

the ME association



In collaboration with
DGMEFM Network

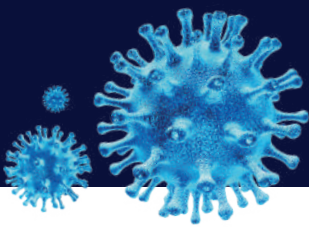
DGMEFM



Dumfries & Galloway
ME and Fibromyalgia Network
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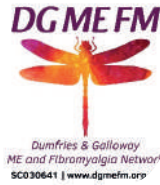
MEA INFORMATION ON

Post-viral fatigue (PVF)
and Post-viral fatigue syndrome (PVFS)
following coronavirus infection



INTRODUCTION

We are receiving reports about previously healthy people who have had (or probably had) coronavirus infection and have not been able to return to their normal level of health and energy levels in the weeks following the onset of symptoms. These reports are largely from people who have managed at home and not had a more serious infection that required hospital admission. Some reports are from health professionals. It seems likely that some of them are experiencing what is called post viral fatigue (PVF), or a post viral fatigue syndrome (PVFS).



We are also receiving reports from people with ME/CFS (myalgic encephalomyelitis/chronic fatigue syndrome) who have had this infection and now have a significant exacerbation of their ME/CFS symptoms - especially a further reduction in energy levels.

The ME Association has a lot of experience in dealing with people who develop prolonged and debilitating fatigue (sometimes with other symptoms as well) following a viral infection – as well as people with ME/CFS who relapse following another infection.



We are now expecting to see a number of new cases of ME/CFS that follow coronavirus infection fatigue. This is why we have produced some guidance on how we feel that convalescence and good basic management of post infection fatigue can lessen the chances of this turning into a more permanent and debilitating illness.

BACKGROUND

WHAT IS POST VIRAL FATIGUE (PVF) AND POST-VIRAL FATIGUE SYNDROME (PVFS)?

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

Fortunately, in most cases, this is short lived and there is a steady return to normal health over a period of a few weeks.



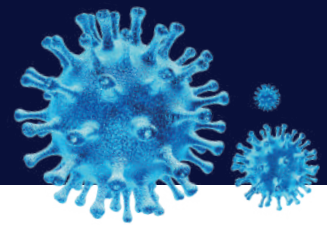
However, in some cases, a full return to normal health takes months rather than weeks. Additional symptoms may also develop, where the term post-viral fatigue syndrome (PVFS) may be a more appropriate diagnosis.

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

The precise explanation for what causes post-infection/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 attack on any viral infection. And it is interesting to note that in people who develop serious respiratory complications from coronavirus infection, this may be due to an overactive immune response involving what is being termed a 'cytokine surge'.

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 research evidence to indicate that what is a perfectly normal immune system response to the acute



BACKGROUND (cont.)

infection has not returned to normal.

It is also possible that, as happens with ME/CFS, there is a problem with the way that 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 the 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, are no longer infective to others in our current state of knowledge.

While most 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. And patient evidence also indicates that good initial management of post-infection fatigue lessens the chances of this turning into an ME/CFS-like illness.



WHAT ARE THE SYMPTOMS OF PVF AND PVFS?

ACTIVITY INDUCED FATIGUE

As the name post-viral fatigue indicates, the main symptom is fatigue, or a failure to return to normal energy levels.

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 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 PVF 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 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.

SLEEP DISTURBANCE

Some form of sleep disturbance often accompanies PVF.

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 is known as hypersomnia and is a natural part of the way in



which human body responds to and recovers from an infective illness.

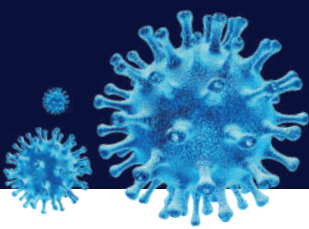
COGNITIVE DYSFUNCTION

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

PVFS AND POSSIBLE PROGRESSION TO ME/CFS

When the symptoms discussed above persist, and are accompanied by other flu like symptoms, it may be more appropriate to diagnose a post-viral fatigue syndrome (PVFS).

If the symptoms persist for more than two to three months, and continue to cause a significant degree of functional impairment that is preventing a return to education, employment or other key activities, a diagnosis of ME/CFS should also be considered.



SYMPTOMS



SYMPTOMS WHICH CAN FORM PART OF A PVFS AND ARE ALSO SUGGESTIVE OF A DIAGNOSIS OF ME/CFS INCLUDE:

- Alcohol intolerance
- Feeling wobbly or unsteady
- Headaches of new onset
- Difficulty in sustaining an upright posture for long periods – known as orthostatic intolerance
- Muscular aches and pains
- Sore throats and tender glands
- Problems with temperature control
- Post exertional malaise/ symptom exacerbation
- The MEA has an information leaflet providing more guidance on the early and accurate diagnosis of ME/CFS:



MANAGEMENT OF PVF AND PVFS

CONVALESCENCE

The most important aspect of management of post infection fatigue involves good old fashioned convalescence.

In practice, this means taking things easy, and having plenty of rest and relaxation. This should be combined with gentle activity within your limitations, having a good night's sleep, eating a healthy diet, avoiding stressful situations, and not returning to work, school or domestic duties until you are well again.

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. 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 characteristic delay in symptom exacerbation is known as post-exertional malaise (PEM). As already noted, where this persists for more than two to three months it should certainly raise the possibility of a diagnosis of ME/CFS.

ACTIVITY MANAGEMENT

Resting and relaxing are both essential components of any convalescence. As energy is required for both physical and mental activity, it's important to make sure that you are

not exceeding what you feel comfortable doing, stopping an activity when you are starting to feel more fatigued, and not carrying on with a task when you are not able to do so.

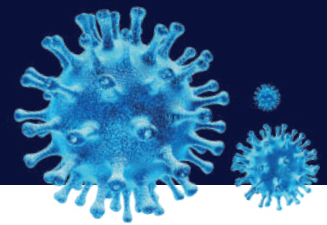
Finding the right balance on an individual basis between activity and rest is a process called pacing and many people find it helpful to alternate small flexible amounts of physical and mental activities with a longer period of rest/relaxation in between.

Physical activities could include things like household tasks and going for a short walk – when you feel ready to do so. Mental activities could include social activities with people you can still be in contact with, reading, listening to the radio, watching some TV, or doing a small amount of computer work.

Do try to 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 safe baseline of physical and mental 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 what is called your 'energy envelope'.

Activity management needs to be carried out in a very flexible manner. So any increase in activity levels need to be gradual and within your physical and mental limitations.



MANAGEMENT OF PVF AND PVFS



Any kind of vigorous, sporting or prolonged physical activity should be given a complete miss until you have fully recovered and remained well for a period of time.

There is clearly quite a lot of trial and error involved in getting the balance right between activity and rest and great care needs to be taken to make sure that you are only doing what you are comfortable with. You cannot exercise your way out of PVF or PVFS!

MENTAL WELL BEING

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

Not surprisingly, having PVF or PVFS, along with all the restrictions that this 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

etc), you must speak to your GP about how this should be managed.

NUTRITION

Some people will lose a significant amount of weight during a serious acute infection. This type of weight loss may 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.

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.

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 to bed and staying there day and night is not the solution, making sure



that you have plenty of good quality sleep, possibly including a daytime nap if you need one, is a key part of good management.

There are a number of simple self-help strategies that can improve sleep quality:

- Relax before going to bed by having a warm bath or listening to a relaxation CD.

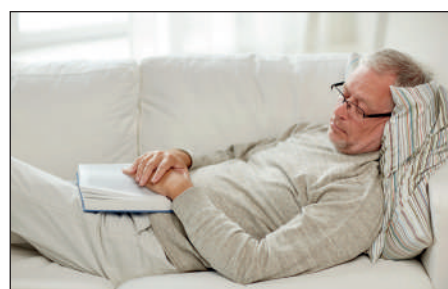
- Avoid caffeine-containing drinks – coffee, cola, tea – in the evening. Caffeine interferes with the natural process of going to sleep. Try a warm milky drink instead.

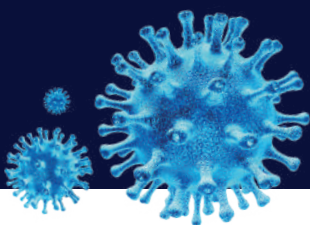
- Avoid heavy meals and alcohol shortly before going to bed. Alcohol may help you to get off to sleep but it can disrupt sleep during the night.

- Try 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.

- Keep 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, try to





MANAGEMENT OF PVF AND PVFS

have eight or nine hours solid uninterrupted sleep each night. The MEA has an information leaflet covering all aspects of sleep management in more detail.

WORK AND EDUCATION

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

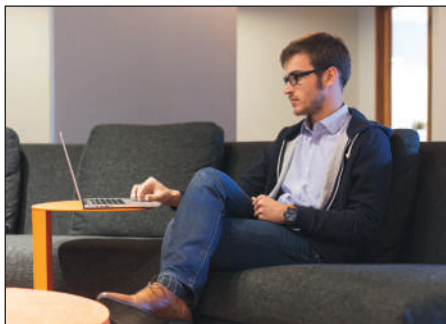
This is especially important if your job involves a significant amount of hard physical activity or high levels of mental stress.

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.

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 (aka a sick 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

There are other state benefits from the DWP, including Universal Credit, that you may be entitled to during the coronavirus epidemic and lockdown. The MEA has produced a guide to benefits that might help you to navigate the benefit system and other guides to specific types of benefit that may be needed in the longer term if your health does not improve.

DRUG TREATMENTS

Finally, it's worth noting that there are no drug treatments or supplements for treating PVF or PVFS. And there is no value in taking products like 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. As many people are no longer going outside in the sunshine, or only doing so for short periods, the risk of vitamin D deficiency is increasing. 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.

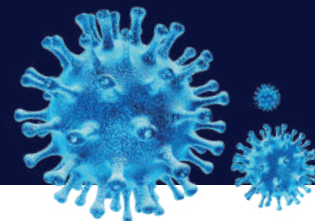
Do talk to your GP or pharmacist if you require help with a specific symptom such as muscle aches and pains.

The MEA has information leaflets providing detailed information on the drug and non drug management of orthostatic intolerance, pain and sleep disturbance.

WHEN TO CHECK WITH YOUR GP

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 or by a video link at the moment. If your post-infectious fatigue is continuing beyond four weeks, and is not improving, it's still worth speaking to your GP to keep him/her apprised of the situation - even though there is no specific drug treatment. You may also need help from a GP when it comes to sick pay and benefit applications.





OTHER INFORMATION



This information and guidance is based on patient evidence collected over many

years on the symptoms and management of PVF and PVFS. The author has personal experience of a PVFS following chickenpox infection, which was caught from a patient. No form of clinical trial research has been carried out and published into the management of PVF and PVFS – so this information and guidance is largely based on clinician and patient evidence.

Dr Charles Shepherd
Hon Medical Adviser, MEA

ME CONNECT

We're here to help

Do you need to talk?

CALL

0344 576 5326

10am-12noon
2pm - 4pm, 7pm - 9pm
every day of the year



THE ME ASSOCIATION:

- Provides information on M.E. and campaigns on issues such as research, the NICE guideline, NHS service provision and care
- Provides support through our ME Connect helpline, ME Essential members magazine and our website and social media
- Funds biomedical research – including the UK ME/CFS Biobank which is managed by an expert team at the London School of Hygiene and Tropical Medicine – through the Ramsay Research Fund
- Is a member of the Forward ME Group of charities and patient representatives that is chaired by the Countess of Mar, and the CFS/ME Research Collaborative, chaired by Professor Stephen Holgate, which aims to raise the profile of M.E. and attract greater research investment

ME ASSOCIATION WORKING ARRANGEMENTS

We issued a statement to provide information on all aspects of our work and the services we provide. Almost all key activities are continuing as normal – the main change being that we have now closed Head Office in Buckingham and office staff are now working from home.

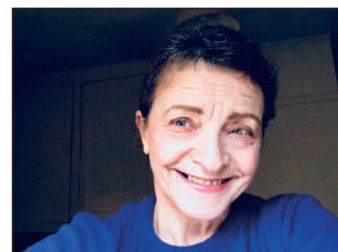
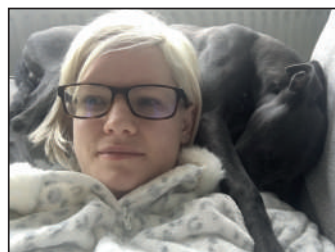
The main impact here is that we will not be able to send out any paper literature, purple books, or merchandise from the office for the foreseeable future.

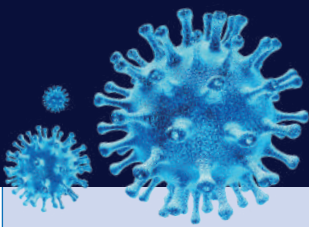
ME Connect – 0344 576 5326 – remains operational, seven days a week, for information and support.

ME Association statement:
<https://meassociation.org.uk/?s=new+working+arrangements>

CORONAVIRUS AND ME/CFS

We have a new MEA information leaflet covering Coronavirus and ME/CFS which is updated weekly. This is available as a free download at www.meassociation.org.uk





Post-viral fatigue (PVF) and Post-viral fatigue syndrome (PVFS) following coronavirus infection



Dumfries & Galloway ME and Fibromyalgia Network (DGMEFM Network) is a registered charity in support of people affected by ME/CFS and Fibromyalgia, primarily across Dumfries & Galloway.

Symptoms of post viral fatigue following Covid 19 are largely consistent with the symptoms of post-viral fatigue syndromes (PVFS), and with post exertional malaise (PEM) which are seen in people who are living with ME/CFS.

The Network offers peer support, sharing experience of living with these illnesses and how best to manage their symptoms. We also raise awareness amongst professionals and the wider public of how these conditions affect us.

Membership is free and open to any person living in Dumfries & Galloway suffering with any of these illnesses and/or their carer / family member.

Visit our website:

www.dgmefm.org.uk

Ask to join our Facebook community:

www.facebook.com/groups/dgmefm

Join our regular Zoom meetings – themed discussions, occasional speakers or invited health and other professionals, peer support, and friendly catch-up.

See our website or Facebook page, or contact us for details –

E-mail:

admin@dgmefm.org.uk

Phone/WhatsApp:

07437 602 610



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