



Module 2

Treatment Options for Kidney Failure





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Please Note

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

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5	a	10	d
4	d	9	True
3	c	8	b
2	b	7	b
1	a	6	False

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

Module 2 – Kidney Quiz Answers





When 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, more than 100,000 people in the U.S. start treatment for kidney failure.

Your health care team can offer support. There are also groups to help people with kidney disease, which we'll list 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 (see photo, above right). 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 if you wait until you're very sick, it can take 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 chronic kidney disease (CKD)? 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 how you look at it—how much control you feel you have over the disease and its treatment.

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, How They Fail, What You Can Do*.





It's common to feel like CKD 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 CKD means being proactive about your health and moving with change instead of fighting it. It means taking action where 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 CKD treatment.

Here are the four main treatment options for kidney failure we'll talk about:

- ❶ Peritoneal dialysis
- ❷ Hemodialysis
- ❸ Kidney transplant
- ❹ No treatment

No single treatment is right for every person. Which one you choose will depend on your body, lifestyle, and health, and also on what is offered in your area.

When Should Dialysis Start?

Good question! Doctors don't all agree on when people with kidney failure need dialysis. Feeling tired, weak, nauseated, 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, down, or staying the same? If not, ask your doctor.

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 your abdominal cavity—it's like a bag, holding your 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. Most PD catheters are placed in the lower abdomen (see Figure 1, next page). The other option is the less known "bathtub" or presternal placement. This places the catheter in the chest (avoiding the bra area for women) and the tip reaches down into the abdomen (see Figure 2, next page). 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



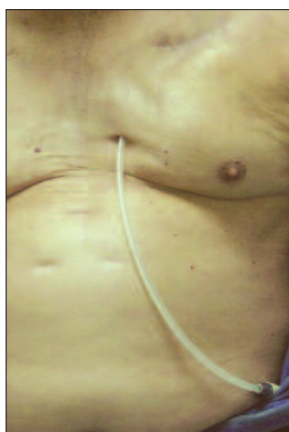


Figure 1. Close-up of abdominal catheter



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Figure 2. Presternal catheter



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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 CAPD can give them. 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

CCPD uses a machine called a cycler to do lots of exchanges 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.

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 peritoneal membrane has small blood vessels). 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 pass through, and stay in the blood.

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



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Module 2 – Treatment Options for Kidney Failure

The cyclor weighs about 25 pounds and fits into a suitcase for travel. Or, people on CCPD can do regular CAPD exchanges when they are traveling. Bags of PD fluid can be shipped to your destination.

Because PD is a self-care form of treatment, Medicare starts right away instead of three months down the line. This can be important for those who don't have other health coverage. If PD training starts before the third month of dialysis, Medicare can pay for PD catheter placement.

Research has found that PD helps people keep their remaining kidney function longer. Having more kidney function can mean feeling better, with fewer diet and fluid limits. Many people with kidney problems also have heart problems. PD is a gentle treatment that is easy on the heart.

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 kidney 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.

So why choose PD? People have different reasons:

“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. 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.” —Michelle

A study of more than 252,000 adult U.S. dialysis and transplant patients found that people on PD were 39% more likely to get a transplant than those who did hemodialysis in a center. We don't know why, but this was true even though the same percent of people in both groups were on the transplant list.

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 make a choice.

- ☐ PD sounds pretty gentle and easy 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.
- ☐ It might bother me to have a catheter in my belly.
- ☐ 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 always have a belly full of fluid.
- ☐ I'm not sure there's a place to do PD exchanges at my work.
- ☐ I wonder if it would be hard to sleep with a cyclor going at night.
- ☐ I'm not sure what my thoughts are.
- ☐ Add your own comment here:

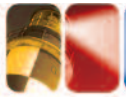




What's Good and Bad About PD?

What's good about PD?	What's bad about PD?
Dialysis takes place all or much of the time, so there are fewer limits on food and fluid. It's easier to choose something that's okay to eat. You also feel much the same all the time, with no "ups and downs."	Carrying a liter or two of fluid around can mean looking a little bloated all the time. PD dialysate has sugar in it, and can change 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 PD.	<i>Every exchange</i> must be done carefully to avoid 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.	With treatment 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.
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, you still need to do your exchanges each day.
You can take part in most of your usual activities, including work and sexual activity.	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).
PD is gentle on the heart.	PD can cause weight gain due to sugar in the PD fluid.





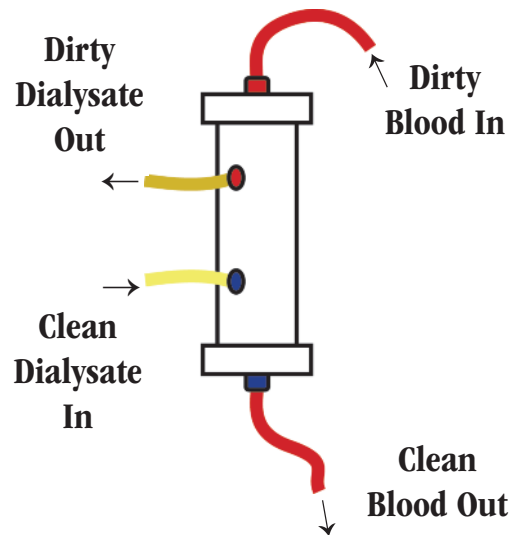
Hemodialysis

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

Hemodialysis, or HD, cleans the 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 pass 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 most often done three times a week in a center, for at least 3 to 4 hours each treatment. *Longer is better.* Here's why: healthy kidneys work 24 hours a day, 7 days a week—but in-center dialysis may work only 12 to 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 one cup), so the body can handle the blood loss.

What Are the 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. This is the *best* type of access.

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—*Vascular Access: A Lifeline for Dialysis*.





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, painful cramping, headaches, faintness, nausea, shortness of breath, and other problems can occur. This is why it is so vital to follow prescribed salt and fluid limits.

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 clinic. In-center HD is so common that many people think it is the only kind of dialysis. It's not. There are a number of other options.

What Is HD Treatment Like?

Here is what a couple of 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

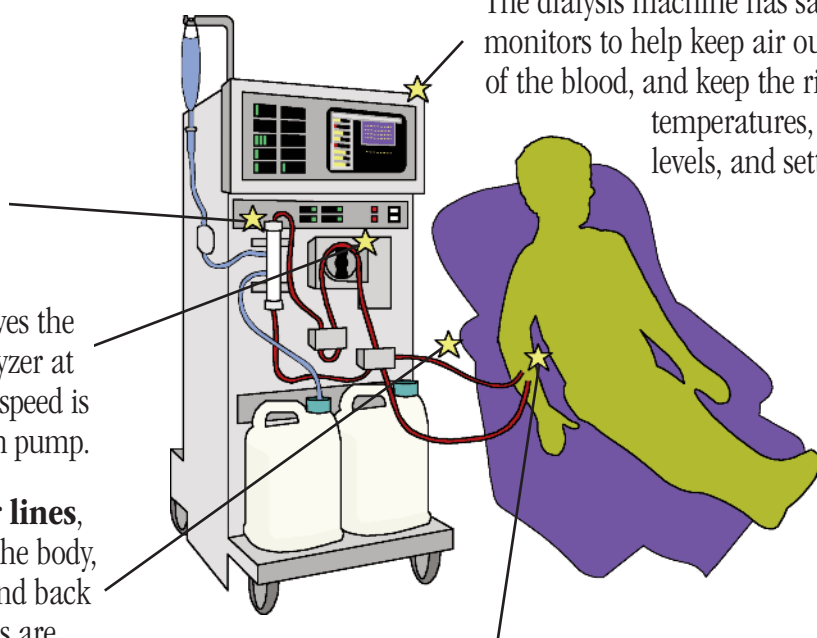
“After my first dialysis treatment I felt wonderful. I’d been pretty ill before starting (uremic—my blood was full of toxins, swollen from fluid, I was coughing a lot from water in my lungs, and I had no energy at all). But after the first treatment most of those symptoms were gone.” –Barney

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 keep 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 to the dialyzer, and the other brings “clean” blood back into the body.





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

What's good about in-center HD?	What's bad about in-center HD?
There are 4 days in the week not to think about or do dialysis.	There is a very strict 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, 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 most often 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 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 for a few hours.
You can feel pretty good from day to day if fluid removal is done well.	Short treatments three times per week don't remove many toxins! Over a period of years, these can build up and damage nerves, joints, and bones. See Module 16— <i>Long-term Effects of Dialysis</i> to learn more.





Home hemodialysis

Anyone who can drive a car can learn to do home HD, with a few weeks of training. People who do home HD most often need to have a partner (or pay someone) to help with treatments. Some programs will allow home HD without a partner. This is because doing longer and/or more frequent HD treatments gets rid of most of the symptoms (like muscle cramps, headaches, nausea, etc.) that occur during standard in-center HD. As with PD, Medicare can start right away if home HD training starts before the third month of dialysis.

One of the new machines for home HD is small and portable. It is a 17-inch cube that weighs 70 lbs. and has a handle. With someone to help, the NxStage machine (below) can be taken on a car trip, cruise, or airplane, with supplies shipped to a destination. This machine does not need special plumbing or wiring. Some other machines built for home HD do need special plumbing or wiring. As with PD, you would need to have space to put the machine and store some supplies.



Photo of NxStage® System One™ with PureFlow™ SL used with permission from NxStage Medical, Inc., 2007.

In-center Self-Care HD

People who decide to do HD in-center can take an active role in their care. Some centers offer in-center self-care, where patients are trained to do as much of the treatment as they want to learn. Training is done during treatments, and can take as long as it needs to. Patients who do self-care may learn to weigh themselves, take their pulse, blood pressure, and temperature, decide how much fluid to remove, gather their supplies, set up the machine, put in their own needles, track their care and take notes for the chart, etc.

Doing in-center self-care lets people feel more in control and have a much better understanding of the treatment and how it works. They can be sure that things are done right, with staff right there on hand to help and answer questions. Plus, since this is a self-care treatment, Medicare will start right away instead of after three months. For the center, there is extra payment for self-care training, self-care requires fewer staff, and patients who help take care of themselves are very rewarding to work with. So, it's a win-win all around.

Medicare pays for dialysis done in the home.

The patient does *not* have to buy the machine; the center supplies it and trains the patient and a partner to do the treatments. With home HD, the center has someone on call 24 hours a day to answer questions.

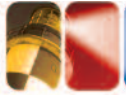
It is possible to do home HD three times a week for a few hours, just the way it is done in-center. But this type of home HD is much less common now. Having a 2-day gap in HD treatments is hard on the heart. In fact, two large studies have shown that sudden death from heart failure is



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twice as likely on the day after the 2-day dialysis “weekend.” So, at a minimum, most people who do HD at home do it every other day.

These days, home HD is most often done as **short daily** treatments (5 to 7 times per week for 2+ hours a day) or **nocturnal** treatments (at night for 8 hours or so during sleep, 3 to 6 nights per week, so days are free). These types of treatments are the fastest growing in the U.S., though the number of people using them is still small.

In-center Nocturnal HD

Did you know that it is possible to get the benefits of long, slow dialysis while you sleep, without doing your treatments at home? A number of centers around the U.S. are now offering *in-center nocturnal HD*. They make use of the machines at night, when they would otherwise be idle, to offer a treatment that can help you feel better and keep your job.

In most cases, people go to the center at about 9 p.m. to start nocturnal in-center treatments and leave at about 4 a.m. Treatments are usually done three times per week.

If you don’t have a partner and still want to do dialysis while you sleep, so your days are free, ask your center about in-center nocturnal HD.

Why would you want to go to the trouble of learning to do home HD—and having equipment in your home—when the staff at the center will do it for you? There are lots of reasons:

- You can control your own schedule at home, so it is much easier to keep your job, care for children or an aging spouse or parents, etc.
- Your access will last longer with just one person putting needles in it, and you are much less likely to get an infection at home than in a center. This means fewer trips to the hospital for access problems.
- You can do more dialysis at home, so you feel much better and have more energy and fewer symptoms. This makes it easier to plan ahead and know that you’ll be able to do things you want to do.
- When you get more dialysis, you have fewer diet and fluid limits. Your diet and fluids may even be normal—and you don’t have to take (and pay for) as many drugs.
- With more HD, your blood pressure is likely to be normal, which can protect your heart from *left ventricular hypertrophy* (a type of enlargement that is the leading cause of death in people on dialysis).
- With more HD, your blood chemistry levels are closer to normal all the time, which may help prevent long-term problems like *neuropathy* (nerve damage), *amyloidosis* (build-up of a waxy protein in the joints, tendons, and bones), and bone disease.
- When you do your own dialysis, you gain vital knowledge about how to care for yourself that will build your self-esteem and win you the respect of medical staff.





Patients who choose home HD like the freedom of choosing their own schedules and being in charge of their treatments:

“My wife has assisted my dialysis treatments at home for the past one and a half years. As a result of being able to determine 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 treat myself 5 days a week. My treatment time is 2 hours. (I am pretty little and also get a good flow with my fistula.) I have been using NxStage for about a year now and really like it. It took me about a month to learn the machine and feel like I could handle it on my own. It really is very easy and, to tell you the truth, I would not want to go back to a unit. It is so nice to be able to do my treatment when I want in the comfort of my own home. The machine is easy to set up and does take little room. My machine sits on a TV stand that I bought at Target.” —Vanessa

“My father just turned 79 and we do dialysis here at home 5 days a week. He is still very active maintaining the 250+ pecan trees in his orchard, runs his pecan shelling machinery in the fall, and also grows over 200 orchids in his bobby greenhouse. There are many options today for kidney failure, and I am very happy that we have found one for our family setup. Yes, we have had to adjust our schedules here at home and at work, but now that we have a routine in place, everyone here is very happy with the results. As of this week, Dad now sets up and primes his own machine, and once I get the needles in place and we take our initial

readings, I start my work day and am in contact (next door) by cell phone all the time. He takes all of his own intermediate readings and charts them in the process, and I show up later to do the rinse-back procedure. My wife has almost learned the whole dialysis setup from watching my Dad and me, and my 75-year-old mother is learning some aspects also. With a family team we have back-up after back-up after back-up so the work is spread out where no one is stressed at all.” —Michael

The scientific community is still debating if daily or nocturnal HD are better treatments—or if the difference is really in the people who choose it. Those who dialyze at home do tend to be younger and have more education. Some small, non-random studies have found that people who do these treatments live longer than those who do standard, in-center HD three times a week.

The National Institutes of Health are doing randomized studies of daily and nocturnal HD right now, with results expected in 2010. And NxStage is doing the FREEDOM study to look at costs and hospital rates of home HD vs. standard in-center HD.

Paying for Home HD More than Three Times per Week

Medicare pays for three HD treatments per week. This means that if you want to do daily home HD (5 to 7 treatments per week), you either need to have health insurance other than Medicare or your doctor needs to write a letter to Medicare to ask them to pay for more treatments. You may need both. For this reason, if you have better insurance, you may be more likely to be offered this treatment option.



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If you want to do HD at home, you can look for a center with home training on the Home Dialysis Central (www.homedialysis.org) website.

Keep in mind that a home dialysis center does *not* have to be right around the corner. After training is through, clinic visits are most often done just once a month—so the center can be as far away as someone is willing to drive once a month. Some people move to another town or drive 3 hours or more to get home HD.

Another option is to ask your doctor or center about starting a program if they don't have one. Patients have been able to advocate to get new home HD programs started all across the U.S.

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

- ☐ I need to be able to keep my job and help support my family.
- ☐ Having 4 dialysis-free days each week sounds good.
- ☐ Getting more treatment and having less risk of long-term problems sounds good.

- ☐ I want trained staff to do my treatments for me.
- ☐ I like the idea of doing treatments in my home, on my own schedule.
- ☐ I would rather have treatments with other patients in a center.
- ☐ I would rather have treatments with my family and friends around me.
- ☐ 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 standard HD.
- ☐ Needing to buy and take fewer drugs sounds like a plus to me.
- ☐ I don't think I want to do dialysis treatments myself—at least not yet.
- ☐ I don't want medical equipment or dialysis in my house.
- ☐ I think my family and I could learn to do HD at home.
- ☐ 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 22 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, 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!"*





What's Good and Bad About Home HD?

What's good about home HD?	What's bad about home HD?
You are in charge of your own day-to-day care, with your care team as consultants to help you feel your best.	You have to be responsible enough to do all the treatments each week.
Treatments are done by you and a partner, after a training course. A nurse is always on call to help you.	If a rare emergency does happen, you will have to keep your cool and deal with it.
You have time to do quiet activities or sleep—in your own home—and you get to decide the rules about eating and visitors yourself.	You don't get to meet and spend time with other patients (but you have more time to spend with your family and friends).
You can do dialysis on your own schedule, which can make keeping a job, finding childcare, or other activities much more possible.	A partner must be there, unless your program doesn't require it. Some centers may use a "Life-Alert" button, or monitor treatments over the internet.
You don't have to spend time driving 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 or your care partner must learn to put in your needles, which can help your access last much longer.	It can be scary to learn to put needles in (but it usually hurts much less when you do it yourself).
You can get a lot more treatment than most centers are able to give you, which can help prevent long-term problems, so you stay healthier.	With equipment in your home and treatments done longer or more often, it is hard to forget about dialysis. You need space to store the machine and boxes of supplies.
You can have a much more normal diet, drink more fluids, and take fewer medications (including phosphate binders).	You need to invest the time in training and in doing the treatments yourself to get these benefits.



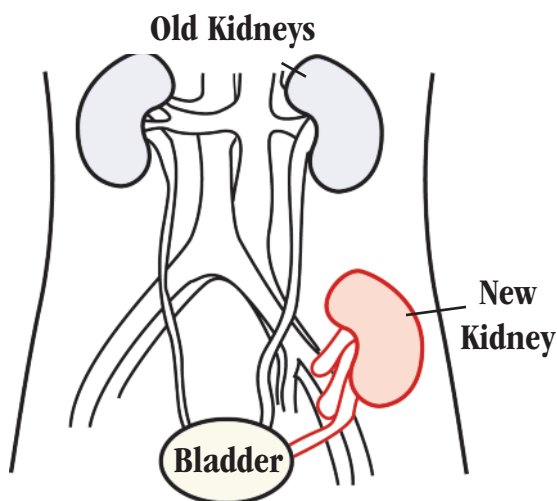


The final two treatment options we will cover are:

- 1 Transplant
- 2 No treatment

Transplant

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



Many 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.

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.

It's important to be realistic about kidney transplant, though. A transplant is just a treatment, not a cure.

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 type 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:

- 1 A blood relative (living-related donor)
- 2 A spouse, in-laws, or friend (living, non-related donor)
- 3 A deceased donor

Living-related and living, non-related transplant

A family member, spouse, or friend may choose to donate a kidney. Living donor transplants typically have better function and last longer. 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 decide whether to have more tests to see if he or she could be a donor.





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.

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.

Sometimes people have one or more willing donors—but none of them are good blood and tissue matches. Some transplant centers have programs where two living donors who do not match their loved one can “trade” a kidney to each other's recipient. The two transplants are done at the same time. In this way, two recipients get a living donor, and neither one has to wait on the deceased donor list.

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

Transplant from a deceased donor

Deceased donor kidney transplants are another option. 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 months to years.

If there is no living donor, someone who wants a deceased donor kidney can be placed on a national transplant waiting list kept by the United Network for Organ Sharing (UNOS). There is a “standard criteria” list and an “extended criteria” list, which has kidneys from older donors or donors

who had health problems. Your transplant team can help you sort out whether to be on one or both lists.

What Patients Say About Transplant

Here are three very different stories of kidney transplant:

“I was on CAPD for almost six 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. It's still 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 five 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 four 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 (from his father) 11 years, and 6 months ago he had number four. 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 three 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



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When a kidney comes up, the two or three patients who are the best matches in the region may be called. Blood tests and medical exams are done to see which one will receive the kidney. You can be on more than one region's waiting list if you are willing to travel to get a transplant.

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

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 use when that transplant comes along.

How well do kidney transplants work? Dr. Tom Peters, a transplant surgeon from Florida, says this:

"If we were to take 100 dialysis patients today,

How Well Do Kidney Transplants Usually Work?



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, and their kidney will last 10 to 20 years.

"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. 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. From 2 to 4 will die in the first year—usually beyond three months post-transplant—from a heart attack, stroke, infection, or other cause. The remaining patients will have had some loss of transplant kidney function, or will have had to return to dialysis. The reasons for kidney function impairment or loss in the first year include rejection, infection, technical or surgical problems, medicine reactions, recurrence of original disease, and other causes. Most patients who lose transplant kidney function will be able to receive another transplant."

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 was not 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*.





What's Good and Bad About Transplant?

What's good about transplant?	What's bad about transplant?
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 to limit how much fluid you drink.	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, so you can work full time and stay active.	Before you feel better, you will have to recover from the surgery.
You can take part in most of your usual activities, including work.*	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.

* **Please note:** If you do not have another reason for disability, you will lose your Social Security Disability Insurance (SSDI) *and Medicare* three years after a successful transplant. This means you will need to have a plan for how to pay for your transplant drugs.



Module 2 – Treatment Options for Kidney Failure

Given what you have read now, what do you think about transplant? Check all that apply:

- ☐ I don't want 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:

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 have many serious 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 an 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 terms with the decision. Patients and families can also turn to a religious advisor for help.

If a patient decides not to get treatment for 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 fear the unknown. In these cases, the care team may suggest a trial of dialysis for a few weeks or months. Talking to other patients and their families may also help. 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.
- ☐ Start, and stick with, a regular exercise program.

- ☐ Talk with others who are living with kidney disease.
- ☐ Do research on living with kidney disease (in print, on the web, at the library, etc.).
- ☐ Write down, and ask your doctor, specific questions for which you want answers.
- ☐ Volunteer to work with others who have kidney disease.
- ☐ Meet with a social worker or other professional counselor.
- ☐ Meet with a renal dietitian to develop a healthy meal plan.
- ☐ Work through all of the modules in Kidney School.

We said at the start of this module that choosing 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

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.



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Module 2 – Treatment Options for Kidney Failure

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.”

Nobody likes feeling any of these emotions. And any time 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 (to learn more, read Module 5—*Coping with Kidney Disease*). 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 eight years old and switched to PD one year later. I did well on PD for five years until I received a deceased donor kidney transplant. The transplant made a huge

difference in my life for the five 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 have.

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 when 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. Earlier, 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.

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 for kidney failure. But before we do, we want to give you a Personal Plan to help you get a start on some of the most important ideas in this module. We encourage you to put it where it will remind you of the goals toward which you're working.





Personal Plan for _____

Treatment Options for Kidney Failure

Change

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

Treatment Options

- Peritoneal dialysis (PD)
- Hemodialysis (HD)
- 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, is drained out through the catheter, and then 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 2-6)

I can explore these further with my doctor.

Hemodialysis

HD uses a dialyzer and a machine to clean the blood three or more 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 at home. Home HD is most often done 3 to 6 nights per week or 5 to 7 days per week.

My thoughts about possibly using HD were:
(Write down your thoughts from page 2-14)

I can explore these further with my doctor.

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
- A deceased donor





Personal Plan for _____ (continued)

My thoughts about possibly having a transplant were: *(Write down your thoughts from page 2-20)*

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. Then I can make choices on the basis of what I know to be healthy, true, responsible, etc.

Principles to live by with chronic illness:

- Develop a positive attitude
- Actively educate myself on an ongoing basis

- Build a support system
- Take responsibility for my health
- Assertively stay with my chosen treatment
- Help 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 the following 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 10 questions. How about it? *(Answers are on page 2-2.)*

- 1. Peritoneal dialysis uses a _____ as the access for treatment.**
 - a) Catheter
 - b) Fistula
 - c) Graft
 - d) Dialysis machine
- 2. In hemodialysis (HD), blood is filtered through a _____.**
 - a) Hemolyzer
 - b) Dialyzer
 - c) Cholesterol screen
 - d) Hemoglobin
- 3. In peritoneal dialysis (PD), 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 HD
- 5. Home HD 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 PD 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. Standard in-center HD is most often done three times a week for at least 3 to 4 hours a treatment:**
___ True ___ False
- 10. Getting longer and/or more frequent HD treatments can:**
 - a) Protect my heart
 - b) Allow fewer diet and fluid limits and medications
 - c) Give me more control over my schedule
 - d) All of the above





Additional Resources

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

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

Book:

- ***Dialysis: An Unanticipated Journey***, by David L. Axtmann
(Tucky Paws Pub, January 2001, ISBN-13: 978-0970705815)

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 face: 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 changes in his sexual needs and desires. He explains his reason for choosing dialysis over a transplant.

Websites:

- ① ***www.homedialysis.org***, developed by the Medical Education Institute, Inc. The Home Dialysis Central website provides up-to-date, unbiased information about home dialysis—in all its forms—for people with kidney disease, their families, and the health care professionals who provide kidney disease care. Features include information about the types of home dialysis, home dialysis products, finding a home dialysis clinic, and resources.
- ② ***www.UNOS.org*** (United Network for Organ Sharing), has information about the waiting list process, transplant center data, and people's stories.
- ③ ***www.trioweb.org***, a support organization for those who have had a transplant.
- ④ ***www.transweb.org***, a website with transplant information.
- ⑤ ***www.ultracare-dialysis.com***, a complete resource for treatment options and lifestyle advice for living with kidney disease. Fresenius Medical Care created this website as a 'one-stop' source of information for anyone—patients, caregivers, family and friends—affected by kidney disease.

Other materials:

- ① ***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.
- ② ***Treatment Options Program (TOPs)***[™], developed by Fresenius Medical Care NA. Free educational program that offers resources for people diagnosed with or who are at risk for kidney disease. Hosted by experts in kidney care, these sessions help people learn about chronic kidney disease and treatment options. Materials include videos, slides, and handouts. To learn more, go to www.ultracare-dialysis.com/TOPS, or call 1-877-TOPS-LIFE (1-877-867-7543).

