

# My Life, My Choice

Patient Options Booklet

Patients share their perspectives about  
treatment options for people with  
chronic kidney disease



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# My Life, My Choice

There are a variety of treatment choices for patients with Chronic Kidney Disease. Making the right choice for your particular lifestyle can be a little intimidating. This booklet describes some of the choices others have made and why they made those particular choices. While there are some common elements to the different types of treatment, such as the need for monitoring laboratory results, weight, and overall health, the treatment types vary considerably in the way and place they are performed. Not all treatment options may be appropriate for your health needs or available in your region, so it is important for you to work with your physician and health care team. We hope that these personal experiences will help you in making that initial choice for treatment or when it might be appropriate to make a change in your treatment plan.

## Hemodialysis

Hemodialysis (HD) can be done at a dialysis center during the day, at night at a dialysis center, or at home. No matter what type of hemodialysis you choose, the process is the same. There are three parts to the hemodialysis process: a filter (dialyzer), cleaning solution (dialysate), and a means to take blood out of your body to pass through the filter (dialysis access). The filter and length of time on treatment vary depending on your body size and laboratory results. The preferred dialysis access is an arteriovenous fistula, which is a small connection between an artery and vein in your arm which is created during a surgical procedure. There are other types of dialysis access but the fistula is the preferred type. Your health care team will assist you to determine which access type is best for you.

## In-Center Hemodialysis

In-center hemodialysis is performed at a dialysis center, usually 3 times per week for 3½-4 hours for each treatment.

Joanne says, “I chose in-center dialysis because it gives me two advantages. The doctor comes to me monthly and



the professional staff (i.e., nurses, social worker, and dietitian) monitor my condition in the center. It allowed me to develop my own community because I was able to see and speak with other dialysis patients who were dealing with similar issues and sharing ways to cope.”

## Nocturnal Hemodialysis

Nocturnal hemodialysis is usually performed in the dialysis center during the evening or night for 6-8 hours each treatment. Vicki began nighttime dialysis 4 years ago. She says, “It is unbelievable

how much better I feel now, how much my labs have improved, and how much more energy I have.”

Carol first heard about nocturnal dialysis through a Peer Mentor workshop. “I feel better now, my labs are better and I like the schedule!”

Others who have commented agree, “The longer stay at the dialysis center allows me to interact more with staff and patients so I actually receive more training and education.” “This process is less stressful to the body and helps to prevent that ‘washed out’ feeling and cramps.”

## Home Hemodialysis

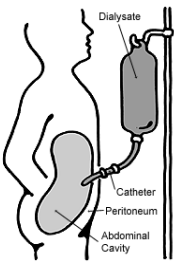
Hemodialysis can also be done at home. You and a partner are trained to do the treatment. At home, you may be better able to fit your treatments into your daily schedule.

Beverly shares, “Home hemodialysis was the best choice for me. I dialyzed in-center for 6 months and then moved to home hemodialysis. I dialyze six

days per week, and it lets me adapt my schedule so I can go to bed after dialysis and wake up ready to go. I don't experience the weakness that I had when I dialyzed three days per week in the center."

## Peritoneal Dialysis

A soft plastic tube (catheter) is placed in your abdomen during a minor surgical



procedure.

A sterile dialysis fluid is put into your abdomen through this catheter.

After a

specific amount of time, the fluid is drained out, and fresh fluid is instilled through the catheter. This is called an exchange. You are trained by your dialysis team to do the exchanges on your own.

There are two kinds of peritoneal dialysis: Continuous Ambulatory Peritoneal Dialysis (CAPD) and Continuous Cycling Peritoneal Dialysis (CCPD).

The basic treatment is the same for each type; however, the number of treatments and the way the treatments are done make each method different.

## CAPD

CAPD is continuous, machine-free, and done while you go about your normal activities such as work or school. You perform an exchange using a sterile connection between a fluid (dialysate) bag and your catheter. This exchange process is usually done three, four, or five times in a day during normal activities. Each exchange takes about 30 to 40 minutes. Some patients like to do their exchanges at mealtimes and at bedtime.

## CCPD

CCPD differs from CAPD in that a machine (cycler) delivers and then drains the cleansing fluid for you. The treatment usually is done at night while you sleep. What kind of peritoneal dialysis is best?

The type of peritoneal dialysis that is best for you depends on your personal choice and your medical condition. Your doctor will help you to choose the one

that is best for you.



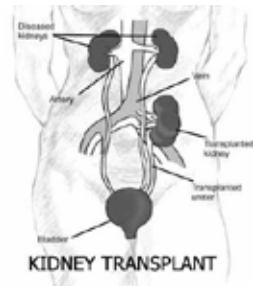
ImoGene says, “One of the main reasons that I chose Peritoneal Dialysis

(PD) is that I only had to visit the Dialysis Center two times a month, and I had more time for things I enjoyed doing. The clinic visits were for blood draws and to see my nephrologist, and usually only lasted two to four hours. I have performed PD exchanges in very interesting circumstances—in my bedroom, my living room, my basement, hotel rooms, hospital rooms, vehicles, at the homes of relatives and friends, and dialysis centers. I even performed exchanges by candlelight during the August 2003 blackout. I am a self-sustaining, independent, *yes I can* type of woman, and I know that

the person who can take the best care of me is me. By choosing PD, I dared to take an active, direct role in my kidney care, and I feel empowered!”

## Transplant

A kidney transplant is an operation in which a person whose own kidneys have failed receives a new kidney to take over the work of the old kidneys. There are two types of kidney transplants: those that come from a living donor and those that come from a deceased donor. A living donor may be someone in



your immediate or extended family or your spouse or close friend, and, in some cases, a stranger who wished to donate a kidney to anyone in need of a transplant.

Following a successful transplant, it is necessary to take medicine to prevent the body from rejecting the new kidney.

## Living Related Donor

Ruth... “I am still convinced that it was the right decision for me. I taught elementary school during the day and was on HD for almost 2 years. After considering the possible side effects of the anti-rejection drugs, I decided the benefits outweighed the risks. My sister was a great match and willing to be my donor. For the past 20 years, I have been able to teach, get a Masters Degree, travel, and live a productive life with my family and friends.”

Ruth’s sister... “It was a learning and enlightening experience for me to go through with my sister. I donated my kidney to her and have had no problems with my remaining kidney. I am thrilled to see my sister well and free from dialysis.”

## Living Non-Related Donor

Scott says that when people in his life knew he needed a kidney, many colleagues, friends, relatives, even old high school classmates stepped forward to donate. In the end, his wife was the best donor match. “My wife and I now share a special bond that few couples will ever have.”

Mitzi... “I love my life after the kidney transplant. I am more mobile and able to do a lot more activities that I was not able to do before. That’s when my recovery began. I live a much healthier life since my transplant.”

## Deceased Donor

One patient shares the story of his deceased donor transplant and how he got the call for his transplant at 4:30 pm on a Sunday afternoon. The surgery was successful and his life has not been the same since the transplant. Through a third-party agency, he even had the opportunity to

send a letter thanking the family of his organ donor for the wonderful gift they had given. “Shortly after, the family sent a letter back, along with a picture of their beautiful 17-year old girl who had died as a result of a car accident. Her picture is on our family’s wall. She is an important part of our family, and her life is celebrated with all the rest of our children and grandchildren.”

## **Kidney-Pancreas Donation**

Sometimes, those patients with diabetes are able to receive a kidney and pancreas transplant at the same time. Christine... “I had Type I diabetes for over 30 years. Along the way, I developed kidney disease and eventually I had to go on dialysis. After 18 months, I received a kidney-pancreas transplant in 1998. It was successful, and I no longer have to take insulin and no longer have to go for dialysis. I have been very blessed and have so much more hope for a future that includes a fairly normal life.”

## **Choosing Not to Dialyze or Choosing to Stop Dialysis Treatment**

Dialysis and transplant are life-saving treatments for people with chronic kidney disease. You do, however, have the option to choose not to start treatment or to stop treatment.

Choosing not to start treatment or to stop treatment is a very personal decision and so you may want to discuss your feelings with your family, spiritual advisor, and other loved ones. It is also important to discuss these feelings with your health care team. They may ask you to meet with a counselor or social worker to support you as you make this decision. No matter what decision you make, your health care team will be available to help you understand what you can expect and to make sure you are comfortable. Home care and hospice care may be available, and they will help with those arrangements.

## Additional Resources

### **Renal Network 11**

1-800-973-3773

[www.esrdnet11.org](http://www.esrdnet11.org)

**Life Options** provides research-based materials for people with kidney disease.

1-800-468-7777

[www.lifeoptions.org](http://www.lifeoptions.org)

### **American Association of Kidney Patients (AAKP)**

1-800-749-2257

[www.aakp.org](http://www.aakp.org)

### **Renal Support Network (RSN)**

Hopeline 1-800-579-1970 will connect you with someone who is living successfully with kidney disease.

[www.rsnhope.org](http://www.rsnhope.org)

**Kidney School** provides online educational materials and interactive modules on living with kidney disease.

[www.kidneyschool.org](http://www.kidneyschool.org)

**Dialysis Facility Compare** is a website that provides important information and resources for patients and family members who want to learn more about chronic kidney disease and dialysis.

[www.medicare.gov/Dialysis](http://www.medicare.gov/Dialysis)

### **US Transplant - Scientific Registry of Transplant**

**Recipients (SRTR)** is a national database that provides information on transplant outcomes and transplant programs.

[www.ustransplant.org](http://www.ustransplant.org)

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