

Get Support

Talking About Your Condition With Your Loved Ones

When you're first diagnosed with chronic kidney disease (CKD), you may want to talk about it with your friends and loved ones. Whomever you choose, the decision is yours and yours alone. At first, the conversations may be a bit hard to get through. Eventually, as you figure out what you want to say, things will get easier.

There's no standard way to talk about your CKD. The best approach is to simply be honest and direct. However, be aware that your loved ones may have feelings of sadness or fear just like you may have had.

What's important to remember is that you have people to rely upon to be a source of comfort and give you peace of mind. So reach out for the support you need.

Include Family and Friends in Your Care

When you're feeling low and needing emotional support, give friends and loved ones a chance to cheer you up or simply listen to you.

Your need for physical help may range from simple tasks, like moving a heavy object, to more involved jobs, like grocery shopping.

Remember, your loved ones care about you and want to help. All you have to do is ask if you might even feel better after doing so.

You're less likely to miss medical appointments if you ask for a ride when you need it. You might eat healthier if someone helps with the cooking or menu planning. And it may be easier to remember to take your medications with someone to remind you.

One of the areas that family can help with most is meals. For example, if your family wants to eat a high-sodium food like ham, tell them you can eat just a small portion (if your weight or sodium levels are at an acceptable level). Or, you may just choose to eat something different from the rest of your family. Letting them know what you can and can't eat may make mealtime easier for everyone.

Loved ones may be able to help you with transportation to dialysis and doctor appointments, assist with household chores, or just be there as a shoulder to lean on during rough patches. Just be sure to let them know that you need their help.

Keeping the Family Meal

Having a limited diet can make you feel different and isolated from your family. You might even feel like your diet is a burden to your family. Often, you may end up having a different meal than everyone else. This might work on occasion, but you don't have to make a habit of giving up meals with your family.

In fact, sharing meals can be a good way to come together, especially if life has changed things for you and your family. You can even cook your meals together. It can be fun for everyone.

Keep in mind that having meals together as a family is less about eating and more about spending time with one another.

While you might draw comfort from family meals, kids get even more out of them. Research has shown that kids in families that spend quality time together, such as mealtime, have healthier eating habits.

Getting Assistance from Others

Do you find it hard to ask for help when you need it? Try these ideas the next time you need a hand:

- Even though you don't want to bother anyone, it's not a good idea to begin your request with an apology. "I'm sorry to put you to so much trouble" sounds as if an awful chore lies ahead! Try being more specific: "I need help taking some clothes to a charity. Do you have about an hour to help me next Saturday?"
- When people ask what they can do to help you, give them a job: "Can you help me move this plant outside?"
- If you're offered help that you don't need or want, be grateful but firm. And don't be afraid to ask for a favor you really need: "Thank you for thinking of me, but I can take care of this. Could you give me a ride to the grocery store later, though?"

Asking for help is not a sign of weakness. Sometimes, you just need assistance with things. Your friends and loved ones care about you and want to help. All you need to do is ask.

Start Conversations with Other Patients at the Clinic

If you go to a dialysis clinic, you may be surprised at how much help you get from other patients you meet. It may be easier to talk with others who share your concerns and experiences.

The next time you're at dialysis, start a conversation with the person next to you. The conversation could be about anything — how to stick with your diet or remember to take your medications. Other topics may include

- Preparing for doctor appointments
- Kidney-friendly recipes
- A support group you attend

- Tips to get things done around the house
- Talking about your own life with chronic kidney disease (CKD)

Of course, there are the old standbys of conversation: the weather, the latest news, children, or grandchildren. You may find that common experiences provide a helpful outlet.

So get to know your fellow patients. Talk to them, and just as importantly, listen to them. You may find their experiences to be helpful and comforting.

Live Your Life as a Chronic Kidney Disease Patient

Traveling

The thought of travel may seem intimidating because of your dialysis schedule, but a little planning can make it easier.

Ask your local dialysis center or your doctor's office for help finding a dialysis center away from home. You or a loved one can also visit www.dialysisfinder.com ^[1] or call 1-866-889-6019 toll free to speak with a dialysis placement specialist.

If your dialysis is done at home, either with hemodialysis or peritoneal dialysis, you may also want to consider contacting one of the services listed above, as traveling with the necessary supplies or finding space to do your dialysis may be difficult.

Be sure to make your appointments ahead of time and check with your insurance company to verify that your treatment will be covered. Your social worker may be able to help you with this.

For your medications, try these tips:

- Refill your prescriptions before you travel for holidays and weekends
- Don't forget to pack your pills. Take your doctor's and pharmacist's phone numbers with you, in case you run out of or lose your medication
- Have family members remind you to take your medications

Physical Activity

Doctors used to think people with chronic kidney disease (CKD) couldn't exercise. But now, doctors know that patients who are active find it easier to do daily activities.

When you and your doctor feel you're ready, consider walking, swimming, dancing, or doing some physical activity you enjoy on a regular basis. Start slowly and add a few minutes each

time, as your doctor recommends.

Remember, being active may help:

- Give you more energy
- Make your joints more flexible
- Prevent and treat high blood pressure

Talk to your doctor before you begin any fitness program.

Take Care of Yourself

Taking Time for Fun

With or without chronic kidney disease (CKD), life is what you make it. Some patients with CKD may choose to withdraw. Others may choose to do as much as possible and live life to the fullest. The choice is yours.

Maybe you want to spend more time with family and friends. If so, plan an outing with them. They'll appreciate your effort and you can feel good about taking charge.

Decide what is most important to you now. Then take the steps necessary to make it happen.

Tips for Coping

You might feel like you are no longer in charge of your life, but the truth is, you're probably finding ways to be more in control than ever. Going to dialysis, changing your diet, and taking your medications takes more strength and dedication than you may realize.

But your physical needs are only part of it. Your mental and emotional needs require attention, too. How you find this happiness is called coping. These coping tips have worked for others and may help you, too.

Learn about CKD. Ask your renal care team for how you can get more involved in your care. The more you learn about treatment options, the more confident you'll feel about getting the best care possible.

Maintain a healthy lifestyle. Following a kidney-friendly diet and staying active with exercise is good for your body and your mind. You'll feel better, which is important to helping you keep a positive attitude.

Talk about CKD with others. Inform loved ones about kidney disease and ways to prevent it ? you may feel like you've taken a positive step.

Open up. If you need to talk, vent, or just let go, it's okay. Sometimes, releasing your thoughts and feelings ? health related or otherwise ? can help you look at a situation in new ways.

Listen without judging. Pay attention to what others have to say. Even if you disagree, hear them out. You might be surprised at what you learn.

Volunteer. As your energy level allows, making a meaningful contribution to helping others – whether it's tutoring, stuffing envelopes, or speaking publicly about the importance of organ donation – can do wonders for your outlook.

Laugh. Enjoying time with friends, watching a funny movie, and seeing the humor in everyday situations can sometimes be the best “medicine” for coping.

Spending Time with Family and Friends

Having the love and support of family and friends can go a long way as you journey through CKD. Your loved ones can help you through the good times and the difficult times. How much you let them is entirely up to you.

When you spend time with loved ones, taking care of yourself can often fall by the wayside. This may be especially true with food. Try these tips for eating with family and friends:

Talk to your renal dietitian about “forbidden” foods. He or she can give you tips for being around food without overdoing it

Eat a little snack at home before you go out so you're not as hungry. Then, eat only small portions, take your time, and don't eat until you're stuffed

Ask your dietitian to recommend a kidney-friendly dish you can share with your family

With a little planning, you can make spending time with loved ones kidney friendly.

Transportation

With chronic kidney disease (CKD) and any additional conditions you have, it may be a challenge getting to doctor appointments, the grocery store, and other places. However, there are some helpful options to consider:

Ask a friend or family member to drive you to your doctor appointments

Take a city bus, taxi, or other public transportation to get around

Talk to your social worker for information about government-sponsored transportation for senior citizens or those who cannot get around easily

While you're at dialysis or with your support group, if you belong to one, talk to others with CKD about how they handle transportation challenges.

Recognizing Emotional Issues

Dealing with CKD can be difficult emotionally and physically. If you feel like you're having trouble with emotional issues, talk to your renal care team. Medications, treatments, and other help may be available.

Seek comfort and guidance from those you trust. Talk to your family and close friends. Keep up any spiritual or religious activities that may help you.

Above all else, tell your doctor right away if you're experiencing any emotional issues.

Manage Your Time Wisely Around Treatment

Scheduling Activities and Tasks

Your time at your dialysis treatment or doctor appointments is a great opportunity to take care of all the things that are a part of your daily life. Use this time to your advantage.

- Talk to others with kidney disease. They can be a source of strength and support, and they may also be able to give you tips on how to stick with your treatment plan
- Learn about something interesting like a new language or photography
- Bring a sketchbook and practice drawing
- Bring your kidney-friendly cookbook and plan meals for the week
- Strengthen your mind with brainteasers and puzzles
- Bring an audio book and a comfy pillow, and use the time to relax If you rely on spirituality for support, spend some time in prayer
- Laughter is the best medicine! Bring something humorous to read.
- Use the time to make a list of questions for your kidney care team
- Make your to-do list for the week
- Bring your checkbook and stamps, and pay your bills

Dialysis can run up to 4 hours each visit, depending on the clinic. Take advantage of your time there. You may find that the work you do at your health care appointments can make your daily life a little less hectic.

Care for Your Overall Health

Preventive Screenings

In addition to managing your chronic kidney disease (CKD), you also need to keep up with

other medical screenings. Talk with your doctor every January about ?preventive maintenance? screenings you?ll need for the coming year and mark them on a calendar.

The tests you need depend on your age, your health, and whether you are male or female, so work with your nephrologist to ensure that your tests are done as necessary. Below are some examples of tests recommended by the US Department of Health & Human Services for the average person:

General Tests

- Cholesterol test
- Blood pressure test
- Diabetes screening
- Fecal blood test
- Mental health screening (depression)

Men

- Prostate exam
- Testicular exam

Women

- Pap smear
- Thyroid test
- Bone density test
- Mammogram

You should also keep your immunizations current. Most of these were done when you were a child, but several need to be updated periodically, such as

- Flu vaccine
- Tetanus, diphtheria, pertussi (Tdp)

Be sure to take advantage of free health screenings at malls, public events, and pharmacies.

Managing Multiple Chronic Conditions

Managing Multiple Medications

Often, patients with end-stage renal disease (ESRD) take multiple medications for a variety of ailments and conditions. Sometimes, it?s a real challenge to remember which medication to take and when, not to mention how much of every medication to take and what each is for.

One thing you can do is to make a chart, like the sample below, to keep track of your medications.

Name of medication	Reason for taking medication	Number of times to take medication	Time to take medication	Take with food?	Prescribing doctor
Med #1	High Phosphorus	3 times per day	At meals	Yes	Matthews
Med #2	Diabetes	2 times per day	8 AM, 8 PM	No	Aaron
Med #3	High Blood Pressure	1 time per day	8 AM	No	Greenberg
Med #4	Anemia	2 times per day	8 AM, 8 PM	No	Greenberg

Here are some steps you can take to help make sure you manage your medications properly:

- Try to have all of your prescriptions filled at the same pharmacy so the pharmacist can keep track of all the medications you are taking
- Make a list of all your medications and their dosages, and keep a copy with you when you're out and about
- Take your medications at the same time each day
- Keep your medications in the same place

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Source URL: <http://www.dpcedcenter.org/classroom/take-active-role-your-treatment/get-support>

Links

[1] <http://www.dialysisfinder.com>