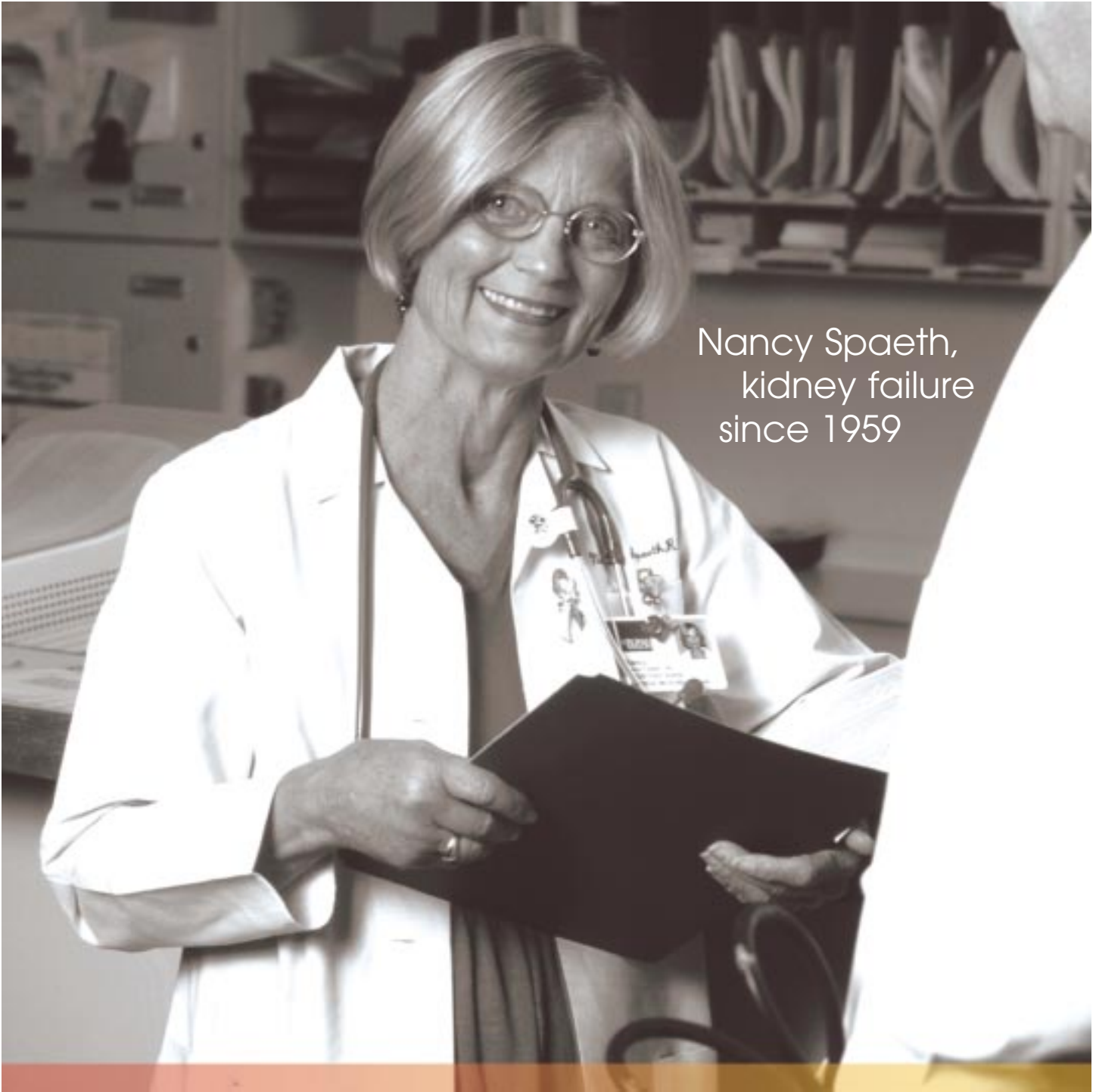


# Kidney School™

## Module Two: Treatment Options for Kidney Disease



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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# **Module 2— Treatment Options for Kidney Disease**

**W**hen you reach the point of choosing a treatment for kidney failure, it may feel like a crisis. You probably hoped this day would never come! You're not alone. Each year, about 60,000 people in the U.S. start treatment for kidney failure.

Your healthcare team can offer support. There are also groups to help people with kidney disease. We'll list them at the end of this module.

Years ago, kidney failure was always fatal. It gives some people hope to know that there are treatments today that can help them to live long and live well.

But others fear they will have no quality of life on dialysis. They may even insist there is no way they want to be kept alive by a machine. Choosing a treatment—or not—is a big decision, and this module of Kidney School is here to help you think about the options.

In this module, you'll hear from people who are living with some of these treatment choices. They'll tell you what they chose and how it worked for them. They'll show you that it is possible to have a good life while being treated for kidney disease.

One of these people is David S., a freelance writer from California. David's kidneys failed in 1985.



David says: “When I first heard that I had to go on dialysis, I can remember thinking that my goose was cooked. That was actually what went through my head! I thought that at the age of 35 my life would end, and I kind of rationalized it in my own mind. I think I was ready to give up. I could never picture myself being hooked up to a machine to keep my life going. I just couldn't accept that at the time. So I was really ready to die.”

What does David think about dialysis now? Keep reading this module to find out.

Some people wait as long as they can before they start treatment. But people who wait until they're very sick can wait a long time to feel better. Starting dialysis early can make a healthy adjustment happen easier and faster.

Why should you learn about the treatments for kidney disease? Because knowing about all of the options can help you feel more in control.

To have a good quality of life, many people need to feel like they're in control. But being in control and having treatment for kidney failure sound like opposites. Are they? That depends on

## **What Happens When Kidneys Fail?**

When the kidneys fail, treatment is needed to filter out wastes and extra fluid from the bloodstream. If you need to learn about how kidneys work, read *Module 1—Kidneys: How They Work, What Happens When They Fail, and What You Can Do*.

## When Should Dialysis Start?

Good question! Doctors don't all agree on when people with kidney failure need dialysis. Feeling tired, weak, nauseous, short of breath, or having a bad taste in the mouth are some signs that treatment is needed right away.

A blood test called creatinine is a way to tell how the kidneys are doing. To pay for dialysis or a transplant, Medicare requires creatinine levels higher than 6.0 in diabetics or 8.0 in non-diabetics.

Do you know what your creatinine level is, or if it is going up, going down, or staying the same? If not, ask your doctor.

how you look at it—how much control you feel you have over the kidney disease.

It's common to feel like kidney disease has the upper hand in your life. We don't have to like the changes that occur in our lives, but we do need to find ways to live with them.

Control over kidney disease means being proactive about your health and moving with change instead of fighting it. It means taking action in the areas you can. It doesn't mean that everything works out the way you want it to. As you will see, a positive attitude is a huge part of successful kidney treatment.

Here are the four main treatment options we'll be talking about:

- 1 Peritoneal dialysis
- 2 Hemodialysis
- 3 Kidney transplant
- 4 No treatment

No single treatment is right for every person. Which one you choose—with the help of your care team—will depend on your body and health, and also on what is offered in your area.

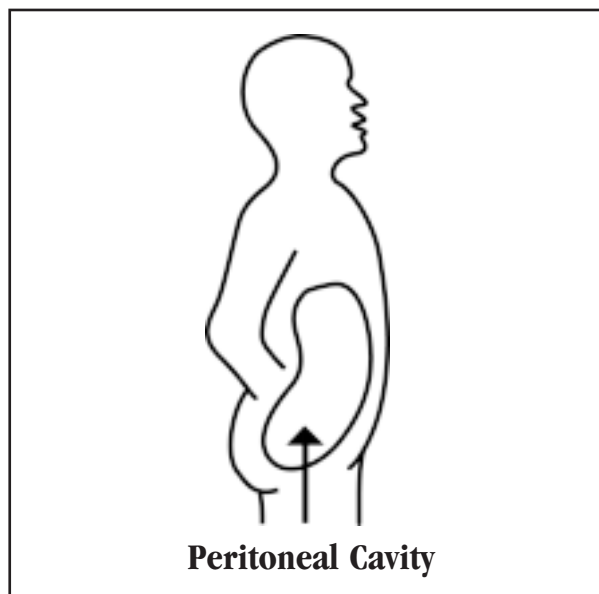
Many people also change treatments, for reasons that may or may not be in their control. So, your treatment choice now may not be permanent—you might pick another one down the road.

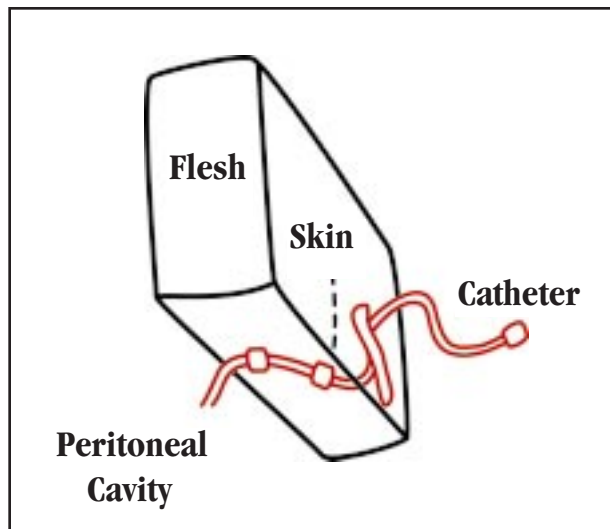
Let's start by talking about peritoneal dialysis, since you may never have heard of it.

## Peritoneal Dialysis

When most people think of dialysis, they think of being hooked up to a machine. And that is true for most kinds of dialysis. But peritoneal dialysis, or PD, doesn't have to use a machine. Instead, it uses part of the body as a blood-cleaning filter.

The peritoneum is a membrane that lines the abdominal cavity—it's like a bag, holding the internal organs. To do PD, this bag is filled up with a special fluid, called "dialysate" (dye-al'-i-sate). Wastes and extra fluid in the blood slowly flow into the dialysate.





After a few hours, the dialysate has all the wastes and fluid it can hold. Then the used dialysate is drained out and clean fluid is put in.

But wait a minute. How does dialysate get in and out of the peritoneum? Good question.

A minor surgery is done to put a soft, flexible plastic tube called a “catheter” (cath’-uh-ter) into the belly (pictured above). Dialysate goes into the peritoneum through the catheter. The catheter stays in the body all the time and hangs out a few inches. It’s covered up when it isn’t being used.

Draining out dirty dialysate and putting in clean dialysate is called an “exchange.” Patients are trained to do PD exchanges themselves at home, at work, or when traveling. PD exchanges are painless.

### **CAPD**

When people do PD exchanges by hand every few hours, this type of dialysis is called CAPD:

- C** = continuous (all the time)
- A** = ambulatory (walking around)
- P** = peritoneal (you know this one)
- D** = dialysis (cleaning the blood)

Most people on CAPD do three to five exchanges a day. Each one takes about 30 minutes. Exchanges must be done very carefully to prevent painful infections called *peritonitis*.

Because dialysis takes place all the time with PD, few food and fluid limits are needed. And because patients do the treatment themselves, on their own schedule, it is easier to work or travel.

### **CCPD**

Some people who like PD need more blood cleaning than PD can give them. And others who like PD can’t do exchanges at work (it might be too dusty or dirty). Luckily, there is another way to do PD: CCPD.

- C** = continuous
- C** = cycling
- P** = peritoneal
- D** = dialysis

Continuous cycling peritoneal dialysis (CCPD) uses a machine called a cycler to do lots of exchanges

## **How Does Dialysis Clean the Blood?**

To clean the blood, dialysis has to take out wastes and extra fluid—but keep in things the body needs, like blood cells.

During dialysis, blood and dialysate are kept apart by a membrane (in PD, the membrane is the small blood vessels in the peritoneum). Wastes and fluid flow out through tiny holes in the membrane. Blood cells and protein, which the body needs to keep, are too big to fit through and stay in the blood.

Dialysate helps to pull the wastes out of the blood. Once dialysate is used, it is thrown away.

at night while the patient is sleeping. Sometimes CCPD is called Automated PD (APD).

Some people who do CCPD have their days free from PD exchanges. Others do CCPD at night plus one or more exchanges during the day to feel their best and remove enough fluid.

The cyclor fits into suitcases for travel, or people on CCPD do regular CAPD exchanges when they are traveling.

## How Effective is PD?

PD is more likely to provide good dialysis for people who are small, and people whose kidneys are still working a little bit (called “residual renal function”). But it is important to measure kidney function. As the kidneys keep failing, more PD may be needed for patients to feel their best.

Infections of the peritoneum, called peritonitis, can make PD less effective by causing scar tissue. Some people who get peritonitis have to stop doing PD and switch to hemodialysis.

So why choose PD? People have different reasons for choosing PD:

“I like the idea of being in control of my treatment. My CAPD exchange takes about 1/2 hour, four times a day. I do it when I get up in the morning, at lunchtime, when I get home, and before I go to bed. It has become routine and is a minor inconvenience. When away from home I exchange in my car.” —*Jose*

“I chose PD mostly because of the relaxed dietary restrictions—I love milk, tomatoes, baked potatoes, apricots, oranges, etc. I would prefer hemo, if it did not involve so many of these restrictions.” —*Michelle*

Here is a list that can help you decide if PD sounds like a good choice for you. Choose any of the items below that you might use to help yourself toward this end. Feel free to add those you think of at the end.

- The gentleness and ease of PD sounds pretty good to me.
- I like the freedom of doing PD on my schedule.
- Having fewer limits on what I eat and drink would be nice.
- I like the idea of using my own peritoneum as a natural filter.
- I think I could travel and/or keep working if I did PD.
- I want to be in charge of my treatments, and PD would let me.
- Doing CCPD at night would leave my days mostly free.
- I don't like the idea of having a catheter hanging out of me.
- I would rather not have to do exchanges several times a day.
- I'm worried I might do something wrong and get an infection.
- I don't want to have a belly full of fluid all the time.
- I'm not sure there's a place to do PD exchanges at my work.
- I don't think I could sleep with a cyclor going at night.
- I'm not sure what my thoughts are.
- Add your own comments here:

## What's Good and Bad About CAPD

<b>What's good about CAPD?</b>	<b>What's bad about CAPD?</b>
Dialysis takes place all the time, so there are fewer food and fluid limits. It's easier to choose something that's okay to eat.	Carrying a liter or two of fluid around in your belly can mean looking a little pregnant all the time. PD dialysate has sugar in it, and can cause weight gain and changes in diabetes control. Extra protein may be needed in the diet.
You do the treatments yourself. You're in charge (with a clinic to call if there are problems). Even blind patients have done CAPD.	<i>Every single exchange</i> must be done carefully, or you risk peritonitis (infection of the peritoneum).
You decide the schedule and can fit dialysis in around your day. This can make it easier to work full-time.	CAPD can feel relentless. With several exchanges each day, it's hard to ever be away from dialysis.
No needles are used for PD.	The catheter is always part of your body. It makes some people feel self-conscious about their bodies.
PD treatments are generally painless.	Abdominal pain can occur after the catheter is placed, while the body is healing.
Your blood doesn't need to be circulated outside your body to be cleaned.	PD may work better for smaller people. Some people may need more blood cleaning than PD can give them. Scars from abdominal surgery may make PD unworkable.
You can do PD at home, at work, on vacation, or in the car.	Storing PD supplies takes a lot of space, the boxes are heavy, and deliveries may not come at convenient times.
PD supply companies can ship supplies to your travel site, so it's easy to travel.	Even on a trip, exchanges still need to be done several times a day.
You can take part in most of your usual activities.	It's important to avoid infection of the PD catheter. Some activities, like swimming in lakes or ponds, may be restricted, or may need special precautions (like a waterproof covering for the catheter).
There is no wiped-out feeling like there can be with hemodialysis. You feel the same all the time.	There are no days off. You have to do PD every day.

## Hemodialysis

Now that you know how PD works, let's talk about the kind of dialysis you probably have heard about.

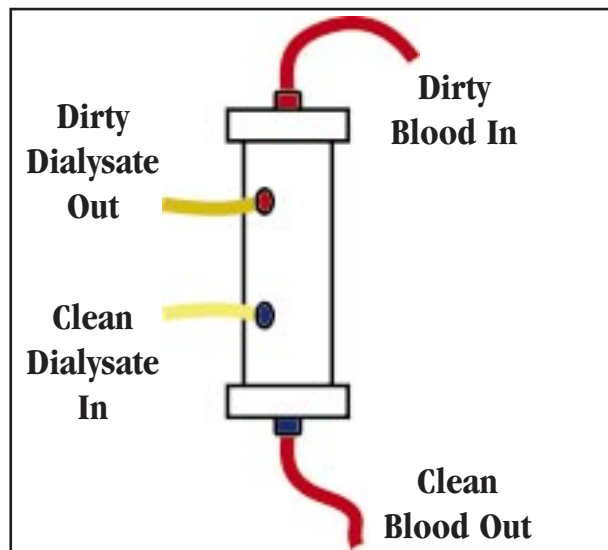
Hemodialysis, or "HD," cleans blood by using a special filter called a dialyzer (dye'-uh-lizer). Inside the dialyzer are thousands of hollow fibers as thin as hairs—punctured with millions of tiny holes.

During HD, blood moves through the inside of the dialyzer fibers. Blood cells and proteins that are needed by the body are too big to fit through the holes. They go back to the body. Wastes and extra water go through the holes and into dialysate fluid that is thrown away.

HD is usually done three times a week, for at least 3–4 hours each treatment. *Longer is better.* Here's why: healthy kidneys work 24 hours a day, 7 days a week—but dialysis works only 12–15 hours a week. The more HD time, the better people feel. The doctor will prescribe the amount of HD time.

Can you guess how much blood is outside of the body at any given time during HD?

- a) 1 cup
- b) 1 pint
- c) 1 quart
- d) 1 gallon



Answer (a) The dialysis machine cleans only a small amount of blood at any one time (about a cup), so the body can handle the blood loss.

### How does HD feel?

How an HD treatment feels has a lot to do with how much fluid must be removed. Normally, the treatments themselves are painless. But if there is a lot of fluid to remove, this can cause painful cramping, headaches, faintness, nausea, shortness of breath, and other problems. This is why it is so important to follow your fluid limits.

## What Are the Different Types of Vascular Access?

A vascular access is the way that blood goes out of your body to be cleaned, and then returns to your body. There are three main types of access:

**Fistula:** An artery and a vein are surgically linked to each other. Fistulas are usually placed in an arm.

**Graft:** An artificial vein is used to surgically link an artery to a vein. Grafts can be placed in an arm or a leg.

**Catheter:** A Y-shaped plastic tube is placed into a large vein in the chest, neck, or groin. Because there is a high risk of infection, catheters are usually used only for temporary access.

Fistulas are the best type of access because they last longer and are less likely to clot or become infected. To learn more about vascular access, read Module 8 of *Kidney School—Vascular Access: A Lifeline for Dialysis*.

Needles are a big worry for many patients. Some people get used to the needles in time. Others ask for skin-numbing products—like EMLA® cream or liquid lidocaine—to “freeze” the skin. And others find that it hurts less when they learn to put in their own needles.

Most people who do HD receive their treatments at a dialysis center. This is called, “in-center” HD. In-center HD is so common that many people think it is the only kind of dialysis.

Here’s what one patient says about in-center HD: “Everybody is scared before they start dialysis, but it is not that bad. It becomes a part of your life just like taking medicines, and with the right attitude it is not that big of a problem. And as long as you keep up with what is going on, you can live almost as you did before you had kidney failure.” —*Wally*

## What Is HD Treatment Like?

Here is what some people on HD say about their treatments:

“Sometimes I do feel tired after a treatment but for me, not nearly as tired as I was before I started dialysis! That’s really the only after-effect. The needles hurt some going in, but once you’re over the treatment, you’re over it until the next time.” —*Robin*

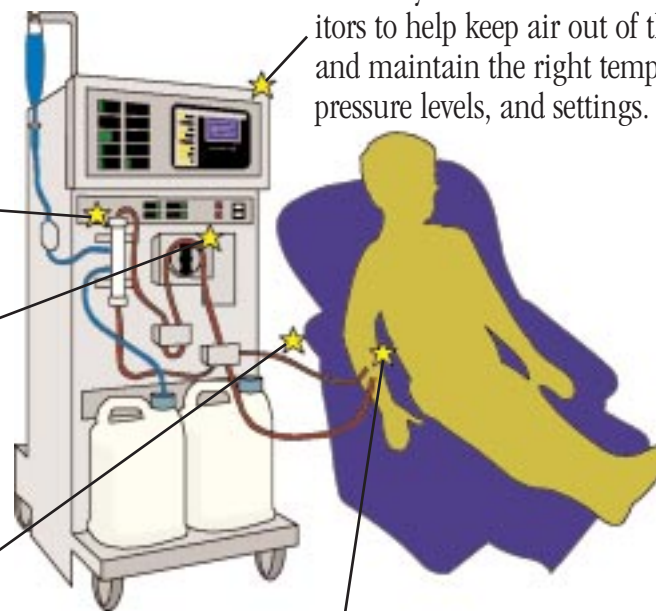
“After my first dialysis treatment I felt wonderful. I’d been pretty ill before starting (uremic—my blood was full of toxins, swollen from fluid, I was coughing a lot from water in my lungs, and I had no energy at all.) But after the first treatment most of those symptoms were gone.” —*Barney*

## How an HD Treatment Might Look

The dialyzer filters out wastes and extra fluids from the blood.

The blood pump moves the blood through the dialyzer at a constant speed. This speed is faster than the heart can pump.

Hollow plastic tubes or “lines” carry the blood out of the body, through the dialyzer, and back into the body. The lines are hooked up to the needles in the access.



The dialysis machine has safety monitors to help keep air out of the blood, and maintain the right temperatures, pressure levels, and settings.

Blood leaves the body through a special blood vessel called a vascular access. Two needles are placed in the access at each treatment. One needle takes “dirty” blood out of the body, and the other brings “clean” blood back into the body.

## What's Good and Bad About In-center HD?

<b>What's good about in-center HD?</b>	<b>What's bad about in-center HD?</b>
There are 4 days in the week <i>not</i> to think about or do dialysis.	There is a fluid limit and meal plan. Going to the unit, waiting for a chair, and having the treatment takes up many hours a week.
Treatments are done by trained nurses and technicians.	The nurses and technicians are taking care of many patients at the same time.
You have several hours three times a week to read, study, write letters, exercise, knit, learn a foreign language, think deep thoughts, or do whatever other quiet activities you want to do.	You have to do these things at the dialysis center. The chairs may not be comfortable. The room may be too cold or too hot. Eating, drinking, or visitors may not be allowed.
You get to meet and spend time with other patients. Treatment times can sometimes be adjusted to allow you to continue to work.	The treatment schedule you get may not fit your life—or your job.
Local anesthetics can be used so the needle sticks don't hurt, and the rest of the treatment is usually painless.	Two needle sticks with large needles are needed for each treatment.
You can learn to monitor the machine and even put in your own needles, so you can be a partner in your care.	The fistula or graft looks like a big, rope-like vein. People may ask what it is.
If you plan trips far enough in advance, it is usually possible to travel on HD.	It is hard to travel on the spur of the moment.
You can take part in most of your usual activities.	With wastes and fluid removed three times a week, you may find that you have good and bad days. Some people feel “washed out” after dialysis and have to rest.

## Home hemodialysis

In some parts of the country—with a few weeks of special training—HD can be done at home. People who do home hemodialysis need to have a partner (or pay someone) to help with treatments. Plumbing and wiring changes in the home are also needed so the machine will work, and storage is needed for supplies. Medicare may help pay for minor modifications to plumbing and wiring for home hemo.

It can be hard to find training for home hemodialysis. Many centers no longer offer it. But patients who do it like the freedom of choosing their own schedules and being in charge of their treatments.

### What Is Home Hemodialysis Like?

“My wife has assisted my dialysis treatments at home for the past one and a half years. As a result of being able to set the time of my hemo sessions, I have been able to work full-time despite hemodialysis. When I feel that I need it, I have dialyzed more often or for longer periods of time. During the past one and a half years, I have felt great!” —*James*

“I chose home hemo so I could dialyze when I wanted to, on my own schedule, and not the center’s. The center cannot schedule you at your convenience—they have to get you when it is convenient for them. So home hemo gives me more control of my schedule and I like that. I also chose it so I could do it in the evening and work full-time. Another plus for me is I have the same person stick me each time (my dad) and he knows my arm very well. We have not had a problem with sticking since coming home.” —*Heather*

Home hemodialysis was very common in the early days of dialysis when there were not enough in-center machines to go around. But it’s pretty rare today, now that there are enough dialysis centers to treat everyone. Fewer than 1% of people on dialysis are doing home hemodialysis.

Even more rare are two new kinds of home hemodialysis that are now being tried in some parts of the country: nocturnal home hemodialysis and daily home hemodialysis.

### Nocturnal home hemodialysis

Nocturnal home hemodialysis is done at night for 8–10 hours, 5 or 6 nights a week, while patients are sleeping. The dialysis machine is hooked up to a monitoring system. This way, professionals can track the treatments and alert patients if there are problems.

Patients who have tried this treatment like it because:

- They have days free from dialysis (except for setting up the machine and cleaning it).
- They get many more hours of treatment, so they feel better, sleep better, and need fewer drugs.
- Because the dialysis is so efficient, they often don’t need a special meal plan or fluid limits.

Since nocturnal home hemodialysis is new, it is not yet offered in many areas. It is still being tested, so Medicare does not pay for the extra treatments. And travel is very challenging for people who use nocturnal home hemodialysis—they feel so good with the extra treatment that it’s hard for them to go back to in-center HD when they want to take a trip.

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## Daily home hemodialysis

*Daily* home hemodialysis is another new type of treatment that patients are testing right now. It uses a new type of machine. People who use daily home hemodialysis do a short treatment (2 hours or less) 5 or 6 days a week.

Since the blood is cleaned almost every day, daily home hemodialysis may be gentler on the body. And since the treatments are very short, they may be easier to fit into an evening schedule.

One day soon, these new kinds of treatment may make their way to your town.

So far, what are your thoughts about HD? Check all that apply:

- Having 4 dialysis-free days each week sounds good.
  - I like the idea of doing treatments in my home, on my own schedule.
  - I want trained medical people to do my treatments for me.
  - I would rather have treatments with other patients in a center.
  - Having built-in quiet time each week would be a good thing.
  - I'm worried about the dialysis needles.
  - I'm not sure I could live with the diet and fluid limits of HD.
  - I don't think I want to do treatments myself.
  - I don't want medical equipment or dialysis in my house.
  - I'm not sure what my thoughts are.
  - Add your own comments here:
- 



Remember David S., who didn't want to go on dialysis, more than 16 years ago? Here's what he thinks about it today: "If you had a fatal disease, and I told you that I had a magic machine that could keep you alive, and all you'd have to do is be hooked up to this machine 12 hours a week...well, if I told you that I had that magic machine that could keep you alive, why you'd jump out of your chair, throw your arms around me, and say, 'where's that machine, and how do I get on it?' And that's the same thing you have to think about dialysis. It's really a magic machine that keeps you alive!"

The final two treatment options we will cover are:

- 1 Transplant
- 2 No treatment

## What's Good and Bad About Home Hemodialysis

<b>What's good about home hemodialysis?</b>	<b>What's bad about home hemodialysis?</b>
There are 4 days in the week <i>not</i> to think about dialysis, and it's possible to do longer or more frequent treatments if your meal plan or fluids are a little off track.	You have to be responsible enough to do the treatments three times a week, every week.
Treatments are done by the patient and a partner, after a training course.	If an emergency happens, you will have to be able to keep your cool and deal with it.
You have several hours three times a week to do quiet activities—in your own home—and you get to decide the rules yourself.	You don't get to meet and spend time with other patients. You have to make room to store the machine and many boxes of supplies.
You can do dialysis on your own schedule.	A partner must be there three times a week to help you, unless you can arrange for back-up help. This can be hard on your relationship.
You don't have to spend time traveling to and from the dialysis center for every treatment.	You do have to spend time setting up the machine, cleaning it after treatments, and ordering supplies. You also must have enough space to store the machine and supplies.
Local anesthetics can be used so the needle sticks don't hurt, and the rest of the treatment is usually painless.	Two needle sticks with large needles are needed for each treatment.
With only one person putting needles in your access (you or a partner), it is likely to last longer.	You or your partner must be willing to learn how to put in the needles. The fistula or graft looks like a big, rope-like vein. People may ask what it is.
You learn enough to be in charge of your care, with your care team as consultants to help you. This can help you live longer.	You and your partner will need to learn—and use—a lot of technical information about how to do dialysis.

## Transplant

A kidney transplant requires major surgery to put a donor kidney into the body of a person who has kidney failure.

Some people with kidney failure see a kidney transplant as the goal. They believe that once they get a kidney, life will go back to normal. And sometimes it does work this way.

It's important to be realistic about kidney transplant, though. A transplant is just a treatment, not a cure. It has some good and some bad sides, like other treatments.

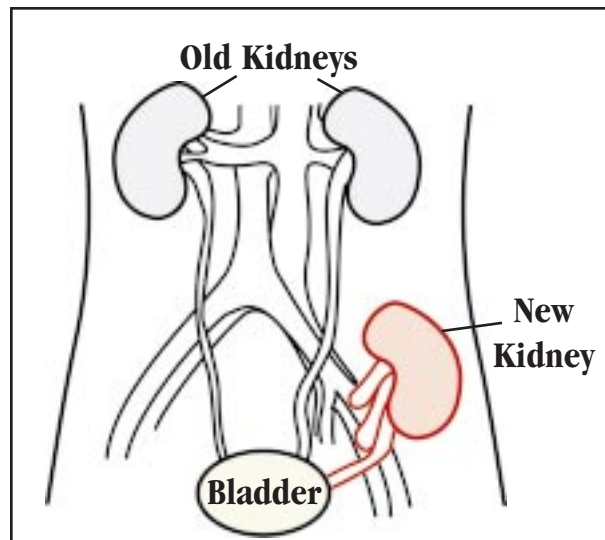
Just any kidney won't do for a kidney transplant. The new kidney has to match the blood and tissue type of the person who needs it. Otherwise, the patient's body would reject the kidney as foreign. The kidney would stop working. Matching blood and tissue types is done through blood tests. Even so, rejection can occur at any time—even years after a transplant.

Where do donor kidneys come from? There are three sources:

### Why Would My Body Try to Reject My New Kidney?

Your body's immune system works like a national defense system. When foreign invaders get into your territory, your body acts to reduce the threat to your safety. Since the new kidney is not originally yours, your body sees it as a foreign invader and tries to reject it.

People who get transplants take drugs every day to suppress the immune system and prevent rejection. These drugs are called immunosuppressants.



- 1 A blood relative (living-related donor)
- 2 A non-blood relative, spouse, or friend (living, non-related donor)
- 3 A transplant from a deceased donor

### Living-related and living, non-related transplant

A family member, spouse, or friend may choose to donate a kidney. The surgery can be done when it is convenient, so there may be a very short wait. This donor also gets health screening to make sure there is no chance for kidney disease or factors that could affect the donor's health.

It is possible for someone to live a healthy life after giving a kidney. And there are not enough deceased donors for everyone who wants a kidney to get one. Many people who need a kidney are urged to ask their friends and family to be tested. If there is a match, then the person can be asked to donate a kidney.

It can be hard to think about asking someone you love to give you a kidney. A living donor must have surgery to have the kidney taken out. The donor will miss work and have to recover for a few weeks. Living donors' medical costs are usually paid by Medicare.

## Can More Than One Organ Be Transplanted at a Time?

Yes. There are combinations of organ transplants depending on the needs of the person. For instance, a person with kidney failure and Type 1 diabetes might receive a kidney and a pancreas during the same surgery.

Sometimes people get angry with their family or friends for not offering to give them a kidney. Others worry about how the donor will feel if the kidney doesn't work.

There are a lot of things to think about with kidney transplant. Usually transplant centers will ask patients and possible living donors to see a social worker before they will do the transplant.

### Transplant from a deceased donor

Deceased donor kidney transplants can work. But there are not enough deceased donors for everyone who wants a kidney to get one. For this reason, the wait can be long—from days or weeks to months or years. Deceased donor kidney transplants are not usually the fastest.

If a living donor is not available, someone who wants a deceased donor kidney can be placed on the national transplant waiting list. This list is kept by the United Network for Organ Sharing (UNOS).

When a kidney comes up, the two or three patients who are the best matches in the region will be called. Blood tests and medical exams are done to see which one will receive the kidney.

There is no way to predict how long the wait for a deceased donor kidney might be. Some people wait just weeks, most wait for months or years.

Although disappointing, the waiting time for a transplant is not the main problem. Some people focus all their energy on the future, hoping to one day have a new kidney. Life will start when they get their transplant. But they neglect their own self-care in the present.

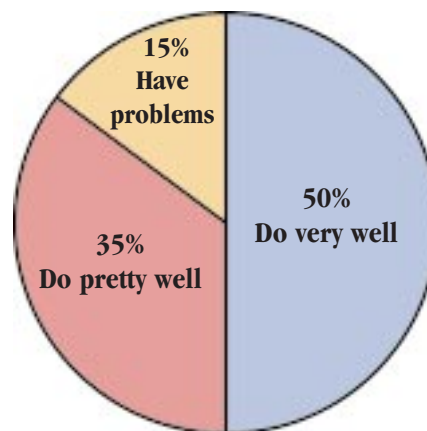
Instead, people who live each day to the fullest and use what they know about kidney disease to live well with it will have a better quality of life *right now*.

If you can do this, you will learn some valuable life skills that you can keep practicing when that transplant comes along.

How well do kidney transplants usually work? Dr. Tom Peters, a transplant surgeon from Shands Jacksonville, in Florida, said this to patients attending the American Association of Kidney Patients (AAKP) meeting in 2000:

“If we were to take 100 dialysis patients today, transplant them with a good kidney, and look at them a year from now, 50 will have done extremely well. They will have gone home from the hospital, had no complications, tolerated their meds, had no additional hospitalizations, good renal function, their kidney will last 10 to 20 years.

### How Well Do Kidney Transplants Usually Work?



“Thirty-five are going to have some problems: new onset of diabetes, heart attack, complications, re-operation, hospitalizations, rejection. At the end of a year, those 35 patients will join the first group.

## What Patients Say About Transplant

Here are 3 very different stories of kidney transplant:

“I was on CAPD for almost 6 years and felt pretty good. The reason I got a transplant was so I could travel more. A transplant is a lot like CAPD in that instead of doing an exchange you take a pill... Keep in mind it’s another form of treatment, not a cure.” —*Mike*

“I have been on dialysis for 25 years and have had two unsuccessful transplants. The first one was a rejection 5 weeks after surgery and was removed. I was never off dialysis at that time. The second transplant was a year ago and I’m still suffering from it. It didn’t work the first 8 1/2 weeks then it woke up, and I was off dialysis for 4 months. Then my blood work started to get bad and the output decreased. I was put back on dialysis and was told the kidney failed but there was no sign of rejection. At no time in this past year have I felt even halfway decent, mainly due to drug side effects.” —*Lois*

“My husband Simon has just celebrated his 30th anniversary of going on dialysis. His first transplant lasted 2 and a half years, the second, 6 months, the third (LRD from his father) 11 years, and 6 months ago he had number 4. He now has the lowest creatinine he has had for those 30 years. Having seen him with transplants three and four, and on hemo for 3 years recently, I can tell you that for Simon there is no comparison between the quality of life with a transplant, and that on hemo. The transplant wins every time!” —*Ruth*

Most of them will be healthy, have normal or near-normal kidney function, and will keep their kidney for a long time (maybe not as well as the first group).

“That leaves 15 patients. About 2, 3, or 4 will die in the first year—at or beyond 3 months—of heart attack, stroke, trauma, or infection. The remaining patients will have either lost kidney function or have remained somewhat ill, some severely so, for other reasons.”

Given what you have read now, what do you think about transplant?

Check all that apply:

- I want to avoid the inconvenience of dialysis.
- A transplant might help me keep my life as normal as possible.
- I think I could take the drugs every day, the right way.
- I have family/friends who might be willing to give me a kidney.
- I could wait for a kidney and still have a good life each day.
- I’m willing to take the risk that a transplant might not work.
- I’m worried about having major surgery.
- I’m worried about my donor having major surgery.
- Possible side effects of the drugs (and cost) concern me.
- I would rather live each day without waiting for a kidney.
- I’m not willing to rock the boat—I’m doing okay the way I am.
- I’m not sure what my thoughts are.
- Add your own comments here:

## What's Good and Bad About Transplant

<b>What's good about transplant?</b>	<b>What's bad about transplant?</b>
If the kidney works well, you won't need dialysis.	If the kidney doesn't work well, you may have a long recovery to get back to where you were.
A kidney transplant won't take hours of treatment time out of your week.	You will have to remember to take the drugs correctly, every day. The drugs are costly and have side effects, including a higher risk of some kinds of cancer, cataracts, diabetes, and excessive weight gain.
You won't need a fluid limit.	You will have to drink lots of fluid to help the kidney stay healthy. You may have a low-salt and/or reduced calorie meal plan or a low-fat and/or reduced cholesterol meal plan to avoid gaining weight from the steroid drugs you'll need.
You won't need a PD catheter or a vascular access if you don't already have one.	Steroid drugs can cause moon face, hair growth on the face, weight gain, and increased anxiety levels. (Usually the dose of these drugs is reduced slowly over time).
You may feel well and physically stronger.	Before you feel better, you will have to recover from the surgery.
You can take part in most of your usual activities.	You may have to avoid contact sports, like hockey and football, where the kidney could be injured. (It is safe to play basketball).
Getting a kidney from a relative or friend can help you to feel closer.	If the kidney doesn't work, you may feel guilty about the donor "wasting" a kidney.
If you get a deceased donor kidney, you won't have to ask a living donor.	There is no way to predict how long you might have to wait for a deceased donor kidney.

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## No Treatment

It may strike some people as strange that “no treatment” would be among the options we talk about in Kidney School. But for a select group—like those who are severely ill, or who have many health problems—not treating kidney failure might be something to consider.

We mention it here not to encourage it, but to tell patients and family members that the option exists.

People with kidney failure, when they are adult, conscious, and able to make decisions, may choose no treatment or choose to end treatment. It’s important for patients to talk about what they decide with their family and the care team. Before treatment stops, or if treatment will not be started, all parties should understand the patient’s decision.

Sometimes the patient and family do not agree that treatment should be stopped. The patient’s wishes must be respected; families do not have the ethical or legal right to override what a patient decides. In this case, if a patient can explain the reason for the decision, it may help family members to understand. Talking with the dialysis social worker, and even an ethics committee, may help everyone come to agreement. Patients and families can also turn to a religious advisor for help.

If a patient decides not to treat kidney failure, the patient, family, and care team can then begin to prepare for a peaceful and meaningful passing. *Palliative care*—keeping the patient as comfortable and free of pain as possible—can be given.

In some areas, hospice is a resource for people who choose no treatment for kidney failure.

It is often hard to draw the line between where hope exists and where it has been lost, never to return.

Anyone with a chronic illness will struggle with times of hopelessness. This may include depression, or even periods of wishing for death to ease the suffering.

Some people with kidney failure don’t want to start dialysis, because they are sure they will have no quality of life. They are afraid of the unknown. In these cases, the care team may suggest a trial of dialysis for a few weeks or months. Learning what treatment is really like can help make the decision more clear.

But if you believe, consistently, over time, that there is no hope for a better quality of life, we suggest you begin by talking with family members.

## Adjusting to Life with Kidney Failure

Now that you know what all of the treatment options are, let’s talk again about change. No matter which treatment you choose, it means that you are going to have changes in your life. Areas such as your work life, home life, social life, and spirituality may be affected.

Here is a list to start you thinking of ways to motivate yourself toward that positive attitude and a sense that you are in control of your kidney disease. Check off the ones that you might do:

- 
- Read about others who have learned to live with kidney disease.
  - Talk with others who are living with kidney disease.
  - Research information on living with kidney disease (in print, on the web, at the library...)
  - Write down and ask your doctor specific questions you want answers for.
  - Volunteer to work with others who have kidney disease.
  - Meet with a social worker or other professional counselor.
  - Start and stick with a regular exercise program.
  - Meet with a dietitian to develop a healthy meal plan.
  - Meet with a professional counselor.
  - Work through all of the modules in Kidney School.

We said at the start of this module that needing to choose a treatment for kidney failure is a crisis for many people. You probably have many emotions swirling around inside you:

- Anger
- Fear
- Resentment
- Hopelessness
- Depression
- Embarrassment

Believe it or not, nearly every person with kidney failure has at least one or more of these feelings from time to time—sometimes they seem to come from nowhere. If we see where they come



from, we can learn how to work with them in a healthy way.

**Fear**, for instance, is often a response to the unknown. We don't know how we will be able to work, have a social life, have a sexual relationship, or carry on with other life events.

Or consider **anger**, and its close cousin, **resentment**. Anger is often a response to feeling like you are a victim. You might be thinking, "Why me? What did I do to deserve this?" When you are angry, it is easy to want to blame someone for your problems. You may be blaming yourself or feeling guilty for not following treatment when you could—or blaming your doctor for not catching the problem in time.

A feeling of **hopelessness** usually comes before **depression**, and enters your life because you see no way out. You feel you have no choice but to accept what fate has thrown you.

Some people find that they feel **embarrassed** about having kidney failure. They don't want people to know about it or to pity them. They don't want to have to explain it or talk about it. They may even feel "unclean."

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Nobody likes feeling any of these emotions. And anytime you feel angry, resentful, hopeless, depressed, or embarrassed, life is a lot like walking around in soaking wet clothes.

These feelings about kidney disease are very real. There are lots of changes and obstacles to overcome. But staying stuck in these emotions will derail your ability to live the way you want to. The goal is to allow yourself to feel the emotion and then make informed *choices* about how to deal with your life and your health. What might those choices look like?

Let's see what Heather has had to overcome. She has lived on kidney treatments most of her life.

"I started on hemo when I was 8 years old and switched to PD one year later. I did well on PD for 5 years until I received a deceased donor kidney transplant. The transplant made a huge difference in my life for the 5 years I was able to use it. The kidney eventually failed and brought me back to PD. Several years later, I developed an infection and had to go back to hemo.

"During all of this treatment switching I graduated from high school, finished a Master's degree in Social Work, and now work full-time for a state branch of the National Kidney Foundation. My current method of treatment is home hemo, and I love it. In the meantime, I am waiting for another kidney transplant."

Heather's life has been full of obstacles. And we only know about the major ones that relate to her kidney failure.

How do you think Heather made it through her diagnosis, switching treatments, and a failed kidney transplant? If she allowed herself to be emotionally paralyzed by these events, how could

she have had the energy and motivation to finish high school, college, graduate school, and now keep a full-time job?

**The answer:** she couldn't.

Heather believes in some basic—yet profound—principles that have gotten her through these tough times. But she is not the only one. Many kidney patients who are living active lives practice the same principles. You can, too. But you must make *choices* to do so.

Here are the principles:

**Keep a Positive Attitude** – Ask long-term kidney patients about what keeps them going and they will tell you how important a positive attitude is. Staying positive allows you to see possibilities where they aren't obvious, to see light where it seems dark, and to see hope instead of discouragement.

**Learn All You Can** – We can't stress enough the importance of education. We at Kidney School believe it is the cornerstone to living well with kidney disease. Remember earlier when we said that fear breeds in the unknown? Educating yourself about all facets of kidney disease, treatment, and management makes you less afraid and puts you more in control of your life. Why not start by working your way through all of the modules in Kidney School?

**Build a Support System** – You need people who care about you and support you. This might include family, friends, neighbors, co-workers, and other people with kidney failure. Surround yourself with people who push you to do your best—while avoiding those who have a bad effect on your mood and behavior.

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**Take Responsibility** – Take an active role in your own health. You are the one who is responsible for your own well-being—both physical and emotional. Your doctor, dialysis staff, family, and friends can all help you, but making the choice to follow through is up to you.

**Follow Your Treatment Plan** – Work with your care team to decide which treatment will work best for you, and stick to it. Don't take a passive approach to getting only the bare minimum treatments. The more consistent and assertive you are in your treatment, the better you will feel, the more energy you will have, and the more hopeful you will be about living with kidney failure.

**Help Others** – One of the best ways to keep a balanced view of your life is to help others. Don't let your treatment use up all of your good energy. Give some of it away. Join a support group, volunteer at a hospital, or write letters of encouragement. It's a terrific way to feel like you're making a difference with your life.

It's time to wrap up this module on treatment options and lifestyle changes. 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 we talked about. We encourage you to put it where it will remind you of what you're working toward.

Kidney School is committed to providing creative learning that is accurate, interesting, and useful to your life. We want to help you learn to keep a positive attitude, get answers, and take action to get the best possible care.

We hope this module has been helpful to you and your loved ones, and invite you to learn from the many other Kidney School modules we offer.

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

### ***Treatment Options for Kidney Disease***

#### **Change**

Change is difficult for everyone, but the choices I make determine the outcome of the changes I go through.

#### **Treatment Options**

- Peritoneal dialysis
- Hemodialysis
- Transplant
- No treatment

#### **Peritoneal Dialysis**

PD uses the peritoneum that lines the belly as a bag to hold dialysate fluid. Dialysate goes into the peritoneum through a catheter. The dialysate absorbs wastes and extra fluid, and then is drained out through the catheter, and fresh fluid is put in.

PD exchanges can be done by hand (CAPD), using a cycler machine (CCPD), or both.

My thoughts about possibly using PD were  
*(Write down your thoughts from page 6):*

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I can explore these further with my doctor.

#### **Hemodialysis**

HD uses a dialyzer and a machine to clean the blood, usually three times a week. Blood gets to the dialyzer through tubing attached to needles placed in a special blood vessel called a vascular access.

HD can be done at a dialysis center or, in some parts of the country, at home. Home hemodialysis can sometimes also be done at night or every day.

My thoughts about possibly using HD were:  
*(Write down your thoughts from page 12):*

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I can explore these further with my doctor.

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## Personal Plan for \_\_\_\_\_ (continued)

### Transplant

Kidney transplant is another option for treatment of kidney failure—not a cure. People who have transplants must take immune-suppressing medication for the rest of their lives to prevent rejection.

A donated kidney used for transplant comes from one of three sources:

- Living-related donor
- Living, non-related donor
- Transplant from a deceased donor

My thoughts about possibly having a transplant were:  
(Write down your thoughts from page 16):

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I can explore these further with my doctor:

### Adjusting to Life with Kidney Failure

My goal is not to avoid or rid myself of emotion, but rather to allow myself to feel it, knowing it can't hurt me, but then make healthy choices on the basis of what I know to be healthy, true, responsible, etc.

*Principles to live by with chronic illness:*

- Developing a positive attitude
- Actively educating myself on an ongoing basis
- Building a support system
- Taking responsibility for my health
- Assertively staying with my chosen treatment
- Helping others in some way

Although I want to make all of these principles work in my life, I've chosen to put my energy into

\_\_\_\_\_ for the immediate future.

Once I have created some change in this area, I will choose another to work on. I want my life to be my own, and I intend to make the necessary choices to see that happen.

## 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. Peritoneal dialysis uses a \_\_\_\_\_ as the access for treatment.**
  - a) Catheter
  - b) Fistula
  - c) Graft
  - d) Dialysis machine
- 2. In hemodialysis, blood is filtered through a \_\_\_\_\_.**
  - a) Hemolyzer
  - b) Dialyzer
  - c) Cholesterol screen
  - d) Hemoglobin
- 3. In peritoneal dialysis, draining out the dirty fluid and putting in clean fluid is called:**
  - a) A replacement
  - b) A hemo cleaning
  - c) An exchange
  - d) A dialysate
- 4. A vascular access is a \_\_\_\_\_.**
  - a) Piece of the dialysis machine
  - b) Medication taken by people with kidney failure
  - c) Medical condition needing treatment
  - d) Special blood vessel used for hemodialysis
- 5. Home hemodialysis is typically done by \_\_\_\_\_.**
  - a) The patient and a partner
  - b) The doctor and a nurse
  - c) Skilled nurses only
  - d) Dialysis technicians
- 6. A kidney transplant is a cure for kidney disease:**  
 True                       False
- 7. Which form of peritoneal dialysis uses a machine:**
  - a) Continuous ambulatory peritoneal dialysis
  - b) Continuous cycling peritoneal dialysis
- 8. Immunosuppressant drugs are taken \_\_\_\_\_.**
  - a) With hemodialysis
  - b) With a kidney transplant
  - c) With peritoneal dialysis
  - d) With major viruses
- 9. Hemodialysis is done three times a week for at least 3–4 hours a treatment:**  
 True                       False

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

- |       |           |
|-------|-----------|
| 1.) a | 6.) False |
| 2.) b | 7.) b     |
| 3.) c | 8.) b     |
| 4.) d | 9.) True  |
| 5.) a |           |

Thank you for completing Module 2 of Kidney School! Educating yourself about kidney disease is one way to help yourself or a loved one live long and live well with kidney disease. We hope you'll read all of the 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 *A Gift of Life: A Page from the Life of a Living Organ Donor*,**

by Lynn Chabot-Long, Paul Jenkins (Editor), and Leo Trevino

This book is a resource for those families thinking about living organ donation. The author describes the living donation process and all that it entails; the risks, fears, and hopes of one who has actually gone through the process. She goes into the many spiritual and emotional issues one must explore before deciding to donate a kidney to a loved one. For the patient weighing dialysis versus transplant, this book clearly spells out the quality of life for both methods.

**2 *Dialysis: An Unanticipated Journey*,** by David L. Axtmann

The author was 26 years old, married, the father of two young children and going to college when he was told his kidneys were failing. He was given the three choices all people with kidney failure must make: dialysis, transplant, or death. Axtmann shares those days of doubt and fear. He explains how he coped with low blood pressure, sleep problems, lack of energy, and even change in his sexual needs and desires. He explains his reason for choosing dialysis over a transplant. At the writing of this book, David has been on dialysis for 32 years. He has seen his two children make it through their graduation days, and is now a grandfather of three.

**3 *Kidney Failure: The Facts*,** by J. Stewart Cameron

Practical, patient education text on kidney disease, for patients and their families. Explains in layman's terms the causes and symptoms of kidney failure and the options for treatment, including dialysis and transplant.

### Other materials:

**1 *End-Stage Renal Disease: Choosing a Treatment That's Right For You***

This and other materials are available from the National Kidney and Urologic Diseases Information Clearinghouse (NKUDIC) by calling (301) 468-6345 or visiting their website at [www.niddk.nih.gov/health/kidney/pubs/kupubs/kuform.htm](http://www.niddk.nih.gov/health/kidney/pubs/kupubs/kuform.htm).

**2 *Facts About Kidney Diseases and Their Treatment*** available from the American Kidney Fund. To obtain this item, call (800) 638-8299 or e-mail [helpline@akfinc.org](mailto:helpline@akfinc.org).

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- ③ ***Kidney Options™***, developed by Fresenius Medical Care, North America, and the American Association of Kidney Patients. This educational program was designed to be a resource for people who are at risk for kidney disease or have just been diagnosed, and for their families and friends. *Kidney Options™* uses seminars, videos, a website at [www.kidneyoptions.com](http://www.kidneyoptions.com), and other materials to help people learn about kidney disease—its causes, symptoms, and treatment options. To request the *Kidney Options™* package of materials, visit the website or call (866) 543-6391.
- ④ ***Stay In Touch, A Kidney Education Program***, developed by the Baxter Healthcare Corporation with the American Association of Kidney Patients. The purpose of this program is to help people achieve health and wellness as they learn to live with kidney disease. *Stay In Touch* provides free information related to kidney disease in easy-to-read language. The program helps people learn about causes, symptoms, and treatments for kidney disease. The program consists of a series of mailings sent to a person's home. In some areas, group classes and consulting with a Baxter Kidney Patient Educator are also available. To enroll, call (877) 543-6394 or visit Baxter's educational website at [www.kidneydirections.com](http://www.kidneydirections.com).
- ⑤ The following items are offered by the National Kidney Foundation:
- ***Choosing a Treatment for Kidney Failure***  
Presents helpful information on choosing a treatment option for those getting close to kidney failure. Also answers questions about how treatments are paid for.
  - ***Getting Ready for a Transplant***  
Provides information for those patients thinking about transplant as a treatment option, such as what is involved in the evaluation for a transplant, getting on the waiting list, and how transplants are paid for.
  - ***Hemodialysis***  
Introduces dialysis and covers questions about how dialysis affects everyday life.
  - ***Home Hemodialysis***  
Discusses what is needed to do home hemodialysis, how long the training is, insurance coverage, as well as pros and cons of this treatment option.
  - ***Kidney Transplant: A New Lease on Life***  
Answers common questions about transplant topics such as patient expectations, drug therapy, problems, and recovery.
  - ***Peritoneal Dialysis***  
Describes the types of peritoneal dialysis, including the pros and cons of each.

For more information or to obtain these materials, please call (800) 622-9010, write to the National Kidney Foundation, 30 East 33rd Street, New York, NY 10016, or visit their website at [www.kidney.org/general/atoz/](http://www.kidney.org/general/atoz/).

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6 The following items are offered by the American Association of Kidney Patients:

■ *AAKP Patient Plan*®

The *AAKP Patient Plan*® provides kidney patients and their family members with a guide to kidney disease as they progress in their treatment. Released in four phases, the Plan offers patients the information they need depending on their stage of treatment. Those not yet on dialysis, new kidney patients, long-term patients, and those changing modalities will benefit from the information included in the Plan.

■ *When Kidneys Fail*

This book talks about the different treatment options available to ESRD patients.

■ *Peritoneal Dialysis...Is It the Best Choice for Me?*

This book talks about the peritoneal dialysis process, required training, and any lifestyle changes. It also has a glossary of medical terms for easy reference.

For more information or to obtain these materials, please call (800) 749-2257, e-mail [AAKPnat@aol.com](mailto:AAKPnat@aol.com), or visiting their website at [www.aakp.org/Programs.htm](http://www.aakp.org/Programs.htm).