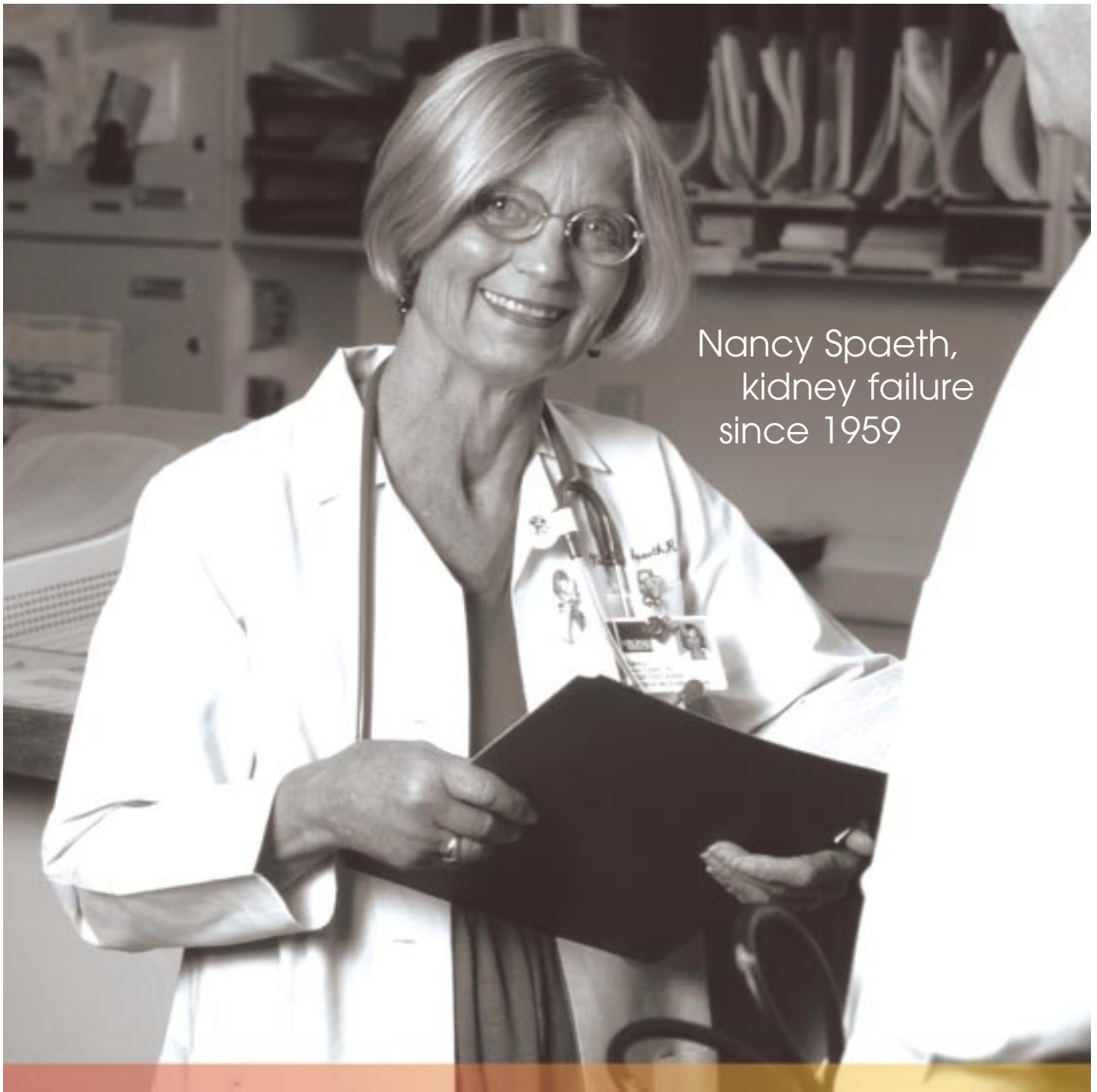


# Kidney School™

## Module Three: Working with Your Healthcare Team



Nancy Spaeth,  
kidney failure  
since 1959

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## About Kidney School

Welcome to the print version of Kidney School! Kidney School will help you learn to take an active role in your healthcare decision making. Research suggests that kidney patients who become active partners in their care are more likely to live long and live well.

Kidney School is an on-line learning program designed to help people understand kidney disease and its treatment, adjust to kidney disease, make good medical choices, and live as fully as possible. You decide which modules to read and when—so what you learn is entirely up to you.

Kidney School was developed to:

- Offer free, up-to-date, research-based information, at your own pace.
- Help you learn what to expect and what questions to ask.
- Provide the tools you need to self-manage your care so you can stay healthier and keep doing the activities you enjoy.

Kidney School is a project of the **Life Options Rehabilitation Program**. Sponsored by Amgen Inc. and administered by the non-profit Medical Education Institute, Life Options is a program of research and research-based educational materials to help people with kidney disease live long and live well.

All Life Options programs, including Kidney School, are guided by the Life Options Rehabilitation Advisory Council (LORAC), a national expert panel of patients, doctors, nurses, researchers, social workers, dietitians, physical therapists, and administrators.

All content for the Life Options program and for Kidney School is developed by Life Options staff and reviewed by members of the multidisciplinary LORAC and by additional patients and kidney professionals. Life Options and Kidney School content is entirely independent of and not influenced by its corporate sponsor(s).

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A special thank you is extended to members of the Dialysis Support mail list at [www.yahogroups.com](http://www.yahogroups.com), who allowed themselves to be quoted, took the time to review Kidney School, and who provide constant inspiration through their compassion, willingness to share, and ability to live fully with kidney disease.



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# **Module 3— Working with Your Healthcare Team**

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**Y**ou have most likely been on a team at some time in your life. Playground games, sports, school clubs, and corporate 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 football team or a work group share a goal. But what does this have to do with kidney disease?

Well, kidney disease is complex. So, 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 members/support people
- Doctor
- Nurse
- Social worker
- Dietitian
- Dialysis technician

Do you notice that the first person on the team is YOU? Whether you know it or not, *you are the leader* of your healthcare 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 healthcare team looks to you to learn how kidney disease and its treatment affect you—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 healthcare 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 healthcare team. Each one has a unique role.

Why should you care about who is on your healthcare 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.

So, let's get started. Since you are the team leader, let's begin with you.

The idea of being the leader of your healthcare 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 healthcare team wants to hear from them. After all, the doctors and nurses are the experts. Right?

It's common to think that healthcare 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 health 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 healthcare workers want patients to be honest. If you tell them how you're feeling, they are better able to help you.

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

If you didn't have to worry about how a certain healthcare 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:

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

- Doctor
- Nurse
- Social worker
- Dietitian
- Dialysis technician
- Other: \_\_\_\_\_

## What Two Patients Say About Being on Their Healthcare Team

Here's what two patients say about being on their healthcare 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?

First Name: \_\_\_\_\_

First Name: \_\_\_\_\_

First Name: \_\_\_\_\_

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 4 days off from dialysis a week with in-center hemodialysis. 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 four times every day. Jack's wife and sister have been very helpful in the years since he learned he had kidney disease. He decides to ask them about which treatment he should try.

Both of them agree that he needs to try to keep his job, which he loves, and get on the transplant list. So, trying to get used to the daily treatments of PD seems like his best choice, for now. If PD doesn't work for him, then he can look into home hemodialysis, or into in-center hemodialysis (HD) and see if he can get a shift that will let him work.

Jack uses this input to decide to get a catheter placed so he can do PD. Jack decided, but he drew on the knowledge of the people closest to him to help him see his choices more clearly.

Another important way family and close friends can be helpful team members is by acting as an

### What Kinds of Dialysis Are There?

For a complete description of these treatment methods and others, see Kidney School Module 2: *Treatment Options and Lifestyle Changes*.

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 raise 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

A team member you probably know is a 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.

## What Does the Word "Nephrologist" Mean?

- "Nephro" is a Greek word meaning kidney.
- The ending, "logist" simply means a specialist.

A nephrologist is a kidney specialist.

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 healthcare 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 do 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 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 normal, healthy person.

"When I was on PD we had clinic appointments. At that time we would see the doctor in an office

## 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*

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’m afraid that:

- 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.
- Other:

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 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 going for you.

### 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 exams 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 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 healthcare 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 looking at their name tags. What initials do you find after their names? Nurses are good sources of information. They can answer many questions about your health concerns. They will be most able to help you if you tell them about any health concerns or related problems you might be having.

If you are on PD, you will probably see a nurse at your clinic visits, and you can ask your questions then, or call between appointments.

If you are on 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.

## One 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., renal nurse since 1976

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. Since your blood is not being cleaned all the time, you need to limit the

## 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, it's important 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.

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



amount and certain types of foods and fluids you consume each day. Your dietitian can suggest healthful food choices that reduce the amount of waste and fluid that builds up in your body.

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 healthcare 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.

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

Another player on your primary healthcare team is the social worker. He or she has a master's degree in social work, and can give you and your family a wealth of information and emotional support as you begin and continue dialysis.

Often, you will speak with a social worker within the first 2 weeks of starting dialysis. The social worker will ask you questions about your lifestyle, your goals, medications, insurance, transportation, family support, finances, work plans, and other issues. These topics are covered to better understand what problems you might be having related to kidney disease and dialysis.

Social workers often spend most of their time dealing with questions of insurance, Medicare, and transportation—and these are important concerns. But of all the team members, the renal social worker is best trained to help you with your emotional struggles, which are common in people who have a chronic disease, like kidney failure.

Below is a list of emotional concerns some dialysis patients face. Do any of these apply to you?

Check all that apply:

- I'm worried that I may die much sooner than I should.
- I feel like I'm all alone dealing with this disease.
- I'm worried about money—how are we going to pay for this?
- I'm concerned about keeping my job or caring for my kids.
- I have no sex drive, and don't know if I ever will again.
- I feel less attractive and worry that my partner will leave me.
- I'm wondering if and when I will ever feel better.
- I want to know, why is this happening to me?
- I'm worried about asking my family/friends about giving me a kidney.
- I'm concerned about being on dialysis for the rest of my life.
- Add your own:

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## Dialysis technician

As the final members of your primary healthcare team, most hemodialysis centers have dialysis 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 patients about kidney disease.

At first glance, it seems that a dialysis technician should be able to do all of these. Dialysis technicians are trained to order supplies; monitor your vitals signs during dialysis; and start, maintain, stop, and clean the dialysis machine. They are not trained or expected to educate you on general healthcare 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.

A typical HD treatment lasts 3–5 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 person's needle technique hurts your access, you may want to tell the charge nurse you don't want that staff person to stick you again. You may have to put your request in writing.

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

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These include:

- Surgeon
- 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 may be needed to create a dialysis access, or do a kidney transplant. Your nephrologist will arrange for you to meet with a surgeon, if needed.

## 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



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 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.

## Pharmacists

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 be harmful to 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
- Vocational Rehabilitation Counselor
- Physical Therapist
- Occupational Therapist
- Pharmacist
- Other:



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 healthcare 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.

So your full team looks like this:

### **Team A:**

- You
- Family/Support People
- Doctor (Nephrologist)
- Nurse
- Dietitian
- Social Worker
- Dialysis Technician

### **Team B:**

- Surgeon
- Vocational Rehabilitation Counselor
- Physical Therapist
- Occupational Therapist
- Pharmacist

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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 on the team is. *You* are the one who must apply the knowledge that your team members give you, by making good choices about your self-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 healthcare 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. Who 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 himself?

Yes, *every* patient deserves to get good care. But when there is limited time, you can bet that Patient A will get his 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 healthcare team. And some answers can be found on the Internet (such as here in *Kidney School*). You can refer to the resources section following this module for links to additional 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 healthcare team?

- Yes
- No

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

- Family
- Doctor
- Nurse
- Dietitian
- Social Worker
- Dialysis Technician
- Other:

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

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It's fine if you don't have any question 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.

## Keep a Notebook About Your Kidney Disease

Some people find it's helpful 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 gets rid of the need to remember questions, and frees up their minds to 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, back when my son was a teenager is, 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*



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 symptoms, emotional struggles, successes you have had, new skills you learned, 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 know 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 healthcare teams.

Being active means taking the initiative to apply all that you know. And when you don't know, find out—then apply it. Before we bring this module to a close, we want to give you a personal plan. This plan will remind you of points you want to act on and give you a summary of this module.

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## Personal Plan for \_\_\_\_\_

### *Working with Your Healthcare Team*

#### **The Members of My Dialysis “A” Team Are:**

- Me
- Family/Support People
- Doctor (Nephrologist)
- Nurse
- Social Worker
- Dietitian
- 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***

Dialysis technicians often order supplies; monitor vitals signs during dialysis; and start, maintain, stop, and clean the dialysis machine.

#### **The Members of My Dialysis “B” Team Are:**

- Surgeon
- Vocational Rehabilitation (VR) 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: to create a dialysis access or obtain a kidney transplant.

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## Personal Plan for \_\_\_\_\_

*(continued)*

### ***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 my function.

### ***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 15):*

\_\_\_\_\_

and will discuss this with my doctor.

To do this 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.

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## 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?

- 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 healthcare 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 treatments 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

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There, you've finished the test! We'll show you the correct answers so you can see how you did:

- |            |   |            |   |
|------------|---|------------|---|
| <b>1.)</b> | b | <b>6.)</b> | b |
| <b>2.)</b> | c | <b>7.)</b> | b |
| <b>3.)</b> | a | <b>8.)</b> | a |
| <b>4.)</b> | b | <b>9.)</b> | c |
| <b>5.)</b> | e |            |   |

Thank you for completing Module 3 of Kidney School! Learning about kidney disease is one way to help yourself or a loved one live long and live well with kidney disease. We hope this module was helpful to you and we invite you to look at other Kidney School modules:

Module 1—Kidneys: How They Work, How They Fail, What You Can Do

Module 2—Treatment Options for Kidney Disease

Module 3—Working with Your Healthcare Team

Module 4—Following Your Treatment Plan

Module 5—Coping with Kidney Disease

Module 6—Anemia and Kidney Disease

Module 7—Understanding Kidney Lab Tests

Module 8—Vascular Access: A Lifeline for Dialysis

Module 9—Nutrition and Fluids for People on Dialysis

Module 10—Getting Adequate Dialysis

Module 11—Sexuality and Fertility

Module 12—Staying Active with Kidney Disease

Module 13—Heart Health, Blood Pressure, and Fluids

Module 14—Patient Responsibilities and Rights

Module 15—Alternative Remedies

Module 16—Long-term Effects of Kidney Disease

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## Additional Resources

In addition to the free Life Options materials you can find at [www.lifeoptions.org/combined/materials/indexpa.shtml](http://www.lifeoptions.org/combined/materials/indexpa.shtml), 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 *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

This book gives advice on getting the most out of doctors 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 doctor's go through, which helps the reader understand the doctor's side of the relationship.

**2 *The Patient's Guide to Medical Terminology,***

by Charlotte Isler

In this guide, the author translates well over 1,000 terms and more than 500 abbreviations into easy-to-understand language. This book is useful for families, taking some of the "fear of the unknown" out of medical language.

**3 *Surviving Modern Medicine: How to Get the Best from Doctors, Family, and Friends,***

by Peter Clarke and Susan H. Evans

The authors talk about five critical areas for patients to focus on to get good care: getting your doctor to pay attention, making the best medical decisions, seeking the right kind of support from family and friends, and protecting your medical choices. The book urges readers to look at their own decisions, emotions, thought patterns, and habits.

**4 *Working with Your Doctor: Getting the Healthcare You Deserve,***

by Nancy Keene  
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:

**● *The 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/general/atoz/](http://www.kidney.org/general/atoz/).