

Influenza Vaccine FAQ for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

It is influenza season. Should I get the flu shot if I have ME/CFS?

The answer is, as with many things in ME/CFS, not a simple or universal yes or no. It depends on many circumstances. Please continue reading below.

What happens if I catch influenza this season?

Influenza can be a ravaging illness, even for healthy people. This is why the vaccine exists. Influenza infection in ME/CFS brings its own challenges. Remember, all additional illness that someone with ME/CFS suffers from must be seen “through the lens of ME/CFS.” In other words, a severe infection like influenza could potentially trigger a deep and prolonged flare of illness that may be difficult to emerge from. ME/CFS patients who have underlying lung disease, prominent asthma, or other major respiratory issues, especially those with mast cell activating syndrome (MCAS), may also be at particularly high risk of major complications, or even hospitalization, from catching influenza. People with ME/CFS have died from influenza. If symptoms of influenza appear, go to an urgent care facility immediately for a nasal swab and obtain a prescription for anti-influenza medication.

Influenza infection on top of ME/CFS sounds bad. Why would I NOT get a vaccine?

Yes, influenza in the setting of ME/CFS can precipitate a very difficult situation. However, the vaccine itself is DESIGNED to instigate the immune system, and this can have some unwanted effects, particularly for those with ME/CFS. When people sometimes say that they “caught the flu from the flu vaccine,” we know from careful studies that they are indeed not experiencing an infection. However, the symptoms of increased achiness, pain, fevers, sore throat, and swollen lymph nodes that can occur are recognized as the immune system’s reaction to a foreign protein (even if that protein is from a killed or inactivated virus). That same reaction can occur in an ME/CFS patient, but those symptoms of immune activation can potentially take a major toll on the energy envelope and even, in some cases, precipitate a flare of amplified pain or post-exertional malaise. While we generally recommend EVERYONE get the influenza vaccine, we also recommend that ME/CFS patients be very careful and choosy about WHEN to get their vaccine completed. Do not get your vaccine when you are run down, already exhausted, or in a flare of PEM. Make sure you are feeling your best, and perhaps are going into a weekend with some anticipation of perhaps having a difficult 24-48 hours after the vaccine as a possibility (but certainly not a guarantee either).

Do I need a higher dose of the influenza vaccine to make sure the vaccine is effective at preventing the infection if I am exposed?

We simply do not know the answer to this question as a true scientific study with good methods specific to ME/CFS patients does not exist to date. There are “high dose” vaccines available that are given to patients over age 65 and other patients whose immune systems do not function as well (such as diabetes patients, or rheumatology patients on immunosuppressive medications for disease management) to help ensure an adequate immune response to the vaccine. While we do know that the immune system in ME/CFS patients is disordered and not functioning properly, this malfunction may not entirely mimic the same type of malfunction as in other immunosuppressed patients. It makes logical sense that a higher dose vaccine may have a better chance of inducing a stronger immune system response, though we do not have proof of this in ME/CFS. Remember, a stronger immune response can mean stronger side effects and immune system reaction (fevers, body aches, chills, lymph nodes, sore throat) to the vaccine, even if it also means a higher likelihood of having the vaccine be effective.

What about the live attenuated (weakened) nasal vaccine?

While we do not have good data about this vaccine in ME/CFS patients, most experts generally agree that we prefer to avoid this method. We do indeed know there is dysfunction of the immune system in ME/CFS. If, by some chance, the immune system did not respond appropriately to this vaccine, even a small risk of actually developing an influenza infection as a result of this vaccine due to poorly understood immune system dysfunction seems like too great of a risk to take when there are plenty of other killed virus vaccine options.