
IS A KIDNEY TRANSPLANT RIGHT FOR ME?

A guide created *by patients for patients* considering transplant



Should I get a transplant?

If you are facing Kidney Failure, you may be wondering if transplant is right for you.



How can this guide help?

We, as ESRD Patients, designed this toolkit to explain the transplant system in such a way that it will readily relate to patient needs.



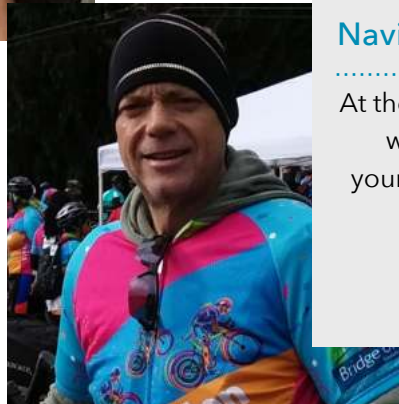
Our Stories

Throughout these pages, we share our patient transplant stories including the risks and rewards of our experience. We include information we wish we had known to help us in our decisions.



Navigating the process

At the end of this toolkit you will find questions to ask your care team as you work your way through the decision and transplant itself.



The Patient Directed Kidney Transplant Toolkit

The Forum of ESRD Networks Kidney Patient Advisory Council (KPAC) has designed this **Patient Directed Kidney Transplant Toolkit** to assist patients as they navigate through the Transplant System. It is intended to be used with the Forum's [Kidney Transplant Toolkit](#)* developed by the **Medical Advisory Council (MAC)** to help guide the conversations between patients and their care teams throughout the entire transplant process.

While transplant is often the recommended choice for a patient dealing with kidney failure, there are factors to consider when determining if transplant is right for you. This guide developed by the Forum's Kidney Patient Advisory Council can help you in the decision process.

During the development process of this toolkit, it became apparent that it could be a useful tool for both patients AND facilities. While all facilities and all Networks have a Transplant assistance requirement, this is the first time that process has been presented through the Patient's eyes.

Thank you

This toolkit would never have existed if not for the contributions, active support, and encouragement from the ESRD Forum's Executive Director Advisory Council (EDAC) and the Medical Advisory Council (MAC). These tireless individuals have donated time and information in so many ways toward the development and completion of this project. Thank you, everyone, for all you have done and continue to do so that we, the patients, can have the best possible life with ESRD.

* The Kidney Transplant Toolkit developed by the Medical Advisory Council (MAC) can be downloaded at www.esrdnetworks.org/toolkits/professional-toolkits/new-kidney-transplant-toolkit



This toolkit is dedicated to the memory of all those we've lost. Without their contributions of energy, passion, insight, experience, intelligence, and bravery none of this is possible. Thank you. We will see you on the other side, dear friends.

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Patient Story



Evan C.
Ohio

“I was the fourth to get kidney failure in my family.”

Chapter 1: OVERVIEW OF DECISIONS

Patient Story



Maile R.

Nevada

“I would like to speak to the love and gratitude that I feel to my father and my sister for giving me a piece of their body. My sister was a senior in high school and had just turned 18. She didn’t think twice, said it was no big deal. What do you say to that? I don’t know. What I say is thank you and I love you. Because there really aren’t any other words to say. I am a very grateful lucky person.”

Should I get a transplant?

If you, or someone you love, is dealing with Kidney Failure (End Stage Renal Disease) you are facing many decisions on how you want to live your new life. One of the first options that comes to mind is Transplant. On the surface, this may seem like a simple question. Why wouldn’t you want to get a transplant and get off dialysis?

It is important to realize that a Transplant is not a cure. It is simply a treatment option - often the best option for many of us. But you will still have Kidney Failure and you must still follow the proper medical procedures to maintain your Transplant. There are a lot of Risks and Rewards to consider before you make an informed decision.

In the following chapters we will be talking about some of the Risks and Rewards. We will be sharing some of the information we wish we had known to help us make our decisions. It is important to stress that no two people will react the same to any situation. We can only share what we experienced and what we learned. We hope this will help you make the first Decision.

What Transplant Center should I choose?

Once you have decided to pursue a Kidney Transplant, you will need to select a Transplant Center and begin the listing process. In some cases, this may not be a difficult decision. You may live in an area that only offers you one obvious choice. You may be limited by transportation needs, or you may have a center associated with your medical team and/or insurance.

If you have multiple options, there are things you will need to consider.

- What financial commitments do they require above my Medicare/ Insurance coverage?
- What time span is required for the initial work-up?
- What aftercare requirements are involved?
- What transportation is available?
- What lodging is available if the Center is not close enough to your home?

Getting on one transplant waitlist is the most important step, since in the U.S. there is one national list for organ donors. However, within this national list, kidneys are often distributed locally and regionally. If you get on a waitlist in more than one 'organ procurement' region, this may increase your chance of receiving an offer. Some people dual list in the hopes of getting transplanted quicker, though of course there are no guarantees.

Very rarely, people choose to be listed at more than one transplant center in the same region, which only increases your chances of receiving an offer if transplantation practices are very different between these two centers.

Multiple Listings

When a patient lists at a transplant hospital, they are generally considered for organs from a donor in that local area first. If a patient is put on the list at more than one transplant hospital, they will be considered for donor organs that become available in more than one local area.

National transplant policy allows a patient to register for a transplant at more than one transplant hospital. However, each hospital may have its own rules for allowing its patients to be on the list at another hospital. Patients should ask each hospital

whether it allows its patients to list at more than one transplant hospital. Being listed in more than one area does not guarantee an organ will become available faster. Generally, each transplant center will require the patient to go through a separate evaluation, even if the patient is already listed at another hospital.

What is the potential downside?

Hassle and potential cost. Your medical insurance may limit where you can list or it may not reimburse you for the cost of additional evaluations. Also, you need to be willing to travel to complete an evaluation at each center you wish to be listed at. After receiving a kidney transplant you will need to stay near the transplant hospital for some time to ensure you are doing well enough to travel back home.

Transferring Waiting Time

Patients may switch to a different transplant hospital and transfer their waiting time to that hospital. Waiting time from the original center is added to the time collected at the new hospital.

The transplant teams at the first hospital and the new hospital will be responsible for coordinating the exchange of information and notifying UNOS of the transfer of waiting time. Patients should ask each hospital if transferred waiting time will be accepted.

Patient Story

Maile R.

“I was not sure if I even wanted a kidney transplant. I decided to go through with the evaluation. I live in an area that does not have a transplant facility locally. I had to decide where I wanted to spend 4 to 6 weeks recovering from the transplant.”

“I got evaluated at three different locations. The University of Iowa, Stanford, and the Mayo Clinic in Scottsdale, Arizona. I chose the Mayo Clinic.”



What kind of Support Team do I need?

Some Transplant Centers have specific requirements for your support team. Some may require another adult in your home for the first few weeks after your transplant. Some may only require someone who is available to drive you to follow-up appointments.

Although many of us came home with an abundance of energy that we were not expecting, we were still recovering from surgery. You may find that you need help in household duties that you were not expecting - shopping, cooking, cleaning, and laundry. It is important to have a support team in place even if your transplant center does not require one.



Patient Story



Patrick G.
Virginia

“On April 21, 2017, after four (4) years on Peritoneal Dialysis, I received my new kidney. When I woke up from the surgery, I was so excited that I had a new kidney but I wasn’t prepared for what happened next. My wife told me that my kidney was still asleep. So, I asked for further information. My care team told me that it is normal for a kidney to stay asleep for a number of days before it would start working. So, with that said, I had to do 24 hour Hemodialysis using a port in my neck.”

Patient Story



Patti B.
Michigan

“My transplant was successful and left me eternally grateful to my brother, my donor, who is five (5) years my senior. I was forewarned of the risks and the side effects that could be possibilities. Hence it did not come as a surprise that I developed Type 2 Diabetes and Hypertension. I also experienced minor weight gain. Despite my concerns over these developments, I would rather experience these complications than continue dialysis – a process that has its own related risks and discomfort.”

Do I have Adequate Transportation Arrangements?

All Transplant Centers require follow-up appointments both prior to the transplant and after you have received one.

If you have selected a Transplant Center close by, this may not be a problem. Friends, family, or public/private companies may be available to help you to and from these appointments. Remember, you may have some driving restrictions immediately after you receive your transplant. Do you have local transportation?

If you have selected a Transplant Center further from your home, transportation may become more of an issue. Some of us have chosen centers that involved airline flights and overnight stays. How often will you have to visit the Center prior to the Transplant? How soon after the transplant will they assign your care to a local provider?

What this Toolkit can offer to You

The following chapters will look at each of these questions and help you to find the resources to help you make your decisions and plans. We will also be providing worksheets that will help you ask questions as you are making your decisions. Lastly, we will provide you with resources that will help you reach out for additional information and support.

Patient Story

Evan C.

“For a long time, because of magical thinking, I imagined I had dodged a bullet, even though a biopsy had told me that I had the early stages of Alport’s Syndrome and would get sick at some point.”

Chapter 2: REWARDS

The decision on whether to pursue a Kidney Transplant is not always easy. Many of us have felt that we were doing okay on dialysis and wonder “Why should we rock the boat?” Some of us feel that we are barely hanging on as it is, and we certainly can’t handle anything else! These are both very valid statements.

It is important to realize that the Rewards of receiving a Kidney Transplant can be life-changing in many ways.

Quality of Life

1. Energy - One of the first things you will notice with your new kidney is the increase in energy and stamina. For many of us it was a surprise. We had not realized that our energy had sunk as low as it had. It was like the sun coming out suddenly. For some, this increase in energy can happen immediately - even in the recovery room. For others, it is a more gradual increase.
2. Fluid and Diet - Another benefit of the transplant is a required increase in fluid intake. You may no longer have fluid restrictions and, in fact, may have levels of fluid that you must meet!! Your food restrictions may also be lifted, however, restrictions vary by patient so be sure to consult your care team and renal dietitian. It is important to remember though, that your appetite is often increased due to the medications and because you are feeling better in general. Make smart food choices to avoid excessive weight gain.
3. Increased Time and Ease of Travel - Many people are amazed at the amount of time that they now have available. Once we have adjusted to dialysis, we often don’t realize how much time we have been spending in preparing, dialyzing, and recovering. Our schedules are now open. We can also travel out of the area without considering dialysis schedules and/or arranging for dialysis in unfamiliar facilities. The flexibility achieved by a kidney transplantation is rewarding and liberating.

Patient Story

Patti B.

“Newly found energy post-transplant may make one open to a return to prior activities and stimulate an interest in pursuing new experiences. One possibility might be a return to school”

Patient Story



Maria C.
Puerto Rico

“I remembered I felt full of energy after my kidney transplant and got my taste for food again. One of the best things about my kidney transplant is that I don't have to go to dialysis anymore.



I have a lot of free time and don't have to follow a restrictive diet anymore. I have gained some pounds, but I know it is because I have more appetite than before, probably because of the Prednisone.”

Increased Life Expectancy

There is a huge survival advantage with a kidney transplant compared to living on dialysis. For example, a 30-year-old on dialysis would have a life expectancy of 15 years. With a deceased kidney donor transplant, life expectancy increases to 30 years. A living donor kidney transplant increases life expectancy to 40 years.

Patient Story

Patti B.

“I was pleasantly surprised when stamina improved. Climbing stairs was a serious challenge pre-transplant but afterwards exercise was no longer such a challenge. I was able to go on long walks exploring the streets in my neighborhood. My physician gave me permission to swim in a well-maintained pool. These activities increased my energy and improved mood.”



Improved Financial Health Possibilities

For many of us a transplant has provided enough time and energy that we have been able to go back to work or school. While these options were available while we were on dialysis, many of us were not able to support a work schedule and a dialysis schedule.

For those re-entering the job market or looking at schooling, Vocational Rehabilitation (VR) Agencies furnish a wide variety of services to help people. These services are designed to provide the client with the training and other services that are needed to return to work, to enter a new line of work, or to enter the workforce for the first time. VR counselors help to evaluate strengths, resources, priorities, concerns, abilities, and career interests.

They help clients get the education or job training they need to get a good job, help with job seeking, and with education-related expenses.



Increased Socialization

Often dialysis tends to isolate us from other people. After a transplant, when our energy returns and our schedules clear up, we find that we can spend more time with friends and family. We need to remember though, that initially we may be at an increased risk for catching illnesses. We should be careful to avoid situations where we may be exposed to obviously sick friends or family.

Patient Story



Maggie C.
Michigan

“I was 40 years old when I started dialysis. We had five children and the youngest was only nine. I really didn’t think about my future – I was just trying to cope with each day as it came. I was 43 when I got my transplant. Now, I am 65, a great grandmother, and thinking about retiring. Yep, pursuing that transplant was a good decision for me.”

Patient Story

Evan C.

“I did not originally sign up to be evaluated for a transplant. I was originally reluctant to get a transplant because of all the side effects I had observed from my brothers’ transplants. What changed my mind was I had a nasty peritonitis infection after a year and a half of PD. The intense and sustained pain led me to think that transplant side effects didn’t sound so bad after all.”

Chapter 3: RISKS

There are very real risks in any surgery. A kidney transplant is no exception. The list of risks is long and varies by patient, but please know that there are resources that can help you prepare for them and overcome many of them.

Preparing for the Transplant Evaluation Visit

There are also some things you can do in advance to help reduce some of the risks and show that you are committed to the transplant process and a successful outcome. If you are a smoker, it is time to quit. Perhaps you can join a smoking cessation group or speak to your doctor about different methods and programs to try. If you are overweight, it is time to look seriously at taking off the extra pounds. Again, speak to your doctor about programs that may be able to help you and supply support. It is also important to have a family member who is prepared to attend the evaluation with you. This will show that you have the social support and help that you may need after the transplant.

Patient Story



Dawn E.
New York

“My kidney and I had a love-hate relationship. I’d do well for a few months and then have a rejection episode. When my temperature rose above 100, I would have to rush back to the hospital for a biopsy and then a week or so of treatment with high doses of anti-rejection medications. After the treatments, things would settle down and I could go back home. It was so frightening thinking I might have to go back on dialysis.”

The Work-up

Your Transplant Center will require a complete work-up to determine if you are a good candidate for a kidney transplant. They want to make sure that you are in a physical, emotional, and financial position to be successful and sustain the transplant.

Physical work-up - Patients have described this as the “best health evaluation ever.” This may take place in one day or it may span several days. Each Transplant Center has different time requirements, and you should be aware of these requirements while you are selecting your Center. This physical work-up often finds health complications of which you were not yet aware. If these health complications disqualify you from immediate listing on the Transplant List, this does not mean that you are permanently disqualified from getting a transplant. You can work with your Medical Team to address the issues and re-apply once they are under control.

Psychological work-up - You will talk to a psychologist and/or social worker to be sure that you are in a strong mental and emotional position. They will determine if you have the Support Team in place for support during the waiting process and after you have received your transplant.

Financial work-up - You will meet with a financial counselor or social worker to determine if you have access to the financial support you need. They will help you look at Medicare coverage, private insurance coverage, and out-of-pocket expenses. It is important to know that, if Medicare is your only



coverage, some Centers require proof of adequate finances to cover the remaining transplant expenses and the cost of the immunosuppressant medications needed to support the transplant. If you do not have the financial resources needed, there are organizations that may be able to help. You can find resources in the [Financial Help Resources Toolkit](#).*

* available at www.esrdnetworks.org/toolkits/patient-toolkits/financial-help-resources/view

KDPI - Kidney Donor Profile Index

One of the many choices you will be presented with is whether you are interested in a high Kidney Donor Profile Index kidney. What is this and why does it matter to YOU?

The Kidney Donor Profile Index (KDPI) is a number assigned to all deceased donor kidneys that represents the quality of each kidney as it compares to other deceased donor kidneys. This number is arrived at by calculating the risk factors of the donor. It looks at such things as age, height, weight, ethnicity, and the health history of the donor. The higher the KDPI number, the more risk is associated with the quality/longevity of a particular donor kidney. This may help your team “predict” how long your transplant will last. However, high KDPI kidneys are still good kidneys for the right patients.

There are limitations, of course. The predictive power of the model is moderate. KDPI should be used as a tool along with all other information to make a fully informed decision about the suitability of a kidney for YOU. Being willing to accept a higher KDPI number may shorten the time you are on the waiting list. It is important that you speak with your transplant team, nephrologist, and personal care team about your choice.

Patient Story

Maria C.

“Since I am also a post liver transplant patient, and have had blood transfusions twice in the past, my antibodies were very high. This will make me have a long wait on the transplant list. When I went into renal failure and got listed for a kidney transplant, the Transplant Center team asked if I would consider a high KDPI Kidney, if available. I immediately said yes, since I knew this will help me have more options and expand organ offers. They told me it could also reduce the waiting time on the waiting list. This is something you should consider based on your personal situation. It’s better than staying on hemodialysis.”

Recovery Complications

It is always our hope that there will be no complications once we receive our transplant. In many cases, this is true. We receive the transplant, recover from the surgery, and never have an issue. But sometimes there are complications and we should be aware of them so that we can prepare for the unexpected.

Patient Story

Dawn E.

“Unfortunately for me, the side effects from the anti-rejection medications were plentiful. The steroids gave me bone disease and the CMV virus and colitis destroyed my colon. After six years the kidney rejected, I developed the early stages of colon cancer and had to have my colon removed. Now I’m back on dialysis and have a permanent ostomy.”



Patient Story

Patrick G.

“Five days after my transplant, I was told that I had a blood clot in my neck, and I needed to have another surgery. Three days after my second surgery, I was told that I was bleeding internally, and I needed to have a third surgery to install a J-Tube to slow down the bleed. Seventeen days later, I had a fourth surgery to remove the J-Tube and create a Peritoneum window so that I could drain internally.”

Delayed Graft Function AKA "Sleepy Kidney"

A deceased donor kidney transplant sometimes will be temporarily slow in functioning—a condition called a "sleepy" kidney or acute tubular necrosis. It can also happen if you have unexpected bleeding during the surgery or during a biopsy. You may need to undergo dialysis a few times. A "sleepy" kidney usually starts working in two to four weeks.

Patient Story

Patrick G.

"Overall, I stayed in the hospital for 33 days and had four surgeries, yet my kidney was still asleep... After 33 days, I was sent home with a non-working kidney. Most people gave up on my kidney, except for me.... I remembered something that my Pastor told me when I was in the hospital. He told me to "Respect the Process." I didn't understand this concept at first but the more I would reflect on this statement, the more I needed to strengthen my faith and begin to speak life into my kidney. On the 44th, my kidney woke up and has been going strong ever since. I was able to urinate for the first time in two and a half (2.5) years. I haven't been sick, nor have I had a problem with my kidney since."



Pain

Your belly and side will be sore for the first 1 to 2 weeks after surgery. You also may have some numbness around the incision. You may feel tired while you are healing. It may take 3 to 6 weeks for your energy to fully return. Many of us, however, felt an immediate increase in energy. All of us recover differently. If you feel pain be sure to talk to your Medical Team immediately to rule out complications.

Bladder Issues

Each of us reacts differently, but for many of us who did not create urine while we were on dialysis, our transplant came as a surprise to our bladders. You may initially experience low bladder capacity, bladder pain, urgency, and/or urinary tract infections. Many of us found that our trip home from the hospital required several stops to urinate. Sleeping through the night can also be problematic. These issues usually resolve themselves, but it is important to be prepared and to speak to your Medical Team about concerns.

Patient Story

Dawn E.

“I was on dialysis 10 years before receiving my transplant. I didn’t know that the bladder shrinks over time from not urinating. I came home from the hospital with a Foley catheter and my urine went into a bag until my bladder “woke up”. It was so uncomfortable! When they removed the catheter about a week later, I had to buy Depends undergarments because my bladder was so weak that I would just pee without knowing. It was great to pee though!”

Medical Appointments

Hospital recovery for a kidney transplant is usually 3-5 days if there are no complications. You will be in transplant care for the rest of your hospital stay. You may be able to get out of bed the day after surgery. Your care continues after you leave the hospital. Your kidney transplant team will continue to monitor your progress closely and address any questions you have along the way.



Appointment requirements vary between Transplant Centers. Often during the first year after your transplant, you will see the kidney transplant team weekly or every other week. As your condition stabilizes, you may be able to return to the care of your personal nephrologist. Your aftercare will be determined by your region and your transplant facility.

It is important that you understand the aftercare requirements of your Transplant Center. This is especially important if you transplant at a center that is a long distance from your home.

Infection Risks

The anti-rejection medicines that help keep your body from rejecting your transplanted kidney also lower your immune system. Because your immune system is lowered, viral and other infections can be a problem. Minor infections, such as urinary tract infections, colds, and flu are common after kidney transplants. Potentially more serious infections such as pneumonia and Cytomegalovirus (CMV) infection can occur and may require hospital treatment.

It is important to establish good hygiene practices, get your flu shots, and consider avoiding situations that put you at risk of infections. Often, this increased risk of infection decreases over time as your body adjusts to its new kidney and medications.

Patient Story



Doris L.
California

“Every time I get a fever, my transplant doctor sends me to the Emergency Room. In the four years since my transplant, I’ve been hospitalized about five times for infections ranging from a simple UTI to e-coli to unknown sources. By now I know when my body is fighting an infection even before the fever hits: My body becomes lethargic, followed a few hours later by chills and then the fever. The good news is that none of the infections developed into anything serious, and I feel very assured that my transplant nephrologists are watching my health closely. With the current COVID19 crisis, I stay vigilant about following safety guidelines.”

Rejection

Rejection is the most common and important complication that may occur after receiving a transplant. There are two types of rejection.

- Acute Rejection - Usually occurs during the first year after your transplant and can usually be successfully treated. This is actually pretty rare now - about 7%.
- Chronic Rejection - Usually occurs slowly over a long period of time. The causes are not well understood and are not always successfully treated.

Rejection episodes may result in hospitalizations and often cause a great deal of emotional stress. For a lot of us who have experienced rejection, there is a strong feeling of frustration and sadness when we must go back on dialysis. No matter how long the kidney worked, we find this to be devastating. We wonder what we did wrong and why we must go through this again.

It is important to know that YOU ARE NOT ALONE!! In fact, over 20% of kidney transplants every year are re-transplants. As the kidney is failing, many people start the process of getting back on the wait list and begin talking to potential living donors before re-starting dialysis. This can give us back a sense of control and hope.

Patient Story

Dawn E.

“After my transplant rejected and I returned to dialysis, I was really depressed. I felt like it was my fault and I wasted someone’s organ. I saw a therapist who really helped me work through my feelings and realize that it wasn’t my fault. I took antidepressants for a long time afterwards. Eventually I was able to accept that life happens, and I would be okay.”

Patient Story

Maggie C.

“Those first few weeks after my transplant, my hormones went into overdrive. I had weird bouts of energy in the middle of the night and hair growth in places I would not have expected. If nothing else, it gave me a sample of what to expect during menopause. LOL.”

Possible Side Effects

Side effects are always possible and should be discussed. It is important to know that not everyone experiences side effects. If you do, however, there are options available to relieve them.

Immunosuppressants

As with all medications, the immunosuppressants required to sustain the kidney may have side effects. Some may increase your appetite - which can result in weight gain. It is important to realize this and make healthy choices when you are reaching for a snack.

Hormonal imbalances are not uncommon when you start taking the immunosuppressants. You may experience such things as night sweats, hot flashes, and/or mood changes. This usually passes as your body adjusts to the new medications.

Patient Story

Maile R.

“I would have to say, that the worst side effects for me personally, were the weight gain and the emotional instability caused by the steroids. My first transplant, which only lasted five weeks, I gained 50 pounds. My second transplant I gained 25 pounds. On a person who starts at only 90 pounds, that’s a lot.”

Doris L.

“I was watching a Warriors game and found myself becoming very nervous and fidgety. That surprised me because I was never an avid basketball fan yet I was pacing the room and my palms were sweating. I realized later the prednisone was causing my extreme emotions. My doctor has since tapered my dosage which is good because I’m also fighting osteoporosis.”

Chapter 4: AFTER THE TRANSPLANT

As explained in earlier chapters, there will be several changes in your life after your transplant. Many are positive and will lead to a happy, healthy recovery. Some of them may be the result of complications and be more difficult to handle immediately. You should prepare for your new reality so that you know what to do and where to find help if you need it.

Patient Story

Patrick G.

“I named my kidney “Lazarus” because of the Biblical story of Lazarus in John 11. They thought he was dead but he was only asleep. What looked like a denial was only a delay. Sometimes you have to read the back of the book before you read the beginning. On the surface, it looked as if my experience would end badly but with perseverance and faith, what was meant as a harm turned out to be an incredible journey of faith.”

Coping and Support

If you experience some of the negative complications that can result from a transplant, you may find it difficult to cope. Many people find it helpful to join a **Support Group**. Here you will be able to listen to others as they talk about their adjustment strategies. There are several benefits of participating in a support group:

- Feeling less lonely or isolated
- Reducing depression, anxiety, or distress
- Talking openly and honestly about your feelings
- Improving your skills as you cope with your new challenges
- Staying motivated to stick to your treatment plan and manage your condition.

You may be able to find a local Support Group. Many transplant centers also offer information about local support groups. If not, there are several on-line options.

Peer Mentoring is another option to consider. Peer Mentoring is a form of mentoring that usually takes place between a person who has lived through a specific experience (a peer mentor) and a person who is new to that experience. Peer Mentoring is often one-on-one and can result in a deep and abiding friendship. Your gains can include:

- Obtaining practical advice, encouragement and support
- Learning from the experiences of others
- Increasing your confidence
- Becoming more empowered
- Developing strategies for moving forward

There are also many **Social Media groups** that are dedicated for the use of Transplant Patients. It is important to stress that the information you gain from social media is not always fact-based. Taking medical advice from these sources without talking it over with your Medical Team is never a good idea. However, Social Media can help you connect with others who are experiencing some of the same issues that you are experiencing. This can help you feel less alone and more in control.

Probably the two most important steps you can take in coping are to:

- Educate yourself
- Set realistic goals

The more you know, the more prepared you are to handle some of the complications that may arise. Accurate knowledge will help remove some of the fear you are experiencing and allow you to make effective plans for dealing with the situation. The goals that you set for yourself need to be realistic and easy to reach. This will keep you motivated and help you reach the level of recovery that you desire.

Diet and Nutrition

After a kidney transplant, plan to follow a diet low in salt and high in fiber. A balanced diet includes a variety of fresh fruits, vegetables, lean meats, reduced-fat dairy products, grains, and lots and lots of water. Transplant recipients are more susceptible to food-borne illness such as listeriosis as a result of our compromised immune system. We need to follow all food safety precautions. Your Transplant Dietician will be your best resource for information on food handling practices and purchasing foods that require special consideration.

Exercise

Exercise, especially cardiovascular exercise, can improve your circulation and help your body better use oxygen. It can also build energy levels so you can do more activities without becoming tired or short of breath.

Walking, bicycling, swimming, low-impact strength training, and other physical activities you enjoy can all be a part of a healthy, active lifestyle after your transplant. But be sure to check in with your transplant team before starting or changing your post-transplant exercise routine.

Patient Story

Maria C.

“I try to stay active and started walking three times a week to maintain a healthy weight. I also follow my doctor's recommendations and that includes having my labs done frequently to monitor my kidney function. One of the most important things in staying healthy after a transplant and to avoid any possible transplant rejection is to take my meds at the required time. That is why I have set my phone alarms twice a day so I remember to take my medications and not miss any doses.”



Immunizations

Vaccines work with the body's immune system. If the immune system does not work properly, the vaccine may not work or may even cause harm. As a transplant recipient, it is important to understand which vaccines you should and should not have. Most vaccines fall into two categories: inactive or live. Inactive vaccines are considered safe for transplant recipients, but live vaccines should be avoided. In general, if you have a transplant, you should avoid:

- Influenza Nasal (Flu Mist). The flu shot that is injected is an inactive vaccine and is safe for transplant patients.
- Chickenpox
- Shingles. It is important that you receive the inactive vaccine, SHINGRIX.
- Measles, Mumps, Rubella
- Yellow Fever



Flu and Pneumonia shots are recommended for transplant patients AND their family members.

Patient Story

Evan C.

“The transplant lasted 12 years... I will forever be grateful to my unknown donor for giving the gift of life. I often say prayers for his family and other recipients of his gift. I cherish the time I had that independence and look forward to again receiving a working kidney so I can be its steward.”

Conclusion

No two people are alike, and no two decisions are the same. It is important that we know the facts and what to expect as we decide what is best for us and whether to apply for a transplant. It is also important to know what questions to ask and where to find the answers that we need.

The following pages provide worksheets that you can use to organize your questions. We are also providing a list of resources that you can use for additional answers and help.

Patient Story



Mary B.
Wisconsin

“I was diagnosed with kidney disease at nine. I had my first transplant at 17 from my brother. Since then, I’ve had three more transplants, the last of which was in 1999. As a result of my life-long experience, I cherish life and have a strong interest to help improve healthcare.”

3. Will I need additional private money to cover incidental medical costs?

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If the Transplant Facility is not close to your home, additional questions will need to be answered.

1. How many days will the initial work-up take?

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2. What lodging options are available? And what is the cost?

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3. What will transportation cost?

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4. What aftercare requirements are involved? Can they be transferred to my local hospital?

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Home Care Questions

Different Transplant Centers have differing requirements for your at-home care. If you have a live-in partner or caregiver, this is usually not a problem. But for those who live alone, this may be an issue.

1. What in-home aftercare is required?

2. Does someone else have to be in the home overnight? If so, for how long?

3. When can I walk upstairs?

4. When can I drive?

5. When can I go into stores?

Aftercare Questions

1. What are the aftercare requirements?

2. How often will I need to report to the Transplant Facility? For how long?

3. Can my blood tests be done locally?

RESOURCES

Selecting a Transplant Facility

Organ Procurement and Transplantation Network. This site helps you find Facilities in your State and in your Region. You can select Kidney, Living Kidney, or Kidney - Pancreas. The site will bring up a list of all facilities that meet your criteria along with addresses, phone numbers, and links. <https://optn.transplant.hrsa.gov/members/member-directory/>

Scientific Registry of Transplant Recipients. This site allows you to compare different facilities on such topics as number of transplants per year (both deceased donor and living donor), length of time on the transplant list, and 1-year survival rate. www.srtr.org/transplant-centers/?organ=kidney

The Kidney Transplant Waitlist - What you Need to Know. This site gives you a lot of information in an easy to understand format. It explains the transplant waiting list, how organs are found, and what affects the wait time. www.kidney.org/atoz/content/transplant-waitlist

Preparing for a Transplant

American Kidney Fund This site walks you through the entire process from deciding if you want to pursue a transplant to recovering at home after the surgery. www.kidneyfund.org/kidney-disease/kidney-failure/treatment-of-kidney-failure/kidney-transplant/preparing-for-transplant/

Johns Hopkins Medicine. This site starts with the definition of Kidney Transplant and goes step by step through What Is Done To Prevent Rejection. It gives an easy to understand guide on what happens during the transplant surgery and what happens after the surgery. www.hopkinsmedicine.org/health/treatment-tests-and-therapies/kidney-transplant

UK HealthCare Pre-Op Kidney Transplant Patient Guide. This booklet was developed by the University of Kentucky HealthCare system to prepare their patients for the transplant experience. Some sections are specific to their facility, but it has a lot of information that all transplant patients can use. www.ukhealthcare.uky.edu/sites/default/files/pre-op-kidney-transplant-patient-guide-6-6869_0.pdf

Missouri Kidney Program My Transplant-ready Workbook. Developed to help kidney patients (and those who support them) through the entire transplant process. www.mokp.org/transplant/

Explore Transplant is a national consortium of leading experts in transplant, health literacy, and research. Our commitment is to provide you with the best education and decision-making tools available. www.exploretransplant.org

Financial Help

Living Kidney Donors Network. This site lists organizations that provide financial help for those who need a kidney transplant and for living donors. www.lkdn.org/financial-assistance/

American Transplant Foundation This site provides access to the Patient Assistance Program. The American Transplant Foundation's Patient Assistance Program provides financial support to the organ donors and transplant recipients. *Applications must be submitted by a transplant program social worker or transplant coordinator.*
www.americantransplantfoundation.org/programs/pap/

The American Living Organ Donor Fund.The American Living Organ Donor Fund is dedicated to helping American living organ donors. They work with donors to help them make the most informed decision possible, and if they decide to donate, they work to make their donation experience as medically and financially safe as possible.
www.helpivingdonorssavelives.org/about-us/

American Organ Transplant Association AOTA's Mission is to help transplant patients obtain and sustain transplantation through resources and free transportation to the transplant center. They also assist with Fundraising and a Medication Assistance Program. www.aotaonline.org/

*Please note that there are Social Security Work Incentives for continued payment and Medicare under **Vocational Rehabilitation (VR)** or a similar program. Section 301 of the Social Security Disability Amendments of 1980 (P.L. 96-265) provides SSDI or SSI cash to people while they're in VR plans. Getting SSDI keeps Medicare. Getting SSI keeps Medicaid. You can find citations for Section 301 including amendments in Social Security's Program Operations Manual System at <https://secure.ssa.gov/apps10/poms.nsf/lrx/0414505010>.*

Kidney Transplant Support Groups

National Kidney Foundation (NKF) Peer Mentor program: www.kidney.org/patients/peers.

Health Unlocked Online community support groups for Kidney transplant, Kidney Disease, Kidney Dialysis and Parents of Children with Kidney Disease. www.healthunlocked.com/nkf-kidneytransplant

American Association of Kidney Patients (AAKP): www.aakp.org/center-for-patient-engagement-and-advocacy/support-groups/

Renal Support Network: www.rsnhope.org/kidney-disease-support-group-and-patient-education-meetings/

UNOS Transplant Living website offers a list of support groups by state. www.transplantliving.org/community/support-groups/

There are also several Facebook Kidney Transplant Support Groups, and your Transplant Center may have a list of local support options.



ESRD Networks

Patient Toll-Free Numbers

	State(s)/Area Covered	Patient Toll-Free Telephone #
Network 1	CT, MA, ME, NH, RI, VT	(866) 286-3773
Network 2	NY	(800) 238-3773
Network 3	NJ, PR*, US VI*	(888) 877-8400
Network 4	DE, PA	(800) 548-9205
Network 5	DC, MD, VA, WV	(866) 651-6272
Network 6	GA, NC, SC	(800) 524-7139
Network 7	FL	(800) 826-3773
Network 8	AL, MS, TN	(877) 936-9260
Network 9	IN, KY, OH	(844) 819-3010
Network 10	IL	(800) 456-6919
Network 11	MI, MN, ND, SD, WI	(800) 973-3773
Network 12	IA, KS, MO, NE	(800) 444-9965
Network 13	AR, LA, OK	(800) 472-8664
Network 14	TX	(877) 886-4435
Network 15	AZ, CO, NM, NV, UT, WY	(800) 783-8818
Network 16	AK, ID, MT, OR, WA	(800) 262-1514
Network 17	AS*, GU*, HI, MP*, N. CA	(800) 232-3773
Network 18	S. CA	(800) 637-4767

* United States Territories:

PR - Puerto Rico

US VI - U.S. Virgin Islands

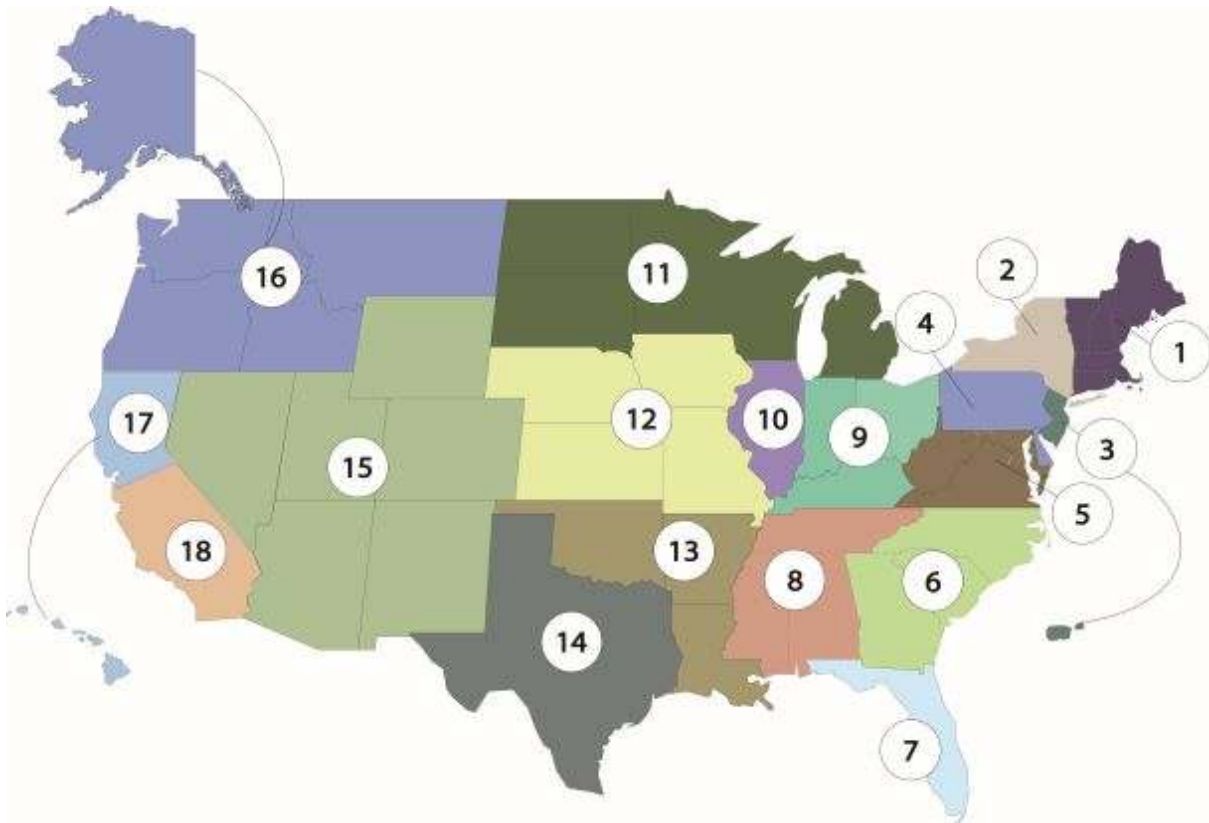
AS - America Samoa

Gu - Guam

MP - Northern Mariana Islands

ESRD Networks Map

You may visit the ESRD National Coordinating Center (NCC) website www.esrdncc.org/en/ESRD-network-map/ for your ESRD Network's information and resources in your state or region.



Acknowledgements

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Dawn Edwards
Kidney Patient Advisory Council
ESRD Network 2

William "Bill" Senior
Kidney Patient Advisory Council
ESRD Network 3

Maria Casas
Kidney Patient Advisory Council
ESRD Network 3

Patrick O. Gee, Sr. PhD
Kidney Patient Advisory Council
ESRD Network 5

Virna Elly
Kidney Patient Advisory Council
ESRD Network 5

Evan Coaker
Kidney Patient Advisory Council
ESRD Network 9

Della Major
Kidney Patient Advisory Council
ESRD Network 10

Mary Baliker
Kidney Patient Advisory Council
ESRD Network 11

Patricia Bologna
Kidney Patient Advisory Council
ESRD Network 11

Maggie Carey
Kidney Patient Advisory Council
ESRD Network 11

Precious McCowan
Kidney Patient Advisory Council
ESRD Network 14

Jeff Needham
Kidney Patient Advisory Council
ESRD Network 15

Maile Robb
Kidney Patient Advisory Council
ESRD Network 15

Nancy Hewitt-Spaeth
Kidney Patient Advisory Council
ESRD Network 16

Derek Forfang
Kidney Patient Advisory Council
ESRD Network 17

Doris Lew
Kidney Patient Advisory Council
ESRD Network 17

Yessi Cubillo, BA
Patient Services Liaison, KPAC
ESRD Network 3

Lisa Hall, MSSW, LICSW
Patient Services Liaison, KPAC
ESRD Network 16

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This resource was created for
Kidney Patients, Caregivers, and Families
by



KIDNEY PATIENT ADVISORY COUNCIL (KPAC)

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This and other patient resources can be downloaded at
<https://esrdnetworks.org/resources/toolkits/patient-toolkits>

The Forum of ESRD Networks
P.O. Box 203 Birchwood, Wisconsin 54817
Phone (715) 354-3735 Fax (888) 571-2065