

My Life My Choice

Patients with kidney disease share their experiences choosing a treatment option.



Midwest
Kidney Network

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Introduction

By Maggie

Midwest Kidney Network Consumer Committee Chair

Purpose

This brochure was written by patients to help you with the choices you are facing. We have all been faced with many of the same challenges, and these challenges can seem overpowering.

My Experience

When my kidneys failed 25 years ago, I felt that my world was collapsing. I was sick, I was scared, and I had a lot of decisions to make. I struggled with decisions about which type of dialysis I would choose and if kidney transplantation was right for me.

I was so worried that I would make the wrong decision. I did not realize at that time that there was no wrong decision. There are several types of dialysis and transplant modalities, and they all work.

Treatment Choices

The trick is to find the modality that best fits the type of life you want to live. Do you want the flexibility of dialyzing yourself at home? Do you want to feel steady every day? Is a transplant right for you? Do you want the peace of mind of knowing that a medical team will be seeing you three times a week? Do you want to deal with it on dialysis days and not on the other 3 or 4 days a week? Do you want some of the freedom to travel?

Life Plan Choices

The point is, you can have a good life on dialysis or a kidney transplant, and you can choose the modality that helps support the things that are important to you. Also, the best part is that your choice is not permanent. If you choose a modality that does not work well for you after all, then you switch to another one.

Please read the patient stories in this brochure. They may give you just the insight you need to make your choices easier and less stressful.

Peritoneal Dialysis (PD)

“I could still do pretty much everything I enjoyed. I was a little slower and had to plan things a little more, but it worked well for me, and I felt really good most of the time.” -Maggie



How long have you been on your current modality?

2 years peritoneal dialysis and 24 years post-transplant

Why did you choose this modality?

I watched the videos they provided and I thought Peritoneal Dialysis would offer me more flexibility and change my life the least. That was what I was looking for – as normal a life as I could get. I was right.

What advice would you give to patients considering this modality?

If you are considering Peritoneal Dialysis, you will need to take into consideration the space needed to store the supplies. There are also a couple plumbing issues that may have to be worked out. Other than that, I highly suggest you just go for it.

Benefits of Peritoneal Dialysis you may experience:

- Greater Flexibility in your schedule.
- Improved outcomes from daily dialysis.
- Better control of fluid removal.
- Needle-free treatments.
- No recovery time and greater energy.
- Fewer fluid and diet restrictions.

Home Hemodialysis (HHD)

“My biggest advantage to this modality is that I am able to do dialysis around my life instead of my life around dialysis.” -Chris



How long have you been on your current modality?

Hemodialysis was chosen for me while in the hospital in 2017. I switched to home hemodialysis in October of 2018.

Why did you choose this modality?

I stayed with hemodialysis for a couple of reasons. I was familiar with the process and I already had a working fistula and did not want another surgery. I chose to go on Home Hemodialysis because it is less stress on your body and your heart. Labs stay more level and in range better.

What advice would you give to patients considering this modality?

Choosing a modality is a personal decision and you need to choose the one you feel you will be most comfortable with.

Benefits of Home Hemodialysis you may experience:

- Schedule your treatment around your life.
- Enjoy fewer food and drink restrictions.
- Take fewer medications.
- Less travel to your dialysis clinic.
- Flexibility to enjoy your social, family and work life.
- Flexibility with travel.

Transition to HHD

“There are still struggles because that is how life goes but being able to dialyze at home and go right to work is a huge plus. If you can, do it!! It made all the difference for me.” -Gail



How long have you been on your current modality?

Initially, I was not really given any different option than In-Center Hemodialysis. Once I was on the transplant list, my transplant doctor did ask if I wanted to do Peritoneal Dialysis. I declined because I like to swim, and immersing your port is not an option. I have been on dialysis for 1 year and 4 months. I did In-Center for 10 months and Home Hemodialysis for the past 4 months.

Why did you choose this modality?

One day I was sitting in dialysis scrolling through my Facebook feed, and I saw and watched a NxStage Home Hemodialysis video. I thought it was interesting. So, I went on YouTube and watched more videos about the treatments. I reviewed the NxStage website to find as much information as possible. After my research, I decided Home Hemodialysis was the modality for me because of its promise of a better quality of life. I went to my next In-Center dialysis and asked the unit scheduling nurse if I could do Home Hemodialysis. She put me in touch with the unit that could help me.

What advice would you give to patients considering this modality?

I would have never done In-Center dialysis if I would have known how much more of my life it would steal. I started my home dialysis training in May of 2020, and my life changed from the first day. I expected a change for the better in time, but I did not think the change would be instantaneous. It was amazing to get such a large part of my life back.

In-Center Hemodialysis

“I feel that this is a great modality to get started on dialysis. Once you are familiar with the procedures, then you can explore the other options if you choose to change.” -Marguerita



How long have you been on your current modality?

14 years, (with 3 years in between with a kidney transplant).

Why did you choose this modality?

I chose this modality because it benefited me to go in-center where there were nurses and technicians to monitor me while I was on the dialysis machine. Also, it was better for someone, other than myself, to place the needles in my vascular access. I was not familiar with the other modes of dialysis right away.

What advice would you give to patients considering this modality?

I feel patients need to keep an open mind when considering the right mode of dialysis or transplantation. Your choice needs to fit your lifestyle. Not every patient is the same. This is your lifeline.

Benefits of In-Center Hemodialysis you may experience:

- Confidence of staff-assisted treatment.
- Ability to visit in person with staff at your scheduled treatments.
- All your dialysis treatments, labs, and nephology visits will be at your clinic.

Kidney Transplant

“Cultivate a support system of friends and family. Inform others. You never know who will decide to be a donor.”

-Patti



How long have you been on your current modality?

7.5 years.

Why did you choose this modality?

I knew that kidney transplant patients had a longer life expectancy. I also did not like being on dialysis.

What advice would you give to patients considering this modality?

Lead a healthy lifestyle. Be informed and educate yourself. I was reluctant to share information about my kidney disease with friends and family. I did not want to ask for a kidney. My doctor strongly recommended that I share my situation with others. By educating my friends and family, I learned that several people I knew were interested in donation.

Benefits of kidney transplant you may experience:

- Improved health outcomes.
- Fewer dietary restrictions.
- More time to enjoy your family, social life, and work.
- Better electrolyte, calcium, and phosphorus, and PTH balance.
- No more guessing at dry weight and no cramping after dialysis.

Second Kidney Transplant

“I knew that a transplant would free up 20 hours of my week. I would be able to spend more time with my family at home after working.” -Mitzi



How long have you been on your current modality?

This is my second kidney transplant. My first transplant lasted 12 years and I was back on in-center hemodialysis for 5 years. I am now 3 years living with my kidney from a deceased donor.

Why did you choose this modality?

I chose to go on the transplant list for several reasons. 1) Because I was still working full time while on dialysis, I would go to work for 8 hours, 5 days a week, and then dialysis after work 3 times a week. 2) I knew that a transplant would free up 20 hours of my week. I would be able to spend more time with my family at home after working. 3) I was at an age where I am still very independent and doing everything for myself. There would be no problem for me to be compliant with taking all my medications that were prescribed for a transplant.

What advice would you give to patients considering this modality?

I would suggest that those who are thinking about a transplant to consider it. If you are a person who wants to be free of time-consuming dialysis treatments and can take all anti-rejection medications up to 20 pills a day, a transplant may be for you.

Preemptive Kidney Transplant

“If you compare kidney transplant with the ups and downs and time commitment of dialysis, kidney transplantation is certainly one of the best routes to a healthy, long, life.” -Sophia



How long have you been on your current modality?

14 years

Why did you choose this modality?

Fourteen years ago, I had symptoms of kidney disease. My sister, family, doctors, and I decided to do a preemptive kidney transplant. I understood that going to surgery healthier would increase my chances of a better outcome. As a result of my transplant, I was able to celebrate 21 years of marriage and see my daughter grow up, graduate from high school, and enter college.

What advice would you give to patients considering this modality?

Having a kidney transplant is a challenging decision, but it is one of the best decisions to maintain life to the fullest. You will take anti-rejection medications all your life, have lab tests done frequently, and will have to make some minor lifestyle changes.

Benefits of preemptive transplant you may experience:

- Potential avoidance of dialysis
- Improved short-term and long-term survival rates
- When your kidney donor is approved, you may schedule your procedure, which may be more convenient for you and your donor

Resources

American Association of Kidney Patients (AAKP)

AAKP is dedicated to improving the lives and long-term outcome of kidney patients through education, advocacy, patient engagement and the fostering of patient communities.

1-800-749-2257

www.aakp.org

American Kidney Fund (AKF)

The American Kidney Fund (AKF) offers programs of prevention, early detection, financial support, disease management, clinical research, innovation and advocacy.

1-800-638-8299

www.kidneyfund.org

Kidney School Online

Educational materials and interactive modules on living with kidney disease.

www.kidneyschool.org

Medicare Care Compare

Helpful tool to compare the services and the quality of care that dialysis facilities provide.

www.medicare.gov/Dialysis

Resources

Midwest Kidney Network (ESRD Network 11)

We are a private, nonprofit organization founded to improve care for patients with end stage renal disease (ESRD).

If you think you may have a grievance or want to have a confidential discussion about a situation, event, or condition involving your ESRD care or services, contact us.

1-800-973-3773

1360 Energy Park Drive, Suite 200

Saint Paul, MN 55108

info@midwestkidneynetwork.org

www.midwestkidneynetwork.org/patients

National Kidney Foundation

Learn about treatment options and find support.

www.kidney.org/treatment-support

National Kidney Foundation Peers

Speak with a trained peer mentor who can share their experiences with you.

1-855-653-7337

www.kidney.org/patients/peers

Renal Support Network (RSN) Hope Line

This service will connect you with someone who is living successfully with kidney disease.

1-800-579-1970

www.rsnhope.org

United Network for Organ Sharing (UNOS)

Information on kidney transplant.

1-888-894-6361

www.transplantliving.org/