prompts, and then write a little more about each point. Pennebaker (1990) originally devised narrative writing therapy in an endeavour to reduce waiting times in psychology clinics, and this paradigm was subsequently found to save consultation time for the clinicians. John's writings were not "time-limited exercises" under laboratory conditions involving "a host of psychological, social and biological processes" (Pennebaker 2004, p240), yet the effects were similar.

Analysis of John's texts over the duration of his Assert programme shows gradual and cumulative changes in the way he thought about events, particularly with respect to the relationship with his father. As Fonagy, *et al.* (2003) point out, the reconstruction of how things actually were in childhood can be therapeutic, but it is having the opportunity of reworking current experiences in the context of other perspectives, rather than the outcome of the reconstruction, that is therapeutic.

As John had not allowed himself to experience emotion while caring for his late father it was possible that he had some unfinished grief regarding his death. In my psychotherapy supervision it was suggested that these issues might be addressed by inviting John to write a letter to his father. When I put this to John at Closure (session LRS.14) he welcomed the idea. Initially he had problems starting, but eventually when he wrote his 'Letter to Dad', he said "I just kept hitting the keyboard and the words came out" (J15/9/5), with no mistakes or alterations afterwards.

J: I couldn't think how to get it started [voice low] ... it came out all in one go. ... I had to be in the right mood to do it (J15/1/2). ... I felt more emotional reading it back two minutes later (J15/2/2) Sadness and waste ... (J15/2/6) .

John gave permission for this piece of narrative writing text to be reproduced here, anonymised but unedited.

‘Letter to Dad’

Dear Dad

How do I start this letter. Why am I writing this letter.

I suppose that since you’ve been gone for more than ten years it’s about time I told you a few things about me. Things which you probably didn’t realise.

I think, in your own way, you always did the best for me. You certainly always provided for me. I also think that you went away to war a young man, and came back a father. This must have been very difficult for you. A ready made family, as it were. I know all about that. Me too (much later), and for different reasons. I don’t remember too clearly my early life, but I have an impression of an overbearing person. Not too understanding, but a good provider. We did things together. I can remember going fishing, flying a kite, kicking about a football and other things. At your parents’ home we often played snooker together. But I never felt close to you. I don’t think I loved you, and I was sure you didn’t love me.

Maybe I was wrong on both counts.

When I eventually left home and married, you were very supportive, both materially and emotionally. I know I wouldn’t have coped without your support for the first 3 months. Strangely, we grew much closer when I wasn’t there. When we weren’t together. Maybe the competitiveness disappeared.

Through the following years we became considerably closer, never ‘huggy’, but something like fond of each other. You helped me with the central heating in the house in [Uptown], I built your kitchen in [Downtown]. Generally a fair exchange.

But never too close! Then came your stroke. I felt so sorry for you. Maybe also for myself. So much time wasted not knowing each other. I did my very best for you when you needed caring for. Maybe I went further than I thought I could. It wasn’t a problem. I could be strong for you with no difficulty. If you needed picking up, I could do it. If you needed washing I had no problems. Whatever it was I could do. Out of duty? I don’t know. Out of love? Maybe! As you may realise, the only thing I left to my mother entirely was your emotional support. She knew you better than I.

And when you wanted to go, I saw the tears in the corner of your eyes. Don’t think you fooled me.

I hope that you drifted off with a few happy thoughts in your mind. I wasn’t sad for you.

I think that you will understand this letter. You used to type your letters in short bursts. Thoughts probably going down faster than they came. Staccato phrases to get the ideas down on paper.

I suppose I should say, and I will,

Lots of love, your son John

In combination with his life review sessions, John's narrative writing was in a sense preparatory, helping to form a secure framework which, once in place, enabled him to see his father through a child's eyes and as his grown-up son. His 'Letter to Dad' is a microcosm of his life and a moving testament to his courage in working through the pain of feeling unloved by his father and emerging as a loving son. Recognising the change within himself, John suggests in his letter that "maybe the competitiveness disappeared". Having expressed the wish to participate in an Assert programme but anticipating he would feel uncomfortable in a group situation, suggests John may have felt competitive in other aspects of his life. It is hoped that, if John has resolved his Oedipal conflict, he has symbolically laid his father to rest, said 'goodbye' to him and 'moved on'.

The Penknife Scenario

John had requested an extra session (LRS.15) in which to reflect upon his letter. As this session was coming to an end he reflected upon his impression of his father having been "hard on him", of having been worried as a child about doing something wrong and "being scared of being found out" (J15/4/9). He continued:

J: I wouldn't have been sent to bed for a year without any food or anything like that. I never had anything ... taken away from me, toys, and so on (J15/5/11).

A sudden gleam came into his eyes as he recalled:

J: I can remember something, though God knows how old I was, I've got no idea. ... I think we were at my grandparents. ... And somebody came across a penknife and gave it to me with the sort of understanding that I had to be sensible with it. And two minutes later I'd opened it up and I was running around like cowboys and Indians with a [waves hand in the air in energetic lasso fashion] – and it got taken away from me and I don't think I ever saw it again. But I mean it was just sort of ... [voice trails off] (J15/5/11).

The sense of fun in John's eyes vanished; he looked away and became thoughtful in uncharacteristic silence. After a few more moments the facilitator, her tone warm and kindly with a hint of appeal, suggested:

C: [Softly] That's understandable, isn't it, really? (J15/6/1).

Slowly meeting the facilitator's gaze again John murmured: "Yes, very understandable" (J15/6/2), with almost imperceptible stress on the word "very".

This exchange prompted me as facilitator to search John's face for an indication of disappointment in my not having shared in his humour, but if there was any, it was not apparent in his expression which seemed questioning. I wondered if perhaps for the first time John was perceiving himself less punitively. In those few reflective moments it was as if he had reviewed and revised a crucial piece of 'data' from his autobiographical memory and connected to 'real' feeling and I sensed that John may have experienced a significant positive shift in his biographical reflective focus after a transference reaction. In a transference reaction the person's feelings are not appropriate to their present situation, but are a repetition of an earlier experience (Brown and Pedder, 1979). In the literal sense transference means "to carry across" and it is generally applied to the process of carrying feelings from past experience into the future (Clarkson 1995, p65). Feelings and attitudes from earlier experiences transferred into the present may be intensified with anxiety. Illness, for example, may re-awaken feelings of dependency in a patient who may then respond to doctors and nurses as if they were their parents (Brown and Pedder 1979). Someone who repetitively reacts aggressively or combatively to institutional organisations, for example, may be reliving unresolved battles with an authoritarian parent (Bateman and Holmes, 1995). The humanistic approach, which underpins the Assert programme, does not dismiss transference, but the facilitator does not react directly to it (Bateman and Holmes 1995).

It is now recognised that transference occurs in every new relationship and that feelings and attitudes developed in earlier, similar situations are transferred into the present, especially where there are no specific clues available to the person on how to react (Bateman and Holmes, 1995). Clues on how to react may have been available to John after his accident, but his ability to recognise them and to transfer feelings and attitudes from a lost past into the present may have been limited due to memory loss. Being both facilitator and researcher I could appreciate that the possible shift in John's biographical reflective focus may have significance as a 'transference epiphany' which might otherwise have been missed and although transference was not intended to be the subject of analysis in this study, in view of the dramatic change in John's attitude towards his late father, I determined that this phenomenon warranted further discussion.

In the therapeutic relationship transference manifests latent meaning (Clarkson 1995, pp60-75) which is in turn shaped and coloured by past experience (Bateman and Holmes 1995). This may have been pertinent for John for two reasons. Firstly, the facilitator/participant relationship was 'safe' and provided a suitable micro-environment into which he could transfer and explore some of his earlier experiences of attachment, separation and loss. Secondly, in this setting John could experience a subliminal attachment to his late father, with the facilitator possibly symbolically representing an 'always there' mother and the life review process itself providing affirmation of his past experience in the present.

As (Butler 1963; 1974) points out, stressful environmental factors can bring about symptoms of mental illness whereas Freudian theory, which adheres to the medical model of treating patients for mental disorder, assumes that child-hood trauma is at the root of everyone's problems and maintains that the 'cure' lies in the patient gaining insight into their inner world (Bateman and Holmes 1995). Intersubjectivity between analyst and patient becomes a complementary process with both contributing from their own psychological worlds to form a unique relationship, with its own history and culture (Bateman and Holmes 1995). This is not unique to the analyst/patient partnership but also occurs in therapist/client and facilitator/participant relationships; in classical psychoanalysis, however, the patient's original Oedipal situation is recreated and strong emotions and wishes arising from their original parental relationships are transferred onto the analyst (Bateman and Holmes 1995). Unaware of the false emotional connection, the patient experiences feelings belonging to their past as if they are alive and 'for real' in the present (Brown and Pedder 1979). The analyst's interpretation of the conflicts that arise are reflected back to the patient, and in the ensuing 'drama' that is 'played out' the patient can safely explore their psychological defences, which helps them to overcome past trauma (Bateman and Holmes 1995).

The modern view of transference de-emphasises reconstruction of the person's past in the therapeutic setting but embraces the notion of a person transferring unconscious wishes and fears onto their therapist or into the therapeutic partnership (Clarkson 1995). The interplay between the patient and analyst is regarded as a medium through which the individual's internal drama is 'played out' as a new experience, influenced by the past rather than as a repetition of the

original Oedipal situation (Bateman and Holmes 1995). In both the therapeutic setting and everyday relationships the transference phenomenon frequently involves the “normal human trait” of a person blaming someone else for their own shortcomings; an example of this is ‘the pot calling the kettle black’ (Brown and Pedder 1979, p26). This is a psychological defence mechanism known as projection (Bateman and Holmes 1995), where a person ‘gets rid of’ unacceptable feelings by projecting them onto someone else. Sometimes people may behave as though not only their feelings but important aspects of their own selves belong to or are contained in others (Brown and Pedder 1979). An example of this is a parent who, unknowingly perhaps, spoils a child and prevents their independence. In psychodynamic terms the parent sees a dependent aspect of themselves in the child, and provokes the child to enact it. This may help the parent to cope with their own frustrated longing for closeness and dependence, but they may thwart the developing needs of their child as a result. This is known as projective identification, where the parent’s feelings are projected *into* the child and ‘played out’. Projection is the mental mechanism underpinning this process and projective identification is the expression of the specific fantasy or mental representation (Bateman and Holmes 1995). Bateman and Holmes (1995) suggest the best example of projective identification is Freud’s concept of the super-ego or ‘internal parent’, an internal representation of parental prohibition. Paranoia is an extreme form of projective identification, where the person may disavow their own hostile feelings and declare that others have hostile designs upon them (Brown and Pedder 1979).

All reactions aroused in the therapist, whether analyst or facilitator, by a person’s transference, conscious or unconscious, including emotional resonance and empathy, are regarded as countertransference. This includes specific aspects of the patient and the results of projective identification (Bateman and Holmes 1995). If the therapist has a direct emotional reaction to an individual’s actions or behaviour, and this reaction is not one into which they are being unconsciously pushed, then this should not be seen as projective identification, but mirroring of whatever the person expresses in verbal or non-verbal form. If this includes unconscious communication, then everything the individual expresses is also fleetingly experienced by the analyst (Bateman and Holmes 1995). The

concordant aspects in the analyst's personality link with those of the patient, and emphasise greater equality within the relationship (Bateman and Holmes 1995). In psychoanalytic terms this is known as complementary or concordant countertransference. Concordant countertransferences are empathic responses based on the analyst's resonances with the patient, and link with affective attunement, empathy and mirroring, but are not necessarily the result of projective identification (Bateman and Holmes 1995). Knowing how and when to use countertransference beneficially are the "quintessential skills of the analyst" (Bateman and Holmes 1995, p116). It is suggested here that the specially devised semi-structured protocols for the Assert programme provide an effective framework for a life review process which employs mirroring as an educative and therapeutic strategy, and, as 'The Penknife Scenario' shows, they are sufficiently robust to accommodate concordant countertransference.

According to psychoanalytic theory an unconscious requirement for the patient and the analyst to enact something may arise through projective identification (Bateman and Holmes 1995). In the therapeutic setting, unlike in an everyday relationship, the analyst, therapist or facilitator becomes aware of and 'tunes in' to their own feelings whilst maintaining an attitude of "free floating attention", and listens empathically with a "third ear" to the message behind the surface communication of the patient without colluding in an invitation to project an identification or succumbing to a projective identification (Brown and Pedder 1979, p62). This skill enabled me to keep separate my dual facilitator/researcher role without difficulty and to 'hold' John in the therapeutic relationship. Thoughts and actions of adulthood continue to be influenced by the "child within" (Sandler 1992 cited in Bateman and Holmes 1995, p49) and during John's humorous enactment of the cowboys and Indians scene I sensed that I was being 'pulled into' childlike exuberance, and being encouraged to take his 'side' about the penknife being taken away, both of which I had instinctively resisted. While showing appropriate appreciation of John's humour, I sensed there was a message about unhealed hurt and shame in a child who felt he had been treated harshly in front of others. My comment: "That's understandable, isn't it, really?" had appealed to John's reasoning which prompted him to reflect and consider the possible consequences had the penknife not been taken away and perhaps see that his father (assuming it was his father) may have acted out of alarm and

parental concern. Interestingly, during his life review sessions John had depicted himself as an almost faultless, always happy child. It was not until after the end of his programme when I re-read his narrative writing that I became aware that he was “always getting into trouble” and had “more than his fair share of punishment at school” (NWO/3/9). That his narrative writing opportunities, though not expressive, had enabled John to own aspects of himself that he may have forgotten, or was not ready to disclose during his life review sessions, highlights the advantage of combining life review and narrative writing therapies in the Assert programme. Further, in view of his poor self-concept, John may have feared that had he mentioned at an early stage that he was “always getting into trouble” he would have been judged harshly, perhaps in the same way as he judged himself to be “unreliable” or “stupid”. Had he mentioned it during the sessions on the other hand, he may have been able to reflect on the possibility that the trouble he was always getting into might have been connected to his memory loss.

Before starting his Assert programme John wrote on his questionnaire that he wanted “to be able to discover a way to relax and put the past *in* the past” (see Appendix A4.1). As discussed in part I of this chapter, in his Aspects of Life Log, a simple life satisfaction measuring tool, John rated his quality of life as completely satisfactory by the end of his programme, which is an indicator of its effectiveness. However this somewhat belies a complex process. According to Brown and Pedder (1979), the past shapes the present, but the present can also re-shape the influence of the past, as John’s ‘Letter to Dad’ verifies. If viewed as a transference epiphany, ‘The Penknife Scenario’, enabled him to put some of his past *in* the past. Although the influence of the ‘child within’ may continue, according to Yalom (1989), an individual either becomes their own parent or remains the eternal child. In his transference epiphany John appeared to shift out of his father’s authoritarian shadow and parent himself, but much less harshly. In finding his ‘lost child’ perhaps John also discovered a way to relax.

Described in the next section, “‘A Genius or An Idiot?’: Knowing How To Be or Not To Be’, is the process for formulating John’s Outlook/Inlook Action Plan for Change, the format for which is shown in Appendix A3.14 and an extract of which is provided in Appendix A4.2.

“A Genius or An Idiot?”: Knowing How To Be or Not To Be

As well as wanting the Assert programme to enable him to put the past *in* the past, John wanted to discover a way of feeling relaxed, as stated in his questionnaire (see Appendix A4.1). Based on John’s own observations, ‘relaxed’ has been interpreted as not feeling emotionally or psychologically stressed. In his fourth life review session (LRS.4), for example, when reflecting on an emotionally painful episode in his life, John commented:

J: I’m surprised I’m as happy as I am thinking about the situation. As relaxed as I am thinking about it. Because it was very unpleasant at times (J4/15/1).

When evaluating his Post-caring, Later Middle Age Phase, (55+ years) (LRS.12), John said: “I felt relaxed and happy talking about the period after caring ...”. Here he was referring to (environmental) stress when dealing with the establishment. After reflecting on his action plan for change (see Appendix A4.2) he said he felt “calm and relaxed” but remembering a contentious issue left him feeling “uptight”, which was interpreted as psychologically stressed. The following discussion focuses on the processes involved in the formulation of John’s action plan to ameliorate his stress, which is described by Gerhardt (2004, p57) as:

... a state of high arousal that is proving difficult to manage, either because there is no respite or because the process of recovery is not working. ... Managing stress is at the extreme end of emotional regulation.

Attachment theory is an evolutionary system for emotional regulation, and the ability to manage emotions is the pre-cursor to mentalisation (Fonagy, *et al.* 2004). Care in infancy shapes the developing nervous system and determines how stress is interpreted and responded to in the future (Gerhardt 2004). Emotional behaviour is a non-volitional ‘fight or flight’ signalling system which needs to be managed, not blocked or ignored, and there is a powerful link between emotional insecurity and the hormone cortisol³ (Gerhardt 2004, p197).

³ On perceiving a threat, an infant produces cortisol which slows down the immune system to allow energy to be focused on the current crisis. If under constant threat and producing continuously high levels of cortisol over prolonged periods, the infant’s cortisol receptors will close down. When anger or distress are not expressed or dealt with constructively, cortisol may remain in the system. Under stress, securely attached children do not release high levels of cortisol whereas insecure children do. By the age of three their neural pathways may be primed to guard against threat which over time can affect their ability for reading social cues and adapting behaviour to social norms. Once embedded the stress response is difficult to alter (Zeedyk 2009; Gerhardt 2009).

Whilst in the short term synthetic drugs can regulate emotions and ameliorate stress, to be long-lasting old habits for responding to stress need to be modified, and new ones introduced for potentially 'rebuilding the emotional brain' (Gerhardt 2004, p201). With renewed psychological functioning comes the possibility of repair of anatomic structures in the brain, but this has to be under the right conditions, without continued stress interfering in the process (Ross 2003). An over-reactive stress response underlies chronic depression (Gerhardt 2004), a condition which, as Butler (1974) points out, along with anxiety, psychosomatic illnesses and paranoid states, can be an internal reaction to external stresses. An individual's mental health and wellbeing according to Winnicott (1971, p41) is:

... not a state of ease or absence of conflict but is characterised by a capacity to experience fear as well as trust, pain as well as pleasure, doubt as well as certainty and frustration as well as satisfaction. Mental health is developing a tolerance of conflicting feelings and impulses and with promoting a fuller awareness of and capacity to become involved in, the various experiences of life.

It is not suggested that John was mentally ill, but it *is* suggested that his stress response may have gone into overdrive after his accident, and that he may have been suffering from untreated depression which is frequently associated with post-traumatic stress disorder (PTSD). According to Karl, *et al.* (2009), current models of PTSD propose that an individual's negative appraisals of the trauma and its sequelae create an enduring sense of current threat that maintains the disorder. Their study of survivors of car accidents suggests that changes to an individual's sense of self occur that are unique to PTSD, which contribute to the maintenance of the disorder. Perhaps high cortisol levels were relevant in John's case as he seemed to live with an enduring sense of current threat. Early in his Assert programme, for example, he had commented that he contemplated the future fearfully, felt his time was limited. Whilst formulating the 'Inlook' section of his Action Plan for Change John observed that throughout his life he had constantly felt that he had to be guarded and wanted to be less so (see Appendix A4.2).

His life review revealed 'intervals of happiness', particularly in his early married life, but there were also many events that were anxiety-ridden and activities that were fear-driven. He seemed to live in fear of himself and the world. Whilst talking about what motivates people he said:

J: Fear is universally the greatest spur to everything, almost every single action, every single thing that people do, at the bottom of it is fear, somewhere, fear of something. Fear of hunger, fear of ridicule, fear of falling off the edge of a cliff, fear of crashing a car, fear of something or other but the biggest fear is probably the fear of ... of not having any money so they can spend on things which don't probably do them much good anyway (J5/10/9)

Anxiety about not having any money appeared to underlie John's own motivations:

J: I have always wanted to be retired (J1/8/4). ... I have to, I think, force myself to [work] because my nature would cause me to think: 'Let's give up work, I'd rather [enjoy myself] (J5/9/10). ... And I have done it quite a few times ... but it's only ever been the need for money that's forced me to go back. I mean, I'm very happy not working all the time (J5/9/10).

Highly anxious individuals tend to derive self-worth from others' acceptance and affection because they cannot regulate self-esteem internally, according to Hepper and Carnelley (2010), whose study echoes those showing that anxious people inadvertently seek negative feedback from others despite depending on them for self-regulation. Negative feedback is "like an acid which eats away at self-esteem" (Gerhardt 2004, p140). Later in his programme John started to think more highly of himself but suggested that maybe it was "only in my eyes" (J12/12/8), as if seeking affirmation from the facilitator for being a person of any value.

As a young person possibly having lost his 'commonsense theory of everything', John may have been unable to 'read' people, and with or without clues and cues on intentionality (Fine, *et al.* 2001), i.e., how to react, John may have had no way of knowing how to be or how not to be. Children use social referencing cues, for example mirroring (Fonagy, *et al.* 2004), and clues from an adult's emotional expression (Bateman and Holmes 1995) as a guide for their behaviour in ambiguous situations. Even if these had been available for John's self-affirmation he may have missed them, or failed to recognise them, or not interpreted them correctly. Had this not been the case, perhaps he would have internalised beliefs that instilled within him a more positive self-concept. He had few consistent positive images of himself (Brown and Pedder 1979). However, self-esteem is not just thinking well of oneself in the abstract, it is a capacity to respond to life's challenges (Gerhardt 2004). John had certainly responded to his life's challenges as a carer but despite this there seemed to be a 'shifting

sand' aspect in him which surfaced at the end of his fourth life review session (LRS.4), when he was reflecting on his academic success after his accident:

J: I found concentrating more difficult – I *think* I found concentrating more difficult. I didn't want to concentrate. I didn't want to be at school. I didn't want to do anything (J4/6/1) ... achievement-wise would be being faced with something that is difficult or awkward or whatever or maybe appeared to be insurmountable but nonetheless succeeded (J4/16/12). ... I don't think I had the challenge (J4/16/14). It's like doing a crossword. If you get the answers right then they're not difficult. ... The only difficult questions are the ones you don't know the answers to. ... I've never had pleasure at achieving something ... (J4/17/1).
C: So you set yourself high standards? (J4/17/4).
J: Oh yes (J4/17/5).
C: ... Would you say those standards were in-built or would you say those standards were demanded from without, for example from your father? (J4/17/6).
Who are you proving it to? (J4/18/1).
J: Me (J4/18/2).
C: To you? (J4/18/3).
J: [Flatly] I could prove anything to me. I can prove that I'm a genius or an idiot. And I tend to do both continuously. I surprise myself with my own brilliance and moronity (J4/18/4).

After completing his Mid-term appraisal of his life review process (session LRS.8(a)), John said he felt "very confused" about himself and that he had "no direction". During the "turbulent times" after separating from his wife, John had numerous relationships which failed, but he could not fathom what had caused "the knocks", although in reflecting on his marriage he supposed he was always the problem. With fresh insight in session LRS.9(b), and less self-blame, he observed that his life "seems to go in phases which match who's in my life at any one time" and "to an extent ... it has been a reflection of the person who's been in my life" (J13/1/4). Bateman and Holmes (1995, p106) suggest that:

Failure of mirroring in childhood leads to lack of cohesion in the self and low self-esteem. In response the child may escalate attempts to be perfect and become a show-off, continually craving approbation and admiration.

Failure of mirroring and aspiring to be perfect may or may not have applied in John's childhood. However, his life review showed that in adulthood he tried to be a perfect parent, reproached himself harshly for his unreliable memory and had 'zero tolerance' of his own and others' failings. Set against the backdrop of turbulence, confusion, sense of waste and no direction, this seems to indicate a lack of cohesion of selfhood and low self-esteem. It is crucial to 'hold' a person and protect a fragile self-esteem in the therapeutic setting, and Bateman and

Holmes (1995, p106) suggest that:

Like a good parent, the [therapist] should act as a mirror to the patient's tentative search for self-esteem rather than puncturing it with premature interpretations.

John was 'held' within the therapeutic setting by a facilitator who made virtually no interpretations, and his fragile self-esteem was safeguarded by mirroring. The humanistic, non-directive approach allowed him to "experience personal authenticity and honesty in relation to others" (Brown and Pedder 1979, p166) in the 'here and now', and to identify and own 'hidden' aspects within himself as and when he was ready to do so.

The process of formulating an action plan for change was based on Yalom's (1980) guiding principle that change requires an act of will in two stages: firstly wishing, and secondly, making the decision to take action. Informed by his Aspects of Life Log ratings (see Table T4.5, p115) and aided by his life reviewed thus far, during his Mid-term Outlook/Inlook Session (LRS.9(a)), John was invited to reflect upon his present situation and the attitudes he held towards his outside world (outlook) and towards himself, his inner world (inlook), consider what aspects of his life he would like to change, and how he might make these changes happen. As described in chapter 4 part I, it was not without difficulty that John entertained the notion of change. His locus of control was external (Gross 1987), whoever was in his life steered it. When reflecting on what he might have done differently about a failed relation-ship, for example, he thought of finding a different person rather than making a change within himself. He felt he was a victim of circumstance and that change was impossible for him. The adult personality is quite resistant to change but it is the situation, not the person, that determines the personality, according to Harris (2009), since people behave differently and have different 'selves' in different social contexts (Harris 2009). Indeed, Advocate's casework shows that carers behave differently when under stress compared to when they feel empowered.

The "yin and yang" of the adult personality, according to Harris (2009, p46), are the inborn and the context-specific effects of the environment. She points out that, as most parents realise shortly after the birth of their second child, children come into this world already different from each other (Harris 2009). Her extensive review of research literature shows that studies tend to focus only on

the parent-to-child effect, not the child-to-parent effect, and “context effects call into question the validity of a great deal of personality research” (Harris 2009, p69). Research into the process of socialisation shows that a parent’s behaviour towards a child affects how the child behaves in the presence of the parent. Babies of depressed mothers, for example, only display “sombre expressions” and “muted” behaviours when interacting with their mothers; children who are “picky eaters” are not such picky eaters away from home (Harris 2009, p59). Behavioural-genetic studies show that personality traits such as disagreeableness and aggressiveness have heritability factors of fifty per cent; a child with a disagreeable temperament will respond unfavourably to other people who consequently respond unfavourably to the child (Harris 2009, p268). People are susceptible to the influence of their peers at all ages (Harris 2009) and, as Zimbardo’s (cited in Gross 1987) prisoner-warrior experiment shows, even the most ‘normal’, ‘stable’ people can behave cruelly to each other under knowingly-simulated conditions of incarceration.

Interestingly, when considering his attitudes towards himself, John described himself as a “glass half-empty person” who tended to hide his hurt and anger. He saw himself as “an empty thing” and overcompensated for his low self-esteem by “playing the fool”. According to Lacanian theory, before change can happen something positive must be available to take the place of something negative (Leader and Groves 1995). If seen in terms of attachment behaviour, ‘playing the fool’ and the failed relationships during his ‘turbulent times’ may have been John’s attempt to acquire craved-for approbation and approval. He wanted to change from being a ‘glass half-empty person’ to someone who could verbalise his feelings and be more ‘true to himself’ (see Appendices A4.2 and A4.8).

As was described in chapter 4 part I, to help him to decide what steps he might take to achieve these changes, John was shown four diagrams representing stressful states which had been devised for the Assert development group and was invited to select the one he felt was most appropriate to him. He identified with all four (see page 117) yet had difficulty identifying which stresses were operating within himself and which stressors in his environment were impacting upon him. According to Winnicott (1971), an individual’s inner and outer world derives from their personal interpretation of past experience. The concept of

having an inner world that relates to outer reality through thinking, feeling, sensation and intuition (Jung 1968) John found confusing. He felt 'outlook creates inlook' (see Appendix A4.2). Being able to distinguish between inner and outer realities involves the reflective self function, the unconscious mentalising process that enables an individual to apply their 'theory of mind' to themselves and become the subject of their own thoughts (Fonagy, *et al.* 1994, p241). This function, which evolves around the time of the Oedipal complex but may not fully emerge until late adolescence, determines the coherence of an individual's autobiographical narrative (Fonagy, *et al.* 1994). It is not clear whether the narrative itself plays some crucial role in creating a secure sense of self, or whether it is a by-product of the attentive relationships and good feedback from others which produce a secure sense of self (Gerhardt 2004). It is suggested here that it is an interaction between the two, between the person's inner reality and their outer experience; it is "the self as the interpreter of experience" (Kaufman 1986, p14) which engenders a sense of security within the individual. The fact that John's narrative was not coherent, that he found the concept of an inner and an outer reality confusing, that he tended to hide his feelings and sought negative feedback, all contributed to his not knowing how to be and suggests his reflective self capacity may have been impaired or its development halted due to his accident (Shaw, *et al.* 2004).

The process of formulating an action plan for change from a humanistic perspective may have helped John to become more true to himself. The extract from John's feedback on his Outlook/Inlook Action Plan for Change in Appendix A4.8 indicates that he has moved from describing himself as a 'glass half-empty person' to someone who felt "happier" and "less angry" and for whom life was worthwhile. As his narrative writing texts about his desperation and anger indicate, he became more open in communicating his feelings, which reduced his cognitive avoidance (Raes, *et al.* 2005, p134).

While it is acknowledged that an Assert programme cannot change someone's personality, John's 'Letter to Dad' is testimony to his will and courage to change. Reflecting on his 'Letter to Dad' at the end of his programme John said:

J: There are probably quite a few people who have known me who would say that I'm not too emotional about things. That I'm callous or whatever ... and the odd thing is, because I sat and typed this out without anything sort of impinging upon me it would probably be easier for me to think yes, that's probably right, I am callous. But ... but it still nonetheless came out of me, I created the words that are down there. The words that are down there aren't callous. So perhaps that's a truer reflection of me and not what everybody sees in me (J15/14/5).

The Assert programme re-educated John in his general communication style, and helped him to deal more effectively with some of his emotions; indeed, perhaps it kick-started a 'rebuilding' of his neural pathways.

The autobiographical self is an extended consciousness which makes an individual aware of having a lived past and an anticipated future (Fonagy, *et al.* 2004). In John's awareness of his lived past his childhood was mostly absent; he had a few really happy memories of his adult life but was fearful of even contemplating the future. According to Fonagy, *et al.* (2004), insecurity in attachment relationships may be a signal of a limitation in mentalisation abilities, but for John it seemed to be the other way around. On the assumption that loss of his childhood autobiographical memory limited his capacity for mentalising, John's sense of security and intentionality (Fine, *et al.* 2001) was undermined. The changes in him suggest the Assert programme altered his neural pathways (Zeedyk 2009; Ross 2003), increasing his capacity for mentalising. For as Fonagy, *et al.* (1994, p250) maintain:

The opportunity of reflection upon intention allows for the modification of unhelpful internal working models of relationships through encounters with new significant figures; it equips the individual with ballast, a self-righting capacity.

With increased psychological congruence indicated by the positive shift in his biographical reflective focus, having put the past in the past and no longer feeling himself to be "a waste" or so fearful of his world, it is hoped that a more relaxed John will continue the process of change in the future.

Chapter 5

Conclusions and Recommendations

Introduction

This single-subject study (Sinclair 1962; MacIntyre 1985; Erben 2000) was undertaken primarily to determine whether the Assert programme (Gardner 2006), which is based on Butler's (1963; 1974) life review therapy and incorporates Pennebaker's (1990) narrative writing paradigm, was safe and effective in an individual setting, and to determine whether mirroring was effective as an educative and therapeutic strategy when employed in facilitating the Assert life review process on a one-to-one basis with John, a former unpaid carer. John's personal aims were: "to discover a way of being more relaxed", and "to put the past in the past". Having lost virtually all his childhood memories due to a road accident in his teens, an additional aim of the study was to ascertain whether John's recall of his autobiographical memory of childhood would be improved. *Verstehen* hermeneutics (Dilthey 1976; Patton 2002) and grounded theory (Glaser and Strauss 1967) were employed in the analysis of the qualitative data with biographical research methods providing a temporal dimension (Erben 1998). A methodology loosely based on that of Sacks, *et al.* (1974) was devised for interpretive conversation analysis. John retrieved no 'new' memories but the coherence of his narrative improved and other outcomes for him were positive; indeed, some of the changes in his outlook and sense of selfhood were startling. It was therefore concluded that the Assert programme (Gardner 2006) was safe and effective in an individual setting and that mirroring was effective as an educative and therapeutic strategy when employed in facilitating John's Assert life review process on a one-to-one basis.

Reflection on the study opens with a discussion on the potential strengths and weaknesses of the methodology. This is followed by an appraisal of John's life review process after which issues pertinent to caregiving as revealed by the research process are outlined. Recommendations for future research are then made and lastly some of the potential applications for the Assert programme (Gardner 2006) are suggested. The findings rely to a large extent on John's self-reports and whilst they cannot be generalised they suggest that applications for the Assert programme could be wide-ranging.

The Methodology: Strengths and Weaknesses

Life review therapy as pioneered by Butler (1963; 1974) utilises the naturally-occurring healing phenomenon of life review. Originally developed to aid the final integration of older people near death, it was not designed for unpaid carers.

The potentially unique methodology for the Assert programme (Gardner 2006) has been specifically tailored to meet the needs of unpaid carers in both a group and an individual setting. It combines life review therapy (Butler 1963; 1974) with Pennebaker's (1990) narrative writing paradigm. Mirroring is employed as an educative and therapeutic strategy to facilitate the life review sessions.

Bender, *et al.* (1999) recommend that life review therapy is most effective when iterative and conducted as groupwork facilitated by a highly-trained psycho-therapist, whilst for Haight (1988) life review should be conducted by a health clinician using rigidly-structured protocols on an individual basis. Since the outcomes from this study were beneficial for John on a one-to-one basis, future Assert programme (Gardner 2006) participants can be offered the choice of either a group or an individual setting with confidence.

The framework for the Assert programme was broadly based on the eight stages in Erikson's (1950) "Eight Ages of Man" theory of psychosocial development. John found reviewing his life in these phases helped him to reflect upon his experience and "think about what he actually did at a particular time and what he was thinking". He saw patterns, made discoveries and began to interpret some aspects of his own hermeneutic circle (Dilthey 1976) which he might otherwise have missed. His most significant discovery, for example, was seeing a pattern in his attachment style, indeed, in the epiphanies (Denzin 1989) in his life, which appeared to be determined by "whoever was in it". In view of the first four of Eriksons' (1950) psychosocial stages that may have been lost to John, his resilience in adversity was remarkable. This gives rise to questioning whether an individual needs to navigate all the stages in Erikson's psychosocial theory to become a 'decent' human being, and whether the theory should be revised to allow for the fact that different people enter different phases earlier or later in their life (young carers for example). According to Erikson's theory (see Table T4.10 on page 134 of chapter 4, part II), caregiving is an element which does not 'normally' feature in an individual's life until middle age, stage VII, which covers forty to sixty-five years.

It is suggested here that a new stage VII should be introduced into Erikson's (1950) theory to cover thirty-five to fifty years; stage VIII would then cover fifty to sixty-five years, not forty to sixty-five and stage IX sixty-five to seventy years. In the new stage VII a person might, for example, aspire to respect self and others and universal ethical principles; the basic virtues attained might be generosity of spirit and compassion. The outcome attitude for the new stage VII might be public spiritedness as opposed to hedonism. Psychology has moved away from determinism and a more flexible approach to Erikson's theory would leave open the possibility of reparation for those who 'miss out' the early stages of psychosocial development for whatever reason. They would not then be denied hope and aspiration which the theory seems to infer, or be perceived by others as having 'missed the boat'. The possibility of therapy, perhaps even of participating in an Assert programme (Gardner 2006), would then be open to them, as in John's case.

The four-month gap after John's tenth session (LRS.10) is interesting because at the time I wondered if he would continue with his Assert programme. After resuming his programme John made only four discordant responses compared with the thirteen prior to his appraisal at Mid-term, so it is possible that his personality may have been doing some of the 'work' Butler (1974) refers to in the process of integration. Whilst four months could be too long a gap, a short break in the Assert programme at Mid-term after formulating their Outlook/Inlook Action Plan for Change would allow participants more time for assimilation and integration of their life reviewed thus far. For participants who welcome the idea of a gap it will be incorporated into the iterative Assert programme schedule.

The process of formulating John's Action Plan for Change was informed by his life satisfaction ratings drawn from his Aspects of Life Logs. This simple measuring tool based on the Likert scale (1-5, 5 being most satisfactory), was originally devised to enable participants to reflect on how satisfied they are with certain aspects of their life that are significant to *them* at the time, rather than rating aspects of their life that are deemed to be significant by a health care practitioner or social worker, for example. At Closure John introduced 'Quality of Life' as an aspect of his life which for him meant a comfortable life style; for someone else it may mean peace of mind or physical wellbeing. His rating for

this aspect was completely satisfactory (5.0). Interestingly, his rating for 'Leisure' was 2.0 at Mid-term increasing to 4.5 at Closure, yet nothing in his home or work aspects had changed, only his perception of it, which suggests the Aspects of Life Log is an effective life satisfaction measuring tool and a robust indicator of shifts in biographical reflective focus.

Other significances in the data relating to subtle changes in John's biographical reflective focus became apparent to me as a former carer in a dual facilitator/researcher role from statements that might have been taken at face value and underlying meaning missed by a non-carer. For example, as facilitator I sensed dissonance when John reflected on his caregiving role, and recognised cognitive avoidance in his acknowledging its cost to him and the bitterness he felt (see Appendix A4.6). As researcher, I noted from John's reminiscence prompt sheet for the session on his Caring Phase that he questioned his decision to care for his late father (see Appendix A4.5) which I interpreted as an indication of his becoming more distanced from his caring role. This increased objectivity and the sudden rise in his mirroring responses in sessions around the same time coupled with decreased dissonance, prompted my 'hunch' about a turning point for John. I reasoned that this positive shift on what I termed a dissonance-concurrence-resonance continuum might have significance other than as an indication of a change in his interaction style over the course of his life review process.

It was not obvious from the comparative content or thematic analysis of the data whether this positive shift was significant which could be regarded as a potential weakness in the methodology and I resolved to re-listen to the audio tapes of the three sessions containing in-depth reflections on John's Caring Phase using conversation analysis (CA) methodology (Sacks, *et al.* 1974) which were time-consuming and unproductive as they failed to reveal anything new. Abandoning conventional CA methods I employed a suitably modified form sufficiently finely tuned to register the minutiae of underlying meaning, and robust enough to identify responses that were subtle cognitive avoidance. It was a case of hearing or not hearing, rather than seeing the point; a case of indexing and categorising not only what John said but *how* he said it and more crucially, when he said the same thing in a different way or paused to consider what he was about to say.

Using this modified CA enabled me to detect discrete changes in John's interaction style over time and identify the session in which John began to consider what he was about to say and was more self-reflective (see sessions LRS.12 and 13 in Table T4.8, on page 128 of chapter 4 part II). Thus, a potential weakness in the methodology was turned into an advantage, since the innovation enabled a pertinent link to turn-taking and maternal attunement (Trevarthen 1977; Stern 1984; Ainsworth, *et al.* 1971) to be made which enhanced the interpretation of the data. Also, should a similar study be undertaken in the future, the methodology would already be available if required.

The Semi-structured Protocols: Strengths and Weaknesses

John was in general happy with the fortnightly sessions and the semi-structured protocols. He found the reminiscence prompt sheets, the session evaluation sheets and the semi-guided narrative writing guidelines easy to follow although he chose to 'do his own thing' when writing. After his accident John's dexterity was slightly impaired and sometimes he found it easier to word process his narrative writing, much of which was factual, not emotionally expressive, and it could be argued that the guidelines for the narrative writing opportunity should have been more directive. I had (wrongly) assumed that John knew how to write expressively but analysis of the data revealed that in fact he had to *learn* how to do this, and a process was taking place for him which, in not having been engineered, was likely to be of greater long-lasting benefit to him. Being invited rather than instructed to write brought about the significant discovery about his attachment style, which was not something he had thought about before he "sat down and just looked at a blank sheet of paper". He was "surprised" that he could write "so easily" about painful events in the past and as 'Letter to Dad', his last piece of writing indicates, John was eventually able to express his feelings "openly and honestly". As writing the letter had been so positive for John a similar exercise may be incorporated in future Assert programmes. The advantage of the semi-guided narrative writing opportunity protocol, which was based on Gidron, *et al.*'s (2002) Guided Disclosure Protocol, became clear when John revealed that writing his brief 'whole life review' had given him "reason to believe" that he was "not entirely the 'waste of time' I've always considered myself to be" (NWO.13). It is a sad indictment that for most of his life John had indeed felt that way about

himself, however, in being able to make this self-disclosure after reviewing his life is testimony to the Assert programme's effectiveness, and to the combination of its reflective, iterative methodologies.

Although forgetting to bring his narrative writing texts to the sessions sometimes was frustrating to John, it did not interfere with his programme. Knowing he could send his texts electronically to me (as facilitator) in between sessions appeared to allay his anxiety. There was no infringement of boundaries since, as facilitator, I was available for support in any case during the non-session weeks. As the strategy succeeded in reducing John's stress, it could be offered to future participants with memory problems providing boundaries are maintained. Apart from the four-month gap there were four other minor departures from the standard protocols as indicated in the notes for Table T4.1, (page 90 of chapter 4, part I), including John's request for two extra sessions to focus on his Caring Phase (session LRS.11(b)) and his 'Letter to Dad' (session LRS.15). In asking for extra sessions it could be inferred that John wanted to prolong the therapeutic relationship or that as facilitator I had not been firm enough about Closure; however flexibility had been built into the Assert programme protocols to allow for the possibility of participants wishing to focus on any unresolved issues.

A transference-countertransference epiphany (Bateman and Holmes 1995; Denzin 1989) occurred at the end of the extra 'Letter to Dad' session when, as facilitator, I refrained from mirroring John's humour as he reflected on 'The Penknife Scenario'. As both facilitator and researcher I was able to intuit that something significant may have taken place, namely a significant shift in John's biographical reflective focus, which might have been interpreted differently by someone else or have been missed altogether. Had John described this scenario much earlier in his programme, my response as facilitator would probably have been one of empathic mirroring which would not have engendered the same quality of transference, if any. 'The Penknife Scenario' highlighted the advantage in my having the dual role and showed that the Assert programme protocols were sufficiently robust for me to create and maintain suitable boundaries within the therapeutic relationship that would accommodate the transference-countertransference phenomenon.

There was some scepticism about the effectiveness of mirroring on the part of my psychotherapy supervisor, who favoured a more structured, directive approach. There is, however, a directive element built into the formulation of the Outlook/Inlook Action Plan for Change involving four spider figures (see page 82) where the participant is invited to consider aspects of their situation and selfhood which they might wish to change. Had I insisted John identified with only one of the 'spider' figures he may not have gained so much insight into some important aspects of selfhood.

John had difficulty in making a distinction between his outer and inner worlds initially which was borne out by his comment "outlook creates inlook" in his Outlook/Inlook Action Plan for Change (see Appendices A4.2 and A4.8). Aided by four 'spider' figures devised for the Assert development group participants, John was invited to select the one that reflected his emotional state. He immediately identified with all four figures, not just one as intended, which reflected aspects of himself that were stressful, namely: (1) Acceptance – having to work; (2) Beaten – it's beaten me; (3) Facing up to things – coming to terms and (4) Fighting – challenging something that is wrong (see page 117). John had no wish or inclination to change in his attitudes towards himself, and his acknowledgement of his inner world and the fact that he did have the capacity to determine his own fate was an unexpected change. Whilst a directive approach may be desirable for individuals engaging in conventional therapies, the positive outcomes from this study and previous development work (Gardner 2006) suggest that the non-directive, iterative methodology of the Assert programme is suitable not only for unpaid carers, but also for those whose emotional or psychological state is not robust enough for intense, conventional psychotherapy. Again, what was thought to be a potential weakness in the methodology for this study, namely the non-directive, semi-structured approach, proved to be an opportunity for methodological innovation and one of its strengths.

John's Life Review Process: An Appraisal

John found the life review sessions "better than I imagined" and for someone who was intolerant of his own and others' "failings" he was "surprised" that he could admit to his faults readily. This is an indication of the trust and confidence he had in the therapeutic relationship. The fact that John's Assert programme

did not enable him to recover lost childhood memories was disappointing, but his narrative became more coherent. He commented that the memories he did have were “sharpened up” and he could see where he “sits in things”. He seemed dismissive about his accident and defensive about his memory loss in the early sessions; interpretation of the data suggests he may have been afraid of ridicule by the facilitator for his poor memory. Apart from having “no experience on which to establish the future” and not knowing “what it was like to be a child”, John appeared to have little interest in what he may have lost in emotional or psychological terms. As can be seen from the ‘Starting Again’ chart on page 135 and interpretation of the data in chapter 4 parts II and III, the accident may have robbed him of much more than his childhood: it suggests that his accident wiped out his ‘blueprint’ for knowing how to be. At the time of his accident there was a lack of appropriate support for traumatic brain injury (TBI) victims (Thornhill, *et al.* 2000). John received no rehabilitation for the emotional and psychological sequelae from his TBI including the possible long-term side effects such as post-traumatic stress. Had an Assert programme or similar therapy been available for John in his teens, he may not have always felt a ‘glass half-empty’ person who had been ‘struggling all his life’, possibly with a constant threat of chaos, and who felt his life had been an ‘entire waste of time’. Having said this, John described caring for his late father as “the best thing” he had done in his life and after his Assert programme he valued himself as “a better person”.

Space does not permit a list of all the benefits and changes in John; suffice to say the most startling was the change in his attitude towards his late father of whom he had felt afraid as a child. This change may have come about through resolution of the Oedipal complex. If so, this supports attachment theory, which suggests that disorganised attachment styles, characterised by incoherent narratives (Fonagy, *et al.* 1994), are linked to insecurity and insensitive mothering (Bowlby 1969; 1973; Winnicott 1965; 1971; Batmanghelidj 2000; Solomon 2004; Ainsworth, *et al.* 1971; Stern 1984; Murray and Trevarthen 1985). However, John’s experience confounds this. Despite feeling ambivalent towards his father, he ‘knew’ his mother loved him and that he had been happy and secure in childhood. Resilient in some ways, which prompts the question of what ‘normal’ development *is* (Fonagy, *et al.* 1994, p233), John had no ‘armour plating’ for withstanding ruptures in emotional attachments in adulthood, which

for him “felt like death” or “injury”, and for which there seemed no reparation. The data suggest that John’s initially discordant, sometimes combative, interaction style within the therapeutic setting was a defence against his anxiety about emotional resonance, or, indeed, silence. The data also suggest that when he emerged from his coma his emotions were in raw, ‘default mode’, devoid of the ‘survival kit’ which most individuals gather from lived experience (van Manen 1990). In feeling unloved and vulnerable and in need of “mending”, he was driven by a need to find “an object” to replace his lost “imago” (Fonagy, *et al.* 2004; Winnicott 1971, pp96-7). In Schopenhauer’s terms, John was in a constant “contest of personal desire with a world that was by nature inimical to its satisfaction” and “inevitably tragical” (Janaway 1998, pp545--54). John’s ‘new’ self was nearer to his ‘true’ self in that he was no longer so anxious and guarded, controlling and controlled. This suggests that as well as being “layered” and the “interpreter of experience” (Kaufman 1986, p14), the self reveals different aspects of itself under different conditions rather like a palimpsest; it does not develop sequentially (Erikson 1950), ‘grow up’ or ‘grow out of’ feeling. The self is itself dynamic, but balances its dynamism within the bounds of its own emotional existence, hidden, unbidden and unwelcome though some feelings are. Threatened abandonment reawakens Oedipal conflict for which requital may only ever be partial, because Oedipus is not in fact absent, he is everywhere.

It would have been fascinating to have researched this and other aspects of selfhood further; however the focus for this study was to ascertain whether mirroring was a safe, effective, educative and therapeutic strategy for John in his individual Assert programme. The findings from this study show that as well as being therapeutic for John, mirroring may have ‘re-educated’ his interaction style.

The Research Process: Issues Pertinent to Caring

Unique for each individual, the caregiving role has commonality in engendering the sense of isolation. Whether a situation is lifelong, long-term or acute, carers regard ‘having someone to talk to’ as a close second to practical support for making a difference for them, according to a recent survey (Carers UK, *et al.* 2009). In his narrative writing on his Caring Phase John comments “I didn’t have anyone around to whom I could talk openly about any emotional problems” (NWO.11/28). ‘John’s Story’ (in chapter 1) suggests he was caring for both his parents although

he did not see it at the time. As depicted in 'Dave's Story' (chapter 2 part I), so distraught was he at the thought of having committed fraud, Dave just blurted out his distress to me over the telephone without being aware of who was on the line. For almost two years Jenny (in chapter 2 part II) kept to herself her anger about being scorned by care home staff and her frustration about the way they were treating her mother. She was too fearful to speak out until she was certain a senior executive would 'do something' if she told him about the problem.

John found the Assert programme gave him an opportunity of "being able to talk about yourself and to be listened to": in 'being listened to' John felt valued. This is the stumbling block in bringing about necessary change with regard to the carer's 'lot', a 'lot' which John felt "dehumanised" him. When people feel valued themselves they are more likely to value others: perhaps this is why the caregiver's role tends to be overlooked and their stress ignored by society. Self-disclosure is good, according to Pennebaker (1995), not only for the individual but also for communities; when cultural values are distorted the health and wellbeing of a community as a whole suffers. The corollary is that the Assert programme, which facilitates self-disclosure, is good for people's health, and therefore suitable for carers (paid and unpaid) who want to voice their concerns but fear officialdom's retribution. Having someone to talk to and being listened to is helpful but the 'someone' must understand what caring means.

Etzioni, *et al.* (1993, p19) urge health care professionals to "speak out ... and act ..." in order to bring about change but given the "coercive culture" of the NHS and associated organisations which, he maintains, "nurture dysfunction" (Penley and Gould 1988, p45), it is understandable why so few professionals speak out for reform. Paid care workers appear just as afraid of 'the system' as unpaid carers but for different reasons, not least the desire to keep their jobs. Despite the photographs John had taken of his father's "damned great bedsore" a district nurse who had seen it for herself would not verify this in front of colleagues; in making her "hell in hospital" public Wenger (2007) brought about improvements in its facilities but failed to challenge its culture, indeed, she made excuses for it; ward staff who do not or cannot do their jobs properly are defended by their chief executive; social workers ally themselves with care home managers who neglect vulnerable people and intimidate their relatives who are without recourse. It is

now a criminal offence to abuse or neglect those who lack mental capacity yet it is not a criminal offence to abuse or neglect those who do not lack capacity and evidence gathered by the Joint Committee on Human Rights (2007) is ignored by the Department of Health. Dave described his experience as “a nightmare” and Wilf’s ward as “a cold, uncaring dungeon” where he was often left sitting in soiled, wet bedding and once there was “poo under his chair”. The duty doctor admitted they had neither the time nor the staff to look after the people in his ward properly and later left or was asked to leave the NHS. After Wilf died Dave felt the system had “chucked me onto the scrapheap”; his solicitor dismissed his poverty and missed the point: namely, Dave’s real fear that he *would* starve and *would* lose his home. Having regarded Wilf as his foster-father it seems reasonable that as his full-time carer Dave should have been able to register as his foster-carer and receive approximately £204 a week as he would if fostering a child.

The eight vignettes (see chapter 2 part II) testify to the hidden emotional and psychological cost of the sole advocate’s care burden, and also to the lip-service paid to them by officialdom which prompts the question: what is the point of fighting for what is right, what is fair and what is just? Regarded by professionals at best as a resource and at worst as a nuisance (as Dave was), unpaid carers are generally seen to be interfering (as Jenny was). Perhaps it is because, like John, they prolong life. Most unpaid carers are motivated primarily to prevent the lives of their loved ones being immiserated, if not shortened, in an institution. As a consequence many suffer in silence and pay a high price for their selflessness and resilience. It is as if carers are punished for the ill health of their loved ones. Wilf taking too long to die is an example: the first attempt to get NHS funding for his end of life care ‘failed’ yet a few weeks later the second succeeded with pressure from his social worker and Advocate. (Wilf also had dementia and it is possible that, as sometimes happens, the people who carried out his initial assessment may not have been adequately trained to recognise his needs; they saw only the physical problems.) Had this funding been obtained soon after diagnosis Wilf’s comfort at home in his last weeks could have been maximised. Instead, he ended up being dehydrated and left to die alone in a care home, which traumatised Dave.

Whilst fictional ethnography can speak for the interests of silenced groups (Sparkes 1997), to be a really effective medium it has to increase the volume of a voice striving to be heard by taking the reader beyond sympathetic identification with the protagonists and galvanise them into actively championing a cause. That the burnout syndrome exists for paid care workers is widely accepted (Maslach 2001), unlike the toll on those unpaid. This thesis suggests the existence of 'the unpaid carer's syndrome' and that it is associated with an establishment whose social policy-makers appear to evade or even avoid "active, rational debate" (MacIntyre, *et al.* 1985, p18). Herein lies irony: in failing to 'countenance' hardship, the establishment is encouraging senior management in an already dysfunctional 'care' arena to perpetuate a coercive culture driven by corporate sociopathy. Further, if this hostile environment is causing burnout in paid care workers, they are in turn exacerbating the unpaid carer's syndrome. Paid care workers can leave their jobs, unpaid carers cannot.

The experiences of people like John, Dave and Jenny strengthen the rationale for the need to address burnout as a symptom of the unpaid carer's syndrome. The conclusion that such a condition exists is strengthened by the fact that certain common psychological and physiological symptoms do not manifest themselves in individuals before or unless the dynamics of unpaid caregiving start operating and tend to continue even after the caregiving role ends. Carers have to deal with situations they do not invite in and from which they cannot 'take flight' because their vulnerable loved one is dependent upon them. Instead they may distance themselves from themselves (Gardner 2006) and, unable to 'fight' the establishment's subjugation, they tend to become ill themselves through stress, as in Jenny's case. Charmaz (1983; 1999) identified a loss of self in the chronically ill as a fundamental form of suffering when a sudden disjuncture between the past and present, a shock diagnosis for example, leads to a diminished sense of selfhood. It is argued here this can also apply to unpaid carers. Jenny's life and aspirations changed when her father died; John's life and future changed the instant he heard his name being called over the public address system on his way to work; Dave was filled with fear and consternation on being handed a leaflet on leukaemia and was traumatised when Wilf died. The Assert life review process is tailored to healing 'disjunctures' between past and present: reflections on the past create a new lens in the present through

which hope for change in the future is perceived. As can be seen from Table T4.4 (page 109 in chapter 4 part I), in John's case, a positive shift in his biographical reflective focus indicating increased psychological congruence led to an improved sense of selfhood and reduced stress (Gardner 2006).

As well as increasing his intentionality, the Assert programme instilled hope in John and his attitudes towards himself and, most particularly, his attitude towards his relationship with his late father became less harsh. The Assert programme also improved his style of interaction. Key to this was the facilitator's mirroring responses that occurred in the dialogue throughout his life review process which may have activated or re-activated his capacity for self-reflection and 'reading' his own and other people's intentions (Fonagy, *et al.* 1994; Fine, *et al.* 2001; Livingstone 2005). In being able to acknowledge what was happening in his own inner world he began to have a greater appreciation of what might be going on in that of others. Asking for the tape to be paused for the facilitator's sake, not for his own, indicated increased empathic mirroring which prompts the question as to whether John's positive shift in biographical reflective focus was linked to a reactivation or re-generation of mirror neurons.

Recommendations for Further Research

Development work on the Assert programme is still underway, and further research is needed to compare its long-lasting effectiveness with conventional therapies. A randomised control trial is therefore recommended involving current and former (unpaid) carers in both group and individual settings. It would be useful to determine whether the stress response of participants changed after completing an Assert programme, and to measure their neural activity pre- and post-programme in order to determine whether any re-generation of mirror neurons had taken place. According to Bower (1995), positive mood can improve memory recall and employing the methodologies from this study, it would be relatively straightforward to track participants' moods in future research. It would also be interesting to re-examine the data from the Assert development programme (Gardner 2006) to track the mood of the participants and discover whether any of them might have been suffering from symptoms of burnout. It is proposed to develop a questionnaire based on Maslach's Burnout Inventory (Maslach, *et al.* 1996) and incorporate this in future Assert programmes. Unlike

conventional therapies, the facilitator of an Assert programme (Gardner 2006) may be a lay person with good listening skills (Butler 1974). It is envisaged that by participating in an Assert programme themselves Assert facilitators can be trained through experiential learning which would be cost-effective and future development work includes preparing a training package to accommodate this.

Other Applications for the Assert Programme

In the current climate of cut-backs in public services and the increasing threat of privatisation of the NHS (Pollock 2008), conventional psychotherapies are gradually being relegated to the province of private practice in favour of short-term therapies that are seen by some as a quick-fix, and increasingly out of financial reach of those who most need help. The Assert programme, on the other hand, has minimal toll on the facilitator who requires less intense and therefore less expensive clinical supervision which makes it extremely cost-effective.

Unlike many conventional therapies which are based on the medical model and seek to 'cure' individuals of 'mental disorder', the Assert programme (Gardner 2006) is a gentle, humanistic, non-elitist intervention where, in a non-clinical setting, the facilitator works with participants, as opposed to treating them. Findings from this study and earlier development work show that the Assert life review process reduces stress and improves the emotional and psychological wellbeing of carers. While not in itself an instrument of social reform, in caring for carers the Assert programme could ameliorate the unpaid carer's syndrome and improve their 'lot' were it routinely available to them.

Further research is needed to confirm that the beneficial effects of the Assert programme are long-lasting, but based on the findings from this study and earlier development work (Gardner 2006), as well as helping to prevent burnout in unpaid carers, its potential applications are wider than first envisaged. The semi-guided protocols could easily be adapted to focus on aspects of a person's life other than their caregiving role, such as bereavement or divorce. Further, the Assert programme could help ease difficulties in interpersonal communication for those with disorganised attachment and quasi-autism and possibly alleviate symptoms of post-traumatic stress disorder and be of benefit to people with memory loss including those with mild dementia.

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The Mental Capacity Act (2005)

[Source: Department for Constitutional Affairs, Department of Health & Public Guardian Office (2007)].

The Mental Capacity Act (2005) is underpinned by a set of five key principles:

1. A presumption of capacity unless proved otherwise;
2. A person must be given all practicable help before anyone treats them as not being able to make their own decisions;
3. Unwise decisions - just because an individual makes what might be seen as an unwise decision, they should not be treated as lacking capacity to make that decision;
4. Best interests – an act done or decision made under the Act for or on behalf of a person who lacks capacity must be done in their best interests;
5. The least restrictive option – anything done for or on behalf of a person who lacks capacity should be the least restrictive of their basic rights and freedoms.

The person caring or giving treatment must follow a checklist of best interests to decide what *is* in the person's best interest. The statutory checklist (Stewart 2007) for best interests is as follows:

- Equal consideration and non-discrimination;
- Considering all relevant circumstances;
- Regaining capacity;
- Permitting and encouraging participation;
- Special considerations for life-sustaining treatment;
- The person's wishes and feelings, beliefs and values;
- The views of other people.

- ❖ -

The Recommendations Made in Respect of Jenny's Case

Below are the recommendations made by the independent investigator of Jenny's case to the council concerned. All were accepted.

1. That the adult protection procedures be amended to add guidance on the circulation of draft and final approved minutes, included timescales and the showing of apologies for absence.
2. That the current practice of a team manager chairing these meetings, with a professional note-taker continues. The function of investigating officer to remain separate. The appointment of an independent chair is believed to be in prospect and this would give added benefit to all those involved.
3. That Miss J Smith's status as a sole advocate for her mother be recognised, noted and respected.
4. That the response of the community care services to the allegations of adult abuse was correct and professional judgement exercised appropriately in the reaction to the allegations, though more work could have been done with Miss Smith to reduce the stress she was suffering.
5. That although the adult protection procedures were correctly instituted in this case, a note be placed prominently on Mrs Smith's file to the effect that evidence shows that care in Castle Court was not always adequate at the time of the incidents and that her daughter, Miss J Smith, was not an abusive perpetrator towards her mother. In addition, that the actions she took were undertaken in good faith for the relief of her mother's pain and distress.
6. There should be an acknowledgement that this process is reported to have caused her distress and an apology given if she believed it lacked the sensitivity needed. It should also be acknowledged that Miss Smith's actions were taken in an effort to assist her mother's pain....
7. Miss Smith should be reassured of the local authority's continuing interest in supporting and reviewing her mother's care and indeed in the social worker liaising with herself as a key person in seeing how the care is delivered by others and to recognise that Miss Smith continues to have a personal and important role in her mother's care which she strongly wishes to retain.

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An Extract from Maslach's Burnout Inventory (MBI) – General Survey

[Source: Maslach, Jackson and Leiter (1996)]

The MBI measures respondents' relationships with their work on a continuum from engagement to burnout. Engagement is an energetic state in which one is dedicated to excellent performance of work and confident of one's effectiveness. In contrast, burnout is a state of exhaustion in which one is cynical about the value of one's occupation and doubtful of one's capacity to perform. The MBI - Human Services Survey is designed to assess three aspects of the burnout syndrome: emotional exhaustion, depersonalisation and lack of personal accomplishment. The MBI-GS is thought to share many features with those measured by the MBI-HSS however it does not focus primarily on the service relationship, but on the performance of the work in general and defines burnout as a crisis in one's relationship with work, not necessarily as a crisis in one's relationships with people at work. The extract below is from the MBI-General Survey. The scoring key for the questionnaire is not available. The MBI takes about 10 to 15 minutes to fill out. It is self-administered. No special qualifications or procedures are required of the person administering the MBI. However if they are well known to the respondent, he or she should be someone they trust.

Modified Extract from the MBI-GS Questionnaire

Item	How often I feel like this						
	0 Never	1 A few times a year or less	2 Once a month or less	3 A few times a month	4 Once a week	5 A few times a week	6 Every day
1. I feel emotionally drained from my work.							
2. I feel used up at the end of the workday.							
3. I feel tired when I get up in the morning and have to face another day on the job.							
4. Working all day is really a strain for me.							
5. I can effectively solve the problems that arise in my work.							
6. I feel burned out from my work.							
7. I feel I am making an effective contribution to what this organisation does.							
8. I have become less interested in my work since I started this job.							
9. I have become less enthusiastic about my work.							
10. In my opinion, I am good at my job.							
11. I feel exhilarated when I accomplish something at work.							
12. I have accomplished many worthwhile things in this job.							
13. I just want to do my job and not be bothered.							
14. I have become more cynical about whether my work contributes anything.							
15. I doubt the significance of my work.							
16. At my work, I feel confident that I am effective at getting things done.							

- ❖ -

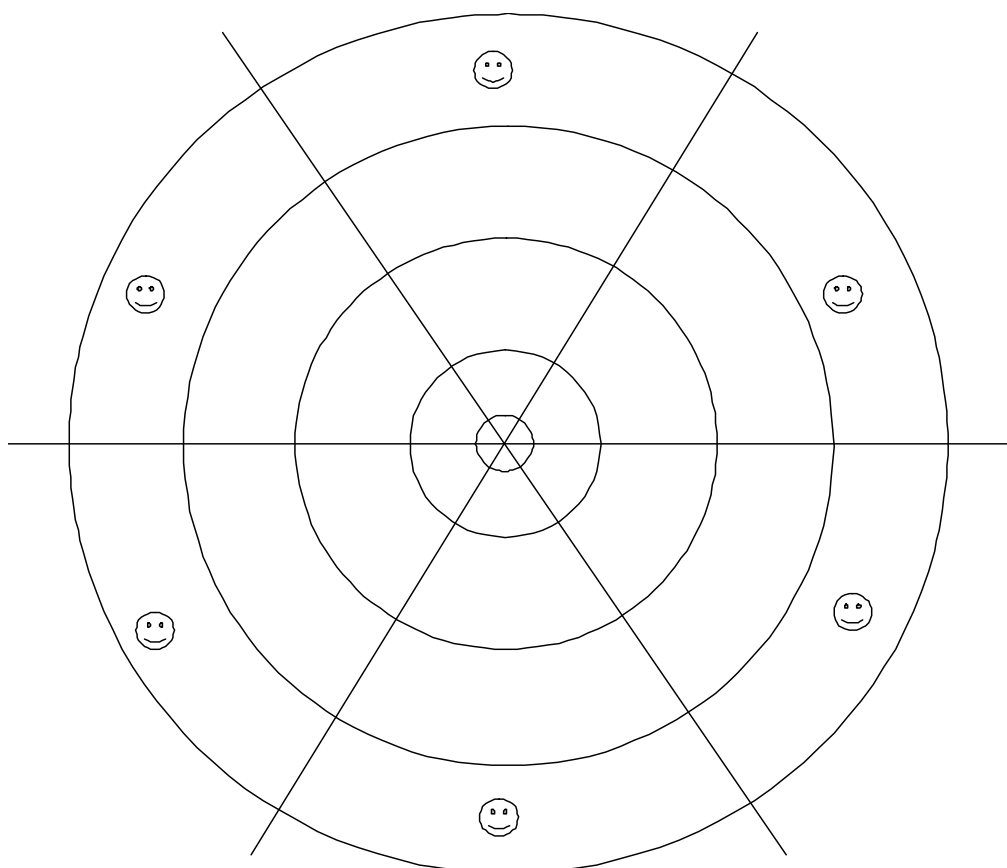
The Assert Programme Life Satisfaction Measuring Tool



The Assert Programme

Name..... Date

Aspects of my life log



1. Imagine you are looking at the end of a log.
2. It has five rings and is chopped into six segments.
3. Beside each segment write one aspect of your life.
4. Now, starting from the centre, shade in each segment according to how satisfied you are with this aspect.
5. The outer band with the 'smiley' shows the most satisfaction.

The Nine Outcome Indicators Chosen for Evaluating the Assert Programme

[Based on Butler's (1974) eight 'benchmarks' and sense of empowerment, Advocare's primary aim for carers (Gardner 2006)]

Butler's recommendation or goal for successful psychotherapy	Description of desired outcome
1 Amelioration of suffering [Main goal of life-cycle groups]	Alleviating pain, anger, grief, guilt, depression, despair, loss, panic (Lewis and Butler 1994, p169). Person develops wisdom and serenity (Butler 1963, p490). Helps person to make sense of and come to terms with their whole life experience (Butler 2002, p1). A comfortable acceptance of the life-cycle (Butler 2002, p3).
2 Preventive	Helps to promote life satisfaction (Butler 2002, p3). Engenders hard-won serenity (Butler 2002, p3). Forges new means of adaptation (Butler 1982, p355). Person able to separate valuable experiences from the inane (Butler 1980, p36-8)
3 Remedial	Brings new meaning to significance of life (Butler 2002, p2). Removes the "crust" people take on as a result of society's indoctrination (Butler 1980, p37). Resolves loss (Butler 1982, p355). Helps to promote well-being (Butler 2002, p3). Helps to promote self-esteem (Butler 2002, p3). Helps to promote a sense of affirmation and hope (Butler 2002, p5)
4 Increased sense of self-fulfilment	Engenders a feeling of having done one's best (Butler 2002, p3) Promotes sense of celebration and growth. Person can enjoy nature, children, forms, colours, warmth, love, humour (Butler 2002, p3). Person develops pride in accomplishment (Butler 2002, p3). Creativity may emerge (Lewis and Butler 1974, p168).
5 Reconciliation of relationships	Person makes amends (Lewis and Butler 1974, p168). Person restores harmony (Lewis and Butler 1974, p168). Reconciles with estranged family members (Butler 2002, p2). Increases intergenerational communication (Butler 1980, pp36-8)
6 Expiation of guilt	Person forgives self or the other person (Butler 2002, p2). Person takes responsibility for acts that caused true harm (Lewis and Butler 1974, p168). Revelations of past may render a deceit honest, free tongues (Butler 1963, p496).
7 Exorcism of problematic childhood identifications	Revelations may forge new relationships, sever peculiar bonds (Butler 1963, p496). Person gains a philosophical acceptance of the past (Butler 2002, p3). Recapitulation of the family (Lewis and Butler 1974, p172).
8 Resolution of intra-psychic conflicts	Person resolves conflicts, reorganises and reintegrates the past (Butler 1980, pp36-8). Person develops ability to tolerate conflict and uncertainty when these exist within self and in relation to others (Lewis & Butler 1974, p168). May defuse anger and envy, especially towards the young (Lewis and Butler 1974, p173).
9 Increased sense of empowerment [Advocare's primary aim for carers]	Personality is reorganised (Butler 1963, p486). Identity is re-examined and restructured (Lewis and Butler 1974, p168). Person attains psychological congruence (Gardner 2006).

Participant Information Sheet

Participant Information Sheet

Study Title: Biography from childhood to adulthood:
Mirroring as an educative and therapeutic strategy in caring for carers

Researcher: Cathey Gardner

Study Ref No:

Ethics Ref No: RGO 5304

Please read this information carefully before deciding to take part in this research. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

This study stems from original development work conducted in a group setting for *Assert*, an empowerment programme for carers. This research project is supervised by Southampton University. It will be conducted, facilitated and funded by Cathey Gardner, Chief Executive of Advocare – Caring for Carers.

Why is my Assert programme being carried out under research conditions?

You expressed a wish to take part in an *Assert* programme but felt a group setting would not be suitable for you. I subsequently designed an individual *Assert* life review process. You will be the first person to 'test out' this individual life review process and as a safeguard for you my work needs to be conducted under strict ethical research conditions.

What is involved for me if I decide to take part?

The *Assert* programme lasts for approximately six months. It is based on a reminiscence and life review process and provides an opportunity for participants to look afresh at their lives and to create 'new' life stories. If you decide to participate in the programme you will be asked to make a commitment to it lasting about six months from the introductory session through to closure. There will usually be thirteen fortnightly life review sessions and a follow-up session three months after closure. In each life review session you will have the opportunity to reminisce, reflect and review phases of your life with Cathey, your facilitator. During the non-session weeks you will have an opportunity to write in private about the phase of your life you have reviewed.

Are there any benefits in my taking part?

There may or may not be a benefit to you in taking part as an individual but there may be a benefit to others perhaps, or in respect of adding to current knowledge.

Are there any risks involved?

There is a small risk that during your reminiscences certain memories you recall or events you reflect upon later could upset or disturb you. You will have access to an independent counsellor, ***** Tel: (*****) *****, should the need arise. As your facilitator I will receive regular supervision from a UKCP registered psychotherapist.

Will my participation be confidential?

In compliance with the Data Protection Act and Southampton University policy the information gathered during your Assert programme will be stored on a password protected computer and remain confidential. In any articles or reports written afterwards you identity and that of anyone else you mention will be anonymised by changing names, ages, gender, dates, localities and disguising situations.

What happens if I change my mind?

Should you wish to change your mind and withdraw from the programme your legal rights will not be affected. All notes and tape recordings will be destroyed.

What happens if something goes wrong?

If you have any complaint you may contact Professor Mary Ratcliffe, Head of the School of Education, University of Southampton.

Where can I get more information?

If you have any questions or would like more information, please contact me, Cathey Gardner on (*****) *****.



Participant Consent Form

Participant consent Form

Study Title: Biography from childhood to adulthood:
Mirroring as an educative and therapeutic strategy in caring for carers

Researcher: Cathey Gardner

Study Ref No:

Ethics Ref No: RGO 5304

Before you decide whether or not to participate in this research programme your consent is required. Please read the following list and initial the boxes if you agree with the statement(s).

I have read and understood the information sheet (Ref) and have had the opportunity to ask questions about the study.	
I understand my participation is voluntary and I may withdraw at any time without my legal rights being affected.	
I agree to take part in this research project and agree for my data to be used for the purpose of this study.	
I understand that my life review sessions will be tape recorded and later transcribed to form my biography.	
I understand that should certain topics arise which I do not wish to be tape recorded I can ask for the recorder to be paused until I say I am ready to continue.	
I understand that any notes, tape recordings and transcriptions relating to my life review sessions will be kept in strict confidence along with my narrative writing texts.	
I accept that there is a small risk I could be upset by my reminiscences in which case I agree to remain with the facilitator until I feel settled again.	
On condition that my identity and that of anyone I mention will be anonymised by changing names, ages, gender, dates and disguising localities and situations I agree to the production of a report.	

I understand and accept the above conditions.

.....
(Name of participant – please print name)

.....
(Signature of participant)

Date.....


Thank you for agreeing to take part in this research programme.

Cathey Gardner

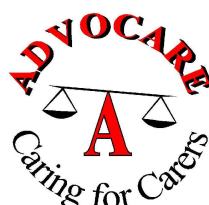
Advocare Casework Questionnaire

CFC.Q3

STRICTLY CONFIDENTIAL

Address Tel No:	 Registered charity No. 1126739	Date of first contact Date of first meeting Advocarer's initials
Your Name: Your date of birth:		
(Please tick appropriate boxes, expanding or deleting as appropriate) Your health: Is it excellent <input type="checkbox"/> very good <input type="checkbox"/> good <input type="checkbox"/> moderately good <input type="checkbox"/> poor <input type="checkbox"/> (Please expand here)		
About the person you cared for: What was their relationship to you?		
Their age last birthday Did they live with you? Yes <input type="checkbox"/> No <input type="checkbox"/>		
What condition(s) did they have?		
About your Caregiving Role: How long were you caring full-time/part time?		
Would you describe yourself as your loved-one's sole advocate? Yes <input type="checkbox"/> No <input type="checkbox"/>		
Did you have to deal with incontinence and/or very personal care? Yes <input type="checkbox"/> No <input type="checkbox"/>		
Did you have to get up in the night to assist your loved-one? Yes <input type="checkbox"/> No <input type="checkbox"/>		
How many hours care per week did you provide? Have free?		
If you received respite services, what type did you find most beneficial?		
Did you give up your own aspirations to take on your caring role? Yes <input type="checkbox"/> No <input type="checkbox"/> (Please expand here)		
Support: Was the professional support from GP, CPN, Social Services, care agency, etc excellent <input type="checkbox"/> very good <input type="checkbox"/> good <input type="checkbox"/> satisfactory <input type="checkbox"/> unsatisfactory <input type="checkbox"/> (Please expand here)		
Was support available from family, friends, Church, voluntary organisations? Yes <input type="checkbox"/> No <input type="checkbox"/> (Please expand here)		
Was it excellent <input type="checkbox"/> very good <input type="checkbox"/> good <input type="checkbox"/> satisfactory <input type="checkbox"/> unsatisfactory <input type="checkbox"/>		
What helped you most in your caring role?		
Did becoming a carer adversely affect your quality of life? Yes <input type="checkbox"/> No <input type="checkbox"/>		
Do you feel stressed now? Yes <input type="checkbox"/> No <input type="checkbox"/> Would you like help from Advocare? Yes <input type="checkbox"/> No <input type="checkbox"/>		
What would you like the outcome to be? (Please expand over the page if necessary)		

Age Phases for the Assert Programme Life Review Process



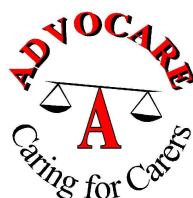
The Assert Programme

Age phases for the Assert life review process

1. Infancy Phase (0-5 Years)
2. Childhood Phase (5-10 years)
3. Early Teen Phase (10-15 years)
4. Later Teen Phase (15-20 years)
5. Early Twenties Phase (20-25 years)
6. Late Twenties Phase (25-30 years)
7. Thirty-something Phase (30+ years)
8. Early Middle Age Phase (40+ years)
9. Middle Age Phase (55+ years)
10. Older Age Phase (65+ years)
11. Senior Phase (75+ years)

Protocol for the Assert Programme Life Review Process

[Showing the link with Erikson's (1950) "Eight Ages of Man".]



Week	Session No	Focus on phase	Erikson's stage	Therapeutic activity	Focus on phase
1	1			Introduction + questionnaire	
2	2	0-5 yrs	I, II & III	Life Review Session	
3	-			Narrative Writing Opportunity	0-5 yrs
4	3	5-10 yrs	IV	Life Review Session	
5	-			Narrative Writing Opportunity	5-10 yrs
6	4	10-15 yrs	V	Life Review Session	
7	-			Narrative Writing Opportunity	10-15 yrs
8	5	15-20 yrs	V	Life Review Session	
9	-			Narrative Writing Opportunity	15-20 yrs
10	6	20-25 yrs	VI	Life Review Session	
11	-			Narrative Writing Opportunity	20-25 yrs
12	7			Review & evaluate process	
13	8	25-30 yrs	VI	Life Review Session	
14	-			Narrative Writing Opportunity	25-30 yrs
15	9	30+ yrs	VI	Life Review Session	
16	-			Narrative Writing Opportunity	30+ yrs
17	10	40+ yrs	VII	Life Review Session	
18	-			Narrative Writing Opportunity	40+ yrs
19	11	55+ yrs	VII	Life Review Session	
20	-			Narrative Writing Opportunity	55+ yrs
21	12	65+ yrs	VIII	Life Review Session	
22	-			Narrative Writing Opportunity	65+ yrs
23	13	75+ yrs	VIII	Life Review Session	
24	-			Narrative Writing Opportunity	75+ yrs
25	14			Review & evaluate process	

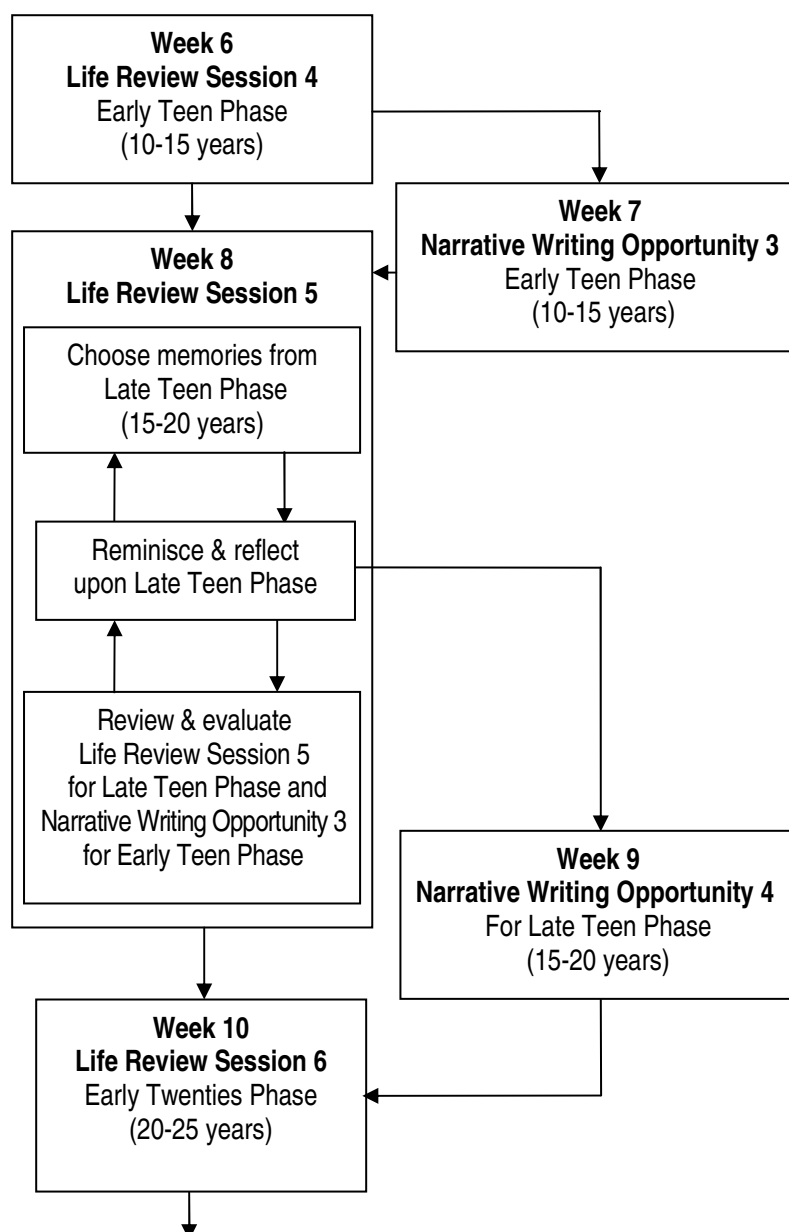
Note:

This protocol is intended to be flexible. In his reminiscence 'slot' in the Introductory Session John chose to focus on his Caring Phase and the years just after it. He also requested an extra session on his Caring Phase (50-55 years). For John the last Age Phase was 55+ years.

The Assert Programme Life Review Process

A typical session would consist of the participant first handing any narrative writing from the previous week to the facilitator before moving into the life review session for the phase s/he has chosen to review. The participant is invited to spend a few minutes reflecting on the phase with a reminiscence prompt sheet writing down memories that come to mind. After spending a few more minutes reflecting on the memories they have chosen to review they are then invited to tell the facilitator more about them. At the end of the session the participant makes a brief evaluation of the life review session and their narrative writing opportunity from the previous week.

The flow chart below shows weeks 6-10 of the Assert programme where session 6 focuses on the participant's early twenties phase.



John's Assert Programme Schedule

[Showing his Life Review Sessions in purple and Narrative Writing Opportunities in blue]



John's Assert Programme Schedule

- Week 1 Introductory Session 1: Review Chosen Age Phase
- Week 2 Narrative Writing Opportunity 1: Infancy Phase (0–5 yrs)
- Week 3 Life Review Session 2: Childhood Phase (5–10 yrs)
- Week 4 Narrative Writing Opportunity 2: Childhood Phase (5–10 yrs)
- Week 5 Life Review Session 3: Early Teen Phase (10–15 yrs)
- Week 6 Narrative Writing Opportunity 3: Early Teen Phase (10–15 yrs)
- Week 7 Life Review Session 4: Late Teen Phase (15–20 yrs)
- Week 8 Narrative Writing Opportunity 4: Late Teen Phase (15–20 yrs)
- Week 9 Life Review Session 5: Early Twenties Phase (20–25 yrs)
- Week 10 Narrative Writing Opportunity 5: Early Twenties Phase 20–25 yrs
- Week 11 Life Review Session 6: Late Twenties Phase (25–30) yrs
- Week 12 Narrative Writing Opportunity 6: Late Twenties Phase (25–30 yrs)
- Week 13 Life Review Session 7: Mid-term appraisal
- Week 14 Narrative Writing Opportunity 7:
- Week 15 Life Review Session 8(a): Mid-term appraisal continued
Life Review Session 8(b): Thirty-something Phase (30+ yrs)
- Week 16 Narrative Writing Opportunity 8: Thirty-something Phase (30+ yrs)
- Week 17 Life Review Session 9(a): Outlook/Inlook session
Life Review Session 9(b): Early Middle Age Phase (40+ yrs)
- Week 18 Narrative Writing Opportunity 9: Early Middle Age Phase (40+ yrs)
- Week 19 Life Review Session 10: Action Plan for Change
- Week 20 Narrative Writing Opportunity 10:
- Week 21 Life Review Session 11(a): Continuation of Action Plan for Change
Life Review Session 11(b): Caring Phase (50–55 yrs)
- Week 22 Narrative Writing Opportunity 11: Caring Phase (50–55 yrs)
- Week 23 Life Review Session 12: Later Middle Age Phase (55+ yrs)
- Week 24 Narrative Writing Opportunity 12: Later Middle Age Phase (55 + yrs)
- Week 25 Life Review Session 13: Whole Life Review
- Week 26 Narrative Writing Opportunity 13: Whole Life
- Week 27 Closure Session 14
- Week 28 Narrative Writing Opportunity 14: 'Letter to Dad'
- Week 29 Life Review Session 15: Reflecting on John's Letter to Dad
- Follow-up Session 16

The Assert Programme Reminiscence Prompt Sheet



The Assert Programme

Reminiscence prompt sheet for my
Late Twenties Phase (25-30 years)

Name *John*

Session *6*

Let your mind focus on a phase of your life you would like to review and reflect upon and then pause for a few moments. When you're ready, see if you can spend a few minutes jotting down whatever thoughts, feelings, memories or impressions come into your mind.

If something else occurs to you about another phase of your life as you're thinking about this one, jot that down too. And don't feel you have to 'tidy up' - the jottings can be in any order.

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Our next session is two weeks from now, on at pm.
Before this next session you have an opportunity to write about the phase of your life that you reviewed today if you would like to do so. A Narrative Writing Opportunity prompt sheet is attached as a guide.

The Assert Programme Chosen Memories Sheet



The Assert Programme

Name

Session

The chosen memories I would like to talk about for this phase are:

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The Assert Programme Life Review Session Evaluation Sheet



The Assert Programme Life Review Session

Evaluation Sheet for

Name:

Session:

I found today's life review session helpful* unhelpful* not sure*
because:

I found my narrative writing for my phase (..... years)
worthwhile* not worthwhile* not sure*
because:

**Please delete as appropriate*

The Semi-guided Protocol for the Assert Programme Narrative Writing Opportunity



The Assert Programme

Your Narrative Writing Opportunity

During the non-session weeks you have the opportunity of doing some narrative writing. The act of writing enables us to integrate images, thoughts and feelings through creating a story – a narrative – about experiences that are important to us. Narrative writing therapy can help us to understand some of the complexities of our lives and reaffirm our sense of identity. All it involves is writing for about twenty minutes on three consecutive days. If we write emotionally about a sad or painful memory or a disturbing experience, this can help us deal with some of the uncomfortable feelings that seem to prevent us from living our lives as effectively as we would like.

For some people the guidelines over the page are too constraining but it is suggested that you try these first and find out what works best for you.

It doesn't matter if you get 'writer's block' and you can't think of anything more to write, you can just repeat what you've already written to fill in the time. You are writing for you and you are not obliged to share what you've written about with anyone else. If you would like me to read it, bring your writing to the next session. I will keep what you've written in strict confidence and return it to you with your biography at the end of the programme.

Cathey



A Guide for your Narrative Writing Opportunity

For your Phase (.... years)

Narrative writing can help people to deal with painful memories and uncomfortable thoughts or feelings. By writing about a disturbing episode expressively, with emotion, people are then able to 'move on' and live their lives more effectively

Narrative writing is likely to be most beneficial to you if you focus on one significant event from the phase of your life you reviewed in your last session but you can include thoughts, feelings or impressions from other phases of your life.

People seem to gain maximum benefit from narrative writing if they write for 15-20 minutes on three consecutive days about a painful or disturbing event as follows:

Day 1:

Describe the event in its chronological order without expressing your emotions.

Day 2:

Describe your thoughts and feelings at the time of the episode and whether the event affected your life.

Day 3:

Describe your thoughts and feelings now about the episode and what you would do in the future were you to encounter a similar event.

Please feel free to either follow the guide and/or to write when you feel moved to do so. It is the very act of writing about certain aspects of your life that is helpful, not the protocol.

The Format for the Assert Programme Mid-term Appraisal



Name:

Mid-term appraisal Session:

A Review and Evaluation of the first part of your Assert Programme

During the first stage of your Assert Programme we have been focussing on the first thirty years of your life. Before we move on to the next phase of your biography, we need to know what has worked well, what hasn't worked so well, and what, if anything, needs to be changed about the sessions. Your thoughts and comments on the following will be helpful for the next part of your life review process.

Prior to starting your Assert Programme

How did you feel about doing the Assert Programme?

How do you feel about it now?

Review of the Life Review Sessions

Would you like the hand-outs changed in any way?

What have the sessions been like for you?

Has anything in them been particularly helpful or unhelpful?

Is there anything about the format of the sessions you would like changed?

Review of your Narrative Writing Therapy

Would you like the hand-outs changed in any way?

When you did some narrative writing, what was that like for you?

Was there anything especially helpful or unhelpful about it?

Would you do it any differently next time?

Evaluation of your Life Review Process

How would you describe yourself prior to doing your Assert programme?

How would you describe yourself now?

Have you had any new recollections or revelations?

To help with our evaluation process I would like you now to take part in a gentle, reflective exercise which will last for about 15-20 minutes.

We will then spend some time reflecting upon some aspects of your early biography.

Do you feel differently about anything now?

Thank you for your co-operation.

Cathey

The 'Observer Self' Exercise

[A mindfulness exercise extracted from Hayes, Strosahl and Wilson (1999, pp193-5)]*

The exercise is carried out with eyes closed. The therapist induces a state of relaxed focus and gradually directs the client's attention to different domains with which people can become over-identified. Each domain is examined in turn, and at key moments the therapist punctuates the attention on content with the instruction to notice that someone is noticing this content. These punctuations can create a brief but powerful psychological state in which there is a sense of transcendence and continuity: a self that is aware of content but not defined by that content. After this exercise, the client's experience is examined, but without analysis and interpretation. It is useful to see whether there were any particular qualities of the experience of connecting with the "you". It is not unusual for clients to report a sense of tranquillity or peace. Life experiences invoked in this exercise, many of which are threatening and anxiety promoting, can be received peacefully and tranquilly (ie, accepted in a posture of psychological willingness) when they are viewed as bits and pieces of self-content and not as defining the self per se.

We are going to do an exercise now that is a way to begin to try to experience that place where you are not your programming. There is no way anyone can fail at the exercise; we're just going to be looking at whatever you are feeling or thinking, so whatever comes up is just right. Close your eyes, get settled into your chair, and follow my voice. If you find yourself wandering, just gently come back to the sound of my voice. For a moment now, turn your attention to yourself in this room. Picture the room. Picture yourself in this room and exactly where you are. Now begin to go inside your skin and get in touch with your body. Notice how you are sitting in the chair. See whether you can notice exactly the shape that is made by the parts of your skin that touch the chair. Notice any bodily sensations that are there. As you see each one, just sort of acknowledge that feeling and allow your consciousness to move on (pause). Now notice any emotions you are having, and if you have any, just acknowledge them (pause). Now get in touch with your thoughts and just quietly watch them for a few moments (pause). Now I want you to notice that as you noticed these things, a part of you noticed them. You noticed those sensations ... those emotions ... those thoughts. And that part of you we will call the "observer you". There is a person in there, behind those eyes, who is aware of what I am saying right now. And it is the same person you've been your whole life. In some deep sense, this observer you is the you that you call you.

I want you to remember something that happened last summer. Raise your finger when you have an image in mind. Good. Now just look around. Remember all the things that were happening then. Remember the sights ... the sounds ... your feelings ... and as you do that, see whether you can notice that you were there then, noticing what you were noticing. See whether you can catch the person behind your eyes who saw, and heard, and felt. You were there then, and you are here now.

*The Observer Exercise is a variant of the Self-identification Exercise developed by Assagioli, R (1971) *The Act of Will*, New York: Viking. pp211-217.

I'm not asking you to believe this. I'm not making a logic point. I am just asking you to note the experience of being aware and check and see whether it isn't so that in some deep sense the you that is here now was there then. The person aware of what you are aware of is here now and was there then. See whether you can notice the essential continuity – in some deep sense, at the level of experience, not of belief, you have been you your whole life.

I want you to remember something that happened when you were a teenager. Raise your finger when you have an image in mind. Good. Now just look around. Remember all the things that were happening then. Remember the sights ... the sounds ... your feelings ... take your time. And when you are clear about what was there, see whether you can, just for a second, catch that there was a person behind your eyes then who saw, and heard, and felt all of this. You were there then too, and see whether it isn't true – as an experienced fact, not a belief – that there is an essential continuity between the person aware of what you are aware of now and the person who was aware of what you were aware of as a teenager in that specific situation. You have been you your whole life.

Finally, remember something that happened when you were a fairly young child, say, around age 6 or 7. Raise your finger when you have an image in mind. Good. Now just look around again. See what was happening. See the sights ... hear the sounds ... feel your feelings ... and then catch the fact that you were there, seeing, hearing, and feeling. Notice that you were there behind your eyes. You were there then, and you are here now. Check and see whether in some deep sense the you that is here now was there then. The person aware of what you are aware of is here now and was there then.

You have been you your whole life. Everywhere you've been, you've been there noticing. This is what I mean by the "observer you". And from that perspective or point of view, I want you to look at some areas of living. Let's start with your body. Notice how your body is constantly changing. Sometimes it is sick, and sometimes it is well. It may be rested or tired. It may be strong or weak. You were once a tiny baby, but your body grew. You may have even have had parts of your body removed, as in an operation. Your cells have died, and not all the cells in your body now were there when you were a teenager, or even last summer. Your bodily sensations come and go. Even as we have spoken, they have changed. So if all this is changing and yet the you that you call you has been there your whole life, that must mean that although you have a body, as a matter of experience and not of belief, you do not experience yourself to be just your body. So just notice your body now for a few moments, and as you do this, every so often notice that you are the one noticing [give client time to do this].

Now let's go to another area: your roles. Notice how many roles you have or have had. Sometimes you are in the role of a [fit these to the client; eg, "mother ... or a friend ... or a daughter ... or a wife ... sometimes you are a respected worker ... other times you are a leader ... or a follower," etc.]. In the world of form you are in some role all the time. If you were to try not to, then you would be playing the role of not playing a role. Even now part of you is playing a role ... the client role. Yet all the while, notice that you are also present. The part of you you call you is watching and aware of what you are aware of. And in some deep sense, that you does not change. So if your roles are constantly changing, and yet the you that you

call you has been there your whole life, it must be that although you have roles, you do not experience yourself to be your roles. Do not believe this. This is not a matter of belief. Just look and notice the distinction between what you are looking at and the you who is looking.

Now let's go to another area: emotions. Notice how your emotions are constantly changing. Sometimes you feel love and sometimes hatred, sometimes calm and then tense, joyful – sorrowful, happy – sad. Even now you may be experiencing emotions – interest, boredom, relaxation. Think of things you have liked and don't like any longer; of fears that you once had that now are resolved. The only thing you can count on with emotions is that they will change. Although a wave of emotion comes, it will pass in time. Yet while these emotions come and go, notice that in some deep sense that "you" does not change. It must be that although you have emotions, you do not experience yourself to be just your emotions. Allow yourself to realise this as an experienced event, not as a belief. In some very important and deep way you experience yourself as a constant. You are you though it all. So just notice your emotions for a moment and as you do, notice also that you are noticing them [allow a brief period of silence].

Now let's turn to a most difficult area. Your own thoughts. Thoughts are difficult because they tend to hook us and pull us out of our role as observer. If that happens, just come back to the sound of my voice. Notice how your thoughts are constantly changing. You used to be ignorant – then you went to school and learned new thought. You have gained new ideas and new knowledge. Sometimes you think about things one way and sometimes another. Sometimes your thoughts may make little sense. Sometimes they seemingly come up automatically, from out of nowhere. They are constantly changing. Look at your thoughts even since you came in today, and notice how many different thoughts you have had. And yet in some deep way the you that knows what you think is not changing. So that must mean that although you have thoughts, you do not experience yourself to be just your thoughts. Do not believe this. Just notice it. And notice, even as you realise this, that your stream of thoughts will continue. And you may get caught up in them. and yet, in the instant you realise that, you also realise that a part of you is standing back, watching it all. So now watch your thoughts for a few moments – and as you do, notice also that you are noticing them [allow a brief period of silence].

So, as a matter of experience and not of belief, you are not just your body ... your roles ... your emotions ... your thoughts. These things are the content of your life, whereas you are the arena ... the context ... the space in which they unfold. As you see that, notice that the things you've been struggling with and trying to change are not you anyway. No matter how this war goes, you will be there, unchanged. See whether you can take advantage of this connection to let go just a little bit, secure in the knowledge that you have been you through it all and that you need not have such an investment in all this psychological content as a measure of your life. Just notice the experiences in all the domains that show up, and as you do, notice that you are still here, being aware of what you are aware of [allow a brief period of silence]. Now again picture yourself in this room. And now picture the room. Picture [describe the room]. And when you are ready to come back into the room, open your eyes.

The Format for the Assert Programme Action Plan for Change



John's Assert Programme Action plan for changes in outlook and inlook

[illegible]

Date of follow-up session: **at** **pm**

The Format for the Assert Programme Closure Session



The Assert Programme

Closure Session Review and Evaluation

Name:

Session:

During your Assert Programme you have been going through a personal life review process. This closure session is an opportunity to look at what has worked well for you, what hasn't worked so well, and how it may have been more beneficial. Your thoughts and comments on the following will be helpful for the follow-up session in three months' time.

Your Assert Programme

How did you feel about doing the Assert Programme?

How do you feel about it now?

Review of the Life Review Sessions

What have the sessions been like for you?

Has anything in them been particularly helpful or unhelpful?

Would you like the hand-outs changed in any way?

Is there anything about the format of the sessions you would like changed?

Review of your Narrative Writing Therapy

When you did some narrative writing, what was that like for you?

Was there anything especially helpful or unhelpful about it?

Would you like the hand-outs changed in any way?

Would you do it any differently next time?

Evaluation of your Life Review Process

How would you describe yourself prior to doing your Assert programme?

How would you describe yourself now?

Have you had any new recollections or revelations?

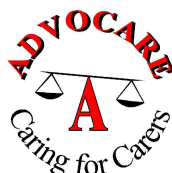
Your Outlook and Inlook Action Plans.

Do you feel differently about anything now?

Thank you for your co-operation.

Cathey

The Format for Feedback on the Assert Programme Action Plan for Change



John's Assert Programme Action Plan Feedback on Changes in Outlook and Inlook

[illegible]

An Example of the Assert Programme Follow-up Session Evaluation Sheet



**The Assert Programme
Evaluation Sheet**

Name:

Follow-up Session:

I found reading my biography helpful* unhelpful* not sure*
because:

I found reading my narrative writing worthwhile* not worthwhile* not sure*
because:

**Please delete as appropriate*

The Initial and Secondary Coding Symbols used in the Comparative Content Analysis of the Qualitative Data

Initial Coding for Comparative Content Analysis of the Qualitative Data:

Each of the statements or extracts from the verbatim transcriptions of John's Life Review Sessions and the texts from his Narrative Writing Opportunities included in the analysis, termed 'texttracts', was given a reference ('J' for John and 'C' for Cathey') and the phenomena dominant in the data coded.

The following lists the coding symbols for the dominant phenomena and also the categories to which texttracts were assigned:

Initial coding symbol for phenomenon	Description of phenomenon	Category
⌘	Statement reflecting on the past	Temporal
®	Statement reflecting on present	
∞	Statement contemplating the future	
✍	Narrative statement	Biographical
🧠	Statement relating to memory	
≡ ≡	Statement relating to an impression	
😊	Positive/happy statement	Attitudinal
😞	Negative statement	
😐	Dismissive statement	
😏	Wry/ironic statement	
<i>I</i>	Statement made with emphasis	
≡ ≡	Statement relating to an impression	Self-perceptive
👁	Self-reflective statement	
Ψ	Statement relating to self-understanding	
☯	Statement relating to feelings or emotions	
💡	Statement relating to gaining new insight	
Φ	Mirroring, i.e., a statement that echoes words, tone, meaning or resonates with the emotion of a previous statement.	Style of interaction

Secondary Coding for Comparative Content Analysis of the Qualitative Data:

Responses from John that appeared to be harmonious for example “Of course!” and “Oh absolutely!” were termed ‘accordant responses’. These phenomena were encoded:



Statements which seemed to create disharmony or dissonance were termed ‘discordant responses’. These phenomena were encoded:



Statements such as “Of course!” or “Oh absolutely!” which are followed by a discordant statement were termed ‘accordant-discordant responses’. These phenomena were encoded:



Significant phases of John’s life were identified and for ease of reference given the following coding symbols:

← = pre-accident phase

↩ = post-accident phase

↶ = pre-caring phase

↷ = during caring phase

↺ = post-caring phase

Definitions of the Conversation Analysis Coding Terms used in the Re-analysis of John's Life Review Session Transcriptions

The terms devised for the conversation analysis in this study were based loosely on the conventions of transcript analysis developed by conversation analysts Sacks, Schegloff and Jefferson who conclude that in conversation, turn-taking is "an organisational device" (Sacks, Schegloff and Jefferson 1974, pp700-731).










Description of conversation phenomenon	Definition of term	Symbol for conversation phenomenon
Turn-taking	Turn-taking in the conversation between two people is when one speaks in turn after the other.	☞
Latching	In conversation a small or imperceptible amount of time between turns of speaking is what Sacks, Schegloff and Jefferson (1974) term 'latching'.	=
Cutting in	When someone speaks before or just before someone else finishes speaking, Sacks, Schegloff and Jefferson (1974) term this as 'cutting in'.	≠
Cutting across	When John cuts across what the facilitator is saying as if on a different tack.	#
Pausing	When someone takes time before responding to someone else this is termed 'pausing' according to Sacks, Schegloff and Jefferson (1974).	//
As if not hearing	When John continues on a theme as if he had not heard the facilitator.	○
Mirroring	When John's words echo the facilitator's, match her tone or meaning or resonate with similar emotion.	Φ
Opposing	When John's response appears to contradict that of the facilitator or her meaning or what he has himself just said.	⊕

Key to Life Review Session Conversation Analysis coding symbols

👉 = Accordant responses	👋 = Discordant responses	⊕ = opposing or contradicting responses	Φ = mirroring
☞ = 'normal' turn-taking	// = pausing	≠ = latching	# = cutting in
			○ = as if not hearing

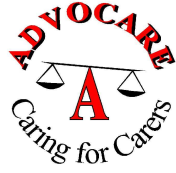
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Full Coding Key for Comparative Content and (Interpretive) Conversation Analysis

Coding for Significant Phases of John's Life:		
← = pre-accident ↶ = post-accident ↷ = pre-caring ↻ = caring ↺ = post-caring		
Coding Symbol	Description of Statement	Category of Statement
Я	Statement reflecting on the past.	Temporal
®	Statement reflecting on present.	
∞	Statement contemplating the future.	
	Narrative statement.	Biographical
	Statement relating to memory.	
≡ ≡	Statement relating to an impression.	
😊	Positive/happy statement.	Attitudinal
☹	Negative statement.	
😐	Dismissive statement.	
😏	Wry/ironic statement.	
<i>I</i>	Statement made with emphasis.	
≡ ≡	Statement relating to an impression.	Self-perceptive
	Self-reflective statement.	
Ψ	Statement relating to self-understanding.	
	Statement relating to feelings or emotions.	
	Statement relating to gaining new insight.	
	'Normal' conversational turn-taking (Sacks, <i>et al.</i> 1974).	Interaction Style
=	Latching: a small or imperceptible amount of time between turns of speaking (Sacks, <i>et al.</i> 1974).	
≠	Cutting in: speaking before or just before someone else has finished speaking (Sacks, <i>et al.</i> 1974).	
#	Cutting across what someone is saying as if on a different tack.	
//	Pausing: taking time before responding (Sacks, <i>et al.</i> 1974).	
○	Continuing on a theme as if not hearing what has just been said.	
Φ	Mirroring: echoing words, tone, meaning or emotion.	
	An accordant response, e.g. "Of course", "oh absolutely!"	
	A discordant response or statement which creates dissonance.	
	An accordant-discordant response or statement: ⊕ = Opposes/contradicts what has just been said. ⊗ = Opposes/contradicts meaning.	
⊖	Statement indicating a shift in biographical reflective focus	

John's Casework Questionnaire**STRICTLY CONFIDENTIAL**

CFC.Q3

Address ***** ***** ***** ***** Tel No: *****	 <p>Registered charity No. 1126739</p>	Date of first contact ... ***** Date of first meeting... ***** Advocarer's initialsCG.....
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Your Name: **John** Your date of birth: *****

(Please tick appropriate boxes, expanding or deleting as appropriate)

Your health: Is it excellent ☐ very good ☐ good ☒ moderately good ☐ poor ☐

(Please expand here) **Difficulty sleeping**

About the person you cared for: What was their relationship to you?**Father**

Their age last birthday **75 years** **Did they live with you?** Yes ☒ No ☐

What condition(s) did they have? **Major strokes, paralysis and mental deterioration**

About your Caregiving Role: How long were you caring full-time/part time? **4+ yrs full time**

Would you describe yourself as your loved-one's sole advocate? Yes ☒ No ☐

Did you have to deal with incontinence and/or very personal care? Yes ☒ No ☐

Did you have to get up in the night to assist your loved-one? Yes ☒ No ☐

How many hours care per week did you provide? **158** **Have free?** **10 hrs/wk**

If you received respite services, what type did you find most beneficial?

Two weeks every two months in local hospital and occasional sitters

Did you give up your own aspirations to take on your caring role? Yes ☒ No ☐

(Please expand here) **Retired from well-paid post with future pension**

Support: **Was the professional support from GP, CPN, Social Services, care agency, etc**

excellent ☐ very good ☐ good ☒ satisfactory ☐ unsatisfactory ☐

(Please expand here) **Support non-existent at first. Improved with time and battles.**

Was support available from family, friends, Church, voluntary organisations? Yes ☒ No ☐

(Please expand here) **Relative was co-carer. Local church minister very supportive.**

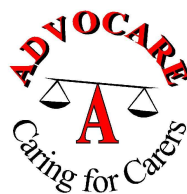
Was it excellent ☐ very good ☒ good ☐ satisfactory ☐ unsatisfactory ☐

What helped you most in your caring role? **Regular respite.**

Did becoming a carer adversely affect your quality of life? Yes ☒ No ☐

Do you feel stressed now? Yes ☒ No ☐ **Would you like help from Advocare?** Yes ☒ No ☐

What would you like the outcome to be? **To be able to discover a way to relax and put the past in the past.**



Registered charity No. 1126739









Extract from John's Assert Outlook/Inlook Action Plan for Change

'OUTLOOK'	'INLOOK'
<p>(Attitudes towards my situation, my world out there)</p> <p>What, if any, aspects of my life would I like to be different?;</p> <p>It may help you to reflect on your Aspects of Life Log ratings which were: <i>Leisure 2.0; Future 2.5; Relaxation 2.5; Health 3.0; Home 3.5; Money/Security 4.5; Romance 3.5; Love 4.0; Work 4.0.</i></p>	<p>(Attitudes towards myself, my inner world)</p> <p>What, if any, aspects in myself would I like to be different?</p> <p>I would like to</p> <p>(1) Be more <i>Relaxed</i> (2) Be less <i>Guarded</i> (4) Risk <i>Being more true to myself</i></p>
<p>How might I consider making these changes happen?</p> <p><i>I'd like to be better off financially. ... I don't know if the young person is in there trying to get out. (Extract from mid-term evaluation session LRS.7)</i></p> <p><i>I think your personality is as a result of what impinges on you so out there - Outlook - creates Inlook. I'm not that unhappy with the person I am so that being the case it probably excludes the 'would like to change within myself'. For other people it might be nice if I changed some of the things that were inside me but then that would be the thing that you're talking about outside because inside it isn't a problem. Outside maybe it is a problem but then that's their problem as well I don't very often try to 'read' people I take it as they come. To relax too much, to ignore things too much would mean that you expose yourself.</i></p> <p>(Extract from continuation of mid-term evaluation session LRS.8(a)).</p>	<p>How might I consider making these changes happen?</p> <p>(1) Being more Relaxed for example when <i>people barge along the pavement inconsiderately don't get annoyed.</i></p> <p>(4) Being less Guarded for example when <i>feeling angry or upset to say what I feel..</i></p> <p>(5) Risk <i>Being more true to myself. Stop trying so hard to be the person that I am.</i></p> <p>for example when <i>in company not to hide feeling unhappy or unsure by playing the fool.</i></p>

Date of follow-up session: at pm

















Examples of Initial and Secondary Coding Symbols for Textracts and Synopses

Examples of Textracts showing Initial Content Coding Symbols:

Textract Reference	Statement made by John	Phase	Initial coding symbols
J4/16/3	C: ... I remember you saying ... you were a confident child ...	Later Teen Phase (15-20 years)	Φ
J4/16/4	J: Mmm. But then I was good at things.		Ψ  
J4/16/6	J: ...I achieved – I got loads of passes at 'O' and 'A' level and so on and so on. ... But not with a sense of achievement, it just happened. That was it. I never felt a sense of achievement.		   Я    Ψ

Examples of Textracts showing Secondary Content Coding Symbols:

Textracts with initial and secondary coding showing a significant phase and John's accordant and discordant responses in blue:

Textract reference	Statement made by John	Phase	Initial and secondary coding symbols
J2/9/3	C: So it takes all the leisure and pleasure out of life really ...?	Childhood Phase	Φ
J2/9/4	J: Yes. Absolutely!		 I
J4/7/2	C: (Laughs softly) What was it about school you didn't like? Were you –	Pre-accident Phase	Φ
J4/7/3	J: It was an intrusion on my private time.		  
J4/16/3	C: ... I remember you saying ... you were a confident child ...	Post Accident Phase	Φ
J4/16/4	J: Mmm. But then I was good at things ...		Ψ    
J4/16/5	C: Mmm. But that must have come from somewhere. Encouragement ...?		Φ
J4/16/6	J: I achieved – I got loads of passes at 'O' and 'A' level ... But not with a sense of achievement, it just happened. That was it. I never felt a sense of achievement.		   Я    Ψ  

Extract from a Textract Synopsis for Statements Relating to Gaining New Insight

The synopsis of textracts with initial and secondary coding showing statements relating to gaining new insight, the coding symbol for which, shown here in red, is:



Textract reference	Statement made by John	Phase	Coding symbols
J11(b)/1/6	I think, though strangely enough I hadn't thought about it before I started to write, ... it was his helplessness, his inability to help himself which was the spur to make me fight harder for his rights.	Caring Phase	Я eye yin-yang pen Ψ thumbs up circular arrow candle
J12/13/6	Looking back I suppose, yes I'm sure I do value myself more than I did six or eight months ago.	Post-Caring Phase	Я smile yin-yang eye Ψ thumbs up circular arrow candle
J13/1/4	(Animatedly) A discovery! And it's odd, it's not something I thought about before I sat down and just looked at a blank sheet of paper. ...	Whole Life Review	I smile Я heart pen eye Ψ thumbs up left arrow right arrow circular arrow circular arrow circular arrow candle

John's Evaluation Sheet for his Closure Session LRS.14 and his
Narrative Writing Opportunity NWO.13



Registered charity No. 1126739

The Assert Programme
Evaluation Sheet
Life Review Session 14
(Closure session)

Name: John

Session: LRS.14

I found the closure session helpful* unhelpful* not sure*
because:

[John was not invited to evaluate this session.]

Narrative Writing Opportunity NWO.13

I found my narrative writing worthwhile* ~~not worthwhile*~~ ~~not sure*~~
because:

*Writing this brief "whole life review" has given me reason to
believe that I'm not entirely the 'waste of time' I've always
considered myself to be. All in all, not so bad.*

**Please delete as appropriate*

John's Reminiscence Prompt Sheet for his Caring Phase (50-55 years) (LRS.11(b))



Registered charity No. 1126739

The Assert Programme
Life Review Session 11(b)

**Reminiscence prompt sheet for my
Caring Phase (50-55 years)**

Name *John*

Date **.**.07*

Let your mind focus on a phase of your life you would like to review and reflect upon and then pause for a few moments. When you're ready, see if you can spend a few minutes jotting down whatever thoughts, feelings, memories or impressions come into your mind.

If something else occurs to you about another phase of your life as you're thinking about this one, jot that down too. And don't feel you have to 'tidy up' - the jottings can be in any order.

Total changes – emotionally and financially crippling.

.....

Why did I do it?

.....

Semi-retirement, as it were, appealed to me, though I did take caring

.....

very seriously.

.....

Did all the right things and fought every battle as hard as I could, and

.....

often succeeded where others would have failed.

.....

Our next session is two weeks from now, on at pm.
Before this next session you have an opportunity to write about the phase of your life that you reviewed today if you would like to do so. A Narrative Writing Opportunity prompt sheet is attached as a guide.

**Examples of John's Accordant-Discordant (⊕) and
Opposing/Contradictory (⊗) Responses**

LRS No	Phase	Texttract Ref	CA coding	John's Statement	Researcher's Observation
1. Care has a cost – “not that I’m conscious about” changed to “it destroys you”					
1	↻	J1/6/7		J: ... Everything was done for his benefit.	John's biographical reflective focus is not on himself but on his father at first. As he reflects on his own life he begins to consider his current status and then concedes there was a cost in caring. This is a shift in his biographical reflective focus. He becomes aware of the emotional cost. Someone who had not been a carer themselves may have accepted his statement ‘not that I’m conscious about’ at face value.
		J1/6/8		C: Mmm. But that has a cost ...?	
		J1/6/9	⊕ ⊗	J: Not that you’re conscious about – not that I’m conscious about.	
		J1/7/12	⊕ ⊗	J: ... but you don’t recover immediately. I don’t know that you recover.	
11(b)	↻	J11(b)/4/2	⊕ ⊗	J: But it did cost a lot.	
		J11(b)/7/8		J: You’re suddenly a pauper	
13	↻	J13/1/4	⊕ ⊗	J: It destroys you emotionally and pretty much financially.	
2. Feeling bitter – denial changed to acknowledgement later in the same session					
11(b)	↻	J11(b)/4/5		C: Does it make you feel bitter ...?	John evades answering the question at first, then later in the same session he admits to having felt bitter. When feeling less bitter, John recognises it. A shift in his biographical focus.
		J11(b)/4/6	⊕ ⊗	J: Against whom? ...	
		J11(b)/13/4	⊕ ⊗	J: I’m not as bitter as I – I used to be fairly bitter about things; whether it’s the Assert programme, whether it’s just time but I’m not as bitter about things as I used to be. ... I don’t need to be because I’m not in that situation any longer.	
3. “It was my own decision” to care changed to “I don’t think I had a choice”					
1	↻	J1/7/6		J: ... the decisions were my pills ...	Initially John insists it was his decision to care but later in the programme concedes that he had little choice in the matter. A shift in his biographical reflective focus.
11(b)	↻	J11(b)/4/6	⊕ ⊗	J: ... it was my own decision. I didn’t have to get caught up in it. I wasn’t forced into it. I didn’t have to do it.	
13	↻	J13/5/8	⊕	J: ... I don’t think I had a choice but I did it.	

Memory Deficit

[Sources: Wilson 2009; Fleming, *et al.* 2005; Kopelman 2002; Atkinson, *et al.* 1990].

Retrospective memory refers to things that have already occurred, past events, incidents and other experiences.

Retrograde amnesia refers to impaired recall of events that took place before any insult to the brain. It is usually considered to be a failure of the ability to retrieve the information rather than a true loss of that information.

Prospective memory refers to the ability to do things in the future such as posting a letter or paying a bill at a particular time, tasks which require an element of motivation and strategy.

Anterograde amnesia refers to memory difficulties that follow an insult to the brain.

Wilson (2009, p1) defines memory for the layman as “the ability to take in, store and retrieve information”. There are two main memory systems: the short term memory store (STM) where information is held for only a few seconds and the long-term memory store (LTM) where information can be held from a few minutes to decades. The LTM is durable with a large and possibly unlimited capacity. The means by which information is retained for a few minutes seems to be essentially the same as that by which it is remembered for years. The LTM encodes information primarily by meaning and part of this system is the episodic memory which enables an individual to recall past experiences or to “time travel” (Wilson 2009, p5). It is this system that is typically affected in people with memory impairments. They may have a relatively normal immediate memory but after a delay or distraction the information is lost.

Most people with memory problems have episodic memory deficits, this being their major handicap in everyday life. Episodic memory problems and semantic problems result from deficits in their LTM. Someone with the classic amnesic syndrome will have no trouble defining words or recalling facts from their fund of general knowledge but it may be difficult for them to lay down new facts because they have to depend initially on their episodic memory in order for new information to enter their semantic store. Most memory-impaired people have a normal semantic memory which stores general knowledge, information about what things mean, look like, sound like, smell like and feel like, the appearance of things, such as the colour of a banana, the capital of Egypt; whether a hippopotamus is larger or smaller than a dog and meanings of words like ‘justice’ (Wilson 2009, p5).

There is increasing evidence that rehabilitation can improve the independence and quality of life of memory-impaired people, especially rehabilitation of those with episodic memory deficits (Wilson 2009).



Registered charity No. 1126739

Extract from John's Feedback on his Assert Outlook/Inlook Action Plan for Change

'OUTLOOK'	'INLOOK'
<p>(Attitudes towards my situation, my world 'out there')</p> <p>Aspects of my life I want to change:</p> <p>My chosen Aspects of Life were as follows: <i>Leisure 4.5; Future 5.0; Relaxation 4.5; Health 4.0; Home 4.0; Security 4.5; Money/Security 4.0; Romance 5.0; Love 5.0; Work 5.0; Quality of Life 5.0.</i></p>	<p>(Attitudes towards myself, my inner world)</p> <p>Aspects in myself I want to change:</p> <p>I would describe myself as a <i>glass half-empty person</i></p> <p>I want to become more <i>optimistic about the future.</i></p>
<p>Since starting the Assert programme:</p> <p>(3) I'm thinking about <i>my retirement.</i></p> <p>(4) I'm starting to <i>plan ahead.</i></p> <p>(3) I want to <i>be in charge of my life.</i></p> <p>I think my attitude towards my situation, my world 'out there', has changed in the following way:</p> <p><i>Since starting the Assert programme I have visited my GP for the first time in more than ten years for a health check up. All ok. I value my health more.</i></p> <p><i>I'm starting to plan ahead for my retirement. I want to look forward to whatever the future brings me.</i></p> <p><i>I don't have a sense of foreboding although I still worry about the future. I'm more hopeful. .</i></p>	<p>How I considered making these changes happen:</p> <p>(4) Being less <i>controlled and guarded</i></p> <p>for example when <i>I feel affronted to say so.</i></p> <p>(5) Being more <i>true to myself</i></p> <p>for example when <i>I lack confidence in company don't play the fool to over-compensate.</i></p> <p>(6) Risking <i>not making out I'm happy when I'm not.</i></p> <p>for example when <i>I feel upset.</i></p> <p>I think my attitude towards myself and my inner world has changed in the following way:</p> <p><i>I'm happier. I feel less angry and am less argumentative.</i></p> <p><i>I realise most of my problems are of my own making.</i></p> <p><i>I regard myself as a better person.</i></p>