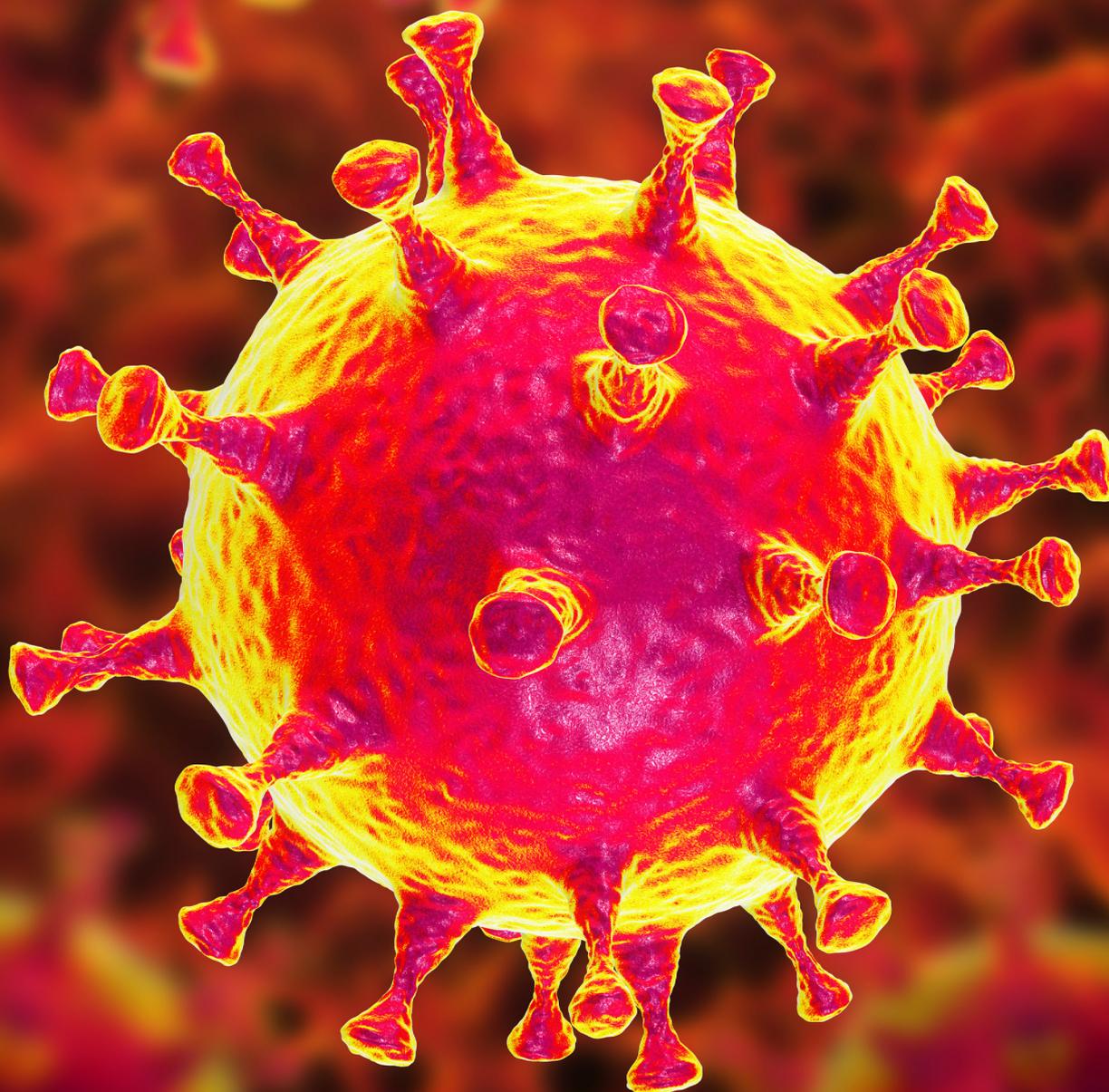


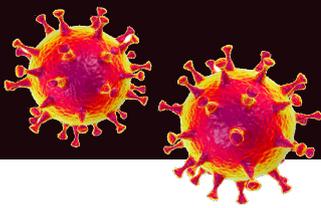
the ME association

me



Coronavirus (COVID-19/Cv19) and ME/CFS

15 April 2020



WHAT THIS LEAFLET COVERS

This update contains all the key information and guidance that has emerged since the last full MEA website summary on Cv19 that was published on Tuesday 31st March.

The [MEA website summary](#) contains comprehensive information on all aspects of Cv19 as it applies to ME/CFS. Individual sections cover the following:

- The Coronavirus (Cv-19) – What it is, testing, treatment, vaccine development etc.
- What are the symptoms of the coronavirus infection?
- What should you do if you have a new onset of cold or flu-like symptoms?
- Who is most at risk of catching this infection?
- Why people with ME/CFS should qualify as being vulnerable
- Why people with ME/CFS are not considered extremely vulnerable
- How can you prevent yourself from getting infected? Can pets transmit the infection?
- What contact can you still have with other people? Social mobility, distancing, self-isolation and shielding
- What help is there for carers?
- Education and Employment
- Shopping, food and medicine delivery
- Foreign Travel
- Hospital and other medical appointments
- Further information



We will continue to keep you up to date on all new developments via MEA social media and answer any questions, where we can, on MEA Facebook.

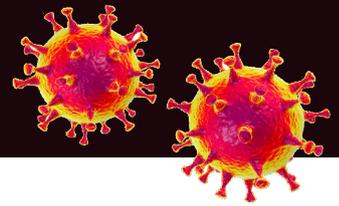
Please look after yourself and stay safe. ME Connect – the [MEA telephone helpline](#) – is open morning, afternoon and evening every day of the week if you want to speak to someone for information or support.

Dr Charles Shepherd
Hon Medical Adviser, The ME Association.

Weekly Update: Wednesday, 15th April 2020

We have made this update (and all future updates) into a downloadable free leaflet. It can also be found in the website shop along with a 'to whom it may concern' letter which might be helpful when arguing your case for additional support and help as a vulnerable person. We will also be adding another free leaflet about changes to benefits as soon as possible.

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CONTROLLING THE SPREAD OF THE VIRUS

The number of new cases and deaths being reported here in the UK has continued to rise again over the past week. However, there are definite signs that social distancing is starting to have a significant effect on the rate of increase with the number of hospital admissions and people occupying critical care beds showing signs of flattening.

If all goes to plan, and we are at, or nearing the peak, we could be looking at the numbers starting to fall towards the end of April. Once this turns into a progressive fall in numbers the Government will be looking at ways in which some of the restrictions could be relaxed or lifted.

■ As of Tuesday 14th April 2020, a total of 93,873 people have tested positive for the virus and 12,107 people in the UK who tested positive for coronavirus (COVID-19) have died.

[Source: UK Government](#)

Although the situation continues to remain very serious in France, Germany Italy and Spain – there are signs that the daily increase in numbers in these countries has also reached a peak and is starting to fall. Whereas several parts of the USA – New York in particular – are still experiencing a serious increase in numbers.



Everyone must stay at home to help stop the spread of coronavirus. You should only leave home for one of four reasons:

- shopping for basic necessities, for example food and medicine, which must be as infrequent as possible
- one form of exercise a day, for example a run, walk, or cycle – alone or with members of your household



- any medical need, or to provide care or to help a vulnerable person
- travelling to and from work, but only where this absolutely cannot be done from home

These four reasons are exceptions – even when doing these activities, you should be minimising time spent outside of the home and ensuring you are at least six feet (2 metres) apart from anyone outside of your household.

[Source: NHS Choices](#)

Judging from feedback to the MEA Facebook page action is still needed to deal with employers who are not taking measures that help to ensure employees are not working closer than six feet (two metres) apart and are receiving appropriate protective equipment.

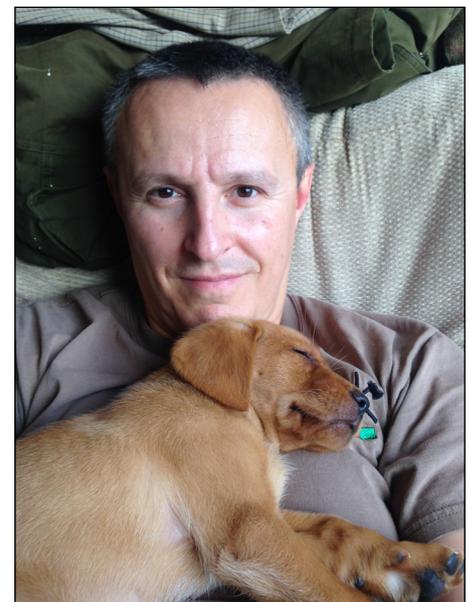
New research from America suggests that to be perfectly safe the space between people should be more than six feet (two metres). On a personal basis, I am now trying to keep my distance to nearer twelve feet (four metres) wherever possible.

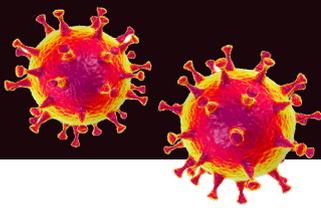
News item:

[The Independent.ie: 'Two metres not enough' when social distancing.](#)

[Academic paper in Journal of American Medical Association:](#)

[Turbulent Gas Clouds and Respiratory Pathogen Emissions: Potential Implications for Reducing Transmission of COVID-19.](#)





HAND AND RESPIRATORY HYGIENE



The two key points on reducing the risk of catching the virus remain the same:

■ Avoid touching any surface that other people have been touching. Always wash your hands, fingers and wrists in soap and hot water for at least 20 seconds after touching any surfaces that could have the virus on them. Soap and water is more effective than sanitizers. This is because the virus is protected by a thin outer layer of fat. Soap causes this fat layer to disintegrate and the virus then decays.

■ Do not touch your face, eyes or mouth with your fingers – especially when you have been touching surfaces that could be infected.

In addition to the very detailed guidance on hand and respiratory hygiene in section E of our main website summary here are two more tips on this vital aspect of preventing you catching Cv19:

■ Careful hand washing is, not surprisingly, leading to some people having dry cracked skin – which is another risk factor as the virus can hide in small skin cracks. Use a good hand moisturizer after washing and drying hands to keep the skin hydrated.

■ As we explain in the main website summary, the virus can remain active on many different types of surface. If you are going supermarket shopping for example, one high risk item is that large numbers of people are touching trolley handles. Some supermarkets are wiping down handles before issuing them to customers, but it could be worth using your own alcohol-based sanitizer to wipe the handle down before use.

TESTING FOR THE VIRUS

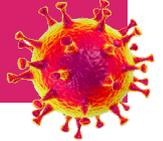
Following a very unsatisfactory initial approach to testing, it does now appear that testing for evidence of current viral infection (the antigen test) is going to be rapidly increased with a Government aim of performing 100,000 tests per day by the end of April.

This should mean that health and other key workers will know if they have the virus. They will also know when they are no longer infective and can go back to work.

However, problems do remain in finding an antibody test that is sufficiently reliable for the purpose of identifying people who have had the infection in the past and one that is not producing false positive results.

Testing for people who have symptoms, and are being managed at home, is not the main priority right now. But I hope that this will soon be the case.

WHAT TO DO IF YOU HAVE SYMPTOMS SUGGESTIVE OF CORONAVIRUS INFECTION



The advice here remains the same in that people with symptoms, or suspected symptoms, should contact NHS 111 for further advice:

[NHS Coronavirus: Advice for everyone](#)

■ There is now [a specific NHS 111 Coronavirus online service](#) should you develop symptoms. This helps the NHS monitor occurrences and should help you to determine if you are likely to have the coronavirus.

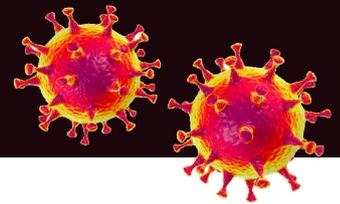
Do not go to your GP surgery or local hospital. Your GP can speak to you on the phone.

If symptoms worsen, especially if you become short of breath, have rapid breathing, or are drowsy, or develop a very high temperature, you must get in contact again with either your GP or NHS 111 – as hospital admission may then be necessary.

New emergency hospitals are being prepared for serious cases all around the UK – including sites in Bristol, Harrogate, Glasgow the use of the Excel Centre in London, where the new NHS Nightingale Hospital is now open.

Finally, there are further reports to indicate that loss or taste of smell is an occasional symptom of Cv19 and can be one of the initial signs of infection. Some people are, not surprisingly, losing several kgs of weight during the active infection stage.

A more detailed summary of symptoms can be found in section B of the main summary.



SHOPPING - FOOD AND MEDICINES



Concerns about the delivery of food and medicine to people who are confined to their homes – the vulnerable and extremely vulnerable – are still a major cause for concern.

The ME Association, along with our charity colleagues in Forward ME, have sent a letter to the Government and the main supermarkets, to express our deep concerns and requesting urgent action to help those most in need. We are awaiting a response.

Some people are now able to access home delivery slots or click and collect slots via supermarkets online - especially if you let the supermarket know you are vulnerable, or extremely vulnerable, or are a regular user of the service and pay monthly for a delivery option.

Most supermarkets are now opening specifically for vulnerable people, and those that care or support them, during special times each week. Check supermarket websites for more information. If you need someone to shop for you, these might offer a good option.

So, there are signs that things might be improving. However, for many people, home delivery and supermarket access remains problematic.

It's worth noting that there are now a huge number of community volunteer groups being set up all around the country who can provide volunteers to do shopping, collect prescriptions etc. – we now have a very active one with over 100 volunteers in the Cotswold village where I live.

Some local councils are also coordinating aid and some local shops who don't normally deliver are now offering delivery.

[ME Charities and MPs send letter to supermarkets asking for more support for people with M.E.](#)

[Jo Moss – who has severe M.E. – has written a fantastic blog with tips for those who are struggling with supermarket home deliveries.](#)

If you are having problems persuading a supermarket that ME/CFS is a vulnerable illness and deserving of home delivery etc. you can make use of the MEA statement and a new 'to whom it may concern letter' on vulnerability.

More information:

[Which magazine on supermarket shopping.](#)

[Comprehensive list of community support groups.](#)

[This website covers offering and requesting help within a neighbourhood.](#)



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 – [the MEA telephone helpline](#) – remains operational, seven days a week, for information and support.

ME Association statement:

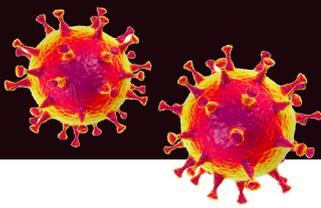
[The ME Association and Coronavirus: New working arrangements](#)

**DID YOU KNOW?
NHS 111**

**IS NOW AVAILABLE ONLINE
AND OVER 30,000 PEOPLE USE
IT EVERY DAY!**

111.NHS.UK





GOVERNMENT GUIDANCE: THE VULNERABLE AND EXTREMELY VULNERABLE

The two lists produced by the government have, not surprisingly, caused some confusion.

VULNERABLE

As we have made clear all along in our main website summaries, **people with ME/CFS should be regarded as vulnerable** in relation to coronavirus infection.

This is because there is a **strong risk** that they will suffer a significant exacerbation of ME/CFS symptoms, or a relapse, if they catch the virus.

■ If you are having problems persuading a medical professional, employer or supermarket that ME/CFS is a vulnerable illness and deserving of additional consideration you can make use of the MEA statement and the new 'to whom it may concern letter' on vulnerability.

Anyone with a chronic neurological condition, or another condition on the vulnerable list, or because of their age, should be practicing stringent **social distancing measures**:

[Govt. Guidance on social distancing measures and vulnerable list.](#)

EXTREMELY VULNERABLE

ME/CFS is **not included** as a specific condition in the second Government list of people who are regarded as being extremely vulnerable.

However, if you have **another medical condition** that is on the extremely vulnerable list,



you will be at very high-risk of developing serious respiratory complications from the infection.

If this is the case, then register as an **extremely vulnerable** person by visiting this [Government website](#). You will be entitled to additional help and support – including home delivery of shopping and medications if you need them.

You should also be practicing shielding measures and avoiding all contact with other people for 12 weeks from the date you receive your letter from NHS England (if you didn't receive a letter by 30 March you are advised to contact your GP surgery).

[Govt. Guidance on shielding and extremely vulnerable list.](#)

Please note that if you are taking the drug **fludrocortisone** for Postural Orthostatic Tachycardia Syndrome (PoTS), which helps to increase blood volume, this drug can cause immune system depression.

One of the categories in the **extremely vulnerable** list is:

“People on immunosuppression therapies sufficient to significantly increase risk of infection”.

It could be worth speaking to your GP to see if they think given your personal situation, you are at increased risk of infection.

[NICE reference: Postural hypotension in adults: fludrocortisone: summary of possible benefits and harms.](#)

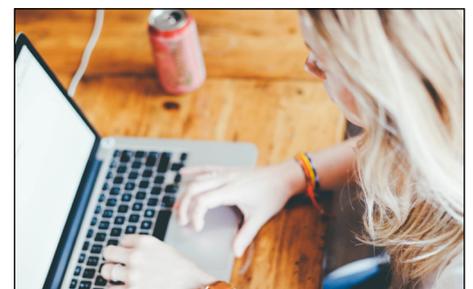
EMPLOYMENT

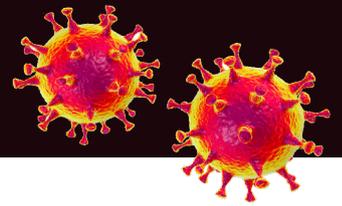
We are receiving an increasing number of queries relating to employment issues. As a result, we have produced a separate and more detailed guide to employment, coronavirus and ME/CFS.

This can be accessed here:

[The ME Association: Ten Key Points on Employment, ME/CFS and the Coronavirus](#)

If you are having problems in persuading an employer that ME/CFS is a vulnerable illness you can make use of the MEA statement and a new 'to whom it may concern letter' on vulnerability.





ME/CFS RESEARCH



Research that is being funded through the MEA Ramsay Research Fund is continuing where possible.

I chaired a video conference of the Biobank Steering Group and joined a Board meeting for the CMRC Research Collaborative.

The ME Biobank is continuing to operate at the Royal Free Hospital, but no patient contact is being made in relation to new blood sample collection.

The MEA is also funding an exciting new research project – although it remains uncertain when this can commence as it will involve patient recruitment. This new study will be publicly announced in May.

A new warning from the FDA about the potential dangers associated with coronavirus and faecal microbiome transplants (FMTs) illustrates how this infection is going to have an impact on research activity relating to ME/CFS, especially any studies that require patient involvement.

Some interesting new research from Australia, which links to the presence of the virus in human faeces, is indicating that monitoring the level of coronavirus in sewage works could be a simple and reliable way of tracking the amount

of infection in the general population.

FDA announcement on FMTs:

[Fecal Microbiota for Transplantation: Safety Alert - Regarding Additional Safety Protections Pertaining to SARS-CoV-2 and COVID-19.](#)

We are in contact with all the research groups that we fund where patient contact is involved and are discussing how this affects the progress of their research.

PROGRESS ON THE NEW NICE CLINICAL GUIDELINE ON ME/CFS

In my capacity as a member of the committee that is preparing the new NICE clinical guideline on ME/CFS I took part in two days of recent video conferences.

However, NICE has decided to halt all further work on the guideline because many of the clinical staff on the committee (myself included) are heavily involved with our duties in relation to coronavirus.

My personal view is that it now seems very unlikely that we will be able to meet the current target of publishing the new NICE guideline in December 2020 and a more realistic date might be Spring 2021.

NICE has also been contacted about guidance on how people with serious pre-existing health problems should be managed if they must be admitted to hospital with coronavirus infection.



CAN PETS TRANSMIT THE INFECTION?

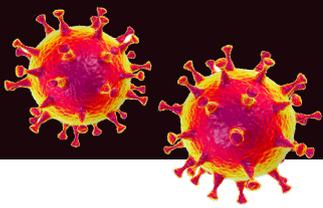
The view from the veterinary experts at present is that humans cannot catch the virus from pets and pets cannot catch the virus from humans.

However, this is another area of scientific uncertainty and to err on the side of caution, you should avoid touching cats and dogs that belong to other people (because the virus can persist on animal fur), and avoid your own pets licking you!

There is also a report of tigers in Bronx Zoo in America having the infection – possibly from a zookeeper.

[Government Guidance: Advice for people with animals.](#)





POSSIBLE FORMS OF TREATMENT

As noted in the full website summary, several experimental treatments are now being assessed and clinical trials completed examining three drugs.

The UK Recovery Trial is currently evaluating HIV drugs lopinavir/ritonavir as well as anti-inflammation steroid dexamethasone and anti-malarial hydroxychloroquine.

“Said to be the largest of its kind in the world, the study is being conducted by the University of Oxford at more than 130 NHS hospitals across the country.”

[Large-scale trial for coronavirus drugs launches in UK.](#)

One of the other developments is the use of what is called convalescent plasma where blood plasma from people who have been infected, recovered, and developed antibodies is given to those who are infected and those who care for them in an attempt to reduce or avoid full-blown infection:

[The Guardian: Coronavirus survivors' blood plasma could be used to fight infection.](#)



WHAT SHOULD PEOPLE WITH ME/CFS DO IF THEY CATCH CV19?



Not surprisingly, we are now starting to receive occasional reports from people with ME/CFS who are making a slow recovery and/or experiencing a significant exacerbation of their ME/CFS symptoms after catching Cv19.

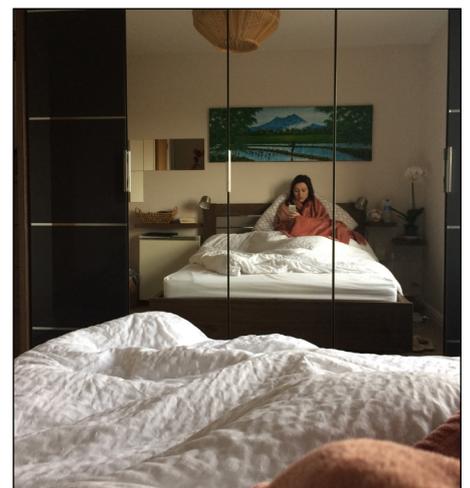
Several people with ME/CFS described their experience of CV19 infection in a discussion on the MEA Facebook page last week. On a more positive note, I am not currently aware of anyone with ME/CFS who has been admitted to hospital with severe respiratory problems.

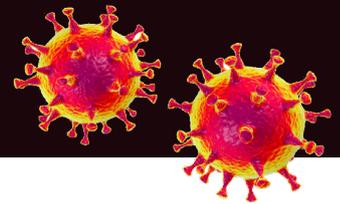
In our current state of knowledge we don't know with any certainty whether people with ME/CFS are more susceptible to catching Cv19 as a result of their immune system dysfunction, which includes low level immune system activation, and whether they are more vulnerable to developing the more serious respiratory complications.

What does seem highly likely is that people with ME/CFS will probably develop an exacerbation of symptoms,



or a relapse of symptoms – because a new and significant infective episode is a common cause of exacerbation/relapse in ME/CFS.





WHAT SHOULD PREVIOUSLY HEALTHY PEOPLE DO IF THEY EXPERIENCE SYMPTOMS SUGGESTIVE OF POST INFECTIOUS FATIGUE AND/OR ME/CFS?

I am aware, through personal and media reports, of a few previously healthy people who are now experiencing what could be a post-infection fatigue syndrome following Cv19 infection.

This is not surprising given that fatigue is often a very prominent symptom of this infection and there are some good epidemiological studies (i.e. the Dubbo research that Ian Hickie et al. carried out in Australia) to show that post-infection fatigue can affect around 10% of people in this sort of situation.

[Dubbo reference: Post-infective and chronic fatigue syndromes precipitated by viral and non-viral pathogens: prospective cohort study.](#)

As to how research might be carried out to investigate what is happening to people after the acute infection is over, this was discussed at the recent ME Biobank Steering Group meeting (as there are plenty of epidemiologists at the London School of Hygiene and Tropical Medicine – some of whom are looking at Cv19) and at the last CMRC Board meeting – where Prof Chris Ponting is taking a special interest.

One possible route here would be to make use of the baseline information on people who already have clinical data and blood samples stored at the UK Biobank but did not have PVFS or ME/CFS at the time of enrollment and then go on to develop prolonged fatigue, or

a fatigue syndrome following Cv19 infection, e.g:

“One possible route here would be to make use of the baseline information on people who already have clinical data and blood samples stored at the UK Biobank but did not have PVFS or ME/CFS at the time of enrolment and then go on to develop prolonged fatigue, or a fatigue syndrome following Cv19 infection”

[Dr Shepherd was interviewed for The New Scientist recently: Could the coronavirus trigger post-viral fatigue syndrome?](#)

As far as management is concerned, the guidance is fairly similar when it comes to people with ME/CFS who experience an exacerbation or relapse, and previously healthy people who are not getting better after 7 to 10 days and go on to develop symptoms suggestive of a post viral fatigue syndrome.

The basics being:

- Old fashioned convalescence involving very careful pacing of physical and mental activities,
- Attention to good nutrition – as some people with Cv19 are experiencing weight loss,
- Good sleep management in relation to either unrefreshing sleep or increased sleep (hypersomnia),

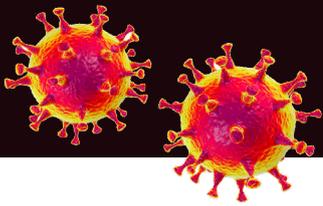
■ Returning to the GP if new symptoms develop, or a fever or chest symptoms continue, or get worse.

Health and care professionals often carry on working when they are ill but in this case, they (and everyone else) should avoid any pressure to return to work until they feel that they are fully capable of doing so.

Two further items of interest involve research from South Africa which indicates that having had a **BCG vaccination** in the past (to protect from TB) may help to reduce the severity of the Cv19 infection.

And there is growing evidence to indicate that older people who go on to develop more serious respiratory complications after a few days may be experiencing an overactive immune system/ inflammatory response to the virus. This could be linked to the way in which they may have been in contact with other **coronavirus infections in the past**, have developed antibodies, and are now producing an overactive immune system response.





HOSPITAL BASED REFERRAL SERVICES FOR ME/CFS

Hospital staff across several disciplines are now being retrained to work in other wards, including the care of Cv19 patients, and this applies to those working in the ME/CFS specialist clinics.

We are now starting to hear about ME/CFS referral services that are reducing their level of service and cancelling

outpatient appointments. So, looks as though these ME/CF: services will be operating with very limited capacity for at least the next three months.

If you have an urgent query it is still worth contacting the service to see if there is someone available who can provide information or guidance over the phone.



FURTHER INFORMATION

If you are keen to keep up with the latest developments, it's worth watching the daily Downing Street News Conference that takes place at 5pm each day and is broadcast live on the BBC news channel.

We will also continue to do our very best to keep you informed through MEA website and social media announcements.

It continues to be an incredibly busy time for your charity and we're doing all we can to help address the many concerns that are reaching us. Responses may be delayed, but we will get back to you as soon as we possibly can.

Please take care. Stay at home and stay safe.

ME CONNECT
We're here to help

Do you need to talk?

ME Connect is the telephone and email helpline service of the ME Association. It provides information and support for people with ME and those who live with or care for them. ME Connect provides a safe and understanding environment for people with ME so that they know they are being heard and understood.

ME Connect is a member of the Helplines Partnership which promotes high standards.

CALL 0344 576 5326

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

Calls cost the same as other standard landline numbers (starting 01 or 02). If you have a call package for your landline or mobile phone then calls will normally come out of your inclusive minutes.

