

From Illness to
WELLNESS:

Life After Transplantation

This book has been written especially for you by those of us who have been transplanted. These pages reflect our sincerest wishes, thoughts and prayers for your well-being. You can read this book from cover to cover or by choosing topics of interest. If you have questions about your transplant, we encourage you to contact the person listed below. Professionals at your treatment or transplant center have answers and resources that will help you.

For more information:

Contact: _____

Address: _____

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Notes: _____

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DEDICATION

To all transplant recipients and their families: May you embrace life and live fully with your newfound wellness.

Our heartfelt thanks . . .

to the heart, lung, liver, pancreas and kidney recipients who shared their most personal experiences about their first year after transplantation. We are grateful for their generosity in sharing their innermost feelings and strengths.


Very special thanks to:

Charles Corr, Ph.D., for listening to transplant recipients and recording their thoughts, feelings and experiences into this text, and to Nancy Swick, RN, BSN, CCTC, and Trent Tipple, MD for facilitating the development of this book.

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recipients who answered surveys and queries requesting that they share their experiences and thoughts.

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*We will never know how high we are
Til we are called to rise;
and then, if we are true to plan,
Our statures touch the skies.*

-Emily Dickinson



Our thoughts are with you.

- National Kidney Foundation and
its transAction Council

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PREFACE

The ups, downs, good things, mood swings, dealing with people (family and friends), illness, the road to recovery, the avenue of new life—this is what the Gift of Life brings to all of us.

In this booklet, we help you identify some issues that you may face after your transplant. We describe some challenges that people faced. We also share information about various choices that recipients have made when dealing with those challenges. We hope to offer suggestions and support that are helpful to you in your effort to move forward and live a new and transformed life.

Most of the writers who prepared this booklet are transplant recipients. But we also sought help from other members of the transAction Council (i.e., parents of recipients, health care professionals), the staff of the National Kidney Foundation, other contributors and reviewers experienced in the field of transplantation. This is the same process that was employed in preparing *Waiting for a Transplant*, a booklet on coping with the problems, challenges and other issues that arise while one is a candidate awaiting a transplant.

You will receive a great deal of information and literature from your transplant team, pharmaceutical companies and other sources in the period immediately following your transplant. For that reason, in this booklet we look beyond short-term concerns and include the goal of looking for wellness. We take a broader perspective that includes the first year of adjustment to a new transplant as well as issues that extend well beyond that time and into the future.

We are not suggesting that the experiences described in this booklet will be the only ones you might encounter as a transplant recipient. Nor are we implying that our ways of coping with our transplants are the only possible alternatives. We hope the contents of this booklet will be helpful as you think about the choices that are open to you and the changes that can be made in order to improve your experiences of living with a transplant.

INTRODUCTION

Many, if not most people—or those who have no direct contact with the experience of living with a transplant—seem to think that once you receive an organ transplant all of your problems are over. That is a perception that you may have had yourself, prior to being transplanted. Some important problems ARE behind you. But other challenges will arise, as well as the opportunity to live a new life with a newfound wellness. There will be new goals in this new and ever-changing phase of your life.

At times it can be difficult to live with a transplant and literally impossible to live without one. There are many issues that demand attention as you strive to develop "new normals" in your life. This booklet is our effort to help you anticipate some of the issues that you might have to face, both from our own experiences and those of others.

We do not want to overemphasize the difficulties that you may encounter. Thousands of transplant recipients have led healthy, productive lives after transplantation. At the same time, we do not want to minimize or underemphasize the issues that one can

encounter in living with a transplant. To stay healthy as a transplant recipient, one has to pay attention to the many implications of transplantation and act on them in appropriate ways.

You can be a healthy transplant recipient! You can create a healthy new life for yourself. Listen carefully to advice from your transplant team and from others who have been in situations similar to those in which you now find yourself. In this booklet, we hope to assist you in your efforts to do just that.

TRANSPLANTATION

PRIOR TO RECEIVING A TRANSPLANT

We came to transplantation in different ways. Most of us experienced a gradual decline in the functioning of a critical organ in our bodies, while some were confronted with the sudden onset of organ failure. As difficult as it is to believe, some were misdiagnosed or avoided medical treatment for several months or even years before being told that a transplant was the sole option left to ensure survival.

Most of us had time to prepare for a transplant and, perhaps, even for life after transplantation (although it is not always clear

in advance what post-transplant life will really be like), while others had very little opportunity to prepare. Regardless of your status prior to transplant, the question of “What do I do now?” seems standard in the months following a successful transplant.

For those who are waiting for a transplant and for those who have been transplanted (because there may still be new challenges), it is important to stay informed and to have an open mind on issues that may affect one's life. Pay attention to your body and what your medical team tells you, read as much as you can about transplantation, new medical treatments and the drugs you take. Never stop learning. We live in the Information Age—take advantage of it.

ATTITUDES TOWARD TRANSPLANTATION

Some people eagerly embrace transplantation as a solution to problems associated with their illness, such as poor quality of life, dependence on dialysis or medications and the imminent threat of death. For example, many parents of young transplant recipients have told us that they eagerly agreed to a transplant for their child when they learned that was the only way to save the child's life.

At the same time, others accepted a transplant with great reluctance. Some had mixed feelings about what would be involved in obtaining a transplantable organ, others feared complications associated with the surgery itself and some expected to be a semi-invalid, dependent on a hospital for the remainder of their lives. One recipient reported that “Certain dietitians and nurses at the...Medical Center gave draconian forecasts about difficulties of life after transplant and reactions to the drugs—none of which has turned out to be true for me.”

We also know some individuals who eventually chose not to be transplanted for various reasons and chose to live (or die) with the consequences that followed from that choice.

One transplant recipient shared the following comment about attitudes toward transplantation: “When I was still a dialysis patient, my cousin in Utah phoned and told me I 'needed' to get a transplant so I could go to the Transplant Games with her. That may have seemed like a selfish attitude, but it was also a good reason to maintain a healthy lifestyle and be compliant before and after the transplant.”

This is not a typical attitude, but it reminds us that individuals come to transplantation with views that are as different from one another as each of the lives they have previously been living.

Friends and family members may also struggle with what to expect from the transplant process. Their attitudes and fears can influence how we react and behave. Attitudes of those around us may affect the information shared with loved ones. In our discussions, we have found there is no single way to prepare ourselves or our families for transplant. Everyone is unique in this process. The important thing is to find an effective and healthy way to develop coping skills that will be helpful to you in facing the bumps that all of us encounter along the transplant journey.

PREPARATION FOR TRANSPLANTATION

We all prepared for life after transplant in different ways. Some of us were given useful information about what living with a transplant would be like. However, many recipients were given what they felt was not very useful information. Many felt unprepared for what life after transplant is really like. Consequently, these recipients did not have the advantages and expectations enjoyed by those who are better prepared, whether for a better life in some ways, or for the “downs” that inevitably affect all of us after receiving an organ from another person.

All transplant centers give recipients information about medications, potential complications, the surgery itself and other factors. But little information may be provided about how to proceed with your daily life after transplant. How does one incorporate a complicated medication schedule into a busy lifestyle? How do you live your daily life with the fear of the unknown? How does a person deal with these questions—and countless others—and not let them sideline one's progress? We know you asked yourself if you would ever return to a “normal” (whatever that is) life after transplant. There are no clear and

easy answers to these questions. Even if we all had such answers, because of the uniqueness of each recipient, his or her history, lifestyle, family, home, job, friends and family, there is no one “right” answer to every question. There are numerous scenarios in daily life; thus, there are many answers to your questions, and all depending on circumstances affecting your life. Nevertheless, we hope this guide to living with a transplant will help you, at least in part, to find your own answers to these questions—answers that will work well for you and will help you in the ongoing process of seeking wellness in your life.

Many transplant candidates consulted whatever literature or sources of information they could find about transplantation and its implications. The transplantation process is always changing, so literature and Web sites often need updating. Drug combinations, for example, that may have been common 10 years ago are seldom used today. New drugs are rapidly being approved by the Food and Drug Administration (FDA). Surgeons today are using new and different procedures. It is important that you evaluate all information and resources, including the information and resources in this booklet.

EXPECTATIONS ABOUT LIVING WITH A TRANSPLANT

What would it would be like to live with a transplant? Expectations vary widely. With the advantage of hindsight, some expectations now appear quite naive, and in some cases that might have been beneficial. If one assumed that a transplant would erase all problems, or that a recipient could simply return to his or her former mode of living (without, of course, any of the difficulties that were part of what led the recipient to transplantation in the first place), he or she now realizes that there is much to learn. Some folks are a bit more realistic, and realized that life after transplant would take some getting used to. Important adjustments would be required in order to live as well as they are able. Some others thought they would be “disabled” for life.

Some people just want to feel better. Others find it difficult to think of themselves as being well. They had been sick and dependent on others for so long. A few thought, “Just get up and walk out of the hospital!”

While waiting for the transplant, the focus is often simply on the goal of holding on until an organ becomes available. Once transplanted, the focus naturally shifts to

learning to live with a whole new set of issues and setting the groundwork for living a full and productive life once again.

Transitioning from pre-transplant is difficult, whether you are a dialysis patient waiting for a heart for over a year in a hospital or suffering a lifetime with lung disease. It is also not easy for families. Remembering what wellness felt like and working to achieve it once again takes a great deal of effort on the part of the entire family. Wellness does not just happen! Making the effort, however, will pay back in big dividends. With lots of hard work and a little luck, it IS possible to enjoy a new life after a transplant.

You will have or did have very different expectations than your family about life and recovery from transplant surgery. One parent of an infant who received a liver transplant stated, “I was surprised that there was little GOOD or accurate information about life after transplant. I also found that no one really agreed with what was a 'normal' life post-transplant.” As a result, this mom said she “knew it would be trading in one set of problems for another.”

However, like all other parents of young transplant recipients who contacted us, she cautioned, “Expect bumps but always remember the alternative. Remember the family that lost their loved one and gave this gift to you. It can help you through the tough times. How can you frown when you have an angel on your shoulder?”

Clearly, this mother viewed the new problems she and her son were facing as highly preferable to the possibility of her child's death.

Needless to say, your primary thoughts and deeds are directed at getting better. Family members, of course, have their own lives. Your recovery may complicate their lives, or you may at least feel that way. They might have less information than you and just need some more insight into what you are experiencing. People may not always understand you or all that can be associated with the transplant process (i.e., mood swings, drug regimens and your preoccupation with the new aspects of your life). You might want to explain to your loved ones about how you feel, why you do the things you do and their important role on your road to wellness. You might want to take those close to you to

the transplant clinic and suggest that they get involved so they feel like they are part of your new life. Remember—they have been through a great deal with your illness. Share your wellness with them too. When you are well enough, celebrate together!

Perhaps the most realistic and constructive way of facing the future is to think of your transplant as “a new beginning in your life.” As one recipient wrote, “I just knew if the lung transplant was successful, I would not live in my illness and would try to lead as normal a life as possible.” The only qualification we have to add to this comment is that “normal” can take on many forms and is different for each of us, transplant recipient or not.

GOING HOME AFTER TRANSPLANT SURGERY

One recipient urged to “really ask about aftercare post transplant, learn about medication assistance if a problem arises and try to find someone who has had a transplant and can serve as a resource to us, either in real life or on the Internet in a community room.” Similarly, another recipient encouraged us to search for ways to educate ourselves about all matters relating to transplantation and advised us to “glean

every drop of knowledge that is out there.” And a third recipient urged an assertive stance: “Drop the modesty. Ask any question without hesitation. Write them [your questions] down if you have to. Ask the nurses. Ask the transplant coordinator. Talk with other recipients. Attend transplant meetings.” Do all of the above with the goal of improving your life. This will make it possible for you to live the life you want after transplant!

Sometimes the questions do not start forming until weeks after the transplant, when reality begins to set in. It can be hard to gather all the necessary information before leaving the hospital. It might be more useful to gather the information in bits and pieces, especially when your energy returns and you are more receptive to learning.

In all of this, as in everything else related to organ transplantation, a number of recipients reminded us of the importance of taking one day or one issue at a time. “Just keep putting one foot in front of the other,” they often said, and “cross each bridge as you come to it.” Simple advice, but in this case simple is usually best. Remember what has always been important to you and keep doing it. If you have

always found music soothing, then listen to music. Use the tools that you already have to help during your recovery period and as you continue to live with your transplant.

One of the things that many of us learned very quickly was that we could not—and often did not want to—return to many aspects of our old lives. For example, although some of us were able to take up our old jobs after a suitable period of recovery, others could not. Our former work was now too strenuous, we no longer had the energy to carry it through, or, in some cases, our former job demanded skills and abilities that we no longer had. At the same time, some realized that they now had new skills and energy to explore new opportunities in life.

Similarly, after transplants many people were welcomed back home by their family members and close friends, while others withdrew from them or were uncomfortable in their presence for various reasons. We chose not to be discouraged by these personal and vocational challenges; instead, we decided to view them as opportunities to make a new start and to identify those people who were there for us. You

might also find that others around you now have opportunities to learn new life lessons too. For all of us, transplantation can enable us to learn the important and sometimes difficult lesson of appreciating life and its opportunities.

“The first year after your transplant is the time when you learn the stuff you're really made of,” one transplant recipient said. Another added, “Getting on with life means going forward and doesn't necessarily mean getting on with everything that I used to do.” Above all, it means moving forward in any direction that you select and that you are able.

OUR BASIC GOAL IN LIVING WITH A TRANSPLANT

The proper goal in living with a transplant is finding an appropriate balance in the new conditions of our lives. For example, shortly after his bilateral lung transplant, Len Geiger purchased a mountain bike and pushed himself hard when riding it. One day, his brakes locked up, the bike stopped but he kept going. Len soon realized the truth of the old saying, “It's not the fall, it's the rapid stop when you land!” What followed was a shattered femur, an ambulance ride to a trauma center, several days' wait until his white blood cell

count rose to appropriate levels, orthopedic surgery, complications with his lungs, treatment at a transplant center and a period of recovery including a wheelchair, walker, crutches and a cane.

In sharing this story with us, Len concluded, “I am looking forward to the second six months of my first year out from transplant. Maybe it will be a little less interesting.”

We don't believe that transplant recipients have to live a life of seclusion, and we know that accidents are always possible no matter who we are or how we live. But perhaps we can temper our ambitions and our adventures so that they match as closely as possible our newly established capacities and abilities?

SUPPORT SYSTEM

CONTACTS WITH OTHER TRANSPLANT RECIPIENTS

While waiting for a transplant, some of us were lucky enough to meet previously transplanted people. Often, the experience was very helpful. Such contacts helped those who became overwhelmed by the idea of even thinking about life after a transplant. As one mother said about her child's transplant, “Meeting other transplant

recipients has been the most helpful. If other people could do it [transplantation], then so can we.”

Another story comes to mind.

A middle-aged man had been waiting in the hospital for over a month but was too ill to go home. On this particular day, the gentleman was advised that the surgeons were about to obtain a new liver for him. Despite all the waiting and the prospect of a new life, the candidate refused to allow the surgeons to prepare him for surgery. His fear was the Swan-Ganz catheter that the surgeons place into the neck, inside of which are placed monitors for the heart and other organs and vital signs. He also feared the Foley catheter, which is inserted into the penis, up the urethra and into the bladder so urine can drain during and following surgery. Quite simply, this man did not want the pain that he understood would accompany these catheters.

One of us was there and quickly left this worried man's room. He sought out an older gentleman, a politician who had been transplanted five days before. The politician agreed to talk to the candidate, who now was intent on going home to die.

Within a half hour, he persuaded the man to stay, go through the surgery and receive the new liver. The surgeons agreed not to insert the Foley catheter until the patient was under full sedation. A week later the candidate was well enough to go home—with his new liver!

This scenario illustrates why some of us like to make ourselves available to talk with transplant candidates in that stressful period before they are transplanted, or even when they are trying to make decisions concerning what to do about transplantation. Some of us also work hard at raising funds for transplant candidates and recipients, or at educating professionals and members of the public about issues related to organ donation and transplantation.

You might want to consider adopting this way of taking charge, learning more about yourself and your health and “giving back” to others. None of this, however, should become an additional burden. One proactive transplant recipient wrote, “You can best promote organ donation by being a productive member of your community.”

MENTORS AND ROLE MODELS

Many of us found it helpful to seek out a mentor or role model, someone who had previous experience in walking the path that followed an organ transplant. A good mentor is someone who chose a path that we admire and who walked that path successfully. Often, the best role models are individuals who had a previous transplant, or family members who had a transplant—people who had successfully achieved the quality of life that they wanted after transplantation. Sometimes a staff member at our transplant center also turned out to be an important guide as we sought to move forward in our post-transplant universe.

In turning to others as role models and mentors, however, we learned to appreciate that those special individuals might at some point no longer be available to us. Some of our transplant peers died during the years after our transplants, whether as a result of transplant-associated complications or from other causes. Others relocated following transplant and some staff members eventually moved on to other kinds of work. Being aware of these possibilities helped us to focus on the present, to value whatever our mentors and role models had to offer to us at the time, and

not to expect too much from those interactions.

SUPPORT GROUPS

Many of us found it helpful to join support groups for transplant recipients. Such groups provide opportunities to share intimate feelings and ask personal questions in a nonjudgmental context. At a support group, we often felt free to concentrate on issues and share with others without criticism and embarrassment. By observing how others in the group were living with their transplants, we came to realize some of the options that were open to us. Members of these groups knew that we did not have to live with our transplants in exactly the same ways as they had. And they did not try to offer us well-meaning but unhelpful “advice.” Instead, their simple presence, their shared experiences and their individual differences helped to empower us to take control of our own lives and make our own decisions about how we should live after transplantation.

Many types of support groups exist—some for pre-transplant, some that include family and some that are for families alone. Some transplant recipients have tried support groups but did not find them helpful.

Typically, those individuals have told us that they felt such groups encourage dependence in the passive role of a “patient.” Some felt that transplant support groups serve a useful function, but were not for them. The goal is to find appropriate sources of support where and when you need them. There is no “right” solution for all individuals who are living with a transplant.

It is possible to find support, solace and comfort in many different ways. Seek out and choose a method that is best for you and for your family. It might be through meditation, finding strength in your faith or spending time in a garden. Whatever rejuvenates you and offers the support you need is beneficial.

FAMILY MEMBERS AND FRIENDS

Family members and friends can become “freaked out” that their loved ones could die as a result of the transplant. One woman stated that some of her family members were so nervous and overbearing that they made the situation worse by transferring their fear and negative energy onto her. Eventually, she had to tell them they could not visit her.

Negative people are a problem for many transplant recipients. One person told us that the main problems he faced arose from other people who told him, “You can't.” In response, he said that his view was, “Try, try, and then do it.” In both of these regards, however, he added, “I am more cautious with day to day encounters.”

It may help to be aware that some of the “You can't do it” messages rise from fear and concern. That fear from family and friends may reflect their concerns that you might hurt yourself in some manner if you try to do too much. These family members and friends may need more education about what is involved in living with a transplant and more time to understand what you are capable of doing. It can often be helpful to try to talk with these people

in your life, explain what you need and show them how important it is to support you in your goals.

In one example of true love and support, one man told us that his wife “ensured that there was always a carrot out just ahead of me.” In addition to helping him live with his transplant, this woman made it possible for the two of them to travel “to the Antarctic (twice), New Zealand (twice), Europe and the Arctic.” He concluded that this was “good motivation.”

Another man wrote, “My wife was of great help, but frankly, I feel that the ultimate responsibility and help must come from the transplant recipients themselves. It is our attitude, awareness of our transplant needs and the self-discipline to properly administer our medications and maintain our best physical condition that makes a transplant successful.” In a similar vein, one teenage transplant recipient said proudly that “it is my job in taking care of my transplant” to understand the names, doses and purposes of her medications, and to take them on schedule.

On occasion, families blame recipients for changing their lives or daily routines, spoiling or cancelling vacations, being disabled, or for the loss of income associated with being out of work for a period of time. These are natural reactions.

In other situations, loved ones will alienate the recipient under the perception that the recipient is selfish or cares too much about herself and her condition. To a certain extent, all recipients will become more absorbed in themselves because it is their responsibility to ensure their own health and mental well-being. But it is equally important not to alienate others. Try to share your experiences so others can understand why you do certain things differently after your transplant.

The roles that family members and friends play in our lives are different for each of us. Regardless of their particular role, it is important for us to remember that our illness and search for wellness will impact them greatly. They will also need information and support to survive and (with good luck) to thrive throughout the transplant process and the time we share in living with a transplant.

COMMUNICATING WITH YOUR TRANSPLANT TEAM

Maintaining good communication with the members of your transplant team and all your health care providers will help you and your family with the numerous concerns and questions that come up after a transplant. There will be what seems like countless questions, big and small, that will need to be answered not only for your good health but also, at times, just to put your mind at ease. Developing an open and honest working relationship with your transplant coordinator, as well as the rest of the team, will be beneficial for everyone in this new, developing and hopefully long-term relationship.

We hope that some of these tips will be useful in making communication productive and successful with your transplant team:

- Record your questions. Then, when you meet with members of your health team, you will have everything you need to discuss your concerns.
- If something bothers you, talk about it! There is no such thing as a dumb question after transplantation.

- Ask your transplant team to direct you to the right “go-to” person to help you, if needed. A dietitian may be the one to answer your diet questions. Your coordinator may handle your medication questions. It's a good idea to talk with the transplant social worker or financial coordinator if you are having trouble with insurance.

Remember that it is your right to have access to transplant physicians, nurses, and social workers (read the “Transplant Recipients Bill of Rights and Responsibilities” published by the National Kidney Foundation in 2001). Sometimes we find it easier to communicate with certain individuals over others. That's okay! Seek out those individuals as much as possible, and work with them to keep the lines of communication open. Remember—we as transplant recipients also have responsibilities! We must be active participants in our health care if there is going to be a comprehensive plan of care that is truly successful.

EMOTIONAL HEALTH

THE IMPORTANCE OF A POSITIVE ATTITUDE IN LIVING WITH OUR TRANSPLANTS

One person who experienced numerous years on dialysis and five renal transplants, as well as some cardiac issues (bypass and subsequent stents), expressed the following recommendations: “After a successful transplant, go out and live life—don't dwell in the past, when you felt bad, were sick or depressed. Also, if things don't work out as expected, don't live an angry life. This is not a guaranteed science and life does go on, yet it is too short to be angry and resentful.”

Don't let yourself become a “permanent patient,” whose whole life is defined by being on the “illness track.” You need not be defined solely by your transplant, but by many other things. Organ transplantation is a life-changing, transformative event that can, if you allow it, become a springboard into vibrant living.

Being realistic without false hopes, and yet not being weighed down with a fatalistic attitude, can be a difficult balance to achieve. We have come to see that a positive attitude is helpful to everyone, transplant recipient or not. Having a positive

attitude does not mean you will not encounter bad events, that you will not have bad days. Still, a positive attitude can help you get through those bad events and stressful days.

Life changes are normal for everyone. You encountered a special life change, but you cannot skip adolescence or menopause or other developmental and personal challenges just because of your transplant. These stages in our lives will impact us whether we have an acute or chronic illness or a transplant. They are unavoidable, even when we do not take the time to acknowledge them. As we age, women will still need to see a primary care physician to take appropriate steps for dealing with menopause, while men will need to be checked for prostate antigen readings. Wherever we find ourselves in life's journey, the basic advice for everyone—transplant recipient or not—is TAKE CARE OF YOURSELF.

We agree with the transplant recipient who wrote, “Find your limits—carefully, but find them—and then live close to them.” At the same time, we would add, “Find what you can do in your new circumstances and capitalize on that.” And we might even try

going one step further: “Find what you want to do and pursue that dream!”

One person who has devoted himself to learning how to live as well as possible with his transplant offered us the following advice: “Take the meds as prescribed. Listen to your body. Eat right. Exercise as much as you can. Work. Learn about everything to do with transplant. Get involved. Read books. Have fun. Travel. Be competitive at work and play. Don't let anyone push you around. Go back to school. Learn how to use the Internet.” This uncompromising, assertive attitude may be too demanding for some transplant recipients, but we can all learn from its underlying messages: take care of yourself. Make as much as you can out of the life you have and define for yourself your own quality of life.

QUALITY OF LIFE

Everyone is free to define his or her own quality of life. The principal challenge for most of us is to be realistic about the differences between our pre-transplant and post-transplant lives. A realistic assessment of what is involved in living with a transplant has served us well in showing us what we can change and what we

simply have to accept—for now and for the future.

The difficult part for us as individuals can be figuring out what “quality” is. This is unique to each of us. Some may see their quality of life as high if they are now free of nausea, others might only find quality in being able to perform physical feats (skiing, cycling, climbing mountains), while still others may be able to have the baby they had dreamed about. The definition of “quality” in living is different for each of us. The common goal, and what is most important for all of us, is to make that definition clear.

We do not believe that in all cases living with a transplant will be a huge burden. As one recipient observed, “I took more drugs prior to my transplant. I am no longer anemic. No exhaustion. No hypo- or hyperglycemic episodes. The transplant eliminated the greatest challenges in my life. Things are great now.”

STRESSFUL LIFE EVENTS

A transplant does not dissolve the other problems in life. Your children may have difficulties, your bills will still have to be paid, life will hopefully continue on after

the transplant. There is no shame in meeting with a mental health care professional if life events get you down, or if you feel sad. You can always ask your transplant health care provider for a referral.

Episodes of stress are inevitable in the lives of all human beings. For example, one transplant recipient reminded us that in the aftermath of her transplant, “the loss of my husband was the worst time of my life.” We learn from this that not all sources of stress in the lives of transplant recipients have to do with their transplants. In other words, recipients are not immune to the stressors that can come into anyone's life.

The important thing is to find constructive ways of dealing with stress. For most of us, it has been helpful to deal promptly with little worries or concerns so one's anxiety levels don't increase. Some have found stress reduction through music, art, drawing, poetry, gardening, meditation, biofeedback or even a good book. We have also found it helpful to seek out places of refuge and quiet or people who will really listen to us.

Coping with stress can take many forms. Sometimes you can be proactive and prevent conflicts from arising. Sometimes you can break down barriers if you are imaginative and persistent. Sometimes you just have to go around those barriers. And sometimes you have to come to terms with them as limitations while learning what is possible at the same time. “Learn to expect the unexpected,” one recipient wrote, “but remember the alternative and then deal with whatever comes up.”

Acknowledging that transplantation, illness and trying to find a path to wellness are stressful may actually reduce some of your stress. If we acknowledge that life is stressful and stop denying that inescapable fact, then we might find some helpful stress reducers and ways to avoid more stress in the future.

DREAMS AND SIGNS

It is natural for some of us to wonder about our donors and to dream about them. We may even imagine we receive signs from or about them. People wonder if the transplanted organ may contain imprinted memories passed to us in the organ's DNA that subtly or not so subtly influence us. There is no scientific

research supporting the theory of cellular memories, yet there is no doubt that this life-changing transplant event is full of powerful emotions and feelings. Know that this emotion and the wonder regarding your new organ is common. Some of us develop new likes or dislikes and we may then wonder if we are being influenced by our donors. Some of us name our donor organ. When asked how we feel to have someone else's organ in our body, one of us said, "It was a gift and I am grateful and thankful to consider it my organ now."

CULTURAL DIFFERENCES

Though we all share the magnificent journey of transplantation, we are influenced in overt and subtle ways by our unique family histories, experiences, belief systems, knowledge and backgrounds. Transplant programs also have a distinct culture of their own. The nature of transplant coincides with Western medicine—it's high powered, high tech, surgery oriented and aggressive in treatment—and it can also involve belief systems or activities that are unfamiliar to us. Hospitals are influenced by managed care, which adds to their fast pace. Our health care providers are learning about us as we

learn about them as individuals and about the culture of their work arena. Listen, take notes and ask questions. One kidney recipient did not want to talk to his social worker because he equated social workers with poverty cases only. Keep an open mind. There are many new things to learn. After a while, transplant centers will become familiar territory and you will learn to fit in with ease.

PHYSICAL HEALTH

REJECTION

Rejection is an immune response that our bodies use to "fight off" the transplanted organ. We take immunosuppressive medications or anti-rejection medications to avoid a rejection episode. It has been our experience that most rejection episodes occur during the first three to six months after transplantation. A rejection episode is much easier to treat and control if caught early, so it is particularly important that you report any signs and symptoms of rejection and to have labs drawn as directed. Although one may be very compliant with the medical regimens and taking medications as prescribed, a rejection episode can still happen. Even though rejection is a

scary thing, almost 50 percent of all transplant recipients will experience one. It may require a trip to the hospital, diagnostic studies and more medications to turn the rejection episode around. Transplantation is not 100 percent successful; therefore, some transplants will be lost to rejection even after appropriate treatment.

Sometimes the difficult part of the transplant process is the fear of the unknown and not knowing when and if a rejection will occur. It is extremely important to report the classic signs of rejection to your transplant team if you experience them, but it is equally important to figure out a way to not let the fear of the unknown overwhelm you.

LIVING WITH MEDICATIONS AND MINIMIZING RISKS

Medicines and their side effects are on the minds of all transplant recipients. As one recipient wrote, “It took a while to get used to drinking more fluids and sometimes the medication was difficult to take in the early days. So MANY pills!”

Another transplant recipient observed that she “had to stay focused on the fact that I still have to be very careful of what I do, especially with diet and taking my meds on

time.” We all recognize the wisdom in that comment, no matter how hard it is to maintain compliance with dietary and medication regimens. As this recipient noted, it is easy to be lured into omissions and inattention to these matters: “Sometimes you just feel so good you think that you are okay to do anything.” As one mother, whose young daughter is a transplant recipient, wrote, “Don't ever think you can't take your meds.” Talk with your physician if you feel like the medications are causing problems. Don't just stop taking your medications or make adjustments without consulting with your doctor.

In the first months after being transplanted you can expect to take many pills several times a day. If you do not have one, you might want to consider buying a daily medication planner. This is a large box with seven columns, one for each day of the week. For each day there are several compartments, usually marked “a.m.,” “midday” and “p.m.” Some recipients find it easier to sit down once a week with the planner and fill each container with all their necessary meds. There are many ways of organizing and remembering to take your medications. Be creative with whatever will work for you. Use a tackle

box, an empty egg crate or even sticky notes on a chart. There is no right or wrong way to get organized. Remember, this is your system! Make it work for you!

Taking medications may certainly be a hassle, but it will most likely be much less bothersome than the alternative of living with a failing organ.

Living with daily medications often means developing new habits so one can remember to take the medications but not allow them to overrun one's lifestyle. The goal for every transplant recipient is to take whatever medications are needed to minimize the risk of rejection while experiencing the least number and degree of side effects possible. This is a goal that you can share and work towards with your transplant physician and the staff at your transplant center, or wherever you receive care. We can only add that it may take some time to achieve this goal. From time to time, medications may need to be monitored and modified, and that will require good communication with your transplant team.

NUTRITION

After our transplants, some of us noticed we had quite an appetite. While waiting for

a kidney, heart, lung, liver or other organ, we may not have had the energy to eat well. Those of us previously on dialysis had a restricted diet and had to learn to eat foods again that we previously avoided under the threat of pain and death! Suddenly we can have oranges and tomatoes and can drink unlimited liquids! Most of us are on prednisone or some kind of steroid, which for a number of us gives a false sense of hunger and increases our appetites. We need to figure out how to distinguish between real hunger and prednisone cravings.

If we gain weight, we may need to lose it since the risks secondary to obesity (such as diabetes, cardiac disease and high cholesterol) are threats to our survival, much more so than for the general population. A healthy diet, along with regular exercise, is an important part of our long-term care along with the immunosuppressant medications. Remember, it is easier to keep the extra pounds off than it is to lose weight.

Diet recommendations are going to change from the first days post-transplant to many months later. We strongly recommend that you discuss these guidelines

and recommendations with a dietitian at your transplant center who can help you craft a healthy eating program. We have been pleased to discover that, in many instances, Medicare pays for a registered dietitian for diabetics and for those with chronic kidney disease. Commercial weight loss programs approved by physicians have also worked for many recipients. In particular, we need to watch our cholesterol, eat fiber, avoid sodium and be mindful of food-medication interactions. For example, grapefruit juice increases our levels of cyclosporine and tacrolimus, so we cannot drink it with our medications. Those of us who are used to taking vitamins and other supplements, or eating an unusual diet or drinking exotic teas, have learned to talk over these preferences with our health care providers. Whatever we ingest can potentially interact with our medications.

DIABETES, HEART DISEASE AND KIDNEY FAILURE

One of the side effects of immunosuppression is the risk it poses to the heart, the endocrine system and the kidneys. Today, high blood pressure, high cholesterol, diabetes, heart disease, malignancies and kidney failure are bigger risks than infection for many transplant recipients, even more than the risk of rejection, which was perhaps most prominent in the minds of recipients who were transplanted years ago. This is because immunosuppression is more specific and more effective than it used to be. This, however, can be a double-edged sword. It may seem ironic that the very drugs that keep our organs from rejecting will expose us to other serious risk factors. Throughout the life of your transplant, your immunosuppressants and other medications may need to be adjusted to minimize these risks.

Cardiac disease is the number one cause of death for transplant recipients after the first year post-transplant. Developing and maintaining good heart-healthy habits now (i.e., exercise, a low-fat diet) will help later.

You may be asked to routinely monitor your blood pressure and temperature at home, as well as complete regular blood tests as

ordered. This lab work will allow the early identification of potential problems.

HEALTH MAINTENANCE

After a transplant, health maintenance not specific to our transplant will still need to be addressed. For example, routine dental care is very important. Teeth harbor bacteria and must be cared for properly. Most likely, you will still be required to see your primary care physician for a routine medical follow-up, as well as gynecological exams for women, prostate checks for men and routine vaccinations and flu shots for everyone. Sometimes it is the simplest health precaution, such as refraining from cigarettes and alcohol, that can be lifesaving. It is important for us to stay educated about our health needs. We are all individuals and our treatment and protocols will be different.

EXERCISE

Your exercise program may start in the hospital with help from the physical therapy department. There will be some physical restrictions for the first few weeks post-transplant (mainly weight lifting limitations), but as soon as you can, you should start walking. For a recipient, proper exercise is extremely important.

Many post-transplant drugs can cause osteoporosis, or a weakening of the bones. Thus, weight-bearing exercise is vital, and this means walking, running, biking, swimming and using weights or other resistance to increase bone and muscle strength. Exercise also increases the efficiency of your major organs. When in a regular jogging program, for example, the heart has to work harder during exercise; as a result, the heart becomes stronger and does not have to work as hard during the rest of the day.

The best thing about exercising every day is that it makes you feel better, both physically and mentally.

Before you start any exercise program, check with your doctor and stay within the limits prescribed by him or her. Start your program as soon as you are comfortably able to do so. Try to implement exercise into your everyday routine, whether it's using the stairs instead of the elevator or walking to the store instead of driving. Choose a form of exercise that you enjoy—that way, you'll stick with it.

Once you have a regular exercise program in place, it's a good idea to challenge yourself. Some of us like to strive for the U.S. Transplant Games, a biennial, week-long event that is organized by the National Kidney Foundation (NKF). There, transplant recipients challenge themselves and others in Olympic-style events that range from bowling to basketball. The NKF also sponsors the biennial World Transplant Games, an event sanctioned by the International Olympic Committee.

These events and others can be used to set goals for all recipients of all athletic abilities. The Transplant Games also showcase the success of organ transplantation and donation. Each time the Games are held, there is a spike in donation. The public gets to see that not only can we function in society, but we can outperform too.

HABITS

Some of us may have struggled with an addiction to alcohol, tobacco or illicit drugs and simply became too ill to continue our habit. Once transplanted, that struggle will most likely continue. We cannot take our abstinence for granted and may even need to ask for help from professionals, our families or health care

providers if we feel we need more support and guidance to remain abstinent.

Talk with your transplant team about alcohol. Ask what amount is and is not safe for you. Avoid drinking alcohol unless your doctors give you permission. Cigarette smoking is dangerous for everyone. There are many tools available to help a smoker quit this difficult habit. Once again, consult with your transplant team about the appropriate form of help for you.

Marijuana and other illicit drugs hold many risks for us, and that's in addition to the usual risks for everyone. Because we never know exactly what we are smoking or ingesting, their use could lead to infection or an illness that our bodies cannot fight off due to our immunosuppressed state.

Before taking any over-the-counter medications, vitamins or herbal supplements, check with your transplant team to make sure there are no harmful interactions.

SEXUAL HEALTH

Before transplantation, many recipients had a poor sex life. After transplantation, however, most recipients can return to normal sexual activity as soon as they feel well enough. Keep in mind that sexual function can be affected by transplantation, and some medications can also affect you. Talk to your transplant team. They have information about when it is safe to return to sexual activity and what precautions to take. They can also refer you to trained professionals who can counsel and advise recipients who encounter sexual problems.

During your first year after transplant, you are under heavy immunosuppression, you still may undergo treatment for opportunistic infection and it is generally not recommended to get pregnant. Talk to your doctor about which is the best method of contraception for you.

TRANSPLANT AND PREGNANCY

After a successful organ transplant, your body's normal functions return, including those of the reproductive system. It is a great triumph for transplant recipients to have children. To father a pregnancy usu-

ally does not affect the transplanted organ. If, however, you are a female recipient in the childbearing age and wish to become pregnant, you will have many concerns that need to be addressed.

It is important to talk with your transplant team when even considering pregnancy. There are risks that you should know about as a transplant recipient—risks for both the unborn baby and the transplanted organ. Changes may be required in some of your medications to prepare for a pregnancy.

All pregnancies carry certain risks, but there will be additional risks as a transplant recipient that you will want to take into consideration. Physiological changes from pregnancy can cause stress to transplanted organs and affect how your immunosuppressive medications are absorbed in your body. It is vital that you talk with your physician, discuss potential complications and together develop a safe plan to proceed.

It is not uncommon for babies to be born premature and have a low birthweight or other complications when the mother is a transplant recipient. Normal vaginal deliv-

ery is still possible, even with the presence of a transplanted organ in the pelvis. Often a Caesarian section is necessary. Your obstetrician should be aware of any change in pelvic structure from previous transplant surgery and may even have a transplant surgeon present for the delivery.

The ultimate risk of getting pregnant is the possible loss of the transplanted organ after delivery. It is important to plan well for a pregnancy. A general guideline for most transplant recipients is:

- Try to wait two years post-transplant prior to planning a pregnancy
- Maintain stable organ function
- Stay on maintenance levels of immunosuppressive medications
- Have well controlled blood pressure
- Be followed by an OB-GYN who specializes in high-risk pregnancies
- Talk with your transplant team when considering pregnancy

- Be aware that some medications are found in high concentrations in mother's milk. Therefore, breast-feeding may affect the growth of the baby and should be discussed with your doctor.

A growing number of transplant recipients are women of reproductive age and are successfully giving birth. Through careful selection and management, pregnancy can be safe and successful in women with transplants. Thousands of pregnancies have been reported in the National Transplant Database; the Pregnancy Register in United Kingdom and the National Transplantation Pregnancy Registry.

CHILDREN WHO ARE TRANSPLANT RECIPIENTS

A number of concerns are especially prominent for children and for the parents of children who are transplant recipients. For example, one parent noted that “most of the barriers we faced have been with others' illnesses and their lack of understanding what that means to our daughter.”

Most children who are transplant recipients just want to be treated like everyone else. They would like to fit in again at school and at home. And they would like to get beyond “people not wanting me to do things because they were afraid I would get hurt,” as one young transplant recipient aptly put it. Many children who had received a transplant told us that it helped to talk with others, especially those who were their own age.

One older child declared that “while the pediatric doctors always made me a part of the medical team, the adult doctors insulted me or acted as if I wasn't even there.” Clearly, we need to be sensitive to the appropriate role for a child or adolescent in making decisions about transplantation. Sometimes a child or any other transplant candidate/recipient may need an inde-

pendent advocate to defend that individual's interests. And perhaps physicians and other members of the health care team need to learn how their behaviors can have harmful consequences.

Nearly every parent who commented on their children's transplants wanted to remind us that, compared to the possibility of losing their child, the challenges they faced and the losses they experienced along the way were minor.

EMPLOYMENT

Our experiences with the working world are varied. The first year after transplant, we still test our strengths and limitations, and though some of us return to jobs right away, many of us need a little time off to settle into our routine of being well and figuring out what we are capable of doing in terms of work. For those of us who need to find new careers because our old ones are neither available nor appropriate (for example, plumbing or heavy equipment operation), we have found that state vocational programs and the Social Security Administration work incentives programs are available to retrain and reeducate us. Our social workers have pointed us in the right direction. How much we disclose to employers and colleagues at work is an

individual matter. Some of us share, and others don't. We have found that the best insurance available comes through employment, and sometimes that is the main reason that a job is attractive to us. For those of us who are unable to work, our social workers have directed us toward government and charitable programs that can help with some of the ongoing costs of our outpatient medical care and medications.

TRAVELING

All of us travel. Some do not go very far, perhaps only to and from work. Others go across the country or overseas. We have a few suggestions concerning long distance travel.

- If traveling internationally, always check with your physician to see if there are any vaccination recommendations prior to travel.
- Always pack your medications and take a supply to tide you over at least one week longer than scheduled. If traveling by air, pack your medicines in your carry-on bag—NOT in checked luggage!
- Make sure your insurance protects you wherever you travel. Indemnity plans usually cover you anywhere in the United States and Canada, but check

before you go. HMOs provide limited coverage, usually emergency coverage only, outside their service area.

Overseas, many insurance plans provide minimal (emergency) or even no care, and if there is coverage it is indemnity, meaning you may have to pay the bill before leaving, which can be very expensive in many parts of the world. You could be held against your will until you pay, which is not uncommon in Eastern Europe and Africa.

We suggest that for any overseas travel, even to Canada, you purchase trip insurance when you book and pay for the trip. The insurance usually has pre-existing condition limitations, which may be waived if you buy it when you pay for the trip.

In addition to health insurance, you might consider evacuation insurance that will pay a certain sum to medivac you to the United States. Unless you are in a country with exceptionally good health care, we strongly suggest that you purchase this protection.

- Know the location of local hospitals and the nearest transplant centers at your destination. This is common sense, but

most people never think they will get sick. Remember, you can get sick just as easily when traveling.

- Avoid drinking any water that is not from a known source. It does not matter if the water is fresh, purified or chlorinated. Your body is used to the water where you live. Buy bottled water for drinking.
- Talk with your physician before you travel. Because of your own special circumstances, your physician may have some special precautions for you, such as wearing face masks on airplanes.

Finally, whether you travel for work or pleasure, enjoy your trip! Even on a business trip, try to find an hour or two to see your surroundings. Always take in the sites and enjoy a new place, even if only for a few moments.

SUMMARY

When we asked a number of transplant recipients to tell us what it was like to live with a transplant, we received many different responses. A few people said they weren't sure if they would want to be transplanted again. One transplant recipient commented, "If I needed a second transplant, I'm not sure what my decision would be." One or two recipients told us they would never want to be transplanted again and might have preferred to go back to dialysis or some other pre-transplant situation. Of course, a return to dialysis is only an option for some (not all) renal transplant patients and the idea of returning to any earlier life condition may be an elusive ideal that is not very realistic for any of us.

For us, however, and for the vast majority of transplant recipients with whom we have had contact, organ transplantation was a positive experience. One person said, "I enjoy living with my transplant." Another remarked, "It has been a blessing. I have attended three Transplant Games, walk five to ten miles a day and volunteer for all organ donation and transplant events so I can help others as I continue to

learn.” Still another individual was even more positive about transplantation: “This was such an incredible journey, I would do it again and recommend anyone that needs to have it done to go for it! I would not wish this on anyone, but it's too bad we all can't experience it because it is the most incredible life experience anyone can go through.”

No one wants to be a transplant recipient unless they need a transplanted organ. Positive experience or not, everyone would like to avoid it. But now that you find yourself in the position where you have needed a transplant and have been transplanted, we wish you all the best in living with your transplant!

ABOUT THE TRANSACTION COUNCIL

The transAction Council was established by the National Kidney Foundation 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, our earlier book, *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), as we strive 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. You can also visit us online at **www.transplantrecipients.org**

RESOURCES

GENERAL READINGS OF ENCOURAGEMENT

Viorst, Judith. *Necessary Losses*. Fireside Edition (Simon & Schuster), NY, 1986, 1998. A sensitive book about coping with all types of losses that occur over a lifetime.

Carnegie, Dale. *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.

Corr, Charles, Corr, Donna and Nabe, Clyde, M. *Death and Dying, Life and Living*. Brooks Cole Publishing, Monterey, CA, 2002. Written as a college textbook, this book can be read as a "life textbook." Includes a special section on organ and tissue donation, and a sensitive look at life for people with chronic illnesses.

Hazeldine Meditation Series

Hazeldine Foundation, Harper & Row Publishing, NY. Daily meditation books to help readers welcome the new day with hope, strength and courage.

Bartlow, Bruce, G. *Medical Care of the Soul*. Johnson Books, Boulder, CO, 2000. A physician writes a practical and healing guide to end of life issues for families, patients and health care providers.

FOR CHILDREN (AND ADULTS)

Bluebond-Langner, Nyra. *In the Shadows of Illness: Parents and Siblings of the Chronically Ill Child*. Princeton University Press, NJ, 1996. A beautifully written book focusing on children who have cystic fibrosis and their families.

Carney, Karen. *Katie Coolican's Story: Barklay and Eve Explain Organ and Tissue Donation*. Dragonfly Publishing, CT, 1999.

McAdams & McCaleb. *Our Hero, Freebird: An Organ Donor's Story*. As told by 8th grade students in Joy McCaleb's reading class. DCI Donor Services and Putnam County Board of Education, Tennessee, 1999.

Flynn, Jessie. *A New Heart for Hannah*. Kids Cope with Grief series, 1996. A coloring book for children ages 4-6 whose parent, sibling or friend received an organ. Order from Accord Aftercare Services: 800-346-3087

O'Donnell, James. *Letters for Lizzie*. O'Northfield Publishing, Chicago, 2004. A true story of love and friendship as a woman tries to obtain a heart transplant.

"Organ Transplants: What Every Kid Needs to Know." United Network for Organ Sharing, Richmond, VA, 2004. www.unos.org

BOOKS WRITTEN BY AND ABOUT RECIPIENTS

Hartwell, Lori. *Chronically Happy.* Poetic Media Press, San Francisco, CA, 2002. A three-time transplant recipient talks about transitioning to wellness and gives emotional and practical advice for those struggling with chronic illness.

Brown, Warren and Hamilton, Martha McNeil. *Black & White & Red All Over.* Public Affairs, a member of the Perseus Books Group, New York, NY, 2002. A thoughtful discussion of race in America and insights into transplantation from a cultural perspective, with insights into how one African American man's cultural background impacted his experience.

Genovese, Kate. *Loving Joe Gallucci: Love and Life with Hepatitis C.* Four Seasons Publishers, FL, 2003. Based on a real-life story, this book details how a family struggled and achieved abstinence from alcoholism and how a liver transplant allowed them a second chance. Order from fseasons@bellsouth.net

Covington McCarty, Barbra. *Time Shared: The Miracle of Transplant.* A woman with a liver transplant shares her thoughts and story.

Weston-Pinzone, Julie Ann. *Four Angels for Julie.* JulMar Publishing, Inc. A story of faith about a woman who overcame the odds and survived four kidney transplants, graduated from college and taught kindergarten for ten years to encourage others to never give up. Order this book at www.fourangels.org

Baines, Lyndsay, Ph.D, and Jindal, Rahil, M. *The Struggle for Life: A Psychological Perspective of Kidney Disease and Transplantation.* Greenwood Publishing Group. A detailed illustration of the challenges and solutions in psychotherapy services for renal dialysis and transplant recipients.

Violino, Bob. *New Life: Lessons in Faith and Courage from Transplant Recipients.* Writers Club Press, an imprint of iUniverse, Lincoln NE, 2003. Short stories about real recipients from around the country provide hope and encouragement to others. www.iuniverse.com

Darling, Richard, S. *ComaLife: What the Hell is Going on Here?* Xlibris Corporation, 2002. A dentist writes about his experience with hepatitis C, cirrhosis and three liver transplants. orders@slibiris.com

Ingelfinger, J., MD, and Zukerman, E. *Coping with Prednisone: It May Work Miracles But How Do You Handle the Side Effects?* St. Martin's Griffin, NY, 1998. Written by a physician and patient for patients and health care professionals.

Schum, Joann (editor) *Taking Flight: Inspirational Stories of Lung Transplantation: Authored by Lung Recipients around the World.* Trafford Publishing, Victoria, BC Canada. Order at www.trafford.com

Chabot-Long, Lynn. *A Gift of Life: A Page from the Life of a Living Organ Donor.* Je-Lynn Publications, Milwaukee, WI, 1996. A living donor chronicles her journey as a living donor.

Green, Reg, and The Nicholas Effect: A Boy's Gift to the World. O'Reilly Publishing, Sebastopol, CA. 1999. A young boy from California was killed by highway robbers while vacationing in Italy with his family. His parents donated his organs and lives were changed around the world.

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 with outpatient medications to persons with disabilities or senior citizens. 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 does and does not pay, 10 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), formerly the Health Care Financing Administration of the U.S. Department of Health and Human Services. Call MEDICARE (800-633-4227) for a free copy.

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 at 800-733-7345.

Medicaid (MediCal, Access) and other state financial programs

Depending on your income and assets, you may be eligible for medical care and insurance through your state or county department of social service office. Benefits and eligibility criteria vary from state to state. State Social Service Departments can review your eligibility to receive help from programs (QMB and SLMB) to help you afford Medicare premiums and co-payments.

Veterans Administration

If you are a veteran, are 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.

Pharmaceutical Assistance Programs

The pharmaceutical companies that manufacture the 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. Two Web sites are available to help you determine if an assistance program is available for your medication—www.phrma.org and www.needymeds.com

Your health care professional (nurse, social worker or physician) is required to submit an application on your behalf.

American Kidney Fund (AKF)

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

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

If you believe your illness will prevent you from working for a year or longer, 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 collecting Medicare already due to your age or diagnosis of end stage renal disease, you will be eligible for Medicare after collecting 24 social security disability (SSDI) checks. If eligible for SSI, many states include the Medicaid benefit.

www.cms.gov—Government site for the Center for Medicare and Medical Services.

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 were disabled while still working. You will be responsible for the full premium cost. If your employer has fewer than 20 employees or you are not eligible for other reasons, you may be eligible for your state's program of benefit continuation. If you become divorced or widowed and your coverage was through your for-

mer spouse, your benefits can continue for 36 months. Visit www.cobrainsurance.net or call 877-279-7959, ext. 214 for an instant quote.

Comprehensive Health Insurance Programs (CHIPS)

Some states have an insurance program for persons with catastrophic illnesses. Premiums may be high and there may be a waiting list. To find out what is available in your state, meet with an independent insurance broker. In some areas, the insurance commissioner in your state's capitol can be helpful.

Health Insurance Portability and Accountability Act of 1996 (HIPAA)

This legislation includes protections for working Americans and their families who have pre-existing medical conditions and are covered under a group plan. Contact the Equal Employment Opportunities Commission at 800-669-3362.

Financing Transplantation: *What Every Patient Needs to Know* is a comprehensive guide to assistance programs, insurance and financing issues. Call 804-330-8500 or write UNOS, 1100 Boulder Parkway, Suite 500, PO Box 13770, Richmond, Virginia 23225-8770. www.patients.unos.org

WEB SITES

www.transplantrecipients.org

The National Kidney Foundation's transAction Council site features facts about transplantation, a message board for recipients and candidates, the ability to post a question privately, frequently asked questions and answers and the *Transplant Chronicles* newsletter.

www.kidney.org

The National Kidney Foundation site features an A-Z guide about kidney disease, news about transplantation and kidney disease and programs to assist patients, families and professionals. It also provides transplant athletic news, including the U.S. Transplant Games, message boards, public policy announcements and information about organ donation.

www.donorfamilies.org

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

www.livingdonors.org

This NKF site features weekly living donor chats, tributes for living donors, a pen pal program and an online discussion group for living donors.

www.ast.org

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

www.organdonor.gov

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

www.kidskare.org

Web site made by kids for kids to teach them about sharing organs and receiving transplants.

www.unos.org

The United Network for Organ Sharing site gives the latest transplant, donation and transplant center statistics, information about transplant centers and educational resources and information about donation and transplant in the United States.

www.shareyourlife.org

The Coalition on Donation is an organization consisting of many national organizations who have banded together to collectively promote organ and tissue donation.

www.transweb.org

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

www.ustransplant.org

Scientific Registry of Transplant Recipients supports the ongoing evaluation of the scientific and clinical status of solid organ transplantation in the United States. It is administered by the University Renal Research and Education Association (URREA) with the University of Michigan.

www.nationalmottep.org

The Minority Organ Tissue Transplant Education Program has publications, things to know, links and resources.

www.usrds.org

The United States Renal Data System (USRDS) is a national data system that collects, analyzes and distributes information about end stage renal disease (ESRD) in the United States. The USRDS is funded directly by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).

www.lola-national.org Information about liver disease and transplantation, in Spanish and English.

www.medscape.com

This site allows you to search for professionally written, published articles on transplantation and news on medical and psychosocial subjects.

www.transplantliving.org

Recipient information available through the United Network for Organ Sharing.

www.lifeoptions.org

Free resources to help kidney patients and recipients get back to work, understand insurance and maximize their quality of life.

www.transweb.org/people/recips/experiences

Read the experiences and life stories of recipients and post your own story.

www.organtransplants.org

Co-sponsored by several organizations, including the Coalition on Donation, this site includes a photo documentary about patients and information about transplantation.

NATIONAL KIDNEY FOUNDATION
RESOURCES

How to Be An Ambassador for Organ and Tissue Donation

An instructional guide to prepare recipients, candidates and family members to speak publicly about donation and transplantation.

Writing to Your Donor Family

A simple brochure to give you ideas and encouragement for sending a letter of thanks to the family of your donor.

Take Time to Talk (Spanish)

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

transAction Council

A group representing transplant recipients, families, professionals and friends whose goal is to ensure that transplant recipients receive the finest possible care and to provide programs and information designed to improve their quality of life. Membership is free and includes a subscription to *Transplant Chronicles*.

Legislative Volunteer Network

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

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.

NKF Organ Transplant Series

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

Patient and Family Council

A council representing dialysis patients, their families and persons with kidney disease, whose goal is to educate and empower patients and families to make informed decisions about the quality of care they or their loved ones receive.

Membership is free and includes a subscription to *Family Focus* newsletter.

The NKF Information Center and Health Information Manager

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

NKF on the Web

www.kidney.org

www.transplantrecipients.org

www.livingdonors.org

www.donorfamilies.org

NKF Web sites for persons with kidney disease, transplant recipients of all organs (lung, heart, pancreas, liver and all others in addition to kidney), living donors and donor families.

Waiting for a Transplant, 2003

Written by recipients who have survived the wait for a donor organ, a compact booklet for those who are still waiting. With input from health care professionals. Includes a comprehensive section on living donation and a discussion about "What if the organ never comes?"

Transplant Recipients' Bill of Rights and Responsibilities

This booklet was the result of an interdisciplinary representation of professionals and recipients from 13 transplant organizations. Recommends and outlines procedures that will help recipients and professionals work together to deliver and receive the best possible post-transplant care. A poster is also available for transplant clinics and offices.

Issues for Today's Transplant Recipients: Understanding the New Extended Medicare Coverage for Immunosuppressive Medications: The Benefits Improvement and Protection Act (BIPA Public Law 106-554) (booklet)

Nutrition and Transplantation

This brochure can help patients prepare for transplantation and help recipients maintain a healthy diet.

Optimal Drug Use: Be a Team Player

A fact sheet with tips about taking medications.

Keeping Your Heart Healthy When You Have a Kidney Transplant: What You Should Know About Lipids

Written for adult kidney transplant recipients, this booklet explains the importance of keeping track of lipid levels after transplant.

Uniform Donor Cards

Individuals may indicate their decision to be a donor by signing these cards and may use them to introduce discussion among families about their wishes.

Organ Donor Brochures

In English and Spanish, these brochures provide basic facts about organ and tissue donation.

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, No. 22, this article recommends practice guidelines for all persons concerned about the well-being of the live organ donor, 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.

Local National Kidney Foundation offices (affiliates) Education, support, volunteer opportunities and information about kidney disease and transplant. Small one-time grants may be available for needy patients. Fifty-one affiliate offices cover the country. Call 800-622-9010 or e-mail transplant@kidney.org to request NKF resources or information.

www.kidney.org/general/affiliates

REGISTRIES AND CLEARINGHOUSES

NDDIC

National Digestive Diseases Information Clearinghouse
National Institutes of Health
2 Information Way
Bethesda, MD 20892-3570
www.niddk.nih.gov

NKUDIC

National Kidney and Urologic Diseases Information Clearinghouse
National Institutes of Health
3 Information Way
Bethesda, MD 20892-3580
www.niddk.nih.gov

NDIC

National Diabetes Information Clearinghouse
National Institutes of Health
1 Information Way
Bethesda, MD 20892-3560
www.niddk.nih.gov

ITSCC

The International Transplant-Skin Cancer Collaboration (ITSCC) was developed to integrate and support basic scientific and clinical research to address the special needs of transplant recipients with skin cancer and to educate health care professionals on these unique issues.
www.itscc.org

NTPR

The purpose of the National Transplantation Pregnancy Registry (NTPR) is to study the outcomes of pregnancies in female transplant recipi-

ents and those fathered by male transplant recipients. Information on NTPR can be found at www.tju.edu/ntpr/index.cfm

MISCELLANEOUS

Greeting cards for recipients to send to donor families (and/or living donors) to acknowledge or thank them for the gift of life are available for the cost of shipping and handling. A written request should be sent to:

Organ Buddies
111 Blue Ribbon Drive
North Wales, PA 19454

Blessing of the Boats

A poet-musician-performance artist performs a one-man show about his journey with kidney disease and transplantation on tour around the United States.

www.multiartsprojects.com/artists/sekousundiata/sekousundiata.php

Sandrine's Gift of Life

An innovative online education program on organ and tissue donation and transplantation delivered into schools worldwide through www.epals.com the world's largest online classroom community. www.sandrinesgift.com

Take a Piece of Me

An on-tour comedic performance by professional actor and comedian Richard Ramirez about his experience as a liver transplant patient. www.richramirez.com

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*From Illness to Wellness:
Life After Transplantation*



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www.kidney.org
www.transplantrecipients.org