



COVID VACCINES AND ME/CFS

Covid-19, Covid Vaccine, ME/CFS and Long Covid

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INTRODUCTION

Having endured all the restrictions imposed by the COVID-19 pandemic for well over a year, we are now in a position where the country is slowly returning to some form of normal life. This is mainly due to the rapid development of COVID-19 vaccines that are turning out to be highly effective.

COVID-19 has caused practical, emotional and financial problems for many people with ME/CFS, especially for those living alone. On the other hand, many of the restrictions on work, social activities and travel may not have made very much difference to these aspects of life if you have ME/CFS.

With Lockdown restrictions being steadily eased, and an end to many of the stricter rules planned for mid June, now seems a good time to review all the key issues relating to COVID-19 that affect people with ME/CFS.

THE CURRENT SITUATION

At the moment there is plenty of positive news around – certainly here in the UK. The vast majority of the population should be vaccinated against COVID-19 by July. Cases of COVID-19, deaths from COVID-19, and hospital admissions have all been falling quite dramatically since mass vaccination started and are now at very low levels.

However, COVID-19 is not going to go away. The chances are that the virus will remain active at low levels, probably with periodic

spikes or surges, and many experts are forecasting that will see another smaller spike in the Autumn. Worryingly, there are still many parts of the world, especially India and South America, where levels of infection remain very high.

Mutations in the genetic coding of the virus are occurring all the time resulting in new variants, where current vaccines may not provide adequate levels of protection. So it's not possible to say that there won't be another more serious wave of infection here in the UK – even if very high levels of vaccination have been achieved.

And we still have a very important part of the population who are not being vaccinated – children and young people up to the age of 16. Hopefully, the clinical trials that are now taking place will confirm that adolescents, and possibly younger children, can also be safely vaccinated against COVID-19 and that this group will be vaccinated before the end of 2021.

Continuing vigilance is therefore going to be required for many months to come.

STAYING SAFE

Although the Oxford Astra Zeneca and Pfizer vaccines are providing a very high degree of



COVID-19, COVID VACCINES, ME/CFS and LONG COVID was written by Dr Charles Shepherd (pictured above), Trustee and Hon Medical Adviser to The ME Association.

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protection, as well as reducing the chances of someone who has been vaccinated still catching and transmitting the virus, this is not a 100% guarantee. And as already noted, a low level of COVID-19 is almost certainly going to remain in general circulation. So all the hands, face and space public health measures aimed at reducing the risk of catching Covid-19 will need to continue for the rest of the year, and possibly well into 2022.

All the various ways in which people can reduce the risk of

coming into contact with the virus are outlined in detail in our MEA information leaflet on this subject.

One very important point to remember relates to the way in which people who are infected spread the virus into the atmosphere through droplets and aerosol contamination. In very simple terms, droplets are larger amounts of virus that are coughed or sneezed out and land on surfaces which become infected. But finer aerosol particles also pass into the air where they can travel for much further distances. The risk of aerosol transmission is very low out of doors if you are two metres apart from other people. However, the risk of transmission can be very high if you are in a room with lots of other people where there is no ventilation – even when you are two metres apart.

On the subject of masks, these are going to be far more effective if they are well fitting, not leaving any space around the mouth, and are of good quality thickness. I know that many people hate wearing a mask (myself included) and it's possible that if all goes to plan this is something that could be relaxed later in the year.

It may also be helpful to think about all the various activities of daily living that affect you on an individual basis and grade them by the rough level of risk that they create:

Low risk activities – which should be safe to do:

- Any form of outdoor activity – such as having a daily walk – that is not going to involve frequent or close contact with other members of the public.

Some risk activities – where you still need to take care or avoid:

- Any form of outdoor activity that involves more frequent or closer contact with members of the public.

- Going into, or working in rooms, shops, supermarkets or offices where good attention is being paid to ventilation, social distancing and creating a covid-free environment.

- Eating or drinking out of doors.

- Using uncrowded public transport or being in unventilated cars with other people.

Higher risk activities – which are still best avoided if possible:

- Going into, or working in rooms, shops, supermarkets or offices where poor attention is being paid to ventilation, social distancing and creating a covid-free environment.

- Using more crowded public transport.

- Attending outdoor gatherings involving larger numbers of people.

- Going into other people's houses that do not form part of any support bubbles.



COVID VACCINES

Researching, developing, testing and producing a number of different vaccines for use against COVID-19 in under a year has been a remarkable scientific achievement.

The MEA has been at the forefront in trying to make sure that everyone with ME/CFS who wants to have a COVID-19 vaccine should be able to do so as part of the JCVI group 6 priority list. Unfortunately, this has turned into a postcode lottery with some doctors being very happy to do so whereas others are refusing to do so. Hopefully, everyone with ME/CFS who would like to have a vaccine will have been able to

do so by the time this issue of the magazine is published.

The MEA has produced a pro forma letter that can be used to explain to your GP why people with ME/CFS should be included in JCVI group 6 – as you have an underlying health condition that is likely to be exacerbated by COVID-19. We have also produced a pro forma letter that can be sent to a Clinical Commissioning Group, or Welsh Health Board, if your GP is not willing to place you in JCVI group 6. We also have information on the MEA website regarding the situation in Scotland.

Here are some of the key considerations that people with ME/CFS need to take into account when deciding on whether or not to have a Covid-19 vaccine:

- COVID-19 is a very serious life-threatening infection that is not going to go away for the foreseeable future. It may never go away completely.

- If someone with ME/CFS catches Covid-19 it is likely to cause a significant exacerbation or relapse of their ME/CFS symptoms. We know this from feedback to the MEA over the past year.

- Your individual circumstances and risk of coming into contact with the virus, or someone who may have the virus.

- All the Covid-19 vaccines are exceptionally safe (apart from the very rare blood clotting and severe allergic reactions with the Astra Zeneca vaccine) and provide a very high degree of protection.

- As with any vaccine, some people with ME/CFS will have an exacerbation of symptoms, especially those that overlap with the commonly reported side-effects of the COVID-19 vaccines. A smaller percentage (possibly around 5 to 10%) are reporting a more severe or persisting exacerbation of ME/CFS.

At the moment there is no evidence to indicate that any of the current vaccines (ie AstraZeneca, Moderna,



Pfizer) currently available in the UK is a better choice for people with ME/CFS in relation to either safety or efficacy. And it is highly unlikely that you will be offered a choice.

Where there is still uncertainty is how much protection any individual will have and how long this immunity will last. What seems likely is that all those over 70, and those in very vulnerable clinical groups (ie JCVI group 4 and possibly group 6), will now be offered a booster dose in September, possibly combined with the annual flu vaccine that is due at the same time.

We are publishing regular updates covering feedback from people who have had a COVID-19 vaccine on the MEA website. Current feedback indicates that most people are coping OK and are experiencing nothing more than a short-lived period of the common side-effects that are known to occur with most other vaccines.

However, a small but significant minority, possibly around 10%, are experiencing a more significant relapse or exacerbation of their ME/CFS, or having more pronounced side-effects. This is clearly a very worrying situation for people in this group, especially when it comes to deciding on whether or not to have the second jab if you have still not recovered.



MEA MARCH 2021 WEBSITE POLL RESULTS

We asked - Have you had your Covid vaccination? If so, how did you feel afterwards? Choose up to three answers.

- I felt fine. No discernible issues even after a few days. (7%, 201 Votes)
- I felt surprisingly better for a few days after the vaccine. (2%, 70 Votes)
- I experienced side effects e.g., sore arm, increased fatigue, headache, chills, slight fever, etc. (19%, 547 Votes)
- I had some of the above side-effects and an increase in ME/CFS symptoms. (12%, 351 Votes)
- I had some of the above side-effects but no increase in ME/CFS symptoms. (9%, 260 Votes)
- I had all of the above side-effects and an increase in ME/CFS symptoms. (12%, 361 Votes)
- I had none of the above side-effects but had an increase in ME/CFS symptoms. (1%, 35 Votes)
- I had significant side-effects and/or a significant increase in ME/CFS symptoms and had to consult my doctor. (4%, 118 Votes)
- The issues resolved within days of the vaccination. (10%, 296 Votes)
- The issues resolved within a week of the vaccination. (8%, 228 Votes)
- The issues took longer than a week to resolve. (9%, 254 Votes)
- The issues remain unresolved and have led to a relapse in ME/CFS. (7%, 208 Votes)

Total Voters: 1,956

We currently have very little feedback from people who have had a second dose and an even smaller number of responses from people who have had a bad reaction to the first dose. Having the second dose should obviously provide a further boost to immune system protection against the virus and possibly lengthen the time this protection lasts. But this may be at the expense of having another exacerbation of symptoms.

If you have already had a bad reaction, this is clearly a difficult decision to make and will depend on all your individual circumstances. On a personal basis I have now had my second dose and experienced no side effects at all. However, amongst the healthy population, side-effects can be more common and pronounced after a second dose because the immune system has been primed by the first dose to react against anything that it recognises as a potential COVID-19 infection – ie a second dose of vaccine.

■ **We have an MEA information leaflet covering all aspects of COVID-19 vaccines in relation to ME/CFS:**

<https://tinyurl.com/4y69a6cm>

EMPLOYMENT AND EDUCATION

Most children are now back at school and university education should be returning to normal in the Autumn. We have an MEA 'To Whom It May Concern' vulnerability letter that explains all the issues that need to be taken into consideration when children and adolescents return to school or university.

People with ME/CFS who are still able to work may now be asked to return to their workplace where work cannot be done from home. We have another TWIMC vulnerability letter that covers all the issues that may affect people with ME/CFS in relation to employment and COVID-19. We also have an MEA information leaflet that covers Employment issues in general in relation to ME/CFS.

If you are going to work in your normal place of work, employers have a legal duty to provide a safe working environment. This includes complying with all the government guidance on how to make the working environment as safe as possible in relation to hygiene, social distancing etc. If you have any concerns about safety at work you should raise them with your employer, human relations department, or occupational health department. If you are not happy with the response, contact your trade union or professional body, or the Health and Safety Executive.

WHAT IS LONG COVID? IS IT THE SAME AS ME/CFS?

We currently estimate that around 10% of people who catch COVID-19 are going on to develop some form of Long covid – a diagnosis that can be made when someone remains symptomatic and unwell 12 weeks after the onset of the infection.

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 and remaining unwell after three months are accurate, this would translate into well over 100,000 people with some form of significant post-covid ill health that has persisted beyond three months. The real figure could be considerably higher.

The latest data (March 2021) from the Office of National Statistics (ONS) indicates that:

- One in five people were still symptomatic at five weeks after the start of the initial infection - approximately 1 million people
- One in seven were symptomatic at 12 weeks - approximately 700,000 people
- Around 70,000 people were still symptomatic one year on from the initial infection
- In 20% of cases this was having a significant effect on day-to-day activities
- Post-covid ill health was more common in people working in health and social care professionals

Most of the people with Long covid that we have been dealing with at the ME Association over the past year are previously fit (some very fit) young adults in their 20s to 50s. We are also starting to hear about a growing number of children and adolescents with Long covid.

People with Long covid have nearly always been self-managed at home during the initial infection. But we are also hearing from people who have been managed in hospital.

As with ME/CFS, there is a significant female predominance

and there appears to be the same overlap in some cases with mast cell activation syndrome (MCAS).

Long covid has a number important clinical and pathological features that overlap with PVFS and ME/CFS.

A significant proportion of people with Long covid have a cluster of symptoms – activity-induced fatigue, myalgia/muscle pain, cognitive dysfunction/brain fog, dysautonomia (ie problems with regulating pulse and blood pressure leading to orthostatic intolerance and PoTS), headaches, poor temperature control, post-exertional malaise/symptom exacerbation - that are consistent with a post-viral fatigue syndrome (PVFS) or even ME/CFS.

Most people with Long covid also have a layer of on-going clusters of symptoms (eg shortness of breath, chest pains, heart rhythm disturbances/cardiac arrhythmias, palpitations on exertion, fevers, loss of taste and smell, abdominal pain and diarrhoea, skin rashes like 'Covid toe') relating to the involvement of their lungs, heart and blood vessels, liver, kidneys, brain, skin etc that occurred at the time of the original infection.

In some cases there is a third layer of symptoms involving mental health - anxiety, depression, even PTSD.

While the underlying causes of both Long covid and ME/CFS remains uncertain, one very interesting overlap between the two conditions is the involvement of immune system chemicals called cytokines – which cause inflammation and many of the symptoms associated with any acute infection.

During the acute stage of COVID-19 there is what is termed a cytokine surge – with a massive over production of cytokines causing inflammation in the lungs and serious respiratory complications. There is research evidence in ME/CFS to indicate that an on-going cytokine response involving

what are called pro-inflammatory cytokines fails to 'switch off' after the initial infection. These cytokines can then pass through what is called the blood brain barrier and affect an area of the brain called the hypothalamus (which acts as a thermostat for temperature control along with appetite, sleep and hormone regulation) and control centres in the brain for the autonomic nervous system (which controls heart rate and blood pressure and leads to orthostatic intolerance and PoTS).

At present there is no treatment for Long covid – just like ME/CFS. So management consists of carefully assessing people to see if there is any on-going damage to the lungs, heart, liver etc and then providing good information and guidance on the management of individual symptoms relating to this damage. In particular this means carefully assessing lung and heart function to try and establish whether any damage to the lungs and heart muscle (myocarditis) are causing symptoms such as shortness of breath and palpitations.

For symptoms that are the same as those found in ME/CFS – ie fatigue, cognitive dysfunction, dysautonomia, unrefreshing sleep, pain – the same sort of self-help management strategies and symptomatic relief using drugs that are used in ME/CFS should be discussed with a health professional.



One interesting therapeutic development is the finding that some people with Long covid have symptoms of what is called mast cell activation – where a viral infection destabilises mast cells causing the release of histamine.. Where this occurs there are reports that treatment with drugs called histamine receptor antagonists and a low histamine diet can be helpful here.

There is now a network of over 70 hospital-based Long covid Clinics where people can be referred. Feedback to the MEA indicates that they are often very good at assessing people but not so good at having the necessary time to spend on management, and lacking the necessary expertise to deal with ME/CFS type symptoms. There have been proposals to have joint Long covid and ME/CFS clinics. The MEA position is that they should be kept separate at present - due to the need to have specialist input for the heart and lung problems - but to establish links to ME/CFS clinics to refer people to for help with management of ME/CFS type symptoms.

The overall outlook in Long covid appears to be very uncertain - as with ME/CFS. Many people with Long covid are finding that their condition fluctuates in severity – often more dramatically than occurs in ME/CFS. Some stabilize and a few have deteriorated. While some are clearly making a progressive improvement, or even full recovery from Long covid, they appear to be in a minority.

Here at the MEA we are trying to build bridges with the Long covid patient and medical communities by offering to provide information and guidance on the management of symptoms that overlap with ME/CFS. We are also explaining how research into ME/CFS, especially relating to immune system dysfunction and problems with creating energy at a cellular level, can help them to understand what may be happening in Long covid. But this should be a two way process with research into the cause and treatment of Long covid helping people with ME/CFS.

Further information

We are regularly updating the MEA information booklet covering the overlap between Long covid and ME/CFS plus the diagnosis and management of Long/Post-covid fatigue and Long/Post-covid ME/CFS. This booklet covers the management of all the common ME/CFS like symptoms that overlap with Long covid in some detail. This is a free download from the Covid-19 literature section in the MEA website shop:

<https://meassociation.org.uk/shop/>

MEA position statement on the overlaps between Long covid and ME/CFS:

<https://tinyurl.com/umr6jbu2>

Article for the BMA/BMJ publications with contributions from Drs Nina Muirhead, David Strain, Amy Small and myself also covers the ME/CFS and Long covid overlap:

<https://tinyurl.com/vdsjcf7y>

Resources

The MEA website has a COVID-19 literature section where all these information leaflets can be found. All our COVID-19 literature is free to download here:

<https://meassociation.org.uk/covid-19-me-cfs-free-resources/>

DISCLAIMER

Medical information contained in this leaflet is not intended to be a substitute for medical advice or treatment from your doctor. The ME Association recommends that you always consult your doctor or dentist about any specific problem. We also recommend that any medical information provided by The MEA is, where appropriate, shown to and discussed with your doctor or dentist.