

Take an Active Role in Your Treatment

As a patient you are constantly told what you can and can't do. By becoming more informed and taking on an active role, you can take back control of your life and improve your own health. This class will help you down the path towards a better life.

Get Informed

Manage Your Chronic Kidney Disease Stage 5

As you are being treated for your chronic kidney disease (CKD) Stage 5, there are 2 areas of concern that you and your renal (kidney) care team should discuss.

Diet

Following a renal-friendly diet can help limit the amount of waste in your body, which will aid in your treatment. You and your renal dietitian can work together to monitor the foods you eat and the fluids you drink. Some things you may discuss include

- Limiting fluids
- Avoiding salt
- Being aware of hidden phosphorus

Sticking to the diet you and your dietitian create may not only help you feel better, it may help make your treatments more comfortable, as limiting sodium, and therefore fluids, can alleviate some cramping.

Nutrient Intake

One of the kidneys' functions is to balance different nutrients in your body. For patients with CKD Stage 5, several nutrients are important to monitor:

- Sodium
- Potassium
- Protein
- Phosphorus
- Calcium

If these nutrients get out of check, serious health problems can occur. That's why it's important for you and your kidney care team to check your nutrient levels regularly.

Patients on dialysis have an increased need for protein. Foods high in protein are often high in phosphorus as well.

So it's important to be aware of what you're eating and to work with your renal dietitian to create a menu that balances your need for protein with your phosphorus intake.

As you read the rest of the articles in this classroom, you'll learn more about treating your CKD Stage 5 and how taking an active role in your treatment is one of the most important things you can do

The Power of 3

Hyperphosphatemia can be a serious condition. In fact, watching what you eat and taking a phosphate binder are very important, as is going to dialysis. It takes the power of 3 ? diet, dialysis, and medication ? to manage chronic kidney disease Stage 5 and high phosphorus levels.

Diet

Making the right food choices, such as eating low-phosphorus foods, can help keep extra phosphorus from building up in your body.

Dialysis

Dialysis cleanses the blood by removing waste and excess fluids that build up. In fact, based on average dietary phosphorus intake, dialysis may remove approximately 50% of the extra phosphorus.

Medication

When diet and dialysis cannot remove enough excess phosphorus, your doctor may prescribe a phosphate binder to help remove the rest.

Your actions ? eating kidney-friendly foods, going to dialysis, and taking your medication ? can help you get the most from your care.

Understanding Your Treatment Options

Understanding your chronic kidney disease (CKD) Stage 5 should be the first step. Knowing what treatment options are available is the next step. For CKD Stage 5 patients, treatment options focus on 3 main areas.

Dialysis

When your kidneys no longer work well enough to cleanse your blood and rid your body of excess waste, dialysis becomes a necessary treatment. You have a couple of dialysis treatment options to choose from.

Hemodialysis - Hemodialysis is a treatment that uses a machine to act as an artificial kidney, removing the fluids and wastes that your kidneys cannot. Tubes transfer small amounts of your blood to the machine to be cleaned and then moved back to your body. You can have hemodialysis in a clinic or at your home.

Peritoneal Dialysis - Peritoneal dialysis uses a membrane in the empty space of your belly to clean your blood. A tube inserted into your torso is injected with a liquid that fills that empty belly space. The waste is filtered through tiny holes in the membrane and into the liquid, which can then be drained out of your body. Clean liquid is again put in your belly and the cleaning begins again.

Your kidney care team will have more information about dialysis options. Together you can decide which option may work best for you.

Know Your Kidney Care Team

Kidney Care Team Responsibilities

Your doctor, renal dietitian, nurses, and technicians are all part of your kidney care team with you. Each team member has a unique set of responsibilities that can help care for your total health.

In the chart below, match the team member with the appropriate description.

TEAM MEMBER	DESCRIPTION
1. Dialysis technician	A. Helps find community resources (support, financial, etc.) to help you manage your chronic kidney disease
2. General practitioner	B. The most valuable member of your kidney care team; responsible for following the treatment plan
3. Nephrologist	C. Monitors your dialysis treatment and handles any other dialysis issues you may have
4. Pharmacist	D. Checks your health and how you respond to medications
5. Renal dietitian	E. Fills prescriptions and gives tips for taking your medications

6. Renal nurse	F. Doctor who specializes in kidney disease
7. Social worker	G. Helps you choose kidney-friendly foods
8. You	H. Performs your yearly physical and monitors your overall health

ANSWERS: 1.C 2.H 3.F 4.E 5.G 6.D 7.A 8.B

Tips for Communicating with Your Kidney Care Team

It's easy to get confused when you're trying to talk with your kidney care team. Sometimes they use complicated, unfamiliar terms.

But being able to communicate effectively with your kidney care team can help you have some control over your health care. One way to help you communicate effectively is to take P.A.R.T.:

Prepare. Make a list of important questions or concerns, and bring these up at the beginning of your visit.

Ask. Ask questions regarding tests, treatments, and any follow-up steps that are necessary. Make sure you understand the doctor's answers. If you don't, ask until you do.

Repeat. Once you have gotten the information from your doctor, repeat some of the key points. This will help you make sure you heard correctly and give the doctor the chance to correct any misunderstandings.

Take Action. When your appointment is over, know what your next steps are. Make sure you understand what you need to do and ask for help if you don't.

You should keep in mind that there are lots of members of your kidney care team, and collectively they're able to help answer any questions you may have.

Support Groups and Resources

Each of these highly regarded organizations has an informative Web site and can be contacted by telephone toll free

- American Association of Kidney Patients at www.aakp.org ^[1] or 1-800-749-2257
- American Kidney Fund at www.kidneyfund.org ^[2] or 1-800-638-8299
- National Kidney Foundation at www.kidney.org ^[3] or 1-800-622-9010
- Renal Support Network at www.rsnhope.org ^[4] or 1-866-903-1728

Support Groups

There are a variety of resources across the country, in your area, and, of course, on the Internet. Typing ?CKD support groups? into a search engine such as Google reveals over 95,000 sites. Consider contacting some of the support groups listed below:

- Renal Support Network at www.rsnhope.org ^[5] or 1-866-903-1728
- Nationwide listing of support groups, by state, at <https://aakp.org/support-groups/> ^[6]
- DaVita at www.davita.com/education/ckd-life/support/support-groups-for-people-living-with-kidney-disease ^[7] or 1-800-244-0680

Be a Part of Your Kidney Care Team

Communicating Effectively with Your Kidney Care Team

You go to dialysis and stay for the entire session. You take your medication as directed by your doctor. You follow your kidney care team?s instructions. Is there anything else you can do to manage your condition?

There is. Learn to talk and work with your kidney care team so you understand their expectations and they understand yours.

Communicating with your kidney care team is more than just listening to them. It?s asking questions, letting them know your thoughts, and taking action. Be specific when talking with your kidney care team and

- Write down your most important questions or concerns, and ask them at the beginning of your visit
- Focus your questions on your tests, treatments, and any follow-up steps. Make sure you understand the health care provider?s answers

By asking for specifics, you can convey the information you want to get across and get the answers you are looking for.

Doing your part can help you get the most from your relationship with your kidney care team.
Teamwork is the name of the game!

Sharing Important Information with Your Kidney Care Team

It may feel awkward to share some things with your kidney care team, but telling them any relevant medical information you have may help them design a more effective treatment plan for you.

Each member of your kidney care team handles different areas of your treatment, so you have plenty of people who can address your needs.

- Taking medications. If you have problems taking your medications as directed, tell your doctor or nurse and let him or her know why
- Trouble following diet. If you have difficulty following a kidney-friendly diet, tell your renal dietitian so that he or she can help you find foods that work for you
- Getting to dialysis. If you're having a hard time making it to all of your dialysis appointments at the clinic, talk to your social worker about making other arrangements for transportation

Also bring a list of the medications you are currently taking, and a list of the physicians you've seen since your last appointment and why. Make sure to tell your kidney care team about your medical history.

Talking to Your Kidney Care Team About Changes in Treatment

If you or your kidney care team may feel that your current treatment plan isn't working well enough. This is when being able to talk openly and honestly to your doctor can benefit you.

- Ask about all treatment options. Learn about the risks and benefits of each treatment option and understand any consequences of not managing your condition to help find the treatment that works for you
- Share your thoughts and concerns. Your kidney care team won't be able to help you if you don't tell them what's bothering you. For example, if you are hesitant to try a new medication due to side effects, **speak up**

Be sure to keep your doctor informed as to how you are feeling. Remember that you and your kidney care team need to communicate in order to get a treatment that works for you.

Get Involved

The following section will provide tips on becoming more active in your own healthcare.

Lab Values

Health Information Trackers

Lab Values

You should have your lab work done on a regular basis to help keep track of your progress. You may be tested for the following at different times:

- Kidney function
- Phosphorus
- Potassium
- Blood pressure
- Diabetes control
- Anemia
- Bone health
- Nutrition

Depending on what your doctor wants to do and any other conditions you may have, he or she may request other labs.

Consider making a chart for all your lab values, including phosphorus, or ask your nurse or renal dietitian if he or she has a chart you can use. It can help you follow your progress.

Medication Schedule

You're not alone in taking several kinds of medicine. Sometimes, it can be tough to keep track of them all. In fact, a lot of patients on dialysis have this trouble.

If you do follow your medication schedule, congratulations! Keep up the good work. But if you're missing doses because you sometimes forget, try these tips:

Use a watch or cell phone with an alarm to remind you to take your medications

Try using a pill organizer

Keep your medicine in a place where you can see it ? but where children can't reach

Use a calendar or planner to check off your medications as you take them each day

Prepare for Appointments

A notebook may be the most valuable tool you can have to help track your treatment plan. Keep a notebook nearby so you can write down any instructions or information the doctor or renal care team gives you, as well as any questions you may have.

Use a notebook to track your phosphorus and other lab values as well as to keep a list of your medical records, important phone numbers, and medications.

It may help to focus your questions in particular areas. For example, medication, nutrition, and

symptoms. But just as important as asking questions is making sure you understand the answers. You or a loved one should write down the information your doctor presented, and read it back to the doctor to make sure it's correct.

Make the notebook work for you, and keep it handy. You'll feel reassured by having everything you need.

Diet Tracking

Food Diary

A food diary is an easy way to monitor the foods and liquids in your diet. The diary can help you identify trouble spots and make quick fixes.

Your renal dietitian can help you get a food diary or you can check for one online.

Food labels can help you with your food diary and help you choose healthier, kidney-friendly foods. Talk to your renal dietitian about what to look for before you shop.

Since imbalances of minerals such as phosphorus and potassium are a concern for patients on dialysis, ask your renal dietitian how many milligrams (mg) of these minerals you should have each day. Remember that %percent daily values% on products are for someone without kidney disease, so your needs may differ. Generally, however,

- A food is low in phosphorus if it has fewer than 50 mg (or less than 5%)
- A food is high in phosphorus if it has more than 150 mg (or greater than 15%)
- A food is low in potassium if it has fewer than 100 mg (or less than 3%)
- A food is high in potassium if it has more than 200 mg (or greater than 6%)

If a food label doesn't list phosphorus or potassium, it doesn't mean they aren't in there. Talk to your renal dietitian if you're unsure.

Before making any changes to your diet, please talk with your doctor or renal dietitian.

Tips for Eating Out

You can stick with a kidney-friendly diet and still enjoy dining out. The key is to plan ahead. You may have to cut back on fluids, sodium, potassium, and phosphorus in your other meals the day you're eating out.

- Tell your server, "No salt, please?"
- Order sauces served on the side
- Don't forget to bring your medications with you and take them as directed

Join Patient Organizations

Organizations That Can Help

There are a number of patient organizations, such as Dialysis Patient Citizens (DPC), to help those living with chronic kidney disease (CKD).

Dialysis Patient Citizens

As a patient-led nationwide organization, DPC's mission is to improve dialysis patients' quality of life by developing awareness of dialysis issues, advocating for dialysis patients, improving the partnership between patients and caregivers, and promoting favorable public policy. Visit www.dialysispatients.org [8] or call 1-866-877-4242 for more information.

Here are other groups and organizations you may be able to get involved with:

- American Association of Kidney Patients at www.aakp.org [9] or 1-800-749-2257
- Renal Support Network at www.rsnhope.org [4] or 1-866-903-1728
- The American Kidney Fund at www.kidneyfund.org [2] or 1-800-638-8299
- National Kidney Foundation at www.kidney.org [3] or 1-800-622-9010
- National Institute of Diabetes and Digestive and Kidney Diseases at www2.niddk.nih.gov [10] or 301-496-3583
- Renal Physicians Association. Keeping Kidney Patients Safe at www.kidneypatientsafety.org [11] or 1-301-468-3515
- The National Forum of End Stage Renal Disease Networks at www.esrdnetworks.org [12] or 1-804-418-7990

These are just a few organizations that offer information, education, and support. Be sure to share this information with your family and friends, and even at the dialysis clinic.

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 or 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 ^[13] 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
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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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