

Surviving Transplantation

- - A Personal Guide for Organ Transplant Patients - -
Their Families, Friends and Caregivers



By [John Craven](#) MD and Susan Farrow OT

freely access the current, full text edition from this site

Welcome to the Home Page of Surviving Transplantation

If you have previously read the following [introduction](#) and agree to our [disclaimer](#), you may proceed directly to read the book. Otherwise, you are expected to read the next few paragraphs before continuing.

It is now three years since the first edition of Surviving Transplantation was published. Several very positive [reviews and comments](#) helped to convince us to publish this Web edition as copyrighted freeware. As with the text edition, our primary goal has been to make this material available to as many transplant candidates and recipients as is possible. By publishing the book digitally, we plan to continuously revise its contents as technological developments occur in the rapidly advancing field of organ transplantation. Many thanks to our supporters at [LARG*net](#) and [St. Joseph's Health Care London, Canada](#).

We will also be able to include additional information on coping as we hear your further comments and questions. These can be sent to jcraven@julian.uwo.ca.

Surviving Transplantation is intended as a guide to coping for persons undertaking major organ

transplant. Any ideas contained within this book should be considered in the context of your personal health circumstances. As you will read in several places in *Surviving Transplantation*, we recommend that you consult a physician or another health professional before undertaking to make any changes in your personal health care.

The contents of *Surviving Transplantation* may be read, downloaded, printed and/or copied for personal use only. Specific sections may be printed and distributed in response to specific questions posed by transplant candidates, recipients or their family members. No changes and/or alterations of any kind may be made to the text. Otherwise, none of the contents of *Surviving Transplantation* may be copied, duplicated or distributed by any means without the previous permission of the authors.

Finally, the reader should keep in mind that none of the comments, personal vignettes or clinical examples refer to any individual person. Any quotation and or reference that is attributed to a fictitious name in *Surviving Transplantation* has been composed by the authors as representative of the many persons who have told us of their experiences. If you have read and agree to the comments in this disclaimer, you may now proceed to read *Surviving Transplantation*.

Copyright © 1996-1997 SupportNET Publications

Best Viewed with:



Reviews and Comments

As well as those organizations who have formally reviewed the first edition of **Surviving Transplantation**, many persons have sent us comments. These are included in this section of our publication. The name and affiliation of each reviewer is listed as at the time of our receipt of the review or comment.

Comments

Linda Burnett, Clinic Nurse, Victoria Regional Transplant Clinic, British Columbia, Canada: Surviving Transplantation has been enjoyed and well used by our transplant patients, families and staff. I am enclosing payment for two further copies to be added to our library.

Jane Harrison ACSW, Heart/Lung/Liver Transplant Programs, Fairfax Hospital, Virginia, USA: I have just finished reading Surviving Transplantation. I hope to convince the hospital gift shop to stock the book. I think it is an excellent resource for candidates, recipients and families of organ transplantation. I have not found another resource that provides factual information with interesting anecdotes about all types of transplants, in one book. The additional readings and relaxation techniques are particularly helpful. I will be recommending it to our patient population.

Monique Pender, Northern Outreach Coordinator, The Kidney Foundation of Canada, Northeastern Ontario Chapter: After reading Surviving Transplantation, I realize that it is the best resource available to our clients here in Northeastern Ontario. It will be added to our patient education series in each dialysis unit throughout our territory. Thank You!

Ms. Cricket Fox, Regional Coordinator, The Canadian Transplant Games Association: Thank you so much for making my life easier! Many pre and post transplantees direct questions my way. The copy I have is busy informing those waiting and those newly transplanted at one of Vancouver's transplant hospitals . . . My brother's kidney has been happily filtering away for over 9 years now - the best 9 years of my life. I know that your book will enable me to more thoroughly help others to enjoy life with their second chance.

Ellen Gordon Woodall, Executive Director, American Organ Transplant Association: Frankly, I found your book to be the best I have read regarding information about how to deal with the stress and emotional upheavals that are an enormous part of the transplant process. The book is in easy to understand layman's language and many of the examples given were all too familiar to me personally.

I hope people are made aware of this book at the beginning of their journey through the transplant maze. I believe it would be a great resource for patients and their families. Thank you for giving me the opportunity to read it.

Leanne McDougall, President, Heart Transplant Association, Quebec, Canada: I personally enjoyed your book and found it very informative even though I am now more than four years post transplant. I have recommended your publication most highly to the members of our Association and have included a copy of the order form with our next newsletter.

Helena Cassidy, Transplant Coordinator, Saskatchewan Transplant Program, Saskatchewan, Canada: I think your book *Surviving Transplantation* is wonderful and I have frequently recommended it to our patients awaiting organ transplant.

Kathleen Dawson, Editor, Primary Biliary Cirrhosis Newsletter: *Surviving Transplantation* is two books in one. It covers transplantation and living with any serious illness. Easy to read.



Linda Rowe, Regional Coordinator, Canadian Transplant Games Association, Northern Ontario: Thank you for signing and sending me the two books on *Surviving Transplantation*. One copy is for myself. The other I will donate to our local library. As we live in a rural community, there are very few resources available.

I sure wish that *Surviving Transplantation* had been around when I first went on dialysis and then got my name on the transplant list. My younger sister and I both have Alport's Syndrome. I have had three kidney transplants by the time I was 30 years old. My sister has had one transplant and has had a beautiful baby boy since then. Your book certainly could have provided us with some answers to your questions during those times. Oh well...let's hope it helps others.

Reviews

New Start News (Newsletter of the National Heart Assist and Transplant Fund): Surviving Transplantation is a clearly written, very understandable account of the transplantation process which includes first hand patient reports. Each chapter discusses a component of the transplant process: the onset of illness, the application process to a transplant center, the emotions involved with waiting for a lifesaving organ, the post-transplant rehabilitation and the stress which may arise during these phases.

The authors also address working with support services and recognizing when a patient and/or his support person should ask for outside help.

Although the causes of stress are discussed, financial stress is not. At NHATF, we hear about the financial burdens placed on patients and their families regularly. It would be interesting to know more about the effects of financial stress on the healing process.

Transplant Recipient International (Reviewer: Mr. Bob Riback): As a heart transplant candidate, waiting now almost one year, I found that much of this material confirmed my own experiences. Had Surviving Transplantation been available to me at the time of my evaluation and initial placement on the waiting list, I would indeed have found it to be a *Personal Guide*. I found it to be a different approach to dealing with the problems of transplant candidates and recipients . . . addressing and respecting the patient/family member as a person and distinct individual. Surviving Transplantation is a valuable and much needed addition to the resources available for people impacted by transplantation.

American Nephrology Nurses' Association Journal (Reviewer: Ms. Angelica Wahrenberger, Transplant Clinical Nurse Specialist, Hermann Hospital, Houston Texas, USA): Surviving Transplantation concerns all types of transplant and is written *for people who are awaiting or recovering from organ transplant surgery*. It addresses questions and concerns frequently voiced by recipients and their families. Rather than explaining technical aspects of transplantation, the authors focus on *adaptive ways of dealing with the challenges that may occur with an organ transplant*. Emphasis is on the personal experience of transplantation.

Chapter 1 is called *Getting Started*. It briefly reviews the history of transplantation and then provides an overview of the rest of the book. Subsequent chapter titles indicate the personal, individualized focus of this book: Living with Illness, Waiting for Transplantation, Understanding Stress, Dealing with Stress, Working with Others, When to Ask for Help, and Transplantation and Personal Growth. The strength of Surviving Transplantation is its focus on the very personal responses to events surrounding a transplant. Numerous personal vignettes help the reader understand the content being presented. Question-and-answer sections at the end of each chapter effectively address frequently asked questions.

Additional resources can be found in the two appendices. The first is a nicely annotated bibliography of selected readings. The second appendix provides simple instructions for three common relaxation techniques.

This resource presents two problems. First, there are several instances of typographical errors. Second, the style of writing and vocabulary make the reading level fairly high, and some people might have difficulty with certain chapters. *Surviving Transplantation* can, however, be very helpful to transplant recipients as well to their families and friends, and is a solid companion to more traditional patient education materials.

Margo L. Akerman, Kidney Transplant Recipient and Member, United Network of Organ Sharing (UNOS) Board of Directors, Patient Affairs Committee, Knoxville, Tennessee, USA: The audience for *Surviving Transplantation* is the underinformed patient and his/her support system. It is a book of simple concepts delivered in simple language and abundantly laced with anecdotes. Intended for the lay reader, the book is attractively packaged in paperback and printed in a large type face with vast amounts of white space, including more than 30 blank pages.

The authors, physician and occupational therapist are Canadian. Occasionally the vocabulary and allusions have a Canadian ring: absence of the definite article before "hospital"; "bellboy" instead of "beeper" or "pager." However, the description of the transplant experience seems no less authentic in a country-to-country comparison than in a center-to-center comparison.

In the preface the authors disclaim any effort to repeat technical information about organ transplantation. The assumption is that sources of this information abound. In nine chapters they discuss coping with the details of serious illness and subsequent organ transplant. They do not discuss the details. "Challenge" and "challenging" appear often.

The first chapter outlines the remainder of the book chapter by chapter. Chapters 2, 3 and 4 broadly describe the stages of a serious illness followed by the wait for a transplant and then the recovery from the transplant. Chapters 5 through 8 focus on stress and how to deal with it. Chapter 9 discusses in a poignant way the personal and spiritual growth many transplant recipients experience after facing major changes in life style and after confronting their own mortality.

Each chapter begins with a short quote relevant to the topic. Some of these are trite or a stretch for the connection. However, two quotes from transplant recipients are very good. Mark Twain's definition of courage and Susan Sontag's description of dual citizenship in the kingdom of the well and the kingdom of the sick are right on.

Chapters conclude with question and answer sections two to six pages long. It is never suggested that these questions have come unsolicited from patients or care-givers. It is clear that they have not. The question/answer is an alternative format and allows the authors to shift style and provide more information in an informal voice.

There are about a dozen tables scattered through Chapters 2-9. These are not graphics but words and phrases grouped and spaced to summarize points made in the text. In some cases the table and text are separated from one another by a flip page or two and it is difficult to join the concepts. Some charts are

so elementary and repeat the text so exactly that a reader may ponder them in search of depth or breadth that isn't there.

Two appendices wrap up the survival text. Appendix A, "Additional Reading," is an excellent resource, much more than a simple book list. It provides paragraph synopses of 35 books and is grouped in categories: "Personal Accounts," "Dealing with Doctors and the Health Care System," "Living with Illness," "Healing, Relieving Tension and Stress," and "Death and Dying, Grief and Near Death Experiences." It is a current list with most books' copyrights in the late '80s and the '90s.

Appendix B is a four-page manual on "Relaxation Techniques." The three methods of relaxing are described in the chapter "Dealing with Stress," but the appendix instructs the reader on how to achieve "The Calming Breath," "Progressive Muscular Relaxation" and "Guided Imagery."

The weakness of the book is that information dealing exclusively with transplantation challenges and the means of meeting them is a very small distillate of the whole. The greatest portion of the book applies to general circumstances of any grave illness or serious injury. In selecting the book based on its title one would expect to read of survival issues such as: How are family dynamics affected by transplantation, especially if donation involves a living relative? What will day-to-day living be like in respect to diet, body functions, personal hygiene? What is involved in my return to work? What are the costs of medications and transplant-related medical treatment and how can these costs be met? What can a recipient do to help the tens of thousands of patients awaiting transplantation? These transplant-specific topics are not discussed.

The strength of the book is that it is conversational and lacks technical jargon that might be threatening or confusing. When it does discuss transplant-exclusive issues, they are well chosen. Early in the book a section called "Thinking About the Donor" addresses recipient guilt. Toward the end, "Mental Effects of Anti-Rejection Drugs" discusses survival with cyclosporine and prednisone. These are approached in a positive and understandable manner.

Surviving Transplantation is not required reading for all organ transplant patients. It would be especially helpful to the patient having trouble adjusting to or understanding his/her illness or the recipient having trouble coping with life after transplantation. The book would be a fine reference for a patient support group. Such a group might also use it as an outline of topics to discuss.

Return to the [Table of Contents](#)

Getting Started

Courage is resistance to fear, mastery of fear. Not absence of fear. (Mark Twain)

At the age of twenty-four, kidney disease had forced Richard Herrick from his work with the U.S. Coast Guard and threatened to take his life. The year was 1954. A treatment for his condition did not exist. Nobody could have predicted that for the first time in medical history, Dr. Joseph Murray would successfully transplant a healthy kidney into Mr. Herrick. This surgery provided the patient with eight additional and healthy years of life.

Ancient myths have held the notion that it was possible to replace a diseased organ with a healthy one. In legend, physicians with the ability to transplant organs could satisfy our desires for renewed health, longer life, or even immortality. The first recorded reference to heart transplantation occurs in a story about Pien Ch'iao, a Chinese physician from the second century BC. As a show of his medical prowess, he allegedly exchanged the hearts of two of his patients. Seven hundred years later, a patient complained about his amputated leg to two physicians named Cosmos and Damian. In this account, they successfully transplanted the leg from a dead soldier to their patient. Because of this and other miraculous feats, Cosmos and Damian were declared Christian Saints. In myth as in reality, a new body part is the ideal treatment for a patient and the highest possible achievement of a medical practitioner.

The scientific advances of later centuries have transformed myth into medical reality. Technical developments in surgery and critical care medicine made transplant surgery possible by the mid twentieth century. However, other obstacles had to be overcome for transplantation to be clinically useful. As part of our immune system, we have blood cells that find and destroy any foreign materials that enter our bodies. These cells protect us from invading bacteria and viruses that may cause disease. Although a transplanted organ can be lifesaving, our immune systems recognize this new organ as different from our own, as a threat, and begin to destroy it. Doctors refer to this destruction as organ rejection. Organ rejection has always been a major impediment to the success of organ transplant. Until very recently, organ rejection greatly limited the clinical usefulness of transplant surgery. For years, it was possible to surgically place an organ into another person, but the recipient's immune system would rapidly render it useless.

Dr. Murray recognized Richard Herrick's situation as a rare opportunity to avoid organ rejection. The patient had an identical twin brother, Ronald, who was willing to donate one of his own two kidneys to his brother. Since their biological makeup was the same, Richard Herrick's immune system wouldn't recognize his brother's kidney as different from his own. No rejection occurred. The success of this surgery proved finally, that transplantation was a potentially viable treatment for life-threatening organ disease. Dr. Murray and others believed that the problem of organ rejection could be overcome in some way. Transplantation could then offer additional years of life to countless patients with severe organ disease.

Today, transplant doctors have learned to control organ rejection by using anti-rejection drugs. These drugs block certain activities of the immune system. The transplant recipient must take these drugs from the time of surgery and usually for the remainder of his or her life. Cyclosporine, an anti-rejection drug made from a fungus, has provided the greatest protection against organ rejection so far. This drug became available for clinical use in the early 1980's. More than any other single factor, cyclosporine has allowed doctors to offer organ transplant as a treatment for many patients with serious illness.

Transplantation represents a true revolution in medical care. Far from the experimental procedure that it was in 1954, transplantation is today a real treatment option for many people with severe organ disease. Before the early 1980's, transplantation was available at only a handful of university medical centers. However, during the past decade, the technology and skills required for transplant procedures have spread to large hospitals throughout the world. Kidney was the first, and remains the most common type of solid organ transplant. But, heart, liver, pancreas, and even lung transplants are almost commonplace today. Because of ongoing research, new approaches to transplant arise frequently. These include small bowel transplants, the transplant of several organs simultaneously, transplantation of a piece of an adult organ to a child, and the controversial transplantation of animal organs into humans. As miraculous as these advances appear, the possibilities for future developments seem unimaginable.

Transplantation can offer seriously ill patients a chance for renewed health and life. However, to take advantage of this opportunity, the candidate must enter a fast-paced and highly technical world at the frontier of medical care. The demands made on candidates, recipients and their families can be huge. Illness can drain personal resources and strength. These demands begin even before acceptance to a transplant list. Transplant applicants must contend with complex assessment protocols, uncertainties about surgery, new doctors in a new hospital, the possibility of relocation to a new city, and large expenses. Following surgery, recipients must face a long recovery period, episodes of rejection, reintegration into family and work roles, and lifelong responsibility for complying with drug and dietary recommendations. Learning to live with these demands can mean the difference between a successful and an unsuccessful transplant.

The demands of organ transplant can be very different to the medical and surgical procedures that most of us are familiar with. For example, consider that you go to your doctor with a chest infection. He or she would diagnose your condition, prescribe an antibiotic and hopefully you will recover well within a short time. You are responsible for taking the antibiotic as suggested, but have little else to do. If you go to a surgeon with a hernia, the surgeon will examine you carefully and then arrange for the appropriate surgery. After a short recovery period, you will continue with your business. Again, you have little to do other than cooperate with your surgeon and trust him or her to provide you with good care. Conditions and treatments like these usually disrupt your life very little.

Compared to these minor procedures, transplantation requires a more interactive process. Multiple people and circumstances interact together to determine the health and well-being of a transplant patient. Your state of health, support people, transplant personnel and many other factors are all influential to the outcome of transplant. Transplant patients are not passive recipients of health care. They are active and influential participants in much of the process. For example, we now know that lung transplant

candidates who take part in an exercise program before surgery are likely to recover more rapidly following transplantation. Transplant recipients and their support people have many responsibilities (e. g., taking immunosuppressant medications on a daily basis, reporting unusual symptoms to the transplant team) that if neglected, can threaten health or life. Your doctors and others hold many expectations of you. Intrusion of these responsibilities upon your lifestyle can be a major source of stress or discontent.

The active role of the transplant patient is most obvious during rehabilitation following surgery. Minor complaints do not require transplant surgery. Typically, the transplant patient has suffered with a major illness that has disrupted his or her life's activities (work, school, relationships with family and friends, finances). Recovery following transplant does not just mean that you are well enough to leave the hospital. It may also mean that you must adjust to a new lifestyle, retrain for work, take up new interests or revitalize intimate relationships. Recovery in these areas takes a lot more energy and motivation than simply lying down on a table and letting a surgeon give you a new liver. Rehabilitation after transplantation involves more than a recovery from surgery. It also means recovering from the disruptions that illness has brought to your life. Many recipients describe rehabilitation and adaptation following transplantation as a lifelong process.

Surviving Transplantation draws on firsthand patient reports to answer your questions about the personal aspects of organ transplant. *What happens? How might I react? How can I best deal with transplantation?* The following chapters provide clear explanations for the unfamiliar and potentially bewildering array of events that can confront the transplant patient. We emphasize the personal impact of transplantation and ways of dealing with the challenges that may occur. Better appreciation of the typical personal reactions to transplant can be reassuring for those involved. For example, one applicant for liver transplant that we remember was anxious about the potential surgery. We mentioned that in our experience, it was normal for many people in his situation to be apprehensive or fearful. This observation appeared to surprise him at first. But then he responded with relief. He said I wasn't sure if other candidates felt the same way. *They all appear so positive,* he said. *I felt embarrassed by my worry.*

In this book we have assumed that you are an active participant during transplantation. We assume that your actions can influence long term outcome. Ideally, you are best to read this book from front to back. This is because later chapters build upon the topics of earlier chapters. However, you may prefer to read first about a particular topic of interest, or one that pertains to your own situation. The organization of *Surviving Transplantation* allows you the option of either reviewing the book from cover to cover, or of selecting topics of greatest personal relevance. Each chapter stands on its own. The words transplant applicant, candidate and recipient refer respectively to people applying to a transplant program, those awaiting surgery or those who have already received an organ. Support person refers to anyone providing emotional or practical support for a transplant patient. Support people include family members, friends, volunteer or professional workers.

Continue reading [Chapter 1](#)

Getting Started: Overview

Chapter two ([Living with Illness](#)) introduces a framework for understanding how illness can disrupt your daily life. We enjoy our lives most when we can be productive, have time for leisure, care for ourselves and have the opportunity for meaningful relationships. By searching out our own balance in these activities, we find meaning and satisfaction in life. Illness disrupts the balance you have found for yourself. This is one way in which illness causes distress.

Waiting for or recovering from a transplant may require major lifestyle changes. Leisure activities that you used to enjoy may not always be feasible. Both illness and transplant can alter work and family roles. Inevitably, you must devote increased time and energy to the care of your health. Large shifts in life values, goals and priorities may occur. This can result in a distressing sense of loss of control, dissatisfaction with life, and alienation from others. Patients and their supports may learn that some emotional upset is common-place before or after transplant. But many do not see clearly how it occurs or how to deal with it. This chapter provides a foundation for understanding how illness and transplant can disrupt the balance in one's life and cause emotional distress. Later chapters add detail to this framework and discuss how to encourage a sense of personal mastery.

Chapter three ([Waiting for Transplantation](#)) takes the reader from the time of application to a transplant program to the day of surgery. Chapter four ([Recovering from Transplantation](#)) continues from surgery through the extended period of rehabilitation and adaptation. The different stages of transplant each present you with unique challenges. Each of these chapters emphasizes what it is like for a person to progress through the various phases of transplantation. Personal examples are drawn from those who have received different types of organ transplants. These examples illustrate the differences in medical circumstances between the types of transplant, but also emphasize the common personal impact. We will attempt to address, in these two chapters, many common questions and concerns about transplantation.

Chapter five ([Understanding Stress](#)) is an introduction to dealing with the personal challenges of organ transplant. Both modern and traditional teachings provide guidelines and techniques for facing the stress that may arise before or after transplant surgery. Lifestyle changes, self reassurance, relaxation techniques and drawing on your support network are all introduced. Also provided is a rationale for deciding which approaches are best for you. We help you to identify your own style of reacting to stress. You can use this awareness to know when it is most important to look to your well-being. In this way, you facilitate a general sense of healing.

Chapter six ([Dealing with Stress](#)) encourages your role as an active health care participant. Caring for your own health and well-being can sometimes mean much more than just doing what your doctor or nurse tells you to do. It may mean dealing with problems that can distract you, or working to resolve nervous tension that can drain your energy. We emphasize an approach that does not require a degree in psychology to understand. We also appreciate that you have more to do in a day than learn stress management. The suggestions provided are those that many transplant patients and their supports have

found calming and reassuring. You might surprise yourself and learn how some common sense strategies can help you deal with the stress of transplant.

There is no question that stress can worsen high blood pressure and contribute to irregular heart beats. Rapid pulse, breathing difficulties and changes in blood sugar can also occur in some people under stress. When physical symptoms like these appear, it is easy to mistake them as a worsening of illness. People who have a physical illness and stress simultaneously can require more tests or medications. Research has shown that people with some types of heart disease can decrease their medications after learning to deal more effectively with stress. Similar improvement in severity of illness, quality of life, or both have occurred in many other physical conditions. Chapter six introduces several approaches for dealing with stress.

Chapter seven ([Working with Others](#)) addresses the value of supportive relationships, both personal and professional. Research over the past decade has shown the health benefits of social contact and social support. People in close contact with supportive others are less likely to get sick than others who are more isolated. When they get sick, they tend to have a better outcome than those who must face illness alone. Obviously, rules or trends like this are not absolute. Many people with large and supportive families become ill and do poorly. Others who go it alone can live long and healthy lives. But research suggests that those who foster stable and supportive relationships face the best odds when faced with illness.

Dr. James House and his colleagues wrote an important paper on the relationship between social support and health ([ref 1](#)) They reported some striking conclusions. You may have read in magazines that one's personality can sometimes contribute to heart disease. Everybody has heard that smoking can cause lung cancer. But did you know that lack of satisfying social relationships is a health risk of comparable size? This is exactly what Dr. House concluded. Illness and transplantation can strain relationships with family and friends. Our emphasis in this book is to help transplant patients and their support people to work together constructively and to minimize any conflict that may arise.

Although usually well-meaning, those who provide support can either be extremely helpful, or contribute to frustration and invalidism. Families commonly ask how they can best help the transplant candidate or recipient. Patients often need help to negotiate with caregivers the type and amount of assistance needed. This chapter illustrates the most frequent conflicts that can arise between transplant patients and their supports. Using guidelines and examples, it encourages mutually satisfying and supportive relationships.

Chapter eight ([When to Ask for Help](#)) can help you to recognize those times when you require, and should ask for professional help. Enhanced autonomy and self-help are major emphases of this book. However, if you do not recognize when you need professional assistance, you may become frustrated or demoralized by failure of your efforts. The transplant team will teach you how to detect physical complications (e.g., organ rejection, infection) early, and to report these to your doctor. This enables the team to provide the appropriate treatment.

Unfortunately, some patients try to conceal mental complications (e.g. confusion, clinical depression). This can result in delayed treatment or further complications. For example, few transplant patients expect that they or their support person could ever become depressed. But statistics consistently show that depression is a common complication of medical illness of any kind. Because the symptoms of depression can be subtle and mimic your physical condition, it can be difficult for either you or your doctor to recognize. Depression in candidates or recipients can interfere with people's ability to give their best to rehabilitation programs. Depressed support people are less available to the transplant patients they wish to help. We have seen many depressed patients and support people who are able to work more constructively with the transplant team following treatment for depression.

There are many examples of personal complications that can benefit from professional attention. A condition that is severe enough to require organ transplant can sometimes impair your concentration, memory, or ability to think through complex plans. In particular, about one-third of liver transplant candidates have severe impairment of their mental abilities at the time of transplant. Your doctors will refer to this condition as confusion, delirium or encephalopathy. It occurs, but is less common in kidney, lung and heart transplant candidates. It is important to recognize the clinical effects of stress, depression or delirium at an early stage. Appropriate management can help you to avoid the negative consequences that can occur when these conditions are unrecognized.

Chapter nine ([Transplantation and Personal Growth](#)) speaks to those people whose lives have been deeply moved by illness or transplantation. Many daily events that occur with transplant are the very types of events that can stimulate any of us to reflect on the deeper meaning and value of life. These include severe and disabling illness, changes in your body or your lifestyle, and confrontation with mortality. Identification with an anonymous, grieving family that offers an organ to save your life is a meaningful event that can strengthen your sense of relatedness to others. For many, it is impossible to live through these events without questioning one's path in life. We weave together some basics of the major spiritual traditions to provide some guideposts for those who are pushed by circumstances, along a spiritual path.

Physical illness can set up a vicious cycle that affects negatively, both your personal and physical well-being. As you feel more unwell, you have less energy available to tend to your well-being. As you are less able to tend to your well-being, the more unwell you are likely to feel. You hope that your doctors can help to break this cycle by treating your condition. But when this is not immediately possible, attention to your own well-being can help counteract the toll that illness takes on you. Our goal is to help you to promote your own health and dignity in the face of the challenges of illness and organ transplantation. You may at times have to cross your fingers and hope for the best for your physical health. Rarely are you forced to do this with your emotional or spiritual well-being. There is usually some potential for control.

Read [Chapter 1 Questions](#)

Questions

What are the stages of transplantation that you refer to?

Your personal interaction with transplantation is the main focus of this book. How can organ transplant affect you as a person? Do you have any potential to influence your outcome after transplantation? These are the questions that we address. But it is important to be aware that at different times, the demands made on you by transplantation can differ widely. We refer to these distinctly different times as the stages of transplant.

The application stage extends from the time that you first consider transplant to the time that you sign on to a waiting list for surgery. Included in this stage is an extensive assessment of your health. This assessment may be undertaken by your own doctors, the transplant team, or both. The waiting stage spans the time that you are accepted to a waiting list until you undergo surgery. After you awake from surgery, there is a time of recovery in the hospital. This is the recovery stage. The stage of rehabilitation and adaptation begins with discharge from the hospital and we believe, continues for the remainder of your life. Each of these four stages holds unique challenges and demands for you and those working with you.

Why can't I just have the transplant and get on with my life? Is it necessary to think about all this stuff?

It is not absolutely necessary. Many people have successfully recovered from transplantation without considering the ideas that we discuss in this book. But your approach may not suit everybody. Some will find it difficult to deal with the sense of powerlessness that may arise during serious illness or transplant. It may benefit them to know in what ways they can take charge and work actively in the service of their health. Others are surprised to find that they react in unfamiliar and unexpected ways to their situation. They may find solace by reading that others have reacted similarly.

You may see no reason to think about the ideas contained in *Surviving Transplantation*. But someone else may. Your husband, wife, a friend, or another may relate to a different approach to transplant. You cannot assume that one approach is for everybody. You cannot even be sure that you will not change your mind later. When a problem arises, it is only human nature to first sit back and hope that the problem resolves itself soon. In our experience, it is the rare and very lucky person who can comfortably negotiate transplantation and recovery using only this approach.

Next Chapter: [Living With Illness](#)

Recommended Reading

While writing a book like *Surviving Transplantation*, it can be hard to know where to stop. There are many topics that we could discuss further. We have emphasized those events that transplant candidates and recipients face commonly. And we have offered some ideas for how you might deal with the challenges that arise. But we have touched only briefly on the many ideas and techniques that you might find helpful.

We hope that you are satisfied with what you have read in this book. If so, then we have achieved what we set out to accomplish, to enlighten but not be overly tedious. However, you may have read something that interests you or is especially relevant to your own situation. We list in this appendix, selected readings for those who wish to pursue some topic in more depth. Dozens of other books are available at any good bookstore.

Personal Accounts

Many Sleepless Nights is a story of transplantation as told by surgeons, nurses, candidates, recipients, and others associated with the University of Pittsburgh School of Medicine, a world renowned transplant center. This book's first section tells of the medical advances that led to the success of organ transplantation. Through the use of personal accounts, **Many Sleepless Nights** leads the reader through the transplant process, from the time of organ donation through to life as an organ transplant recipient. (Lee Gutkind; W. W. Norton & Company, Inc. and Penguin Books Canada Ltd., 1988)

Two Lives on Hold describes what it was like for Joan and William Squadron to wait for the heart-lung transplant. The surgery was necessary to save Joan from dying with cystic fibrosis. Their story is told with the realism and insight that comes only with firsthand experience. (William Squadron; *The New York Times Magazine*, December 18, 1988)

"We Have A Donor:" The Bold New World of Organ Transplantation tracks through the medical system, several organs that are generously offered for transplantation by a grieving family. Separate chapters describe heart, kidney, corneal and other types of transplant as different recipients receive an organ from this single donor. Insightful and compelling, the reader will be amazed by the huge network of persons whose lives are touched by this one act of giving. (Mark Dowie; St. Martin's Press, New York, NY, 1988)

Transplant: A Heart Surgeon's Account of the Life-And-Death Dilemmas of the New Medicine is written by the director of the Heart and Heart-Lung Transplant Program of the Vanderbilt University Medical Centre. It describes first hand, the day to day decisions and excitement of working on a transplant team. Only a surgeon at the center of it all could write a book with detail as compelling and real to life. (William Frist; Ballantine Books, New York, NY, 1989)

Dealing with Doctors and the Health Care System

Building A New Dream is the best and most comprehensive guide available for finding your way through the health care system. Written by a director of the Toronto Lung Transplant Program and an educator, it tells you how to approach your doctor, what questions to ask and what happens when you are ill. Real life examples explain how patients and their families deal with physical illness. Janet Maurer and P. Strasberg; Simon & Schuster Inc., New York, NY, 198)

Take Charge of Your Health: A Personal Health Record ant Reference. Do you get tired of providing your history over and over again? Do doctors and nurses sometimes forget to ask about important information? Do you sometimes forget the name of that drug that you took for a few months, several years back? This pocket size, personal health record will help you to organize all important information about any previous illness and treatment. (Elizabeth Etue and P.D. Chalmers; Summerhill Press Ltd., 1985)

Patient Beware: Dealing With Doctors and Other Medical Dilemmas describes some problems with how women are perceived and treated by the medical profession. It explains how a female health care consumer can improve her communication with doctors. (Cynthia Carver; Prentice-Hall Canada Inc., Scarborough, Ontario, 1984)

Medical Choices - Medical Chances is a highly unique book. Most people find comfort in their lives in part, by expecting a predictable course to their future life. Serious illness can challenge this assumption. It does not discuss transplantation. But this book intertwines personal accounts and philosophical discussion to help the medical or surgical patient deal with uncertainty. (Harold Busztajn, Richard Feinbloom, Robert Hamm, and Archie Bodsky; Rortledge, New York, NY, 1990)

The People's Book of Medical Tests describes over 200 tests. We suggest that you ask your doctor or nurse any questions that you have. But if you like detailed information, this is the book for you. It tells you why your doctor may have ordered a test, what it will be like for you, and what the results mean. Generally, this book is easy to read, with little medical jargon. It is written by two doctors. (David Sobel and Tom Ferguson; Summit Books, 1985, New York, 1985)

Living with Illness

Coping With Kidney Failure is a guide to living with kidney disease and dialysis. Like other books on coping with illness, it deals with the personal aspects of kidney failure. This book is written for both patients and their families. (Robert Phillips; Avery Publishing Group Inc., New York, NY, 1987)

Living With Diabetes offers strategies for facing the challenges of this illness. It is written for anybody with insulin dependent diabetes. Endorsed by the Canadian Diabetic Association. (Heather MacLean and Barbara Oram; University of Toronto Press, Toronto, 1988)

Living With Angina covers everything that you might want to know about angina. It is written by a cardiologist. James Pantaro; Harper Collins, New York, NY, 1990)

The Healing Heart is an appropriate title for this book. Written by a heart attack survivor, it suggests how you can overcome panic, optimize healing and rediscover living. (Norman Cousins; Avon Books, New York, NY, 1983)

Healing, Relieving Tension and Stress

The Relaxation & Stress Reduction Workbook is a shopping catalogue of ideas for stress management. A few pages are taken to describe each of the various relaxation and stress management techniques. Topics include self hypnosis, guided imagery, meditation, progressive muscular relaxation, and assertiveness training. Step-by-step instructions allow self-directed learning. This book has won a Medical Self Care book award and sold over 200,000 copies. (Third Edition by Martha Davis, Elizabeth Robbins Eshelman and Matthew McKay; New Harbinger Publications, Oakland, Cal, 1988)

The Relaxation Response boils the relaxation movement down to its basics. It explains a simple technique that elicits a state that the author calls the relaxation response. Examples show the usefulness of the relaxation response for those with high blood pressure and irregular heart beats. This book is widely recognized as a classic in the field. It is written by a professor of medicine at Harvard University. (Herbert Benson; William Morrow and Co., 1975)

Beyond The Relaxation Response again describes the basic principles of physiological relaxation. But this book also introduces the concept of mantra. Using both traditional and modern teachings, the author makes a case for the mantra's role in the benefits derived from relaxation practices. (By Herbert Benson; Times Books, 1984)

Minding the Body, Mending the Mind takes a broad approach to the health benefits of tension release. Several strategies for dealing with stress are discussed. The book includes step by step directions and personal accounts of their use. Written by a leading medical researcher into the health benefits of relaxation. Jean Borysenko; Bantam Books, 1988)

Full Catastrophe Living: Using the Wisdom of Your Body and Mind to Face Stress, Pain, and Illness describes a program taught by the Stress Reduction Clinic of the University of Massachusetts Medical Centre. It is written by a leading expert on the health benefits of mindfulness meditation. The application of this ancient technique is explained with a sophistication and detail that is not available elsewhere. The reader will learn about basic meditation techniques and their use in daily life. Jon Kabat-Zinn; Dell Publishing, New York, NY, 1990)

The Complete Book of Self Hypnosis is an introductory, step by step guide for the reader who wishes to develop their hypnotic ability. John Yates and Elizabeth Wallace; Ballantine Books, New York, NY, 1984)

Imagery in Healing: Shamanism and Modern Medicine is a thoughtful rendition of the role of mental imagery in healing. Ancient healing rituals are discussed along with modern psychological techniques. It is written for the serious reader who wants to explore this topic fully. (Jeanne Achterberg; New Science Library, Boston, 1985)

Hope and Help For Your Nerves has become a standard for therapists to recommend to their anxious clients. It helps the reader to deal with excessive worry, nervous tension, and phobias. The book is easily readable and full of helpful hints. (Claire Weekes; Signet Edition, Penguin Books, New York, NY, 1990)

Peace From Nervous Suffering has sold over one-quarter million copies. What more can we say? (Claire Weekes; Signet Edition, Penguin Books, New York, NY, 1990)

Love, Medicine, and Miracles is now a classic. It draws upon a variety of traditional and popular systems to offer inspiration for those living with physical illness. (Bernie Siegel; Harper & Row, 1986)

The Joy of Stress talks about many causes of stress, both physical and emotional. Since we all have to live with some degree of stress in life, why not read a book that tells us how to make the best of it. It explains how to use stress as a vitalizing force. (Peter Hanson; Hanson Stress Management Organization, Toronto, 1985)

Death and Dying, Grief; Near Death Experiences

On Death And Dying is the classic work that describes the author's work with terminally ill patients. This is the author largely responsible for popularizing a compassionate attitude towards the dying. The stages of grief and the psychological sequelae of death and dying are described. The personal examples are heart rendering. (Elizabeth Kubler-Ross; Macmillan Publishing Co., New York, NY, 1969)

Beyond Loss: A Practical Guide Through Grief to a Meaningful Life talks directly to the grieving reader. Comprehensive and compassionate, it provides some guidance and reassurance during the pain of bereavement. (Lilly Singer, Margarot Sirot and Susan Rodd; E.P. Dutton, New York, NY, 1988)

The Death of Ivan Ilyich can be read in less than an hour. But you are not likely to forget what you read. Leo Tolstoy spent over a decade musing about death and dying. This short novel was the result. Written long before any psychological or scientific studies were undertaken, it describes a man's life and death. The Death of Ivan Ilyich is remarkable reading. It cannot help but make you think about your own life. (Leo Tolstoy; Bantam Books, New York, NY, 1987)

Choices: For People Who Have a Terminal Illness, Their Families and Their Caregivers. Few people are much prepared for their own or a loved one's imminent death. Compassion and practicality are combined in this book that guides you through the final weeks of life. Excellent chapters are

included on hospice care, pain control, euthanasia, and funeral arrangements.

Many who would have previously been considered terminally ill, now have the option of an organ transplant. Transplantation offers hope for recovery where none before existed. But transplantation does not eradicate any risk of death. Many sections of this book are highly applicable to transplant candidates and recipients who take the approach of hoping for the best, but preparing for the worst. (Harry van Bommel; NC Press Limited, Toronto, 1989)

When Bad Things Happen To Good People tells of one man's search for meaning after his son is diagnosed with a deadly disease. A compassionate and deeply personal account. Publisher's Weekly said that this book should be read by all people in trouble, no matter what their religious faith . . . An unprecedented source of comfort and reassurance. (Harold S. Kushner; Avon Books, New York, NY, 1981)

Healing Into Life And Death. We are led to believe that healing entails a fight against illness. Our weapons include drugs, surgery, imagery, positive thinking, and so on. But Stephen Levine re-examines the question: What is healing?

Acceptance of illness is typically equated with resignation. This author suggests that healing involves, but is not limited to, fighting illness. He offers that healing may require acceptance of illness and grief, allowing one to move beyond suffering to a new perspective on illness. Recommended only for readers who wish to tear themselves apart in a search for meaning within illness and death. (Stephen Levine; Bantam Doubleday Dell Publishing Group, 1987)

Who Dies? An Investigation of Conscious Living and Conscious Dying quotes the following passage from a headstone in Ashly, Massachusetts: *Remember, friends, as you pass by, as you are now, so once was I. As I am now, so you must be. Prepare yourself to follow me.* A challenging guide for working with death, your own or others. Written for those who desire to live life to the fullest. (Stephen Levine; Anchor Press/Doubleday, 1982)

On Children and Death discusses a painful topic with compassion and insight. To understand how children of different ages understand death is vital. This is true whether helping them to deal with their own potential death or the death of someone close to them. Contains an extensive list of other reading resources. (Elizabeth Kubler-Ross; Macmillan Publishing Company, New York, 1983)

Life After Life: The Investigation of a Phenomenon, Survival of Bodily Death is the classic citation for near death experiences. Personal accounts as told by patients to a physician. (Raymond Moody Jr.; Stackpole Books, Harrisburg, P.A., 1976)

The Light Beyond reports on a further decade of this author's investigation of near-death experiences. (Raymond Moody; Bantam Books, 1988)

Otherworld Journeys: Accounts of Near-Death Experience in Medieval and Modern Times takes a broad and scholarly approach. Rich with historical accounts, this book refers to each of religious, paranormal and scientific interpretations of near-death experiences. (Carol Zaleski; Oxford University Press, 1987)

Return to the [Table of Contents](#)

Introduction to Relaxation Exercises

The Calming Breath

Close your eyes gently and focus attention on your breath. Take a breath through your nose and feel it enter deeply into your abdomen. Then let go and feel the air ease out on its own. As you are ready, take another breath deeply into your abdomen. Feel your abdomen rise slowly as the air flows in. Let it out through your nostrils or lips. Feel the gentle pressure of your breath as it moves through your nose. Each breath flows in through your nose and deeply into your abdomen. Cool as it moves through your nose. Calming as it fills your abdomen and chest. Each breath out leaves you more and more relaxed. No effort is needed for your breath to flow out. Just let go. Let your chest and shoulders relax heavily.

Imagine with your next breath that clean, white air is coming inwards. Feel it pour deeply into your abdomen. As each breath leaves, your chest, shoulders, and face relax deeply.

Progressive Muscular Relaxation

While the rest of your body remains relaxed, clench your right fist tightly. Tighter and tighter . . . Now relax your hand completely. Notice the difference between your hand clenched tightly and your hand fully relaxed. The difference between a tight muscle and a loose one. You may notice a pleasant sort of warmth that occurs when your muscle relaxes. Now let your hand and arm relax even more. As if your hand and arm is becoming heavier and heavier. Let your arms sink into your lap as you let go of the last bit of muscular tension.

Now clench your left hand tightly. Tighter and tighter . . . Then relax your hand completely. Relax and enjoy the feeling of looseness that enters your left arm. The warmth and heaviness that occurs as your arm becomes more and more relaxed. Again, give yourself a few moments to feel the difference between tension and relaxation.

Now bend your elbows and tense the muscles in your upper arms. As you tense these muscles, feel the tautness. Then relax your arms completely. Let your arms rest again on your lap. Feel the difference as your arms lose the tension and relax your arms completely. Let them sink heavily into your lap.

Now turn your attention to your forehead. Wrinkle up your forehead as tightly as you can . . . Now relax your entire forehead and scalp. This may feel as though the muscles of your head and scalp will fall off of your head. Imagine your entire scalp and forehead is smooth, relaxed, and heavy . . . Now frown. Notice the strain spreading throughout your forehead. Notice the tension and the tightness that results. And then let go. Relax your brow. Allow it to become smooth again. Feel the difference between a tense and relaxed forehead.

Now clench your teeth together, and notice the tension throughout your jaw. Then relax your jaw. As your jaw relaxes, your teeth will begin to part. Let your lower jaw fall loosely, as all of the muscles on your scalp, forehead, face and jaw loosen and relax. Feel the difference between tension and relaxation in your jaw. Notice how it feel for your jaw, lips and tongue to relax fully.

Now shrug your shoulders. Keep the tension in your shoulders a your shoulders hunch upwards . . . Then relax fully. Loosen and drop your shoulders fully. Feel the heaviness and warmth spreading through you neck, throat and shoulders. Full relaxation. Deeper and deeper. Feel how loose and easy your neck feels balanced on your shoulders.

Now give your entire body a chance to relax. Feel the comfort and the pleasant heaviness. Enjoy a few breaths that flows smoothly and deeply into your abdomen. Continue breathing deeply for a few seconds. Continue to relax. Let your breath come freely and gently. Now, tighten your stomach and hold it for a few moments. Notice the tension. Then relax your stomach fully. Feel the cool air of your breath flow deeply into your lower abdomen. Feel the complete sense of relaxation as the air flows back out of your chest.

Now concentrate on your back. Arch it very slightly, without straining. Then relax your back. Notice the contrast between tension and the looseness that remains. Experience what it is like for your back and body to relax fully. Now curl your toes downward and tense your calves. Study the tension carefully for a moment or two. Then relax your legs fully. Enjoy the warmth and heaviness that enters your legs as the tension flows out. Now bend your foot upwards, creating tension in your shins . . . And relax again fully. Enjoy the heaviness that spreads throughout your legs. As if they are sinking more and more heavily to the floor. As if only the floor keeps your heavy legs from sinking downwards further.

Feel the heaviness and relaxation that is present throughout your body. You can enjoy the feeling of being deeply relaxed. Peaceful. Calm. Enjoy this state for a few moments.

Guided Imagery

Once you find yourself in a more relaxed state, imagine yourself in a place where you feel peaceful, calm, and relaxed.

Everybody can imagine a place where they feel safe and secure. It may be indoors or outdoors. It may be a place where you have been in the past or a place you have never really seen. Imagine this comfortable place as your haven, your retreat. You may find yourself on a beach, watching the ocean. Or in a valley, looking at a tall mountain with snow at the top. Wherever you find yourself, imagine sitting in soft and comfortably easy chair.

As you sit comfortably in your chair, you can calmly look around at your surroundings. Maybe there is a warm sun shining down on you. You may feel the warmth on your face. Or your place may have a pleasant smell that flows into your nose with your breath. Take a breath deeply into your abdomen as

you let the peace and tranquillity of your special place spread throughout your entire body. Enjoy your place for a while. Let it nourish and relax you for a few minutes.

Return to the [Table of Contents](#)

References

1. House, Landis, Umberson. Science, vol. 241:540-545.
2. Illness as Metaphor. Vintage Books, New York.
3. Reed and Sanderson. Concepts of Occupational Therapy, Williams and Wilkins, Baltimore, 1980.
4. Robert Fulghum. Villard Books, New York.
5. Tao Te Ching: The Classic of the Natural Way. English translation by John Stubbs, Toronto, 1990.
6. The Pregnant Virgin: A Problem of Psychological Transformations. Inner City Books, Toronto.
7. Squadron. New York Times Magazine. vol. 75, pg. 39.
8. New Lease on Sports, by Debora Van Brenk. London Free Press, Saturday, April 10, 1993.
9. O'Sullivan (with Rod McQueen). Key Porter Books Ltd., 198b. 10. Expression of the Emotions in Man and Animals. University of Chicago Press, Chicago, 1965 [1872].
11. Bantam Doubleday Dell Publishing Group, New York, 1987. Bantam Books, New York, 1957.
13. Avon Books, New York, 1981.
14. Religious Perspectives on Transplantation. In Craven and Rodin (eds.) Psychiatric Aspects of Organ Transplantation. Oxford University Press, London, 1992.
15. Bantam Books, New York, 1988.

Return to the [Table of Contents](#)

Living with Illness

Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us will be obliged, at least for a spell, to identify ourselves as citizens of that other place. ([Susan Sontag, 1977](#))

People sometimes behave as if they take their health for granted. However, most regard good health highly. Ralph Waldo Emerson said that *health is the first wealth*. Good health provides us with a fundamental opportunity to live our life the way we choose. Impaired health may at times frustrate our ambitions, despite wealth and other personal resources.

Although most of us would agree that one's state of health is important, exactly what we mean by the word health is not always clear. Does it refer only to the absence of disease? Or does good health require a total sense of well-being? Is a chronically tired person who does not have a serious disease, healthy or unhealthy? What about a man who feels well, but has high blood pressure? Is he healthy or unhealthy?

Consider the following story. You slip on some stairs and break your wrist. Over the next few days you find the cast uncomfortable. You become frustrated by the inconvenience, irritated by this impairment in your usual state of health. After a couple of weeks, you attend your doctor's office, hoping that she will say it is time to remove the cast. In the waiting room, you notice a young woman with hands that are deformed by arthritis. Her hands look as though they are painful. But she is chatting amicably with the receptionist. At the time of your appointment, the doctor tells you that the cast must stay on your arm for at least another two weeks. Rather than the increased irritation that you had expected to experience, you find that it doesn't seem like a big deal. You leave the office with the hope that the doctor can help this woman with her condition. Seeing her has helped you to view your own health from a different perspective. Nothing has changed with your wrist, but you feel lucky to be so healthy.

Clearly, the word health refers to a complicated idea that is difficult to pin down. In this book, we define health as having three aspects. These are physical, emotional and spiritual. These three aspects overlap and affect each other. For example, we all know that improvement or deterioration in physical health can alter our emotional well-being accordingly. But it is equally important to recognize that the physical, emotional, and spiritual do not overlap entirely. As in the example of the person with a broken wrist, one's state of mind may shift without any tangible change in physical health. Later in chapter nine, we discuss how physical health problems may result in either challenges to or enhancement of spiritual awareness.

The assumptions you hold about the meaning of health can exert huge impact on how you react to sickness. By viewing health too narrowly, you can easily convince yourself that you are much more helpless than is truly the case. Imagine a man who assumed that his well-being was dependent entirely upon his physical condition. For him, a sense of well-being could occur only when physical disease is absent. Should physical illness arise, only hope for a complete cure would restore his sense of well-

being. A delay in treatment, or anything less than a cure would leave a residue of despair and helplessness. By ignoring other aspects of health and well-being, an uneasy sense of dependence upon doctors and fate is all that remains. Such a person would tend to fear sickness and try to pretend that it could never happen to him.

Another very different assumption about health can also lead to great distress. We encourage a broad rather than narrow understanding of health and well-being. But what if somebody takes this idea to its own extreme? What about the person who equates well-being only with an ideal state of total health? Only when the physical, emotional and spiritual aspects of health were all in perfect order would a sense of well-being occur. Unfortunately, real life has an irritating tendency to not cooperate with our wish for absolute tranquility. It always seems that something, somewhere, is not exactly as we might prefer. As a result, this ideal outlook on health and well-being is far too fragile. If anything were out of place, you would feel unwell.

Sarah: Diagnosed with diabetes as a young child, Sarah had treated herself with insulin as long as she could remember. The disease had never affected her life to any great extent. She was now thirty-two years old and trained as a lawyer.

During the past year, Sarah's doctor had noticed some changes in her eyes that were early complications of diabetes. After some discussion with her doctors, she had decided to have a pancreas transplant. Their expectation was that this surgery would decrease the seriousness of future eye complications. Following surgery, Sarah recovered as expected. Her new pancreas functioned well and she steadily needed less and less insulin. She now felt reassured that sight problems would not interfere with her life or work.

Unfortunately, Sarah developed some side effects from the anti-rejection drugs. While not severe, they bothered her greatly. She talked with her doctor, but he said that there was little that he could do. It was possible that the side effects would decrease over time. Sarah had known before surgery that she might have some of these side effects afterwards. But it wasn't important to her then. All that had mattered to her was saving her vision. But that was then. Now, she began to think, *Why did I have this transplant anyway? I feel worse now than before the surgery.*

For several weeks, the side effects persisted. Over and again, Sarah would check out how she felt, hoping to notice some change, some relief. Concerns about how she felt were a constant distraction. Even at work, she couldn't concentrate well. At night, preoccupation with her health kept her alert. At doctors appointments, Sarah always asked if there was not something that they could do. It was obvious that she was beginning to frustrate them. Eventually, a nurse said to Sarah that her side effects were similar to those of an average recipient. They were less severe in fact, than many who were far less distressed than she.

Sarah believed that she was not performing her best at work. But her supervisor often commented that she was the hardest worker in the law office. When her firm offered a course in management training, Sarah's supervisor suggested that she enroll.

Included in the course was a talk on perfectionism. Sarah immediately recognized the pattern in herself. She was always impatient. Everything in her life had to be in order. If she was not striving to achieve high standards, her confidence suffered. This applied to her health as well. She had to feel perfectly well physically or health concerns would occupy her mind. To reassure or distract herself was almost impossible. It occurred to her that perfectionist tendencies had contributed to her preoccupation with the side effects. When present, she found it hard to think of anything else. If she didn't feel perfectly well, she worried, even after the transplant staff reassured her that she was not ill or in any danger. In her mind, she was not perfectly well and that worried her.

After this insight, Sarah asked further about perfectionism. The course instructor recommended some books on stress and stress management. Sarah didn't stop asking the doctors if they could do something about her side effects. She wasn't going to give up trying. But meanwhile, she shifted her own energies to better learn how to tolerate the side effects and to otherwise deal with her worry. Now Sarah had a direction in which to work.

Physical, emotional and spiritual aspects of life interact to decide your health. People can show remarkable resilience during times of serious illness. One reason for this is our ability to adjust our selves and our lives to work around physical limitations. The suggestion that uncontrollable physical changes need not dominate our lives is a message of hope and optimism. Other aspects of one's health and life are there to draw upon at times of physical challenge.

Continue reading [Chapter 2](#)

The Intrusion of Illness

Serious illness will at least for a time, intrude upon and disrupt your life. Indeed, a most disturbing aspect of illness is its tendency to disrupt your preferred interests and lifestyle. In this section, we offer some basic ideas about how you structure your life. This will help you to see how illness can throw a lifestyle into disarray. Our hope is that this instruction will lay a foundation that will enhance your ability to respond confidently to the intrusion of illness into your life.

You divide your days between four types of activity. These are work, leisure, looking after yourself, and relations with others ([ref 3](#)). Each of us strives for our preferred balance among these pursuits. Of course this is a dynamic balance, meaning that it constantly shifts according to one's needs, interests and resources. When you have control over the time and energy that you divide between these areas of life, you are likely to be more at ease with your lifestyle. To the extent that you are not in control of this balance, you risk frustration and resentment. To again find satisfaction, you must regain some control, adjust yourself to new circumstances, or both. Your interest in transplantation is an effort to regain some control over your health. Meanwhile, you may find yourself challenged to accept circumstances that are not your preference. This is always difficult.

Illness confronts your ability to maintain a preferred balance between different life activities. It may force you to spend more time than previously in looking after your health. End-stage renal disease requires several hours of dialysis treatment each week. A doctor or nurse may recommend an exercise program to help with a heart, lung or other condition. Illness may also demand that you take some time off work or make it difficult to pursue certain leisure activities. People who have spent a great deal of their time engaged in sports and other physically demanding activities may have to curtail these interests for a time. During your involvement with a transplant program, there can be a great deal for you to do and learn. These demands may have to take priority over other interests or goals until after you recover from surgery.

When illness disrupts your preferred lifestyle, a difficult dilemma immediately arises. Stated simply, do you fight or do you adjust? Do you stand firm and refuse to change? Or do you alter your lifestyle to meet the new demands or limitations of illness? Does this mean that you are 'giving in' to the illness? That it is getting the better of you? Or is it sensible to adjust, a sign that you are being reasonable?

We describe this decision as a dilemma because it can seem at times like there is no good answer. For example, is it better to work part time and get more rest when ill? It may be, unless you are a person likely to become bored and isolated when not working full time. Or it might be best for your health, but what if you would then be unable to keep up your mortgage payments? These are difficult decisions.

On the other hand, is it better to keep working full time? Again, this might be the correct answer for the person who enjoys and is not too fatigued by their work. But what about the person who holds a physically demanding job that they do not enjoy? Will they have enough energy left over at the end of

the day to apply themselves fully to a recommended treatment program?

Without any doubt, this question of 'stand firm' or 'adjust' can be a difficult dilemma. The correct decision depends on a huge variety of considerations, both to do with yourself and with medical circumstances. Much of what we discuss in **Surviving Transplantation** has the goal of helping you to face this type of decision with a more informed confidence.

Work: Work does not only mean paid employment. It can also refer to a volunteer job, going to school, community work, caring for others, or maintaining your home. Anything that involves productive activity is a type of work.

For many people, work is a core and defining aspect of their life. It is the most common source of financial support. It can be a major source of satisfaction and accomplishment. Many social interactions are an extension of the work that one does. Work is so central to our personal identity that we often define ourselves in terms of the work that we do. We usually don't say, *I work as a teacher* or *I work as a homemaker*. We are more likely to say, *I am a teacher* or *I am a homemaker*. You may ask a child, *What do you want to be when you grow up?* But the question that you are usually asking is, *What type of work do you want to do?* Work almost defines who we are as a person. It is a statement of who we are instead of just something that we do.

Should serious illness limit your ability to work, it is not just your work that is threatened. It may be your income, your self-esteem, your social life, your personal identity. It is not likely to surprise you that we suggest that diminished work capacity can be a most disturbing effect of illness. Many transplant candidates, when asked why they wish a transplant, will reply that it is their only hope to return to their work and career.

Robert: Robert had been on his own since a teenager. His father had died when he was ten years old. By the time he was 14, Robert was working in construction to help support his mother and younger brother. As he grew older, he took pride in his labor and enjoyed his position as the provider for his family. As an adult, Robert was proud that he could support his own family with the income from the construction company he now owned.

He couldn't believe it when his doctor told him that he had a serious heart condition. Robert knew that he had chest pain at times. But he had assumed it was indigestion. Now the doctor was suggesting that he would have to work less. Medications could treat his condition for now, but it was possible that he would need a heart transplant some-time in the future. Robert asked if he could have the transplant now. He couldn't imagine what it would be like to work less. *What will I do with myself? What will others think of me? Am I supposed to just lie around the house all day long?*

The doctor had said only that he might need a transplant in the future. Meanwhile, she offered to work with Robert to maintain his health. But he left the office feeling horrible, lost, and angry. *It couldn't be true. He would find another doctor to give another opinion.*

The threat to Robert's security and identity is obvious. What could be a greater insult to his expectations for his life? But it is remarkable that after a period of shock and despair, many people like Robert will adapt to their new reality. They shift priorities, rework budgets, make new plans, find new interests. Hopefully this shift will be on a temporary basis. But sometimes it is not. This ability to adapt to new situations is central to the strength that helps people through tragedy.

One of the shifts that may be helpful is to consider the idea of defining work more broadly. Few would argue that it is ideal that you are paid well for work that you do. But when full time employment is not feasible, remember our earlier definition that work refers to any productive activity. Many people whose health limits their work will turn to volunteer or community work. Some transplant recipients offer their time to counsel new applicants or candidates, or speak on behalf of transplant groups. One woman we met was unable to work steadily enough to return to paid employment. She supported herself with a disability pension but volunteered her time to several charity organizations. The amount of time that he had to spend on dialysis treatment demoralized another man we knew. One day a nurse mentioned to him that she thought that dialysis was just part of the work that he must do to sustain a productive life. Something about this perspective helped this man pursue his dialysis with renewed interest and diligence.

We all need to be productive. The social and personal rewards are not entirely dependent upon financial gain. And they may be available through a variety of productive activities that you may not have previously considered.

Leisure: Leisure refers to activities that you do for enjoyment. Another word for leisure activities is play. Some people are lucky in that there is little difference between their leisure and work pursuits. While some people write, play hockey, or paint as a hobby, these are enjoyable professions for others. For most of us, there is some distinction between what we do for work and what we do for leisure.

Unfortunately, given the demands of work and other of life's responsibilities, it is not always easy to set aside time for leisure. Some people spend so much of their time working that they have no time left for leisure. This may occur out of necessity. But in the example of Robert above, circumstances forced him to grow up too rapidly.

He never had much opportunity for enjoyment. There were too many responsibilities. Although Robert might have found greater opportunity to enjoy leisure time as an adult, he was by then in the habit of a steady diet of work. Illness caused a crisis for Robert in part, because he knew little else in his life but work. Others can have exactly the opposite problem. Illness can limit involvement in leisure activities that are very important to them.

Stephen: Stephen knew he was addicted. He loved to bowl. This was his exercise and his outlet for stress. He had met most of his friends through bowling. No matter how busy work became, he always spent weekends on the lanes. If for no other reason, he would have had his kidney transplant just so that he could regain the freedom and strength to bowl more often. Therefore, Steven responded with shock when his doctor told him months after the transplant that he had to stop bowling for awhile. He had

developed a bone condition due to an anti-rejection medication and was risking bone fractures in his wrist and ankles if he continued to play. *What am I going to do with myself now?* he thought.

Like work, leisure pursuits can be a source of personal identity, social interaction and pride of accomplishment. For some, leisure activities more accurately reflect their interests and abilities than their work. Leisure may allow more of an opportunity to explore creative, athletic or intellectual abilities than you are able through work. Understandably, sports and pastimes can take on great importance for some.

We remember seeing one young man, Scott, who was training for the Olympic Games when he became ill with liver disease. He decorated his ward room with pictures of himself skiing. *It helps to remind the hospital staff that am a real person*, he commented. Scott maintained the single-minded goal that he must survive transplant so that he could return to his sport. Pursuit of this goal was a major source of strength to him in the face of illness and transplant. Many others derive greater satisfaction from activities other than their paid employment. Anne, a liver transplant recipient, worked as a secretary, but most evenings, volunteered as a yoga teacher at her local YWCA. Although not paid for the classes, the sense of achievement that Anne derived from teaching yoga was far greater than that from her work.

Given the importance that leisure pursuits hold for some people, we would expect a varying impact of illness. For some, a most distressing aspect of illness is that it limits their pursuit of an interest. For others, time off work may allow more time to pursue interests they never used to have time for. We know of one man who is now a national representative for a model airplane group. He attributes this accomplishment in part, to illness having forced him to slow his pace at work. Rather than work, he now enjoyed his hobby during evenings and weekends. Some will always have an interest at hand to keep them busy. Others are not so ready or able to think of new activities to enjoy. These people can find a distressing void in their lives should illness force them off work.

Someone on the transplant team may notice if you have difficulty in adjusting your activities according to your current medical circumstances. If so, they may suggest that you speak with someone who can help you to redefine your interests. A transplant coordinator referred a man named Colin to us, concerned that he appeared depressed. This turned out not to be the case, but it was clear why the coordinator had been concerned.

Colin: Since his enrollment on the waiting list for transplant, Colin appeared listless. He alienated himself from the other candidates, and showed little interest in much of what was going on around him. When we asked how he spent his time, he could not really say.

Colin had been happy when he was working as a product manager for a small company. Sports took up most of his spare time. He and his wife played softball with local teams in the summer. During the winter, they curled and he coached hockey. Besides work, illness had forced Colin to defer these interests for a time. Sports had also been the main emphasis of his relations with friends. But when we talked about his current schedule, he said, *You might as well not bother with me. Its not as if I'm going to take up knitting*. Obviously, Colin had some ideas about what it was that we might suggest for him.

Of course, nobody was going to ask Colin to knit, or to do anything else that would not interest him. But in our experience, there are always alternatives. Fortunately, Colin had a mind that was open enough to consider other options. As it turned out, he told us that he had collected hockey and baseball cards when he was younger. He had a large collection in his basement, but never had the time to organize it. Not much more discussion was necessary. It was obvious that he had reminded himself of his interest in this hobby.

Several weeks later, Colin told us that he had reviewed the collection and had attended some shows. He was enjoying himself and had met some new people through the hobby. And he no longer cared if he had to wait before clinic appointments. He always carried his price guide with him for reading.

Relations with Others: Much of what we work or play at has something to do with others. These may be friends, acquaintances, work colleagues, classmates, neighbors, lovers, and family. The nourishment that we give and receive from those around us is immeasurable. Much research has shown that satisfying relations with others has both physical and emotional health benefits. We fulfill our social, intellectual and sexual needs in part, by those with whom we interact.

You have likely heard it said that serious illness will either draw people together or pull them apart. This has been our experience when working with organ transplant candidates and recipients. It is difficult to imagine how serious illness and transplant could not have some effect on our relationships with those around us. Throughout this book, and particularly in chapter seven ([Working with Others](#)), we emphasize the importance of your relations with those around you. We encourage in all discussions, an approach that can ease interpersonal tension and solidify your relations with others.

However, we also stress that some of your friends may find it difficult to deal with illness or other aspects of your situation. With some, you may have to accept that they are not able to interact comfortably with you. Either you or they may become ill at ease in the relationship. It has often been said that we find out who our real versus fair-weather friends are when life challenges us most.

Looking After Yourself: Eating, sleeping, exercise, grooming, and relaxing are all examples of things you do to look after yourself and your health. Illness can affect the time that you spend looking after yourself.

First, illness may interfere with your best efforts. You may not always sleep as well as previously. You may not feel like eating or exercising regularly as before. Second, illness challenges your ability to look after yourself, at exactly the time when it is most important to do so. The potential benefits of looking after your health and well-being are always great. But the benefits may be the greatest at times when illness impairs your health. Third, you may have to spend time looking after your health in ways other than you might prefer. Attending doctors' appointments, going for tests, and spending time in hospital may be in the best interest of your health and well-being. But this doesn't mean that this is how you would choose to spend your time.

The destructiveness of these three effects can be striking. You may expend more of your time and energy caring for your health. But at the same time, be less able to care for your well-being the way you had before you became ill. With the business and worry that can occur with illness, time previously taken for relaxation and rejuvenation can appear expendable. The simple things that we do to care for our well-being may appear less pressing than the more immediate demands of illness. This is common and understandable. It is likely that most people respond this way when illness first arises. But if illness persists, neglecting yourself can allow the illness to have a much greater negative effect on your well-being than is necessary. Much of what we discuss throughout **Surviving Transplantation** strives to counteract this natural tendency.

Continue reading [Chapter 2](#)

Balance

In his 1990 book **All I Really Need to Know I Learned in Kindergarten** ([ref 4](#)), Robert Fulghum stresses the importance of balance in daily life. He writes, *Live a balanced life - learn some and think some and draw and paint and sing and dance and play and work everyday some*. Of course, none of us will (or will want to) meet this ideal on a daily basis. But the message is clear. Personal well-being is in part dependent upon our ability to balance our time and energies between a variety of pursuits. It is similar to what nutrition experts teach us. Eat a portion from each of the four food groups (meat, vegetable, dairy, and grain) each day.

Illness and the treatment it requires can force shifts in the balance between the activities of your daily life. You may have been more or less satisfied with your lifestyle before you became ill. But regardless, the onset or worsening of illness will throw you even more off balance. You may have to spend more time dealing with your health care needs. Or you may be off work and find that you suddenly have too much time on your hands. If your leisure interests require physical exertion, you may temporarily lose your preferred means of play and relaxation. You may not have the time or energy to go golfing with your friends. But at the same time, you may find that you have to rely on friends or family for things that you have previously done for yourself. There are countless more examples of how illness can disrupt your preferred balance of lifestyle activities. You are likely aware of other examples from your own life.

Our goal is not to simply explain how illness can disrupt your life. Most readers already know firsthand, of the distress that serious illness can cause. But not everybody has the time to stop and think about how the distress arises. How is it that illness leaves you feeling thrown off balance and out of control? With this simple framework, we hope to lay a foundation of understanding that will encourage helpful problem solving. Later chapters build on this foundation and offer ideas for reclaiming your sense of control and well-being.

You had a lifestyle before illness or transplant. Your life has or will be, at least temporarily disrupted by health circumstances. To regain your equilibrium will inevitably require some combination of problem solving, working with others, and adjustment on your own part.

Continue reading [Chapter 2](#)

Dealing With Change

Lifestyle changes inevitably occur with serious illness and transplant. However, it is a natural tendency for most of us to resist change. This is particularly likely when changes are imposed on us unwillingly. When our health deteriorates, the last thing that most of us want to do is to 'give in' and adjust something about ourselves or our lifestyle. Even if we recognize that it is necessary, it is not easy to know how. At first, it may seem easier to do nothing than to face making all the necessary changes. Taking the first step is often the most difficult.

There are times when it is best to remember that you do not always have immediate control over all aspects of an illness or its treatment. But you can always assert some choice about how to respond. By setting priorities and making choices sooner instead of waiting for the last possible moment, you are more likely to adjust things to your liking. You are also more likely to exert your preferences and to retain a sense of control. An ancient Chinese passage from the Tao Te Ching ([Ref 15](#)) suggests the benefits of acting early by telling us to plan for the difficult while it is easy.

Roger: Roger was looking forward to his lung transplant. He had lived with cystic fibrosis all his life and had struggled successfully to face the challenges his illness had set before him. Despite this, he had always kept up with others at school and work. Often Roger excelled, despite the limitations his illness placed on him.

The past year awaiting transplant had not been easy. Roger was on sick leave from work and had to wear an oxygen mask most of the day and night. *I can 't fool anyone now, he thought, everybody can see that I am sick.*

Weeks ago, the physiotherapist on the lung transplant team had suggested that Roger might use a wheelchair when he went outside. This would enable him to stay out longer and keep up with others. He would also have more energy for rehabilitation exercises. But Roger had always promised himself that he would never use a wheelchair. *That would be too much*, he always had said. To Roger, a wheelchair signaled that cystic fibrosis had bettered him. He had seen others arrive at the hospital's cystic clinic in a wheelchair. Before long, they did not come any more.

It eventually became obvious to Roger that he was avoiding certain activities because he did not have the energy to keep up. It had become easier for him to stay in the house than to go out. He knew this had an impact on the family. Someone would always stay at home with him. They would change their plans instead of leave him home alone.

When he did go out with family, everybody walked slowly so that he didn't fall behind. Last week when out at the mall, he saw tears in his mother's eyes. He knew how painful it was for her to see him trying to keep up and getting short of breath.

One day his sister brought a wheelchair home with her. She said, *We're going out for a walk. You're going to go stir crazy if you don't get outside.* Roger surprised both himself and his sister when he just said *okay*. That day they walked for longer than Roger had been out for months.

Roger remembered something that the transplant coordinator had told him when he first entered the program. He had said that a transplant candidate must do *whatever it takes to build and conserve strength for the transplant*. Now Roger saw that he had allowed his pride to postpone his use of a wheelchair, an aid that could clearly benefit his health and well being. *Live and learn*, he thought, *but as soon as I've had the transplant, I'm getting rid of this chair.*

We all live within the boundaries allowed by our health, abilities and resources. Serious illness and transplant can impose limits and challenges that nobody would choose. But to be human and to live in this world requires flexibility. As our world changes, so must we. Fighting something over which you have no control is a drain on your energy and resources. The trick is to recognize when to fight and when to adapt. There is a big difference between fighting illness and fighting reality. Roger was not fighting cystic fibrosis when he avoided the use of a wheelchair. He was trying to fight the reality of his health. By doing so, he let illness rob him of the chance to remain involved in life. To adjust does not mean that you must give up hope, or give in to some predetermined destiny. By working with what life offers you today, you conserve yourself for the opportunities and challenges of tomorrow.

When time or energy are scarce, you may have to set priorities for your activities. But this is not something that most of us do very easily, or very well. This is especially true if it means saying no to activities or people we enjoy. Many of us tend to take on more than we can handle comfortably at once.

Tory: Age thirty-three and newly married, Tory had an unusually hectic schedule when she became ill with liver disease. She often worked late, volunteered at a nursing home, played league basketball, attended her husband's amateur comedy group and sustained a very active social life.

Tory found it difficult to slow down and set priorities after she became ill. The waiting period before transplant was frustrating because she could do so few of the things that she enjoyed. She always felt that she should be able to get more accomplished than she did.

When illness or other circumstances force you to rank your interests or activities, watch out for the word 'should' in your thinking. It is too easy to identify with other's expectations for yourself. This may be a costly error when you have only a limited amount of energy. Your health can suffer.

For example, you may believe that you should always have dinner ready when your family gets home. Tory felt that she should stay overtime at work to be certain that she was always ahead in her work. When you notice yourself saying I really should do this or that, see if you can replace the phrase I should with I want or I need. *Do I really want or need to do this? Is it really necessary or important? And who exactly is it important for, me or someone else?* When time or energy is scarce, these can be useful questions to help you decide your priorities

Questions

Before I became ill, I felt as though I had some control over my life. Now it is as if illness and doctors have taken over. Is there nothing that I can do?

This question strikes at the heart of how illness can frustrate and demoralize people. Illness chips away at your personal sense of mastery. It disrupts your plans and frustrates your goals. It can tire you, slow you down, distract your mind. It can make you feel or look differently than you wish. When ill, a great challenge is to retain a sense of control. Otherwise, dignity is eroded. A sense of resignation takes hold.

In response to your question, there is lots that you can do. Each chapter in *Surviving Transplantation* aims to enhance your ability to live life fully in the face of illness. The approach that we encourage is simple. Many events occur in your life each day. You have influence over some. Others you do not. Your first job is to realize this truth. Your second job is to learn which is which.

What do you have the potential to influence? What do you not at this time? When you see some potential for control, seize the opportunity. For those events over which you have little or no control, you may find someone else who can help. This of course, is how you came to consider transplantation. Your hope is that the transplant team can help you to do something that you cannot do alone. You hope that they will help you to regain your physical health.

But these comments only begin to address your question. Next, you must look at how you have directed your efforts at control. Many people work very hard to influence their lives and health. Yet, many also ignore much of their potential to do so. This is why we have tried to broaden your view of health. You may not have full control over all aspects of your physical health. But you have great potential to influence your approach to illness, your response, and the meaning that illness holds in your life.

Too many people assume that control means they should not have to adjust their own lifestyle. To them, control implies that they have to either change their circumstances or resign themselves to fate. This is mistaken thinking. It severely limits your options for influence. Even if you could directly change nothing about your physical health, there are always adjustments in your self that can positively affect your health. By addressing these and many other personal issues, you allow a greater opportunity to directly enhance your health. Further, a healthy state of mind is likely the best nourishment that you can give your body in its efforts to combat illness.

Waiting for Transplantation

I rage for life. I want so much to be free. ([Marion Woodman 1985](#))

Each candidate will have their own story of how they came to require organ transplantation. Common to all, is the presence of a physical condition that has caused a body organ to cease working properly. Discussion of the many illnesses that might result in transplant surgery is beyond the scope of this book. Appendix A lists several books that deal with specific illnesses such as heart disease or diabetes. Your transplant coordinator or doctors probably can suggest other books that pertain to your condition. Our discussion continues from the time that you first consider an organ transplant.

Application for Transplant

Your initiation into the world of organ transplant typically begins when a doctor first suggests that you may need to consider transplantation as a treatment option. Ideally, you would have had some previous warning that transplant was a possibility. If so, you might have had a chance to search out some information on transplantation. Or maybe you have spoken to someone who has had a transplant. For example, those receiving dialysis treatment have usually heard that they may someday benefit from a kidney transplant. Knowing of this can help them to prepare themselves for referral to a transplant program.

But many will react with shock at first mention of organ transplant. This is most likely to occur when the patient has never before considered the idea of transplant. Fear and apprehension are likely to occur when either the doctor or the patient consider transplantation a last option for treatment. Referral for transplant can be a potent reminder of the severity of one's medical condition. Consequently, referral can be an important landmark in an ongoing process of adjustment to illness.

At the time of referral, your doctor will send information about you to the transplant team. But many transplant programs also insist on their own assessment before they will place your name on their waiting list for surgery. This assessment typically involves a series of interviews, physical examinations and medical tests. You may be lucky enough to live near a hospital that offers the type of transplant that you need. If so, your assessment for transplant may just require a few extra appointments. Some programs will admit you to hospital for a few days to complete their assessment. If the hospital is not near your home, you may need to travel to a transplant center for assessment. Travel, meeting new staff, and staying in a new hospital can contribute greatly to the stress of the application process.

The transplant assessment can have several goals. The tests and consultations help the team decide if your medical condition is one that can benefit from a type of transplant that they can offer. They will assess how well the target organ (e.g., heart, liver, etc.) is or is not working. Transplant surgery usually occurs at or near the point when the diseased organ ceases to work at all.

This initial assessment also ensures that the team is thoroughly familiar with your general health. They must deal with any other medical condition you may have. And they must be certain that another condition will not unduly impair the outcome of transplant surgery. A transplant team looks for a candidate who has severe disease in the organ for transplant, but who is otherwise healthy. This ideal is seldom found. The teams become expert at managing many medical conditions.

Another goal of the pre-transplant assessment is to ensure that you are aware of what you are heading into. Your transplant team will prefer that you and your family make an informed decision about transplantation. The coordinator will provide you with booklets to read. You should ask questions about anything that is not clear to you.

Sometimes, the team will offer to introduce you to other candidates or recipients. This is an excellent opportunity to find out first hand what it is like to wait for, receive and recover from transplantation. But keep in mind that you will learn only of one person's experience. Your own experience with transplant may be similar or very different from theirs.

Often, it is enjoyable to meet others with similar challenges to their health. Several candidates have told us that it was not until their assessment for transplant that they first met others with an illness similar to their own. One woman named Janet, had lived almost twenty years with an illness so rare that most doctors have never even heard of it. During her assessment for lung transplant, she met another candidate with the same condition. Janet was overjoyed. *I had never met anyone before who could really appreciate what I had been through*, she said. Later, Janet described their meeting by saying that, *This must be what it is like for brothers or sisters, separated by adoption at birth, to later meet as adults*.

The pre-transplant assessment is not just a time for the team to decide if they can offer you a transplant. It is also a time for you to learn more about your condition. And for you to finalize your decision about whether you wish to pursue a transplant at this time.

Continue reading [Chapter 3](#)

Non-medical Criteria for Transplant

The transplant team must be alert to any illness that they cannot treat or that will unduly impair the success of the transplant. The reason for this is simple. Organ transplant requires valuable and scarce resources that must be used so that the greatest possible benefit results. Few would suggest that transplantation should proceed when it is predictable that another illness will rapidly cause the graft to fail.

Besides physical conditions, problematic behavior can result in graft failure. For example, if a recipient does not take their anti-rejection drugs properly, the transplant will fail. If the team could predict this unfortunate outcome, they would try to resolve the problem early. Otherwise, they would likely defer surgery. The argument against surgery would be that the applicant will do poorly with or without transplant. If the team knows that a recipient will reject an organ, it is most judicious not to go ahead with the transplant. The reason for the rejection may not matter. The important factor is whether rejection is preventable.

A transplant team will agonize over any decision that may require them to defer necessary surgery for a patient. Their goal is to transplant people, not turn them down. But they have a responsibility to conserve scarce resources for those who can benefit. Unfortunately, the prediction of human behavior can be very inexact. Partly because of this uncertainty, some transplant programs do not apply anything other than medical criteria for the acceptance of applicants for transplant. Other teams have exclusion criteria for patients with severely problematic behavior. For example, one's use of drugs or alcohol may be out of control. If so, it is likely that a transplant team would refer this applicant for treatment before considering a transplant.

If you have an assessment before transplantation, you may have an interview with someone who asks questions about your personal life. This interviewer may be a nurse, social worker, psychologist or psychiatrist. They may also wish to interview members of your family. The purpose of this interview is to identify your individual strengths and vulnerabilities. These specialists may suggest strategies that can help you or your caregivers deal with transplantation. Usually, they are available to you from the time that you apply to a program until long after surgery. Many transplant programs offer counseling services for candidates and recipients. Their goal is to predict and deal with any personal circumstances that might have a negative influence on you or your health.

This assessment of your personal life might have one additional purpose. The team may wish to assess your personal circumstances against criteria for acceptance to their program. As we have said, some programs will require that you first receive treatment for drug or alcohol addiction before enrollment on their waiting list. A personal interview is the usual way for the team to decide if you require this or another type of help. Each transplant team differs about what, if any, personal criteria they use to decide about your acceptance to their program. This is a controversial practice that each program will approach in its own way.

As an applicant for transplant, you and your family have both rights and responsibilities when providing personal information to the program. You have a right to know beforehand, the team's criteria for enrollment. The interviewer has a responsibility to tell you the purpose of their assessment and how the team will use the information that you provide. This ensures that you are properly informed about this important part of your assessment. Your responsibility is to answer questions honestly. If you withhold relevant information about yourself, you may jeopardize your health and your working relationship with the transplant team. Only with awareness of these rights and responsibilities can a transplant team and applicant hope to work together toward the desired outcome.

Bertram: Bertram did not have an easy time during his recovery from liver transplant. But after one month, he was well enough to walk around the ward and look after his own medications. At least this was what the nursing and medical staff expected of him. Bertram still spent most of the day lying in bed. He said that he didn't have the energy to get up. Often, he didn't feel like eating or seeing visitors.

The transplant team could find nothing wrong with Bertram's physical health. But after another week with no improvement, it became clear that Bertram was severely depressed. A psychiatrist interviewed Bertram and his wife, then suggested an antidepressant medication. However, three weeks later, Bertram remained very depressed. This worried the team greatly. If he stayed in bed longer, he risked dangerous complications.

Finally, the psychiatrist contacted the family doctor that had referred the patient to the transplant team. This doctor confirmed that he had treated Bertram for serious depression before. Several members of his family also suffered with depression. He said that many treatments had failed to help Bertram. But he had responded well to one antidepressant drug. The doctor said that the family had instructed him not to release this information before. They assumed that the transplant team would decline Bertram for surgery if they knew of his problem with depression. Unfortunately, if the family had told the transplant team of Bertram's history, the team could have provided him with appropriate treatment earlier.

Most transplant teams will have a therapist available to treat mental health problems. Their goal is to minimize any risk to the transplant's success. But these specialists must know the patient's clinical history to ensure the proper treatment. Otherwise, you risk wasted time and poor treatment. Of course, the greatest danger is that lack of accurate information will compromise the health of the transplant candidate or recipient needlessly.

We suggest that you learn what, if any, criteria that a transplant team uses to choose candidates for surgery. Describe honestly to them, any mental health problems and treatment that you have had. Only in this way can you and the team work together to ensure the best possible outcome.

Continue reading [Chapter 3](#)

Acceptance to a Transplant Waiting List

A sense of relief can occur when an applicant first enrolls on a transplant waiting list. Enrollment resolves any uncertainty about acceptance to a program. It is reassuring to know that you are now in the care of professionals who will do everything possible to help you regain your health. We wish that relief was the only feeling that ever occurred during this time. Everybody would be overjoyed if there were no further hurdles to overcome. But in reality, the events and personal reactions that follow enrollment on a waiting list are many.

Your previous experience with illness will influence your reaction to enrollment on a waiting list. Kidney transplant offers two examples for comparison. Someone on dialysis for several years is likely to look at transplant as a welcome opportunity for relief from the constraints of dialysis. There is usually at least mild apprehension about surgery. But for the candidate with a lengthy history of illness, their excitement over the potential outcome is often a potent antidote to any fear of surgery.

Now consider a person whose kidneys have failed slowly over several years, but who has never required dialysis. For him or her, kidney disease has been an inconvenience. But it has not intruded on their lives nearly as much as dialysis can. Compared to these circumstances, kidney transplant can seem a great intrusion and risk. It is now not uncommon for those with kidney disease to have a transplant without ever requiring dialysis. These recipients may imagine that immediate treatment by transplant is preferable to dialysis. But they will likely hold far greater ambivalence about transplant than someone who has received dialysis for years. The prospect of transplant seems a little less exciting, a little less of a relief. A woman known to the authors offers another example.

Barbara: At age nineteen, Barbara had required dialysis for three years. We heard from Barbara how two previous attempts at transplant had failed. Her doctors now recommended a third try. But her lack of optimism concerned them. They had known Barbara as excited and optimistic before her previous transplants. Her mood was now very blue. But they hadn't known how demoralized she had been after the second failed attempt. Barbara had decided then that her lot in life was to remain on dialysis indefinitely. The failed transplants had taken their toll on Barbara's confidence in herself and toward her future.

The team worried that Barbara was far more pessimistic than necessary. They believed that in her case, a successful transplant should still be possible. It worried them that due to her diminished confidence, she might decline an opportunity for what she most wished.

Although skeptical that she would change her mind, Barbara agreed to join a group that met and talked about dealing with illness. She quickly learned that many others faced circumstances similar to or worse than her own. From their own experience, they recognized Barbara's fear of getting her hopes up again. The potential for disappointment was painful.

Nobody tried to change Barbara's mind about another transplant. But the discussions did give her lots to think about. She knew that several others in the group would jump at her chance for better health. Eventually, Barbara accepted the team's suggestion of a third transplant. But she still did not show much enthusiasm about the surgery. Given her previous experience, there was no way that she could ignore the possibility that things could go wrong. The transplant team understood that for Barbara, this was a way of trying to protect herself from any future disappointments.

Besides previous experience with illness, other factors can influence your attitude toward transplantation. Are you well informed about what to expect? What have others told you? Do you hold some mistaken views? Have you considered your decision fully?

The type of transplant that is proposed will affect your reaction. Very high risk surgery will arouse greater apprehension than surgery that involves lower risk. A greater degree of apprehension may occur in those who must travel to an unfamiliar city for transplantation. Of course, different people will react differently to the same situation. We each bring our own life history, attitudes, and expectations to a new situation.

There always exists some combination of excitement and trepidation at the prospect of transplantation. A certain amount of fear is both common and normal. For some, their anticipation of benefit far outweighs any apprehension. They agree to transplant with little apparent hesitation. Others must make their decision in the face of marked ambivalence. What may seem like an obvious decision for many, can be more complicated or lead to an opposite conclusion for others.

One dialysis patient has written of his rationale for declining kidney transplant at a time when most others readily agree to the surgery. His reasons, based on intensive and insightful personal reflection, resulted from his consideration of the risks and benefits to his own life. New candidates have often asked us if others had expressed fear about transplantation. They say to us that, *Everybody looks so excited about transplant. It's like they can 't wait for surgery.* Although apprehension is common and normal, new candidates can sometimes feel very alone with their fear.

There is no single attitude that you must hold about transplantation. Your own reaction is as valid as the next. And don't assume that everybody else is as calm as they appear. You cannot know what somebody else is thinking or feeling without asking them. Once you ask, you will find that you are not alone.

Continue reading [Chapter 3](#)

Waiting for Transplantation

The length of wait for a transplant can vary widely. Hopefully, you will only have to wait a few weeks. But for some transplants, you could wait two years or more. The type of transplant that you require and the availability of donor organs largely decide the length of wait before transplantation. Most candidates find awaiting surgery a stressful time. The longer the wait, the greater the stress.

Waiting for transplant is most challenging for those who require a vital organ transplant (e.g., lung, heart, liver). Without transplantation, these candidates expect to die. One lung transplant candidate's husband has aptly described this time as like *two lives on hold*. ([ref 8](#)) Due to serious illness, his wife was unable to enjoy much activity. They were left waiting for transplant surgery to turn things around for her. Lack of control over when the transplant would occur resulted in an uneasy sense of waiting for something to happen.

Reality Sets In: The work involved in applying to a transplant program and completing their assessment will preoccupy the potential candidate. When concerns arise, they usually focus on whether the team will accept the applicant to their waiting list. *What if I am not found suitable for transplant? What will happen to me then? What if they find something unexpected? Will they turn me down? Could I be more ill than anybody knew?* Ideally, the results of the team's assessment will reassure these concerns.

Once enrolled on a waiting list, room exists for other concerns to arise. Those waiting for a vital organ transplant face vastly opposing outcomes. The opportunity for renewed health is close at hand. But the risk of further decline in health or death persists. For some candidates, periodic thoughts of these undesirable possibilities create distress. We have often heard comments such as, *I try not to think about dying. I have to keep my hopes up for the transplant. Or I want to be optimistic. But negative thoughts still pop into my mind.*

When death is even a remote possibility, it is difficult for many candidates to ignore it completely. Reality presses on their minds. Candidates have asked us how they can best deal with these types of thoughts. Many worry that 'negative' thinking will harm their health. Our suggestion is to hope for the best, but prepare for the worst. This approach encourages a healthy balance. You can focus your mind on the desired outcome, but not completely ignore the alternatives.

For some, to face and prepare for the worst possible outcome results in a sense of relief. At the very least, this can free you from worry that potentially important chores remain undone. This approach is not for everybody. Many will find that these worrisome thoughts do not cross their mind at all. But for others, preparation for any possibility is one way to reduce ruminative worry.

Ken: Ken hoped for a good recovery after heart transplant. But he was also aware of the risk involved with the surgery. He didn't want to upset his wife Maureen. But he couldn't stop thinking that he should look after his affairs. *Should I talk to Maureen about our finances, or about my will? Will she think me*

morbid? Or will it look as though I am pessimistic? She would want me to think positively.

Eventually, Ken decided that he must confront the concerns that played on his mind. It was painful for his wife and family to hear him talk of a will and his wishes for a funeral. But he reassured them that he did not want or expect to die. It's just that he had always been a person who planned ahead. He could not feel at ease with the nagging concern that he was unprepared. After talking with Maureen and others, Ken found that he was less distracted. He was better able to focus his mind and devote all of his mental energy to the upcoming transplant. And Ken found that he could enjoy time with his family, without worries arising constantly in his mind.

The wait for transplant is a time to remind yourself of the resources available to help you. Remind yourself of the confidence you hold in your doctors and other caregivers. These include the internists, the transplant surgeons, the nursing staff and the technical staff who handle the blood tests and other equipment. They have years of training and experience that they will devote to your health care. Remind yourself of the family and friends who are ready to see you through the transplant and recovery. And remind yourself of any spiritual or philosophical beliefs that have in the past, provided you strength and comfort. These are the resources to draw upon during this time of stress and little control.

Thinking About the Donor: Candidates awaiting a donor organ find themselves in a dilemma. They hope for transplantation, and the possibility for renewed life and health that it promises. But they are also aware that someone else must die before an organ will be available for transplant. Candidates also know that others wish for and need the same donor organ as they. At times, candidates feel that they will benefit only from the misfortune of others. It is not unusual to find yourself fantasizing about an accident that will make an organ available for transplant. These can be disturbing thoughts to notice on your mind. They arouse guilt in some candidates.

Logic suggests that there is no reason to confuse your wishing for a donor organ with wishing for another person's misfortune. Your thoughts will in no way influence what will happen to another person. Many surveys suggest that people appreciate the idea that after death, their organs may grant life to another person. The ability to transplant organs provides a tangible meaning to death that has not previously been available. You cannot stop yourself from wanting to recover from illness. You might as well try to reassure yourself that such thoughts are normal and not reason to feel guilty.

Gallows Humor: During the French revolution, an aristocrat was placed in the guillotine. He looked upwards and said, *Hey! Is this thing safe?* This is an often quoted example of gallows humor.

Laughing in the face of danger is a very human response. You are likely to hear gallows humor among transplant candidates and recipients. *I always make sure that my bellboy is working before a holiday weekend.* This type of sardonic wit can help to relieve the tension for some. Within the bounds of social acceptability, gallows humor can help some to deal with the strain of awaiting transplant.

Superstitions and Rumors: We recently overheard a candidate comment that, *I've heard that they will kick you off the transplant list if you can't cope.* After several years of work with the transplant programs

at our hospital, it appalled us that beliefs such as this would still be circulating. But this comment should not have surprised us. Nobody should underestimate the degree of uncertainty, unpredictability and ambiguity that candidates for transplantation must face. This context is fertile ground for any comment that plays on a candidate's worst fears.

Gather a group of people together. Place their health at risk. Make their fate dependent upon others. Force inactivity. All sorts of wild rumors and superstitions will fly. *I hear if they don't like you, you will wait longer for transplant. If the surgeon is at a party, they pass up on donor organs. Deaths always come in threes. If you don't take part in their research, they will stop prescribing cyclosporine for you.* As unbelievable as these comments may appear, these are all rumors that people have reported to us, seeking our reassurance of their inaccuracy.

Take any rumors that you hear with a grain of salt. Check them out with staff who will know the facts. Most important, don't pass along questionable information. The rumor may sound harmless to you, but have a threatening implication for another candidate. If you attend a transplant support group, mention any rumors that are circulating. This will clarify the facts for yourself and other candidates.

Competition: Concern about competition with other candidates enters the mind of many transplant candidates at some time or another.

Lawrence: After waiting almost two years for a lung transplant, Lawrence was worried. The move to the transplant hospital had separated him from his family. And it concerned him to see his health deteriorate. Earlier, Lawrence disagreed about how the transplant team treated him for his lung condition. They had a very different approach from his usual doctors. Now he wondered if they had passed him over for transplant because of this disagreement. So many others had waited a much shorter time.

Transplant teams usually strive to follow fair guidelines regarding the priority of candidates for transplant. Typically these guidelines are available to read. But you will not always know exactly where you stand in relation to other candidates. The team does not wish to arouse competitiveness. And the priority of candidates for transplant can change rapidly.

Many teams will try to transplant those candidates in most urgent need. But many factors influence the decision of whom to transplant. For example, there must be an acceptable match (e.g., in blood type) between the donor and recipient. For lung transplant, the size of the donor lung must approximate the size of the candidate's chest. Candidates with unusually large or small lung cavities often wait longer for an appropriate donor. This factor is not so important with other types of transplants.

Finally, most teams try to minimize the number of people on their list who are in direct competition for donor organs. For example, a lung transplant team would try to not have several people with similar sized lungs and blood type waiting simultaneously. Obviously this is unavoidable at times. When competition for a donor organ does occur, those who have waited the longest or who are the most severely ill would usually be ranked highest for transplant.

The Call for Transplantation

There isn't a lot that we need to say about this event. It is what everything else has been in preparation for. Have a small bag packed to go. The team will call. You will go to the hospital. At this time, you place your confidence in the transplant team. You trust them to do their jobs well.

There is one interesting aspect of this time that we would like to point out. Until the day of surgery, the transplant team, your family and this text have all encouraged you to remain as independent as possible. They have encouraged you to be an active participant in your health care. Now, you are beginning a highly technical phase of transplantation, during which you will be largely dependent upon the staff and their tools. For the next few hours at least, there is only one good approach to take. Do as directed and allow the staff to complete their assigned tasks. Ask questions if you like. But remember that the best time for questions is before this stage. The team may be very busy for the few hours before, during and just after your surgery. This is the time they have trained for.

We have tried in our writing to avoid suggestions that are much easier said than done. But this time it is unavoidable. Let the team work while you rest. Very shortly, the doctors and nurses will be encouraging you to be more active again. Soon after surgery, they will expect you to start looking after yourself again.

Continue reading [Chapter 3 Questions](#)

Questions

The heart transplant program at our university hospital declined my brother for surgery. Is there anything else that we can do?

It is fortunate for your brother that he has family around him at this time. We are sure that you are all greatly disappointed. There are several things that you should try to find out from the transplant group. You or your brother might talk with them directly. Or you may question the doctor that referred your brother to the program.

First, you need to know if the team believes that your brother needs surgery right now. They may have decided that some other type of treatment is best. Or he may not be sick enough to warrant heart transplant currently. If so, your brother's own doctors can continue with his treatment for now. They can refer him again when the time is appropriate.

Alternatively, the transplant team may respond that your brother's heart does need replacement. You should then ask why they are unable to accept him to their program. They may have found that your brother is too ill to survive the surgery. Or they may not offer exactly the type of surgery that your brother requires.

These are only some of the several potential reasons why the team might have decided that they cannot transplant your brother successfully. You can ask them if there is anything that you or your brother can do to make transplantation feasible. Ask also if there is any other transplant center to which your brother might apply.

The transplant coordinator has asked me to read several booklets about the surgery and what will happen afterwards. They even want me to take a tour of the intensive care unit. I don 't like to think about what it will be like after surgery. Is all this really necessary?

This is a complex question to answer. There is no doubt that there are things that you must learn to assume the responsibilities of a transplant recipient. The coordinator will typically give you booklets to read when your name is first placed on the waiting list for surgery. The team's goal is to provide you with an opportunity to prepare yourself for what is ahead. Some candidates find it helpful to know in advance what will happen to them. Unfortunately, others find that it makes them more nervous.

You might speak with the coordinator to find out what is most necessary to know. Consequently, you can read some topics now and leave others for later. But you might also consider why you hesitate to follow the coordinator's suggestions. Likely, you are uneasy about what lies ahead.. Nobody finds it comforting to think about what it will be like to recover after major surgery. Some prefer to know what to expect. Others, like yourself, may wish to not think about it until the time arrives.

By not preparing yourself, there is a greater risk that some unexpected occurrence will catch you by surprise. Since you must face surgery and recovery eventually, you might think of some ways to be more at ease with what is to come. Later chapters in *Surviving Transplantation* suggest ideas. You will have enough to deal with after surgery without having to deal with surprises that you could have prepared for.

The liver transplant coordinator has suggested that I should have a will. Does this mean that they expect me to die?

Everybody should have a will. It has nothing to do with how likely you are to die. A will ensures that those who survive you will know how to carry out your wishes. Since none of us knows when we might die, we should all have a will prepared.

Writing your will is no pleasure. Few like to contemplate their own mortality. But it can be a relief to have it completed. Once done, you have prepared for the worst possibility. Then you can hope for and work toward the best outcome. You will not have the nagging worry that something important remains undone. This is likely why the transplant coordinator has discussed your will with you. He or she has learned that it is best for candidates to have other matters arranged as best as possible. Then, they can focus their attention on their health and the upcoming transplant. Unfortunately, the coordinator has likely also witnessed the problems that can arise when a death occurs, but no will is available.

If you are unsure about your chances of survival, you should ask the transplant team for their opinion. But again, their response has no bearing on whether you should have a will. Everybody should have a will.

My husband is waiting for a pancreas transplant. The team knows that he had an alcohol problem several years ago. Recently, he has started to drink at night to help with his sleep. I don't know what to do. If I tell the transplant coordinator, will they take him off the transplant list?

You have good reason for concern. Stress and other problems can disrupt sleep. But alcohol is never a solution. It will not allow your husband to have a restful sleep. Alcohol disrupts the sleep cycle and is highly toxic to normal sleep. Your husband risks losing control of his drinking. He is fooling himself.

Transplantation will present your husband with several challenges to his physical and emotional well-being. He needs a good working relationship with the transplant staff to best deal with sleep or other problems. The transplant team could learn in another way about his drinking. There is no doubt. Your husband is placing his health and his relationship with the transplant team in jeopardy.

You are in an awkward position. Only you are aware of the problem. But informing the coordinator is not the first approach. You should first consider speaking to your husband. Ideally, let him know of your concern. Insist that he discuss his situation with the coordinator or another person on the team. Remember that they accepted your husband to the transplant list knowing of his previous problem with alcohol. Even if this was not so, the team should respect his ability to confront a potentially serious problem. By working with the team, your husband is more likely to find adaptive solutions to his

troubles. Your husband may require treatment specifically for misuse of alcohol. If so, the team must decide if it is best for him to be off the waiting list while receiving this help. It may or may not be necessary.

If you are unable to discuss this with your husband yourself, maybe you could ask a trusted friend or other family member to approach him. What you should not do is ignore his drinking. This is a potentially serious problem. Should none of our suggestions be helpful, you can be sure that you and your husband have a serious problem. You may have to tell him that if he doesn't get help, it is your responsibility to see that he does. If necessary, you may have to approach the transplant coordinator yourself. Although not ideal, it is a better solution than allowing a severe problem to develop.

We have known several applicants with a previous alcohol or drug problem. Their risk of future substance misuse varies and is hard to predict. But regardless, our approach was to meet with the applicant and their support person, preferably somebody who lived with them. We asked them for an agreement. If either became concerned about the applicant's use of alcohol or drugs, they would first discuss it and then always let us know of their concern. This agreement insured that preferably the applicant, but if necessary the support person, would have permission to let us know that they needed help.

I have been waiting several months for a liver transplant. One recipient does not look after his health well. At clinic, everybody talks about his reckless behavior. I wish they could take his liver back and give it to somebody who deserves it. Is it wrong to think this way?

If there is one thing that we have learned, it is that there is not one right or wrong way for a transplant candidate to think. Certain thoughts may make one uneasy when they arise. But this does not make them abnormal or wrong. It is easy to understand how you might feel this way. It must be unbearably frustrating to see someone neglect what you and others need desperately to live. Transplantation allows recipients to move on with their lives. It is not possible to change everybody's behavior to our liking.

I see so many different hospital staff I am not even sure which doctor is in charge of my care. How do I keep track of them all?

Anybody who has worked in a large hospital has heard this complaint before. Transplantation can involve huge numbers of caregivers. The team approach to patient care is a result of modern hospital practice and the complexities of caring for transplant candidates and recipients. It is helpful to have some idea of the role that different staff members plays in your care.

A teaching hospital trains students from many clinical disciplines. If you receive care in such a setting, you will meet several types of trainees. Students work under the close supervision of their seniors. A medical student (sometimes called a clinical clerk), intern, or junior resident will often assume first responsibility for your day to day care. A senior resident, chief resident or fellow supervise the day to day care and report in turn to a specialist. Do not underestimate the experience of the senior trainees. Many of them have several years of specialty experience. Any trainee not qualified to make a particular

decision or to answer a question is expected to take the problem to their senior. It is their responsibility to know which clinical problems they cannot manage.

To further confuse you, there may be several different teams of doctors involved in your care. Imagine for example that a transplant team is assessing you for a pancreas transplant. At the very least, a surgeon and endocrinologist will see you. But they may require the opinion of a cardiologist, a nephrologist or an anesthetist. If you also happen to have arthritis, they may ask a rheumatologist to help with your care. Each of these specialists may have their own trainees (an intern, resident or fellow). No wonder it can be so difficult to keep track of all the doctors.

Nursing students may also take part in your care. But usually, no more than one student and one nursing supervisor work together at a time. You may also meet someone called a clinical nurse specialist. This is a nurse with specialized training. A clinical nurse specialist may help you and the other nursing staff deal with some particular problem. Typically, there is also a charge nurse, nursing manager, or head nurse who is responsible for supervising the duties of the other nursing staff.

Besides doctors and nurses, the hospital team may include a nutritionist, physiotherapist, occupational therapist, psychologist, social worker, chaplain, and others. You should not hesitate to ask any of them exactly what role they play in your care. You might find it helpful to keep a list of names and titles for each person who you meet.

I have to explain my medical history repeatedly to different staff. Can't they just read my chart?

The team will record your history on a clinical chart. But there are several reasons why different staff will ask you to repeat your story.

Most simply, the doctors, nurses and others who assess you will find your story easier to remember if they hear it from you face to face. It is also important for members of the team to get to know you as a person, not just as a collection of medical facts. Various specialists will emphasize different questions and listen for different information in your answers. The chart may list the basics, but not the specifics that each specialist may require.

Finally, part of the role of a teaching hospital is to help the junior staff improve their interviewing skills. You obtain the benefits of having more doctors reviewing your care. Their benefit is their education.

Some parts of your medical history are very routine. You may find it less tedious to keep a written outline of past illness, surgery, medication and other treatment. You can easily refer to it when answering basic questions.

A nurse said that my husband was in denial. What exactly does this mean?

Denial is a normal means of dealing with trauma. Depending upon the circumstances, it can be either

adaptive or problematic. The nurse may believe that your husband has not responded to his situation in a way that others would. Denial could be one reason for this. She could be saying that your husband may not fully appreciate his true circumstances.

It may be useful for you to find out two things. Ask why the nurse believes your husband to be in denial. Then ask the nurse or someone else on the team if his denial is causing any problem.

For example, the nurse may have found that after repeatedly explaining the medical situation to your husband, he still does not appear to take advice seriously. He may not follow treatment suggestions or may talk of unrealistic plans. Doctors and nurses usually assume that sensible people work hard to maintain their health and recover from illness. When this does not occur, it is reasonable for them to suspect that a patient has not fully come to terms with their situation. Sometimes, the problem is denial.

If the team finds that denial has caused a problem, they will usually talk directly with you and your husband. If the problem persists, they may request help from a psychologist or psychiatrist. Sometimes, it turns out that denial has not been the problem at all. There may be some other reason why your husband has had difficulty following the team's recommendations, or the rationale behind them. Other emotional problems (e.g. depression or mild confusion) may sometimes look like denial.

Staff may also suspect denial if your husband does not appear to react emotionally to his medical condition. Obvious grief is common after one learns of a serious illness. When grief does not occur, it is reasonable for staff to wonder if the person fully appreciates their situation.

But the team must also remember that people can react very differently to similar situations. Not everybody shows their feelings openly. It may take time for a candidate to fully appreciate the meaning of new information. Emotional reactions are highly individual and difficult to predict. Some show their distress when medically unwell. Others appear calm when they are most ill, but experience grief later. A personal reaction to illness is problematic only if it hinders clinical management.

I have so many tests and appointments booked that it is hard to keep track of them all. What can I do?

Buy a daily scheduling book. You or a support person can write down your appointments. But use a pencil. The appointments can be changed by the team or others.

Whenever I go to the hospital for a test or an appointment, I have to wait. I find it irritating. Is there anything that I can do?

Hospitals and medical clinics are complex and busy settings. Rightly or wrongly, staff get used to working to their own schedule, not to yours. Your transplant coordinator is familiar with the hospital. He or she might have some suggestions. Otherwise, you may have to tolerate the situation.

Get in the habit of carrying a magazine, book, cassette player, or miniature television with you whenever

you go for an appointment. We have seen people knitting in the waiting areas. One woman wrote letters to friends while waiting for appointments.

Is it a good idea to ask other candidates and recipients what to expect?

This is a very good idea. Others who have been through similar circumstances can sometimes explain things in a way that a professional cannot. Even if you don't learn anything new, it is a great way to make new acquaintances. Many people like to talk about their experience, especially if they think that it might be helpful to you.

However, we would suggest that you keep a couple of points in mind. Do not assume that what you hear applies to you. It may or it may not. As we have emphasized throughout this book, there are as many differences as there are similarities in one's experience with transplantation.

Take any advice you receive with a grain of salt. We do not suggest that you ignore advice. But consider what you hear along with that from other sources of information. Never weigh a co-patient's advice over advice from your transplant team. Remember that the team's advice results from their work with dozens or even hundreds of other transplant patients. A co-patient's advice may be well intended, but is founded on a more narrow perspective.

Recovering from Transplantation

There is more to living than just not dying. (Heart Transplant Recipient, 1991)

What happens after surgery depends on the organ transplanted and the specifics of your own medical situation. There are some similarities, but many differences in experience between the various types of transplant. For example, compared to kidney transplant surgery, a heart recipient will typically have a longer recovery time. He or she is also more likely to spend time in an intensive care unit. Drug side effects and other complications occur more frequently with heart versus kidney transplant.

But one cannot assume that any two recipients of the same organ type will have an identical postoperative course of events. One recipient may have an additional illness, for example diabetes or a heart condition, that requires special postoperative care. A transplant team can often deal with any other health problems that you bring to transplantation. Otherwise, they will ask a specialist doctor or nurse to help with your care. Depending on their nature, other health conditions may or may not influence your recovery after transplantation.

Your experience with other illness will no doubt affect your attitude and expectations after surgery. Kidney transplant again offers an example of what we mean. When this surgery was first available as a treatment option, surgeons offered it almost exclusively to those already receiving renal dialysis. Almost all candidates for kidney transplant had been treated for months or years with dialysis. Depending on a dialysis machine to clean one's blood can be a tremendous intrusion on one's lifestyle. Doctors place restrictions on the diet of dialysis patients. They risk periodic complications. And they must allow a great deal of time for health care. Still, many dialysis patients will report that they do not feel physically very well. Usually, the intrusion of kidney transplant is far less than dialysis. As a result, those on dialysis will often look to transplant with anticipation of relief and increased freedom.

However, it is now possible for surgeons to plan a kidney transplant prior to the complete shutdown of one's kidneys. It may be possible to avoid dialysis completely. Also avoided, is the discomfort and intrusion on lifestyle that occurs with dialysis.

Nobody would argue that this would be ideal for anybody with renal disease. But in one small way, it is a double-edged sword. Rather than view kidney transplant as a source of relief and freedom, the candidate or recipient may see the surgery as an intrusion into life and work. For example, a recipient without previous dialysis treatment will not find that the side effects of anti-rejection drugs are easy to tolerate compared to the hassles of dialysis. They become an irritating complication of transplant.

Years of treatment with dialysis will ready a kidney transplant candidate to see surgery as a welcome relief. Another candidate who had never been treated with dialysis, might be more likely to view the surgery and recovery as burdensome compared to his or her previous health. It is like a man who wakes up on the morning of his wedding day and sees that the sky looks partly overcast. Assuming it had been

storming heavily for several days before, he would be pleased that the weather had partly cleared. But had it been sunny for days before, the potential groom might be a little distressed.

Other types of transplant offer similar examples. With liver transplant, four out of five candidates have had several months or years of progressive illness before the time of transplant. But for the other one of five, liver failure occurs suddenly. The need for transplant is immediate. As mental confusion is common in this situation, these candidates often have little or no memory of events since the time they first became ill.

One month after surgery, a physician might find that two liver transplant recipients had recovered equally well. But the attitudes of the recipients could be very different. One who had been increasingly more ill over a period of years would likely be overjoyed at the improvement in his or her health. Another, who suddenly became ill and remembered little from the onset of liver failure until after transplant, would view their health as much worsened than before. From what others will tell them of what has happened, they will be happy to be alive. But it will take more time and discussion for these recipients to adjust to their new life circumstances.

In this chapter, we discuss the sequence of events after organ transplant surgery. The reader must keep in mind that each recipient's experience will differ. Your past and current health circumstances will greatly influence your own path after transplant. You may wish to take a few moments to think of how your experience with illness, doctors and hospitals may have influenced your expectations of transplantation and recovery.

Continue reading [Chapter 4](#)

Postoperative Recovery

The nursing staff who work in the recovery area will likely be the first people you see when you awake. These caregivers will ensure that you are safe and as comfortable as possible. At some point, you can expect a member of the surgical team to come to tell you about the surgery. They may have already talked with your family in the waiting area. The staff will decide when you are well enough to see visitors.

When you first wake up, you may be a little drowsy. The anesthetic drugs take a while to wear off. And a nurse may give you some pain medications. These can also make you sleepy. But this will not likely dampen your excitement about finishing the surgery. A feeling of relief and euphoria may occur once you realize that the surgery is over. Regardless, the nursing staff will encourage you to lie still and try to remain calm.

Depending on your type of transplant, you may spend a few days after surgery in an intensive care unit. A stay in this specialized area of the hospital allows your body the time it needs to regain control over basic bodily functions (e.g., breathing, heart rate, blood pressure). The staff who work in an intensive care unit have trained to provide the care that you need to see you safely through this period. This care may entail the use of a machine that helps with your breathing (called a ventilator); tubes that go to and from your blood vessels; a small tube to empty your bladder; and a heart monitor. As your body resumes control, the staff will remove some of these connections. This will assure you that you are recovering well.

Not all transplant recipients will require a stay in an intensive care unit. After a short time in the recovery room, you may go directly to a surgical ward. Some wards now have specialized rooms called step down units. The care that is available in a step down unit is sort of halfway between that of an intensive care unit and a general ward. Any of the doctors or nurses with the transplant team can tell you in what area of the hospital you will go to from surgery.

These first few hours or days after transplantation can be a trying experience. Few find it easy to lie in bed calmly while uncomfortable. It is not usual for any of us to lie around while others care for our health and personal hygiene. But immediately after surgery, you are very much dependent upon the skills and sensitivity of the nursing and medical staff who look after you. It is best to place your trust in them. Let them do the work that they have trained for.

Approach the time immediately after surgery with the attitude that others will look to your needs. Let them know how you are. If you cannot talk, write your message on a notepad. Even if you cannot write, surgical and intensive care unit nurses become expert at interpreting your gestures. Let them know if you are in pain, confused or frightened. They will do their best to make you as comfortable as possible. Of course, the only time that you will really be comfortable is once you are sitting at home in your favorite chair.

Major surgery can disrupt your sleep for a few days or more. The surroundings are unfamiliar. It may be noisy. Or you may fall asleep during the daytime and then find yourself alert in the night. The drugs and other treatments that the team will prescribe after surgery can sometimes interfere with sleep. The team might prescribe a sedative to help you get some rest. But this does not guarantee a peaceful sleep. This may be a problem that has to run its own course. Your sleep should eventually return to what is normal for you.

During this time, it is not uncommon for some transplant recipients to have dreams while they are half awake. If this occurs, let the staff know. They may or may not need to do something about the problem. It may pass on its own. But it will make their job easier to know what is happening with you. Sometimes, disorientation accompanies sleep disturbance or waking dreams. Staff will call this delirium or confusion. We discuss delirium more in chapter eight.

As you recover your health, the team will expect you to be more active. At times, you and your doctor or nurse may disagree about how active it is best to be. For example, you may not feel well enough to be out of bed as much as they wish. On the other hand, you may feel able to do much more than the team prefers. Should disagreement arise, discuss a compromise. Better yet, try to accept their guidelines.

We suggest this because how you feel at any moment is not the only, and may not be the best indicator of how much activity is advisable. Remember that the team uses many factors to measure your state of health. These include their bedside examination, laboratory tests and other observations. The team has extensive experience. They know the potential pitfalls of too little or too much exertion. They care about how you feel. And they can respect your opinion. But they have many other things to consider. You may know best how you feel. But you do not have their experience or perspective.

Family and Friends: Others often ask how they can best help during the early recovery period. Remember, it is the nursing staff's duty to care for the transplant recipient. They are very much in charge, particularly during the early recovery period. Generally, only close family members can visit at first, usually at most two at a time.

When visiting, try to be alert to the recipient's condition. It can be helpful to check with a nurse at the start of your visit. They can tell you if the recipient has been busy, has had many visitors, is tired, feeling well, or not. Quiet companionship for a short time is often the best approach.

Follow the recipient's lead. They may want to hear about work, world events or what is going on at home. If so, tell them. If they just want to lie quietly, sit quietly aside. Boredom can be a real problem in hospital. A recipient may enjoy it if you read something aloud. You could read from the newspaper or from cards that others have sent to them. The important thing to remember is that you are there to comfort them. Do not impose your preferences on them.

It is painful to sit by someone that you care about, yet not know how to ease their discomfort. Always notify a staffperson if you think that something is seriously wrong. But this is a time to remember that

your presence may be the most important source of reassurance that you can provide. Time and again, support people underestimate the value of just being there.

Jill: One of us visited Jill in the intensive care unit the second day after surgery. Her mother was sitting at the bedside. She looked distraught and asked what more she could do to help make her daughter comfortable. Obviously, she was finding it painful to see her daughter in the intensive care setting. The nursing staff had recognized her distress and asked her to help them wash her daughter. This helped her to feel more useful. But she still wanted to do more. She felt helpless.

Several weeks later, Jill had recovered well. We talked with her about her stay in the intensive care unit. Jill smiled and said that she probably had found it frightening and uncomfortable at the time.

But she now remembered very little of what had happened. All that she could remember were the people who were there for her. *The staff were so efficient and caring. It was comforting to see my mother and father when they visited, even my brother. Just knowing that they were in the waiting room, as if they were watching over me, was a great comfort. I could relax and feel loved.*

Not once did Jill mention any specific act that either the nurses or her family did for her. What had fixed in her mind was simply their presence, and the meaning that their presence held for her.

Touching can be a comfort, assuming you know the recipient well. Sometimes, friends and family nervously avoid close contact with someone who is ill, or is in the midst of highly technical equipment. Many people in the intensive care unit are seldom touched unless a staffperson is performing some procedure. It can be very reassuring just to hold the recipient's hand for a few moments or to touch them on the shoulder when you speak with them. Many times, this will communicate your caring as well or better than conversation. A warm touch will be remembered by even a confused recipient.

Due to the ventilator or drowsiness, a recent recipient might not easily talk with you. They might have to write notes. But this does not mean that they cannot hear. Even if they appear asleep, it is a good rule to not say anything that you would prefer they didn't hear. If they describe discomfort, mention this to the nursing staff. If they appear confused, mention this also. Since you know the recipient well, you may be the first to recognize mild confusion. Then, allow the team to deal with things in their own way. If the recipient expresses a fear that things are not going well, respond how you feel is best. But don't lie or be too evasive. They will see the truth in your eyes. Should you not know how to respond to a comment by the recipient, discuss this with their nurse.

As a rule, you can calmly reassure a confused recipient that he or she is safe. Periodically remind them of the day and the fact that they are in hospital. Place a few familiar objects in the room to help orient them. These could include a clock, a large calendar, or a photograph of family members. Sometimes a confused recipient can misinterpret the activities of the nursing staff. They may look frightened or tell you that the staff are trying to harm them. If this occurs, notify the nurse immediately. Reassure the recipient that they are safe in hospital.

Finally, as a support, you have a duty to look after yourself as well. Of course you want to be available to the new recipient. But you must also conserve some energy for the days ahead. Try to get a little rest. Spell yourself off with other supports. Make sure the hospital staff know how to reach you always. But pace yourself for long term.

Our advice is most important when complications or other events extend recovery time. More than once, a transplant recipient has said to us that for the few days after surgery, family and friends were everywhere. But after a while, many of them drifted away. This may occur in part, because supports overtax themselves early.

Continue reading [Chapter 4](#)

Complications

Everybody would wish that after surgery, you were home free. You have crossed a great barrier. And there are some lucky recipients who sail through their recovery with no setbacks. But this is not always the case. You should know of the two main complications that can sidetrack your recovery. These are organ rejection and infection.

It is important to remember that both of complications are common and treatable. You are likely best to count on a few setbacks after surgery. Your transplant team considers it a daily part of their job to deal with side effects and complications.

Organ Rejection: Your body is very particular about what it allows inside. As a rule, it considers anything that is different from itself as undesirable. It is the job of the immune system to protect your body from foreign materials. Anything that it does not recognize as belonging to you, it attacks and destroys. In this way, your body can fight off the bacteria and viruses that cause disease. Unfortunately, your immune system recognizes a transplanted organ as foreign. It attacks the organ, not knowing that the organ is a benefit to your health. The team will call this organ rejection.

Your doctor will prescribe drugs (e.g., prednisone, azathioprine, cyclosporine) to control organ rejection. It is vital to take these drugs properly. To neglect them is to allow your immune system to attack your new organ. This can begin in only a few days. Even with proper use of these drugs, rejection may still occur. Your transplant team will teach you the warning signs of rejection. They can then begin treatment early. Usually, a change in drugs or dosage can successfully deal with organ rejection.

Infection: Anti-rejection drugs inhibit part of your immune system. This helps stop the system from attacking a transplanted organ. But it also holds the immune system back from its real job, fighting infections. Consequently, transplant recipients are susceptible to certain infections. This does not mean that you are likely to catch every cold or flu that is going around. The drugs inhibit only some parts of the immune system. You are not at risk from all, but only certain infections.

In our experience, a recipient can become demoralized with any major complication. Logic suggests otherwise. But many new recipients assume that once the transplant is over, the greatest risk is past. The occurrence of a serious complication will force you to rethink this assumption. From this point on, the fragility of life is never far from your mind. As a heart recipient said to us, *The team told me otherwise, but I still thought that if I made it through the transplant, everything would be like before. I guess that was what I wanted to believe. I did great after the surgery. But now here I am, back in hospital three months later. How can I enjoy life knowing that I could become this sick any time?*

Like other events that can occur with transplantation, serious complications can challenge one's assumptions about life. This will inevitably lead to a feeling of disquiet. When reality confronts the way that we wish life to be, it is time to reflect and consider how to adapt.

Adaptation to Transplant

Adaptation implies that something has changed. Consequently, you must shift or make some change. Seasoned recipients will tell you that adaptation after transplant continues throughout life. How you must adapt depends on how illness or transplant has affected your life.

Talk of adaptation after transplant may surprise some. Most undertake transplant with the goal of resuming their normal life. This is usually another way of saying that you want the life that you had before you were sick. This is a natural expectation. Organ transplant can offer a miraculous opportunity for a second chance at life. It is also true that after an extended illness, your life will normalize with transplantation. But just the fact that you have had an organ transplant means that your life cannot again be just the same.

Your satisfaction with life after transplant depends on several factors. How successful was the transplant? Are you able to work or do the things that you enjoy? Have you lost things that were important for you? Some results will not be entirely within your control. But satisfaction also depends on your adaptation to life after transplant. It may be helpful for you to think of life after transplant as a new reality to enjoy. That was then, this is now.

Despite how successful your surgery and recovery were, some things will have changed in your life. It is to these changes that you must adjust. Your satisfaction with life is in part, dependent upon your ability to adapt. Fortunately, you have a great deal of potential influence on this part of the process.

Changes in Your Body: For many, who we are as a person has a great deal to do with the look and feel of our body. We may take pride in how we appear to others and dislike it if we don't look our best. For some, hairstyle is an important expression of their personality. For others, the weight or shape of their bodies is important. Much of what we see in the media would have us believe that to be happy, we must have bodies of a certain appearance. This identification with our bodies helps several industries (e.g. diet programs, cosmetic surgery) to thrive.

In short, we see our bodies as an integral part of our selves. We are most satisfied when our physical health and appearance reflect how we see ourselves as a person. But in addition, our health also greatly affects our personality.

Unfortunately, this situation creates a dilemma when illness occurs. With one's body so integral to identity, what happens to our identity when illness causes changes in our body? Several questions arise. *I look different. Who am I now? Am I a different person? Am I the same person in a different body? Do others think that I am unusual because I look different? What if I don't like the changes in my body? Does this mean that I no longer like myself?* Rapid and noticeable bodily changes are most likely to throw your sense of identity off balance.

As a transplant candidate or recipient, you have likely already had some unwanted or unexpected changes in your body or appearance. People with severe lung disease can lose weight. They may have to wear equipment to provide themselves with oxygen. It is not unusual for these people to feel stigmatized by their appearance. They wonder what others are thinking of them. One young man commented, *Can nobody look past this mask and see me as I am?* The skin of those with liver or kidney disease may discolor. Anybody with chronic or severe illness will at times notice some changes in how their body looks or feels.

Physical changes are a major source of distress for many transplant candidates and recipients. Shifts can occur in appearance, feel and ability. Adaptation to these changes, whether temporary or permanent, is a sizable hurdle to overcome.

During the process of adjustment, you may ask yourself some of these questions. *Do I really believe that appearance decides a person's identity? Can I not find satisfaction in life with a different physical body? Do I need everything my way to find satisfaction? Could I not live with this for now? Should I respect the opinion of those who see me differently because of the changes in my body? What really is most important to me? How can I reorganize my life to find satisfaction again?* Reflection on these and other questions may help you to think through your health condition's effect on your identity.

You should find that after transplant, you welcome many bodily changes. For example, you may regain some weight that you lost. Your energy will increase. Or the color of your skin may return to normal. No doubt you will be pleased with these changes. But there are always a few physical changes that will be troublesome to some. These include the presence of the transplanted organ, a surgical scar, and the physical side effects of anti-rejection drugs.

The New Organ: For many, the transplanted organ most prominently represents an exciting relief from illness and disability. But it can still take some time to accept it as your own. It is noticeable that very recent transplant recipients will refer to their new liver or heart as *the liver or the heart*. You may not immediately consider it part of yourself. But eventually, most recipients will refer to their organ as *my liver* or *my heart* in the same way that any of us might. This shift results from a gradual acceptance of the transplanted organ as your own. There is then little distinction between it and yourself.

Difficulty accepting the transplanted organ as your own can suggest a problem in adaptation. There may be something troubling you. It might help to mention this to a friend, clergy, or professional caregiver.

Constance: The heart transplant surgeon was frustrated. He could find no reason for Constance's complaints of pain in her chest. As far as he knew, the surgery had been a great success. Constance had suffered with heart disability since an early teenager. Now thirty-two, she had a new heart and appeared in excellent health. But every time that she came to clinic, she told him of the pain in her chest. Constance should be back at work by now. But she said that she did not have the energy to work. And she couldn't get her mind off the discomfort in her chest.

To the surgeon, Constance's description of the pain did not sound dangerous. All of the tests were

normal. Often, she did not even describe the problem as a pain. Once she said, *I can feel the heart. Like it has a casing around it. It's uncomfortable. As if someone has reached inside me and wrapped the heart in a bag of some sort. It is not me.*

An internist who assessed Constance also found no physical problem. But she wondered if Constance could be depressed. This was readily apparent to the psychiatrist who assessed her. Constance was not depressed due to the transplant. She had probably been depressed for several years.

During the psychiatric interview, Constance had mentioned that more than anything, she wanted children. It surprised her greatly to hear herself say this. Her doctors had told her years ago that she could never give birth. At age eighteen, she had a tubal ligation. Due to the condition of her health, she could not adopt. She believed that she had fully accepted the idea that she would never have a child. The psychiatrist suggested antidepressant treatment for Constance. And he suggested that she reconsider whether she and her husband could now adopt a child.

Several weeks later, Constance told the psychiatrist that she was feeling well for the first time in years. She had found a lawyer who would help her to adopt. Her husband was ecstatic about having a family. And she no longer had any pain in her chest. Her heart was working fine. Constance paid little attention to it. She had more interesting things on her mind. She commented, *My new heart has given me this opportunity. It is as much a part of me as my child will someday be.* Interestingly, she never again mentioned chest pain to the surgeon.

Transplant candidates or recipients sometimes wonder if their new organ carries some donor characteristics. One recipient jokingly said, *I heard that the guy who gave me his heart was a musician. I should take up the piano again. Maybe now I will have some talent.* Others question whether their new organ came from a man or a woman. We assume also jokingly, one man said, *This kidney might have come from a woman. I hope so. I might understand my wife better.*

Heart transplant recipients may be particularly prone to wonder about the transmission of donor characteristics. The heart has always held great symbolic significance. Poets, philosophers and others have described the heart as the center of emotion or the resting place of the soul. These traditional beliefs may contribute to ideas that personal characteristics could be transplanted along with a heart. Most of us would chuckle at the idea that much of our soul would reside in a liver or kidney.

Usually, transplant programs discourage serious thinking of this type. They keep secret, most information about the donor. This helps to minimize such magical thinking. There is no substance to these ideas. Personal characteristics do not reside in any one body organ. Organs do not differ with the sex or race of the donor. They do not retain characteristics of those who donate them. If they did, we couldn't transplant organs freely. Can you imagine the upset that would occur in a recipient's life if he or she began to think or behave like some unknown person?

Surgical Scars: It is always interesting to see how different people react to their surgical scar or scars. At a swimming pool that one of the authors use, there is a weekly swim for men who have had coronary

artery bypass surgery. These men all have a large scar on their chest. In the locker room, few are shy about their scar. The surgery and its resultant scar are what they have in common. It is like a club. They compare the size of their scar with others. Some brag about how difficult the surgeon found their case. To these men, the surgical scar is a trophy that they won for confronting heart disease and major surgery. It is a sign of strength.

Young boys who have had a heart transplant can respond similarly. They may show their scar in the locker room at school or in the yard at recess. For a youth who has lived with chronic illness, the scar proves the vitality to survive threatening surgery. Again, it is a badge of courage.

But not everyone will view their surgical scar this way. Some with chronic illness have taken great pains to hide illness from others. Their goal has been to live a normal life, and to appear normal to others. They do not wish others to treat them differently due to illness. To these people, a surgical scar is visible evidence of what they have worked hard to keep private. You will not find these recipients proudly showing off their scar to friends. Others may believe that a scar diminishes their attractiveness. Research suggests that this may be true for some young women. Hopefully, these recipients will eventually realize the truth in the saying that beauty is only skin deep. Anyone who cares for you as a person, will not care about a scar.

Whether pride, shame, or another response occurs with changes in your body depends upon the personal meaning that you attach to your body parts. But maybe transplantation can teach us a lesson in this regard. A heart, liver, or kidney can be transplanted into another person without the transfer of personal characteristics. Maybe this means that bodily parts are not as integral to identity as we have often assumed. It is possible that normality, beauty, or whatever, does not reside in our bodily parts or appearance at all.

Anti-rejection Side Effects: Some drugs that you will take after surgery can cause changes in your appearance. In the early days of transplantation, doctors prescribed very high doses of prednisone and other corticosteroid drugs to help avoid rejection. Surgeons and others involved with transplant programs can easily identify a transplant recipient by their appearance. This is usually due to the bodily changes that prednisone can cause.

Prednisone can cause a rounded appearance in the face and upper body. This effect still occurs. But it is less severe now since transplant teams can now prescribe lower amounts of this drug. Still, physical changes due to anti-rejection drugs are a well known problem. New research continues to look for better anti-rejection drugs with fewer side effects.

Cyclosporine can cause your hands to shake or increase bodily hair growth. We have met a few recipients who did not know that cyclosporine could cause a tremor. Some had assumed that nervousness was the cause. Increased hair growth may or may not be a problem. We have seen men overjoyed to have the hair on their head fill in. Unfortunately the growth is not limited to the top of your head. Cyclosporine can cause unwanted bodily hair to grow faster in both men and women.

Changes in Your Person

As we have discussed, most transplant recipients will notice some changes in their bodies or their lifestyle. But some also report changes that seem to occur within themselves. These can take many forms. You may hear a recipient comment that their priorities or goals for their life have shifted. This can occur after living through a serious illness or recovering from transplantation. Some say that they are much less preoccupied with long range plans. They focus more on their life as it unfurls one day at a time. But it can surprise some that changes occur in their interests, relations with others, and what they consider important.

Andrew: Before he became ill, Andrew regularly played golf Friday evenings. He had golfed with his business partners for years. Often in hospital he had imagined himself on the course. But now that he had recovered from his liver transplant, Andrew didn't look forward to golf as before. This puzzled him.

He also noticed a shift in his attitude at work. No one else had noticed. But Andrew was certain. As an accountant in a large firm, he had always worked hard, often late into the evening. Frequently, he had been the company's top billing partner. But now he had little interest in working late. By five-thirty, he was ready to go home and enjoy himself with his family.

While ill, he had spent many evenings watching his son or daughter play sports. And he had taken up a new hobby that he enjoyed. Now he could resume his previous lifestyle. But Andrew found that he preferred spending time at home with his family.

Monica: Several months after a double lung transplant, Monica was back to work as a homemaker. She had always enjoyed this life. But now she found herself a bit dissatisfied. *I feel that I would like to give something back. I am so lucky to have this time. I just enjoy life so much. I would like to help others enjoy their time as much as I.* She decided to volunteer two mornings a week at a senior citizen's home. Monica had thought of this before. But there never seemed to be enough time. Now it seemed important for her to make the time.

Julia: Julia had been ill for several years before liver transplant. She had been very frustrated, feeling as if she were living life on the sidelines.

Shortly after recovering from surgery, Julia met a man named Jim. He surprised her when he told her that he found her attractive. She had never been popular with men. Because of this and her difficulties with illness, she had convinced herself that she would not marry. Julia's family found Jim pleasant. But they worried when she accepted his proposal of marriage after only two months. They were skeptical that she knew him well enough to make this decision yet.

Within one year, Julia left her husband. He had begun to drink heavily shortly after their marriage. And he had hit her when he was drunk. She learned from his sister that Jim was abusive before. He had gone

to jail for abusing his ex-wife.

Julia couldn't believe how wrong she had been about Jim. *I guess I was in too much of a rush*, she said to her closest friend. *But I had always watched others enjoy themselves . And how do I know how long I will be well?*

Andrew, Monica and Julia each found some shift within themselves after recovering from transplant surgery. Rather than working late or spending as much time with his friends, Andrew enjoyed himself at home with his family. But he didn't plan this adjustment. He just noticed that it had occurred.

Monica noticed within herself a compelling sense that she must give something of herself to others. While present before, this desire took on greater importance to Monica after her surgery. She made changes in her life to fit in volunteer work.

Julia sensed an urgency about her life. She felt well after surgery, with better health than she had enjoyed for years. But she feared it would not last. It was never far from Julia's mind that her life was fragile and the future uncertain. She felt physically vulnerable. This is a difficult reality to deal with. Unfortunately, Julia rushed a major life decision due to a sense that she must act urgently to enjoy her time.

There are many reasons why transplant candidates or recipients may notice changes in their outlook on life. Truly, life is short. And it is fragile. Serious illness or transplantation can make these realities hard to ignore. They compel you to evaluate how you allot your time, to review what is really important.

Also, illness or transplant can force changes in your usual habits of daily life. This is usually an unwanted intrusion. But sometimes, it can help one to break out of the rut of living life automatically. One heart transplant recipient commented, *When I look back, it seems as if I were sleepwalking. The days moved on. But I stayed the same. I lived out the routine that was supposed to be me. I woke up the day my doctor told me that I would not likely live two more years without a transplant. Life has never been worse since then. And it has never been better.*

Continue reading [Chapter 4 Questions](#)

Questions

I never used to dream much. But since my heart transplant, I have dreams or nightmares most nights. Is there anything that I can do?

There may be. It depends on what is causing the dreams and nightmares.

Possibly, the surgery has disrupted your sleep. If you wake up often in the night, you are likely to remember more dreams. You may not dream more than before. But you remember more dreams because you wake periodically. If this is the cause, you will have less trouble once your sleep normalizes. If the problem persists, your doctor probably can help by suggesting a sleep aid.

Some drugs that you take after transplant (e.g. cyclosporine, prednisone) can cause dreams or nightmares. Sometimes, the team can change the drug or its dosage to help with this side effect. Even if this is not possible, many recipients describe a lessening of this problem with time.

There is also a condition, called Post Traumatic Stress Disorder, that can cause nightmares. This condition can occur after a very traumatic event that occurs beyond your ability for control. People will report this disorder after returning from war, after a severe accident or after a stay in an intensive care unit. It can also occur after organ transplantation. There are treatments available to help.

You could have Post Traumatic Stress Disorder if besides nightmares, you have disturbing mental images of surgery or recovery that occur during the daytime. You may also find that you are edgy, worried or in low spirits much of the time.

One of the authors remembers giving a lecture on this topic to a class of nurses. During the discussion afterwards, one said that for the first time, she now realized that she had this condition. For years after her own liver transplant, recurrent dreams of her confinement in the intensive care unit plagued her. It is unfortunate when this problem continues for this long. There are various treatments that may help.

Some will wonder what meaning their dreams hold for their lives. Whatever causes a dream or nightmare, its content may still tell of something that is on your mind. One recipient told us of a very disturbing dream that he had several times. In it, the mother of his donor's kidney would ask him to return the transplanted kidney to her child.

The dream eventually disappeared. But this recipient said that he had learned something of himself from the dream. Although he logically knew that he had done nothing wrong, he felt guilty about the transplant. Because of this recognition, he wrote a letter of thanks to the donor family. And he resolved to make good use of the time that they had given to him.

As far as I can tell, my life is much the same now as before transplant. I don't see things any

differently. Is this okay?

We do not wish to suggest that any one person will experience everything that we describe in **Surviving Transplantation**. There is no correct or incorrect way to adjust after transplantation. If something that you read sounds familiar, we hope that our comments are useful to you. If you read things that do not apply to your situation, you are welcome to ignore them.

I don't seem to remember things as well as before the transplant. What could be causing this?

This is a common complaint of transplant recipients. Unfortunately, researchers have not examined this problem to the extent that it deserves. The cause is not always clear.

There are at least three likely possibilities. You might ask if anything occurred during surgery that could account for memory problems. Sometimes, this is the cause. Or a drug that you take after surgery may be the cause. Many believe that cyclosporine can cause forgetfulness. In others, the illness that led to their need for transplant has caused some lasting memory problems. Your doctor can tell you if this is likely.

Do not assume too quickly that your memory will not improve. This is most true if you were confused after surgery. Your memory can take much longer than many suspect to recover from this problem. Some recipients report that memory problems interfere with their work or other activities. If this is the case, a psychological specialist can assess your memory. They probably can tell you how much improvement to expect. And they can often counsel you how to work around the problems that exist.

I would like to thank the donor family. Is this possible?

Your transplant coordinator can usually tell you how you can give a thank-you card or note to the donor family. They will not likely help you to contact the donor family directly. But sometimes the team will do this when both the donor family and recipient ask to meet.

My husband and I have always enjoyed our intimate time together. But since his heart transplant, he seems to avoid sex. Should I discuss this with him?

It is ideal for couples to discuss their sexual relations openly with each other. This does not always occur. But without discussion, do not assume that you know the reasons for any changes you notice.

There are several possible causes for you and your husband to consider. Drugs, surgery or another physical condition may interfere with sexual interest or activity. If you think that this could be the cause, your husband's doctor might suggest a treatment change to help with the problem. Alternatively, your husband may be hesitant about intimate relations due to worries or concerns. Apprehension about sexual intimacy can occur after certain illnesses or surgery. This is true for heart and other types of transplantation.

Physical exertion may worry your husband. After recovery from serious illness, people can worry that exercise may harm their health. Most people know that their heart has to pump blood faster during exercise. A recent heart transplant recipient may fear that sex can overly strain his new heart. He may try to protect the organ by avoiding physical exertion. A knowledgeable doctor or nurse can best tell you and your husband what amount and type of exertion is safe.

Illness or transplant can also give rise to concerns about ability or attractiveness. Your husband may quietly harbor fears that he is not as sexually able or attractive as before. Surgical scars, drug side effects, or other factors may alter one's appearance. You may need to remind your husband that these concerns are likely more prominent in his mind than in yours.

Concerns such as these may be at the root of your husband's hesitancy. If so, we have some suggestions that might help. Remember that sexual arousal is something that occurs when you feel at ease and attracted to one another. Spend quiet time together. Talk about whatever. Do not first concern yourselves with whether you will have sexual intercourse. You may even agree to try and avoid intercourse for a time. Quiet time together can help to alleviate many anxieties.

What if I am not always in the mood for visitors after surgery. Is it rude to let people know this?

No. It is your responsibility to tell them. Visitors who have you interest at heart will understand if you are not up to seeing them. Your well-being must be your priority. If you cannot place limits on visitors, you might ask the nursing staff to help.

Everybody wants to wish a new transplant recipient well. Other than for close family and friends, a card or letter is a good way to send your wishes. Visits are most enjoyable when you are feeling better. If your ward has a resting period (often just after lunch), never entertain visitors during this time.

I have had a kidney and pancreas transplant. Is it safe for me to play sports?

The answer to this question applies to any type of transplant. Only your transplant team can tell you what if any, limitations they expect of you. Do not assume what they will say. Ask them. Each recipient's circumstances are different.

They will suggest a gradually increasing level of activity during recovery from surgery. After that, the team may discourage you from engaging in sports that involve bodily impact. But depending on the type of surgery and your skill at protecting yourself, they may place no restrictions on sports.

There is nothing about transplantation that necessarily limits the level of physical exertion for recipients. One liver transplant recipient has described her experience at the International Transplant Games held in Budapest in 1991 ([Ref 8](#)). One year after surgery, she won three silver and two bronze medals in swimming and track events at the Games. Her training now includes swimming about eight thousand meters weekly besides cycling and running. She has commented, *when something comes along and you*

get another chance, you don 't want to miss anything. There are no ways to thank the donor family, except to make full use of this second chance.

My father is in hospital recovering from a heart-lung transplant. We just found out that his brother died in Europe. If we tell him, will grief harm his recovery?

There may be some circumstances when it is best to withhold tragic news for a few hours or a day or two. But even for this short time, you risk that your father may learn the news from somebody else. Or he may later be angry that you did not tell him outright. Remember that a great fear for those who are seriously ill is that others will isolate them by treating them differently. You do not want to contribute to this fear by hiding something important from your father. He is likely to see the pain in your eyes anyway.

Throughout history, physicians have held the belief that troubled emotions can be harmful to health. In many times and countries, this belief has led to the practice that doctors did not even tell patients their own diagnosis. Doctors have feared that resultant low mood may impede recovery. Until modern times, they had little to offer a seriously ill and demoralized patient.

Today, there is scientific evidence for a close association between emotions and physical health. But the relationship is much more complicated than previously known. We now know that it is very difficult to predict how, if at all, one person's emotional state will affect their health. And we know much more about how to deal with grief and other painful emotions. With your support and the experience of the transplant team, it is likely respectful of your father that you allow him to face important events in his life as they occur.

Understanding Stress

Grant me the serenity to accept the things that I cannot change, The courage to change the things that I can, And the wisdom to know the difference. (Traditional)

We assume in this book that stress is a natural and daily part of life. It occurs when we interact with the world around us and within ourselves. Stress can manifest itself in countless ways. It may appear as a feeling of uneasiness or disquiet, as difficulty falling asleep, or as physical discomfort. Regardless, the presence of stress suggests that some event or change is challenging you. Your stress reaction is an indication that something has happened to require your attention.

It may surprise some readers that we say stress is a natural and daily part of life. But life is unpredictable. It seldom behaves just the way that we prefer. Our interaction with the moment to moment flux of life makes stress commonplace.

There are countless examples of stress in daily life. Just when it looks like you will get your credit card paid up, your car breaks down. The airline goes on strike shortly before your holiday. You go to your doctor for what you expect to be a routine examination. But she tells you that you may have developed an illness or complication. The boss asks you to work late on the night that you had wanted to be home early. You probably can think of countless events in your life that have been more or less stressful. By learning how to approach the tensions of daily life, we prepare ourselves for any greater challenges that may come our way.

Stress

There are two root causes of stress. First, the world in which we live is always changing. One moment is never the same as the next. This creates stress because most of us prefer the comfort and security of sameness. Consequently, we strive for consistency and certainty in our lives. This places us in a position of conflict with the reality of life's unpredictability.

Secondly, most of us prefer to have some sense of control over what happens to us. But many of life's changes are beyond our ability for control. Not only are they unpredictable, but we do not have full control over them. These discrepancies between how life works and what we prefer, is at the root of stress.

Fortunately, there are times when everything proceeds as we wish. These are the times when we tend to be most at ease. But sooner and usually not later, some upset occurs. Reality intrudes. We lose our sense of contentment. Distress arises. Then we strive again to assert our preferences.

When things do go our way, we can be easily convinced of our potential for control. We wish to believe

in our ability to guide our lives. Given the great advances in medicine and other technologies of the past century, it has become easy for many of us to assert a great deal of control. Few truly believe that they know what will happen to them even a few moments from now. But most still live their lives as if they assume that they are fully in control. This is why the occurrence of major illness or other trauma is always a great shock.

Serious physical illness holds great potential to cause stress. It challenges one's wish for stability and control. You can easily think of examples of how illness has disrupted your life. Transplantation can help you to regain your health. It promises a greater degree of control over life and health. But meanwhile, you must wait for and recover from surgery. Before it helps, organ transplant can add many further disruptions and stress, to your life. A common sense approach to dealing with the stress of illness and transplant can be helpful. [Table 5.1](#) shows one way to interact adaptively with change.

Table 5.1: Dealing with the Stress of Illness and Transplant

An Event of Change Occurs

You React to What Has Happened

You Choose Your Response

1. Problem Solve
 2. Look After Yourself
 3. Adapt
 4. Ask For Help
 5. Do Nothing
-

When some event or change occurs, you will first react in some automatic or habitual way. For example, your initial reaction may be a feeling of uneasiness, a desire to eat more, or difficulty with sleep. We each have one or more ways of first reacting to stress. A stress reaction says to you that some event or change has given rise to conflict between your preferences and the way things really are. [Table 5.2](#) lists some automatic reactions that people notice with stress. Once you learn to notice your reaction, you can decide what has changed and how best to respond.

The approach we encourage is an optimistic one. Ants are programmed to react to change. They do so without choice. But we need not be like ants. People can reflect upon a new situation. We can take each

new opportunity to choose our best response. Unfortunately, people do not always or even often, exercise their potential for choice. Often, people will ignore the reactions that suggest, stress. But the opportunity remains for us to choose an appropriate response to change. Each moment, you have an opportunity to respond to your changing world. Whether we choose to recognize or ignore it, the potential for influence is there.

Table 5.2: Habitual and Automatic Reactions to Stress

talk with others
ignore it, refuse to think about it
drink alcohol, take drugs, smoke a cigarette
blame yourself or somebody else
become irritable, angry or frustrated
make jokes
exercise, take a break, talk yourself down
avoid others, isolate yourself
explode angrily or panic
worry
hope that somebody else will fix things
accept the stress as punishment

Continue reading [Chapter 5](#)

An Event or Change Occurs

There are many potential causes of stress for the transplant candidate or recipient. We have discussed these in chapters two, three and four of this book. It doesn't matter if you have yet experienced a few or many of the challenges that we have mentioned in these chapters. This and the next two chapters offer an approach that can enhance your ability to deal with what has or may arise.

Important to remember is that the same event may result in various levels of stress for different people. There are no rules. Something that a friend finds distressing, may not upset you at all. You will automatically assess any occurrence by what it means to you. This assessment largely decides whether you find it stressful. For example, the onset of arthritis will carry a more sinister meaning for a carpenter than for a person that does not work daily with his or her hands. Arthritis will stress a carpenter more than a singer.

Jean: Jean accompanied her husband Alex to the city where he hoped to receive a heart transplant. They expected to wait from one to three months.

During their stay, they made the acquaintance of several other candidates, including Joel, a teenage boy who had been born with a heart defect. Jean in particular, befriended Joel. Months later, they heard at clinic that Joel had died suddenly over the previous weekend.

This tragic news visibly upset both Alex and Jean. But Jean was affected far more strongly. Whereas she had always before held an optimistic outlook for her husband, she became preoccupied with worrisome thoughts that he might die. She had trouble getting to sleep at night. And she worried excessively about every symptom that Alex showed. Two weeks later, Jean still came to tears when anything reminded her of Joel's death.

Alex had tried to understand how his wife felt. Joel's death had saddened him. And it reminded Alex of his own predicament. But he couldn't understand why Jean was still so upset by what had happened.

Finally, Jean told him of what was going on inside her. She told Alex that Joel had always reminded her of a young brother who had died in a car accident. She remembers only that once the funeral was over, her parents never spoke of her brother again. Alex now understood that Jean's tears were in part for Joel, but also for the loss of her brother. She had little opportunity as a youth to grieve his death.

In this example, Joel's death upset both Alex and Jean. But due to Jean's memories of her brother, she was more affected. The tragedy reminded her of grief not before expressed openly. When she cried, Jean held the images of both Joel and her brother in mind. Her grief appeared extreme because it was for the loss of two.

The events of our past contribute to whom we are today. They shape our approach to life and inevitably

affect our response to new events. Since we each have a different life history, it follows that our response to a new occurrence will be highly personal. This helps to explain why different people will react variously to the same situation.

Not only unwanted changes can cause stress. A large amount of research has examined the relationship between life events and stress. In this research, people have been asked to rate events in their lives according to the degree of stress that resulted. Although not usually considered to be unwanted life changes, gaining a promotion, buying a larger house and getting married are typically rated as highly stressful events. Most would consider the birth of a child as desirable. But generally this is rated as stressful. By and large, the meaning that an event holds to people is most important. Even highly desirable life events can hold potentially stressful meaning.

Similarly, many events that you look forward to, either before or after transplantation, entail some stress. For example, discharge from hospital after transplant is a desirable event for any recipient. But some apprehension can also occur at this time. Don't assume that stress only results from undesirable events. You will find yourself puzzled at times when searching for the cause of stress.

Lillian: For several years, Lillian had looked forward to kidney transplant. Now eighteen, she had lived all of her life with failing kidneys. During the past four years, she spent three afternoons a week at the dialysis center. Until recently, other health problems had prevented her from transplant surgery. Lillian was excited when the team told her that they could now go ahead.

One month after kidney transplant, Lillian felt great in most ways. It thrilled her to have recovered well from the surgery. But she was restless during the day and had difficulty sleeping at night. She ate more junk food than was good for her. She was irritable when her friends asked her out. This in particular, Lillian could not understand. While on dialysis, she had always felt that she did not have enough freedom. And when she used the washroom, she was sure that there was a pain in the area of her new kidney. However, the doctors found nothing wrong.

Lillian asked her transplant coordinator if she could talk with him. She had looked forward to the transplant for so long. Now it seemed to her that she was not able to enjoy her health. The coordinator commented that Lillian appeared very worried about upcoming exams at school. When she first mentioned this, Lillian thought that the coordinator had misunderstood her. She had never been nervous about exams.

Later, Lillian found herself thinking of the coordinator's comment. She never worried about exams. But it was true. She was worrying now. And she was nervous that she wouldn't excel as she wished. This played on her mind during nights when she could not sleep. *If I don't do well, I will not have the excuse of dialysis to fall back on.* It seemed that she was placing extreme pressure on herself. *I should get higher marks now. I am healthier than before,* she thought.

Lillian told the school guidance counselor about her concerns. The counselor described this type of worry as performance anxiety. It occurred when someone was uncertain if they could live up to their

own expectations for success. *That fits, said Lillian. I expect more of myself now. And I don't have dialysis to blame if I fail. I am more on my own. And it makes me nervous.*

There will be many times, both before and after transplantation, when you will expect yourself to achieve some goal. Many of these goals (e.g., gaining strength with rehabilitation exercises, losing or gaining weight with a recommended diet, leaving hospital after recovery from surgery) will be important to both you and the transplant team. The occurrence of stress related symptoms may suggest that you are placing too much pressure on yourself to excel. Of course, you will want to work hard to achieve your goals. But too much pressure can impair your ability to act.

Finally, don't assume that stress can occur only after some event or change. You may experience stress in anticipation of some upcoming event. We have all had the experience when we couldn't fall asleep easily the night before an important day. This is a normal and common example of anticipatory stress.

Stuart: When the team found a donor for his lung transplant, Stuart understood that they would first telephone him at home. If they could not reach him, they would call the pager that he carried with him always. Stuart looked forward to getting the transplant over. But of course, he was also a little apprehensive.

Stuart startled whenever his telephone would ring. He wondered if it was his call for surgery. Sometimes the pager beeped accidentally. His fingers would shake when he dialed a telephone to call the transplant coordinator. *Does this mean that I am not ready for the surgery? Am I afraid?* he asked himself. One night, the team called Stuart to the hospital for transplant. But once there, the team told him that they were not able to use the donor lungs. Stuart was terribly disappointed. And he worried about how nervous he had been in the taxi on the way to the hospital.

After this false alarm, Stuart found that he wondered constantly when the telephone or bellboy would ring. Sometimes he couldn't sleep at night, imagining that the telephone was about to ring. Another candidate noticed that he looked run down. *Are you okay?* she asked. Stuart decided then that he must have some diversion to take his mind off the upcoming transplant. *Its going to happen when it happens,* he thought. *Meanwhile, I am going to find something to keep myself occupied.*

Continue reading [Chapter 5](#)

You Respond to What Has Happened

A change around you generally results in some change within you. By habit, you will react immediately in some way to a stressful event. [Table 5.2](#) lists some automatic ways that different people react to stress. We will call these experiences that occur within yourself, a stress reaction. Your stress reaction is an indication that some event or change is demanding your attention.

Susan: Heart transplant offered Susan an exciting opportunity to regain her independence. Three weeks after the surgery, she already felt stronger than she had for years.

But the first time that she had walked upstairs alone, she thought that her heart was going to pound out of her chest. She was terrified. The team prescribed a drug for what they recognized to be an irregular heart rhythm. But the problem continued. It occurred twice when she was walking alone outside the hospital. This frightened her most. *What if I can't get to help in time*, Susan worried. More tests found nothing wrong with her heart. The irregular rhythm was no longer present.

At their monthly support group, Susan talked about her frustration with these symptoms. To her surprise, another recipient said that he had experienced a similar problem. After recovering from an episode of rejection, he had tightness in his chest whenever he left the hospital. Again, all of the tests were perfectly normal.

Eventually, he had figured out that the rejection episode had frightened him deeply. It terrified him that something might be wrong with his new heart. But he had learned from reading, that stress could sometimes cause physical symptoms like his. After he learned to better reassure and calm himself, the problem eventually disappeared. He suggested that Susan might deal with her symptoms similarly.

One's stress reaction can take many forms. But physical effects of stress are likely the most tricky to deal with. This is particularly true for those with a medical illness. Few appreciate how common it is for stress to mimic the symptoms of a physical condition. In Susan's case, the transplant team diagnosed a heart arrhythmia as the cause of her first episode. But they could find no physical problem to explain the other episodes. Although the symptoms felt the same to Susan, it is highly likely that they were due to stress.

Research has shown that for those with diabetes, it is not uncommon for stress to result in symptoms very similar to those that occur with blood sugar problems. People with arthritis report increased pain when under stress. In those with asthma or emphysema, stress can manifest first as shortness of breath or chest tightness. You should never assume that physical symptoms are due to stress without a thorough examination. But an unexplained worsening of symptoms may suggest that you are under greater stress than you have been aware.

Continue reading [Chapter 5](#)

You Choose Your Response

This is the point that can separate the ants from the people. Instincts alone guide ants. They have no choice. Unfortunately, people can act more like ants than we like to think. It is easy to fall into habitual ways of responding to stress. Many respond to any stress with habitual responses that may or may not be appropriate to the situation at hand.

The ability to choose between various options is a hallmark of humanity. Usually, there are more ways to approach a problem than first come to mind. Not all events, even stressful ones, require a response. But, sometimes you must respond to new events or situations in some way. This requires effort at a time when you might prefer to sit quietly and hope for things to resolve themselves. But it can be effort well spent. Even if you decide that the best thing to do is nothing, you have at least asserted your choice.

There are five strategies to consider when a problem arises. You can: try to solve the problem; try to calm or otherwise look after yourself; adjust yourself to fit the new circumstances; ask for help; or do nothing. These options are not mutually exclusive. You may choose one or more strategy when responding to a stressful event.

Problem Solve: The tire on your car goes flat. You change it. You lose your birth certificate. You request another. Events like these lend themselves well to problem solving action. Of course, problems that you can easily solve are bothersome. But they are not usually that stressful.

Health problems do not always fall into the category of easily solved problems. A serious illness that cannot be cured rapidly is deeply disturbing. We do not have to tell this to most readers. If you were in a health situation that you could resolve, you would not be reading this book. Obviously, we encourage you here and elsewhere to search for a solution to any problem that occurs. But for the times when this is not immediately possible, we also emphasize other strategies.

Look After Yourself: The more persistent an illness, the greater the toll that stress and tension can exact on your energy. Caring for your well-being can help you to conserve your strength for use as needed. This may be as simple as taking a break or treating yourself to something you enjoy. Sometimes, you may find specific techniques useful for relieving nervous tension. In the next chapter, we offer several suggestions from which to choose.

Adapt: Much to our displeasure, we must suggest that sometimes unwanted changes occur that you cannot immediately do much about. This is challenging for most of us to accept. Nobody likes to lose control. But sometimes the best approach is to accept at least temporarily, the circumstances in which you find yourself. In this way, you save your fight for when it will be most productive.

We have already said the obvious. It is best to view problems as challenges to resolve. But it can be equally important to recognize when you cannot rapidly resolve your situation. This does not mean that

you must give up hope. But you will avoid wasting vital energy by fighting situations over which you have no control. Some adjustment on your part may help you to tolerate unwanted changes.

We realize that nobody likes to hear this advice. Nobody likes to hear that they must change something of themselves. We all want to change the world to our liking. And nothing is more difficult than to adjust ourselves to an undesirable situation. It usually means that we must give up something that we want. But to fight reality at any cost, can eventually take a great toll on your health.

Ask For Help: There is an old joke in which a wife complains that her husband would prefer to drive around lost for hours than ask for directions. Asking for help is something that many find difficult. Some will consider it a last choice option.

Your transplant team will not appreciate it if you hesitate to request help for a health problem. They will expect you to notify them immediately if certain complications or symptoms arise. They know that they can more easily deal with most medical problems early. The same is true for many other problems. Transplant teams will usually arrange for help with dietary, social and emotional problems, just as they do with medical and surgical ones. Let them know what is happening with you. In chapter eight, we discuss the common emotional effects of transplant that may require professional help.

Do Nothing: When a problem first arises, one's first tendency is usually to ignore it and hope that it goes away. Suspected problems sometimes turn out not to be a problem at all. Or they can resolve on their own. Otherwise, you must consider other options.

There are situations in which you are best to do nothing for a time. But some assume that just because they can do nothing to directly resolve a health situation immediately, there is nothing that they can do. Someone who adopts this approach risks shifting between fruitless struggle and despair. This is unfortunate and not necessary. As we emphasize throughout *Surviving Transplantation*, there is always something that you can do to help yourself.

Continue reading [Chapter 5 Questions](#)

Questions

I tried progressive relaxation before. It did nothing for me. Is there anything else I should try?

There are hundreds of different relaxation techniques. Finding one that is helpful can be like shopping for a new car. There are many to choose from. But you must find the one that suits you best. If you do not find a technique comfortable or helpful, try something else. We discuss several in the next chapter.

Some do best with exercises that involve muscular movement (e.g. progressive muscular relaxation, Tai Chi, yoga). Others find techniques that emphasize deep breathing or mental imagery most soothing. Others create their own approach. One woman told us that she relaxed best by sitting in an easy chair and playing some favorite music. She would take a break every afternoon and sit alone with her music.

There are several reasons why you could find relaxation or other stress management techniques unhelpful. If you expect any approach to eliminate stress from your life, you will be disappointed. In fact, the harder you try the more frustrated you can become. We have no choice but to deal with stress on a daily basis. This is why we refer to stress management, not stress elimination. You may need to examine your expectations.

Another way to ensure that a stress management technique will prove unhelpful is to use it only when you are under great stress. You would not go to a freeway to learn how to drive a car. You would start in an empty parking lot or quiet street. Once you had mastered the basic skills, you would apply your ability to a more challenging situation.

Unfortunately, many will only apply their lessons in relaxation when they find themselves highly stressed. Relaxation is a skill to learn during quiet times. Once mastered, you have a useful skill to apply during times of stress.

I never feel stressed. Is there any point in me reading this?

There are three possible reasons for your lack of stress. First, your life maybe just as you wish. Where there is no conflict between what you prefer and the way things are, there is no stress. Second, you may be highly adaptable to whatever situation you find yourself in. We do not pretend to have a corner on the market for dealing with stress. Throughout history, people have found ways to face life's challenges. Some of the most resilient candidates and recipients bring to transplantation a lifelong style of taking life as it comes. Third, you may not be aware of stress when it occurs. Or you may be so used to feeling tense, that it seems normal.

We are not able to know which of these possibilities apply to your situation. If you are not certain, you might ask someone who knows you well.

Dealing with Stress

My strength is the strength of ten. Because my heart is pure. (Tennyson)

When life confronts you with a challenge, dealing with it will require time and energy. This may mean that for at least a short time, you must give up some activities or interests. Unfortunately, the first things to go are often those that give you some enjoyment and pleasure. A hobby, sport or other activity is more expendable than work. If something has to go, it is usually leisure.

This is unfortunate because leisure activities help you combat day to day tensions and stress. They distract your thoughts from worries, calm your mind and body, and provide relief from boredom. Enjoyable activities are common and provide natural ways of relieving tension. When set aside, you rapidly lose their benefits. This is typically what happens when illness arises. We spend less time with leisure, more time with other demands. At exactly the time when you most need to attend to your general well-being, you are likely to spend less time involved in pursuits that you enjoy. This is one way that illness can take its toll on your well-being.

Looking after yourself is the topic of this chapter. We discuss methods for you to soothe and rejuvenate yourself. And we explain strategies that can help you rest in preparation for the challenges ahead. This idea is important to transplant candidates, recipients and their families. You will live with a serious illness and its treatment over a lengthy period. It can seem as though there is always something more important to do than to relax. We emphasize, in this chapter, the important role of leisure and other means of relaxation.

Our goal is to counter the common tendency to defer relaxing pursuits during times of stress. However, we recognize that there are many demands on your time and energy. We do not wish to add another chore to your schedule. Therefore, we emphasize strategies that offer the greatest potential gain for the least possible effort.

Continue reading [Chapter 6](#)

Start With What You Know

Many transplant candidates and recipients are at some time or another, overwhelmed with tension and stress. They have often asked us how they can better deal with nervous tension. Frequently, they have asked about cassette tapes with relaxation exercises on them. People usually assume that if they are tense, they should learn some new way to deal with their stress. This may or may not be necessary.

We agree fully that relaxation and other stress management techniques can be an enjoyable way to refresh yourself. If you are already familiar with progressive muscular relaxation, self-hypnosis or meditation, we encourage you to pursue these calming practices. Otherwise, don't jump on the bandwagon just yet. First, we have some ideas for you to consider. Later, we review some specific relaxation techniques.

First, we suggest that you take a few moments to recall any activities that you have ever used to enjoy yourself or to relax. Write them down on a list. Reading, taking a walk, bingo or cards, building models, knitting, listening to music or watching sports are not activities that most people think of as means of dealing with stress. Most just think of them as fun. But they are also ways that you have found to relieve tension.

You can learn some things about yourself by listing your leisure interests. Is the list long? If there are many items on your list, then you likely value your leisure time highly. This may also be the case if you have a short list, but spend a great deal of time with these interests. But you may have very few items on your list. Or you may rarely find time for the things you enjoy. If this describes you, you may not take enough time to relax and refresh yourself.

Illness may have forced you to give up preferred leisure pursuits. This can occur with people who were very active in sports or other physically demanding activities. This is always a double blow. You lose an important way of relieving stress while you are under greater stress with illness. If you have been very athletic, you may or may not have had much interest in quieter hobbies. It will be a great challenge for you to adapt to any physical limitations imposed by illness. Those who have had a passion for stamp collecting will not have the same adjustment to make as a long distance runner.

No matter whether your first choice of leisure activity is crafts, model building, collecting, or whatever, it will help you to keep busy. You will be better off keeping active than doing nothing. These activities will help to keep your mind off other concerns. Everybody needs a break from worry. Enjoyable hobbies are an excellent way to occupy your mind. Besides, you may surprise yourself and find out that you enjoy or have an aptitude for some new interest.

Others that we have met, found that they could channel their skills into entirely new interests and activities. Some have formed a self help group, raised funds, printed a transplant newsletter or organized welcome packages for new candidates. One librarian used her skills to develop a reading list for

transplant patients. When one of her fellow candidates had a question, she would search out reading materials with her home computer. Within a day or two, the candidate would have the information that he or she wanted.

You may feel too preoccupied with other demands to pursue your favorite leisure activities. Some feel guilty about taking time for a seemingly frivolous activity. This is understandable during acute illness. But the longer that you or a family member must live with illness, the more important it is for you to normalize your life as much as is possible. Take up some old or new interests. You don't want illness to control your life more than necessary. Eventually, it will be time to take your life back. You can begin this by resuming interests that you have put aside.

After reviewing your situation in this way, you may find that you don't need any new strategies to deal with your stress right now. You may have just set aside some strategies that you could renew. Too often, we neglect previously enjoyed activities in the search for something new. Look first to those recreations with which you are most familiar. If they are not possible to pursue, consider some new interests.

Continue reading [Chapter 6](#)

Self Talk

There is a scientific term for talking to yourself. Psychologists refer to the thoughts on your mind as cognitive self statements. We have decided to use a simpler term for talking to yourself. This is because self talk is a simple mental activity that occurs constantly. Unfortunately, most people vastly underestimate the influence of the thoughts that occupy their minds.

Let's get one thing straight right now. It is not crazy to talk to yourself in your mind. It is normal. Everybody does it, every day, most of the time. The problem is that most people do not realize the hypnotic power of the messages that pass repeatedly through their minds. We allow self talk to ramble on with little heed. At best, the potential benefits of self talk are lost. At worst, we allow a constant barrage of worry or self criticism to play constantly on our minds, and to steadily erode our self confidence. Rather than view self talk as having great influence on ourselves, we dismiss it as an inconsequential mental activity. We allow it to run out of control.

It is truly amazing what people can talk themselves into, or out of. Learning to adapt the way you talk to yourself encourages constructive use of an activity that you do all of the time anyway. For the small effort involved, there is no more useful way for transplant patients and their families to help themselves manage stressful events.

Jennifer: At sixteen, Jennifer believed that kidney disease had ruined her life. She was sure that the others at school pitied her. They probably talked about her behind her back. She had to leave school early twice weekly for dialysis. *Why do I have to be so different? Why can't I be like everybody else?* she thought.

One day during lunch, a classmate told Jennifer that a boy was going to ask her to a school dance. Jennifer couldn't concentrate for the rest of the day. Her mind raced. *Was this a practical joke? Why would anybody ask me for a date? I'm not attractive. My skin looks like paste. Everybody knows that I am sick. I can't even dance that well. Did my brother ask him to do it? What excuse can I use to not go? I can't let him make a fool of me.*

At the end of the day, Jennifer told the boy's sister that she was going camping on the weekend. She hoped that he would get this message. Then he could ask somebody else to the dance.

Whether you always realize it or not, self talk influences you greatly. It affects your decisions, your actions, your confidence and your mood. When Jennifer accepted the critical self talk that played on her mind, she may have talked herself out of a fun evening. She did not stop to question or test out, the validity of her thoughts. She automatically assumed their truth. Many have missed jobs, new friendships and rewarding experiences by allowing negative self talk to decide their actions.

Melissa: Melissa asked her doctor if she really had to have the lung function tests again. She had hated

them the last time. Unfortunately, the doctor said that they were necessary.

The tests were booked for two weeks ahead. She had lots of time to worry. She thought, *It was so uncomfortable in the testing room. I felt confined, as if I could not get out if I needed to. The last time my heart pounded so hard that I thought that they would have to stop the test.* She just had to picture herself, alone in the testing room, and her chest would tighten. *It is stupid of me to be so afraid. People have these tests every day. What is wrong with me?*

But Melissa couldn't stop worrying about what would happen if her heart began to pound again. *What if I have to leave the room? They will think me a child. Why can't I take control?* And it bothered her to think that the test results might be worse than before. *Why else would the doctor want to repeat them?*

As each day passed, Melissa talked herself into a worse state of anxiety. She knew what she was doing. And she blamed herself for not having greater control. She tried hard to force the worries out of her mind. But they would always pop back. By the day of the lung tests, Melissa was in a panic.

Many factors influence your approach to a medical test or procedure. One is how you talk to yourself before, during and after the test. Unfortunately, many habitually talk themselves into increased distress. This can only make the test or procedure more uncomfortable. It is obvious to any reader that Melissa was talking herself into expecting the worst. Her level of apprehension increased accordingly.

We are not suggesting that medical tests or procedures are a pleasant way to spend an afternoon. We are also not suggesting that you can talk yourself into believing that they are. But given the obvious influence of self talk, we do suggest that there is merit in questioning the thoughts that pass through your mind.

By questioning the thoughts that pass through you mind, you will counteract the grip that they have on you. *Is there any reason to think that this thought is true? How likely is the catastrophe about which I worry? Am I exaggerating dangers? How is this worry affecting me? Is there anything else that I can do to help with the situation? I wonder what someone else would say if they knew what I was thinking? Would they really find my thoughts so crazy? Or would they likely find them perfectly normal? Is it helpful to blame myself for unwanted thoughts? Is there any point in trying to force them away? Has this been helpful in the past? Would it be better to simply notice them and let them pass on? Could I then get on with other things that I enjoy.*

[Table 6.1](#) lists some examples of self talk that are usually unhelpful. Many of us allow critical or worrisome thoughts to occur unnoticed. By doing so, we allow them to influence us automatically and without question. By allowing this, you implicitly accept the statements as truth. For better or worse, you tend to believe and to identify with this habitual mental view of yourself. This can at times, begin a vicious cycle of demoralization and lowering self-esteem, fueling more negative self statements.

Table 6.1: Anxiety Provoking Types of Self Talk

Catastrophic Thinking

If I don't get control, It's all over for me.
I might as well forget the whole thing.
I missed an appointment. The surgeon will hate me.

Over Generalizing

I hate needles. I will never tolerate transplant.
I can't do anything right.
They are always on my back.

Black or White Thinking

Anxiety is bad.
If I can't be well, I'd rather be dead.

Self Criticism

I must be an idiot to think like this.
I should be able to control myself.
It is stupid to be afraid. I have to grow up.

Personalizing

Everybody can see that I take prednisone.
They are short of donors. I will never get my transplant.
He didn't do well with transplant. I probably won't either.

Perfectionism

I should do better.
I will never get it right.
If I gain one pound, I will look terrible.

Working With Your Thoughts: The steps to working with your self talk are as follows. First, take time to notice the thoughts that pass through your mind. In particular, pay attention to your thoughts during times of stress. *I am going to make a fool of myself. I am sure that nobody else is silly enough to worry about this. I should be able to control myself better. I can't let anybody see that I am worried.* You can easily see that this barrage of self criticism cannot possibly have anything other than an upsetting effect. It will tend to increase your sensitivity to pain or other discomfort. How could self talk like this possibly be helpful?

Second, question the truth of the self talk that passes through your mind. *Are things really as bad as I imagine? Am I sure that others aren't thinking similarly? Do I expect too much of myself? Is this really what I think? Or is the thought not at all consistent with my beliefs?*

You may not have an immediate answer for all the questions that may arise. But by simply noticing your thoughts and questioning their accuracy, you help to break the grip that they have on your life.

We cannot emphasize this enough. When you allow critical self talk to pass through your mind unnoticed and without question, you implicitly accept the statements as truth. The thoughts take hold on you as if they were as much a part of you as your arm or leg. But when you question negative self talk, you loosen its grip. You free yourself, little by little, from its automatic influence. Consequently, your sense of confidence and mastery grow.

Finally, don't try to overtly control your mind. Just by reading this section, you may notice more of your thoughts. If you find undesirable self talk, your first impulse will be to try to stop it. You may try to force your mind into submission. But remember that you are likely fighting years of habit. You are unlikely to force thoughts forever out of mind just because you do not wish them to be there. The problem is not best approached as a battle of wills. This is a setup for frustration.

The reason for this is simple. Habit has made these thoughts a part of you. You can't erase them any more than you can pull a weak muscle out of your leg and throw it away. But if you are not happy with the muscles in your legs, you can work with them. You can strengthen them with exercise, stretch them for relaxation, and eat nourishing foods to provide them with nutrients. With persistence and time, the muscles in your legs will adjust more to your liking.

It is the same with thoughts. Notice them. Question whether they are true for you or not. Accept those that reflect your true beliefs and expectations. Let those that don't, pass on. Refine your thoughts by discussing them with others whom you trust and respect. Use logic and facts to counter unrealistic fears. Reassure yourself when your thoughts exaggerate danger. Try them on for size, as if you were shopping for new clothes. But remember that you do not need to buy them all. If they don't suit, just hang them back on a rack and walk on.

In this way, you will gradually learn of the distinction between you and your thoughts. You do not have to be carried away by a river of habitual self talk. See your thoughts for what they are, ideas to embrace

or discard as you wish.

[Table 6.2](#) lists some reassuring types of self talk. How often do you find yourself saying things like these to yourself? Unfortunately for many, the answer is not very often. It can almost seem unnatural to have complimentary or self assuring thoughts on mind for some. But what if you were eventually able to replace critical and derogatory thoughts with these? What if Melissa had thought differently?

Melissa: Melissa asked her doctor if she really had to have the lung function tests again. She had hated them the last time. Unfortunately, the doctor said that they were necessary.

Although the tests were two weeks away, Melissa was already worried. But she thought, *I'm not going to let myself worry for two weeks. I've got better things to do.*

Melissa tried to notice whenever she began to worry about the tests. When she did, she would chuckle at her mind's tenacity. *Its always trying to get the better of me,* she thought. Then Melissa would say loudly in her mind, *I'll do everything possible to prepare. I'll get through it okay.* She imagined that she was talking in her mind and to her own mind, letting it know that she knew better than it.

Sometimes, Melissa would review the plans that she had made. She was going to a movie the night before the tests. Otherwise, she could not keep her mind off the next day. And she would take her Walkman and a magazine to the hospital. *They always keep me waiting. But I'm not going to sit there and let myself get all worked up.* She had already chosen the tape that she would play while waiting.

During the tests, she was going to pretend that she was on the midway at a fair, playing a game. *My imagination is always trying to frighten me. I might as well see if I can get it to help me this time.* And despite what happened, she planned to treat herself to dinner out with a friend after it was all over. *Maybe all this would seem silly to somebody else,* she thought. *But that's their problem. It's better than worrying all the time.*

Table 6.2: Reassuring Self-Talk

I can face this step by step

I will just get on with what I have to do

This is my cue to take a break

As long as I keep my cool, I will be okay

I don't have to let stress get the better of me

The anxiety will pass. It always does

Everybody becomes tense sometimes

Time to take a few slow breaths

I have got myself through this before

I am a survivor

I can talk myself through this

Continue reading [Chapter 6](#)

Mantra

A mantra is a phrase, sentence or paragraph that you repeat in your mind. Usually, you choose some passage that is meaningful or soothing to you, one that reassures and calms you. For example, some will use a quotation from a famous person whom they respect. Others choose a favorite religious passage. It doesn't matter what phrase you choose. As you say your mantra over to yourself, it becomes like a favorite old pair of pants, soothing and comfortable.

Take your time when you set out to choose a mantra for yourself. After you have chosen, say it to yourself during times of calm and relaxation. If you do relaxation exercises, remember to repeat your mantra a few times when most relaxed. This will help your body to associate serenity with the sound of the mantra in your mind. It becomes a cue for your body to relax whenever you think it over in your mind.

Sometimes it is soothing to say your mantra in rhythm with your breath. One young man told us that he would repeat his mantra, *Within myself at peace*, in time with his out breath. He said that *wherever I am during the day, whatever I am doing, I can touch a space inside myself that is at peace. It doesn't matter what is going on around me, I can feel at ease.*

There are many reasons why a mantra is a useful aid. A mantra is private. Nobody knows what you are saying in your mind. They only know that you look at ease. It is also very portable. A mantra is always with you. You will never forget it at home. When you find yourself caught up in the business of the day, your mantra reminds you of the calmness and serenity that occur during quiet times of relaxation.

During times of stress or anxiety, a mantra provides a focus for your inner attention. Many find that they can ride out fear, panic, anxiety and other disturbing emotional states by repeating their mantra over continuously in their mind. It helps you maintain your presence of mind. This reassures you that there is a part of you that is not overwhelmed by emotion. You and your mantra sit in the center of the panic, like the calm eye in the center of a cyclone, an anchor to hold to in a storm. This will enhance your ability to tolerate stressful times.

Paul: Although he didn't consider himself religious, Paul remembered one bible verse from his childhood. He had memorized it for a recital. For some reason, he still remembered the words. When he said it to himself, he found it calming. No matter what was happening around him, he could repeat the verse and feel warm inside. The passage seemed to remind him of an easier time in his life. He repeated it in his mind whenever he had a blood test taken.

Continue reading [Chapter 6](#)

Writing

In the past, letter writing was more common than it is today. It wasn't possible to pick up the telephone and talk to a relative or friend. People took pride in their writing. They carefully searched their thoughts for what they wished to write down. Similarly, writing in a diary was fashionable for many years. Much of what we know about the lives of famous people from the past comes from the letters they wrote and the diaries they kept.

This kind of writing is rapidly becoming a lost art. Writing takes time. But it can seem like there is always something more important to require our attention. Quiet reflection and writing are easy to put aside.

This is unfortunate because the busier that life is, the more important it is to make time to reflect on events. For the transplant patient or their family, much can happen very rapidly. It is almost impossible to keep track of everything that is going on inside and around you. This leaves a candidate or recipient with a demoralizing sense that he or she is not in control, not keeping up.

Writing about your days in a diary can counteract the sense that too much is happening for you to keep track of. The quiet time that you spend writing your thoughts down is itself beneficial. For many people who keep a diary, this is the only time in their day that they spend alone, reflecting on the day's events. It may be the only time possible to catch up with your thoughts. You can write about what has happened to you, how it feels and what the changes mean for you and those around you. Often, writing in this way will remind you of meaningful events that you have forgotten.

Writing things down on paper forces you to organize the thoughts in your mind. And you don't have to worry about what others will think. What you write down is for your eyes only. Writing also contributes to a sense of closure or resolution to your day. It is a way to put the day's events behind you before relaxing or going to sleep. Beyond these immediate, and therapeutic benefits of keeping a diary, you will have a record of your transplant experience to look back on later. Several transplant recipients have published books from their personal record of transplantation.

Continue reading [Chapter 6](#)

Talking with Others

We are often asked questions like, *Is it really necessary to talk about this?* Or, *What's the point of talking? It won't change the situation.* Hesitancy to talk about a stressful or tragic situation may arise for many reasons. However, most common is a fear that associated emotional experience will prove overwhelming. This is more openly expressed by the question, *Why should I upset myself by talking about things that I cannot change?* Few enjoy emotional upset. Even fewer wish this in public. But by persistently avoiding any discussion of one's situation, the potential benefits of interaction are lost.

History has shown that during times of tragedy, people gather for mutual support. They share more than just information. Listening to another talk about his or herself can help you organize your own thoughts better. You may hear something that helps you to understand your situation in a new way. Or you might learn from another person's description of how they deal with transplantation. And while you derive benefit from conversation, someone else may hear welcome news or reassurance in what you say.

For these and other reasons, many transplant centers offer meetings for transplant candidates, recipients and their families to talk together. These include informal gatherings, parties, welcoming committees, support groups, and social outings. Clinic waiting areas are popular settings for conversation. The team told one recipient who had recovered well after kidney transplant that she only needed to attend clinic once every three months. She commented that she preferred more regular meetings so that she could keep up with the gossip that circulated regularly.

You are likely to be the only person on your block (or at your workplace, or from your circle of friends) who has had or is waiting for a transplantation. Talking with other candidates or recipients is a valuable way to learn more about transplantation. Someone else in similar circumstances can sometimes understand in ways that nobody else can. Many have commented to us how meaningful the acquaintances were that they made while awaiting or recovering from transplantation.

Sometimes, others will encourage you to speak openly of your situation. This can happen when someone else thinks that you could benefit from talking. If a transplant staff person finds you to be troubled or isolated, he or she is likely to suggest that you attend some group gatherings with other candidates or recipients.

Usually, it is best for you to at least consider this advice. But those who offer their advice should also keep a few things in mind. Not everybody likes attending group gatherings. If you have never been at ease talking in a group, the idea of doing this may seem strange. Also important to remember is that while some talk of their situation while it is ongoing, others hold onto their thoughts and feelings until much later. It can sometimes be easier to talk about things once you are otherwise less burdened. Some will try to deal with their circumstances by diverting their attention to other activities. For these, talking frequently about transplantation can arouse anxiety.

If this describes you, there are a couple of points to keep in mind. First, remember that there will always be several people in any group who are also uneasy about speaking in front of others. You will not be alone. Second, just because you attend a group meeting does not mean that you have to talk much. You can gain a lot just by listening. When you feel ready, you can speak up. Finally, most programs offer private counseling for those who are troubled but cannot benefit from group meetings.

For the effort and time involved, working with your self talk, keeping a diary, and talking with others are the most useful tools available for coping with the daily tensions that arise with transplantation.

Continue reading [Chapter 6](#)

Physiological Relaxation

Physiological relaxation occurs when your body is deeply relaxed, your mind calm but alert. Many physical activities of the body change during this fully relaxed state. Breathing is slow and rhythmic. Muscles loosen. Pulse and blood pressure decrease. And the electrical impulses in the brain steady. Physiological relaxation is usually only possible when your body is still and your mind not occupied with its usual rapid stream of thoughts and images. There are many different ways of learning physiological relaxation.

When people hear of this type of deep relaxation, a common first reaction is, *What do I need that for? I relax fine when I listen to music.* So far in this chapter, we have encouraged strategies that can help to calm you any time throughout the day. Not everyone is familiar with the profound calmness possible with physiological relaxation. Reserve practice in this more complete form of relaxation for a quiet and private time that you set aside for yourself. It is a time when you learn the art of relaxing yourself deeply.

The potential benefits of physiological relaxation are many. This profound state of relaxation is a refreshing break in any day. Many people learn with time, to enter this state almost at will. With regular practice, the benefits generalize throughout your day. As you become familiar with this experience of deep relaxation, you will more easily notice signs of tension early. Your use of self talk, a mantra, or any other technique to release tension, is more effective because stress has not had a chance to build.

These and other benefits are largely based on one basic principle of psychology: it is not possible to feel tense and relaxed simultaneously. When you notice tension, do not bother trying to 'make it stop.' This forced approach will only frustrate you more. Just remember the ways that you have learned to calm and relax yourself. In this way, calmness will replace feelings of tension. It is not possible for them to coexist.

You have probably heard of some relaxation techniques. Examples include progressive muscular relaxation, self hypnosis and meditation. Introductions to these techniques are commonly available on cassette tapes. The benefits of each, arise in part due to physiological relaxation. Each technique provides a different means of achieving this calm state. You are free to experiment with any of the techniques that we or others describe. Whatever approach you choose, there are a few principles to keep in mind.

Basic Principles: However you approach deep relaxation, there are a few principles to follow. Practice privately, during a time when no one will disturb you. A short period, ten to twenty minutes at a time, is best to start with. It can help to set aside a regular time each day for practice. Early morning, mid-afternoon or later in the evening are popular times. Ideally, you shouldn't even have to worry about answering the telephone. Your goal is to be free from all potential distractions during this time. This will help you focus and calm your mind.

Sit in a chair with your back and neck straight. Look straight forward. If you lie down or lean back in your chair, you are likely to fall asleep. Release your belt, necktie or any other clothing that fits tightly. Place the soles of your feet flat on the floor and let your hands rest on your lap. You should cross neither your legs nor your arms. This stable and confident posture is ideal for any relaxation practice. If you start to slump, straighten your back and neck. Breathe deeply into your abdomen a few times at the beginning of each session. Allow your eyes to close if that feels comfortable.

Consider physiological relaxation a new skill that you must acquire. With regular practice, this skill can help you to relieve tension whenever it occurs. But remember, you would not learn to drive a car, for example by first experimenting on a freeway. Unfortunately, this is exactly what many attempt with relaxation techniques. They read about a strategy and maybe practice it once or twice. Then, they forget it until a time of severe stress. When the technique fails to eradicate tension during this time, it is discarded in frustration. Usually, most techniques can be helpful when correct instruction and practice occur.

Progressive Muscular Relaxation: This technique is a straight-forward introduction to physiological relaxation. It guides you to systematically tense and then relax, each of the major muscle groups in your body. Relaxation cassette tapes commonly use this approach. With the basic principles in mind, progressive muscular relaxation is an excellent and introductory method for tension release.

This approach is ideal for those with tension localized in the muscles of their back, neck and jaw. After learning this technique, many will comment that they never realized how tense their shoulder or jaw muscles were. Progressive muscular relaxation also helps you develop basic skills for use with any other technique. Appendix B provides a guide for those interested in pursuing progressive muscular relaxation.

The Calming Breath: Traditional healers have for centuries described breathing as man's window to the emotions. The truth of this statement is easily argued. When you are calm and relaxed, your breathing is slow and rhythmic. When tense, anxious or frightened, your breathing becomes irregular and shallow. Those with panic anxiety often describe a sense that they are smothering. People with lung diseases are at risk for anxiety. Some of us think that this is in part, due to a disturbing sense of smothering that they sometimes experience.

Other bodily functions (e.g., blood pressure, pulse) also shift according to your moods. But breathing is unique. It is the only body activity that is closely associated with your mood and over which you have some control. Breathing is an accurate and easily observable measure of your level of tension or calmness. It is also a potentially powerful tool for encouraging calmness in the place of tension. Appendix B provides some direction for learning a method we call the calming breath.

Breathing techniques are known by many names. These include deep breathing, abdominal breathing, yogic breathing and the healing breath. For our purposes, there are more similarities than differences between these methods. However, the term deep breathing has led to some confusion that we wish to

clarify.

Deep breathing does not refer to taking a large breath. When someone tells us that they practice deep breathing, we always ask them to demonstrate. Unfortunately, what we often see is the person take a huge breath, with their chest expanding uncomfortably, their shoulders raised and their chin pressed downwards. This hardly looks relaxing to us. It is usually not.

Deep breathing refers to a sense that your breath is entering deeply into your body. As you inhale, it is as if the breath shoots through to your abdomen. Your stomach bulges first. Your chest may or may not rise a bit. Your shoulders need not move at all. When you exhale, your chest relaxes first. Then, the muscles in your abdomen pull inwards. The term abdominal breathing is a less confusing description for this relaxing type of breath.

You can use abdominal breathing on its own as a relaxation strategy. Or you can join it with almost any other technique. Herbert Benson, a physician and Harvard professor of medicine, has described a technique that he calls the relaxation response. His easily learned technique combines general principles of relaxation, mantra and attention to breathing. His books are readily available in most bookstores. We offer further information on these and other books in Appendix A.

Guided Imagery: The association of mental imagery with body activity is shown easily enough. Picture in your mind, a bowl of potato chips or another of your favorite snacks. Imagine the food's look, smell and taste. Your mouth will immediately begin to water. A colleague of ours has a fear of heights. He says that all he has to do to stir up anxiety is to imagine himself looking over the edge of a cliff. The pit of his stomach comes alive.

Many have used mental imagery to promote physiological relaxation, face fears, increase confidence and promote healing. It is beyond the scope of this book to discuss each of these topics. But if you are interested, we list some suggestions for further reading in Appendix A. Also, Appendix B describes one example of guided imagery that can promote relaxation.

Like abdominal breathing, you can combine mental imagery with any of the other techniques for relaxation that we describe. Many people who practice progressive muscular relaxation will hold a comforting image in their mind when fully relaxed. This helps to anchor the feeling of relaxation in their memory. At other times of the day, they can picture the image in their minds. This reminds them of the pleasant feeling of calmness with which they associate the image.

We need to offer one word of clarification about mental imagery. The therapeutic ingredient is not the vividness of the image in your mind. Do not feel badly if you find that you do not form clear images. Most important is the focusing of your mind inwards and the process of imagining. Also remember that there are many different types of images. Some people can hear or smell images better than they visualize them. This is a no less helpful approach than picturing images in your mind's eye. In fact, imagery is likely most powerful when you combine several of these sensory modalities together.

Meditation: Meditation refers to a group of practices that together, span thousands of years of history. Many types of meditation result in a state of physiological relaxation. You can use other meditation techniques to help you sustain a relaxed state throughout the day. Our earlier section on mantra borrowed heavily from teachings on meditation. We can barely begin to introduce this vast topic in our book. But we have included suggestions for further reading in Appendix A.

There is now evidence to support the value of meditation for physical and mental health. Traditional disciplines have known this for centuries. Meditation is not for everyone. But for those so inclined, it is an extraordinary ability to develop.

Self-Hypnosis: Self-hypnosis can enhance most other relaxation and healing techniques. Unfortunately, hypnosis has received some bad press due to exaggerated claims of its misuse. But some will find that they are very adept at self-hypnosis. There is nothing inherently strange or dangerous about self-hypnosis. It holds great potential value. If you would like to know more, there are several introductory books available. We suggest one in Appendix A.

Continue reading [Chapter 6 Questions](#)

Questions

Am I hurting myself if I don't feel up to all these suggestions?

No. There are often times when medical circumstances will override your ability to promote your own well-being. Particularly for these times, we encourage you to foster the support of others and accept, but not resign yourself to, your medical circumstances. We do not suggest that even at the best of times, you try to follow all of our suggestions. We offer a variety of ideas from which to choose one or a few at most.

In his book **Both My Houses** ([Ref 9](#)), Father Sean O'Sullivan makes this point well. Father O'Sullivan underwent a bone marrow transplant after several years of living with leukemia. He writes, *There is a happy heresy abroad about what it is like to be desperately sick . . . Hollywood would have you believe that critical illness is a time of profound heroism . . . This was not my experience. . . When you are sick, you are sick . . . I just wanted to be left alone.* Hopefully, nobody must feel this sick for long. But the point is clear. Look to your well-being when you feel up to it. These efforts will help you through the times when you feel too unwell to be active.

No one should have to feel guilty about being sick. Unfortunately, much of what we hear today can place great expectations on those who are ill. Everybody seems to have advice. *You have to maintain a positive attitude. If you think this way you will recover. Visualize yourself as well. Hold this in your mind and it will happen.* At best, suggestions voiced in this way are insensitive. Worse, they encourage guilt. The implication is that if you don't try hard enough, you are responsible by omission for your own doom. This is improper. It is not possible to immediately change your altitude just because someone else thinks it best. Just try to hold a positive attitude when you are in severe pain.

Rigid directives such as these are offered by those who wish us to believe that if we just think or act in a certain way, all in this world is under our control. Living with dignity, particularly with impaired health, means working with the circumstances at hand. It does not mean that everything is within your control. Some people around you can probably offer you comforting or helpful insights. But whatever you hear, remember that others have to assume what it is like to be in your position. Only you know what it is like for you.

I enjoy progressive muscular relaxation. On one occasion, I became very anxious while practicing. My heart pounded and I felt as though I couldn't catch my breath. I had to go outside for some fresh air. What could cause this?

This is called relaxation-induced panic. There are several possible reasons for it to occur. It could be that you fell asleep and startled yourself when you awoke abruptly. Or it could be that you became relaxed very rapidly and it felt as if you were losing control. If there is a psychologist or some similar person that works with your transplant group, he or she can likely guide you. It is likely that with proper

guidance, this will not occur.

There is another reason why anxiety might disturb a relaxation session. It is not unlikely that many transplant patients and their family members harbor fears of danger in the back of their minds. When you relax fully, you let your mental guard down a bit. This can let deep felt fears pop into your mind and frighten you. If this seems a likely explanation, you are best to not proceed too rapidly with relaxation exercises at this time. You may want to think of ways that you might reassure yourself or otherwise confront the fear.

If you are threatened with some potential tragedy, you may find it difficult to sit quietly in relaxation. Sometimes, it is better to keep busy until the threat is over. Then, you can rejuvenate yourself with some of the techniques that you have learned. It takes a very practiced mind and body to relax fully during times of great threat.

I have meditated for years. I don't know how anyone could live comfortably without it. Wouldn't it be good if all transplant patients were taught to meditate?

You have obviously found personal benefit from your practice. But there are hundreds of ways to relax and to refresh oneself. Meditation is not suitable for everyone. Each must search for a means of tension release that best suits them. We have not found value in trying to convert people to any one type of practice.

I find that prayer is my best means of relieving tension. How does this fit in with the approaches that you describe?

It is our goal to encourage you to look after your well-being, and to give you some ideas about how to begin this process. It is not our intent to tell you how you must do this.

Prayer is one of the oldest and most practiced means of soothing oneself. For the devout, it has many potential benefits. There is nothing about any of our suggestions that is in anyway incompatible with prayer. In fact, many traditions combine prayer with relaxation. They find the mental calmness that occurs in a deeply relaxed state helps with spiritual awareness. Others recite brief prayers in time with their breathing, like we have described for mantra.

I try to think only positive thoughts. But negative thoughts keep intruding on my mind. What am I doing wrong?

This is a complicated question. There are several possible answers. First, you need to figure out what you mean by positive and negative thoughts. Often, the answer to this question is, *positive thoughts are those that are pleasant to think. Negative thoughts are undesirable to me.* If your definitions sound something like these, you may be working from a mistaken assumption. You may be assuming that you can close out an unwanted situation by shutting it out of your mind.

If you live with a severe illness, thoughts of health complications or death may cross your mind at times. It can demoralize you to dwell on these thoughts. But it can be equally problematic to strive to eradicate them completely from your mind. The fact that they have entered your mind may suggest that you need to work some things through. To face a worrisome situation head on may be your best way to relieve yourself of distressing worry. Then reassure yourself that you have done the best you can. This helps to free your mind for other thoughts.

It is also important to know how often you find undesirable thoughts occurring. If they are continuous, this is a problem that you should discuss with someone. Overly pessimistic thoughts may be a sign of depression. But if they occur only occasionally, your expectations may be too strict. Working with the reality of your situation is your best way to sustain a contented mind in the face of adversity. This task will inevitably require you to deal with some unpleasant thoughts or mental images. The alternative is to expend tremendous energy trying to force your mind to submit to your preferences.

I have heard that it promotes healing to hold positive thoughts in mind. Is this true?

It depends what you mean by healing and what you mean by positive. Your mental and physical life are closely intertwined. The repetition of soothing phrases in your mind can encourage an assured attitude. As a rule, a relaxed attitude promotes healing. But you cannot force this. There are a lucky few who naturally hold an optimistic attitude no matter what. But there is no way to rapidly change yourself into such a person.

Many have grossly overstated the power of positive thinking. We think you are unlikely to become a millionaire just by thinking positively. Similarly, you are unlikely to cure yourself of serious disease with so-called positive thoughts alone. Due to exaggerated claims, some people with serious illness strain to hold positive thoughts or images continuously. They are told that this can help their disease remit. Discouragement or guilt occurs when this does not happen.

There are other potential complications with this approach. It is tiring. You may miss some important prompts to action by trying to ignore thoughts that you label negative. Finally, frustration and demoralization may arise when you find that you cannot control completely, the thoughts that occur in your mind. There is little in these consequences that will encourage any type of healing.

Working With Others

My father [a physician] told me of a careful observer, who certainly had heart disease . . . and who positively stated that his pulse was habitually irregular to an extreme degree; yet to his great disappointment it invariably became regular as soon as my father entered the room. ([Charles Darwin, 1872](#))

For most, it is a comfort to have family or friends nearby. But few find it easy for others to be too much in charge. Generally, we wish for freedom to live life without interference.

Serious illness challenges this preference. It can force you to rely on others for things that you might otherwise do for yourself. Illness can draw family and friends together. But it also holds potential for discord between you and those providing help. This chapter will discuss how transplant candidates and recipients may best negotiate help from others. It also provides some guidelines for the complex tasks that face support people.

We should point out that we hold two assumptions in this chapter. The first is that transplant patients do best when they remain as independent as is safe and comfortable for them. Secondly, the ideal supportive relationship enhances a transplant patient's dignity as well as their health. A satisfying and supportive relationship will most likely occur when open discussion occurs around these two assumptions.

Sheila: Two years ago, Sheila lost the use of her kidneys in a car accident. She has required physiotherapy and renal dialysis since then. Now, she is waiting for a kidney transplant.

Before her accident, Sheila had worked part-time and volunteered with a neighborhood recreational program for stay-at-home mothers. Between work and caring for their two daughters, Sheila and her husband were busy. But she found many frustrations with her current situation. Sheila was often tired and had to spend a great deal of time on dialysis treatment. Transplantation offered Sheila hope for the freedom she wanted. Meanwhile, she had gratefully accepted her mother's offer to move in and help until after transplant.

It was a relief for Sheila that her mother was at home when her girls finished school. But she also insisted on doing housework while Sheila was away at dialysis. This irritated Sheila, who enjoyed looking after her own home. And she had her own way of doing the household chores. However, she didn't want to upset her mother by telling her this. Sheila would hurry to get as much done as possible before her mother had a chance to get involved.

Recently, her eldest daughter came home from school and said that she had been late arriving for class that morning. Sheila's mother was quick to comment that this would not have occurred if she, rather than

Sheila, had made breakfast that morning. In a brief moment of anger, Sheila snapped at her mother to stop interfering. This sharp comment hurt her mother who said that she was only trying to help. Sheila immediately felt guilty for what she had said.

This case is not a very dramatic example of anything. It simply shows how failure to express oneself clearly (on Sheila's part) and an assumption (on her mother's part) resulted in a few moments of unpleasant tension for their family. It was true that Sheila's mother had only been trying to help. And Sheila appreciated her help. But neither knew exactly what was on the other's mind.

Sheila made a common error in working with her mother. She didn't explain what help she wanted. Did she want her mother to help only when needed? Or did she want her mother to routinely undertake certain chores? Did she wish her mother to make meals, vacuum or do the laundry? Or would Sheila have preferred her mother look after the girls and do the household jobs herself? Did she expect the house to run as efficiently as usual? Or, if it meant that she could remain involved, could she tolerate things a little less than perfect?

There are several reasons why Sheila or any other transplant candidate might hesitate to face these questions. Most likely, she had not fully considered how she wanted her mother to help. Or she had not expected her mother to get so involved. It could be that Sheila believed she was imposing on her mother. This might have led her to avoid or postpone open discussion about how her mother might best be of help. Perhaps Sheila wasn't even that irritated with her mother. Maybe she was just frustrated by her inability to look after things herself. Whatever the reason, Sheila's failure to express herself clearly had set the stage for conflict.

Sheila had left it vague about how her mother was to help. So her mother assumed what was best to do. And she had decided to help as much as possible, as often as possible. It was best, she believed, for Sheila to save her energy. She was proud to be useful to her daughter again. It never occurred to her that Sheila would resent her help.

Both Sheila and her mother contributed in their own way to the conflict that occurred. Failure to talk clearly and acting on assumptions are the two most common sources of conflict between people. Ideally, transplant candidates and recipients will make others aware of preferences. Otherwise, supports have no alternative but to make assumptions. Sometimes they will assume correctly, and sometimes not. Support people must realize that nobody likes to ask for assistance. Try to avoid making assumptions about what is helpful for the candidate or recipient. Encourage them to tell you directly.

Blake: Blake was severely ill and awaiting heart transplant. His doctors had told him that he should not exert himself physically. They were optimistic that he would regain his strength after surgery.

But when Blake's wife, Liana, returned from work each day, she often found that he had been busy with household chores. And she knew that he worked on his car whenever he thought that she would not catch him. Liana felt torn. She did not want to nag Blake about following the transplant team's advice. He was already frustrated by remaining at home while she was at work. *But am I really helping him if I*

keep quiet? she thought.

Liana remembered that the transplant coordinator had told them that the position of a support person held many responsibilities. Blake had agreed to the coordinator's request that if either of them saw a problem, they would discuss it together and then with her. Eventually, Liana decided that she had to speak up. She couldn't live with herself if anything happened to Blake unnecessarily. He would have to adjust.

Ellen: Ellen had moved to another city to await lung transplant. The transplant team did not want her to live alone, so Ellen's mother-in-law offered to live with her until after surgery. Ellen was thankful that she had this help available. It was not possible for her husband to leave his job for as long as necessary.

One month later, the team thought that Ellen showed signs of severe stress. They asked her to talk with the psychologist who worked with the transplant program. During this meeting, Ellen said that she missed her husband and children terribly. She also had several complaints about her mother-in-law's care. *She never leaves me alone*, Ellen explained. *I can't even talk privately on the phone with my husband. And she's always asking me if I am okay. It's as if she expects me to die any time. But I can't say anything to her. She would tell my husband. If he knew that I wasn't happy, he would leave his job to come here.*

After hearing this, the psychologist suggested a meeting with Ellen and her mother-in-law. She encouraged Ellen to explain how she had always valued her privacy. *I appreciate your help. But I need some time alone. It is the only way that I can sort through what is happening*, Ellen said. *I haven't said anything before. I need your help and I don't want to upset you.*

Ellen's mother-in-law responded that she wanted to do whatever was best. *But I don't really know what to do*, she said. *The transplant coordinator told me that I should let him know if anything happened. I thought that he meant that I was responsible to watch over you.* To herself, she quietly remembered how strained her relations were with her son. *I can't let anything happen to Ellen*, she thought. *He would never forgive me.*

After further discussion, they agreed that Ellen would spend a few hours alone every day. Her mother-in-law joined a senior's group that played cards each afternoon. This gave her a break. But she always made sure that Ellen knew how to reach her. This simple agreement relieved a great deal of Ellen's tension.

From what we have seen, illness and transplantation bring people together in ways that might not otherwise occur. Relatives, friends or work acquaintances will offer you help. You may find that you spend more time, or live in closer quarters with certain people. Or you may find that you must accept help from someone you don't know or even like well.

Karen: A co-worker offered Karen a ride from work to dialysis three times weekly. Karen needed the ride and appreciated the offer. But she and her driver had not known each other well. Eventually, Karen found her to be a nuisance. During their drives together, the co-worker irritated Karen with repeated

questions about her illness. This was all that she wanted to hear about. Karen hinted that she would prefer to talk about other topics. But nothing changed. *How can I get myself out of this situation?* Karen thought.

Circumstances such as these can try your patience and strain your relationship with the very people who are there to help you. Problems in communication arise frequently. [Table 7.1](#) lists the most common ways that transplant patients and their support people set themselves up for disagreement.

Look over the items in this list. It is the rare person who does not recognize some of these patterns from their own relations with others. There is nothing about this list that is specific to transplantation. It just describes the common communication problems that can occur between any two people.

The two examples of Sheila and Ellen suggest some useful guidelines that may help transplant patients and their support people minimize conflict. Know what the transplant team expects of you as a candidate, recipient or support person. This will help you to work out an agreement with each other. If any problems arise, try to talk openly. Or you might ask the transplant coordinator for suggestions. Sometimes, you have no choice but to set limits on the aid that others offer.

Table 7.1: Common Foundations for Miscommunication

Don't tell your support people how they can best help.

Don't tell others what you need and what you don't need.

Let mild resentments or irritations build up over time.

Don't let people know when they are intruding on private time.

Don't let supports know when they are taking over tasks that you would prefer to do yourself.

Hide your preferences and feelings from your support persons.

Support Persons

Assume that you know what is best for a candidate or recipient.

Underestimate the value of just being there.

Feel responsible for taking over everything.

Impose your values, expectations and opinions.

Don't ask what you can do to be helpful and supportive.

Arthur: Arthur's life had changed dramatically over the past two years. First, his doctor diagnosed him with cardiomyopathy. Fatigue severely limited his activity. But his doctors said that other than an eventual heart transplant, there was no treatment available. Shortly after this diagnosis, his wife left him to live with another man. He knew that their marriage had been distant for several years. But that she left in this way shocked him.

During their assessment, the heart transplant team wondered if he had the necessary support available. But when the social worker interviewed Arthur, she was surprised that he complained of an opposite problem. He wanted her advice about how to deal with all the people that were offering help.

Those who knew Arthur liked him very well. Everybody wanted to help. His daughter was angry with her mother. She came to his home every day to clean and make dinner. He suspected that to make his work day easier, his manager was giving some of his work to others in the office. He couldn't leave his desk without a coworker asking if they could do something for him.

For someone who usually led a quiet life, this attention was overwhelming. He appreciated the help. He knew that he would need assistance to get through transplantation. But some of his friends were intrusive. He needed his space. Even more, he felt that others pitied him. He wasn't just Arthur anymore. He was *poor, sick Arthur whose wife had left him*. How could he tell his friends to ease up, but not offend or turn them away?

The social worker had heard this question before. She suggested that he pick one person to be the manager of his support network. His daughter was a likely choice. He could decide with her, what he wished help with and what he preferred to do on his own. She could then organize the appropriate help. They could keep a list of those who offered their time. But unless something specific was needed, they could reassure them that Arthur was well looked after.

Arthur and the social worker talked of how he could respond to these offers of help. They decided that he might say, *Thank you, but I am fine right now. My daughter or I will call you if we need more help later.*

Continue reading [Chapter 7](#)

When Coping Styles Clash

There are almost as many different ways to face illness as there are people. It is helpful to have some awareness of your approach. This will help you understand why you are more comfortable around some people than others. Depending on how their way of dealing with illness fits with yours, you will be more or less at ease with them.

Geoff: What Geoff wanted most was to put distance between himself and transplant. After years of living with a slowly progressive disease, a liver transplant had provided him the chance to recover his life. He attended the team's follow-up clinic each month. But besides this and taking the anti-rejection drugs, Geoff preferred not to dwell on what was past.

His sister had helped him throughout illness and transplant. But Geoff commented that *she doesn't seem to realize that I want to get on with a normal life. She calls me several times a week to ask how I am feeling. I keep telling her that I am fine. But it's like she is waiting for something to happen, waiting for me to get sick again. I know that I have no guarantees about tomorrow. I don't need to be reminded of it every day.*

We couldn't count the number of times we have heard this type of comment. *I don't wish to dwell on what happened. But everybody keeps asking me about it. . . All I want is to get on with my life. Why are others so fascinated by what I have been through? . . . I avoid my brother whenever possible. His comments remind me always that I could get sick again any time.*

People facing serious illness divide themselves into two broad groups. Nobody likes to dwell constantly on health related worries and concerns. But some find it easier than others to focus their minds on other topics. It comes naturally to some to not worry. These people may not wish you to remind them of potential concerns. For others, thoughts of illness and transplant are never far from their mind. When these two groups interact, neither are entirely at ease. Irritations can arise from these different styles of dealing with illness.

Two other topics stand out as common sources of disagreement. Different people have vastly different interests in how much they want to know about illness. Also, people commonly disagree about how necessary it is to talk with others about personal issues.

Interest in Information: Some like to know a great deal. They will read all that is available about their illness and transplant. These people always have a question for the transplant team. *What is this test for? What were the results of my bone scan? What will it be like in the intensive care unit? What are side effects of cyclosporine? What are my chances of doing well with transplant?* For these candidates and recipients, knowing as much as possible about their situation helps them to feel more at ease. If you are like this, you know how unsettling it is when your questions are not answered.

Others take an opposite approach. They prefer to know only what is necessary. Instead of discussing what might happen in the future, they prefer to take things as they arise. At best, these candidates and recipients are indifferent to pamphlets or videotapes that explain the surgery and what will happen afterwards. For them, more information does not result in greater comfort. It encourages apprehension and worry. It would be much simpler if everybody had one approach to transplantation. Unfortunately, this is not the case.

Betty: Betty, wanted to know everything possible about her upcoming heart transplant. *No matter how good or bad, if I know what is going to happen, I can better prepare myself. If I don 't have the facts, I worry more.*

Betty's husband approached things differently. He knew that his wife was reassured by talking to her doctors. But he was bothered by talk of tests, surgery and other treatment. He tried to hide this from her. But she knew him too well. She recognized that what he heard was stressful for him. And she knew how much he worried about her.

After discussing their differences, they agreed that it was best for Betty to talk with her doctors alone. She could then tell him what was necessary for him to know. He could ask other questions if he wanted. Otherwise, they tried to spend their time together doing things that they both enjoyed. This helped them both to take their minds off of the wait for surgery.

Others have told us that some friends or acquaintances are overly preoccupied with the transplant. One recent recipient said, *When I have visitors, I like to hear about what's in the news, or what has happened in their lives. It helps me to remain connected to the world, to remain a part of things while I'm in the hospital. But some of them are so fascinated with what I have been through, that's all they want to talk about.* Janet, a young liver transplant recipient complained that her classmates asked her often what it was like to have another person's liver inside her. *It makes me feel like a sideshow freak,* she said in frustration.

There is no strict rule about how much you must know about transplantation. But a few guidelines are possible. Your transplant team will expect you to learn basic facts about your condition and treatment. This is necessary for you to prepare for major events and to work with the team on your own behalf. Your transplant coordinator can tell you what is most important to learn. If you find yourself avoiding this instructional material, you need to discuss this with someone. Your hesitation is placing your health in jeopardy.

If you find it interesting or helpful to learn more about your situation, most programs offer lots of materials for you to read. These include pamphlets, articles and videotapes. Some even track down a few medical books or journals to read about their condition. But don't expect that everybody else wants to review them also. Remember that what you find interesting, another may find unsettling.

Talking with Others: Some like to share their thoughts and experiences with others. They leave a conversation more settled. Others rarely talk about themselves. They are used to keeping private matters

private. *Does it really help to talk about these things?* is an often asked question.

Too often, these two types of people do not understand each other well. Those who enjoy talking, believe that everybody would be better off if they talked more. If they notice that you are upset, they may ask you if you wish to talk about it. But others wonder what is the point of all the talk. *The transplant coordinator suggested that I start attending the monthly group meetings. I could never talk about my situation in front of others. It makes me depressed even to think about it. Others might see how upset I am.*

As we have discussed earlier, there is little doubt that confiding in others can at times, result in relief and comfort. But this does not mean that it is always best for everybody. No one should be forced to talk, or made to feel wrong if they prefer to keep their matters private. It is usually best to respect their preference. This of course assumes that the person is not doing serious harm to him or herself by keeping quiet about something. Some are just not ready to talk.

What is important in this situation, is to let others know that they can talk with you if and when they wish. *I understand that you don't want to talk now. But I want you to know that I'm available if you want to later.* This permissive stance lets another know that you are there for them if needed. But it also does not intrude on their private space.

There is one other point to keep in mind about people facing transplantation. Some people think about the personal effects of this and other challenging events while they occur. Simone, a kidney transplant recipient, had several complications after her surgery. She let it be known that she wanted others around her. Her family, several friends and a hospital chaplain all found that she wanted to talk with them. It was her way of dealing with a frightening situation.

Tara responded very differently when she was in trouble with her health. She questioned the doctors carefully when they came to see her. Otherwise, she only wanted her husband to visit. *I don't want to think about what is happening more than is necessary. I will think about it later, when I am safe.* Most of her days were spent listening to her Walkman. She enjoyed books-on-tape.

Some will want to talk about what they are going through right now. Others prefer to wait until the situation has played itself out. Either way, talking will help them adjust to what has happened. Don't force your preferences onto others.

Continue reading [Chapter 7](#)

Support People

Because of the obvious challenge to the transplant candidate or recipient, people sometimes forget how hard it can be for support people. Many examples in this chapter suggest that it is not a simple role. There is no doubt that it is painful to watch a family member, friend or anyone else suffer with an illness and work through transplantation. Nobody would choose to be in either position.

There are two types of support. These are practical and emotional. Examples of practical support include driving someone to a doctor's appointment or looking after a child while a parent is in hospital. Emotional support is less specific. It refers to being there for the person. This includes talking with them as they wish. Or likely more to the point, it involves listening when they wish to talk.

We have asked different candidates and recipients to tell us how their family and friends help. Some of course, told us of how others helped them out with grocery shopping, or travel, or helped them financially. But many couldn't give us any specific examples. It was just important to them that family and friends were close by and cared for their welfare. Unfortunately, as we have pointed out several times in this chapter, it is impossible to know the best approach at all times. Anyone can err on the side of being overly intrusive or preoccupied sometimes.

Tia: Tia knew that the transplant team was irritated by her husband. He was having a terrible time while she was in hospital. He worked as a pharmacist during the day and looked after the house and kids when he came home. They had talked of getting help in the household. But he wanted to do it all himself. Tia knew that Carl was pushing himself too hard.

Unfortunately, Carl also tried to look after everything when he visited her at the hospital. He wanted to know all that had happened that day, what drugs had been given, when and by whom. Carl read up on all of the drugs that she was receiving. He constantly checked the amount that was given. He questioned whatever was done. The doctors had become tired of answering the same questions repeatedly. The nursing staff were clearly nervous about caring for Tia while Carl was in the room. It was as if they expected him to explode if they did any small thing wrong.

One day, a social worker with the transplant team came into her room. He said that the chief surgeon had asked him to see if there was something that could be done to help with a situation that was making everybody tense. The social worker recognized the problem right away. He explained that keeping very active was a way that some people responded to the stress of illness. It was a way of feeling in control and warding off fears and worries. The mistaken assumption is that if you could keep busy enough, the pain would not catch up with you.

He wanted to speak with Carl. He thought that Carl could be convinced of having some help in the home. Hopefully, Carl would also talk about his concerns for his wife and family. He was obviously in need of some time out to look after himself. Likely, he would then be in a much better frame of mind to

be supportive of his wife. Without some change, Carl risked burning himself out and alienating those around him.

With all the emphasis on helping the transplant candidate or recipient, the well-being of the support person can sometimes be forgotten. This role can take a toll on the strongest of support people. Keep in mind that you must look after your own well-being if you hope to remain in a position to be of assistance to another.

Friends and Acquaintances

You come into contact with many people each day. Many will be interested in your situation. Hopefully, they will respect your preferences about when and how much you wish to talk.

There are two common complaints that we have heard from transplant candidates and recipients. One is that some friends or acquaintances become uneasy when they find out that you are ill or have had a transplant. They may even try to avoid you. Another is that some are overly free with advice about how you should deal with your situation.

Those Who are Ill at Ease: Many have described how during illness, friends tend to divide into two groups. Many gather around. But others distance themselves. Those that are the most uneasy have generally not yet accepted the reality that illness is a part of life. They would like to pretend that illness does not exist, or that it could not strike at them. By avoiding you, they avoid their own fear.

You can rapidly tell who these people are. Ian, a kidney transplant recipient, had previously spent three years on renal dialysis. He said to us, *Some are uncomfortable with my illness. It is easy to tell. When the topic comes up, they use any opportunity to change the subject or stop the conversation. And they avoid eye contact. I guess that makes it easier for them.*

Almost every reader will have at least once, received a response that seems to say, *I can't tolerate talking about this.* For example, somebody might ask you, *How are you doing?* You might reply, *Okay, but it looks like I have to be in hospital again for a bit.* Responses that stop the conversation short are *Well, I'm sure that things will be fine. How is your family? Or Oh well . . . It's all for the best.*

Unfortunately, due to their discomfort, some will unwittingly respond in a way that is callous. Examples are, *Do you think that those doctors really know what they are doing?* or, *I thought that you were all through with that stuff now?* Even more insensitive, *You should try to think positively. It always helps me.*

Another person's discomfort can be most obvious when they visit you in hospital. Particularly if you are in pain, or are seriously ill, some visitors may be ill at ease. The following passage, quoted from Steven Levine's **Healing into Life and Death** (1987) ([Ref 11](#)) describes this well. *A woman in a hospital in considerable pain told us she felt there were two kinds of people who came into her room. She said she*

noticed one kind of person could hardly sit down next to her, and when they did, they used to shift from cheek to cheek. they couldn't sit still at all. They would fluff my hair or put lipstick on me, or thumb through my magazines. I hey would go to the window and open it if it was closed or close it if it was open. But they couldn't stay long with my pain. She said they had no room in their hearts for her pain because they had no room in their hearts for their own.

But, she said there were others who could just come in and sit down with me. And if my pain was so intense or I was too fidgety that day and couldn't stand to even be touched, they would just sit quietly next to me. They didn't need to give me anything or to take anything away for themselves. They didn't need to take my pain away, and they didn't make me feel that I needed to be different when I was in pain. They had room for my pain because they had room for their own.

We encourage you to find compassion for those people who are not at ease with illness or hospitals. They simply do not appreciate what it means to be in your situation. Through your experience, they may begin to learn what it means to be ill. But you do not have to let yourself be abused. At the very least, you can reassure yourself in your mind that these people are the ones who are out of touch with the reality of life. At times, you may want to say to them that you prefer not to talk about illness or transplant. Or gently tell them that you wish to be alone to rest. Sometimes, there is nothing to do but avoid certain people who are very insensitive.

Advice: Pregnant women face this problem all of the time. Everybody has an opinion about how they look, what they should eat, whether they will have a boy or a girl, why they should have a natural childbirth. Worse yet, many feel no shame about freely voicing their advice.

You can find yourself in a similar position. Opinions about how to deal with illness are everywhere. Almost every popular magazine on the news stands has an article in it about dealing with illness. Friends, even those who have never had to deal with a serious health problem, will have advice. This can be a perplexing problem to deal with. You certainly don't need incorrect or harmful advice. But you may wish to sift through the stuff you hear for some suggestions that might be helpful to you.

Likely the most unhelpful advice is that which tends to make you feel responsible or even guilty about being sick. Examples include, *I've always watched my diet and exercised well. You should try this. or Visualize your body destroying the illness. This is a powerful cure if done properly.* The underlying message is that if you don't or cannot follow their advice, you will make yourself sicker. People may not always know what to say to someone who is seriously ill. This can result in them making insensitive comments. It would be helpful for them to remember an age old principle from medicine. This is, *If you cannot help with a problem, at least don 't make it worse.*

The comments people offer stem from a major trend in North American health over the past two decades. To a greater extent than ever before, people believe that they have a great deal of control over their health. Everybody likes to believe that if they just think the correct thoughts, do the right things, or avoid unhealthy activities, they will stay healthy. Of course this is silly. Anybody who has faced serious adversity knows this.

As a transplant candidate or recipient, you can at times feel like a stranger in a strange land. The above attitudes can be one of the reasons for this. You are unable to maintain the common illusion that you have total control over your health. But many hold this assumption. The current health promotion movement is positive in that it promotes health-enhancing activities and practices. It is harmful when it contributes to guilt among those who are ill. Of course you have some responsibility for your health. This does not mean that illness cannot strike regardless of your efforts.

Having said this, we will offer some advice of our own. We suggest that you consider advice from those who you respect, from professionals you trust, or from another who has achieved what you wish to achieve. Too often we have heard comments like, *I think that it is important to think about what may happen to me in the future. But my sister says that this is crazy. She says I shouldn't worry about things that might not happen.* The first thing that we ask is, *Do you always see things the same way as your sister?* This usually helps to clarify thinking.

Because you are in unfamiliar territory, you may wish for some guidance. But take it from people who know what they are talking about, and preferably from people who think similarly to yourself. Be skeptical of simple solutions to complex problems. Many people cling to their beliefs very strongly. They can inadvertently try to impose these on you.

Continue reading [Chapter 7 Questions](#)

Questions

I used to attend a support group regularly. But twice, friends who I made, have died. I am not returning to the group because I don't want this to happen again. Will the team accept this?

Yes. Support groups offer many benefits for those who attend. But there are sometimes complications. There is little that is more painful than what you describe.

You may want to take a break from the group. Later, you could reconsider its role for you. If you wish to talk with a professional, private meetings are usually possible. If you have been associated with a transplant program for a very long time, it may be best to consider some outside interests or groups. But don't commit yourself to never returning to the group. It sounds like you enjoy people. Try not to cut yourself off completely.

Do all transplant programs expect candidates to have an identified support person?

No, but some do. It depends upon the program and your circumstances. Each team has different rules.

A transplant team may expect you to have a support person nearby if your health is very fragile, if you must move away from home for the transplant, or if the team believes that you will need help with certain chores. It is their responsibility to ensure that you have the resources available to successfully wait for and recover from transplantation.

You may not be able to name one person who can commit to this role. Sometimes, candidates can arrange a group of people who are willing to take turns on their behalf. One heart-lung candidate whom we met had a friend who maintained a roster of supports. There was always a person available if help was needed. Volunteer agencies can often help. We have known church groups to organize help for a candidate through transplantation. Usually, the transplant team will have some people who are able to offer some extra time for those who do not have an identified support person.

When to Ask for Help

No man is an island. (John Donne)

Candidates or recipients have often asked us if we thought they were 'crazy.' In our experience, this question can have many different meanings. For example, it can mean, *Is it normal to think this way?* or *Do others experience this?* It can also mean, *My friends think I am out of touch. What do you think?* More to the point is, *Tell me what is happening to me. How can I regain control?* These questions arise when one is overwhelmed by anxiety, low mood, or confusing thoughts.

Transplantation can evoke intense and distressing personal reactions. This is normal and to be expected in such an extreme situation. But there may be times when you feel overwhelmed by circumstances or your reactions. Similar to physical complications, personal or emotional complications can arise both before and after transplant. Your transplant team will teach you about the early warning signs of infection and organ rejection. They will expect you to report these to them right away. States of anxiety, depression or confusion are also common. In this chapter, we alert you to the signs that suggest an emotional complication which requires professional attention.

There are two main reasons why it is important to recognize personal complications in yourself or someone you care for. When you know what is happening, you can avoid unnecessary worry. If you know when you need professional help, then you also know when you don't. You will not have to worry that you are abnormal or neglecting something important. Also, the complications that we describe are common and treatable. By ignoring them, you risk greater distress than necessary. Untreated emotional complications can have a negative influence on your general physical health and your recovery after transplantation.

Depression

The word depression has different meanings. Many use it to refer to a low, blue or sad mood. Anybody can feel down at times. For those dealing with a serious illness, it is both common and natural to sometimes feel blue.

Doctors can mean something different when they use this word. For them, depression is a potentially serious emotional complication that persists over time. They may call this Clinical or Major Depression. People with this type of depression are uninterested, down or blue most of the time for two or more weeks. [Table 8.1](#) lists several other features of Major Depression that occur along with low mood. This condition can last for months or years if not treated properly.

If this description fits you or someone you know well, you should have an assessment by a professional. There are several ways that Clinical Depression can compromise the outcome of transplantation.

Fortunately, we have excellent treatments available today.

Table 8.1: Symptoms and Signs of Clinical Depression

feeling low, down, blue or sad most of the time

loss of interest or pleasure in activities or people that you enjoyed before

loss of energy, loss of appetite, poor sleep

personal sense of hopelessness, worthlessness

ruminative worry, excessive self-blame

indecisiveness, poor concentration, slowed thinking

feeling as though life is not worth living

Claire: After over one year on a list for heart-lung transplant, Claire still waited. For the first few months, she had been optimistic about transplant. She worked hard at her exercise program, trying to build strength for the surgery. But now, she spent most of her time in front of the television. She thought of other candidates who had waited less time than she. *They have their lives back*, she thought. *Maybe I was never meant to have the surgery.*

When friends called, Claire found little to say to them. On her mind were troubled thoughts. *They just call because they pity me. I'm sure they know others who they would rather talk with.* Claire's attitude worried her mother. Claire was not eating or sleeping well. She had lost weight and looked run down. Some days she would not even get dressed. *This is not like Claire*, her mother said to the transplant coordinator. *There is something wrong.*

During a clinic visit, Claire said to her doctor that she had wondered if there was any point staying on the transplant list. Surprised, he asked why she thought this. Claire replied, *I'm not sure that it's worth the trouble. I don't think it is going to work out. Somebody else might as well have the organs.*

Claire's doctor reassured her that her physical health was stable. He believed that she could do well with transplantation. *But it worries me that you've lost weight and are not exercising regularly*, he said. *I*

think that the long wait has taken a toll on your confidence. You might need help for depression. He asked her to talk with a psychiatrist who worked with the transplant program. She has helped others who became demoralized while waiting for surgery, he said.

This is a typical way for depression to show itself, as a change in personal habits, loss of interest in friends and activities, and loss of hope. An extended wait is a common cause of depression in trans-plant candidates. Recipients can also become depressed when medical complications arise.

Tony: Tony was thrilled when the time finally arrived for his kidney transplant. He was fed up with dialysis. And he hated coming to the hospital every few days. The staff understood. Teenagers often had a hard time accepting the limitations of dialysis.

Tony had one dream in mind. This was to spend an entire summer at his uncle's cottage in the far north. He imagined himself hiking, canoeing and fishing. Dialysis made it impossible for him to be isolated for so long. But the dream kept his spirits high while waiting for his turn at transplantation.

Unfortunately, Tony became very ill after surgery. He was terrified that he would lose his new kidney. *I never expected anything to go wrong, he said to his nurse. I wanted a kidney so badly. I figured I would recover faster than any other recipient in history.*

One month later, Tony had recovered well and was ready to leave the hospital. He had not lost his kidney. It worked well. But he had faced several setbacks while in hospital. It had seemed like whenever the team fixed one problem, another occurred. They told him that he was fine now. But Tony thought, *they've been wrong before. They don't really know what is going to happen with me.*

Tony's family knew that he wasn't himself. He had so many plans for his life after transplantation. But he wasn't even keeping up with the things he had done before. His schoolwork suffered. He missed doctors' appointments. When his uncle asked him when he would be well enough to come to the cottage, Tony replied only *Who knows?* He looked sullen. He showed little optimism for his future. It was obvious to Tony's family that he needed help.

Reluctantly, Tony agreed to let the team know what was happening. They knew that his expectations for rapid recovery had been severely challenged. *What you have been through would discourage anybody, they said. It might help you work things through if you attended the support group that our psychologist holds.* But they also thought that some of Tony's trouble might be due to prednisone. This anti-rejection drug can cause depression in some recipients. They decided that they could lower the dose of this drug. After a few weeks, Tony felt more himself. He could describe what was on his mind during the weeks after surgery. *I couldn't help but think that I was doomed. There didn't seem to be any point in trying. I knew that I could get sick again any time. Because of this, I was afraid to go to the cottage. I still know that life is risky. So I'll be careful. Others in the group have been through as much or worse. They're getting on with their lives. I'm not going to give in. I'm going fishing.*

In these examples of Claire and Tony, their families recognized that they needed help. Unfortunately,

depression is not always so obvious. Or there may not be others around to encourage the candidate or recipient to seek guidance.

Raj: One year after liver transplant, Raj had finished a job retraining program. He moved to another city to manage a department store. It was the first time that he lived away from home. But the work experience would offer him better career opportunities.

Shortly after the move, Raj complained to his new doctor that he could not concentrate or sleep well. He felt run down. A dull ache in his right side was always present. *I have lost my appetite*, he said. *Something must be wrong. Maybe my liver is not working as it should.* But a series of tests showed nothing wrong. The doctor's response irritated him. *Maybe you are working too hard. Try to take it easy*, he had said. *Hard work has never bothered me*, Raj thought to himself with anger.

Unfortunately, Raj had not told the doctor all of his symptoms. And the doctor neglected to ask. Raj found himself crying in the evening when home alone. Sometimes he thought that everybody might have been better off if he had not survived the surgery. But he had been ashamed to tell the doctor these things. *I should be thankful for the opportunity that I have. I should not bother a doctor with stupid things like this.*

Due to his isolation, Raj did not have others who knew him well enough to know that he was in trouble. If he had still been living at home, somebody might have encouraged him to search out proper help. Unfortunately, doctors do not always think of depression as a possible cause for unexplained physical complaints. For this and other reasons, doctors and nurses often miss depression. This is a great tragedy. We now know a great deal about how to help with depression that happens before or after transplantation.

Continue reading [Chapter 8](#)

Anxiety

What we call anxiety has many other names. Nervousness, tension, stress and worry are just a few of the names that people use. Whatever you call it, anxiety is a normal, everyday occurrence. Although some won't admit it, all transplant candidates and recipients have at times been anxious. Much of what we discuss in **Surviving Transplantation** has to do with the tensions that can arise while awaiting or recovering from organ transplant.

We hope that the ideas in this book will help you to deal with any anxiety that illness or transplantation provoke. But there are times when you may benefit from professional help.

Peter: Before the heart transplant team would consider Peter for transplant, they wanted some tests done. For one of them, he had to lie still underneath a scanning machine for forty minutes.

During the test, Peter felt his chest tighten. There was no pain. But it was hard to breathe in. His hands trembled and perspired. Within a few short minutes, Peter was terrified. *Could this be a heart attack?* he thought. *Am I dying?* He got up from the table. It had seemed like an eternity while he was lying there. But it was only fifteen minutes. Soon after he stood up, Peter felt better.

The doctor who assessed Peter looked worried. She admitted him to hospital right away and ordered several tests. The symptoms did not recur and the tests showed nothing new. He was discharged home two days later.

One week later, similar symptoms occurred while Peter was showering. He felt like the small room was closing in on him. Nobody else was home. *What's going to happen to me?* he thought. Peter couldn't jump out of the shower fast enough. When he did, the discomfort eased off. Again, the doctor found nothing wrong.

Peter began to worry that these episodes might happen again. *What if they hadn't ordered the correct tests? Maybe I am sick. Nothing like this has ever happened before. Something must be causing it.* He thought, *What if it happens again and I can't get to help in time? I am going to have to be careful. I can avoid the shower. But they will expect me to repeat the heart scan. What if it happens again.*

Unfortunately, episodes like these are not uncommon. Without a proper assessment, you should never assume that these symptoms are due to anxiety. But for Peter, all investigation was normal. With this in mind, we can say that Peter likely suffered two panic attacks. People with lung, heart and other types of serious illness may be particularly prone to these episodes. [Table 8.2](#) lists the features of panic type anxiety. Only with the help of a doctor can you decide the cause of symptoms like these.

Table 8.2: Symptoms and Signs of Panic Anxiety

shortness of breath, smothering sensation

dizzy, faint or unsteady feeling

hands trembling, shaking, numbness and tingling

sweating, hot flushes or chills

feeling out of control, fearfulness

feeling of dread, unreality

loose bowels, racing heart, bladder urgency

Many people will have one or two panic attacks, but no more. For others they can recur frequently. Trying to solve the problem, some will avoid situations that might bring on the attacks. Some people have panic attacks in confining spaces, in busy shopping malls, or when alone. Unfortunately, by avoiding these or other places, anxiety takes a tighter grip on your life.

Sometimes, people will avoid health practices or other activities due to anxiety.

Jeanne: Jeanne wanted a pancreas transplant. But she worried about what the transplant team would think of her. Living with diabetes, she had always kept a record of blood sugar levels. But it had many blank spaces. *Will they think that I neglect my health?* she thought. *Maybe I can tell them that on some days, I was just too busy to test.*

But Jeanne knew the truth. She avoided testing on days when she had eaten improperly. It worried her to see a high blood sugar. Her hand would tremble when she wrote an abnormal result in her record. Whenever she opened her book, all that she would see were the one or two abnormal results. This made her feel very uneasy. She had learned that it was better not to test at all on those days that she knew beforehand, the result would make her anxious.

Jamie: Jamie couldn't have asked for better results after his heart transplant. He hadn't felt as well for years. So he couldn't understand why he was so nervous about sex. He loved his wife and wanted to be with her. But whenever they got close, he became nervous. His shoulder muscles tensed up and he developed a cool sweat. The moment was ruined. After this occurred twice, his wife noticed that he was

always too busy to be with her. He is avoiding me, she said to her friend. I wish that I knew how to make him more comfortable.

These examples illustrate how people can avoid important or enjoyable activities because of anxiety. Jeanne became nervous when she tested high blood sugar levels. So she didn't test when she suspected that they might be high. Jamie became anxious during intimate times with his wife. Consequently, he began to avoid her because he did not want to disappoint either her or himself. This type of anxiety is also called performance anxiety. This means that you want so badly to do well at something, you become anxious about what will happen if you fail. For Jeanne and Jamie, performance anxiety can make you stop or avoid what you most want to do well with.

Many tensions can occur with illness and transplantation. Often, you can tolerate and soothe these with the simple procedures that we discuss in this book. Whenever you notice that anxiety is influencing your actions, it is time to address the tension directly. But there are times when you may wish to consider professional guidance. If anxiety is severe, or if it interferes much with important duties, you should probably seek help.

Continue reading [Chapter 8](#)

Delirium

It is not uncommon for transplant patients to become confused after surgery. Usually, it does not start immediately. Confusion first starts after two or three days. It can last from a couple of nights to a week or more. Doctors will also refer to this condition as either delirium or encephalopathy.

The symptoms of delirium (see [Table 8.3](#)) include disorientation. This means that the delirious person may not know where they are or what is the correct month or year. Delirium also disturbs one's sleep cycle. People will tend to be awake and restless during the night, but drowsy during the day. Typically, it is hard for delirious recipients to concentrate. They are easily distracted. Also, confused people may sometimes misinterpret events and have unusual thoughts or visions. For example, they might mistakenly think that nursing staff are trying to harm them. If this occurs, it is important for you to let the transplant team know.

Table 8.3: Symptoms and Signs of Delirium

poor concentration, easy distractibility

restless during the night, drowsy during the day

disorientation to place and time

dreaming while awake

unusual or disturbing beliefs, visions, hallucinations

Delirium results from some medical condition or drug that temporarily short-circuits the brain's ability to keep track of what is happening. Drugs are a common cause. Infections, organ rejection and other complications can also cause confusion in some recipients. Delirium also occurs without apparent reason in about one-fifth of heart, lung or heart-lung transplant recipients. Delirium is less common with kidney or pancreas transplant recipients.

Liver transplant candidates and recipients are particularly prone to confusion. As you may know, part of the liver's work is to detoxify chemicals and drugs in your body. If your liver does not work properly,

waste materials accumulate in your blood. As a result, people with liver disease can develop a condition that doctors call hepatic encephalopathy. This term just means confusion and drowsiness due to a liver problem. Any liver transplant team can deal with this problem. Abrupt onset of confusion in someone with liver disease is an indication for immediate assessment.

Immediately after transplantation, your new liver begins its work. Consequently, confusion resolves rapidly. We have seen liver transplant recipients who were alert and oriented only a few hours after surgery, although they were delirious for weeks before transplantation. But for reasons that are not fully known, about one-quarter of liver transplant recipients again become confused later in their recovery. This typically occurs three to seven days after surgery.

Some believe that liver disease makes the brain more prone to delirium for the first few weeks after surgery. This would mean that drugs or complications are more likely to cause confusion in liver transplant recipients, compared to other transplant recipients.

Proper management of delirium depends upon several factors. The team will look for its cause. For safety reasons, it is important that someone watches over a delirious recipient closely. The team may elect to not give any specific treatment. Delirium will eventually go away. If necessary, a doctor may prescribe a sedative drug. This can help to calm a confused person and to make him or her more comfortable.

Heather: Her family hoped that Heather had come through the worst of it. A few days after her liver transplant, she had become confused. She had been wide awake and restless in the night. But still, it had seemed as if she were dreaming at times.

One night she thought that she was in a hotel. *I want to go for a walk on the beach*, she had said. It was all the family and staff could do to keep her from getting out of bed. It was difficult to see her like this. But the transplant team had said that they knew how to deal with this problem. They were correct when they said that she would recover. One week after it all began, Heather was herself again.

A few days later, the nursing staff tried to teach Heather how to take her anti-rejection and other drugs herself. But Heather couldn't seem to keep it all straight. She had always had a good memory. But now she kept making mistakes with the drug amounts.

This is a typical story of confusion after liver transplant. What is important for everybody to remember is that even after the most obvious symptoms of confusion disappear, mild memory problems can persist. It is not that the memory problems are permanent. They are not. But memory is very sensitive to any insult and will be the last mental ability to recover fully. It may take two or more weeks for memory and concentration to recover fully after a few days of delirium.

Continue reading [Chapter 8](#)

Mental Effects of Anti-Rejection Drugs

After transplant, you will take drugs to prevent rejection. Many transplant recipients have to take some of these drugs for the rest of their lives. Two of the most common anti-rejection drugs have some mental effects of which you should be aware.

Cyclosporine: This drug can sometimes cause confusion or memory problems during the first few weeks of use. Usually, this is a temporary problem. The transplant team will deal with confusion due to cyclosporine similarly to what we have described above. Cyclosporine can also cause other transient mental disturbances that are even more common than delirium.

Mary: A few days after her heart transplant, the team administered cyclosporine to Mary through an intrave-nous line. During the following night, Mary remembered having several vivid and strange dreams. The next morn-ing, the nursing staff told her that she was awake often in the night. They said that she was at times, restless and confused. One night, she told them that her cousin had just been killed in a car accident. They had to stop her from getting out of bed to attend the imagined funeral.

Mary had no recollection of much of what the nurses told her. But she felt fine now. The problem did not happen again.

Philip: Four days after lung transplant, Philip was recovering well. The team ordered cyclosporine to start. One day later, Philip told his wife that whenever he closed his eyes, he saw cartoon characters dancing before him.

They talked mainly to each other and sometimes to him. *They don't bother me*, he said. *But they are there whenever I shut my eyes. It's like sitting in the front row of a dark movie theater, watching the show. Otherwise, I am fine.* The images continued for the next few days. Eventually, they disappear.

Prednisone: This drug is notorious for causing mental side effects. It doesn't matter whether the team gives it to you by pill or intravenously. (When given intravenously, it is known by other names.) The higher the amount that you are given, the more likely it is to cause mental changes. [Table 8.4](#) lists the types of problems that can occur with prednisone. These changes may be noticeable to you or to those around you. Depending on how severe or persistent the symptoms, the team may or may not have to treat these side effects.

Table 8.4: Mental and Behavioral Effects of Prednisone

irritability, emotional sensitivity, restlessness, sleep disturbance, erratic emotional changes, overactivity, talkativeness, inability to settle down, racing thoughts, distractability

or

low mood, tearfulness, loss of energy, disinterest, loss of enjoyment

or

disorientation, erratic behavior, unusual beliefs, extreme fear, severe agitation

Jacob: Jacob knew that he was not himself. For weeks he had felt edgy. His mood was all over the place. One minute he was happy. A short while later he would have tears in his eyes. He wasn't depressed. But everything affected him much more than was usual for him. He was too sensitive to anything that occurred.

His wife and children knew that something was wrong. They found him short tempered and irritable. For the past two weeks, he was awake late into the night. *It's like I can't turn my mind off*, Jacob complained. *I guess that I wasn't as prepared for the kidney transplant as I had thought. I don't seem to be coping very well.*

This describes some mental side effects that occur commonly with prednisone. Jacob was taking prednisone each day to avoid organ rejection. Unfortunately, he was not aware that these changes could result from prednisone. Like many others, he assumed that his difficulty resulted from some failure on his own part to deal with transplantation.

When side effects of prednisone are recognized, your doctor can perhaps decrease the amount of the drug that you have to take. If necessary, there are other drugs that can counteract these side effects. They can help you to regain control over your moods. But remember, you should never make any changes in your anti-rejection drugs without first talking with your transplant team.

Continue reading [Chapter 8 Questions](#)

Questions

Isn't it normal for sick people to be depressed?

It is normal for sick people to sometimes feel sad. It is normal for them to dislike their situation. But it is a myth that sick people are all clinically depressed. The resilience with which people confront illness is truly remarkable. Countless surveys and research studies have shown that most people with a physical illness are not depressed. If you suspect depression to be a problem for someone, do not assume that it is a normal response to illness. Remember, if you were run down by a truck, it would be 'normal' for you to have several bones broken. But you wouldn't appreciate it if those around you just called this 'normal' and then ignored your pain.

As long as the medical problem remains, won't the depression persist?

Not necessarily. Improvement in medical state will most likely help with depression. But antidepressant treatment can result in a better mood and outlook, even if the medical situation does not improve. We have treated people for depression while awaiting transplant. They often did well, although with some, their illness had progressed further.

I am waiting for a heart transplant. After reading Table 8.1, I am sure that my wife is depressed. But she doesn't want me to tell anyone. What can I do?

The first thing you can do is to show her the table. She might see her own situation there. Hopefully, this will encourage her to take our advice and ask for help.

Like anyone, support people may hesitate to let on that they are having difficulty. They might say, *There is enough going on already. I don't want to add to the problems.* Or, *The doctors are too busy to bother with me. I will be fine.* Transplantation can take an emotional toll on support people. But they may not feel comfortable asking for help. After all, they are not supposed to be the ones who are sick. But as we have said before, if support people wish to be in the best position to help, they must look after their health also.

I have tried many of your suggestions. But I am still very anxious. What can I do?

Persistent problems with anxiety are a reason to ask for some professional advice. Often, another person can see answers to your difficulty more easily than you can.

Do I cause my own anxiety?

This is a difficult question to answer. There might be some things that you do or think that contributes to anxiety. It is also likely that there are things beyond your control that are causing tension. Everybody

contributes in some way to their level of stress. It is not correct or helpful to blame yourself for how you feel.

Whatever causes anxiety in the first place, most people seem to have a natural tendency to make it worse. First, we try to ignore it and hope that it goes away. Then, we try to force it away. We say to ourselves, *This is silly. There is no reason for me to feel like this. I have to pull myself together.* If this does not work (and why should it?), we interpret anxiety as a sign of personal failure and become demoralized.

We have said that stress and anxiety result from an interaction between us and the world. But we do not mean this to be a contest to see who is the strongest. This is not the value of this approach to stress. The value of this approach lies in its optimism. If you are a part of the process, then you can affect it. We do not suggest that you struggle with anxiety as if you were in a contest with it. It is better to work with anxiety, avoid letting it overwhelm you, tolerate it, wait it out, and laugh in its face. In this way, you decrease its grip on you. You do not let it get the better of you.

Twice, I have had the same nightmare. In it, I am in the hospital shortly after my transplant. The nurses are dressed like cannibals. They are trying to kill me. What does this mean?

Most likely, this is a memory that you have buried in your mind from a time when you were confused. This is a common, but disturbing type of hallucination that can occur with delirium. You may want to ask your family or your doctor if they can tell you what it was like for you shortly after your transplant. They may even remember that you were confused. They might even know that you told them of disturbing images and dreams.

There are some other reasons why a dream like this could recur. If it persists, is very disturbing or is associated with daytime images or other symptoms, you should discuss the problem with someone.

My uncle is confused. What can we do to help?

To help confused people, make sure that they are safe and gently remind them of what is happening around them. Delirious patients may need a family member or staffperson to sit with them. This will ensure that they do not wander off or accidentally harm themselves. To help reorient confused people, you can place a large clock or calendar within their sight. Having familiar objects in the room (e.g., a family photograph) may also be helpful.

When talking to confused people, gently remind them of where they are and what is happening. Say their name often. For example, you might say, *Matthew, this is your wife Jenny. I am sitting with you here in the hospital.* Or you could say, *Jim, you are a bit confused right now. The doctors say that it is due to some drugs. You are safe and will be better soon.*

If delirious patients say something that is inaccurate, you can either let it pass or gently correct them. For

example, a confused person might believe that she is at a hotel. You could respond, *No, Emily, you are in the hospital. We expect you to get better and come home soon.* But only continue if the patient is calmed by your response. Don't argue or struggle to convince her of the truth. If she becomes irritated with you, stop immediately. It may be best to just sit quietly nearby. The transplant team may decide to calm an easily agitated recipient with medication.

My husband is recovering from heart transplant. He is still in the intensive care unit. The last time I visited, he didn't know where he was. And he said some very strange things. Can transplantation cause dementia or schizophrenia?

What you describe is typical of delirium. It has nothing to do with schizophrenia. Unless a senior doctor tells you otherwise, there is no reason to think that these problems will not resolve. Only in very rare situations, when things go terribly wrong, can dementia result from transplantation. There is nothing that you describe to suggest this.

Transplantation and Personal Growth

I feel great just to be alive. So appreciative, just having the chance to be a part of things. It's not that I want to spend the rest of my life kissing the ground. But I would like to do something meaningful.
(Lung Transplant Recipient, 1990)

Certain life events prompt one to contemplate the deeper meaning and value of life. A birth, marriage, serious illness, or death can lead any of us to pause in moments of self-reflection. As a result, changes in one's values, priorities and outlook on life can occur. These have long been recognized to occur with major or traumatic life events.

These adjustments can occur with serious illness and organ transplant. The personal changes may be so meaningful that they propel some candidates and recipients on a journey that could be considered spiritual. Some will readily embrace these shifts, finding them calming and reassuring. But others will be confused. A feeling of unease can arise from the sense that something is different. Exactly what has changed may not be readily apparent. We hope that this chapter will help guide you through the deep felt personal effects that transplant can have on you or someone close to you.

Personal Changes with Organ Transplant

There are several different types of personal changes that can occur with illness and transplant. We will begin with some examples.

Trevor: When Trevor first learned that he had cardiomyopathy, he decided to fight the illness with all he had at his disposal. However, as his heart muscle steadily weakened, Trevor found his life gradually taken from him.

Trevor learned that he could save strength by traveling less with work. Later, he gave up going to the golf club. It tired him too much. Each year, he had to further decrease his time at the office. The other partners in the law firm took over many of his clients. Even when at home, he could do less and less around the house. When his doctor finally told him that it was time to consider a heart transplant, there was no hesitation on Trevor's part. If a new heart could give him his life back, he was ready to take any chance.

Only one year later, Trevor returned to work with a new heart in his chest. His drive to recover his life had pulled him through whatever illness and transplant had placed in his way. His partners were thrilled to see him back at the office.

But Trevor quickly noticed that all was not the same. At a six month review, he had fewer new clients than several of the other partners. Before, this would have bothered him greatly. He would have thought,

I can't let the others earn more than I do. I am a better lawyer. How does it look? What will they think?

Earning less didn't bother Trevor now. It seemed a small price to pay for more time at home. He found himself daydreaming about an early retirement. And he thought about taking his family on an extended trip through Asia. When young, he had promised himself that he would see the world. At other times, he had difficulty falling sleep. The work that he was doing on behalf of a company charged with pollution was always on his mind. He would never have let this bother him before. He had always kept his professional and personal life separate.

These new attitudes puzzled Trevor. *What does it mean? Am I not the same as before the transplant? Has it changed me?* He had worked so hard to regain his health and life. But now he seemed to want a very different life.

Candice: Growing up with cystic fibrosis had not been easy. But Candice had never let it get the better of her. Her priority had always been to live as normal a life as possible. Before her lung transplant, she had always kept this and other goals clearly in mind. Now that she had a new pair of lungs, it seemed that the world had opened up for her.

But Candice knew that she was different than many of her friends. And it wasn't just the disease. Although only eighteen, she had a calmness and a steadiness about her that was beyond her years. Many of the concerns that upset her friends, did not have an impact on her at all. What appeared of great importance and urgency to her friends, seemed far less pressing to Candice. She could keep a clear head no matter what was happening.

Her friends recognized the strength in Candice. Many of them would ask her advice about their life decisions. She wasn't always sure why they respected her opinion this way. But she knew that she could usually see through their confusion at a glance. Sometimes, their problems appeared so unimportant to her that their concern irritated her. But deep in her mind, she knew that they had not been tested the way that she had. They had not seen how fragile life was.

Elaine: Before having a bone marrow transplant for a blood cancer, Elaine had believed her life was very normal. She was not always happy. But there was nothing to complain about.

Recently, Elaine had attended a cousin's wedding. To her surprise, she felt uncomfortable at the reception afterwards. She noticed how few in her family said what was really on their mind. Most had a sociable front that they wore like their suits and dresses. The ones who did speak up also disturbed her. One aunt talked badly about the bride's sister who suffered emotional problems. Several others gossiped about how successful family members had or had not been in life. She found them either insincere or insensitive.

Elaine could not enjoy herself. She felt very distant. This bothered her greatly. *Have they changed? Or have I not seen this before?* she thought. *Is there something wrong with me? How can I enjoy them if I feel this way. I can't let anyone know what I am thinking.*

After living through illness and transplant, Trevor, Candice and Elaine each noticed changes in themselves. Trevor's goal for a heart transplant was to return his life to normal. But after recovery, it seemed as though his priorities had shifted. What was normal for him before transplant, now didn't feel right.

Candice had matured far beyond her years. Friends sensed qualities in her that led them to search out her counsel. She saw life differently than most others her own age. Elaine was startled and confused by disturbing qualities that she now saw in some family members. Neither Trevor, Candice nor Elaine had set out with any goal for personal change. Instead, they noticed shifts in their outlook only after they had occurred.

Medical care today is far more advanced than even thirty years ago. As a result, people are likely to live much longer after serious illness. This is not only true for organ transplant recipients. Those with severe injuries or cancer are much more likely to recover their health. Survivors of these and other life-threatening conditions often describe remarkably similar changes in their outlook on life. Some of these are listed in [Table 9.1](#).

Table 9.1: Personal Changes with Illness and Transplantation

shifts in values, beliefs and priorities for life

changes in what is considered important versus unimportant

greater emphasis on the present

decreased preoccupation with the distant future

increased interest in family, friends, one's place in society

greater transpersonal awareness

increased appreciation of life

decreased procrastination

increased awareness of interpersonal relations

We do not wish to imply that this is a recently discovered phenomenon. More correctly, medical science has now observed what has been described elsewhere for centuries. Many spiritual and religious traditions have suggested the mutative potential of illness and adversity. Christian passages are filled

with stories of those who find renewed compassion for life and humanity after recovering from serious illness. In Buddhist teachings, confrontation with one's own mortality is said to result in a greater appreciation of life, less neurotic thinking and a more purposeful life. Native Indian and other aboriginal peoples often chose their shamans or 'medicine men' from those who had survived great tragedy or illness. These great traditions lend validity to modern observations of personal growth after illness and transplantation.

Continue reading [Chapter 9](#)

How Personal Changes Occur

How can serious illness and organ transplant cause deep felt personal change? Why do changes occur in some but not in others? Are they real or imagined, good or bad? Why do we suggest that these changes may represent personal or spiritual growth? These are complex questions to which any response will be incomplete. But some insight into their answers can be found by investigating two very simple questions. Who do we believe ourselves to be? And how can illness challenge these beliefs?

Personal Identity: If you think of any person you know well, several images will come to mind. You might remember that he or she is attractive or a good singer. He or she may eat a bit too much, like to dress in a colorful manner, enjoy old movies, and so on. These are some of the many features of your friend's identity. Each of us has a distinct personal identity. It is this identity that those around you are familiar with and recognize.

Three aspects of identity are usually highly regarded and sought after. These are stability, desirability, and control. A stable identity allows one to build enduring relationships with others. It helps one to set goals and work steadily towards them. We are surprised when someone we know well does something that appears out of character. We might say to ourselves It doesn't seem like Steven to do something like that. Most prefer themselves and the people they know well to stay pretty much the same.

Desirability is another valued aspect of personal identity. Depending on personal goals, one might exercise, have plastic surgery, take courses, or work hard to buy new possessions. Many people truly derive enjoyment or satisfaction from these aspirations. But often there is also motivation to enhance personal identity. We strive for a more desirable identity to show to the world.

If anything could be more important to us than a stable and desirable identity, it is the need to feel in control. We work to secure and maintain a safe house, a fit body, and financial stability. All this in part, aims to satisfy our desire for greater control over our life and future. A person who appears to be in control of their life generally earns the respect of their peers. Affluent societies have been highly successful in providing the opportunity for personal control. The opportunity for good health, a long life and worldly gain is infinitely greater than only one century ago. Organ transplant is a tremendous advance in our effort to gain control over ill health.

The Strain of Personal Identity: The importance that we attach to personal identity is not without its drawbacks. Tremendous energy can be consumed by the persistent effort required to sustain a desirable front. The work involved can be draining, even when one is in good health. When ill, the time and energy may not be available. A demoralizing crisis of identity may result. This is an important and common way that illness causes distress.

The search for a more desirable identity also results in competitive ambition. We find ourselves looking down on others who have not accomplished as much. We come to value some people less and others

more. Our compassion for humanity becomes restricted by how important or unimportant different people are viewed. The pain of this competitive ambition led Franny (in J.D. Salinger's, *Franny and Zooey*) ([ref 12](#)) to say, *I'm just sick of ego, ego, ego. My own and everybody else's ... Its not that I'm afraid to compete ... I'm afraid I will compete--that's what scares me. Just because I'm so horribly conditioned to accept everybody else's values, and just because I like applause and people to rave about me, doesn't make it right. I'm ashamed of it. I'm sick of it. I'm sick of not having the courage to be an absolute nobody.*

Similarly, there are problems with our intense need for personal control. Many can avoid confrontation with uncontrollable or tragic illness for longer periods of time than was previously possible.

Unfortunately, this is not always viewed as the result of medical advances and personal good fortune. We have come to expect good health. Or at least we expect to be saved by medical science. When serious illness occurs, our expectations are confronted. Illness challenges these and other inaccurate assumptions that we make of ourselves. As a result, our confidence is eroded at just the time we need it most.

Health has also come to be viewed largely as a product of one's own effort. Daily, we are told that we will stay healthy if we exercise, eat the right foods, don't smoke, or think positively. Many readers of this book will know firsthand that serious illness can occur regardless of any and all efforts to stay healthy. To exercise and eat properly will certainly help you feel at your best. It can lessen your chances of becoming ill with certain diseases. But nothing can guarantee that you will never become ill. We do not have that much control.

Unfortunately, our assumptions about one's potential for control can leave one floundering when life-threatening illness occurs. A good analogy may be that of a champion swimmer who is so confident of her own skills that she goes sailing without a life jacket. A severe storm arises suddenly and overturns the boat. The swimmer is overcome and drowns. Those who read the newspaper the next day wonder why anyone would sail in a storm without access to a life jacket. But, this is just what many of us do. We sail through life, expecting nothing bad to happen and live as if we deny personal vulnerability. We are self-assured until a serious illness confronts us.

Illness as a Challenge to Personal Identity: Serious illness and organ transplant directly challenge many of our basic assumptions about personal identity. Such challenges may impose shifts upon the candidate or recipient. These shifts in personal identity are those that we discuss throughout this chapter and elsewhere in this book.

Serious illness proves that we do not have the control we wish. Our ability to assert personal preferences is limited. When ill, your activities slow down and your energy level is decreased. You need to give up some of your time for doctors' appointments or treatment. These demands force you to prioritize your activities more than usual. You must decide what is most important to do. These and countless other impositions confront directly, the assumption that you are fully in control.

What of our efforts for a stable and desirable identity? Is all lost just because you have a scar on your

chest? Is there no hope for you if some things about your self or your lifestyle must change? Of course not. The history of humanity is based on our ability to confront and adapt to adversity.

But is this the ideal that most hold in their minds while they go about daily life? No. Most people live their lives as if they had all eternity available to them. As if the most important aspect of their life was whether their hair is properly in place, or whether they will be able to get a new car this year. If you walked up to somebody and asked them if they thought that these were the most important aspects of their life, they would think you a fool. Of course not, they would say. However, if you were a fly on the wall, you would see how preoccupied most people are with their struggle to sustain indefinitely, the identity to which they aspire. Illness shows us how transparent are many of our deep felt assumptions about personal identity.

When challenged in this way, frantic struggle or despair are not the only possible consequences. An opportunity exists to appreciate a new and potentially less egocentric way of relating to the world, an opportunity to see that while your personal identity is important, it may not be all that there is. Your identity can change, but you go on. It shifts along with illness or other life changes, but you survive. An opportunity is offered to appreciate your strength beyond the boundaries of identity or self-image. Whenever the limits to personal identity are forced before us, the door is opened to question. *Is this really all there is? If I don't really have the control that I thought, where does my strength come from? Am I as important as I thought that I was? What are my priorities? What do I really believe in?*

It is during these times when we are most likely to question our assumptions about the absolute importance and power of our own personal identity. *If I can't stop this illness, then who is in control? Where can I find security, if not in my own abilities? I have lost for now, much of what I thought was me. Is there something else, something deeper that still remains? Or you may begin to appreciate better your connections with humanity. I always thought that I was so independent, so capable. Now I am waiting for some kind family to donate a liver for me. I don't care who they are, whether they are important or not. I just know that I will love them for the gift they will offer me.*

Few of us would choose adversity over an easier road. Certainly we would not choose to become ill if we were given a choice. But of course, this is not the point. Life is as it is, with its mixture of pleasure and pain, health and illness. We do not always have a choice over our destiny. It is exactly this reality that forces us to look beyond our own person when trying to make sense of adversity. It is exactly this reality that offers each of us the opportunity to search for ourselves beyond the narrow limits of personal identity.

Harold Kushner said in his book **When Bad Things Happen To Good People** (1981). ([Ref 13](#)) Let me suggest that the bad things that happen to us in our lives do not have meaning when they happen to us. They do not happen for any good reason which would cause us to accept them willingly. But we can give them a meaning. We can redeem these tragedies from senselessness by imposing meaning on them. The question we should be asking is not *Why did this happen to me? What did I do to deserve this?* That is really an unanswerable, pointless question. A better question would be *Now that this has happened to me, what am I going to do about it?* Alternatively, you might wonder, *now that this has happened to me,*

what does it mean to me. What do I learn from this event? How does it affect who I am?

Spiritual Growth: As we have seen, serious illness, organ transplant and other adversities can challenge one's belief in the strength and durability of personal identity. This is one reason why these traumatic events can be a time of great personal crisis. It is also the reason for the association between serious illness and profound personal changes. It is only when our deep felt beliefs about personal identity are challenged, that we shift or begin to question whether another viewpoint exists. Is all lost when personal identity is challenged? Or can we still exist and find contentment?

Spiritual growth typically involves a shift away from self-centered existence. It involves a decreased reliance on the immediate concerns of personal identity and a greater awareness of one's position in the world community. A sense of being one member in a grand symphony results, replacing the feeling that you are alone and playing out your life in isolation. Greater awareness of the connections within humanity has helped many find the strength to deal with tragic life events that occur beyond any one person's immediate control. The door to these shifts in perspective is opened each time that illness or some other adverse situation challenges our assumptions and our preferences.

The calmness, confidence, and resilience that some transplant patients show may arise as a result of their decreased reliance on the importance of personal identity. The huge amounts of emotional energy that are required to build and perpetuate a durable and controlling identity are available to them for other use. They do not need to defend themselves against helplessness and vulnerability. They have faced these horrors and survived. Their happiness is less reliant upon beliefs and desires that can be stripped out from under them by illness. Therefore there is less to be anxious and fearful about. Their personhood is based on a more durable foundation that exists beyond the apparent strength of personal identity. Their need for a desirable identity weakens. The color of one's hair, or the style of one's dress can rapidly appear of minimal consequence from the perspective of one who is confronting their own death. The need to dominate or interact with others competitively is also lessened. Some who have lived through tragedy can see through others' confusion at a glance. This is because the complex ways by which others support their identity appear transparent to them.

Continue reading [Chapter 9 Questions](#)

Questions

Some of what you say sounds almost religious. Why is this?

At the root of all religious practice is the search for meaning, strength, and solace in the face of adversity. Their teachings attempt to provide guidance not only for surviving the traumas of life, but for personal and spiritual growth as well. Religions all emphasize decreased reliance on personal identity and material possessions. They all share an interest in other, less material sources of strength. Similarly, all religions view personal change as part of the work of spiritual growth.

We could not begin to discuss the many perspectives that different religions hold on personal and spiritual change. But nothing of what we have discussed is either specific to any one religion, nor do we believe it to be in conflict with any major religious practice.

How does religion view organ donation and transplantation?

Of course, organ transplantation was not possible when the world's religions first laid down their teachings. But in recent years, the various traditions have evaluated transplantation according to their basic beliefs and values. For both the devout and the non-devout, religious traditions offer the basis for many of our beliefs regarding the afterlife, the sanctity of the body, and the relationship between body and soul. It is from the viewpoint of these beliefs that transplantation is understood by religion. We realize that there is no quick way to answer your question and to do justice to each religion. Also, there is likely to be as much disagreement regarding these issues within each religion as between different religions. With these limitations in mind, we will try to explain how various religions interpret organ donation and transplantation.

Caring for another as if all are brothers, self-donating love, and benevolence towards others were demonstrated in the teachings and actions of Jesus. Christianity has held these values in high regard. These priorities, and the fact that most Christians do not recognize any laws against organ transplant likely account for the relative ease with which many Christians donate and receive organs. While Christians hold strong beliefs in an afterlife, most do not believe that resurrection is dependent literally, on the body being whole at the time of death. Although some controversy exists within the church, it is generally held that it is the soul rather than the body that persists into the afterlife. Therefore, it does not matter greatly if at the time of burial, the body has another person's organ, or had donated one or more organs.

On the other hand, belief in bodily resurrection is held strongly by the Islamic faith. Literally, a person's body parts are believed to be held accountable for the actions of that person on the day of judgment following death. Further, the sacred writings of this faith emphasize rules against bodily mutilation. Interpretations of these strongly held beliefs have led some Islamic scholars to suggest that organ transplant is inconsistent with their traditional teachings. However, like Christianity, Islam holds a deep

respect for the value of life, the nobility of life-saving acts, and a benevolent desire to preserve all life. As a result, a majority of the faithful consider organ transplant permissible if the risk to the donor (in this or the afterlife) is on behalf of another person's life.

Judaism appears quite clear in its acceptance of organ transplant. Jewish law does argue to respect highly, the corpse of a deceased person and to preserve one's own life and health. Taken alone, these judgments would conflict with organ donation from either deceased donors (where the bodily remains are operated upon) or living donors (where their own health is placed in some jeopardy). However, Jewish law is also clear that life is of supreme value. Its preservation and safekeeping overrides virtually all other considerations. That transplantation serves this priority assures its acceptance within this tradition.

The fundamental tenets of Hinduism and Buddhism are strikingly different from the above traditions. It is interesting therefore, to see how these faiths have come to view organ transplant as an acceptable surgical procedure. In these traditions, the divine is considered to be a sacred reality that is all present, but distinct from worldly existence. The spiritual goal of human life is to place one's self in close proximity with the divine. Meditation and other practices, both spiritual and worldly, are used to attain this goal that may take many lifetimes to accomplish. The essence of human life spans many worldly lifetimes and is not dependent upon the body for sustenance. Therefore, rules against transplantation are not commonly held. Rather, the attitude of the donor and recipient would determine the spiritual nature of the interaction. An attitude of single-minded compassion for the other would offer the donor or recipient the greatest spiritual benefit and shift one closer to the divine. In these traditions, right minded compassion and donation are held in highest regard.

The complex religions of the Far East differ in the degree to which they have come to terms with transplantation. Shinto, a prevalent religious tradition of Japan, is very much oriented to life, fertility, and growth. Transplantation or other procedures that potentially promote good health are readily accepted by the followers of Shinto. Unfortunately, the survival of two of China's major religious traditions, Confucianism and Taoism, are in jeopardy today. Due to repression by political forces, these religions have had their ability to engage in debate restrained. Although there is every reason to expect that the life affirming aspects of these faiths will lead to an acceptance of transplantation, their viewpoints remain open for debate.

Maybe the best overall answer to the question of religion and transplantation is offered in a quote by Dr. David Dixon (1992) ([Ref. 14](#)) In his review of the major religious and spiritual viewpoints on transplantation, he concludes that, *It seems as if each religion, in its own way, articulates a sacred reality understood implicitly by all humanity: that life is holy, and that acts of self-giving touch on the divine.*

My friend said last night that she couldn't stop worrying about the color of her hair. I felt like telling her to shut up, it sounded so silly. Why am I like this?

As a transplant recipient, you may have lost much through illness. Many of the worldly things that seem

so important to others, you may have come to realize are not quite so important to you. Without realizing it, you have learned to identify with another source of strength within yourself. What you need to do now is learn to harness this strength to help you with the tolerance and compassion with which you will wish to deal with your friends.

Is it only with illness that spiritual growth can occur?

Marion Woodman asked this same question in her book, *The Pregnant Virgin* (1985) by asking, *If it takes a holocaust, inner or outer, to help us realize what is really essential in life.* The answer to this question is no, it is not absolutely necessary. But many of us need some event to shake us out of our habitual, self-centered way of life. Questions, self-reflection and spiritual growth are always waiting to occur. Unfortunately, most of us tend to ignore this potential.

I think that I had a near death experience shortly after my transplantation. How can I find out if it was real?

Near death experiences can occur any time that a person is fatally ill. They seem to be reported most commonly after an acute or traumatic event like an accident or an arrest of the heart. Since some transplant candidates and recipients are prone to sudden changes in their health, near death experiences have been reported both before or while recovering from transplantation. Many patients have told us that they do not talk about their experience with the transplant team for fear that they will be considered to be crazy.

Several books have been written about near death experiences. Some of these are listed in Appendix A. Dr. Raymond Moody, a physician, spoke with over 1,000 people who reported having had a near death experience. He found that there was a great consistency among these reports. In his book **Life After Life** (1975) ([Ref. 15](#)), he recorded the following composite description of a near death experience. This description includes the most common features of these events. Your experience may have had some or all of these characteristics.

A man is dying and as he reaches the point of greatest distress, he hears himself pronounced dead by his doctor. He begins to hear an uncomfortable noise, a loud ringing or buzzing, and at the same time feels himself moving very rapidly through a long dark tunnel. After this, he suddenly finds himself outside of his own physical body, but still in the immediate physical environment, and he sees his own body from a distance, as though he is a spectator. He watches the resuscitation attempt from this unusual vantage point and is in a state of emotional upheaval.

After a while, he collects himself and becomes more accustomed to his odd condition. He notices that he still has a 'body,' but one of a very different nature and with very different powers from the physical body he has left behind. Soon other things begin to happen. Others come to meet and to help him. He glimpses the spirits of relatives and friends who have already died, and a loving, warm spirit of a kind he has never encountered before--a being of light--appears before him. This being asks him a question, non-verbally, and stimulates him to evaluate his life. A panoramic, instantaneous playback of the major

events of his life occurs. At some point he finds himself approaching some sort of barrier or border, apparently representing the limit between earthly life and the next life. Yet, he finds that he must go back to the earth, that the time for his death has not yet come. At this point he resists, for by now he is taken up with his experiences in the afterlife and does not wish to return. He is overwhelmed by intense feelings of joy, love, and peace. But shortly, he reunites with his physical body and lives.

He feels changed as a result of the experience. Less afraid, less nervous. Different things seem to interest him. Later he tries to tell others, but he has trouble doing so. In the first place, he can find no human words adequate to describe these seemingly 'unearthly' episodes. He also finds that others scoff so he stops telling other people. Still the experience affects his life profoundly, especially his views about death and its relationship to life.

Experts disagree about what causes the near death experience. Some call it imagination. Others believe the visual images to be caused by changes in the eye during acute illness. Still others consider the experience to result from actual contact with another realm of existence, or with an afterlife. Others believe it a type of religious conversion. So far, nobody has been able to prove what causes these events in all people who describe them. It may be that there are different causes in different people. We can tell you that there is no evidence that a near death experience is a sign of mental illness.

For our purposes, it does not really matter what causes these experiences. What is important to realize, is that their occurrence can exert a powerful influence on your life. As we discussed, any event that reminds you of your own mortality can cause you to reflect seriously on your life. It is not uncommon for people to reflect at length, on the meaning of their lives after having a near death experience. This can be a productive and healing activity. However, well before making any major life decisions as a result of this reflection, we would encourage you to discuss your thoughts with others around you. These may be close friends or family, a professional person or someone from the clergy.

A lot of things that seem important to others, just don't seem that important to me. Do you have any ideas why?

There is a difference between you and others who have not lived through transplantation, or between you now compared to you before you lived through these experiences. It is not just that you have seen first hand the fragility of the human condition, but that the illusion of worldly immortality in which we find comfort in has been eroded. The difference is not in the belief that you are more vulnerable to death than another, or than you once were. Any of us could die tomorrow. The difference is that this reality has been forced into your awareness. You can no longer ignore it the way many do. And you can no longer find comfort in this illusion, its falsity is too transparent to you. You can no longer live your life as if you had all of the time in the world.

This awakening can be comforting or disquieting. You may find that your new perspective offers you a comforting sense of appreciation for life. That you are freed from striving to protect the future and freer to enjoy the moment of today. You may find that it is not as important to keep your hair perfectly coiffured, or your waistline perfectly proportioned, that (given that you only have so much time on this

earth) these things are not worth the effort or energy. There are other, more important things to enjoy.

But changes can take you by surprise. You can find yourself thinking differently about life, but unsure why. Changes in your values, priorities, and the importance you attach to worldly pursuits can occur without your planning. The adjustment may be comfortable for you. Or you may find that you are uneasy with an unfamiliar approach to life. You may feel dissatisfied with previously enjoyable activities or acquaintances. If this occurs, this may be an indication of a need for self-reflection or discussion with others.