National Kidney Foundation's Kidney Disease Outcomes Quality Initiative

Did you know that the National Kidney Foundation's Kidney Disease Outcomes Quality Initiative (KDOQI®) offers guidelines and commentaries that help your healthcare team make important decisions about your medical treatment? The information in this booklet is based on those recommended guidelines.

Stages of kidney disease

There are 5 stages of kidney disease. They are shown in the table below. Your healthcare professional determines your stage of kidney disease, based on the presence of kidney damage and your glomerular filtration rate (GFR), which is a measure of your level of kidney function. Your treatment is based on your stage of kidney disease. Speak to your healthcare professional if you have any questions about your stage of kidney disease or your treatment.

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<th>Stage</th>
<th>Description</th>
<th>Glomerular Filtration Rate (GFR)*</th>
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<td>1</td>
<td>Kidney damage (e.g., protein in the urine) with normal GFR</td>
<td>90 or above</td>
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<tr>
<td>2</td>
<td>Kidney damage with mild decrease in GFR</td>
<td>60 to 89</td>
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<tr>
<td>3a</td>
<td>Moderate decrease in GFR</td>
<td>45 to 59</td>
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<tr>
<td>3b</td>
<td>Moderate decrease in GFR</td>
<td>30 to 44</td>
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<tr>
<td>4</td>
<td>Severe reduction in GFR</td>
<td>15 to 29</td>
</tr>
<tr>
<td>5</td>
<td>Kidney failure</td>
<td>Less than 15</td>
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*Your GFR number tells your healthcare professional how much kidney function you have. As chronic kidney disease progresses, your GFR number decreases.
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For many people who are on dialysis or have had a kidney transplant, the ability to travel is an important part of their lifestyle. Working patients may need to attend business meetings or conferences. Older patients may have dreamed of traveling during their retirement. A family event such as a wedding, graduation, or family reunion may require travel away from home. At times, emergencies such as illness or a death in the family may require travel.
Is it possible for me to travel?

Yes. Most people who receive dialysis or have had a kidney transplant can travel safely and continue their treatment while away from home. Of course, you should always consult your healthcare professional before planning to travel. Most healthcare professionals encourage travel if the patient’s health is stable. Traveling can give a big boost to a patient’s sense of well-being.

How should hemodialysis patients begin to plan a trip?

Many dialysis centers have a staff member who is experienced in arranging dialysis treatments away from home (transient dialysis). Some centers will assist patients in making their own arrangements. Ask your social worker or primary nurse if there is such a person at your center.

You should start planning at least six to eight weeks in advance. More time should be allowed for popular vacation spots or for travel during holidays. Be flexible about the dates for your trip, as space in dialysis centers may be limited. If you prefer to have your treatments on specific days and at specific times, let the center know in advance. The center may not always be able to honor your request, however, because space may be limited, especially on popular shifts.
You or your patient travel coordinator may need to contact more than one center to find a center that can provide dialysis for you. Check with that center as soon as you arrive to confirm your appointment. You may also want to visit the center and meet the staff, so you will feel more comfortable. Before doing this, however, make an appointment with the social worker or nurse manager of the dialysis center you plan to visit.

**How will I find a center to dialyze?**

If you plan to visit friends or family out of town, they may be able to give you the name and address of the dialysis center nearest them. You can find information on dialysis clinics in the U.S.: medicare.gov/dialysisfacilitycompare/ and internationally: globaldialysis.com. Your social worker or the patient travel coordinator at your center will be able to assist you.

**What if I need to travel in an emergency?**

Many dialysis centers make every effort to accommodate patients in an emergency, such as illness or death of a family member. Dialysis records will need to be faxed by your home dialysis center. You can also ask for a copy to carry with you.
What information will my transient dialysis center need to safely provide dialysis for me?

Most dialysis centers require the following information to assess your health and your treatment plan:

- the dates you need dialysis treatment
- your name, address, home contact information, etc.
- medical history and recent physical exam reports
- recent lab results (Hepatitis status within 30 days)
- recent EKG (usually within 1 year)
- recent chest x-ray or PPD
- your dialysis prescription/orders and three recent treatment sheets
- dialysis access type
- special needs or dialysis requirements
- information about your general health
- insurance information and contact information
- where you will be staying in the area and local contact information
- a list of the medications you take during treatment and at home.

This information will be sent to your destination center for review. It is important for the transient dialysis center to know as much about you as possible to give you the best care while visiting.
their center. Your home dialysis center will help send all this information to the center where you’ll be traveling. You can also request copies of any of this information to take with you.

**How can I be sure about the quality of care I will be getting away from my regular center?**

You may want to **ask the following questions** when making your arrangements for hemodialysis during your trip:

- What are the hours and days of operation? Traveling patients are often placed on shifts that are less popular. These shifts could be very early or very late.
- What types of dialyzers are used?
- Can you use the same type of dialyzer you use at your home center?
- What types of dialysis machines does the center have (conventional, high flux)?
- Does the center routinely provide lidocaine to numb the area where the needles are inserted?
- Are patients permitted to eat or drink while on dialysis?
- Are visitors allowed?
- Is an ice machine available for patients?
- Is public transportation available to the center?
How many patients are assigned to each nurse or patient care technician?

Can you get all the medications that you get at your home center during dialysis?

What if I get sick while I am visiting another center?

Be realistic when planning activities. Allow enough time to enjoy sightseeing and outings without becoming too tired. Also, be sure to watch your diet and fluid intake. Before you begin your trip, you will most likely have a healthcare professional assigned to you by your transient dialysis center. Find out how to contact the assigned healthcare professional when you first arrive. If you do become ill, call the dialysis center or the transient healthcare professional as instructed.

Occasionally, dialysis patients need to be hospitalized while traveling. If this
should happen to you, your transient healthcare professional is prepared for this possibility and will care for you during your hospital stay. He or she will probably talk to your regular healthcare professional to coordinate your care. You may feel more comfortable knowing if this coordination has taken place, so ask if your home healthcare professional has been consulted. Being hospitalized while away from home can be a stressful experience for any patient, and it certainly can change your travel plans. **Preparing ahead** for this possibility can help make the experience less stressful.

The following suggestions may be helpful:

- Make sure your family knows your travel plans.
- Make sure you have important phone numbers with you, such as your regular healthcare professional, dialysis center, etc.
- Have a copy of your medical records with you while you travel.
- Make sure anyone who is traveling with you knows where you keep your records and about your medical needs.
- Bring enough of the medications you need to last for the entire trip, with enough extra to deal with possible delays or emergencies.
- Carry a list of your medications with you.
Is home hemodialysis possible on a trip?

Yes. Some home hemodialysis patients arrange for in-center treatments while traveling, but others travel with their machines, supplies, and portable water treatment equipment. Some people even use specially equipped travel trailers and do hemodialysis in campsites that have hook-ups for water and electricity.

Even if you do your own treatment, it is important to know the location of the closest dialysis center where you can go for assistance. Let the center know when you will be in the area and ask if they would be willing to provide medical assistance if needed.
Carry complete medical information with you. Remember that most dialysis and equipment companies have toll-free numbers for assistance 24 hours a day. Carry these numbers with you. If it isn’t possible for you to do home hemodialysis while traveling, find out how much of your treatment you or your care partner can do at the transient dialysis center during your visit.

**What should peritoneal dialysis patients know about traveling?**

Traveling is often easier for peritoneal dialysis patients because they are not dependent on the availability of a dialysis center. Peritoneal dialysis patients still need to plan ahead and arrange for back-up medical care for their trips, as do home hemodialysis patients. Typically, this means contacting a dialysis center in the area where you will be and asking if they can help you if a problem comes up.

The center may want a copy of your medical records in advance. Carry a copy of your records with you as well. Your travel needs may differ, depending on the type of peritoneal dialysis you perform. There are two main types: CAPD (continuous ambulatory peritoneal dialysis: you perform the dialysis exchange manually) or CCPD (continuous cycling peritoneal dialysis: you use a machine called a cycler for the dialysis exchange).
CAPD patients should **carry enough supplies** for the length of the trip, plus some extra supplies in case of problems. For longer stays, you may also arrange for supplies to be delivered to the hotel or home where you’ll be staying. Make sure these supplies have arrived before you leave on your trip. CAPD patients also need to plan ahead for adequate clean space where they may do their exchanges while traveling. Airlines will make special rooms available, should you need to do your CAPD exchange between flight connections. If you have concerns about traveling long distances and performing your PD treatment, talk with your healthcare professional. Adjustments may be made to your schedule for travel purposes. Do not change your treatment without first discussing the change with your healthcare professional.

CCPD patients who plan to travel for one week or longer can arrange for supplies to be delivered to their destination. **Smaller cycler machines** are easier to take on airplanes and to use in hotel rooms, campers, etc. Some CCPD patients do CAPD on trips, rather than carry their cycler with them.
What should kidney transplant recipients know about traveling?

Ask your care team to give you the name, address, and phone number of a healthcare professional you can contact for medical help in case of an emergency. You should also be sure to bring enough medication to last for your entire trip, with enough extra to deal with an emergency, such as lost luggage or a spill.

It is a good idea to always carry a list of your medications, just in case. Carry your medications in your carry-on luggage. But be aware that due to stricter security measures at the national airports, rules regarding carry-on luggage can change. Therefore, it is a good idea to check with your airline at least one day before your scheduled flight.
Is it possible to travel if I am active on a transplant waiting list?

Yes. Simply inform your transplant coordinator about your travel plans. The coordinator will help you decide whether to be “on hold” during the trip, or whether you would be able to return within a reasonable amount of time if a kidney became available. If you want to remain active on the transplant list, provide contact information so you can be notified if a kidney becomes available while you are traveling.

If I have diabetes, what else should I know about traveling?

Since the unexpected may happen during a trip and meals may be delayed or unavailable, you should carry glucose tablets and appropriate snacks, such as low-potassium juice boxes or hard candy, to treat low blood sugar. It’s a good idea to travel with a “brown-bag” lunch or a packaged nutritional supplement, especially since many airlines do not provide meals or snacks.

Managing your diabetes can be made simpler by having insulin, syringes, and blood glucose monitoring supplies handy. Follow your usual regimen of checking blood sugar and taking insulin during your trip.
If you plan to travel by air, you should be aware that stricter security measures at the nation’s airports may affect you, especially if you need to travel with medical supplies, such as syringes and lancets. For flights in the U.S., you can board the plane with your syringes or insulin delivery system if you have a vial of insulin with a professional, pharmaceutical pre-printed label that clearly identifies the medication.

If you must test your blood sugar, you may board with your lancets as long as they are capped, and you have a glucose meter with the manufacturer’s name embossed on it. If you use glucagon, keep it in the original plastic container with its pre-printed label. Requirements may differ on international flights.

Since airlines may have additional requirements that affect passengers with diabetes, the Federal Aviation Administration (FAA) recommends that you check with your airline at least one day before your scheduled flight.

You may also get more information by contacting the American Diabetes Association at 800.342.2383 or emailing them at askada@diabetes.org and the FAA at 866.835.5322.
How can I stick to my diet while traveling?

While part of the fun of traveling is trying new foods, it is important for you to stick to your diet. Your dietitian will be able to suggest some good food choices for your trip. Here are some other suggestions you may find helpful:

- For short trips, pack a picnic lunch to eat along the way rather than stopping for fast food.
- When staying with friends or family, send information about your diet beforehand. You may want to make some suggestions about dishes you enjoy that are on your diet.
Choose a hotel that offers a kitchenette, so you can prepare your own meals.

When eating out choose restaurants that offer a wide variety of choices. (See the National Kidney Foundation brochure Dining Out with Confidence: A Guide for Kidney Patients for suggestions about sticking to your diet when eating out.)
How do I pay for my dialysis when traveling?

It is important that you understand fully your financial obligations when you travel. Unexpected costs while traveling or bills when you return can be a financial burden for you.

If Medicare is your primary insurance coverage, Medicare will pay for 80 percent of your treatment costs within the U.S. and its territories. You will be responsible for the remaining 20 percent not covered by Medicare. If you have a Medicare supplement policy, it may cover this 20 percent. However, you may have to pay this 20 percent “up front” and bill your insurance later. Check with the transient dialysis center about their transient billing policy. Most state Medicaid programs will not pay for treatment outside of your home state.

If you have commercial insurance as your primary insurance, you may need to request a letter from your insurance company stating they will pay for your treatment at the transient dialysis center. Some commercial insurance will pay for dialysis outside of the U.S. Transient dialysis centers will often call and verify this coverage themselves.
Be sure to allow enough planning time to make these arrangements.

A healthcare professional’s fee may also be charged by the transient dialysis center. Be sure to ask what portion of this charge will be your responsibility.
Where can I get more information?
The following resources may be helpful:

- Searchable list of dialysis centers in the U.S., available at medicare.gov/dialysisfacilitycompare/
- International travel information available at globaldialysis.com

You can also call the NKF Cares Patient Help Line toll-free at:
855.NKF.CARES (855.653.2273)
or email nkfcares@kidney.org

Learn more at kidney.org

Remember...

✔ Hand carry essential medical information, your medicines and other medical supplies in case of the unexpected, such as lost luggage.

✔ Bring enough of your medications to last for your entire trip, with enough extra to deal with possible emergencies. Also, carry a list of your prescriptions, just in case.

✔ If you need extra assistance boarding a plane or train, inform personnel when you check in so they can give you special instructions.
✓ If you need a wheelchair at an airport where you need to catch a connecting flight, let your travel agent or the airline know when you make your reservations—and again when you check in.

✓ If you are planning to travel by plane or train, plan for any special meals (such as low-salt, low-fat, or diabetic) when you make your reservations. If special meals are not available, be sure to bring your own food when traveling. You may also buy food at the terminal and bring it with you on the plane.

✓ When making a hotel reservation, you can request a first-floor room or a handicapped-accessible room if stairs or distances are a problem.

✓ If you use a travel agent, tell the agent about any special needs you may have, such as special meals, accessible rooms, and assistance while changing planes. The agent can also advise you about special considerations regarding safe transport of dialysis supplies while traveling to foreign countries.
Traveling with kidney disease requires more advance preparation, but the benefits of travel usually outweigh the inconveniences.
Fueled by passion and urgency, NKF is a lifeline for all people affected by kidney disease. As pioneers of scientific research and innovation, NKF focuses on the whole patient through the lens of kidney health. Relentless in our work, we enhance lives through action, education, and accelerating change.