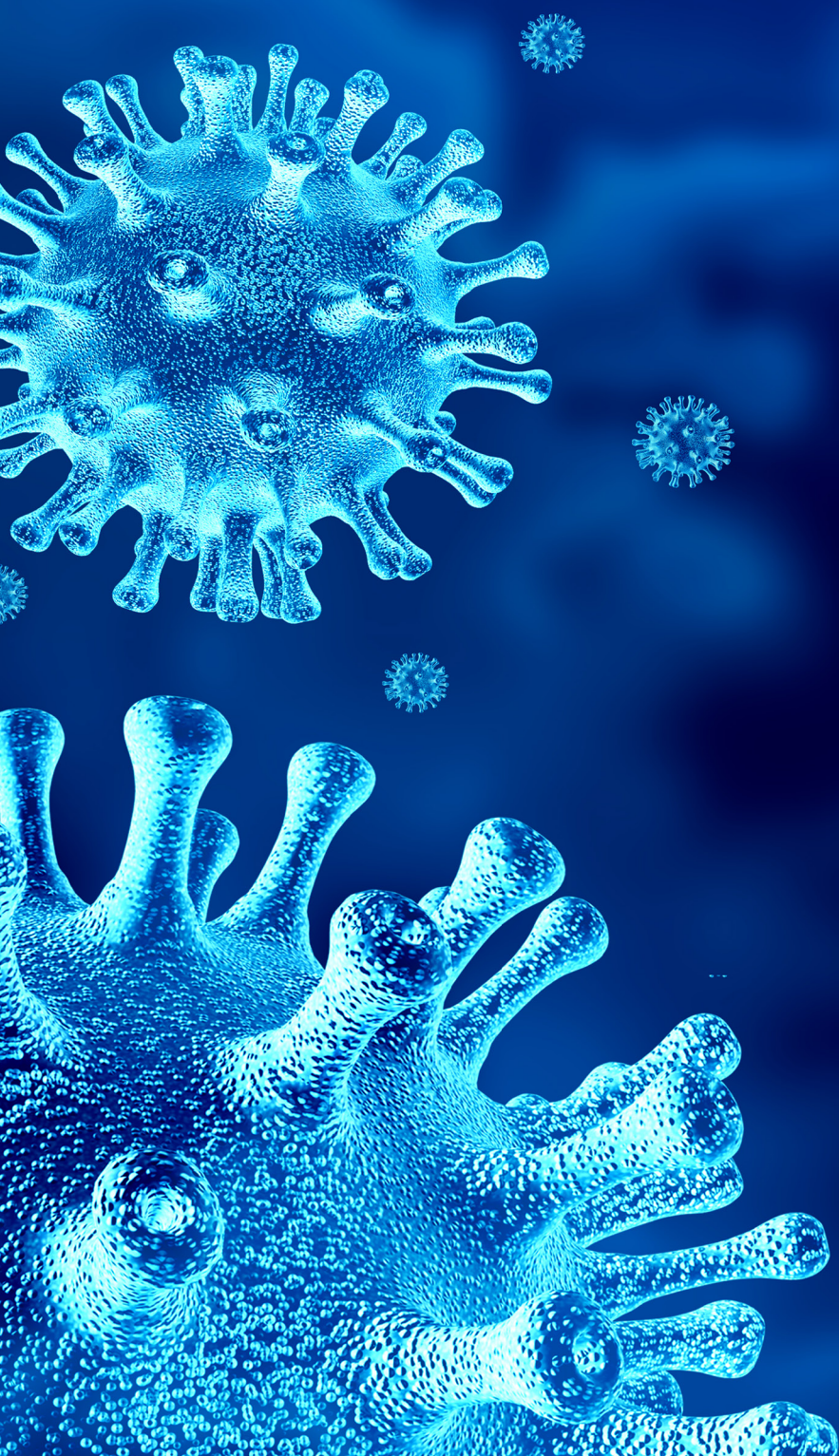


POST COVID-19 FATIGUE,  
POST/LONG COVID-19 SYNDROMES  
AND POST-COVID ME/CFS

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THE ME ASSOCIATION

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# 01

## INTRODUCTION and KEY MESSAGES

Back in April the ME Association (MEA) became aware of an increasing number of people who had been ill with COVID-19 and were not improving, even after several weeks.

Almost all had been self-managed at home with an illness that mostly varied from mild to moderate in severity, but not requiring hospital admission.

Most had debilitating fatigue, sometimes with continuing COVID-19 symptoms involving the lungs or heart in particular. Some had symptoms that are more consistent with the sort of post viral fatigue syndromes that may precede ME/CFS. Five months on and we are now in a situation where some people are being given a diagnosis, or a possible diagnosis, of post COVID-19 ME/CFS.

Back in April we produced an MEA guide to post COVID fatigue and post COVID fatigue syndromes. This information and guidance has now been fully updated to cover all the developments that have occurred since then.

■ At present, we have no firm indication as to how many people are experiencing persisting ill health following COVID-19. However, if current estimates of around 10% of people who were home managed are accurate, this could translate into around 60,000 people with some form of post COVID ill health that has persisted beyond a month. According to Tim Spector, professor of genetic epidemiology at King's College London, around 12% of sufferers report symptoms to the Covid Tracker app for longer than 30 days. One in 200 says the effects last for more than 90 days."

Ref: <https://tinyurl.com/y3dnerj5>

- Long COVID, post COVID fatigue and post COVID syndrome are all being used as diagnostic labels.
- Many have debilitating fatigue as a primary symptom.
- Some have respiratory, heart and other symptoms that are the same, or very similar, to their acute infection - i.e. breathlessness, palpitations, intermittent fevers, loss of taste or smell.
- Others have symptoms that are very similar to those seen in post viral fatigue syndromes that can follow any infective illness and may precede ME/CFS.
- Some have a combination of post viral fatigue syndrome symptoms and acute COVID-19 infection symptoms.
- In cases where post COVID syndrome symptoms have persisted for more than three months, and are consistent with those of ME/CFS, a diagnosis of post COVID ME/CFS should be considered.
- The MEA has longstanding experience in the management of post viral debility, post viral fatigue syndromes and post infection ME/CFS.
- The information and guidance in this leaflet should therefore be of help to people in relation to the management of post COVID fatigue and some aspects of post COVID syndromes where they overlap with ME/CFS symptomatology.

## 02 The current situation regarding POST COVID-19 FATIGUE, POST COVID-19 SYNDROMES, POST COVID-19 ME/CFS and COVID-19 in people who already have ME/CFS

Most of the people we have been dealing with fall into one of four broad groups. However, there is quite a lot of overlap and not everyone fits neatly into one of these groups

### 02.1 Post COVID-19 Intensive Care/Hospital Care Syndrome

This group is confined to people who have been sufficiently unwell to require hospital-based treatment. They often had significant respiratory, cardiovascular and/or blood clotting complications whilst in hospital. They now have a range of health and disability problems that are frequently seen in people who have been treated in intensive care units and required ventilation.

These problems include loss of muscle mass (people can lose around 3% of muscle mass per day whilst in intensive care), cognitive dysfunction (from reduced levels of oxygen to the brain), loss of taste and smell and complications relating to ventilation tubes, catheters etc. Some also had gastrointestinal and neurological involvement. Not surprisingly many people in this group also have debilitating fatigue.

This group are likely to require a prolonged period of specialist rehabilitation – preferably under the care of a multidisciplinary hospital-based team that is used to dealing with respiratory, neurological and cardiovascular rehabilitation. The new rehabilitation unit at Headley Court – the Seacole Centre - in Surrey is an example of the care facilities that are being set up for this group.

### 02.2 Post COVID-19 and Long COVID-19 Syndromes

This group consists of people who are still suffering from most or all of the initial symptoms of COVID. Most were self-managed at home and often had no significant contact with health professionals while they were ill.

They still have COVID-19 symptoms such as breathlessness, a dry cough, 'lung burn', palpitations, fevers, loss of smell or taste. These symptoms are often accompanied by debilitating fatigue – but not always.

In some cases, the symptoms are fairly constant. In others, the overall clinical picture fluctuates – sometimes quite dramatically. So they may have days, or parts of a day, when they feel reasonably well. The symptoms then recur – sometimes following undue exertion. Sometimes for no apparent reason.

## 02.3 Post COVID-19 and Long COVID-19 Fatigue Syndrome

This group have a range of symptoms that are more consistent with the sort of post-viral fatigue syndromes (PVFS) that we are used to dealing with in people who go on to develop ME/CFS. Symptoms relating to the initial infection are generally less prominent and may be completely absent. However, in some cases there are additional and significant respiratory or cardiac symptoms.

In addition to the debilitating activity-induced muscle fatigue, they may have muscle and joint pains, 'brain fog' / cognitive dysfunction (problems with short term/working memory, concentration, information processing), orthostatic intolerance (problems in remaining upright, feeling dizzy or faint), unrefreshing sleep and the cardinal feature of ME/CFS – post-exertional malaise (PEM) or symptom exacerbation.

## 02.4 Post COVID-19 ME/CFS

Where post COVID fatigue syndrome symptoms have persisted for more than three or four months, some people are now being given a diagnosis of post COVID ME/CFS, or possible post COVID ME/CFS.

This is not surprising given the fact that:

- Fatigue is a very prominent symptom of COVID-19.
- SARS (severe acute respiratory syndrome), which is another coronavirus infection, produced a severe and protracted ME/CFS-like illness in a significant number of people when it occurred in 2002/3.
- COVID-19 triggers the release of immune system chemicals called cytokines, especially interleukins 6 and 10, and sometimes in excessive amounts. These cytokines are also thought to play a key role in the causation of and perpetuation of ME/CFS.

## 02.5 COVID-19 in people who already have ME/CFS

We have also been dealing with people who already have ME/CFS and have caught COVID-19. They have, not surprisingly, had a significant exacerbation or relapse of their ME/CFS symptoms. However, it is interesting to note that we have received very few reports about people with ME/CFS being seriously ill with COVID-19 and being admitted to hospital. We have received very few reports about children and adolescents with ME/CFS catching COVID-19.

## 03

### Patient Evidence – ‘Citizen Science’ - on Post COVID-10 and Long COVID-19 Fatigue

People with what has become known as ‘Long COVID’ have been making some very valuable contributions on internet forums and support groups to aid our understanding of what is happening and how we should be managing these conditions.

As happens with ME/CFS, there appears to be a significant female to male bias in people with Long/Post COVID-19 - but not as large as in ME/CFS. Many are also previously fit young adults in their 20s, 30s and 40s. What is notable is the number who were regularly taking part in regular sporting activities, including running, and/or are health professionals.

Professor Paul Garner, an infectious disease specialist from Liverpool, has been writing a series of very informative blogs for the British Medical Journal:

**Paul Garner, COVID-19 - A Game of Snakes and Ladders:**

<https://tinyurl.com/yab6no8e>

**Paul Garner on long haul covid-19 — Don't try to dominate this virus, accommodate it:**

<https://tinyurl.com/yyv52v5t>

**A series of very useful educational videos has also been produced by a person with Long COVID:**

<https://tinyurl.com/y5jpfptz>

**A group of health professionals who are suffering from Post/Long COVID symptoms have written to the British Medical Journal with a manifesto for tackling persistent COVID-19 symptoms:**

*Alwan NA et al. From doctors as patients: a manifesto for tackling persisting symptoms of covid-19*

*British Medical Journal 2020; 370*

<https://tinyurl.com/y62b4mha>

## 04 What do we already know about POST VIRAL FATIGUE, POST-VIRAL FATIGUE SYNDROMES and the development of ME/CFS?

### 04.1 Post Viral Fatigue

Some degree of post-viral fatigue (PVF) or debility is a fairly common occurrence after any type of viral infection.

In most cases this is short lived and there is normally a steady return to normal health and activity levels over a period of a few weeks. However, a full return to normal health can take rather longer.

Additional symptoms may also develop, where the term post-viral fatigue syndrome (PVFS) becomes a more appropriate diagnosis.

### 04.2 What causes Post Viral fatigue and Post COVID-19 Fatigue?

The situation with persisting fatigue following coronavirus infection is turning out to be far more complicated than what happens with most other viral illnesses. It is also more serious - as fatigue and lack of energy are a very characteristic symptom of the acute infection.

The precise explanation for what causes post viral fatigue remains uncertain. But one of the reasons why people have fatigue, loss of energy, muscular aches and pains, and generally feel unwell, when they have an acute infection is the production of chemicals called cytokines by the body's immune system. These immune system chemicals form part of the front line response to any viral infection. And in people who develop serious respiratory complications with coronavirus infection, this appears to be partly due to an overactive immune response involving what is being termed a 'cytokine storm'.

When fatigue and flu-like symptoms persist for a longer period of time once the acute infection is over, as they do in ME/CFS, there is growing research evidence to indicate that what is a perfectly normal immune system response to the acute infection has not returned to normal and there is on-going immune system activation.

It is also possible that, as happens with ME/CFS, there is a problem with the way in which energy production is taking place at a cellular level in structures called mitochondria.

We are still on a very steep learning curve when it comes to understanding how this particular coronavirus behaves. However, there is no evidence to indicate that it persists like hepatitis C infection or HIV. So the continuing fatigue does not appear to be due to a persisting viral infection. Consequently, people who have continuing fatigue, but no other coronavirus symptoms, appear to be no longer infective to others in our current state of knowledge.

While the vast majority of people with post-infection fatigue will improve and return to normal health, good management during the very early stage is an important factor in trying to help any natural recovery process take place. Patient evidence also indicates that good initial management of post viral fatigue and post viral fatigue syndromes reduces the likelihood of this turning into ME/CFS.

## 04.3 Post Viral Fatigue Syndromes

Where a period of post-viral fatigue persists and fails to improve after more than a few weeks, and is accompanied by other symptoms, a diagnosis of a post viral fatigue syndrome is often more appropriate

**Symptoms that are typical of a general post viral fatigue syndrome (PVFS) are:**

### ■ ACTIVITY INDUCED FATIGUE:

In practical terms this means no longer being able to carry out a normal range of physical activities in the home, at work or school, or anywhere else.

In terms of severity this can range from a relatively mild impairment to a really quite severe functional impairment.

A useful comparison here is trying to operate a radio with a battery that no longer functions properly. The radio may work reasonably well for short periods of time but then starts to fail quite quickly. After a rest it will work again - but only for another short period.

In a similar manner, people with a PVFS find they can carry out short periods of physical and/or mental activity but then have to stop and rest and 'recharge their batteries'. They are no longer able to sustain their normal levels of physical activity and find anything that involves using a large amount of energy in a short period of time, such as going for a run, is no longer possible.

There is no loss of motivation to do things - as occurs in the 'tired all the time' fatigue that often forms part of a depressive illness.

### ■ SLEEP DISTURBANCE:

During the actual infection, and shortly afterwards, this may involve sleeping for much longer than usual - as well as wanting to sleep for periods during the day. This type of excessive sleep is known as hypersomnia and is a natural part of the way in which human body responds to and recovers from an infective illness. As time goes on hypersomnia often decreases and is replaced by other types of sleep disturbance - including fragmented sleep.

### ■ COGNITIVE DYSFUNCTION:

Just as energy is required for physical activity, it is also required for mental/cognitive activity. So in a similar way to easily running out of energy when doing a physical task, people cannot cope with longer periods of mental/cognitive activity and start to lose concentration and their ability to process and retrieve information. Short-term (working) memory may also be affected.



#### ■ ORTHOSTATIC INTOLERANCE AND OTHER SYMPTOMS OF DYSAUTONOMIA:

This is caused by a problem with what is called the autonomic nervous system - a part of the brain that helps to regulate pulse and blood pressure when we move from lying or sitting to standing. **Orthostatic intolerance** means being unable to stand and do things for any length of time. This can be accompanied by a **postural orthostatic tachycardia syndrome** (where the pulse rate rises when standing and makes people feel dizzy, faint, and nauseous) or **postural hypotension** (where the blood pressure falls on standing). The medical term for these autonomic symptoms is **dysautonomia**.

## 04.4 PVFS and possible progression to ME/CFS

Many cases of PVFS slowly resolve and people return to normal health. However, if PVFS symptoms persist for more than two to three months, and continue to cause a significant degree of functional impairment that prevents a return to education, employment or other key activities, a diagnosis of ME/CFS should be considered.

Other symptoms that can form part of a PVFS and are also very suggestive of a diagnosis of ME/CFS include:

- Alcohol intolerance
- Balance problems
- Headaches
- Muscle or joint pain but without swelling or inflammation
- Sore throats, tender glands and flu-like feelings
- Problems with temperature control - including increased sensitivity to hot and cold temperatures
- Post exertional malaise/symptom exacerbation

## 05

### Management of Post Viral/COVID-19 Fatigue and Post COVID-19 Fatigue

This information and guidance relates to post COVID-19 fatigue and a post COVID-19 fatigue syndrome where the symptomatology is consistent with the sort of post viral fatigue syndromes that are either self-limiting, or have features that are very similar to ME/CFS.

**The situation in relation to a post COVID-19 or Long COVID-19 syndromes where there are persisting and significant respiratory, cardiac/heart or other symptoms that are not normally associated with ME/CFS is far more complex. This is briefly covered in the next section – but is outside the scope of this guidance.**

## 05.1

### Convalescence: Rest, relaxation and cautiously increasing activity levels

The most important initial aspect of management of any form of significant post viral fatigue involves good old-fashioned convalescence. The aim is to make a gradual and flexible return to normal daily activities. -

In practice, this means taking things easy, and having plenty of rest and relaxation during the immediate post infection stage. This should be combined with very gentle physical activity that is always within your limitations, having a good night's sleep, eating a healthy diet, and avoiding stressful situations. **Above all, do not return to work, school or domestic duties until you are well enough to do so.**

Some people find that adding in approaches like meditation or yoga can help with relaxation. Others do not.

Overall, progress can be very variable with some people making a steady improvement back to normal health fairly quickly. Others follow a less predictable pattern with good days and bad days. Doing too much on a good day will often lead to an exacerbation of fatigue and any other symptoms the following day - this is called post-exertional malaise (PEM) or post exertional symptom exacerbation.

## 05.2 Four important basics: Planning, Prioritising, Delegating and Explaining!

### ■ PLANNING:

When you start each day with a very significant reduction in your energy reserve, and when this reserve is going to fluctuate from day to day, it's important to give careful thought to planning the day ahead, as well as the week ahead. So if you have important physical or mental/cognitive tasks that need to be done, try to spread them out throughout the day and in the week ahead. If they are going to be time consuming split them into small manageable chunks that can be completed one day at a time. This sort of planning needs to be very flexible and changed when you are clearly not having a good day or a good week.

### ■ PRIORITISING:

When it comes to any of the energy requiring activities - physical, mental/cognitive, social and family - that you would normally be doing, sort them into those that still need to be done and those which can be deferred or omitted for the time being.

### ■ DELEGATING:

Draw up a list of activities and actions that you might be able to delegate to other members of your family or to friends.

### ■ EXPLAINING:

Having to cope with a major reduction in what you are able to do physically and mentally is bound to affect your close relationships, especially with partners and children. Explain to people close to you what has happened and, where appropriate, indicate how they might be able to offer some practical help. Hopefully, they will understand and accept that you are dealing with a serious medical problem that is going to impose significant restrictions on everything you normally do – work, family, social - for the foreseeable future.

## 05.3 Activity and Energy Management

To start with it's often helpful to think about having a daily energy reserve - rather like having tank of petrol. Most people learn to sense how full their energy tank is at the start of each day. But this is very likely to fluctuate from day to day. So planning the day ahead, physically and mentally, in relation to what you hope to achieve is going to have to be within your likely energy limits for that day – so not ending up with any empty tank before the day is over!. This isn't easy, especially at the start, and involves lots of trial and error to get it right. But it's a crucial component when it comes to providing the right basis for the body's natural ability to heal and improve.

As energy is required for physical, cognitive and mental/emotional activity, it's important to make sure that you are not exceeding what you feel comfortable doing. Where possible stop an activity before you are starting to feel more fatigued. Don't try to carry on with a task when you are starting to flag or not able to do so.

Finding the right balance on an individual basis between activity and rest is a process called **pacing**. Many people find it helpful to alternate small flexible amounts of physical and cognitive activities with a longer period of rest/relaxation in between.

Physical activities could include light household tasks and going for a short walk – when you feel ready to do so. Mental/cognitive activities could include social activities with people you can still be in contact with, reading, listening to the radio or music, watching TV, or doing a small amount of computer work. Whatever mix you choose, try to make sure that you are also doing things that you enjoy!

Limit screen time on computers, phones and TV, and avoid using electronic devices to catch up on your normal work!

Having established what is a fairly safe baseline of physical and mental/cognitive activity that is not exacerbating symptoms, the next step is to gradually try and increase the amount you are doing – whilst sticking to the rule of not exceeding limitations and living within your 'energy tank'.

When it comes to physical activity, walking is a good option - starting off with very short walks and building up slowly. If you are progressing well and want to do something more active, swimming in a warm pool is worth considering, or even going for a short slow jog if you enjoy running. But do take medical advice before starting to do anything more active, especially if you still have any heart or respiratory symptoms. At this stage. the use of heart rate monitoring may also be helpful. This is explained in the video produced by the Physios4ME group – see section 10.

Any kind of very vigorous sport or exercise (e.g. running) should be given a complete miss until you have fully recovered and remained well for a reasonable period of time. Graded exercise programmes are not appropriate for people with post COVID fatigue – this has been confirmed by NICE. You cannot exercise your way out of post COVID fatigue!

In addition to the warning from NICE about the use of graded exercise therapy in COVID-19, Professor Lynn Turner-Stokes, a consultant in rehabilitation medicine, told a webinar meeting at the Royal Society of Medicine that "Before we get people exercising, it's important to be sure that it's going to be safe. We need proper evaluation of cardiac and respiratory function, and we need to take things slowly and in a paced measure."

And a recent study in Journal of the American Medical Association of 100 patients (67 of whom had not been admitted to hospital) undergoing a cardiac magnetic resonance imaging (MRI) scan after COVID-19 found "cardiac involvement in 78 patients (78%) and ongoing myocardial inflammation in 60 patients (60%)." The authors say that participants "with mostly home based recovery had frequent cardiac inflammatory involvement, which was similar to the hospitalised subgroup with regards to severity and extent."

Reference: <https://tinyurl.com/y6plsg97>

## 05.4 Sleep

As already noted, having an increased sleep requirement (hypersomnia) is an important part of the body's natural healing process during, and sometimes following, an acute infection.

So whilst going bed and staying there is not the solution, making sure that you have plenty of good quality sleep, possibly including a daytime nap if you need one in the early stages, is a key part of good management.

Simple self-help strategies that can improve sleep quality include:

- Relaxing before going to bed by having a warm bath or listening to a relaxation CD.
- Avoiding caffeine-containing drinks – coffee, cola, tea – in the evening. Caffeine interferes with the natural process of going to sleep. Try a warm milky drink instead.
- Avoiding heavy meals and alcohol shortly before going to bed. Alcohol may help you to get off to sleep but it can disrupt sleep during the night.
- Trying to establish a routine for getting up and going to bed at roughly the same time each day that also accommodates any increased sleep requirements.
- Keeping the bedroom as a quiet, peaceful and relaxing place for going to sleep – not too hot or too cold and not a place for watching TV or doing computer work.

If you don't have increased sleep requirements, or the need to sleep for excessive periods has reduced, aim to have 7 or 8 hours solid uninterrupted sleep each night.

- The MEA has an information leaflet covering all aspects of sleep management in more detail: <https://tinyurl.com/vmp38w5>

## 05.5 Drug Treatments and Symptom Relief

There are no drugs or supplements that can be used to treat PVF or PVFS. And there is no value in taking products such as iron supplements (which are unnecessary and can even be harmful) and high doses of vitamin C, or any other vitamins. However, if you are not having a healthy balanced diet it would be worth taking a multivitamin supplement.

Although there are encouraging indications that some antiviral (i.e. remdesivir) and immunosuppressive drugs (i.e. dexamethasone) are of benefit in hospitalised patients during the acute infective stage of COVID-19, there is no evidence at present that they could be useful in treating post or Long COVID syndromes.

The only indication to use prescription-only or over-the-counter drugs at present is for the relief of symptoms such as pain and headaches.

As many people are no longer going outside in the sunshine, or only doing so for short periods, there is a risk of vitamin D deficiency. Vitamin D is made in the body in response to sunshine and is essential for bone and muscle health. So taking a daily 10 microgram vitamin D supplement is a sensible precaution.

## 05.6 Mental Wellbeing and Relationships

Looking after your mental and emotional health is another important part of management. In particular, this means avoiding stressful situations wherever possible.

Not surprisingly, all the restrictions that this illness imposes on what you are able to do can make people feel fed up, frustrated and sometimes even anxious or depressed.

If you are feeling anxious, or your mood is obviously low, and you are feeling depressed (with tearfulness, loss of interest in activities, loss of self-esteem), you must speak to your GP about how this should be managed.

## 05.7 Nutrition and Fluid Intake

Some people lose a significant amount of weight during a serious acute infection. This type of weight loss will need to be built up again if you are not overweight before being ill.

Try to stick to a healthy balanced diet with plenty of fresh fruit and vegetables, possibly with small frequent meals if you find this easier.

Make sure your fluid intake is adequate. It's probably better to avoid alcohol, or cut right down and abstain, especially if alcohol is making you feel worse. I take the view that alcohol intolerance as an important diagnostic feature of post viral fatigue syndromes and ME/CFS.

If your appetite is still poor, or you need to put on some weight again, ask for help from a dietitian on foods that are worth trying.

## 05.8 Education and Employment

The simple message here is to switch off from anything to do with work, school or college and do not go back to work until you are fit to do so.

This is especially important if your job involves a significant amount of hard physical activity, intense cognitive activity or high levels of mental stress. Similarly, intense periods of study and cramming for exams etc should normally be avoided or postponed until you have recovered

But do keep in touch with your employer or education provider - as there may be a number of options to explore once you start to improve and reach a point where a return to work or school/college looks possible. This could involve doing some work from home, or having a part time or flexible return to normal activities at school/college or duties in the workplace.

■ MEA information leaflet covering COVID-19 and Employment:

<https://tinyurl.com/ya3zhvuj>

## 05.9 Finances

If you are employed, and entitled to state or other sickness benefits, you will need to discuss sick pay, including what is called statutory sick pay, with your employer and obtain a fit note from your GP, or other health professional, who can confirm that you are unable to return to work. A fit note will inform your employer that the health professional has confirmed that you are either 'not fit for work' or 'may be fit for work'.

■ Information from the Citizens Advice Bureau on Statutory Sick Pay:

<https://tinyurl.com/ybfq4ey>

There are other state benefits from the DWP, including Employment and Support Allowance and Universal Credit, that you may be entitled to. The MEA has information on all the sickness and disability benefits that you may need to consider and apply for in the longer term if your health does not improve.

■ Information on DWP benefits:

<https://tinyurl.com/y7v86xvt>

## 05.10 Keeping Your GP Informed

Do let your GP know that you are having health problems post COVID, especially if symptoms are getting worse or new symptoms develop. COVID can also affect pre-existing medical conditions like diabetes - where normal blood sugar control may be upset.

Although a face-to-face consultation with your GP may be difficult to arrange, most GPs are happy to speak to their patients on the phone. Some GPs are now offering video consultations - which can be helpful if a more thorough assessment is required. A face to face consultation should also be considered if the problem is more serious or urgent.

Talk to your GP if you require help with a specific symptom such as muscle aches and pains or support with sick pay and DWP benefit applications.

The diagnosis of a post COVID syndrome is made on your symptoms. There is no diagnostic blood test. However, a serious infection like this has the potential to unmask medical conditions that were previously not causing any obvious symptoms or physical signs. Examples include low thyroid function/hypothyroidism, liver disease and inflammatory bowel disease. This is why it's sensible to check the baseline blood tests that are normally used when the cause of chronic fatigue is being investigated.

If you have any of the following symptoms, which are not part of normal post viral syndromes, you must speak to your GP:

- Continuing fever or periodic spikes of fever
- Persisting cough, shortness of breath, chest pain or other respiratory symptoms
- Palpitations
- Weight loss
- Feeling depressed
- Persisting diarrhoea or abdominal pain

As already noted, specialist multidisciplinary rehabilitation units are being established for people who are leaving hospital with complex and multiple problems. And if the problem is respiratory or heart related, you can be referred to a cardiologist or respiratory physician.

There is, however, a serious lack of information and support for everyone else in many parts of the UK. Using a Freedom of Information request, the *BBC File on 4* programme found that of 86 Clinical Commissioning Groups who replied, only 16 were running a service with 10 having plans to do so. This means that people in many parts of the UK are going to have considerable difficulty in obtaining specialist help.

Physiotherapists and occupational therapists, especially those working in the community, have an important role to play here in providing information and guidance. However, this must be dependent on them having the proper training on how to manage people with post viral fatigue syndromes. The Physios4ME



group have been delivering presentations on post COVID fatigue to meetings of community physiotherapists and the Royal College of Occupational Therapists has produced some useful guidance - [see section 9.2](#)

If symptoms are still present after two to three months, and are still having a significant impact on daily living, consideration will have to be given as to whether a PVFS has progressed into ME/CFS. As with a PVFS, this is a diagnosis based on symptoms. There is no diagnostic blood test for ME/CFS.

However, a number of baseline blood tests that are used to diagnose other causes of chronic fatigue – eg adrenal insufficiency/Addison's disease, anaemia; coeliac disease; liver, kidney, and thyroid disease, malignancy – should be checked before a diagnosis is confirmed.

NB: What has been term the systemic COVID-19 syndrome is usually accompanied by mild lymphopaenia (a reduction in white blood cells), neutrophilia (reduced levels of neutrophils, which act as a primary defence against infections), thrombocytopenia (a reduction in platelets that are involved in blood clotting), hyperferritinaemia (elevated levels of a protein that is involved in iron storage), and elevation of inflammatory and clotting factors.

The MEA has an information leaflet providing detailed guidance on the early and accurate diagnosis of ME/CFS.

<https://tinyurl.com/y8fueq4v>

■ The MEA has information leaflets covering all aspects of management of symptoms that are common to post viral fatigue syndromes and to ME/CFS:

**Activity and Energy Management:** <https://tinyurl.com/y8fueq4v>

**Cognitive Dysfunction:** <https://tinyurl.com/y4fpxxk8>

**Orthostatic Intolerance:** <https://tinyurl.com/y3kn8fzh>

**Postural Orthostatic Tachycardia Syndrome:** <https://tinyurl.com/y632sha6>

**Sleep Management:** <https://tinyurl.com/y2tnqbsb>

**MEA website shop:** <https://meassociation.org.uk/shop>

## 06

## Management of more complex Post/Long COVID-19 Fatigue Syndromes

Management of more complex post COVID fatigue syndromes has to take account of the wide range of other symptoms that relate to the direct effect of COVID-19 at the time of the initial infection.

These symptoms may relate to involvement of the lungs (e.g. breathlessness, dry cough, chest pain), heart (e.g. palpitations) and blood clotting mechanisms. COVID-19 can affect many other parts of the body – taste, smell, gastrointestinal function and the skin – where people are reporting unusual skin rashes and chilblain like lesions on the extremities, including 'covid toe'.

Management of these problems should be undertaken by health professionals with expertise in these areas. Where respiratory or cardiac symptoms are persisting, self-management could involve checking your oxygen levels at home using a pulse oximeter or pulse rate with a self monitoring device. Blood tests and other investigations to assess respiratory and cardiac function might include measuring blood troponin levels, chest X-ray and lung function tests, and an electrocardiogram.

■ This is a good source of self management information from Homerton Hospital for symptoms that are not related to ME/CFS:

<https://tinyurl.com/yy4c8jj9>

## 07

## Management of Post COVID-19 ME/CFS

As already noted, a wide range of viral infections can trigger ME/CFS, including other coronavirus infections like SARS. So we are expecting to see a growing number of people who currently have a diagnosis of a post or long COVID syndrome being diagnosed as having post COVID-19 ME/CFS.

To confirm a diagnosis of ME/CFS there should be activity-induced muscle fatigue, post exertional malaise/symptom exacerbation and all or most of three core symptoms: cognitive dysfunction/brain fog, unrefreshing sleep and orthostatic intolerance. The symptoms should have persisted for three months or more, and be causing a substantial (50% or more) reduction in capacity to carry out aspects of normal daily living. Other medical explanations for chronic fatigue should have been considered and excluded.

Self-management of ME/CFS is broadly along the lines of that for a post viral fatigue syndrome. There are no drugs that can treat or cure the underlying condition. So medication - prescribed and over the counter - is only used for symptomatic relief of symptoms such as pain.

Management of post COVID ME/CFS will also have to take account of the wide range of other symptoms that relate to the direct effect of COVID at the time of the initial infection. These symptoms may include involvement of the lungs (breathlessness, chest pain), heart (palpitations), blood clotting mechanisms etc. As already noted, management of these problems should be undertaken by health professionals with expertise in these areas.

■ More information on the diagnosis of ME/CFS can be found on the MEA website:

<https://tinyurl.com/y8fueq4v>

■ This is a good source of self management information for symptoms that are not related to ME/CFS:

<https://tinyurl.com/yy4c8jj9>

## 08

**Research into what causes Post Viral/ COVID-19 Fatigue**

Three possible explanations have been put forward to explain the long-term effects after infection by COVID-19. Firstly, those with long-term symptoms might still harbour infectious virus in some reservoir organs - but there is no firm evidence at present to indicate that COVID-19 becomes a persisting viral infection. Secondly, persistent fragments of viral genes, though not infectious, may still be triggering an immune system overreaction. Thirdly, although the virus is cleared, the immune system continues in an overactive or state, with the on-going production of increased levels of cytokines.

**RESEARCH INTO PVS AND PVFS**

Several epidemiological studies have looked at the development of fatigue syndromes following an acute viral infection.

An Australian research group followed up 253 people with glandular fever (Epstein Barr virus infection), Q fever (*Coxiella burnetii*) and Ross River Fever (epidemic polyarthritis) in a rural part of Australia at regular intervals over a period of 12 months.

Approximately 12% developed a post-infection fatigue syndrome involving fatigue, cognitive dysfunction, musculoskeletal pain and mood disturbance. The predictability of developing a post-infectious fatigue syndrome was largely determined by the severity of the triggering infection and not by any demographic or psychological factors, or the type of infection that triggered the symptoms.

Reference: <https://tinyurl.com/y8l44shb>

During an outbreak of SARS (Severe Acute Respiratory Syndrome - another coronavirus infection) in Toronto during 2002 and 2003, 273 people were diagnosed with the infection, of whom 44 died. After the outbreak ended, Dr Harvey Moldofsky and colleagues at the University of Toronto, studied 22 people, mostly health workers, who had on-going health problems that prevented them from returning to work.

They concluded that there was a chronic post SARS infection syndrome characterised by persistent fatigue, non-restorative sleep, daytime fatigue, pain and weakness in muscles all over their body, and depression.

Reference: <https://tinyurl.com/tho95ax>

A second study from Toronto, which reported on one year outcomes on patients who were hospitalised, reported that survivors of the acute respiratory distress syndrome had persistent significant functional disability one year after discharge. Most of these patients had extra-pulmonary conditions, with muscle wasting and weakness being most prominent.

Reference: <https://tinyurl.com/y3n3m24f>

A large number of research studies both here and abroad are now collecting data from people who are not recovering from COVID-19.

Most of these studies, including the large study that has been organised by the University of Leicester, are looking at people who have been hospitalised. But there are some studies starting to emerge on home-managed patients - including one from the ME Biobank that is funded by the MEA Ramsay Research Fund.

When it comes to laboratory based research into post COVID-19 we need to look at how the immune system is responding, especially the levels of various cytokines and T cell status (as T cells play a crucial role in anti-viral protection), and the hypothalamic-pituitary-adrenal axis in relation to cortisol output, in people who are not recovering and now have post-infectious fatigue.

Among the more interesting findings to emerge are three case reports in the Annals of Internal Medicine of COVID-19 triggering the autoimmune muscle disease myasthenia gravis:

Reference: <https://tinyurl.com/y2aheny5>

The MEA Ramsay Research Fund would be very happy to consider research proposals to investigate immune system status in coronavirus infection.

**The important point to note here is that research into COVID-19 and ME/CFS is a two way process. What we already know about causation and management of ME/CFS is of considerable help to many people with post COVID illness. And research into COVID-19 may lead to a much clearer understanding of why some people develop post viral syndromes and ME/CFS and what role is being played by the body's immune system.**

## 09

### Further Information

## 09.1

### Information and Guidance from NHS Sources:

- The Royal College of Occupational Therapists: guidance on the management of Post-COVID Syndrome:

<https://tinyurl.com/y6kzdhwu>

- The Physios4ME Group: useful video on heart rate monitoring for activity management in ME/CFS:

<https://tinyurl.com/y25u9epr>

- NHS England: guidance on the management of post COVID symptoms, including fatigue. However, the MEA does not agree with their guidance on fatigue management and we have written to Professor Stephen Powis at NHS England about our concerns:

<https://tinyurl.com/yy92ngqr>

- NICE: no specific guidance has been issued so far but NICE has made it clear that recommendations relating to graded exercise therapy are not appropriate for people with post COVID fatigue:

<https://tinyurl.com/y2hexe6j>

## 09.2

### Health Professional Responses

Among the helpful information from clinicians and researchers is that from Professor Frances Williams at Kings College Hospital, who is carrying out research into post COVID fatigue:

<https://tinyurl.com/y4kbqzvg>

BMJ review: Management of post-acute covid-19 in primary care by Professor Trisha Greehalgh:

**BMJ 2020; 370 doi: <https://doi.org/10.1136/bmj.m3026>**

In America, Dr Anthony Fauci, one of the main government advisers from the National Institutes of Health, has stated that some people with post COVID fatigue will go on to develop post COVID ME/CFS:

<https://tinyurl.com/ycwvyosw>

## 09.3 Media Responses

Since April, there has been growing interest in the media about the problems faced by people who are not recovering from COVID-19.

The more useful articles are being made available in the news section of the MEA website as we receive them.

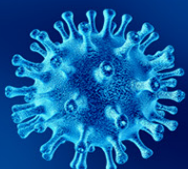
Of particular interest is this article in The Observer relating to the how previously fit young adults are developing post COVID syndromes:

<https://tinyurl.com/y35cmysy>

## 09.4 ME Association Portfolio of COVID-19 Information

The ME Association has a full range of free downloadable leaflets covering all aspects of COVID-19 and ME/CFS:

<https://tinyurl.com/y7eo5do9>



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