

LITTLE BOOK

Of

NARRATIVES

Compiled by - HELEN STRANO

CATEGORIES

- “Advice from Post Transplant Patients”- Jenny Watson
(Clinical Nurse Consultant)
- “Medications” - Dr. Simone Strasser
(Medical Team)
- “Dietary Needs” - Helen Vidot
(Dietitian)
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- “Body Image” - Helen Strano
(Social Work Student UNSW)
- “Spirituality for Life” - Rev. Rex Matthews
(Minister)

This is a Narrative Booklet comprised of interviews with post transplant patients, their partners and families. It contains comments on various issues, with additional remarks by professionals.

The patients interviewed were both male and female and ranged in age from 18-65+. They had been transplanted as early as six weeks to fourteen years ago. Their comments and reactions to transplant are recorded under the various categories with added comments by professionals within the RPA National Liver Transplant Unit.

I would like to acknowledge and thank all those who participated in this project. Especially thanks to all the post transplant patients, their partners and families who took the time to answer questions and whose names cannot be recorded due to confidentiality.

Also a special thanks to a pre-transplant patient whose comments gave the spark of life to begin this booklet.

The aim of this booklet was to aid, assist and help pre- transplant patients, partners and families to travel lighter on their journey of transplantation.

ADVICE FROM POST TX PATIENTS

CLINICAL NURSE CONSULTANT – comments by Jenny Watson

“I see the patients and their families/carers when they come to sign the consent for transplant. I explain what will happen to them when a liver becomes available and they have to come to RPA to be prepared for their operation. I explain why it is important that they do not have anything to eat or drink before the operation and why it is necessary to shave the hair from their abdomen. Even the unpleasant procedures are described. But the benefits to the patient are explained so that they are able to tolerate it when it happens. I have found patients, although still apprehensive when they come to theatre, have benefited from knowing what will happen to them once they come through the door and leave their relatives. The relevance of irritating questions such as, “are you allergic to anything?”, being asked a lot of times is explained. The incision is discussed and the drains are shown to them. It is often upsetting to see drains in the Intensive Care Unit if they have not been previously explained and seen. The skin clips and the dressings are shown. Also the time immediately post operation in ICU is discussed and what drains and equipment will be attached to the patient and what their function is.

I emphasise to the families/carers the importance of their own self-care and resting while the operation is in progress so that they are able to provide support for the next few days without tiring themselves out too much.

We discuss the blue book and anything that the patients want to know. I give them my card and encourage them to ring. I tell them that they should remain positive and take the roller coaster for the next few days one at a time.

Having a transplant is like being on the bottom rung of the ladder and the only way to go is up...

“[The advice I would give to patients about to undergo transplant] is it’s very important that they sort out anything that is necessary as

regards to their will and [what is] important before they get to their operation. When they go for their operation they need to be focused on what is going to happen to be positive.” *(Male, mid 60’s)*

“[It’s] very important to have the greatest family support and not be afraid to ask a lot of questions. Make sure that you get answers to your questions so that you have a clear understanding of what you are letting yourself go into.” *(Male, late 30’s)*

“It’s not as dark as it is painted and having seen both sides of it now you only go forward, you never go back ... I said to my parents two days after the transplant if I died now it was worth every bit of it to have the clear mind that I had for those two days.” *(Male, late 30’s)*

“[The education day] is already in place for pre transplant people. It’s a daunting task but there is light at the end of the tunnel ... its well worth undertaking. You reach the lowest depths before you can come up. There is a lot of counselling needed and a lot of support from your family and friends.” *(Male, late 40’s)*

“We appreciate life more, we appreciate each other more and we appreciate the kids more ... life is something we take for granted and once you’ve been through this you realise how lucky you are to be alive and have a second chance at life.” *(Partner of male, late 40’s)*

“Well it’s hard work, but it is worth it in the end. You’ve just got to stick with it. I have talked to a few people awaiting transplant and it really helps to treat each case as individual and answer their questions ... you have to be honest and straight forward. If it comes to how people feel emotionally, that really is something [individual]. I did find that patients are too afraid to ask questions, because they think that they will be seen as being stupid and I encourage people to ask as many questions as they like.” *(Female, early 20’s)*

“It’s going to be really tough, the first couple of weeks it’s going to be like living hell. It’s one of the worst experiences that I have ever gone through.” *(Male, early 20’s)*

“I think a few things that I found helped me were the love and support of your friends ... to have the confidence to connect with the clinic ... all

of us had little notebooks which we carried around with us and we wrote the questions down and had the confidence to ask ... because I like having the information I don't like being in the dark. I know the team does a lot to make you as well informed as you want to be [and] the blue book laid it all out. Sitting in the clinic waiting room and chatting with other people I had also a membership group. You had shared experiences, through the transplant clinic. There was also a Primary Biliary Cirrhosis (PBC) support group [that] had a newsletter, were on the web and you could communicate with one another.” *(Female, late 40's)*

“I remember how daunting it was at the time ... there is life after the operation.” *(Male, early 20's)*

MEDICATIONS

MEDICAL TEAM - comments by Dr. Simone Strasser

“It is really important that patients coming up for liver transplantation realise that they are going to be taking medications for the rest of their lives. Everyone has to be on immunosuppressive medications to prevent rejection of the new liver. The problem is that the drugs that are used frequently cause side effects and lead to complications that require even more medications. Particularly in the first few months it is not unusual to be on three different immunosuppressive drugs, one or two blood pressure drugs, antibiotics, antifungals, antivirals and treatment for diabetes. The good news is that as time goes by many of these medications can be reduced and even stopped.”

“[The medication and rejection] was fully explained and made clear to me ... but the medication makes it hard ... because sometimes I get the shakes really bad” *(Male, late 30's)*

“I have to [take] medication and that's a hassle ... [it has to be] at the same time each day, at 8'oclock in the morning and 8 o'clock at night. It also makes it difficult to remember to take medications as I am studying at TAFE at night.” *(Male, early 20's)*

“I had to take a lot of medications ... [such as] prednisone which gave me the usual moon face reaction ... I went through a number of bouts of rejection. I had steroids and rejection medications ... they warned me of all the side effects. But the only thing that I got was a headache and lack of sleep. I was lucky in that respect because I had talked to other people and they said that they had hallucinations”. *(Male, early 30's)*

“I have had to pop anything from ten to fourteen pills in my mouth ... [people] just sort of looked at me in wonder ... but it is just part of what goes with the territory.” *(Male, early 20's)*

“I was on about twelve different medications but now I am only on two. I was a bit worried about the prednisone ... it had a lot of side effects....

It makes you put on weight, that's not very good for your body image and self esteem. But now I have lost a lot of weight and the medication doesn't bother me, it keeps me alive so I don't worry about having to take it every day." *(Female, early 20's)*

"The prednisone was making my face round and I was a bit yellow after the transplant but now I am getting back to where I was. I wear a bikini now and I am not bothered about my scar." *(Female, early 30's)*

"I have been on tablets my whole life because I have been an asthmatic so being on medication is just a way of life for me ... there are side effects to most medications. Prednisone causes puffiness and depression and osteoporosis and other medication causes mushy brain, you forget a lot. You also get the shakes from time to time ... but that's manageable they're all things that you can cope with." *(Female, early 30's)*

"It's always a juggling game of finding the right combination [of medication]. I've been on medications for as long as I can remember ... since I was about eight and I'm slowly coming off them. But I'm still on immuno-suppressants. I am managing that ... I'm on calcium and Vitamin D every three months." *(Male, early 20's)*

"I take several medications [including] insulin. As a result of the transplant I became [a] diabetic" *(Male, early 20's)*

"I didn't find much difficulty with the medications until I had the transplant. Post transplant I had quite heavy dosages of anti rejection medication. Side effects have not been too difficult to live with although the Tacrolimus has given me a tremble. Hopefully that will disappear as they bring the dosage down. Initially the high dosage of prednisone makes you puff up like a puffy frog ... but that now seems to have lessened and I don't think that I have the pharmaceutical effects". *(Female, late 40's)*

DIETRY NEEDS

DIETITIAN – comments by Helen Vidot

“Nutrition is an important aspect of liver transplantation. There are three phases of nutrition during the transplant journey. Pre- transplant. Post operative phase and long term post transplant.

- 1. Pre - transplant phase: This can be very difficult for some patients for a number of reasons- appetite may change, tastes may change, and they may have ascities which leads to reduced stomach capacity. Also salt and fluid may be restricted. There is a need to eat a lot of food which is high in calories and protein. Patients may need to use supplements to increase their intake.*
- 2. Post - operative phase: The restrictions are lifted but patients are still required to eat a high calorie and protein diet. This can be difficult as there are taste changes and nausea. In this phase there is a lot of nagging by dietitians, nurses and doctors. At this time patients need high protein and high energy to promote wound healing, as they are often malnourished when they come to transplant. The high energy and protein drinks are on the ward to supplement intakes. If the patients can't get enough calories and protein, then we will start feeding via a nasogastric tube. There are some basic food safety information issues that patients are given. Families are encouraged to bring in patient's favourite foods to help increase their intake.*
- 3. Post - transplant phase: You don't need to eat a lot at this stage but once taste buds return it is difficult to stop eating. Patients tend to put on a lot of weight around 2-3 months after transplant. They may develop diabetes and high cholesterol levels. They may also struggle to keep their weight down. Exercise and modifying their diet is very important.”*

“My mum brought in pasta and stuff like that so that I could get back to eating normal ... I remember when I first came out of the transplant operation I couldn't eat, every time I'd eat or even drink I'd throw it up, that was really bad. Special drinks were given to me to help [supplement my diet]. Eventually I did start eating.” *(Male, early 20's)*

“My mum and dad brought in food. I had frozen meat pies, breakfast cereals, vegetables and biscuits. Also packets of cup-a-soup. You are encouraged to eat whatever you can.” *(Female, early 30’s)*

“If you find something that makes you sick ...avoid it.” *(Male, early 20’s)*

“[I’ve had] no real diet restrictions only I have to be more careful with food. Soft cheeses and salamis you probably can’t have but generally it’s pretty much open.” *(Male, early 30’s)*

“I used to love raw things ... like oysters, sushi, smoked salmon and olives. Anything now in brine or anything that is smoked or any meat not properly cooked even medium steaks have to be well cooked ... I have just come back from nearly four weeks in China and I [had to] double boil [everything even] water when I was brushing my teeth. I made one mistake initially by just popping grapes into my mouth before realising had they been washed. But to think that I have done that travel and been able to get through it without a lot of gastric problems has given me confidence.” *(Female, late 40’s)*

“I am now a diabetic as a result of the transplant ... I don’t eat anywhere as [much] sugar as I used to. The transplant recipient’s diet can be exactly the same as it was before with one exception. If you had a transplant because of [cirrhosis] definitely steer clear of alcohol” *(Male, late 30’s)*

“I know I’m not supposed to eat soft serve ice-cream from McDonald’s but I do anyway.” *(Female, early 20’s)*

FEELINGS

PSYCHIATRIST - comments by Dr. Rob Gribble

"Liver Transplant is a remarkable medical process. Emotionally it offers hope at a dark time and it does offer the potential of improved health and longevity. The exchange on offer is that of taking on the "illness" of having a liver transplant in place of the illness that led to liver failure. This is usually a pretty good deal, but there is no doubt that liver transplantation is difficult, dangerous and without guarantees. It is always emotionally, as well as physically challenging. Each step in the ongoing process presents different issues: the shock and disbelief of diagnosis; the apprehension, uncertainty and fear of waiting first for a decision and then for a donor; the alternating periods of confusion, drama, despair and relief during post operative recovery; the periods of anxiety, depression and uncertainty in the slow period of rehabilitation when, with the intensity abated, the challenge is of returning or at times re-creating a life "after transplant". Most people who get through the process describe it as one of the hardest times they have had. Most are pleased that they have done it - even though they are not always sure they would sign up again - and it is hard not to develop a great respect both for what people have to go through and for what they and their families, do."

"I was shattered [when diagnosed with liver disease] because initially we thought that it was just a series of strokes ... the second meeting I had with Professor McCaughan told me that I needed a transplant [because] my body was rejecting the liver. I was very shocked." *(Male, mid 60's)*

"I was shocked at the time because I was at school, I was about fourteen. I just went yellow. I wasn't sick or anything I just went yellow." *(Female, early 30's)*

"I really was faced with my own mortality. A very dangerous procedure that I was being faced with." *(Male, late 30's)*

"[When my partner was diagnosed I was] worried, scared, protective, every word that you can think of, so afraid that I was going to lose him."

When we came in to see Professor McCaughan we knew nothing about liver transplants. He examined [my partner and said] ‘yes we can do a liver transplant’. You have never seen two happier people walking along the passageway, we laughed, we cuddled we did everything.”

(Partner of male, mid 60’s)

“I was devastated; I thought it was a death notice that I was nearing the end of my useful life. [It] is very personal but you’ve got to share it with people because you feel very isolated. When you think that the only person it’s ever happened to is you.” *(Male, late 30’s)*

“I was very surprised [when first diagnosed]. It was only after I saw Professor McCaughan that he said it was ‘Hepatitis B that’s causing your problem’.” *(Male, mid 60’s)*

“I get a bit of depression sometimes and that’s hard. You get very down from the tablets [and] the side effects. You feel really low and really down. So I tend to go out more with friends and do things like that.” *(Female, early 30’s)*

“I was very lucky [that] I have very strong family support. We sat around, talked it through and given the alternatives there was only one way to go. I had every support in the world and we proceeded with [the transplant].” *(Male, late 30’s)*

“[My children] were so afraid [but] I could ring them at any time and they would be there. I am so proud of them. They were always happy when they came to visit [their father].” *(Partner of male, mid 60’s)*

“How am I going to live without him? We come from Tamworth, we had never heard of liver transplants before, it’s really quite frightening.” *(Partner of male, late 40’s)*

“I’m very happy now. We [now] have a good life together. We’ve learnt a lot through [transplant] and how to appreciate your life. You tend to take your health and everything for granted.” *(Partner of male, mid 60’s)*

“I was told that I had a life threatening illness and that the answer was possibly a liver transplant operation ... otherwise it was death ... at the time it was a shock ... [that] hit me tremendously. I think that if I didn’t

have very supportive friends and family it would have been a hard forty eight hours.” (*Female, late 40’s*)

FIRST MEMORY AFTER T/X

CLINICAL NURSE SPECIALIST - comments by Leonard Cox

“You will first experience the transplant nursing staff when you come up to the ward after your operation .The nurses are responsible for your daily care, they will assess and prioritise your needs .These needs include the dispensing of medication, administering intravenous fluids and the taking of observations that reflect your condition. We will relay any problems to the medical staff and do our best to assess your needs. But sometimes we may need you the patient to communicate to us what your needs are, as we are very busy and may not always be aware of other problems you may be experiencing. Communication is very important”.

“The first thing when I woke up was [I] immediately felt better. The pain factor and the recovery factor come into it later but I feel better every day. I have my ups and downs but initially the first thing you feel is better.” *(Male, late 40’s)*

“I remember trying to pull the tube out of my throat. I was in intensive care and someone was telling me that I was very sick.” *(Male, early 20’s)*

“I remember the ICU a little bit. There was an artery that couldn’t stop bleeding. That vision. I met a nurse and the surgeon. I remember asking for my parents.” *(Male, late teen’s)*

“The first thing that I remember was my uncle and aunty standing beside my bed. I remember having a tube down my throat I could feel that there were tubes all through my body.” *(Male, early 20’s)*

“[I remember] mum and dad because they were there. I was very groggy but pleased they were there.” *(Female, early 30’s)*

“[I first saw after the operation] my wife’s face as she was leaning over and smiling at me, wiping my face with a cloth.” *(Male, late 30’s)*

“My first memory [was of the doctor] he had a red beard and red hair and he was wheeling me down the hallway and they were bagging me with the bag ... I thought I had broken my leg and I was saying I can walk I’m fine there’s nothing wrong with me.” *(Female, early 20’s)*

“First memory coming out of the transplant was seeing the family around me. I tried to speak to them but not being able to. It [was also] my cousin’s birthday and I wanted to sing happy birthday. On the medical side the first thing that a doctor asked me was did I see the gates of heaven.” *(Male, early 40’s)*

“The first time that I came out of the operation my wife and daughter were at my bedside ... that was a wonderful feeling to see them both there. I remember my daughter saying ‘well you’ve come through this we’ve only got to get you well again now’.” *(Male, mid 60’s)*

HARDEST THING THROUGH THE PROCESS OF LIVER T/X.

SOCIAL WORKER – comments by Lee Bratel

“Living with illness is one of the hardest aspects of the transplant process. The effects are far reaching and naturally have implications for all those close to the person awaiting transplant. As this narrative booklet highlights, the transplant experience is unique and different for everyone. I am constantly amazed and impressed with the resilience of the human spirit and the strength that I see in people throughout this process.

Royal Prince Alfred Hospital (RPA) is the only hospital in NSW where liver transplants are performed, and people come from all over the state. People bring a variety of life experiences and knowledge, however if required the liver transplant (T/X) unit can assist people with additional support and information. For example, access to accommodation and travel options around the hospital. Also available is information relating to income support, multi-cultural services and leisure and recreational ideas. We also hold education days, where the highlight of the day is meeting individuals who have had the transplant and their partners and families.

“Before I had the transplant I was still doing normal teenage things ... all of a sudden from being normal to being confined to a bed was real bad.” *(Male, early 20’s)*

“I think that [the hardest thing] is pre-transplant. I found that I was so sick that I was unable to do many things that previously I was capable of doing.” *(Male, early 40’s)*

“I was in hospital five months before the transplant as I was so sick ... it was very hard to adjust going back outside the hospital with all the [surrounding] noises. I am not a really good patient I want to go home too early ... I annoy the hell out of the staff. I am a home body, Sydney

is very isolative to me because I am a country boy, but I can't complain about the hospital stuff.” *(Male, late 40's)*

“We have two boys, back then one was doing his HSC ... it was very difficult for them especially the 18 year old ... he passed out when he saw his father with all the tubes. It was a shock for him. *(Partner of male, mid 60's)*

“My children were really good but the rest of my family was no support to me. But my two sons were positive all the way.” *(Partner of male, late 40's)*

“The hardest thing for me was associated with finance. My manager was very co-operative with me and helped me in every sort of way [but] the senior management were looking to get rid of staff ... I happened to be one of them ... [and] I only had six years of superannuation to fall back on . I was hoping that I would be able to start work again after my transplant but I became sick again and I had to have a second transplant. I was on a disability pension and we were able to manage with it.” *(Male, mid 60's)*

“[My partner] was frustrated in not to be able to do things ... I wanted to do them [for him] because he couldn't. But I had to be careful how I did them so that he didn't get upset and frustrated. Looking after him wasn't hard.” *(Partner of male, mid 60's)*

“Accepting, the first thing was to accept that I needed the transplant and from being a person that is always in control to let go and let other people [help was the hardest thing].” *(Male, late 30's)*

“The worst time is pre liver transplant ... the waiting period ... recovery after transplant is bearable because you know that you are going to get better but the waiting period is definitely the worst part, because you have this death threat over your head and you are in pain.” *(Male, late 40's)*

The side effects of some of the tablets that [my partner] was taking [was] causing problems [for] him and that was hard [for me] to take [and] coming to Sydney 'cause I was terrified, I didn't know anyone ... having no family down here really terrified me. *(Partner of male, late 40's)*

“When I [had] my transplant my mum was by my side she took it the hardest. She is one of those parents that always worries. Everything is okay now. She works I go by myself to the doctors she doesn’t need to take time off work.” *(Male, early 20’s)*

“I get a bit of depression sometimes and that’s hard. The transplant itself at the time seemed hard but it’s not really because there are people there to help you. The nurses are very helpful and you have other patients to talk to that are going through the same thing.” *(Female, early 30’s)*

“The first month of waiting was difficult ... I waited by the phone. You think that the call can come any moment. Every phone call that you get you jump because you think that it might be the hospital. After about a month you think you have to let go of this it’s a life out there and try and return to normality. You do still live by the phone but you have a much more rational approach.” *(Female, late 40’s)*

LIFESTYLE CHANGES

CLINICAL NURSE CONSULTANT - comments by Margaret Gleeson

“My relationship with liver patients is an ongoing one. I like patients to feel secure in their relationship with the liver unit. We are here for the whole journey, not just part of it from pre transplant to long term post transplant. Through the whole process we are here. If you have any issues please feel free to call anytime if we can help you in any way.”

CLINICAL NURSE SPECIALIST - comments by Tina Van Weelderen

“Coming to terms with the reality of needing and receiving a liver transplant can be overwhelming. My role as ‘Clinical Nurse Specialist’ in liver transplant is to provide you and your family with maximum support and encouragement from the moment you are assessed, transplanted and after transplant. I work alongside Margaret Gleeson and our focus is to pay close attention to your emotional, physical and medical needs as well as the concerns of your partners and family.

Currently I’m in the process of organizing a liver support group for young transplant patients. There is already a liver support group in place but not one specific to the younger transplant patients.”

“My life style is totally different now before [transplant] I was lethargic and couldn’t do much, but now I can do things very actively. I’m three years post transplant. I can do most of the things a normal person can do and my lifestyle is a lot better.” *(Male, late 40’s)*

“We appreciate life more, we appreciate each other more and we appreciate the kids more, life is something we take for granted.” *(Partner of male, late 40’s)*

“Well it gave me my life, if I hadn’t had the transplant I would have been dead within four months.” *(Male, early 40’s)*

“[Transplant has] given me a great life. I am better now than I have been in the last twenty years. The clarity of my mind is incredible I spent three and a half years not knowing my name or where I was for ninety percent of the time now I can run around with the best of them.” *(Male, early 40’s)*

“Before the transplant by ten o’clock in the morning I had a shower made the bed and had breakfast and I was exhausted. But now I get up I mow the lawn, wash the car I do everything. I painted the gutters on the house and fixed my own car.” *(Female, early 20’s)*

“I’ve been studying and I am working full time now. I’m unbelievably fit compared to how I was before. Everything is going really well in that respect. I’ve been doing martial arts.” *(Male, late teens)*

“It’s hard, I can’t really explain ... it changes everything. I tried swimming ... even if I run I can’t muck around and kick the footy with my brother because I’ll get that puffed out.” *(Male, early 20’s)*

“I had some friends before the transplant but after transplant they disappeared ... the people that I knew from the church did stick by me. But through the transplant I made a whole new group of friends. People that I was in hospital with swapped phone numbers [with me] and have kept in touch. We all write to each other and try to get together once a year.” *(Female, early 20’s)*

“I had a boyfriend for a while after the transplant. I haven’t at the minute but that is my choice. I had to stop work twelve months before [transplant] because I was falling asleep at work, it wasn’t good. Now I go through the day and do stuff when I get home. I work five days a week from 9-5pm. I’m learning guitar. Also I do three hours traveling each day to work.” *(Female, early 20’s)*

“[I work] a couple of days a week, my energy is down. I will return it’s just my mobility; you’re still a little sore six weeks later, just a tiny bit not too much. I am moving quite okay six weeks after [transplant]. I’m

moving freely, I couldn't run, I tried yesterday. I have unlimited sick leave and full pay so work has been really supportive.” *(Male, early 20's)*

“I worked until about eighteen months before my transplant. It was in a very demanding role and highly pressured as a management consultant ... but I loved the work. I felt that while I was still able I was going to continue working. I found that I used to get very tired if there were early evening meetings, seminars or workshops that I went to. I found it extremely difficult to stay awake. But then people used to say to me well any normal person would have the same difficulty at seminars. In the nineteen months prior to t/x I couldn't get through the afternoon without having a nap of about hour. But my energy levels were not too bad until probably the last month when I really had to make an effort to drag myself around. I wondered about my quality of life and whether I would last until a donor of liver was found.” *(Male, late 30's)*

“I haven't returned to work mainly because when I left my job it was on my twentieth anniversary of working and I thought that I had put in a long enough stint ... socialising I have many supportive friends. I also found solace in my own solitude. I just loved moments to be on my own whether it was sitting reading or going for a walk. It brought some balance into my life from the pace that I used to go along with.” *(Female, late 40's)*

“Energy is fine. I am not working now and if I am going out at night I have a cat nap of about twenty minutes. Before the transplant I could sleep for an hour or an hour and a half without any trouble ... at night I would sleep anything from seven to nine hours. But now I think I have as normal a life as one can. I think that the only issue that I have to worry about is dietary issues.” *(Female, early 20's)*

“[Before transplant] I was doing my doctorate for my PhD studies at the University of Sydney. I was training for the Sydney soccer team and then one day someone pointed out to me that my eyes were yellow. Then I went bright yellow all over and six weeks later I was in hospital and three weeks after that I was in a coma. I had no inkling of the disease before that. [After transplant] I went back and completed my PhD. I even went skydiving six months after transplant. I play hockey and do lots of sports. I have now got a job in brain research. The job and the transplant link up.” *(Male, early 40's)*

“I always had a very close family. They were always there to help when I fell sick ... my sister was working in England and she flew back to be with me for the first month and a half after transplant. She is a physiotherapist [and] gave me twelve hours of torture a day. Probably helped my recovery not that I appreciated it at the time.” *(Male, early 30’s)*

“Instead of going to get a nice cup of coffee we ended up going to McDonalds to get a free cup of coffee ... [regarding financial lifestyle changes].” *(Male, mid 60’s)*

“Maybe slowed me down a bit [sex life], but not really. I am out chasing girls. I have a girlfriend on and off at the moment. But the transplant hasn’t interfered a great lot ... I wouldn’t go out with anyone that may be funny about it.” *(Male, early 20’s)*

“Well before the transplant [my] sex life wasn’t very good at all. My libido dropped to zero. Two weeks after the transplant I was still in hospital [and] I had the feeling that it would be coming back very quickly ... it did. Everything happened just as I got back out of hospital. Everything has been very successful over the last ten years.” *(Male, mid 60’s)*

“Before we realised what was happening I can honestly say I cried. Two weeks after [the transplant] I came into the hospital and he was lying there with a huge grin on his face, I said ‘What’s wrong?’ ‘Nothing’s wrong ... everything is working no problems at all [regarding sex life].” *(Partner of male, mid 60’s)*

“You just change your lifestyle ... the things that you like you either wait longer for or forget them ... you make do with what you’ve got.” *(Partner of male, mid 60’s)*

“My lifestyle has changed. It is much richer now than what it was before I don’t think that I take things for granted like I did before ... both my wife and I and the rest of the family really appreciate what we have.” *(Male, early 40’s)*

BODY IMAGE

*FINAL YEAR SOCIAL WORK STUDENT & AUTHOR of
NARRATIVE BOOKLET- comments by Helen Strano*

“Working on this project and interviewing post transplant patients I learnt that the whole process of liver transplant is an extremely personal one. The reactions and the effects can be individually unique, even though the process of transplant can be the same. Whether you are male or female, younger person or older person body image can play an important part. Also an important element is how we perceive ourselves and how others perceive us. Also an important element is how the transplant operation and scars are perceived for survival. Like the following quotes from post transplant patients, some hide their scar while others hold their scar as a ‘trophy’.”

I tried to hide [my scar] at first but now I figure that it’s something to be proud of ... I worked hard for that scar. Because of the shape of it they call it the ‘Mercedes Scar’. That’s my Mercedes. That’s my trophy.” *(Female, early 20’s)*

“I have never been very open about my operation but afterwards people have been great. Funny but everyone is fine with my scar and I am fine with it, it’s not a big issue. I may be a little bit paranoid but that is natural. My scar is only a half ‘Mercedes’, just a V.” *(Male, early 20’s)*

“I got teased a bit because I had a fat stomach when I was young. But then again every kid probably gets teased you know what I mean. So it was a bit hard like you know.” *(Male, early 20’s)*

“Scars never worried me ... I had a big scar from previous abdominal surgery, now there’s a lot of things from tubes and drainage. If I went swimming I am not going in a bikini competition anyway, I’d wear a one piece. My Mercedes scar hasn’t healed too well ... it’s healed inwardly so it’s like a tri shaped girdle and has left some flaps of skin. I am going to hopefully get that corrected in February next year.”
(Female, early 40’s)

“I find it hard when you do go with someone and you get into bed, you take your shirt off [and] they look at your scars [and] ask questions and stuff.” *(Male, early 20's)*

This booklet cannot be complete without the comments from Rev. Rex Mathews on spirituality; an area whereby people lean for support and coping mechanisms from their faith.

“When our life is endangered we have cause to reflect on the meaning of it all. Those with a traditional Christian upbringing and training turn to prayer and the ministry of their church. It seems to be helpful to both them and to non-churchgoing people to have a chaplain to talk to about the whole-of-life implications of their illness and its treatment.

Those who wish to have someone pray with them usually gain comfort and strength from a chaplain’s visit. Many who are agnostic or indifferent to religion also seem to find value in meeting a non judgmental chaplain who can identify with them and share even for a moment, their exploration of the dark corners of life. I sometimes find such meetings have been mutually very satisfying.

People vary greatly in their self-understanding, but the experience of liver transplant frequently leads to spiritual growth that makes for a more focused life in the future. Life is seen to be precious, and maintaining it often becomes a mix of determination and thankfulness. Both of these are in large measure directed to their medical team, but also their faith, which they see as the author and director of life.

All this applies equally to members of other faith communities. Jews, Muslims, Buddhists, Hindus, and those of other religions have similar experiences. At request the RPA chaplains will endeavour to contact qualified practitioners of their religion to visit them.