



Module 14

Patient Rights and Responsibilities



Module 14 – Rights and Responsibilities

Kidney School is Supported by:



Kidney School would not be possible without the help of our generous sponsors. Kidney School is run by the non-profit [Medical Education Institute \(MEI\)](#), which helps people with chronic diseases learn to manage and improve their health. To learn more about Kidney School sponsorship, please visit: <http://kidneyschool.org/sponsors/>



Module 14 – Table of Contents

Your Right to Information.....	14-4
<i>Your health problems and treatment options</i>	14-4
<i>Services your clinic offers</i>	14-7
<i>Rules and policies for patient care</i>	14-8
<i>Costs of care</i>	14-9
<i>What to do in an emergency</i>	14-10
<i>How to file a complaint</i>	14-12
<i>Your medical chart</i>	14-14
<i>Advance Directive</i>	14-14
Your Right to Take Part in Your Care and Treatment.....	14-16
<i>Choosing or changing your treatment</i>	14-16
<i>Refusing treatments, tests, or research</i>	14-18
<i>Getting information you can understand</i>	14-19
<i>Seeing a social worker and dietitian as often as you need to</i>	14-19
<i>Getting a second opinion or changing doctors</i>	14-20
<i>Transferring to another clinic</i>	14-21
Your Right to Respect and Dignity	14-22
<i>Being treated with respect</i>	14-22
<i>Receive equal treatment</i>	14-23
<i>Medical privacy</i>	14-23
Personal Plan	14-25
Take the Kidney Quiz!	14-30
Additional Resources	14-31

- | | | | |
|---|------|---|-----|
| b | (10) | a | (5) |
| c | (9) | d | (4) |
| b | (8) | d | (3) |
| d | (7) | b | (2) |
| a | (6) | b | (1) |

Congratulations, you've finished the quiz! Here are the correct answers so you can see how you did:

Module 14 – Kidney Quiz Answers





There is an old tale about twin brothers who were orphaned as infants. An uncle adopted the boys, but was so poor that he could barely feed them.

One day, when the boys were grown, a finely dressed man came to their home. He said he had spent years searching for them. He told the boys that their father had entrusted him with a deed to many acres of land he owned, and that he'd promised to hold it for the boys until they were of age. He kept his promise by giving them the deed.

The boys could hardly believe they now had rights to many acres of land. They were no longer poor! But each had his own ideas about how to use their rights. One wanted to sell the land and live off the profits. The other wanted to farm the land and build a home. So, they split the land in two and each did as he chose.

Before long, the brother who sold his land ran out of money. But the brother who farmed was doing well. Both brothers had the same land rights—but only one used his rights in a responsible way.

This story teaches us a lesson. Each role we take on in life, as worker, parent, patient, or homeowner, carries some rights. But our rights can only work in our favor if we use them responsibly.



You can think of rights and responsibilities as balancing each other on a scale.



You may not have thought about it before, but being a person on dialysis means you have certain rights. Knowing what these rights are can help you to:

- Get the best care.
- Know key facts about your health.
- Make good decisions about your treatment.
- Be treated in the manner you deserve.

Having rights also means having responsibilities. For you, this means the “job” of being an active partner in your health care. Active partners do more learning, listening, speaking, and decision-making than people who let their doctor or care team do it all for them.

Your payoff is much bigger when you are an active partner:

- You'll be less afraid of health problems, because you're always learning about new ways to take care of yourself
- Your health may be better
- You'll feel more in control of your life—because you are the one deciding
- You will have more hope for the future



Here's what one patient says about how he stays involved in his standard in-center hemodialysis (HD) care:

“My nurses are great. I have my flow sheet filled in before they put my needles in and then they can program the machine. I always have them move the machine so I can see the numbers and I can reach to take my blood pressure if I start feeling ‘funny’! I usually beat them to the punch and have the vitals filled in before they come by every half hour. They have come to see that I know my body. If things aren't perfect then I make sure they get as close to perfect as they can at any given time.”

In this module, we will walk you through the key rights—and responsibilities—you have as a kidney patient. These fall into three main areas:

- 1 Seeking information
- 2 Taking part in your care and treatment
- 3 Being treated with respect and dignity

As we tell you about each right, we will also help tell you about your job, so you can get the most out of each one. Your starting point is learning what your rights are.

For years, the brothers in our story were poor because they didn't know they had rights to their father's land. Once they knew, they each chose how to use their rights. One did well and the other did not. Our goal is to help you to live well with the rights that belong to you.

Note: *You have some rights under the Federal rules that govern dialysis clinics. You have other rights under Federal law. Other rights may vary by State law.*

So, let's get started!

Your Right to Information

You don't have to be a spy to gain access to your vital health facts. In fact, you have a right to know:

- Your health problems and treatment options
- That you can do as much of your care as you are willing to take on
- What services your clinic offers and who provides your care
- Rules for patient care at your clinic
- How much your care will cost and sources of payment
- What to do in case of an emergency
- How to file a complaint or a grievance
- How to get a copy of your medical chart
- That you can have an Advance Directive

Let's look at these one at a time, along with the jobs that go with each one. We'll include a chart of all of them in your Personal Plan at the end of this module.

Your health problems and treatment options

Rights

You have the right to know about your health problem. Your doctor or care team should explain—in plain words—the name of your condition, what you can expect, problems you might run into, and your treatment options—all of them.

If you have early kidney disease, lifestyle changes, drugs, or other treatments may help slow it down or even stop it in its tracks. Talk with your doctor about your options and learn which ones will work best for you.





If you have kidney failure, you may be surprised to learn that there are treatment options other than standard in-center HD.

- Standard in-center HD is done three times a week—Monday-Wednesday-Friday or Tuesday-Thursday-Saturday. You have the right to ask for a shift that will fit your life. If your center does not have one, they must tell you where you can find it. HD can be done *at home*, either three times a week, 5-6 days/week for 2.5-4 hours, or even at night so your days are free. You can also do self-care HD in a center.
- Peritoneal dialysis (PD) is treatment that you can learn to do at home. It uses the lining of the abdomen to clean your blood *inside* your body. You can use a machine to do PD treatments at night while you sleep, or do a 30-minute treatment by hand four times a day.
- You may be able to get a kidney transplant—or a kidney-pancreas transplant if you have type 1 diabetes.
- You also have the option of medical care without dialysis.

Talk with your doctor about your options and learn which ones will work best for you. If your center does not offer the treatment you want, they are still required to tell you about them. You are the one who must live with your treatment each day. Your choice needs to fit your life. If you qualify and decide you want a transplant, you have the right to choose which transplant center to work with, keeping in mind what your health plan will pay for.

Responsibilities

Your health problem is *your* health problem. What do we mean? Well, you *are* the one who has to live

with the treatment each day. So your job is to:

- Learn all you can: Ask questions, go to the library, look on the Internet, or call a kidney disease support group or your local ESRD Network
- Make an informed choice about what treatment you want
- Do your part to follow through so you can feel your best and keep doing what you enjoy

If you decide you want a treatment your doctor doesn't offer, you may need to change doctors. Some patients have even moved to another town to get a treatment that wasn't offered where they lived. It's *your* life, and *your* call. And you can choose to change treatments if the one you picked is not helping you to feel better and stay active.

Where Can I Learn About My Treatment Options?

Talk to your doctor and your care team, and tell them that you want to know about all of the treatments for your health problem. You can also read Module 2—*Treatment Options for Kidney Failure*, to learn more. To find centers that offer home dialysis, visit <http://locator.homedialysis.org/>.





“When my kidneys shut down, I first went on emergency hemo, but I don’t like needles, so I went straight away to PD. PD was great the first 2 years, but after a second bout of peritonitis, my dialysis became less and less efficient. Toward the end, I was fluid restricted and could not control my phosphorus. When I came down with a serious case of peritonitis, I had the PD catheter pulled and have been on standard in-center HD since. Once I got my problems resolved, I have been stable—in fact the most stable since I have had kidney disease. I drink about a liter a day—which isn’t fun—and I miss fruit salad and orange juice, but overall, I’m doing great.”

Once you choose a treatment, your job is to do your part to stay healthy. This includes:

- Taking all your medications at the right times

One Spouse’s Advice on Information

“The more you know about your illness and treatment, the better off you’ll be. My husband is a home hemo patient. The nurses who taught us were great. Once in a while he has to go to the center. He always asks questions, and always gets answers. Question everything: That is your right! You’re responsible to yourself to see that your treatment is the best you can get. Don’t be afraid or timid. Please speak up for yourself. My husband learns from the internet and from our online support group. We take any information we want to the nephrologist. We ask him questions all the time. The more you know, the healthier you will be.”

- Coming to your clinic visits on time
- Telling the doctor or nurse about any symptoms or problems you are having
- Staying as physically active as you can
- Asking questions when you don’t understand something
- Getting all of the treatments your doctor prescribes
- Caring for your catheter, if you are on PD
- Caring for your vascular access, if you are on HD
- Following your meal plan and fluid limits, if you are on dialysis

As one transplant patient puts it:

“I’ve learned that you have to keep asking questions, keep showing an interest in your care. Where I was, once you showed that you were interested, they did a lot to help you. I knew a lot of patients who didn’t want to know about dialysis—they came in, sat down and didn’t seem to care. Another person and I were the only ones who seemed interested. They used to bring in nephrology magazines they got for me to read, a lot of stuff from the kidney groups also. Maybe they feel it’s rare for a patient to be so involved? I don’t know.”





I've learned a lot about hemo and PD. Each day it's in the back of my mind that I may have to go on it again, so I have to keep up with everything!"

Services your clinic offers

Rights

You have the right to expect a clean, well-run, and adequately-staffed clinic that follows laws and safety rules. The clinic should try hard to see patients at their set times (although this can't always happen). Care team members need to wash their hands and put on clean gloves before they touch you.

Good health care starts with a skilled, well-trained staff. You have the right to ask any health care worker about his or her training and background. Ask your center about your rights when trainees work with you. Can you refuse to allow them to treat you unless an experienced staff person is on

Do I Have a Right to Know if a Dialysis Center Reuses Dialyzers?

Yes! If your center reuses dialyzers, you have the right to ask them to show you how they will keep you safe. Plan to be one of the people who check the label before treatment to be sure you get your own dialyzer back. Getting someone else's could expose you to their illnesses.

You can also ask the technician to show you the test strip proving that the chemicals used to clean the dialyzer have been rinsed out so they don't get into your bloodstream.

hand to supervise? If you plan to do standard in-center HD, this will be important for you to know, as new trainees are common. Here is how one patient handled it when her center had students in training:

What if I Don't Want a Certain Staff Person to Care for Me?

This question comes up most often for people using standard in-center HD. If every patient refused care from certain staff, it would be very hard to run a center. Some centers even have a policy of not letting patients refuse care from a staff person.

You need to know your center's rules, and you need a good reason to refuse care from a trained staff person. It's wise to write down your concerns. Ask yourself:

- If the person made a mistake, did he or she apologize to me?

- Does this staff person treat me with respect?
- Is this a one-time mistake, or is there a pattern of errors?

Your first concern is to stay safe and healthy. If you fear that a certain staff person will harm your access or risk your safety, ask to meet with the charge nurse or head nurse. Explain the problem and offer an answer if you can.

Later in this module we'll talk about complaints and grievances, but it's best if problems can be settled without taking these steps.



“Recently we’ve had a number of ‘visitors’ in white smocks staring at me. Okay, common sense says they are students, but I don’t like it. Since I am deaf, I am very uneasy with two people standing there talking about me without me understanding. The tech was showing them my chart, and they were clearly talking about me. I kept staring right back at them but no one said a word to me. So, I brought this up in a meeting with the nurses, and they said, ‘Oh, they were only students.’ I said, ‘I don’t care who they were...I expect them to introduce themselves and tell me why they are here.’ They asked what they could do and I said ‘hire a sign language interpreter when you know they are coming or tell them to train on someone else.’ So that’s what we decided.”

Here is what one patient looks for when deciding if a clinic is right for her:

“When I go to a doctor’s office, I always check out the sink in the room. If it doesn’t look used, I’m a tad suspicious. One time the sink had a dust film on it. Hmmm!”—Robin

Responsibilities

Your job is to help your clinic work as well as it can by being on time for your visits. If you know you’ll be late or can’t be there, call. This will help the clinic serve all of its patients better—including you.

You also have a job to treat your clinic staff with respect. Yes, they work with you. But if you want something that isn’t urgent and you can see that they’re busy, try saying, “When you have a minute, would you mind...” (On a very busy day, you may have to ask more than once.)



“Please” and “thank you” go a long way toward making relationships better.

Some day, you may be the one with the urgent need, and others will have to wait while the staff takes care of you.

Rules and policies for patient care

Rights

Any clinic you go to will have rules for how care is given. These may include hours that the clinic is open, having a payment plan in place, and even how patients must behave in the clinic. You have the right to know what the clinic rules are, and to be told when they change.

The more time you spend in a clinic, the more these rules can affect you. So, if you are on HD in a center, the rules may govern your life for 15 hours or more a week. In a center, the rules may cover:

- Whether you can eat or drink during treatment
- Whether you can get a shift time that will let you keep your job
- Whether you can have a visitor during treatment
- Whether you can use a cell phone or a laptop computer





- Whether your treatment time will be cut short if you are late
- When the center can refuse to treat you
- What you need to bring if you visit a center while on vacation
- When the center will provide treatment during holidays

Responsibilities

Your job, as a patient who goes to a clinic, is to know what the rules are and to follow them.

If you don't agree with a clinic's rules, you have some options:

- Ask to meet with the head nurse or administrator and see if there is another way for the clinic to get the same result.
- Talk to your doctor to see if he or she can help you make a change or find an answer.
- Follow your clinic's grievance process to file a complaint (we'll talk more about this later in this module).
- Vote with your feet: Find another clinic. This may mean changing doctors or even moving, but it may be worth it for you.
- If you are on dialysis and you don't agree with your center's rules, you may want to think about doing a home treatment, where you have more control over your day-to-day care.

Yelling, making threats, and violence are *not* responsible ways to behave, and will not help you get what you want. In fact, these behaviors can get you discharged from a clinic and make it hard to find a clinic that will treat you. Even though some rules can be very frustrating for you, your best and safest bets are to advocate with

the clinic manager and/or your doctor to change the rules, file a complaint or grievance, or find another clinic.

Costs of care

Rights

Medical care in the U.S. can be costly. Even if you have Medicare for dialysis or a transplant, you could still be facing high out-of-pocket costs for drugs, tests, doctor visits, and treatments. It's always best—for you and your clinic—if you have other health insurance, too, that will pay for some or all of the amount that Medicare won't pay.

You have the right to know what your costs will be that are not paid for by Medicare, and to know what resources may be able to help you pay your share. You also have the right to the full details of all clinic and doctor bills. Your clinic's billing office should file insurance claims and send them in. Your social worker or your clinic's financial counselor can suggest places you can turn to for help paying your bills.

Responsibilities

It's your job to know what your coverage is and to pay bills that your insurance and/or Medicare don't cover. It's in your best interest to check over your medical bills and make sure they are correct.





Errors can happen, and you or your clinic could be overcharged.

If your health plan changes, tell your clinic right away. It can add more stress if your clinic bills you because your old health plan turns down your claim.

If you are on dialysis, the American Kidney Fund's Health Insurance Premium Program (HIPP) may help you pay your Medicare or insurance premiums if you meet their guidelines. This program is funded by donations from dialysis clinics. To learn more about it, talk with your social worker or visit www.kidneyfund.org and look under AKF Programs.

Here is what one patient had to say about payment for dialysis care:

"I know that I have been amazed at how costly dialysis is and that it is paid for by Medicare for most people. I know we have donated to the cause all of our working lives, but I, for one, do not take for granted what a blessing it is to have the financial help with something so expensive."

What to do in an emergency Rights

- You are on PD and your catheter pulled apart.
- You are on standard in-center HD and your center is closed due to three feet of snow.
- You are doing nocturnal home HD and have a question at midnight.
- You have food poisoning and can't take your transplant meds.

What do you do? Kidney disease can be scary at the best of times. [It's your right to know what](#)

[you should do if you run into an emergency or your clinic has to close.](#) As one patient says:

"Last year, during a winter storm, the power at our unit went off while 12 people were being dialyzed. The unit did not have a backup generator. We had been taught how to turn our own cranks if we were able and those who could began. Our unit is in an office complex and people from all over the complex came running to help us turn the cranks. Those with less than an hour were taken off quickly and those with longer times were cranked until the power came back on about 40 minutes later. Very scary, but I was pleased to see how ready the staff were for the emergency and how helpful the office workers were."

—Nancy

Whether you do treatment at home or in a clinic, your doctor or nurse should tell you what to do if you have an urgent question or an emergency during clinic hours or after hours. He or she should also teach you what symptoms to watch for so you'll know if your kidney disease requires a change in your treatment plan. To learn more about symptoms of kidney disease, read Module 1—*Kidneys: How They Work, How They Fail, What You Can Do*.

- 1 **If you do PD**, your PD training nurse will tell you what to do or who to call if you have an emergency. You should be given an emergency clamp kit in case you have a problem with your catheter. Your nurse will teach you how to watch for problems like *peritonitis*, an infection of the lining of your abdomen, so you can start on antibiotics right away.

Keep at least one week of your medications on hand at all times, so you don't run out.





Ask your clinic what you should do if you don't get your supplies on time.

Talk with your care team about how to make an emergency plan and kit for your home, with foods to have on hand if the power goes out. *If you use a PD cyclor,* make sure your name is on your electric company's priority turn-on list so you get power faster. Your center can help you do this.

- 2** *If you do home HD,* your home training nurse will tell you what to do or who to call if you have an emergency. You'll learn the signs of problems, how to solve problems during the treatment, and what to do if your machine is not working right. And, you have the right to know what to do if you have a problem with your access.



Talk with your care team about how to make an emergency plan and kit for your home, foods to have on hand if the power goes out. Make sure your name is on your electric company's priority turn-on list so you get power faster. Your center can help you do this.

Keep at least one week of your medications on hand at all times, so you don't run out.

- 3** *If you do standard in-center HD,* your center should teach you what to do or where to go for dialysis in emergencies like bad weather, earthquake, fire or flood, power outages, and other problems. By law, each center must have a written emergency plan and update it each year.

A dialysis center also must have an emergency tray or "crash cart" on hand and the staff should know how to use it. You have the right to know what to do in case you have a problem with your fistula, graft, or catheter.

Talk with your care team about how to make an emergency plan and kit for your home, with foods to have on hand if the power goes out. Keep at least one week of your medications on hand at all times, so you don't run out.

- 4** *If you have a transplant,* your transplant nurse will tell you what to do or who to call in an emergency. If you are on the transplant waiting list, you'll need to be in reach of a phone or pager in case a kidney is offered. Keep at least one week of your medications on hand at all times, so you don't run out. Once you have a transplant, you'll learn the signs of problems, so you can get the treatment you need to keep your new kidney working well.

Responsibilities

You can avoid some emergencies if you know what to look for. *Your job is to learn all you can about kidney disease and your treatment.* Then you can ask good questions and get the care you need to stay healthy for as long as you can.



- 1 **If you do PD**, watch your catheter, keep your emergency information handy at all times, keep an emergency food supply in a safe place, and take good care of yourself so you can stay healthy. Be sure your loved ones know what you should do in an emergency, so they're ready—just in case.
- 2 **If you do home HD**, your job is to watch your access, learn how to do an emergency disconnect from your machine, and keep an emergency food supply in a safe place—just in case. If you don't know what to do if your center is closed or your access is clotted, ask! Write down the answer and keep it where you can find it when you need it.
- 3 **If you do standard in-center HD**, keep your emergency information handy at all times, and take good care of yourself so you can stay healthy. Keep an emergency food supply on hand. Be sure your loved ones know what you should do in an emergency, so they're ready—just in case.
- 4 **If you have a transplant**, your job is to learn what symptoms to watch out for, take your drugs as prescribed, and keep emergency information handy—just in case.

Don't just expect facts to come to you—write down the name of your health problem and go out and look for more information at the library, on the internet, or from kidney groups. You can then talk over what you learn with your doctor. Be wary of internet sites that try to sell you drugs or other products to cure CKD. There is no cure for kidney failure. Be sure to look at the date the book or article was written, so you are sure it is up-to-date. Knowledge is power!

How to file a complaint

Rights

If you feel your care is not safe or is not helping you feel better, you have the right to file a complaint or a grievance. Your clinic will have a process for complaints, and you have the right to know what the process is. Write down your complaint, in detail, with:

- Dates
- Times
- What happened
- Who was involved
- Who said what
- What you tried to do to solve the problem

If there were witnesses, ask them to write down their accounts, too. There can be strength in numbers if a few people all have the same problem.

Most complaints follow a step-by-step process.

- **Step 1.** Take your concern to the person you have the problem with. Most conflicts come from communication breakdowns. You may have felt that your needs were ignored, or you weren't heard or understood. Tell that person your concerns using "I" sentences, e.g., "I felt (fill in the blank) when you said (fill in the blank)." Most conflicts can be worked out at this point if both parties are willing to talk.
- **Step 2.** The social worker at your clinic is often the next person you should speak with. He or she can gather more facts from both sides and try to work out a fair answer. You could also talk to your doctor.





- ❑ **Step 3.** You may take your grievance to the clinic administrator. You can ask for a meeting of all parties and ask for help from the social worker. You may also choose a neutral party to act as a mediator, and ask to keep your complaint private.
- ❑ **Step 4.** You can take your complaint to your local End Stage Renal Disease (ESRD) Network by calling (804) 418-7990 (or see the Personal Plan at the end of this module to find your Network). The U.S. has 18 ESRD Networks that oversee the quality of dialysis care and patient satisfaction. Your Network will explain your options and what they need from you, and then refer you to the agency that can best help you.
- ❑ **Step 5.** You can go further by calling your State Survey Agency, which inspects dialysis centers to be sure they are safe. Go to [https://www.cms.gov/SurveyCertificationGen Info/Downloads/State_Agency_Contacts.pdf](https://www.cms.gov/SurveyCertificationGenInfo/Downloads/State_Agency_Contacts.pdf) for a list.

Responsibilities

If these steps don't end in an answer you can feel good about, you have some other options, too. Keep in mind, though, that some of these can create bad feelings between you and your clinic, or get you a label as a "problem" patient who may have

a hard time finding a place to get care. Choose your battles wisely. Make sure they're worth the cost.

Here are some other steps you can take if your complaint is about a safety issue (*not* a staff member):

- ❑ Write to the regional or corporate office of the company that owns your clinic.
- ❑ Write a letter and ask patients who agree with you to sign it. Include this in your complaint or other steps you take.
- ❑ Contact your Congress person or senator's local office. You can find your Congress person at www.house.gov, and your senators at www.senate.gov.
- ❑ Find the consumer action reporter for your local newspaper or TV station and see if he or she will take on your problem.
- ❑ Talk to an attorney about your legal rights.

How One Patient Handled a Problem...

"I won't leave after a treatment until I'm sure I'm not going to bleed some more, but I'm willing to have my chair moved and wait. I have had times where they did seem to want to rush me out of the chair. I use a wheelchair and have to use my arms to move, and I can't do that if I'm still bleeding. I simply say, 'I'm not ready yet.'

"If I have a problem, first I try talking to the staff member. If that doesn't work, I go to the director of nursing. Since I'm deaf, I write a friendly note, stick to the facts, and say what I expect—that also gives you documentation. I've never had to go further than that." — Robin, on dialysis since 1997



You have no doubt seen in your life that *how* you ask for something can matter just as much as *what* you ask for. Your job is to try to be part of the solution, not part of the problem. Be polite. Stay calm. Work with your team to solve problems that you run into. In most cases, they want to help you to feel as well as you can.

Your medical chart

Rights

Did you know that you have a right to know what's in your medical chart? It's true. You can also ask your doctor to explain parts of your chart to you or a family member in plain language. What might you want to know? How about:

- Your condition
- Treatment options
- Your treatment plan
- Problems you might run into
- Prognosis (or the progress you can expect to make)
- Your lab tests, what they mean, and how you can get them closer to the normal range

If you want a copy of your chart to keep, you can ask for one—but most clinics will charge you for the cost to copy each page.

Responsibilities

To be an active partner in your care, you need to have a good sense of your own health history, such as:

- Other illnesses you have now or had in the past
- Health problems that affect members of your close family
- Drugs you are now taking or are allergic to
- Surgery you have had, why, when, etc.



It is *your* job to remind your doctor of your health care needs, and to ask if something doesn't sound right to you. Mistakes can happen. Don't let them happen to you. Here's what one patient says:

"I have a classic line from my doctor to share with you. After he finally agreed to do a 24-hour urine, he said, 'Well, your clearance was 12%. I guess you really are as sick as you said you were.' He had been telling me he thought I was about 15% to 18%. Those of you with doctors who don't listen will appreciate my restraint in not saying, 'I told you so!'"

Advance Directive

Rights

What if you had a health setback and couldn't tell the doctor your wishes? Would you ever want to be on a machine to help you breathe? Would you want someone in your family to speak for you? How can you protect yourself?





The good news is, you have the right to sign an “Advance Directive” to state your wishes ahead of time. If you sign an advance directive, it is your job to give a copy to your clinic, your doctor, and your loved ones. Every adult should think about having an advance directive. There are two types, and you can sign one or both:

- 1 A **Living Will** is a way to state your wishes for your health care, in case a time comes when you can't speak up for yourself.
- 2 A **Health Care Power of Attorney** form lets you choose someone to work with your doctors and decide what treatment you should receive if you can't state your wishes yourself.

Health care advance directives are legal in all states, but some states require certain forms. Ask your social worker about the laws and forms in your state. The Partnership for Caring has advance directives for each state at <http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3289>.

The American Medical Association offers four main questions that you should ask yourself when you think about an advance directive:

- 1 **What are my goals for medical treatment?** Your advance directive will be different if your goal is to live as long as you can than if you want to have a certain quality of life, or you just want to be kept comfortable and have a peaceful passing. What are your thoughts right now about goals for your treatment?
- 2 **Who should be my agent (if I can't direct my own care)?** You may or may not have someone you trust enough to put in charge if you can't decide for yourself. Talk to the person you choose as your agent

to be sure he or she is willing to take on the role. Have a back-up agent, in case your first choice is not around when you need help. What are your thoughts right now about who to choose for an agent?

- 3 **How specific should I be?** Your advance directive can state your values and wishes in general, or you can add a lot of detail about just what treatments you would or would not want. You can't cover every case, so talk with your agents and be clear about *why* you are making your choices. What are your thoughts right now about how much detail you want to go into?
- 4 **How can I make sure that health care providers will follow my advance directive?** Your doctor may not agree with your choices. By law, a doctor can follow his or her own conscience, but will need to help you find a doctor who will follow your wishes. Your job is to give a signed copy of your advance directive to your doctor and talk about it. Your center must tell you its policy about advance directives. If the center will not honor your wishes, you may want to choose another center.

What if I Change My Mind About My Advance Directive?

No problem! You can change an advance directive at any time by writing out a new one and destroying all copies of the old one. Give a copy of the new one to your doctor, your clinic, your family, and anyone else who had the old one. Be sure to ask them to destroy your old one.



Your Right to Take Part in Your Care and Treatment

So far in this module, we've talked about your rights and responsibilities for information. Now we'll move on to our second main point: your rights and responsibilities for taking part in your care and treatment. *You have a care plan and can take part in team meetings about your care.* Ask when the meeting is and plan to attend.

When it comes to your health care, your voice matters. You have the right to help decide about things that affect your care. This may sound strange to you, if your doctor has made most of your medical decisions until now. But kidney disease care is a team effort, and you are the most important person on your team.

After all, it is your health at stake. So it makes sense that you would have a large part to play in:

- Choosing or changing your treatment
- Refusing treatments, tests, or research
- Getting information you can understand
- Seeing a social worker and dietitian as often as you need to

On Dialysis? Take Part in Your Care Plan

If you are on dialysis, your care team must make a long-term care plan for you at least twice a year. You may have been given a copy of your care plan to sign after your team put it together.

But you may not know that you have the right to take part in making your care plan. Ask your team to include you in care plan meetings, and you can have more input into your treatments.

- Getting a second opinion or changing doctors
- Transferring to another clinic

Let's look at these one at a time, along with the jobs that go along with each one.

Choosing or changing your treatment

Rights

You have the right to choose what treatments you want for your kidney disease. If you choose a treatment and it doesn't fit your life or make you feel better, you have the right to change treatments. You also have the right to know what your lab tests mean and how their results guide your treatment.

As you can imagine, your right to choose treatments depends on what treatments will work best for you. This right also depends on how willing you are to seek out a treatment you want that your doctor or clinic may not offer.

Responsibilities

You are the one who will have to fit your kidney disease treatment into your life. *Your job is to be sure you know enough to make an informed choice.*

If you don't feel like you have enough facts, ask for more! Take a class. Ask to talk to patients who are doing the treatments you're thinking about. Go to the library. Get on the internet. Find what you need. Ask your doctor and care team:

- What tests you are being given, why, what the results are, and how the results will guide your care.
- What drugs you are being given, what they do, what side effects to watch out for, and if there are less costly drugs that do the same thing.



- What treatments there are to help your problem, and where you can get them if your doctor or clinic do not offer them.
- How well your treatments are working and if any other treatments might work better for you.
- Other questions: _____



Once your treatment plan is set, it is also your job to follow it. This means taking prescribed drugs, having your lab tests done, going to clinic visits, following your meal plan and fluid limits, and getting all of your prescribed dialysis.

An active role in your care means that you learn as much as you can about your disease and its treatment. Speak up if you are confused or don't know what something means. Ask for information in plain language, or write things down so you can look them up later (ask how to spell medical terms). Here is what one person says about taking an active role:

“How could someone with kidney failure not be involved with their care? My husband does home hemo. We are both very involved with his treatment. He has taken info off the internet to his doctors.”

“We discuss everything and question what we don't understand. Even some of our friends who go to a center to be dialyzed take an active part in their treatment. It doesn't matter what treatment you use. Just ask questions and be involved. Believe me, life will be much better.”

What Patients Say About Working with Doctors

“I once told my doctor that I was feeling very tired. He told me my blood work looked normal and that it ‘must be in my head’. I asked him how he knew how I felt? I also told him that I didn't care how many years' experience he had or how many patients he has seen, he will never know just how another person feels. After that he had a new attitude.” –Mike

“When I was first diagnosed, my doctor was excited because he thought I could go right from a kidney that wasn't working to a transplant and skip dialysis. I had tons of info on transplant before I finally got any on dialysis (and that wasn't even from my health care team, it was from my state chapter of the National Kidney Foundation—my health care team gave me little info on dialysis!). At the time, I did not feel that transplant was the right option for me. I realized that a quick change in my health care team was essential. You're the boss. It's your choice and your life and body. I found the perfect team for me and couldn't be happier.” –Andy



Refusing treatments, tests, or research

Rights

Medicine is both a science and an art, so health care choices are not always clear cut. Your care team may suggest treatments you don't agree with. Or, you may have two or more doctors who don't agree on what your best treatment option is.

Just as you have the right to choose which treatments to do, you also have the right to refuse treatments you *don't* want to do. You can refuse to take drugs and/or have tests done.

What Are My Rights in Research?

Research can help doctors and scientists improve care—which may benefit you, or may help other people in the future. If you are asked to take part in a research study, you have the right to:

- Have the study explained to you in detail
- Sign an informed consent if you take part, and keep a copy
- Have your chart kept private for the study staff only
- Be given a number to call if you have questions
- Drop out of the study at any time

Ask questions to be sure of what you're being asked to do. Some studies ask you to fill out forms, some ask you to take certain drugs, and some studies even test out new surgery methods. Make sure you know the benefits and risks to you, and that you feel comfortable with them.

The decisions you make will affect your health. You can refuse to take part in research studies, too. This will not affect the care you receive.

Responsibilities

As an informed health care consumer, before you refuse a treatment, drug, or test, you need to know:

- What the treatment is
- How it is supposed to help you
- What your other options are
- What is likely to happen if you don't have the treatment

Ask questions until you have enough answers to make a good choice.

If you decide not to do a treatment, take a drug or a test, or take part in research, you may be asked to put your refusal in writing. In some cases, you may be asked to sign an “Against Medical Advice”





(AMA) form. This form protects the clinic from lawsuits later, makes it clear that you know that your doctors and nurses believe you need the treatment, drug, or test for your health, and that you are taking responsibility for refusing the treatment.

Getting information you can understand

Rights

You can't take part in your care if you don't know what your care team is saying. [Whether you have a hearing impairment or you speak a language other than English, you have the right to translation or an interpreter to help you talk with your care team.](#) The dialysis center cannot charge you a fee for this service.

The rules do not say how often an interpreter must be offered. The courts have found that not having an interpreter can be a violation of the Americans with Disabilities Act if a patient is not able to communicate with the care team.

[If you have a vision problem, you have the right to be told information in large print, Braille, or some form that will be useful for you.](#)

Responsibilities

Ask for an interpreter before a clinic visit if there is something you want to talk about. If you will be starting dialysis, you may want to ask for an interpreter to be on hand for your first two or three treatments so you can ask questions and the staff can tell you what is going on.

Some clinics will let you bring along a family member or friend to interpret for you, between professional interpreter visits. If you use a family member or friend to interpret for you, this person



will learn things you may not want them to know. Never ask a young child to interpret for you, since this can be emotionally harmful.

When you use an interpreter, ask questions to be sure he or she understands your language and your health problem and medical terms well enough to be able to talk to your health care team.

You may also want to think about other ways you might talk with your team, such as writing notes back and forth. (A family member or friend may be able to help you if English is not your first language.)

Seeing a social worker and dietitian as often as you need to

Rights

The Medicare Conditions for Coverage require all dialysis centers to have a social worker with a master's degree and a renal dietitian to help patients. If you are on dialysis, you have the right to receive social work and dietitian services.

Responsibilities

As much as your health care team wants to help you, they can't read your mind. [It's your job to ask for what you need, take notes, and ask](#)



What Can a Social Worker and Dietitian Do for Me?

A **social worker** might:

- Help you and your family to cope with dialysis
- Suggest tips to help you solve problems with your family, friends, or clinic staff
- Offer counseling or referrals to help you fight depression
- Refer you to vocational rehabilitation to help you keep your job or get a new one
- Give you a list of dialysis centers you could go to on your vacation, so you can make travel plans
- Find resources to help you pay for your treatments
- Help you find transportation to get to your treatments
- Help you find programs to help you pay for your prescribed drugs

A **dietitian** might:

- Help you understand your meal plan and fluid limits
- Tell you the nutrient contents of your favorite foods, so you can fit them into your meal plan
- Suggest ways to season your food without salt to make it tasty
- Give you tips for what to order in restaurants that will suit your meal plan
- Explain your lab test results, how they relate to your meal plan, and whether you are getting enough dialysis
- Counsel you about exercise to help you get started with an activity plan
- Suggest healthy ways to gain or lose weight (if needed)
- Give you tips for dealing with thirst



follow-up questions if you need to. If the social worker or dietitian is not at the clinic when you are, set up a time to meet or leave a message with your number and the best time to call. If you don't get a call back, talk with the clinic manager and ask if he or she can relay the message. Help your social worker and dietitian help you do better!

Getting a second opinion or changing doctors

Rights

Some people are shy about asking for a second opinion, or worry that their doctor will be upset. But asking for a second opinion is well within your rights, and most doctors don't take offense. In fact, some insurance companies require a second opinion before they will approve a costly treatment. **If you want a second opinion, you have the right to expect that your doctor will refer you to someone.**

With a chronic disease like kidney disease, you need to find a doctor who:

- Offers you the most effective treatment options for your health problem
- Respects your knowledge of your own body





- Is willing to answer your questions and help you learn more
- Stays up-to-date on treatment advances that could help you
- Listens to you and takes your values and lifestyle into account
- Takes your insurance

You need to work so closely with your nephrologist that if you don't get along well, you may want to think about changing doctors.

Responsibilities

Your insurance may or may not pay for a second opinion if you want one. If it doesn't, it is your job to pay for the visit.

Relationships with doctors—as with others—are a two-way street. If you have a hard time getting along with your doctor, talk to him or her and see if you can work it out before you move on. Each patient has different needs, and your doctor may be able to meet yours—if he or she knows what they are.

If you decide to change doctors, it is polite to tell your current doctor. Your new doctor's office will ask you to sign a form to get a copy of your health records from your old doctor.



Transferring to another clinic

Rights

If you're not happy with the care at your clinic, you can switch—if there is another clinic in your area that your health plan covers, and if it has a spot for you. You might also think about doing a home treatment where you can have more control over who helps you with your care. Changing clinics may mean changing doctors as well. You will have to ask your doctor if he or she treats patients at another clinic.

You have the right *not* to be discharged from your clinic without your consent, as long as you pay your bills, your behavior does not harm you or other patients or clinic staff, and the clinic can provide the care you need. If you are discharged, the clinic must give you a 30-day notice (unless the issue is your behavior) and try to find you another center.

Some dialysis centers may discharge patients who:

- Shorten or miss dialysis treatments
- Don't follow their diet or fluid limits
- Advocate for themselves or others with center staff
- Complain about center conditions or staff

While some of these behaviors may not be in your own best interests, and others may upset the center staff, *they should not be the cause of a discharge action*. Medicare's Conditions for Coverage for dialysis centers (section 405.2138) gives you the right to be transferred or discharged *only* for medical reasons, for your welfare or for the welfare of other patients, or for nonpayment of fees. If your center discharges you, staff must



give you advance notice—unless your behavior is threatening or violent. Then the action can be immediate.

Responsibilities

If you have kidney disease and are not happy with your clinic, it's your job to talk to your doctor, insurance company, or the clinic administrator about your other options. You'll need to find out if there are other clinics nearby that can help you—and that are paid for by your insurance.

If you are on dialysis and need to transfer to another dialysis center, it's your job to talk with your social worker about your options. He or she can tell you about other centers in your area. You can also look for a new center yourself. There are a few ways you can find a new center if you're not happy with your current one, if you're moving to

a new place, or if you'd like to travel:

- ❑ At www.globaldialysis.com, you can look for centers in the U.S. or around the world.
- ❑ To find a clinic that offers home dialysis (PD or home hemo), go to the “Find a Center” database at Home Dialysis Central: www.homedialysis.org.
- ❑ Once you find a center, go to Medicare's Dialysis Facility Compare site at www.medicare.gov/Dialysis/Home.asp or the Dialysis Facility Tracker by ProPublica (<http://projects.propublica.org/dialysis/>) to learn how it compares to other nearby centers for dialysis adequacy, anemia control, and patient survival, what types of dialysis they offer, and more!

Your Right to Respect and Dignity

We've talked about your rights and responsibilities for information, and for taking part in your care and treatment. Now we'll move to our last main point: your rights and responsibilities for respect and dignity.

Needing treatment for kidney failure does not make you less of a person. *You have the right to be treated with consideration and respect, to receive treatment that is equal to what other patients are getting—at home or in a center—and to have your privacy and confidentiality maintained.*

Being treated with respect Rights

You have the right to be treated with respect by your doctor and all staff members of the clinic. This means, among other things, that you will be treated kindly, that your requests will be heard and

What Things Could Get My Center to Discharge Me?

The kinds of behaviors that have caused patients to be discharged include:

- Yelling at, swearing at, or threatening staff or other patients
- Assaulting staff or other patients
- Sexually inappropriate behavior
- Bringing a weapon to treatment
- Not following center rules

Standing up for yourself if you have a real grievance should not get you discharged—stay calm, document your problem, and follow the steps in this module.



responded to, and that you will be safe. Expect that your modesty will be protected, i.e., curtains will be pulled if you need to use a bedpan or if use of your access will expose part of your body.

In turn, your job is to treat the staff with the same respect you expect from them. Try to be patient about getting your needs met when your team is busy caring for others. Be clear about which of your requests are urgent, and which can wait a little while until someone can help you.

In the dialysis center, it is also your job to respect the rights of other patients and visitors who share the same space with you, sometimes for a few hours at a time. This might mean that you:

- Ask before you choose a TV channel, if you need to share a TV.
- Take turns choosing a channel, if you don't agree on what to watch.
- Bring headphones when you listen to music, so others don't have to hear it, too.
- Turn off the sound on hand-held games so the beeping doesn't annoy others.
- Cover your nose if you sneeze, or your mouth if you cough.
- Skip perfume, in case people are allergic to it.
- Talk softly if you are using a cell phone.
- Don't share medical information you hear about someone else.

Receive equal treatment

Rights

You have a right to receive health care without discrimination. Each person—no matter what



race, color, sex, religion, sexual preference, national origin, or how they pay for treatment—has a right to expect good, safe medical care.

Responsibilities

If you believe you are being treated differently by your care team or clinic because of your race, color, sex, religion, sexual preference, national origin, or how you pay for treatment, follow the steps we talked about to file a complaint. We'll add those steps to your Personal Plan at the end of this module.

Medical privacy

Rights

It is your right to expect that your health and payment records will be kept private unless you give written permission to release them.

A law called the "Health Insurance Portability and Accountability Act" (HIPAA) gives you even more rights to ensure that your health records stay private. This law makes sure your personal health information goes only to people who need to see it to care for you.



Module 14 – Rights and Responsibilities

The HIPAA Privacy Rule also lets you:

- Request to correct your chart or have a letter of disagreement put in your chart if you think there is an error, like a wrong diagnosis
- Decide who can see your chart
- Keep a hospital from telling people if you are admitted
- Ask your care team to keep communication to you private (such as sending letters instead of postcards or leaving messages on your voice mail at home, but not at work)

Keep your health records private, know your rights, and don't be afraid to ask for them. Many health providers are now giving you their privacy policies. Read and keep them. It's just one more way of being an active part of your health care team.

We're ready to wrap up this module on Rights and Responsibilities. You may have a lot more rights than you knew about before reading this module! This is good news, because knowing what your rights are allows you to use them to your benefit. And, of course, you benefit most when you use your rights responsibly. It's time to move on to your Personal Plan, which you can use as a reminder of what you've learned.



Personal Plan for _____
Patient Rights and Responsibilities

My Right to Information	
I have the right to:	My job is to:
Know about my health problem: my diagnosis, what I can expect, and my treatment options.	Learn all I can, decide what treatment I want, and: <ul style="list-style-type: none"> ■ Follow my meal plan and fluid limits ■ Take my medications ■ Come to my clinic visits on time ■ Get all my prescribed treatments ■ Report my symptoms or problems ■ Ask questions if I don't understand
A clean, well-run, adequately-staffed clinic that follows laws.	Be on time for my visits, and call if I have to be late or miss a treatment.
Care team members who wash their hands and put on clean gloves before touching me.	Ask my care team members to wash their hands and put on fresh gloves if they forget.
Ask health care workers about their training, and refuse treatment by a trainee unless a staff member is supervising.	Treat my clinic staff with respect, say “please” and “thank you,” and wait my turn if my request isn't urgent.
Know the rules at my clinic.	Follow the rules—if I don't agree, I can talk to the staff, find another clinic, or try home dialysis.
Know how much my care will cost and what resources can help me pay.	<ul style="list-style-type: none"> ■ Know my insurance coverage ■ Check my bills for errors ■ Pay my share ■ Tell my clinic if my insurance changes ■ Ask for help if I can't afford care



Personal Plan for _____ (continued)

My Right to Information (continued)	
I have the right to:	My job is to:
Know what drugs are prescribed for me, what they do, what side effects they may have, and what I should watch out for.	Ask my doctor or pharmacist about my drugs and take them: <ul style="list-style-type: none"> ■ At the right time ■ In the right dose ■ As prescribed ■ With or without certain foods
Know what to do in an emergency if I'm on PD, home HD, standard in-center HD, or have a transplant.	Avoid some emergencies by knowing what to look for, and: <ul style="list-style-type: none"> ■ Learn all I can about my disease ■ Keep at least one week of medications on hand ■ Keep an emergency food supply ■ Keep my clamp kit handy, if I do PD ■ Know the signs of peritonitis, if I do PD ■ Know the signs of access problems, if I do HD
File a complaint or grievance if I feel my care is not safe or is not meeting standards for good care.	<ul style="list-style-type: none"> ■ Write down my complaint ■ Talk to the person involved ■ Ask my social worker to help ■ Talk to the clinic administrator ■ Talk to the ESRD Network ■ Talk to the Medicare State Survey Agency
Know what is in my medical chart.	Know my medical history, remind my doctor of my needs, and ask if something sounds wrong to me.
Complete an Advance Directive of my health wishes.	<ul style="list-style-type: none"> ■ Give a copy of my Advance Directive to my clinic, my doctor, and my family ■ Be sure my doctor and the person I ask to act for me know my wishes and agree to follow them



Personal Plan for _____ (continued)

My Right to Take Part in My Care and Treatment	
I have the right to:	My job is to:
Decide what treatment I want, and change treatments if I'm not happy.	Think through what I decide and learn enough to choose wisely.
Understand my lab tests and how their results guide my treatment.	Ask my doctor and team: <ul style="list-style-type: none"> ■ What tests I'm being given and why ■ What the results mean ■ How my test results will guide my care
Refuse treatments, drugs, or research that I don't want.	Know what I'm refusing, what my options are, and what will happen to me.
Have an interpreter if I can't hear or understand my care team.	Ask for an interpreter when I need one.
Have social work and dietitian services (if I'm on dialysis).	Ask for what I need, take notes, and ask follow-up questions as needed.
Get a second opinion.	Pay for the visit if my insurance doesn't cover it and talk to my doctor about my needs.
Not be discharged against my will except for medical reasons, for my own welfare or the welfare other patients, or for non-payment.	File a complaint or grievance, and refer to Medicare's Conditions for Coverage, section 405.2138.
Transfer to another clinic.	Talk to my clinic, doctor, insurance company, or social worker about my other options.

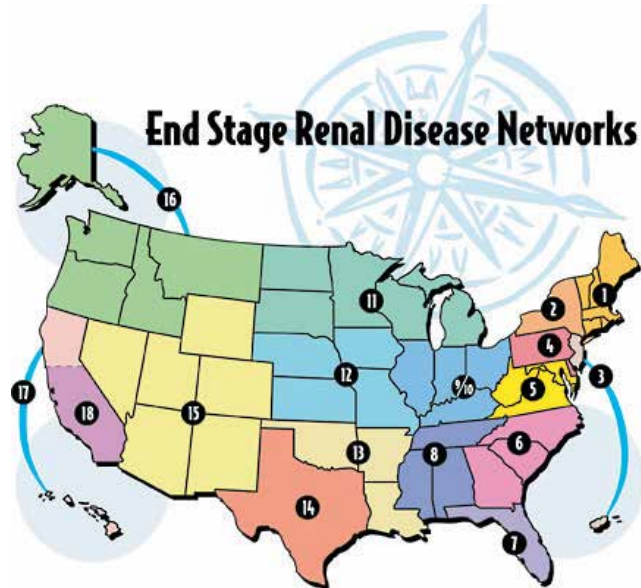


Personal Plan for _____ (continued)

My Right to Respect and Dignity	
I have the right to:	My job is to:
Be treated with consideration and respect.	Treat the clinic staff with respect, and respect the privacy and rights of others.
Receive medical care without discrimination.	File a complaint or grievance.
Medical privacy.	Ask for my medical records if I need them, keep my records private, and know my rights.



Personal Plan for _____ (continued)



Network 1 – Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont
Phone: (203) 387-9332

Network 2 – New York
Phone: (800) 238-ESRD

Network 3 – New Jersey, Puerto Rico, Virgin Islands
Phone: (609) 490-0310

Network 4 – Delaware, Pennsylvania
Phone: (412) 325-2250

Network 5 – Virginia, West Virginia, Maryland, District of Columbia
Phone: (804) 794-3757

Network 6 – Georgia, North Carolina, South Carolina
Phone: (919) 855-0882

Network 7 – Florida
Phone: (813) 383-1530

Network 8 – Alabama, Mississippi, Tennessee
Phone: (601) 936-9260

Network 9/10 – Illinois, Indiana, Kentucky, Ohio
Phone: (317) 257-8265

Network 11 – Minnesota, Michigan, North Dakota, South Dakota, Wisconsin
Phone: (651) 644-9877

Network 12 – Iowa, Kansas, Missouri, Nebraska
Phone: (816) 880-9990

Network 13 – Arkansas, Louisiana, Oklahoma
Phone: (405) 942-6000

Network 14 – Texas
Phone: (972) 503-3215

Network 15 – Arizona, Colorado, Nevada, New Mexico, Utah, Wyoming
Phone: (303) 831-8818

Network 16 – Alaska, Idaho, Montana, Oregon, Washington
Phone: (206) 923-0714

Network 17 – American Samoa, Guam, Mariana Islands, Hawaii, Northern California
Phone: (415) 897-2400

Network 18 – Southern California
Phone: (323) 962-2020



Take the Kidney Quiz!

You'll see how much you're learning if you take our quick kidney quiz. It's just 10 questions. How about it? (*Answers are on page 14-2.*)

- 1. Knowing about your rights as a patient can help you to:**
 - a) Get free drug prescriptions
 - b) Get the best care and make good decisions
 - c) Get more medical care for less money
 - d) Get rid of your health problem
- 2. You have a right to know all of the following *except*:**
 - a) The name of your condition
 - b) Your doctor's home phone number
 - c) Possible problems that might happen down the road
 - d) All of the treatment options available to you
- 3. Once a treatment plan is in place, whose main job is it to follow the plan?**
 - a) Your doctor's
 - b) Your nurses'
 - c) Your clinic staff's
 - d) Yours
- 4. If a staff person helping you is a trainee, you have the right to:**
 - a) Ask a trained person to supervise them
 - b) Refuse treatment
 - c) Ask about his or her training and background
 - d) All of the above
- 5. When you take prescription drugs, which of these is *not* your job?**
 - a) Know the chemical formula of each drug
 - b) Know what each drug is for
 - c) Know what side effects each drug might have
 - d) Take the drug at the right time, in the right dose
- 6. You have the right to get a list of rules from your clinic and to be told when the rules change.**
 - a) True
 - b) False
- 7. If you have a grievance about your clinic or how a staff person treats you, your best first step is to:**
 - a) Go to the media
 - b) File a lawsuit
 - c) Complain to your family
 - d) Talk to the person you have a problem with
- 8. An *Advance Directive* is:**
 - a) Driving directions your clinic mails you before your first visit
 - b) A way for you to describe your medical wishes
 - c) A way for your doctor to give you instructions
 - d) A legal notice of your clinic's rules and policies
- 9. You have the right to decide what treatment you want for kidney disease, and to change treatments if your treatment:**
 - a) Doesn't fit your lifestyle
 - b) Doesn't make you feel better
 - c) Both a and b
 - d) None of the above
- 10. If you decide to change doctors, make sure you:**
 - a) Don't tell your current doctor
 - b) Ask for a copy of your medical records to be sent to your new doctor
 - c) Apologize to your current doctor for leaving
 - d) Move to another state





Additional Resources

In addition to the free Life Options materials you can find at www.lifeoptions.org, the resources below may help you learn more about the topics in this module of Kidney School.

PLEASE NOTE: Life Options does not endorse these materials. Rather, we believe you are the best person to choose what will meet your needs from these or other resources you find. Please check with your local library, bookstore, or the internet to find these items.

Materials:

- 1 ***Advance Directives, Dialysis Patient's Bill of Rights and Responsibilities***, and ***Transplant Recipients Bill of Rights and Responsibilities***, are all available from the National Kidney Foundation (NKF). If you would like more information, please call (800) 622-9010 or visit the NKF website at www.kidney.org/atoz/index.cfm, click on "Search by Letter."
- 2 ***Consumer's Tool Kit for Health Care Advance Planning***, available from the American Bar Association's Commission on Law and Aging at www.abanet.org/aging/toolkit/home.html.

Websites:

For more information about your rights and responsibilities as a person with kidney disease, visit the following websites:

- 1 Home Dialysis Central has information about the five types of dialysis that can be done at home, and where to find them—plus patient stories, equipment, message boards, and much more at www.homedialysis.org.
- 2 Kidney Community Emergency Response Coalition (KCER). Learn what to do in case of an emergency at www.kcercoalition.com.
- 3 The Center for Practical Bioethics (provides Advance Directive and other information) at www.practicalbioethics.org/cpb.aspx?pgID=886.
- 4 The Forum of End Stage Renal Disease Networks (map) at www.esrdnetworks.org.
- 5 Kidney End-of-Life Coalition (for more information on advance directives and end-of-life care for people with kidney failure) at www.kidneyeol.org/.
- 6 Medicare's Dialysis Facility Compare website will let you compare the quality of dialysis centers at www.medicare.gov/Dialysis/Home.asp.
- 7 Medicare general information at www.medicare.gov/, Medicare contacts and questions at www.medicare.gov/Contacts/Home.asp, and Medicare dialysis publications list at www.medicare.gov/Health/Dialysis.asp.



Module 14 – Rights and Responsibilities

Please Note

Use of Kidney School does not replace the need to talk with your health care team about your care and your options.

Legal Disclaimer

The information you find on the Life Options website or printed pages, including Kidney School, is provided “as is,” and to the extent permitted by law, the Life Options Rehabilitation Program, the Medical Education Institute, Inc., and their affiliates, employees, officers, board of directors, or shareholders give no warranty of any kind, either express or implied, including without limitation any warranties of condition, quality, performance, merchantability, fitness for a particular purpose, or non-infringement in relation to information, services, or products provided through or in connection with the Life Options website or printed pages. To the extent permitted by law, the Life Options Rehabilitation Program and the Medical Education Institute, Inc. disclaim all liability for any damages or injury caused by any failure of performance, error, omission, deletion, defect, access to, alteration of, or use of record, whether as a result of breach of contract, tortious behavior, negligence, or under any other cause of action. The contents of the Life Options website and printed pages, including, but not limited to text, graphics, and icons, are trademarked materials owned or controlled by the Medical Education Institute, Inc. *No permission is granted here for you to reprint in whole or in part Life Options or Kidney School content, graphics, illustrations, photographs, or icons.* (Revised March, 2015)

