

Managing the long-term effects of COVID-19

Implementation support note for clinicians to support the management of long-term effects of COVID-19

Version history

Version	Date	Summary of changes (page numbers refer to the version described)
1.0	05/05/21	First version of document published
2.0	01/02/22	<p>Page 2 – addition of contents page</p> <p>Page 5 – addition of COVID-19 related ICD codes. Updated definition of post-COVID 19 syndrome</p> <p>Page 6 – addition of follow up advice</p> <p>Page 7 – updated figure 1 with new investigations and rehab advice</p> <p>Page 8 – addition of guidance with underserved or vulnerable groups</p> <p>Page 9 – addition of heart rate monitoring for suspected PoTS</p> <p>Page 12 – updated wording in figure 2</p> <p>Page 14 – addition of further advice regarding delirium and dementia</p> <p>Page 18 – updated guidance for smell training</p> <p>Page 19 – updated wording within section 12, added advice in section 13 regarding investigation of GI symptoms</p> <p>Page 21 – updated advice on rehabilitation measures included link to its-ok-to-ask website</p> <p>Page 22 – updated contact information for support services</p> <p>Page 25 – added symptoms in neurology, gastrointestinal, psychological and psychiatric, ENT & dermatology</p>
2.1	06/05/22	<p>Page 19 – added signs and symptoms for CYP</p> <p>Page 20 – added detail for investigation and management</p> <p>Page 21 – added referral guidance for CYP</p> <p>Page 22 – added flow chart for CYP</p>
2.2	30/06/22	<p>Page 20 – addition of personal care plan and care co-ordinator</p> <p>Page 21 – added AHP referral guidance</p> <p>Page 23 – updated flow chart</p>

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1. Who is this for?

This implementation support note provides additional targeted information for clinicians and to support health care teams caring for people who have signs and symptoms that develop during or after an acute COVID-19 infection which continue for more than four weeks that are consistent with long-term effects of COVID-19 whilst the possibility of an alternative underlying disease is also being assessed.

This Scottish Government publication is intended to complement the [SIGN/NICE/RCGP joint Guideline on managing the long-term effects of COVID-19](#). This document was first developed with input from key stakeholders including those from the Clinical Leads Advisory Group for Scotland (CLAGS), COVID-19 Clinical Guidance Cell, Specialty Advisors to the Chief Medical Officer, senior medical advisors to the Scottish Government (Annex A), people with lived experience and the third sector. This subsequent updated version has been produced with guidance sought from those parties as required.

This is a living document, and will be updated as needed as new information and clinical evidence continues to emerge.

It does not replace or supersede the SIGN/NICE/RCGP Guideline as the primary source of clinical guidance on managing the long-term effects of COVID-19.

2. What does it provide?

It provides supplementary information to support the implementation of the SIGN/NICE/RCGP Guideline recommendations, with information and links to resources to support a consistent national approach to clinical assessment, shared decision making and individualised care planning conversations, including self-management and further referral where needed.

It should be used to support:

- shared decision making conversations around diagnosis and care planning, based on Realistic Medicine principles
- local pathway development (including resource requirements) through Board primary-secondary care interface arrangements
- multi-disciplinary assessment, support and co-ordination of specialty input building on local needs and pathways
- local services which help to address inequalities and access for all
- the development of local information and resources to aid care navigation and supported self-management for people affected by long-term effects of COVID-19 and their carers and families.

3. Recording within primary care information systems

The following table summarises the appropriate EMIS and Vision codes:

Table 1: Coding for primary care systems

System	Term	Search keyword	Code
EMIS PCS	Acute COVID-19 infection	Acute COV	^ESCT1348646
EMIS PCS	Ongoing symptomatic COVID-19	Ongoing cov	^ESCT1348648
EMIS PCS	Post-COVID-19 syndrome	Post-COV	^ESCT1348645
Vision	Acute diseases caused SARS-CoV-2	CORONA	A795400
Vision	Ongoing symptomatic COVID-19	CORONA	A7955
Vision	Post-COVID-19 syndrome	POSTCOVID	AyuJC

- 'Acute COVID-19' - Signs and symptoms of COVID-19 for up to 4 weeks.
- 'Ongoing symptomatic COVID-19' - Signs and symptoms of COVID-19 from 4 weeks up to 12 weeks.
- 'Post-COVID-19 syndrome' - Signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis.

Note - In addition to the clinical case definitions, the term 'long COVID' is commonly used to describe signs and symptoms that continue or develop after acute COVID-19. It includes both ongoing symptomatic COVID-19 (from 4 to 12 weeks) and post-COVID-19 syndrome (12 weeks or more). It usually presents with clusters of symptoms, often overlapping, which can fluctuate and change over time and can affect any system in the body. Post-COVID-19 syndrome may be considered before 12 weeks while the possibility of an alternative underlying disease is also being assessed.

Use of the term 'long COVID' when communicating with people accessing support and services can support health literacy.

Note - Acute COVID-19 is typically characterised clinically by the presence of at least one of the following: new continuous cough; fever; loss or change in sense of smell or taste. It is important to recognise that many people who experienced these symptoms in the first wave of the pandemic would not have had a COVID-19 test performed. In addition, on occasion a test may be falsely negative.

Absence of a positive SARS-CoV-2 test (PCR or antigen) does not exclude COVID-19 as a potential cause of longer lasting symptoms. Although serological (antibody) tests are now known to be sensitive and specific, the duration of a positive test result after infection is not known and antibody levels are known to decline over

time. Thus, a negative antibody test for SARS-CoV-2 does not exclude the diagnosis of previous infection with this virus.

Table 2: [Emergency use ICD codes for COVID-19 disease outbreak –World Health Organization](#)

Term	ICD-10 Code	ICD-11 Code
COVID-19 virus identified	U07.1	RA01.0
COVID-19 virus not identified	U07.2	RA01.1
Personal history of COVID-19	U08	QC42.0
Multisystem inflammatory syndrome associated with COVID-19	U10	RA03
Post COVID-19 condition	U09 + specific condition	RA02 + specific condition
Need for immunisation against COVID-19	U11	QC01.9 + vaccine code
Adverse reaction to COVID-19 vaccine	U12	Adverse reaction/PL00 + vaccine code

Further detail on selected codes can be found in [Scottish Clinical Coding Standards, Number 30](#).

4. Community management

It has been advised to consider following up patients in primary care or community services who are in vulnerable or high-risk groups who have self-managed in the community after suspected or confirmed acute COVID-19. Anyone admitted with acute COVID-19 infection should be offered a follow up consultation by a secondary care healthcare professional 6 weeks after discharge home for review of new or ongoing symptoms or complications.

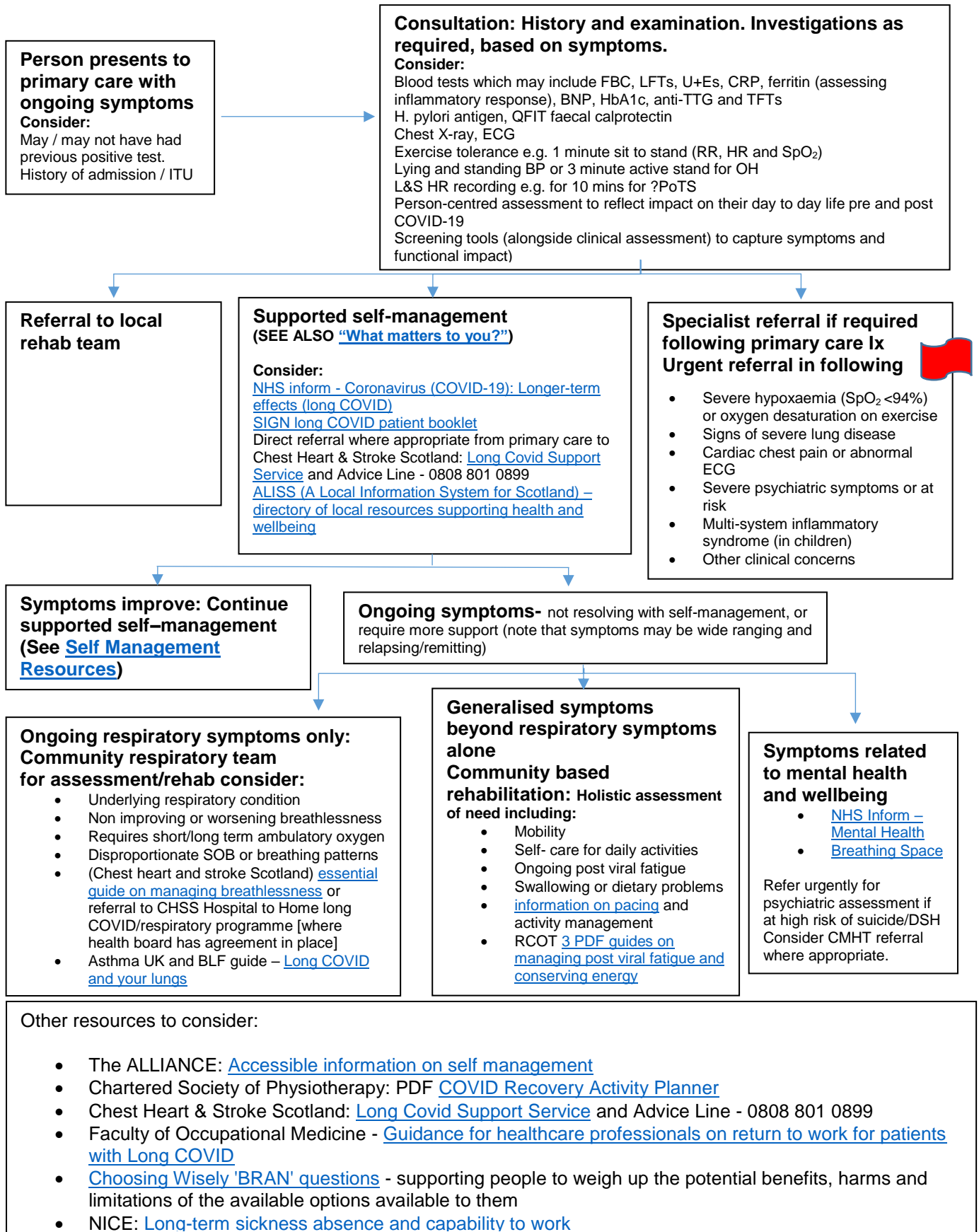
The following flow chart and advice for clinicians around management of symptoms has been adapted from sources including the BMJ and Leeds primary care guidance, with input from Scottish national speciality advisors.

It can be used to help support a collaborative conversation with the person (and their families and carers as appropriate) to understand their symptoms in the context of their own life and the things that are most important to them.

Where appropriate, appointed member / members of the primary and community care team should aim to act as a care and support co-ordinator to facilitate co-ordination across pathways and signposting to services – this could be the professional most appropriate for the person and could include the GP, General Practice Nurse, AHPs, care worker or link workers according to patient need and local services.

Managing the long-term effects of COVID-19 in primary care ([Guideline](#))

Figure 1: Initial assessment and management



5. Symptom specific management guidance for primary care

The following has been developed in collaboration with national specialty advisors and clinical specialists, and should be considered in the context of local guidelines and referral management pathways.

Some areas to consider:

- Discussing the referral with specialist (telephone / [Consultant Connect](#), digital advice route) and wherever possible for the patient to be copied in to any correspondence
- Encourage patient involvement in referral decisions—taking into account opportunities for asynchronous consulting, Near Me and importantly utilising self-referral
- Manage expectations around waiting times, the potential outcomes of any investigations regarding management, who will update the patient on the outcomes of investigations, as part of a care planning conversation.
- The patient journey – particularly when there may be multiple symptoms, or the person may struggle navigating the system- system co-ordination where possible
- Support from local community resources, such as link workers, to facilitate access to services in local community as well as specialist clinics.
- Consider the impact of health inequalities and that some people may have difficulty in accessing services as well as sources of support
- People's [lived experience of symptoms](#), and how this affects their physical, psychological and social wellbeing

Support access to assessment and care for people with new or ongoing symptoms after acute COVID-19, particularly for those in underserved or vulnerable groups who may have difficulty accessing services, for example by:

- providing extra time or additional support (such as an interpreter or advocate) during consultations
- raising awareness about possible new or ongoing symptomatic COVID-19 or post-COVID-19 syndrome – this may include working with local community leaders or organisations – particularly in vulnerable groups and black, Asian and minority ethnic groups.

The table below lists common symptoms and signs with additional information and resource links, a [full list of common symptoms adapted from the SIGN/NICE/RCGP guideline](#) can be found in Annex B.

Table 3: Symptom specific management

Long-term COVID-19 symptom or sign	Considerations specific to COVID-19	Initial investigations to consider / resources to support	Red flags
Fatigue	<ul style="list-style-type: none"> • Consider impact on role-e.g. carer, time off work and phased return • Reassure that with time and self-management, fatigue usually improves gradually • Consider local support groups, referral to community based services or CHSS Long COVID Service • Advice on pacing and energy management 	<ul style="list-style-type: none"> • Consider bloods as part of clinical assessment • Modified Fatigue Impact Scale 	<ul style="list-style-type: none"> • Consider underlying cardio/respiratory disease
Breathlessness	<ul style="list-style-type: none"> • On exertion – may persist for many weeks to months, usually with a gradual recovery • Consider increased risk of VTE/PE post COVID-19 infection • Intermitting chest pain not unusual 	<ul style="list-style-type: none"> • Consider CXR • Patients discharged from hospital may have ongoing respiratory rehab requirements • Consider BNP as part of any blood samples • O₂ sats, and access to oxygen saturation remote monitoring pathway 	
Cough	<ul style="list-style-type: none"> • Can persist for some weeks 	<ul style="list-style-type: none"> • Consider sputum culture if productive • Any antibiotic treatment should follow current guidelines • Follow local guidelines for suspected asthma/COPD 	<ul style="list-style-type: none"> • Be mindful of national criteria for suspicion of lung cancer

Palpitations/ tachycardia	<ul style="list-style-type: none"> • May need to exclude eg infection 	<ul style="list-style-type: none"> • Bloods (incl TFTs) • Lying and standing BP • ECG • Consider orthostatic hypotension- NICE guidance • HR monitoring for suspected PoTS 	<ul style="list-style-type: none"> • Urgent and non-urgent referral criteria for palpitations
Neurological symptoms	<ul style="list-style-type: none"> • Cognitive impairment, migraine, dizziness commonly reported • Concentration and memory impairment can be linked to structural damage in more severe initial infections. In milder community managed cases (“brain fog”) appears to be commonly caused by functional cognitive disorders 	<ul style="list-style-type: none"> • 4AT tool and SIGN guideline if delirium • Information on functional cognitive disorders from neurosymptoms.org and BMJ • Full guidance on assessment and management below 	<ul style="list-style-type: none"> • Focal neurological symptoms or stroke should be referred as per local pathways
Anosmia	<ul style="list-style-type: none"> • Very common – up to 50% • Commonly improves over a few weeks 	<ul style="list-style-type: none"> • Associated nasal symptoms • Neurological symptoms • ‘NoseWell’ – guide created by abScent and British Rhinological Society 	<ul style="list-style-type: none"> • Consider MRI / ENT referral if uncertainty or neurological finding
Pain	<ul style="list-style-type: none"> • Commonly encountered symptoms of headache, abdominal pain, musculoskeletal pains • Recovery may be prolonged • Consider impacts on activities as well as personal and professional roles 	<ul style="list-style-type: none"> • Guided by clinical assessment, exclude alternative or treatable causes • See Rheumatology advice regarding inflammatory conditions • Pain Concern and Pain Association provide useful resources around guidance and management 	
Dysautonomia	<ul style="list-style-type: none"> • Can persist for weeks to months but should resolve 	<ul style="list-style-type: none"> • PUO work up should be considered 	<ul style="list-style-type: none"> • Unexplained weight loss • Persistent lymphadenopathy

	<ul style="list-style-type: none"> • May cause ongoing pyrexia, tachycardia and breathlessness • Respond well to conservative measures • Some may need medication for a short period • Respond well to pulmonary rehab 		
Mental health including low mood, PTSD, anxiety.	<ul style="list-style-type: none"> • Common features post COVID-19 infection • PTSD may be as a result of hospital admission / ITU –ask about intrusive thoughts, nightmares, avoiding behaviours 	<ul style="list-style-type: none"> • Consider screening tools such as: CORE10 for psychological distress, PHQ9 for depression, GAD7 for anxiety, PCL5 for PTSD. • HDU/ITU patients may also be followed up through specialist services • Multiple factors- carer strain, employment, finance, relationship strain or loss of support 	<ul style="list-style-type: none"> • Immediate risk of self-harm • Neurocognitive problems in presence of new or pre-existing neurological diagnosis
Urticaria, angioedema	<ul style="list-style-type: none"> • These symptoms can be triggered by intercurrent infection or post viral illness and so can be expected following COVID-19 infection • Further triggers include psychological stress, NSAIDs • Treatment should follow same principles with anti-histamines, titrated to achieve symptom control 	<ul style="list-style-type: none"> • Please read Annex C for full Immunology advice and resources • Further guidelines on Chronic Urticaria and Angioedema - BSACI • Where allergy suspected, this should be managed as per local guidelines 	<ul style="list-style-type: none"> • Anaphylaxis

6. Additional specialty advice to support primary care management

The following advice has been agreed with national clinical advisors and is based upon current experiences and evidence base. Further specialty advice may be added as the research and evidence base continues to develop, with plans to keep this updated to reflect current practice.

7. Respiratory symptoms

The pathways below demonstrate suggested management strategies for those discharged following COVID-19 pneumonia (Figure 2) and those who present to primary care with persisting respiratory symptoms (Figure 3). Further resources are available from the [Primary Care Respiratory Society](#).

Figure 2: COVID-19 Pneumonia follow-up following discharge from secondary care

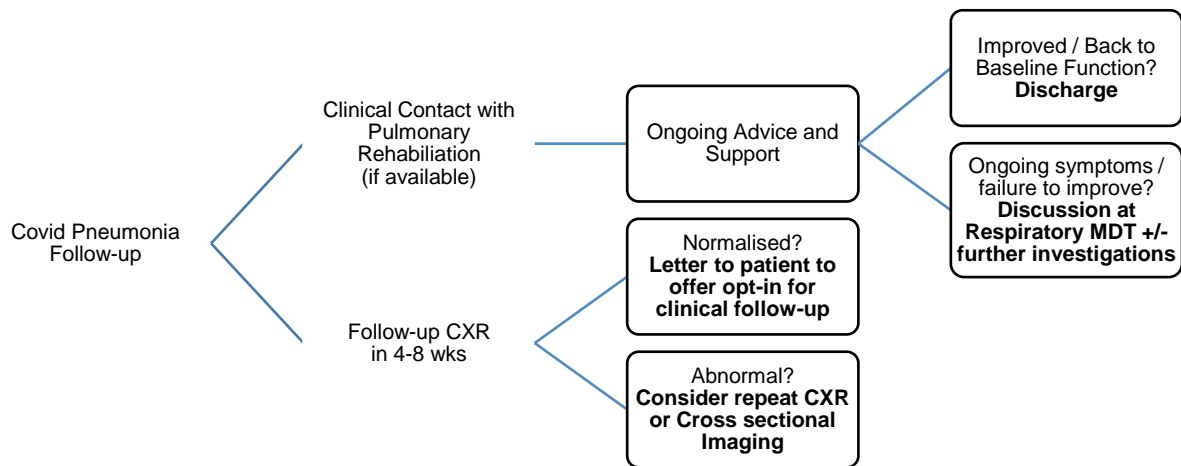
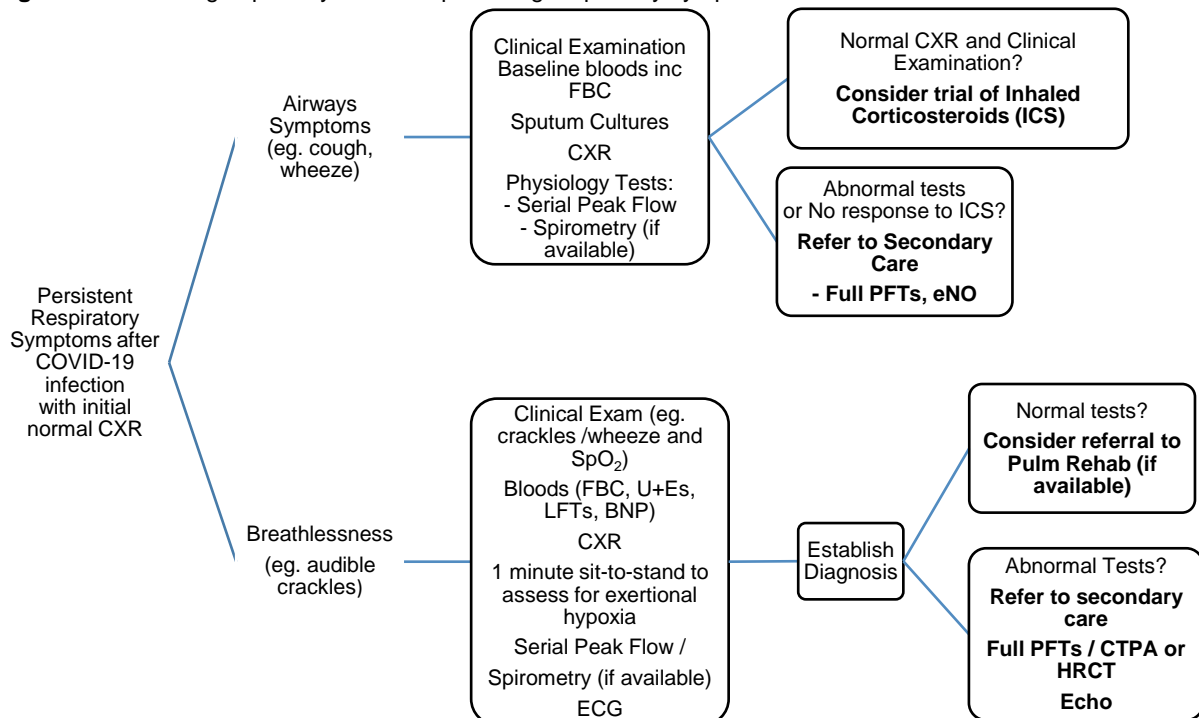
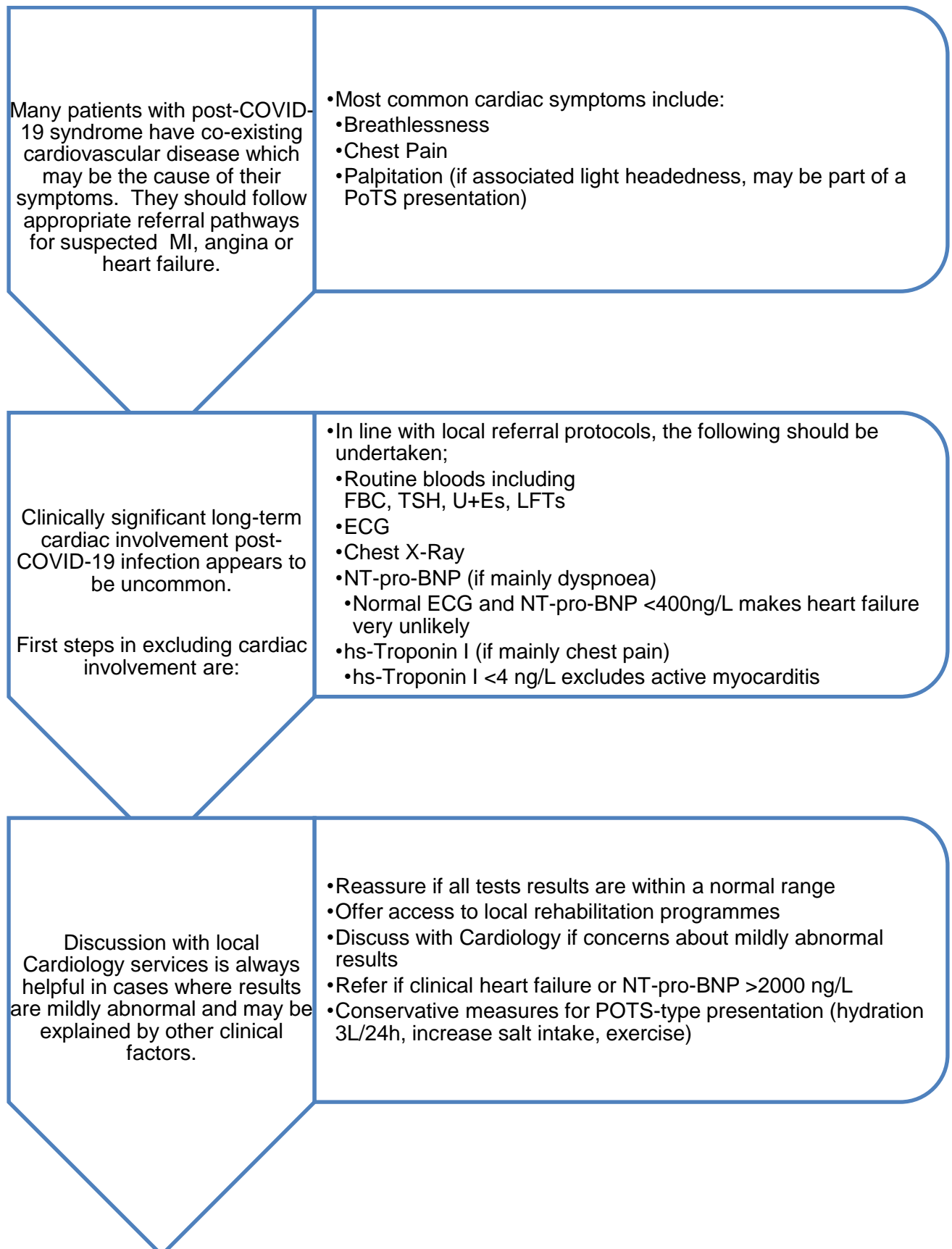


Figure 3: Presenting to primary care with persisting respiratory symptoms



8. Cardiology symptoms and tests

Figure 4: Assessment and referral for cardiology symptoms



9. Neurological and neuropsychiatric symptoms

The commonest neurological/neuropsychiatric complications 3 months or longer post COVID-19 seem to be migraine, memory and concentration problems, dizziness, and paraesthesia. Stroke and dementia are known serious complications in a minority of older patients (less than 1 in 20).

For those aged >65 the major risk factor for significant structural neurological disease is severe initial infection. The risk of stroke and dementia increases significantly in those who were hospitalised. In particular, the main risk factor for onset of dementia post COVID-19 infection appears to be the presence of delirium during the acute illness. Structured cognitive assessment tools are useful aids to evaluate cognitive impairment but are not dementia diagnostic tools in their own right. Their result should be used in conjunction with clinical assessment to determine whether referral to memory clinic is warranted.

Persistent symptoms of delirium should be assessed using the 4AT tool then managed according to the [SIGN guideline for delirium](#).

It is unclear whether focal neurological symptoms occur at an increased rate post COVID-19 infection but any that do occur should be referred to neurology.

Assessment and management of stroke and migraine follows normal principles and should follow local pathways. Further resources on managing migraine include those from [SIGN](#) and [NHS Lothian](#).

For those with initial COVID-19 infections treated in the community (i.e. not so severe as to have required hospital treatment), the causes of symptoms appear to vary considerably between individuals.

Functional cognitive disorders seem the most common cause of concentration and memory impairment or “brain fog”. Anxiety is common in such scenarios but may not be present. Pointers to the likelihood of cognitive symptoms being the result of a functional disorder, rather than primarily the result of degenerative brain disease or other structural pathology, are listed below in in Table 4. Patient-facing advice about functional cognitive disorders may be found at [neurosymptoms.org](#). If cognitive disorders are disabling referral for assessment is appropriate.

For balance disorders and dizziness, consider common causes such as vestibular migraine, BPPV or lightheadedness and orthostatic intolerance related to prolonged recumbence. Be aware of **persistent postural perceptual dizziness**; which leads to dizziness, unsteadiness or non-spinning vertigo lasting for hours or longer, exacerbated by upright posture, active or passive motion without regard to direction or position, and exposure to moving visual stimuli or complex visual patterns. It is appropriate to refer such patients for assistance and diagnostic confirmation. More information on PPPD can be found at [neurosymptoms.org/dizziness](#).

Paraesthesia is common in the population and has many causes. Consider benign explanations such as ulnar nerve irritation, carpal tunnel symptoms, meralgia or lumbar radiculopathy. In hospitalised patients consider critical illness neuropathy.

Have a low threshold for measuring B12, Glucose and Thyroid Function. In many patients with functional disorders, dysfunctional breathing may exacerbate or cause paraesthesia. More information on benign sensory symptoms can be found [here](#).

Persistent fatigue, without clear evidence of alternate pathology, should be assessed according to guidance in the [Scottish Good Practice Statement on ME-CFS](#).

The definitive cause of persistent non-specific neurological symptoms after COVID-19 infection remains a research question and advice may be subject to change. At the current time clinical experience and early scientific evidence suggests that in many cases neurological/ neuropsychiatric symptoms stem from a period of post-viral illness that has given way to a functional disorder. With regard to functional disorders in general, the cardinal rule is they are disorders in their own right and are not the same as anxiety. Diagnosis should, where possible, be made on basis of identifying positive features of the condition on a 'rule in' basis. Explanations based on reattribution - "this is all due to anxiety" have been shown not to work and fail to recognise that functional disorders do have a distinct pathophysiology. An explanation based on "brain is not working properly, it's like it is out of tune, the physical and emotional stresses of COVID have had an impact on it, but it is potentially reversible" is more scientifically accurate. (see [Recognising and explaining functional neurological disorder. *BMJ*, 371](#) for a more detailed discussion).

Table 4: Differentiating functional cognitive disorders from degenerative brain disease

Features of individual with functional cognitive disorders	Features of individual with degenerative brain disease
Attends alone	Attends with someone
Patient more aware of the problem than others	Others more aware of the problem than patient
Answers independently	Turns to accompanying adult for support in answering questions (eg, head turn sign)
Speaks for longer in response to open question about nature of difficulties	Answers briefly in response to open question (<1 minute)
Gives a detailed description of complaints (might bring written list)	Absence of details when describing symptoms
Frequently offers elaboration and detail	Unlikely to give spontaneous elaboration or detail
Can answer questions with multiple components	Can only answer single-component questions
Detailed account of personal history, drugs, and previous interactions with doctors	Less detailed account
Loss of recent and remote autobiographical memories	Relative preservation of remote autobiographical memories
Complaint of memory gaps for specific periods and events	Complaint of specific memory gaps unusual
Inattentive memory symptoms, within most people's normal experience	Memory symptoms are often outside normal experience
Reports exceptional pre-morbid cognitive function	Views current and past cognitive function as normal
Evidence of active cognitive engagement with current news, media, and social media	May be unaware of current events; poorly engaged with media or social media
Dates symptom onset with precision	Difficult to pinpoint date of onset
Unstable longitudinal course	Cognitive impairment progressive over time
Marked variability	Less variability

10. Stroke

Where there is clinical suspicion of stroke following appropriate assessment, this should be referred as an emergency in the usual manner. It is important to note that loss of smell or taste as the only abnormal sign in a clinical examination does not indicate a stroke, though may be a persisting symptom after COVID-19 disease.

Any increased risk of stroke is thought to be in the acute phase of infection and there are currently studies investigating this.

Although COVID-19 infection is thought to be associated with hypercoagulopathy, this is associated more with venous thrombosis rather than arterial thrombosis. There is currently no evidence nor recommendation to prescribe antiplatelet medication as a preventative measure following infection.

11. Change or loss of smell (anosmia, hyposmia or cacosmia)

A common symptom associated with COVID-19 infection is change in sense of smell. Anosmia or hyposmia (reduced sense of smell) is most common. Some people describe altered smell (cacosmia - typically an unpleasant rotting or burning smell sensation). Although the longer-term effects remain unknown, the recovery of smell appears to be better after COVID-19 than with standard post-viral anosmia which can recover for up to two years.

An appropriate history and clinical examination should be performed to exclude alternate causes. The commonest alternate diagnosis seen is nasal polyps, though here the onset of smell reduction is usually gradual and associated with nasal block. If nasal block is suspected a trial of nasal steroid sprays is advised.

In the absence of any abnormal examination findings, it is important to have an informed discussion to manage expectations. There are no medical or surgical treatments available and ENT specialty referral is not required. "Smell training" can offer some benefit and so patients should be directed to the [AbScent](#) or [Fifth Sense](#) websites for helpful resources they can use for this. Smell training may be more effective if started as soon as possible.

Losing smell has important safety issues (gas, smoke, rotten food, poor ventilation when using cleaning fluids, personal hygiene) and particular attention should be paid to highlighting the importance of these issues.

12. Musculoskeletal symptoms

Assess patients with musculoskeletal symptoms as per normal good practice – this includes relevant physical examination.

Individuals with signs or symptoms suggestive of inflammatory arthritis should be referred to secondary care as per local policies / guidelines – do not attribute these to long term effects of COVID-19.

There is no evidence to support a trial of steroids as an effective therapeutic intervention and, prescription of steroids for symptom relief should be avoided unless evidence emerges to support their use.

Non-specific musculoskeletal symptoms such as aches and pains and muscle weakness are common and are frequently seen after COVID-19 disease. The evidence thus far suggests spontaneous recovery, albeit with varying time courses. Realistic advice on recovery and rehabilitation strategies including resumption of activity should be made available.

13. Gastrointestinal symptoms

A number of patients with long-term effects of COVID-19 report gastrointestinal symptoms such as abdominal pains, nausea and diarrhoea. In many cases these are self-limiting symptoms that will settle over time. Patients should be assessed in the usual manner by history taking to look for red flag symptoms and screening investigations including coeliac serology, H. pylori testing, QFIT or faecal calprotectin depending on the nature of the symptoms and local protocols. Patients should be managed as per standard local protocols and referral to secondary care should be considered if there are red flag symptoms or evidence of GI inflammation. In the absence any such features then patients should be treated symptomatically.

14. Chronic spontaneous urticarial +/- angioedema (CUSA) and related symptoms

The Scottish Immunologists' Group have produced [the following document \(Annex C\)](#) to aid primary care in the management of chronic spontaneous urticarial +/- angioedema (CUSA) and related symptoms, including in the context of COVID-19 disease. This includes advice on diagnosis, management and further helpful resources and links.

15. Children and young people with symptoms consistent with the long term effects of COVID-19

The following information is to help guide the assessment and management of children and young people presenting with possible long COVID to primary care.

There is currently no separate clinical case definition for 'long COVID' among children and young people (CYP) in the UK.

Some people (including children and older people) may not have the most commonly reported new or ongoing symptoms after acute COVID-19. Their wide-ranging symptoms can fluctuate and relapse over time.

Most CYP will not have been hospitalised with acute COVID-19 and some will not have received a positive PCR test, this does not exclude them from developing long COVID. If there is a clinical suspicion of long COVID they should be investigated alongside those with confirmed previous acute COVID-19 infection.

History and Assessment

During the assessment it is important to provide an empathetic holistic approach.

- Assessment should include physical, cognitive, psychological and psychiatric symptoms, as well as functional abilities
- Establish their pre-COVID-19 infection baseline
- Consider the effect on their day to day activities of daily living, education, socialising, hobbies etc.
- Explore the impact on the patient's family as a whole
- Discuss and assess possible feelings of worry or distress
- Consider other diagnoses for their presentation and investigate appropriately
- Those with special education needs, neurodisability or neurodiversity may not express their symptoms typically and therefore changes in behaviour should be considered

Be aware of and seek paediatrician support early for those with signs and symptoms that could indicate:

- Specific organ impairment e.g. chest pain, palpitations or breathlessness (these symptoms may also indicate dysautonomias e.g. PoTS, and referrals should ensure these are considered in the absence of structural impairment)
- Ongoing inflammatory or autoimmune response e.g. recurrent fever, joint involvement, rashes or weight loss

Common signs and symptoms of long COVID in children:

- Extreme exhaustion
- Dizziness
- Rashes

- Cognitive dysfunction (brain fog - difficulties with memory and concentration)
- Headaches
- Chest pain
- Stomach pain or upset
- Sore throat
- Mood and/or behavioural changes
- Joint or muscle pain, weakness and/ or swelling
- Sickness or nausea
- Loss and/or change of sense of taste or smell

The following symptoms and signs are less commonly reported in children and young people than in adults:

- Shortness of breath
- Persistent cough
- Pain on breathing
- Palpitations
- Variations in heart rate

Long COVID and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

It is recognised that there is a significant overlap in symptomology between long COVID and ME/CFS but it is unclear whether the coronavirus itself is a potential trigger for ME/CFS or whether the pathophysiology of long COVID is fundamentally different. The relationship between the two conditions is not clear and research is underway to further investigate this.

Given the similarities found in both conditions many of the investigations and management options available are the same, as detailed below.

Investigations

Investigations will be individual to each patient's presenting symptoms. There is currently no single diagnostic test for long COVID. Investigations are to ensure there is no acute condition requiring urgent treatment as well as to rule out other non-COVID-19 related diagnoses.

Investigations may include:

- Baseline observations – heart rate, blood pressure, oxygen saturations
- Blood tests – FBC, blood film, U&Es, LFTs, TFTs, ESR, CRP, blood glucose, coeliac screen, CK, ferritin, vit D and vit B12
- Urinalysis – for blood, protein, glucose

Initial Management

Following assessment and initial investigations to rule out alternative diagnoses many CYP will not require onward referral to secondary care.

Self-management techniques and simple measures, e.g. sleep hygiene advice and gentle exercise can be effective with support of the family and the school. Consider referral to community occupational therapy and/or physiotherapy for further support.

It may be beneficial to create a personalised care plan with the CYP and their guardian which can be reviewed and updated when required. Having a named clinical team member co-ordinating care is helpful to provide continuity and clear communication.

However, referral to paediatric services is required if these measures are ineffective and there is a significant impact on the CYP's education, quality of life or home circumstances.

GPs should refer children and young people presenting with chronic fatigue to routine general paediatric services for initial investigation and management. Children and young people presenting with other suspected 'long COVID' symptoms should be investigated as appropriate within primary care and where necessary be referred to local paediatric pathways for investigation and management.

Referral

Refer the patient to paediatric services via your local pathway guidance

Urgent

- Acute illness
- Signs and symptoms that suggest specific organ impairment e.g. chest pain and/or palpitations
- Ongoing inflammatory or autoimmune response e.g. recurrent fever, joint involvement, rashes or weight loss
- Positive examination findings e.g. hepatosplenomegaly, palpable masses, unexplained bruising or bleeding
- Abnormal investigation results requiring further support

Routine

- Simple measures are ineffective and there is a significant impact on CYP especially regular school absence
- Ongoing symptoms >12 weeks or at >4 weeks and clinical concern
- Unclear diagnosis
- Further investigations required

Consider referring to allied health professional services directly where required, for example:

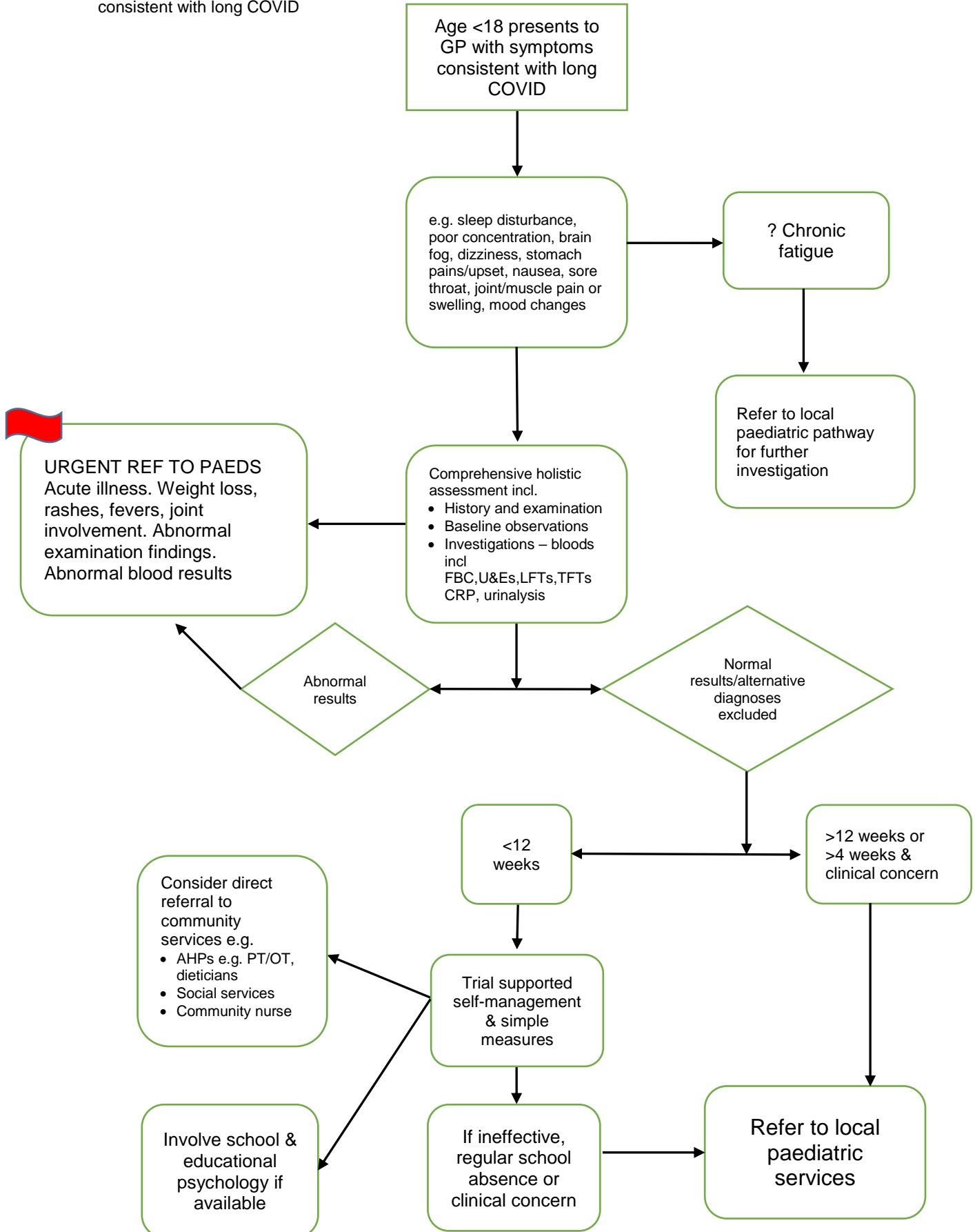
- Physiotherapy
- Occupational therapy

- SALT
- Dietician
- Social services

Further Information

[Long Covid Kids](#) is a UK-based, international charity that represents and supports children and young people living with long COVID and related illnesses, and the parents and caregivers that look after them. See Long Covid Kids [website](#) for online resources and further information.

Figure 5: Assessment, management and referral of children and young people presenting with symptoms consistent with long COVID



16. The patient journey and sources to support self-management

Primary care teams should have rapid access to support in local communities, including local patient groups, community based rehabilitation services, and recourse to usual primary and community care pathways, including physiotherapy, occupational therapy, speech and language, dietetics, podiatry, long term condition management, pain management and social support. It would be beneficial for this to be accessible directly by self-referral from patients after clinical review to exclude other causes. A single point of contact can appropriately involve suitable services.

Many primary care teams now have access to community link workers, pharmacists and mental health support as part of the extended multi-disciplinary team.

Practices can refer people with, or suspected to have long-term effects of COVID-19, into the Chest Heart & Stroke Scotland 'Long Covid Support service'. This service supports people with long-term effects of COVID-19 whether they have been hospitalised or not and is built on the existing Hospital to Home service currently operating in a number of health boards for respiratory conditions.

It provides support and pro-active advice around self-management while awaiting clinical appointments, to complement NHS interventions to encourage self-management and recovery and to take on the non-complex cases allowing pressure to be reduced on the system and for clinicians to be able to work to the top of their licence.

Practices should consider how they can share and signpost people to self-management resources – training and information to [support care navigation](#), links to resources on practice websites, local links through practice patient groups can all support people living with long-term effects of COVID-19.

It should be recognised that many people may have multiple symptoms, and time over more than 1 appointment may be needed to assess a person's physical, psychological and social concerns. Where possible continuity of care, and shared decision making which supports good care planning conversations (and [anticipatory care plans](#) where appropriate) will support positive therapeutic relationships, with the GP as the expert medical generalist working with the extended multi-disciplinary team to support a person's management across health and care.

There is currently insufficient evidence to support or refute the use of graded exercise therapy (GET) in those living with long-term effects of COVID-19. It should be noted that the updated NICE guideline of 29 October 2021 makes it clear that any programme based on fixed incremental increases in physical activity or exercise, for example graded exercise therapy (GET), should not be offered for the treatment of ME/Chronic Fatigue Syndrome. [Advice published from RCOT](#) gives practical support for activities of daily living.

Working across the extended MDT to provide tailored support for people with long-term effects of COVID-19 to manage their condition, (seeking specialist advice where appropriate) should be the cornerstone of local service provision and be

reflected in local pathways which support multi-disciplinary and multi-agency collaboration.

Decisions about specialist referral, and the risks / benefits of further investigations should be explored in partnership with the patient using [Realistic Medicine principles](#), ([Choosing Wisely 'BRAN' questions](#)) recognising that waiting times for referrals or specific investigation may be long, and should not preclude ongoing community rehabilitation and support. Further resources in a range of accessible formats can be found on the [its ok to ask](#) website that support patients in informed decision making regarding their healthcare.

There are a number of national sources of support, including:

Table 5: Further resources for support

Theme	Further information
Sources of direct advice and support [including psychosocial recovery support]	Chest Heart & Stroke Scotland: Long Covid Support Service and Advice Line <ul style="list-style-type: none"> • 0808 801 0899 (free from landline and mobiles) • emailing adviceline@chss.org.uk • texting NURSE to 66777
Peer support (patient led and independent views expressed are their own)	Long Covid Scotland – signposts people with long-term effects of COVID-19 to support, advocacy, resources and opportunities to actively participate in research
Employment and return to work	Faculty of Occupational Medicine – ‘Guidance for healthcare professionals on return to work for patients with post-COVID syndrome’ Society of Occupational Medicine – COVID-19 Return to work guide for recovering workers
Finding local community resources	ALISS (A Local Information System for Scotland) is a service to help you find services, groups and activities which can support health and wellbeing.

The COVID-19 pandemic has highlighted the challenges many people face in accessing information and support to manage their condition, and the impact of the pandemic on all non-COVID-19 related health conditions is yet to be fully realised. However, it has also offered many new opportunities – through increased use of digital consulting, services working closely and planning care together in different ways to support people in their communities, and a recognition of the importance of community support and infrastructure.

17. Acknowledgements

This living document is being developed with the input of Specialty Advisors to the Chief Medical Officer and senior medical advisors to the Scottish Government for;

- Cardiology
- ENT
- Gastroenterology
- Immunology
- Mental Health
- Neuropsychiatry
- Paediatrics and Child Health
- Primary Care
- Respiratory
- Rheumatology
- Stroke.

18. Common symptoms of ongoing symptomatic COVID-19 and post-COVID-19 syndrome (as per SIGN/NICE/RCGP guideline)

Table 7: Common symptoms

Symptoms and signs after acute COVID-19 are highly variable and wide ranging. The most commonly-reported symptoms and signs include (but are not limited to):	
Respiratory Symptoms	<ul style="list-style-type: none"> • Breathlessness • Cough
Cardiovascular Symptoms	<ul style="list-style-type: none"> • Chest tightness • Chest pain • Palpitations
Generalised Symptoms	<ul style="list-style-type: none"> • Fatigue • Fever • Pain
Neurological Symptoms	<ul style="list-style-type: none"> • Cognitive impairment ('brain fog', loss of concentration or memory issues) • Headache • Sleep disturbance • Peripheral neuropathy symptoms (pins and needles and numbness) • Dizziness • Delirium (in older populations) • Mobility impairment • Visual impairment
Gastrointestinal Symptoms	<ul style="list-style-type: none"> • Abdominal pain • Nausea • Diarrhoea • Weight loss and reduced appetite
Musculoskeletal Symptoms	<ul style="list-style-type: none"> • Joint pain • Muscle pain
Psychological / psychiatric symptoms	<ul style="list-style-type: none"> • Symptoms of depression • Symptoms of anxiety • Symptoms of post-traumatic stress disorder
Ear, nose and throat symptoms	<ul style="list-style-type: none"> • Tinnitus • Earache • Sore throat • Dizziness • Loss of taste and/or smell • Nasal congestion
Dermatological	<ul style="list-style-type: none"> • Skin rashes • Hair loss

19. Managing chronic spontaneous urticaria +/- angioedema (CSUA) /related symptoms (including in the context of long COVID)

Definitions

The most common clinical manifestations of histamine release / mast cell degranulation are acute / episodic urticaria (weals) or skin itch, angioedema; and less commonly acute vomiting, abdominal pain and anaphylaxis. Therefore, the diagnosis of mast cell / histamine release mediated conditions relies primarily around clinical history.

Scope

This is a brief guide aimed at Primary Care providers on the approach to diagnosis and management of patients with symptoms of chronic urticaria (weals) +/- angioedema, occurring daily / almost daily for a period lasting > 6 weeks (some patients may be affected by symptoms occurring intermittently over months or years). This brief guide does not replace more detailed guidance issued by NICE and the [British Society of Allergists and Clinical Immunologists](#).

Allergic urticaria and angioedema is usually identified by a clinical history of a temporal relationship of symptoms in relation to a particular food / trigger, by either ingestion or contact. Most episodes of urticaria are **not** allergic. Allergic urticaria/ angioedema; and angioedema due to C1 inhibitor deficiency are outside the scope of this brief guidance note. More information on investigating isolated angioedema (i.e. angioedema without weals) symptoms can be found in complement testing section at [Immunology \(nhslothian.scot\)](#) and is not covered in detail here - please also refer to [Chronic Urticaria and Angioedema - BSACI](#)

Anecdotally, many patients with long COVID have described concomitant symptoms of urticaria and angioedema. It is well recognised that intercurrent infection or post viral illnesses can serve as triggers and exacerbators of urticaria and angioedema symptoms. Understanding the natural course of these symptoms in the context of long COVID, specifically, requires further research. Currently, there is no evidence to suggest that these symptoms arising in the context of long COVID should be managed any differently.

This guidance note does not serve to advise around referral pathways for patients requiring secondary care input, which will vary regionally across Scotland.

Introduction

Urticaria and angioedema is identified clinically. Images of typical appearances are available via the links below:

[Angioedema | DermNet NZ](#)
[Acute urticaria | DermNet NZ](#)

Chronic urticaria (+/- angioedema) affects 2-3% of the population and significantly reduces quality of life. Early recognition of symptoms and instigating treatment is recommended.

Triggers and exacerbators of CSUA

CSUA is not caused by an allergy.

Common recognised triggers of CSUA symptoms include infections (especially viral infection), psychological stress, and NSAIDs medications. There is also an association with hormone fluctuations (e.g association with oral contraceptive pill use in some women), and thyroid autoimmune disease. For many individuals, however, symptoms are largely idiopathic.

The natural history of CSUA is that for most individuals, symptoms 'burn out' with time (6-12 months). For ~20% of individuals with CSUA, they remain symptomatic for many years and some may require specialist referral.

Treatment in CSUA

Treatment is based around symptom control, mainly by anti-histamine therapy which may need to be titrated up to 4 times the standard recommended doses to achieve symptom control. The figure below is inserted from the BSACI guideline: [Chronic Urticaria and Angioedema - BSACI](#)

Step 4 in the figure below would normally be applicable to secondary care management.

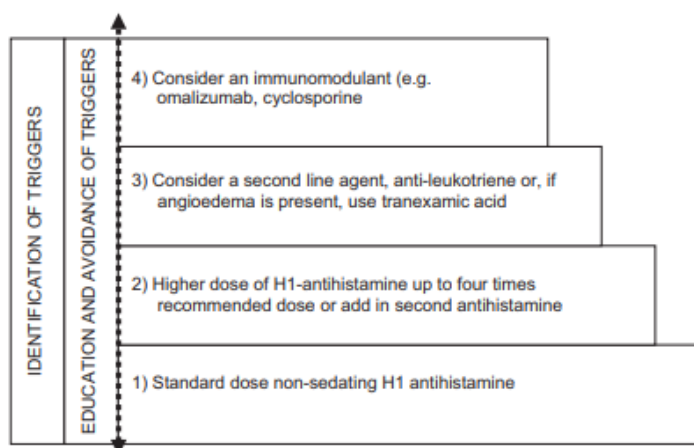


Fig. 2. General management plan for chronic urticaria (Adults and children). The starting point and the rate of progression between steps depend on clinical severity and response. Short course of corticosteroids (e.g. 1 mg/kg prednisolone twice a day, up to 40 mg total per day, for 3 days) may be used for severe exacerbations [74, 146], see also section on rescue medication. The treatment should be stepped down once control is achieved. Observations on the mechanism of antihistamine action [147] suggest that it is probably sensible to withdraw such therapy gradually, rather than stopping it abruptly.

Other resources around Treatment:

NHS Scotland www.dermatology.nhs.scot/dermatology-pathways/pathways/urticaria/

Patient information leaflets on CSUA are available at the links below:

[British Association of Dermatologists - Patient Information Leaflets \(PILs\)](http://bad.org.uk)

[\(bad.org.uk\)](http://bad.org.uk)

[Urticaria and Angioedema | Information on Hives | Allergy UK](#)

Mast Cell Activation Syndrome (MCAS)

MCAS has been characterised by episodic signs and symptoms of systemic anaphylaxis / symptoms associated with mast cell degranulation that concurrently affect at least two organ systems.

Due to the broad range of possible symptoms affecting many organs, the MCAS diagnostic label may be used to inappropriately ascribe many symptoms to, e.g fatigue, rashes of many sorts, chronic illness, oedema, adenopathy, tinnitus, brain fog and many others – all of which are not associated with mast cell / histamine induced symptoms. In addition, many symptoms which can less commonly be associated with histamine release e.g flushing and diarrhoea may be more chronic rather than episodic, which again would point towards other underlying diagnoses. This can cause marked uncertainty for patients and indeed lead to misdiagnosis.

In some forums / groups, certain disorders have been used to diagnose MCAS with no scientific basis / evidence for any association with mast cell activation. Such conditions include Ehlers-Danlos syndrome, postural orthostatic tachycardia syndrome (PoTS), sclerosing mediastinitis, psychiatric and other idiopathic disorders and others.

A detailed consensus document on MCAS can be found at [AAAAI Mast Cell Disorders Committee Work Group Report: Mast cell activation syndrome \(MCAS\) diagnosis and management](#) (2019)

Summary

The clinical characterisation of a patient's symptoms in terms of urticaria / angioedema / CSUA is much more useful, clinically, and helps tailor effective treatment more specifically for the patient. In the context of long COVID / the COVID-19 pandemic, it would be reasonable to expect that more individuals will present with symptoms of urticaria, angioedema and idiopathic anaphylaxis – all of which can be precipitated and associated with infections, as well as any other acute or prolonged physiological or psychological stresses.

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Date: March 2021 Reviewed Dec 2021