

COVID-19 VACCINE UPDATE

Options, eligibility, safety and ME/CFS – what we know so far

ME CONNECT HELPLINE: **0344 576 5326**

Monday 4th January marked the start of the UK mass vaccination programme against COVID-19. The current aim is to vaccinate around 2 million people each week. To start with, over the next three months, priority is being given to key workers and people who are far more vulnerable to the effects of COVID-19 due to either age (ie being over 70) or having an underlying health condition.

Back in December the vaccination of health workers started with the use of the Pfizer/BioNTech vaccine and this will still be in use. However, the government has ordered 100 million doses of the newly approved Oxford AstraZeneca vaccine. This is going to be the vaccine of choice from now on for almost everyone in the UK, including people with ME/CFS, for the following reasons:

- Developed and tested on volunteers here in the UK
- On current evidence it provides a high degree of protection (up to 90% after the second dose) and has a very good safety profile
- Much cheaper to manufacture than the Pfizer/BioNTech vaccine
- Much easier to transport, store and deliver than the Pfizer vaccine – as it can be stored in a GP surgery fridge. The Pfizer vaccine has to be stored in a freezer at minus 70 degrees centigrade



COVID-19 VACCINE PRIORITY AND ME/CFS

The Joint Committee on Vaccination and Immunisation (JCVI) produces a regularly updated list of different groups of people in the order that they are going to be offered one of the new COVID-19 vaccines.

Current (30th December 2020) JCVI priority list:

<https://tinyurl.com/ybzazoc7>

At the top of the JCVI list are people who are living and working in care homes, health workers, the very elderly (ie those over 80 years of age) and people who are extremely vulnerable to COVID-19 – because they have a high risk of developing serious or life-threatening complications if they catch COVID-19. Which is fair enough...

While anecdotal evidence indicates that people with ME/CFS are very likely to suffer an exacerbation or relapse of their ME/CFS symptoms if they catch COVID-19, there is no evidence to indicate that they are at significantly increased risk of developing serious or life-threatening complications. So it is unlikely that ME/CFS will move up to very high priority status.

The priority list is followed by a group of people (in group 6) who have what are termed by the JCVI as 'underlying health conditions' that make them vulnerable in relation to COVID-19. This list includes people with chronic neurological conditions.

ME/CFS should be included in the 'underlying health conditions'

by Dr Charles Shepherd
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COVID-19 vaccines: Options, eligibility, safety and ME/CFS – what we know so far was written by Dr Charles Shepherd (pictured above), Trustee and Hon Medical Adviser to The ME Association.

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list – as it is classified as a neurological disease by both the WHO (in ICD10, G93:3) and NHS England: <https://tinyurl.com/ryv2x4d>

In addition, COVID-19 will almost certainly exacerbate pre-existing ME/CFS symptoms and/or cause a relapse of ME/CFS.

The MEA has therefore written to the Chief Medical Officer, Professor Chris Whitty, on January 3rd to ask him to confirm that people with ME/CFS are in group 6 of the JCVI list.

Link to CMO/JCVI correspondence: <https://tinyurl.com/y33e3vqk>

People in group 6 of the JCVI list will only become high priority once the over-65 age group has been vaccinated.

So people with ME/CFS below the age of 65 may not be offered a COVID-19 vaccine until March or April this year. However, it could be sooner if the number of weekly vaccinations taking place can be significantly increased.

HOW SAFE ARE THE COVID-19 VACCINES OVERALL?

The safety data so far on the two vaccines that have been approved for use in the UK (ie Pfizer/BioNTech and Oxford/AstraZeneca) indicate that they can cause the sort of short-lived side-effects – fatigue, headache, myalgia/muscle pain, slight fever, sore arm etc – that are found with most other vaccines and don't normally cause any significant or persisting problems for fit healthy people.

There have been a small number of reports of severe allergic reactions occurring in people who have a past history of allergic reactions in relation to the Pfizer vaccine. So this is not being recommended for use in people with a history of severe allergic reactions. This does not appear to be a problem with the AstraZeneca vaccine so far.

Useful information from the US Centres for Disease Control on the severe allergic reactions/ anaphylaxis and COVID-19 vaccines: <https://tinyurl.com/y cyn4s7>

If you are concerned about the contents of the Oxford vaccine they are listed here: <https://tinyurl.com/y5wa27wc>

It's important to note that neither of the two COVID-19 vaccines that are being used in the UK are live vaccines – they contain no live virus.



Otherwise, there is no indication at present of any serious side-effects occurring with either of the approved vaccines. However, as with any vaccine, rare and more serious side effects may not become apparent until large numbers of people (ie 100,000+) have been vaccinated and followed up.

Two cases of transverse myelitis have been reported in relation to the Astra Zeneca vaccine:

Nature: COVID-vaccine results are on the way — and scientists' concerns are growing: <https://tinyurl.com/y6tehk68>

However, on further investigation it was concluded that these events were not vaccine related. With over 20,000 people being involved in the initial clinical trial of the Oxford vaccine there are always going to be people who develop other medical conditions at around the same time as being vaccinated.

The US Centres for Disease Control has produced a useful short guide to the use of these vaccines in people with underlying neurological and autoimmune conditions: <https://tinyurl.com/y7qq5fkl>

HOW SAFE ARE THESE VACCINES FOR PEOPLE WITH ME/CFS?

As with most vaccines, there is a risk that some of the commonly reported side-effects which overlap with ME/CFS symptoms – eg fatigue, muscle pain, feeling feverish - are going to be exacerbated by having a COVID-19 vaccine. There is also a possibility that a COVID-19 vaccine

could trigger a more significant exacerbation of ME/CFS symptoms.

At present, we have no data from the clinical trials as to what happens to people with ME/CFS with any of these vaccines. And I am not aware of anyone with ME/CFS who has taken part in any of the clinical trials.

Patient evidence from people with ME/CFS, mainly health workers, who have had a COVID-19 vaccine is now starting to arrive at the MEA. The numbers are very small at the moment but initial feedback indicates that some people are, not surprisingly, having an exacerbation of ME/CFS symptoms.

If you do have a COVID-19 vaccination please let us know what happens – so we can build up a patient evidence database. If you have a more severe reaction this must be reported to your GP so that the information can be passed on to the regulatory authorities through the Yellow Card reporting system.

VACCINE ADMINISTRATION PRACTICALITIES

At the moment it looks as though vaccine administration in the community is going to be carried out via hospital centres and GP surgery hubs – where groups of GPs are working together to administer vaccine to those at the top of the JCVI priority list. It appears that the GP hub system is working very efficiently in some areas but not so well in others. It is also possible, as with flu vaccination, that pharmacies will be providing a vaccination service.

There is no point in contacting your GP to find out if you can have a COVID-19 vaccine – unless you are in one of the high priority groups who are going to be given the vaccine over the coming weeks and months and an invite has not appeared. People should, in theory, be contacted by their GP when a vaccination is due, and told where it will take place.



In order to vaccinate as many as people as possible, and as quickly as possible, a decision has been made to extend the gap between the first vaccination and the second vaccination to 12 weeks. The JCVI has concluded that one vaccination provides a fairly high degree of protection after about two weeks and also significantly reduces the risk of severe disease or hospital admission occurring.

In our current state of knowledge we do not know how long immunity to COVID-19 will persist after vaccination. It seems likely that boosters, or an annual vaccination to take account of changes in the genetic make up of COVID-19 will be required – as with flu vaccination.

The scientists seem confident that these vaccines will be effective against the new strain of virus that is now spreading quite rapidly. But they are more concerned about the new South African variant and whether this may have some resistance to the new vaccines.

As with any vaccine, if you have ME/CFS, it is sensible to defer having a vaccination if you are experiencing any feverish or flu

like symptoms, or going through an exacerbation of your ME/CFS. It is also a good idea to plan ahead to try to make sure that you are not going to have to do anything that involves physical or mental stress on the days before, during, or after having a vaccination.

MAKING A DECISION

When it comes to deciding if you are going to have a COVID-19 vaccine people with ME/CFS are going to have to make an individual decision that is based on the information that we have so far:

- 1 A risk that some or all of your existing ME/CFS symptoms may be exacerbated for a short period of time.
- 2 A lower risk of a more significant or prolonged exacerbation of ME/CFS symptoms.
- 3 The possibility that once very large numbers of people have been vaccinated we will learn about some rare or more serious side-effects that could be relevant to people with ME/CFS.
- 4 Obtaining a high degree of protection from COVID-19

in return for taking a risk of exacerbating ME/CFS symptoms.

Life is full of risks and based on what we know so far on safety and efficacy of these vaccines my personal view is that taking a risk of having an exacerbation of existing ME/CFS symptoms is a small price to pay for having a high degree of protection against a life threatening infection that we are all going to have to live with, just like flu, for the foreseeable future.

If you decide against having a COVID-19 vaccine it is extremely important to make sure that you continue to do all you can to ensure that you do not catch COVID-19 – as this will almost certainly cause an exacerbation, possibly prolonged, of your ME/CFS symptoms. You could also develop the far more serious heart and lung complications that are associated with COVID-19. You should also try to ensure that anyone you come into regular contact with, especially any carers, has the vaccine.

Further information

More details on the various vaccines that are available in the UK: <https://tinyurl.com/yxtgw3pf>

The MEA website shop:

The ME Association has the largest selection of ME/CFS advice leaflets in the UK on:

- Medical Management
- Mental Health
- Diet & Nutrition
- General Information
- Fundraising Leaflets
- Benefits & Social Care
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<https://meassociation.org.uk/shop>

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Full Membership is available to all adults with ME/CFS, carers and

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- £18.00 (UK residents and BFPO)
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- £30.00 (Rest of the World)

Each full member is entitled to vote at our Annual and Extraordinary General Meetings.

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