

COVID-19 Vaccines: Frequently Asked Questions

Myotonic Dystrophy Foundation

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Does having myotonic dystrophy (DM) make a person more susceptible to getting COVID-19 infection?

Not that we know of. The immune system is the main defense against viruses. DM can affect the immune system, but generally not in a big way. For example, people who have DM1 or DM2 sometimes have lower amounts of antibodies (part of the immune system) in the blood. However, it is not generally believed that this makes people more susceptible to infection.

If a person with DM gets COVID-19 infection, do they have a higher risk of severe illness?

So far there is not much information about how people with DM respond to COVID-19. It probably depends on how DM affects a person. Some people with DM have a weak cough, reduced breathing capacity, heart conditions, or diabetes. Any of these would be expected to increase the risk of severe COVID-19. If you have one of these problems, it makes sense to stay cautious, obtain the vaccine as soon as it becomes available to you, and remain cautious after you are vaccinated, since vaccines are not 100% effective.

What are RNA vaccines, and how well do they work?

The first COVID-19 vaccines in North America and Europe are RNA vaccines, a new type of vaccine. They were designed, manufactured, and tested in an amazingly short time, and they are remarkably effective. RNA vaccines are 94-95% protective against COVID-19, and more than 98% protective against severe COVID-19. RNA is a natural substance in every living thing, similar to DNA. Like DNA, RNA contains a genetic code. The vaccine is a custom-made snippet of RNA (sometimes called mRNA), packaged in a slippery material so that it can travel into the muscle cells where it is injected. The genetic code of vaccine RNA then trains the muscle cells to produce a shape or “spike”, similar to what is found on the surface of the virus. This tricks the immune system into reacting against the “spike”. Once this happens, the immune system can guard against COVID-19 in the future. The vaccine RNA only lasts a few hours before breaking down, and the

“spike” only lingers for a few days, but that is long enough for the immune system to learn to react against it. Fortunately, the immune system has a long memory.

The RNA vaccines do not contain any preservatives or animal products, including eggs, and they cannot cause COVID infection. Other types of vaccines will be coming along, but it is too early to know if they will work as well or better than RNA vaccines.

Research has shown that one of the problems with DM is that some of the body’s natural RNAs do not work properly. Will that interfere with RNA vaccines?

Not that we know of. The RNA with repeats in a person with DM, and the RNA in the COVID-19 vaccine, are different and are not expected to mix together or interfere with one another. Based on current information, there is no reason to expect that RNA vaccines will not work properly in people with DM, or that RNA vaccines should make DM worse. However, this certainly needs to be monitored and studied going forward. The MDF is continually talking to researchers about that.

It is important to note that vaccine RNA never enters the cell’s nucleus or affects genetic material - so it does not alter or modify someone’s DNA or genetic makeup in any way.

All vaccines have possible side effects. What are the side effects of COVID-19 RNA vaccines?

RNA vaccines, like all vaccines, are designed to trigger a reaction of the immune system. Most of the side effects have to do with inflammation, which is part of the reaction. These reactions occur inside the muscle where the vaccine is injected, but can also affect a person more generally. These side effects typically go away after a few days. Here is what we know about side effects up to now.

Pfizer-BioNTech vaccine is given by 2 injections, 3 weeks apart. This vaccine was tested in 21,720 healthy people. The most common side effects in the testing phases were:

- 84% of people had pain where the vaccine was injected, usually lasting for 1 or 2 days. Sometimes there was also redness or swelling (around 10%).

- Other common side effects were fatigue (63%), headache (55%), muscle aches (38%), chills (32%), joint aches (24%), and fever (14%).

Moderna vaccine is given by 2 injections, 4 weeks apart. This vaccine was tested in 15,419 healthy people. The most common side effects in the testing phases were:

- 92% of people had pain where the vaccine was injected, usually lasting for 1 or 2 days. Sometimes there was also redness or swelling (around 10-15%).
- Other common side effects were fatigue (70%), headache (65%), muscle aches (62%), chills (45%), joint aches (46%), nausea/vomiting (23%), or fever (15%).

These two RNA vaccines work in similar ways, have similar side effects, and produce similar protection against COVID-19. Based on current information there is not much reason to pick one over the other. That could change in the future as we get more experience and learn more.

Can COVID-19 RNA vaccines cause severe side effects?

Severe allergic reactions to the COVID-19 vaccine have occurred. These reactions are potentially life threatening but fortunately they are rare and can be treated. The symptoms may include difficulty breathing, swelling of face or throat, rash all over the body, dizziness and weakness. It is too early to know exactly how often this happens. It never happened in the testing phase, when more than 37,000 people received vaccine. However, in the first 3 weeks after the vaccine was authorized, around 6 people in the U.S. have had severe allergic reactions, out of 272,000 people who were vaccinated. This seems higher than other types of vaccines, which generally cause severe allergic reaction in around 1 in a million people. The U.S. Centers for Disease Control and Prevention (CDC) recommends that RNA vaccines should be given by people equipped and trained to handle rare severe allergic reactions. The reactions tend to occur soon after the vaccine is injected, so people are requested to remain on-site for at least 15 minutes, or longer if they ever had a serious allergic reaction of any type (such as bee sting, shell-fish, etc.). For people who have had severe allergic reactions to other

vaccines or drug injections in the past, the CDC recommends asking your doctor whether you should get the COVID-19 vaccine.

DM can affect muscles in the face. Sometimes this is treated by injecting “filler” to restore the facial contours. When the Moderna vaccine was tested, a few people who had previous “filler” injections developed facial swelling that started 1 or 2 days after vaccination. If you have had filler injections, ask your doctor whether you should receive the COVID-19 vaccine.

Which muscle is the vaccine injected into?

RNA vaccines are designed for injection into muscle. If an injection is given but it “misses” the muscle tissue, no one knows whether this will be just as effective. So far, RNA vaccines have only been injected into the deltoid muscle, near the shoulder. One vaccine maker, Pfizer, has indicated that they do not recommend injection into any other muscle.

For people affected by DM1, the deltoid muscle usually does not have severe weakness or atrophy (shrinkage), but sometimes this can occur. Injection into deltoid should be possible in most cases, but not always. In DM2, particularly in older people, the deltoid muscle can atrophy, so that injecting into muscle tissue could be difficult. To our knowledge there is no harm in trying, though protection against COVID-19 might be lower. With time, we expect that there will be more flexibility about which muscles can be injected.

Will vaccine injection cause muscle damage?

The vaccine for COVID-19 is expected to trigger inflammation and minor damage in a small part of the injected muscle. This heals quickly in healthy people. In theory, it is possible that healing could be slower or less complete in people affected by DM, but no one knows for sure yet. If you have soreness or pain in the shoulder for more than a few days after vaccine injection, talk with your doctor and consider doing some shoulder mobility exercises to keep the shoulder flexible, such as: <https://www.myotonic.org/sites/default/files/pages/files/Shoulder-Range-of-Motion.pdf>

What about vaccinating children and teenagers?

This is not recommended yet. The RNA vaccines have not been thoroughly tested in people below the age of 16. The Pfizer-BioNTech vaccine is authorized for people age 16 years and older, and the Moderna vaccine is authorized for people age 18 years and older. Testing in younger people is underway, so this will likely change in the future. As long as there is no vaccine for children, children are best protected if most adults around them are vaccinated, to reduce the risk of the virus spreading.

When can I get the vaccine? As a person with DM, will I be eligible for the vaccine sooner than other people?

This summer MDF advocated to the CDC that DM should be on the list of medical conditions that cause higher risk of severe COVID-19. So far that has not happened – there just isn't enough information about COVID-19 in people who have DM or other uncommon diseases for CDC to make that recommendation. As discussed above, if you have heart problems, diabetes, or breathing weakness, a strong case could be made for higher risk of severe COVID-19 and early access to the vaccine. The procedures for getting the vaccine distributed and administered are still being worked out. You can check the CDC website for updates <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/evidence-table.html>

As more people receive the vaccines, our information about them will continue to grow. Even after we receive the vaccine, we should all continue to social distance, wear masks, wash our hands carefully, and continue to follow the CDC guidelines to help prevent the spread of the virus.

How long will vaccine protect against COVID-19? Will there be a need for repeat vaccination in the future?

These are important questions, but no one has answers yet. This is currently being researched.

Should I get a vaccine? What is the balance of risk and benefit?

For most people, including people with DM, it is safer to get the vaccine than not to get it. COVID-19 is taking a terrible toll, and the risk of getting severe COVID-19 illness is much higher than the risk of severe side effects from the vaccines.

Will the vaccine work against new strains of the virus?

This is not yet known. Scientists expected that the virus may change over time, so it is not surprising that this is happening. Scientists hope that RNA vaccines may protect against new strains of the virus, but this needs to be checked more thoroughly. Even though there are new virus strains, this should not be a reason for not getting the vaccine.

Links to more information:

CDC vaccination info: <https://www.cdc.gov/vaccines/covid-19/index.html>

U.S. Department of Health and Human Service COVID info:

<https://combatcovid.hhs.gov>

CDC information on high risk conditions: <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/evidence-table.html>

Pfizer vaccine info: https://www.pfizermedicalinformation.com/en-us/front?autologout_timeout=1

Moderna vaccine info: <https://www.modernatx.com/covid-19-resources/publications-and-external-resources>