



The Comfort Cookbook

**African and Caribbean recipes
for those in care towards the end of life**

**A coproduced community book by
Jenny Baverstock, Karla Buck,
Anne Cato, Gabriel Galvez-Prado,
Jennifer Gordon, Lucy Green,
Jane Lavery, Marion Tasker, Jessica Teeling**



**Illustrated by
Karla Buck**



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‘Here’s a recipe book to be used and shared, celebrating African and Caribbean food throughout our lives, including at the end of life. Karla’s drawings are beautiful. I believe the community will take pride in the recipe book, and I am proud to be a part of it. It is also a good reminder that food not only nurtures us; its flavours, aromas, and textures deeply connect us to the world we belong to, reminding us of the community we are a part of.’

Gabriel Galvez-Prado

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Introduction

'I feel that this project is needed now more than ever. For a community as diverse as ours the food provided by hospitals and care homes does not reflect the cultural, religious and individual needs of society.'

Karla Buck



*The Comfort Cookbook: African and Caribbean** recipes for those in care towards the end of life was coproduced by an African and Caribbean community living in Southampton with support from academics from the University of Southampton (*see page 43).

This book is inspired by an event we cocreated to explore this community's experiences of inequalities and issues of trust in the British healthcare system, and their experiences and views of end of life care for their friends and families in hospitals or care settings. All the participants saw drafts of the book and suggested changes.

We met in the church hall of the New Testament Church of God in St Denys on September 16th, 2023. To begin with, community lead and professional dancer Gabriel Galvez-Prado from Mexico showed his short film 'Building Bridges' - a moving choreography of loss, pain and reconciliation in honour of his mother, who received palliative care and passed away in a hospital in Mexico during the COVID-19 restrictions.

Participants then took part in the creation of a 'life and death' triptych artwork led by artists Marion Tasker and Karla Buck. Here we all talked about how food and recipes can help people to explore feelings of loss and grief, and to share experiences at end of life.

We had moving conversations about the loss of loved ones in hospitals. The community shared perspectives and experiences of getting support and care at the end of life in hospitals. Some experiences were positive and some much less so. We discussed what the community thought the best end of life care looked like: Is it at home? Is it led by community carers? Or is it hospice care?

‘Spending a day with this community was joyful and sad at times. They generously shared food, stories and insights into their culture.’

Marion Tasker

The community shared experiences of poor communication and lack of trust in healthcare services, including experiences of racism. They also discussed problems experienced with healthcare services.

We ate delicious African and Caribbean food made by Knolburn, Jenny and Joel Gordon. We talked about values of sharing, and supporting and caring for others. We discussed the importance of healthy and nurturing food choices, the joys of food, cooking, and sharing of recipes with families.

For the community, food is deeply connected to pride in cultural heritage, values and care giving. Food is part of death and burial rituals in helping people to talk about death, grief, and to celebrate life and commemorate loved ones. People spoke about their cultural pride and differences of providing care for others in their country of origin compared with the UK.

The community shared stories of food, recipes and cooking. They spoke of how comforting and healthy African and Caribbean food, made by the community, can help loved ones who are reaching end of life to have the best possible experiences, at home or in hospital.

Our book does not cover all African and Caribbean recipes. It is not a traditional recipe book. It comes from a community group, and captures their experiences and issues of trust in healthcare settings at the end of life, and their reflections on death, dying, pride in heritage, food and cooking. The book is interleaved with some recipes which they cook, photos and illustrations.

The book also provides recommendations by this community about how they and their loved ones would like to be looked after and treated in hospital and care settings.

The community event: art engagement



The 'life and death' triptych and Marion Tasker



Karla Buck in action



Watching 'Building Bridges': film by Gabriel Galvez-Prado (right)

Acknowledgements

Anne Cato, Karla Buck, Gabriel Galvez-Prado and 15 members of an African and Caribbean community from Southampton shared their voices at the St Denys New Testament Church of God church hall, and made it a great success.

Karla Buck, Gabriel Galvez-Prado and Marion Tasker were the creative force in the project.

Our book captures the community discussions as anonymous word-for-word quotes, interleaved with recipes from participants and illustrations by Karla Buck (some created on the day).

Knolburn (Nobby), Jenny and Joel Gordon prepared the delicious food that we ate.

Photos taken during the community event and biographical details are included with the consent of participants.

Our thanks to Mountbatten Hospice and all who took part in the scoping workshop that led up to this event.

We thank Don John, founder of Black History Month South, for his invaluable etymological insights and broader support of the project.

The project was funded by the University of Southampton ('Places and Inequalities' Sandpit). The project was co-led by Professor Lucy Green (Faculty of Medicine), Dr Jane Lavery (Faculty of Arts and Humanities, Languages Cultures and Linguistics), Dr Jenny Baverstock and Professor Jessica Teeling (Faculty of Environmental and Life Sciences).



A selection of African and Caribbean food

'I bought all these things today to show how easy it is to find simple staple foods to provide for us. [...] There's no reason why the NHS care homes and people coming into the homes cannot be preparing culturally suitable foods.'

Family and friends at the heart

‘When working, we need somebody else to take care of our loved ones. But if it was in Africa, we don’t do this because the family is very big and we take care of each other. We allow each other to take care of that person at home.’

‘In fact, it is disrespectful to send your loved one into a care home. It means you’ve abandoned them. You know? They looked after you when you were born. They fed you, they clothed you and now when you are ready, you have shipped them off. They don’t like that. It’s seen as shameful in our community.’

‘I would like to be at home with my family and friends. I love laughter. Make sure you come to see me and make me happy. When I am dead, I want everyone to sing well.’

I would like to be at home with my family and friends...

‘Being around the person and people in birth and death is a huge thing [in African culture] and being with the person who is dying is important as it allows the person to go peacefully. In the Caribbean community, it is believed that the dead do not go. They are still around and people come to visit to pay their respects, and people are respected even in death. There is also that fear that when we come into the hospital and they say go home at 8 o’clock, what if they are ready to go? We need to be able to say our last words and what if this happens after 8?’



‘You could see cancer moving from one part of her body; it was like a crab. Mum made us laugh even at the time of death so you didn’t feel bad when she actually went. She could help you with the experience and she tells us what she wanted.’



‘We don't have many relatives around. [...] we still have to go to work to get money. To pay bills. So that is a barrier on its own from taking care of our relatives.’

‘You've got the boldness to take your mum to a care home, a stranger to look after your mum. How does that make you feel? So there's also guilt, you know, and you feel obliged that it is your responsibility as a child or family to look after your loved ones, regardless of your position in life.’

‘Life is intergenerational from the moment you're born. You grew up in a house with your grandparents, your uncle, your aunt, your parents, your cousins - all live in the same house. So looking after the elderly, that's why you were born, to look after your parents.’

More information

‘Part of the issue here [UK] is that we do not know what kind of treatment is available, what kind of help is available, even like the home healthcare nurses. We've got neighbours in the community here, I see them (nurses) going in and out of homes and I wonder how come that lady there isn't getting the help?’

‘Nurses or whoever's taking care of people know that it's their responsibility to let people know about the choices that we might have.’

‘What needs to be available, what needs to be known, for the Caribbean community is that these services are there, and that when people come to your home, they will enable you to stay at home.’

‘Most black people fight to stay at home even when they are very ill. But the support systems are not known.’



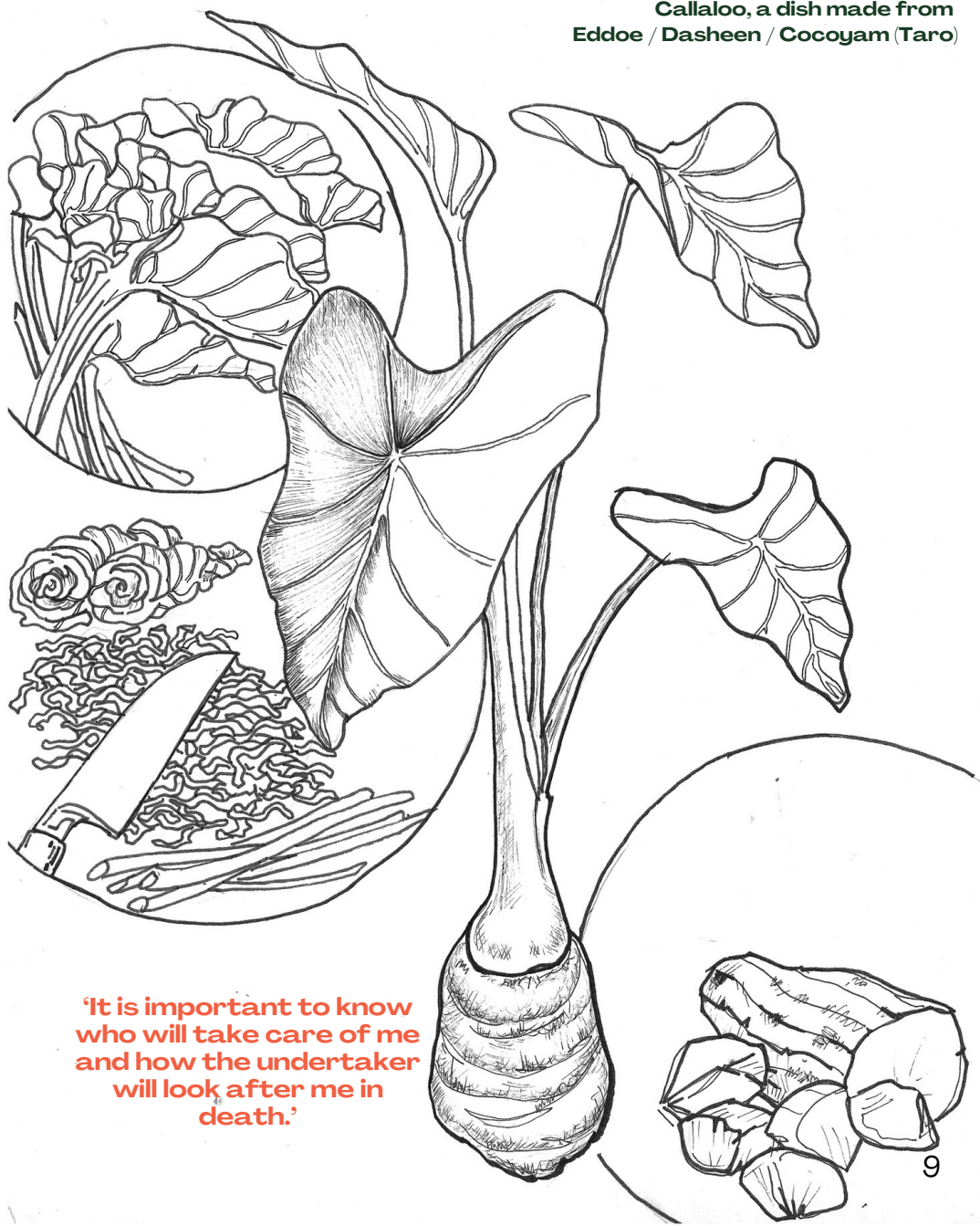
'We don't want to say that we don't want the hospice, but the best place for somebody is home.'

Jamaican
Rice and Peas

'We were all in this side room with our relative and the nurses had placed a radio in there for her. When we went in, they turned it off and, we were singing and we were singing hymns too. You know, we knew that for the grandchildren and the great grandchildren this was probably going to be the last time they'd see her. We raised the roof. We were told that this was going to happen so people could come. You should ask. Some people can do this.'

'I'd like to be treated with dignity. Everyone in this world has different customs, a different culture. That is what needs to be taken on board. Don't just wipe things under the carpet because it's different for you.'

**Callaloo, a dish made from
Eddoe / Dasheen / Cocoyam (Taro)**



**'It is important to know
who will take care of me
and how the undertaker
will look after me in
death.'**

Poor experiences and trust

'It's not until I came to England I realised, ooh I'm a different colour. You know, I was nursing and this African girl, we were given certain patients to look after. You were told to look after this side, that side. This African girl was given a white woman to look after. She had a stroke, but she didn't want that black person to touch her. So she called me over, and she said, 'you're not too bad, you're not as black as her'.'

'I can't say I've had a bad experience in the hospital and have been going to hospital for the last 11 years.'

'Now, before she went into the coma, we would collect my two sisters every day and we would go to visit my mum. And when we go to the hospital, why would I be thinking she's not being fed? She's in the hospital. You feed people in hospital [...] How can she eat if she cannot feed herself? And my cousin said to them, please go and get something and give it to my aunt to eat. That really shocked me. And after that, when my mum died, not so long after, what came to me is that she was starved to death because they were not feeding her.'

'So my son will tell you, my mum will starve to death if you put her in a care home. She won't have anything. So they'd rather look after me in my own house.'

'I think maybe she could have lasted a bit longer had she been at home, or had she been fed properly.'

'So I have no love for the system. No, not at all.'



Cassava

‘When my dad died, the people that were looking after him couldn’t even look at me. They would avoid me when they saw me on the ward. And that’s doctors and consultants! They ignored me because they didn’t know what to say and they didn’t want to say it. It would have been better if they said sorry your dad passed. It didn’t make a nice environment.’

‘In the country where I’m from, we don’t go to hospital. Hospital is the last place we want to go to when we are sick because of the horrible things you can imagine. So it’s better to stay at home and get treated. It’s always been this history [in the country I’m from].’

‘I’m fortunate. I always see myself as blessed because at least I’m here in the UK. [Because of experiences in hospitals where I am from...] When I go in I am always judging what’s gonna happen. How I’m being treated.’

They were not feeding her at hospital, and she died.

‘Every time I step into a hospital I already have a prejudged relationship with doctors and hospital. I’m always on high alert and I don’t trust them. My aunt was mistreated so badly and it’s just destroyed my trust in going into hospital. I was the first child to be born in hospital and I was out in hours because they thought I was gonna die in there.’

‘My sister was at hospital. They were not feeding her at hospital, and she died. They never told us that she was dying. They hadn’t called us or tell us anything. This was very traumatic. And these are memories that last forever.’

‘I learned that there was a process at the hospital where they don’t tell you that she’s going to die, which is, I don’t know if it’s still called that. It’s called the Liverpool Pathway*. [...] she was in a lot of pain and they couldn’t give her a medication to help with the pain even though they had the medication. [...] But I think also we have an opportunity now to maybe challenge some of these systems.’

**Note: phased out in 2013*

Cultural needs, dignity and respect

'I want somebody who looks like me, who can actually identify with my culture, and who can prepare the food that I want.'

'They can offer different foods for other nationalities, but they just don't put us in that equation.'

'When you are ill they put you in care. But it's different for us. For us the State and everyone needs to know our culture and how we are. We are not aggressive. We speak differently. We eat differently. And we get excited. And we are animated a lot, so it's not aggression, it is a way of life. I think when we are loud and we are excited, they think it is aggression.'

'And staff within the different healthcare situations need to know the cultural norms of people they care for. They need to know what should be done, how to communicate with the family. I think it should be an integral part of the training for staff and carers. For other cultures they have notes and their rules about how they have to be followed.'

'I'm saying if he's in the side room and we could stay there, we would see him more happier.'



'If it comes to end of life and I can't get home, if I was in hospital, I want to be in a side room where my family can come and visit and spend time with me. I would want someone of my own colour doing the primary care, because I want them to do my hair, wash it, and make me look presentable. I want to feel comfortable.'

'I would prefer to stay home. And my family can choose for a carer to be coming home and look after me if it is possible.'

... people will feel better if they have the dignity of being in the side room.

'If you die in the hospital, I think people will feel better if they have the dignity of being in the side room, you know, people can go and see you. Their families can go and sit with them. And I think if the hospital did that, and supported us or give us more support, then we would be, I suppose, more happier to be dying in hospital. I've also been a carer and to see someone at end of life and looking after them, it's quite hard.'

'If it's the last few days, I want a side room where my family can come and see me. I have had family that died and they'd only allow one or two people at the bed side. When someone like us is in hospital, family and friends come literally everyday and they think it's a bit of a bother that people are like taking over the hospital. So if you are in a side room, then at least they could come there and they could have a little thing together.'

'When I was home after surgery, I was washed by my daughter-in-law before she went to work. How lucky I am. She moisturised me. My granddaughter wanted to do it and she was teaching her. If I was aware I would like to be in a side room because people can come and go. And if you talk to ward staff and explain the situation, they should understand. I don't know what's changed but you used to be able to do this in the past. I know people who are doing shift work and want to come in after eight. That's ok, come in, as long as not all together. Visit them for a couple of hours and leave. I think when there used to be Matrons on the ward things were totally different.'



'We are people, not just black people. I'm talking about the human race. I started nursing in '75 but I gave it up because it wasn't for me. Then there were times when you had time to talk to the patients, but now everyone sits in front of the computer screen and on the telephone, and the patients don't have that now. They don't communicate with them. So we need to take more care of our patients and be more sensitive to their needs. Each is an individual. There are some who like to talk. There are some who like to be peaceful. So we need to look at these things.'

**We are people, not just black people.
I'm talking about the human race.**

'We would appreciate if the government would, just as science and technology are, look into different cultures. They may not be able to meet everybody's needs but at least, let there be a choice. And if someone is admitted in hospital, the family shouldn't be limited to certain times to go and visit, because they trust their families. For example, [name of loved one] was not eating at the hospital. If her family was allowed to come in and care for her, in the hospital, you will see that [loved one's name] will be eating food. So yeah, we're very, very family oriented.'

'I would like to be given the choice and if I cannot talk then my close family can choose for me.'

'I speak for Africans as a whole and as an individual. We are very family orientated so even for end of life we would still like our family to play a major role and we want to be at home. I'd like my traditional food. My husband made the effort to bring me traditional food to hospital. If it's end of life and I'm at home, I'd get this at home. Family is very important at that stage.'

The community event: Nobby's delicious food

'We want to have the voice sometimes to say a few things which includes our culture. It is very important to us and trust [in end of life].'



Food at the end of life

‘All I would wish for is if I got placed into a care home and I'm treated well there, where they understand culture and respect that there are certain foods I don't like and not to put it on the plate. I'd also like them to be able to understand a bit of my culture. So talk to my family. Don't just ignore it. If I was in hospital, I don't want to be like my uncle was at one stage, not being fed, because they claim that he was knocking food away where he was starving.’

‘The complicated food, they don't have to try and put it in their menu [in hospitals]. They can try little simple ones, like porridge.’

‘Sometimes you're so ill you can't even swallow.’

‘[In hospital] I was taking him mashed pumpkin and sweet potato, mashed with butter, 'cos he couldn't eat properly – and I take that every single day for him, and he'd love it.’

‘You want broth.’

‘In many Caribbean countries we celebrate the ‘nine night’ when the soul leaves the body. So we have a big celebration with mannish water and we have fried fish and bread and also curry goat sometimes, rather than the mannish water.’

‘Food is a symbolic interaction. In any way we see it in [African Country]. I was just saying to them, for us this is like a drink. It's a vegetable. It's a dream. We wash [people's bodies] when you die, we wash your feet with sorrow because it's seen as a delicate flower, the hibiscus, and the smell, it cleanses you in death. [...] In fact, when you die, people come visit you. To pay their lasting statement, bring tokens [...] they'll buy a cow, or a goat, chicken, a bag of rice. [...] In the UK we'll give flowers and a card. I mean you'll be looked at strangely if you come to a funeral just holding a card – we respect the dead and you'll bring a cow or goat. You know, cook good food, make sacrifices and we pay gestures to the community for this person that's passed, and depending on their age.’



'In many Caribbean countries when someone dies we don't put on the Celebration of Life announcement or anything like born and died. We use sunrise and sunset.'

'I want to be treated with dignity and respect. Most family have died back in the West Indies and we have not had many of them die here. We watched my father's funeral online. He was not done right and we complained to the undertaker. I said to my daughter please put me away nicely (i.e. after death).'

'In Africa, everybody shares in the grief. The kids come to funerals and they are involved with everything and [even] in the lead up to death. Everybody shares the grief. The community comes round. We celebrate every anniversary. You remember them and continue in their spirit.'

I want to be treated with dignity and respect.

'One of my English friends came to the funeral and recorded videos. He thought it was morbid at first. He went to work on the Monday, and when talking to work colleagues he slipped up, saying he'd been to a beautiful wedding instead of a funeral! There was every kind of food you could think about, soft drinks and alcoholic drinks and people were dancing and playing dominoes and playing cards, you know. Its a funeral not a wedding! That is something we do. We celebrate everything.'

'The undertaker wasn't aware until my cousin started using the shovel and the undertaker asked me why, and I told him we bury our own dead. The grave digger doesn't do it, we put the soil in and arrange the flowers and the grave. We sing for ages. He made notes of that. A lot of our system and our culture is totally different to what the English understand. I think that because so many black people now have died, a lot of the white undertakers know it and they know that they don't interfere with the grave site.'



Anne Cato - Kenya

Favourite food: Spicy stew eaten with chapati or ughali; roast goat meat cooked on charcoal – barbeque (Nyama Choma); Maize porridge for breakfast.

'I came to the UK from Kenya in 1972. I trained as a nurse and worked as a nurse for one year. I then went on to do my midwifery training and worked as a midwife for many years. I became a midwife practice educator. I then went on to do a Master's degree in Health Education/Promotion at the University of Southampton. I carried on working as midwifery practice Educator, part seconded by University and part employed by University Hospital Southampton. I retired 7 years ago. I do voluntary work with people with mental health issues. I am also a member of an African and Caribbean club. Within the University Hospital Southampton, I was very active in influencing equal opportunities for all and worked with the HR department.

Conversations about end of life are a very important topic to me. It is something that some black people avoid talking about because sometimes it is seen as a bad omen to talk about death. My feeling is that we need to encourage our communities to talk about death and also plan for death because we all will die one day.'



'The community come together when someone is sick or during death. You never feel alone. There is always someone knocking at the door so you never feel isolated. People offer help and support to the carer when someone is sick.'

'People show genuine kindness and love. Those who don't have things can knock at the door and say, "I am hungry," and you give them food.'



'What I loved most during my youth was that although some people did not have much there was lots of happiness. We played together with the children of the village I belonged to. We loved walking to school together sometimes for a few miles but it was fun. Everyone just seemed to get on well with each other. No appointments to visit each other was required, you just turned up.'



'Once we had enough food we were happy. The upbringing was disciplined. From an early age you were taught to respect and care for old people. Things may have changed now but those are the things I value about my heritage. Love! Education was also important.'

Maize Porridge

‘Simple recipe for those who are unwell and need energy!’
- Anne Cato

Ingredients

6 heaped tbsp

maize flour

2 cups cold

water (add extra

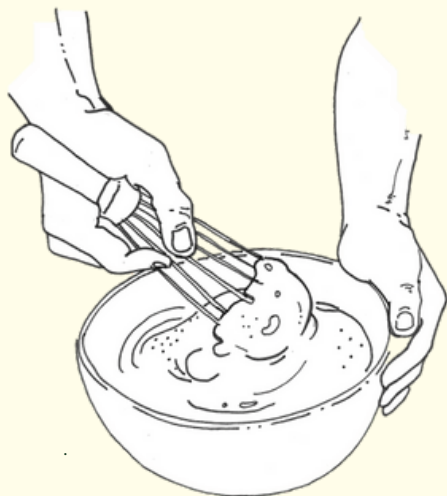
if too thick)

100 mls milk

2 tbsp sugar

- 1** Put cold water in the pan and place the pot on the fire
- 2** Add maize flour slowly and continue stirring slowly until the porridge gets to medium thickness
- 3** Once the porridge begins to boil, turn the fire right down and cover. Continue cooking for another 15 minutes stirring on and off
- 4** Put in a bowl, and add milk and sugar
- 5** Eat with a spoon or feed your sick person with a spoon. It is digestible and gives you lots of energy. Some people prefer this in a cup and drink it from a cup

Anne said: ‘Different tribes in Kenya may cook this differently. I am from Embu tribe. My mother used to feed us with this when we were sick. Some people squeeze lemon to the porridge.’



Full of carbs for energy!
Maize flour is usually
fortified with vitamins
and minerals too



Len Cato - Trinidad

Favourite food: Jerk chicken, salads, rice and peas and nice lamb curry, fish, prawns and many others. Things I associate with this food is my growing up. There was always nice food, especially fish caught from the sea the same day.

‘I came from Trinidad at the age of 16 to join my parents. I went to college and completed college. After that I worked with an insurance company. Finally, I trained as a social worker and became a probation officer. I worked as a probation officer until I retired.

The reason why I participated in the community event is because the subject itself interested me and I wanted to find out what it was all about. I also knew Gabriel was going to talk about his experience about the loss of his mum. Black people don’t really talk about death and dying much. Also, food is key to all the celebrations, birthdays, weddings, funerals, celebrating the birth of a child etc. My recipe is from Trinidad.’



‘A sense of belonging, family, friends and food, and togetherness are things I most value about my cultural heritage.’



**Jerk chicken, rice and peas
and more...**

Trinidadian Tomato and Onion Salad

‘Food is key to all the celebrations, birthdays, weddings, funerals, celebrating the birth of a child.’

- Len Cato

Ingredients

3 tbsp olive oil
2 tbsp lime juice
2 tsp finely
chopped parsley
1 tsp salt
1 tsp sugar
1 tsp black pepper
1 lb firm/ripe
tomatoes, thinly
sliced
 $\frac{3}{4}$ cup onion thinly
sliced

- 1** Blend the oil, lime, parsley, salt, black pepper well to make a dressing
- 2** Place a layer of sliced tomato in a dish, then a layer of onion and add a teaspoon of dressing
- 3** Repeat layers until all the ingredients are used up. Chill until ready to use

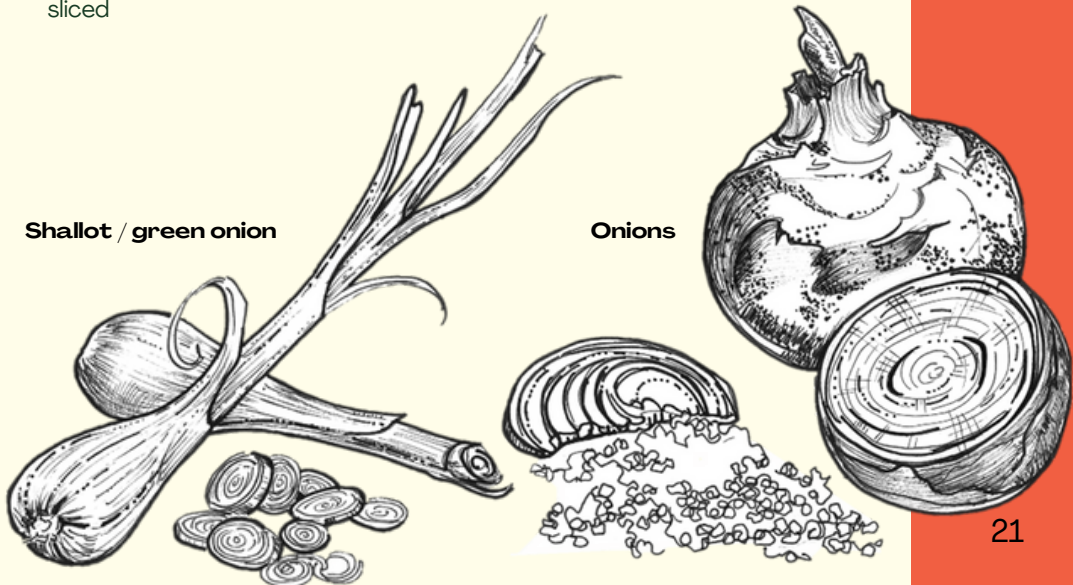
Len said: ‘Sit and enjoy - delicious!’.

Tomato is a great source of vitamin A and antioxidant lycopene



Shallot / green onion

Onions



Jennifer Gordon

- Trinidad

Favourite food: Pilau Trinidadian style. If I know I'm dying, it will be my last wish. Other than that, I am quite happy with Caribbean food. Pilau rice can be cooked at burials.

'I am an entrepreneur in the catering business. I took part in the community event because I believe it is important to be heard and that it is important for me to be catered for while in hospital with meals I'm familiar with.'



'Extended family, keeping the family together, and plenty of love and laughter are things I most value about my cultural heritage.'



Ripe plantain



Green banana

Pilau

Trinidadian style

‘A dish that can be made at wakes.’

- Jennifer Gordon

Ingredients

Brown sugar
Chicken for stew,
cut and seasoned
(green seasoning)
1½ cups uncooked
rice (washed)
1 cup coconut milk
1 cup pigeon peas
2 cups chopped
pumpkin
1 bay leaf
2 tsp chopped
onion
Salt & black
pepper to taste
Water
1 scotch bonnet
pepper
Thyme

- 1** Wash the chicken with some vinegar / lime and some water, then leave it to drain off onto a plate
- 2** Season the chicken with salt, black pepper or all purpose seasoning and garlic. This can be left in the fridge over night or for a couple of hours
- 3** In a heavy pot, cook the sugar over medium heat until it begins to caramelise (dark brown colour)
- 4** Add the chicken, and cook until browned and add the onions, coconut milk, and some water
- 5** Add your pigeon peas, garlic, the bonnet pepper. Add salt and pepper to taste
- 6** You can leave 12 minutes to cook then you can add your rice. Leave until it is tender then it is ready to eat



**Jennifer with
Pilau Rice dish**

Great protein source. Pumpkin is a high source of vitamin A. Lots of fibre!



Nobby Gordon

- Jamaica

Favourite food: Chicken Curry from Jamaica, in the Caribbean.

'I am a retired restaurant owner and part-time cook. I took part in the community event because I am interested in conversations about end of life. I was interested to find out more about the requirements around the end of life.'

✦ ✦ ✦
'The food, the music like reggae, and the people are things I most value about my cultural heritage.'



Dasheen

Jamaican Chicken Curry

‘Pilau rice can be cooked at wakes.’

- Nobby Gordon

Ingredients

Chicken
Ginger
Garlic
Turmeric
Onions
Tomatoes
Sweet peppers
Black pepper
Salt
Any vegetable
that you like

- 1** First season the chicken with chicken all-purpose seasoning, garlic, black pepper, salt and the curry powder. Marinate for around 4 hours or over night in the fridge. Make sure not to add too much extra salt as the marinade is already salty
- 2** Heat a heavy bottom pot with a little oil. Add curry powder, ginger, garlic and turmeric and cook to a golden brown
- 3** Add the chicken. Stir constantly to incorporate flavours and colour into the chicken
- 4** Add the stock/water, cover and continue cooking
- 5** Just half way through then you can add the onions, tomatoes and sweet pepper
- 6** Simmer down until all the vegetables are well cooked



Garlic

Fab recipe for adding
to your 5-a-day:
Sweet peppers are a
great source of
vitamin C



Rachel Meadows

- Kenya

Favourite food: Porridge with corn maize and millet or sorghum and Mukimo with chicken. Porridge can be a dish for the dying. Mukimo with chicken is Kenyan and is also made during burials.

‘I am a support worker. I took part in the workshop because it is important to support and learn from each other and maybe to make some changes in the way we look after our beloved ones and hoping these experiences can pass to future generations.’



‘The things that I value most about my cultural heritage is the way we treat our funeral in Kenya. We take the body to church and pray.’

‘Our burials are not private. Usually the whole community come together. The people communicate with each other and agree to meet on that day of the funeral and come together to support the family in anything the family need. For example: financially to pay the hospital bill, to buy the coffin, and also people can volunteer themselves to do anything the family needs.

We communicate through WhatsApp groups for the praying and also to comfort the family as well as supporting them financially.

No one is obliged to do it. There is the belief that if you don’t follow the wish in the way you want to be buried, you might haunt your loved ones or you might bring bad luck.’



**Rachel eating Nobby's
delicious food**

Porridge

‘Dish for the Dying.’

- Rachel Meadows

Millet/sorghum: is a slow release energy food (low GI food), rich in niacin, and contributes to vitamin A and other nutrient needs



Ingredients

Corn maize

Millet or sorghum

Milk

Butter

Peanut butter

(optional to add on top)

- 1** In a bowl mix the corn maize with the millet
- 2** Add some milk to mix the corn maize with the millet to make a smooth paste
- 3** In a separate pan boil milk and, when the milk is warm, add the paste with corn and millet and mix all the ingredients together
- 4** Add butter to your own taste. Also you can add peanut butter

Mukimo with Chicken Stew

‘A dish for the dying and at burials in Kenya.’

- Rachel Meadows

Great contribution to 5-a-day. Frozen peas have higher nutrient content than fresh!



Ingredients

Chicken, lamb or beef

Paprika

Cinnamon

Sweet pepper

Carrots cut into small pieces

Peas fresh / frozen

- 1** First mix the meat with the spices the paprika, cinnamon and sweet pepper and salt
- 2** Next fry the meat in oil until brown
- 3** Cover the meat and vegetables with water until cooked
- 4** Can be served with traditional Kenyan dish Mukimo



Grits

Ugali

Sodza

Roast

Porridge
Cornmeal Pap

Mukimo

‘Food for the ill or dying.’

- Rachel Meadows

Ingredients

Potatoes

Green peas

White corn

Butter or

margarine

Nettles, or spinach

- 1** Boil the potatoes and, when they are soft and well cooked, mash them
- 2** Boil the green peas and the white corn separately
- 3** When all the ingredients are cooked you mix them
- 4** Boil the nettles or spinach, blend them and add to the mix
- 5** Add salt and butter to your taste

Spinach is a superfood!
Rich in folates and iron!



Rachel said: ‘For the ill and dying, you can mix all the ingredients without the corn and mash with a spoon or a fork, and remove the skin from the peas or anything hard to chew. Or you can blend.’



Mukimo at the St Deny's community event

Margaret Martin

- Kenya

Favourite food: 'Usuu' Akamba porridge originates from a Kenyan community in the African continent called the Akamba tribe and is a traditional meal. The Akamba tribe shares these meals with other tribes so as to embrace their culture at large. I associate this meal and recipe with looking after the elderly, the sick, children and expectant mothers.

'I have worked in the health sector as a support worker for 20 years. The reason for taking part in the workshop about trust in end of life care was that we as a black minority suffer in care facilities because the care management and carers don't understand and consider our choices and values in terms of our traditional foods. The black minority feels left out on these and are not given a chance to choose what they want to embrace from their culture.'



'Religious beliefs, my traditional wear, and family bonding/togetherness are what I value the most about my cultural heritage.'



Dasheen



Margaret and Rachel

‘Usuu’, Akamba Porridge

‘Recipe for the elderly, the ill, children and expectant mothers.’
- Margaret Martin

Sardines – great for protein, vitamins B12 and D. High in calcium.
Peanuts are packed full of essential nutrients and fibre



Ingredients

Ground peanuts

Dried ground sardines

Ground millet

Ground wheat

Ground sorghum

Ground white maize

Dried ground cassava

Fresh cow’s milk

- 1** Mix all the dry ingredients to form a uniform mixture
- 2** Fill a sauce pan/sufuria three-quarter full of water and bring to the boil
- 3** Put some cold water a mixing bowl, add the dry mixture and stir gently until it combines. Add it into the boiling water and stir well to form a consistent mixture
- 4** Once the porridge is cooked, remove from the fire. Put in a bowl and add milk and sugar. Serve it warm

Margaret said: ‘1) The elderly – the meal helps them to gain strength and grow healthier in their old age; 2) The sick – helps to boost immunity and appetite; 3) Children – it helps the them to grow stronger, happier and healthier; 4) The expectant mothers – it helps to boost the health of the unborn child and the mother. Helps in boosting the production of nutritious milk production for breast feeding after birth. Helps the mothers to regain their strength after delivery.

The meal is nutritious and can be taken by every member of the family at anytime – once or twice a day, as a breakfast, appetiser or as a long meal.’

‘Sometimes even for lunch, I’ll eat porridge and sometimes in the evening I love porridge. And being in hospital, what’s wrong with giving us porridge?’

Paulette Julius

- Jamaican

Favourite food: Rice and peas with curry goat. The food that I associate with end of life care is a flavoursome soup or broth. It can be wholesome and comforting.

'I came to the UK from Jamaica aged 10 to join my parents. I lived in London for several years, then the family relocated to Southampton. I trained as a nurse and continued to work as such until retirement. I took part in the community event about end of life because I know it's a good thing to do and we can make a difference. We can all learn from each other. I have experiences which I can share. Sharing is good!'



'I am proud to be Jamaican. The things that I value most about my cultural heritage are that we are very friendly people, we are very laid back and vibrant. We look after our elderly relatives.'



Sliced Casava

Chicken / Lamb Broth

‘Can be used for the really sick or for an easy and quick recipe.’

- Paulette Julius

Ingredients

Lamb neck / chicken

Onion, chopped

Thyme

Carrots, chopped

Potatoes - sweet or

otherwise, chopped

Garlic, grated

Chicken or Vegetable

stock

1 Lightly fry the meat with onions and garlic

2 Add the stock and cook until meat is half cooked

3 Add the remainder of ingredients

4 Cook until done

Sweet potatoes and carrots are high in vitamin A. Potatoes provide vitamin C and a number of minerals



Paulette said: ‘You can add a packet of chicken noodle soup to thicken the mix towards the end of cooking. You can also use Grace chicken noodle soup or for a soup without vegetables. This version can be used for the really sick or for an easy and quick recipe. This is a widely used recipe! You can add or remove any vegetable to suit your taste. You can also add scotch bonnet pepper whole, just for flavour.’



Evelyn Bent - Jamaica

Favourite food: My favorite dish is stew chicken with rice and peas.

‘My mother sent for me to come to England from Jamaica in 1967 when I was 15 years old. I used to watch my grandmother cook. I did this recipe for when my husband became ill following a stroke. I would bring him chicken soup whilst he was in hospital. When he returned home he would have chicken soup at times.’



‘The things that I value most about my cultural heritage are waking up in the morning, seeing the sunshine, the beautiful scenery, and being surrounded by my people.’

Kerwin Rodgers - Saint Vincent & the Grenadines

Favourite food: Escovitch fish and fried bakes (dumplings). It is a marvellous dish seasoned with onions, garlic, carrots, peppers, and spices. It is then fried slowly in a saucepan on moderate heat. It is garnished with parsley and steeped in white vinegar.



‘The things that I value most about my cultural heritage are my pluralistic ancestral bloodlines. African, East Indian, Portuguese, and Scottish/Welsh bloodlines. The different food that was always cooked in our household and the music from all four ancestors.’



Chicken Soup

Evelyn Bent

Yams are packed with vitamins and fibre. Parsnip is great for folate



Ingredients

5 chicken wings/ pieces	4 carrots peeled/chopped
4 medium potatoes or 1 medium sweet potato, chopped	1/2 medium swede, peeled /diced
1 slice pumpkin	1 large parsnip chopped
1/2 chow chow (Christophine / Chayote)	1 pkt chicken noodles/cock soup
4 pieces of a medium yam	1/2 large leek, chopped
	1/2 tsp salt

- 1** Wash the chicken in a bowl of lemon, lime or vinegar in warm water. Drain and add to a large pan of 3 L boiling water with the salt. Boil for 15 mins
- 2** Add all the vegetables except the leeks. Cover with a lid and simmer for 45 mins
- 3** Add the chopped leek and noodle soup. Leave to simmer for further 10 mins

Caribbean Fish Soup

Kerwin Rodgers

Four of your 5-a -day!



Ingredients

12 oz filleted white fish, chopped	1 bay leaf
12 large cooked prawns	2 chive blades
2 onions, chopped	1 piece root garlic (chop)
2 large tomatoes, skinned & peeled (can use tinned tomatoes)	1 tsp all-purpose spice
2 large carrots peeled & sliced	1 sprig thyme
small piece of pumpkin, chopped	Pinch paprika
1 green pepper, chopped	1 tsp salt
1 clove garlic, chopped	1/2 tsp ground black pepper
	3 pt water

- 1** In a large saucepan, bring 2 pt water to boil. Add the fish, all the seasoning and vegetables. Simmer 40 mins
- 2** Add 1 pt of water, prawns, and a knob of butter and simmer for 5-10 mins. For a thicker soup, mix 1 tsp of cornflour with a little water and add to the soup during the last 10 mins

Christine Ddungu

- Grenada

Favourite food: Grenadian chicken stew with mashed potatoes. You need calalu, cabbage, carrots, chive, thyme, garlic, ginger, cloves, turmeric. Not much, just a bit of everything.

'I am an auxiliary nurse. I was born in Grenada and grew up in Trinidad and Tobago. I took part in the community event because I would like to share my experiences of looking after my elderly mother at home. She didn't want to be in hospital because she didn't trust in the hospital despite herself being a nurse. Then I decided to work in the hospital to provide the best care to the elderly.

Working with the elderly people, I learnt how people behave, understand the importance of well-being and listening to what they want to eat. They like to talk about the past. It's important to have supervision when the elderly are in hospitals to make sure the person is eating because I witnessed many times people were not eating because they didn't have the strength to feed themselves.'



'Making the Christmas cake with the whole family and Calypso music are things that I value about my cultural heritage.'

Lawrence Kuria

- Kenya

Favourite food: Ugali. This dish is eaten with meat stew and greens at the side. This dish is from Kenya.

'I work in a warehouse. Having trust in healthcare services is important because it is part of life and I like to support people. I think it is important to support each other. I know how important it is to have good food.'



'The extended family, keeping the family together, and plenty of love and laughter are things I most value about my cultural heritage.'

Cooking food

‘Having my husband at home would have made me feel better. [...] I don't think it was a burden. To see the person he was and to see him like that in hospital was very sad. So if it was me, all the way, I would be at home. If I have family and friends like we have here now, and I knew they were sick and they was at home and there is anything I can do, I will be there [...] **Cooking soup for them** or combing their hair and putting on their night dress. I would be there doing this.’



‘**Broth has popular benefits** [...] whatever meat you choose to put in there. You might put some vegetables and if you want, you can blend it. If not, you can take out all the big lumps.’

‘In many different African countries, and in many different Caribbean countries, we use corn, the **same ingredient, but prepare it in different ways.**’

Food across generations

'The [Mexican] 'Day of the Dead', we call it 'All Souls' [...] The women would prepare all their food and the foods and everything, and we would go to the churchyard or the cemetery and light the candles. We spend about two or three hours there and, you know, the elders would do things and say things. As a child you didn't take it on board because all you wanted to do was go back home or wherever so we could eat and drink.'

'My grandchildren can cook.'

'[My grandmother], she taught me to cook.'

'My children have always eaten West Indian food. They have English food as well, but they have grown up with it.'

'You see that around you. You're seeing your mother cook for the mother-in-law. The father cooks for the father-in-law.'

'In my case I was allowed in the kitchen. I grew up in a house full of women. The men really were non-existent. You know, when I came to England and my mother was saying you wait until your father come home. It's the mothers, aunts and so on that would chastise you.'

'I used to watch. I never was allowed to cook. [...] I used to sit and watch my grandma cooking dinner [...], you just sit there. We all were able to sit and watch. We're only allowed to do the washing up. We were not allowed near fires.'

'I grew up with an aunt and so [cooking] was something that I just picked up, because I was interested in cooking and food. Where I grew up in [Caribbean country], I taught myself and I'd like to experiment with all different kinds of stuff.'

'We weren't allowed in the kitchen, but then I remember my mum used to bake a lot. Every Saturday, my mum baked bread and cake, and she was always teaching me to do it. When I got married and went off, I was making a thing and she thought that I was thick. You know, it took me forever. One day I managed it and she asked me if I had bought it!'

'When he was about 15, the son, he said, Aunt show me how you brown that chicken? To burn the sugar you put some sugar in the pan with some oil. And you brown the chicken. You know? And then he wanted to know how you make peas and rice. So I'm teaching them to do all these things. The younger generation want to know how to cook.'

'Africans are more family oriented. Even if some of us have come here, and had our children here, our children are British and so is their way of life. But you still find that they know from the conversation with their parents, where they are from and what they like. We like taking care of our own.'

'After the birth of my daughter the hospital treated me as if I had done something wrong. I was on bed rest for a month. With all my dietary requirements the hospital did not provide me with one single meal. My husband would bring thermoses of food in for me.'



‘The nurses are limited in number and so many patients to deal with. If the hospital managers can take it upon themselves that if someone is in end of life, it is very important for the family to be with them. So even if they can’t come home, the family should be given unlimited time to get ourselves to the hospital. They shouldn’t be restricted. If you can’t take them home, take their family to where they are.’

‘The spicy stew with chapati is associated with celebrations. Goat roast meat is also associated with celebrations or when people are relaxing in bars having a drink. It is cooked after funerals for people to sit and enjoy and talk about the person who has died remembering good old days.’

‘She had to go in the home. If the system could have come in and said I could have respite. I didn’t know about that then and no one told us about it so things would have been different – she would have died at home.’

‘Let’s say somebody goes to care or hospice. They ask for the relatives to cook and bring food, and adds even more pressure to the families. So I think these things need to be known: that we need support in this country and now we can’t bring our family here to look after us, because obviously immigration and all that stuff. But people can be supported to be able to care for their loved ones until the last minute.’

‘So when they come here from [the African country] they think, you can’t ask the doctor a question. Then we don’t like being told as well, we don’t like being told something bad is about to happen. To avoid that, we don’t ask the question. So we’re a second generation. We’re changing that now, as I am now in every aspect of my life that I deal with, is actually questioning the status quo. Why aren’t I having this? My mother would not have done the same, my dad cannot do the same. But I think this is where the NHS needs to look at what diversity means for the people.’

What would make a difference to end of life care?



‘Though it's everybody's responsibility to let people know about the choices that we might have, the government don't have capacity. Then it's like they ignore you.’

‘Communication in hospital is very poor and you don't get informed about what is happening.’

‘What we are saying is for the Africans, if you empower the government or NHS, it will empower the family. They will do more than what the NHS is doing.’

‘They should allow the families to play a major role. Because even if the NHS cannot put rice and peas there, that family member who comes in to see his dad will bring him occasionally food he knows – and this is end of life we are talking about.’



Takeaways

Our arts-based approach provided focus, and a positive way to express diverse emotions. It allowed participants to unwind and be more open to share information and discussion.

Different forms of art, in our case a film and an interactive triptych, bring a unique element to knowledge exchange and create a memorable atmosphere.

Traditionally prepared food helped to bring together the workshop participants to share their experiences of care at the end of life. The conversations highlighted how access to food can be unequal and not equitable in care settings, and that culture and food are very important in care at the end of life.

Coproduction of the engagement with academics, artists and community leaders and members was a key strength in provoking and inception of project. The result is this beautiful, illustrated comfort cookbook, that everybody can be proud of.

We will be delighted to share the book with policy makers, and with those working in social care and healthcare. They may draw from these stories and soul food recipes to give the best possible quality of care for patients at end of life from the Caribbean or African community, and build trust within the community.

Links and resources

The decision to use the terms 'African and Caribbean' aligns with current UK practice in acknowledging ethnic and cultural diversity in the Caribbean. While this reflects contemporary terminology, some community members expressed a preference for self-describing as 'Afro-Caribbean' during our discussions.

Priory Road Community Group (Priory Road Luncheon Club)

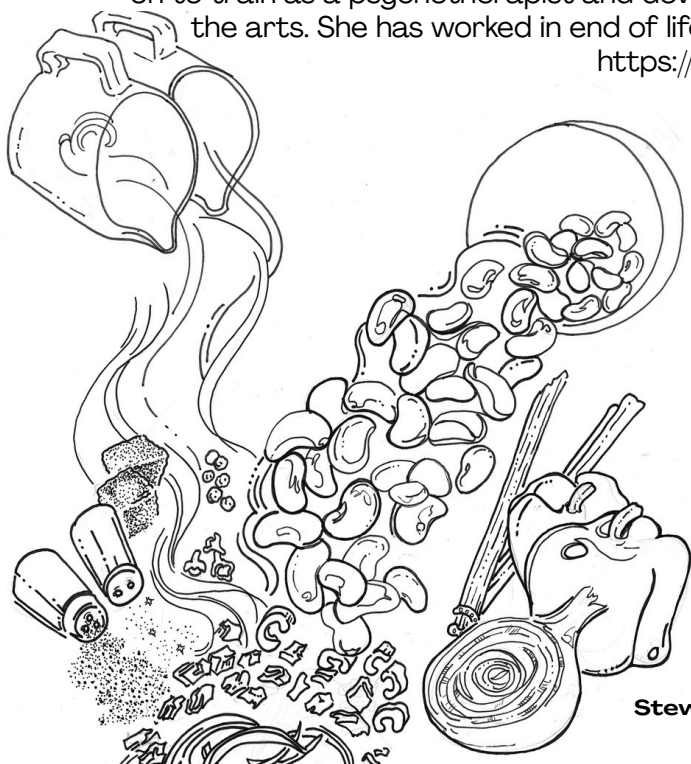
A community group based in St Denys, Southampton. Set up in 2009 to meet the social, cultural, wellbeing and health needs of people over 50. <https://www.facebook.com/groups/prioryroadcommunitygroup>

Gabriel Galvez-Prado is a dancer and choreographer from Mexico, trained in contemporary dance, improvisation, and somatic dance techniques. He holds classes for elderly people and individuals living with Parkinson's. Additionally, he has his own practice, combining dance and film. <https://gabrielgalvezdance.com/home>

Marion Tasker trained as an illustrator and worked in publishing and advertising before volunteering in a south London hospice. She went on to train as a psychotherapist and developed her practice using the arts. She has worked in end of life care for over 29 years. <https://www.mountbatten.org.uk>

This work received ethics approval from The University of Southampton (ERGO 92453).

'I think it's important to have different textured food, not just pureed consistency. Softly mashed pumpkin or sweet potato, variety of foods from their cultural heritage.'



'Food has always been an important factor in the cultural welfare of all communities and recognises the quality of the life lived.'

DON JOHN, Founder Black History Month South



An African and Caribbean community from Southampton
who met at New Testament Church of God church hall

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