**19 March 2021**

**MEA Template Letter to CCGs & Welsh Health Boards**

**RE: COVID VACCINE PRIORITY FOR PEOPLE WITH ME/CFS**

This is a new template letter that can be suitably edited and sent to a Clinical Commissioning Group in England or Welsh Health Board if you have been unsuccessful at getting the vaccine from your GP.

* [Find your Clinical Commissioning Group (England)](https://www.nhs.uk/Service-Search/other-services/Clinical%20Commissioning%20Group/LocationSearch/1)
* [Find your Health Board (Wales)](https://www.wales.nhs.uk/ourservices/directory/LocalHealthBoards)
* Please modify the letter template to suit your individual circumstances.
* Then copy and paste to your own letterhead or email.
* Make sure it’s dated and signed, contains your home address and date of birth – then either email it or send by royal mail.

Dear **[Name of official at CCG or Welsh Health Board]**,

**Request to include ME/CFS in Group 6 for Covid vaccine priority**

I have the neurological disease, myalgic encephalomyelitis (ME), also known as chronic fatigue syndrome (CFS), and believe that I should be eligible for priority Covid vaccination.

However, my GP has refused to place me in Group 6 of the JCVI vaccine priority list because he/she believes that people with ME/CFS are not eligible and that my individual circumstances do not put me at greater risk.

ME/CFS is classified by the World Health Organisation and NHS England as a neurological disease. It is often triggered by an infection, including coronavirus infections, and infections are probably the most common cause of relapse or exacerbation in ME/CFS.

There is strong patient evidence to indicate that people with ME/CFS are suffering an exacerbation or relapse of symptoms if they catch Covid-19 leading some to become housebound or bedbound and reliant on the care of others.

The NHS Green Book guidance (Chapter 14a, page 12) makes it very clear that doctors can and should be using their clinical judgement to identify anyone with an underlying health condition that is likely to be exacerbated by COVID-19 and then place them in Group 6.

NHS Green Book:

* <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/961287/Greenbook_chapter_14a_v7_12Feb2021.pdf>

As ME/CFS is a post infectious illness that is very likely to be exacerbated by any new infection, and people with ME/CFS have had their condition exacerbated by COVID-19, they do therefore meet this aspect of the Group 6 criteria.

The evidence for doing so is described in more detail in a pro forma letter that  has been prepared by The ME Association. A copy of this letter can be accessed via the link below and you might also like to read the email response from the Secretary of State, Matt Hancock:

* [ME Association Covid Priority Vaccine Eligibility Letter to GPs | 19 March 2021](https://meassociation.org.uk/wp-content/uploads/ME-Association-Covid-Vaccine-Priority-Template-Letter-GPs-V5-19.03.21.docx)
* [ME Association: Matt Hancock on ME/CFS Covid Vaccine Priority for people with ME/CFS | 19 February 2021](https://meassociation.org.uk/2021/02/matt-hancock-on-me-cfs-covid-vaccine-priority/)

As well as the confirmation from Matt Hancock, there are now a number of very clear statements from CCGs, Vaccination Hubs, and Welsh Health Boards acknowledging that people with ME/CFS can be placed in JCVI Group 6.

**Examples of statements from CCGs, and Welsh Health Boards:**

1. **Gloucestershire CCG**

We do acknowledge though the statement from the chairman of the JCVI in response to Dr Shepherd which states that a ‘prescriber should apply clinical judgment to take into account the risk of COVID-19 exacerbating any underlying disease that a patient may have, as well as the risk of serious illness from COVID-19 itself.’

Therefore, whilst we are supportive of clinicians adhering to the current JCVI guidelines we would also be supportive of clinicians if they have placed an individual into cohort based on their own professional and clinical judgement

Patient Advice and Liaison Service(PALS) & Complaints
NHS Gloucestershire Clinical Commissioning Group

1. **Surrey Heartlands CCG**

I have always informed GPs that they can use clinical discretion when making priority decisions but need to balance this with the need to ensure vaccine is prioritised for those most at risk.

I will remind our GPs in my weekly comms that they always have the option to apply clinical discretion when determining if a patient with M.E needs to be prioritised for vaccine.

Dr Sally Johnson  |  Clinical Director Urgent & Emergency Care, Covid Vaccination | Surrey Heartlands Clinical Commissioning Group

1. **Powys Health Board – Director of Public Health**

I have taken clinical advice from our Director of Public Health who is content to say that ME/CFS is a neurological condition and that it is likely COVID-19 would exacerbate the underlying disease and that individuals with ME/CFS should be considered eligible under Priority Group 6.

On the basis that there is local flexibility, then we would support ME/CFS sufferers being offered vaccination.

I have asked for this information to be shared with the xxxx practice and would ask that your daughter contact them to arrange a suitable time to be vaccinated under the Priority 6 cohort.

Amanda Edwards

Cyfarwyddwr Rhaglen Brechu Torfol | Programme Director Mass Vaccination

Bwrdd Iechyd Addysgu Powys | Powys Teaching Health Board

**[*Include a brief paragraph here about your own situation and why you think you should receive the vaccine as a priority.]***

In light of this information and guidance, and considering my personal situation, I would be grateful if you could confirm that GPs in the area covered by the [XXXX CCG/XXXX Welsh Health Board] can use their clinical judgement to place people with ME/CFS in JCVI Group 6 because Covid-19 infection is highly likely to lead to a deterioration in health.

Thank you very much in advance for your time and indeed for everything you and your colleagues are doing during this pandemic.

Yours sincerely

**[*Your Full name. Address. Contact phone number. Date of birth. NHS Patient Number.*]**