INTRODUCTION

To link in with the launch of the NHS flu vaccination campaign this year I have updated our flu and pneumococcal vaccine leaflet. I have included some information about COVID-19 boosters as well.

The key message from this year’s flu vaccine campaign is that having been isolating ourselves from respiratory infections for almost two years our natural immunity to flu viruses has decreased significantly. So we are likely to see a large rise in the number of people catching flu this winter.

At the same time, flu viruses and COVID-19 virus are going to be circulating in combination – which makes the chances of serious illness far more likely, especially in the elderly and people with underlying health conditions. COVID-19 is not going to go away in the foreseeable future and it looks as though high case numbers may well persist into early 2022 before hopefully starting to decline. Consequently, some experts are predicting that the number of deaths from flu this winter could even reach 60,000.

So the aim of this year’s campaign is to vaccinate around 40 million people. In addition to all the usual groups, anyone over the age of 50 can now have a free NHS flu jab and children up to the age of 16 will also be offered one.

All the key points relating to the 2021/2022 flu vaccine and eligibility criteria for the COVID-19 boosters are covered in the Questions and Answers below.

More detailed information on flu vaccine, as well as the pneumococcal vaccine, can be found in the second part of this information leaflet.

1. Are people with ME/CFS entitled to have a free NHS flu vaccine if they choose to do so?

The simple answer here should be yes. This is because one of the at risk health conditions for being eligible for an NHS flu vaccine is having a chronic neurological disease.

NHS information leaflet on flu vaccine and chronic neurological disease:

https://tinyurl.com/8rxber83

Confirmation that ME/CFS is classified as a neurological disease:

- ME/CFS is classified by the World Health Organisation as a neurological disease in section G93.3 of ICD10
- NHS England classifies ME as a fluctuating long-term neurological condition:

https://tinyurl.com/v7wv48m2

DISCLAIMER

We recommend that the medical information in this leaflet is discussed with your doctor. It is not intended to be a substitute for personalised medical advice or treatment. You should consult your doctor whenever a new symptom arises, or an existing symptom worsens. It is important to obtain medical advice that considers other causes and possible treatments. Do not assume that new or worsened symptoms are solely because of ME/CFS.
The SNOMED disease classification system, which is used by the NHS, classifies CFS as a chronic disorder of the nervous system:

https://tinyurl.com/fuk9h8f6

If you are still being refused an NHS flu jab by your GP surgery it’s worth going to a pharmacy that is administering NHS flu jabs. This is because feedback to the MEA in previous years indicates that pharmacists are normally quite happy to accept that ME/CFS is a chronic neurological disease. All of this information is described in more detail in the second part of this MEA information leaflet.

2. Is it safe to have a flu vaccine and a COVID-19 booster vaccine together?

For largely administrative reasons, it looks as though some people are going to be offered both vaccines together - where they are entitled to have both.

However, we know that people with ME/CFS do sometimes react badly to vaccinations, including flu vaccine and COVID-19 vaccines. All the pros and cons of having a flu vaccine are summarised in more detail in the second part of this leaflet. So it’s possible that having both vaccines together may increase this risk still further.

On the other hand, attending two vaccination sessions on separate occasions, and possibly having to deal with two separate adverse reactions, also carries a risk.

As we just don’t know the answer to this question at the moment in relation to ME/CFS people will have to make an individual judgement.

3. Will people with ME/CFS be automatically offered a COVID-19 booster jab?

The JCVI (joint committee on vaccination and immunisation) has now recommended that everyone on JCVI priority groups 1 - 9 should receive a booster jab. So this will include everyone in JCVI group 6 (which should include people with ME/CFS) and everyone over the age of 50 (group 9).

However, if the same descending JCVI priority list that was used for first and second doses is applied to booster doses, we may still see people with ME/CFS who are below the age of 50 having to once again prove that they have a medical condition that is likely to be made worse by COVID-19.

If so, we will be updating the MEA letter that explains why people with ME/CFS under the age of 50 should be regarded as having a vulnerable medical condition in relation to COVID-19.

In theory, if your doctor agreed that you should be in JCVI group 6 for the first and second doses, the same reasoning should automatically apply to a booster dose.

Unfortunately, anyone who was refused a first or second dose of vaccine on the basis that they did not meet JCVI group 6 criteria may have to battle with the medical authorities all over again.

Latest information (September 14th) from the JCVI on COVID-19 booster jabs:

https://tinyurl.com/yama85ru6

4. Should I have a COVID-19 booster if I had a bad reaction to the first or second dose?

This is another difficult question because we know that a small but significant minority of people with ME/CFS experienced a bad reaction to their first or second vaccine. In some cases this resulted in a prolonged exacerbation or relapse of their ME/CFS.

On the one hand, COVID-19 is going to be with us for the foreseeable future and there is growing evidence that vaccine-induced immunity starts to progressively decline from around 6 months after the second dose of vaccine.

On the other hand, we just don’t know if having a bad adverse reaction to a first or second dose of COVID-19 vaccine means that you will probably have a bad reaction to a booster with or without a different vaccine. Intuition suggests that this could well be the case….

One important point to note here is that booster jabs will be with either the Pfizer or (half dose) Moderna vaccine - regardless of which vaccine was used to start with. Both of these vaccines have been shown to produce a strong booster response. AstraZeneca vaccine is only being used for booster jabs in exceptional circumstances.

5. Can I get a booster jab at home if I cannot get to the surgery or vaccination hub?

There are likely to be problems here in that the Pfizer vaccine has to be stored at very low temperatures - so this isn’t a good choice for home vaccinations.

If you are being told that you cannot be vaccinated at home with a Pfizer vaccine you will need to ask about having the (half dose) Moderna vaccine.
FLU VACCINES FOR 2021 - 2022

Seasonal flu (also known as influenza) is a highly infectious illness caused by several types of flu virus. Flu normally causes anywhere between about 1,000 and 20,000 deaths per year in England alone. The flu virus spreads rapidly through small infected droplets that are coughed or sneezed into the air by an infected person. Even people with mild or no symptoms can infect other people. So the spread of infection is just the same as with COVID-19.

As there is no simple answer as to whether you should have flu vaccine if you have ME/CFS, the purpose of this leaflet is to provide information on all aspects of flu vaccination in relation to ME/CFS. You and your doctor can then decide if you ought to have this protection.

**What is the science behind flu viruses and flu vaccines?**

There are three types of influenza virus. Type A viruses are the most dangerous and cause outbreaks in most years. Type B viruses tend to cause less severe disease and smaller outbreaks, often in children. Type C viruses cause a minor respiratory illness.

Type A viruses are sub-divided by the type of immune-system markers known as antigens that are found on the surface of the virus. These are known as haemagglutinin (H) antigens and neuraminidase (N) antigens. These markers help the virus to invade the body cells. 18 types of H antigen and 11 types of N antigen have been identified so far. The surface antigens constantly change their identity by what is called antigenic drift (which involves minor changes from season to season) and antigenic shift (where a major change and new subtype of virus emerges).

Previous exposure to flu or flu vaccination will not provide protection against all these new viral sub-types. So the changes in composition are constantly monitored by the World Health Organisation in order to try and make sure that each year’s flu vaccine is going to be effective as possible against new and emerging strains of flu virus. However, the COVID-19 pandemic has made this type of virus forecasting more difficult this year. So it’s impossible to say at this stage how effective the flu jab will be this year.

Studies have shown that flu vaccine reduces the risk of catching flu. However, protection will not be complete and will vary from person to person. Protection gradually decreases over time and flu strains change over time. So new vaccines have to be made each year and people at increased risk are encouraged to be vaccinated every year. There is also research evidence to indicate that flu vaccine can reduce the risk of having a stroke.

Swine flu is the popular name for influenza caused by a relatively new strain of influenza virus A. It was responsible for the flu pandemic in 2009-10. The virus is officially known as influenza virus A/H1N1pdm09.

**THE 2021 - 2022 FLU VACCINES**

For 2021-2022 there are three types of flu vaccine available. You will normally be offered the one that is considered to be the most effective for your age group. The protection provided varies according to age and due to the decreased effectiveness in people over 65, their vaccine also contains what is called an adjuvant. This is a substance that is added to a vaccine to increase the body’s immune response to the vaccine.

- **Children aged two to 15 will be offered a live attenuated quadrivalent vaccine (LAIV) unless contra-indicated. This gives protection against four strains of flu. The vaccine is given as a nasal spray.**
- **Adults aged 18 to 64 will be offered a quadrivalent injected vaccine - the vaccine will have been grown in cells (QIVc) or be recombinant (QIVr).**
- **Adults aged 65 and over will be offered an adjuvanted quadrivalent vaccine (aQIV).**

The quadrivalent flu vaccines offer protection against the four strains of flu (two A strains and two B strains) that are most likely to be present this coming winter.

Comprehensive information from the US CDC on current flu vaccines:

https://tinyurl.com/4h2attbk

**WHO SHOULD HAVE A FLU JAB?**

Flu vaccine is offered free on the NHS to people in certain at-risk groups. These are mainly people who have a medical condition that places them at greater risk of developing serious complications if they catch flu.

The list includes a number of pre-existing health conditions - chronic neurological and immunological diseases, heart and respiratory diseases, pregnant women, and obesity.

As a result of the COVID-19 pandemic, the Department of Health has widened the list of people who should be encouraged to have flu vaccine. So this now includes health and social care workers, people in residential care homes, household contacts of people who are shielding, and everyone over the age of 50 and under the age of 16.

People who receive a Carer’s Allowance, or are the main carer for a sick or disabled person, are also eligible for a free NHS vaccine.
The best time to have a flu jab is in the autumn - from mid-September onwards through until early November. It takes two to three weeks for the vaccine to become fully effective.

**WHAT ARE THE MAIN POINTS IN FAVOUR OF HAVING A FLU JAB IF YOU HAVE ME/CFS?**

- Flu vaccination should provide a fairly high degree of protection against the strains that are likely to be around this winter.
- Overall, the vaccine produces a different degree of protection each year - usually around 40% - 50%.
- Protection continues for about a year.
- Anyone with serious health problems in addition to ME/CFS such as chest (especially asthma or bronchitis), heart, liver or kidney disease, diabetes, a weakened immune system, or who is taking steroid medication, is particularly at risk of developing serious complications from flu.
- If you have already had a flu vaccine while suffering from ME/CFS, and not suffered any adverse effects, it is reasonable (but not guaranteed) to assume that you should be OK this time round (although the viral make-up of the vaccine is changed from year to year).
- Serious adverse reactions are very rare although minor transient problems such as malaise, headache and muscle pain do sometimes occur. A full list of potential side-effects is listed later in this leaflet.

The only published research study into adverse reactions to flu vaccine in people with ME/CFS concluded that people with ME/CFS were no more likely to have a serious adverse reaction than people receiving this vaccine for recommended reasons.

**CAN SOMEONE WITH ME/CFS HAVE A FREE FLU JAB IF THEY CHOOSE TO DO SO?**

Having a chronic neurological disease is one of the recommendations for having an NHS flu vaccination. ME/CFS is classified by the World Health Organisation as a neurological disease. This classification is fully recognised by the Department of Health and NHS England. So the ME Association believes that people with ME/CFS should therefore automatically qualify for a free NHS flu jab if they decide to have one. In addition, we know that new infections are one of the most likely causes of a relapse or exacerbation of symptoms in people with ME/CFS.

If your GP is querying whether someone with ME/CFS is eligible to have a free flu vaccination on the NHS you need to point out that the answer is YES they can because:

- People with a chronic neurological disease are eligible for an NHS flu jab (NHS Green Book - Chapter 19, page 14): https://tinyurl.com/yf2spxpm

This publication is produced by Public Health England and provides detailed guidance on the administration of all vaccines. The list of medical conditions where flu vaccine is recommended makes it clear that the list of neurological conditions (and other conditions) is not exhaustive and that decisions on individual neurological diseases can be made on clinical judgment.

- NHS England classifies ME as a neurological condition: https://tinyurl.com/y6h33er2
- Dame Sally Davies, former Chief Medical Officer at the Department of Health, has also stated in 2014: "As you know, the risk of serious illness from flu and consequent hospitalisation and death is higher among those with underlying health conditions such as M.E."

"We know that people with chronic neurological conditions are approximately 40 times more likely to die if they develop flu than individuals who have no other underlying health conditions."

"The best way for people at risk from flu to protect themselves and their families is to get the flu vaccine. People with clinical risk factors are eligible to receive the seasonal flu vaccine free each winter."

- Serious adverse reactions are very rare although minor transient problems such as malaise, headache and muscle pain do sometimes occur. A full list of potential side-effects is listed later in this leaflet.

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**WHAT ARE THE POSSIBLE DISADVANTAGES?**

There are plenty of anecdotal reports of people with ME/CFS suffering a relapse, or even developing ME/CFS, after this vaccine. This is possibly because research into immune-
system dysfunction in ME/CFS has found evidence of what is called immune-system activation. This equates to a persisting and overactive immune response to a triggering infection. Vaccines mimic the infection they are designed to protect against and will therefore trigger an immune-system response.

In a small survey carried out by The ME Association among its members a few years ago, seven out of 21 people had no problems at all with flu vaccine; 13 reported an exacerbation of symptoms ranging from mild (3) or moderate (7) through to a severe relapse in three cases. Interestingly, there was also one report of a teenager who noticed a slight improvement in symptoms following vaccination.

An MEA website online survey carried out in November 2008 asked how the flu jab affected ME symptoms. There were 191 responses. 86 (45%) reported no change; 52 (27%) said they were much worse; 42 (22%) said they were slightly worse; seven (4%) said they were slightly better and four (2%) said they were much better after the jab.

It is impossible to predict if someone with ME/CFS is going to experience an adverse reaction to flu vaccine. However, some doctors (myself included) believe that this may be more likely if you still have on-going flu-like/infection symptoms such as enlarged glands, sore throats, problems with temperature control, etc.

WHAT ARE THE GENERAL CAUTIONS & CONTRA-INDICATIONS

Flu vaccine may be contra-indicated in people who have had a previous reaction, or are allergic to eggs and poultry – as the inactivated vaccine may contain small amounts of egg and poultry proteins. This is something you need to discuss with your doctor because there are now egg-free vaccines available.

You should also inform your doctor if you are allergic to any of the possible vaccine components and preservatives: eg, formaldehyde, gentamicin sulphate and sodium deoxycholate. One further contra-indication is having an active febrile illness.

Some flu vaccines used to include thimerosal – a controversial mercury-containing preservative. This has now been gradually withdrawn from vaccines following concerns that it could cause neurological problems.

WHERE CAN YOU HAVE A FLU JAB?

Most people have a flu jab at their GP surgery – where it is free if you have one of the conditions listed above where flu vaccination is recommended by the NHS. If you are on the list of people who are eligible you will probably receive a letter, text or email asking you to book an appointment at one of their flu vaccine clinics.

Many community pharmacies offer flu vaccination and it is now widely available for a small charge (or free if you are eligible) at many pharmacies such as Boots and Lloyds. If you want to pay for a flu jab at a pharmacy it will cost about £15. See also Further Information.

GP surgeries and pharmacies will be following the social-distancing rules and only seeing one person at a time. So most will require some form of advance pre-booking. If you are housebound, you can ask your GP surgery if someone, possibly a practice nurse, could come out and do the vaccination in your own home.

HOW CAN YOU REDUCE THE RISK OF CATCHING FLU?

Children are a major source of infection – because flu is essentially a disease of childhood. So, just as with COVID-19, keep a safe distance – at least two metres – from anyone who is coughing, sneezing, or may have flu, wear a mask and avoid crowded unventilated public places. The virus can also be caught by contact with infected surfaces, including hands – so regular hand washing with soap, as for COVID-19 – is a sensible precaution to take.

The use of a specific adjuvant known as AS03 – an emulsion designed to protect against and mimic the infection they are – as the overactive immune response in a previous vaccine – has been linked to narcolepsy.
Sneezing into your elbow – not the palm of your hand – reduces the risk of spreading the virus.

**Research into Flu Vaccines and ME/CFS**

The effect of influenza vaccination on ME/CFS was examined in an Australian pilot study which found that vaccination is accompanied by a degree of immune-system dysregulation in ME/CFS patients compared to healthy controls and that the vaccine has the ability to increase cytotoxic activity and pro-inflammatory reactions post-vaccination (Brenu et al 2012).

However, Prinsen et al (2012) found that humoral and cellular immune responses following influenza vaccination were comparable in ME/CFS patients and healthy controls.

References:


**Pneumococcal Vaccination**

This vaccine is now being offered to everyone over the age of 65 and those with other health conditions (e.g. heart and lung disease) that place them at increased risk from this bacterial infection. It provides very valuable protection against an infection that can cause a severe type of pneumonia.

We only have feedback from a small number of people with ME/CFS who have received the pneumococcal vaccination. We have not received any reports of significant adverse reactions occurring to this vaccine so far. However, that is not a guarantee that you will not have any side-effects, or an exacerbation of your ME/CFS symptoms.

If there are good indications for having this protection (and a pneumococcal infection would probably cause a significant relapse of ME/CFS), this is something that you should seriously consider and discuss with your GP. This vaccine can also be given to people under the age of 65 who are at increased risk of developing pneumonia. The list of eligible health conditions is basically the same as the flu vaccine list.

Please note that it is normally sensible to defer being vaccinated if you are currently having any significant flu-like symptoms (i.e. sore throats, tender glands, feeling feverish) in relation to your ME/CFS.

More information on pneumococcal vaccine can be found here:

https://tinyurl.com/2pxfsspn

**Further Information**

The NHS website gives helpful and more detailed general guidance on flu vaccine and how to obtain flu vaccine:

https://tinyurl.com/529ec6us

Children and flu vaccine:

https://tinyurl.com/2sdeyd6z

Find a pharmacy that offers NHS flu jobs:

https://tinyurl.com/6bau7fp

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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**

‘To Whom It May Concern’ letters and leaflets written by ME Connect

https://meassociation.org.uk/shop

**MEA Membership:**

From just £2 a month you can help support others affected by M.E. and will receive the excellent and exclusive ME Essential magazine delivered straight to your door.

Subscriptions are a vital part of our charity income and – together with donations – they allow us to help make the UK a better place for people with M.E.

Full Membership is available to all adults with ME/CFS, carers and anyone with an interest in the disease. Annual membership costs:

- £18.00 (UK residents and BFPO)
- £24.00 (Mainland Europe including Republic of Ireland)
- £30.00 (Rest of the World)

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

To become a member please visit

https://meassociation.org.uk/about-the-mea/membership