University of Alberta

The Value of Adding Personal Stories to Printed Educational Materials for Liver Transplant Recipients

by

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Dedication

For my parents Rex and Marie-Louise Hobson whose unfailing support and absolute belief that I am capable and worthy made this possible.

For my husband who tended the flock so I could write. Thank you.

Abstract

The search for connections with others is the nature of humanity. Being able to make connections with those who experience the same chronic illness is very important to some. The purpose of this study was to explore whether the addition of personal stories to patient education teaching manuals has an impact on patient satisfaction and self-efficacy. Two versions of the same teaching manual were randomly assigned to liver transplant candidates who agreed to participate in the study. One of the manuals was the standard teaching manual while the other had a number of patient stories added to the traditional text. Although there were no significant differences between the groups a sub-set of participants appeared to be more highly satisfied with the teaching manual that contained the stories. Open-ended questions revealed a trend toward improved assimilation of the information in this group. There was no significant difference in self-efficacy.

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Chapter 1

Introduction

The number of people waiting for solid organ transplant in Canada has increased markedly over the past ten years. In 1994, there were 2159 individuals on the waiting list, but by 2003 there were 3914, almost double in just 9 years (Canadian Institute for Health Information, 2004). Solid organ transplants include, heart, lung, liver, intestine, pancreas and kidney. From 1994 to 2003 there were 3658 liver transplants done in Canada, 345 people who reside across Western Canada received liver transplants in the province of Alberta.

These people are often isolated and have little or no contact with other transplant recipients who have experience with similar situations. Individuals are distanced geographically from others who could offer meaningful support. This isolation from others with similar experiences contributes to a feeling of aloneness, without a community of peers. One author described the search for connections as a major part of the life of pediatric transplant recipients (Wise, 2002). In her phenomenological study, Wise described how children felt disconnected with their physical selves and different from their peers following transplantation.

Community has been described in the literature as a sense that all beings are connected and experience common circumstances (Tompkins, 2001). The challenge for many patient educators becomes finding a way to encourage this sense of community by connecting patients to their community of peers through print.

Nurses around the world hand out printed educational materials everyday to the public for health education. These materials are one of the favored tools of every educator as they provide a cost-effective way of distributing information to a large audience. Patient educators use pamphlets, manuals, and information sheets extensively. They are easy to create, easy to find, and easy to transport. However, not all print materials contain quality information. Bowbeer and Hiss (1990) surveyed educational resources for diabetes and found that cost, not quality, is the primary factor when choosing materials for distribution to patient groups. They found that funding for patient education did not support the use of the best quality print materials and that the materials selected were prone to commercial influence.

The literature in education and nursing guided the development of a teaching manual at a major tertiary care facility in Western Canada that attempts to meet the needs of potential liver transplant recipients and facilitate feelings of community through print media. It is a traditional teaching manual that includes information related to the team the transplant candidate will be working with, the normal function of the liver, signs and symptoms of end-stage liver disease, the risks and benefits of transplantation, the process of transplantation, and an introduction to complications of transplantation including rejection and infection.

Anecdotal information from nurses working with this population suggests that candidates for transplantation are eager to meet others who have already experienced what they are about to encounter. They want to hear personal views from those who have taken the transplant journey about what it was like. Candidates for transplantation want to know how it feels, what to expect, and how to cope. They often state they want the "real story". This real life connection is not always easy to facilitate because of the vast geographic area covered by the transplant center, the financial constraints of those suffering with chronic disease, and the health of the recipients available for consultation. Every effort is made to find a recipient close to the location of the candidate in question. The revised liver transplant manual exposes the potential recipient to a number of stories from diverse personalities regarding their transplant experiences.

If personal stories, as told by individuals who have experience with transplantation, add value to the content, the learner may readily apply the knowledge to their own experiences. The knowledge becomes personalized for the reader (Cohen, 1994). Reading of other's success with transplantation should increase confidence in the individual's own ability to experience similar success. This may translate into improved adherence with treatment regimes.

The authors of a recent report suggested that social isolation contributed to decreased adherence and increased depression and stress rates among a group of adult stroke sufferers (Boden-Albala, Liwak, Elkind, Rundek & Sacco, 2005). Non-adherence to medication regimes by transplant recipients has been reported to average 33% in North America (Dew, DiMartini et al., 2007). Non-adherence is particularly high in the adolescent group and is the number one cause of graft failure leading to organ loss (Sudan, Shaw & Langnas, 1998).

If recipients have a better understanding of the importance of the different aspects of their care, they may experience fewer complications. They may live longer (Cleemput, Kesteloot, Vanrenterghem, & De Geest, 2004; Simpson et al., 2006) and enjoy better health after transplantation (Dew, Kormos et al., 1999). Better outcomes are directly related to reduced health care costs.

Purpose and Objective of the Study

The purpose of this study was to add to our knowledge of effective written patient educational materials for patients referred for transplantation. The objective of this study was to determine if adding personal stories to print material had any impact on transplant candidates.

Research Questions

The following research questions guided the study:

1. Is there a difference in satisfaction and self-efficacy between patients exposed to traditional pre-transplant teaching materials and those exposed to enhanced pre-transplant teaching material that included personal stories?

2. What printed information in the pre-transplant teaching manuals do patients find most helpful and why?
3. Do patients use any of the additional resources suggested in the teaching manuals?

It is anticipated that there will be some change in satisfaction and self-efficacy after exposure to the teaching materials that embody this novel approach to sharing information.

Definition of Terms

Community: sense that we are all connected and have common experiences. While environments may differ, there are basic common experiences and emotions that all human beings share (Tompkins, 2001). In this project the researcher attempted to create a virtual community of persons with similar experiences shared through shared personal stories.

Satisfaction: a measure of how useful the participants find the print explanations that describe the process and other people's experiences of liver transplantation.

Self-efficacy: as defined by Bandura (1997), "belief[s] in one's capabilities to organize and execute the courses of action required to produce given attainments" (pp. 3).

Significance of the Study

If newer teaching manuals that include personal stories have a positive effect on learning outcomes, the intervention can be applied to other areas of patient teaching in many other clinical areas. Patient educators can create a sense of virtual community to their own materials by sharing information in the form of stories with their target group. Nurses can learn to reduce a person's sense of isolation and increase their self-efficacy through print. Nurses can also be encouraged to explore other methods of sharing information through personal for the benefit of their patients. If social isolation contributes to poor compliance, depression and stress, the addition of personal stories could increase compliance and alleviate depression and stress by alleviating some of the sense of isolation that accompanies illness (Boden-Albala, Liwak, Elkind, Rundek & Sacco, 2005).

The inclusion of patient stories exposes the reader to the idea that the educator values that kind of information, so much so that it is part of the information necessary to prepare for transplantation. Information in the context of common experiences is shared with the transplant candidate in the teaching manuals in vignettes. The research is guided by the concept that educators must move towards an exchange of information with the public instead of simply trying to deposit information without an appropriate social or emotional context.

Chapter 2

A Review of the Literature

Three aspects of printed educational materials are explored in this review: technique, a group mentality, and outcome measures. Much of the literature in patient education explores techniques for developing printed educational materials (Bernier & Yasko, 1991; Kennedy, Robinson, Thompson, & Wilkin, 1999; Wilson, Wood, Risk, & Kershaw, 2003). These techniques are an important foundation for any educator developing printed materials but two further topics need exploration when developing materials. First, there is the discovery of developing a sense of virtual community in print that encourages the reader to feel there are others who share their experiences and concerns. There is little to be found in the literature that enlightens the educator about methods to facilitate this process. Second, there is a need to measure learning outcomes to discover whether there has been some significant change in satisfaction or self-efficacy as a result of developing this sense of community in print.

Technical Aspects of Designing Print Materials

Printed educational materials are distributed by every nurse in every clinic and by many at the bedside. They permeate public education because they are inexpensive and portable. The current health care atmosphere of restraint has popularized this method of information distribution. There are numerous tools described in the literature to guide development of the structural components of printed educational materials (Bernier, 1993; Wilson, Wood, Risk & Kershaw, 2003).

One of the most referenced guides for evaluating printed materials is Bernier and Yasko's (1991) Evaluating Printed Education Material or EPEM. This guide is written for nurse educators, and has been tested and widely used (Kennedy, Robinson et al., 1999; Wilson et al., 2003). This five-phase guide encompasses an exhaustive list of steps including predesign, design, pilot testing, distribution and implementation, and evaluation of intended outcome. The EPEM was developed based on expert opinion from both the literature and a convenience sample of educators.

The EPEM describes many of the structural components that need to be part of any printed material. The authors place importance on the articulation of purpose, goal, audience and objectives early in the pre-design phase (Bernier & Yasko, 1991). Patients did not participate in the development of the guide, although a brief survey of patient needs was done in the beginning and a pilot study was conducted with the EPEM. Thus, the developmental process of the EPEM did not allow for the inclusion of expert patient knowledge.

Others have reported the importance of patient participation in a more meaningful way during the development of teaching materials (Kennedy, Robinson et al., 1999). Kennedy, Robinson et al. solicited patient's perspectives throughout the development of their guidebook with the objective of meeting patient needs for knowledge, empowerment, and communication with health care professionals. A series of articles described a process that paralleled the methodology of grounded theory and culminated in a random control trial that tested learning outcomes (Kennedy, Nelson et al., 2003; Kennedy, Robinson et al., 1999; Kennedy & Rogers, 2002). The authors identified the value of shared experiences, but did not explore the matter in any depth. The research focused instead on promoting self-managed care and evaluating the effect of chronic disease on medical costs. Patients who were surveyed shared that knowing that others had successfully negotiated the same medical journey was a source of encouragement to them. This body of work reveals the need for patient input into the development of materials for patient self-management. It supports the need and importance of personalized information and experience in educational materials.

A recent guide for the development of printed educational materials used Orem's self-care deficit theory to evaluate the materials (Wilson et al., 2003). The focus was on literacy; using nursing theory's framework with the educator first assessing the reader's literacy skills before deciding what materials to provide. Wilson validated the need for multiple types of print material at differing literacy levels for each subject. That way, patient educators can provide individuals with customized print materials that better meet their needs. From their large sample of 238 patients, these researchers found that the highest-grade level attained was not reflected in the individual's actual reading and comprehension ability. Wilson et al. used the Rapid Estimate of Adult Literacy in Medicine tool to determine the mean reading level of patients as grade 7 to 8 even though the mean education level completed was grade 13. This suggests that populations who report a specific grade level of education may actually comprehend at grade levels lower than they report. It may also be a reflection of the patient's wish to be seen as better educated than they are which speaks to the effect of social responsibility. Nonetheless, this is vital information for those who construct and distribute print materials to the public. Although persons may have attained a particular grade level at one time in their lives, their literacy levels may not have been maintained over time.

Literacy is discussed at length in the literature and is obviously an important structural element when creating educational materials (Doak, Doak, Friedell & Meade, 1998; Redman, 1997; Wilson et al., 2003). When describing the literacy related problems in her pediatric population, one authority stated, "The inability to read and understand written information can interfere with a parent's ability to follow a treatment regimen" (Redman, 1997, p.257). Statistics Canada (1997) reported that 22% of Canadians feel that they have difficulty with reading, and a further 26% reported not reading well. The literacy level is a fundamental consideration when writing materials for members of the public, but there are other barriers to change that healthcare professionals may not appreciate. For example societal and cultural norms, the prevalence of medical terminology in patient literature, and the lack of time professionals spend listening to patient concerns (Lee & Garvin, 2003).

Exploring a Sense of Community in Print

The trend in the literature seems to be moving away from a focus on technical elements and towards a focus on a more personalized approach to education with the aim of empowering individuals to participate in their own health care (Dixon-Woods, 2001). This is reflective of an emancipatory paradigm that is infusing many areas of education today. Post-modern educators revolutionized education by discarding traditional approaches where the teacher "deposits" information into the passive learner, arguing that this fails to stimulate real learning (Friere, 1979). Educators preparing written materials for their patient populations cannot expect information alone to inform. Instead, there must be a balance between information and the art of teaching and learning which is made through connected relationships (Palmer, 1998). Introducing shared experience and personal knowledge is one method of creating a connection with the reader (Kennedy & Rogers, 2002). It acknowledges the importance of a person's story.

Stories are part of an oral tradition that has been used from the beginning of time to help and guide the next generation. Healing stories are the stories that tell of coping with struggle (Swatton & O'Callaghan, 1999). These stories may be told by therapists to help clients make sense of their life experiences. Swatton and O'Callaghan used grounded theory to increase their understanding of what healing stories meant to the storyteller. They found that when individuals shared their own healing story it gave them an opportunity to reflect on their experiences. Further exploration is needed to determine what these healing stories mean to the reader. The findings may be similar to those found by Cohen (1994) in her examination of bibliotherapy, the use of literature in therapy.

Cohen (1994), a psychiatric nurse, used a phenomenological approach to study the effect of bibliotherapy with eight clients. Cohen hypothesized that the bibliotherapy experience was similar to that of group therapy as participants reported that they no longer felt alone. Sharing common experiences is the strength of group therapy. Cohen used a series of two in depth interviews to determine how reading was helpful to the participants in a variety of difficult situations.

Participants were recruited through an advertisement asking for people who used reading to cope with a difficult life situation. Participant's situations included physical illness, death of a loved one, divorce, and depression. Cohen's (1994) three-hour tape-recorded interviews were transcribed and analyzed using a phenomenological approach. In this study, the most important factor was the ability of the readers to recognize themselves in the subject matter. Readers reported benefiting more from the story if they were able to identify with the content. The impact of the story can be therapeutic when the experiences of the author reflect one's own experience; then the story becomes very personal.

An anecdotal report from a nurse educator, who promoted the use of written personal accounts as a teaching tool with nursing students (Sayre, 2001), suggested that personal stories add to what students learned about diagnoses and theory and allowed them to gain insight into patient's experiences. Perhaps the same would be true for the readers of print materials? Reading personal stories in print might allow the reader to identify with and learn from another's experience.

These reports, taken together, guided the effort to solicit stories from members of the liver transplant population in a large metropolitan hospital for inclusion within the teaching manuals distributed by the program. Few individuals have practical experience with transplantation and it was anticipated that readers would gain insight into the transplant experience through organ recipients' stories.

Effect of Printed Materials

Satisfaction is typically measured in any intervention that employs the use of written materials. Paul, Jones, Hendry, & Adair (2007) conducted a randomized control trial to examine the effect of a newly developed leaflet for parents of children suffering from febrile seizures. They had improved the presentation and readability of the leaflet, involving parents in the procedure, then trialed it in 120 families at a hospital in Scotland. Although the primary outcome was focused on behavioral knowledge, their pretest, post-test measures included the Strait-Trait Anxiety Inventory (Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983); a 10 question measure of worry, confidence and fear; and a measure of satisfaction with the leaflet designed by the researchers. Paul et al. found no significant difference in satisfaction between the control and intervention groups but parents in the intervention group reported better understanding with the improved leaflet.

It has been reported in the literature that general satisfaction questions can be limiting and often mask concerns and dissatisfaction (Cohen, Forbes, & Garraway, 1996). Rather one should solicit likes and dislikes to obtain detailed information about readers' responses to the various components of printed educational materials (Paul et al. 2007). Persons may be satisfied in general with the majority of a document but the satisfaction score does not tell you what in particular was liked and more importantly what things should be changed to improve satisfaction. Additional questions soliciting the readers' views regarding improvements or concerns aid in the further development of quality materials.

A Cochrane review comparing written and verbal information versus verbal information alone also reported mixed results regarding satisfaction scores. The review included only two studies, last reviewed in 2005, one of which reported no statistical difference, the other reported a significant difference in favor of written and verbal instructions over verbal instructions alone (Johnson, Sanford & Tyndall, 2003). The review concluded that a combination of written and verbal information does improve both knowledge and satisfaction in addition to standardizing instructions for patient care.

There are a number of studies of people with chronic illnesses where researchers have explored self-efficacy as motivation for change (Bissonette, Logan, Davies & Graham, 2005; Tsay & Hung, 2004). These studies examined patient educational models to promote confidence and behavioral change. Tsay and Hung randomly assigned participants to groups where the intervention group received empowerment training and the control group did not. They then used the Strategies Used by People to Promote Health (SUPPH-29) to measure self-efficacy (Lev & Owen, 1996). Results showed significant differences between the two groups. The group that received empowerment training had increased empowerment, self-efficacy, and decreased levels of depression.

Self Efficacy

Self-efficacy is an individual's perception of their ability to perform a task in specific circumstances. Bandura (1997), the originator of social cognitive theory, stated, "If people believe they have no power to produce results, they will not attempt to make things happen" (p 3). Self-efficacy is not synonymous with self-concept, nor is it simply knowing what to do, it is a personal belief about what one can accomplish. Self-efficacy permeates every decision; it influences choice, effort, perseverance, and task-related stress (LeFrancois, 2006). Self-efficacy varies according to the specific circumstances of the event as it unfolds.

Bandura (1997) postulated that there were four sources of knowledge that inform an individual's self-efficacy. These are mastery experiences, vicarious experiences, verbal persuasion, and physiological and affective states. Personal mastery is the most influential. This involves successful completion of the same or similar experiences which give people confidence about their future performance. Vicarious experience enhances self-efficacy as people make inferences about their abilities when they compare themselves with others. Verbal persuasion is associated with the power of social influences in our lives; others can persuade us that we posses certain abilities and encourage us to use them. Physiological and affective states influence our ability to judge our competence in any given situation. For example fatigue and anxiety can have negative effects on our level of performance.

Vicarious experience is applicable to this research. Individuals learn by observing others (Pajares, 2002). This is more probable when the individual has little experience with a situation. When people are inexperienced, they tend to base their perceptions of self-efficacy by comparing their performance with others who have more experience. Kennedy and Roger's (2002) observations concerning learning from other's successes and Cohen's (1994) confirmation of the value of shared experience involved vicarious learning. It is hoped that by encouraging transplant candidates to see that they are not alone in their journeys and that others have succeeded, that their self-efficacy in relation to the overall transplant experience will be increased.

The literature suggests that people are not passive receivers of information. Increasingly patients are being viewed as individuals who are able to consider their health care options and make socially appropriate choices (Dixon-Woods, 2001). The outcomes of three studies in different settings are relevant to issues in health communication (Lee & Garvin, 2003). These authors examined information flow and were concerned that in all three settings there was no evidence of a meaningful dialogue with patients that explored their needs and values. Instead, the most common scenario was one where the expert teacher directed information to the novice learner whether they had a need to know or not. Lee and Garvin concluded that an information exchange based on a meaningful dialogue was what was needed to influence any behavioural change. This can be achieved in part by recognizing that people have valid contributions to make when it comes to health information.

Chapter 3

Research Method and Procedures

The purpose of this study was to add to our knowledge of effective written preoperative information for people referred for liver transplantation. A descriptive comparative study design was used to answer the following research questions:

1. Is there a difference in satisfaction and self-efficacy between patients exposed to traditional pre-transplant teaching materials and those exposed to enhanced pre-transplant teaching material that included personal stories?
2. What printed information in the pre-transplant teaching manuals do patients find most helpful and why?
3. Do patients use any of the additional resources suggested in the teaching manuals?

Participants were randomly assigned to one of two groups. In one group, the "no story group" (NSG) participants were given the traditional teaching manual that included; information about liver function, treatment for liver failure, details about what to expect during pre and post transplantation and sources of support. The second group, the "story group" (SG), participants received an enhanced teaching manual that included personal stories in addition to the information included in the traditional manual. The traditional manual and the enhanced teaching manuals are shown in Appendix A and B. A number of patients who had received a liver transplantation previously, consented in 2003 to share their personal stories anonymously with future transplant recipients. The stories related to living with end stage liver disease, being placed on a transplant waiting list, receiving a transplant and life after transplantation.

Sample

Consecutive adults referred for liver transplantation at a major transplant centre in western Canada were invited to participate in the study. Eligibility criteria included age ≥ 18 years, a candidate for liver transplantation, and the ability to read and comprehend English. Exclusion criteria included Stage III encephalopathy, fulminant liver disease, and lack of dependable support.

Encephalopathy is one of the symptoms of end stage liver disease that affects cognition which is likely to affect patient's reading and comprehension. The physician identified patients with encephalopathy at the time of referral. Fulminant candidates are usually assessed and transplanted in emergent circumstances. They are often intubated in the ICU at the time of listing so it is unlikely that they would have read any educational materials. Patients without dependable support often have complicated social histories. They need formalized program support to assist them in meeting their learning needs.

It was estimated that a sample of 32 participants in each condition were required to achieve a power of 0.8 with alpha set at 0.05 (Cohen, 1988). In 2006 there were 212 individuals referred for liver transplant assessment at this centre (Glenda Meeberg, personal communication, January 25, 2007). It was anticipated that a six-month period of recruitment would be sufficient to obtain the sample of 64 participants.

Instruments

The Patient Education Questionnaire (Appendix C) has a total of 19 items and is divided into four sections. Section 1 was designed by the researcher to collect demographic information including date of birth, gender, last grade completed in school and length of time the candidate was aware of the need for transplant (four items). Literacy was assessed simply by asking about the last grade completed at school. The second section measured satisfaction with the enhanced or traditional teaching manual using one item: "How satisfied are you with the information in the teaching manual?" A likert type scale was used where 1 meant not satisfied at all and 10 meant extremely satisfied.

The third section included 11 items from two domains of the Chronic Disease Self-Efficacy Scale (CDSES); managing and controlling disease in general (MCD) and management of depression (MD). The CDSES is a self-report tool developed at the Stanford Patient Education Research Center for a Chronic Disease Self-Management study (Lorig et al., 1996). The MCD domain has five items and the MD domain has six items. Participants are instructed to use a 10-point likert type scale to report their current level of confidence in engaging in relevant self-management activities where 1 = not at all confident and 10 =

totally confident. Thus, the range of scores for the MCD and MD domains are 5-50 and 6-60 respectively. Higher scores on both domains indicate greater confidence. The reported internal consistencies for the MCD and for the MD are greater than .75.

The final section of the Patient Education Questionnaire included three general open-ended questions designed to elicit comments on the content and format of information provided.

Data Collection

Referrals come to the transplant office from numerous physicians across Western Canada. A program physician must approve the assessment before any appointments are made. Clerical staff routinely contact the transplant candidates by telephone to confirm the timing of the assessment before booking the consult appointments. During this telephone contact, the clerical support staff briefly informed eligible patients about the study and those who were interested in learning more about the study received a telephone call from the researcher. The researcher explained the study, addressed any questions and obtained the patients verbal consent to participate.

Patients routinely receive the teaching manual by mail, as it is included in a package sent from the transplant centre that details the assessment appointments. This study took advantage of the normal distribution of information and included the study information with the assessment appointment mailing. The program secretary mailed study packages in numerical order to participants as directed by the researcher. Those who did not wish to participate in the study received the routine package. This meant that the program secretary knew who was participating in the study but she did not know whether the patient was in the non-story or story group. The packages for the study were numbered so that every other package contained an enhanced manual. Packages were distributed in that order to the participants. The control group received the traditional teaching manual while the experimental group received the enhanced manual that contained the personal stories. All participants received the questionnaire as part of the package with directions to complete and return within one month. Consent was considered implicit if the questionnaire had been completed and returned. At one week and again at one month, a telephone call was made by the researcher to remind participants of the need to complete and return the questionnaire.

Typically, it may be weeks or months before the participants are seen at the transplant centre for their assessment. Participants were instructed to read the manual and fill out the questionnaire. Their options were to bring the completed questionnaire to the transplant centre when they came for assessment or return it by mail within one month, whichever was soonest. A stamped self-addressed envelope was included in the mail out. The study closed after 64 participants returned their questionnaires.

Data Analysis

The Statistical Package for the Social Sciences version 13 for Windows (SPSS) was used for all statistical analyses. Demographic data and outcome data were summarized using descriptive statistical procedures. Group equivalence on categorical and continuous demographic variables was assessed using chi-square and independent t-tests respectively. Independent t tests were used to determine if participants in the NSG and SG differed on satisfaction and on self-efficacy. Responses to the open ended questions were compiled in a word document and analyzed for common themes without knowledge of group assignment. Frequencies and percentages were used to categorize the general responses to the open-ended questions.

Ethical Considerations

The research proposal was submitted to the Health Research Ethics Board at the University of Alberta and received ethical clearance (Appendix D). The transplant centre received letters of support from the administrative and physician leads of the Liver Transplant Program and in turn approved data collection within the facility.

Verbal consent was obtained from the participants by the researcher over the telephone. A script was developed that outlined the purpose of the study and ensured that each participant received the same information about the study (see Appendix E). Consent was implied if participants completed and returned their questionnaire. An information sheet was mailed out with the teaching materials that repeated the same information in the telephone script and included contact information for the researcher (see Appendix F).

The researcher was not involved in patient care or any of the teaching sessions that were given during the assessment period. It was made clear to the participants that the researcher had no influence over the decisions about their transplant status. Patients agreeing to participate were offered the option of refusing to continue with the study at any time.

Confidentiality was protected at all times. Only the researcher had access to documents that contained patient identification and personal information. These documents were stored in a locked cabinet to which only the researcher had access and will be destroyed after seven years.

People in this population are vulnerable. These peoples conditions are terminal and feel that transplantation might be their only hope for survival. Because of this, it was important that participants understood that their listing for transplant would not be affected in any way if they refused to participate in the study. There was no potential harm to subjects by exposing them to either the traditional or enhanced teaching manuals. If people refused to participate, they were given the current teaching materials.

Chapter 4

Results

In this chapter, the sample is described and the results of comparisons between the stories (SG) and no stories (NSG) groups on demographic and outcome variables are provided. Finally, the results of content analysis of the open-ended questions are summarized.

Sample

Ninety-seven adult referrals were made to the transplant centre over the study period. Of these, 30 individuals were ineligible as determined by the inclusion/exclusion criteria. The remaining individuals were all approached by the clerical staff and 33 people agreed to receive the study materials. Following a reminder at one month, 23 returned the questionnaire to the researcher.

Of the 23 patients who returned the Patient Education Questionnaire, two individuals were eliminated from the study. One individual stated that they had received a liver transplant previously and were now being assessed for re-transplant while the second individual filled out the questionnaire after attending the in-person teaching session and assessment at the transplant centre. Both of these individuals likely had other exposure to transplant information that may have affected their self-efficacy. Therefore, the final sample contained 21 participants: 10 people in the SG and 11 in the NSG.

Demographic Characteristics

There were 14 men and 7 women who agreed to participate in the study (Table 1). The results of a Chi-Square analysis showed there were no group differences on gender ($\chi^2 = 2.33$, $p = 0.13$). The age of the control group ranged from 46-64 years (mean = 57.00) while the range of individuals in the experimental group ranged from 46-66 years (mean = 54.60). Most participants had at least some high school education while others had college or university experience. Years of education ranged from grade 10 to grade 15 with a mean of grade 11.20 and 12.20 for the NSG and SG respectively. The greatest variance was seen in the number of years the participants had been aware that they would require transplantation to extend their life. Some had known for as little as 2 months while others reported knowing for 10 years and one for 29 years. Based on the results of independent t-tests the groups did not significantly differ on age ($t = 0.66$, $p > .05$) or years of education ($t = 1.94$, $p > .05$)

Table 1. Summary of demographic and clinical data

	No Story Group (NSG) N=11	Story Group (SG) N=10	p
Female f (%)	f 5 (45)	f 2 (20)	0.13
Mean Age in years (SD)	57 (6.54)	54.60 (6.96)	0.43
Mean years of Education (SD)	11.18 (1.72)	12.20 (1.62)	0.18
Mean years in Need of Transplant (%)	2.9 (3.50)	4.94 (8.87)	0.49

Note: SD = Standard Deviation, Statistical significance is accepted at p = .05.

Satisfaction

Participants were asked to rate their satisfaction with the teaching manual on a scale of 1 to 10. Responses could range from 1 (not satisfied at all) to 10 (extremely satisfied) on a likert type scale. Satisfaction scores ranged from 6-10 with some participants offering suggestions for improvement. This happened on two occasions and included requests for information regarding the likelihood of surviving surgery, post transplant life expectancy, and length of time one would spend in surgery and in hospital. Mean satisfaction was 8.82 and 8.50 respectively for the NSG and SG (Table 2). No significant difference was found between the groups on satisfaction (t = 0.36, p >.05).

Table 2. Summary of Scores on Satisfaction and Self-Efficacy by group.

Characteristic Measured	No Story Group (NSG) N=11 Mean (SD)	Story Group (SG) N=10 Mean (SD)	P value
Satisfaction with Manual	8.82 (1.17)	8.50 (1.27)	0.56
Self-Efficacy			
MCD Domain	40.30 (6.90)	39.70 (8.30)	0.86
MD Domain	46.09 (11.50)	48.10 (7.98)	0.65

Note: MCD = Managing and Controlling Disease, MD = Managing Depression, SD = standard deviation, Statistical significance is accepted at p=0.05

Self-Efficacy

Two domains of the Chronic Disease Self-Efficacy Scale (CDSES) were measured. The first domain contained five self-efficacy questions that referred to the participants' confidence in managing different aspects of their disease. The second domain contained six self-efficacy questions that referred to their confidence in their ability to control or manage symptoms of depression. Self-Efficacy was rated on a likert scale from 1 to 10. A higher score infers greater perceived self-efficacy. Therefore, the total score possible for the first five questions was 50 and would indicate that participants were very confident that at this time and in this situation that they were able to manage their condition. The total score possible for the next six questions was 60 which would indicate that at this time, in this situation, the participants felt that they were very confident that they could manage or control any symptoms of depression.

One of the respondents in each group answered 10 out of 10 to all of the questions in both domains with a further six answering 8, 9 or 10, and 10 was the most common answer in both domains. The NSG and the SG did not significantly differ on the MCD domain ($t= -0.18$, $p > .05$) or the MD domain ($t = 0.46$, $p > .05$) of the Chronic Disease Self-Efficacy Scale (Table 2).

Open Ended Questions

At the end of the questionnaire, three open-ended questions were asked: 1) What did you find most helpful? 2) Why was it helpful? 3) After you read the information, did you use any of the suggested resources?

The NSG and SG responses were first analyzed separately looking for trends in the data. Then a comparison of the two groups was made looking for similarities and differences in participants responses. In response to the question, "What did you find most helpful?" Three respondents from the SG indicated that everything was helpful. Almost equal numbers of participants from both groups identified descriptions of procedures and going through the process "step by step" as most helpful. Two respondents from the NSG mentioned rejection/infection and explanations about liver failure as being most helpful. Three respondents from the SG identified "what happens during surgery" as being most helpful while another respondent from the SG identified learning that one could have a "normal life after transplant" as the most helpful information.

Participants were then asked, "Why the information was helpful?" The majority of respondents from both groups suggested that the information was helpful in preparing them for "what to expect". The NSG also indicated that "the unknown is usually the scariest", it was "simply written", they felt more comfortable and they "knew when to act". The SG indicated that the information was helpful because they "needed it to understand" and it assisted them in "getting the bigger picture". In addition, one participant suggested that the information provided "hope and peace of mind".

The final open-ended question asked participants if they had explored any of the resources suggested in the teaching manual. Equal numbers of respondents from both NSG and SG indicated that they either had (n=7) or had not yet (n=8) used the suggested resources. One respondent from the NSG indicated that they were not able to find the suggested resources. A number of respondents (n= 4) left this question unanswered.

A trend was identified in the open-ended questions that distinguished the NSG from the SG. The word "knowing" was used three times in the NSG to describe why the information was useful to participants; it was not used at all in the SG. The phrase "what to expect" was used four times to relay why the information in the teaching manual was useful to the participants. They needed to know what to expect.

The word "understand" is found once in the NSG to answer the question about why the teaching manual is useful. In contrast to the NSG, the SG uses the word "understand" three times to describe their experience with the information in the teaching manual. The SG understands what to expect.

After learning that "a normal life" after transplant was possible, one participant in the SG shared that "hope and peace of mind" was the outcome of reading the teaching manual. Another participant in the SG referred to the "bigger picture" told in the teaching manuals containing personal stories. The only comment in the NSG related to quality of life is one participants' description of feeling "more comfortable" but the participant then goes on to clarify that his comfort level increased knowing that there are a number of "professional people involved" in the transplant program.

Chapter 5

Discussion

In this chapter, interpretations of the results for each of the three main research questions are discussed in relation to research method, theory and previous studies. The limitations of this study and the recommendations for future research are then presented. Finally, some key conclusions from the study are put forward.

Effect of Stories on Patients' Satisfaction

The NSG and SG did not differ on satisfaction. The results of the statistical analysis may reflect a true lack of differences. Personal stories may not influence satisfaction with printed educational material. However, our knowledge about the importance of stories and their relationship to developing a 'sense of community' would not support that conclusion. Alternatively, failure to find group differences on satisfaction may have been a result of two things: the small sample size may have resulted in insufficient power to capture actual differences, and the reading level for the personal stories may have exceeded the literacy level of the sample. The reading level of the personal stories was grade 8.5 but the range of Flesch-Kincaid grade levels found in the stories varies from 6.10 to 12.00. As there were ten contributors to the personal stories there is considerable variation from story to story. Despite this, the stories were left relatively unedited to eliminate the chance of changing the nature of the message.

The literature on literacy in health education suggests that individuals actually read at a lower comprehension level than they report as their last grade completed. Wilson et al. (2003) reported that individuals often read up to five grade levels lower than their last grade completed. If the sample is reflective of the population of individuals being referred for transplantation, the patient education materials should then be aimed at a grade 6 level. Bernier (1993) recommended that all materials be designed for grade 6-8 reading level. The reading level of the Liver Transplant Teaching Manual was at a grade 8 reading level; therefore, some revision may be needed to target lower comprehension levels. Paul et al. (2007) identified the need to solicit more than just satisfaction as a number of studies have un-interpretable results looking at satisfaction alone. Rather they suggest soliciting specific likes and dislikes from the target population. For this information, the open-ended questions must be examined for meaning.

Effect of Stories on Patients' Self-Efficacy

The NSG and SG did not differ on the measure of self-efficacy. Again, the results of the statistical analysis may reflect a true lack of group differences. This interpretation would contradict Bandura's theory, which supports the notion of a positive relationship between vicarious experience and self-efficacy.

Self-efficacy was reported as consistently high with several individuals documenting 10 as their level of confidence on most items. There were four participants who reported their self-efficacy as 5 or lower on more than one of the questions asked, these will be discussed separately later in the text.

There may be a few explanations for the reported high self-efficacy across groups. It may be that the study participants are overwhelmed by this critical event in their lives. The participants perhaps completed the questionnaire without thought or attention to individual questions. They were generally pleased with the information presented, but may also have given socially desirable responses.

In this instance, the participants have been given a great deal of important information that will profoundly affect their lives. Their immediate need is medical information: what will happen to me? Once given the material their confidence in their ability to proceed is affected to the degree seen here. They feel able to take on transplantation at this point. These individuals usually have no other medical options. Transplantation is only offered when all other medical therapies have been exhausted. Without many other options and armed with facts the participants feel ready for the challenge.

This is reflective of the emotive source of self-efficacy described by Bandura (1997). These physiological and affective states influence our ability to judge competence in any given situation. Our emotional state at a particular time can influence how confident we feel about accomplishing a specific task. Those who were very satisfied with the information were obviously pleased by the quality of the teaching manual, this may have led them to be more confident about their ability to manage their disease and cope with depression. Relief at having the information they needed, their fear of the unknown diminished, confident they now "knew what to expect" participants felt equally confident in their ability to proceed. A strong emotional response magnifies the perception of self-efficacy in a particular situation and could have a positive influence on participant's self-efficacy in this study. Whereas dissatisfaction may have had the opposite effect and participants would be left feeling less confident of their ability to cope with their condition.

There is a group of four participants, two each from the NSG and SG, who reported their self-efficacy as less than five on more than one item of the self-efficacy tool. The two participants in the NSG group identified their satisfaction with the teaching manual as 6 and 8 respectively. The participant with the lower satisfaction score had the lowest self-efficacy scores answering "not at all confident" to three of the questions. This was in response to questions asking about ability to reduce emotional distress, do more than take medication to reduce the affect of illness on everyday life, and their ability to keep from getting discouraged when nothing you do seems to make any difference. In contrast when asked about the ability to do something to make yourself feel better, the same recipient gave responses of 8 and 6. The participant with the lowest self-efficacy scores felt unable to prevent the feelings of sadness but felt able to do something to help feel better when the time came. In response to the open-ended question why the information was helpful, the individual responded that it "makes a person feel a little more comfortable knowing about all the professional people involved". Both the participants in the NSG used some of the suggested resources.

The two recipients in the SG scored their satisfaction as 9 and 10. One had three scores of 5 in the self-efficacy questions, all other responses were higher than 5. The answers to open-ended questions were similar to others reported elsewhere, based on the medical information given in the teaching manuals. The second participant in this group had lower scores; seven responses were scored as 3 and one as "not at all". The majority of these low scores were in the ability to manage/control depression domain of the self-efficacy testing. There is little response to the open-ended questions. When asked what was most helpful the participant responded the pre-op teaching manual, when asked why this was helpful the participant responded: "yes, very".

These individuals have scores closer to what the researcher expected to find in this population and although there are some slight differences with the two individuals in the NSG scoring lower in satisfaction than the two in the SG, there is not enough data here to form any conclusions. Their self-efficacy scores were similar, one individual scoring very low in each group and one scoring in the middle in each group.

What printed information is most helpful and why?

An examination of the literature on patient education has shown that information alone is not enough to affect a behavioral change (Lee & Garvin, 2003). The information must be understood, and it must have some value to the audience before it will be applied to their own life experiences (Kennedy, Robinson et al., 1999). Evidence supports implementing educational programs that foster knowledge and understanding. Three themes emerged from the content analysis of the responses to the three open-ended questions: moving toward knowing, moving towards understanding and moving towards quality of life.

Moving toward Knowing

There was considerable evidence of moving toward knowing from the NSG responses. The participants appreciated knowing "the order in the way things happen leading up to the operation", the explanation about "how it works", and the "description of procedures for before and after transplant". This knowledge had relevance for them as "it gave [them] an idea of what to expect". Having This knowledge was satisfying. Simply having knowledge does not denote being able to understand or denote meaning nor does it automatically lead to changes in behaviour (Kennedy, Robinson et al., 1999).

Moving towards Understanding

Understanding is the word most frequently used in the SG to describe their learning. This movement toward understanding may be reflective of the content of the personal stories. Knowledge is useful but unless participants understand how they can apply that knowledge in the context of their lives, it will not change the way they behave. Cohen (1994) demonstrated that shared experiences in the form of personal stories provide the context for moving towards understanding. The SG participants appear to have gained understanding of what to expect from reading the enhanced teaching manual.

Moving towards Quality of Life

Although the traditional and enhanced manuals do say that you can get on with living your life after transplant, it also says that transplant is not a cure; candidates should expect to be living with chronic disease. The most powerful reference to a long and healthy life post transplant is contained in the last story in the enhanced teaching manual and is shared by a recipient who is now 19 years post transplant. This recipient shares her thoughts about her grandchildren, her hobbies and her volunteer work talking about the importance of organ donation in the community.

None of the SG participants referred to the stories in any part of their answers. Their focus appeared at first to be very similar to the NSG responses. However, on closer examination the SG participants appear to have moved from merely possessing some new knowledge to understanding that knowledge in the context of their own life experiences. References to quality of life only appear in the SG responses; suggesting that they had read and valued the experiences others shared.

When an individual gets sick, the first question that they ask is what is wrong with me? The next is how do I get better? (Bernier, 1993) Participants in this study had the same needs and this guided the development of the traditional teaching manual. Following Bernier & Yasko's (1991) guidelines, a simply written, systematic guide to transplantation was written. This traditional manual was reviewed several times by staff and patients and is updated regularly to ensure that transplant candidates are receiving current information. Following the recommendations in the literature, candidates are given both written and verbal instruction as part of their assessment for transplantation (Johnson, Sandford & Tyndall, 2003). With their basic needs being met by the traditional manual, participants do not seem particularly concerned at this point in their transplant journey with the need for additional information (e.g. accounts of personal experiences). The lack of comments about the personal stories in the SG appears to support such a conclusion. However, the SG participants' responses to the open-ended questions demonstrated that the context of the personal stories had facilitated their understanding through the examples that help to relate the new medical information to their life circumstances.

Do Patients use any of the Suggested Resources?

Candidates have been using the information provided in the teaching manuals to explore other literary and internet resources. This item was a new addition to the teaching manuals in 2003 and 40% of the participants in this study reported that they had used the additional resources and another 30% intended to do so in the future. This is congruent with previous reports in the literature that have shown how easily people can access quantities of information on the internet regarding treatment and the personal experiences of others in the same treatment modality (Cutilli, 2006). As of 2005, the Computer Industry Almanac estimated that 67.9% of Canadians had access to the internet (Internet World Stats, 2006).

Impact of Stories

There is evidence that one story directly influenced a participant in the SG by offering hope for a normal life. The evidence from the analysis of the answers to the open-ended questions suggested that the NSG had moved toward knowledge whereas the SG had moved toward understanding. Participants in both groups valued the information in the teaching manuals as indicated by the high satisfaction ratings for both versions. The SG appears to have assimilated the personal stories, which provide motivation and hope for a better life following transplantation. However, these results cannot be generalized to the liver transplant population without a replication using a larger sample.

Overall, this study did not reveal any significant difference between the control and experimental groups for satisfaction or self-efficacy. The sub-group of participants with low to moderate self-efficacy scores demonstrated a difference in their satisfaction with the teaching manuals with the NSG having an average of 7.00 and the SG having an average of 9.50 on the 10 point likert type scale. This difference is not significant and should be interpreted with caution. The increased satisfaction of the SG participants might coincide with the sense of connection that the personal stories elicited. These stories did provide the SG participants with a context for their learning.

Limitations of the Study

Sample size proved to be a major limiting factor in this study. Unfortunately, recruitment of participants proved to be more difficult than expected. Of the 67 eligible referrals over the six months of data collection, only 33 individuals agreed to participate in the study protocol. Candidates were asked to read the teaching manual in preparation for their assessment at the transplant centre whether or not they participated in the study. Study participants did have to fill out a three-page questionnaire in addition to the required reading and it could be that prospective transplant recipients are too overwhelmed by the need for referral for transplantation to take on any additional responsibilities.

Learning takes time and the time limits necessary for the completion of the study may not have allowed the participants' time to reflect and learn from the teaching manuals appropriately. It may be that with time there would be a greater difference between the two groups. Testing at the end of the assessment week or a month after the participants visit to the transplant centre may show different results than those found here.

Assessment for liver transplantation is a time of great uncertainty for prospective recipients and both physically and emotionally challenging. Patients do not know what to expect and as one participant so wisely said, "the unknown is usually the scariest". Despite receiving information that addresses their fears the additional request to participate in a study that has no perceived benefit for them may be too much.

Another route to consider is blanket mailing of the questionnaire to all referrals. As we found no significant difference between the NSG and SG groups, and satisfaction levels were high for both, the value of the information to all candidates can be assumed to be high.

The clerical staff was supplied with a script describing the project and the type of commitment that was required. It is not known how closely the script was followed or how supportive the staff person was when questioned about the work involved in participating in the study. However the staff member involved were well known to the researcher and is presumed that they were supportive of the study and affable with candidates.

It is acknowledged that other sources of knowledge are available to the participants not controlled by the researcher. All participants, whether assigned to the NSG or SG, had the same opportunity to research transplantation prior to receiving information from the transplant program.

Recommendations for Future Research

The liver transplant team at this transplant centre has clearly developed a very satisfactory teaching manual that, with few exceptions, received excellent reviews from the participants in this study. However, further studies are needed to determine the effect of the addition of personal stories as part of patient educational materials.

Perhaps a study set at a time when the uncertainty described by one participant is not so prohibitive would be beneficial. This could be done later in the process after their candidacy has been confirmed. The problem with this scenario is that subjects would be exposed to multiple sources of information about transplantation prior to testing. Therefore, their factual knowledge could be high but their connection to personal transplant information might be low if they have not had access to personal stories of transplantation. If the participants were then introduced to a collection of stories and those in a control group were not, one could measure self-efficacy as it is affected by the collection of personal stories alone.

As previously noted sample size might be a reflection of uncertainty at the time of referral. If at each referral the manuals were randomly sent along with the questionnaire and the fact sheet without the pre-screening phone call, some of the candidates who were not interested at first contact may consider filling out the questionnaire after reading the teaching manual.

There is an opportunity to speak to candidates face to face during their assessment week. If the researcher approached them immediately before their teaching class and asked if they could fill out a brief questionnaire regarding the teaching material before the class starts some individuals might be more willing to participate. As this would not be first contact with the program they would have had opportunity to have read and reflected on the teaching manual. This may lead more individuals to participate but would make tracking which participant was assigned to which group more difficult. Again, the manuals would have to be mailed out initially in a random manner to all referrals.

A measure of anxiety might have been useful in this study. Spielberger's State-Train Anxiety Inventory (STAI) (Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983) has been used in as many as ten transplant studies to measure the level of anxiety in liver and lung transplant candidates (ITNS, 2006). This instrument has acceptable reliability and validity data and has been used with several patient populations both pre and post transplantation. A tool such as this would help to decipher whether high levels of anxiety are generating some of the problems discovered in the study.

The open-ended questions should have contained a more direct measure of stories. This would necessitate having different questionnaires for the NSG and SG. The NSG could be asked; would you find it helpful to read short stories of other patient's experience? (1-10 scale). The SG could be asked; how helpful did you find the stories from other patients? (1-10 scale). Their feedback to these questions would be much more helpful to illuminating the questions posed by this researcher than the information gathered to this time.

Conclusion

Liver transplant recipients are part of the growing number of people living with chronic diseases in our communities. The ability to manage both their physical condition and their emotional health is key to long-term success after transplantation. Isolation and the search for connectedness within a community have been shown to be important in the self-management of chronic conditions. Patient educators have a responsibility to continue to search for the best tools; personal stories could be an important tool for patient educators to consider when developing educational materials. Answers to open-ended questions demonstrated that the context of the stories for learning helped to move the SG group beyond general knowledge and toward a better understanding of their transplant journey.

References

Bandura, A. (1997). Self-Efficacy: The exercise of control. New York: W. H. Freeman and Company.

Bernier, M. J. (1993). *Patient education in nursing: development of a scale to evaluate the instructional design quality of printed education materials.* Doctoral dissertation abstract. Pittsburgh: University of Pittsburgh.

Bernier, M. J., & Yasko, J. (1991). Designing and evaluating printed education materials: Model and instrument development. *Patient Education & Counseling, 18*(3), 253-63.

Bissonnette, J., Logan, J., Davies, B., & Graham, I. D. (2005). Methodological issues encountered in a study of hospitalized COPD patients. *Clinical Nursing Research, 14*(1), 81-97.

Boden-Albala, B., Liwak, E., Elkind, M. S. V., Rundek, T., & Sacco, R.L. (2005). Social isolation and outcomes post stroke. *Neurology, 64*, 1888-1892.

Bowbeer, M. A., Hiss, R. G. (1990). Use of educational resources in diabetes patient education. Commentary in *The diabetes educator. 16*(1) p 15.

Canadian Institute for Health Information. (2004). *Preliminary Statistics on Organ Donation, Transplantation and Waiting List 2004 CORR Preliminary Report* Ottawa: Author. Retrieved March 23, 2005, from http://secure.cihi.ca/cihiweb/dispPage.jsp?cw_page=services_corr_e

Cleemput, I., Kesteloot, K., Vanrenterghem, Y., and De Geest, S. (2004). The Economic Implications of Non-Adherence after Renal Transplantation. *PharmacoEconomics, 22*(18), 1217-1234.

Cohen, G., Forbes, J., Garraway, M. (1996). Can different patient satisfaction survey methods yield consistent results? Comparison of three surveys. *British Medical Journal*, 313:841-4.

Cohen, L. J. (1994). Bibliotherapy: a valid treatment modality...research-based practice. *Journal of Psychosocial Nursing & Mental Health Services, 32*(9), 40-4.

Cohen, J. (1988). Statistical power analysis for the behavioral sciences. (2nd ed.). Hillsdale, New Jersey: L. Erlbaum Associates.

Cutilli, C. C. (2006). Accessing and evaluating the Internet for patient and family education.. *Orthopaedic Nursing, 25*(5), 333-8.

Dew, M. A., DiMartini, A. F., De Vito Dabbs, A., Myaskovsky, L., Steel, J., Unruh, M. et al. (2007). Rates and risk factors for nonadherence to the medical regimen after adult solid organ transplantation. *Transplantation.*

Dew, M. A., Kormos, R. L., Roth, L. H., Murali, S., DiMartini, A., Griffith, B. P. (1999). Early post-transplant medical compliance and mental health predict physical morbidity and mortality one to three years after heart transplantation. *Journal of Heart and Lung Transplantation, 18*, 549-562.

Dixon-Woods, M. (2001). Writing wrongs? An analysis of published discourses about the use of patient information leaflets. *Social Science & Medicine, 52*, 1417-1432.

Doak, C. C., Doak, L. G., Friedell, G. H., Meade, C. D. (1998). Improving comprehension for cancer patients with low literacy skills: Strategies for clinicians. *Ca: A Cancer Journal for Clinicians, 48*(3), 151-62.

Friere, P. (1979). *Pedagogy of the oppressed.* New York: The Sea bury Press.

International Transplant Nurses Society (ITNS). (2006). Research Resources: author. Viewed at http://itns.org/research/resources, accessed September 2, 2008.

Internet World Stats. (2006). Usage and Population Statistics: North America. Viewed at http://www.internetworldstats.com/america.htm . Accessed January 23, 2007.

Johnson, A., Sandford, J., Tyndall, J. (2003). Written and verbal information versus verbal information only for patients being discharged from acute hospital settings to home. *Cochrane Database of Systematic Reviews*, 4. Art. No.: CD003716. DOI: 10.1002/14651858.CD003716.

Kennedy, A., Nelson, E., Reeves, D., Richardson, G., Roberts, C., Robinson, A. et al. (2003). A randomized controlled trial to assess the impact of a package comprising a patient-orientated, evidence-based self-help guidebook and patient-centered consultations on disease management and satisfaction in inflammatory bowel disease. *Health Technology Assessment, 7*(28), iii-x,1-113.

Kennedy, A. P., Robinson, A. J., Thompson, D. G., & Wilkin, D. (1999). Development of a guidebook to promote patient participation in the management of ulcerative colitis. *Health and Social Care in the Community, 7*(3), 177-186.

Kennedy, A. P., & Rogers, A. E. (2002). Improving patient involvement in chronic disease management: the views of patients, GPs and specialists on a guidebook for ulcerative colitis. *Patient Education and Counseling, 47*, 257-263.

Lee, R. G., & Garvin, T. (2003). Moving from information transfer to information exchange in health and health care. *Social Science & Medicine, 56*, 449-464.

LeFrancois, G. (2006). *Theories of Human Learning: What the Old Woman Said.* Fifth Edition. Belmont, CA: Thomson Wadsworth.

Lev, E. L. & Owen, S. V. (1996). A measure of self-care self-efficacy. *Research In Nursing & Health, 19*, 421-429.

Lorig, K. Stewart, A., Ritter, P., Ganzalez, V., Laurent, D., & Lynch., J. (1996). Outcome measures for health education and other health care interventions. Thousand Oaks: Sage Publications, pp. 24-25, 41-45.

Pajares, F. (2002). Overview of social cognitive theory and of self-efficacy. Retrieved March 28, 2005, from http://www.emory.edu/EDUCATION/mfp/eff.html.

Palmer, P. (1998). *The courage to teach.* San Francisco: Jossey-Bass Publishers.

Paul, F., Jones, MC., Hendry, C., & Adair, P.M. (2007). The quality of written information for parents regarding the management of a febrile convulsion: A randomized controlled trial. *Journal of Clinical Nursing,16*(12), 2308-22.

Redman, B. K. (1997). *The practice of patient education.* Eighth Edition. Mosby-Year Book, Inc.

Sayre, J. (2001). Using personal accounts of mental illness as a teaching tool. *Journal of Nursing Education, 40*(2), 93-96.

Simpson, S. H., Eurich, D. T., Majumdar, S. R., Padwal, R. S., Tsuyuki, R. T., Varney, J., Johnson, J. A. (2006). A meta-analysis of the association between adherence to drug therapy and mortality BMJ,333:15 downloaded from http://www.bmj.com.login.ezproxy.library.ualberta.ca/cgi/reprint/333/7557/15 March 6, 2007.

Statistics Canada. (1997). Reading the future: A portrait of literacy in Canada. Literacy. Viewed at www.statscan.ca. accessed March 25, 2005.

Spielberger, C.D., Gorsuch, R.L., Lushene, R., Vagg, P.R. & Jacobs, G.A. (1983). *Manual for the Stait.Trait Anxiety Inventory*. Palo Alto,CA: Consulting Psychology Press.

Sudan, D., Shaw Jr, B. W., Langnas, A. (1998). Causes of late mortality in pediatric liver transplant recipients. *Annals of Surgery, 227*(2), 289-295.

Swatton, S., & O'Callaghan, J. (1999). The experience of 'healing stories' in the life narrative: a grounded theory. *Counseling Psychology Quarterly, 12*(4), 413-29.

Tompkins, C. (2001). Nursing education for the twenty-first century. In E. Rideout (Ed.*) Transforming nursing education through problem-based learning.* Mississauga, ON: Jones and Bartlett Publishers.

Tsay, S. & Hung, L. (2004). Empowerment of patients with end-stage renal disease: a randomized controlled trial. *International Journal of Nursing Studies, 41*(1), 59-65.

Wilson, F. L., Wood, D. W., Risk, J., & Kershaw, T. (2003). Evaluation of Education Materials Using Orem's Self Care Deficit Theory. *Nursing Science Quarterly, 16*(1), 68-76.

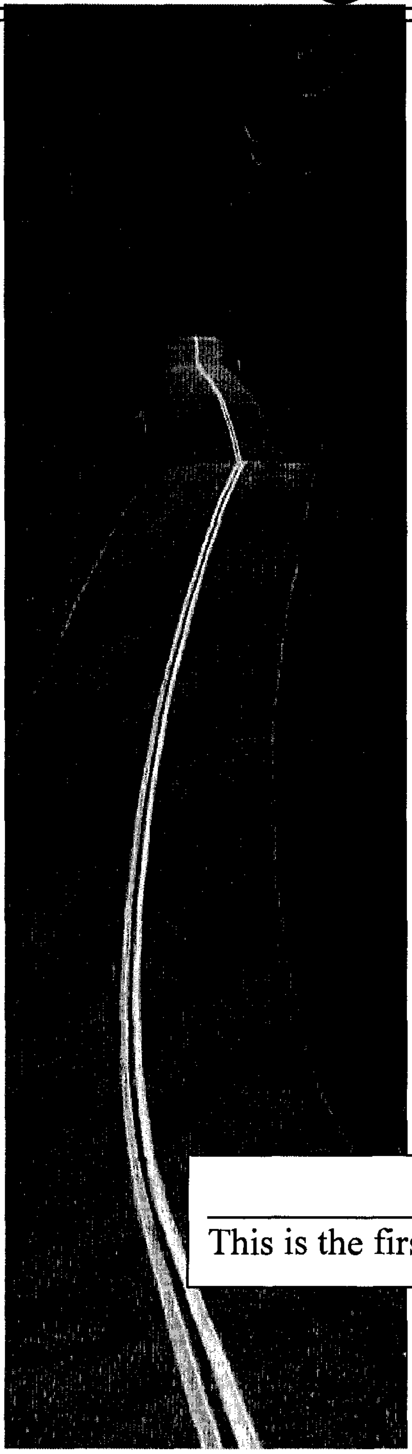
Wise, B. V. (2002). In their own words: The lived experience of pediatric liver transplantation. *Qualitative Health Research, 12*(1), 74-90.

Appendix A – Manual without Stories – Control Condition

Liver Transplant
Pre-op Teaching Manual

hope

health



life

This is the first step in your transplant journey

TABLE OF CONTENTS

This manual is based on the work of dedicated medical professionals, past and present, associated with liver transplantation. *Prepared by the University of Alberta Liver Transplant Team. Last revised 2004*

INTRODUCTION

The purpose of this handbook is to introduce you and your family to the **University of Alberta Hospital Liver Transplant Program.** Your physician has referred you to the program because you have a terminal liver disease. Here we will provide you with information about the process of organ transplant to help you to prepare for the procedures involved.

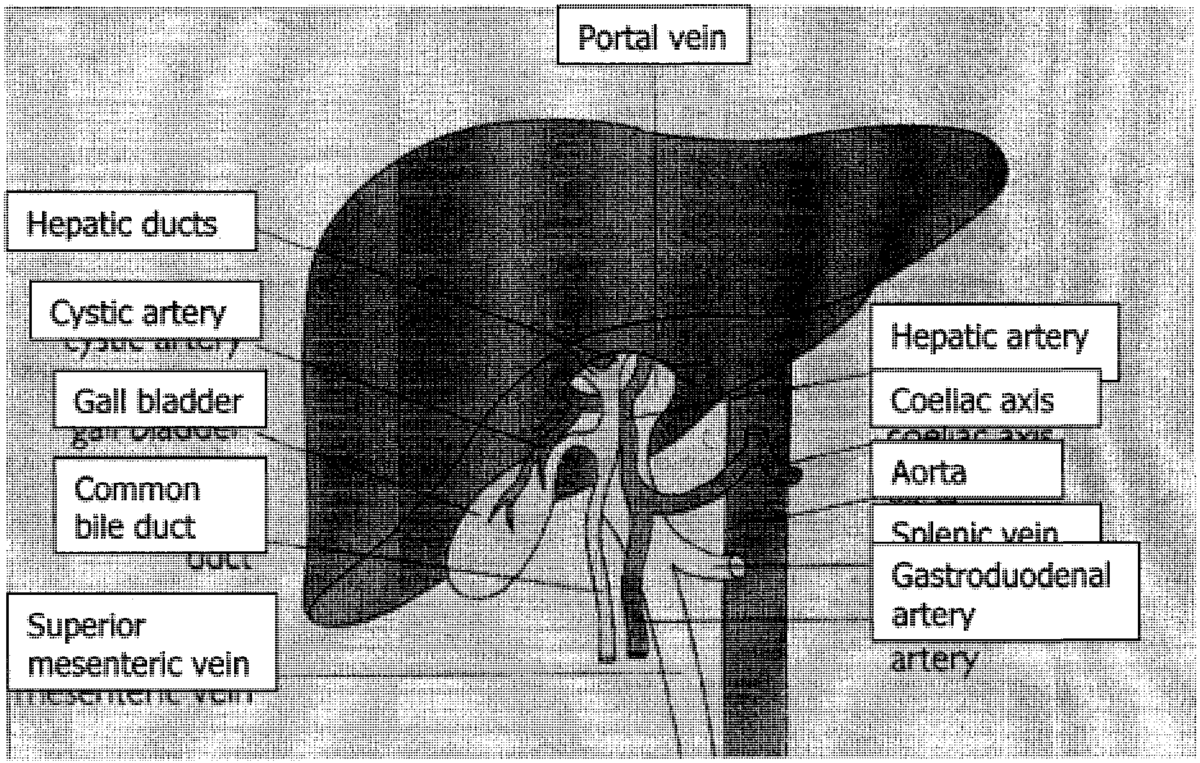
Transplant is not suitable for everyone nor is it a "cure" so that you never have to worry about your health again. You will be exchanging your diseased organ for a healthy one that can give you a longer and a better quality life. Transplant requires a lifetime of commitment to medical treatment including medication every day and ongoing follow-up. A transplant occurs when a healthy organ is removed from one person and placed in another person whose organ has failed. The person who gives an organ is called a donor. There are two types of donors: a living person and a person who has died. The person who receives the organ is called a recipient – YOU!

When you have finished reading this manual you will be able to:

- Understand the symptoms of liver disease
- Know when to go to the emergency room or doctor
- Understand how the transplant process works
- Find the information you need to cope with your illness

The first part of this teaching manual talks about liver disease and the things that can make you ill and perhaps cause your death. The second part of the manual talks about liver transplant and how it works. It is our hope that by the time you reach the end of this manual you will know what you can expect on your transplant journey.

The Liver



WHAT DOES THE LIVER DO?

The liver is the largest organ in the body weighing 1200-1500 grams. It is located on the right side of the abdomen, to the right of the stomach, behind the lower ribs beginning 1-2 cm below the nipple line. Blood is supplied by the portal vein and hepatic artery. It is made up of several segments but can be divided into two lobes, the right and left. The liver serves as the body's factory and waste processing system. A few of the main functions of the liver are to:

1. Help to absorb food and change food into nutrients the body can use. For example, the liver makes bile to help breakdown fats and fat soluble vitamins such as vitamins A,D,E,K and allow their absorption.

2. Store fats, sugars, iron, and vitamins for later use by the body.

3. Filter the blood to remove substances like drugs, alcohol and other toxins, that can be harmful to the body.

4. Make proteins needed for normal blood clotting, normal blood pressure and helping the immune system.

WHAT ARE THE SYMPTOMS OF LIVER DISEASE?

The three life threatening symptoms of end-stage liver disease are:

1. vomiting of blood or passing black stools
2. mental confusion that leads to coma
3. abnormal build-up of fluid in the abdomen that becomes infected

**** Go to the nearest emergency if you become confused, vomit up blood, pass black stools, or develop a fever. A physician must assess you if any of these occur.*

There are non-life-threatening symptoms experienced by people with End-Stage Liver Disease.

- yellowing of eyes and skin is called jaundice (jon-dis)
- severe itching
- dark tea-coloured urine
- grey or clay-coloured stools
- easy bruising and tendency to bleed
- malnutrition, nausea, diarrhea
- muscle wasting
- a tendency to osteoporosis
- difficulty sleeping

There are about 100 causes of cirrhosis (sir-ro-sis) but once you have cirrhosis the experience of everyone is much the same. Cirrhosis is simply scarring in the liver that makes the liver unable to do any of the jobs it is supposed to do. Cirrhosis also leads to some mechanical problems like: high blood pressure in the veins around the liver. This is called "Portal Hypertension". This high blood pressure is the root cause of vomiting blood from varicose veins in your throat and the fluid collecting in your belly called ascites (ah-site-ees).

Varices (var-i[t]-sees) are varicose veins that form in the blood vessels upstream from the liver. When the liver is cirrhotic it is very hard and rigid, more like a rock than the sponge it should be. The Portal Vein is the main blood supply to the liver. When blood flow to the liver is restricted, the blood pressure in the portal vein becomes very high and the blood vessels upstream become swollen with blood. These blood vessels in the esophagus and stomach can leak blood causing chronic anemia or they can break and bleed suddenly causing the person to vomit blood or pass blood in their stool. Any change in pressure from coughing, straining, or lifting can cause the blood vessels to break. The spleen is also upstream and can become very large and damage some of your blood cells called platelets. The high pressure in the portal vein also causes the build up of fluid in the abdomen or ascites.

Confusion or encephalopathy (in-sef-a-lop-ithy) can be caused by the failure of the liver to remove ammonia and other toxins from the blood.

TREATMENTS FOR LIVER DISEASE

There is no cure for End-Stage Liver Disease. It is a slippery slope that starts with cirrhosis. Some people are able to live well with cirrhosis for many years but once they start to have one or more of the life-threatening symptoms of liver disease it is time to think about Liver Transplant. There are many ways to manage the symptoms of someone with End Stage disease. All treatment should be under the supervision of a Gastroenterologist or Hepatologist, specialist doctors who treat liver disease.

How has liver disease affected
your role in the family?
How does that make you feel?

LIVER TRANSPLANT

STEPS TO TRANSPLANTATION

Referral
↓
Assessment
↓
Listing for Transplant

↓
Waiting

↓

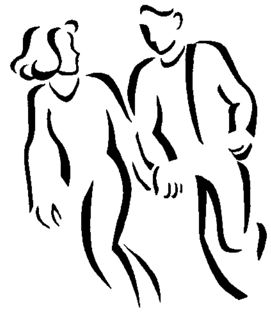
Phone Call (Organ Available)

↓
Admitted to Hospital
↙ ↘
Dry Run **Liver Transplant**

This section is about the transplant process. This is what happens step by step when you have been referred to the transplant program until after you have your transplant.

TRANSPLANT REFERRAL

Your family physician or a specialist has referred you to the transplant program because you have end-stage liver disease. Other treatments are not available to you any longer and so transplantation becomes the only treatment left. Liver transplantation is a treatment for liver disease; it is not "a cure". You will not be able to live a "normal" life after. You will have to take medication every day, you will have to have tests to see how your new liver is working, and you will have to visit the doctor on a regular basis. You can have a good life, you just have to learn to pay attention to your health. A referral is made to one of the liver specialists on the transplant team, called hepatologists. The hepatologist decides if you meet the requirements for liver transplant as developed by the transplant team. The hepatologist then passes your information on to the assessment coordinator who will arrange and complete your assessment.



SUPPORT

Learning that you may need a transplant is very stressful. For this reason it is mandatory that Liver Transplant Candidates have a support person throughout the whole process of transplantation. There is a lot of information given to the family about liver disease and transplantation, about the surgery and medications. The process of transplantation can be overwhelming and we believe a support person makes a difference to the outcome. A support person is anyone you choose who will be there for you during ALL phases of transplant, both before and after. The support person should be able to provide you with the physical and emotional support needed at these different times.

You could choose someone like your spouse, a family member, or a good friend. Choose someone who knows you well and is willing to make the long-standing commitment. It is expected that the assessment will take from two to six weeks to complete. Once it is complete the decision is made about whether you should be on the transplant list. The waiting time for transplant is up to one and one half years. You will need your support person to encourage you, listen to your concerns, and help you cope with emotions. Also, after transplant they will be responsible for helping you learn medications and routines, keep appointments, and be there for you while you recover. After transplant we expect the patient and support person to stay here in Edmonton for two months before allowing them to return to their community.

TRANSPLANT ASSESSMENT

The assessment is an information gathering stage. The purpose of the assessment is to help us determine if a liver transplant is the best option for your medical condition. You and your support person will meet with various members of the transplant team and you will have several tests done. Your appointments will take at least 3-5 days to complete. Accommodations can be arranged for patients who do not reside in the Edmonton region by notifying the Liver Transplant secretary at (780) 407-1184.

It is very important to remember that no decisions about listing you for transplant will be made until <u>ALL</u> the information requested is received and the whole team has had a chance to meet and discuss your case. Your transplant coordinator will notify you of our decision once we have determined whether or not transplantation is an option for you.

All persons with a history of drug or alcohol use will be required to have an assessment by their provincial addictions counseling association, in Alberta this is AADAC. The transplant program expects that you will take advantage of any counseling or follow up that they recommend. You may be required to sign a contract with the liver transplant program stating that you will not drink alcohol or use illegal street drugs. This contract also allows the liver transplant program to do blood tests to check for alcohol or drugs in your blood stream. If the test is ever positive you will be taken off the waiting list for transplantation. You will be required to stop smoking before you are able to go on the waiting list for transplantation.

"Who is who" on the Transplant Team?

The Transplant Team is a multidisciplinary group made up of doctors, nurses, social workers, physiotherapists, occupational therapists, dietitians and pastoral care personnel. Together we will determine the best course of action based on your particular circumstances. During your assessment you will see the following team members:

1) Transplant Surgeon
   The transplant surgeons perform both adult and pediatric liver transplants at the University of Alberta Hospital. One of these doctors will meet with you and your support person to discuss your medical condition and explain your surgical options. A physical examination is required.

2) Transplant Hepatologist

A hepatologist is a doctor who specializes in liver diseases. One of the transplant hepatologists will meet with you and your support person to discuss your medical condition. A physical examination is required.

3) Transplant Coordinator
The transplant coordinator is a registered nurse with expertise in the area of liver transplantation. You are assigned a coordinator when the referral is made. She/He will teach you how to monitor your general health and will answer most of your questions about transplantation. Your coordinator is involved in all aspects of your care and is your primary contact with the liver transplant program.

4) Social Worker
The social worker provides emotional support and financial counseling to you and your family. He /She can assist you in coping with the change experienced by you and your family as a result of your illness or the transplant.

5) Dietitian
The dietitian will meet with you and your support person to review what you normally eat and counsel you on how to improve your diet before the transplant.

<u>Diagnostic Tests</u>

Several tests will also be done during this time. These include:

Ultrasound of your liver
Chest x-ray
Bone Density Scan
Blood work
Urine tests
Sputum tests
Electrocardiogram

It may be decided that you have other medical or social needs that need further evaluation. You may be referred for additional tests and/or consultations with other health professionals, like a heart or lung specialist. Your transplant coordinator will arrange any additional appointments required and tell you of the bookings.

The following letters are also included in your information package:

1) <u>Dental letter</u> – Dental problems can be a source of infection after a liver transplant. Make an appointment with your dentist as soon as possible to assess your dental health. Take the letter from the transplant office with you when you go for your appointment and give it to your dentist. The

dentist must fax a copy of any findings to your coordinator once completed.

2) Tuberculosis letter – Tuberculosis (TB) can be activated or reactivated by the anti-rejection medication after a liver transplant. Make an appointment at the nearest community health clinic for a TB test and take the letter from the transplant office with you. The nurse will administer a small amount of fluid under the skin of your forearm. You must return 2 days later so she/he can check the site for any signs of reaction. The nurse must fax a copy of your TB results to your coordinator once completed.

While you are at the community health clinic you may ask about getting all your vaccinations up to date. The transplant team recommends that you get the vaccine for Hepatitis A and Hepatitis B before transplant. There is a small risk of being exposed to the Hepatitis B virus at the time of transplant. As part of your transplant assessment, we need to test your blood to see if you have had exposure to certain viruses and diseases. This testing includes tests for HIV (the virus that causes AIDS), Hepatitis C, Hepatitis B and Syphillis. If we receive unexpected positive results (meaning you have unknowingly been exposed) you will be contacted by the program and a physician will explain the results to you. They will also review what follow up may be required which may include public health follow up. Should you have any questions or concerns regarding this testing process, please do not hesitate to contact your transplant coordinator PRIOR to going for your bloodwork.

Remember that no decision about listing you for transplant will be made until ALL the information is received and discussed by your transplant team.

You are NOT on the transplant list when you finish your appointments at the end of the week.

LISTING FOR TRANSPLANT

How is the Decision Made to Transplant?

It will take some time for all the information to be collected and reviewed. Once this is done, your case will be presented to the entire transplant team. The transplant team meets every Thursday to discuss patients. All the people you meet during your assessment are present at the meeting. The transplant team reviews information from the various examinations and tests. If they feel a transplant is your best treatment option, you are placed on the transplant list.

People are listed according to three criteria:

1) blood group
2) donor weight range (size)
3) status

There are four separate liver transplant lists, one for each of the four blood types (A, B, O, and AB). The surgeons will determine the weight range of acceptable donors for you. This allows them to match the size of the liver to your body. At the time of listing each patient is assigned a "status", which refers to how sick you are. If you are not in the hospital you will be the same status as everyone else who is not in hospital. If you are admitted to hospital please let us know. People who are urgently ill will be transplanted before others on the list no matter how long you have been on the list.

When the decision is made to list you, your coordinator will contact you and confirm that you still want to proceed with the transplant. You will then be instructed to rent a pager and contact your coordinator with all your contact numbers. If it is felt that a transplant is NOT in your best interest or you decide that you are not ready to accept the responsibilities of transplant, your referring doctor will be contacted. They will be told of the decision and appropriate follow-up will be arranged.

Pagers

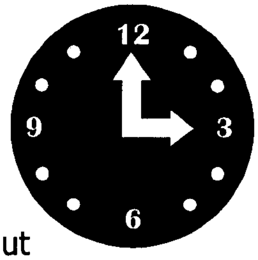
In case an organ becomes available, you must be able to be contacted 24 hours a day. You must rent a pager from a local telecommunications company and tell your coordinator the number. This makes it easier for the transplant team to contact you when an organ becomes available. You will keep the pager until you come into the hospital for your transplant.

WAITING AND LEARNING ABOUT TRANSPLANTATION

How long do I have to wait for an organ?

There is no way to tell how long you will wait for an organ but the average waiting time is 18-24 months. When a suitable organ becomes available, a transplant coordinator will call you. Your most important responsibility during the waiting period is to stay as healthy as possible. Try to stay as active as you can with regular walks and/or light exercise. This will help you recover faster after transplant. If you have any questions, the coordinator can refer you to a physical therapist for more information. A healthy diet, exercise, and enough rest are essential. It is very important that you follow the advice you are given by your transplant team.

Planning Ahead



Now is also the time to plan ahead. Remember, if you do not live in Edmonton both you and your support person are required to stay here for at least 2 months after your surgery. You need to think about how to manage your personal affairs while you are away from home (i.e. paying the bills, caring for children/pets, watering the plants, etc.). Talk about these things with your family or friends and make a plan. After your surgery is not the right time to have to worry about these kinds of things – your focus then needs to be on getting well.

Once you receive the call that a liver is available for you, you will not have much time to prepare. Here is a checklist guideline to help you when you get the call:

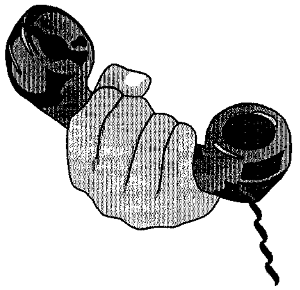
- In advance, pack a small suitcase including slippers and loose clothing. Have a list ready for the items you will need to pack at the last minute.
- Bring a small amount of cash in case you need to take a taxi to the hospital and have some loose change available for phone calls.
- Designate someone to look after your household responsibilities like watering plants, caring for pets, picking up mail, and paying bills.
- Make a list of people you will need to notify and their phone numbers. Use this to create a fan-out plan - where you will call 1 person who will call 2 people and, they, in turn will call 2 people until everyone is aware. You may be asked to stay off the phone for a period of time once you receive the initial call, therefore, the less you have to do the better.
- Bring a book or some magazines, a Walkman and tapes, some stationary, and maybe a favourite reminder of home. The more you feel at home and have things to do, the faster your recovery will seem.
- Consider getting a calling card if you are from a distant town or city within Alberta or from another province.

WHAT HAPPENS WHEN A LIVER BECOMES AVAILABLE?

The Phone Call

The Recipient transplant coordinator will contact you to come to the hospital. The first attempt will be made to reach you at home. If the coordinator cannot reach you at home you will be paged on your beeper. When your beeper sounds, go to the nearest phone and call 780-407-8822 and ask for the "*Recipient Transplant Coordinator on call.*" Please identify yourself by name and by the organ you are waiting for. EXAMPLE: MY NAME IS JOE GREEN I AM WAITING FOR A LIVER TRANSPLANT AND MY BEEPER JUST WENT OFF. The coordinator on call may not be your coordinator so may not be as familiar with your name.

Sometimes your beeper will go off and we are not calling you. The beeper may go off when the batteries run low or when you are near equipment that sends out a signal over the airwaves. We will simply tell you there is no transplant happening and please check your battery.



If we have a liver available for you we will tell you so and ask if you are ready to go ahead with transplantation at this time. If you are ready to go ahead we will give you instructions about what time to be at the hospital admitting department and what time we think the operation will be.

<u>REMEMBER:</u>

- Do not eat or drink ANYTHING after receiving the call.
- Please drive carefully. It is a good idea for a support person or someone else who is close to drive.
- If you are from BC, NWT, SK, MB, or far distances within AB and if time is a factor, air ambulance may be arranged to bring you to the hospital. You may need money for a taxi to and from the airport.
- Bring the bag you have packed, your patient teaching booklets, a list of medications you are presently taking, your pager, and a cellular phone if you have one.

- ➢Go to the Admitting Department when you arrive at the University of Alberta Hospital between 6:30 a.m. and 8:00 p.m. After 8:00 p.m. and before 6:30 a.m. please go to the Registration area in the Emergency Department.
- ➢Tell the Admitting Department clerk your name and that you are here for a Liver Transplant. They will be expecting you and will tell you what to do next. Have your Health Care number ready (AB, BC, SK, NW or NWT).

The Transplant Coordinator will likely meet you in the Admitting or X-ray Department. If not, you will be directed to the appropriate Nursing Unit to be prepared for surgery.

Sometimes people feel a little stunned when they are called to come for transplant, especially in the middle of the night. Some have reacted by saying, "No, I'm not ready for transplant!" when that is not what they intended at all. If that should happen when we call you for transplant, the coordinator will give you ten minutes to think it over and will then call you back. If you still say no, you will not come off the list but we will be talking to you and your family doctor over the next few days about your commitment to transplant.

At the Hospital

When you arrive at the hospital, you will first go to Admitting during the day or the Emergency registration desk at night. From there you will go to the Radiology and Diagnostic Imaging department for your chest X-ray. Then you will be escorted to the nursing station and your preparation for surgery will begin. It will consist of a history and physical examination, blood and urine tests, skin preparation (shave your body hair from chin to knee and shower with special soap), insertion of an intravenous line, and an enema. You will be asked to sign consent forms for:

- Orthotopic liver transplant
- Multiple liver biopsies

The transplant coordinator will explain these to you in detail. Feel free to ask any questions you may have. After you are prepared for surgery, you should try to rest until they are ready for you in the Operating Room. Quite often the time of the operation is a guess so it may be sooner or much later than we originally tell you. At any time the surgery may be cancelled. Be prepared for a dry run and make plans for getting home again if this happens.

What happens in the Operating Room?

When you are taken into the Operating Room, the anaesthetist will ask you a few questions and then administer medication to put you to sleep. After you are asleep, the following tubes will be inserted:

- Intravenous lines - these lines give you fluid, salts, sugar and medications
- central lines - these lines measure the volume of fluids in your body
- arterial line - this line measures your blood pressure
- endotracheal tube (breathing tube) - assists your breathing, it is attached to a breathing machine (a ventilator)
- nasogastric tube - drains the contents of your stomach
- foley catheter - drains urine from your bladder

Following surgery, you may also have some additional tubes:

- Bile tube (T or C tube) - this tube drains bile and is used to x-ray your bile ducts. Bile ducts drain bile from your liver
- Jackson Pratt drains - drains blood and body fluids from around the surgical area. You may have two or more of these tubes.

What Happens during the surgery?

During your operation, the surgeon will remove your diseased liver and reattach a new liver at 5 sites. They are as follows:

1. Suprahepatic vena cava
2. intrahepatic vena cava
3. Portal vein
4. Hepatic artery
5. Common bile duct

The first four sites are blood vessels, the fifth site drains bile from the liver. Staples will hold your incision together. As it heals, your nurse will remove them. A large bandage called a "dressing" will cover the incision. The dressing serves as a protection and will be changed by the nurses.

There are a few types of transplants possible.

Cadaveric Transplant:

This means the family of a person who has died has given their loved one's organs as a gift of life. This would mean that you would get a whole organ that fits. The donor would have to match your blood group and general size. If you are small it is possible to give you part of a liver like the living donor liver transplant surgery but with a cadaveric donor.

Patients that are Hepatitis C or Hepatitis B positive may receive an organ from a donor with the same virus. The liver is screened for cirrhosis, and only used if it is cirrhosis free. This means that the outcomes after transplant are the same as for an organ without the virus, because removing the diseased liver does not rid the patient of the virus, so it can reoccur in either case. Please discuss this with your hepatologist if you have further concerns.

Living Donor Liver Transplant:
This procedure involves a healthy person or live donor having part of their liver removed in the operating room and then having that piece of liver immediately placed into the recipient in another operating room next door. There is a booklet of information provided to you with much more information about living related liver transplant.

How do you feel about organ donation? How has this experience changed you thoughts about organ donation? What do you tell other people about organ donation?

Where do I go after surgery?

After surgery you will be taken to the Intensive Care Unit (ICU). The nurses in the ICU will care for you and all your tubing. Yours responsibilities are:

1. To follow the instructions of your nurse and physical therapist.
2. To practice deep-breathing and coughing techniques, changing position in bed and keeping your arms and legs mobile.
3. To ask for medication when you are in pain.
4. To write and signal your wishes since you will not be able to speak with the breathing tube in.

Where do I go after ICU?

After you are stabilized and the breathing tube is removed you will be sent to the transplant unit. You will be weak, but will gradually resume an active role in caring for yourself. You will be taught to take your own medications and to recognize the signs of infection and rejection. You will attend physiotherapy and occupational therapy every day. You may have already begun to sit-up in bed or transfer to a chair when you were in the ICU. Your therapist will show you the best way to move to reduce pain and be safe.

You will go home when:

1. You have learned how to take your own medications.
2. You are able to recognize the signs of infection/rejection.
3. You are physically stable.

TIME TO GO HOME

Medications

You will be on a number of medications when you leave the hospital. At home, you will continue taking most of the medicines you began taking in the hospital after the transplant surgery, especially the anti-rejection medications. These medications, called immunosuppression or anti-rejection drugs, are to help protect your new liver from your own immune system. You will probably have to take one or more of these drugs for the rest of your life, in addition to other medications. You will have antibiotics to help protect you against infection. You will need medication to protect your stomach from ulcers caused by other medication. Your body may need some help for a while in getting rid of water or keeping up essential nutrients like potassium and magnesium or iron.

You need to be an expert in the medication you are expected to take. You must know your dose and what times you take it and what it does for you. The coordinator will teach you these things while you are in hospital in addition to helping you through the discharge teaching manual. Once the coordinator has reviewed the medications with you, you will be expected to start giving them yourself, with the nurses' help, while you are still in hospital. This will help you to get used to the number of new medications before you go home and have to do it by yourself.

How will you manage your care at home for the first couple of months?

You are responsible for taking the medications that have been prescribed for you. You should talk to your physician, pharmacist, transplant nurse, and/or coordinator to understand fully:

The name and purpose of each medication
When to take each medication
How to take each medication
How long to continue taking each medication
Principal side effects of each medication
What to do if you forget to take a dose
When to order more medication so it doesn't run out
How to order or obtain medications
What to avoid while taking medications

Rejection

Rejection occurs when your body identifies your transplanted organ as foreign and attempts to get rid of it. It may happen at any time. It is very important to

watch for the signs of rejection so that the doctor can treat it quickly, it may be as simple as increasing the dose of anti-rejection medication.
The signs of rejection are:

- jaundice (yellowing of eyes or skin)
- fever
- loss of appetite
- nausea and vomiting
- extreme fatigue
- pain in the right lower rib area

You may have noticed some or all of these signs before having the transplant. Since liver rejection is a process that starts out with only mild changes, some people reject their liver and feel fine. You will notice the signs when the changes are more advanced. Liver rejection is usually detected through blood tests before you have any symptoms. If you have a rejection and it is treated successfully, your new liver will repair itself and the damage will not be permanent.

Report signs of rejection to your Transplant Coordinator right away!

Infection

An infection occurs when your body is invaded by very small organisms like bacteria, a virus or a fungus. The organism multiplies very quickly and can cause damage to your body. After having a transplant, you will be less able to fight infection because of the medications you are taking. The signs of infection include:

- Temperature greater than 37.5°C
- sweating, chills and shaking
- pain
- redness and swelling around the incision
- change in color, amount and odor of your urine, stool or phlegm
- shortness of breath
- open sores that have drainage
- burning when you pass urine

Report signs of infection to your Transplant Coordinator right away!

What can I expect after discharge?

The first few months after transplant are the most critical. This is when the rates of rejection and infection are at there highest. It is important that you remain in the Edmonton area so you have quick access to the necessary expertise. Clinic visits and blood work will now be part of your life. The coordinator will review the signs of infection and rejection, the medications you are on and how to contact the Transplant Team. You will need to attend physiotherapy until you and your therapist are confident that you are strong enough to manage your daily activities.

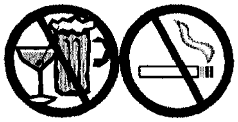
What occurs at clinic?

You will attend clinic once a week when you are first discharged. Your clinic visits will become less frequent as your overall health improves. Eventually you will be seen in the transplant clinic once a year. When you come to clinic in the Liver Transplant Office a coordinator and a physician will see you. If you are unable to attend clinic, please call the Transplant Office in advance.

What should I do when I go home?

After transplantation you will continue to improve. How well you do is up to you. To assist your recovery you must follow a few basic rules:

- Follow the instructions of your doctors and transplant coordinators.
- Eat a balanced diet and ensure that you maintain a healthy weight.
- Find a healthy balance between exercise and activity; follow the guidelines provided by your therapists and doctors.
- Do not drink alcohol.
- Do not smoke or chew tobacco.
- When traveling always carry enough medication for unexpected delays.
- When going out into the sunshine, wear a hat and blocking sunscreen; do not get sunburnt. The medications necessary to prevent rejection of your liver will increase the risk of skin cancer from exposure to sunlight or ultraviolet radiation in tanning booths.
- Take good care of your teeth. See a dentist regularly. Before any major dental work, call your doctor.
- Sexual activity is permitted as long as it does not cause discomfort.
- Do not get pregnant in the first year after transplant and consult your doctor before attempting to become pregnant.



- Have regular yearly physicals including breast examinations and pap smears or prostate examinations from your family doctor.
- Do monthly breast or testicular self-examinations.

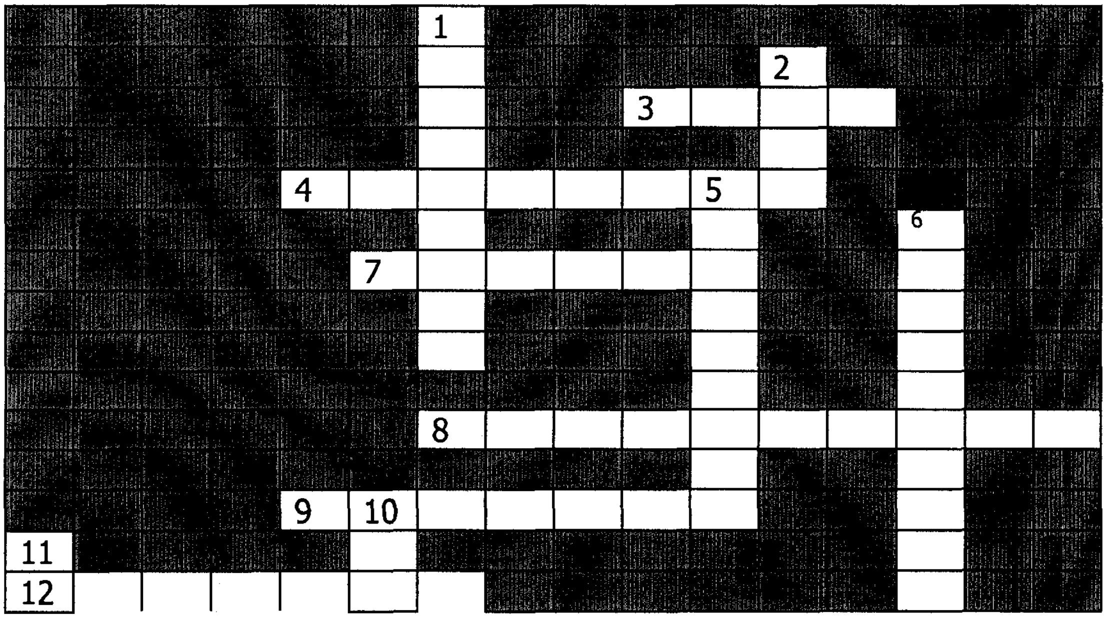
LIVER TRANSPLANT CROSSWORD PUZZLE

Across

3. What you must do for 18-24 months before you receive a transplant
4. Yellow skin & eyes
7. What does the liver do to get rid of toxins
8. Organ exchange
9. These swollen blood vessels can cause you to vomit blood
12. Fluid in belly

Down

1. High levels of ammonia can cause this
2. Helps us absorb fat
5. Scar tissue in the liver is called ---------
6. A bracelet you wear to let emergency medical staff know you have had a liver transplant
10. Fat soluble vitamins
11. You need to rent one of these



SUPPORT SYSTEMS

Suggested Reading Lists and Web sites

"Caring for Donor Families: Before, During and After" by Raelynn Maloney and Alan Wolfelt, Release Date: September, 2001, ISBN: 187965122X, Publisher: Center for Loss & Life Transition

"Organ Transplants Making the Most of Your Gift of Life: " by Robert Finn and Reg Green

Release Date: 15 February, 2000, ISBN: 156592634X, Publisher: Patient-Centered Guides

"I'm Glad You Are Not Dead: A Liver Transplant Story" Second Edition by Elizabeth Parr Release Date: 20 January, 2000, ISBN: 0965472817, Publisher: Journey Pub

www.thanks100timesover.ca use the hero icon to find more stories from transplant recipients as well as stories from donor families about their transplant experiences.

www.members.shaw.ca/jpdonald read about Jeff Donald's transplant experience at the U of A.

www.kurz-family.com follow the links to read Rachel's story of her transplant experience.

www.transweb.org is based at the University of Michigan and has a full time editor responsible for maintaining the web site.

www.trioweb.org Transplantation and organ donation information and resources for transplant candidates, recipients, donors, and their families.

www.tppp.net This stands for the Transplant Patient Partnering Program. This site is sponsored by Roche pharmaceutical company. It has information about most organ transplants.

Transplant Buddies – A program to help liver transplant candidates and previous liver transplant recipients meet and share experiences. Contact the Canadian Liver Foundation. In Edmonton the number is 444-1547 or anywhere in Canada call toll free at 1-800-563-5483.

How To Reach The Transplant Team

To reach any of the team members call the Liver Transplant Secretary at 780-407-1184. Ask for the person you are seeking and the secretary will direct your call. For clinic appointments call the receptionist at 780-407-3796. For urgent matters only, after business hours call the University of Alberta Hospital at 780-407-8822 and ask for the Transplant Coordinator on call.

If the situation is an EMERGENCY, call 911 and take an ambulance to the Hospital.

IMPORTANT PHONE NUMBERS

University of Alberta Hospital Liver Transplant Program PHONE: (780) 407- 1184,

FAX: (780) 407-1198

Coordinator

Name:

Phone:

Family Doctor

Name:

Phone:

Gastroenterologist

Name:

Phone:

Social Worker

Name:

Phone:

Dietician

Name:

Phone:

Physiotherapist

Name:

Phone:

Pharmacist

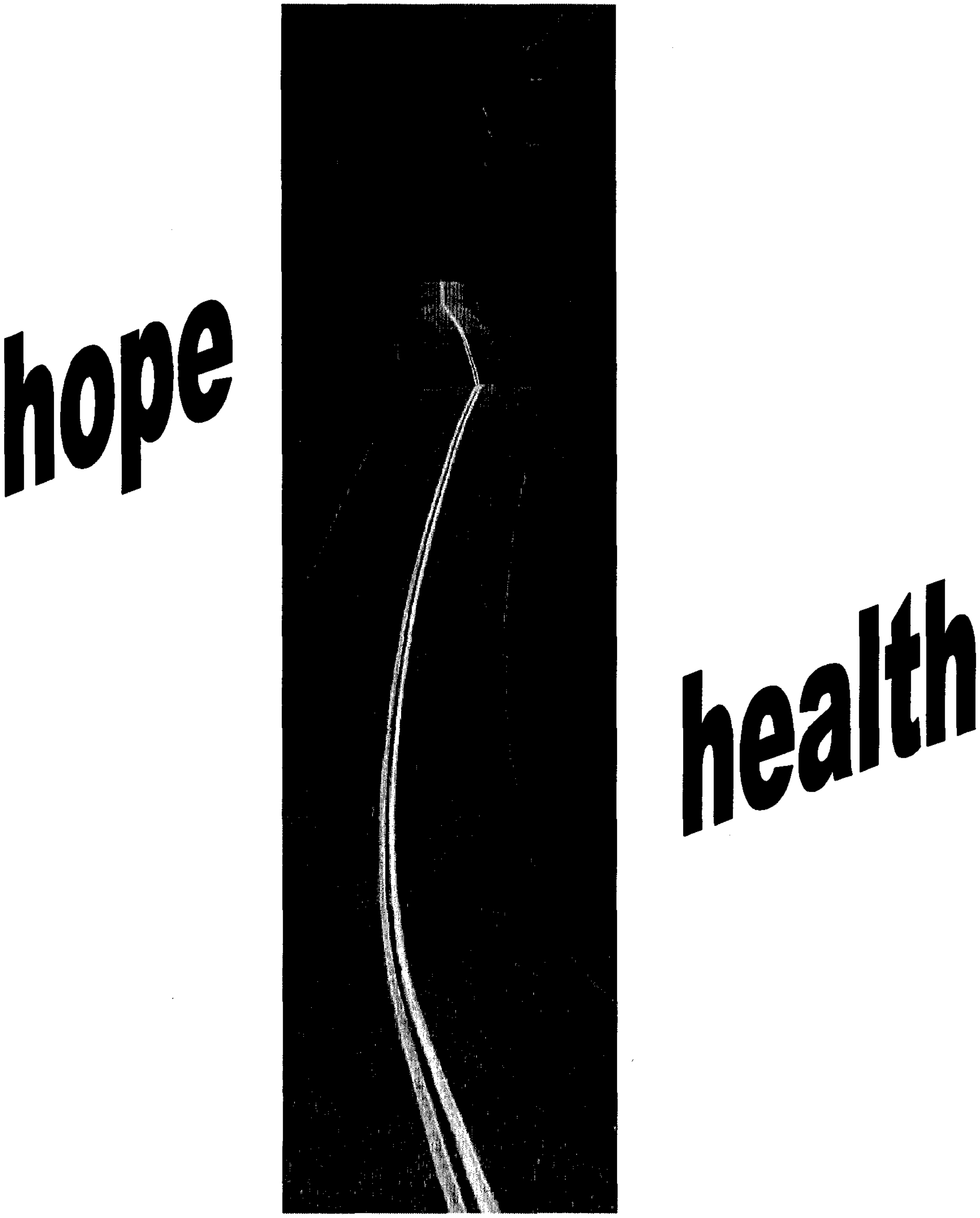
Name:

Phone:

The liver transplant program at the University of Alberta celebrated 10 years of success in 1999. A team of doctors, nurses, social workers, dietitians, occupational and physical therapists and a dedicated clerical staff have made us one of the most recognized centers for transplantation in Canada. As the new millennium unfolds, patient care remains our focus. New techniques and drugs will be trialed to determine how they can help us to help our patients and improve upon the successful job we already do.

Appendix B – Manual with Stories, Experimental Condition

Liver Transplant
Pre-op Teaching Manual



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This manual is based on the work of dedicated medical professionals, past and present, associated with liver transplantation. *Prepared by the University of Alberta Liver Transplant Team. Last revised 2003*

INTRODUCTION

The purpose of this handbook is to introduce you and your family to the **University of Alberta Hospital Liver Transplant Program.** Your physician has referred you to the program because you have a terminal liver disease. Here we will provide you with information about the process of organ transplant to help you to prepare for the procedures involved.

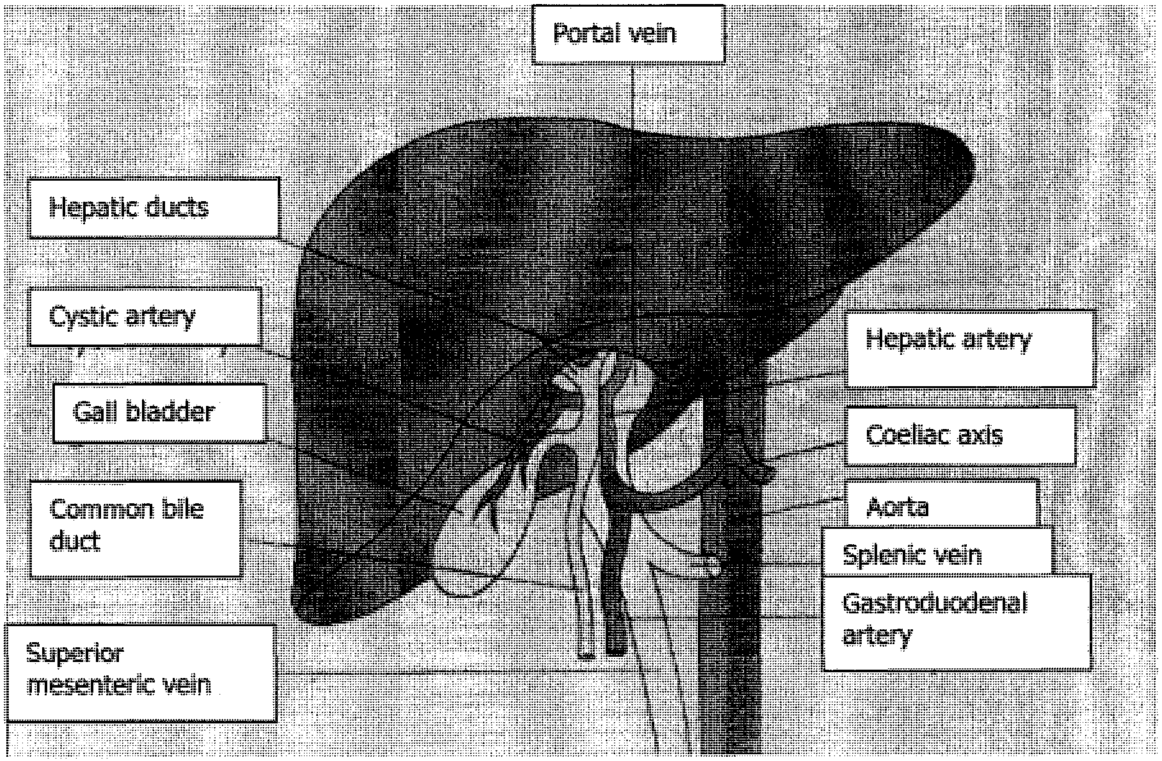
Transplant is not suitable for everyone nor is it a "cure" so that you never have to worry about your health again. You will be exchanging your diseased organ for a healthy one that can give you a longer and a better quality life. Transplant requires a lifetime of commitment to medical treatment including medication every day and ongoing follow-up. A transplant occurs when a healthy organ is removed from one person and placed in another person whose organ has failed. The person who gives an organ is called a donor. There are two types of donors: a living person and a person who has died. The person who receives the organ is called a recipient – YOU!

When you have finished reading this manual you will be able to:

- Understand the symptoms of liver disease
- Know when to go to the emergency room or doctor
- Understand how the transplant process works
- Find the information you need to cope with your illness

The first part of this teaching manual talks about liver disease and the things that can make you ill and perhaps cause your death. The second part of the manual talks about liver transplant and how it works. It is our hope that by the time you reach the end of this manual you will know what you can expect on your transplant journey.

The Liver



WHAT DOES THE LIVER DO?

The liver is the largest organ in the body weighing 1200-1500 grams. It is located on the right side of the abdomen, to the right of the stomach, behind the lower ribs beginning 1-2 cm below the nipple line. Blood is supplied by the portal vein and hepatic artery. It is made up of several segments but can be divided into two lobes, the right and left. The liver serves as the body's factory and waste processing system. A few of the main functions of the liver are to:

5. Help to absorb food and change food into nutrients the body can use. For example, the liver makes bile to help breakdown fats and fat soluble vitamins such as vitamins A,D,E,K and allow their absorption.

6. Store fats, sugars, iron, and vitamins for later use by the body.

7. Filter the blood to remove substances like drugs, alcohol and other toxins, that can be harmful to the body.

8. Make proteins needed for normal blood clotting, normal blood pressure and helping the immune system.

WHAT ARE THE SYMPTOMS OF LIVER DISEASE?

The three life threatening symptoms of end-stage liver disease are:

4. vomiting of blood or passing black stools
5. mental confusion that leads to coma
6. abnormal build-up of fluid in the abdomen that becomes infected

**** Go to the nearest emergency if you become confused, vomit up blood, pass black stools, or develop a fever. A physician must assess you if any of these occur.*

There are non-life-threatening symptoms experienced by people with End-Stage Liver Disease.

- yellowing of eyes and skin is called jaundice (jon-dis)
- severe itching
- dark tea-coloured urine
- grey or clay-coloured stools
- easy bruising and tendency to bleed
- malnutrition, nausea, diarrhea
- muscle wasting
- a tendency to osteoporosis
- difficulty sleeping

There are about 100 causes of cirrhosis (sir-ro-sis) but once you have cirrhosis the experience of everyone is much the same. Cirrhosis is simply scarring in the liver that makes the liver unable to do any of the jobs it is supposed to do. Cirrhosis also leads to some mechanical problems like: high blood pressure in the veins around the liver. This is called "Portal Hypertension". This high blood pressure is the root cause of vomiting blood from varicose veins in your throat and the fluid collecting in your belly called ascites (ah-site-ees).

Varices (var-i[t]-sees) are varicose veins that form in the blood vessels upstream from the liver. When the liver is cirrhotic it is very hard and rigid, more like a rock than the sponge it should be. The Portal Vein is the main blood supply to the liver. When blood flow to the liver is restricted, the blood pressure in the portal vein becomes very high and the blood vessels upstream become swollen with blood. These blood vessels in the esophagus and stomach can leak blood causing chronic anemia or they can break and bleed suddenly causing the person to vomit blood or pass blood in their stool. Any change in pressure from coughing, straining, or lifting can cause the blood vessels to break. The spleen is also upstream and can become very large and damage some of your blood cells called platelets. The high pressure in the portal vein also causes the build up of fluid in the abdomen or ascites.

Confusion or encephalopathy (in-sef-a-lop-ithy) can be caused by the failure of the liver to remove ammonia and other toxins from the blood.

TREATMENTS FOR LIVER DISEASE

There is no cure for End-Stage Liver Disease. It is a slippery slope that starts with cirrhosis. Some people are able to live well with cirrhosis for many years but once they start to have one or more of the life-threatening symptoms of liver disease it is time to think about Liver Transplant. There are many ways to manage the symptoms of someone with End Stage disease. All treatment should be under the supervision of a Gastroenterologist or Hepatologist, specialist doctors who treat liver disease.

How has liver disease affected your role in the family?
How does that make you feel?

What do other people say about living with End Stage Liver Disease?

JB, transplanted September 2000

My health was going downhill daily. Six to eight litres of fluid were being drained from my abdomen every three weeks. I had lost fat and muscle to the point where my body was always cold in the heat of a very warm summer. I could not write my name legibly. Many a night was spent pacing the floor to fight cramps in my feet and legs. My liver was close to shutting down. My wife was my 24/7 care giver keeping me alive both mentally and physically. One morning in a fit of belligerency four paramedics had to drag me from the home to hospital as I suffered a bout of encephalopathy.

RH, transplanted December 2001

I had been in the hospital for approximately six months prior to transplant. With the severity of the liver disease, humanly speaking I was fading away. The last few days before the transplant I found that my hearing, sight, ascites and attention span were becoming unbearable. There was turmoil within me because of the unknown. I didn't know how this would turn out. It was totally in God's hands.

LIVER TRANSPLANT

STEPS TO TRANSPLANTATION

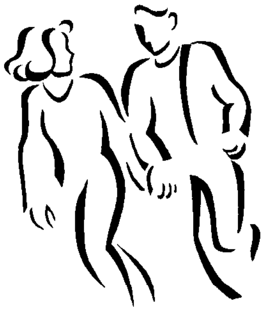
Referral
↓
Assessment
↓
Listing for Transplant
↓
Waiting
↓
Phone Call (Organ Available)
↓
Admitted to Hospital
↙ ↘
Dry Run **Liver Transplant**

This section is about the transplant process. This is what happens step by step when you have been referred to the transplant program until after you have your transplant.

TRANSPLANT REFERRAL

Your family physician or a specialist has referred you to the transplant program because you have end-stage liver disease. Other treatments are not available to you any longer and so transplantation becomes the only treatment left. Liver transplantation is a treatment for liver disease; it is not "a cure". You will not be able to live a "normal" life after. You will have to take medication every day, you will have to have tests to see how your new liver is working, and you will have to visit the doctor on a regular basis. You can have a good life, you just have to learn to pay attention to your health. A referral is made to one of the liver specialists on the transplant team, called hepatologists. The hepatologist decides if you meet the requirements for liver transplant as developed by the transplant team. The hepatologist then passes your information on to the assessment coordinator who will arrange and complete your assessment.

SUPPORT



Learning that you may need a transplant is very stressful. For this reason it is mandatory that Liver Transplant Candidates have a support person throughout the whole process of transplantation. There is a lot of information given to the family about liver disease and transplantation, about the surgery and medications. The process of transplantation can be overwhelming and we believe a support person makes a difference to the outcome. A support person is anyone you choose who will be there for you during **ALL** phases of transplant, both before and after. The support person should be able to provide you with the physical and emotional support needed at these different times.

You could choose someone like your spouse, a family member, or a good friend. Choose someone who knows you well and is willing to make the long-standing commitment. It is expected that the assessment will take from two to six weeks to complete. Once it is complete the decision is made about whether you should be on the transplant list. The waiting time for transplant is up to one and one half years. You will need your support person to encourage you, listen to your concerns, and help you cope with emotions. Also, after transplant they will be responsible for helping you learn medications and routines, keep appointments, and be there for you while you recover. **After transplant we expect the patient and support person to stay here in Edmonton for two months before allowing them to return to their community.**

What have other people said about their support?

JB, transplanted September 2000

I cannot envision going through a transplant ordeal without a constant caregiver. J was my inspiration throughout. She took me everywhere when I could not drive. She gave me the strength to dream about a healing when death seemed so close. Her resolve never wavered as doubts crept into my psyche through the ordeal.

AP, transplanted January 2000

In total it took nine months from beginning to end before we were able to go home. A strong will to live and the support of my family, friends and the professionals made it worth while. But the love and patience of my support person, my husband, gave me the biggest reason for living. Without him, I know I wouldn't be here today.

TRANSPLANT ASSESSMENT

The assessment is an information gathering stage. The purpose of the assessment is to help us determine if a liver transplant is the best option for your medical condition. You and your support person will meet with various members of the transplant team and you will have several tests done. Your appointments will take at least 3-5 days to complete. Accommodations can be arranged for patients who do not reside in the Edmonton region by notifying the Liver Transplant secretary at (780) 407-1184.

It is very important to remember that no decisions about listing you for transplant will be made until ALL the information requested is received and the whole team has had a chance to meet and discuss your case. Your transplant coordinator will notify you of our decision once we have determined whether or not transplantation is an option for you.

All persons with a history of drug or alcohol use will be required to have an assessment by their provincial addictions counseling association, in Alberta this is AADAC. The transplant program expects that you will take advantage of any counseling or follow up that they recommend. You may be required to sign a contract with the liver transplant program stating that you will not drink alcohol or use illegal street drugs. This contract also allows the liver transplant program to do blood tests to check for alcohol or drugs in your blood stream. **If the test is ever positive you will be taken off the waiting list for transplantation.**

You will be required to stop smoking before you are able to go on the waiting list for transplantation.

"Who is who" on the Transplant Team?

The Transplant Team is a multidisciplinary group made up of doctors, nurses, social workers, physiotherapists, occupational therapists, dietitians and pastoral care personnel. Together we will determine the best course of action based on your particular circumstances. During your assessment you will see the following team members:

6) **Transplant Surgeon**
   The transplant surgeons perform both adult and pediatric liver transplants at the University of Alberta Hospital. One of these doctors will meet with you

and your support person to discuss your medical condition and explain your surgical options. A physical examination is required.

7) Transplant Hepatologist
A hepatologist is a doctor who specializes in liver diseases. One of the transplant hepatologists will meet with you and your support person to discuss your medical condition. A physical examination is required.

8) Transplant Coordinator
The transplant coordinator is a registered nurse with expertise in the area of liver transplantation. You are assigned a coordinator when the referral is made. She/He will teach you how to monitor your general health and will answer most of your questions about transplantation. Your coordinator is involved in all aspects of your care and is your primary contact with the liver transplant program.

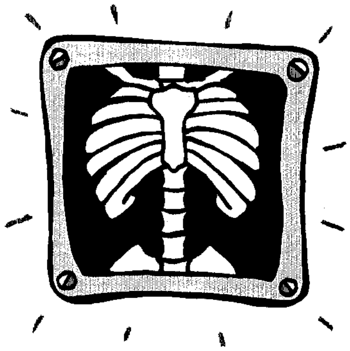
9) Social Worker
The social worker provides emotional support and financial counseling to you and your family. He /She can assist you in coping with the change experienced by you and your family as a result of your illness or the transplant.

10) Dietitian
The dietitian will meet with you and your support person to review what you normally eat and counsel you on how to improve your diet before the transplant.

Diagnostic Tests

Several tests will also be done during this time. These include:

1. Ultrasound of your liver
2. Chest x-ray
3. Bone Density Scan
4. Blood work
5. Urine tests
6. Sputum tests
7. Electrocardiogram



It may be decided that you have other medical or social needs that need further evaluation. You may be referred for additional tests and/or consultations with other health professionals, like a heart or lung specialist. Your transplant coordinator will arrange any additional appointments required and tell you of the bookings.

The following letters are also included in your information package:

2) **Dental letter** – Dental problems can be a source of infection after a liver transplant. Make an appointment with your dentist as soon as possible to assess your dental health. Take the letter from the transplant office with you when you go for your appointment and give it to your dentist. The dentist must fax a copy of any findings to your coordinator once completed.

3) **Tuberculosis letter** – Tuberculosis (TB) can be activated or reactivated by the anti-rejection medication after a liver transplant. Make an appointment at the nearest community health clinic for a TB test and take the letter from the transplant office with you. The nurse will administer a small amount of fluid under the skin of your forearm. You must return 2 days later so she/he can check the site for any signs of reaction. The nurse must fax a copy of your TB results to your coordinator once completed.

While you are at the community health clinic you may ask about getting all your vaccinations up to date. The transplant team recommends that you get the vaccine for Hepatitis A and Hepatitis B before transplant.

Remember that no decision about listing you for transplant will be made until ALL the information is received and discussed by your transplant team.

You are NOT on the transplant list when you finish your appointments at the end of the week.

LISTING FOR TRANSPLANT

How is the Decision Made to Transplant?

It will take some time for all the information to be collected and reviewed. Once this is done, your case will be presented to the entire transplant team. The transplant team meets every Thursday to discuss patients. All the people you meet during your assessment are present at the meeting. The transplant team reviews information from the various examinations and tests. If they feel a transplant is your best treatment option, you are placed on the transplant list.

People are listed according to three criteria:

4) blood group
5) donor weight range (size)
6) status

There are four separate liver transplant lists, one for each of the four blood types (A, B, O, and AB). The surgeons will determine the weight range of acceptable donors for you. This allows them to match the size of the liver to your body. At the time of listing each patient is assigned a "status", which refers to how sick you are. If you are not in the hospital you will be the same status as everyone else who is not in hospital. **If you are admitted to hospital please let us know.** People who are urgently ill will be transplanted before others on the list no matter how long you have been on the list.

When the decision is made to list you, your coordinator will contact you and confirm that you still want to proceed with the transplant. You will then be instructed to rent a pager and contact your coordinator with all your contact numbers. If it is felt that a transplant is NOT in your best interest or you decide that you are not ready to accept the responsibilities of transplant, your referring doctor will be contacted. They will be told of the decision and appropriate follow-up will be arranged.

Pagers

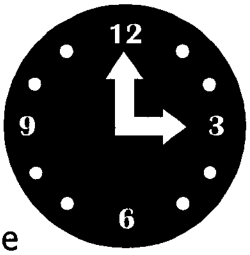
In case an organ becomes available, you must be able to be contacted 24 hours a day. You must rent a pager from a local telecommunications company and tell your coordinator the number. This makes it easier for the transplant team to contact you when an organ becomes available. You will keep the pager until you come into the hospital for your transplant.

WAITING AND LEARNING ABOUT TRANSPLANTATION

How long do I have to wait for an organ?

There is no way to tell how long you will wait for an organ but the average waiting time is 12-18 months. When a suitable organ becomes available, a transplant coordinator will call you. Your most important responsibility during the waiting period is to stay as healthy as possible. Try to stay as active as you can with regular walks and/or light exercise. This will help you recover faster after transplant. If you have any questions, the coordinator can refer you to a physical therapist for more information. A healthy diet, exercise, and enough rest are essential. It is very important that you follow the advice you are given by your transplant team.

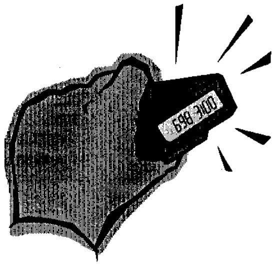
Planning Ahead



Now is also the time to plan ahead. Remember, if you do not live in Edmonton both you and your support person are required to stay here for at least 2 months after your surgery. You need to think about how to manage your personal affairs while you are away from home (i.e. paying the bills, caring for children/pets, watering the plants, etc.). Talk about these things with your family or friends and make a plan. After your surgery is not the right time to have to worry about these kinds of things – your focus then needs to be on getting well.

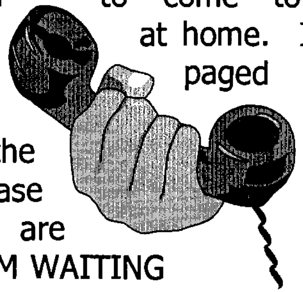
Once you receive the call that a liver is available for you, you will not have much time to prepare. Here is a checklist guideline to help you when you get the call:

- In advance, pack a small suitcase including slippers and loose clothing. Have a list ready for the items you will need to pack at the last minute.
- Bring a small amount of cash in case you need to take a taxi to the hospital and have some loose change available for phone calls.
- Designate someone to look after your household responsibilities like watering plants, caring for pets, picking up mail, and paying bills.
- Make a list of people you will need to notify and their phone numbers. Use this to create a fan-out plan - where you will call 1 person who will call 2 people and, they, in turn will call 2 people until everyone is aware. You may be asked to stay off the phone for a period of time once you receive the initial call, therefore, the less you have to do the better.
- Bring a book or some magazines, a Walkman and tapes, some stationary, and maybe a favourite reminder of home. The more you feel at home and have things to do, the faster your recovery will seem.
- Consider getting a calling card if you are from a distant town or city within Alberta or from another province.



WHAT HAPPENS WHEN A LIVER BECOMES AVAILABLE?

The Phone Call



The Recipient transplant coordinator will contact you to come to the hospital. The first attempt will be made to reach you at home. If the coordinator cannot reach you at home you will be paged on your beeper. When your beeper sounds, go to the nearest phone and call 780-407-8822 and ask for the "***Recipient Transplant Coordinator on call.***" Please identify yourself by name and by the organ you are waiting for. EXAMPLE: MY NAME IS JOE GREEN I AM WAITING FOR A LIVER TRANSPLANT AND MY BEEPER JUST WENT OFF. The coordinator on call may not be your coordinator so may not be as familiar with your name.
Sometimes your beeper will go off and we are not calling you. The beeper may go off when the batteries run low or when you are near equipment that sends out a signal over the airwaves. We will simply tell you there is no transplant happening and please check your battery.

If we have a liver available for you we will tell you so and ask if you are ready to go ahead with transplantation at this time. If you are ready to go ahead we will give you instructions about what time to be at the hospital admitting department and what time we think the operation will be.

REMEMBER:

- Do not eat or drink ANYTHING after receiving the call.
- Please drive carefully. It is a good idea for a support person or someone else who is close to drive.
- If you are from BC, NWT, SK, MB, or far distances within AB **and** if time is a factor, air ambulance may be arranged to bring you to the hospital. You may need money for a taxi to and from the airport.
- Bring the bag you have packed, your patient teaching booklets, a list of medications you are presently taking, your pager, and a cellular phone if you have one.
- Go to the Admitting Department when you arrive at the University of Alberta Hospital between 6:30 a.m. and 8:00 p.m. After 8:00 p.m. and before 6:30 a.m. please go to the Registration area in the Emergency Department.

- Tell the Admitting Department clerk your name and that you are here for a Liver Transplant. They will be expecting you and will tell you what to do next. Have your Health Care number ready (AB, BC, SK, NW or NWT).

The Transplant Coordinator will likely meet you in the Admitting or X-ray Department. If not, you will be directed to the appropriate Nursing Unit to be prepared for surgery.

Sometimes people feel a little stunned when they are called to come for transplant, especially in the middle of the night. Some have reacted by saying, "No, I'm not ready for transplant!" when that is not what they intended at all. If that should happen when we call you for transplant, the coordinator will give you ten minutes to think it over and will then call you back. If you still say no, you will not come off the list but we will be talking to you and your family doctor over the next few days about your commitment to transplant.

How did other people feel when called for transplant?

DS, transplanted October 2002

My call came on Friday, October 11, 2002 at 6:15 p.m.; it was my transplant coordinator saying to me "I have a new liver for you." I thanked her and told her I would be at the hospital right away. After I hung up, I must admit, I sat down and sobbed for about two minutes – I was so fortunate.

RH, transplanted December 2001

It was 2:30 in the morning the next day when my nurse came in and told me there was a possibility that a liver may be available for me. It was an emotional time, and it was hard to believe after such a long time waiting that getting a liver may be a reality.

At the Hospital

When you arrive at the hospital, you will first go to Admitting during the day or the Emergency registration desk at night. From there you will go to the Radiology and Diagnostic Imaging department for your chest X-ray. Then you will be escorted to the nursing station and your preparation for surgery will begin. It will consist of a history and physical examination, blood and urine tests, skin preparation (shave your body hair from chin to knee and shower with special soap), insertion of an intravenous line, and an enema. You will be asked to sign consent forms for:

- Orthotopic liver transplant
- Multiple liver biopsies

The transplant coordinator will explain these to you in detail. Feel free to ask any questions you may have. After you are prepared for surgery, you should try to rest until they are ready for you in the Operating Room. Quite often the time of the operation is a guess so it may be sooner or much later than we originally tell you. At any time the surgery may be cancelled. Be prepared for a dry run and make plans for getting home again if this happens.

What happens in the Operating Room?

When you are taken into the Operating Room, the anaesthetist will ask you a few questions and then administer medication to put you to sleep. After you are asleep, the following tubes will be inserted:

- Intravenous lines - these lines give you fluid, salts, sugar and medications
- central lines - these lines measure the volume of fluids in your body
- arterial line - this line measures your blood pressure
- endotracheal tube (breathing tube) - assists your breathing, it is attached to a breathing machine (a ventilator)
- nasogastric tube - drains the contents of your stomach
- foley catheter - drains urine from your bladder

Following surgery, you may also have some additional tubes:

- Bile tube (T or C tube) - this tube drains bile and is used to x-ray your bile ducts. Bile ducts drain bile from your liver
- Jackson Pratt drains - drains blood and body fluids from around the surgical area. You may have two or more of these tubes.

What Happens during the surgery?

During your operation, the surgeon will remove your diseased liver and reattach a new liver at 5 sites. They are as follows:

1. Suprahepatic vena cava
2. intrahepatic vena cava
3. Portal vein
4. Hepatic artery
5. Common bile duct

The first four sites are blood vessels, the fifth site drains bile from the liver.

Staples will hold your incision together. As it heals, your nurse will remove them. A large bandage called a "dressing" will cover the incision. The dressing serves as a protection and will be changed by the nurses.

There are a few types of transplants possible.

Cadaveric Transplant:

This means the family of a person who has died has given their loved one's organs as a gift of life. This would mean that you would get a whole organ that fits. The donor would have to match your blood group and general size. If you are small it is possible to give you part of a liver like the living donor liver transplant surgery but with a cadaveric donor.

Patients that are Hepatitis C or Hepatitis B positive may receive an organ from a donor with the same virus. The liver is screened for cirrhosis, and only used if it is cirrhosis free. This means that the outcomes after transplant are the same as for an organ without the virus, because removing the diseased liver does not rid the patient of the virus, so it can reoccur in either case. Please discuss this with your hepatologist if you have further concerns.

Living Donor Liver Transplant:

This procedure involves a healthy person or live donor having part of their liver removed in the operating room and then having that piece of liver immediately placed into the recipient in another operating room next door. There is a booklet of information provided to you with much more information about living related liver transplant.

How do you feel about organ donation? How has this experience changed you thoughts about organ donation? What do you tell other people about organ donation?

What have other people said about their donor experiences?

DM, transplanted March 2001

I came across the following words shortly after my transplant and they have been very thought provoking to me. Dr. James Burdick, from the John Hopkins Hospital said, "Transplantation is much more than a surgical procedure, it is a profound connection with another Human Being."

CHP, transplanted October 2002

My donor family will always be very special to me. During the difficult and emotional time they faced in the loss of a loved one, their strong, caring and giving nature allowed them to make a decision that allowed others to benefit from their loss. That they thought of the possibility of helping others in a time of grief is surely a sign of the generosity and kindness of the human spirit. They will be forever in my thoughts and a constant reminder that no matter how things turn out in my life, they have shared a most precious gift with me, a gift that cannot be appreciated by words alone. And for that, I am truly blessed.

CW, transplanted September 2001

I was a perfect candidate for a live related donor (LRD) and we now had to find a donor. The first place we looked was to my immediate family and my brother was a perfect match. Going through knowing that this person so close to you is putting his life on the line for you brings so many emotions flooding in that waiting on that list was a much better feeling. I would not change my decision of going with the LRD because I would not be here today to tell of my experience and I want to help other patients by giving them hope that life will go on. I feel bad for my brother that he had a harder time than I did and still I wish that it would have went smoother for him but I know in my heart that he would not have changed his decision. We have a wonderful bond and matching scars now that will forever remind us of what we have endured, I am very proud.

Where do I go After Surgery?

After surgery you will be taken to the Intensive Care Unit (ICU). The nurses in the ICU will care for you and all your tubing. Yours responsibilities are:

5. To follow the instructions of your nurse and physical therapist.
6. To practice deep-breathing and coughing techniques, changing position in bed and keeping your arms and legs mobile.
7. To ask for medication when you are in pain.
8. To write and signal your wishes since you will not be able to speak with the breathing tube in.

Where do I go after ICU?

After you are stabilized and the breathing tube is removed you will be sent to the transplant unit. You will be weak, but will gradually resume an active role in caring for yourself. You will be taught to take your own medications and to recognize the signs of infection and rejection. You will attend physiotherapy and occupational therapy every day. You may have already begun to sit-up in bed or transfer to a chair when you were in the ICU. Your therapist will show you the best way to move to reduce pain and be safe.

You will go home when:

4. You have learned how to take your own medications.
5. You are able to recognize the signs of infection/rejection.
6. You are physically stable.

TIME TO GO HOME

Medications

You will be on a number of medications when you leave the hospital. At home, you will continue taking most of the medicines you began taking in the hospital after the transplant surgery, especially the anti-rejection medications. These medications, called immunosuppression or anti-rejection drugs, are to help protect your new liver from your own immune system. You will probably have to take one or more of these drugs for the rest of your life, in addition to other medications. You will have antibiotics to help protect you against infection. You will need medication to protect your stomach from ulcers caused by other medication. Your body may need some help for a while in getting rid of water or keeping up essential nutrients like potassium and magnesium or iron.

You need to be an expert in the medication you are expected to take. You must know your dose and what times you take it and what it does for you. The coordinator will teach you these things while you are in hospital in addition to helping you through the discharge teaching manual. Once the coordinator has reviewed the medications with you, you will be expected to start giving them yourself, with the nurses' help, while you are still in hospital. This will help you to get used to the number of new medications before you go home and have to do it by yourself.

How will you manage your care at home for the first couple of months?

How have others felt about going home?

DS, transplanted October 2002
Friday I was discharged – glad to be coming home, a bit frightened, but confident in my recovery. My coordinator had drawn up a daily routine for me, which greatly helped. I carefully followed the routine set out for me. So here I was, home within less than a week – well five hours less – with a new liver and a second chance.

AP, transplanted January 2000
There seemed to be no end to the extra expenses at times, lodging, food, some of the exorbitant high cost of drugs even with drug plan coverage. The worry of trying to deal with someone taking care of our home. We met wonderful people with same problems, we helped one another. A family like bond occurred. I would not of gone to my appointments/physio but for my husband who did exercises right along with me, of course he got trim. Some days I was very uncooperative, but he always had a smile, a touch or kind word for me.

You are responsible for taking the medications that have been prescribed for you. You should talk to your physician, pharmacist, transplant nurse, and/or coordinator to understand **fully:**

The name and purpose of each medication
When to take each medication
How to take each medication
How long to continue taking each medication
Principal side effects of each medication
What to do if you forget to take a dose
When to order more medication so it doesn't run out
How to order or obtain medications
What to avoid while taking medications

Rejection

Rejection occurs when your body identifies your transplanted organ as foreign and attempts to get rid of it. It may happen at any time. It is very important to watch for the signs of rejection so that the doctor can treat it quickly, it may be as simple as increasing the dose of anti-rejection medication.
The signs of rejection are:

- jaundice (yellowing of eyes or skin)
- fever
- loss of appetite
- nausea and vomiting
- extreme fatigue
- pain in the right lower rib area

You may have noticed some or all of these signs before having the transplant. Since liver rejection is a process that starts out with only mild changes, some people reject their liver and feel fine. You will notice the signs when the changes are more advanced. Liver rejection is usually detected through blood tests before you have any symptoms. If you have a rejection and it is treated successfully, your new liver will repair itself and the damage will not be permanent.

Report signs of rejection to your Transplant Coordinator right away!

Infection
An infection occurs when your body is invaded by very small organisms like bacteria, a virus or a fungus. The organism multiplies very quickly and can cause damage to your body. After having a transplant, you will be less able to fight infection because of the medications you are taking. The signs of infection include:

- Temperature greater than 37.5°C
- sweating, chills and shaking
- pain
- redness and swelling around the incision
- change in color, amount and odor of your urine, stool or phlegm
- shortness of breath
- open sores that have drainage
- burning when you pass urine

Report signs of infection to your Transplant Coordinator right away!

What can I expect after discharge?

The first few months after transplant are the most critical. This is when the rates of rejection and infection are at there highest. It is important that you remain in the Edmonton area so you have quick access to the necessary expertise. Clinic visits and blood work will now be part of your life. The coordinator will review the signs of infection and rejection, the medications you are on and how to contact the Transplant Team. You will need to attend physiotherapy until you and your therapist are confident that you are strong enough to manage your daily activities.

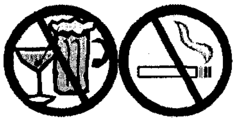
What occurs at clinic?

You will attend clinic once a week when you are first discharged. Your clinic visits will become less frequent as your overall health improves. Eventually you will be seen in the transplant clinic once a year. When you come to clinic in the Liver Transplant Office a coordinator and a physician will see you. If you are unable to attend clinic, please call the Transplant Office in advance.

What should I do when I go home?

After transplantation you will continue to improve. How well you do is up to you. To assist your recovery you must follow a few basic rules:

- Follow the instructions of your doctors and transplant coordinators.
- Eat a balanced diet and ensure that you maintain a healthy weight.
- Find a healthy balance between exercise and activity; follow the guidelines provided by your therapists and doctors.
- Do not drink alcohol.
- Do not smoke or chew tobacco.
- When traveling always carry enough medication for unexpected delays.
- When going out into the sunshine, wear a hat and blocking sunscreen; do not get sunburnt. The medications necessary to prevent rejection of your liver will increase the risk of skin cancer from exposure to sunlight or ultraviolet radiation in tanning booths.
- Take good care of your teeth. See a dentist regularly. Before any major dental work, call your doctor.
- Sexual activity is permitted as long as it does not cause discomfort.
- Do not get pregnant in the first year after transplant and consult your doctor before attempting to become pregnant.



- Have regular yearly physicals including breast examinations and pap smears or prostate examinations from your family doctor.
- Do monthly breast or testicular self-examinations.

Transplant Works!

HD, transplanted October 1989
I was the third person to have a liver transplant at the University of Alberta Hospital. I am now able to travel, spend time playing with our grandchildren, work in my flower beds, sew for my family and myself, do volunteer work in the community and just enjoy life to the fullest. Before my transplant, I would have been terrified to speak publicly to a group of people. Now, I enjoy talking to school children, service clubs, ladies church groups, etc. explaining the importance of transplantation and signing your donor card. I guess when you mention long-term success – I am experiencing it every day.

LIVER TRANSPLANT CROSSWORD PUZZLE

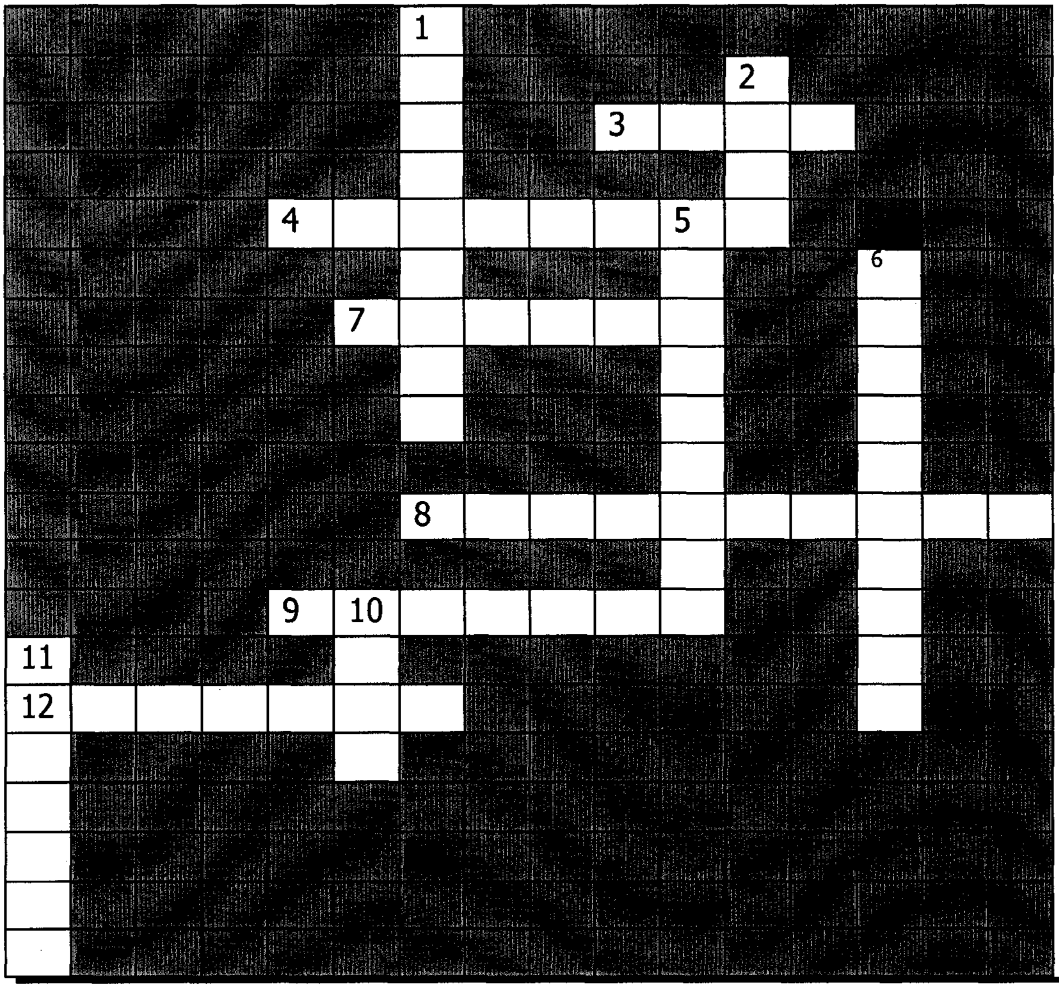
Across

3. What you must do for 12-18 months before you receive a transplant
4. Yellow skin & eyes
7. What does the liver do to get rid of toxins
8. Organ exchange
9. These swollen blood vessels can cause you to vomit blood
12. Fluid in belly

Down

1. High levels of ammonia can cause this
2. Helps us absorb fat
5. Scar tissue in the liver is called ---------
6. A bracelet you wear to let emergency medical staff know you have had a

liver transplant
10. Fat soluble vitamins
11. You need to rent one of these



SUPPORT SYSTEMS

Suggested Reading Lists and Web sites

"Caring for Donor Families: Before, During and After" by Raelynn Maloney and Alan Wolfelt, Release Date: September, 2001, ISBN: 187965122X, Publisher: Center for Loss & Life Transition

"Organ Transplants Making the Most of Your Gift of Life: " by Robert Finn and Reg Green Release Date: 15 February, 2000, ISBN: 156592634X, Publisher: Patient-Centered Guides

"I'm Glad You Are Not Dead: A Liver Transplant Story" Second Edition by Elizabeth Parr Release Date: 20 January, 2000, ISBN: 0965472817, Publisher: Journey Pub

www.thanks100timesover.ca use the hero icon to find more stories from transplant recipients as well as stories from donor families about their transplant experiences.

www.kurz-family.com follow the links to read Rachel's story of her transplant experience.

www.transweb.org is based at the University of Michigan and has a full time editor responsible for maintaining the web site.

www.trioweb.org Transplantation and organ donation information and resources for transplant candidates, recipients, donors, and their families.

Transplant Buddies – A program to help liver transplant candidates and previous liver transplant recipients meet and share experiences. Contact the Canadian Liver Foundation. In Edmonton the number is 444-1547 or anywhere in Canada call toll free at 1-800-563-5483.

How To Reach The Transplant Team

To reach any of the team members call the Liver Transplant Secretary at 780-407-1184. Ask for the person you are seeking and the secretary will direct your call. For clinic appointments call the receptionist at 780-407-3796. For urgent matters only, after business hours call the University of Alberta Hospital at 780-407-8822 and ask for the Transplant Coordinator on call.

If the situation is an EMERGENCY, call 911 and take an ambulance to the Hospital.

IMPORTANT PHONE NUMBERS

University of Alberta Hospital Liver Transplant Program PHONE: (780) 407- 1184, FAX: (780) 407-1198

Coordinator

Name:

Phone:

Family Doctor

Name:

Phone:

Gastroenterologist

Name:

Phone:

Social Worker

Name:

Phone:

Dietician

Name:

Phone:

Physiotherapist

Name:

Phone:

Pharmacist

Name:

Phone:

Appendix C

Patient Education Questionnaire

Thank you for agreeing to be part of a study looking at patient teaching manuals in the liver transplant program. Your participation will help others to get teaching materials designed to help people understand liver transplant better.

Please fill out the following information, answering the questions the best way you can. This is not a test. Your transplant coordinator and doctor will never see your personal responses. They will only ever get the completed graphs and tables informing them of trends seen in many people's responses.

Demographic Information

Name: ________________________________ Sex: M F

Date of birth: (day/month/year) ____________________

Last grade completed in school? _______________

How long have you known you might need a liver transplant? _______

Satisfaction

How satisfied are you with the information in the teaching manual? Please circle the number that best reflects how satisfied you are. Please answer using a scale of 1 to 10, 1 means you are not satisfied at all, 10 means you are very satisfied.

1. Not satisfied at all 1 2 3 4 5 6 7 8 9 10 Very satisfied

Confidence

We would like to know how confident you are in doing certain activities. For each of the following questions, please circle the number that equals your confidence that you can do the tasks regularly at the present time.

Manage Disease

2. Having an illness often means doing different tasks and activities to manage your condition. How confident are you that you can do all the things necessary to manage your condition on a regular basis?

____

not at all totally

confident 1 2 3 4 5 6 7 8 9 10 confident

3. How confident are you that you can judge when the changes in your illness mean you should visit a doctor?

____

not at all totally

confident 1 2 3 4 5 6 7 8 9 10 confident

4. How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor?

____

not at all totally

confident 1 2 3 4 5 6 7 8 9 10 confident

5. How confident are you that you can reduce the emotional distress caused by your health condition so that it does not affect your everyday life?

____

not at all totally

confident 1 2 3 4 5 6 7 8 9 10 confident

6. How confident are you that you can do things other than just taking medication to reduce how much your illness affects your everyday life?

____

not at all totally

confident 1 2 3 4 5 6 7 8 9 10 confident

Control/Manage Depression

7. How confident are you that you can keep from getting discouraged when nothing you do seems to make any difference?

____

not at all totally

confident 1 2 3 4 5 6 7 8 9 10 confident

8. How confident are you that you can keep from feeling sad or down in the dumps?

____

not at all totally

confident 1 2 3 4 5 6 7 8 9 10 confident

9. How confident are you that you can keep yourself from feeling lonely?

____

not at all totally

confident 1 2 3 4 5 6 7 8 9 10 confident

10. How confident are you that you can do something to make yourself feel better when you are feeling lonely?

____
not at all totally
confident 1 2 3 4 5 6 7 8 9 10 confident

11. How confident are you that you can do something to make yourself feel better when you are feeling discouraged?

____
not at all totally
confident 1 2 3 4 5 6 7 8 9 10 confident

12. How confident are you that you can do something to make yourself feel better when you feel sad or down in the dumps?

____
not at all totally
confident 1 2 3 4 5 6 7 8 9 10 confident

You were given a great deal of information about transplantation.

13. What did you find most helpful?
14. Why was it helpful?
15. After you read the information, did you use any of the suggested resources?

Appendix D – Ethics Approval

213 Heritage Medical Research Centre
University of Alberta, Edmonton, Alberta T6G 2S2
p.780.492.9724 (Biomedical Panel)
p.780.492.0302 (Health Panel)
p.780.492.0459
p.780.492.0839
f.780.492.7808

HEALTH RESEARCH ETHICS APPROVAL FORM

Date: December 2007

Name of Applicant: **Dr. Beverley Williams**

Organization: **U of A**

Department: **Nursing**

Project Title: **The Value of Adding Personal Stories to Printed Education Materials for Liver Transplant Recipients**

The Health Research Ethics Board (HREB) has reviewed the protocol for this project and found it to be acceptable within the limitations of human experimentation. The HREB has also reviewed and approved the subject information letter and consent form.

The approval for the study as presented is valid for one year. It may be extended following completion of the yearly report form. Any proposed changes to the study must be submitted to the Health Research Ethics Board for approval. Written notification must be sent to the HREB when the project is complete or terminated.

Special Comments:The Research Ethics Board assessed all matters required by section 50(1)(a) of the Health Information Act. Subject consent for access to identifiable health information is required for the research described in the ethics application, and appropriate procedures for such consent have been approved by the REB Panel.

JAN 11 2008

Dr. Glenn Griener, PhD
Chair of the Health Research Ethics Board
(B: Health Research)

Date of Approval Release

File Number: B-020108

UNIVERSITY OF ALBERTA

Capital Health
Edmonton and area

CARITAS HEALTH GROUP

Appendix E – Telephone Script

Hello, my name is Bernadette Dodd. I am a nurse doing research with the transplant team at the University of Alberta. I understand you are interested in hearing about the research we are doing with the teaching information that we send out to patients. Do you have time for me to talk to you about that now?

The transplant program gives out written teaching material to people referred for transplantation. We know how to organize information to make it readable. We don't know much about how to make information useful to the reader.
We are asking you to participate in a study to compare two teaching manuals. You will get one of the two manuals to read in the mail with your assessment appointments. Then you will be asked to fill out a questionnaire and mail it to me in the envelope supplied. You have an equal chance of getting either teaching manual. Your doctor and your transplant coordinator will not know which teaching manual you received. When you come for your assessment appointment, your coordinator will give you the manual that is usually given to new patients to read.
There are no risks to participating in this study. The information is the same in both manuals. Some of it is presented in a different form.
Participating in this study will not affect your assessment or listing for transplant in any way. I am not part of your personal transplant team.
Your personal information will be kept confidential. Any information collected about you during this study will identify you by number only. Any report published about this study will not identify you by name.
You are free to withdraw from the research study at any time. Your medical care will not be affected in any way. If the study is not carried out or if it is stopped at any time, the quality of your medical care will not be affected. If we learn anything from this study which could affect your decision to continue, you will be informed right away.
Do you agree to be part of this study?

IF YES: Thank you very much for your time, you will be helping other people who need a transplant to get the best teaching manual that the program can provide. I will send your package out in the mail tomorrow. Please mail the questionnaire back to me within a month. I will call you again in a month if I haven't heard from you. Thanks again and goodbye.

IF NO: Thank you very much for your time. The secretary will be mailing your appointments for your transplant assessment within the next few days. Goodbye.

Appendix F - Information Sheet for Participants

The Value of Adding Personal Stories to Printed Education Materials for Liver Transplant Recipients

Principle Investigator: Bernadette Dodd RN, MN(c)

Background:

The transplant program gives out written teaching manuals to people who need a transplant. We know how to organize information to make it clear and logical. We don't know much about how to make information important to the reader.

Purpose:

We are asking you to take part in a study to compare two teaching manuals. The researcher is exploring how to make information important to the reader.

Procedure:

Participating in this study will involve reading the teaching manual you receive in the mail. Then you will fill out a survey and mail it to the researcher in the envelope supplied.

You have an equal chance of getting either teaching manual. Your doctor and your transplant coordinator will not know which teaching manual you receive. When you come for your liver clinic appointment, your coordinator will give you the manual that is normally given to new patients to read.

Possible Benefits:

You will be helping other people who need a transplant to get the best teaching manual that the program can provide. It may help you and others like you to feel more confident about the transplant experience.

Possible Risks:

There are no risks to being in this study. The information is the same in both manuals. Some of it appears in a different form. Being in this study will not change your assessment or listing for transplant.

Confidentiality:

Your personal information will be kept private. Any information collected about you during this study will identify you by number only. Any report published about this study will not identify you by name. By finishing and returning the survey, you are agreeing to be in this study. The researcher does not access your medical information.

Voluntary Participation:
You are free to leave the research study at any time. Your medical care will not change in any way. The quality of your medical care will not change if the study is not finished or if it is stopped at any time. If we learn anything from this study which could change your decision to continue, you will be notified quickly.

Contact Names and Telephone Numbers:
If you have concerns about your rights as a member of this study, you may contact the Patient Relations Office of Capital Health (780 482-8080). You could also contact Dr Christine Newburn-Cook at the Faculty of Nursing (780 492-5929)

Please contact the person identified below if you have any questions or concerns:
Bernadette Dodd RN, MN(c), Transplant Coordinator Phone: 780-407-1861
After Hours: 780-407-8822 ask the switchboard to page the investigator by name.