

Flu Vaccination and ME/CFS

2024-2025 Vaccination information



OCTOBER
2024

Including:

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FLU VACCINE

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Flu Vaccination and ME/CFS was written by **Dr Charles Shepherd**, Trustee and Hon. Medical Adviser to The ME Association.

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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 information 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 up to about a year. The vaccine takes about 2 weeks before it is fully effective.
- If you have any other chronic health conditions - especially affecting the heart, kidneys 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 over the years (see below) indicates that while many people (possibly around half) don't have any significant problems after having a flu vaccination, others do and some experience 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.



*Vaccinations
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cases where this
has happened
following flu
or swine flu
vaccination*

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 and infections are the commonest 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://meassociation.org.uk/p0bg>

■ 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; 7 (4%) said they were slightly better and 4 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 involves 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
- are under 65 and 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





You can have the flu vaccine on the NHS if you meet certain criteria, including if you are under 65 and have certain health conditions - including chronic neurological diseases

CAN I HAVE THE FLU VACCINE ON THE NHS?

■ live with someone who is more likely to have 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 pre-existing long-term health conditions, a number of specific diseases are covered. These include:

- if you live with respiratory conditions, such as asthma (needing a steroid inhaler or tablets), COPD, emphysema and bronchitis
- 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 specifically include ME/CFS, the official guidance on flu vaccine eligibility in the NHS Green Book states:

The list is not exhaustive, and the medical practitioner should apply clinical judgement 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.





People with ME/CFS in England, Wales, Scotland and Northern Ireland should be able to have an NHS flu vaccination if you wish to have one



CAN I HAVE THE FLU VACCINE ON THE NHS?

NHS Green Book – Chapter 19:

<https://tinyurl.com/4swa9hnm>

This means that people with ME/CFS in England, Wales, Scotland and Northern Ireland should be able to have an NHS flu vaccination if you wish to have one 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 on flu vaccination:

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

Children who are at primary and secondary school are being given the vaccination via a nasal spray.

<https://www.nhs.uk/vaccinations/child-flu-vaccine/>

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.

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



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 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
- taking 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.

WHEN TO GET THE FLU VACCINE - IF YOU WANT ONE

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 have the vaccine from 3rd October 2024.



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.

While some GPs are very reluctant or will not give a flu vaccine on the NHS to people with ME/CFS pharmacies are normally very willing to provide a free NHS flu vaccine to people with ME/CFS.

Please note that feedback from previous years indicates that, while some GPs are very reluctant or will not give a flu vaccine on the NHS to people with ME/CFS, 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 such as Boots or Lloyds.

Boots charge £21.95: <https://tinyurl.com/2ju8twnc>

Lloyds pharmacy flu vaccine service: <https://tinyurl.com/4t74dyby>

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 from your GP surgery, but you do not have to wait for this before booking an appointment.





Having a flu vaccine and a Covid booster at the same time reduces the number of surgery visits, but having two vaccinations on the same day may increase the risk of an adverse reaction

HOW TO BOOK YOUR 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.

Book an NHS flu vaccine online at a pharmacy:

<https://www.nhs.uk/nhs-services/pharmacies/book-flu-vaccination/>

HAVING A FLU VACCINE AND COVID BOOSTER AT THE SAME APPOINTMENT

You may be offered a flu vaccine and a 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 risk of an adverse reaction. On a personal basis, I am going to have a gap between the two.

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.

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

<https://www.nhs.uk/vaccinations/flu-vaccine/>



RESEARCH 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.

1) 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.

2) 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).

Reference:

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.

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

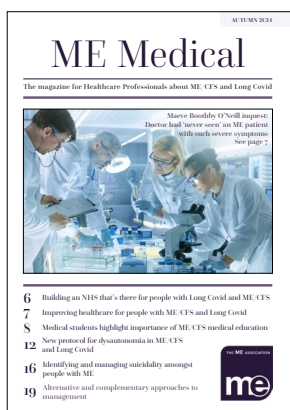
Reference:

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





“Thank you for producing such a helpful magazine. The standard is consistently high and each edition is interesting and varied. I need all the help I can get and this magazine is consistently encouraging, realistic, and helpful.”



THE ME ASSOCIATION

Changing attitudes and improving lives...

■ **COMMUNITY:** We provide a safe and welcoming community for people affected by ME/CFS and Long Covid who come together and benefit from sharing their experiences. We provide membership, an essential support service, excellent website resources and we host engaging discussions on the most popular social media channels. Knowing that you are not alone can be a great comfort and we are happy to answer your questions and share helpful tips.

■ **MEMBERSHIP:** We put the interests of members at the heart of everything we do. Your subscription means that we can support more people, campaign more effectively and fund more medical research. Members receive the exclusive ME Essential magazine which carries the latest news, medical information, personal stories, and feature articles. **Join us today!**

■ **SUPPORT:** ME Connect is the charity's support and information service. We listen and we understand. We provide a personalised service and we're here when you need us most. Most of us have personal experience of these medical conditions, or care for a loved one who does. To view the ME Connect telephone helpline opening hours please visit: <https://www.meassociation.org.uk/me-connect>

■ **INFORMATION:** We produce reliable and timely information written by topic experts and have the **largest range of literature covering all aspects of life with ME/CFS and Long Covid**. We can show you how to recognise and manage symptoms, to get an accurate diagnosis, a referral to specialists, and to obtain the healthcare that you deserve. We also provide an **e-newsletter** and free access on the website to **Medical Matters** and other relevant information.

■ **RESEARCH:** We fund medical research via the **Ramsay Research Fund** and are especially interested in research that can find diagnostic markers, causes, and treatments. We support the UK ME/CFS Biobank and the Manchester Brain Bank, and have invested over £1m in medical research in the last 10 years.

■ **MEDICAL EDUCATION:** We arrange training for healthcare professionals, offer a medical magazine, ME Medical, and are working with the Government, NHS, Royal Colleges of Medicine, and Local Authorities to implement the recommendations from the 2021 NICE Clinical Guideline on ME/CFS – the successful result of 14 years lobbying and hard work.

■ **LOBBYING:** We campaign to raise awareness and bring about positive

“The MEA is doing exactly what it said it would by providing support, actively lobbying for recognition, improvements to health and social care, and funding biomedical research.”



THE ME ASSOCIATION

Changing attitudes and improving lives...

change. We believe in collaboration and work with the NHS and social care services, the Department of Health and Social Care, the British Association of Clinicians in ME/CFS (BACME), Forward-ME, the ME Research Collaborative (MERC), DecodeME, the All-Party Parliamentary Group (APPG) on ME, Physios4ME, the Chronic Illness Inclusion project (CII), Hidden Disabilities Sunflower, and Long Covid initiatives.

■ **HEALTH & SOCIAL CARE:** The charity works with healthcare providers to successfully implement the NICE Guideline recommendations on ME/CFS and Long Covid to ensure that everyone receives the very best healthcare, wherever they live in the UK. We want well-trained healthcare professionals providing excellent services because timely intervention can lead to better health outcomes and improved quality of life.

■ **DONATIONS:** In order to help more people and invest in medical research we depend on your generosity. If you feel able to make a donation or want to raise funds in other ways, please get in touch with the fundraising team: fundraising@meassociation.org.uk or you can **make a direct donation via the website.**

WHAT ARE ME/CFS AND LONG COVID?

We answer key questions about these medical conditions and compare similarities and differences. You'll also find the NICE Guidelines reproduced in full in an easy-to-use **database**.

MEDICAL MATTERS

Medical Matters is an easy-to-use online supplement to the more detailed literature. The same topic experts provide answers to commonly asked questions.

NHS REFERRAL SERVICES

If you need to locate an ME/CFS specialist service or Long Covid Clinic then we can help. We have listed all secondary care referral services in an easy to use **database**.

THE ME ASSOCIATION



Freephone

0808 801 0484

For opening hours visit:

meassociation.org.uk/me-connect

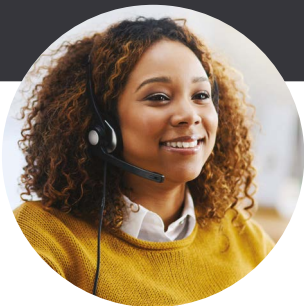
ME CONNECT

The Support and Information Service
for people affected by ME/CFS/PVFS
and Long Covid

Contact ME Connect

3 WAYS TO GET IN TOUCH:

by phone, email or
social media private message



HERE TO LISTEN

We are here to listen,
validate and empathise
with any issues you might
be facing.



VITAL SUPPORT

We are here to help
you reach an informed
decision.



SAFE ENVIRONMENT

We provide a safe,
confidential and
understanding
environment where
you can be heard
and understood.

We're here for you!



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