# 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

<table>
<thead>
<tr>
<th>Version</th>
<th>Date</th>
<th>Summary of changes (page numbers refer to the version described)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.0</td>
<td>05/05/21</td>
<td>First version of document published</td>
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</tbody>
</table>
| 2.0     | 01/02/22 | Page 2 – addition of contents page
Page 5 – addition of COVID-19 related ICD codes. Updated definition of post-COVID 19 syndrome
Page 6 – addition of follow up advice
Page 7 – updated figure 1 with new investigations and rehab advice
Page 8 – addition of guidance with underserved or vulnerable groups
Page 9 – addition of heart rate monitoring for suspected PoTS
Page 12 – updated wording in figure 2
Page 14 – addition of further advice regarding delirium and dementia
Page 18 – updated guidance for smell training
Page 19 – updated wording within section 12, added advice in section 13 regarding investigation of GI symptoms
Page 21 – updated advice on rehabilitation measures included link to its-ok-to-ask website
Page 22 – updated contact information for support services
Page 25 – added symptoms in neurology, gastrointestinal, psychological and psychiatric, ENT & dermatology |
| 2.1     | 06/05/22 | Page 19 – added signs and symptoms for CYP
Page 20 – added detail for investigation and management
Page 21 – added referral guidance for CYP
Page 22 – added flow chart for CYP |
Contents
1. Who is this for? .................................................................................................... 3
2. What does it provide? .......................................................................................... 3
3. Recording within primary care information systems ............................................. 4
4. Community management ..................................................................................... 6
5. Symptom specific management guidance for primary care ................................. 8
6. Additional specialty advice to support primary care management ..................... 12
7. Respiratory symptoms ....................................................................................... 12
8. Cardiology symptoms and tests ......................................................................... 13
9. Neurological and neuropsychiatric symptoms .................................................... 14
10. Stroke ................................................................................................................ 17
11. Change or loss of smell (anosmia, hyposmia or cacosmia) ............................... 17
12. Musculoskeletal symptoms ................................................................................ 17
13. Gastrointestinal symptoms ................................................................................ 18
14. Chronic spontaneous urticarial +/- angioedema (CUSA) and related symptoms 18
15. Children and young people with symptoms consistent with the long-term effects of COVID-19 ............................................................................................................. 19
16. The patient journey and sources to support self-management .......................... 23
17. Acknowledgements ........................................................................................... 26
18. Common symptoms of ongoing symptomatic COVID-19 and post-COVID-19 syndrome (as per SIGN/NICE/RCGP guideline) ................................................................. 27
19. Managing chronic spontaneous urticaria +/- angioedema (CSUA) /related symptoms (including in the context of Long Covid) ................................................................. 28
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

<table>
<thead>
<tr>
<th>System</th>
<th>Term</th>
<th>Search keyword</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>EMIS PCS</td>
<td>Acute COVID-19 infection</td>
<td>Acute COV</td>
<td>^ESCT1348646</td>
</tr>
<tr>
<td>EMIS PCS</td>
<td>Ongoing symptomatic COVID-19</td>
<td>Ongoing cov</td>
<td>^ESCT1348648</td>
</tr>
<tr>
<td>EMIS PCS</td>
<td>Post-COVID-19 syndrome</td>
<td>Post-COV</td>
<td>^ESCT1348645</td>
</tr>
<tr>
<td>Vision</td>
<td>Acute disease caused SARS-CoV-2</td>
<td>CORONA</td>
<td>A795400</td>
</tr>
<tr>
<td>Vision</td>
<td>Ongoing symptomatic COVID-19</td>
<td>CORONA</td>
<td>A7955</td>
</tr>
<tr>
<td>Vision</td>
<td>Post-COVID-19 syndrome</td>
<td>POSTCOVID</td>
<td>AyuJC</td>
</tr>
</tbody>
</table>

- ‘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

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

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**

**Person presents to primary care with ongoing symptoms**
Consider:
May / may not have had previous positive test. History of admission / ITU

**Consultation: History and examination. Investigations as required, based on symptoms.**
Consider:
- Blood tests which may include FBC, LFTs, U+E, CRP, ferritin (assessing inflammatory response), BNP, HbA1c, anti-TTG and TFFs
- H. pylori antigen, QFIT faecal calprotectin
- Chest X-ray, ECG
- Exercise tolerance e.g. 1 minute sit to stand (RR, HR and SpO2)
- Lying and standing BP or 3 minute active stand for OH
- L&S HR recording e.g. for 10 mins for ?PoTS

Person-centred assessment to reflect impact on their day to day life pre and post COVID-19
Screening tools (alongside clinical assessment) to capture symptoms and functional impact

**Referral to local rehab team**

**Supported self-management** (SEE ALSO “What matters to you?”)
Consider:
- NHS inform - Coronavirus (COVID-19): Longer-term effects (long COVID)
- SIGN Long Covid patient booklet
- Direct referral where appropriate from primary care to Chest Heart & Stroke Scotland: Long COVID Support Service and Advice Line - 0808 801 0899
- ALISS (A Local Information System for Scotland) – directory of local resources supporting health and wellbeing

**Specialist referral if required following primary care Ix**
Urgent referral in following:
- Severe hypoxaemia (SpO2 <94%) or oxygen desaturation on exercise
- Signs of severe lung disease
- Cardiac chest pain or abnormal ECG
- Severe psychiatric symptoms or at risk
- Multi-system inflammatory syndrome (in children)
- Other clinical concerns

**Symptoms improve: Continue supported self–management (See Self Management Resources)**

**Ongoing symptoms - not resolving with self-management, or require more support (note that symptoms may be wide ranging and relapsing/remitting)**

**Generalised symptoms beyond respiratory symptoms alone**
Community based rehabilitation: Holistic assessment of need including:
- Mobility
- Self-care for daily activities
- Ongoing post viral fatigue
- Swallowing or dietary problems
- Information on pacing and activity management
- RCOT 3 PDF guides on managing post viral fatigue and conserving energy

**Ongoing respiratory symptoms only:**
Community respiratory team for assessment/rehab consider:
- Underlying respiratory condition
- Non improving or worsening breathlessness
- Requires short/long term ambulatory oxygen
- Disproportionate SOB or breathing patterns
- (Chest heart and stroke Scotland) essential guide on managing breathlessness or referral to CHSS Hospital to Home Long Covid/respiratory programme [where health board has agreement in place]
- Asthma UK and BLF guide – Long COVID and your lungs

**Other resources to consider:**
- The ALLIANCE: Accessible information on self management
- Chartered Society of Physiotherapy: PDF COVID Recovery Activity Planner
- Chest Heart & Stroke Scotland: Long COVID Support Service and Advice Line - 0808 801 0899
- Faculty of Occupational Medicine - Guidance for healthcare professionals on return to work for patients with Long COVID
- Choosing Wisely ‘BRAN’ questions - supporting people to weigh up the potential benefits, harms and limitations of the available options available to them
- NICE: Long-term sickness absence and capability to work
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

<table>
<thead>
<tr>
<th>Long-term COVID-19 symptom or sign</th>
<th>Considerations specific to COVID-19</th>
<th>Initial investigations to consider / resources to support</th>
<th>Red flags</th>
</tr>
</thead>
</table>
| Fatigue                           | • 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 | • Consider bloods as part of clinical assessment  
  • Modified Fatigue Impact Scale | • Consider underlying cardio/respiratory disease |
| Breathlessness                    | • On exertion – may persist for many weeks to months, usually with a gradual recovery  
  • Consider increased risk of VTE/PE post COVID-19 infection  
  • Intermittent chest pain not unusual | • 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                             | • Can persist for some weeks | • Consider sputum culture if productive  
  • Any antibiotic treatment should follow current guidelines  
  • Follow local guidelines for suspected asthma/COPD | • Be mindful of national criteria for suspicion of lung cancer |
### Palpitations/ tachycardia
- May need to exclude eg infection
- Bloods (incl TFTs)
- Lying and standing BP
- ECG
- Consider orthostatic hypotension- NICE guidance
- HR monitoring for suspected PoTS
- Urgent and non-urgent referral criteria for palpitations

### Neurological symptoms
- 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
- 4AT tool and SIGN guideline if delirium
- Information on functional cognitive disorders from neurosymptoms.org and BMJ
- Full guidance on assessment and management below
- Focal neurological symptoms or stroke should be referred as per local pathways

### Anosmia
- Very common – up to 50%
- Commonly improves over a few weeks
- Associated nasal symptoms
- Neurological symptoms
- ‘NoseWell’ – guide created by abScent and British Rhinological Society
- Consider MRI / ENT referral if uncertainty or neurological finding

### Pain
- Commonly encountered symptoms of headache, abdominal pain, musculoskeletal pains
- Recovery may be prolonged
- Consider impacts on activities as well as personal and professional roles
- 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
- Can persist for weeks to months but should resolve
- PUO work up should be considered
- Unexplained weight loss
- Persistent lymphadenopathy
| **Mental health including low mood, PTSD, anxiety.** | **Common features** post COVID-19 infection  
PTSD may be as a result of hospital admission / ITU –ask about intrusive thoughts, nightmares, avoiding behaviours  
HDU/ITU patients may also be followed up through specialist services  
Multiple factors- carer strain, employment, finance, relationship strain or loss of support  
Immediate risk of self-harm  
Neurocognitive problems in presence of new or pre-existing neurological diagnosis | **Consider screening tools** such as:  
CORE10 for psychological distress,  
PHQ9 for depression,  
GAD7 for anxiety,  
PCL5 for PTSD.  
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 | **Neurocognitive problems in presence of new or pre-existing neurological diagnosis** |
|-------|-------------------------------------------------|-------------------------------------------------|------------------------|
| **Urticaria, angioedema** | 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 | 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 | **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

Many patients with post-COVID-19 syndrome have co-existing cardiovascular disease which may be the cause of their symptoms. They should follow appropriate referral pathways for suspected MI, angina or heart failure.

• Most common cardiac symptoms include:
  • Breathlessness
  • Chest Pain
  • Palpitation (if associated light headedness, may be part of a PoTS presentation)

Clinically significant long-term cardiac involvement post-COVID-19 infection appears to be uncommon.

First steps in excluding cardiac involvement are:

• In line with local referral protocols, the following should be undertaken;
  • Routine bloods including FBC, TSH, U+Es, LFTs
  • ECG
  • Chest X-Ray
  • NT-pro-BNP (if mainly dyspnoea)
    • Normal ECG and NT-pro-BNP <400ng/L makes heart failure very unlikely
  • hs-Troponin I (if mainly chest pain)
    • hs-Troponin I <4 ng/L excludes active myocarditis

Discussion with local Cardiology services is always helpful in cases where results are mildly abnormal and may be explained by other clinical factors.

• Reassure if all tests results are within a normal range
• Offer access to local rehabilitation programmes
• Discuss with Cardiology if concerns about mildly abnormal results
• Refer if clinical heart failure or NT-pro-BNP >2000 ng/L
• Conservative measures for POTS-type presentation (hydration 3L/24h, increase salt intake, exercise)
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 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

<table>
<thead>
<tr>
<th>Features of individual with functional cognitive disorders</th>
<th>Features of individual with degenerative brain disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attends alone</td>
<td>Attends with someone</td>
</tr>
<tr>
<td>Patient more aware of the problem than others</td>
<td>Others more aware of the problem than patient</td>
</tr>
<tr>
<td>Answers independently</td>
<td>Turns to accompanying adult for support in answering questions (eg, head turn sign)</td>
</tr>
<tr>
<td>Speaks for longer in response to open question about nature of difficulties</td>
<td>Answers briefly in response to open question (&lt;1 minute)</td>
</tr>
<tr>
<td>Gives a detailed description of complaints (might bring written list)</td>
<td>Absence of details when describing symptoms</td>
</tr>
<tr>
<td>Frequently offers elaboration and detail</td>
<td>Unlikely to give spontaneous elaboration or detail</td>
</tr>
<tr>
<td>Can answer questions with multiple components</td>
<td>Can only answer single-component questions</td>
</tr>
<tr>
<td>Detailed account of personal history, drugs, and previous interactions with doctors</td>
<td>Less detailed account</td>
</tr>
<tr>
<td>Loss of recent and remote autobiographical memories</td>
<td>Relative preservation of remote autobiographical memories</td>
</tr>
<tr>
<td>Complaint of memory gaps for specific periods and events</td>
<td>Complaint of specific memory gaps unusual</td>
</tr>
<tr>
<td>Inattentive memory symptoms, within most people's normal experience</td>
<td>Memory symptoms are often outside normal experience</td>
</tr>
<tr>
<td>Reports exceptional pre-morbid cognitive function</td>
<td>Views current and past cognitive function as normal</td>
</tr>
<tr>
<td>Evidence of active cognitive engagement with current news, media, and social media</td>
<td>May be unaware of current events; poorly engaged with media or social media</td>
</tr>
<tr>
<td>Dates symptom onset with precision</td>
<td>Difficult to pinpoint date of onset</td>
</tr>
<tr>
<td>Unstable longitudinal course</td>
<td>Cognitive impairment progressive over time</td>
</tr>
<tr>
<td>Marked variability</td>
<td>Less variability</td>
</tr>
</tbody>
</table>
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 and 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 a 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 possible feelings of worry or distress
- Consider other diagnoses for their presentation and investigate appropriately
- Be mindful that those with special education needs or neurodisability 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
- 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 tiredness
- Dizziness
- Rashes
- Brain fog (difficulties with memory and concentration)
- Headaches
- Chest pain
- Stomach pain or upset
- Sore throat
- Mood changes
• Joint or muscle or swelling
• Sickness or nausea

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 or life threatening 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 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.

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 specialist paediatric services for investigation and management.

**Referral**

Refer the patient to paediatric services via your local pathway guidance

**Urgent**
- Acute or life threatening 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

**Further Information**

[Long COVID Kids](#) is a charity that provides support to CYP with long COVID and their families. They have produced online resources for further information.
Figure 5: Assessment, management and referral of children and young people presenting with symptoms consistent with long COVID

Age <18 presents to GP with symptoms consistent with long COVID

- Comprehensive holistic assessment incl.
  - History and examination
  - Baseline observations
  - Investigations – bloods incl FBC, U&Es, LFTs, TFTs, CRP, urinalysis

- e.g. sleep disturbance, poor concentration, brain fog, dizziness, stomach pains/upset, nausea, sore throat, joint/muscle pain or swelling, mood changes

- ? Chronic fatigue

- URGENT REF TO PAEDS
  - Acute illness. Weight loss, rashes, fevers, joint involvement. Abnormal examination findings. Abnormal blood results

- Refer to local paediatric services for further investigation

- Normal results/alternative diagnoses excluded

- Abnormal results

- >12 weeks or >4 weeks & clinical concern

- If ineffective, regular school absence or clinical concern

- Refer to local paediatric services

- <12 weeks

- Trial supported self management/simple measures

- Involve school, educational psychology if available
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

<table>
<thead>
<tr>
<th>Theme</th>
<th>Further information</th>
</tr>
</thead>
</table>
| Sources of direct advice and support [including psychosocial recovery support] | Chest Heart & Stroke Scotland: Long COVID Support Service and Advice Line  
- 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 long-COVID’  
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.
Table 6: Additional resources for healthcare teams

<table>
<thead>
<tr>
<th>Resource</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Long COVID marketing toolkit</strong></td>
<td>Contains useful campaign materials which healthcare teams can share with their service users, including:</td>
</tr>
<tr>
<td></td>
<td>• Poster (A1, A3 and A4)</td>
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<tr>
<td></td>
<td>• Social media post (Facebook, Instagram and Twitter)</td>
</tr>
<tr>
<td></td>
<td>• Summary sheet in multiple languages and formats</td>
</tr>
<tr>
<td></td>
<td>• WhatsApp/text message copy</td>
</tr>
<tr>
<td><strong>Primary Care Resilience Series</strong></td>
<td>Webinar featuring contributions on a number of aspects of long COVID, including:</td>
</tr>
<tr>
<td><strong>Webinar recording – 7 October 2021</strong></td>
<td>• Update of the SIGN/NICE/RCGP clinical guideline</td>
</tr>
<tr>
<td></td>
<td>• Respiratory perspective</td>
</tr>
<tr>
<td></td>
<td>• Occupational therapy and long COVID</td>
</tr>
<tr>
<td></td>
<td>• Neuropsychiatric symptoms</td>
</tr>
<tr>
<td><strong>SIGN Decision Support Tool</strong></td>
<td>Mobile App (Android and Apple iOS) and accompanying website provides a single, integrated point of access to key information contained in the SIGN/NICE/RCGP guideline, and the Implementation Support Note.</td>
</tr>
<tr>
<td><strong>SIGN Patient Decision Support Tool</strong></td>
<td>Mobile App (Android and Apple iOS) and accompanying website offering information and guidance for patients from SIGN’s patient booklet. It includes an interactive symptom diary for recording and tracking symptoms and sharing with healthcare professionals.</td>
</tr>
<tr>
<td><strong>RCGP Learning – long term effects of COVID-19 and Post COVID-19 Syndrome</strong></td>
<td>eLearning module introduces;</td>
</tr>
<tr>
<td></td>
<td>• the key recommendations from the NICE/SIGN/RCGP guidance,</td>
</tr>
<tr>
<td></td>
<td>• Post-COVID-19’s impact on patients</td>
</tr>
<tr>
<td></td>
<td>• how to manage symptoms and expectations in primary care.</td>
</tr>
</tbody>
</table>
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

<table>
<thead>
<tr>
<th>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):</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respiratory Symptoms</td>
</tr>
<tr>
<td>• Breathlessness</td>
</tr>
<tr>
<td>• Cough</td>
</tr>
<tr>
<td>Cardiovascular Symptoms</td>
</tr>
<tr>
<td>• Chest tightness</td>
</tr>
<tr>
<td>• Chest pain</td>
</tr>
<tr>
<td>• Palpitations</td>
</tr>
<tr>
<td>Generalised Symptoms</td>
</tr>
<tr>
<td>• Fatigue</td>
</tr>
<tr>
<td>• Fever</td>
</tr>
<tr>
<td>• Pain</td>
</tr>
<tr>
<td>Neurological Symptoms</td>
</tr>
<tr>
<td>• Cognitive impairment (‘brain fog’, loss of concentration or memory issues)</td>
</tr>
<tr>
<td>• Headache</td>
</tr>
<tr>
<td>• Sleep disturbance</td>
</tr>
<tr>
<td>• Peripheral neuropathy symptoms (pins and needles and numbness)</td>
</tr>
<tr>
<td>• Dizziness</td>
</tr>
<tr>
<td>• Delirium (in older populations)</td>
</tr>
<tr>
<td>• Mobility impairment</td>
</tr>
<tr>
<td>• Visual impairment</td>
</tr>
<tr>
<td>Gastrointestinal Symptoms</td>
</tr>
<tr>
<td>• Abdominal pain</td>
</tr>
<tr>
<td>• Nausea</td>
</tr>
<tr>
<td>• Diarrhoea</td>
</tr>
<tr>
<td>• Weight loss and reduced appetite</td>
</tr>
<tr>
<td>Musculoskeletal Symptoms</td>
</tr>
<tr>
<td>• Joint pain</td>
</tr>
<tr>
<td>• Muscle pain</td>
</tr>
<tr>
<td>Psychological / psychiatric symptoms</td>
</tr>
<tr>
<td>• Symptoms of depression</td>
</tr>
<tr>
<td>• Symptoms of anxiety</td>
</tr>
<tr>
<td>• Symptoms of post-traumatic stress disorder</td>
</tr>
<tr>
<td>Ear, nose and throat symptoms</td>
</tr>
<tr>
<td>• Tinnitus</td>
</tr>
<tr>
<td>• Earache</td>
</tr>
<tr>
<td>• Sore throat</td>
</tr>
<tr>
<td>• Dizziness</td>
</tr>
<tr>
<td>• Loss of taste and/or smell</td>
</tr>
<tr>
<td>• Nasal congestion</td>
</tr>
<tr>
<td>Dermatological</td>
</tr>
<tr>
<td>• Skin rashes</td>
</tr>
<tr>
<td>• Hair loss</td>
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</tbody>
</table>
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.
Other resources around Treatment:


Patient information leaflets on CSUA are available at the links below:
[British Association of Dermatologists - Patient Information Leaflets (PILs) (bad.org.uk)](https://www.bad.org.uk)
[Urticaria and Angioedema | Information on Hives | Allergy UK](https://www.allergyuk.org)

**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)](https://www.aaaai.org/)

**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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