



Easy Read Edition

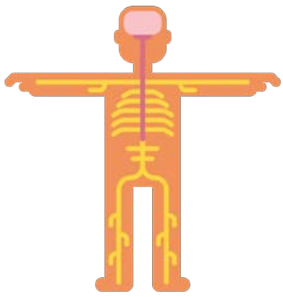
**What you need to
know about COVID-19
and Long COVID**

Words to Know in this Fact Sheet



Accommodations

Changes that make things easier for people with disabilities. They help us get the same things as non-disabled people.



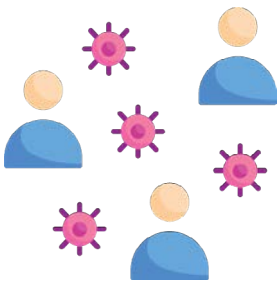
Autonomic nervous system

A system in your body that controls things your body does automatically, like breathing, your heartbeat, or how hot or cold you are.



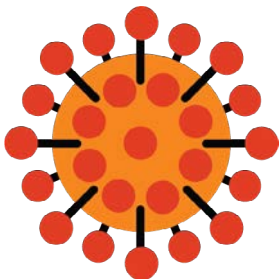
Cognitive dysfunction

When you have a hard time thinking or remembering.



Contagious

When someone can spread a disease.



COVID-19

A bad disease that has spread around the world. It makes people very sick and can kill people.



Dysautonomia

When your autonomic nervous system does not work properly.



Fatigue

Feeling really tired no matter how much you sleep.



Long COVID

When you have symptoms over three months after you first got COVID-19



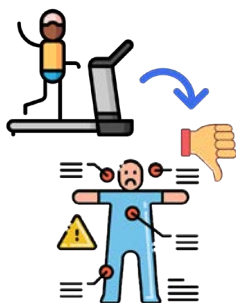
Mass disabling event

When many people end up disabled because they got sick or injured by something.



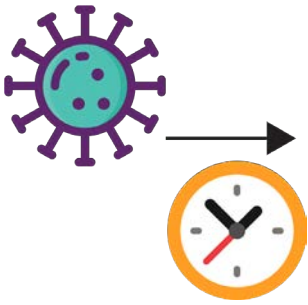
Paralyzed

When someone can't move their body easily or at all.



Post-exertional malaise (PEM)

Having symptoms that get worse after you exercise or do activities.



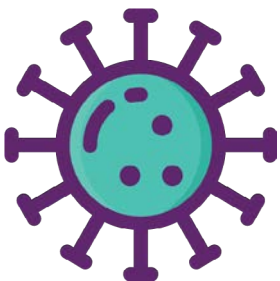
Post-viral condition

A condition that happens after you get sick with a virus.



Tachycardia

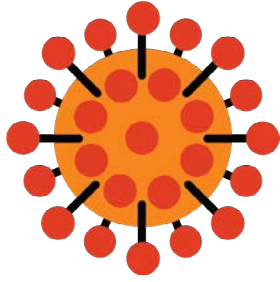
Having your heart beat really fast.



Virus

A very small type of germ.

What is COVID-19?



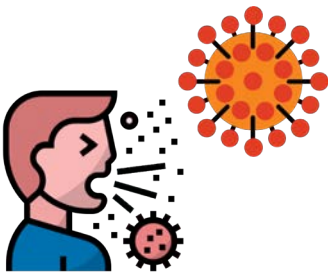
COVID-19 is a bad disease.



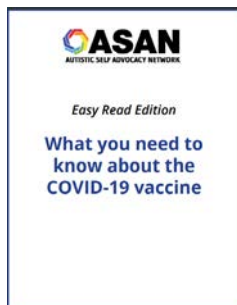
It makes people very sick.



COVID-19 has spread around the world.



COVID-19 is still spreading.



You can learn more about COVID-19 by reading [our fact sheet on the COVID-19 vaccine](#).

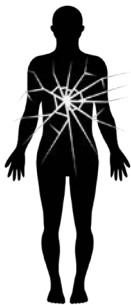
What is Long COVID?



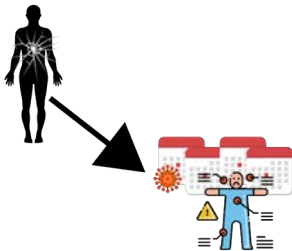
Long COVID is when you are still sick over three months after you first got COVID-19.



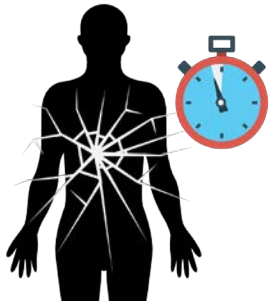
Long COVID happens because you got sick with COVID-19.



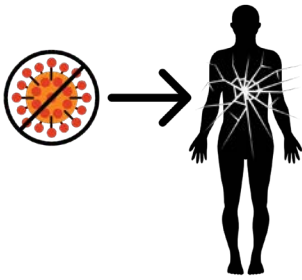
Being sick with COVID-19 can damage your body.



That damage is called Long COVID.



The damage from Long COVID can last a long time.



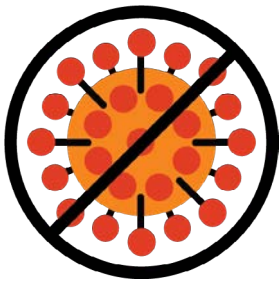
The damage can last even after you no longer have COVID-19.



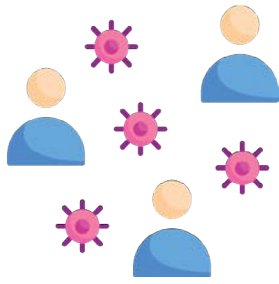
Having Long COVID does **not** mean you are still sick with COVID-19.



Having Long COVID might mean you still feel sick.



But it does not mean you still have COVID-19.



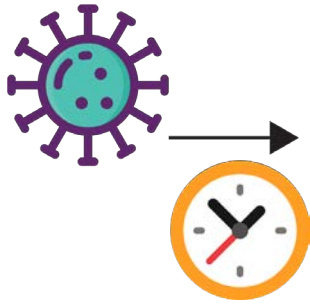
People who have Long COVID are not still **contagious** with COVID-19.



They can't spread COVID-19.



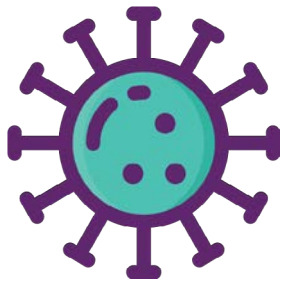
That means you can't catch COVID-19 from them.



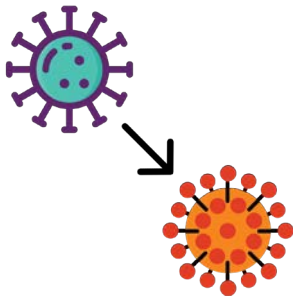
Long COVID is a **post-viral condition**.



That means that it happens after you get sick with a virus.



A **virus** is a type of very small germ.



COVID-19 is caused by a virus.

There are many different names for Long COVID. Some other names for Long COVID are:



- Long-haul COVID



- Post-acute COVID-19



- Post-acute sequelae SARS-CoV-2 infection



- Long-term effects of COVID



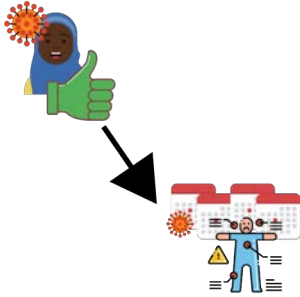
- Chronic COVID



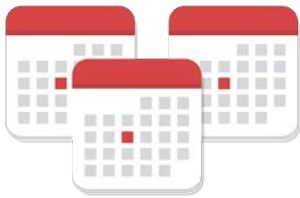
All these terms mean the same thing.



You don't have to get very sick with COVID-19 to have Long COVID.



People who didn't feel sick at all when they got COVID-19 can get Long COVID.



For some people, Long COVID lasts for only a few months.



For other people, it can last years.

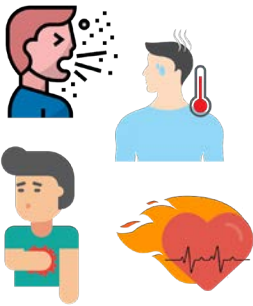


We still don't know a lot about Long COVID.



Doctors and scientists are studying Long COVID to learn more about it.

What are some symptoms of Long COVID?



There are many different symptoms of Long COVID.



Not everyone has every symptom.

But some of the most common symptoms are:



- Having a hard time breathing.



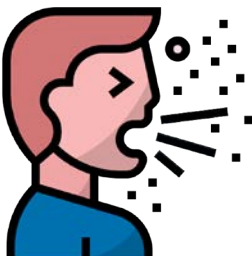
- Feeling really tired no matter how much you sleep. This is also called “**fatigue.**”



- Having symptoms that get worse after you exercise or do activities. This is also called “**post-exertional malaise**” or **PEM.**



- Having trouble thinking.



- Coughing.



- Pain in your chest.



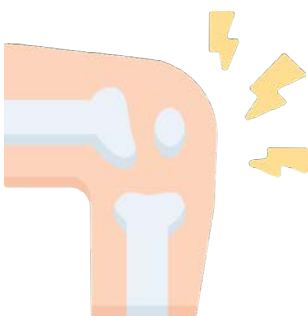
- Pain in your stomach.



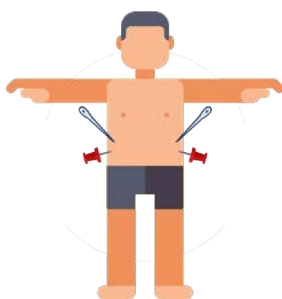
- Headaches.



- Having your heart beat really fast.
This is also called “**tachycardia.**”



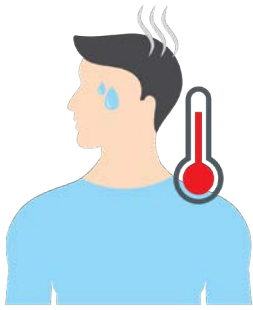
- Pain in your joints or muscles.



- Feeling like there are “pins and needles” in your body.



- Having trouble sleeping.



- Having a fever.



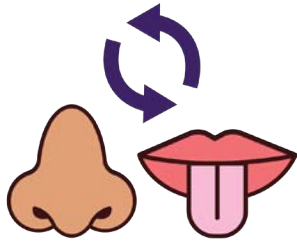
- Feeling dizzy or lightheaded when you stand up.



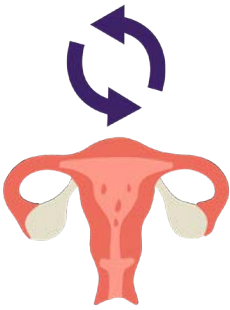
- Rashes.



- Having changes in your mood or how you feel.



- Having changes in your senses of smell or taste, including losing your ability to smell or taste things.



- If you get a menstrual period, having changes in your menstrual period.



These are not all the symptoms of Long COVID.



If you have Long COVID, you might have other symptoms that aren't on this list.

What is cognitive dysfunction?



Some people with Long COVID have **cognitive dysfunction**.



Cognitive dysfunction is when you have a hard time thinking or remembering.



Some people call cognitive dysfunction "brain fog."



Cognitive dysfunction is a spectrum.



That means that different people with cognitive dysfunction have different levels of a hard time thinking or remembering.



Some people with cognitive dysfunction only have a little bit of a hard time thinking or remembering.



Some people with cognitive dysfunction have a very hard time thinking or remembering.



What is dysautonomia?

Some people with Long COVID have **dysautonomia**.



(Dysautonomia is pronounced “diss-oughta-no-me-uh.”)



Dysautonomia is when your autonomic nervous system does not work properly.

Your **autonomic nervous system** controls things your body does automatically, such as:



- Breathing.



- Heart beating.



- Controlling how hot or cold your body is.



When you have dysautonomia, your body can't control all these things as well.

Some symptoms of dysautonomia are:



- Your heart beating too fast. This is also called “tachycardia.”



- Feeling really tired. This is also called “fatigue.”



- Feeling like it’s hard to breathe.



- Headaches, especially a type of headache called migraines.



- Having a hard time standing



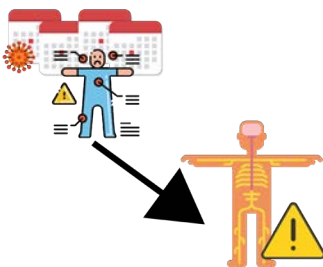
- Passing out/fainting



- Blood getting stuck in your legs. This can lead to your legs looking really red.



There are many different types of dysautonomia.



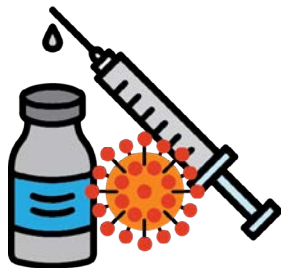
Long COVID can cause different types of dysautonomia.

How can I keep myself from getting Long COVID?

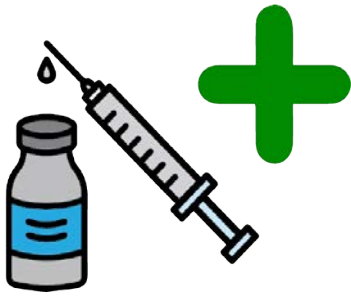


The best way to keep yourself from getting Long COVID is to not get sick with COVID-19.

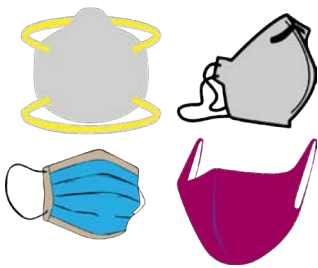
You can protect yourself by:



- Getting vaccinated for COVID-19. You can read more about getting vaccinated in [our fact sheet about the COVID-19 vaccine](#).



- Getting your booster shot or shots for COVID-19, if you can. You can read more about booster shots in [our fact sheet about boosters](#).



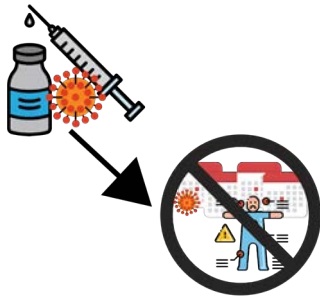
- Wearing a good quality mask, if you can. You can read more about masks in [our fact sheet about masks](#).



- Staying home, if you can.



- Washing your hands.

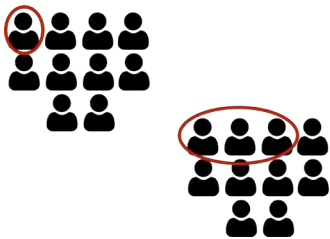


We also think getting vaccinated can make it less likely that you will get Long COVID even if you do get sick with COVID-19.

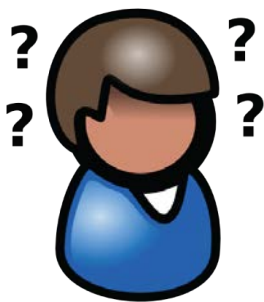
Why do some people get Long COVID but others don't?



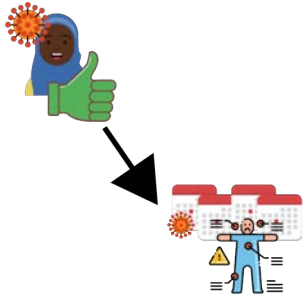
Not everyone who gets sick with COVID-19 will get Long COVID.



We think between 1 in 10 and 3 in 10 people who get sick with COVID-19 will get Long COVID.



We don't know exactly why some people get Long COVID but others don't.

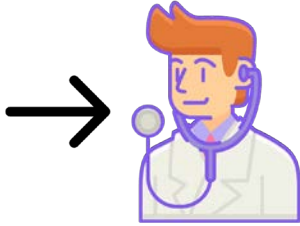


We know that anyone who got COVID-19 can get Long COVID, even if they didn't feel sick at all.



You don't have to have gotten very sick with COVID-19 to get Long COVID.

What should I do if I think I have Long COVID?



You should see your doctor.



Tell your doctor you think you have Long COVID.



Tell your doctor about your symptoms.

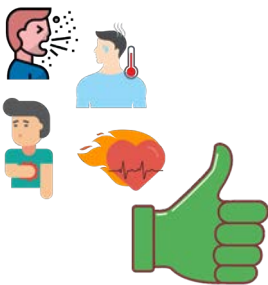
Keep a list of the symptoms you have. For each symptom, write down:



- What the symptom is



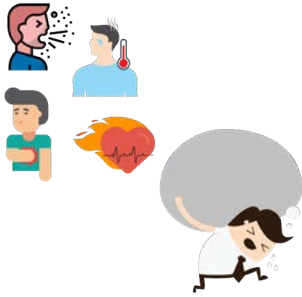
- When you have the symptom (for example, if you only have it at night)



- What makes the symptom get better



- What makes the symptom get worse

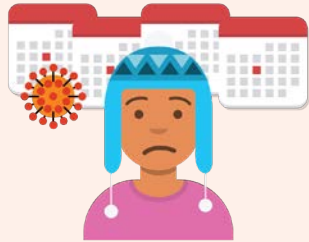


- Anything that the symptom makes it hard for you to do



Show the list of symptoms to your doctor

For example:



Gerald has Long COVID.



He is taking notes on his symptoms.



Gerald has a bad cough.



He writes that his cough is worse at night.



Gerald writes that his cough gets better if he takes deep breaths.



He writes that his cough gets worse if he goes for a long walk.



He writes that his cough makes it hard to sleep because he keeps coughing at night.



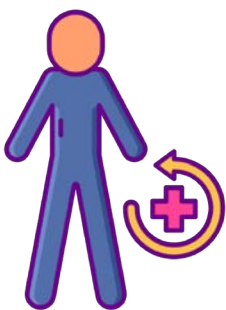
You should try to rest as much as possible.



Your body needs to heal and get better from Long COVID.



Long COVID can be really stressful on your body.



You want to give your body time to recover.

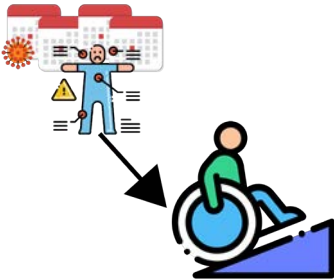
What are my rights if I have Long COVID?



If you have Long COVID, you have the same rights as anyone else.



In 2021, the United States government said that Long COVID can be a disability.



That means that if you have Long COVID, you can get accommodations to help you.



Accommodations are changes that make things easier for people with disabilities.



They help us get the same things as non-disabled people.

Some examples of accommodations are:



- If you have a job, having more breaks during work so you can rest



- If you go to school, having more time when you take tests or do homework

For example:



Lilliana has Long COVID.



Lilliana goes to college.



Lilliana's Long COVID makes it hard for them to think quickly.

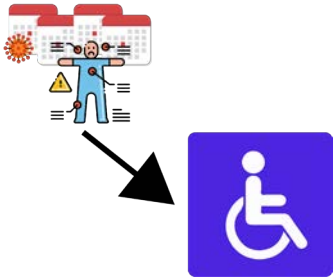


So Lilliana gets extra time on their tests in class.



That makes it easier for them to remember all the information they need for the tests.

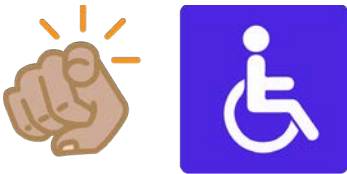
Long COVID can be a disability



Long COVID can be a disability.



It can make it hard for people to do everyday activities.



If you have Long COVID, you could have a disability.



People with disabilities have been working together for a long time.



We worked together to change laws.



We worked together so we could have more rights.



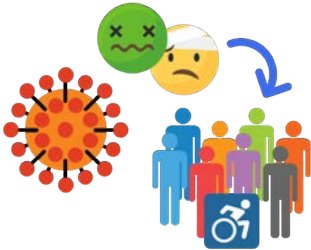
We worked together to make the world more accessible for us.



We are still working together on all of these issues.



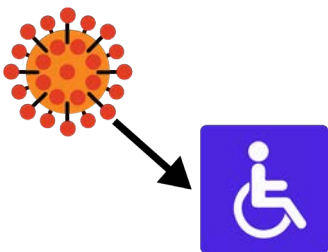
About 1 in 4 people in the United States have a disability.



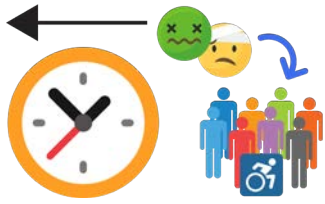
COVID-19 is a **mass disabling event**.



A mass disabling event is when many people end up disabled because they got sick or injured by something.



That means that many people who get COVID-19 will end up with a disability because they got COVID-19.



There have been other mass disabling events before.



One example of a mass disabling event was polio.



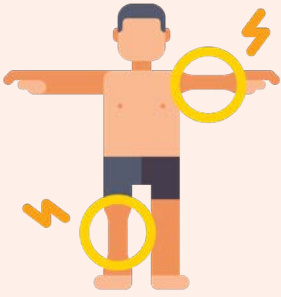
Polio is a very bad disease.



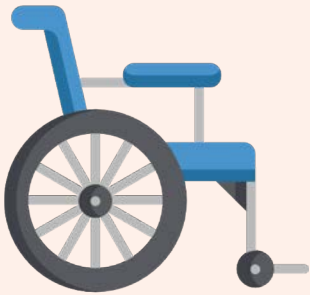
It makes people very sick.



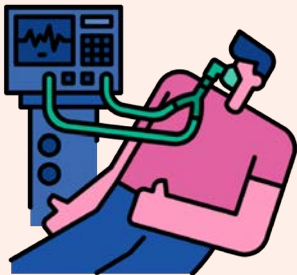
Some people who get polio are **paralyzed** by polio.



Paralyzed means they can't move their bodies easily or at all.



People who were paralyzed by polio might need to use wheelchairs to help them move.



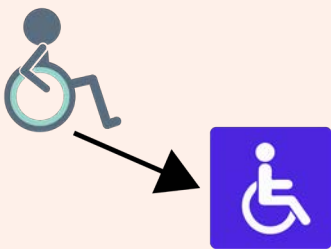
They might need help from a machine to breathe.



In the 1950s, lots and lots of people in the U.S. got polio.



Some of these people were paralyzed by polio.



They had a disability because they were paralyzed.



They worked together to change the world.



They worked with people with other kinds of disabilities, too.

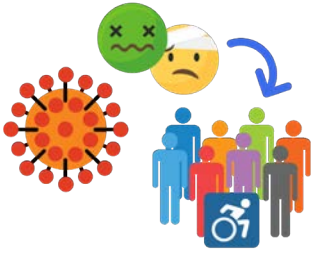


They worked together to make things more accessible for people who use wheelchairs.

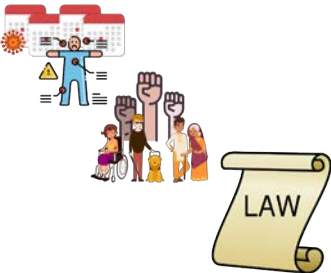


They worked to change the laws so people with disabilities would be protected.

COVID-19 is another mass disabling event.



People with Long COVID need to work together to fight for their rights.



People with Long COVID need to work together to make the world more accessible for people with disabilities.

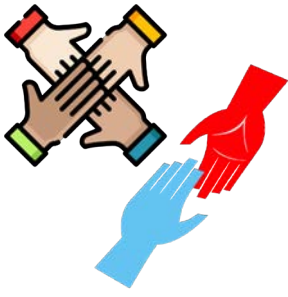


People with Long COVID can work with people with other kinds of disabilities, too.



We can all work together to make a more accessible world.





We can all work together to help each other out.

How can I help someone who has Long COVID?

You might know someone who has Long COVID. Here are some tips to help you help them:



- Listen and hear what they have to say.



People with Long COVID can often feel really stressed.



We don't know much about Long COVID right now.



And Long COVID can last a long time.



So it can be really hard to be sick with Long COVID.



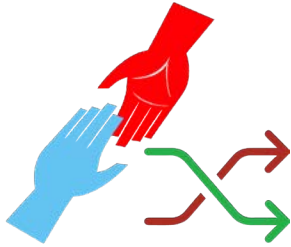
Listen to what the person has to say.



Think about what they're going through.



- Talk to them to figure out what they need.



Different people need different kinds of support.



You can ask the person questions to figure out what kinds of support they need.



Start with a big question, like “how are you doing these days?”



Then, you can ask smaller questions to figure out what kinds of support would help.

For example:



David is talking to his friend Mikaela.



Mikaela has Long COVID.



David says, "How are you doing these days?"



Mikaela says, "I'm not doing great. I feel really lonely a lot of the time."



David says, "Would it help for me to call you everyday to talk?"



Mikaela says, "Yes, that would be great."



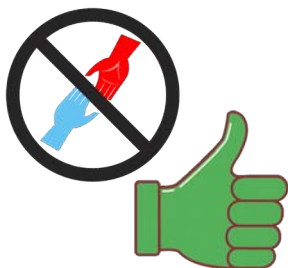
- Figure out how you can help with what they need.



Some people will want someone to listen to their experiences.



Other people will need help doing physical things, like doing chores or running errands.

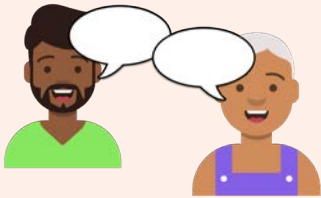


It's okay if you can't help with everything a person needs.

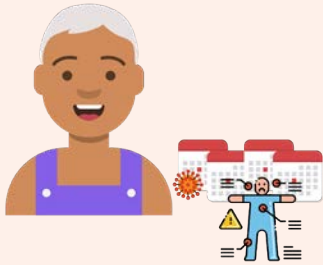


Just let them know what you can help with.

For example:



Kong is talking to his roommate Jake.



Jake has Long COVID.



Kong says, "How can I support you?"



Jake says, "I need help getting to doctor appointments."



Kong says, "I can't drive you since I don't have a car. But I can help you take the bus."

Long COVID Symptom Tracker

Use pages 63-66 to keep track of your Long COVID symptoms. Circle the symptoms you have. Then, show these pages to your doctor at your next appointment.



Having trouble breathing



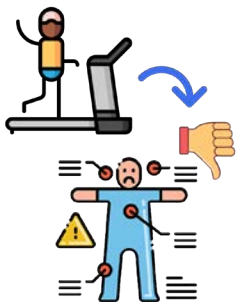
Coughing



Feeling really tired (fatigue)



Pain in your chest



Symptoms get worse with exercise (post-exertional malaise/PEM)



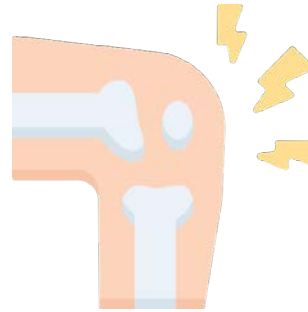
Having trouble thinking or remembering (cognitive dysfunction)

Long COVID Symptom Tracker

Use pages 63-66 to keep track of your Long COVID symptoms. Circle the symptoms you have. Then, show these pages to your doctor at your next appointment.



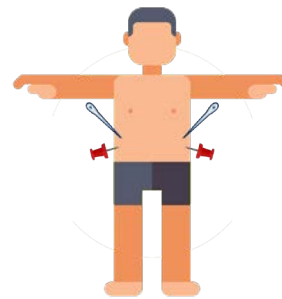
Pain in your stomach



Pain in your muscles and joints



Headaches



Feeling “pins and needles” in your body



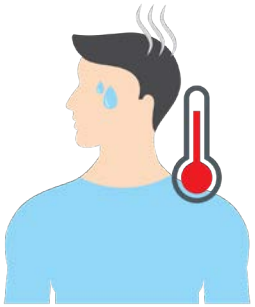
Very fast heartbeat (tachycardia)



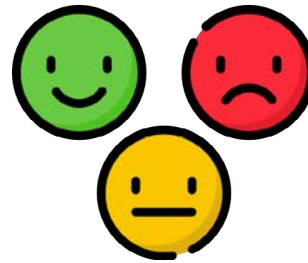
Having trouble sleeping

Long COVID Symptom Tracker

Use pages 63-66 to keep track of your Long COVID symptoms. Circle the symptoms you have. Then, show these pages to your doctor at your next appointment.



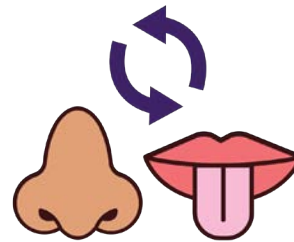
Having a fever



Changes in mood



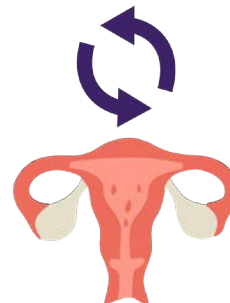
Feeling dizzy/
lightheaded



Changes in sense of
smell or taste



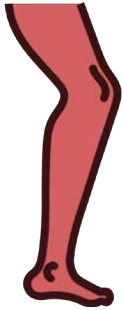
Rashes



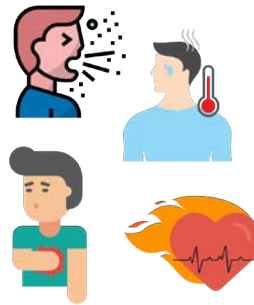
Changes in
menstrual period

Long COVID Symptom Tracker

Use pages 63-66 to keep track of your Long COVID symptoms. Circle the symptoms you have. Then, show these pages to your doctor at your next appointment.



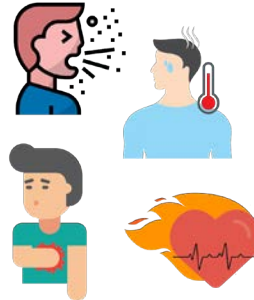
Red legs



Other symptom:



Passing out/fainting



Other symptom:



Having a hard time standing up



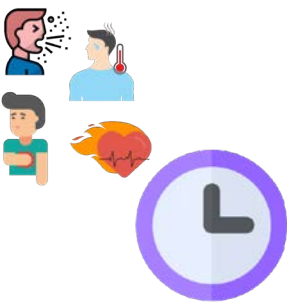
Other symptom:

Long COVID Symptom Worksheet

Pages 67-69 have questions about your symptoms. Print them out once for each symptom you have. Then, you can answer the questions about each of your symptoms.



What is the symptom? (for example, coughing)



When do you have the symptom? (for example, all the time or only at night?)

Long COVID Symptom Worksheet

Pages 67-69 have questions about your symptoms. Print them out once for each symptom you have. Then, you can answer the questions about each of your symptoms.



What makes the symptom get better? (for example, taking medication)



What makes the symptom worse? (for example, exercise)

Long COVID Symptom Worksheet

Pages 67-69 have questions about your symptoms. Print them out once for each symptom you have. Then, you can answer the questions about each of your symptoms.



What does the symptom make it hard to do? (for example, sleeping)

To Learn More:

Learning more about Long COVID:

1

Centers for Disease Control and Prevention (CDC): Post-COVID Conditions (Not Easy-Read/plain language): <https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/index.html>

2

CDC: Caring for People with Post-COVID Conditions (Not Easy-Read/plain language): <https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/care-post-covid.html>

3

Long-term effects of COVID-19 (long COVID) (Easy Read): <https://www.nhsinform.scot/translations/formats/easy-read/long-term-effects-of-covid-19-long-covid-easy-read/> (These fact sheets were made in Scotland. Some of the information will not apply to the United States.)

4

Department of Health and Human Services (HHS): Guidance on “Long COVID” as a Disability: https://www.hhs.gov/civil-rights/for-providers/civil-rights-covid19/guidance-long-covid-disability/index.html#footnote10_0ac8mdc

Support for people who have Long COVID (all are *not* Easy-Read/plain language):

1

Administration on Community Living (ACL): How ACL's Disability and Aging Networks Can Help People with Long COVID: https://acl.gov/sites/default/files/COVID19/ACL_LongCOVID.pdf

2

ACL: Resources for People with Long COVID: <https://acl.gov/covid19/resources-people-experiencing-long-covid>

3

CDC: How Right Now: <https://www.cdc.gov/howrightnow/index.html>

4

World Health Organization (WHO): Support for rehabilitation: self-management after COVID-19-related illness: <https://apps.who.int/iris/bitstream/handle/10665/344472/WHO-EURO-2021-855-40590-59892-eng.pdf>

5

Job Accommodations Network (JAN): <https://askjan.org/topics/COVID-19.cfm>

6

Body Politic: <https://www.wearebodypolitic.com/covid-19>

7

COVID-19 Longhailer Advocacy Project <https://www.longhailer-advocacy.org/>

8

COVID-19 Longhailer Advocacy Project:
A Comprehensive Guide for COVID-19
Longhailers and Physicians: The PASC
Master Document: <https://docs.google.com/document/d/1VfENjAiOBKryT-dIOFyU8CyEAAKVR5xk9WyvIZF-u4M/edit>

9

Patient-Led Research Collaborative:
<https://patientresearchcovid19.com/>

10

Long COVID Alliance: <https://longcovidalliance.org/>

11

Dysautonomia International: <http://www.dysautonomiainternational.org/>