

Focus on COVID-19

This newsletter is full of information relevant to the COVID-19 vaccine and to supporting people who have had COVID-19 infections.

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In This Issue

1. COVID-19 Vaccine Information
2. Supporting People with Current or Previous COVID-19 Infection
3. COVID-19 Long Haulers

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COVID-19 Vaccine Information

Deciding on Vaccination

Recently, the FDA approved specific vaccines to provide protection against the virus that causes COVID-19. These vaccines have been shown to be safe and effective for the vast majority of people who receive them (Mayo Clinic, 2021).

According to Dr. Andrew Badley, who chairs the Mayo Clinic COVID-19 Research Task Force, the new vaccines have been tested in nearly 75,000 people with an extremely small number of adverse side-effects (Mayo Clinic, 2021). However, as with any new medical development, some people are hesitant to get vaccinated. People with intellectual disability/autism (ID/A) might feel an even higher level of anxiety if they had unpleasant experiences involving previous medical appointments or vaccinations, do not fully understand why the vaccine is necessary, or are uncertain of its safety.

To make an informed decision about COVID-19 vaccination, one must rely on facts presented by credible sources, like the Centers for Disease Control and Prevention (CDC). The information should include the risks, benefits, and other factors to consider when deciding whether to be vaccinated. The “COVID-19 Vaccines” fact sheet from the CDC, available at <https://www.cdc.gov/coronavirus/2019-ncov/downloads/vaccines/facts-covid-vaccines-english-508.pdf>, might be a good place to start.

Caregivers and the individuals they support can work together to make informed decisions about COVID-19 vaccination. The following suggestions might help to increase the effectiveness of such conversations.

1. Consider the following questions to prepare for the conversation.

- What communication techniques would assist each person to understand the information?
- What is each participant’s level of understanding with regard to the COVID-19 virus and vaccines?
- Where should the conversation take place?
- What can be done to reduce distractions and stressors to support effective communication and understanding?

2. Be mindful of each person’s feelings about the vaccine.

Information can help ease worries and fears about the vaccine and the pandemic itself. Consider using the CDC’s “Myths and Facts about COVID-19 Vaccines” resource, available at <https://www.cdc.gov/coronavirus/2019-ncov/vaccines/facts.html>.

3. Engage in respectful conversation.

Start from a place of empathy and understanding. Keep in mind that people have different experiences and reactions to stressful events. Acknowledge the

disruption COVID-19 has caused in each person's life and encourage participants to share their feelings, fears, and thoughts about the pandemic. This is an opportunity to recognize common concerns and discuss how the vaccines might affect them.

4. Be prepared for questions.

It is likely that participants will have questions. Share information about the necessity of COVID-19 vaccination to keep people safe and return to "normal". Acknowledge if an answer is unknown; the COVID-19 pandemic is unlike anything experienced in our lifetime. Explain that one answer that *is* known is that being vaccinated can help slow the spread of COVID and protect others (CDC, 2021).

- Address misinformation by sharing key facts.
- Listen and respond to questions.
- Proactively explain side effects.

The CDC's list of the benefits of the vaccine is available at <https://www.cdc.gov/coronavirus/2019-ncov/vaccines/vaccine-benefits.html>.

Additional Resources:

COVID-19 Vaccine Social Stories. <https://aidinpa.org/resource/covid-19-vaccine-social-stories/>

Doctor Visits and Checkups Rehearsal Guide. <https://hcqu.kepro.com/media/2876/doctor-visits-rehearsal-guide-dec2020.pdf>

Getting a Shot Rehearsal Guide with COVID-19 Addendum. <https://hcqu.kepro.com/media/2872/getting-a-shot-rehearsal-guide-w-covid-addendum-dec2020.pdf>

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How and Where to Receive the COVID-19 Vaccine

Pennsylvania has begun implementing its COVID-19 Vaccination Plan. Limited vaccine supplies make it necessary to prioritize people according to CDC guidelines and vaccinate in phases. The *Getting the COVID Vaccine* page of the Commonwealth of Pennsylvania's website (<https://www.pa.gov/guides/get-vaccinated/>) guides people through an easy 4-step COVID-19 vaccination process.

Note: Philadelphia County is a separate vaccine jurisdiction with its own information about vaccine distribution (Commonwealth of Pennsylvania, 2021).

Step 1: Check to see if you're eligible

The Pennsylvania Department of Health developed the "Your Turn" tool to help people know when they are eligible for vaccination. The "Your Turn" tool, available on the Getting the COVID Vaccine page or at <https://covidportal.health.pa.gov/s/Your-Turn>, requests the following information.

- County of residence
- Date of birth
- Current living status
- Whether or not a person works in healthcare
- High risk conditions applicable (Down syndrome, obesity, asthma, diabetes, etc.)

If a person is not eligible for vaccination during the current phase, the tool will display, "It's not your turn yet." If a person is eligible, the tool will display, "It's your turn!", and prompt the person to find a vaccine provider.

Individuals with an intellectual disability/autism (ID/A) and caregivers are eligible for vaccination during Phase 1A.

Step 2: Find a vaccine provider

The *Getting the COVID Vaccine* page includes an interactive map to help people locate a nearby vaccine provider, which could be a hospital, urgent care center, doctor's office, or pharmacy.

"Providers have to be registered to receive the vaccine — so make sure your chosen provider is listed on our map before continuing to Step 3 (Commonwealth of Pennsylvania, 2021)."

Step 3: Contact a provider to schedule an appointment

Clicking on a vaccine provider's dot on the interactive map displays links for the provider's location, website, and telephone number, making it easy for a person to contact the provider to schedule an appointment.

Clicking on the address link displays directions to the location. Clicking on the website brings up the vaccine provider's website, many of which permit one to schedule an appointment. Clicking the telephone number initiates a call via Skype to the vaccine provider.

Step 4: Be sure to get all recommended doses

The Moderna and Pfizer vaccines require 2 doses. Make sure individuals and caregivers receive both doses if these vaccines are used. The Johnson and Johnson vaccine requires one dose.

Questions about the vaccination process in Pennsylvania may be directed to the Pennsylvania Department of Health hotline at 1-877-724-3258.

References

Commonwealth of Pennsylvania. *Getting the COVID Vaccine*. (February 9, 2021). Retrieved from <https://www.pa.gov/guides/get-vaccinated/> on February 11, 2021.

Pennsylvania Department of Human Services. *Covid-19 Vaccine Toolkit For Long-Term and Congregate Care*. (2021). Retrieved from: https://www.dhs.pa.gov/coronavirus/Documents/Combined%20COVID-19%20Toolkit_FINAL.pdf on February 16, 2021.



Vaccine Distribution

Now that COVID-19 vaccination has begun, people may wonder what to do and/or expect before, during, and after receiving the vaccine.

Before

The first step is to learn about the benefits and possible side effects of receiving a COVID-19 vaccine (CDC, 2021). Once the decision to be vaccinated has been made, use the *Getting the COVID Vaccine* page of the Commonwealth of Pennsylvania's website to determine eligibility, select a location, and schedule an appointment for vaccination. Caregivers and individuals with ID/A are eligible for vaccination during Phase 1A, the current phase in Pennsylvania.

Getting the COVID Vaccine page:

<https://www.pa.gov/guides/get-vaccinated/>

During

During the visit, the person receiving the vaccine and the vaccine provider will wear masks to cover their noses and mouths. Consider bringing a fun activity along to do while waiting. If it is necessary to wait in a line, people need to remain 6 feet apart from others.

The vaccine provider administers the vaccine into the upper arm through a small needle; it might hurt a bit. Try to relax and breathe deeply when receiving the vaccine and keep arm muscles relaxed.

A fact sheet about the vaccine is provided to explain the risks and benefits of receiving the COVID-19 vaccine. Each person receives a COVID-19 vaccination card indicating the type of vaccine administered, the date it was administered, the location, and the date to return for the second dose, if applicable.

After

Afterward, each person is monitored at the vaccination site for 15-30 minutes for signs of serious reactions to the vaccine.

Call 911 if a person shows signs of at least one the following after leaving the vaccination site:

- Swollen airway or tongue
- Difficulty breathing
- Low blood pressure
- Rapid heart rate
- Hives/itching

These symptoms might indicate a severe allergic reaction requiring immediate medical attention (CDC, 2021).

The last step in the vaccination process is to return for the second COVID-19 vaccine if needed. Return for a second dose of the vaccine, unless a healthcare provider instructs otherwise, even if there are side effects with the first one.

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Centers for Disease Control and Prevention. (2021 b). What to Expect at Your Appointment to Get Vaccinated for COVID-19. Retrieved on February 11, 2021 from <https://www.cdc.gov/coronavirus/2019-ncov/vaccines/expect.html>.



Vaccine Side Effects

Most people who have received the COVID-19 vaccine have described side effects similar to those associated with the flu vaccine. If side effects occur, they usually appear within about a week of getting vaccinated and may last several days. More side effects tend to occur following the second dose of vaccine, a sign that your body is building an immune response; however, an immune response can develop without side effects (UC Davis Health, 2021).

The U.S. Food and Drug Administration (FDA) lists the following mild to moderate side effects associated with the COVID-19 vaccines:

- Pain at injection site
- Tiredness
- Headache
- Muscle pain
- Chills
- Joint pain
- Swollen lymph nodes in the same arm as the injection
- Nausea and vomiting
- Fever

(2021a; 2021b)

To manage side effects, the CDC recommends asking a doctor to suggest an over-the-counter medication to help with pain (e.g., ibuprofen or acetaminophen); applying a clean, cool, wet washcloth over the injection site; and using/exercising the affected arm. For fever discomfort, drinking adequate fluids and dressing in light-weight clothing are recommended (CDC, 2021d).

Serious side effects from COVID-19 vaccines appear to be uncommon. Contact a doctor if one or both of the following occur:

- **Redness or tenderness around the injection site increases after 24 hours**
- **Side effects are concerning or do not decrease within a few days**

(FDA, 2021a; FDA, 2021b)

Seek immediate treatment for symptoms associated with anaphylaxis, a severe allergic reaction. These symptoms include:

- **Sensation of throat closing, shortness of breath, wheezing, coughing**
- **Nausea, vomiting, diarrhea, abdominal pain**
- **Dizziness, fainting, very fast heartrate, very low blood pressure**
- **Hives, itching, swelling of lips, face, or throat**

(FDA, 2021a; FDA, 2021b)

Important: Individuals with a history of severe allergic reaction to a COVID-19 vaccine or any ingredient of the vaccine should *not* be vaccinated (CDC, 2021c).

Side effects and allergic reactions might be more difficult to recognize in individuals with ID/A. Individuals who use alternate forms of communication, have cognitive challenges, have neurological conditions, or take medications that cause sedation, should be monitored closely after receiving a COVID-19 vaccination (or any vaccination). Signs of an adverse reaction include “flushing, sudden increase in secretions (from eyes, nose, or mouth), coughing, trouble swallowing, agitation, or acute change in mental status” (CDC, 2021c).

Why get a second shot? Both the Moderna and Pfizer vaccines are most effective against COVID-19 after two injections. It is recommended that the second

injection of the Pfizer vaccine be given 21 days after the first injection and that the second injection of the Moderna vaccine be given 28 days after the first injection (FDA, 2021a; FDA, 2021b). Full immunity is achieved 2 weeks after the final vaccine dose for all available vaccines (CDC, 2021e). A second injection is not needed for the Johnson & Johnson vaccine.

CDC printable handout: “What to Expect after Getting a COVID-19 Vaccine”

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Centers for Disease Control and Prevention. (2021a). COVID-19 Vaccines and Allergic Reactions. Retrieved February 1, 2021, from <https://www.cdc.gov/coronavirus/2019-ncov/vaccines/safety/allergic-reaction.html>

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Guidelines to Follow After Vaccination

The question that many people are asking: Is it necessary to continue wearing a mask and social distancing after getting the vaccine? According to the CDC, the answer is a resounding yes, for several reasons.

There are two types of immunity to viruses. Natural immunity develops after a person is exposed to or contracts the virus. Vaccine-induced immunity develops after a person is vaccinated against the virus. Factors that influence immunity effectiveness vary from person to person; however, researchers currently do not believe natural immunity to COVID-19 lasts very long and recommend vaccination and precautions even for people who tested positive for COVID-19 at some point (CDC, 2021a).

Vaccine-induced immunity is not immediate nor 100% effective. Following the final shot in the COVID-19 vaccination series, it still takes the human body at least 2 weeks to build immunity to the virus. Although initial research indicates a very high percentage of immunity for vaccines currently offered in the United States, immunity is not 100% (Silberner, 2021).

The roll out of current vaccine is progressing in stages, based on current federal guidelines. It is expected to take months for everyone who wants the vaccine to be vaccinated. In addition, not everyone will volunteer to become vaccinated.

When these factors are considered, it is clear that even those who are vaccinated must continue to be vigilant to remain protected. To protect yourself and those you support following vaccination, continue to follow the CDC guidelines.

- **Wear a mask that covers both nose and mouth consistently.**
- **Practice social distancing, remaining at least 6 feet apart from others.**
- **Avoid crowds; limit time in crowded areas when unavoidable.**
- **Avoid places that are poorly ventilated.**
- **Wash hands for at least 20 seconds with soap and water or alcohol-based hand sanitizer if soap and water is unavailable.**



- **Choose outside, well-ventilated activities and events when away from home, if possible.**
- **Stay home if not feeling well; avoid others who appear ill.**
- **Avoid touching the face, especially the nose, mouth and eyes.**

(CDC, 2021b)

There is no definitive date or projected timeline for when the COVID-19 pandemic will end. Until it does, protect yourself and others by following current CDC best practice guidelines. It is the responsible and most effective way to remain safe and healthy.

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Supporting People with Current or Previous COVID-19 Infection

Taking Care of People with Current or Past COVID-19 Infection

As with other health conditions, COVID-19 affects people in different ways. One person might experience active symptoms throughout the illness; another might exhibit worsening symptoms as the infection progresses; and another person might appear to recover, only to have symptoms reappear. Studies confirm that, in some people, symptoms are mild for the first week, then worsen 8-15 days after the initial infection (Harvard Health Publishing 2020). In addition, it is possible for a person who recovered fully to be re-infected following re-exposure to the virus.

Because cases are individualized and symptoms vary from person to person, it is critical for caregivers to be aware of the symptoms and patterns associated with the virus. Being aware and proactive can protect the health and safety of caregivers and the people they support.

Remember, a person may exhibit symptoms, appear to recover fully, and then begin exhibiting symptoms again. If symptoms are observed, contact the individual's healthcare provider for direction and treatment.

Symptoms of COVID-19

- Fever and chills
- Cough
- Shortness of breath
- Fatigue
- Muscle and body ache
- Headache
- New loss of taste or smell
- Sore throat
- Congestion or runny nose
- Nausea or vomiting
- Diarrhea

(CDC, 2020a)

Support methods

Caregivers can use the following steps to support individuals infected with COVID-19 and help prevent further complications.

- **Help the person follow instructions from the healthcare provider, including taking medications as prescribed.**
- **Encourage the person to drink plenty of fluids and get adequate rest.**



- Ensure the person's healthcare provider's phone number is readily accessible for all caregivers.
- Contact the healthcare provider if symptoms worsen or any new symptoms appear that cause concern.

(CDC, 2020b)

When to seek emergency medical attention

Seek emergency medical attention immediately if any of the following symptoms are observed. Notify the 911 operator that you are caring for someone who has or may have COVID-19.

- Trouble breathing
- Pressure or pain in chest that will not stop
- Confusion that is new
- Inability to wake from sleep or stay awake
- Bluish lips or face

(CDC, 2020b)

These symptoms are not all inclusive. Contact a healthcare provider immediately for direction on questions or concerns related to any other severe symptoms (CDC, 2020b).

Protecting caregivers

The health and safety of caregivers affects the health and safety of the individuals they support. The following guidelines can decrease a caregiver's risk of COVID-19 exposure and infection.

Guidelines

- Wear a Mask
- Maintain at least a 6-foot distance from others when possible.
- Avoid crowds.
- Avoid poorly ventilated spaces.
- Wash hands often, for 20 seconds each time.
- Cover nose and mouth when coughing or sneezing.
- Clean and disinfect frequently touched surfaces daily.
- Pay attention to symptoms associated with COVID-19.
- Check temperature if symptoms develop.
- Follow recommendations from the Centers for Disease Control (CDC) and healthcare provider.
- Get vaccinated.

(CDC, 2020b; CDC, 2021)

Caregivers play an essential role in helping to protect the health of self-advocates and others during the COVID-19 pandemic. Knowing the signs and symptoms, when to report to a healthcare provider, and when to seek emergency medical care, along with following effective support and protective/preventive guidelines, promotes the health and safety of both caregivers and individuals with ID/A.

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COVID-19 Long Haulers

Prolonged Symptoms of COVID-19

When a person tests positive for COVID-19, the hope is the symptoms will be mild and there will be a full recovery in a short period of time. However, this is not always the case. A growing number of people are being identified as COVID-19 “long haulers”, which means they appear to have fully recovered from COVID-19 and have received a negative COVID-19 test result (University of California Davis Health, 2021), but continue to have a wide range of symptoms that last more than 28 days (Collins, 2021). These symptoms can be different from those they had initially (University of California Davis Health, 2021) and can be so debilitating that their functional ability and quality of life are impacted (Collins, 2021).

There is evidence that, in addition to the lungs, the COVID-19 virus can affect the heart, kidneys, and brain. Experts do not know if damage to an organ will be permanent or if long-term functioning will be affected (Harvard Health Publishing, 2021).

“Common symptoms for COVID long haulers are:

- Coughing
- Ongoing, sometimes debilitating, fatigue
- Body aches
- Joint pain

- Shortness of breath
- Loss of taste or smell, even if this didn't occur at the height of illness
- Difficulty sleeping
- Headaches
- Brain fog”

(University of California Davis Health, 2021)

Some people who participated in a study conducted by researchers with Patient-Led Research for COVID-19 and University College, London, England, reported “a relapse of symptoms, seemingly triggered by exercise, mental activity, or just everyday stress” (Collins, 2021).

It is estimated that “approximately 10% of people who've had COVID-19 experience prolonged symptoms” (Rubin, 2020, para.12). In another recent study by researchers at the University of Washington, “33% of COVID-19 patients who were never sick enough to require hospitalization continue to complain months later of symptoms like fatigue, loss of smell or taste, and brain fog” (Northern Regional Hospital, 2021). Since COVID-19 has only existed for a little over a year, the medical community is not sure why some people experience prolonged symptoms and others do not. What is known is that this unpredictable phenomenon is occurring throughout the world among people who were infected.

It seems to strike randomly, regardless of age, severity of the initial COVID-19 infection, or presence of underlying health diagnoses. Studies are currently underway to determine why this is happening and what can be done about it. Until definitive answers are discovered, there are strategies that may be useful when supporting a “long hauler.”

Be Observant

For “long haulers,” symptoms persist after the acute period of a COVID-19 infection has ended, and new (sometimes unrelated) symptoms might begin. People have reported symptoms such as chronic cough, fatigue, shortness of breath, dizziness, chest pain, cardiac symptoms, body aches, joint pain, muscle weakness, exercise intolerance, headache, impaired memory, difficulty concentrating, “brain fog,” depression, and anxiety (Hernandez-Romieu, Possick, & Navis, 2021; Rubin, 2020). It is extremely important that caregivers watch for these symptoms in the people they support during *and after* COVID-19 infection. People who do not use words to communicate what they are feeling or experiencing might communicate symptoms through behaviors not typical of them and/or through decreased functional capabilities. Awareness of each person’s baseline behaviors and capabilities, along with the ability to recognize when something “isn’t quite right,” are essential!

Document and Communicate

Upon making a diagnosis of COVID-19, a doctor provides care instructions and guidance on how and when to seek additional medical attention. If a person experiences symptoms of COVID-19 longer than anticipated, displays new or unusual symptoms (such as those mentioned in the paragraph above), or behaves in a way that is not typical of their baseline, document specific observations and communicate the information to the person’s health care team. The doctor may take additional actions, such as having the person re-examined, ordering diagnostic testing, or prescribing medications. Inform all members of the person’s direct support team, as well, to ensure the person’s care plan is updated properly and care is consistent.



Anticipate and Accommodate

While supporting a “long hauler” through a prolonged COVID-19 recovery, adjustments to the person’s living environment and daily activities may be necessary to ensure that health and safety are prioritized. Try to anticipate situations that could cause difficulty given the person’s symptoms and limitations. For example, accommodations may be needed for a person who is experiencing muscle weakness and is unable to navigate stairs without assistance. A person experiencing overwhelming fatigue might require brief naps or periods of rest throughout the day. A person experiencing shortness of breath may be advised to limit the amount of exertional activity until fully recovered. A person who is experiencing memory impairment might need reminders to complete activities previously performed independently. If necessary, seek consultations with physical and occupational therapy professionals for guidance on effective care techniques to support the person through recovery.

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