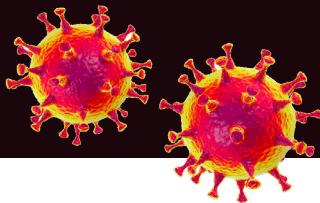


Coronavirus (COVID-19/Cv19) and ME/CFS

June 2020



THE CURRENT SITUATION

Having reached the peak of infection in mid April, the number of people being admitted to hospital with COVID-19, along with the number of deaths, is now gradually falling.

Hopefully, this trend will continue for the next few weeks and months until we reach a very low level of residual infection in the community.

However, we are then going to enter a position where a low but hopefully manageable level of infection persists, possibly with periodic spikes in certain parts of the country. This situation will almost certainly remain for the rest of 2020, and probably well into 2021 – until a vaccine becomes available, or the disease goes away, or largely disappears.

Although vaccine development research is proceeding at a very rapid rate in several centres, I don't think we are going to see a safe and effective vaccine being made available for public use until 2021. And while the chances of success appear to be fairly good, there is no guarantee that we will have a vaccine.



So the whole country is going to have to live with COVID-19 for the foreseeable future. And this means adjusting the way we all live according to the level of individual risk we face. We are all on a steep learning curve here and at a national policy level there is going to be quite a lot of trial and error before we get this right.

EASING THE LOCKDOWN

The second item of news, which follows on from the progressive fall in numbers, is the way in which a very cautious easing of Lockdown has been announced.

The various items of relaxation announced by the Prime Minister mean that changes in relation to exercise, education and employment are moving faster in England than elsewhere in the UK. But none of these changes are going to have any significant affect on most people with ME/CFS - unless someone is planning to return to work or school.

As far as education in England is concerned, the key point here in relation to ME/CFS is that any return to school is not compulsory - the government has simply issued guidance on returning to school for certain groups of children. My understanding is that nobody is going to be in trouble, or even fined, if they choose to continue to keep their children at home.

For people with ME/CFS who may now be asked to return

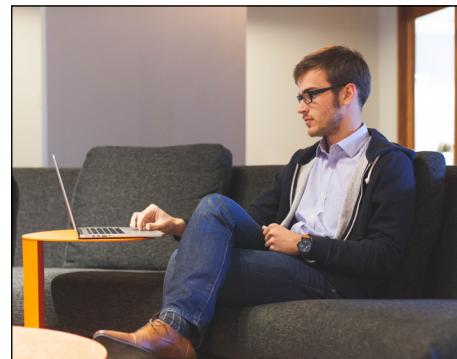


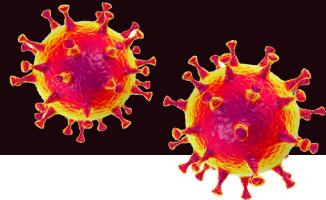
to work, or choose to return to work, this has to be on the basis of people being able to travel to work safely. And all aspects of the workplace must be safe in relation to hygiene and social distancing measures.

Employers have a clear duty under Health and Safety legislation to provide a safe working environment and the Health and Safety Executive has opened a hotline for people to call if they are not happy about what an employer is proposing or doing: 0300 790 6787, Monday to Friday 8.30am to 10pm.

If you have concerns about working arrangements you should discuss them with your trade union or professional body representative. The MEA has produced more detailed guidance on employment – see our COVID-19 Resources.

Dr Charles Shepherd
Hon Medical Adviser, MEA





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

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.

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.

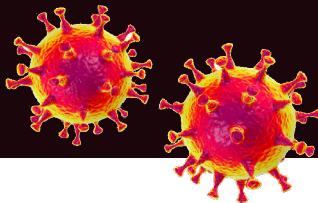
Dr Charles Shepherd
Hon Medical Adviser, The ME Association.

Regular Updates:

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. Our welfare rights adviser has written a new leaflet that covers all the main DWP benefit changes that relate to COVID-19.

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CONTROLLING THE SPREAD OF THE VIRUS

There are now consistent indications from the daily government statistics on new cases and deaths, and from the bed occupancy figures all round the UK (which are falling) that we are well past the peak and approaching a situation where there is a very low level of infection out in the community.

As a result there will continue to be a progressive easing of all lockdown measures - certainly for some healthy groups in the population, and for certain occupations and businesses.

However, for people with ME/CFS, social distancing and isolation is going to have to remain for many months to come - until a vaccine is developed (probable), a successful antiviral treatment has been found (possible) or what is called herd immunity has occurred (ie a large number of people are now immune to the infection) and the virus can no longer spread effectively.



■ As of Wednesday 17th June 2020, a total of 298,136 people have tested positive for the virus and 41,969 people in the UK who tested positive for coronavirus (COVID-19) have died.

Source: UK Government

Although the situation has been very serious in France, Germany, Italy and parts of the USA, the numbers of new cases are all now falling to very low levels.

People who are vulnerable, including anyone with ME/CFS, should try to stay at home except for:

- Shopping for essential items such as food and medicines
- A walk or some form of daily exercise
- Medical appointments
- Travel to work/school if you are able to do so

You should also ensure that 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.

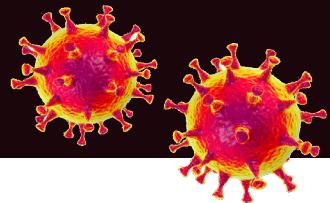
News item:

[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 is still worth using your own alcohol-based sanitizer to wipe the handle down before use.

VACCINE DEVELOPMENT

Scientists in Oxford and Imperial College London have made really rapid progress in developing a vaccine and clinical trials have now started. The Oxford trial will take 1000 people and split them into two equal groups - one group being given the vaccine, the other group receiving another vaccine. They will then be followed up and asked to report if they develop any symptoms suggestive of Cv19 and tested for the virus. If the Cv19 vaccine group are not catching the infection and the other group are this will be a good indicator of efficacy. The researchers will also want to make sure that the vaccine is safe.

All this will take time - at least six months. The results will then have to be analysed and manufacture of the vaccine started up. So a vaccine is not an immediate solution.

[Click here for a helpful news link.](#)

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 being rapidly increased with a Government aim of performing 100,000 tests per day. 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.

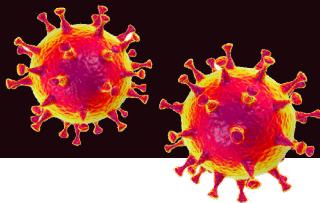
Anyone who has symptoms that are suggestive of COVID-19 should now be able to have a test.

GENERAL MANAGEMENT

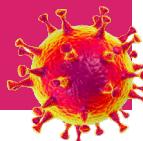
As many people are no longer going outside in the sunshine, or only doing so for short periods, the risk of vitamin D deficiency is increasing. So new advice is for everyone to take a daily 10 microgram vitamin D supplement.

People with ME/CFS are already at risk of vitamin D deficiency - so this is sound advice. Vitamin D is also essential for bone and muscle health. We have an MEA information leaflet covering vitamin D symptoms, prevention and treatment of deficiency.

Helpful links: [MEA Leaflet: Vitamin D Deficiency in ME/CFS](#) and [Vitamin D Supplements](#)



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.

Finally, there are further reports to indicate that loss or taste of smell is an important 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.

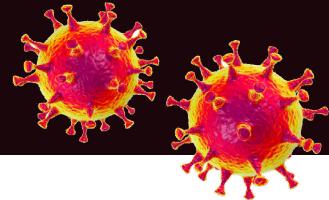
More information:

[Which magazine on supermarket shopping.](#)

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

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





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.](#)

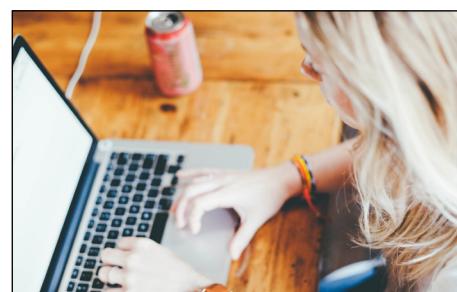
EMPLOYMENT

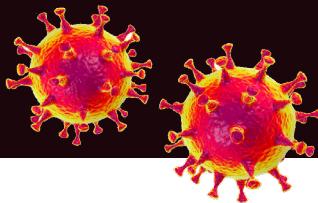
We are receiving an increasing number of queries relating to employment issues. As a result, we have produced a separate and more detailed guide to employment, coronavirus and ME/CFS.

This can be accessed here:

[The ME Association: 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 am chairing or attending regular virtual meetings for the ME Biobank and the ME/CFS 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 funding a new research study involving cardiopulmonary exercise testing at the University of Leicester - although it remains uncertain when this can commence as it will involve patient recruitment. More information can be found in the MEA website May news archive.

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

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. However, work is now resuming with working groups on specific topics meeting in June and the full committee meeting again in July.

My personal view is that we may not 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 have to be admitted to hospital with coronavirus infection.



CAN PETS TRANSMIT THE INFECTION?

The view from the veterinary experts is that humans are unlikely to 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.](#)

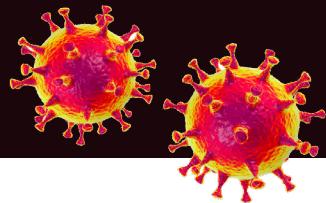
**DID YOU KNOW?
NHS 111**

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

111.NHS.UK

NHS





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-inflammatory 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.](#)

Preliminary results indicate that dexamethasone could be a real breakthrough in the treatment of COVID-19 for people in hospital who have severe respiratory complications:

[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.

People with ME/CFS have been describing their experiences of COVID-19 infection in several discussions on MEA Facebook. 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 is becoming increasingly clear 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.

FACE MASKS

There is a great deal of debate in the media about the value of wearing disposable or home-made face masks.

Most doctors agree that these sort of non medical face masks can provide some protection when it comes to the person wearing the mask and the spread of any respiratory infection they may have. But these sort of cheap masks provide very little protection to the person wearing the mask when it comes to prevention of viral droplets from someone else who is coughing or sneezing entering their mouth or nose. They may even be counter-productive in that they become moist and trap viral particles during the day.

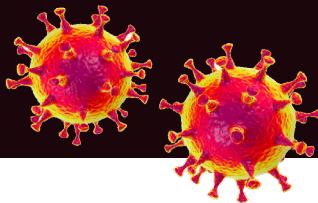
People also end up touching their face to fiddle with the mask and don't properly clean them before they are used again.

In current circumstances NHS staff need all the high grade medical face and eye masks and visors that do provide a high level of personal protection from the virus. The situation may therefore change when these sort of masks can be purchased by the public.

To help prevent the spread of infection many shops are now asking people to wear a face mask and wearing a mask



on public transport in England is now compulsory - unless you have a medical exemption.



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 an increasing number of 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),

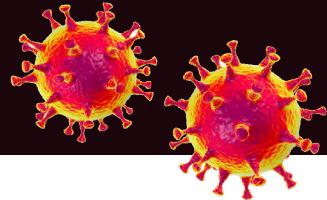
- Returning to the GP if new symptoms develop, or a fever or chest symptoms continue, or get worse.

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 many disciplines have been retrained to work in other wards, including the care of Cv19 patients, and this applies to those working in the ME/CFS specialist clinics.

As a result, some ME/CFS referral services have reduced their level of service or cancelled outpatient

appointments. So, it looks as though these ME/CFS 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 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](#)

PVF AND PVFS

We have a new MEA information leaflet covering the diagnosis and management of Cv19 PVF and PVFS. This is now available as a free website download.





The Ramsay Research Fund

the research arm of the ME Association

Please help us to further The Ramsay Fund's invaluable work in supporting biomedical research into M.E. (Myalgic Encephalopathy)/Chronic Fatigue Syndrome.

The Ramsay Research Fund was set up to find answers to:

- how and why M.E. starts.
- how we can develop a test. And better still...
- how we can cure more of the 250,000 people with M.E. in the UK today.

With your help, that day could be much sooner.

You can donate

- By cheque (payable to The ME Association) and with a covering note explaining that you wish your donation to go to research
- Online through our JustGiving campaign page for Ramsay Research Fund: www.justgiving.com/campaigns/charity/meassociation/ramsayresearchfund
- Or if you would like to make a regular donation, please contact our office to set up a standing order or use this link and type RRF in the message www.justgiving.com/meassociation/Donate



**ME Association's Ramsay Research Fund
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