

FLU VACCINATION AND ME/CFS

THE 2023-2024 VACCINE

OCTOBER 2023



2023-2024 FLU VACCINATION AND ME/CFS

INTRODUCTION

Flu vaccination is important because, although flu is often unpleasant, it can be dangerous. This is especially so for anyone with certain chronic health conditions, including ME/CFS. And with Covid still around, a combination of flu and Covid could be even more serious.

As there is no simple yes/no answer as to whether people with ME/CFS should have a flu vaccine, the purpose of this leaflet is to supply you with everything you need to know about flu vaccines and ME/CFS. You and your doctor can then decide whether you ought to have this protection.

IN FAVOUR OF HAVING A FLU VACCINE

- The vaccine should provide a fairly high degree of protection against all the flu viruses that are predicted to be around in the coming months. This protection should persist for about a year. The vaccine takes about two weeks before it is fully effective.
- If you have any other chronic health conditions - especially affecting the heart or lungs - this will pose a further significant risk if you catch flu.
- Most healthy people do not experience any serious side-effects to flu vaccine. Evidence collected by the MEA some years ago (see page 3) indicated that, while many people (possibly around half) don't have any significant problems after having flu vaccinations, others do - and some experienced more severe or prolonged adverse effects.
- If you have had a flu vaccine in the past whilst having ME/CFS and not suffered any adverse effects, it's reasonable (but not guaranteed as the vaccine composition changes each year) to assume that you should be OK this time.

Cautionary notes

- We know from patient evidence collected over many years that some people with ME/CFS experience a significant exacerbation of symptoms, or even a prolonged relapse, after having a flu vaccination. This is probably because vaccines mimic the effect of infections on the body's immune system



2023-2024 Flu vaccination and ME/CFS was written by Dr Charles Shepherd, Trustee and Hon. Medical Adviser to The ME Association.

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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 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.



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and infections are the most common cause of symptom exacerbation or relapse in ME/CFS.

■ Vaccinations can occasionally trigger ME/CFS and we are aware of occasional cases where this has happened following flu or swine flu vaccination:

<https://tinyurl.com/mr4db3r9>

■ An MEA website poll on reactions to flu vaccine carried out in November 2008 had 191 responses. 86 people (45%) reported no change in their ME/CFS symptoms; 42 (22%) said they were worse; 52 (27%) said they were much worse; seven (4%) said they were slightly better and four (2%) said they were much better. We have received very little feedback in the past regarding children and young people who have had flu vaccination.

■ As with any vaccination this should be deferred if you are feeling unwell, especially if this includes having flu-like symptoms or a temperature.

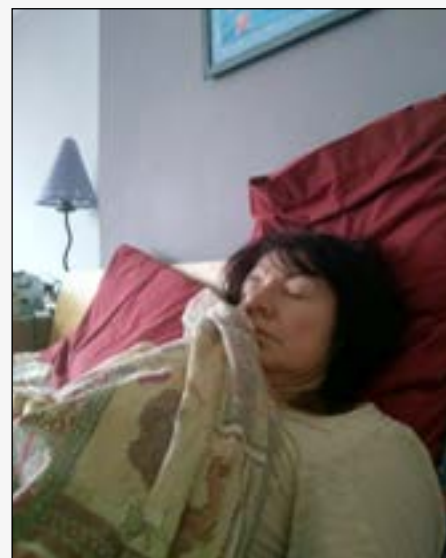
CAN I HAVE THE FLU VACCINE ON THE NHS?

If you have weighed up the pros and cons and decided to have a flu vaccination, this is given free on the NHS to adults who meet any of the following criteria:

- are 65 and over (including those who will be 65 by 31 March 2024).
- have certain health conditions - including chronic neurological diseases.
- are pregnant.
- are in long-stay residential care.
- receive a carer's allowance, or are the main carer for an older or disabled person who may be at risk if you get sick.
- live with someone who is more likely to get a severe infection due to a weakened immune system, such as someone living with HIV, someone who has had a transplant, or is having certain treatments for cancer, lupus or rheumatoid arthritis.

In relation to pre-existing, long-term health conditions, a number of specific diseases are covered. These include:

- respiratory conditions, such as asthma (needing a steroid inhaler or tablets), COPD, emphysema and bronchitis.



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- diabetes.
- heart conditions, such as coronary heart disease or heart failure.
- being very overweight – having a body mass index of 40 or above.
- chronic kidney disease.
- liver disease, such as cirrhosis or hepatitis.
- neurological conditions, such as Parkinson’s disease, motor neurone disease, multiple sclerosis or cerebral palsy.
- a learning disability.
- problems with your spleen like sickle cell disease, or if you’ve had your spleen removed.
- a weakened immune system as a result of conditions such as HIV and AIDS, or taking medicines such as steroid tablets or chemotherapy.

Although the neurological list does not include ME/CFS, the accompanying NHS guidance states that you can talk to your doctor if you have a long-term health condition that is not in one of these groups. They should offer you a flu vaccine if they think you’re at risk of serious health problems if you get flu.

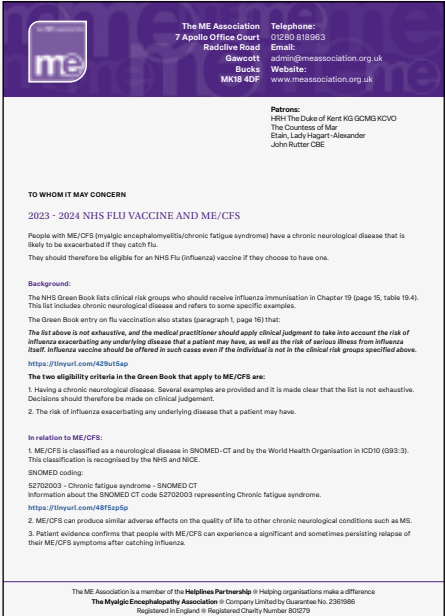
This means that people with ME/CFS in England, Wales, Scotland and Northern Ireland should be able to have an NHS flu vaccination if they choose to do so because ME/CFS is classified as a neurological disease in the SNOMED CT electronic classification system (which is used by the NHS) and by the World Health Organisation (in ICD10; G93.3).

The reasons why are covered in more detail in our **To Whom It May Concern** letter available free to download from the ME Association website:

<https://tinyurl.com/2wpeyaya>

Children who are at primary and secondary school are being given the vaccination via a nasal spray. Information is available on the government website healthmedia blog here:

<https://tinyurl.com/2r8aw2nr>



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TO WHOM IT MAY CONCERN

2023 - 2024 NHS FLU VACCINE AND ME/CFS

People with ME/CFS (myalgic encephalomyelitis/chronic fatigue syndrome) have a chronic neurological disease that is likely to be exacerbated if they catch flu.
They should therefore be eligible for an NHS Flu (Influenza) vaccine if they choose to have one.

Background:
The NHS Green Book lists clinical risk groups who should receive influenza immunisation in Chapter 19 (page 15, table 19.4). This list includes chronic neurological disease and refers to some specific examples.
The Green Book entry on flu vaccination also states (paragraph 1, page 16) that:
The list above is not exhaustive, and the medical practitioner should apply clinical judgment to take into account the risk of influenza exacerbating any underlying disease that a patient may have, as well as the risk of serious illness from influenza itself. Influenza vaccine should be offered in such cases even if the individual is not in the clinical risk groups specified above.
<https://tinyurl.com/429t5ap>
The two eligibility criteria in the Green Book that apply to ME/CFS are:
1. Having a chronic neurological disease. Several examples are provided and it is made clear that the list is not exhaustive. Decisions should therefore be made on clinical judgement.
2. The risk of influenza exacerbating any underlying disease that a patient may have.

In relation to ME/CFS:
1. ME/CFS is classified as a neurological disease in SNOMED-CT and by the World Health Organisation in ICD10 (G93.3). This classification is recognised by the NHS and NICE.
SNOMED coding:
S2702003 - Chronic fatigue syndrome - SNOMED CT
Information about the SNOMED CT code S2702003 representing Chronic fatigue syndrome.
<https://tinyurl.com/48F5p5p>
2. ME/CFS can produce similar adverse effects on the quality of life to other chronic neurological conditions such as MS.
3. Patient evidence confirms that people with ME/CFS can experience a significant and sometimes persisting relapse of their ME/CFS symptoms after catching influenza.

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Please refer to our **To Whom It May Concern** letter:

<https://tinyurl.com/2wpeyaya>



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PRECAUTIONS AND ALLERGIC REACTIONS

■ If you are ill with flu-like symptoms (i.e a sore throat, enlarged glands) or a temperature, you should wait until these symptoms subside before having the flu vaccine.

■ You should avoid having a flu vaccine if you have had a serious allergic reaction to a flu vaccine in the past. You may be at risk of an allergic reaction to the flu-vaccine injection if you have an egg allergy. This is because some flu vaccines are made using eggs. If necessary, you can ask a GP or pharmacist for a low-egg or egg-free vaccine.

Fortunately, it's very rare for anyone to have a serious allergic reaction (anaphylaxis) to the flu vaccine. If this does happen, it usually happens very quickly and within minutes. The person who vaccinates you will be trained in how to deal with allergic reactions and treat them immediately.

Side-effects

For healthy people flu vaccines are usually very safe. All adult flu vaccines are given by injection into the muscle of the upper arm.

Side-effects, where they occur, are usually mild and only last for a day or so. These include:

- a slightly raised temperature.
- muscle aches.
- sore arm where the needle went in.

Arm discomfort can be reduced by:

- continuing to move your arm regularly.
- take a painkiller, such as paracetamol or ibuprofen – but some people should not take ibuprofen unless a doctor recommends it.

Less common side-effects, some of which are symptoms of ME/CFS, include fatigue, shivering, sweating, headache, joint pain, nerve pain, paraesthesiae (pins and needles sensations) and skin reactions (itching, urticaria).

Serious side-effects are fortunately very rare. These include convulsions, thrombocytopenia (lowered level of platelets), encephalomyelitis, vasculitis (blood vessel inflammation), Guillain-Barre syndrome.



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WHEN AND WHERE TO GET THE FLU VACCINE - IF YOU CHOOSE TO DO SO

When to get the flu vaccine - if you choose to do so

If you choose to have a flu vaccination, the best time to have it is in the autumn or early winter before flu starts spreading.

Most people who are eligible for a free flu vaccine will be able to get the vaccine from 7th October 2023. Some people will be able to get the flu vaccine from 2nd October 2023. This includes people who live or work in a care home.

Where to get the flu vaccine - if you choose to do so

You can have the NHS flu vaccine at:

- your GP surgery
- a pharmacy offering the service – if you're aged 18 or over
- some maternity services if you're pregnant

Sometimes, you might be offered the flu vaccine at a hospital appointment.

If you have a flu vaccine at any NHS service except your GP surgery, you do not have to tell the surgery to update your records. This will be done for you. If you've been given a flu vaccine privately, or through an occupational health scheme, you can tell your GP surgery if you would like it added to your NHS record.

Please note that feedback from previous years indicates that pharmacies are normally very willing to provide a free NHS flu vaccine to people with ME/CFS.

If you are having difficulty in obtaining a free NHS vaccine you can pay to have one at a pharmacy. Boots charge £19.95.

Boots pharmacy flu vaccine service:

<https://tinyurl.com/4xbe3f2f>

Lloyds pharmacy flu vaccine service:

<https://tinyurl.com/5eamh3zr>



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HOW TO BOOK YOUR APPOINTMENT

If you're eligible for a free flu vaccine, you can book an appointment at your GP surgery.

You can also book online to get a flu vaccine from a pharmacy that offers it on the NHS. Some pharmacies may also offer walk-in NHS flu vaccination.

You may also receive an invitation to get vaccinated, but you do not have to wait for this before booking an appointment.

GP surgeries and pharmacies receive the flu vaccine in batches throughout the flu season. If you cannot get an appointment straight away, ask if you can book one for when more vaccines are available.

HAVING A FLU VACCINE AND COVID BOOSTER AT THE SAME APPOINTMENT

You may be offered a flu vaccine and autumn Covid booster at the same appointment. We have very little feedback from people who have had both together. Whilst having both at the same time reduces the number of surgery visits, having two vaccinations on the same day may increase the immune-system response and the risk of an adverse reaction. On a personal basis I am going to have a gap between the two.

We have some website information covering the Autumn Covid booster:

<https://tinyurl.com/35ycb23w>

SHINGLES AND PNEUMOCOCCAL VACCINES

If you are elderly you may also be offered a pneumococcal pneumonia vaccine (for 65+) or a shingles vaccine (for 70+). These two vaccines are covered in the MEA website **Medical Matters** Question and Answer archive:

<https://meassociation.org.uk/medical-matters>

Further information on flu vaccines can be found on the NHS website:

<https://tinyurl.com/2dyx7752>



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On a personal basis I am going to have a gap between the two.

Dr Charles Shepherd



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RESEARCH INTO FLU VACCINATION AND ME/CFS

There hasn't been any robust research carried out into flu vaccination and ME/CFS. One research review 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.

Reference: Influenza Vaccination: Is it appropriate for Chronic Fatigue Syndrome? (American Journal of Respiratory Medicine 2002,1: 3-9).

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.

Brenu EW *et al*. The effects of influenza vaccination on immune function in patients with chronic fatigue syndrome/myalgic encephalomyelitis. International Journal of Clinical Medicine, 2012, 3, 544 – 551.

Prinsen H *et al*. Humoral and cellular immune responses after influenza vaccination in patients with chronic fatigue syndrome. 2012, BMC Immunology, 13, 71.



One research study into flu vaccine and ME/CFS found that the vaccine produced a different type of immune system response in people with ME/CFS.

