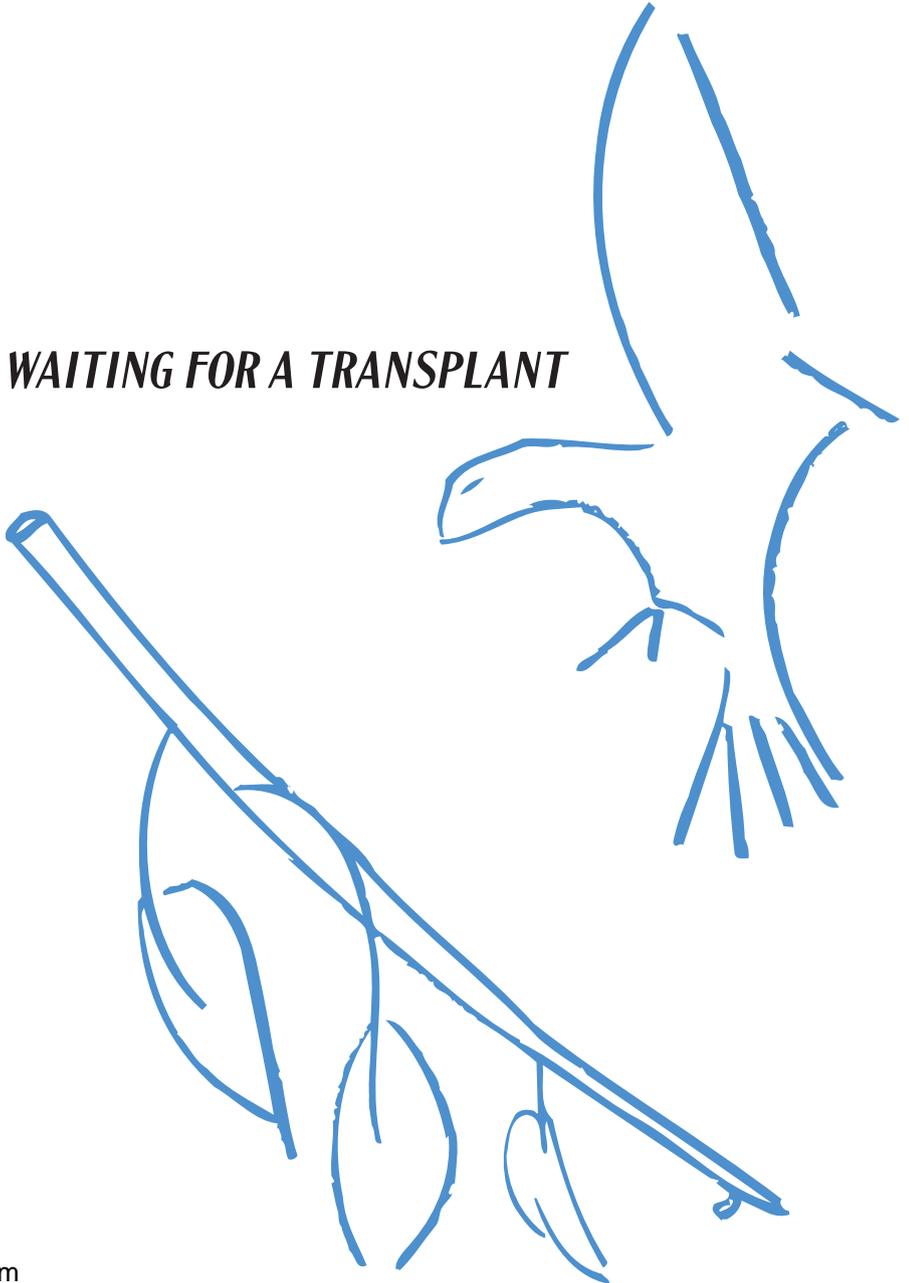


National Kidney
Foundation™

WAITING FOR A TRANSPLANT



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2005 Edition

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This book has been written especially for you by those of us who have waited. These pages reflect our sincerest wishes, thoughts and prayers for your well-being. If you are not able to read this booklet today, please put it aside; you may be able to return to it at a later time.

If you have any questions or concerns about your wait for a donor organ or what to expect, we encourage you to contact the person listed below. Professionals at your treatment or transplant center have a lot of answers and resources for you.

For more information:

Contact: _____

Address: _____

Phone: _____

Notes: _____

DEDICATION

To all candidates and their families, may you find courage, love and hope.



*Hope is the thing with feathers
That perches in the soul
And sings the tune without the words
And never stops at all*

-Emily Dickinson



Our thoughts are with you.

- National Kidney Foundation and
its transAction Council



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Table of Contents

Should I Consider Transplantation?

| | |
|--|---|
| Who Are Organ Transplant Candidates? _____ | 2 |
| Who Are Potential Donors? _____ | 2 |

Living Donation

| | |
|--|----|
| What Is Living Donation? _____ | 2 |
| What Organs Can Come From Living Donors? _____ | 3 |
| What Are the Advantages of Living Donation Over Deceased Donation to the Recipient? _____ | 3 |
| Who Can Be a Living Kidney Donor? _____ | 4 |
| How Will Living Donation Affect the Kidney Donor? _____ | 5 |
| What Is the Recovery Period for Kidney Donors? _____ | 6 |
| What Testing is Required to Determine Whether Someone Can Be a Kidney Donor? _____ | 6 |
| What if My Living Donor Decides Not to Donate? _____ | 7 |
| How Do I Ask Someone to Be My Living Donor? _____ | 8 |
| Non-Directed Donation _____ | 8 |
| Plasmapheresis _____ | 10 |
| Incompatible Donation Paired Exchange _____ | 11 |
| What Are the Risks Associated With Kidney Donor Surgery? _____ | 12 |
| Live Liver Donation _____ | 14 |
| Live Lung Donation _____ | 14 |
| What Is a Donor Advocate? _____ | 15 |
| Who Pays for Living Donation? _____ | 15 |
| Will Donors Be Able to Obtain Insurance Coverage After Donating? _____ | 16 |
| Are Transplants From Living Donors Always Successful? _____ | 17 |
| Deceased Donors _____ | 17 |
| The Transplant Evaluation _____ | 20 |
| Do I Really Need a Transplant? _____ | 21 |
| The List _____ | 21 |

| | |
|-----------------------------------|----|
| Multiple Listing | 22 |
| What to Expect After a Transplant | 24 |
| Re-Transplantation | 24 |
| Paying for the Transplant | 25 |
| Informing Your Employer | 26 |
| Preparing to Return to Work | 27 |

The Experience of Waiting

| | |
|-------------------------------------|----|
| Living With Illness | 31 |
| What Do People Think? | 31 |
| Family and Friends | 32 |
| Couples | 33 |
| When There Is a Child in the Family | 34 |
| Dating While Waiting | 35 |
| When a Child is the Candidate | 35 |
| Stress and Our Emotions | 37 |
| False Alarms | 37 |

What Helps

| | |
|--|----|
| Planning Ahead | 41 |
| Caring For Yourself Emotionally and Physically | 42 |
| Exercise | 43 |
| Pacing Yourself | 43 |
| Relaxation | 43 |
| Treating Anxiety and Depression | 44 |
| Learn About Addictions | 44 |
| Support Groups | 45 |
| Hopeful Thinking | 45 |
| Telling Our Stories | 46 |
| Spirituality | 46 |
| Taking Care of Our Caretakers | 47 |
| What Family and Friends Can Do | 48 |

End-of-Life Decisions

| | |
|--|----|
| Talking About Death With Your Family _____ | 50 |
| Keep Living While Waiting _____ | 50 |
| What if the Transplant Never Comes...? _____ | 51 |

Other Sources of Help

| | |
|-------------------------------------|----|
| About the transAction Council _____ | 53 |
| Resources _____ | 56 |



“I was very shocked and angry when I realized I was sick. I needed time to process this information. Then I was able to shift perspective from bitterness to thankfulness to be alive through whatever means. I found insight into my own mortality and of the true blessing of life.”

- Alicia Guerro, kidney recipient



“Many of my questions truly had no answers. It was my faith and trust in others that I turned to.”

- Vanessa Underwood, kidney recipient



“I made patience my friend...”

- Tamra Lewis, kidney recipient



SHOULD I CONSIDER TRANSPLANTATION?

WHO ARE ORGAN TRANSPLANT CANDIDATES?

Organ transplant candidates are people like you and me who have had their lives interrupted by illness. We are of every age, and of many different cultures and religions. Though every one of us is unique, the transplant journey has many universal experiences we all share. We all face uncertainty, loss of our life as we knew it, a variety of emotions as our physical health ranges from critical to okay, a wait of unknown duration and a fear of “Will we beat the clock? Will we live or die?”

Success rates for heart, liver, lung, kidney and pancreas, and all transplants continue to improve each year. Some of us have been candidates only once. Others of us have been re-transplanted and have waited two or three times for a donor organ.

WHO ARE POTENTIAL DONORS?

They can be deceased or living donors.

LIVING DONATION

WHAT IS LIVING DONATION?

Living donation (LD) has all the risks of major surgery for the donor, but can result in positive outcomes for the recipient and living donor in carefully selected situations. LD has

increased because there are not enough organs from deceased donors for persons on the waiting list who need one.

Living donation takes place when a living person donates an organ or part of an organ to be transplanted into another person. The living donor can be a family member, such as a parent, their child (over 18 years of age), brother or sister. Donation can also occur between two individuals who are not biologically related. A living unrelated donor could be a good friend, or a spouse. The donation may even come from a stranger, in which case it is called a non-directed donation.

WHAT ORGANS CAN COME FROM LIVING DONORS?

The most commonly donated organ is a kidney. People usually have two kidneys, and one is all that is needed to live a normal life. It is also possible to transplant part of a lung, (two donors are needed for every lung recipient) liver or pancreas from a living donor.

WHAT ARE THE ADVANTAGES OF LIVING DONATION OVER DECEASED DONATION TO THE RECIPIENT?

An organ from a living donor can have a number of advantages over a deceased donor organ for the recipient. First, the donor organ is in excellent condition. The

kidney usually functions immediately and there is less chance of rejection, leading to better long-term results. Second, the transplant can be scheduled when most appropriate and the usual lengthy waiting time for a deceased donor organ is avoided. Risks to the donor organ itself are minimized because it has only a short journey from the donor's body to the recipient. Not only are there advantages for the recipient, but the donor may feel a great sense of honor and privilege to give the gift of life.

WHO CAN BE A LIVING KIDNEY DONOR?

A donor must be in excellent health and have normal kidney function and anatomy. The prospective donor must have a compatible blood type. High blood pressure, diabetes, some forms of cancer or certain infectious diseases such as AIDS or hepatitis B would be contraindications for donation.

The decision to donate must be voluntary and free from emotional duress or family pressure. The donor needs to have all the information necessary to make an informed educated choice. If the donor meets the criteria for donation, there will be tests to check for compatibility (cross-matching and tissue typing) as well as physical and psychological examinations.

HOW WILL LIVING DONATION AFFECT THE KIDNEY DONOR?

Most living donors tell us they feel good about the decision to donate. Everyone is different. Anyone choosing to undergo the surgery should be prepared for a variety of outcomes afterwards. The living donor should be psychologically stable and prepared to handle negative outcomes from the surgery, should they occur. These outcomes include death of the recipient, loss of transplant organ, experience of pain by the donor, a change in the relationship between donor and recipient, depression and more. These possible outcomes are why a potential living donor will be evaluated by a psychologist, psychiatrist or a social worker.

People can live normal lives with only one kidney. In fact, some people are born with only one. A donor who has been evaluated thoroughly and cleared for donation can participate in normal activities after donation. Donors are encouraged to have good long-term medical follow-up with their primary care doctor. People with one kidney may be at an increased risk of developing high blood pressure. Certain career choices may be limited. If you are thinking of getting pregnant, talk to your doctor. Pregnancy after donation is possible, but not recommended for at least six months to a year afterwards.

WHAT IS THE RECOVERY PERIOD FOR KIDNEY DONORS?

The length of stay in the hospital will vary, depending on the individual's rate of recovery and the type of procedure performed (traditional open nephrectomy vs. laparoscopic), although the usual stay is less than a week. After leaving the hospital the donor will typically feel tenderness, itching and some pain as the incision continues to heal. Generally, heavy lifting is not recommended for approximately six weeks following surgery. It is also recommended that donors avoid contact sports where the remaining kidney could be injured. It is important for the donor to speak with the transplant staff about the best ways to return to physical fitness as quickly as possible.

WHAT TESTING IS REQUIRED TO DETERMINE WHETHER SOMEONE CAN BE A KIDNEY DONOR?

Potential donors will have blood, urine and radiology testing to determine suitability for donation. A full physical examination and psychological examination will be required. Time will be allotted to ask questions and address any concerns that may arise.

Before surgery, special x-rays will be taken of the donor's kidneys, including an intra-

venous pyelogram, and/or renal arteriogram, or spinal CT scan testing to check the anatomy of the kidney. Additional blood testing will determine the quality of matching between the donor and the recipient (HLA typing or tissue typing).

WHAT IF MY LIVING DONOR DECIDES NOT TO DONATE?

The decision to become a living donor must be voluntary and made without pressure. Individuals have the right to decide donation is not for them. Likewise, some individuals with kidney failure may decide they do not want the transplant or may choose not to consider a living donor. The decisions of the potential donor and recipient must be respected. Living donors may change their mind at any time during the evaluation process without fear of embarrassment or repercussions.

It is quite normal for a donor and the donor's family to have fears and concerns about potential complications. This might be felt by some as a reluctance to donate, yet it is a natural reaction to major surgery. The donor should be encouraged to speak openly with the transplant team about these fears. All conversations between the living donor and the transplant team

including those with the recipient and others, as well as the results of medical testing, will be kept confidential.

HOW DO I ASK SOMEONE TO BE MY LIVING DONOR?

This depends on you and your loved ones. All families are different. Many of us found that our family members or friends asked us. Others found that asking someone we loved to donate to us was too hard to do. Others of us were able to overcome our fear of asking our loved ones to risk surgery as we learned more about transplantation and donation. Taking the time to educate our families and friends about transplantation and donation helped. Sharing as much factual information as we could, along with sharing our thoughts about our progress, our options, our hopes and dreams helped us and our families think about whether living donation was for us.

Buying and selling organs has been illegal in the United States since 1984, when it was outlawed by the National Organ Transplant Act PO 98.507.

NON-DIRECTED DONATION

Immunosuppressive medications, which keep the recipient's body from rejecting the

donor kidney, have been so improved over the last few years that a genetic link from donor to recipient is no longer necessary to ensure a successful transplant. Therefore, strangers who wish to donate a kidney for altruistic reasons are accepted as suitable donors for kidney transplant by some transplant programs. A stranger who wishes to donate a kidney is advised to contact a nearby transplant center that has a non-directed donation program. The non-directed donor will go through the same extensive medical testing and rigorous psychological exam as any living donor. If the donor is accepted, the transplant team will choose a candidate from the waiting list who would best be suited for the kidney.

We encourage people considering non-directed donation to familiarize themselves with what is involved with living donation by visiting **www.livingdonors.org**. Some Web sites attempt to match recipients with non-directed donors. Instead, we encourage non-directed living donors to work with a transplant center to find the most appropriate recipient. It is important for the transplant center to be involved and notified if the recipient advertises on the Internet or in any advertising campaigns. The center's role is to evaluate potential donors, and if approved

for donation, find an appropriate recipient for the organs. This process helps protect donor and recipient confidentiality and ensures that potential living donors fully understand the risks and processes involved. We have concerns that commercial advertising for donors via Web sites or billboards can create undue competition among transplant candidates and can give an unfair advantage to those who have the resources to advertise. Regardless of how recipients and donors are matched, we feel it is important to involve the transplant center in the process.

PLASMAPHERESIS

A new procedure currently being provided at a limited number of transplant centers allows a recipient to be able to receive a kidney from a donor of a different blood type.

Until recently, a transplant recipient could only receive an organ from a living donor who had the same blood type. For example, a recipient with blood type A could only receive a kidney from a donor with blood type A. An organ from a donor of a different blood type would be perceived as foreign and vulnerable to attack by the recipient's natural antibodies.

The recipient undergoes plasmapheresis, a process involving the removal of the plasma portion of the blood that contains harmful antibodies, and the administration of a medication to prevent their production. The patient is then ready to undergo transplant surgery where, in addition to receiving a donor organ, the patient's spleen, home to harmful antibodies, is removed using minimally invasive surgical techniques. In some cases, spleen removal can be avoided through the use of a new drug that creates similar effects. Post-transplant, the recipient undergoes additional plasmapheresis treatments before being discharged from the hospital. The transplant recipient will then take the same immunosuppression medications as patients receiving a compatible kidney.

INCOMPATIBLE DONATION PAIRED EXCHANGE

Sometimes a loved one may want to donate a kidney, but has an incompatible blood type. For example, someone with type A blood wishes to donate to a type B recipient. This incompatible pair may be able to locate (on their own or through a transplant center offering this option) another pair who have the opposite situation – a type B donor and a type A recipient. If the recipient from one pair is compatible with the donor from

the other pair, and vice versa, some transplant centers may arrange for two simultaneous transplants to take place. This allows two transplant candidates to receive organs and two donors to give organs, even though the original recipient/donor pairs were unable to do so with each other. As with every potential donation, both donors and candidates are carefully evaluated and tested medically and psychologically to assure that the benefits outweigh the risks. It is important for both surgeries to be scheduled at the same time in case either donor has a change of mind at the time of surgery. Surgeries can take place at the same or different hospitals. It can be advantageous if the surgeries take place at the same hospital, although this may mean extra travel and housing costs for one pair.

WHAT ARE THE RISKS ASSOCIATED WITH KIDNEY DONOR SURGERY?

The surgery involves the same level of risk for the donor as any other major surgery. The risks associated with surgery and donation will be discussed in detail during the evaluation process.

Traditional living donor kidney surgery, known as a nephrectomy, has been the standard surgery since living donation

began in 1954. It requires an incision in the donor's side to remove the kidney, blood vessels and ureter.

Laparoscopic donor surgery began in 1996. The operation requires only four small incisions in the donor's abdomen. In most cases, surgical instruments are inserted into the smallest incisions and the kidney is removed from the fourth incision. Scarring is less, donor's typically feel less pain and experience a shorter hospital stay and recovery.

Laparoscopic surgery, though less invasive, is still major surgery. Advantages to this surgery over the traditional nephrectomy for the living donor are minimal surgical scarring, a generally quicker return to full activities and work and a shorter hospital stay. While this is a suitable option for some, it involves risks (like any major surgery) and may not be appropriate for some living donors or transplant recipients. Both laparoscopic and traditional open nephrectomy surgery carry risks.

Again, please be sure to discuss the associated risks with your doctor and visit **www.livingdonors.org** for detailed information.

LIVE LIVER DONATION

Transplanting a piece of the liver is possible because the liver regenerates itself in both the donor and recipient after transplantation. Donating a section of liver is riskier than kidney donation. The liver donor must undergo extensive examination and testing to determine excellent physical and psychological health. Radiological imaging of the liver is done to assess the anatomy, liver volume and size. A liver biopsy may be performed. Usually parents donate a piece of a liver to a child. Adult-to-adult live liver transplant is still relatively rare and carries a higher risk to living donors, compared to kidney transplant. We recommend talking to your transplant center about their experience and success rates, which can provide you with critical information.

LIVE LUNG DONATION

Live lung donation involves two adults, one giving the right lower lobe and the other giving the left lower lobe to an adult or pediatric recipient. The potential donors' lungs must be the right size and volume. For adults, donors should be at least as tall as the recipient. Ideally, donors should not be overweight and should be non-smokers. Potential donors receive a series of exams and tests including chest radiography, pul-

monary function testing, ventilation-perfusion and CT scans and a cardiac stress test. Again, donating a lung is riskier than live kidney donation and the risks and benefits should be discussed with the transplant team.

WHAT IS A DONOR ADVOCATE?

A donor advocate is a medical professional, usually a doctor, whose sole focus in the evaluation is to protect the best interests of the donor. Physicians involved in the care of potential recipients are, and ought to be, primarily an advocate concerned with the recipient's interests. Two separate physicians, one of whom is exclusively an advocate for the donor and not involved in the candidate or recipient's care, can be a way to eliminate any conflict of interest between the potential needs of the donor and candidate. Ideally, the donor advocate is in a position to veto the transplant if it could cause unacceptable risk to the donor.

WHO PAYS FOR LIVING DONATION?

The costs of living kidney donation, which include those associated with the donor evaluation and surgery are usually paid for by the recipient's insurance. There are some exceptions to this rule (such as when a donor work-up is repeated at a second transplant center within a certain time

frame), so check with the transplant center financial counselor.

Time off from work, travel and lodging expenses are not covered. Donors are eligible for sick leave, state disability and are covered under the Family Medical Leave Act (FMLA). Federal employees are eligible for 30 days' paid leave. Many federal employees are eligible for 30 days' paid leave. Wisconsin and Georgia allow live organ donors to deduct up to \$10,000 in expenses from state income tax. Other states, where such legislation is pending include Illinois, Massachusetts, New Jersey, New York and Pennsylvania.

WILL DONORS BE ABLE TO OBTAIN INSURANCE COVERAGE AFTER DONATING?

We are aware of a small percentage of kidney donors who have reported having to wait after donating to obtain insurance coverage because their donation was considered to be a pre-existing condition. Lung and liver donors face more risks. Future insurability must be evaluated by each potential living donor. We encourage living donors to contact the National Kidney Foundation regarding their experiences obtaining insurance.

ARE TRANSPLANTS FROM LIVING DONORS ALWAYS SUCCESSFUL?

Although transplantation is highly successful, and success rates continue to improve, problems can occur, sometimes without warning. Sometimes the kidney is lost immediately due to rejection or surgical complications. Over the long term, the original disease that caused the recipient's organ to fail may recur. Our immunosuppressive medications leave us susceptible to infections and new diseases. Transplantation is not a cure, but a treatment option. It is reported that 95 percent of transplants performed between living donors and recipients are successful at one year.

For more information about living donation, visit **www.livingdonors.org**

DECEASED DONORS

Some of us have struggled with the knowledge that our donor organ came from a grief-stricken family willing to donate a loved one's organ at the time of death. This painful awareness is balanced by the hope that the donor organ will provide us with a chance for a new beginning. We have found that donor families are not unlike our own families. The gift of your donor organ is a family's choice and has not been coerced. Families often feel comforted by the knowl-

edge that their loved one was able to help others through donation. A survey conducted by the National Kidney Foundation of 500 families found that nine out of ten believed donation was a positive experience. Excellent success rates are reported for transplants of vital organs. At one year, 88 percent of kidney transplants from cadaver donors, 81 percent of liver transplants and 85 percent of heart transplants are still functioning well.

Due to the critical organ shortage in our country, some recipients benefit from accepting organs from older donors. During your transplant evaluation, or at another time well in advance of your transplant operation, you can discuss this possibility with your physician or surgeon. This option is not for all candidates, but may be considered for those who face a substantial risk to their health by remaining on the waiting list. In general, an organ from an older donor can increase life expectancy by adding several years to what would have been a candidate's life expectancy without a transplant.

Transplant centers also use what is called extended criteria or marginal organs. These are usually from older donors, but may be from younger donors who have

some risk factors, such as high blood pressure, cancer, infectious disease, a history of smoking or drug or alcohol use. The definition of a marginal donor and various organs varies between hospitals and transplant programs, so you should talk to your doctor about your options. There is an expectation from the transplant team that these organs, if offered to you, will work well, despite the risk factors, however, like any organ transplant, there are risks and unknowns.

In an effort to increase the number available for transplantation, some recipients decide to accept a donor liver that has been divided into two sections—thus saving the lives of two candidates. This usually reduces time on the waiting list.

Most transplant centers will provide basic information about your donor. You may also write to your donor's family. If the family is willing to receive a letter from you, your letter will be forwarded. Donor family members may also initiate correspondence.

Some of us waited years after our transplant to write because we did not know what to say. A simple thank you is fine.

Some of us just sent a store-bought thank you card prior to leaving the hospital after our transplant. Some of us wondered how we would feel having another person's organ. Once it was transplanted, we came to think of it as our own.

THE TRANSPLANT EVALUATION

Your evaluation is a snapshot of one moment in your life. Most of us don't like tests or being evaluated under any circumstances. When we are not feeling well, and the outcome can mean life or death, the evaluation is likely to provoke anxiety.

The transplant evaluation is a thorough medical examination consisting of a chest x-ray, blood tests, cardiac (heart) and pulmonary (lung) exams. It is a time to ask questions, obtain information and meet the transplant health care team. It is a time for you to call upon your inner strengths and to activate your social support system. The evaluation gives you an opportunity to demonstrate to yourself and the health care professionals that you have the resilience and fortitude to weather the rocky road of the transplant journey.

A few of us were evaluated by several transplant centers before we found one that was

right for us. Most of us went to the transplant center referred by our specialist or one that was approved by our insurance company. None of us wanted to go through the trauma of surgery if it was not our best treatment option. If it wasn't, we enlisted the help of health care professionals to find other specialists to help us.

DO I REALLY NEED A TRANSPLANT?

During the wait you will have good days and bad days. Some days you may feel so good you'll think you don't need a transplant. Other times you may be sick enough to be hospitalized in intensive care.

You can always change your mind if you decide you do not want a transplant, at any time during the wait, even when you receive the call. However, since one can never know when or if the next call will come, most of us accepted the organ when we received notice that it was available.

THE LIST

Once you have completed your evaluation and are found to be a good candidate, your name will be added to a local, regional and national computerized list of all candidates waiting for organs. The list is maintained by a non-profit organization—United Network for Organ Sharing (UNOS)—that is under contract

to the federal government to maintain the list 24 hours a day, seven days a week, year round. Visit www.unos.org for information about the listing criteria and maintenance of the list. Many factors contribute to whether or not an organ will be offered to you: your blood type, where you live (an organ must be able to safely travel the distance to the transplant hospital), in some instances your weight and size, tissue typing and more. Different criteria will affect your place on the list and the length of your wait. Your transplant health care team can answer your specific questions.

It is natural to wonder if the list is fair. To protect the access to organs for persons of all incomes, it is illegal to buy or sell organs. Celebrities are listed using the same criteria as the average citizen.

MULTIPLE LISTING

Usually, the less time an organ is out of the donor's body before placement in the recipient's body, the better chance it has of working well. Because of this, deceased donor organs are offered locally, regionally and then nationally, except in cases of a perfect match—where the possibility of a successful transplant is high. Because of this, the list may progress faster in some geographic areas than others. Recipients

having the physical ability, the family support and financial resources to travel can look at being evaluated and listed at more than one transplant center in different regions of the country. Some transplant physicians encourage their patients to multiple list, if possible. Other physicians don't. Talk to your transplant health care team to see what they advise. It is important to multiple list in coordination and cooperation with your original transplant hospital. There may be insurance, financial and travel complexities that need to be arranged. The waiting time incurred at the first center where you listed can be transferred to a subsequent transplant center in another region if you wish to change centers rather than multiple list.

Some of us decided to list at more than one hospital in different parts of the country. Because many donor organs are first offered locally, then regionally, our waiting time could be reduced. Most of us found that our insurance would not pay for listing at more than one transplant center; we had to be prepared to repeat tests and exams and also pay out-of-pocket for evaluation, travel and other related expenses.

WHAT TO EXPECT AFTER A TRANSPLANT

There is an old joke about a patient who asks his doctor, “Will I be able to play the piano after my surgery?” The doctor reassures him that of course he will. The patient responds, “Good, because I couldn’t play a note before!” People sometimes have unrealistic expectations about transplantation. Think about how you expect life to be after transplantation and talk over your expectations with family, friends and professionals to see if your expectations are realistic. It may help to talk with other candidates and recipients, however, your journey will be unique. Everyone reacts differently to surgery. Some people wake up after surgery and feel great; others struggle in the beginning and then do fine. Once again, we brace ourselves for the unknown.

RE-TRANSPLANTATION

Re-transplantation is no longer an uncommon occurrence. On one hand, most of us who have had more than one transplant were more prepared in many ways. We didn’t fear the unknown. On the other hand, sometimes ignorance is bliss! The second time around can be more frightening when you know what could happen. However, surgical techniques and medications are always improving. We must remember that people waiting for a second

or third transplant are subject to the same listing criteria as persons waiting for their first transplant. Again, a range of emotions can leave us feeling overwhelmed. Those of us who are waiting again struggle with difficult feelings. Feelings of failure, even though not logical, can burden us. Know that you are in good company. We need to remember that transplantation is a treatment, not a cure.

PAYING FOR THE TRANSPLANT

In the midst of our anxiety and concern about our well-being, we also had to deal with hospital/physician payments, and job security. This was confusing at times and caused us to worry about our family's future financial security.

Find out what your insurance covers and what it does not. If you have a choice of coverage, pay particular attention to co-payments for medications. Understand your benefits. Is there a maximum amount your insurance will pay yearly or for your lifetime? What paperwork is involved? Transplant programs usually have financial administrators and social workers who can help you apply for federal, state, local or charitable benefits, or they can direct you to other types of coverage. You may need to

revise your family budget. Sometimes relatives pull together and help out in unexpected ways. Some family and friends raise funds with a reputable nonprofit organization while you wait. Some candidates' houses of worship (churches, mosques, synagogues) assist with fund-raising. Negotiating with insurance carriers, case managers and employers for increased benefits can also help. Some of us have worried that our families have to "go without" in order to pay for our medical care. It helps to share these painful feelings and to work together to find solutions.

INFORMING YOUR EMPLOYER

When we are working and need a transplant, it is unrealistic to think we can fool everyone and no one need know. We are protected under the Americans with Disability Act and our employers should be able to make reasonable adjustments to our job, if feasible, when we need assistance. Many of us have been pleasantly surprised by the support we have received from employers and coworkers.

When should you tell? Give your employer enough notice to know why you may be in late or miss work. You may apply for the Family Medical Leave Act (FMLA). Under

this law, you can take time off from work in 15-minute increments for up to 12 weeks for illness-related appointments, etc. Let your doctor know what your job entails and what physical demands are required. If you are unable to continue working, there may be other benefits available. Ask your supervisors and human resources professionals about these options. Transplant social workers can advise you about social security disability, job training and other benefits.

PREPARING TO RETURN TO WORK

Do you like the work you do or did (before transplant)? If so, the most direct path to employment is returning to your prior role with the same employer. In some companies, short-term disability is available, and in other instances you may be eligible for state disability and have a job waiting for you when you return. But, not everyone is so fortunate. You may have been too long out of work and no longer have a job to return to, or, because of the transplant, you may no longer be suitable for your previous job responsibilities. If this is the case, now would be the time to take advantage of what is called a 'forced sabbatical'. This time can allow you to reconsider your

future, re-educate yourself and develop new skills. If you are collecting Social Security disability, you can take advantage of work incentives which include innovative ways to get back to work, and can qualify you for funded state vocational job training and education. Volunteer work can help you gain experience and references in a new field.

Our best advice is to find something you are passionate about, and determine what you need to do to enter the field. It may help to talk with other transplant recipients who have transitioned back to work. Support groups can be a good place to find an organ recipient who can act as a mentor. Your transplant social worker can also help. Some transplant programs also have vocational rehabilitation specialists and back-to-work programs.

Also, remember that perception is your reality. If you see yourself as disabled by your transplant, you are. At first, your transplant experience may come across to potential employers as a liability. It is up to you to educate them and turn that liability into an asset as many before you have already done. Let potential employers see you as someone who can overcome the

lesser challenges of daily work life. If you see yourself as getting past this setback and moving on to be stronger, that will come across in your interviews. You can discuss benefits after you have been offered the job. You will need a good insurance plan that includes prescription drug coverage. Some states have special Medicaid programs for working people that may not be highly publicized. Talk to a knowledgeable benefit specialist in your area. Remember—you have a whole new life to live. Make it your best life yet.



“People would stare and I’m sure they were making their own conclusions about my health. I was extremely thin and I often heard people say things about girls with anorexia. If they only knew!” – Kelly Helms, lung recipient



“Our families saw us at our worst and although we had to remember that they loved us, some days they may not have liked us at all.”
– Brenda Dyson, kidney recipient



“Being re-listed, and enjoying life as best I can, providing for family, reading and exercising, I take life one day at a time and enjoy it. As someone who has faced death many times, I have a gift most do not – the realization that our time is fleeting. It is not important how long we live but how we live.”
– Alexander Whitetaker, awaiting a second liver transplant



THE EXPERIENCE OF WAITING

LIVING WITH ILLNESS

Those of us whose illness is recent or of sudden onset have experienced anguish and stress at the sudden loss of life as we know it. Those of us who have lived with a chronic or terminal illness for months or years continually seek new ways of coping and grieving for all we have had to give up and leave behind. Waiting can provide you with the opportunity to overcome difficult feelings such as denial or anger at being ill.

WHAT DO PEOPLE THINK?

Appearance is so important in our culture. When we have an illness and our body changes, we may become self-conscious. We have found that paying attention to what makes us feel good about ourselves can make a difference. For example, wear colors that perk you up. Some of us don't look sick. Some of us men have felt the pain of watching our wives or children carry heavy packages in from the car, knowing that the neighbors probably thought we just didn't care. Although we look fine on the outside, no one could tell that a heart transplant candidate's heart is operating at 10 percent.

Others of us who, for example, might look sick because we carry oxygen tanks around, may be self-conscious about the attention. Some of us have concerns about our body image and wonder if we will ever look like we used to. Perhaps only you notice that your skin tone is not the same or your eyes are not as bright. Perhaps you have more noticeable physical changes to your body. None of us ever look the same forever; we all grow and change.

Don't let self-consciousness and fear of attention keep you from things you want to do. Some of us have put others at ease by tying ribbons on oxygen tanks or on our IV poles, giving others permission to look and interact and respond.

FAMILY AND FRIENDS

As difficult as this is for us to accept, it can be equally as difficult for our loved ones. Some may rise to the occasion and really be there for us; others may find it just too painful to provide the support we need. We wonder if loved ones will still care for us if we become sick. Some of our friends and family have an impressive ability to adapt to the change in our life situation. Others may not, and may stay away. We need to allow our families and friends room to

grieve for the loss of our health and the impact it has on them. We may develop new support systems that we never had before—we just need to be open to new opportunities. We have learned that our care partners will need support, too.

COUPLES

Intimacy may be a struggle even for lifetime companions. We may fear that our partner will desert us. Some of us have felt guilty that we cannot be the companions we want to be. Emotions, medications and illness can affect sex drive. We may lose our sex drive due to physical or psychological pressures, or both. We may feel jealous of our healthy partner and feel angry and guilty that we cannot live up to our own expectations of partnership.

Be gentle with yourself and your spouse or partner. Be aware of unrealistic expectations you may have for yourself or your mate. Try to remember that you are both doing the best you can. The physical changes that accompany our illness can generate distressing feelings. Because these changes affect our body image, we may need special support in this area from our partners. We should talk to our partner about how we feel and what we need, including what kind of

physical contact we want. A psychotherapist, psychologist or psychiatrist was a great help to some of us.

Some of us were hit by illness before we started a family. We may wonder if we will ever be a mother or father. Many of us, both male and female recipients of all organs, have gone on after transplantation to have biological children. We have also adopted children. Others of us have built extraordinarily rich satisfying lives without children.

WHEN THERE IS A CHILD IN THE FAMILY

It is important for children to be told what is happening in language they can understand. Left alone, imaginations take over and children might experience unnecessary fear. Expressing your feelings honestly and allowing your child to express his or her own is the best way you can help. Help the child talk openly about his or her feelings without negating the fear or anger or sadness.

Children feel like they are an important part of the family when they help out. Yet you must be careful not to place too much responsibility on them; they still need time to be kids. Let children know they are loved and will continue to be taken care of, even though family members may be sick, upset or tired.

DATING WHILE WAITING

Some of us are not in long-term relationships but would like to be. We wonder how much to share with dates and how to explain our situation. We try not to put our life on hold but to take risks that we deem worth taking. Though it may feel all encompassing, the wait for an organ is just a part of our experience as a human being. A desire to have fun and a sense of humor helps, too! Some of us married our companions who supported us through the wait. Some of us moved on to new relationships.

WHEN A CHILD IS THE CANDIDATE

As all parents know, children have unique needs when they are ill. Children experience stress and emotions, and at times feel set apart from their friends and classmates. Teenagers feel acutely self-conscious about their physical changes, let alone the added embarrassment of medical exams and tests. At an age when teenagers are striving for independence, it is hard to need assistance, to be different, and not be able to participate in all school and extracurricular activities.

Knowing what to expect is helpful. Visit the transplant hospital to see where things are located, learn about procedures, and meet with the personnel so a familiar face can be

found when the time comes. Some pediatric transplant centers have child life specialists who can help. Discuss what to expect with the whole family. Find out what family support is available, such as support groups, or the opportunity to meet with the transplant coordinator or team.

Children need help to express their emotions. Talk directly to your child to learn what their worries might be. He or she may be anxious about feeling pain, embarrassed by procedures, or frightened that the transplant won't work. It is important that the child have an opportunity to express feelings so that they don't come out in harmful ways, such as refusing to take medicine. Let children and teenagers make as many decisions and do as much for themselves as is appropriate for their age. Taking charge even of small things (watering and caring for a plant, for example) can bring them a sense of well-being and a needed sense of control.

Focus on other parts of life, too. Plan family outings and talk about school and friends. Keep things as normal as possible, which may include continued discussion about curfew time!

STRESS AND OUR EMOTIONS

Waiting is stressful for our loved ones as well as for us. Some feelings are a reaction to loss, some to the uncertainty of the future and some to our current physical health. It is possible to experience many different feelings in a short period of time, or at the same time, and to not always know why you are feeling the way you do.

Not all of our stress is purely emotional. Chemical abnormalities and fatigue associated with illness have effects on our thoughts and perceptions. Severe heart disease may diminish blood flow to the brain. Kidney failure results in anemia and fatigue. Chronic liver and kidney diseases can cause waste products to build up in the body and interfere with mental functioning and alertness. The medications we take can affect our moods and thinking.

FALSE ALARMS

Our anxiety can seem out of control at times. For example, some of us have had our pager go off by mistake, creating excitement followed by disappointment. It is not uncommon to be called and think, "This is it!" only to find that final testing showed that the organ was incompatible, or that it

is best matched with someone else. This is tremendously disappointing. It takes some work to accept that waiting is associated with random events that cannot be controlled. When your transplant coordinator calls, be aware that he or she will say, “We may have a potential organ for you...”



“When you are tempted to give up, confide in someone. A problem shared is a problem solved.”

– Ian Netherway, waiting for a kidney/pancreas



“We found maintaining a positive and independent attitude wasn't always easy. Nor did it make a transplant happen any sooner. However, it helped make our lives more productive, enjoyable and meaningful while we were waiting.”

– Gerard Migliore, kidney recipient



“While waiting, I didn't count the days since there is no known target amount of days of when an organ will come. I focused instead on making the most of each day – setting and achieving daily goals, no matter how big or small.”

– Jim Gleason, heart recipient

WHAT HELPS

For many of us, information reduces the fear of the unknown. We learn not to be afraid to ask questions no matter how “off the wall” they may seem. Many of us get information through reading and getting involved in our own care.

Some of us want our doctors to be helpful and blunt. Sugarcoating has never helped those of us who like to know what we have to deal with. Some of us overcame long-time fears about our health, learned how to put in our own dialysis needles, or researched everything on our disease. Having the courage to share ideas with our doctors and working in tandem with them on our care gave us emotional and physical strength.

We all need things to look forward to. For one man with a long hospital wait, a schedule of TV shows, particularly big sports events, gave his days a rhythm. For another, getting shaved and dressed, even on the hardest days, is a moral boost. Do something every day. One woman makes herself sketch. For others, writing poetry, keeping up with current events, working on crafts or walking slowly, even in a limited way, is helpful. What brings us

comfort may be the same thing that helped us before we became ill, or it may be a new discovery. That “something” may be different for each one of us. Seek it out. It will be worth the time and effort.

PLANNING AHEAD

Planning ahead is helpful for practical reasons as well as to reduce anxiety. Issues we have already taken care of should not drain our energy or cause us worry. Many of us have found that we can reduce uncertainty by taking charge of what we can do. Having our bags packed and ready to go when the call comes helps ease anxiety. We recommend including money (or a card) for tolls and change (or a calling card) for the telephone. You may want to bring any medications you are currently taking and, if you are on peritoneal dialysis, your supplies and equipment. Bring a list of any medications you are on, know your allergies and, most importantly, bring your health insurance card. You may want to keep a log of surgical tests, medical events and hospitalizations, and bring it with you.

Make detailed plans for living arrangements if you have to move to another town for your transplant. If the transplant cen-

ter is several hours away or in another state, have access to flight information. Find out how to arrange for a police escort, if warranted, from your home to the hospital. Pre-plan for child care. Set up a pager system for family and friends involved in your plan. Know what to expect at the hospital; see where the intensive care unit (where you would wake up) is located. See the transplant floor. Since the medications you will need after transplant may not be in stock at your local pharmacy, arrange to have a pharmacy ready and willing to supply you with the medications you will need. Your transplant coordinator or social worker can help you. If your transplant center offers an orientation program, we encourage you to attend.

CARING FOR YOURSELF, EMOTIONALLY AND PHYSICALLY

We all benefit from taking an active role in our health care. We need to report how we are doing physically and let health care providers know immediately if there are changes in our physical or emotional health and well-being. Sometimes we hesitate to speak up for fear of being “poked and prodded” if more tests are needed.

EXERCISE

As poor as we felt physically, some of us managed to stay in good shape or become more physically fit by swimming, stretching, and practicing tai chi or yoga. Some of us looked at the waiting time as if we were “in training”: We refrained from smoking, struggled to maintain normal body weight and kept up an exercise program, even if it was all done from a sitting position!

PACING YOURSELF

Many of us found that we were able to do more if we paced ourselves over a longer period of time or broke down large tasks into smaller ones. Let your family know that there are times when you have to save your energy. Remind them that you don't love them less just because they get less of your time.

RELAXATION

Learning relaxation techniques was a great help for those of us who could not control our worry. We found that a few visits to a psychologist specializing in stress management and relaxation techniques helped. Learning about breathing, imagery and biofeedback taught us how to relax. It was amazing! Doing anything we find relaxing can help. For some of us this may be a relaxing bath or talking with a friend. Music and art also have therapeutic benefits.

TREAT ANXIETY AND DEPRESSION

Never having considered psychotherapy before, some of us found it to be just what we needed. Antidepressant medications helped some of us, too. Though it is perfectly natural that we would be depressed given our situation, the medications helped some of us feel better. Do not take over-the-counter or herbal antidepressant medications (St. John's Wort or others) without discussing them with your physician first.

Some symptoms of depression such as fatigue and difficulty sleeping are often related to our illnesses. However, if symptoms such as hopelessness, despair and diminished self-worth (is my life not worth saving?) persist, it is important to let your health care team know. Antidepressant medication in combination with psychological counseling can help alleviate these debilitating symptoms.

LEARN ABOUT ADDICTIONS

Some of us found it easier to live a healthier life while we were waiting. It helped those of us with addiction problems take the time to learn about our addictions and develop new interests in their place. After our transplant, many of us faced the same temptations we did before we began our

wait. We must prepare to live our lives in a way that negates the possibility of again picking up addictive habits. Addictions—even some socially accepted habits—can limit the life of our transplanted organs.

SUPPORT GROUPS

Support groups can take away some of the loneliness. During our wait, many of us were introduced to a group of individuals who, like us, were waiting. Your transplant social worker can help you locate a support group near you. Support groups allow you to share practical tips and information about the wait and transplant process.

HOPEFUL THINKING

We've been helped by not second-guessing our decisions. We trust our gut instinct and stay out of the trap of wondering, "What if it doesn't work out? What if...?" Instead, we learned to refocus our thoughts. Squelch the doubts, especially when you are not feeling well. Share your hopes and dreams with people you love, and look forward to special days and celebrations.

TELLING OUR STORIES

Sometimes it is therapeutic to tell our stories. We can do this by talking to trusted friends or by writing in a journal. Photographs and scrapbooks can help us remember and reflect on joyous times. Putting feelings into prose, poems and stories can help. We found that sharing our stories publicly had the added benefit of encouraging people to talk with their families about organ and tissue donation and to sign their donor cards.

SPIRITUALITY

Many of us draw courage and hope from spiritual sources when times are difficult. There may be days when the uncertainty of illness makes life seem unreal and terribly wrong. We are not being punished or tested. Some of us feel calm and unafraid when we take strength from our beliefs. Faith may help us find moments of hope and peace in each day.

Houses of worship can provide the social support to our families and to ourselves as well. Many have provided emotional support and practical assistance to congregants. Many are active in educating the community about organ and tissue donation.

TAKING CARE OF OUR CARETAKERS

Our care partners can become physically and emotionally exhausted at times. We need to encourage them to take time for themselves so they can recharge. We need to encourage them to take care of their own health—to go to the doctor when they are sick and keep routine appointments.

It helps to be specific about what assistance we need from our care partners. One person let her family members know that making the bed each day was hard. This may seem like a small thing but it meant a lot to her to see the bed made. It made the world seem less chaotic. Being able to do this made the family members feel good.

Learn to accept help. Accepting help was not easy for those of us who were independent before our illness. Some of us thought receiving help meant we were weak or accepting charity. We learned this was not so. If we give a smile, a thank you, a request for assistance freely, we are giving our care partners a gift and helping them deal with their sense of helplessness.

Some days we may push ourselves beyond our limits. It may be hard for our families to watch us make demands on our bodies

knowing that we will both pay for it later. Yet, we do not want to be nagged or treated like children. If you pay attention to your body and listen to others, you can learn how much you can physically do and when you need to stop.

WHAT FAMILY AND FRIENDS CAN DO

Family members can learn CPR and basic first-aid. Others take this time to educate people about organ and tissue donation. Don't let your family and friends underestimate the value of simply being with you, even when declining health may drain your energy for conversation. Encourage family who live far away to write to you, and write back.

We found it helpful to let trusted family members know where we kept records and other important information. Reviewing your finances and arranging for power of attorney with your bank will allow your household to run smoothly when you are hospitalized or otherwise unable to manage finances.



“I don't know how long I have to live. Sometimes I cry, sometimes I feel disgusted, like giving up. Then I turn it over to God.”

– Artis Fox, waiting for a heart



“I became the person that I am because of what I've been through. Everything I have gone through helps me value and cherish life more.”

– Deborah Rodriguez, kidney recipient



END-OF-LIFE DECISIONS

TALKING ABOUT DEATH WITH YOUR FAMILY

Death is inherently difficult to talk about. It is tempting to avoid talking about it. However, talking about the possibility of death made us feel more in control and able to focus our energy on staying healthy. This is a time for all adult family members to talk about practical matters. What burial and funeral arrangements do we want? If we are able to pre-plan these arrangements, our families will have one less burden. Is our will in order? Have we given a loved one medical power of attorney or appointed a health care proxy? Have we discussed with our surrogate what type of care we want if we become critically ill? Do we want, if able, to donate organs or tissue at the time of our death? What are our loved ones' anxieties about life without us? Can we help prepare and comfort them? We found talking about death did not make it happen and it did not mean we had given up.

KEEP LIVING WHILE WAITING

All of us would benefit by living as if each day were our last. Perhaps we would die with fewer regrets if we told people we loved them, asked for forgiveness, if necessary, and thanked people we are grateful to. Seize

the opportunity to be the type of person you want to be. You will have the same personal problems after your transplant, so use this time to work on the conflicts in your life. Try to stay active and involved, and live as normally as possible. Entertainment is important. Some of us who have dialysis or other treatments try to do this in a pleasant environment—we read books and magazines or watch a movie.

Look for ways to help others, no matter how insignificant your help may seem. Be generous in giving thanks. Have fun with people you care about. Never forget to laugh, especially at yourself. Humor is a wonderful weapon against depression. Live each day as fully as possible.

WHAT IF THE TRANSPLANT NEVER COMES...?

Modern medicine is highly sophisticated and successful at keeping people alive until a donor organ is available. Heart pumps (left ventricular assist devices), dialysis machines, medication, stem cell transplants, operations (heart reductions), spontaneous recoveries and remissions are all part of the picture. Never give up hope.

None of us knows when the call will come; some of us wait one day, and some wait over one thousand days. One of the toughest things we have to do is prepare for life and prepare for death at the same time. We do not know if the transplant will happen or if it will work. As we travel the transplant journey, we have had to cope with the death of fellow candidates, recipients and friends. Death is no stranger to us.

Daily, people are dying while they wait for an organ transplant. It is natural to worry about how things will go, but try to focus on living each day. None of us knows what life will bring. All we know is that we have today and we have hope for tomorrow. All we can do is try to be the person we want to be today, and to help our loved ones to prepare to face tomorrow.



*Our best wishes are with you
on your waiting journey.*

ABOUT THE TRANSACTION COUNCIL

The transAction Council was established in 1996 to ensure that organ transplant recipients receive the finest possible care. It is the largest group of transplant recipients in the United States and has international members as well. The transAction Council is “us”—candidates and recipients bringing each other information and educational materials such as this book on waiting for a transplant and the “Transplant Recipients’ Bill of Rights and Responsibilities.”

The name transAction comes from “Transplant Recipients” + “Action.” Many of us who have joined the transAction Council are actively working with the National Kidney Foundation, the largest not-for-profit organization serving individuals with all types of organ transplants (not just kidney), striving to increase the number of organs available for transplantation.

The transAction Council provides advice and assistance to transplant recipients and candidates. Our programs and services include educational symposia, national surveys, health and fitness programs and other support activities.

Membership in the transAction Council is free and open to all individuals who have received a life-saving or life-enhancing organ transplant, transplant candidates, their families and friends and the health care professionals who care for them. To join or to help start a local council, please call **800-622-9010** and we will mail you information and a membership application, or visit us on-line at **www.transplantrecipients.org**



*“I found that reading my cards and mail over
and over again makes me feel cared for.”*

– Corey Lyman, waiting for a heart



*“It is important for me to get answers.
I want to know what I have to deal with.”*

– Susie Garfulo, liver recipient



RESOURCES

GENERAL READINGS OF ENCOURAGEMENT

Judith Viorst, *Necessary Losses*

Fireside Edition (Simon & Schuster), NY, 1986, 1998—a sensitive book about coping with all types of losses that occur over a lifetime.

Dale Carnegie, *How to Stop Worrying & Start Living*

(Pocket Books) NY, 1944, 1985—techniques to break the worry habit and adopt new mental attitudes that lead to security and happiness.

FINANCIAL AND INSURANCE RESOURCES

Your Transplant Hospital Social Worker and Financial Counselor

These professionals can find access to financial, insurance and pharmaceutical assistance, fund raising organizations, emergency air transportation, hotel and lodging assistance near the hospital, Medicare and other assistance programs.

State Pharmaceutical Assistance Programs

A number of states have programs (with specific financial eligibility guidelines) that offer assistance to persons with disabilities or senior citizens with outpatient medications. Contact your local Department of Social Services or Medicaid office to see if any programs are available in your state.

A Guide to Health Insurance for People With Medicare

This booklet covers what Medicare pays and what it doesn't, ten standard Medigap insurance plans, your right to Medigap insurance and tips on shopping for private health insurance. Developed jointly by the National Association of Insurance Commissioners and the Centers for Medicare and Medicaid Services (CMS). Call 800-638-6833 for a free copy.

Local NKF Affiliates

NKF local offices may provide small grants of varying amounts to recipients in need. To locate the NKF affiliate office serving your geographic area, call 800-622-9010.

State Kidney Programs

Approximately 25 states have programs that offer assistance for kidney transplant or dialysis patients with outpatient medications and other expenses. To find out if your state has such a program, contact the National Organization for State Kidney Programs in Missouri at 800-733-7345.

Medicaid and Other State Financial Programs (MediCal, Access)

Depending on your income and assets, you may be eligible for health care coverage through the Department of Social Service in your state or county. Benefits and eligibility criteria vary. State Social Service departments can determine your eligibility to receive help from programs (QMB and SLMB) that help you afford Medicare premiums and co-payments.

Veterans Administration

If you are a veteran treated by a V.A. physician and meet income and other eligibility criteria, you may be eligible for low-cost prescriptions and follow-up care. Call 877-222-8387.

Patient Services Incorporated

Helps recipients and ESRD patients with the cost of medical co-payments. Call 800-366-7741 or visit www.uneedpsi.org

Pharmaceutical Assistance Programs

Pharmaceutical companies that manufacture transplant medications prescribed by your physician may have programs to help you obtain the medications free or at a reduced cost. Most of these programs assist individuals on a temporary basis and require you to meet income guidelines. Three Web sites are available to help you determine if an assistance program is available for your medication—www.phrma.org www.needymeds.com and www.Rxassist.org Your health care professional (nurse, social worker or physician) is required to submit an application on your behalf. Another helpful Web site is www.benefitscheck.com

American Kidney Fund (AKF)

Kidney patients can apply for financial assistance through nephrology social workers in dialysis and transplant facilities. The AKF can be reached at 800-638-8299 or www.akfinc.org

Social Security Disability Insurance (SSDI) or SSI (Supplemental Security Income)

If you believe your illness will prevent you from

working for a year or more, contact your local Social Security Administration office to apply for disability. Visit www.ssa.gov or call 800-772-1213 for information, to file a claim or to request publications. If you are not already collecting Medicare because of your age or End Stage Renal Disease diagnosis, you will be eligible for Medicare after collecting 24 social security disability Insurance (SSDI) checks. If you are eligible for SSI, many states also include the Medicaid benefit.

COBRA (Consolidated Omnibus Budget Reconciliation Act)

If you become too ill to work, you may be eligible to continue your group health plan for 29 months if you can prove you became disabled while employed. You will be responsible for full premium costs. If your company has less than 20 employees or you do not qualify for other reasons, you may be eligible for a program of benefit continuation in your state. If you become divorced or widowed and you were covered through your former spouse, you may continue to receive benefits for three years. Call 800-998-7543 for a booklet further describing these benefits.

Comprehensive Health Insurance Programs (CHIPS)

Some states have insurance programs for persons with catastrophic illnesses. Premiums, however, may be high and there may be a waiting list. To find out what programs are available in your state, meet with an independent insurance broker. In some areas, the insurance commissioner located in your state capital might be helpful.

Health Insurance Portability and Accountability Act of 1996 (HIPAA)

This legislation includes protection for working Americans and families that have pre-existing medical conditions and are covered under a group health plan. Contact the Equal Employment Opportunity Commission at 800-669-4000.

What Every Patient Needs to Know is a comprehensive guide to assistance programs, insurance and financing issues. Call 888-894-6361 to request a free copy or download it from **www.unos.org/resources/productCatalog** Finances are also discussed in the “Before the Transplant” section at **www.transplantliving.org**

EMPLOYMENT RESOURCES

The Effective Strategies for Improving Employment Outcomes for People with Chronic Kidney Disease; 27th Institute on Rehabilitation Issues

University of Arkansas - RRCEP

Region 6 - Rehabilitation Continuing Education Center

PO Box 1358, 105 Reserve, Bldg. #35

Hot Springs, AR 71902

501-623-7700

www.rcep6.org/IRI_Publications.htm

This publication can assist all transplant recipients in working with rehabilitation services agencies.

Life Options Rehabilitation Advisory Council

800-468-7777

www.lifeoptions.org

Life Options is dedicated to helping people live long and live well with kidney disease. Life Options is actively engaged in research, partnering with other organizations and offering technical support for individuals with kidney disease.

Ticket to Work

The Ticket to Work and Self-Sufficiency Program is an employment program for people with disabilities who are interested in going to work. The ticket program is part of the Ticket to Work and Work Incentives Improvement Act of 1999, which was designed to remove many of the barriers that previously influenced decisions about going to work due to the concerns over losing health care coverage.

www.yourtickettowork.com

Equal Employment Opportunity Commission (EEOC)

www.eeoc.gov

A Guide to Work, Insurance and Finance for People on Dialysis (Life Options)

www.lifeoptions.org

Job Accommodation Network

<http://janweb.icdi.wvu.edu>

National Center on Accessibility

www.indiana.edu/~nca

National Council on Disability

www.ncd.gov

National Institute on Disability and Rehabilitation Research

www.ed.gov/about/offices.list/osers/nidrr/index.html?src=mr

National Rehabilitation Information Center

www.cais.net/naric

U.S. Department of Labor

Office of Disability Employment Policy

www.dol.gov/odep

Rehabilitation Services Administration

www.ed.gov/offices/OSERS/RSA/rsa.html

SSA Office of Employment Support Programs

www.ssa.gov/work/index2.html

Social Security Disability

Features information on work incentives for people wishing to return to work.

www.ssa.gov

WEB SITES

www.transplantrecipients.org

The National Kidney Foundation's transAction Web site contains facts about transplantation, a message board for recipients and candidates, a forum to post questions privately, frequently asked questions and answers, the newsletter *Transplant Chronicles*, an e-mail announcement service and more.

www.kidney.org

The National Kidney Foundation Web site includes an A-Z guide about kidney disease, news and programs

about transplantation and kidney disease to assist patients, families and professionals. It also provides transplant athletic news, including information on the U.S. Transplant Games, message boards, public policy announcements and information about organ donation.

www.livingdonors.org

This NKF site features chats on living donation, tributes to living donors, a pen pal program and an online discussion group for living donors, as well as comprehensive information on the evaluation process for potential donors, surgery, risks and factors to consider before deciding to become a donor.

www.organdonor.gov

The Department of Health and Human Services, Division of Transplantation Web site lists commonly asked questions and answers about donation, news releases and other information.

www.unos.org

The United Network for Organ Sharing Web site features statistics, educational resources and information about donation and transplant in the United States.

www.transweb.org

This Web site, based at the University of Michigan, provides access to opinions, ideas and information for and about transplant recipients and candidates.

www.a-s-t.org

The American Society of Transplantation Web site provides comprehensive, clinically-focused information about transplantation, with areas devoted to patient and family issues and medications.

www.donorfamily.org

The National Kidney Foundation's National Donor Family Council's Web site features information about the donor family quilt and accompanying stories, tributes, a message board, newsletters and publications, including information about donor families and recipients.

www.shareyourlife.org

The Coalition on Donation is a group of national organizations that have banded together to collectively promote organ and tissue donation.

www.nationalmottep.org

The Minority Organ Tissue Transplant Education Program Web site features a list of publications, links and resources.

NATIONAL KIDNEY FOUNDATION RESOURCES

Call 800-622-9010 to receive information and answers to your questions, to receive a membership application, the phone number of the NKF affiliate nearest you or any of the following publications:

Information Packet on Living Donation

Includes a booklet about donation and more.

How to be an Ambassador for Organ and Tissue Donation

A series of fact sheets with instructional guidelines that helps to prepare recipients, candidates and family members speak publicly about donation and transplantation.

Writing to Donor Family and Living Donors

A simple brochure that helps give ideas and encouragement for sending a letter of thanks to your living donor or their family.

Take Time to Talk (English and Spanish)

An informative and encouraging book explaining the benefits of discussing organ and tissue donation prior to a death in the family.

transAction Council

transAction Council represents transplant recipients, families, professionals and friends, whose goals are to ensure that transplant recipients receive the finest possible care and also to provide programs and information designed to improve their quality of life. Membership is free and includes a subscription to the newsletter ***Transplant Chronicles***.

Legislative Volunteer Network

A grassroots group of thousands of transplant candidates and recipients of all organs who, with the assistance of the National Kidney Foundation's Public Policy office in Washington, DC, advocate for health care legislation and reform.

U.S. Transplant Games

A biennial, Olympic-style event for persons with solid organ and bone marrow transplants. The event is presented by the National Kidney Foundation and supported by the transplant community at-large.

National Kidney Foundation Affiliates

Located throughout the country, the National Kidney Foundation affiliates provide support and information to organ recipients and candidates. Some affiliates provide patients with MedicAlert bracelets and transplant centers with beepers for candidates waiting for an organ,

NKF Fact Sheets

A series of pamphlets including “The Transplant Waiting List” and “Questions and Answers About Living Donation.”

NKF Organ Transplant Series

Separate brochures discussing heart, lung, liver, kidney and kidney-pancreas transplantation.

Patient and Family Council

The goal of the Patient and Family Council is to educate and empower persons with kidney disease, dialysis patients and their families to make informed decisions about the quality of care they or their loved ones receive. Membership is free and includes a subscription to the newspaper ***Family Focus***.

The NKF Information Center and Health Information Manager

Knowledgeable staff will send you educational materials and answer your questions about kidney disease, transplantation and living donation.

NKF on the Web

www.kidney.org

www.transplantrecipients.org

www.livingdonors.org

www.donorfamilies.org

www.kidney.org/patients

NKF Web sites for persons with kidney disease, transplant recipients of all organs, living donors and donor families. Contact us at **peoplelikeus@kidney.org**

The Transplant Recipients' Bill of Rights and Responsibilities

This document helps organ recipients prepare for the rigors of transplantation, and encourages them to obtain the specialized care they need.

Nutrition and Transplantation

This brochure helps patients prepare for transplantation and also helps them to maintain a healthy diet.

Uniform Donor Cards

By signing these cards, individuals indicate their decision to be a donor. They may also use them to initiate discussion among family members regarding their wishes.

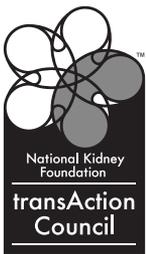
Organ Donor Brochures

These brochures provide basic facts about organ and tissue donation. Available in English and Spanish.

Reprint of the Consensus Statement on the Live Organ Donor

As published in the *Journal of the American Medical Association*, December 13, 2000; Volume 284, Number 22.

This article recommends practice guidelines for all persons concerned about the well-being of live organ donors, including physicians and health care planners. It is the result of a national conference of more than 100 representatives of the transplant community (physicians, nurses, ethicists, psychologists, lawyers, scientists, social workers, transplant recipients and living donors) convened by the National Kidney Foundation, the American Societies of Transplantation, Transplant Surgeons, and Nephrology.



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