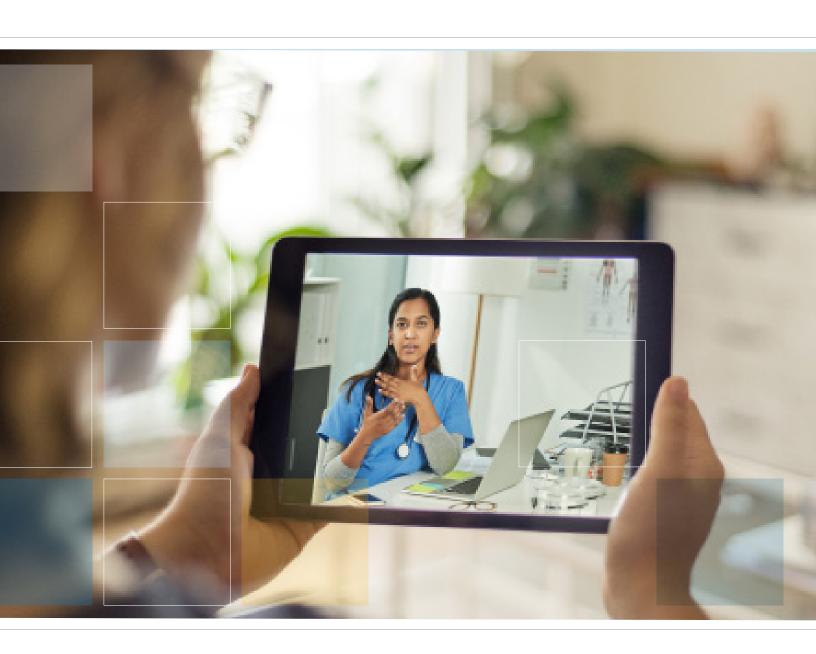


# Doing everything you can during COVID-19

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.

This material was last updated on June 2, 2020. For regular updates go to exploretransplant.org.

## For kidney & transplant patients, the most important things you can 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 waiting for transplant or donation must also understand any needed 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. Consult your doctor when making any decisions about your care.

#### Content contributors

This patient guide includes relevant content from these sites:

- Centers for Disease Control and Prevention (CDC)
- Centers for Medicare and Medicaid Services (CMS)

- World Health Organization (WHO)
- American Society of Transplantation (AST)
- American Society of Nephrology (ASN)
- 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 (HLM).

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



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# How to prevent getting and spreading COVID-19

## How does someone get COVID-19?

The virus that causes COVID-19 is called SARS-CoV-2.

People get infected with COVID-19 when they are in close, direct contact with someone who carries the virus. The virus is mainly spread through respiratory droplets and contact with infected surfaces.



- Droplets are released when an infected person coughs, sneezes, or even talks. The droplets contain the virus and can fall to surfaces and live for hours to days.
  - The droplets can be inhaled by others if they are too close.
  - Touching surfaces that have the virus on them and then touching your face can also spread COVID-19.
- The virus needs to get inside your body to survive. It can enter through your mouth, nose, or eyes. It cannot enter through your skin.
- People are thought to be most contagious when they have symptoms (and 2 days before symptoms start).
- Some people may spread the virus even if they do not show any symptoms. Or they could be only mildly sick.

The safest thing is to stay home if you can. Limit your contact with people. If you must go out, 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. Common examples are:

- Handles, such as door handles and toilet handles
- Tabletops
- Phones
- Pens
- Silverware and dishes

The virus can live for several hours or up to several days, depending on the type of surface.

The most important way to keep yourself safe is to wash your hands often and disinfect surfaces of your house with disinfecting wipes.





## What can I do to prevent getting COVID-19?

To prevent getting COVID-19, do these 6 things:



Wash your hands often with soap and water. Scrub for at least 20 seconds. If handwashing is not possible, use hand sanitizer and rub it on your hands for 20 seconds until they are dry.



Avoid touching your face, especially your mouth, nose, and eyes. Wash your hands with soap and water before touching your face.



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



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



Kidney & transplant patients: You are at higher risk of problems if you are infected. Wear a mask when out in public, and maintain at least 6 feet of distance between yourself and others, even if you are both wearing masks. Wearing a surgical or cloth mask does not protect you – rather, it protects others from your breath in case you are infected. Social distancing is what will help to protect you.

- An N95 respirator is recommended for essential healthcare workers only.
- It's safer if everyone wears a surgical mask or cloth face covering, because it helps lower the spread of infection.



Use disinfecting wipes to regularly disinfect the frequently-touched surfaces in your home. Pay attention to the things you touch.



## How do I wash my hands correctly?

See a video on washing your hands correctly. Washing your hands is important protection.

- Always wash for at least 20 seconds (about as long as it takes to sing Happy Birthday twice).
- Apply enough soap to cover your hand. The kind of soap does not matter.

### Here's how to wash your hands:



Run water on your hands.



Put soap on your hands.



Rub the inside of your hands together.



Put one hand over the back of the other and rub them. Then switch.



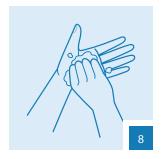
Put your palms together, interlace your fingers, and rub.



Interlock your palms and fingers and rub.



Rub each thumb and under your nails.



Rub your fingers back and forth on the opposite palm. Then switch.



Rinse your hands with water.



Dry your hand off with a paper towel.



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

Use hand sanitizer with at least 60% alcohol.

Use these same steps when using hand sanitizer. Rub for at least 20 seconds, until it's dry on your hands.

Use it often if you leave your home. When you get home, wash your hands with soap and water.



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

Only go out for essential trips. These include to get groceries or for medical needs, dialysis, or necessary medical tests. Do not go out in public if you have any symptoms, such as a cough or fever, unless it is for medical help.

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



Wear a face covering, such as a mask or other cloth covering. Avoid touching the outside of the mask to prevent infection.



Carry hand sanitizer in case you are not able to wash your hands while out in public. Always wash your hands with soap and water for at least 20 seconds once you are able to.



Stay 6 feet or more away from others – 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 60% alcohol) as you enter and leave public places. Do not make your own hand sanitizer.



If possible, don't use public transportation. If you must ride the bus or subway, wear a mask and stay 6 feet away from others. You may want to consider wearing a face shield. Do not touch your face, and wash your hands with soap afterwards.

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

When you get back home:



Remove your mask by touching only the loops or ties that keep it in place, not the front.



Wash your hands with soap and water for at least 20 seconds (this is best). Or use an alcoholbased hand sanitizer with at least 60% alcohol.



Use disinfecting wipes or spray to disinfect any surfaces you touched after you were in a public place, such as the steering wheel, keys, credit card, cell phone, and doorknobs.



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 again 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, stay at least 6 feet apart as much as possible and clean and disinfect the surfaces of your home regularly.
- Ask the sick person to sneeze or cough into a tissue or sleeve. And wash their hands!
- The sick person should wear a mask or cloth face covering if they must pass through shared rooms.
- Only the sick person should disinfect their own room, or a shared bathroom after they use it.
- Everyone in your home should stay home as much as possible.

## 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, however:



- Pets that go outside could carry COVID-19 on their coats or paws back into the home.
- You may want to wipe off their paws and coat with a wet, soapy wash cloth before letting them come back inside. Do not use disinfectants on pets.
- Petting other people's animals or allowing others to pet your animal means they are too close, so avoid this. Wash your hands before and after caring for or feeding pets.
- Regularly disinfect 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 them, being licked, or sleeping in the same location.

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

Experts say there is a 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, they could contaminate the outside of the package. To be safe, open packages outside and throw away the outer packaging. Then wash your hands thoroughly with soap and water. That should be enough.



## 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.

Before you disinfect, clean the surface with soap and water. This is often a missed step. For more information, visit cdc.gov/coronavirus/2019-ncov/prevent-getting-sick/disinfecting-your-home.html

Disinfectants are not always good for cleaning as well as disinfecting. Check the label:

- Does it clean and disinfect at the same time?
- Check for the "dwell time", which can vary by product.



Approved wipes and sprays include:

- Various brands such as Lysol<sup>®</sup> Disinfecting Wipes, Lysol<sup>®</sup> Disinfectant Spray, Clorox<sup>®</sup> Multi Surface Cleaner + Bleach, Clorox® Disinfecting Wipes, and Soft Scrub® with Bleach.
- Alcohol solutions with at least 70% alcohol.

For some surfaces, you can also make diluted bleach solution to disinfect. Use a ratio of 4 teaspoons bleach per quart of water (that is the same as 1 teaspoon of bleach per cup of water). Tips for making bleach solution:

- Check the bleach container to make sure it is not past the expiration date.
- Make fresh solution every day because it becomes less effective as time passes.
- Clean the surface, then apply the bleach solution and let it air dry.

Do not use bleach solution on metal or other surfaces that could be discolored by bleach. Do not use full strength bleach to disinfect surfaces.

## 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. Ask for "no touch" service.



If you get takeout, put the food in new containers, throw the packaging in the trash, and wash your hands before sitting down to enjoy your food.



# How to maintain your health and treatment routine

## What should I do to stay healthy during COVID-19?

To stay healthy, follow your doctor's recommendations. Take your medicines as directed and follow your treatment plan.



To be safe and prepared, 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 yet for COVID-19. Researchers are working as fast as possible to create one. If a vaccine becomes available, your care team will tell you if it is safe and recommended for you as a dialysis or transplant patient. Stay tuned!

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

No. Always ask your doctor before taking any new supplements or natural remedies. These can interact or interfere with other medicines that you take. Some mixes can be dangerous. Be safe.

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

No, do not stop taking your medicines or reduce your dose. It is important to make sure you have enough of all medicines you need. Call your doctor and ask to get a 3-month supply of your medicines. If your insurance only allows a 30-day supply, refill at least one week before you need it.

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

## Should I decrease my immunosuppressant to lower my risk of COVID-19?

No. If you are a transplant patient taking immunosuppressant or anti-rejection drugs, you should not lower your dose or stop taking them. Reducing these medicines increases your risk of transplant rejection.





# How to monitor for COVID-19 symptoms

## What symptoms of COVID-19 should I watch for?

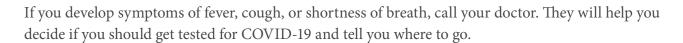
Many people who get COVID-19, about 1 in 4 (25%), do not have any symptoms or have only mild symptoms that can be managed at home.



COVID-19 symptoms are like flu symptoms and appear 2-14 days after exposure.

The most common symptoms may include:

- Fever greater than 100° F
- Feeling tired
- Runny nose
- Cough
- · Shortness of breath or difficulty breathing
- Chills, or repeated shaking with chills
- Muscle pain
- Headache
- Sore throat
- New loss of taste or smell
- Diarrhea



TIP: You can check your symptoms using the following resources:

- CDC Coronavirus Self-Checker: 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 we do not know about how this virus affects different people.

The American Society of Transplantation warns 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 likely to develop serious complications with a COVID-19 infection.





## 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.

- Avoid contact or sharing spaces with family members to avoid infecting them. You could infect others even if you are not having symptoms yourself.
- 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. The CDC recommends telehealth (video visits) over in-person visits to avoid spreading the infection. Could the symptoms of COVID-19 be different for certain patients?



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

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

Be prepared. You should learn what to do ahead of time so you know how to get medical care easily at home in case your health changes.

- Call and ask your provider if they offer a telehealth option.
- Call your insurance company to find out about their coverage for telehealth visits.
- 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.

If you have to schedule an in-person visit with your doctor, remind them that you have a health condition and ask if they have extended hours, either early or late, to limit contact with other people as much as possible.

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

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



#### Viral swab test

This test is used to find if you are currently infected (are positive for COVID-19). A health care worker will swab your nasal passage, send it to a lab, and then the lab will test for the coronavirus.

TIP: If you don't get your results right away, don't worry. It may make take up to two days for UCLA's lab to process your results, depending on the type of test.



#### Antibody blood test

This is a blood test to see if you had COVID-19 and have recovered. 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.



- The expected turnaround time at UCLA is 24 to 48 hours for this test.
- If antibodies for COVID-19 are found in your blood, it tells doctors you have been exposed to COVID-19 and your body already fought it off. You may not have even known you were sick.
- Antibody tests are not perfect yet. We do not know what having antibodies to COVID-19 really means as far as risk of getting sick again. Follow the important safety steps in this guide, regardless of your antibody test results. You could still get sick.

## 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. Keep in touch with your doctor.

If your symptoms worsen, you may need to get medical help. If you develop any of these emergency warning signs for COVID-19, get medical attention right away:

- Any trouble breathing
- Persistent pain or pressure in the chest
- New confusion or inability to wake up
- Bluish lips or face
- Throwing up (vomiting) so can't keep fluids down
- Dry mouth and less urine (dehydration)
- Other serious symptoms



- Tell the 911 operator that you may have COVID-19 and need medical help.
- If possible, put on a mask or cloth face covering before the ambulance arrives.







## 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:



At the hospital, you will be screened for COVID-19 symptoms and have your temperature taken.



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



You may have a swab test for 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 symptoms and test results, 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 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.

To prevent spreading the virus, it's likely you will not be able to have visitors.



# 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 lasting forever, remind yourself that this is temporary. This period of life will pass and we will slowly return to the more normal 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 is being done to develop a vaccine.
- Research is being done to find out what medicines work best to treat COVID-19.
- Healthcare providers everywhere are ready to help people who become sick.
- Telehealth is being set up to make it easier for people to talk with their doctors from home.
- To slow the spread of COVID-19, people are staying home and wearing masks in public places.

The transplant system is vital 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. Reach out and ask for help or support. It can make a positive difference in how you feel. It may seem hard to ask for help, but people want 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.

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

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

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. Each of us do different things to help us deal with it.



Here are helpful tips for what you can do when you have these feelings:

#### Follow daily routines

Try to do as much as you did before COVID-19. 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 chat). Write a daily schedule to help you stick to your routine.

#### Practice self-acceptance

We are all living in a new and challenging time. Things 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 what you expect from yourself and have small daily goals. There is no roadmap for this experience, and we are all doing our best.

#### Limit watching news reports

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 can focus on the negatives. Find a few trusted sources you can check a few times a day for a set number of minutes. Also, keep children away from the news and alarming conversations. They can become very frightened by what they hear and may not understand.

## Work on something you can control

Take back control by working on something small that you have power over. Now is the time to take charge of your life to keep you and your household safe. Clean out your closet, organize your pantry, or sort through old mail on your desk. Work on that home project you've been meaning to do! If possible, include children and others to build and strengthen your connections to them. Share joy.



## 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:



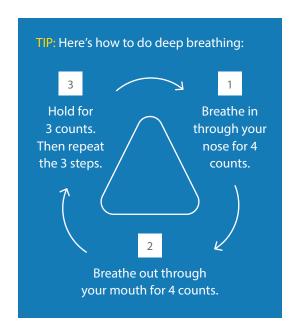
Set aside time to practice deep breathing, as shown at right.



Meditate or sit quietly outside. As you breathe, focus on a personally meaningful mantra - word(s) you repeat in your mind, like, "This, too, shall pass", "I can do this", 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, play a board game, or stream free online concerts, talks, or arts events.



Call or video chat with a friend or family member.





Try making a new recipe.

## 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?

Having a dedicated space and time to talk to important people in your life can help reduce your stress or anxiety. It keeps you connected to your loved ones.

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

> 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:

Screening patients for temperature and asking about COVID-19 symptoms before they enter.

- Limiting visitors.
- Placing dialysis chairs further apart, where possible.
- Isolating patients with possible COVID-19 symptoms in a separate treatment area or even sending them to a different dialysis center designated to care for COVID-19 patients safely.

## What can I do to stay safe at dialysis?

When going to a dialysis center or any medical setting, 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 they are doing 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 arrange for you to go to another dialysis center in your area where they can safely treat patients with COVID-19.

After 14 days, you should be able to return to your original clinic.

TIP: Call your nephrologist or primary care doctor to talk about steps to manage your symptoms.

## What if my transportation company refuses services because of COVID-19?

Call your social worker at your dialysis facility right away if your transportation refuses to transport you. Your social worker may be able to find and arrange safe transport. There may be state resources to help pay for it.



## 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.

UCLA is screening all patients for symptoms and travel history. When you arrive at the clinic a UCLA Health employee will greet you outside, take your temperature and ask you a few questions about any symptoms you're experiencing that may be related to COVID-19. Testing is available to patients that have been referred by their physician. For patients being tested or confirmed with novel coronavirus, we adhere to rigorous CDC and public health protocols designed to prevent transmission.

- Some patients may be asked to use telehealth to begin evaluation or meet with their doctor. Some patients may be able to safely delay their visits.
- Please contact your transplant coordinator for further instructions.

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

It is recommended that immunosuppressed patients work from home, or take a leave from work. 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 at the end of this guide to help you and your provider know what to write.

Do not go to work if you are sick in any way. If you must go to work:



Wear a face covering, such as a mask or other cloth covering. One that fits snuggly around your nose and chin is best.



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



Hold 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 medicines 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 at the end of this guide, which may be helpful.





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

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.

The transplant center continues to monitor the risk of patients being exposed to COVID-19. Your position on the transplant waiting list is still the same during this time. Transplants at UCLA are proceeding on a case by case basis, with the goal of returning to normal as quickly as possible. Transplants that can be delayed without harming the health of the patient may be pushed for a later date. Call your transplant coordinator to ask what is happening at your center.

TIP: Call your transplant center to find out more.

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





## 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 is proceeding on a case-by-case basis at UCLA. The transplant center is returning to normal living donor kidney transplant capacity as new safety measures are being implemented. 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.

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

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.



## 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 in 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 the risks and benefits with your doctor, family, and friends. There is no one right answer for everyone.

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 COVID-19, 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?

- Being temporarily inactive 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, 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 transplant can be rescheduled.



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

If you do get a transplant at this time, there will be extra things to watch for. Doctors will monitor your general health and kidney function closely after surgery. They will pay special attention to keep you free of COVID-19. It will be important to isolate at home and be in close contact with your doctor if you have any symptoms. Having someone to help you recover is especially 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 to the hospital.

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.
- Limit visitors and stay away from anyone who is sick.
- Use grocery store delivery or curbside pickup services.
- Wash your hands often with soap and water for at least
- 20 seconds.

TIP: Check to see if your insurance allows a 90-day supply of medicines rather than a 30-day supply. See if your medicines can be delivered instead of you picking them up.

TIP: If your insurance supplies 30 days of medicine at a time, call in refills a week in advance each time. Do not wait until the day before to call in a refill.

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. They will be tested for COVID-19 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 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 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 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 cdc.gov/coronavirus/2019-ncov/index.html

## American Society of Transplantation (AST)

#### **COVID-19 Resource Page**

COVID-19 resources for transplant patients.

Visit myast.org/covid-19-information

#### American Society of Nephrology (ASN)

Information on protection during COVID-19.

Visit asn-online.org

#### United Network for Organ Sharing (UNOS) COVID-19 Web Page

News and resources about COVID-19

Visit unos.org/covid/

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



## To find out if your dialysis center is open:

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

ARA DCI Donor Hotline/ RAI

**Transient Patients** 888-880-6867 800-403-2530

800-969-4438

DaVita Satellite Healthcare

DSI 800-400-8331 650-830-7954

877-364-3375 DCI **US Renal Care** 

866-424-1900 Fresenius 866-671-8772

800-626-1297

All dialysis centers including Independent Centers Visit dialysisunits.com

## 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.

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"

#### Visit bit.ly/3bDTEQk

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 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 nndc.org/resource-links/



#### Help lines

Disaster Distress Helpline call 1-800-985-5990 or 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 suicidepreventionlifeline.org/chat/ to chat with a counselor 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 bit.ly/39P9czi

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

Visit 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 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.

TIP: Clink the links or search the app names in the iOS App store or Google Play.

Visit inhand.org.uk/

#### Resources for financial concerns

#### Help paying for medicine

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

Roche Patient Assitance Program (Cellcept)

Call 800-772-5790

**Novartis Patient Assitance Program (Cyclosporine)** 

Call 888-455-6655

Novartis Transplant Reimbursement Program (Neoral)

Call 877-952-1000

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

AKF fund »



**Astellas Patient Assistance Progam (Prograf)** 

Call 800-477-6472

Abbott Patient Assistance Program (Gengraf)

Call 800-633-9110

TIP: Visit 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) or visit 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 or visit 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 or visit 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 or visit 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) or visit 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 or visit 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 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) or visit 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.

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

Visit 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 bit.ly/2VoWlQj

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

Visit mohfw.gov.in/pdf/Corona\_com



KidsHealth provides information to help kids, teens, and parents understand health topics. It 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 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 mindheart.co/descargables

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

Visit bit.ly/2KmfYlF

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

Visit 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.	TIP: Don't be afraid to ask the hospital or center what safety measures they are taking to protect patients.			
☐ 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.				
How will you get there?				

## Gather the items you need to take with you

#### Safety items:

☐ Cloth or surgica	al face mask	( O )
☐ Hand sanitizer	<b>T</b>	







Medical items:		
☐ Health insurance card/s		
$\hfill \square$ 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 t	eam  TIP: When you list your health care team, include your doctor/s, dialysis center, transplant center and coordinator.	
Personal items:		
□ Photo ID card	<ul> <li>TIP: If you are staying overnight, also take:</li> <li>Spare set of clothes, shoes, pajamas, slippers</li> <li>Toiletry items such as toothbrush, toothpaste,</li> </ul>	
☐ Credit card or debit card		
☐ Mobile phone and phone charger	deodorant, hairbrush, lip balm.	
Once you arrive at the hospital or center, fo	llow these main tips for safety:	
☐ Wear a face mask. ( )		
☐ Stay 6 feet or more away from other people – exc who need to test you or give you treatment.	rept for health care workers	
☐ Avoid touching your eyes, mouth, and nose		
☐ Wash your hands often with soap and water for a	at least 20 seconds	



# Sample doctor's letter to patient's employer

[Date] To Whom It May Concern Re: [Patient name]

TIP: 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.

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.]



# Sample doctor's letter to spouse's employer

[Date] To Whom It May Concern Re: [Spouse First and Last Name] 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.

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.]

