

Doing everything you can during COVID-19:

A Kidney & Transplant Patient Guide

There are many things you can do during this time of COVID-19 to take care of yourself, your living donors, friends, and your family. This kidney and transplant patient guide has been developed by leading healthcare professionals, after reviewing national guidelines, to answer commonly asked questions and explain actions you can take to help.

For kidney and transplant patients, the most important things to do are to:

- Prevent getting and spreading COVID-19
- Maintain your health and follow your kidney, dialysis, and transplant regimen
- Monitor yourself for COVID-19 symptoms and get prepared if you need to act
- Seek medical care if your health worsens
- Stay calm and supported

Patients and potential living donors who are in the process of pursuing transplant or donation must also understand the changes in their dialysis and transplant care and weigh the risks and benefits of pursuing or receiving a transplant, or of becoming a donor, at this time.

The following information is intended only for health education purposes, and does not take the place of a doctor's advice. You should consult with your doctor when making any decisions about your care.

Go to www.exploretransplant.org for regular updates to this guide.

Content contributors

This patient guide includes relevant content from the Centers for Disease Control and Prevention (CDC), the Centers for Medicare and Medicaid Services (CMS), and the World Health Organization (WHO), as well as from kidney and transplant organizations including the American Society of Transplantation (AST), the American Society of Nephrology (ASN), and the United Network for Organ Sharing (UNOS). This guide was designed by kidney and transplant educators and clinicians at the University of California Los-Angeles (UCLA), Terasaki Institute of Biomedical Innovation (TIBI), and Health Literacy Media.

We particularly thank the kidney patient and donor panel who have submitted questions and reviewed content.

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What's in this guide:

Frequently asked questions

How to prevent getting and spreading COVID-19	6
How does someone get COVID-19?	6
What can I do to prevent getting COVID-19?	6
How do I wash my hands correctly?	7
How can I protect myself if I need to go out in public?	8
What should I do when I get back home to stay safe?	8
How can my family members avoid spreading the virus to me?	9
Can I get COVID-19 from my pet or other pets in my neighborhood?	9
How should I clean and sanitize mail and packages that come into my house?	9
What can I do if I run out of disinfecting wipes and can't get more?	10
Is it okay to get takeout food, such as fast food, delivery, or to-go meals?	10
 How to maintain your health and treatment routine	 11
What should I do to maintain my health as a patient during COVID-19?	11
Is there a vaccine for COVID-19 that I should get?	11
To boost my immunity, should I take supplements, natural remedies, or medicines that haven't been prescribed to me?	11
Should I stop taking my medicines or lower my dose if I am concerned about running low?	11
Should I reduce my immunosuppressant use to make me less vulnerable to infection?	11
 How to monitor for COVID-19 symptoms	 12
What symptoms of COVID-19 should I watch for?	12
Could the symptoms of COVID-19 be different for certain patients?	12
What should I do if I think I might have been exposed to COVID-19 but don't have symptoms?	13
What's telehealth, and how could it help me?	13
How do they test to see if I might have COVID-19?	13
How do I know if I should go to the hospital?	14
What will happen if I have to go to the emergency room?	14
What would happen if I needed to be hospitalized?	15

FAQs continued

How to stay calm and supported.....	16
Can kidney and transplant patients recover from having COVID-19?	16
How can I stay hopeful during this time?	16
How can caregivers, family members, and friends support me?	17
What can I do if I'm feeling really anxious, stressed, or sad?	17
What else can I do to help relieve my stress?	18
How can I stay active during this time?	19
Who can I talk to if I am feeling overwhelmed?	19
 How your kidney care might change during COVID-19	20
Dialysis care changes during COVID-19	20
How could my dialysis care change?	20
What can I do to stay safe at dialysis?	20
What happens if I have, or may have, COVID-19 and I need dialysis?	20
 Transplant care changes during COVID-19	21
Should I still go to the transplant center for routine medical tests?	21
Can I get a doctor's note for my employer so I can work from home?	21
How can I get help paying for my immunosuppressant medications right now?	22
If a deceased donor kidney becomes available, can I still get a transplant?	22
How can I know that a deceased donor didn't have COVID-19?	22
Can I still get a living donor kidney transplant now?	22
Are paired kidney donations (swaps or chains) still happening?	22
 Deciding about transplant & living donation during COVID-19.....	23
Would it be better to stay on dialysis than to get a transplant during COVID-19?	23
If I turn down a deceased donor organ offered to me, will I get another?	23
What does it mean to be temporarily inactive?	23
Should I delay my living donor transplant?	24
How will my recovery from transplant surgery change due to COVID-19?	24
Are living donors screened for COVID-19?	24

Helpful resources for patients & caregivers

Trusted COVID-19 resources for patients & caregivers.....	25
To find out if your dialysis center is open	26
Resources for mental wellness and stress management	26
Resources for financial concerns	27
Resources for children, teens, and families	29
Checklist for being ready for a health care visit during COVID-19.....	31
Sample doctor's letter to patient's employer	33
Sample doctor's letter to employer of spouse's employer.....	34
Door signs to post if you are immunosuppressed	35

How to prevent getting and spreading COVID-19



How does someone get COVID-19?

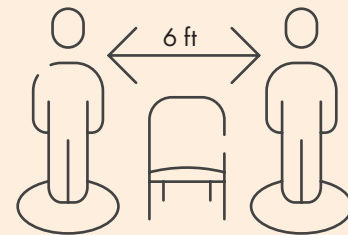
People get infected with COVID-19 when they are in close, direct contact with someone who is carrying the virus. The virus is spread through respiratory droplets that are released when an infected person coughs, sneezes, or talks. These droplets can be inhaled by others who are too close.

People are thought to be most contagious when they have symptoms, but some people may carry the virus even if they are not showing symptoms or are only mildly sick. The safest thing is to stay home if you can or stay 6 feet or more away from other people.

It may also be possible to catch the virus from a surface that droplets landed on, or that an infected person touched after touching their face. This is called community transmission. Common examples are door handles, toilet handles, tabletops, phones, pens, silverware, or dishes. The virus can live for several hours or up to several days, depending on the type of surface. Wash your hands often and sanitize the surfaces of your house with disinfecting wipes.

Tip:

Think of it as “**6 feet for safety.**”



What can I do to prevent getting COVID-19?

To prevent getting COVID-19, **make sure you are doing these 6 things:**



Wash your hands often with soap and water, for at least 20 seconds, especially when returning home from a public place. Use hand sanitizer if handwashing is not possible.



Avoid touching your face.



Stay home except for essential trips to the grocery store or pharmacy.



Practice social distancing. If you must go out in public, keep 6 feet between yourself and others. That's about the distance of one sofa.



Wear an N95 mask when out in public, if you have one. Fabric or surgical masks will not protect you – they help limit virus droplets being breathed out by people who may be ill.



Use disinfecting wipes to regularly sanitize the frequently-touched surfaces in your home.

How do I wash my hands correctly?

Washing your hands correctly should take you at least 20 seconds – about as long as it takes to sing Happy Birthday twice. Apply enough soap to cover your hand. Don't forget to scrub between your fingers, and under your nails.

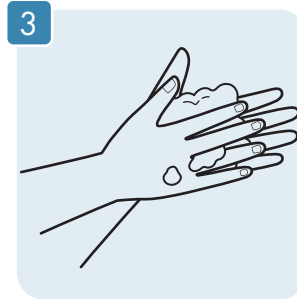
Here's how to wash your hands:



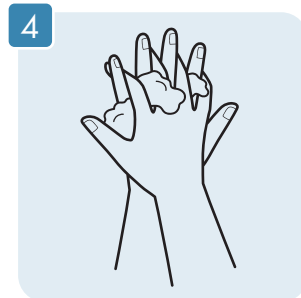
1
Run water on your hands.



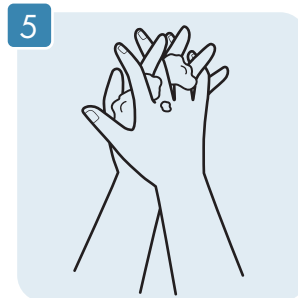
2
Put soap on your hands.



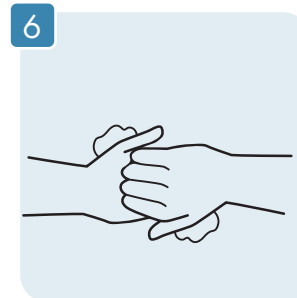
3
Rub the inside of your hands together.



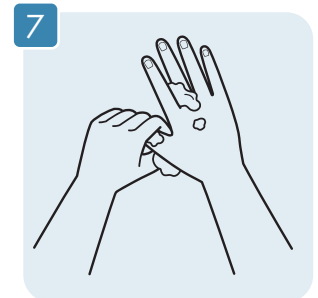
4
Put your hand over the back of your left, rub them. Then switch.



5
Put your palms together and interlace your fingers.



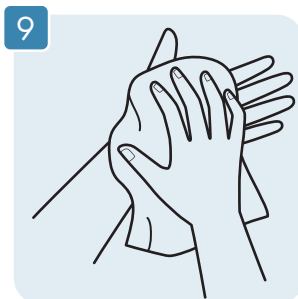
6
Interlock your palms and fingers.



7
Rub your thumbs.



8
Rinse your hands with water.



9
Dry your hand off with a paper towel.



10
Turn the water off with the paper towel and throw it away.

How can I protect myself if I need to go out in public?

You should only go out for essential trips such as to get groceries or for medical needs, including going to dialysis or to get necessary medical tests. Do not go out in public if you have any symptoms, such as a cough or fever.

Regardless of whether you are sick or not, **if you must go out:**



Wear disposable gloves and an N95 mask, if you have one.



Stay 6 feet or more away from other people – except for health care workers who need to test you or give you treatment.



Avoid touching your eyes, mouth, and nose until you can wash your hands.



Take hand sanitizer with you. Wash your hands or use hand sanitizer (of at least 70% alcohol) as you enter and leave public places.

What should I do when I get back home to stay safe?

When you get back home:



With disinfecting wipes or spray, sanitize any surfaces you touched after you were in a public place.

Tip:

Don't forget:



The steering wheel and other surfaces in your car



Your car keys and cell phone



Any doorknobs or garage door opener/closer



Remove your shoes right inside your entryway or leave them outside.



Take off your clothes and wash them. Washing with regular detergent and drying them is good enough to kill any germs.



Wash your hands with soap and water for at least 20 seconds.



Relax in your home knowing you have kept yourself and your family as safe as possible.

How can my family members avoid spreading the virus to me?

If you live with someone who might have been exposed to COVID-19 at work, school, in the community, or has just returned from traveling, avoid any contact with them for 14 days. Stay in separate rooms, use separate bathrooms, and don't share towels, dishes, or beds.

If you cannot do this, maintain as much physical separation as possible and clean the surfaces of your home regularly. If someone in your home is sneezing or coughing, ask them to sneeze or cough into a tissue or sleeve. The sick person should wear a mask if they must enter or pass through common spaces. While they may not feel like it, only the sick person should do sanitizing or cleaning in their space, or after using a shared bathroom.

Tip:

Everyone should minimize trips outside your home.



Can I get COVID-19 from my pet or other pets in my neighborhood?

At this time, there is no evidence that COVID-19 can be transmitted from pets to humans.

Like humans, household pets who leave the house could carry COVID-19 on their coats or paws back into the home. You may want to wipe off their paws with regular soap and water before letting them come back inside.



Petting other people's animals or allowing others to pet yours would require getting too close, so it's not recommended. Pet owners should wash their hands before and after caring for or feeding pets. We also recommend regularly disinfecting surfaces that pets have contact with.

People who are isolating at home because they have COVID-19 should limit their direct contact with animals including petting, being licked, or sleeping in the same location.

How should I clean and sanitize mail or packages that come into my house?

There is a very low chance of getting COVID-19 from products or packaging. The virus will not survive during the 2-3 days it takes to mail something to your home.

However, if a delivery person is infected, this could contaminate the outside of the package. Open the packages outside, throw away the outer packaging, and then wash your hands thoroughly with soap and water.



What can I do if I run out of disinfecting wipes and can't get more?

If you run out of disinfecting wipes, use a disinfectant spray and paper towels.

A list of products that are approved for use against the virus that causes COVID-19 include many common products like Lysol® Disinfecting Wipes, Lysol® Disinfectant Spray, Clorox Multi Surface Cleaner + Bleach, Clorox Disinfecting Wipes, and Soft Scrub with Bleach. A full list can be found on the CDC COVID-19 website.

For some surfaces, you can also use diluted bleach for cleaning, at a ratio of 4 teaspoons bleach per quart of water. Alcohol solutions with at least 70% concentration of alcohol are also effective.

It is not recommended to make your own hand sanitizer or use essential oils, as these may not be effective at killing the virus.

Tip:

Do not use bleach on metal or other surfaces that could be discolored by bleach.

Is it okay to get takeout food, such as fast food, delivery, or to-go meals?

The safest thing is to make your own food at home, if you can. There is a chance you could get the virus from touching food containers, if they've been touched by someone who is infected. If you get takeout, put the food in new containers, throw the packaging in the trash, and wash your hands.



How to maintain your health and treatment routine



What should I do to maintain my health as a patient during COVID-19?

To maintain your health, follow your doctor's recommendations, take your medicines without interruption, and follow your treatment plan. Continue to do what you've been told to do.

You should locate your health insurance card and prepare a list of the medicines you currently take, to share with any medical professionals who may need this information.

Is there a vaccine for COVID-19 I should get?

There is no vaccine, currently, but researchers are working as fast as possible to create one. If a vaccine becomes available, your care team will advise you about whether it is safe and recommended for dialysis or transplant patients.

Should I take supplements, remedies, or medicines that haven't been prescribed?

Ask your doctor before taking any new supplements or natural remedies, as these can interact or interfere with other medicines that you take to manage your health.

Tip:

Do not take any medicines related to COVID-19 unless they are approved by your doctor.

Should I stop taking my medicines or lower my dose so I don't run low?

No, do not stop taking your medicines or lower your dose. It is important to make sure you have enough medicine available for all of your health conditions. Call doctor and ask about options for getting 3-month supplies of your critical medicines.



Should I reduce my immunosuppressant use to make me less vulnerable?

If you are a transplant patient who is taking immunosuppressant or anti-rejection drugs, you should not lower your dose or stop taking them, because this increases the risk of your transplant rejecting.

How to monitor for COVID-19 symptoms

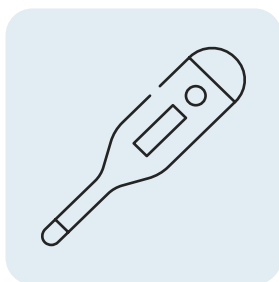


What symptoms of COVID-19 should I watch for?

Remember, nearly 1 in 4 (25%) of people who get COVID-19 do not have symptoms. Many people who do have symptoms only have mild symptoms that can be managed at home.

Symptoms can be similar to those of the flu and appear 2-14 days after exposure.

If you have symptoms, they usually include:



Fever of 101° F
or higher

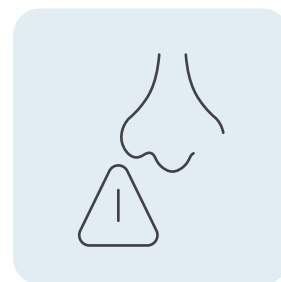


Cough and shortness
of breath

Symptoms may also include:



Tiredness, aches, runny
nose, and sore throat



Sometimes, temporary
loss of smell or taste

If you develop fever, cough, or shortness of breath, call your doctor. They will help you decide if you should seek COVID-19 testing based on your symptoms and your health status as a patient with an underlying condition.

Tip:

You can check your symptoms using the following resources:

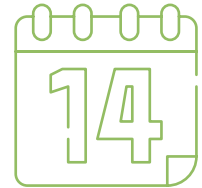
- CDC Coronavirus Self-Checker:
<https://www.cdc.gov/coronavirus/2019-ncov/symptoms-testing/symptoms.html>
- Emory University's Coronavirus Checker: c19check.com

Could the symptoms of COVID-19 be different for certain patients?

There is still much that we do not know about how the virus affects different people, including transplant patients and the immunosuppressed. The American Society of Transplantation notes that some transplant recipients may develop pneumonia if they get COVID-19. People who are older or who have suppressed immune systems have been more prone to developing serious complications from COVID-19.

What should I do if I think I might have been exposed to COVID-19?

If you think you may have been exposed to COVID-19, begin self-isolation at home for 14 days, even if you're not showing symptoms. Avoid contact or sharing spaces with family members to avoid infecting them. You could infect others even if you are not experiencing symptoms yourself. Also, call your doctor's office or ask for a telehealth visit (a digital health care visit) to discuss your concerns and find out what to do if you begin to develop symptoms.



What's telehealth, and how could it help me?

Telehealth is a way to meet with your doctor virtually. If you've ever had a video call with friends or family using FaceTime or Skype, telehealth is similar, but more secure. Many health providers are now offering telephone or telehealth appointments so you can meet with them safely from your home.

If possible, you should learn what to do ahead of time so you know how to seek medical care easily at home if your health changes. Call and ask your provider if they offer a telehealth option. You may also wish to call your insurance company to find out about their coverage for telehealth visits.

If you have to schedule an in-person visit with your doctor, remind them that you have an underlying health condition and ask if they have extended hours, either early or late, which might allow you to minimize contact with other people around the hospital or doctor office.

Tip:

If you are a Medicare patient and your provider does telehealth visits, you can schedule a virtual check-in appointment. You'll pay your usual Medicare copay and deductible for these services.

How do they test to see if I might have COVID-19?

If the doctor thinks it is necessary, you will receive a test for COVID-19. There are 2 main types of tests that you might receive:



Viral swab test

This test is used to find if you have an active infection (are positive for COVID-19). A health care worker will swab your nasal passage and then the lab will look for the coronavirus.

Tip:

If you don't get your results right away, don't worry. It may take up to a week to get your results, depending on the type of test. Doctors and researchers are working hard to develop tests with quicker results.



Antibody blood test

This is a blood test to see if you have already had COVID-19. It looks for your body's immune response to COVID-19, not for the virus itself. When a person's body recognizes an invader, it begins to produce antibodies, much like soldiers defending the body against a specific threat. If antibodies against COVID-19 are present in your blood, it tells the doctor that you've been exposed to COVID-19, but your body already fought it off. This type of test can identify people who have already developed immunity to COVID-19, without necessarily even having had symptoms.

How do I know if I should go to the hospital?

If you test positive for COVID-19 but are having only mild symptoms, you should continue to rest and recover at home as you self-isolate.

If your symptoms worsen, you may need to seek treatment. Seek immediate medical attention by going to the Emergency Room or calling 9-1-1 if you have any of these **warning signs**:



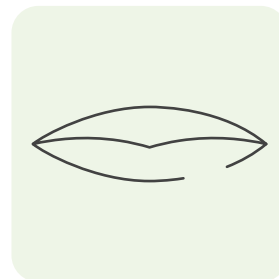
Trouble breathing



Pain or pressure in your chest that won't go away



Confusion or inability to wake up



Blue tint to your lips or face

If your symptoms are severe, or your fever is becoming dangerously high (104° F or above for an adult), you should go to the hospital. The hospital will be able to provide the best supportive treatments.



What will happen if I have to go to the emergency room?

Most hospitals are not allowing visitors at this time, so if someone brought you to the hospital, they may not be able to go inside the building with you. When you get there, patients with possible COVID-19 symptoms will be separated from those without symptoms.



Here are some things that you may experience at the hospital:



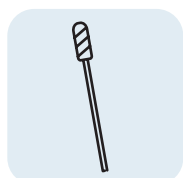
Entering the hospital, you may be screened for symptoms and have your temperature taken.



The Emergency Room may be crowded.



Doctors and nurses may be wearing more protective gear – like masks, gowns, and face shields – than you are used to seeing.



You may have a swab test for an active COVID-19 infection or a blood test for COVID-19 antibodies. If your blood shows antibodies, it means your immune system has already fought COVID-19.



Depending on your test results and symptoms, the doctors will decide if you need to be admitted to the hospital or can go home to self-isolate.

What would happen if I needed to be hospitalized?

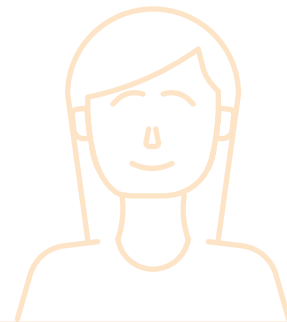
If you need to be hospitalized for COVID-19, the doctors will make sure that you get excellent supportive treatment to manage your symptoms. This might include giving you fluids or breathing treatments to make breathing easier. If necessary, you will be placed on a ventilator, a machine that helps you breathe.



A ventilator helps a patient's lungs receive oxygen with a tube inserted through the nose or mouth. The ventilator can do some or all of the work of breathing for the patient, and can also be used to deliver high concentration oxygen. Patients can be either conscious or unconscious while on a ventilator. The ventilator is removed once the patient is able to breathe on their own again.

Most likely, you will not be able to have visitors to prevent spreading the virus.

How to stay calm and supported



Can kidney and transplant patients recover from having COVID-19?

We know the idea of getting COVID-19 is very scary, but most people do recover, including many kidney and transplant patients. There are already kidney and transplant patients who have tested positive for COVID-19 and have recovered. There are patients who needed to be hospitalized and have recovered.

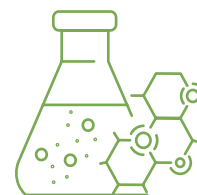
Tip:

Try to remember that prevention is the key and that recovery is possible.

How can I stay hopeful during this difficult time?

While it may seem like this quarantine is never-ending, remind yourself that this is temporary. This period of life will pass and we will slowly return to the more normal and busy routines of daily life soon.

You may not always know it, but a lot is happening to help kidney and transplant patients. Scientists are working to develop a larger number of COVID-19 tests to get results to people faster. Research studies are taking place to develop a vaccine and find out what medicines work the best for treating COVID-19.



Healthcare providers everywhere are standing by to help people who become sick. Telehealth is being set up to make it easier for people to communicate with their doctors from home. To help each other, people are staying home and wearing masks when they go to public places.

The transplant system is very important and will return to full operation as soon as it is safe to do so. In all the ways we can, everyone is working hard to keep patients safe and healthy. Hold on to the hope that while it is hard now, this will eventually end.

How can caregivers, family members, and friends help me feel supported?

Caregivers, family members, and friends are essential to your wellbeing during this time. Reaching out for help or support can make a positive difference in how you feel. It may seem difficult to ask, but many people are looking for ways to help you stay safe. Friends, family, or neighbors can help you by picking up essentials like groceries or prescriptions and delivering them to your porch.



They can also meet your need for emotional connection through regular texting, phone calls, video conferencing, and social media posts. If possible, set up weekly conversations with certain people so you can look forward to their regular visits. Use these times to discuss what's on your mind or talk about topics that help you feel good.

What can I do if I'm feeling really anxious, stressed, or sad?

Know that you are not alone in feeling this way. It's okay to feel anxious, stressed, overwhelmed, sad, angry, or scared. Many other people are also dealing with these feelings right now.



Use these tips to help yourself cope:

Follow daily routines

Try to do as much as you did before the pandemic hit. For example, go to bed and wake up at your normal times, make breakfast, get dressed, and talk to your friends or co-workers (by phone or video conference). Writing a schedule and sticking to it can help.

Practice self-acceptance

It's easy for us to forget how situations affect our well-being even if, on the surface, we feel like we're coping well. We are all living in a new and challenging time. Tasks like meeting deadlines, helping kids with homework, and putting meals on the table are all harder to manage. Be kind to yourself. Try to adjust your self-expectations and have small, measurable, and achievable goals. There is no roadmap for how to approach this period of time, and we are all doing our best.

Limit news

It may help you feel better to limit the time you spend on COVID-19 news through TV, radio, and social media. Keep in mind that news is often sensationalized, negatively skewed, and alarmist. Find a few trusted sources you can check a few times a day, for a set number of minutes. Also, keep news and alarming conversations out of the earshot of children. They can become very frightened by what they hear.

Work on something you can control

There are a lot of big uncertainties in the world right now. Take back control by working on something small that you have power over, such as cleaning out your closet, organizing the pantry, or sorting through the old mail on your desk. Work on that home project you've been meaning to do. Now is the time to take charge of your life in a way that will keep you and your household safe. If possible, include children and others to build and strengthen your connections to them.

What else can I do to help relieve my stress?

Take some time to connect with yourself and find out what helps you the most. Everyone copes with stress differently.

Here are some stress-relieving ideas:



Set aside time to practice deep breathing, as shown at right.



Meditate or sit quietly outside. As you breathe, focus on a personally meaningful mantra (word you repeat in your mind) like, "This, too, shall pass", "I can do it" or "Peace".



Go for a walk or exercise or dance at home.



Write in a journal, color, or knit – anything creative that relaxes you.



Watch television, stream free online concerts, talks, or arts events, or play a board game.



Call or video chat with a friend or family member.



Try making a new recipe.

Tip:

Here's how to do deep breathing:

3

Hold for 3 counts. Then repeat the 3 steps.

1

Breathe in through your nose for 4 counts.

2

Breathe out through your mouth for 4 counts.

Tip:

Check out the "Resources for mental wellness and stress management."

Page 26 →

How can I stay active during this time?

Staying active is a great way to lower stress and maintain your health. Try to get 30 minutes of physical activity each day. If you're not comfortable walking outside, there are many ways to be active at home. You can find many workout video tutorials on YouTube, such as for yoga or HIIT, that don't require special equipment. Or just put on your favorite music and dance like no one is watching!

Who can I talk to if I am feeling overwhelmed?

You can reach out to those who love you – your caregiver, family members, and close friends. Having a dedicated space and time to talk to important people in your life can help reduce your stress or anxiety and keep you connected to your loved ones.

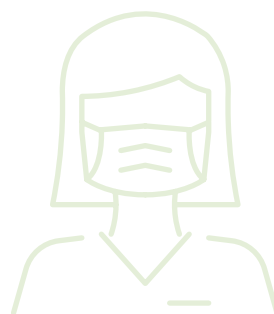
There are also many resources that you can use to talk to professionals when you are feeling overwhelmed or your community is not available to support at that time.

Tip:

Check out the “Help lines” in the Resources for mental wellness and stress management.

Page 27 →

How your kidney care might change during COVID-19



Dialysis care changes during COVID-19

How could my dialysis care change?

As a dialysis patient, how and where you access care may change in response to COVID-19.

Dialysis facilities are implementing new policies to help keep patients safe. For example:

- Centers are doing temperature screenings as patients enter the facility.
- Patients are asked if they are experiencing any symptoms including cough, shortness of breath, or sore throat before they enter.
- Centers are also limiting visitors. Where possible, centers are spreading dialysis chairs further apart.
- Patients with a fever or possible COVID-19 symptoms may be isolated in a different treatment area or even be taken to a different dialysis center designated to take care of COVID-19 patients safely.

What can I do to stay safe at dialysis?

When going to a dialysis center or any medical setting, you should take all of the recommended precautions for staying safe when going out in public and after returning home (see **How can I protect myself if I need to go out in public?** and **What should I do when I get back home to stay safe?**).

Ask your dialysis center what measures they are taking to keep you safe. Contact the providers you trust, including social workers, to ask questions about anything that is unclear to you.



What happens if I have, or may have, COVID-19 and need dialysis?

Call the dialysis center if you develop symptoms or test positive for COVID-19. The center will schedule your dialysis if and when the isolation room is available at your dialysis unit. If your center doesn't have an isolation room, your dialysis social worker will need to make arrangements for you to go to another dialysis center in your area where they are giving treatment to COVID-19 patients. After 14 days, you will be able to return to your original clinic.

Tip:

It's a good idea to also call your nephrologist or primary care doctor to talk about steps to manage your symptoms.

Transplant care changes during COVID-19

Should I still go to the transplant center for routine medical tests?

Patients who recently received a transplant may need to be seen in person at the transplant center. You can call the transplant center to see if they have a “safe pass through” entrance in place that enables patients who don’t have COVID-19 symptoms to enter the center with minimal risk.

Other patients may be asked to use telehealth to begin evaluation or meet with their doctor. Others may delay their visits.

Tip:

Please contact your transplant coordinator for further instructions.

Can I get a doctor’s note for my employer so I can work from home?

Immunosuppressed patients are recommended to work from home, or to take leave. Transplant centers can write letters to employers for patients and family members living with them, especially if the patient must use public transportation. See a **sample letter to an employer** on page xx to help your provider know what to write.

If you must go to work:



Wear an N95 mask, if you have one. If you don’t, wear a surgical or fabric mask.



Stay at least 6 feet away from everyone else. If there is an isolated office with a door that you can use, that’s safer than sitting in a room full of cubicles.



Hold all meetings as virtual meetings or calls.



Wash your hands often with soap and water.



Avoid using public transportation to get there.

How can I get help paying for my immunosuppressant medications right now?

Contact your transplant coordinator if you are concerned about not having funds to cover your medicines. Also, see our **list of Resources for financial concerns**, which may be helpful.



If a deceased donor kidney becomes available, can I still get a transplant?

As you probably know, a deceased donor kidney transplant is a surgery where doctors put a kidney from someone who has died into someone whose kidneys no longer work.

Your position on the transplant waiting list is still the same during this time. However, since transplant centers are focusing on reducing the risk of patients being exposed to COVID-19, they are only doing selected transplants during this time.

Some centers may be holding off on transplants that can be delayed without harming the health of the patient. Transplant centers also may be closing and reopening because the hospital needs more beds available for ill COVID-19 patients. Since transplant is an essential healthcare service, any closure will not be permanent.

Tip:

Call your transplant center to ask what their policy is.

How can I know that the deceased donor didn't have COVID-19?

Doctors screen all organ donors for COVID-19. Only people who are confirmed not to have COVID-19 can donate organs.



Can I still get a living donor kidney transplant now?

A living donor kidney transplant is a surgery where doctors put a kidney from a living person into someone whose kidneys no longer work.

Since people who enter a hospital are at higher risk of being exposed to COVID-19, living donation has stopped at some centers and slowed at others. Some centers are still doing living donor transplants on a case-by-case basis. Living donor kidney transplants for patients who are about to start dialysis may still be happening. COVID-19 testing will be done to make sure the living donor does not have COVID-19 before any transplant takes place. Call your transplant coordinator to ask what is happening at your center.

Are paired kidney donations (swaps or chains) still happening?

Paired kidney donation is a form of living donor kidney transplant where a donor donates their kidney to another recipient in exchange for a compatible kidney for their intended recipient.

Paired kidney donation can require coordination across multiple transplant centers and flying kidneys to different locations. This is the most complex type of transplant to coordinate. New services like home blood draws and antibody testing are being developed to allow potential living

donors to be evaluated without having to come into the hospital. Paired donor kidney donation can take place when living donor transplants happen across many centers.

Tip:

Call your transplant coordinator to ask what is happening at your center.

Deciding about transplant & living donation during COVID-19

Would it be better to stay on dialysis than to get a transplant during COVID-19?

There is no way to know when the COVID-19 crisis will be over. Despite our best efforts, anyone can become exposed to COVID-19 when they go out in public or medical settings. Each patient must weigh the risks of going into a hospital for transplant surgery against the benefits of having a functioning transplant.

Tip:

You must decide what is best after talking about these risks and benefits with your doctor, family and friends. There is no one right answer.

Some patients will decide that it is best not to get a transplant right now to avoid being near patients who have been hospitalized with COVID-19. They want to reduce the risk of getting the virus, especially when they would be recovering from surgery and taking medicines that would suppress their immune system.

Other patients will want to move forward with transplant so they do not have to begin dialysis or because a deceased donor kidney that matches them has become available. These patients believe that the benefits of transplant to their overall health outweigh the risks of getting COVID-19. They also believe that if they got COVID-19, they could recover.

If I turn down a deceased donor organ offered to me, will I get another?

You still remain active on the waiting list for future organ offers. You will not be penalized and will remain active on the waiting list for future organ offers. However, if you choose to decline a donated organ, it may take some time before another becomes available. Sometimes another kidney that matches you may never become available. If you are a kidney patient, this would mean remaining on dialysis.



What does it mean to be temporarily inactive?

A temporary inactivation means that the transplant program has determined that a candidate is temporarily unavailable or unsuitable for transplantation and should not receive organ offers. The transplant program may reactivate the candidate at any time.

Should I delay my living donor transplant?

Some centers are postponing living donor surgeries until it is safer. If you or your living donor are uncomfortable about the risk, you should delay your transplant surgery until the chance of getting COVID-19 is lower. Both you and your living donor should share your concerns with your coordinators so you can make a plan about when the living donor transplant can be rescheduled.

How will my recovery from transplant surgery change due to COVID-19?

If you do receive a transplant at this time, there will be extra things to watch for. Doctors will monitor your general health and kidney function after surgery, and will also pay special attention to keeping you free of COVID-19. You will need to isolate at home and be in contact with your doctor if you have any symptoms. Having a caregiver who can help you is particularly important at this time.

It will be important for you to take safety precautions:

Before your surgery:

- Ensure you have enough medicines and home supplies, such as food, paper goods, and cleaning supplies, for at least 2 weeks.
- Gather the items you'll need to take with you.

Tip:

Check to see if your insurance allows you to get a 90-day supply of medicines rather than a 30-day supply or if you can have your medicines delivered instead of picking them up.

After your surgery:

- Stay at home except for doctor appointments. To help you stay home, many programs are offering follow-up visits by telehealth. Have your home caregiver get any medicines or supplies you need.
- Use grocery store delivery or curbside pickup services.
- Wash your hands often with soap and water for at least 20 seconds.

Tip:

If your insurance supplies 30 days of medicine at a time, do not wait until the day before to refill, but refill a week in advance each time.

For a helpful checklist you can download and print, see **Being ready for a health visit during COVID-19**.

Are living donors screened for COVID-19?

Living donors who have been exposed to someone who may have COVID-19 are generally being asked to postpone donation for 14-28 days. Also, living donors are being asked not to travel to high-risk areas for at least 14 days before donation, and will be tested for COVID-19 several times before donating a kidney to make sure they do not have the virus. Donors are screened 48 hours before donation, and only people who test negative for COVID-19 can donate kidneys.



Helpful resources



Trusted COVID-19 resources for patients and caregivers

Your own healthcare team

Talk to your own healthcare team first when making decisions about your health. Don't forget to use telehealth when possible.

COVID-19 Kidney/Transplant Patient Listening and Resource Center

The Kidney/Transplant Patient Listening and Resource Center will answer your questions, help direct you to additional resources, listen to your experience, and help improve what is available for you and other patients during this time.

Call 1-800-830-0484

Explore Transplant COVID-19 Patient Information Page

Comprehensive resource for dialysis and transplant patients to learn about what to do in the time of COVID-19. The PDF you are reading now is from THIS WEBSITE. Regular updates are available here.

Visit <https://exploretransplant.org/preparing-for-covid-19-patients/>

National Kidney Foundation (NKF) Coronavirus Web Page

List of Frequently Asked Questions about COVID-19 that are updated regularly.

Visit <https://www.kidney.org/covid-19>

CDC (Centers for Disease Control)

Up-to-date information on all COVID-19 health topics in both English and Spanish. Also has a symptom checker tool.

Visit <https://www.cdc.gov/coronavirus/2019-ncov/index.html>

American Society of Transplantation (AST) COVID-19 Resource Page

COVID-19 resources for transplant patients.

Visit <https://www.myast.org/covid-19-information>

American Society of Nephrology (ASN)

Information on protection during COVID-19.

Visit <https://www.asn-online.org>

Tip:

Check out AST's Transplant Community FAQ in English and Spanish at:
www.myast.org/covid-19-information

FAQ →

United Network for Organ Sharing (UNOS) COVID-19 Web Page
News and resources about COVID-19

Visit <https://unos.org/covid/>

To find out if your dialysis center is open:

Call your dialysis organization's toll-free emergency number:

DaVita

800-400-8331

DCI Donor Hotline/Transient Patients

800-969-4438

RAI

800-403-2530

Fresenius

800-626-1297

DSI

877-364-3375

US Renal Care

866-671-8772

DCI

866-424-1900

ARA

888-880-6867

Satellite Healthcare

650-830-7954

Resources for mental wellness and stress management

Guides and articles

CDC (Centers for Disease Control) Guidelines for managing stress and anxiety during COVID-19 information and tips to help people identify and address their emotions. Includes information for high-risk communities, people coming out of quarantine, and responders.

Visit <https://bit.ly/3bDTEQk>

Tip:

If you are viewing this as a printed guide, search the organization and article name in Google. For example, you could search: "CDC guidelines for managing stress and anxiety during COVID-19"

National Alliance on Mental Illness' (NAMI) guide with resources ranging from how to manage stress or anxiety because of COVID-19, to accessing health care or assistance programs for financial support.

Visit <https://www.nami.org/covid-19-guide>

The National Network of Depression Centers complete resource page with resources for what to do if you are having a personal crisis need general mental health resources, or need resources for specific conditions such as depression, bipolar disorder, PTSD, and substance abuse.

Visit <https://nndc.org/resource-links/>

Help lines

Disaster Distress Helpline call 1-800-985-5990 text TalkWithUs to 66746

Crisis Text Line text 741741 to communicate with a trained, supervised crisis counselor

National Suicide Prevention Lifeline call 1-800-273-8255 or
visit <https://suicidepreventionlifeline.org/chat/> to chat with a counselor

Apps

Talkspace connects users to licensed therapists who can help with anxiety and depression management. Communication can include text, video or audio messaging, and live sessions.

Visit <https://bit.ly/39P9czi>

Headspace offers guided meditation, breathing exercises, sleep exercises, mindfulness workouts, and many more ways to help manage stress and anxiety.

Visit <http://www.headspace.com/headspace-meditation-app>

Happify offers activities and games that are evidence-based and can help you overcome negative thoughts and build resilience.

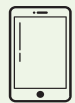
Visit <http://www.happify.com/>

In Hand is a simple way to check in with yourself about how you are feeling and receive suggested activities or inspirational quotes that match your level of stress and mood. Activities include taking photos, viewing photos and videos from your own library, listening to music, journaling, or talking to a trained volunteer.

Visit <http://www.inhand.org.uk/>

Tip:

Click the links or search the app names in the iOS App store or Google Play.



Resources for financial concerns

Help paying for medicine

Financial assistance for medicines is available through pharmaceutical companies and charitable foundations including:

Roche Patient Assistance Program (Cellcept) Call 800-772-5790

Novartis Patient Assistance Program (Cyclosporine) Call 888-455-6655

Tip:

Check charitable assistance options that you may qualify for, such as the American Kidney Fund COVID-19 emergency fund.

AKF fund



Novartis Transplant Reimbursement Program (Neoral) Call 877-952-1000

Astellas Patient Assistance Program (Prograf) Call 800-477-6472

Abbott Patient Assistance Program (Gengraf) Call 800-633-9110

Tip:

Visit www.kidney.org/patients/resources_prescription for additional resources

Kidney.org →

Additional help

Ticket to Work Program

Ticket to Work (TTW) is a voluntary work incentive program for Social Security Administration's Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) beneficiaries ages 18-64 who want help getting employment and working to become self-sufficient.

Call 866-968-7942 (TDD: 866-833-2957) Visit www.choosework.net

Meals on Wheels

This organization is composed of and representing local, community-based Senior Nutrition Programs. These programs provide well over one million meals to seniors and, in some cases, those with disabilities. Programs vary with respect to eligibility, delivery method, delivery times, and special meal options. Call the toll free number or search online to find a program near you.

Call toll free 888-998-6325 Visit www.mealsonwheelsamerica.org/

Area Agency on Aging (AAA)

Provides resources for a variety of services for seniors such as senior lunch and home-delivered meals, nutrition programs, care management, and home-based care.

Call 800-677-1116 Visit <https://eldercare.acl.gov/Public/Index.aspx>

Women, Infants, and Children (WIC) Program

This program serves pregnant, breastfeeding, and postpartum women, infants, and children up to 5 years old in low-income families.

Call toll free 888-942-2229 Visit <https://www.fns.usda.gov/wic/wic-fact-sheet>

Homeownership Preservation Foundation

This program is for any homeowner in America having trouble paying their mortgage. Available 24 hours a day, 7 days a week. Absolutely free foreclosure prevention counseling by expert counselors at Housing and Urban Development-approved agencies. Usually, services can begin right away—the counselors themselves answer the phone. Homeowners can get budget help, a written financial plan, and assistance contacting their lender. If they'd like face-to-face counseling or need local resources, homeowners are referred to their local NeighborWorks® organization.

Call 888-995-HOPE (4673) Visit www.995hope.org

United Way-Funded Helpline, 2-1-1

2-1-1 is an easy to remember, three-digit dialing code that connects people in need with essential health and human services 24 hours a day, 7 days a week. Calls to the helpline are answered by Community Resource Advisors who search a database of listings and provide practical information about how to get food, money and other help from government programs and community agencies in the caller's area.

Call **2-1-1** Visit **www.211la.org**

Lifeline

Lifeline is a government assistance program that helps income-eligible customers save money on their phone bills and stay connected to vital emergency and community services, friends, and family. Under the Lifeline program, wireline customers receive a discount, which varies depending on their local telephone service provider.

Visit **www.lifeline.gov**

Los Angeles Local Transit Services Directory (RIDEINFO)

A facilitated referral service for people in Los Angeles that matches a person's transportation needs with available accessible transportation like Dial-A-Ride, Lift Van/Shuttle, and Taxi services. The agencies referenced include those which provide transportation to persons in certain communities, medical patients, or agency clients only; some fares are minimal, others may be costly.

Call **800-431-7882 (TDD: 800-431-9731)** Visit **www.accessla.org**

Veterans Care Coordination

Coordinates affordable home care for veterans and their surviving spouses.

Call toll free **855-380-4400**

Resources for children, teens, and families

Use these if you are sheltering in place with children and teens.

Nation Public Radio (NPR) comic for parents to talk to their kids about the coronavirus

Visit **<https://n.pr/2VqiGgf>**

Psychology Today's comic on how to talk to kids and teens about the coronavirus, includes comics, podcasts and other helpful links

Visit **<https://bit.ly/2VoWlQj>**

Government of India partnered with physicians to create a comic for COVID-19 awareness

Visit **LINK NOT FOUND**

KidsHealth provides information on helping kids understand health topics. Covers COVID-19 topics for parents on how to talk to your child, what to do if your child is sick, and social distancing with children

Visit <https://bit.ly/2yvaOBa>

Covibook is a short book about COVID-19 to support and reassure children under the age of 7; available in multiple languages

Visit <https://www.mindheart.co/descargables>

WHO (World Health Organization) one-pager on helping children cope with stress during COVID-19 outbreak

Visit <https://bit.ly/2KmfYlF>

The National Child Traumatic Stress Network's handouts parents/caregivers helping their families cope with coronavirus; available in multiple languages

Visit <https://bit.ly/2Scjq6X>

Being ready for a health visit during COVID-19:

A Kidney & Transplant Patient Checklist

You may need to go to a hospital or treatment center during COVID-19. This kidney and transplant patient guide has been developed by leading healthcare professionals, after reviewing national guidelines, to help you create a safety plan.



Prepare for your appointment or stay

- ☐ Call the hospital ahead of time to let them know you are on your way and that you have a health issue that puts you at greater risk of having problems from COVID-19.
- ☐ If you're going for a reason that is unrelated to COVID-19, ask if there is a separate entrance for non-COVID patients.
- ☐ Know how you will get to the hospital or center, such as with a family member or a transportation company. Know that the person driving you will probably not be able to go inside with you.





Tip:

Don't be afraid to ask the hospital or center what safety measures they are taking to protect patients.

How will you get there?

Gather the items you need to take with you

Safety items:

- ☐ Face mask – an N95 mask if you have one, or a fabric or surgical mask 
- ☐ Disposable gloves 
- ☐ Hand sanitizer 
- ☐ Your own pen (and touch-screen stylus, if you have one) to use at registration 

Medical items:

- ☐ Health insurance card/s
- ☐ List of any medicines and supplements you take (and/or bring them with you)

- ☐ List of any allergies you have

- ☐ Names and phone numbers of your health care team

Tip:

When you list your health care team, include your doctor/s, dialysis center, transplant center and coordinator.

Personal items:





- ☐ Photo ID card
- ☐ Credit card or debit card
- ☐ Mobile phone and phone charger

Tip:

If you are staying overnight, also take:

- Spare set of clothes, shoes, pajamas, slippers
- Toiletry items such as toothbrush, toothpaste, deodorant, hairbrush, lip balm

Once you arrive at the hospital or center, follow these main tips for safety:

- ☐ Wear a face mask and disposable gloves. 
- ☐ Stay 6 feet or more away from other people – except for health care workers who need to test you or give you treatment. 
- ☐ Avoid touching your eyes, mouth, and nose 
- ☐ Wash your hands often with soap and water for at least 20 seconds 

Patients, show this sample letter to your doctor if you need them to explain to your employer why you should stay away from your workplace. The doctor should place it on their letterhead and tailor the bracketed information to fit your situation.

Sample doctor's letter to patient's employer

[Date]

To Whom It May Concern

Re: [Patient name]

Dear Sir or Madam,

I am writing to you today concerning my patient, [Mr. John Doe], who is an immunocompromised kidney transplant recipient. I am a [Specialty, e.g. Nephrologist] at [Hospital or Practice Name]. [Mr. Doe] asked that I communicate with you about [his/her] unique health risks during this coronavirus (COVID-19) pandemic and what you can do to help.

With the rapidly increasing number of cases of COVID-19, we are very worried about the risk to transplant recipients, who are highly vulnerable to infections because of the powerful immunosuppressive medications that they must take for life to prevent rejection of their transplant. Such patients are more likely to experience severe illness if they acquire COVID-19.

We are encouraging our patients to explore ways to reduce their risk, including tele-working and/or temporary leave. This will help avoid potential exposures in the workplace.

We are strongly recommending that [Mr. Doe] avoid going in to work for at least [time period]. We appreciate anything you can do to support [Mr. Doe] in this regard. Thank you for considering this request; our entire Transplant Team appreciates it!

Sincerely yours,

[Doctor's printed name, credentials, title, etc.]

Tip:

If you are a spouse of a transplant patient, show this sample letter to your spouse's doctor. They can explain to your employer why you should stay away from your workplace. The doctor should place it on their letterhead and tailor the bracketed information to fit your situation.

Sample doctor's letter to spouse's employer

[Date]

To Whom It May Concern

Re: [Spouse First and Last Name]

Dear Sir or Madam,

I am writing concerning your employee, [Spouse Name], who is the spouse of my patient, [Patient Name], who is a highly immunocompromised transplant recipient. I am a [Specialty, e.g. Nephrologist] at [Hospital or Practice Name]. Mr. and Ms. [Name] asked that I write you about [his/her] unique health risks during this COVID-19 pandemic and what you can do to help.

During this time, we are very worried about the risk to transplant recipients, who are highly vulnerable to infections because of the powerful immunosuppressive medications they must take to prevent rejection of their transplant. Such patients are more likely to experience severe illness if they acquire COVID-19.

We are encouraging our patients to try and reduce their risk, including by tele-working and/or temporary work leave. This will help avoid potential exposures in the workplace.

Although [Patient Name] is able to telework, [Spouse Name], is a possible transmission risk due to [his/her] possible workplace exposure. If [he/she] acquires COVID-19, perhaps with mild or no symptoms, the infection may transfer to [his/her] spouse, which could be devastating for them.

We would greatly appreciate if you could increase telework time or other accommodations to help [Spouse Name] maintain greater social isolation until [time period]. Thank you for considering this request; our entire Transplant Team appreciates it!

Sincerely yours,

[Doctor's printed name, credentials, title, etc.]