



Module 3

Working with Your Healthcare Team



Module 3 – Table of Contents

Your Team	3-5
<i>Family and friends</i>	3-5
<i>Primary care doctor</i>	3-6
<i>Nephrologist</i>	3-6
<i>Nurse</i>	3-8
<i>Dietitian</i>	3-9
<i>Social worker</i>	3-11
<i>Dialysis technician</i>	3-12
<i>Surgeon</i>	3-13
<i>Home dialysis supplier</i>	3-13
<i>Vocational rehabilitation counselor</i>	3-13
<i>Physical therapist</i>	3-13
<i>Occupational therapist</i>	3-14
<i>Pharmacist</i>	3-14
Personal Plan	3-18
Take the Kidney Quiz!	3-20
Additional Resources	3-21

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)

- | | |
|---|-----|
| e | (5) |
| c | (6) |
| a | (8) |
| b | (7) |
| b | (9) |

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

Module 3 – Kidney Quiz Answers





You have most likely been on a team at some time in your life. Playground games, sports, school clubs, and company work groups are just a few of the many teams you might know. And all of these teams have one thing in common: they start out with a shared goal.

It's easy to see how members of a sports team or a work group share a goal. But what does this have to do with chronic kidney disease (CKD)?

Well, kidney disease is complex. You need a team of committed experts to help you manage it. The common goal for your team is to help you live well with kidney disease.

Depending on what kind of treatment you choose for your kidney failure, key players on your team might include:

- **You**
- **Family/Support People**
- **Primary Care Doctor**
- **Nephrologist**
- **Nurse/Home Training Nurse**
- **Dietitian**
- **Social Worker**
- **Dialysis Technician**

Did you notice that the first person on the team is YOU? Whether you know it or not, *you are the leader* of your health care team. All of the other people on your team come together at various times and places to help you manage your kidney disease. But you are the one who is always there. And *you* are the one who knows *you* best!

Your health care team looks to you to see how CKD and its treatment make you feel—and for follow-through on what they suggest.



Some teams achieve great things—and others lack focus. You need to do your part, so your health care team can help you to do better. They depend on you as much as you depend on them.

In this module, we'll take a closer look at each of the key people who make up your health care team. Each one has a unique role.

Why should you care about who is on your health care team? Because when you know what each team member does, and what each one needs from you, you'll be better able to make sure that you get the quality care you need to feel your best.

Let's get started. And, since you are the team leader, let's begin with you.

The idea of being the leader of your health care team may be new to you. If so, you're not alone.



Many people take a passive role with medical professionals. They don't see themselves as having anything to offer, or don't think their health care team wants to hear from them. After all, the doctors and nurses are the experts. Right?

It's common to think that health care professionals know a lot more about your disease and treatment than you do. But, while they are experts in their field, they are not experts on what happens inside *you*. They can't read your mind to learn what questions you have, or what suggestions you might like to make about your treatment. They also don't know how you feel physically or emotionally—unless you tell them.

You might also feel unsure about how to talk with your care team members. They are the ones with

the technical knowledge, and it may seem as if you don't even speak the same language! It may surprise you to learn that most health care workers want patients to be honest. If you tell them how you're feeling, they will be better able to help you.

If you ask questions already, that's great. Asking questions is one of the best ways to learn what health care professionals are thinking and planning for your treatment.

If you didn't have to worry about how a certain health care team member might react, which of these would you like to do? Check all that apply:

- Ask questions about my condition and treatment
- Offer suggestions about my treatment
- Explain symptoms that worry me
- Discuss emotional issues I am having about kidney disease
- Add your own comments here:

Which of these professionals would you like to work with on these issues? Check all that apply:

- Primary Care Doctor
- Nephrologist
- Nurse/Home Training Nurse
- Dietitian
- Social Worker
- Dialysis Technician
- Other: _____

What Two Patients Say About Being on Their Health Care Team

"I'm part of the team. I can tell them if something's wrong with me and how I'm feeling, and then ask a question, 'Is that normal?' And they can say, 'Well, I don't know,' or, 'Yeah, it is kind of normal.' And so then you're not thinking of yourself as, 'Well, I'm feeling crazy.'"

—Kelly R., hemodialysis patient

"I think before the treatments can be effective, you've got to kind of do your part. Like liquids—taking in too many liquids, that's something that's done very innocently. I didn't know that I would want a glass of lemonade as bad as I do, but now I'm very conscious of the fact that, you know, I take a half a glass, not the full glass."

—Harold R., hemodialysis patient





Your Team

Family and friends

The team members who probably mean the most to you are loved ones. Think of at least one person (or more) that you find is a good source of support for you in your journey with kidney disease. Who are your team members?

- 1 First Name: _____
- 2 First Name: _____
- 3 First Name: _____
- 4 First Name: _____

Loved ones can act as more than support members of the team. They can also help you make decisions about your treatment. Even though you are the best expert on you, sometimes you need an objective opinion from someone who knows you well. Let's look at an example.

Jack, age 56, has had kidney disease for 14 years. Now his kidney function has dropped, and he has been trying to decide which type of dialysis will work best for him. His doctor has told him about all of the options. Jack likes the idea of having four days off from dialysis a week with in-center hemodialysis (HD). But, he worries about how he will keep his full-time job when he has to be at a dialysis center three times each week. The center can't promise him a shift that will allow him to work.

So, Jack is thinking about peritoneal dialysis (PD), but wonders if he can discipline himself to do the exchanges each night with a cycler machine. He asks his wife and sister what he should do and they agree that he needs to choose a treatment that allows him keep his job, which he loves. They



also suggest that he ask his doctor about getting listed for a transplant before he starts dialysis and they offer to be tested as possible donors.

Since it looks as if Jack will need dialysis soon, he asks the home dialysis training nurse if he can talk with someone who has been doing PD for a while, so he can learn how PD can fit into his life and work. The home training nurse has patients who like to talk with other new patients. After talking with a couple of patients, Jack decides that using a cycler and doing PD at night, while he sleeps, would best fit his lifestyle and his job.

Jack has learned about many new options. He may be able to get a living donor transplant; or, he can get on the list for a deceased donor kidney. He can do automated PD (APD) with a cycler—or switch to PD by hand. If PD no longer fits his life, he can do home HD with his wife and sister as

What Kinds of Dialysis Are There?

For a complete description of these treatment methods and others, see Module 2—*Treatment Options for Kidney Failure*.



helpers. Home HD can be done for just a couple of hours each day—so Jack won't have ups and downs in how he feels—or at night while he sleeps, so his days are free. Either way, he'd have fewer diet and fluid limits, need fewer drugs, and have more energy. Or, he could try to do in-center HD and ask for a shift time that fits with his work hours.

Jack decides to start PD and makes an appointment to get a catheter. Jack made his own choice. His doctor, wife, sister, the home dialysis training nurse, and other patients helped him to see his options more clearly. He feels more in control and more hopeful about his future with kidney disease.

Another important way family and close friends can be helpful team members is by acting as an extra set of eyes, ears, and mouths. Whenever you can, bring a support person with you to your doctor's visit, dialysis treatment, etc. Your support person might see things you didn't see, or ask questions that you hadn't thought of. Plus, having another person along can be comforting.

Remember, though, that it's not your loved ones' job to make decisions that you can make for yourself. They can support you, give their opinions, and help with problem solving, but *you* need to make the decisions and follow through with them. And don't forget to tell them how important their support is to you!

When you start to expect family and friends to do *for* you what is really *yours* to do, they might resent your lack of responsibility. This, in turn, might cause your close relationships to be less supportive than they could be. Don't take these vital team members for granted!

Primary care doctor

The care team member you may know the best is your primary care doctor. This doctor may be



a general practitioner, an internist, or a family practice doctor. He or she may care for your usual health concerns, like regular checkups and blood tests. Your primary care doctor may also care for your health problems, like diabetes, arthritis, high blood pressure, heart problems, and other ailments—including kidney disease.

Depending on your health, you may even have a few doctors. If you do, you'll want to be sure that they're all working together as members of your team. How? Ask your doctors if they speak or write to each other about your case. Make sure that you know what each doctor says so you can fill in gaps for them about your care.

Nephrologist

People who are on dialysis have even more members on their health care teams. Under Medicare rules, each dialysis center must provide





a nephrologist, registered nurse (RN), registered dietitian (RD), and social worker with a master's degree (MSW). Other professionals may be called upon to help as needed. Medicare pays for most of the treatment, which is why it can require certain team members and training.

Let's find out what each of these people does and how they work together as part of your team.

A nephrologist is a doctor who has had special training in kidney diseases. Your nephrologist is the point person for your dialysis team. He or she prescribes the treatment, monitors your health, and makes any needed changes to your treatments, based on how they are affecting you.

People on dialysis should see their nephrologist often, either at the office or at the dialysis center. Some patients prefer to set up an office visit every month or two so they can talk about their concerns in private. In this way, the doctor sees you on your feet, dressed nicely, and looking like a healthy person.

"When I was on PD we had clinic appointments. At that time we would see the doctor in an office privately. Now that I'm on hemo, the doctor comes around to our chair, either every or every other Monday. I know this is good that he comes around while we are at dialysis because of our time, but that has a lot of drawbacks, too. For one thing, it's not private at all. Our unit is pretty noisy, so to be heard you must speak loud. The doctor is standing and we are sitting. I guess I'm just not comfortable sharing my medical problems with those around me. I know sometimes I don't even ask the questions that I should." —Joyce

The nephrologist can answer medical questions that you and your support team may have. Some people don't ask their doctors questions. Do you?

If not, check the reasons below that apply to you.

I don't ask questions because:

- The doctor will think I'm stupid if I ask a dumb question.
- The doctor might be harsh in his/her answer.
- I'm taking up too much of the doctor's valuable time.
- The doctor will think I don't trust him/her if I ask questions.
- I can never remember my questions once I get in the doctor's office, or because I feel unwell on dialysis.
- I won't understand the medical terms in the answer, anyway.

These are just a few of the many reasons people with kidney disease do not get the information they need from their doctors. The more you

A Nephrologist Talks About Working with Patients

"In the setting of chronic illnesses, passive roles equate with sick roles. People who assume the sick role want a great deal of care handed to them. And while all of us, I think, recognize that when we don't feel good we like to be cared for, long-term, that does not instill the ability for people to fit the illness into their lives. If we alter the passive role into a more active role, we get patients to assume day-in, day-out life—be it work, play, family—the things that really are more important than just one dialysis treatment. In order to get to those things, people have to be active. We have to encourage the active role."
—Bryan Becker, MD, nephrologist



What Does the Word “Nephrologist” Mean?

- **Nepbro** is a Greek word meaning *kidney*.
- The ending, **logist**, means *a specialist*.

A nephrologist is a kidney specialist.

pursue answers to your questions, the better informed you will be. The better informed you are, the more control you will feel over your kidney disease.

It’s true that doctors are busy and have limited time to spend with each patient. Still, you have a right to expect that your doctor will spend some time answering your questions and listening to your ideas and concerns about how your treatment is working for you.

One In-center Dialysis Nurse’s Thoughts on Patients as Partners

“I think it’s very important that the staff and patients are partners. We see these patients three times a week. They get to be our friends, almost, because they’re there a long time, some people are there for years, three times a week. And if they’re not involved in their own care, you don’t have as good communication with them, and you don’t have that openness between the patient and the staff. So we try to encourage, from the day they start on dialysis, that they communicate with us and ask if they have questions. We try to tell them everything they need to know.” —Jan S., dialysis nurse since 1976

Choosing a nephrologist

How do you choose a nephrologist? Your choice may be very easy if there is only one kidney specialist in your area, or if a doctor you trust refers you to a nephrologist. Your choices may also depend on your insurance plan’s list.

What is most important with a chronic disease, like kidney failure, is that you find a doctor who can explain things to you in a way that you understand. The disease will never go away—so you need to be able to take part in your care and help make medical decisions. To do this, you need a good working relationship with your doctor.

Some people are very surprised to learn that all doctors are not the same! Sometimes one doctor’s personality can be a better fit for you than another’s, even if they both have the same medical knowledge. And some doctors may be more up-to-date on new treatments than others.

It’s okay to change doctors to find one who can work well with you. Ask your doctor if he or she is “board certified” in nephrology. This means that he or she passed a test to become a specialist in kidney disease.

Nurse

Your doctor may suggest that you speak with a nurse to learn more about your treatment choices and daily care. Dialysis centers—both for HD and PD—always have nurses on staff to supervise treatments and educate patients.

Nurses differ in their training. Some of the nurses you may encounter in your unit include:

- Licensed Practical Nurse (LPN) – completes a 2-year training program
- Registered Nurse (RN) – completes a 2- or 4-year college degree and passes a special test





- Certified Nephrology Nurse (CNN) – a registered nurse who also completes training focused on nephrology and passes a special test
- Nurse Practitioner (NP) – completes special training for providing primary health care and passes a special test

Other credentials that you may see include:

- Bachelor's of Science Degree in Nursing (BSN) – completes at least 4 years of college coursework focusing on nursing
- Master's of Science Degree in Nursing (MSN) – completes *at least* 1 more year of college coursework beyond a BSN

You can find out what type of nurse training the nurses on your team have by asking or looking at their name tags if they're wearing a tag. What initials do you find after their names? Nurses are good sources of information. They can answer many questions about your health. They will be most able to help you if you tell them about any health concerns or related problems you might be having.

You can call with questions any time. PD and home HD programs have someone on call 24 hours a day to help you answer questions and find solutions.

If you are on in-center HD, remember that your nurse is busy taking care of a number of patients at one time. You can expect a nurse to answer your questions and provide a listening ear—but the nurse can expect you to wait until there is time to talk. Try not to ask your questions while patients are being put on the machine or taken off, or if there is a medical crisis.

Waiting just a few minutes, and being respectful of nurses' jobs, will go a long way toward helping you get what you need from them.



Dietitian

On dialysis, one of the first team members you might see is the dietitian. The dietitian plays a key role in the treatment of your kidney disease. He or she will explain why you need to control your eating habits and food choices, and will work with you to develop an eating plan that meets your special needs.

Renal dietitians (renal is a word that means kidney) are registered with the American Dietetic Association (ADA). They have a college degree and have special training and work experience in the field of renal nutrition.

The renal dietitian's main goal is to help people make wise food choices and learn how to include their favorite foods in their "eating plan," when they can. To make this plan, the dietitian will ask you about your eating habits and food choices. Then other information is taken into account, like blood test results, medical history, current health concerns, and other factors.

All of this is then woven into a meal plan for you and your family to follow. Although the plan may be easy to understand, it's not always easy to follow. The dietitian will try to include as many



of your favorite foods in your meal plan as possible. But it's important that you know why your dietitian might suggest certain food and drink limits.

Healthy kidneys work 24 hours a day to remove waste products from the blood that build up mainly from the foods we eat. If you're only getting standard in-center HD treatments 3 times a week, you will need to strictly limit the amount and types of foods you eat and fluids you drink each day. Standard in-center HD requires the most limits on food and fluids of any treatment. The diet and fluids on PD are less limited. Doing HD more often or longer means fewer limits on diet and fluids, too. If you do short daily home HD (2 to 3 hour treatments 5 to 7 days per week), you may have *very* few limits. The *most* normal diet and fluids are found with nocturnal HD (8-hour-long treatments done at night, while

you sleep, 3 to 6 nights per week). Nocturnal HD gets the blood very clean, so you don't have to do as much of the work yourself with what you eat and drink. Your dietitian can suggest healthy food choices based on the type of treatment you do.

By making better food choices, you will have more comfortable dialysis treatments, better long-term health, and be able to have an active and healthier lifestyle. You will feel better and be more able to do the activities you like.

Your health care team can usually tell if you are following your meal plan by looking at your blood test results.

Once the dietitian has looked at your nutritional needs and designed a meal plan, he or she will track your blood tests monthly to see how you're doing. The dietitian will also teach you and your family ways to maintain or improve your food and fluid intake.

What Do Blood Tests Have to Do with What I Eat?

Blood tests are done to measure levels of certain chemicals in your blood. Many of these chemicals are parts of the foods you eat. For example, many fruits and vegetables—like avocados, bananas, dried fruit, oranges, tomatoes, potatoes, strawberries, and watermelon—are high in potassium.

Since damaged kidneys can't remove potassium, you need to keep a close watch on how much potassium you eat. If blood levels of potassium get too high, sudden heart failure (death) can occur.

Module 7—*Understanding Kidney Lab Tests* talks about lab tests and how to use them to check on how you're doing.





Your dietitian can offer education and practical tips to improve your health and make meal times pleasant for you and your family. Check the topics on the list below that you would like to know more about. I would like to (check all that apply):

- Learn how certain foods and fluid levels affect my body
- Understand my blood test results
- Know how to make good food choices at restaurants
- Make the meals I eat similar to those my family eats
- Find some cookbooks for dialysis patients
- Add your own:

Because we must eat a few times each day and so many social events involve food, sticking with your meal plan can be a challenge. Your dietitian knows this and can help you fine-tune your food choices. Ask for recipes and sample meal plans. See if your dietitian can help you adjust your favorite recipes so you can have them—at least once in a while. Dietitians can also help with eating out and fitting diet into social activities.

If you waiver from your meal plan, don't be afraid to tell! Your dietitian doesn't want to be the food police or make you feel guilty. Instead, the aim is to help you get back on track. Ask questions whenever you need to. Many dietitians will welcome a phone call when you have questions between visits.

Social worker

When most people think of social workers, they think of government workers who help the poor. Few patients starting dialysis know that the social worker on their team can help them get financial

and other help, and also help them cope with kidney disease and treatment.

Your social worker will talk with you soon after you start treatment and can help you most if you are open and honest about how you feel. He or she may ask about your background and concerns, including:

- Who is in your family and who is at home with you
- What other support you can count on
- Your work and vocational goals
- Your treatment choice and how it affects your lifestyle and job, if you have one
- Your health insurance
- Your money concerns
- How you plan to get to and from dialysis three times each week, if you choose standard in-center HD
- Your household chores
- Your other health problems and how you have coped with them
- What activities you enjoy

Your social worker can help you address problems or concerns and plan for changes that you will likely face. Your social worker wants to help you live a full life, whether you do dialysis at home or in a clinic.





Dialysis technician

As the final members of your primary health care team, most HD centers have technicians who perform the treatments, under a nurse's supervision. Which of the tasks below do you think a technician might do? Check all that apply:

- Monitor vital signs like blood pressure.
- Ensure proper functioning of the dialysis machine.
- Order needed supplies for dialysis.
- Clean the dialyzer (filter) in the dialysis machine.
- Educate me about kidney disease.
- Put in and remove needles—until I learn to do this myself.

At first glance, it seems that a dialysis technician should be able to do all of these. Most standard in-center HD clinics have three types of technicians. Patient care technicians (PCTs) run the dialysis treatment under the supervision of the nurse. Machine technicians maintain and repair broken machines. Reuse technicians clean dialyzers if your clinic reuses them. Some technicians do more than one of these roles. They are not trained or expected to teach you on general health care questions. Most technicians can explain dialysis and how it works to filter your blood, but questions beyond this are best asked of your doctor or nurse.

If you choose standard in-center HD, the technicians are the members of the care team you will see and talk to most often. They can even grow to seem like family. But they are health care workers, not your friends. Don't cross the line and offer them gifts, loan them money, or spend time with them outside of the clinic. You can treat each other with respect and enjoy each other's company while you're at the center.

A typical HD treatment lasts 3 to 5 hours, three times a week. As the technician checks your progress during each treatment, you will have many chances to ask questions and learn more about dialysis.

In many HD units, technicians are the team members who put the needles into the patients' accesses. You need to learn where the needles should go in your access at each treatment, so you can guide the technician. If one staff member's needle technique hurts you or causes swelling and a bad bruise, consider asking to learn how to put in your own needles. If you have a graft, you'll learn the "ladder technique" to choose different places and avoid harming your graft. You can learn to place needles in the same spot over and over using the "buttonhole technique" if you have a fistula. Patients who put in their own needles say they have less fear and pain, and feel more in control. They seem to have fewer problems and their accesses last longer. You can learn more about dialysis access in Module 8—*Vascular Access: A Lifeline for Dialysis*.

Now you've learned about all of the primary players in your starting line-up. Every person on dialysis will need to work with them. There are other health care professionals that you won't likely see at a dialysis center, but may need to see at some point. These include:

- Surgeon
- Home Dialysis Supplier
- Vocational Rehabilitation Counselor
- Physical Therapist
- Occupational Therapist
- Pharmacist

Let's take a brief look at how each of these professionals might be able to help you.





Surgeon

A surgeon will be needed to place a PD catheter, create an HD access, or do a kidney transplant. Your nephrologist will arrange for you to meet with a surgeon, if needed. Before you get an access for dialysis, ask your nephrologist to refer you to a surgeon who does an excellent job creating dialysis accesses. You want the surgeon that your doctor would send his own mother to. This surgeon might not be in your town—but if you are able and willing to find the best surgeon, your access may last longer with fewer problems.

Home dialysis supplier

When you do home HD or PD, your nephrologist prescribes the machine and supplies you need to do home dialysis. The machine and supplies generally come from the company that makes them. Most patients order supplies once a month by calling customer service. During training, your home training nurse will talk with you about when to call the clinic and when to call the company if you have a problem at home.

Vocational rehabilitation counselor

If you are of working age, kidney disease and dialysis can make it a challenge for you to work. A vocational rehabilitation (VR) counselor can help you find ways to begin or keep working while on dialysis. VR counselors may be able to help you get retrained for another job—if you can't keep doing the job you were doing—or even go to school. Ask your renal social worker about how to get VR counseling.

Physical therapist

Did you know that even people in their 80's and 90's can become stronger, more flexible, and better able to prevent falls? A physical therapist (PT) can help you improve your strength, flexibility, and endurance. Physical therapists can test your abilities and give you exercises to do at home or on dialysis.

Physical therapists can also help treat certain types of pain and help the body recover from

Your full team looks like this:

Team A:

- You
- Family/Support People
- Primary Care Doctor
- Nephrologist
- Nurse/Home Training Nurse
- Dietitian
- Social Worker
- Dialysis Technician

Team B:

- Surgeon
- Home Dialysis Supplier
- Vocational Rehabilitation Counselor
- Physical Therapist
- Occupational Therapist
- Pharmacist



damage caused by an accident or illness. If you have a problem, injury, or illness that is limiting your activities, your doctor may refer you to a physical therapist.

Occupational therapist

Day-to-day skills like opening jars, buttoning clothes, and tying shoes can be hard if the fine motor skills of the hands and fingers are poor. An occupational therapist works on fine motor skills, like building hand strength or improving daily living skills.

Your doctor can refer you to an occupational therapist if you have a problem that limits your ability to take care of yourself at home.

Pharmacist

And finally, pharmacists play a role familiar to most of us. They are experts on any drug questions you might have. Most are willing to answer any questions you have over the phone.

It is important to tell the pharmacist **all** of the drugs you are taking, including over-the-counter and herbal medicines, because some drugs may react badly with other drugs. Even some vitamins or food supplements can harm people with kidney disease. Do not assume every drug

you take is “in the computer.” Sometimes errors are made—and you don’t want them made on you! Keep your own up-to-date list of what drugs you take, and in what doses.

Although most dialysis centers do not employ these additional health professionals, they can refer you to one if the need arises. Do you have a current need to consult with one or more of these team members? If so, check the ones that apply:

- Surgeon
- Home Dialysis Supplier
- Vocational Rehabilitation Counselor
- Physical Therapist
- Occupational Therapist
- Pharmacist

At the start of this module, we talked about the goal the team has for you. Your goal is to be as healthy as possible, despite kidney disease—to live long and live well. And that is also the goal each member of your health care team should have as they work with you.

Think of this shared goal as you and your team trying to work a jigsaw puzzle. Each member





puts clusters of pieces together by carefully looking at all of the colors and contours of your condition.

They then hand you those clusters in the form of education and care. The picture becomes visible when you connect those clusters of pieces to other pieces. If *you* put them where they don't belong, or choose to not fit them in at all, the picture (goal) will never be reached.

This puzzle example is meant to reinforce how important your role is on the team. *You* are the one who must apply the knowledge that your team members give you, by making good choices about your care and treatment.

Your team members can teach, encourage, support, and train you—but they can't make daily decisions

for you. It is *your* life, not theirs. That is why in this module, and in *all* of the modules of Kidney School, we stress choice and responsibility as keys to living long and living well with kidney disease.

Before we wrap up this module, let's talk about three ways you can take responsibility with your health care team. Just remember these words:

1 Positive Attitude

2 Get Answers

3 Take Action

Sometimes how you present yourself to the other members of your team can make a difference in the care you get. Let's imagine, for a moment, that you are the nurse.

Keep a Notebook About Your Kidney Disease

Some people find it useful to keep a notebook to help them keep track of kidney disease over time. In the notebook, they write down lab tests, drugs they take, questions they have for members of the team, and other information.

Bringing the notebook to each visit helps patients to remember questions and lets them focus on other important things. As one patient says:

"I actually carry a notebook. It's always with me. It's either in my car or it's at home. And in that notebook are things that the doctors and nurses have told me to do, or suggested that I read. It also gives you progression on how you're being treated, what are those vital signs. It forces you to say, 'Oh, yeah, I am getting better here and

I'm getting worse here, and we need to do something about that.' For me, that's key.

"I try, as best as I can, to focus on positives. You can't always do that, because as you think about what's wrong with you, you're led to certain conclusions that aren't always positive. And you deal with that as best as you can. One of the things that I've done is, back when my son was a teenager, we wrote down things to be grateful for. It's kind of a gratitude book. It's actually part of the notebook that I carry around. And whenever I get down, I'll pick out a page or two and just read about those things that I'm grateful for—it's mostly people, relationships, things that I've done, things that I've accomplished, people that I've affected. That's what I'm grateful for." —Jim H., hemodialysis patient



Whom would you rather care for and answer questions for:

Patient A, who has a **positive attitude** and is trying to stay as healthy as possible?

Or **Patient B**, who is rude and demanding, yells at the staff, and isn't making any effort to help him- or herself?

Yes, *every* patient deserves to get good care. But when there is limited time, you can bet that Patient A will get his or her needs met more completely than Patient B. Staying positive and respecting the staff's time will help you to work well with your care team toward your common goal: helping *you* do better.

Here's what one patient has to say about knowing how and when to ask questions:

"You've got to use your head. At the beginning of the shift when they're putting lots of people onto the machines and things are buzzing—in my opinion, that's not the time to talk about a headache you had last night. But when things simmer down and you see people kind of getting a little relaxed, my favorite lead is, 'When you get time, I've got a couple questions I want to ask you. But no hurry, I'll be here for 4 hours, so you just go ahead and do what you've got to do.' And you find out then that they'll take more time with you because you're respecting their workload."

—Harold R., hemodialysis patient

The second way to take responsibility is to **get answers** to your questions. You can seek answers to some of your questions by going to the library and looking in books or journals. Some questions can be answered by members of your health care team. And some answers can be found on the internet. You can refer to

the resources section following this module for links to other internet resources.

Now that you know who does what on your team, think about which team member would be most likely to have the answer to your question. Look for a good chance to ask it. Any question, however basic, is a good one!

Do you have questions right now that you would like to ask someone on your health care team?

- Yes
- No

Which team member(s) do you have questions for? Check all that apply:

- Family/Support People
- Primary Care Doctor
- Nephrologist
- Nurse/Home Training Nurse
- Dietitian
- Social Worker
- Dialysis Technician
- Other:

Write a brief sentence or two that will help you to remember your question.

It's fine if you don't have any questions for now. At some point, you will. When they do occur to





you, be sure to write them down.

The third way to take responsibility: **take action.**

Part of taking action is talking about your health, lifestyle habits, emotions, and struggles to your team members. Each one wants to help you. But because they are busy or distracted, they may not ask you as much as you would like. So it becomes *your* job to make sure your team knows what your needs are.

A notebook, if you start one, can be a helpful tool for this. Use the second half of your notebook as a journal. Use it to write down your

symptoms, any life changes, new skills you have learned, emotional struggles, successes you have had, etc. Review your notes often and transfer any points you want to mention to team members to the front section, along with questions to ask.

Finally, another part of taking action is to apply what you learn from the wealth of knowledge, training, and resources your team offers you. You and your team need to work together. People who have lived 20, 30, or more years on dialysis share one key thing in common: they are active players on their own health care teams.

It's time to wrap up this module on working with your health care team. But before we do, we want to give you a Personal Plan to help you get a start on some of the most important ideas in this module. We encourage you to put it where it will remind you of the goals toward which you're working.



Personal Plan for _____ *Working with Your Health Care Team*

The Members of My Dialysis “A” Team Are:

- Me
- Family/Support People
- Primary Care Doctor
- Nephrologist
- Nurse/Home Training Nurse
- Dietitian
- Social Worker
- Dialysis Technician

Family/Support People

I will let my family and close friends support me, offer feedback, and help me while I make my decisions and follow through on those decisions.

Doctor/Nurse

My doctor and nurse are my best resources for questions about my overall health, kidney disease, drugs, and related matters. I can expect them to answer my questions if I am willing to ask them.

Dietitian

I will use the dietitian to understand my meal plan and ask any questions about my food and fluid intake.

Social Worker

I will honestly discuss my lifestyle habits, emotional and support issues, and other matters with the social worker.

Dialysis Technician

I will respect and work with my technician, if I do standard in-center HD, but I won't offer gifts, loan money, or spend time with him or her outside of the clinic.

The Members of My Dialysis “B” Team Are:

- Surgeon
- Home Dialysis Supplier
- Vocational Rehabilitation Counselor
- Physical Therapist
- Occupational Therapist
- Pharmacist

Each member of the “B” team can be used if and when the need arises.

Surgeon

Reason to consult: when I need to place a PD catheter, create an HD access, or for a kidney transplant.





Personal Plan for _____ (continued)

Home Dialysis Supplier

If I do home dialysis, I will order my supplies once a month by calling my home dialysis supplier.

Vocational Rehabilitation Counselor

Reason to consult: find ways to keep working or start working while I have dialysis, or find and fund retraining or school in order to return to work.

Physical Therapist

Reason to consult: to improve my physical stamina, fitness, flexibility, and mood.

Occupational Therapist

Reason to consult: to develop my fine motor skills/hand strength, and to give me the tools and tips to improve how I do my daily chores and tasks.

Pharmacist

Reason to consult: to ask about my drugs and their interactions.

The Goal

My goal, as well as my team's goal, is to maintain or improve my health while living with kidney failure. I am the one who must apply the knowledge I gain from my team members by making good choices.

I feel there is a current need to consult with a
(*write down your answer from page 3-14*):

and will discuss this with my doctor.

To reach my goals, I must practice three important principles:

- 1 Keep a Positive Attitude** — Choose to focus on the good things in my life. Think about how I present myself and my concerns to people on my team.
- 2 Get Answers** — Seek out the answers to my questions. Other members of my team can help me find the information I need.
- 3 Take Action** — Apply what I know from the knowledge, training, and resources I find.

One practical way to achieve these three principles is to use a notebook to record questions and concerns to share with other team members.



Take the Kidney Quiz!

You'll see how much you're learning if you take our quick kidney quiz. It's just 9 questions. How about it? (*Answers are on page 3-2.*)

- 1. A nephrologist is:**
 - a) A doctor specializing in foot problems
 - b) A doctor who is a kidney specialist
 - c) A nurse who specializes in kidney problems
 - d) The person who runs the dialysis machine
- 2. If you have a question about how much protein you should eat in a day, the best person to ask is the:**
 - a) Technician
 - b) Nephrologist
 - c) Dietitian
 - d) Nurse
 - e) Social worker
- 3. The dialysis team member you most likely will spend the most time with is a:**
 - a) Technician
 - b) Nephrologist
 - c) Dietitian
 - d) Nurse
 - e) Social worker
- 4. The team member who will adjust treatments, based on how your body reacts, is a:**
 - a) Technician
 - b) Nephrologist
 - c) Dietitian
 - d) Nurse
 - e) Social worker
- 5. The team member who can talk with you and your family about coping with kidney disease is a:**
 - a) Technician
 - b) Nephrologist
 - c) Dietitian
 - d) Nurse
 - e) Social worker
- 6. You are a key player on your own health care team because:**
 - a) You get to call the shots and make all the decisions
 - b) You are the expert in how your treatments affect your body
 - c) You can file a complaint if you are not included
 - d) You know everything there is to know
- 7. A surgeon is an additional team member you may need to see to discuss:**
 - a) Drugs and their interactions
 - b) Having an access or a transplant
 - c) Dietary concerns
 - d) Developing fine motor skills
- 8. The team member you would see to discuss continuing or beginning work as you participate in dialysis treatment is the:**
 - a) Vocational rehabilitation counselor or social worker
 - b) Occupational therapist
 - c) Career counselor
 - d) Physical therapist
- 9. A physical therapist can help you:**
 - a) Choose a physician
 - b) Improve fine motor skills
 - c) Develop physical stamina and overall muscle strength
 - d) Negotiate employer/employee conflicts





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.

Books:

- 1 ***Help, I Need Dialysis!*** by Dori Schatell, MS, and Dr. John Agar
(Medical Education Institute, 2012, http://www.lifeoptions.org/help_book, ISBN-13: 978-1937886004)
Easy to read, fully referenced book covers the lifestyle impact of each type of dialysis—including a chapter on how to choose a dialysis clinic.
- 2 ***The Intelligent Patient's Guide to the Doctor-Patient Relationship: Learning How to Talk So Your Doctor Will Listen***, by Barbara M. Korsch and Caroline Harding (Oxford University Press, August 1998, ISBN-13: 978-0195126570)
This book gives advice on getting the most out of doctor visits and is based on both sample and real-life doctor-patient conversations. You will learn how to ask the right questions and understand the answers. This book also describes the training that doctors go through, which helps the reader understand the doctor's side of the relationship.
- 3 ***The Patient's Guide to Medical Terminology***,
by Charlotte Isler (Practice Mgt. Information Corp., September 1997, ISBN-13: 978-1885987082)
The author translates well over 1,000 terms and more than 500 abbreviations into easy-to-understand language. This book takes some of the “fear of the unknown” out of medical language.
- 4 ***Working with Your Doctor: Getting the Healthcare You Deserve***,
by Nancy Keene (Patient Centered Guides, July 1998, ISBN-13: 978-1565922730)
This book contains stories from both doctors and patients who share, in their own words, the lessons and strategies they have learned in their medical journeys. This book presents helpful information on topics such as finding the right doctor, communication, rights and responsibilities of the physician and patient, handling conflict, and options for taking action if you've been wronged.

Other materials:

- 1 ***Health Care Team***, by the National Kidney Foundation (NKF). For more information or to obtain this item, please call the NKF at (800) 622-9010 or visit their website at www.kidney.org/atoz/atozItem.cfm?id=70.
- 2 ***Ask Me 3™—Good Questions for Your Good Health***, by the Partnership for Clear Health Communication. For more information visit their website at www.npsf.org/askme3/.