

Supplementary Material

Supplementary Table 1: Development of items, with consensus statistics (% agreement)

Item ID	Category	Round 1	Round 2
1	Clinic organisation	<i>(initial item)</i> Consider long covid in patients with a clinical diagnosis of covid-19 as per WHO criteria ¹ or test-positive history with new or fluctuating symptoms including but not limited to breathlessness, chest pain, palpitations, disproportionate tachycardia, wheeze, stridor, urticaria, abdominal pain, diarrhoea, arthralgia, neuralgia, dysphonia, fatigue including neurocognitive fatigue, cognitive impairment, prolonged pyrexia and neuropathy occurring beyond 4 weeks of initial covid-19. 30/33, 91% (consensus)	N/A (consensus achieved in Round 1)
2	Clinic organisation	<i>(initial item)</i> MDT long covid clinics should be led by a consultant from an appropriate specialty such as a medical rehabilitation specialist, respiratory consultant or cardiologist or general medicine. 30/33, 91% (consensus)	<i>(amended item)</i> Multispecialty long covid clinics should be led by a doctor with cross-specialty knowledge and experience of this condition. 32/33, 97% (consensus)
3	Clinic organisation	<i>(initial item)</i> Consider individualised investigations, management and rehabilitation planning via a multispecialty long covid assessment service as local services allow. Prioritise medical assessments and diagnostics initially, and consider physiotherapy and OT input as adjuncts. 32/33, 97% (consensus)	N/A (consensus achieved in Round 1)
4	Clinic organisation	<i>(initial item)</i> It is inappropriate for the long covid clinics to be led by mental health specialists e.g. IAPT, clinical or health psychologist. They may be useful in supporting the MDT team but do not have the expertise to investigate and manage potential organ damage. 33/33, 100% (consensus)	N/A (consensus achieved in Round 1)
5	Clinic organisation	<i>(initial item)</i> All under-18-year-olds need access to similar services run by paediatric specialists with knowledge of how presentations and treatments differ to adults and with close liaison with school. 33/33, 100% (consensus)	N/A (consensus achieved in Round 1)
6	Clinic organisation	<i>(initial item)</i> Patients with comorbid mental health difficulties should have equal access to care as a patient without mental health difficulties and should not be triaged away from services. 33/33, 100% (consensus)	N/A (consensus achieved in Round 1)
7	Diagnosis of underlying disorder (general approach)	N/A (not presented in Round 1)	<i>(added to Round 2)</i> In someone with long covid, symptoms of possible non-covid-19 related issues should be investigated and referred as per local guidelines. Long covid alone is not a sufficient diagnosis unless other causes have been excluded. 31/33, 94% (consensus)
8	Diagnosis of underlying	<i>(initial item)</i> Carry out a face-to-face assessment including a thorough history and	<i>(amended item)</i> Carry out a face-to-face assessment including a thorough history and

	disorder (general approach)	examination, consider other non-covid-related diagnoses and measure FBC, renal function, CRP, LFT, thyroid function, HbA1c, Vitamin D, Magnesium, and B12 in those presenting with symptoms of neuropathies, to exclude other underlying disorders. 33/33, 100% (consensus)	examination, consider other non-covid-19 related diagnoses, and measure FBC, renal function, CRP, LFT, thyroid function, HbA1c, Vitamin D, Magnesium, B12, folate, ferritin and bone studies. 33/33, 100% (consensus)
9	Diagnosis of underlying disorder (respiratory)	N/A (not presented in Round 1)	<i>(added to Round 2)</i> In those with respiratory symptoms, consider CXR at an early stage. Be aware that a normal appearance does not exclude respiratory pathology. 32/33, 97% (consensus)
10	Diagnosis of underlying disorder (respiratory)	<i>(initial item)</i> Be aware that spirometry may be normal but patients may have diffusion defects indicative of scarring, chronic PEs or microthrombi. Consider referral to respiratory for full lung function testing. 33/33, 100% (consensus)	N/A (consensus achieved in Round 1)
11	Diagnosis of underlying disorder (respiratory)	<i>(initial item)</i> Measure oxygen saturation at rest and after an age-appropriate brief exercise test in people with breathlessness and refer for investigation if hypoxaemic or if any desaturation on exercise. 33/33, 100% (consensus)	N/A (consensus achieved in Round 1)
12	Diagnosis of underlying disorder (cardiac)	<i>(initial item)</i> Consider the possibility of a cardiac cause of breathlessness if pulmonary function is normal. 31/33, 94% (consensus)	<i>(amended item)</i> Consider the possibility of a cardiac cause of breathlessness. 32/33, 97% (consensus)
13	Diagnosis of underlying disorder (cardiac)	<i>(initial item)</i> Be aware that a normal D-dimer may not exclude thromboembolism, especially in a chronic setting, and referral for investigation is therefore indicated if there is a clinical suspicion of pulmonary emboli. Additionally, be mindful that thromboembolism may occur at any stage during the disease course. 33/33, 100% (consensus)	N/A (consensus achieved in Round 1)
14	Diagnosis of underlying disorder (cardiac)	<i>(initial item)</i> In patients with disproportional tachycardia and/or chest pain, carry out ECG, Holter monitoring, and echocardiography. Be aware that myocarditis and pericarditis cannot be excluded on echocardiography alone. 32/33, 97% (consensus)	N/A (consensus achieved in Round 1)
15	Diagnosis of underlying disorder (cardiac)	<i>(initial item)</i> Consider a referral to cardiology as cardiac MRI may be indicated in a normal echo to rule out myopericarditis and microvascular angina. 32/33, 97% (consensus)	N/A (consensus achieved in Round 1)
16	Diagnosis of underlying disorder (cardiac)	<i>(initial item)</i> Perform a 24hr Ambulatory Heart Rate Monitoring (and Ambulatory Blood Pressure Monitoring) with a symptom and activity diary to exclude Postural Orthostatic Tachycardia Syndrome (PoTS) in patients reporting palpitations and tachycardia. Alternatively, perform the NASA lean test. 30/33, 91% (consensus)	<i>(amended item)</i> In patients with palpitations and/or tachycardia, consider autonomic dysfunction. 32/33, 97% (consensus)
17	Diagnosis of underlying disorder (others)	<i>(initial item)</i> Consider a one-month trial of therapy for Mast Cell Activation or Histamine Intolerance (low histamine diet, H1 and H2 blockade at minimum twice daily) in patients with urticaria, conjunctivitis, wheeze, <i>(amended item)</i> In patients with urticaria, conjunctivitis, wheeze, inappropriate tachycardia, palpitations, shortness of breath, heartburn, abdominal cramps or bloating, diarrhoea, sleep disturbance, or	

		disproportionate tachycardia, palpitations, shortness of breath, heartburn, abdominal cramps or bloating, diarrhoea, sleep disturbance, or neurocognitive fatigue. ² If partial effect consider increasing H1 blocker to cetirizine 20mg bd or fexofenadine 360mg am + 180mg nocte. 31/33, 94% (consensus)	neurocognitive fatigue, ² consider mast cell disorder. 33/33, 100% (consensus)
18	Diagnosis of underlying disorder (others)	<i>(initial item)</i> Consider neurocognitive assessment in patients reporting cognitive difficulties sufficient to interfere with work or social functioning. 32/33, 97% (consensus)	N/A (consensus achieved in Round 1)
19	Diagnosis of underlying disorder (others)	<i>(initial item)</i> In patients with joint swelling and arthralgia consider a diagnosis of reactive arthritis or new connective tissue disease and investigate and refer as appropriate. 33/33, 100% (consensus)	N/A (consensus achieved in Round 1)
20	Management (general approach)	<i>(initial item)</i> For patients with fatigue and worsening symptoms hours to days following an activity emphasise the importance of an initial phase of convalescence followed by careful pacing and rest. 33/33, 100% (consensus)	N/A (consensus achieved in Round 1)
21	Management (general approach)	<i>(initial item)</i> Support patients in shifting their mental timeline of recovery to reflect the likely prolonged course, with a possibly long phased return to work. 33/33, 100% (consensus)	N/A (consensus achieved in Round 1)
22	Management (general approach)	<i>(initial item)</i> Further support patients with signposting to patient resources. Applicable resources may include: management of post-exertional symptom exacerbation; pacing; acupuncture; diagnosis-specific management as relevant. 32/33, 97% (consensus)	<i>(amended item)</i> Further support patients with signposting to patient resources. Applicable resources may include: management of post-exertional symptom exacerbation, activity pacing, acupuncture, diagnosis-specific management as relevant. 31/33, 94% (consensus)
23	Management (general approach)	<i>(initial item)</i> Provide patients with signposting to social prescribing, sickness certification and financial advice. 33/33, 100% (consensus)	<i>(amended item)</i> Provide patients with signposting to social prescribing, sickness certification and financial advice. Discuss with patient whether sickness certification will state long covid as diagnosis. 33/33, 100% (consensus)
24	Management (general approach)	N/A (not presented in Round 1)	<i>(added to Round 2)</i> Clinicians should ensure that the occupational status of patients with long covid is recorded (in/out of work, part/full time, student). 33/33, 100% (consensus)
25	Management (general approach)	<i>(initial item)</i> Follow patients up regularly to monitor progress from a full biopsychosocial and occupational perspective. 33/33, 100% (consensus)	N/A (consensus achieved in Round 1)
26	Management (general approach)	<i>(initial item)</i> Encourage reporting of new symptoms (expected) and expectation of waxing-waning course. 33/33, 100% (consensus)	N/A (consensus achieved in Round 1)
27	Management (general approach)	N/A (not presented in Round 1)	<i>(added to Round 2)</i> Consider contributing patient data to research on long covid, using the WHO Case Report Form or similar. ³ 33/33, 100% (consensus)
28	Management (specific)	<i>(initial item)</i> Patients with cardiac symptoms should be advised to limit their HR to 60% of	N/A (consensus achieved in Round 1)

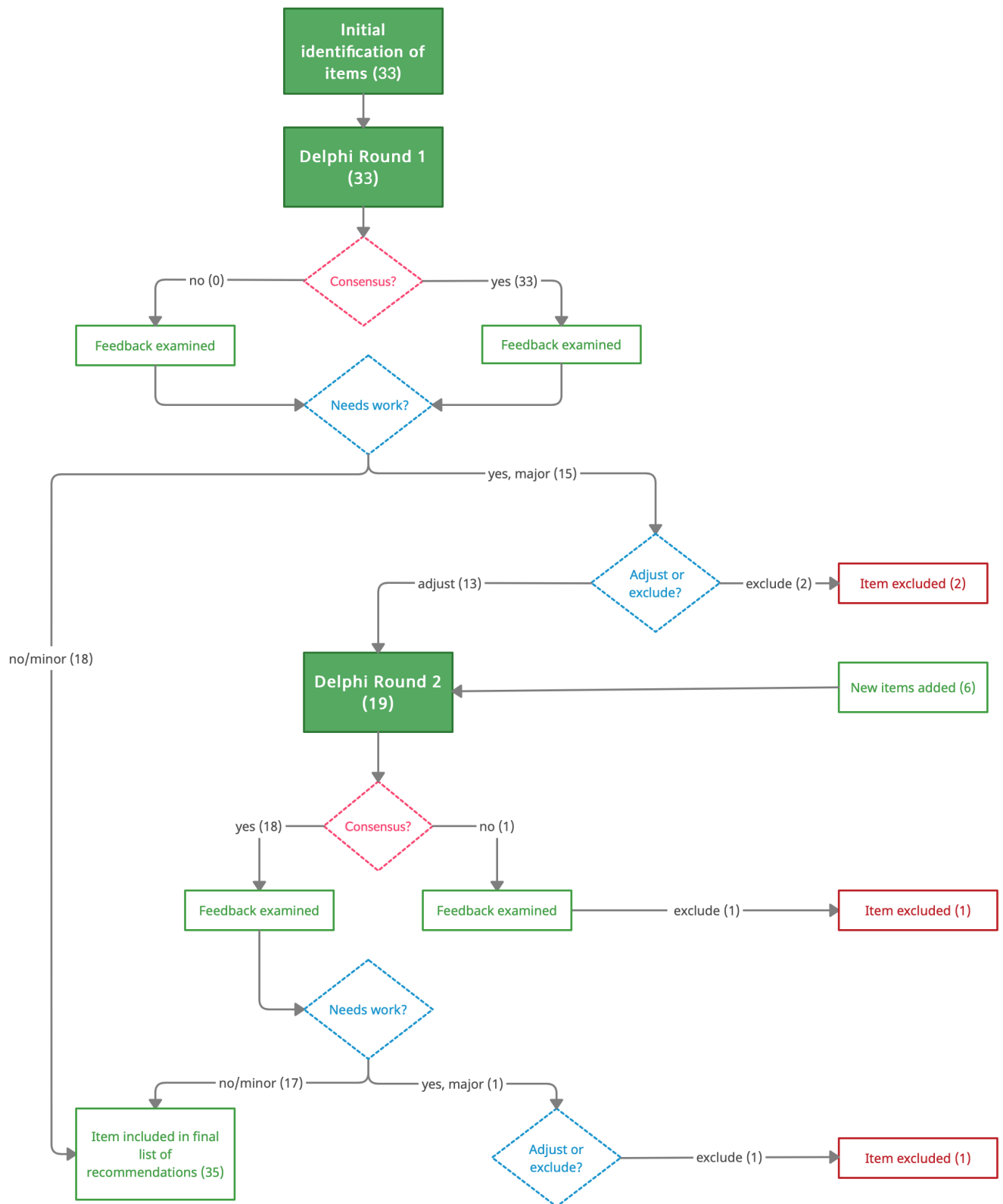
	conditions)	maximum (usually around 100-110bpm) and investigated with at least ECG and Echo before taking up exercise. Supervised exercise testing should be considered for this patient group as they may have myocarditis and exercise carries risk of arrhythmia and worsening cardiac function. ⁴ 32/33, 97% (consensus)	
29	Management (specific conditions)	<i>(initial item)</i> If PoTS (Postural Orthostatic Tachycardia Syndrome) identified consider first increased fluids, salts, compression hosiery and specific rehabilitation. ⁵ 33/33, 100% (consensus)	N/A (consensus achieved in Round 1)
30	Management (specific conditions)	<i>(initial item)</i> If PoTS and no or inadequate response to non-pharmacological therapy consider beta blocker, Ivabradine or Midodrine (with BP and response monitoring). 33/33, 100% (consensus)	<i>(amended item)</i> If PoTS and no or inadequate response to non-pharmacological therapy consider beta blocker, Ivabradine or Fludrocortisone (with BP and response monitoring). 32/33, 97% (consensus)
31	Management (specific conditions)	<i>(initial item)</i> Continue treating Mast Cell Activation if patients are responsive to one-month trial, consider Montelukast, Ketotifen. ^{6 7} 32/33, 97% (consensus)	<i>(amended item)</i> In patients with possible mast cell disorder, consider a one-month trial of initial medical treatment and dietary advice. Higher than standard dose of antihistamines are commonly used for this indication. If partial effect consider adding second level treatment such as Montelukast, as well as referral to allergy or immunology specialists. ^{6 7} 33/33, 100% (consensus)
32	Management (specific conditions)	N/A (not presented in Round 1)	<i>(added to Round 2)</i> Be aware that adverse drug reactions are more common in patients with mast cell activation, for example to beta lactam antibiotics, NSAIDs, codeine, morphine or buprenorphine. 33/33, 100% (consensus)
33	Management (specific conditions)	<i>(initial item)</i> Consider specialist physiotherapy and/or using alternative therapies such as yoga and meditation to manage dysautonomia, especially disordered breathing. 31/33, 94% (consensus)	<i>(amended item)</i> For disordered breathing, consider specialist physiotherapy and/or using alternative therapies such as yoga and meditation. 30/33, 91% (consensus)
34	Management (specific conditions)	<i>(initial item)</i> Consider psychological therapies, as per pre-existing guidelines, in patients expressing distress, significant low mood or anxiety and PTSD in those admitted to ICU. Treatments for PTSD should not start until after a month following trauma to avoid worsening symptoms. 31/33, 94% (consensus)	<i>(amended item)</i> In patients expressing distress, significant low mood, anxiety or symptoms of PTSD, consider mental health assessment. 33/33, 100% (consensus)
35	Management (specific conditions)	N/A (not presented in Round 1)	<i>(added to Round 2)</i> Over the counter supplementation is common, including vitamin C, D, niacin (nicotinic acid) and quercetin. Be aware of significant drug interactions, such as with niacin or quercetin. 32/33, 97% (consensus)
36*	N/A	<i>(initial item)</i> Advise against exercise for patients: reporting worsening symptoms hours to days following an activity; with cardiac symptoms; who are undergoing investigation for organ damage, as exercise may be harmful. 32/33, 97% (consensus)	<i>(amended item)</i> Careful activity pacing may be needed as some patients may experience worsening of symptoms in the days after physical or cognitive tasks. Appreciate that on the severe end of the spectrum even stretching exercises in bed may provoke worsening of symptoms. 32/33, 97% (consensus)

37*	N/A	<i>(initial item)</i> Use the term “long covid” in preference to “Post Covid-19 Syndrome” as this properly reflects uncertainty as to the aetiology, case-mix and prognosis of this new multi-system disorder. 31/33, 94% (consensus)	<i>(amended item)</i> Use the term “Post Covid-19 Condition” in preference to “Post Covid-19 Syndrome” or “long covid”, as this is internationally agreed by the WHO. 21/33, 64% (no consensus)
38*	N/A	<i>(initial item)</i> Symptoms that started before covid-19 infection and continued post covid-19 infection should not be managed in the long covid service. 30/33, 91% (consensus)	N/A (item excluded at Round 1)
39*	N/A	<i>(initial item)</i> Consider serial peak flow measurement to test for airway obstruction (and reversibility) in patients with wheeze and/or breathlessness. 31/33, 94% (consensus)	N/A (item excluded at Round 1)

Note. Blue text indicates that the item was included in the final list of recommendations; green text indicates that the item was amended and re-tested; red text indicates that the item was excluded. Fractions and percentages indicate the number and proportion of participants that responded “strongly agree”, “agree”, or “neither agree nor disagree”. Cells contain the exact items that participants saw; some were subsequently adjusted to reflect participants’ feedback.

* Item not included in final list of recommendations.

Supplementary Figure 1: Flowchart of the Delphi procedure and results



Supplementary Box 1: Recommendations for the recognition, diagnosis, and management of patients with Post Covid-19 Condition (“long covid”)

Recommendations pertaining to clinic organisation

- 1) Consider long covid in patients with a clinical diagnosis of covid-19 as per WHO criteria¹ or test-positive history with new or fluctuating symptoms including but not limited to breathlessness, chest pain, palpitations, inappropriate tachycardia, wheeze, stridor, urticaria, abdominal pain, diarrhoea, arthralgia, neuralgia, dysphonia, fatigue including neurocognitive fatigue, cognitive impairment, prolonged pyrexia and neuropathy occurring beyond 4 weeks of initial covid-19.
- 2) Multispecialty long covid clinics should be led by a doctor with cross-specialty knowledge and experience of managing this condition.
- 3) Consider individualised investigations, management and rehabilitation planning via a multispecialty long covid assessment service as local services allow. Prioritise physician-led medical assessments and diagnostics initially, and consider allied health professionals including physiotherapy and OT input as adjuncts.
- 4) It is inappropriate for long covid clinics to be led by mental health specialists e.g., IAPT, clinical or health psychologist. They may be useful in supporting the multispecialty team but do not have the expertise to investigate and manage potential organ damage.
- 5) All under-18-year-olds need access to similar services run by paediatric specialists with knowledge of how presentations and treatments differ to adults and with close liaison with school.
- 6) Patients with comorbid mental health difficulties should have equal access to medical care as a patient without mental health difficulties and should not be triaged away from services.

Recommendations pertaining to diagnosis of underlying disorder

General approach:

- 7) In someone with long covid, symptoms of possible non-covid-19 related issues should be investigated and referred as per local guidelines. Long covid alone is not a sufficient diagnosis unless other causes have been excluded.
- 8) Carry out a face-to-face assessment including a thorough history and examination, consider other non-covid-19 related diagnoses, and measure FBC, renal function, CRP, LFT, thyroid function, HbA1c, Vitamin D, Magnesium, B12, folate, ferritin and bone studies.

Respiratory:

- 9) In those with respiratory symptoms, consider CXR at an early stage. Be aware that a normal appearance does not exclude respiratory pathology.
- 10) Be aware that simple spirometry may be normal but patients may have diffusion defects indicative of scarring, chronic PEs or microthrombi. Consider referral to respiratory for full lung function testing.
- 11) Measure oxygen saturation at rest and after an age-appropriate brief exercise test in people with breathlessness and refer for investigation if hypoxaemic or if any desaturation on exercise.

Cardiac:

- 12) Consider the possibility of a cardiac cause of breathlessness.
- 13) Be aware that a normal D-dimer may not exclude thromboembolism, especially in a chronic setting, and referral for investigation is therefore indicated if there is a clinical suspicion of pulmonary emboli. Additionally, be mindful that thromboembolism may occur at any stage during the disease course.
- 14) In patients with inappropriate tachycardia and/or chest pain, carry out ECG, troponin, Holter monitoring, and echocardiography. Be aware that myocarditis and pericarditis cannot be excluded on echocardiography alone.
- 15) In patients with chest pain consider a referral to cardiology as cardiac MRI may be indicated in a normal echo to rule out myopericarditis and microvascular angina.
- 16) In patients with palpitations and/or tachycardia, consider autonomic dysfunction.

Others:

- 17) In patients with urticaria, conjunctivitis, wheeze, inappropriate tachycardia, palpitations, shortness of breath, heartburn, abdominal cramps or bloating, diarrhoea, sleep disturbance, or neurocognitive fatigue,² consider mast cell disorder.

- 18) In patients with cognitive difficulties sufficient to interfere with work or social functioning consider neurocognitive assessment.
- 19) In patients with joint swelling and arthralgia consider a diagnosis of reactive arthritis or new connective tissue disease and investigate and refer as appropriate.

Recommendations pertaining to management

General approach:

- 20) For patients with fatigue and worsening symptoms hours to days following an activity emphasise the importance of an initial phase of convalescence followed by careful pacing and rest.
- 21) Support patients in shifting their mental timeline of recovery to reflect the likely prolonged course, with a possibly long phased return to work.
- 22) Further support patients with signposting to patient resources. Applicable resources may include: management of post-exertional symptom exacerbation, activity pacing, acupuncture, diagnosis-specific management as relevant.
- 23) Provide patients with signposting to social prescribing, sickness certification and financial advice. Discuss with the patient whether sickness certification will state long covid as diagnosis.
- 24) Clinicians should ensure that the occupational status of patients with long covid is recorded (in/out of work, part/full time, student).
- 25) Follow patients up regularly to monitor progress from a full biopsychosocial and occupational perspective.
- 26) Encourage reporting of new symptoms (expected) and expectation of waxing-waning course.
- 27) Consider contributing patient data to research on long covid, using the WHO Case Report Form or similar.³

Management of specific conditions:

- 28) Patients with cardiac symptoms should be advised to limit their HR to 60% of maximum (usually around 100-110bpm) and investigated with at least ECG and echocardiogram before taking up exercise. Supervised exercise testing should be considered for this patient group as they may have perimyocarditis and exercise carries risk of arrhythmia and worsening cardiac function.⁴
- 29) For autonomic dysfunction including PoTS (Postural Orthostatic Tachycardia Syndrome), consider first increased fluids, salts, compression hosiery and specific rehabilitation.⁵
- 30) If PoTS and no or inadequate response to non-pharmacological therapy consider beta blocker, Ivabradine or Fludrocortisone (with BP and response monitoring).
- 31) In patients with possible mast cell disorder, consider a one-month trial of initial medical treatment and dietary advice. Higher than standard dose of antihistamines are commonly used for this indication. If partial effect consider adding second level treatment such as Montelukast, as well as referral to allergy or immunology specialists.^{6 7}
- 32) Be aware that adverse drug reactions are more common in patients with mast cell disorder, for example to beta lactam antibiotics, NSAIDs, codeine, morphine or buprenorphine.
- 33) For breathing pattern disorder, consider specialist physiotherapy and/or using alternative therapies such as pranayama breathing and meditation.
- 34) In patients expressing distress, significant low mood, anxiety or symptoms of PTSD, consider mental health assessment.
- 35) Over the counter supplementation is common, including vitamin C, D, niacin (nicotinic acid) and quercetin. Be aware of significant drug interactions, such as with niacin or quercetin.

REFERENCES (SUPPLEMENTARY MATERIAL)

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