

ABSTRACT

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Thousands of U.S. citizens are fortunate to be alive today after having their lives spared by liver transplantation surgery. While this second chance at life is a phenomenon for which all are extremely grateful, recipients often find that this situation poses many new challenges and uncertainties. Medical, social, psychological, and financial circumstances unique to the recipient population are taken in stride by some, while causing considerable distress for others. This project is a compilation of first-hand information and insights relating to these issues gained through interviews with recipients and transplant medical staff. The researcher has combined these results with his own transplant experience and a review of relevant literature to prepare this guide for liver transplant candidates, recipients, and their loved ones. This recipient based guide provides a relevant source of information, advice, and comfort for those going through the process of liver transplantation. It will be an easily read resource intended to supplement literature already available.

DEVELOPMENT OF A RECIPIENT BASED GUIDE FOR COPING
WITH THE PROCESS OF LIVER TRANSPLANTATION

A GRADUATE PROJECT PRESENTED
TO
THE GRADUATE FACULTY
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IN PARTIAL FULFILLMENT
OF THE REQUIREMENTS FOR THE
MASTER OF PUBLIC HEALTH IN COMMUNITY HEALTH EDUCATION

BY
JIM SOLBERG
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COLLEGE OF HEALTH, PHYSICAL EDUCATION, AND RECREATION
UNIVERSITY OF WISCONSIN-LA CROSSE
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GRADUATE PROJECT FINAL APPROVAL FORM

Candidate: Jim Solberg

I recommend acceptance of this Graduate Project in partial fulfillment of this candidate's requirements for the degree:

Master of Public Health in Community Health Education

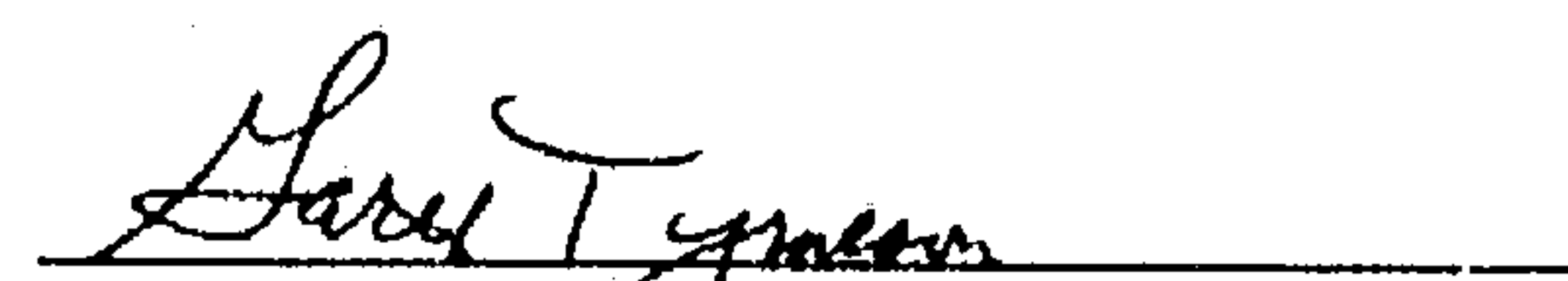
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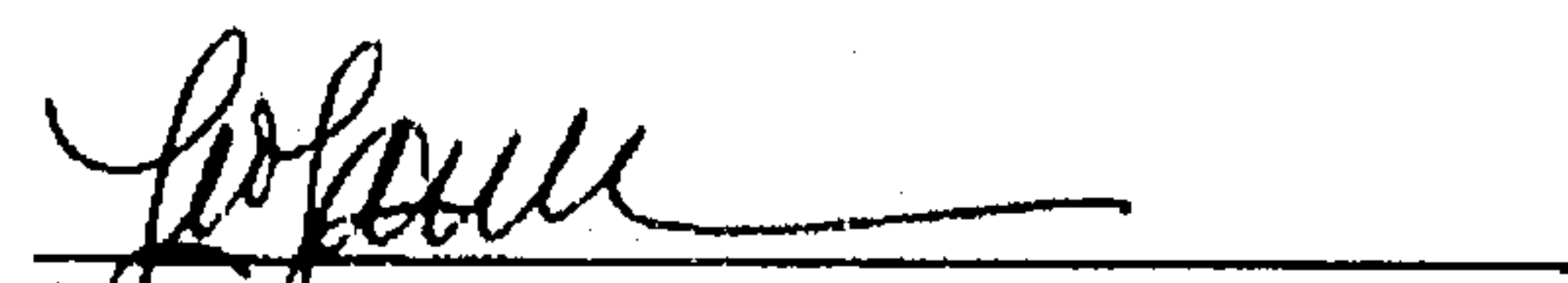
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I would like to thank Dr. D'Allessandro, Dr. Kalayoglu, Dr. Knechtle, Dr. Pirsch, and *everyone* else in the team at University Hospital and Clinics Transplant Department in Madison, Wisconsin, who helped save my life by assisting during my liver transplant surgery and recovery in the summer of 1992 and the follow-up care which continues to this time.

I want to express my special gratitude to family and friends whose love and support throughout my ordeal gave me the strength I needed to endure.

I would also like to thank the other recipients and staff, especially Deb Cole, who gave of their time to share their insights on this miraculous process to help me in completing this graduate project. I hope our combined efforts will bring knowledge, solace, and relief to other liver transplant candidates, recipients and their loved ones in the future.

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SECTION I

INTRODUCTION AND OVERVIEW

In the past decade over 30,000 people, including this researcher, have faced a prognosis of death due to liver failure, and then been given a second chance at life through the life-saving procedure of liver transplantation. While feeling grateful beyond words for this opportunity, the researcher now realizes that he faces the challenges for the remainder of his life that can perhaps be understood only by other recipients.

Statement of Purpose/Rationale

The researcher is conducting this project to shed new light upon the issues surrounding liver transplantation (Tx). This project will utilize interviews with liver transplant (Tx) recipients, comments from Tx experts, and a review of relevant literature to clarify and add significant insights to the issues. With this information, this researcher will then fulfill the first part of the project, which is to write a guide for liver Tx candidates and recipients that is based upon actual experience. It will be an easily read alternative source of information and comfort to those awaiting or recently having received a liver Tx.

Foley, Davis, and Conway (1989) concluded in a study of self-reported perceptions of the quality of life by 26 liver transplant recipients that:

While the health care professional may judge a patient's quality of life on objective evidence such as normal lab values and level of immunosuppression, patients appear to judge their quality of life differently. Data indicate that patients judge their quality of life as a function of cumulative personal gains and losses. Health care professionals must continue to gather data on quality of life from those who have experienced liver transplantation to develop a better understanding of the important components that comprise their quality of life (p. 2418).

Most recipients eventually discover, as did this researcher's own family, that we can also apply the advice of Foley et al. We can usually get the best preparation for facing our problems by getting pertinent information from someone who has actually experienced the same procedure.

It seems reasonable, therefore, that a guide could be best prepared by utilizing this concept to help meet the communication difficulties faced by extremely ill, highly stressed patients anticipating liver transplantation, especially if outside support is minimal or nonexistent. Such personal, relevant information may mean as much or more to those under such stress than the more technical information presently provided. Rather than replacing the medical preparation provided by hospital staff, such a guide would supplement these aids with support from other recipients.

The purpose of this project is therefore to meet this need through the following steps:

1. Assemble relevant insights on the before and after liver Tx experience from:
 - Comments from selected liver Tx doctors, social workers and Tx coordinators from University of Wisconsin Hospital and Clinics (UWHC).
 - Interviews with 6 to 12 liver Tx recipients,
 - The author's own transplant experience.
 - A review of relevant literature on liver transplantation issues.
2. Prepare an informative, supportive booklet for liver Tx candidates and families based on information obtained.
3. Submit booklet for review and feedback from transplant providers at UWHC and incorporate any significant changes before submitting for publication.

Background

Development of Liver Transplantation

In 1995, 20,064 Americans received an organ transplant. Of these, 3,924 were liver transplantations (United Network for Organ Sharing [UNOS], 1997a). When first attempted in the 1960s, however, liver transplantation was not as successful as hoped. Only 30 to 40% of the recipients survived longer than a year due to a high rate of organ rejection by the recipients' own bodies.

The human body reacts to a new liver in the same way that it reacts to invading organisms and substances; it produces antibodies and sends white blood cells to fight the "invasion". The new organ, which is recognized by the recipient's body as a foreign, invading tissue, is simply destroyed in most cases by the genetically programmed functioning of the immune system.

To successfully introduce any donor tissue or organ, the body must, therefore, be effectively "tricked" in some fashion into recognizing the new organ as nonthreatening, essentially accepting it as part of itself. Called immunosuppression, the technique first became feasible in the early 1960s when drugs such as prednisone were administered to recipients organ and tissue Tx experiments. When these drugs were used along with close donor matching, usually by using relatives as donors, the procedure began to have reasonable success in suppressing tissue rejection. Human organ Tx, most notably that of the kidneys, soon became a standard medical procedure.

Liver transplantation success, however, did not reach acceptable levels until 1984 with the discovery of a more effective immune-suppressant drug, cyclosporin. Somehow, this chemical, discovered serendipitously from a soil bacteria in Sweden, is capable of inducing the immune system to tolerate the presence of a donor liver. With the

administration of this compound after transplantation, a much higher rate of survival was achieved, making liver Tx a viable and accepted part of modern medical practice.

The medical and therapeutic results of liver Tx have since been well documented in the literature, with one year survival rates of up to 90% and long term survival estimated at better than 75% (Liang, 1996). Most recipients are relieved of most of the dire consequences brought on by the previous failure of their own livers and recover to a much healthier state. Quality of life is considered by most observers to improve significantly over the pretransplant condition. Under continued, life-long medical supervision, a regular regimen of medications, and regular lab work, most liver recipients are now able to maintain significantly greater medical stability than they had before their Tx surgery.

Much more difficult to measure, however, and less well documented, are the overall emotional, social, and financial impacts on the lives of recipients and their families after transplantation. Many researchers report findings that show a general improvement in quality of life of recipients compared to their pretransplant status. Others note, however, that most recipients nevertheless will not achieve the same levels as the normal population (Liang, 1996).

Selection and Preparation of Candidates

When first diagnosed, those who qualify as candidates for liver Tx are desperately ill, terminally so in most cases. Facing the trauma of liver Tx surgery, however, is often more frightening to some patients than the original illness itself, and some choose not to even consider going through the operation. Those who choose to consider the option of transplantation then face the stress and uncertainty of being carefully scrutinized to determine whether or not they will even be accepted as a candidate for the procedure by an accredited Tx center.

Patients who are accepted as candidates for liver Tx are soon evaluated according to established criteria and placed in a priority status category and are put on a nationally distributed register with all other liver Tx candidates. A system was created in 1984 by an act of Congress to establish a nationwide network coordinating approximately 70 Tx centers across the U.S. This system is now managed by a nonprofit organization, the United Network for Organ Sharing (UNOS).

Before a determination of their transplant eligibility can be made, individuals must first receive a thorough physical workup by the Tx center. A battery of diagnostic tests, along with interviews, help to determine, among other things, the seriousness of the organ failure, absence of other nontreatable terminal complications such as cancer, and the eventual likelihood of the success of the Tx. Other factors such as advanced age, chronic, unchecked alcoholism, cancer, aids, and rejection of previous transplants are examples of factors considered which might affect a patient's candidacy.

Since the supply of donor organs available is far less than the demand, a process of elimination must be practiced to insure that the organs available will be put to the best use. Once a patient has been placed on the UNOS list of candidates for liver Tx, they begin the wait for a suitable organ to become available, a prospect that brings hope to the candidate, but also means the demise of a potential donor. While waiting along with the other 8,000 or more recipients on the list, some with higher priority, the suspense can at times become overwhelming.

Early in 1997 the UNOS priority policy for liver Tx candidates was revised, giving higher preference to acutely ill liver patients. This means that chronically ill liver Tx candidates, who are the majority of those on the list, may have to wait even longer before getting a liver Tx. Even before this change in policy, up to 25% of those on the list have died while waiting for an appropriate donor liver to become available (UNOS,

1997). Unless there is a change in this trend, out of the 7,576 registered liver candidates on the list as of January 22, 1997 (UNOS), approximately 2,000 will eventually die before they get a chance to have a transplant. There are simply not enough organ donors at this time to meet the demand.

A partial listing of some of the present status categories follows:

Status 1 - Life expectancy under 7 days due to sudden or complete liver failure due to acute viral hepatitis or reactions to prescription or over-the-counter drugs. Includes patients who have received a transplant that has failed immediately.

Status 2 - Patients with continuous hospitalization.

Status 3 - Continuous medical care necessary, hospital or home.

Status 7 - Temporarily inactive.

Obviously, the stress of the wait for a new liver can be terribly difficult, both for the candidates and their loved ones. Many become upset upon seeing transplantations occurring all around them; each operation seen as an opportunity that passed them by. Especially frustrating is reading about celebrity liver transplantations which appear to the uninformed to be unusually swift and preferential.

It is important, therefore, for recipients and others concerned with their fate, to realize that a strict procedure is in place, even for celebrities and high profile cases. The UNOS policy, as noted by Benjamin, Cohen & Grochowski (1994), has four aims: "to apply equitable medical criteria, to serve patients fairly, to maximize the chance of a successful outcome, and to minimize organ wastage and encourage organ donation". The appearance of favoritism can occur when by chance the combination of factors cited above just happen to fall into place fortuitously for a particular candidate. Unfortunately,

as mentioned above, the reverse situation also can occur all too frequently, with a patient succumbing to liver disease before a suitable organ becomes available in his or her case.

In addition to the emotional ordeal and worry of waiting, the pre-Tx candidate is usually also suffering from a deteriorating health condition, as well as a decreasing capacity to work, do physical activity or even attend to his or her daily needs. Along with these problems, liver failure often brings on mental confusion, decreased alertness, and even coma.

Life Before and After Transplantation

A different kind of stress, not usually as apparent to outside observers, is also taking a heavy toll. In addition to the physical plight, there is the fear of the unavoidable financial crunch that a liver Tx candidate faces. Increasing medical expenses for the accelerating medical deterioration are an immediate concern and, of course, there is the anticipation of the \$250,000 Tx surgery itself, not to mention the expensive posttransplant hospitalization and recovery afterward. The problem doesn't end there. Once out of the hospital, expenses can be expected to continue with regular follow-up visits, monthly lab work, and immune suppressant drugs becoming a critically important and regular responsibility along with extensive follow-up for the rest of the recipient's life (Gholson, McDonald, & McMillan, 1995). The medications alone can cost a recipient more than \$1,000 a month, an awesome burden for most families.

In spite of the worry, once an appropriate organ is procured, the candidate usually feels a powerful rush of conflicting emotions; joy and relief that the wait is over, balanced by terror of the realization that they are about to undergo one of the most radical and dramatic surgeries attempted by modern medicine. He or she must arrive at the transplant center within 6-12 hours of the procurement of a suitable organ. A donor liver, however, can now remain viable for up to 24 hours with the use of a preservative solution

developed by transplant surgeons at the University of Wisconsin Hospital (UWH) and Clinics Transplant Department Center. The transplantation procedure which follows is complicated and lengthy. This researcher's surgery lasted about 12 hours. The recovery from such a traumatic operation can be difficult for both the patient and the family. Complications and setbacks are not uncommon; in fact, some sort of complication is expected in virtually all cases (Clavien et. al., 1994).

The medical staff at centers like UWHC try hard to prepare patients and families with appropriate details of most aspects of the procedure, but there still seem to be many ramifications for which patients can not really be fully prepared. This researcher was caught completely off guard, for instance, by a five day, postsurgical period of continual terror. While not experienced by all Tx patients, many, like the researcher suffer confusion at the time about how they have become totally immobilized, unable to breathe on their own, and are pierced by tubing and monitors over their entire body.

Adding to the horror of their confused mental state, many Tx patients have terrifyingly realistic hallucinations of bizarre creatures, voices, and in this researcher's case, a paranoid but totally genuine fear that much of the staff was actually plotting to kill him. Even the nurses (some, of course, involved in the plot) were unable to calm the terror during this episode making the initial days of recovery one of the most horrifying and traumatic periods in this researcher's experience. Fortunately, but unbeknown to him at the time, the horror was mostly in his own mind, the presumed effect of surgical trauma and medications.

Later it was explained that this experience was a particularly vivid and persistent case of a perplexing syndrome known as "ICU (Intensive Care Unit) psychosis". Though patients may be warned before surgery of the possibility of this condition, apparently the medications and trauma combine to produce a mental state that not only contributes to the

psychotic state but prohibits rational comprehension of the reality of what is happening at the same time. The sensations and reactions are so "real" that even afterwards, some patients cling to the belief that some of their hallucinated experiences actually happened.

In general, however, the process of post-Tx recovery is made more tolerable by the fact that it is, indeed, a period of actual recovery. For most recipients, as this realization becomes clear, it signifies a dramatic, almost miraculous change from the slow and agonizing deterioration toward death that preceded the surgery. This change of circumstances is profoundly moving, and can inspire tremendous feelings of joy, relief, and gratitude for recipients and their loved ones.

Challenges Facing the Recipient

The reality of life after transplantation, however, soon proves to be full of unique challenges and obstacles to the majority who survive and recover well enough to leave the hospital. Some recipients recover to a fairly normal existence in only a few weeks, while others struggle with rejection or other complications for a long time. Some, once they leave the hospital, are eventually able to return to work while others are not. Over 50% who do return to work, however, will have to undertake a new career (Tarter, Switala, Arria, Plail, & Van Thiel, 1991).

Some are well insured but approximately 17% do not have any health insurance. About 71% of recipients are covered by Medicare and 16% by Medicaid, which varies in what is covered from state to state (Dooha, 1995). Unfortunately, many face a prejudicial reluctance on the part of some employers or insurance companies because of the impact of anticipated high posttransplant medical costs inevitably incurred by liver Tx recipients (Levy et al., 1995).

This researcher has, in the last five years, experienced many of these situations firsthand. He has also met several other liver Tx recipients during this period who have

also shared their own experiences with him, both joyful and difficult. A common observation noted by many is the difficulty with the unexpected consequences of living experienced after liver Tx. Often, recipients reported that they and their families felt ill-prepared for some of the obstacles they now faced.

The literature and counseling provided by transplant centers seems very appropriate for getting patients ready for the surgery and medical aspects of the process, but can't be expected to cover all the variations and complications encountered outside the hospital. Each patient's experience will be different, so it would be impossible to fully anticipate every possibility, especially at a time when patients are in a state of medical distress with accompanying mental and emotional duress.

For many recipients, therefore, there is a need for an alternative source of insightful, meaningful, and relevant guidance to help prepare them and their families for the inevitable and unique challenges that lie ahead. In this researcher's personal experience, his family was able to find solace and needed information from liver recipients who were visiting the clinic while he was waiting for the surgery. These recipients were able to give his family a perspective and insight that none of the staff could anticipate or duplicate.

Some of the problem areas the researcher has encountered personally or during conversations with other recipients are listed below. Though recipients' experiences range from incapacitation to virtually normal existence, the following seemed to be concerns felt by many in all circumstances.

- Feelings of isolation once released from the protective atmosphere of the hospital.
- Difficulty in adjusting to daily life after long illness.
- Physical rehabilitation and recovery.
- Rehabilitation or retraining for employment
- Financial concerns especially the extraordinary, continuing medical expenses.
- Availability of adequate medical insurance.

- Medicare/Medicaid cutoff once employment is achieved
- Family/marital stresses.

Review of Literature

General Background

There is little doubt that liver transplantation has become a very successful procedure. Although it is a "resource-intensive and costly treatment, this therapy gives value for money spent in terms of survival and quality of life sustained for at least up to 5 years after transplantation" (Liang, 1996). This is an important conclusion, considering that an average liver transplantation will cost around \$250,000 (Liang, 1996). As Evans (1995) concludes "Liver transplantation is a very expensive procedure." He notes further, that "Actuaries now estimate that the total first year charges for liver transplantation exceed \$302,000. Total 5-year charges approximate \$364,000, with annual follow-up charges of about \$22,000."

In addition to the monetary expense, each surgery is also using a precious, scarce resource; the donor organ, along with intensive and costly medical resources (Busuttil et al., 1994). In spite of these enormous costs, we will see that Liang's conclusion of the overall value of liver Tx has been supported by findings in several studies in the last decade. We will also see that some studies find that many recipients do experience difficulties, often vaguely defined and difficult to accurately document.

The generally accepted success of this medical procedure in improving the lives of recipients is largely the result of three factors: (1) the new liver, which, of course, is not burdened with the original disease, (2) the pharmacotherapeutic drugs, such as cyclosporin which suppress rejection, and (3) close and continuous medical follow-up (Busuttil et al., 1994; Munoz, 1996).

Many studies have focused on this posttransplant improvement over the past decade, sometimes with seemingly conflicting results. Tarter et al. (1991), for instance,

report in a study of 53 nonalcoholic recipients, that patients improved significantly in "almost all areas of health and psychological functioning" especially in physical functions (p. 1525).

A study by Leyendecker et al. (1993), found some physical difficulties among recipients, but that "surprisingly, all other parameters of quality of life are as high or higher than those of healthy control groups" (p. 565). A prospective study of a broader scope done by Levy et al. (1995), indicates that liver transplantation not only improves survival, but shows a general improvement in quality of life of recipients that continues over time after transplantation.

Foley et al. (1989) in a study based upon self-reported perception of quality of life found that liver Tx recipients showed a generally positive and accepting attitude. Most recipients seemed to be unconcerned by drug side effects and other stresses. In their conclusion it was even suggested that a denial mechanism could account for some of this lack of concern. On the other hand, the authors suggest, many recipients may also be reflecting an appreciation for living life to the fullest (p. 2418).

In contrast to the 1989 Foley et al. study, Collis, Burroughs, Rolles, and Lloyd (1995) report that "there was significant psychiatric morbidity, most commonly anxiety and depression, in a quarter of the patients interviewed after liver transplantation. Collis et al. surmise that "continuing physical symptoms after transplantation, the need for follow-up and medication, and the risk of organ rejection may be as important in causing symptoms of anxiety and depression as the more acute physical ill health found before transplantation." Collis et al. also cited a 1992 study by Commander et al. which suggests that even when this psychiatric morbidity is near normal, there is still impairment in social functioning amongst liver recipients (p. 521).

It is interesting to note that the same researchers also indicate that alcoholic patients "have a particularly high risk of psychiatric morbidity" (p. 523). Rommelspacher et al., (1996), however, cite the results of a study by Howard et al., (1994) which concludes, as did their own work, that "the alcoholic liver transplant patients did not have higher levels of psychiatric morbidity than nonalcoholic patients at follow-up." Clearly, psychiatric results shown by different studies are variable, so potential recipients need to be aware that psychological problems do occur, but they certainly are not an inevitable consequence of liver Tx.

Liver transplantation, as the literature has shown, is generally associated with dramatic improvement in the overall condition of recipients. Liver transplant candidates and recent recipients should also be aware that there can be negative psychological consequences following Tx surgery and during the long recovery process. These conditions often arise from trying to cope with other complications and concerns that accompany the procedure. Recipients should understand clearly that most Tx patients will experience some physical complications.

One of this researcher's transplant physicians stated in an editorial on the outcomes of organ transplantation, that "Liver transplantation has a significantly increased order and frequency of complications" (Pirsch & Sollinger, 1994, p. 108). In agreement with this appraisal and being more specific, Clavien, et al. (1994) found that virtually all, 99.1%, of the liver transplant recipients studied had at least one complication, around 25% of them of a serious nature (p. 113).

Clavien et. al. (1994) proposed an improved system for classifying the negative outcomes of organ transplantation. Their recommendations include incorporating recipient perspectives regarding the quality of life following liver Tx in the analysis.

According to these researchers, the morbidity data following liver Tx at the time of the study had been "poorly reported" (p. 110).

Although there does, indeed, seem to be a lack of consistent standards for reporting of morbidity following Tx, there have been many studies reporting on physical complications following liver Tx, many of them published since Clavien et al. (1994).

This review will examine studies concerning post liver Tx conditions such as:

- Immunosuppressant reduction of ability to resist infections and cancers
- Metabolic problems: diabetes, obesity, hypercholesterolemia, and high blood pressure
- Liver and biliary dysfunctions
- Musculoskeletal complications.
- Allograft rejection.

Reduction of Resistance

Antirejection medications, while they are doing their work to suppress immune system attack upon the new liver, also suppress the immune system's efforts in combating infectious disease agents and carcinogens.

"Chronic immunosuppression has been associated with the following malignancies: skin cancer; non-Hodgkin's lymphoma; Kaposi's sarcoma; uterine cervical carcinoma; and carcinomas of the external genitalia, perineum, and anus" (Munoz, 1996, p. 1106). Recipients are well advised, therefore, to be extra cautious in avoiding carcinogens and excessive exposure to sunlight.

Infections are a serious concern for all Tx recipients. They are, in fact, "the most common cause of morbidity and mortality in liver transplant recipients" (Munoz, 1996). Munoz in the same report, lists some of the infections that are commonly incurred by recipients, which include: Cytomegalovirus (CMV); Herpes simplex; Candida; Epstein-Barr virus; Sinusitis; upper respiratory infection; pneumonia; urinary tract infections; and various hepatic problems specific to liver transplant recipients (p. 1111).

Metabolic Complications

Immunosuppression after Tx is also associated with other potentially serious complications. Stegall, Everson, Schroter, Billr, and Karrigan (1995) "conclude that metabolic complications such as diabetes, hypertension, hypercholesterolemia, and obesity are common after liver transplantation and seem to contribute to patient morbidity and mortality (p. 1059).

Obesity incidence after Tx is not well reported, but according to Munoz (1996), "obesity is a frequent problem for liver transplant recipients, even those who had been profoundly malnourished before transplantation. Forty to 70% of liver transplant recipients become overweight or obese at 1 year posttransplant" (p. 1107). Munoz (1996) suggested reasons for this problem are:

- (1) increased caloric intake.
- (2) the dose of corticosteroids.
- (3) decreased physical activity.
- (4) development of diabetes (p. 1107).

Obesity among recipients is a cause for concern for many reasons (Stegall et al., 1995). As is the case with nonrecipients, for instance, obesity may contribute to cardiovascular (CV) risk factors, and may also make this high risk group even more prone to pathologic fractures (p. 1059).

Increased diabetes in liver transplant recipients was reported by Stegall et al. (1995). Several patients with diabetes before Tx worsened after transplantation while many became diabetics posttransplantation. As with nonrecipient diabetics, it is important that recipients with diabetes modify their diets or even take insulin to correct the condition and avoid dangerous blood glucose levels. (Munoz, 1996).

High cholesterol levels are a concern for many recipients as well, affecting 31% at one year after liver Tx (Stegall et al., 1995). This report also found that another risk factor

for CV problems, high blood pressure, is even more prevalent among recipients, affecting 69% one year after Tx (p. 1058). Although at present, mortality due to CV complications is not found to be higher for liver Tx recipients than the normal population, vigilance is still advised as the recipient population ages with continued survival, especially those with more than one of these CV risk factors (Munoz, 1996).

Several vascular problems directly affect the functional success of the new liver and are serious complications in some cases. This researcher, along with approximately 4 to 26% of other liver Tx recipients (Langnas et al., 1991), had suffered an hepatic artery thrombosis (HAT) shortly after his Tx operation. In this project researcher's case, a vigorous but futile effort was made to procure another liver for retransplantation. The procurement team even flew to Florida to retrieve a donor liver, only to find it unsuitable for transplantation. Successful management of HAT usually involves revascularization or retransplantation (Langnas et. al.), neither done in his situation. This researcher is considered very fortunate to still be alive after 5 years without an hepatic artery and with the same transplanted liver still functioning well. Other vascular complications that may occur after liver transplantation include portal vein thrombosis (PVT), hepatic artery rupture (HAR), and combinations of HAT and PVT. (Langnas et al., 1991).

Liver and Biliary Complications

In addition to vascular difficulties, the new liver may be compromised by complications of the biliary tract. Sometimes, as once again, the misfortune of this researcher has demonstrated, biliary failure can be related to vascular complications; HAT in the author's case (Kalayoglu, Knetchle, & Pirsch, 1992, personal communication). Surgical management is the usual approach to most biliary complications (Sherman et al., 1995). This author underwent a nine hour operation that was almost as traumatic as the original transplantation to correct the condition. Less

invasive percutaneous transhepatic manipulation and stenting which is recommended by Sherman et al. (1995) was actually tried first, but failed to open the strictured bile duct.

According to Sherman et al., "early diagnosis and prompt therapy have resulted in decreased mortality from these complications." Since up to 34% of liver transplant recipients may experience a biliary complication (Sherman et al., 1995), it may be some consolation to those who face this problem to know that most victims, including the author of this project, do survive.

Musculoskeletal Complications

A cluster of complications that can continue to occur long after the transplant surgery involves the musculoskeletal system. These are not usually life threatening, as were many of the physical complications previously discussed, but they can have a major impact on many aspects of the quality of life of the recipient. The level of musculoskeletal morbidity after liver transplantation is reported to be high. Nicholas et. al. (1994) found "62% of the sample reporting weakness, loss of full motion of an extremity, pain, gout, or arthritis". Nicholas et. al., in this study further found "this morbidity to be associated with the likelihood of not returning to work".

Fortunately, these problems do not prevent most recipients from being able to manage their activities of daily living (ADL) or enjoy life in general (Liang, 1996; Nicholas et al, 1994; Leyendecker et al., 1993). Nicholas et. al. (1994) do suggest that their findings point out a "need for intensive posttransplant management of these problems, not only to minimize personal discomfort, but also to return these individuals to a maximally productive life" (p. 434).

Allograft Rejection

Perhaps the most pervasive fear of many recipients is the threat of losing the new liver; an untreatable rejection. In this researcher's case, it took time to accept the new

organ as a permanent part of himself, especially after the threat imposed by the HAT episode and the biliary complications. Fortunately, however, late rejection of liver transplants is rare in number and severity, especially when rates are compared to those of renal transplants (Stegall et al., 1995). Acute rejection was the most common (69% of the total of patients) "grade one" (least severe) complication in the negative outcomes classification offered by Clavien et al. (1994), but "was seldom the cause of permanent graft injury (grade 3) or graft loss (grade 4)" (p. 119). Though relatively uncommon for liver transplant recipients, rejection is the third most frequent indication for retransplantation (1.9% of the total of patients), after second place hepatic artery thrombosis (2.3%), and first place primary dysfunction (2.9%) Clavien et al., p. 119).

A New Hope for Liver Transplant Recipients

In fact, there are ongoing studies that are showing good success in weaning liver transplant recipients away from their immunosuppressant medication completely without rejection. In a recent study, only 19% of patients weaned from immunosuppressants experienced rejection during or after weaning. Due to close monitoring, the rejections were successfully reversed, in most cases simply by resuming the old levels of medication (Mazariegos et al., 1997). This process offers a new source of hope for recipients. It could save recipients and their health insurance providers a considerable amount of money now spent on the expensive immunosuppressants. It could also provide some obvious benefits by providing relief from some of the immunosuppressant related complications described in this review, though the evidence for this is slim at this point.

Summary

In summary, the literature reviewed has documented the medical success and efficacy of the liver transplantation procedure in improving the medical condition of recipients. It has also given a less well documented, but encouragingly positive picture of

an improved overall quality of life for most surviving recipients. Clearly, complications are a part of life for virtually all recipients, with infection representing the greatest threat. Constant vigilance and care ensure that most will survive. As techniques continue to improve, the selection process becomes better, and data continues to accumulate, our understanding of this phenomenal medical achievement will continue to be clarified.

The unfolding turmoil in the financial aspects of the health care system, however, casts a shadow of doubt and concern over the future of this expensive process (Evans, 1995). Liver transplantation has, in effect, created an increasingly larger class of chronic, medically needy individuals, which, unfortunately, is not presently recognized as such and, who have no organized political voice (Warren, 1996). At this time, however, the literature seems to indicate a recipient population somehow adjusting to their new life, and for the most part happy with the opportunity to have a second chance at life .

Overall, the literature has provided encouragement and insight for this researcher, helping to put the interviews he has conducted with other recipients into perspective against the broader picture of the liver transplant experience. The resulting recipient based guide will offer other liver transplant candidates and new recipients an easily read and relevant source of information, comfort, and hope.

SECTION II

METHODS

Activities and Procedures

Introduction

The recipient based guide to the process of liver transplantation is based on information from three main sources: (1) a review of relevant literature to provide technical background and a broad view of the subject, (2) interviews with several other liver transplant recipients, and (3) this researcher's own transplant experience.

The Review of Relevant Literature

The author's research of the literature actually began in 1996 in preparation for a report on the quality of life after liver Tx. Much of the literature reviewed for that report is very relevant to the concerns of the present project's target audience. Further research was done in January through March of 1997 at UW-L Murphy Library and the medical libraries at Franciscan Skemp and Lutheran Hospitals in La Crosse to gather further data on the medical, social, and financial consequences following liver transplantation. Although a good deal of material was uncovered, a lack of comprehensive data on financial and social aspects was noted.

Nevertheless, the author gained a background perspective upon which to relate to his own experience and that of participating recipients. This process was especially useful

in clarifying the medical complications associated with liver transplantation and the morbidity and mortality experienced by recipients over the last decade.

The Interviews

Liver transplant recipients were contacted from two sources: (1) the membership of the La Crosse Area Transplant Support Group (LATSG), which meets every fourth Wednesday of each month at Franciscan Skemp Hospital (FSH) in La Crosse, Wisconsin and (2) liver transplant recipients that were scheduled to attend the regular Wednesday liver Tx follow-up clinics at University of Wisconsin Hospital and Clinics (UWHC) in Madison, Wisconsin.

The first step taken, before any arrangements could be made was to submit a proposal to the Institutional Review Board (IRB) at UW-L for review and approval to conduct a project with human subject participation. Approval was granted on February 19, 1997.

Once approval was granted, members of LATSG were informed of the project at the February 26, 1997 meeting by this researcher, who is a cofounder and member of the group. Five persons volunteered to participate in the project, and appointments were made with each to establish a time to conduct interviews. Each was met at a time and location of their own choosing and interviews were held between March 4 and June 30, 1997.

The interviews lasted approximately 1/2 hour, and participants were told that they could stop at that point if they wished. The project was explained once again, and each

volunteer was given a copy of the project report to review and were asked to sign the consent form approved by the IRB (see Appendix B). After being assured of confidentiality, each participant was given a chance to leave their name and address if they wished to receive a copy of the guide when completed.

Each item on the questionnaire (see Appendix A) was read by the researcher and answers were recorded on paper by the interviewer. Answers were open-ended and conversational, each participant being given a chance to expand or minimize each subject as they wished. All interviews, except one that was conducted over breakfast, lasted about 1/2 hour as planned.

The interviews at UWHC in Madison were conducted in two separate sessions, the first on March 19, 1997. At the first session, Drs. Pirsch and Kalayoglu were reminded of the purpose of the visit and the project. Mike Armbrust, RN and transplant coordinator, gathered three liver transplant patients and their spouses, who had completed their clinic procedures and were willing to participate in the study. Mike made an examination room available for the interviews and introduced each volunteer to the author.

With a larger group present, the interviews had to be conducted with less individual attention than planned. Each participant was given the questionnaire and a pen and asked to record their own responses. Spouses were encouraged to contribute if they wished. As a group, each question was read to make sure everyone understood the questions. At this time there was some spontaneous conversation on the part of all

participants, and it was clear that they all enjoyed the opportunity to be sharing their experiences. Answers that were recorded seemed less detailed than what would be expected in a more personalized interview, however, so the next session was conducted individually whenever possible. The first session lasted a little over 45 minutes.

The second interview session at UWHC in Madison occurred during the regular Wednesday liver transplant clinic day on April 9, 1997. On this day the interviews began earlier, enabling the researcher to interview one or two volunteers at one time. This enabled the volunteers to give better feedback, sometimes with one spouse responding orally while the other wrote down answers. As with the first session, a room was provided for the interviews, and Mike Armbrust, a transplant coordinator, explained the project to recipients in the waiting area and eventually gathered the 6 volunteers to be interviewed.

One volunteer had accompanied her father who was suffering from liver disease but not yet listed as a candidate for transplantation. When she heard about the interviews for the proposed guide, she requested a chance to talk with the author. She was seeking information on the process and seemed very excited about the prospect of a guide such as the one being produced through this project. She asked several questions and appreciated the information given by the author. This unexpected interaction with a nonrecipient gave the author some excellent insight into the concerns of those involved with someone in the early stages of the process of transplantation.

When the interviews were completed, the information gathered was categorized into the following general areas:

- Pretransplant illness

- Preparing for the transplant
- The surgery
- The immediate posttransplant recovery (ICU psychosis, etc.)
- Long term recovery

The Researcher's Own Experience

The author's own liver transplant experience has provided the basis for the intimate knowledge and insight shared in the recipient based guide for transplant candidates and recipients. A brief summary of his experience follows.

The author began to feel ill much of the time in 1990 and gradually worsened through the year. He finally sought medical advice in the summer of 1991 when he found that he could no longer complete a full week of work. At that time, the problem was diagnosed as serious liver failure, and several days of hospitalization followed. After being stabilized and discharged, the author returned to work on a somewhat limited status. The condition generally worsened, however, and eventually it became difficult to even complete two days of work a week. In February of 1992, everything came to an immediate halt when the author lapsed into coma and was placed in the Intensive Care Unit at FSH in La Crosse. He remained comatose for two days and was hospitalized again for several days.

Eventually he was transferred to UWHC in Madison where he underwent a liver transplant workup. After thorough testing he was placed on "the list" of candidates for liver transplantation. After some initial improvement due to careful medical intervention, his condition eventually began to deteriorate, and in time he was spending more time in

the hospital than out. His physicians decided in June of 1992 to place him in a nursing home where he could receive appropriate care, a move which also put him higher on the UNOS transplant candidate list. In three days, a suitable liver became available and the author was rushed to Madison for his transplant.

Because he had been so ill beforehand, the recovery after the 12 hour surgery was somewhat more difficult than usual. He suffered several days of terrifying hallucinations and at the end of his first week of recovery, suffered a life-threatening thrombosis of the hepatic artery.

Since that time, the author has faced two more life-threatening complications, and, as with the hepatic artery thrombosis, has been on the list for retransplantation each time. Fortunately, he has survived each ordeal without further transplantation surgery. The second crisis, however, required surgery almost as serious as a transplantation; a 9 hour operation to reconstruct a new bile duct from a portion of the small intestine was required.

Overall, this experience has given to this author a personal and unique understanding of both the joys and the disappointments surrounding liver transplantation. The information provided by the interviews, the professional feedback, and the literature review has provided him with a broader background for his discussion of the transplant experience. The guide has been written incorporating all three sources. It has been written in a conversational, nontechnical style that will be easily read, relatively brief, but

thorough enough to cover the major concerns of someone facing the process of liver transplantation.

Readability is a goal of the author. Testing for this factor however, would be difficult to conduct for a guide on a medically complex subject such as transplantation. The author has minimized the use of unfamiliar medical or technical terms as much as possible. Many such terms, though, are important to better understanding or are terms the candidate or recipient will have to know anyway. Since many of these terms are several syllables, the booklet has not been tested for readability. The author felt that the complicated medical terms, while necessary to the context of the material, would obviously give a higher readability rating if tested by commonly used readability rating systems like the SMOG readability grading system.

Project Timeline

January, 1997	Meetings with Dr. Becker to determine scope of project
February ,1997	Received approval from IRB to conduct project with human subject participation.
February 26, 1997	Request for volunteers at the monthly meeting of the LATSG.
March - June, 1997	Conducted individual interviews with 5 members of LATSG.
March 19, 1997	Conducted interviews with first group of 3 volunteers and their spouses at UWHC in Madison.
April 9, 1997	Conducted interviews with second group of 6 volunteers and their spouses at UWHC.
August, 1997	Submit draft of completed guide to transplant staff at UWHC.

Evaluation

The interview process used in this project utilized volunteers who were not randomly selected and the questions themselves were open ended and subjective. Data has therefore been organized in categories for the purpose of clarification and comparison.

The information gathered through the review of relevant literature has provided a documented background of the medical success and expected complications experienced with liver Tx over the past decade. This has helped the author to put his own experience and those of his volunteer respondents into perspective against this broader background. It has also clarified some of the issues of concern to the medical profession and patients regarding the process of liver transplantation as well as the social and ethical issues.

Upon completion of the guide, the author has submitted copies to the transplant physicians and coordinators at UWHC in Madison for their general comments and evaluation. He has asked them to respond to the guide's (1) accuracy, (2) relevance, and (3) usefulness to their patients in their opinion. Any major changes or corrections that would improve the impact of the guide are to be incorporated before submission for publication.

SECTION III

FINDINGS

Most of the recipients interviewed for this graduate project have reported complications after liver Tx, some serious. All of those interviewed by the author, however, appeared to be in good spirits and expressed gratitude for being alive. Although all interviewees were ambulatory, some of the other liver Tx recipients at UWHC were observed to be using wheelchairs.

Following is a summary of the responses of volunteers, grouped according to the categories mentioned previously:

- Pretransplant illness.
- Preparing for the transplant.
- The surgery.
- The immediate posttransplant recovery.
- Long term recovery.

Pretransplant Illness

Five respondents either didn't know, or chose not to reveal the nature of their liver failure. One had an unspecified liver problem from birth, but its seriousness wasn't diagnosed until she was in her sixties. Two had primary biliary cirrhosis, one of a very rare form. Three persons reported that alcohol was involved, but two of these cases were exacerbated by other toxins as well. Two had some form of terminal hepatitis.

Most knew for years that they were ill, but often didn't think they'd need a transplant until the end. Two had been stricken very suddenly and unexpectedly, one

discovering that her liver was failing at a routine checkup. The biggest surprise to her was that she hadn't even been feeling ill. Apparently, the lack of drawn out illness was a blessing, since her surgery and recovery was the least complicated and brief of any of the recipients interviewed. Virtually all expressed some degree of shock at hearing of the need for a transplant, regardless of the length or severity of their illness.

Most of the recipients interviewed reported that the waiting period was difficult. Most were anxious for the process to be over with because of their fear they could die before they would get a chance for the transplant along with the misery inherent in their conditions. They reported many problems during this waiting period, including confusion, comas, severe itching, vision difficulty, jaundice, and a painful abdominal swelling called ascites. Many became very sick in the period before getting their transplant. Several suffered from dangerous comas or needed extensive hospitalization. Ironically, for some interviewees, and the author himself, such downturns actually accelerated the process by moving the patient higher up on the waiting list.

Preparing for the Transplant

The responses given by those interviewed indicated that most recipients noted two waiting periods: waiting to find out if they would be "on the list", and the wait for the transplant afterward. For most, the first wait didn't last long; once they were being considered for candidacy, the final decision usually didn't take very long. The wait for a liver, though, could last much longer, and depended on where they were placed on the list and the availability of a donor liver. In two cases, the wait was nonexistent; the recipients

had simply become catastrophically ill, comatose, and were transplanted without their even being aware of it until recovering from the surgery. Both reported considerable surprise upon eventually learning that they had a new liver, though their previous illness kept it from being a total shock.

Other recipients interviewed reported waiting periods of as short as 2 days, to as long as 9 months, with 2 to 3 months being average for the group studied. All were fortunate to be transplanted in time, but the researcher is aware of one person awaiting transplantation, who was not so fortunate. She had attended meetings of the LATSG before this study began, and died before a suitable liver could be obtained.

To help them deal with these issues, every respondent had a social support system. Virtually all mentioned family as an important source of support, with friends a close second. About half cited support from coworkers and about the same number cited spiritual belief or church as important. About a third reported that they received additional help from counselors or ministers.

A few respondents specifically mentioned medical staff or their doctors as key to their support during the process, but all recipients, of course, had received some preparation as their conditions were diagnosed and when they were evaluated for candidacy for transplantation. Responses that the author received from transplant coordinators and staff clearly indicated a supportive and helpful attitude. Many recipients verbally reported their gratitude and appreciation for the overall efforts of their doctors and hospitals.

Although none of the respondents mentioned literature as a source of support, all eagerly signed up to receive a copy of the guide for Tx recipients and candidates when the project is completed.

The Surgery

Liver transplantation surgery is a very complex, difficult, and lengthy operation. Those interviewed had been too heavily sedated during the actual surgery to recall anything about their own operation. Afterwards, though, all were given information from doctors and relatives about how their surgery went. Some reported that the operation lasted 9 to 10 hours with relatively few complications, but many reported operations that lasted 12 to 13 hours.

Some were consciously aware immediately upon awakening in the recovery room that they had survived the operation and one reported that she was "overjoyed" at the realization. Others, including the author, were only gradually aware of the success of the procedure. A period of disorientation, hallucinations, and delusions left some patients confused and frightened for a few days afterward, delaying the sense of relief and gratitude which they all felt once they became more clear headed..

Immediate Posttransplant Recovery

Recovery after the operation varied considerably among those interviewed for this project. Two were out of the Intensive Care Unit (ICU) in 9 to 10 hours, while two others reported ICU stays of about a week. Some transplant centers equip and designate some of their private patient rooms as ICUs if needed, so the exact time in ICU or postsurgery

recovery is thereby blurred in some instances. For some of those interviewed, the hallucinations they experienced further confused details of this early period of recovery. It is fair to conclude, however, that some had a much more difficult time than others.

Many of the recipients suffered early setbacks that placed them in need of much more extended care than expected. One patient, for instance, suffered an air embolism after he somehow accidentally pulled out some of his IV tubes. The result was a near fatal stroke which required extensive recovery and therapy. He is still disabled and undergoing therapy to overcome the effects of that incident, but continues to be optimistic and glad to be alive. Respondents in this study also reported a variety of other serious setbacks following surgery including hepatic artery thrombosis, infections, and hemorrhaging that required reopening the wound for repair. One woman required two kidney dialysis sessions after surgery when her kidneys failed for a time. She, along with the staff, felt tremendous relief and joy when her kidneys finally began functioning along with her new liver.

For most recipients, the release from ICU to a regular room was welcomed and represented a big step on the way to full recovery. During this time, most patients began to eat regular food again. For some this was a particular joy since they had been on very restricted diets previous to surgery. One woman reported that one of the biggest surprises during the process was being able to walk again after the transplant. She was so weak previously that she had been unable to walk.

As with the length of stay in ICU, the time spent in the hospital after surgery varied. Some were released in about 10 days, but stays of 3 weeks or more are common. The trend seems to be shorter stays in the hospital, but much depends on the individual situation, especially if serious complications arise. Interviewees who reported longer, more debilitating illness seemed to typically have longer recovery periods. The woman who became ill unexpectedly and had her transplant before she underwent an extended period of illness was released in about 9 days and is still doing well after several months at home.

Another respondent who had waited on the list for at least 2 years, reported that her surgery and recovery went remarkably well at first. Although her wait was very long, she had not developed severe illness, but at the time of the transplant her liver was found to be in much worse condition than expected. She was released in only 10 days, but within a couple of months had to return with a serious CMV infection. Eventually she was further challenged by serious complications due to osteoporosis and at the time of the interview was being considered for hip replacement.

Long Term Recovery

Liver transplant recipients interviewed for this project had received their transplants as recently as 3 months to as long as 10 years ago, effectively spanning the whole era of liver transplantation. All are living at home, but several have spent at least a week or more in the hospital since being discharged after the transplant.

One recipient reported that after a relatively smooth postsurgical recovery, he has since been hospitalized frequently with persistent and debilitating infections. Surprisingly, he reported this with a smile on his face and an attitude of acceptance. The person mentioned previously whose embolism induced stroke that occurred shortly after surgery still has difficulty speaking and moving after nearly 10 years of recovery and therapy, but also acted cheerful and accepting. The other 10 year survivor has been treated for several skin cancer lesions. He has also had kidney problems, high blood pressure and has retired early but is living a relatively active and full life.

Most respondents, in spite of occasional setbacks, and the rigorous regimen of care, considered their lives to be fairly normal. One half of those interviewed noted that they had returned to full time work, some within a few weeks after their discharge. Most reported that their return to full time work was gradual, and some reported a change in career or job duties. Three were working part time at the time of interview and 6 were retired (at an early age) or were disabled. Those not working reported that they were still able to do many of the activities that they liked to do such as fishing, gardening, housework, or volunteer work for example.

Most respondents reported that they have experienced remarkable improvement in their condition compared to their months or years of illness before the transplant. Two, who were ill for a very long time, even noted that they felt much better at the time of the interview than they ever had.

Several, however, in addition to those reporting disability, noted that they were "often fatigued", had "low energy levels" or worrisome "little aches and pains", but only one of these felt that such negative complications were affecting their work performance. Most left the answer space blank, so the written responses were inconclusive. In verbal discussion, however, several did comment that they had difficulty in general or during certain tasks on the job.

A real concern for over a third of the women and one male recipient was brittle or broken bones, due mainly to osteoporosis. The problem was disabling for at least three respondents. Though few wrote down arthritic symptoms as a long term complication, the problem was verbally mentioned during interview discussions by several respondents. A few also mentioned memory problems but, again, failed to note this in writing.

All were required to keep regular follow-up clinic visits, monthly lab work, and daily medications. A few expressed verbal or written displeasure about constantly having to take so much medication, but most accepted the inconvenience as a necessity of their new life. None who were interviewed by the author expressed any intent to personally reduce or discontinue taking their medications, but two mentioned that they had heard accounts of other recipients from their transplant clinic who had made the choice to quit.

Although not specifically asked in the questionnaire, many voluntarily expressed a sense of gratitude to their doctors and clinics for their work in returning them to health and helping to maintain it. Most indicated verbally, and were supported by spouses when present, that they were simply grateful for the opportunity to be alive, whatever their

circumstances. Even very serious complications were discussed without bitterness or regret during these interviews, and the lesser complications were discussed with an obvious air of resignation and even good humor by virtually all respondents.

Advice From the Liver Transplant Team

One transplant surgeon, two transplant coordinators, and a social worker at UWHC responded verbally and/or in writing with some insights for liver Tx recipients and candidates. Some very basic ideas were stressed by these professionals. Perhaps most consistently emphasized was the need for the patients to become well informed about their condition and its requirements, both before and after transplantation. All urged strict compliance with medication and checkup prescriptions. For those waiting for a transplant it is important to learn the options and the consequences of Tx and not having Tx. It is also important to learn expected hospital routines, as well as the recovery protocol after transplant.

They also urged the patients to try to understand why these procedures and medications were needed, and to inquire for explanations anytime there was any confusion. The recipients and candidates were also urged to keep in touch, and remember to keep appointments. All four of these professionals were very dedicated to helping candidates and recipients in achieving the knowledge they would need to successfully survive and gain maximum benefit from their liver transplantation.

One coordinator commented emphatically on the importance of avoiding the inclination to overeat, a common problem for liver Tx recipients. The transplant

coordinators reminded recipients that consistent compliance with the doctor's recommendations, even when they may seem to be annoying or inconvenient, is very important.

Both recipients and candidates were reminded by the transplant surgeon of the importance of becoming involved in educating others of the importance of organ donation. Above all, the recipients were urged to "liven up", to enjoy their lives fully, and "live a long life."

SECTION IV

CONCLUSIONS

Difficulties

Conducting interviews with the members of the LATSG presented no extraordinary problems. The interviews in Madison at UWHC presented some difficulties however. The staff was very cooperative and helpful in gathering volunteers and providing facilities for the interviews, but the number of respondents necessitated sessions involving as many as 6 people at a time. This resulted in lively and enjoyable discussions, but left the author with inconsistent written records of responses. Some of those interviewed simply spent more time talking and less time writing their responses down.

Two volunteers even requested to finish the questionnaire at home and mail the completed forms to the author at a later date. They were both supplied with envelopes already addressed to the author but only one was returned. Fortunately, the other volunteer was very responsive in discussion, as was his spouse, so most of their responses were recalled, but depending on respondents to return the questionnaires obviously risks losing data. In this project, of the four self-addressed letters and forms left for the professional staff, three were returned. Since the author also discussed the project with various staff during the interview visits, he felt that he did get a satisfactory input from staff.

The only other problem encountered in general was the amount of time needed for writing responses. In order to gain a more complete record of responses, much more time would be needed than the half hour or so that each interview lasted, or some of the items would have to be eliminated. The fact that verbal discussion and explanations of items did accompany each interview, however, did allow for more complete input for the author than was actually written down.

Recommendations

This author would recommend individual interviews, if possible, for the collection of data from transplant recipients with no more than two recipients and their spouses at one time. I would also recommend that after the explanation and discussion of each item that a specific period of time be given for the recipients and interviewer to write their responses. Perhaps some questionnaires could be distributed for return at a later date, but this author feels that personally interviewing and collecting data at the same time is a more effective approach for the researcher to recall and comprehend the responses.

Although some recipients mentioned their medications during discussions, the author would also recommend a specific item requesting information on amounts and types of medications.

Conclusions

The verbal and written responses gained through the interviews provided a good range of personal experiences to complement the author's own experience and the review of literature on the topic of liver transplantation. The insights gained from recipients'

responses gave confirmation and reality to the data presented in the studies reviewed by the author. The interviews, along with contacts with other liver recipients, also helped to put the author's experience into perspective, making clear the uniqueness of each case and the many ways all are similar.

For most, the realization that transplantation is needed comes as a shock. The waiting is usually a difficult ordeal, requiring a good system of social support, usually lead by one's close family and friends. It is expected that the resulting guide can be a supportive and comforting source for candidates, recipients, and their supporters.

We learned that there is a shortage of available donor organs, making the waiting period even more stressful. This necessitates understanding and acceptance on the part of the liver patient, as well as increased education of the public to increase the number of people willing to become donors.

Liver transplantation, though techniques are constantly improving, continues to be a traumatic form of surgery. The length of the operation, and recovery afterwards vary somewhat, but in general, patients are released in a shorter period of time as the process continues to be improved. It is important for all to know, however, that some complications are likely to occur, and one cannot expect his/her own recovery to match that of someone else.

Upon release from the hospital, most recipients are able to live very full and satisfactory lives. Again, it seems important to note that each should try to live his own life as best he or she can, and not try to compare his/ her progress with that of others. All

will assuredly have to adjust to a different sort of existence than the one they lived before, but as the recipients interviewed in this study indicated, even those debilitated to varying degrees, the new life is very much worth living. Acceptance of one's situation, and cooperation with their doctors is surely crucial to living life as fully as each recipient can.

Throughout the research and data gathering in preparation for writing the guide, the author has received enthusiastic encouragement from professionals and recipients alike. Most recipients and many of their supporters expressed eagerness to see the finished result. The experience has enriched the author in many ways, adding not only to his understanding of the transplantation process, but a renewed appreciation for the efforts and sacrifices of all involved, and the great privilege involved in surviving liver failure. The opportunity to share these insights with others through this guide has proven to be a labor of great inspiration and joy for this author, and will hopefully serve to provide solace and comfort to readers.

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APPENDIX A
INTERVIEW QUESTIONS

4. (a) INTERVIEW QUESTIONS

LIVING WITH LIVER TRANSPLANTATION (Tx) ADVISORY STUDY

This interview is being conducted by Jim Solberg, a University of Wisconsin-La Crosse graduate student in Community Health Education. Its purpose is to obtain advice and information to guide in making an informational booklet for patients and their families who are facing or have recently experienced the process of liver transplantation. The investigator, a liver transplant recipient himself, intends to produce this booklet as the final product for his graduate project towards the Master of Public Health (MPH) degree. Your assistance is greatly appreciated. If you want follow-up information on results of the study or a copy of the completed booklet contact the investigator at: 1406 So. 6th Street, La Crosse, WI 54601 or call at (608) 782-2560. Project advisor is Dr. Kenneth Becker, Dep't. of Health Education and Health Promotion, University of Wisconsin-La Crosse. (608) 785-6786.

PART I: DEMOGRAPHICS

- 1) Age _____ 2) Gender ____M ____F 3) Marital Status _____ 4) Date of Tx _____
- 5) Employment Status: _____ Disabled _____ Retired _____ Full Time
_____ Same job as before? _____ Does Tx interfere with your career?

PART II: SHARING

- *Please comment briefly on your experience in the following areas:*
- *Also, what advice in each area would you give to liver Tx candidates:*

- 1) Finding out that you needed a liver Tx
- 2) The waiting period
- 3) Facing the finances
- 4) What emotional/psychological/spiritual support you had
- 5) Your biggest surprises (a) before and (b) after Tx
- 6) The surgery/recovery
- 7) Quality of life after liver Tx

APPENDIX B
CONSENT FORM

4. (B) CONSENT FORM

LIVING WITH LIVER TRANSPLANTATION (Tx) ADVISORY STUDY

I give my informed consent to participate in this study of what it is like to experience the process of liver transplantation. I consent to publication of a booklet describing this process so long as the information is anonymous and disguised so that no identification can be made. I further understand that although a record will be kept of my having participated in this study, all personal information regarding my experiences will not be identified by name.

- (1) I have been informed that my participation in this study will involve an interview with the researcher.
- (2) I understand that the general purpose of this study is to study is to gain information leading to a booklet designed to help individuals facing or recently having received a liver Tx.
- (3) I understand that there are no known discomforts or risks involved in my participation in this study. This judgment is based upon the fact that my participation will be based on an interview and will not involve physical effort or experimentation.
- (4) I have been informed that there are no "disguised" questions or procedures in this study. All questions and procedures can be taken at face value.
- (5) I have been informed that the investigator will gladly answer any questions regarding this study and will provide a copy of the final booklet if requested.
- (7) I have been informed that I am free to withhold response to any question I do not wish to answer. I can withdraw my participation at any time during the interview if I Wish.

Investigator. (608) 782-2560
Jim Solberg, 1406 So. 6th Street
La Crosse, WI 54601

Interview Participant

DATE _____

Project Advisor: Dr. Kenneth Becker, Dept. of Health Education and Health Promotion
University of Wisconsin-La Crosse
La Crosse, WI 54601 (608) 785-6786

APPENDIX C
PROFESSIONAL INPUT FORM

1406 So 6th Street
La Crosse, WI 54601
April 8, 1997

Transplant Department
University Hospital & Clinics
600 Highland Avenue
Madison, WI

Dear Transplant Physician or Coordinator:

I am very grateful to all in your team who worked to save my life in 1992 and continue to care for me to this day.

As many of you know, I am near completion of my graduate work towards an M.P.H. degree in Community Health Education at the University of Wisconsin-La Crosse. For my graduate project I have chosen to develop a recipient based guide for liver transplant candidates and recipients. I am hoping that this relatively brief booklet will supplement the excellent material already out there with an honest and encouraging perspective that is more relevant and meaningful.

I would appreciate a few moments of your time to share with me on the sheet provided any "words of wisdom" you would like to share with these people. Perhaps you may consider the questions you have heard most frequently or the lessons you have learned that surprised or impressed you the most in your liver transplant experience.

Your comments will help to supplement other information I am gathering from a review of the literature, interviews with other liver recipients, and, of course, my own experience. I thank you very much for your cooperation.

Sincerely,

Jim Solberg

SUGGESTIONS FOR THE RECIPIENT BASED GUIDE FOR LIVER TRANSPLANT CANDIDATES AND RECIPIENTS

Please indicate any hints, advice, encouragements, warnings, etc. you feel might benefit the above mentioned population. Please leave your name and address and check if:

_____a. I would like to receive a copy of the guide when completed (By August, 1997).

_____b. You can quote my advice in the guide if you wish.

Your signature

Mail to:

I offer the following for liver transplant candidates and recipients:

APPENDIX D

THE GUIDE FOR TRANSPLANT CANDIDATES AND RECIPIENTS

UNEXPECTED JOURNEY

THE ADVENTURE OF LIVER TRANSPLANTATION

A GUIDE FOR CANDIDATES,
RECIPIENTS, AND THEIR LOVED ONES
FROM
RECIPIENTS' PERSPECTIVE

BY

JIM SOLBERG
(LIVER Tx, JUNE 1992)

DEDICATION

Words can hardly express the gratitude I feel to all of the following:

To Dr. D'Allessandro, Dr. Kalayoglu, Dr. Knechtle,
Dr. Pirsch, and everyone else on the transplant team at
University Hospital & Clinics Transplant Department
in Madison, Wisconsin, who helped save my life
by assisting during my liver transplant surgery and recovery
in the summer of 1992 and the follow-up care
which continues to this day.

To my family and friends whose love and support throughout
my ordeal gave me strength that I needed to endure.

To other recipients, Deb Cole, Mike Armbrust,
Mary Douglas and other staff at UWH&C who shared
with me their own insights upon this marvelous process.

To Dr. Gilmore, Dr. Becker and others in the
Department of Health Education and Health Promotion
at the University of Wisconsin-La Crosse,
who have helped to put new knowledge,
meaning, and hope in my second chance at life.

Special thanks, of course, to the donor and her family
whose gift of a liver continues to sustain my life
even though she has left us.

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INTRODUCTION

Life in general has its ups and downs. At times we might feel like there are more downs than ups or vice-versa. Most of us, though, would agree that learning that you or a loved one is about to die is definitely a *major* down. What could be a greater turnaround, then, than finding out that this same terminal illness can be completely reversed. This is the topsy turvy experience that all of us who have had a liver transplant have gone through.

This booklet is intended to help those waiting for liver transplantation or are recent recipients. Hopefully it will ease some of the fear of the unknown that can accompany this chaotic adventure. By sharing some of my own transplant experiences, the results of interviews with other recipients, the advice of transplant physicians and coordinators, and insights from research on the subject, I hope to give you a clearer understanding of the process of liver transplantation. I have tried to present a balanced picture, sharing with you the joys as well as the pitfalls that accompany this journey.

An introduction to the experience of others may help you to accept the ups and downs that face you on your personal adventure. Be aware, though, that you do not have to be alone in your ordeal; there are many who will help you with their support.

Trust your team, trust yourself, and trust your God. Whatever course it takes, this journey is *yours*, a unique adventure you could never have expected. It can actually become a tremendous opportunity that will strengthen you in ways you never imagined when you accept the challenge and experience it fully. Life *will* be different, why not make it better.

1 "WHAT'S UP, DOC ?!?"

Whether we've been sick a long time or found out unexpectedly, we're all in the same boat; traveling on the same journey. If you are "on the list" (more about *that* later!) or if you're a liver transplant recipient, we either have, or are waiting for, a new liver. We've all experienced the same unthinkable problem; terminal liver failure. There's just no other good reason for wanting to switch livers. Let's face it ... It's a real hassle! For whatever reason, our original livers are ruined; there's no turning back, the warranty is expired ... well, enough of that, you get the picture!

The reasons for our liver failures are varied. For some it was a lifetime in coming, for some it struck suddenly. For some it was expected, for others it came as a shock. For some it was beyond our control, for others it resulted from our own life choices. Some recipients take great pains to distinguish their problem from those of drug users, alcoholics, and victims of poor health habits. Whatever the cause for our own liver problems though, we all face the same horror, the same hope. This is *not* a time for self-judgment, self-pity, or passing judgment upon fellow recipients.

Thank God, the medical community tends not to pass judgment upon us. When a person is in medical need, generally they are given the care they need. As recipients of such an incredible gift, however, we often judge ourselves too harshly, but I urge you not to fall into this trap. It is pointless, unnecessary and can actually be harmful to your recovery. Many studies have shown that a positive attitude is far more conducive to healing and maintaining good health.

Fortunately for us, the process of liver transplantation has become remarkably successful in returning recipients to relatively normal lives. Better than 70% can eventually expect to get a new chance at life. If we can muster the patience, inner strength and will to undertake the journey, there will be plenty of medical, emotional, social and spiritual support to help us on our way. As with all great adventures, though, the going can get very rough. Keep in mind that the goal is well worth the struggle; a return to health, joy and continued life with those we love.

Whatever the underlying cause of our liver problems, the suffering that results is just as unpleasant for each of us. For all it is a medical emergency, one that would certainly have ended in death until about a decade ago. Over 25,000 Americans may still die each year from liver failure, but today there is hope where once there was none.

Your doctors will explain as much as you need to know regarding your own liver condition. Some folks want to know everything, others would prefer not to know the details. The same can be said for the process of transplantation; you will have to decide upon your own comfort level. I was formerly a science teacher, so naturally I was inclined to want to know quite a bit. Much of the time, however, I was just too sick to care or even comprehend. Many of us simply learn to listen to the advice of our physicians and our family, learning only enough to keep track of what is going on and help to take proper care of ourselves.

Regardless of what explanation we get for our condition, the consequences of liver failure must be taken seriously. Your physicians will monitor your situation closely. You will be asked to have lab work done occasionally to monitor your body chemistry and your diet may be restricted. Appropriate medications will be prescribed for your particular situation. You, your family, and your medical team will also have to become alert to some common complications that may beset a person suffering from liver failure.

Most of these complications will occur because of the loss of important liver functions. Our livers are very complex, normally performing over 500 different jobs. It plays a significant role in our immune system. With liver failure we become more vulnerable to viral and bacterial infections. We will need to exercise extra care at home and in the hospital to avoid unnecessary exposure to infection. Ironically, we will have the same problem after the transplant, since then we will be taking immune-suppressing medications to prevent rejection of our new liver. During periods of especially high risk your physician may even require that you wear a mask and avoid people with colds and other infections.

A damaged liver also loses some of its ability to detoxify harmful substances in our bloodstream. When this function begins to fail, toxic byproducts carried in our blood, including ammonia, can begin to accumulate in our brains. This results in a condition called encephalopathy. Affected patients become confused, lose coordination or can even become comatose. The hazards of this condition are obvious. I very nearly died a couple of times when I became comatose from the condition, and once, before I was "grounded" by my doctor, I almost crashed my car when I could no longer steer it properly. Some other signs of encephalopathy are disorientation, loss of memory, and bizarre, sometimes dangerous behavior.

During this time, I began wearing a medic alert bracelet, noting my encephalopathy. I didn't want the slurring of words and lack of coordination that accompanies the early stage of an episode to cause me to be thrown in a cell for drunkenness where I could die for lack of treatment. Fortunately, my family

monitored me closely enough that they recognized the warning signals every time that they occurred and rushed me immediately to the emergency room. It is very important to be given immediate treatment to counteract the buildup of toxins.

Another recipient I met needed an immediate transplantation to save his life after he had suddenly lapsed into coma. He was extremely fortunate that a suitable donor liver became available upon short notice. Everything happened so suddenly, in fact, that he awoke with a new liver without ever realizing that he would be having the surgery at that time.

The main reason for many of these complications is a scarring of liver tissue known as cirrhosis. Many people associate cirrhosis with alcoholism, but it is actually caused by many liver diseases, including viral hepatitis and others. Whatever the source, this scarring of the cirrhotic liver will effectively block the normal flow of blood and other fluids through the organ. The resultant obstruction dangerously raises blood pressure in other organs, especially in the upper digestive system, resulting in potential bleeding from ulcers or varicose veins in the esophagus or stomach.

This backup in circulation can occur at the same time as impaired clotting of blood that is also associated with liver failure. This deadly combination of circumstances can result in severe hemorrhaging from what might otherwise be a relatively harmless bleed. This can be a time of grave danger to the liver patient. One should seek immediate help if signs of internal bleeding occur.

Another important liver function that can be compromised by disease is the role that it plays in the processing of the food we eat. Our livers assist, for instance, in digesting fats, producing proteins, converting fats to energy, and storing vitamins and carbohydrates. This is why it may be necessary to modify our diets at this time. Proteins in meats and other foods, for instance, produce the toxic by-products which can cause encephalopathy. Many transplant candidates are put on low protein, low sodium, (in my opinion -low *taste*!) diet. Rather than just feeling miserable about it, some candidates wisely take this as a challenge, searching out recipes that meet the restrictions, but are still pleasing to them.

The decrease in food intake, of course, can cause many liver transplant candidates to lose weight, sometimes drastically. The patient can become quite gaunt if the wait continues over any months. Ironically, in spite of this overall weight loss, some liver patients will take on a markedly bloated appearance, at least in the abdominal area. This is caused by another side effect from cirrhosis; the steady leaking of fluid from the liver into the abdominal cavity. This swelling, called ascites, is not only uncomfortable, but the pressure within can cause

painful hernias as well. As if that were not enough, the condition resembles an advanced pregnancy; not a very enjoyable situation, especially for the men! Fortunately, some of the excess fluid can be at least temporarily drained by a minor operation called paracentesis.

Besides our strangely bloated bellies, there is usually another visible clue that something is wrong with us. The buildup of bile byproducts can cause a yellowing of the skin called jaundice. I can only imagine what kind of impression I made on people during my "better" moments as I staggered about with my pathetically skinny body, grotesquely swollen belly, and radiant yellow eyeballs, muttering incoherently about God knows what!

Eventually, as the body remains under unrelenting assault from within, and as it becomes more difficult to eat properly, some candidates gradually begin to weaken. This situation can seem to be turning into a deadly race against time. At any moment, one of the complications caused by our liver failure could cause a crisis from which we could not be rescued. The danger of excessive bleeding looms constantly, and may even prevent us from getting needed surgery to correct other serious problems. Ironically, in many cases, we must wait through this grinding deterioration until nearly dead before the attempt to save our lives will finally be made. A will to survive, therefore, along with confidence in your team, and your support system are needed to help carry you through these trying times.

Hopefully, before all of these problems have gotten completely out of hand, we will have had our transplant. Sadly, though, around 25% of the candidates for liver transplants will not be able to hold out long enough to get the needed operation. There simply are not enough organs donated to meet the demand. Clearly, we must do whatever we can to help improve this figure. One way we can help is to do whatever we can to increase general awareness of the shortage of organs. We need to encourage the public to sign up as potential organ donors, and also learn the importance of making their wishes known to relatives.

Obviously, not enough people are now taking the time to fill out a donor card or make their loved ones aware of their intentions to donate their organs if they die. Both steps are necessary, since relatives may still decide in the end to deny organ donation if the personal wishes of the deceased was not made clear to them beforehand. The signature or card alone is not enough. Communication and general education are crucial to meet the increasing need for donor organs in the United States.

Part of the reason for the shortage, ironically, is the remarkable success and improvement in liver transplantation. The number of liver transplantations

done annually in the United States has risen dramatically since the mid-80s when the introduction of the immune suppressant cyclosporin made liver transplantation feasible by dramatically reducing the rate of organ rejection.

Making a fair and equitable distribution of such a precious and limited resource has become a real challenge to the medical profession. Public outcry over alleged celebrity favoritism in highly publicized cases and the personal anguish felt by families upon seeing others transplanted while a loved one waits have fueled the debate. In an effort to address such complaints, and more importantly, to fulfill basic medical fairness and high ethical standards, a system has emerged in the United States to oversee the distribution of donor organs. While the course of our liver failure is caused by a variety of different circumstances, once there we should all be treated fairly. This is why a standardized, nationwide system has had to be created. We will take a brief look at this sometimes confusing but well thought out system that has emerged over the years in the next section.

2 "WHO'S ON FIRST ?"

Learning that you have a terminal liver condition is bad enough, but wondering whether or not you will be chosen to get be a candidate for a transplant can be even more stressful. Some people have had to wait for months or even years with serious liver problems before even being considered. With the shortage of donor organs that we face today, only those who are in greatest need for a transplant are likely to be placed on the list for a liver transplant..

Every transplant center conducts reviews of their own patients for candidacy for transplantation. Each center has its own specific protocol which may or may not be explained to you depending on their policy and your persistence. All are essentially similar however, and two overriding considerations determine all selections; to be on the list for a liver transplantation there must be no other reasonable means of assuring immediate survival, and there is a definite likelihood of a reasonable quality of life afterward. In other words, death from liver failure must be more or less imminent and there must be no other obvious circumstances (such as uncontrolled cancer, for instance,) that would make the operation pointless.

A question that is often asked is "how can I afford it?" Liver transplantation is, indeed, a very expensive procedure, costing up to \$250,000. I think I was more distressed worrying about finances than the physical aspects of my situation. Fortunately, a very understanding person from the billing department heard of my plight and spent considerable time consoling and comforting me. Certainly, each center has to consider how the surgery will be paid for, but I was assured that I wouldn't be refused if I eventually needed the transplant. In my case, my insurance company through work was canceled leaving me feeling very vulnerable.

Things were eventually worked out, and I use my example only to encourage you to face the problem early and reach out until you find someone who can help. Social workers, financial advisors, transplant coordinators are all potential sources of help and advice. Some families or business associates sometimes even organize fund raisers, and organizations such as The Transplant Foundation will help qualified individuals. Each recipient I interviewed reported different circumstances and means of financial support. My "angel" in this regard came from the last place I would have expected; the hospital billing department.

Anyone whose condition is found serious enough to be placed on the list (talk about your "good news - bad news"!) will be ranked according to their medical prognosis to determine who has priority when a donor organ becomes available. This is the point where emotions can really run high if we aren't careful. After all, in our own eyes, a loved one's crisis ranks most importantly in our hearts, and it is extremely difficult to watch them or ourselves, for that matter, suffer any longer than necessary.

A strict protocol is in place, however, to insure that the most needy candidate be selected in a given situation no matter who is involved. Race, creed, sex, social importance or fame should have no bearing. The National Organization for Organ Sharing (UNOS), a nonprofit organization, keeps nationwide information on all candidates and donor organs so that anyone rated "1" (Critically ill in need of *immediate* transplantation) will get first chance to get a suitable organ that becomes available.

UNOS can also help to find a suitable recipient if an organ is not needed in the region where it became available. Basically, a donor organ will go to the most seriously ill individual whose blood type and size matches the available organ. A recent ruling change has been suggested that will give higher priority in general to candidates suffering an acutely critical liver condition, potentially delaying even further the plight of the chronically ill patient.

Candidates must therefore learn to be patient and tolerant when the waiting begins to exceed their expectations. Negative emotions, especially anger, are only going to make matters worse, not only emotionally, but physically as well. An attitude of acceptance can be crucial while the process moves forward. This is the time when a good support system can really help. Another thing we can do is to keep busy and preoccupied. Reading, being as active as our bodies will allow and keeping in contact with other people will help keep our minds off the tension of the wait.

Other people, in fact, can be an especially powerful source for the strength we need during this time. The tension of waiting can be shared by our support system. Many transplant centers offer support group meetings, and it is worth seeking out support groups in your community as well. The other members can not only offer encouragement, but those who are recipients will eagerly share their actual experiences, both the good and the bad. Nothing can help give a better sense of reality and hope than those who have gone through a transplant themselves. Although everyone's experience will be unique, each example can give us ideas on the range of experiences we might encounter. It is particularly useful as a candidate to hear how others have learned to cope with the waiting and anticipation of the operation.

Transplant centers also provide professional support staff. There are social workers, counselors and transplant coordinators at centers who can provide information and comfort throughout the process. We should learn to reach out to anyone who can help whenever we need it. For some candidates, their own family or close friends may be enough. Others may need professional counselors or social workers. Whatever it takes, we must ensure our mental and emotional health if we want to be able to survive the physical challenge of the transplantation process.

It is ironic that the process of getting into the "official" transplant system can be one of the major stresses that we face. All we can really do is place ourselves into the hands of the best hospital, the best physicians and trust that they will present the best case for us in our own circumstances. Beyond that, we must learn to occupy our time as fully as possible, accepting the situation as it comes. In the next section we will look at what it can be like when you are selected as a candidate for transplantation.

3 "RIDERS ON THE STORM"

Thank God, you're on "the list". Now what? As mentioned in the last chapter, acceptance of the situation becomes crucial as we wait for our transplant surgery. Depending on our condition and the availability of donor organs, our wait could go on for months. To endure this period, not knowing how long it will last, especially while we are probably feeling very poorly on top of it, will take courage and determination. A good deal of emotional and spiritual support is recommended. Most candidates find family and friends will rally during this time, but our ministers, transplant center staff and counselors will help to fill in the gaps when needed. We must also develop our own inner strength and spirituality. This could become extremely important, especially when a particularly long wait thins the ranks of our support team or during those times at home or in the hospital when we lay alone in our suffering.

Even in the hospital, with a nurse call button at the side of the bed, a patient may feel helpless and alone when there is nothing specific to call for. The long night hours can become especially trying when sleep does not come easily or pain is persistent. For some patients, medications that might offer some relief are deemed too risky and one simply has to endure. Inner strength, an ability to reach an inner calm, or being able to tap into a strong spiritual source of hope and faith are all we have in such moments. Life as a transplant candidate or recipient then becomes more than a process of coping one day at a time; it becomes a struggle to endure one *minute* at a time.

Candidates must learn to adjust their diet as their condition deteriorates. It is also important to consistently take the prescribed medications, and showing up consistently for lab work. Creatinine levels, SGPT, bilirubin and HCT, and other strange sounding tests will become significant clues to the status of our livers. The physicians will carefully track these results to determine when conditions in our bodies are improving or deteriorating. Any sudden increases or decreases may indicate a need for a change in medication or other precautions to be taken. During this period it is very important that the transplant candidates are faithful in getting the lab work done and following the recommendations from the doctor.

The transplant physicians usually also request that candidates remain within reasonable traveling distance from the transplant center. Many carry some sort of beeper or communication device just in case a suitable liver becomes available.

In spite of the illness and the increased medical demands, most candidates try to live as normal a life as possible. Eventually, as complications and their effects mount up many will have to stop working and may be spending increasing amounts of time in the hospital. Ironically, as mentioned earlier, this could be considered good news since the sicker a candidate becomes, the higher he or she will be on the list. Once admitted to the hospital in serious condition, a candidate is more likely to be next in line when donor organs become available.

After several admissions to the hospital for a variety of complications, my physicians decided I would be better off by being admitted to a nursing home. This step automatically elevated my UNOS status, since I had become institutionalized. I was there only three days before I was called to the Hospital for the transplant.

This curious jockeying for position on the list causes mixed emotions and extraordinary stress for many candidates and their supporters. I have heard some people complain bitterly when their conditions *improved*. Reason: they feared they would now be passed over when a liver became available. Obviously, this is a trying time, and one needs to be very careful not to let the situation pull them down. Remember that an accepting, cooperative, understanding patient will establish a far better rapport with physicians and staff than a bitter, complaining one. One's own inner peace is also far better served with a calm and patient approach. As the song says, "Whatever will be, will be!"

This does not mean that any patient should be complacent, or uncaring. In fact, an observant, concerned, and knowledgeable patient can help to see that their care is going along as it should. We can be informed and assertive regarding our needs without being obnoxious or abusive. Sometimes we can catch inadvertent oversights and actually help our caregivers by politely noting our concerns. At times though, a staff member may just be having a bad day. A few people, even hospital caregivers, turn out to be just plain jerks. I have learned that sometimes resolving conflicts with an uncooperative nurse or staff person requires going over their head. Simply explaining my side of a conflict and emphasizing that I had no grudge against the other person, restored the peace. I have also given into the urge to feel sorry for myself and retire into a deep funk. Believe me, the former works a lot better.

Once everything finally falls into place for a candidate and a suitable organ is ready for transplantation, events will move swiftly. Today, a donor liver can be preserved for up to 24 hours, so there is a reasonable amount of time to get ready. Some candidates, however, may find themselves subjected to further frustration at the last minute. It is not unknown for the procurement team to find, once the donor liver is removed, that the liver is unsuitable in some way. Unless

the recipient would die within hours, most centers will pass up an inferior organ. When this occurs, one must swallow hard, go back to the routine and pray for a good liver to come along soon.

If a good liver has been obtained, the team at the center will begin to prep the recipient-to-be as the procurement team rushes back with the vital organ. The body is scrubbed with disinfectant, an enema is administered to clean the bowels, and the patient is relaxed. Some recipients clearly remember every face, every comment, every second of these important moments. I distinctly recall the moment I got the call. I have never in my life felt such a strong rush of opposing emotions. I was filled with joy and fear in equal proportions. Eventually, I went into an autopilot state. As I was driven the 150 miles to the center, I spoke little. I was more or less numb. Underneath I was excited, but on the surface I seemed calm. Unlike many others, I do not remember much about the actual prep at the Tx clinic.

Liver Transplant surgery is very complex. It will usually last several hours. In my case I was in surgery about 12 hours. The operating surgeons performed two hernia repairs while my abdomen was open, a great relief to me in itself. Recovery from the surgery has become shorter as techniques continue to improve. In the next section we will review the recovery process.

4 "WE'RE NOT IN KANSAS ANYMORE!"

What will you wake up to after the operation? For some of us, Alice's adventure in Wonderland may seem tame by comparison. Awareness may unfold within a few hours, but for many, full re-emergence into the "real world" may take considerably longer. The initial stay to recover from surgery may last a day or two in ICU, but I have met recipients who were out of ICU in less than a day. I remained there for over four days but some people may linger even longer if serious complications occur.

Some recipients are quite lucid and aware soon after they awaken in the recovery room. Many others, however, go through a period of bizarre hallucinations and frightening paranoid delusions. This apparently results from a combination of the long illness, the surgery and the medications. Even if warned, as I was, that I might experience such sensations, they still seemed horrifyingly real. Everyone has their own particular terrors, ranging from feelings that staff or someone else is trying to kill them, to strange creatures or people visiting their room.

I have attended transplant support meetings that sounded like fairy tale conventions when recipients were eagerly exchanging "war stories" about their incredible hallucinatory adventures in transplant center ICUs. Mine were incredibly complex, realistic and ironically much more terrifying to me at the time than the reality of recovering from the traumatic operation.

I am not talking here about bad dreams or nightmares. These experiences seemed to be actually happening, and no matter how bizarre they were, our minds reacted as if they were actually occurring. This is why they were so frightening for some of us. This is a time for vigilance. Being at least partially irrational, we can accidentally or intentionally pull at tubing. One recipient I spoke with suffered severely when some of his IVs were "accidentally" torn out. I know I pulled out an IV one time before my transplant and have a memory of doing it again shortly after surgery. I am pretty sure now, though, that the second incident was part of the fantasy world that blended so thoroughly with reality at that time. At any rate, I do remember the "sitters" that were assigned to stay with me throughout this period to prevent such a catastrophe. I actually got to know some of them, but others remain fuzzy to me. Some of the people that I can still vividly recall from this period I now know did not actually exist.

More than a year after my transplant, I requested a visit back to the Trauma Life Center (TLC), the ICU for patients in critical condition. I was anxious to see how close my memory of the place matched reality. I recognized some

aspects of the room but it was actually about 10 times smaller than I remembered it. As I looked around, I was pleased to see that one of the nurses from my recollection really did exist. "I remember you" I said with a tone of astonishment. "And you were there also" pointing eagerly to yet another familiar face. I didn't realize how much I was sounding like Dorothy in The Wizard of Oz until another nurse piped in, "And Toto was there, too!"

Whether you experience hallucinations or not, the reality of recovery after surgery is strange enough. To others, we must look like something in a horror movie. We have tubes protruding from all parts of the body; urinary catheters, abdominal drainage tubes, T-tubes to drain bile, endotracheal tube to aid breathing, and a nasogastric tube to the stomach. Add in the dressings, IVs and monitors and you have a pretty grim picture. Another way to look at it though, is to think of it in another light. Rather than an inconvenience all the riggings are really a life support system; a medical miracle in action.

By the time we leave ICU, the ventilator and nasogastric tubing are gone, meaning we can finally talk again. We are slowly, step by painful step returning to "normal". Rather than grumble about the slow progress at this time, try to savor each new advance. Everyone moves at their own pace so enjoy your own progress as it comes. It is hard to believe when we have our regular health, how joyful being able to eat solid food can be, the thrill of sitting up by oneself, actually taking a step on your own again. Even finally passing gas during the recovery is a cause for celebration by recipients and staff. It signals the reawakening of the digestive system after the trauma of surgery.

As anxious as we are to return to normal, it seems that the physicians and especially the nurses seem even more anxious. Believe me, they mean well but they can seem a little like drill sergeants sometimes, as they hustle us into action, and try to get us doing more each day than we might think we can do. Our muscles become very weak after several days or weeks in the hospital so they need exercise to get back in shape. We learn to pack up our IVs on rolling supports and cruise the halls. Even when hooked to catheters or other exotic equipment, we roll out for cumbersome but adventurous trips around the transplant ward. At University Hospital and Clinics in Madison, patients wear their own attire rather than the notorious little hospital gowns. From day one the only way you can tell patients is by their extra attachments and lack of speed.

The period of recovery and rehabilitation in the hospital is also a time of emotional adjustment. For some recipients, the powerful anti-rejection drugs can cause mood swings. Even without such side effects from the meds, we can easily tumble from the euphoria of being plucked from certain death to the realization that some hard work and difficulty lie ahead. A sense of guilt and

unworthiness sometimes plague recipients when they consider that their life was spared only because someone else, the donor, had died.

The counselors will help to overcome these negative feelings. Gratitude is extremely appropriate at this time, guilt is not. The donor willingly made his or her organs available while they were alive, realizing they might have the opportunity to save lives. I have met donor families who also expressed satisfaction that their loved one, in a sense, lived on. Their grief is muted somewhat by the thought that several other people may have received life-giving organs from their lost relative.

Eventually most recipients begin to settle into a new pattern of life. The emotions of recovery are replaced by feelings about our new lives. Some more or less resume their old patterns. If the old job is still there things may seem to be back to normal. Usually, however, it is fair to say; life will never be exactly the same. In the next section, we will examine the transition from liver transplant patient to liver recipient in the "real world".

5 "LET IT BE"

OK ... I've got a new liver. I'm still alive. When can I go home?

In 9 days? How about 45 days? 20 days? If we could choose, of course, we'd take the shortest time possible. Some people actually *are* recovered enough to be released about ten days, but these are rather exceptional, especially in the past. Shorter stays after surgery are now the case as surgeons continue to perfect the procedure and health care plans encourage shorter hospital time. Around twenty days in the hospital after liver transplantation is standard now with 30 days not unusual. These are only average numbers however. They are a general description of what happens.

One thing we can learn from others who have had liver transplants is that each person's experience is unique. It is important not to expect your own situation to be just like that of another. An acceptance of whatever is happening at a given time will help to prevent the negative consequences of giving in to frustration or anger. Again, this does not mean we should become passive or give up; just that we recognize how much valuable energy we can waste by fussing over what *isn't* happening. Our bodies need all the concentration and energy that we have to work on healing whatever *is* happening in our own systems.

We will need to learn to deal with whatever length of time that our own body will require to be well enough to leave the hospital. It will be what it will be. The medical staff alone can determine what is best in each case. If we can learn to accept this while in the hospital, we will be better prepared to properly approach our recovery and readjustment for the long haul. And let's face it now; it will seem to be a long haul. Again, for each of us, it will take its own unique path. For some recipients, things will seem to go smoothly. For others it is a roller coaster experience, with distinct ups and downs. Others will endure an unimproving or even downhill course. Whichever way we go, however, there is peace of mind and even joy that can be found in every journey. We must learn, as others have, to find these treasures and use them as tools to endure the trials.

Many books have been written in the last few years describing the value of a healthy attitude to healing and health. Some are listed at the back of this guide. I know from my own experiences during periods of severe pain and at the hovering on the brink of death, that there is profound truth in many of these ideas. Many of the survivors with whom I spoke in preparing this guide, along with cancer survivors I have met share the same insights. Surviving and healing

is usually accompanied by a will to persist, a joy in living, whatever the circumstances. This is not to say that this positive thinking guarantees anything; we all know people who have passed away despite heroic struggle to survive. We only know it helps. Giving up, angering over matters we cannot control, or failing to do our share in the healing process are surefire ways of bringing more problems upon ourselves.

How can we possibly be positive in the face of the kinds of trauma faced by liver transplant recipients? The answer, or rather answers, to this question would require much more space than the scope of this guide permits. That is why I would recommend that you try to absorb some of the ideas contained and explained at greater length in the sources mentioned in the bibliography. Attending a good support group is another way to gain insights to the transplant experience. I can only attempt to summarize some of the concepts here.

The recipients that I've spoken with who seem happiest, have all told me in some way that they have accepted their situation as it is. Some were doing well, physically, but some were having real problems. It isn't hard for most of us to have a good attitude when things seem to be improving and going right. The challenge comes during the difficult times, and there is no shortage of them for most recipients. It is most important, according to successful recipients, to accept these times as they come. Pain is pain. Long periods of illness are unpleasant. Setbacks are setbacks. We have no choice over these facts.

We do choose our reactions, however. Having the will to live, feelings of patience, joy, forgiveness, and cooperation are choices that we make. So are anger, frustration, jealousy and stubbornness. In other words, we can't choose our physical state at any given moment; but we do choose the psychological/spiritual atmosphere that we will face it with.

As recipients we are all truly embarking upon a new chance at life. The attitude we choose will have a great impact upon the degree of satisfaction we will experience. Happy recipients as a group, are also active recipients. Many have less strength than they once had, but this has not meant they had to be less active. If necessary, they have simply changed the kinds of activities they do, or at least the degree of intensity is modified.

A little ingenuity, however, will enable one to maintain a sense of purpose and control, even in a bed with tubes hooked up to every conceivable entry point on our body. Many of the books listed later include methods of relaxation that have worked for people under duress and are not difficult to learn. Even something as simple as properly done deep breathing techniques can have a remarkable calming and healing effect.

Problems with overall mood swings and depression, however good our intentions may be, can still continue well after discharge. They are a fairly common complication after liver transplantation. Depending on the severity and the individual circumstances, some recipients are prescribed anti-depressants such as prozac to control this problem. This problem may contribute to a negative outlook if unchecked, but as many recipients have found out, they can still control how they think about their recovery. There is a fine line sometimes between medical depression and a simple bad attitude. The point is though; both are a problem and we must deal with it appropriately if we want to recover and live a full post-transplant life.

It is also worth remembering that perfection in this effort, as with most aspects of life, is impossible. We all have our grumpy moments, and the euphoria that we may have felt right after the transplant mellows as we settle into "real life"- whatever that is. It's incredible how precious all our loved ones and friends become after surgery. We truly come to appreciate life in a way that only those who have almost lost it can understand. Be prepared, though, for eventually realizing that sometimes these same folks can be almost as annoying as they were before! (You *will* have the new perspective, however, that will be there for you no matter how pesky they become.)

Emotional and psychological problems will, in fact, have an effect upon others around us as well. Close relationships, especially between spouses, may be stressed to the breaking point. I have heard many spouses say they suffered almost as much, at least emotionally, as the recipient. And, indeed, they do. A big difference however, is that the recipient is always the center of attention. The spouse suffers but is often left out, and often feel helpless or even useless in the whirl of activity around the patient.

This is why it is important to work as a team if possible. Support groups should be focused on loved ones as well as the recipients, and they must be considered in the recovery process. If the bond is not strong all along or if the spouses role is not taken into consideration, some may feel compelled to leave the picture, or be forced to suffer needlessly.

Since I was divorced, my Mom fell naturally into the role of my main support system. There were times, though, that I begged the nurses to pay some attention to the anguish and worry my mother was feeling. I often was more concerned for the effect the ordeal was having on her than what was happening to myself.

Other long range problems may continue to strain relationships after discharge. A recipient may still be needy in many ways. While most become very independent and can assume normal activities, some face repeated bouts with

infection or rejection that require further hospitalization and assistance at home. Others may function quite normally in most ways but may have become impotent, have lost their libido or simply lost any interest in sex. This is not unusual, but in some cases may improve with continued recovery or therapy. For others the damage may be cumulative and physically irreversible. Therapy or counseling can help to establish a better relationship and help a couple to find their own level of comfort in their situation.

We will need to continue heeding the advice of our transplant team. For the first year or so we will have frequent lab work and clinic visits. As time goes on, and our bodies demonstrate that they have adjusted well to the new liver, our checkups will become fewer. We can expect monthly labs for some time, though, to monitor our condition and catch any sudden changes.

Recipients are expected to take responsibility on their own to make sure that their recovery and readjustment goes as smoothly as possible. We are urged to eat wisely. Overeating is a particular problem to many recipients due to the steroid medications we will be taking for our lifetimes. We need to also remain vigilant to avoid unnecessary risk of infection. Since our immune systems are compromised we also have to be particularly watchful for cancer agents and avoid overexposure to sunlight.

Each recipient is likely to also be given more specific precautions. Women, for instance, will be more prone than normal to osteoporosis. They must therefore take care to avoid falls and possibly modify diet or medications to minimize the risks. Our doctors may also be watchful for problems with high blood pressure and diabetes that are sometimes also associated with some of our medications.

For virtually all recipients, there will be some complications to face, new routines, new responsibilities, new worries. Fortunately, we will not have to face these challenges alone. Our transplant team will be with us for life, ensuring that our new livers function as well as hoped for. Others will be there to give support in other areas of our lives, but we must learn who they are and make sure we access them when we need them. A few resources are mentioned at the back of this booklet, but your transplant center can help provide local support information.

Each recipient can build his or her own list of resources. For the lucky ones, the complications of living with a new liver will be minimal, for others the challenges may seem overwhelming at times. Whatever the case, life is, indeed, a privilege for liver transplant recipients. We are all able to continue experiencing the wonder of our universe, the love of our families and friends, the challenge of citizenship, the joy of creative expression and the richness of spiritual fulfillment.

Whether we go on to climb mountains or master using a wheelchair, life can be our own unique treasure, a gift from a thoughtful stranger. We owe it to them and ourselves to gratefully accept this gift and fulfill the challenges of our second lifetime.

SOME RESOURCES FOR LIVER TRANSPLANT CANDIDATES AND RECIPIENTS

ORGANIZATIONS:

United Network for Organ Sharing, UNOS
1100 Boulders Parkway, Suite 500
P.O. Box 13770
Richmond, Virginia 23225-877
(804) 330-8500

Statlander's Pharmacy
600 Penn Center Boulevard
Pittsburgh, PA 15235-9928
1-(800) 238-7828

Chronimed Pharmacy
P.O. Box 46181
Minneapolis, MN 55446-9920
1-(800) 888-5753

American Liver Foundation
Cedar Grove, NJ 07009
1-(800) 223-0179

National Organization for Rare Disorders, Inc. (NORD)
P.O. Box 8923
New Fairfield, CT 06812-8923
1-(800) 447-NORD
<http://204.127.237.11>

Organ Transplant Fund
1102 Brookfield, Suite 202
Memphis, TN 38119
1-(800) 489-3863
otfnatl@aol.com
<http://www.otf.org>

Transplant Recipients International Organization, Inc. (TRIO)
244 N. Bellefield Avenue
Pittsburgh, PA 15213
412) 687-2210

SOME OTHER TRANSPLANT RELATED LINKS AVAILABLE ON INTERNET:

DOT (The Division of Transplantation), U.S. Gov't. organization.

American Share Foundation.

National Transplant Assistance Fund.

SELECTED BOOKS, MAGAZINES:

Encore, (Newsletter), Chronimed Pharmacy, Minneapolis, MN.

Transplant Support Groups Directory, 1997, Chronimed.

LifeTIMES, (Magazine), Statlander's Pharmacy, Pittsburgh, PA.

Gutkind, Lee. Many Sleepless Nights, University of Pittsburgh Press, (1990).

Helmberger, Pat, Transplants: Unwrapping the Second Gift of Life- the Inside Story of Organ Transplants as told by Recipients and their families, Donor Families and Health Professionals, Chronimed, (1992).

Maier, Frank. Sweet Reprieve, Crown Publishing, 1991.

Parr, Elizabeth. I'm Glad You're Not Dead, Journey Publishing, Galveston, Texas, (1996).

Pizer, Hank. Organ Transplants: A Patients Guide, Harvard University Press, (1991).