# CONTENTS

**Introduction** ...................................................................................................................................... 3

Section 1. How the liver works 4

Section 2. Assessment 6

Section 3. Nutrition in liver transplantation 9

Section 4. Information you might need 10

Section 5. Waiting for the transplant 12

Section 6. The right donor for you 13

Section 7. Preparation for surgery 15

Section 8. The transplant itself 16

Section 9. After surgery 18

Section 10. The immune system 19

Section 11. Infection 20

Section 12. Rejection 21

Section 13. Nutrition following liver transplantation 22

Section 14. Recurrence of original disease 25

Section 15. Drugs used in transplantation 26

Section 16. Patient information about drug trials 30

Section 17. Other post-transplant problems 31

Section 18. Outpatient visits 33

Section 19. Follow-up medical care 34

Section 20. Travel 35

Section 21. Vaccinations 36

Section 22. After discharge 37

Section 23. Common Tests Performed 41

Appendix A: Glossary 43

Appendix B: Copy of Consent Form 48

Appendix C: Contact numbers 49

The RPA Transplant Institute 50

Professional Websites 51
INTRODUCTION

This booklet has been designed to give you the information you and your family need to help you understand what is involved in liver transplantation. Various members of the Transplant Team will discuss this information with you. You are encouraged to ask questions or talk about any anxieties concerning any of this information. Our aim is to inform you about liver transplantation, so that you can make decisions about your treatment based on a good knowledge of the procedures, benefits and risks of liver transplantation.

The Liver Transplant Unit at Royal Prince Alfred Hospital was opened in 1986. Since then the Unit has performed more than 1500 liver transplants.

The general goals of liver transplantation are to prolong life and improve the quality of life while optimising the use of available liver donors. The liver transplant process continues to evolve and improve, demonstrating excellent survival rates, now over 90% one year patient survival rates.

Most diseases that end with liver failure have been successfully treated by liver transplantation. The most common indications for liver transplantation in adults are chronic hepatitis C, hepatitis B, nonalcoholic fatty disease, primary liver cancer (also known as hepatocellular carcinoma), primary biliary cirrhosis, primary sclerosing cholangitis, autoimmune liver disease and alcoholic liver disease. Other indications include metabolic liver diseases including haemochromatosis and Wilson’s disease, acute liver failure and massive liver enlargement due to a variety of causes.

Liver transplantation is usually recommended when there is a progressive deterioration in liver function. Liver failure is manifested by a number of physical and clinical symptoms eg: ascites (abdominal swelling due to fluid accumulation), variceal bleeding (bleeding from large veins in the oesophagus), hepatic encephalopathy (confusion and vagueness), or malnutrition and by changes in blood results that suggest deteriorating liver function (eg: low albumin, rising bilirubin and blood clotting abnormalities).
SECTION 1: HOW THE LIVER WORKS

Liver functions
The liver is the largest and one of the most complex organs in the body. It has many functions; some of the most important include:

- as a biochemical factory, it processes nutrients absorbed from the gut, and makes them available for use by other parts of the body
- the production of bile and its excretion into the intestine is important for absorption of fats and certain vitamins
- the production of blood factors including many of those necessary for blood clotting, and for normal body fluid balance
- the removal of toxins from the blood including those produced by bacteria in the gut and for the breakdown of alcohol and many drugs
- the removal of germs in the blood absorbed from the gut
- the processing of some hormones and vitamins

Liver disease
Unless liver damage is fairly severe or advanced, diseases of the liver are often “silent” and patients may be unaware of any problem.

The signs and symptoms of liver disease can be explained by considering the various liver functions. Different liver diseases may affect some functions more than others, resulting in variability between patients.

The impairment of processing of nutrients results in wasting of tissues, particularly muscle.

Impairment of the liver’s ability to excrete bile causes accumulation of its constituents including bilirubin pigment, responsible for the yellow discolouration of skin and urine (jaundice), and bile acids which may be responsible for the chronic itch suffered by some patients.

The decreased absorption of vitamin K and inadequate production of blood clotting factors causes easy bruising and bleeding, initially from the gums.

Massive bleeding from the gut is due, in part, to blood from the gut being diverted away from its usual course through the liver, to other channels in the oesophagus (gullet), which may rupture under pressure.

The decreased production of blood proteins involved in body fluid balance and the scarring of the liver contribute to the accumulation of fluid in the abdomen and legs.

The failure of the liver to deal adequately with poisons produced in the gut can cause drowsiness, forgetfulness, and lack of concentration, confusion and coma.

A damaged liver is also much slower at dealing with alcohol and drugs causing increasing sensitivity to their use.

Inadequate removal of micro-organisms or “germs” from the blood coming from the gut partly explains the increased incidence of serious infections in patients with liver disease.

Signs and symptoms of cirrhosis
As continued scarring and damage to the liver occur, the following signs and symptoms may appear:

- Loss of appetite
- Weight loss
- Jaundice - yellow discoloration of the whites of the eyes and skin occurs because bile pigment can no longer be removed from the liver
- Itching – due to the retention of bile products in the skin
- Ascites – abdominal swelling due to an accumulation of fluid caused by the obstruction of blood flow through the liver
- Vomiting of blood – frequently occurs from swollen ruptured varices (veins that burst) in the lower end of the oesophagus due to the
increased pressure in these vessels caused by scar tissue formation
• Encephalopathy – subtle mental changes ranging from poor concentration advancing to profound confusion and coma.

Treatment for these conditions
• Ascites is treated by reducing the intake of salt and the administration of medications to improve excretion of salt and water by the kidneys (fluid tablets or diuretics). Some people are unable to take fluid tablets because of side-effects. In some instances, large amounts of fluid are removed by direct catheter drainage through the abdominal wall (a ‘tap’) either at RPA or a local hospital.
• Treatment of encephalopathy includes the use of specific medications such as lactulose syrup, rifaximin and bramino.
• Treatment of bleeding from varices (internal varicose veins) includes taking medication to reduce the likelihood of bleeding or rebleeding, ‘banding’ (the placement of rubber bands on the varices at the time of endoscopy), and occasionally, a radiological procedure called transjugular intrahepatic portosystemic shunt (TIPSS).

Management of encephalopathy

When this condition develops at home it can be distressing to deal with, so if you have noticed any worrying mental changes in your family member or friend, please feel free to discuss it with a member of the transplant team. We can give you strategies to help prevent it or manage it, if it occurs.
SECTION 2: ASSESSMENT

Transplant Assessment

Liver Specialist Doctor/Hepatologist
The doctor will assess the severity of your disease and will commence the process for you to be considered for a liver transplant. They will manage, treat and coordinate your care.

Liver Transplant Nurses
From commencement of your assessment you will be given a named nurse and they will be responsible in guiding you through the assessment process. Your nurse will be your first point of contact and will answer any questions or concerns you may have. Your liver specialist and nurse work closely together to provide the best possible care.

A detailed assessment is carried out prior to deciding whether a patient is a candidate for liver transplantation.

As a general rule there are four basic requirements, which would indicate that you may be considered suitable for assessment:

a. irreversible, progressive liver disease
b. the liver disease fails to respond to all other forms of medical and surgical treatment
c. absence of other major diseases
d. ability to understand the nature and risks of liver transplantation

The assessment process
There are a number of tests that will need to be performed while you are undergoing assessment for transplantation. The results of these tests provide an overall assessment of your current state of health and help determine if transplantation is the right option for you. There are a number of baseline tests that all patients need to undergo; extra tests are tailored to the individual situation.

In most people, these tests are performed on an outpatient basis.

Time: usually 2 - 3 weeks needed to complete tests.

The assessment period may vary greatly depending on the availability of test procedures, personnel and, in particular, the complexity of the individual case.

An outline of the tests you will need to undergo

Blood tests
A number of tests including:
- Biochemistry
- Haematology
- Blood clotting profile
- Cross-matching
- Tissue typing
- Hormone levels
- Hepatitis screening
- Screening for exposure to certain viruses, which will help to optimise your post transplant management
- A 24-hour urine collection to assess kidney function

Other tests include:
- Chest X-ray, hip X-ray, spine X-ray
- ECG and cardiac ECHO
- Lung function tests
- Abdominal CT scan (This computerised image will show the size and shape of the liver and major blood vessels. At times, this test reveals previously unsuspected liver tumour.)
- Bone density scan
- Endoscopy
- Female patients must have a Mammogram and Pap smear
- Dental check

Other tests as individually indicated

Tissue typing
Although we perform tissue typing on all patients awaiting transplantation, we do not match donors on the basis of tissue type. There are three reasons:
1. It does not seem to make any difference to the outcome.
2. There is usually insufficient time to accurately tissue type a donor.
3. There is a shortage of donors, so we would never do any liver transplants if we had to wait to have a tissue-type match.
However the donor organ has to be matched with you with regard to blood group and size.

**What else happens?**

During the course of the assessment you will have the opportunity to meet one of our dietitians who will advise you about your particular dietary requirements.

You will also be able to meet with a social worker, who can advise and help you with any specific issues you may need assistance with in relation to family, employment or financial issues etc, you may be experiencing.

Your doctor will also decide whether you would benefit from a consultation with our psychiatrist or clinical psychologist, or a specialist from Drug Health Services.

Depending on the results obtained from these tests, and the complexity of your case, further tests may be arranged as necessary in order to establish suitability. You may also need to be seen by other specialists, such as a lung specialist or heart specialist. Following review of your tests by your liver specialist, an appointment will then be arranged for you with one of our Transplant Surgeons and our Transplant Anaesthetist.

**Following Assessment**

After you have gone through all these various stages, the decision whether to proceed to transplantation is discussed with you and your family.

At this time, possible outcomes include:

A. You are considered suitable for transplant and the severity of your liver disease warrants your name being placed on the active waiting list.

B. You are considered as suitable for transplant, but deferred for an indefinite period because you are too well. This may be months, years or never. You return home and remain under the care of your specialist if appropriate, who remains in contact with the specialists at Royal Prince Alfred Liver Transplant Unit.

C. There is the possibility you are unsuitable for transplant for whatever reason. The main reason may be that the risks of transplant are too great, and you might not survive the operation. You then have the choice of returning home or, if appropriate remaining at Royal Prince Alfred Hospital for continued hospitalisation or return to your “home” hospital. If you have liver cancer, your doctor may determine that it is not in your best interest to proceed with transplantation, because of a high risk of tumour recurrence after transplantation.

If you are suitable for transplant now or later, you retain the right to decide that you would prefer NOT to undergo transplantation. The team will respect your decision.

Having proceeded through these stages, if it is agreed the timing is right for you to proceed to transplantation, your case is discussed at a meeting of the Liver Transplant Team. If the team agrees that there are no significant obstacles to your successful transplantation, you are formally placed onto the Active Waiting List to await a suitable donor organ becoming available for you.

*See page 41 for an outline of common liver tests performed in people with liver disease performed before or after the transplant.*
Members of the Liver Transplant Team at RPAH

Physicians:
Professor Geoff McCaughan, A/Professor David Koorey, A/Professor Simone Strasser, A/Prof David Bowen, Dr Avik Majumdar

Surgeons:
Dr Michael Crawford, Dr Deborah Verran, Dr David Joseph, Prof Henry Pleass and A/Prof Charbel Sandroussi, A/Prof Jerome Laurence, Dr David Yeo

Anaesthetists:
Dr Andrew Watts and Dr Michael Paleologos, Dr Mark Porter, Dr Gerald Wong

Dietitians:
Helen Vidot and Joanne Heyman

Transplant Coordinators:
Claire West, Nick Koutalistras
Fiona Burrell, Allyson Newman
Mike Utsiwsota, Victoria McCarthy

Social Worker:
Annabelle Lynch

Psychiatrist:
Dr Robert Gribble

Psychologist:
Ms Suzanne Roche

Drug and Alcohol Specialist:
Professor Paul Haber

Liver Transplant Clinical Nurse Consultants:
Fiona Burrell, Catherine Brannigan, Eamonn Browne

Nursing Unit Manager, 9E Transplant Ward:
Susan Virtue

You will come into contact with many of these people during the course of your assessment and ongoing association with the transplant unit. You may be provided with the opportunity of meeting someone who has already had a liver transplant.
SECTION 3: NUTRITION IN LIVER TRANSPLANTATION

Adequate nutrition is a very important aspect of liver transplantation. Your nutritional requirements will change over a relatively short period of time depending upon where you are in the transplantation process i.e. before the liver transplant, in hospital after the transplant or months to years after the transplant.

Your diet whilst you are awaiting your transplant

Most people with severe liver disease have lost a significant amount of muscle and body fat by the time they are referred to the liver transplant unit. The most important nutrition goal whilst waiting for your transplant is to eat enough food to stop this process. You will need to work very hard at eating and this can be difficult if you don’t have any appetite or if you feel nauseated. You may need to be more careful with the foods you eat if you have been advised to avoid particular foods. The priority, however, is always to eat enough to stop you losing more muscle.

The diet you were following when you first met the transplant team may be changed whilst you are waiting for transplantation. The dietitian and the doctor will discuss your individual requirements with you.

The most common restriction for people waiting for a liver transplant is a salt (sodium) restriction. Quite simply, salt retains fluid in your body and if you have ascites or excessive fluid in other parts of your body you will be asked to limit both your salt intake and to avoid salty foods. You will need to discuss this further with the dieticians as it can be tricky trying to balance the low salt intake with your increased need for protein rich foods and calories.

Most people waiting for a liver transplant cannot eat enough protein to meet their increased needs and many will be asked to use dietary supplements such as Ensure, Resource Protein, Bramino, Fortisip or Polyjoule or any combination of these. It is particularly important to reduce the time without eating or drinking supplements. As many people have difficulty sleeping, we suggest that you use some of these supplement drinks through the night.

The Social Worker’s Role in the Liver Transplantation Unit

The Social Worker on the team is available to work together with you and your family, to assist you with the ongoing process of liver transplantation and to support you in the decisions you need to make.

Some of the ways the Social Worker can assist are:

- helping with the adjustment to living with an illness and negotiating the transplant process
- relationship and family concerns
- advising individuals of their rights
- financial concerns, such as Centrelink options
- accommodation – in or near the hospital
- travel issues eg IPTAAS (Isolated Patients’ Travel and Accommodation Assistance Scheme)
- provide education resources eg books, web pages about liver transplantation
- lifestyle options such as recreation activities
- organise interpreters and liaise with cultural community services
- discharge planning eg community support referrals

The social work service is free and confidential and available to all patients, their families and carers.

You can contact a Social Worker through the Social Work Department telephone 9515 3787 or ask the staff of the liver transplant team to contact a social worker by page.
SECTION 4: INFORMATION YOU MIGHT NEED

Accommodation
The hospital does not provide patient/relative accommodation on site. There is accommodation available at a hostel in Ashfield which is about 15 minutes drive from the hospital. The hostel consists of 26 rooms, some of which contain one single bed and four rooms have two single beds.

Accommodation bookings for the hostel can be made by contacting the RPA Accommodation Coordinator, Noeleen Franks on (02) 9515 9901. She will be able to advise you regarding other accommodation options in the area. After hours phone Nursing Administration on (02) 9515 6111 to assist with organising emergency accommodation.

Ambulance fund
It is ABSOLUTELY VITAL that you have or get ambulance cover while you are on the waiting list. If you are on a Social Security Pension or Benefit you are already covered. You can check this with the Department of Social Security. If you have private health insurance, you are probably covered. You should check with your insurance company. If you have neither, you should obtain ambulance cover from a private health insurance company (e.g. NIB or Medibank Private).

Travel and accommodation expenses
You are responsible for your own travel and accommodation expenses. However, if you live more than 100 kilometres away from the hospital, you may be entitled to a refund of part of your travel and accommodation expenses when you come to the hospital to see a doctor.

IPTAAS (Isolated Patients Transport and Accommodation Assistance Scheme)
IPTAAS provides reimbursement for travel and accommodation costs to people who need to travel more than 100 kilometres one way from their home to obtain specialist medical treatment. IPTAAS forms can be obtained via your local doctor or the links below:

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Income issues
If you are still working, you may need to plan now for the time when you are not working because of deteriorating health or while you are recovering from your transplant. You may be entitled to a Department of Social Security Benefit or Pension, especially if you have no other income. Your carer may be entitled to a Carers Pension. Please see the Social Worker if you have any questions about this.

Hospital charges
Patients’ costs for Liver Transplant

1. Do I have to pay for the liver transplantation?

The Australian National Transplant Unit is funded by the New South Wales State Government. All your patient costs in hospital for the transplant admission are covered by this funding. You should not receive any bill associated with your liver transplant procedure. This applies to your hospital admissions for the transplant procedure. Once you are discharged, you will require ongoing drug prescriptions via the hospital Pharmacy. The Pharmacy will charge you the standard nominal charge associated with hospital prescriptions for an outpatient. Many of your medications will also be available through community pharmacies. If you require further hospitalisation after your transplant for whatever reason, you have the right to nominate your insurance category as you think most appropriate.

The Internet
You may find information about liver transplantation on the Internet. This information may be of interest you. However, you should remember that most of it applies to the United States, Canada or Europe. The information included may not apply to Australia or the Australian National Liver Transplantation Unit in Sydney. Please check with your doctors about any questions you have about material you have found on the Internet.
You may be interested in looking up the following sites for information:

3. www.transplant.org.au
4. www.myDr.com.au
SECTION 5: WAITING FOR THE TRANSPLANT

To those people who have been told to prepare for placement on the Waiting List.

(If you are unsure then you have not been told).

1. Have a mobile phone and answer unknown/blocked calls
2. Install “call waiting” on your home phone.
3. Make sure you have ambulance cover.
4. Let the Transplant Team know as soon as possible for any changes in your circumstances.
5. Do not hesitate to contact us regarding any issues that are of concern to you.
7. It is strongly advised that you have all your affairs in order prior to being actively listed for transplant. This includes making a will and organising power of attorney.
8. It will be very much to your advantage if you can arrange for your GP to be involved in your ongoing care after the transplant. Please discuss this with them.
9. Await further instructions.

Meeting with Transplant Coordinator

If you are considered as suitable for immediate “Listing” for Transplant, the Transplant Coordinator will contact you to arrange an appointment.

At this appointment:
• Details of the surgery will be discussed with you.
• Discussion will take place of what to do when the call comes.
• The Coordinator will confirm your contact details with you, this will include all relevant telephone numbers including a mobile telephone number (you will need to be contactable at all times).
• The Transplant Coordinator can be contacted on:
  Claire West/ Victoria McCarthy
  Mon-Fri 7.00am - 3.30pm
  Tel: 9515 7274
  After hours:
  Switchboard 9515 6111 and ask to speak to the Transplant Coordinator on-call

Once you have been accepted on the waiting list, the final decision to have a transplant is still up to you. Be ready and available for a transplant call at all times, unless otherwise discussed with medical staff and the Transplant Coordinator.

You will need to be contactable 24 hours a day, 7 days a week. The Liver Transplant Coordinator will discuss this with you. They also discuss travel and accommodation arrangements with you. Waiting time can vary from one day to many months, possibly years. There can be much anxiety and stress whilst you wait for a suitable organ.

Whilst waiting for transplant, you will return to the clinic for regular follow up, usually on a monthly basis. You need to notify us if you become unwell or if you are admitted to hospital for any reason.

WHAT TO DO IF YOU BECOME UNWELL AT HOME OR HAVE ANY CONCERNS RELATED TO YOUR TREATMENT:

• Contact your liver transplant nurse at the AW Morrow Liver Centre, Monday - Friday 8am - 4.30pm.
• After hours: Call Liver Registrar on-call Tel. 9515 6111
• If you feel your illness is unrelated to your transplant or liver disease, you should see your local General Practitioner (GP)
• If you are admitted to another hospital, please ask the team caring for you to contact the transplant unit to inform us of your condition
SECTION 6:
THE RIGHT DONOR FOR YOU

Selection of a suitable donor

It is important to understand that no one knows exactly when a donor organ will be available for you. In Australia, only around 1% of all deaths occur in such a way that organ donation is possible. Injuries or illnesses that result in organ donation may include bleeding into the brain, accidents, infections or tumours. Potential organ donors are always on a mechanical ventilator and in hospital (because without a supply of oxygen, organs would not be suitable for transplantation). The vast majority of organ donors in Australia are ‘Brain Dead’. Brain death is the permanent loss of brain function which is determined by rigorous testing. Brain dead people are able to donate because the heart is still beating blood around to the organs. The alternate deceased donor is one who donates after ‘Cardiac Death’.

Donation after cardiac death is a newer initiative to allow more people to be deceased organ donors. These donors have severe and irreversible injuries or illnesses. Following an independent decision by the family and treating medical team to withdraw active treatment, some families request that organ donation be considered. When suitable, organ donation can occur in this setting particularly for kidneys, liver and lungs. Following withdrawal of treatment, organs are retrieved as rapidly as possible after the donor has died (determined by the heart stopping) according to a strict NSW government approved protocol. There is a small amount of damage that can occur during the dying phase especially to the liver, so the transplant doctors are very selective about the donors they would use for liver transplantation to minimise problems for the recipient.

Equally important is the decision to donate. If the deceased did wish to donate his/her organs and the family support that decision, then all steps will be taken to ensure those wishes are fulfilled. Over 90% of Australians support organ donation ‘in-principle’. However, actual consents in the hospital setting are lower, at around 60%. Following rigorous tests to confirm brain death and after consent for organ donation is obtained from the next of kin, the donor will be assessed for their suitability to donate. If the donor is suitable to donate organs, they will be taken to the operating theatre for organ retrieval surgery that takes several hours to complete. Donor organs are allocated by matching the blood group, size of the donor and the recipient. The liver is offered to the neediest patient on the waiting list who is the best match.

Increasingly, donor organs that are offered for transplantation have some reason why they are not absolutely optimal. With the poor organ donation rates in Australia, and the increasing number of people that need a transplant, even suboptimal donor organs are considered for transplantation. Thus, donors may be older, have some evidence of excess fat in the liver or have evidence of exposure to hepatitis virus infection.

Hepatitis C-positive donor livers (that do not have evidence of significant liver disease) are offered to recipients with chronic hepatitis C. In some instances the liver donor may have evidence of Hepatitis C infection. If the liver is otherwise suitable for donation, then this liver may be accepted for the transplantation if the risk of waiting longer for another donor is considered unacceptably high. Following transplantation from a donor with hepatitis C, medications will be used to clear the hepatitis C infection. These medications are extremely effective, safe and well tolerated after liver transplantation. These issues will be discussed with you if they apply.

Some donors have evidence of previous exposure to another hepatitis virus, hepatitis B. In most of these cases the donor does not have evidence of active infection, but on the basis of blood tests, we can tell that there are small quantities of the virus in the liver. Without preventative medication, this virus can reactivate in the new liver and cause long-term problems. Therefore, it is policy of transplant units to transplant such a liver and then to use highly effective preventative medicine (an extra tablet a day) to prevent reactivation.
If it is thought that it is in your best interest to accept such a donor, the issues will be discussed with you prior to proceeding to transplant.

In all cases, the transplant team will consider the quality of the donor organ carefully, and will not proceed to transplantation if it is thought that the risks to the recipient are too high. A decision not to proceed may be made fairly early in the process, just after a recipient has been notified, or if new information comes available, may be made even after the recipient has been transferred to the operating room. While this is obviously disappointing, it is in the patient’s best interest not to proceed to transplantation under such circumstances.

**WRITING TO THE DONOR FAMILY**

For the family of an organ donor, receiving a card or letter of thanks from a transplant recipient is very special. Donor information and details are confidential, but if you would like to send an anonymous card or letter to the donors’ family, contact the Transplant Coordinator.
SECTION 7:
PREPARATION FOR SURGERY

When a suitable donor has been found
When a suitable donor has been found, you will be contacted and asked to activate the travel arrangements as discussed with the Liver Transplant Coordinator. The form of transport chosen for your journey to the hospital will depend upon your health and the distance travelled. Private cars are the usual first option. Ideally, you should travel with at least one member of your family, although this is not always possible.

When you receive the call about your transplant the coordinator will tell you the time when you should stop eating. The general rule is that you must not any any solid food for six hours before the scheduled start time for your operation. You can have water, diluted cordial and Pre-Op drinks for up to two hours before the time your operation is due to start. The transplant coordinator will give you these times when you ‘get the call’.

Consent for surgery
At the time of entry on to the Waiting List or before, you will be required to sign a “Consent for an operation for liver transplantation”. A copy of this form can be found on the at the back of this booklet. It says the risks from the operation are three kinds. Firstly, although every effort has been made to screen the donor for transmissible disorders, there can be no guarantee that the donor did not have such a disorder. Secondly, the drugs required to control rejection have side effects specific for each drug. Thirdly, the complications of the operation itself include infection, bleeding, poor function and rejection of the liver. There is a possibility (currently about one in ten) of death. This information needs to be explained to you in detail before you sign the consent.

You will need to sign that you understand that liver transplantation is a treatment for liver failure, not a cure, and that you understand you will need to take drugs to suppress rejection indefinitely. You need to be satisfied with the explanation of the risks of liver transplant and discuss it further with your doctors if you need to. Signing of the consent form does not interfere with your legal rights in the event of negligence. Following admission to hospital you will be asked to sign a separate hospital consent form prior to transfer to the operating theatre.

Cancellation of surgery
The fact that you have been called to the hospital does not guarantee that you will have a transplant. It is quite possible that you could be contacted on more than one occasion without the transplant going ahead. If the liver is found to be unsuitable for you at any point then the procedure will be cancelled These facts can sometimes only be ascertained in the last hours before the transplant goes ahead. In these circumstances, it is in your best interest not to proceed with the surgery.
SECTION 8:
THE TRANSPLANT ITSELF

The surgical procedure
The diseased liver is removed and a normal liver is transplanted into the space where the diseased liver was located, i.e. on the right-hand side of the upper abdominal region. This requires a large incision on the upper abdomen.

The operation is very complicated and takes approximately four to eight hours. Removing the old liver can be extremely difficult, particularly if you have had previous abdominal operations.

Diagram of the operation
Fig. 1

During surgery your old diseased liver will be removed and a new healthy looking liver transplanted in its place. (A gallbladder will not be transplanted with the liver).

The Liver Transplant Operation.
The liver is attached to a number of vital structures, all of which have to be cut and rejoined. These are:
- the inferior vena cava (IVC), the major vein that drains into the heart above the liver
- the portal vein, the vein that feeds blood from the intestines into the liver
- the hepatic artery that carries oxygen to the liver
- the common bile duct, the major duct transporting bile from the liver to the intestine

Once all these major structures have been joined from the donor liver to yours the abdominal cavity is washed with warm saline.

Two white drains called Jackson Pratt drains are inserted into your abdominal cavity. They will be attached to another suction container. The fluid which drains into them will be blood stained. This is quite normal. Your abdomen is closed in layers of muscle under the skin. You will be transferred to ICU from the operating theatre where the staff will observe the drainage. Once drainage ceases, the Jackson Pratt drains will be removed, usually one to two days after the operation.

Gall bladder
Both your own gallbladder (if you still have one), and the gallbladder attached to the transplanted liver will be removed at the time of the operation. Do check with your surgeon if you have any questions.

Dressings
We use clear dressings to cover the incision. The skin clips used to close the skin are visible through them. The dressings are permeable to water vapour but impermeable to organisms. Sometimes blood or fluid will be visible but it will not effect the skin healing. The dressings are left on for up to 7 days. You are able to shower with them on.

Split-Liver Transplantation
Because of the disparity between the increasing numbers of people waiting for transplant, and the numbers of donor livers available, ways are
always being undertaken to increase the number of people able to undergo transplantation. A strategy that is used in many transplant centres around the world, including RPAH, is split-liver transplantation. In this procedure, a donor liver is divided into two parts, a larger right lobe, and a smaller left lobe (see figure 2). With this strategy, an adult and a child can be transplanted from the same donor organ. Not all people waiting for transplants are suitable to have a right lobe transplant and the transplant team will always select an appropriate recipient. The chance of developing complications from a split liver transplant is slightly higher than if a whole liver graft is used. Within the first few months after transplantation, the split liver increases in size until it is the size of a full-sized liver. Since the implementation of split liver transplantation, the number of children waiting for transplantation in Australia has significantly reduced.

Donation after Cardiac Death (DCD)
Livers retrieved from these donors (see section 6) have been under more stress than normal just prior to the donor surgery. This can mean a slight increase in both early and late complications. Early on the experience is that there is a slightly higher risk of the liver not working straight away after transplant. Later on there seems to be a higher risk of problems with the bile ducts. We reduce these risks by being very cautious about which of these livers we will accept for you.

Transplantation from living donors

Adult to Child transplantation
Liver donation from living relatives to paediatric recipients is performed when the circumstances justify it. The procedure is almost identical to the split procedure. There is a separate information booklet for live donor transplant to paediatric recipients. If you are interested please speak to the liver transplant coordinator.

Adult to Adult transplantation
A new initiative is adult to adult live donor liver transplant where an adult patient can receive a portion of liver from a relative or close friend. The donor is a healthy adult 18-55 years old. The donation must be completely voluntary. The donor undergoes rigorous testing to ensure their safety and that there is a good match with the recipient. The operation to donate a large part of the liver to an adult is a major one and carries a risk of dying that is as high as 1 in 200 chance. There is a separate information booklet about adult to adult live donor liver transplantation. If you are interested, you should check with your transplant doctors to see if you are suitable and ask for a copy of the live donor transplant booklet.

Survival chances
Liver transplantation is a major operation. However, due to various recent advances the peri-operative mortality is now less than 10%. The 10-year post-transplant patient survival is about 70%. No doubt, these figures will continue to improve.

Figure 2. Split liver transplantation. The left lobe is used for a child, and the right lobe is used for an adult.
SECTION 9: AFTER SURGERY

Intensive care
Following surgery you will return from the operating theatre to the Intensive Care Unit, which is located on Level 3 of the hospital. When you first wake up, you may be a little drowsy. The anaesthetic drugs take a while to wear off. You will be given pain relief intravenously during the early postoperative period. These can also make you sleepy. A stay in the intensive care unit allows your body time to recover its basic bodily functions (e.g. breathing, heart rate, blood pressure).

Most patients will have a breathing tube still in place attached to a breathing machine called a ventilator for the first 24 hours. You will also have a number of intravenous lines (tubes) in place, one in your neck and also attached to blood vessels in your arms. You will have a nasogastric tube (a tube coming out through your nose). You will be fed through this tube for up to 7 days after the operation - occasionally longer.

You will have a number of tubes draining fluid from your abdomen. You will also be attached to a heart monitor, which will record your vital signs. The staff who work in an intensive care unit have been specially trained to see you safely through this period. Family will be allowed to visit once you are settled in intensive care. If you cannot talk, you will be provided with a message board to write on. As time passes, the I.V. lines and drainage tubes will gradually be removed. All tubes should be able to be removed in the days following the operation.

You will not be able to eat straight away, but can usually have something to drink within hours of the breathing tube being removed, and something to eat a day or so later.

The Transplant Ward
After a short stay in the intensive care unit you will be transferred to the transplant ward on Level 9. Once on the transplant ward you will be encouraged to mobilise as early as possible to facilitate your recovery. You will have regular chest physiotherapy to help with your breathing and you will also be given breathing exercises to do. If at all possible the nursing staff will assist you to get out of bed to shower by day two or three at the latest.

Your sleep pattern may be disrupted initially. This is not uncommon after major surgery and a stay in the ICU, which can be noisy at night. The high doses of anti-rejection medication doses you are given in the first few days can also be disruptive to your sleep, but this usually settles down after a few days on the transplant ward.

Your daily routine will include, daily blood tests, showering, wound dressings, assistance with activities of daily living until you gradually become more independent. There will be regular ward rounds by the Transplant Team, which include Surgical and Medical Doctors. Your medications will be given intravenously at first, and then by mouth once you commence solid food.

Family and friends are encouraged to visit and their help and support plays an important role in your recovery. As you recover your health, you will be expected to become more active. This means spending more time out of bed, and walking a little more each day.

The hospital has chaplains from many denominations and religions. If you would like a visit from a member of your own religion, please let the ward staff know.

Recovery time
The average stay in the Intensive Care Ward is 2 to 3 days. The average stay in hospital wards is 1 to 4 weeks. This may be extended due to complications. Most people, although well, take many months to get over the effects of the surgery and may not feel their normal selves again for several months.
SECTION 10: THE IMMUNE SYSTEM

The immune system creates our defence against infectious organisms, such as bacteria and viruses, foreign substances or transplanted organs, including a new liver.

Your body will recognise your new liver as foreign tissue and your immune system will attempt to reject it. This is a normal reaction. After your operation, medications such as tacrolimus/cyclosporin, prednisone and mycophenolate/azathioprine are used to lower your body’s immune response (immunosuppression), so as to lessen the chance of rejection.

These medications do result in less rejection. However, because they alter your immune response, they also make you more likely to suffer from infections, because the immune system also serves as a defence mechanism against bacteria and viruses entering your body.

In many ways your medication treatment is a careful balancing act - to give enough so that your body does not reject your new liver but not too much so as to predispose you to infections or other side-effects. Because these medications have such an important function, they are medications that you will always have to take. You will also have to be closely followed by the Transplant Team.

Despite the tremendous progress in liver transplantation, it is still not a cure. It is a treatment for your liver disease. This is why it is so important for you to follow the medication and lifestyle regime that will be recommended for you. Your efforts, together with those of the Transplant Team, are intended to increase your quality of life and return you to as normal life as possible. Complications that can be prevented will be picked up early with regular follow-up and allow treatment to be given straight away.

You will be on anti-rejection drugs for the rest of your life.
SECTION 11: INFECTION

With immunosuppression, your ability to fight infection is decreased; this is particularly so in the first few months when the doses of immunosuppressive medications are relatively high.

Common sense precautions need to be taken: avoid exposure to sources of infection, such as people with the flu and colds, children with chicken pox or other viral infections, dirty and dusty buildings (buildings under construction or destruction), and large compact crowds at least initially. Normal hygiene precautions should help prevent infection and no extra measures need to be taken.

Care of your skin is very important. If a cut or graze does occur, cleanse the area and apply a clean, dry dressing or plaster and watch for signs of infection. Should healing be prolonged and/or pain, swelling, redness, or infection be noted, you should notify your GP or the Transplant Team. Symptoms of cystitis (urinary tract infection), sore throat, cold sores or mouth sores should also be reported to your GP or your Transplant doctor if visiting clinic.

As your general health improves, the dosages of your immunosuppressive medications are usually reduced, which means that you will regain resistance to most infections.

Pay careful attention to personal hygiene. This involves regular showering and keeping your mouth clean, regular brushing of your teeth after each meal and last thing at night with a soft toothbrush.

- Avoid changing cat litter boxes or bird cages; they can be major sources of infection
- Wash your hands as often as possible
SECTION 12: REJECTION

Rejection is common following liver transplantation. Your body recognises the transplanted liver as a foreign object and tries to destroy it through a process known as rejection. It is not uncommon to experience one or more episodes of rejection during the recovery period. It most commonly occurs 7 - 10 days after surgery. It is controlled in over 90% of cases by transient increases in medication.

The chances of rejection diminish with time, but rejection can occur at ANY TIME following transplantation. Frequently an episode of rejection is not associated with symptoms, however it is important that you be aware of some signs and symptoms of possible rejection.

Signs and symptoms of rejection may include:

1. Fatigue, lethargy or malaise
2. Lack of appetite
3. Fever
4. Abdominal pain or tenderness
5. Light coloured stools (faeces from the bowel)
6. Dark coloured urine
7. Yellow eyes and skin
8. Elevations in liver function tests

If you develop any of these signs or symptoms of rejection once you leave hospital, notify the Liver Transplant team. However these symptoms do not always appear before a rejection episode. Many episodes are picked up by routine blood tests at the time of your outpatient visits. A biopsy may be required to make a definitive diagnosis.

Rejection may be mild or severe. In most cases, liver rejection can be controlled satisfactorily if treated promptly.

There are many methods for controlling rejection and they may include:
- Tacrolimus or Cyclosporin dosage adjustment
- Intravenous steroids (IV methylprednisolone) (a ‘pulse’)
- Other immunosuppressive drugs such as Azathioprine (Imuran), Mycophenolate (Cellcept) or ATG.

The onset of rejection does not mean that your liver will be lost but prompt treatment is important.

Very rarely, a transplanted liver fails to function or undergoes irreversible rejection. There is no dialysis treatment for livers as with kidneys. Thus, if a liver fails completely, the only hope is for a second transplant.
SECTION 13: NUTRITION FOLLOWING LIVER TRANSPLANTATION

Your diet in hospital after transplantation

You will be fed through a feeding tube from shortly after the operation for up to 7 days or longer after your transplant. There are many studies which show that your protein and energy requirements are higher immediately after the surgery than they were before the transplant. We know that people who are malnourished take longer to recover, longer to heal their wounds after an operation and are more likely to develop infections.

Most people don’t start eating solid foods until the second or third day after their operation. Your first meal will usually consist of fluids and you will progress rapidly to a full ward diet. You will be asked to use the high protein supplements which are available from the transplant ward fridge to supplement your diet (Resource Protein, Fortisip).

By the end of the first week of eating you will find that not just the dietitian but the nurses and doctors will all be very concerned about how much food you are eating and how many supplements you are drinking and you will receive constant enquiries about your food and fluid intake. Once we are comfortable that you are close to meeting your increased nutritional needs we will remove the nasogastric feeding tube.

At this stage eating may seem to be one of the hardest things you have ever had to do. This can be related your body’s reaction to an operation and to the medications. You may have no sense of taste and no sense of enjoyment in your food. This is normal and you will need to work very hard to get the protein and calories you need to recover and to heal your wound.

You may receive large meals. Remember that you are not expected to eat all the food at one meal but, rather, you should spread it out over the day so that your day is spent grazing. Your family is encouraged to bring in some of your favourite home-prepared foods in an effort to increase your intake. Food safety is particularly important after transplant and the dietitian will discuss this with you and your family/carer.

The dietitian will monitor your weight and your nutritional progress closely and you will be constantly pushed to increase your protein and energy intake. It will be reassuring for you to remember that these increased requirements do not last forever. Your goal weight after transplant will be identified with the help of the dietitian and when you are nearing this goal you will need to reduce your food intake dramatically and you will also need to stop all the high protein/high energy supplement drinks. Long-term weight control can be a serious problem in the future if you do not reduce your intake when advised to do so.

Any dietary restrictions that were needed before your transplant are no longer necessary. Some people may have high blood sugar levels after their transplant which is often related to their medication doses. It is not necessary to go onto a special diet to control blood sugar levels and insulin or tablets are used to control blood sugar levels if necessary as it is much more important to eat enough protein and calories in the early weeks after transplantation. As the medication doses are reduced blood sugar levels often normalise. If not, then dietary modification will be necessary to help long-term control of blood sugar levels.

If you continue to have problems with fluid retention after your transplant reducing your salt intake may help to make it easier to control the excess fluid.

Your diet when you go home after transplant

There is a great tendency for most people to gain weight rapidly somewhere between six to eight weeks after their liver transplant. Unfortunately, this usually happens around the same time that you are starting to taste food again and to really enjoy eating for the first time in many years. Most people will need to regain some weight but it is important to remember
your goal weight and when you are 3 – 4 kg from this weight you need to reduce your intake and stop all supplement drinks.

Weight control is a very significant challenge for most people in the long-term after their liver transplant. We now know that rapid and/or excessive weight gain can affect your liver function tests and can result in fatty liver which, in turn, can have a serious impact on your long-term health. Increasing your daily activity along with some regular exercise and a sensible eating plan will help you to control your weight. Your exercise programme should start from the time you leave hospital even if you are still significantly underweight. Gentle regular exercise such as walking will not harm your new liver nor will it open up your scars. Increasing your daily activity will increase your strength and stamina, improve your blood sugar levels and improve your overall feeling of well-being in addition to helping to control your weight.

The following nutritional guidelines will help you in your struggle to control your weight:

- Try to eat regularly. Do not miss meals as you tend to overeat when you finally get around to eating.
- Frequent snacking between meals will make it harder for you to control your weight. If you need to eat between meals, choose high fibre foods such as crisp, crunchy vegetables. Vegetable soups are often satisfying on a cold winter’s day without giving you a load of unnecessary calories. A serve of diet jelly may help to satisfy the craving for something sweet.
- High fat foods are high in calories or kilojoules. There is growing evidence that a diet rich in saturated fats (predominantly animal fats) leads to the development of fatty liver. Try to choose fat reduced alternatives at all times. These include fish, lean poultry, lean meats, eggs, fat reduced milk and cheeses, legumes such as chick peas, kidney beans, etc)
- Choose fresh fruit or fresh fruit combinations to finish off a meal rather than the higher calorie dessert alternatives.
- Sucking sweets or lollies, eating chocolate and snack foods such as potato chips regularly makes it very difficult to control your weight.

Some people will go home with high blood sugar levels and may require insulin injections or tablets to control their blood sugar levels. If this is the case you should try not to have any supplement drinks between midday and 8.00pm and avoid foods with a high sugar content during this period as they will push up your blood sugar levels during this time. If your blood sugar levels remain high six months or longer after your transplant you will need to seek more specialised dietary advice to help control your blood sugar levels. Regular exercise also makes it easier to control your blood sugar levels. You may find it useful to monitor your activity using a pedometer or a fit bit.

Your dietitian will discuss your diet details with you and your family/carer prior to discharge. In addition to food safety, this will basically involve eating at regular intervals with an emphasis on reducing the amount of fat you eat and avoiding foods with a high sugar load.

You may find that your blood sugar levels normalise within twelve months after transplantation and that you will then be able to eat an unrestricted diet. Remember if this does happen, you still have the capacity to gain
excess weight easily and this, in turn, will make it more likely that you will develop diabetes in the long-term.

Fluid retention may be still a problem when you leave hospital. Avoiding added salt and foods with an obviously high salt content will help in reducing this excess fluid. Many people will have reduced the salt in their diet prior to their transplant. All Australians are advised to reduce their salt intake as part of as healthy diet. Whilst you do not need to limit your salt intake as severely as you did before your transplant, as a general health measure, it is important that you do not develop a taste for foods with a high salt content.

All patients who receive an organ transplant need to take medications which dampen their immune system and therefore need to take a little more care to avoid food poisoning. Safe food handling practices become more important. In addition, there are three food borne bacteria in particular which may be a serious problem for people who are immunosuppressed. They are listeria monocytogenes, vibrio vulnificans and yersinia.

Vibrio vulnificans is a bacterium which may be present in raw shellfish. It is particularly harmful for people who have a suppressed immune system. Although contamination with the bacterium is rare, all patients who have had an organ transplant are advised not to eat any raw shellfish, including oysters.

Listeria monocytogenes is a bacterium that is more widespread in our food supply. It thrives in cold temperatures. Keeping contaminated foods in the refrigerator will not protect you from this “bug”. Careful food handling and an awareness of possible contamination of specific foods will help prevent infection. You will receive a detailed brochure about safe food handling and possible food sources of this bacterium from the dietitian after your transplant or at the patient education day that the Unit runs throughout the year. Foods to be avoided include raw meats and raw fish, uncooked eggs, raw shellfish, commercial coleslaw, potato and pasta salads, commercial fruit salads, soft serve ice creams, soft cheeses and blue cheeses. If you acquire a listeria infection it can be treated with antibiotics but avoiding the potential sources of listeria is a much safer alternative.

Yersinia is predominantly found in raw and undercooked poultry. Following the listeria guidelines reduces the risk of yersinia infection.

Finally, you always have access to the liver transplant dietitian. If you have any enquiries about your nutrition at any stage you should not hesitate to contact the dietitian. Similarly, if you are having difficulty controlling your weight at home after your transplant you should contact the dietitian earlier rather than later.

You can contact the dietitian through the Department of Nutrition and Dietetics on 9515 8053. Alternatively, you can ask the staff at the Liver Transplant Clinic to contact staff.
SECTION 14: RECURRENCE OF ORIGINAL DISEASE

Recurrence of your original disease may occur.

Hepatitis B recurrence after the transplant was previously common. However, antiviral medications are extremely effective at preventing recurrence. All patients undergoing transplant for hepatitis B will remain on antiviral medication long term.

Hepatitis C virus recurrence was previously universal and caused significant problems in the months and years after transplant. However, most people with hepatitis C infection are now treated before liver transplantation, and recurrence is rare. If there is not an opportunity to treat hepatitis C before transplant, then it will be treated in the months after transplant. Current treatments for hepatitis C involve tablets only, which are very safe and highly effective resulting in clearance of infection in almost everyone. Your liver specialist will discuss with you about the most appropriate timing and medications to treat your hepatitis C.

If you had a liver cancer in your old liver, there is a possibility that this may recur after transplantation. Your doctor will take all steps to minimise the chance of this occurring, but it is always a risk. Recurrence of liver cancer, may be first noticed by changes in the blood tests, or with symptoms in the bones or in the lungs, rather than in the new liver. Your doctor will be constantly monitoring your condition. If liver cancer does recur, then your doctor will discuss the most appropriate treatment for you.

Primary sclerosing cholangitis may recur after liver transplantation. Recurrence may result in narrowing of bile ducts within the liver which may cause symptoms similar to those prior to the transplant.

Recurrence of primary biliary cirrhosis and autoimmune hepatitis has been reported but is uncommon.
SECTION 15: DRUGS USED IN TRANSPLANTATION

In order to control rejection a combination of drugs are given which suppress or reduce the effectiveness of the body’s immune system. These drugs are called immunosuppressives and must be taken for life. Other drugs are used for a period of time after transplant to prevent infections and to manage other health problems. All patients will have a MEDICATION CARD, on which current medications and dosages are recorded. This card should be brought to all clinic appointments.

Immunosuppression Drugs
Life-long immunosuppression is necessary and tablets must be taken daily. Some patients may remain on a small dose of prednisone. Currently, most patients also take tacrolimus (Prograf) or cyclosporin (Neoral) twice daily, with the dose being decided on the basis of blood test levels taken just before the morning dose is due. Some patients require a third drug, azathioprine (Imuran) or mycophenolate (Cellcept), taken once or twice a day. All drugs as an outpatient are taken orally (by mouth).

Side-effects
Any form of long-term immunosuppression brings with it an increased risk from infection. The risk is highest during high-dose prednisone therapy, so during such times patients need to be isolated from anyone suffering from an infection. Other risks include the development of diabetes, high blood pressure, high cholesterol and kidney damage. Most of these complications can be managed by reducing or changing the immunosuppressive drugs or using additional medications. In the long-term, there is also a slightly increased risk of malignancy in patients taking immunosuppressive drugs. These risks have to be balanced against the necessity to take the drugs that prevent the body from rejecting the liver.

There are three main drugs used for liver transplant patients and your liver specialist will determine which drugs and dosages are best suited to you.

Here is a list of the drugs that may be used after a liver transplant, giving the reasons for their use and possible side effects.

Tacrolimus (Prograf, Advagraf XL)
Stops special white cells (T cells) from becoming active in your blood and attacking your transplanted liver

Tacrolimus and Cyclosporin are similar drugs and work in a similar way but have some different side effects. Tacrolimus/Cyclosporin are the mainstay of the immunosuppression post liver transplant. Doses are adjusted according to blood levels. They are never used together because of their shared toxicities.

Side effects of Tacrolimus include:
   i) impaired kidney function (picked up on routine blood tests).
   ii) increase in blood pressure.
   iii) neurological side effects that include headaches, mild tremors, insomnia, possible nightmares. Rarely patients may experience severe side effects including confusion, seizures and coma.
   iv) raised blood sugar levels or diabetes.
   v) increased risk of infection.
   vi) raised potassium level.
   vii) nausea and vomiting.
   viiii) mild hairloss

Cyclosporin (Neoral)
Cyclosporin is a strong immunosuppressive drug that stops special white cells (T-cells) from becoming active in your blood and attacking your transplanted liver that normally fight against transplanted tissue introduced into your body. It is almost always given along with prednisone.

Side-effects of Cyclosporin include:
   i) impaired kidney function (picked up on routine blood tests).
   ii) high blood pressure.
   iii) hot flushes or sweating.
   iv) numbness or tingling in the hands, feet or mouth.
   v) shaking or trembling hands and feet, but this decreases with the reduction in dose over time.
   vi) hair growth, most commonly noted on the face, arms and legs but this decreases with reduction in dose over time.
vii) overgrowth of gums, sometimes associated with soreness, swelling and redness, hence the need for regular mouth care.

viii) sinus drainage, “runny” or “stuffy” nose.

ix) increased risk of infection.

**How to take your Tacrolimus (Prograf) or Cyclosporin (Neoral).**

i) Tacrolimus/cyclosporin is given in two divided doses 12 hours apart usually taken at 8am and 8pm.

ii) It is very important to take tacrolimus/cyclosporin regularly exactly as prescribed. You must not alter the dose or time taken without medical advice.

iii) Advagraf XL is a prolonged release preparation that is taken once in the morning.

**DO NOT RUN OUT OF MEDICATION.**

iv) Tacrolimus/cyclosporin is usually dispensed initially through the hospital pharmacy. In patients who are on stable doses, the medication may be available from your local pharmacy using an Authority Script.

v) Do not take your Tacrolimus or Cyclosporin prior to having your blood taken on the morning of your visit. Bring your morning dose of medication with you and take as soon as possible after the test. Some people taking Cyclosporin will be asked to have their blood tests exactly 2 hours after taking the morning dose.

**Generic Medication**

There are now some generic brands of immunosuppression medication on the market. You may be dispensed one of these if you get your medications from a pharmacy other than here at RPA. As a general rule, it is preferred you continue on the same brand as supplied by the hospital. Please discuss with your Doctor before taking any generic immunosuppression.

**Once Daily Tacrolimus**

Some patients on stable doses of twice daily tacrolimus may be switched to a once daily prolonged release formulation (Advagraf XL). This should be taken at least 1 hour before breakfast or 2-3 hours after breakfast. It is much easier to remember to take a capsule once a day! Blood tests to monitor the level are taken just prior to taking the next dose.

**Prednisone** is a steroid hormone similar to cortisol, which your body produces normally. It reduces the number of circulating white cells in the blood by dampening down the inflammatory response. The dose given is initially high post transplant and is gradually tapered down until you are on fairly small dose. It is given in conjunction with other drugs to prevent rejection.

**Side-effects include:**

i) Stomach irritation that may occasionally cause stomach ulcers. Never take prednisone on an empty stomach so you should take it after breakfast each day.

ii) Fluid retention, high blood pressure and swelling of the face, hands or ankles.

iii) Weight gain due to an increase in your appetite and subsequent increase in food intake.

iv) Increased risk of infection, especially in the first few months after transplantation while your prednisone dose is high.

v) High blood sugar (diabetes) may occur with high doses of prednisone therapy. This is called “steroid-induced” diabetes. If you are a diabetic, you may require additional insulin to maintain a normal blood sugar. You will be instructed in a diet that will help you control this side-effect if necessary.

vi) Skin changes such as acne, rashes or bruising.

vii) Mood changes that may swing from feeling “up” to feeling “down”.

viii) Softening of the bones (osteoporosis) can be experienced after long-term use of steroids. A diet high in calcium or supplementation with calcium and vitamin D capsules will help, and the prednisone dose is reduced as soon as possible after transplant.
NEVER STOP OR REDUCE PREDNISONE WITHOUT MEDICAL ADVICE

Azathioprine (Imuran)
Azathioprine is used for the suppression of your immune response. It acts on the bone marrow by decreasing the number of white blood cells which fight infection. With azathioprine there is an increased risk of infection and an increased tendency for skin cancers.

Side-effects include:

i) Bone marrow depression - a low white cell count is the most common problem, but a low platelet count and anaemia may occur.
ii) Nausea or vomiting - so take your Imuran after meals to lessen stomach upset.
iii) Occasionally, people are allergic to azathioprine, and are unable to take it.

Mycophenolate mofetil (Cellcept)
One of the newer immunosuppressant medications similar to azathioprine that may be added to some patients drug regimen. It is taken twice a day 12 hours apart.

Side – effects include:

i) Vomiting
ii) Diarrhoea
iii) Low white cell count
iv) Foetal developmental abnormalities

Do not take if trying to get pregnant. Talk to your doctor.

Sirolimus/Everolimus
These belong to a newer generation of immunosuppressant drugs. They act by stopping special white cells (T cells) from becoming active in your blood and attacking your transplanted liver. They have a different side effect profile from tacrolimus/cyclosporine. They are taken once a day and the dose given is dependent on the level of the drug in your blood.

Side – effects include:

(i) Hyperlipidemia (high cholesterol levels in the blood)
(ii) Abdominal pain and diarrhoea
(iii) Low red blood cell count (anaemia)
(iv) Low white blood cell count
(v) Low platelet count (thrombocytopenia)
(vi) Acne and rash

Other Drugs used after Transplantation

Valganciclovir (Valcyte)
Valganciclovir is used for the prevention and treatment of CMV (cytomegalovirus) viral infection. This is a viral infection transplanted patients may be prone to because of their suppressed immune systems and usually reactivates from prior infection in either the recipient or donor. It is given as capsules for 3-6 months after transplantation. Some patients may still develop CMV once valganciclovir tablets are stopped and this will require treatment with either intravenous (through a vein) ganciclovir or oral (by mouth) valganciclovir.

Valaciclovir (Valtrex)
Valaciclovir is used for prevention and treatment for viruses know as herpes simplex (causing cold sores) and varicella zoster (which causes chickenpox). A large proportion of the population have been exposed to the herpes virus and it may become activated during times of stress, or when a person is immunocompromised (lowered resistance to infection, by medication or disease). This medication is not used routinely after transplant.

Bactrim/Resprim
One Bactrim/Resprim tablet is given three times a week to all patients after transplant to prevent a type of chest infection called Pneumocystis jiroveci Pneumon (PJP) which immunosuppressed patients may be prone to. This medication is continued for 12 months.

Pentamidine
This is an alternative drug to Bactrim, which is used as preventative treatment for PJP, for patients who are allergic to Bactrim or those who have a low white cell count. It is inhaled through a nebuliser once a month for 12 months. Must have at RPA

Fluconazole
Fluconazole is a medication used for treatment and prevention of yeast infections. An example of a yeast infection is thrush. Fluconazole may interact with some of the other medications, so it is important not to start or stop fluconazole without direction from your transplant doctor. It is usually stopped 1-2 months after transplant.
Antihypertensives
Antihypertensives are drugs used to treat high blood pressure. Patients taking Cyclosporin or Tacrolimus often get an increase in their blood pressure. If this occurs, a variety of medications can be used.

Listed below are other medications that may be required after a transplant:

Insulin
Insulin may be required for patients who have high blood sugar levels after transplant.

Oral diabetes medications
Some patients develop only mild diabetes that can be managed with tablets such as gliclazide (Diamicron) or metformin (Diabex, Glucophage).

Acid-lowering medications (proton-pump inhibitors)
Rabeprazole (Pariet), pantoprazole (Somac), esomeprazole (Nexium) and similar drugs are used to prevent the development of stomach ulcers that can be caused by stress and/or prednisone.

DRUG INTERACTIONS
Many drugs have the potential to interact with your transplant medications. Please check with your doctor about the possibility of any drug interactions with your transplant medications before commencing any new medication.

Drugs that may increase blood levels of tacrolimus/cyclosporin include macrolide antibiotics such as erythromycin or roxithromycin (Rulide), antifungal medications such as fluconazole, certain blood pressure medication (calcium channel blockers), and grapefruit juice.

Levels may be lowered by other medications, including rifampicin, St John’s Wort, and anti epileptics.

Over-the-counter drugs
Check with your physician before you take ANY over-the-counter medications, such as cold or cough medications. These medications may mask a serious infection that must be investigated by your doctor. Unless specifically ordered by your physician do not take aspirin or anti-inflammatory drugs such as ibuprofen (Nurofen), as they may cause stomach irritation and kidney impairment.

Paying for your drugs
Once you are discharged you will be responsible for paying for your own drugs. This can be expensive, especially at the beginning. You may be entitled to one of the various concession cards. Check with the Social Worker about this.

You will then be able to get your drugs at a reduced rate. Please talk with the pharmacist or Social Workers if you need further information about these schemes.

Compliance: a crucial factor
When you, as a patient, are said to be “compliant”, it simply means that you are, to the best of your ability, following the instructions of the doctors, nurses, and other professionals responsible for your care. Specific examples of compliance include:

- not missing any of your follow-up visits and laboratory tests
- exercising regularly and maintaining your weight
- learning all you can about the long-term care of your transplant

However, for transplant recipients the most important aspect of compliance is taking your medication exactly as the transplant team instructed you - without missing a single dose - even if you feel fine. For as long as you have a transplant, you will have to take immunosuppressive drugs. Not taking your immunosuppressive medication at the right time and in the correct amount is one of the most common reasons for rejection and transplant failure.
SECTION 16: PATIENT INFORMATION ABOUT DRUG TRIALS

Transplantation has been improving steadily over the years because of better surgical techniques and better use of immunosuppressive drug therapy.

In most transplant centres clinical trials are carried out with the aim of finding the best regime of immunosuppression to improve organ survival rates, decrease the number of rejection episodes and to reduce side effects.

The usual means of carrying out these trials is by comparing the “new” treatment with the best available standard treatment. This is called a controlled clinical trial.

Where does this fit in for me as a patient on the transplant list? The transplant team will discuss any clinical trials that the Liver Transplant Unit at Royal Prince Alfred Hospital is currently involved in. All trials are approved by the Ethics Review Committee at the hospital. You may be invited to participate in such a clinical trial, and if so, you will be provided with a written Information Sheet. By taking part in a trial you may have access to treatments that are not currently approved in Australia and will also be helping to advance medical science and thus improve prospects for patients in the future. Remember if you choose to participate in a trial it should be your choice. If you choose not to participate you will receive the standard treatment in use at the time.
SECTION 17: OTHER POST-TRANSPLANT PROBLEMS

You may not have any problems after your transplant but most people experience at least a few minor or possibly more serious problems. These are some of the problems transplant patients may experience:

Infection
You will be given fairly high doses of immunosuppressant medications during your early postoperative period to overcome the risk of your body rejecting your new liver. This will make you more susceptible to infection. You will be monitored for the presence of any infection on an ongoing basis while you are recovering in hospital following your transplant. Any infection that is of concern will be treated promptly with appropriate antibiotics.

During the first few weeks following transplant the most common sites of possible infection are your chest, (particularly if you are not coughing and doing your breathing exercises) and your wound.
If you had a lot of ascites prior to transplant, this tends to persist for a short period after the transplant operation. It will eventually disappear, but is prone to cause infection and leakage.

Wound Complications
If wound infections develop, treatment consists of opening the wound, changing the dressings, and allowing healing to occur spontaneously. You will also require antibiotic therapy. Occasionally infection may develop in the abdominal cavity, if this should happen it would be diagnosed and treated promptly. A surgical procedure may be required.

Diabetes
There is an increase in the frequency of diabetes in the first year following transplant. This is due to the side effects of two of the transplant medications, in particular, prednisone and Tacrolimus. This often settles down over time as the doses of your immunosuppressive medication are reduced.
Drugs that lower blood sugar levels may be required. This may take the form of tablets (oral hypoglycaemic agents) or Insulin by injection.

If it is likely that you will be discharged home requiring regular Insulin injections, education will be provided by specialist Diabetic nurses. Arrangements will be made for you to be followed by the RPAH Diabetes Centre or your own doctor.

CMV Infection
Prior to the routine use of valganciclovir (Valcyte) after transplant, this was quite a common infection that could cause fevers, aches and pains and diarrhoea. Now it is extremely uncommon early after transplant but may come on weeks to months after stopping valganciclovir. If you get this infection, you will receive anti-viral treatment (either oral valganciclovir or intravenous ganciclovir) and may require admission to hospital.

Other possible post operative problems
These include problems related to the flow of bile from your liver, either a bile leak (which usually results in abdominal pain) or the development of a stricture (narrowing) in one of the bile ducts which may cause abnormal liver tests and jaundice. There may be problems with flow with the blood vessels going into the liver. These complications may require invasive procedures or even surgery to correct.

Emotional changes to expect
Not only does transplantation involve many physical changes to the body, but it also means many emotional changes. It is a tense, anxious time for both patient and family while they live through the waiting period, the transplant itself and often a prolonged recovery period. Along the way they may encounter and have to cope with many problems as they occur.

The drugs given produce physical side effects that can be distressing to patients as they face changes in their body image and can also contribute to increased mood changes. Such mood changes may be irritability, depression and feelings of elation.

High blood pressure
High blood pressure may be caused by the tacrolimus/cyclosporin or prednisone. It this is
a problem you may require treatment with antihypertensive medication or alteration in your drug dosage.

**PJP (Pneumocystis)**
This is a lung infection that doesn’t harm healthy people even when we are exposed to it all the time. When the immune system is modified by drugs, this infection can cause a serious form of pneumonia, especially in the first six months after transplant. This is prevented by taking Bactrim/Resprim three times a week for the first year following transplantation.

**Osteoporosis**
Bone mineral density can decrease during the first 3 months after transplant, due to the high doses of immunosuppressant medication required to prevent rejection. This ‘thinning of the bones’ may result in fracture, particularly in the vertebrae (back-bones) or the ribs. Oral Calcium and Vitamin D supplements are given to prevent this. Other treatments are also available for patients at higher risk.

**MRSA Infection (Golden Staph)**
MRSA is a bacterial infection that can be acquired in hospital. It is a bacteria that is resistant to a number of antibiotics. If you should happen to acquire this infection while in hospital, you may be treated by an intravenous antibiotic (vancomycin). To stop the spread of this infection, you will be nursed in a single room or in a ward with other patients who have this infection. Visitors will be asked to wear protective clothing.

**VRE**
VRE stands for Vancomycin Resistant Enterococcus. Enterococcus is a bacteria that can be found normally in the bowel. On rare occasions it can go to other parts of the body and cause infection. Sometime VRE can be found in your body and not make you feel unwell or give you any signs or symptoms of infection. Most patients with VRE are colonised with the bacteria and do not have an infection. Patients with VRE may be isolated from other patients to prevent the spread of bacteria.

**Potential ongoing/long-term problems post transplant**

**Problems with Kidney function**
Regular blood tests will monitor your kidney function. Medication you are required to take following your transplant, particularly tacrolimus/cyclosporin can cause deterioration of your kidney function. Your renal function is monitored in all your regular blood tests. The transplant team will adjust your medications to minimise the risk of kidney dysfunction. It is a good idea for you to maintain a good fluid intake at all times, particularly in hot summer weather to minimise any adverse effects your medication regime may have on your kidney function.

**High cholesterol (hyperlipidaemia) and high blood pressure**
These are common problems after transplant. Other risk factors, which may influence the development of hyperlipidaemia, include age, diabetes and obesity. Dietary reduction in calories and fat intake is recommended, combined with exercise. Your lipid (blood fat) levels will be monitored at regular intervals following your transplant. Your blood pressure is also checked at each clinic visit. Many patients require ongoing treatment with antihypertensive medication and your doctor may suggest the use of cholesterol-lowering therapy.

Early recognition and treatment of high blood pressure, control of hyperlipidemia, control of obesity and good blood sugar control for diabetic patients are important in preventing **long-term cardiovascular problems**, such as heart problems or strokes.
SECTION 18:
OUTPATIENT VISITS

Following discharge your progress will be monitored in the Liver Transplant Clinic on 9 East.

You will probably need to attend two to three times in the first week following discharge from hospital, then once or twice a week for another week or two, and then less frequently as time progresses. After one year from transplantation most patients will only be required to come for clinic visits every 3 months. However, lifelong follow-up is necessary.

Preparing for your outpatient visits:

1. Check your medicine supply to see whether you have enough medication until your next visit. If not, remember to get a new prescription while at the clinic.
2. Do not take your morning dose of Cyclosporin/Tacrolimus (Neoral) until after your blood has been taken.
3. Bring your MEDICATION CARD, so that it can be updated.
4. If necessary, write down any questions you have so that you remember to ask them while at the clinic.

Post-op surgical appointment

On discharge, you will be given an appointment card to visit the surgeon around 6 weeks after your transplant operation. On the same day you may have a Doppler Ultrasound of your liver performed on Level 2 of the Missenden Medical Centre, 54-60 Briggs Street, Camperdown (Tel. No. 9550-4733). This appointment will also be made prior to discharge.
SECTION 19: FOLLOW-UP MEDICAL CARE

Dentist
1. Routine dental care should be maintained. However, gums may swell or bleed because of Cyclosporin therapy.
2. You should make your dentist aware of your medications, particularly of your Cyclosporin regime.
3. Cyclosporin may cause an overgrowth of your gums that will decrease when your dosage is reduced.
4. If you have your teeth cleaned or filled or require dental surgery, such as a tooth extraction, or root canal work, you will need to tell your dentist that you need antibiotics to prevent infection.

Ophthalmologist
Routine eye examinations are very important because prednisone may cause a change in your eyesight or blurry vision. You should alert your eye doctor to all of your medications, especially your prednisone. It is recommended that you not change your glasses prescription until your doses of prednisone have stabilised.

Pap smears and mammograms
Women should continue to have second yearly pap smears and gynaecological examinations. Examine your breasts regularly, one week after your period and report to your doctor if any lumps develop. Mammograms should be performed according to standard recommendations.

Screening for bowel cancer
Some patients are at increased risk of bowel cancer after liver transplantation. In particular, patients with a history of Primary Sclerosing Cholangitis, Inflammatory Bowel Disease, previous polyps or bowel cancer or a strong family history of bowel cancer should undergo regular colonoscopy after transplant.

Monitoring for osteoporosis
Regular bone density scans (DEXA) are recommended for patients with a history of thinning of the bones, or who require ongoing use of significant doses of prednisone. These are usually performed every one to two years.
SECTION 20: TRAVEL

The major aim of transplantation is to enable you to resume a normal or near-normal lifestyle. This includes resuming work and enjoying leisure activities.

Many people want to take a holiday after the Transplant Team has given them clearance. This is both welcomed and encouraged.

If you wish to travel, especially overseas or to a remote area, you need to make some extra plans. Check with the Transplant Team first, because there are special problems if you want to travel in some countries.

1. If travelling outside of Australia, you must carry a letter from your doctor detailing what medicine you are on, how much you are taking, and that the medicine is for your personal use.
2. You must leave all medicine in its original packaging.
3. Ensure you have enough supply of medications to last for the duration of your holiday. You should carry extra in case some are destroyed. If travelling overseas, put some medications in your luggage and carry spare stock in your hand luggage. This is in case of loss or theft of luggage.
4. You should make a note of where local hospitals are in case of a problem and have a contact number for RPAH to give them if you need to.
5. NEVER travel with a depleted stock of drugs - this is both irresponsible and dangerous.
6. You should travel overseas with some form of travel insurance that covers you for illness associated with your transplant and for other illnesses and accidents. You might find it very difficult, if not impossible, to obtain insurance coverage for transplant-related conditions. You should be aware that overseas medical treatment can be very costly.
7. Check with the doctors on the Transplant Team before receiving any vaccinations. Transplant patients MUST NOT receive live vaccines.
SECTION 21: VACCINATIONS

If you are planning a holiday, please check with the clinic about vaccinations.

YOU MUST NOT RECEIVE ANY LIVE VACCINES AT ANY TIME

Live vaccines:
- BCG
- Yellow fever vaccine
- MMR (mumps, measles and rubella) vaccine
- Varicella-zoster virus vaccine
- Smallpox
- Oral polio (live) Sabin vaccine

Vaccines which you may have:
- Tetanus toxoid
- Inactivated polio vaccine (IVP)
- Hepatitis B vaccine
- Hepatitis A vaccine
- Meningococcal polysaccharide vaccine
- Diphtheria
- Influenza
- Pertussis (whooping cough)
- Pneumococcal vaccine
- Cholera (in patients over 6 months of age)
- Typhoid (in patients over 12 months of age)

If you come into contact with chicken pox or other viruses, notify the Transplant Team immediately.

Check with the doctors on the Transplant Team before receiving any vaccinations.

We recommend that all patients have an annual ‘Flu Shot’. This can be obtained from your GP. Pneumococcal vaccine every 5 years may also be recommended for some patients.
SECTION 22: AFTER DISCHARGE

The whole purpose of your transplant is to return you to a normal lifestyle. There are very few restrictions. Here are some points to note that might answer some questions you have about your new lifestyle.

Activity and exercise
This is very important in maintaining your optimum health. It increases energy, reduces stress, aids sleep, improves digestion and helps your emotional and psychological stability.

Build up your exercising gradually from walking to more strenuous activities, such as running and cycling. Indoor/outdoor activities are limited only by threat of potential injury or limits of physical stamina. Swimming may be resumed after about six months. Once you are discharged you are encouraged to return to your normal activities. Your energy level will slowly increase. Each day you will find you can do more and more. Moderation is the key. You may take long walks or walk up and down stairs.

Muscle weakness is common in most liver diseases and it will be worse immediately after liver transplantation. You should maintain a regular exercise program that is geared for your individual progress.

Regular physical activity and exercise are necessary post-liver transplant in order to maintain normal weight, minimise the destructive effects of prednisone on muscles and bones and to reverse pre-transplant deconditioning. It will also increase energy levels and fitness, reduce stress and help emotional and psychological wellbeing.

You must maintain a regular exercise program, progressed specifically to your own individual needs.

Exercise - Guidelines
Frequency – daily - you should aim to exercise on a daily basis.

Intensity - light to moderate - you should still be able to talk whilst exercising.

Avoid strenuous activities particularly in the initial stages post-transplant. These can be resumed once your energy levels and physical stamina have improved.

Duration - up to 45min of continuous exercise - 15-20 mins if exercise is more strenuous.

Initially you may need to exercise for shorter periods several times a day until you build up strength and endurance.

Type - walking is recommended;

Walking is an easy, effective and inexpensive form of exercise, associated with very few injuries. Other safe forms of exercise include swimming and stationary cycling.

Running/jogging/jumping and other high-impact activities are not recommended due to the increased risk and severity of injuries.

Warm up/cool down;
5 minutes of each is encouraged to help prevent muscle tears and unnecessary soreness with exercise. Gentle stretching is also encouraged prior to exercising.

Sample of program progression:
- Week 1 walk 10min 2 x day
- Week 2 walk 15min 2 x day
- Week 3 walk 20min 2 x day
- Week 4 walk 30min 2 x day
- Week 5 walk 45min 1 x day & thereafter

Remember:
- start slowly & progress gradually;
- a physiotherapist is available for further advice.

Alcohol
People whose liver disease was caused by alcohol should never drink alcohol again.

Alcohol should be avoided for the first year after your liver transplant under any circumstances. Alcohol is processed by the liver and may produce changes in your liver function tests. These changes can be confused with signs of
rejection or liver infection. Moderate alcohol consumption may damage the new liver. If you wish, you may have an alcoholic beverage to celebrate special occasions. Please limit your intake to one to two glasses of wine or champagne or one to two glasses of beer.

People whose liver disease was caused by alcohol, or people who have a history of excessive alcohol use that is thought to have contributed to their liver disease, should not drink again. This is sometimes a difficult task, and issues surrounding life-long abstinence should be explored prior to transplant. If you feel you are having difficulties complying with this requirement following transplant, it is very important you discuss these issues with your transplant doctor or nurse who will arrange appropriate support.

**Pregnancy and birth control**

We advise you do not become pregnant within the first 12 months after transplant. If you do become pregnant inform your liver doctor as soon as possible.

The choice to have children is an important decision that is influenced by a number of factors that should be discussed with your partner, transplant physician, general practitioner and obstetrician/gynaecologist. Medications you are taking may have an effect on a developing foetus, therefore it is unwise to embark on an unplanned pregnancy.

Mycophenolate (Cellcept) is of particular concern in pregnancy and should not be used unless absolutely necessary. Women receiving Mycophenolate who are of childbearing potential must use effective contraception before, during and for six weeks after receiving Mycophenolate.

Female patients generally resume their menstrual cycle after liver transplantation. High-dose prednisone may stop the menstrual flow, but ovulation (the time when you are fertile) will continue. Therefore, you may become pregnant even though you are not yet having normal periods, so birth control is necessary. Ask your physician for advice.

**Contact phone numbers**

It is vitally important you notify your Transplant Nurses or the Reception Staff if you change your contact telephone number, even temporarily. We sometimes need to notify you urgently about blood test results and must have the correct contact telephone numbers at all times. If you have an email address, you should ensure we have it recorded.

**Smoking**

It is highly recommended you quit smoking. Research has shown smoking is associated with an increased risk of a number of diseases including heart, lung and some cancers. In the liver transplant patient smoking has also been associated with an increased risk of complications therefore it’s important for you to stop. If you require help to quit smoking please discuss with your doctor or nurse.

**Tattoos and body piercing**

There is a risk of increased infection with tattoos and body piercing therefore you should discuss with your liver doctor before having any. It is particularly important you do not have any within the first 12 months after transplant.

**Pets**

Usually there is no reason why you cannot keep pets after a transplant. However, the only exception to the rule is if you have birds, especially pigeons. Birds are known to carry a germ which can increase risk of serious lung infection. If you have birds please discuss with your liver doctor before transplant.

**Diet**

If you are underweight, you need to gain weight to ensure that you have adequate nutritional reserves for protection during any periods of rejection or infection. Being overweight increases the risk of developing other problems. Keeping your weight within an ideal range is therefore most important. The dietitian will be able to discuss with you what your target weight should be and how to attain it.
Driving
All States and Territories in Australia have laws about reporting health conditions that might affect a person’s ability to drive safely. These laws have been created to protect public safety.

The laws require drivers to report to the Driver Licensing Authority any permanent or long-term illness that is likely to affect their ability to drive safely.

Your doctor or other members of the transplant team will not normally communicate directly with the Driver Licensing Authority (RTA in NSW). However, your doctor will provide you with advice about your ability to drive safely and can provide a letter or report to take to the authority.

The guidelines list a number of conditions that drivers **MUST** report to the Driver Licensing Authority, if they wish to continue to hold a drivers license. These conditions include

- If the person has chronic liver disease and clinical evidence of hepatic encephalopathy
- If a person has had a liver transplant

In both conditions, a conditional license may be granted. Further information can be obtained from the AUSTRoads website at http://www.austroads.com.au.

Most people can resume driving about six weeks after the operation. Even if granted a conditional license, you should ask yourself the following questions before driving:

- Am I well enough to drive today?
- Am I experiencing side-effects from my medications that would interfere with my manual dexterity, such as severe tremors, blurry vision or light headedness?
- Am I experiencing significant discomfort around my scar area that would stop me from being able to brake suddenly?

Caution and restraint in this early post-operative period will help assure your personal safety and the safety of others.

Emotional issues
Although you will have been looking forward to the day when you leave the hospital, it is normal to feel slightly apprehensive and insecure. These feelings usually only last a few days. Once you realise that nothing awful is going to happen because you are not having your blood pressure checked regularly, you will soon gain your confidence and independence.

It may take time to adjust to your new healthy role, not only in yourself and your capabilities, but also in your relationships with your family and friends. They too have to adjust to accepting and treating you as normal and healthy. At the same time, you may miss the constant attention you have received before and throughout your transplant. It is important to remember that family and friends have been under enormous pressure as well.

Herbal remedies
Transplant patients are advised **not to take any herbal remedies** as abnormalities of Liver Function Tests have been reported after use of certain herbal preparations, while the effects of many herbal preparations on the liver are not known.

There have been a number of rejection episodes reported in patient’s taking the herbal preparation “St. John’s Wort”, which many people take for depression. Valerian is another preparation which is known to cause abnormality in liver function tests. These preparations may interact with the absorption or metabolism of your immunosuppressive medications, tacrolimus/cyclosporin and altering your blood levels.

Do not self-medicate with any medication other than those prescribed by your doctor.

Lifting
You may not lift anything that weighs more than 7kg (15lbs) - about the weight of an average bag of groceries - for eight weeks after your surgery.
Liver Support Group
The Liver Support Group does valuable work for liver patients. It also offers the chance for liver recipients and their families to get together socially. Ask at the clinic for more information or go to the website
http://www.liversupportgroup.org/.
An Application Form to join the Liver Support Group can be found on the website and is also included in the back of this Manual. Please photocopy it or tear it out if you want to join.

Nursing care after discharge
When a patient goes home after a transplant it is very rare for them to need full time nursing care. It may be necessary for a community nurse to visit to do daily wound dressings. The nursing staff will arrange this before you are discharged. Apart from that, you should be well enough to do most things, like showering and dressing yourself.

School and work
Following your transplant you should be able to return to your normal lifestyle. Most people are able to return to school or work. You will know when you are ready for this. Going back to work part-time, if possible, is a good way to build up your stamina.

You will be advised at the clinic about your fitness for work. Individual circumstances will vary.

Sexual activity
Sexual activity can be resumed as soon as you feel able. It is a good form of exercise! It may take a while to regain confidence and your sex drive, partly due to your medications and also your previous feelings and attitudes from experience of your illness. Please feel that you are able to discuss any concerns or worries with members of the Liver Transplant Team.

Skin cancer
There is a much higher risk of skin cancer amongst all transplant patients. Therefore it is most important to avoid sunlight for prolonged periods of time. Wear long sleeves and a hat at all times when outdoors and avoid being out in the sun between the hours of 11.00am to 3.00pm daylight-saving time and 10.00am to 2:00pm in Eastern Standard Time. Apply SPF50 or higher sun protection cream or lotion to any exposed areas of the skin. If you are sitting outdoors, you should sit in the shade.

Sport
You may wish to get involved in sport again. If you do, do it gradually. Ask at the clinic for more information about ‘come and try’ days with Transplant Australia (see below).

Transplant Australia
Transplant Australia activities include sports, social events, weekends away and fund raising activities. Transplant Australia organises the Transplant Games, held nationally and internationally. Phone: (02) 9531 2589 or visit www.transplant.org.au

REMEMBRANCE AND THANKSGIVING SERVICE - RPAH
The Remembrance and Thanksgiving Service is held annually at RPAH. This service is held for anyone who has been touched by organ donation or transplant.

ANNUAL ECUMENICAL ORGAN DONOR THANKSGIVING & REMEMBRANCE SERVICE
The Organ Donor Thanksgiving and Remembrance Service is held annually – usually in May. This service is held for anyone who has been affected by organ donation or transplant.

COMPLAINTS & FEEDBACK
Making a complaint will not affect your right to quality service and may help us to improve our service. If you feel there is difficulty in resolving your issue, please contact the Patient Representative on (02) 9515 5115. Positive feedback is encouraged and welcomed.
SECTION 23: COMMON TESTS PERFORMED IN PEOPLE WITH LIVER DISEASE OR AFTER TRANSPLANT

Ultrasound - This is the most commonly used technique to get a picture of the liver and bile duct system. Ultrasound involves using a transducer or handpiece to generate sound waves, which are bounced off the liver to produce an image of it on a television screen. In this way, ultrasound can show how big the liver is and whether there are any changes, lumps or areas of abnormality. It also shows the size of the bile ducts and whether they are blocked. If necessary, ultrasound can be used to measure blood flow through the veins and arteries supplying the liver (doppler ultrasound). Ultrasound is done after six hours of fasting. It is an easy and painless test and does not involve x-rays.

CT scan (Computed Tomography) - In this procedure, a series of x-rays are taken which a computer builds into a three-dimensional picture of the area under investigation. The liver, blood vessels, gall bladder, bile ducts and nearby organs such as the pancreas, spleen and kidneys can be seen, as can any cysts or tumours. It is usual to need to fast for 4 hours before the test. Just before the test is performed, you may be asked to drink a special liquid so that the stomach and intestines are more easily identified. The radiologist may inject a dye into the bloodstream to obtain a clearer picture of blood vessels. This dye may cause an allergic reaction in some people. If you know you are allergic to iodine or contrast dye, you should notify your doctor. If your kidneys are not functioning normally, your doctor may decide to perform the study without the injection of dye. A CT scan takes about 45 minutes and is performed lying down in a comfortable position.

Angiogram - This test is not required in all patients. It involves passage of a fine catheter into the artery in the groin, which is then passed internally up to the artery supplying blood to the liver. Contrast dye is injected through the catheter and x-ray pictures are taken of the blood supply of the liver. In patients with suspected or known liver cancer, this test may be combined with a CT scan.

MRI / MRCP (Magnetic Resonance Imaging) - MRI is another way of taking pictures of the liver and other internal organs, and does not involve x-rays. MRCP is a special form of MRI that allows examination of the bile ducts without insertion of any tubes or catheters. For an MRI scan, you have to lie on a narrow bed that slides inside a tunnel. People with claustrophobia (fear of closed spaces) may find this test difficult.

ERCP (Endoscopic Retrograde Cholangio - Pancreatography) - This test is not required in all patients. It is a special test for examining the bile ducts. An endoscope is passed down through the mouth and stomach and into the upper part of the small intestine. A special fluid that shows up on X-ray is then injected into the opening of the main bile duct at the point where it drains into the small intestine. The resulting x-ray picture is used to diagnose certain diseases affecting the bile ducts. Additional procedures can be performed at the same time, such as removal of bile duct stones, or insertion of a plastic tube (stent) if bile flow is impeded. ERCP may be associated with complications. You should discuss these risks with your doctor.

PTC (Percutaneous Transhepatic Cholangiogram) - With the use of sedation or local anaesthetic, a small needle or catheter is passed into the bile ducts through the skin and liver. Pictures are taken of the bile ducts. This procedure allows access to the liver so that procedures, such as treatment of bile duct narrowing, can be performed.

Endoscopy - The inside of the oesophagus (gullet), stomach and upper small bowel can be examined using a flexible telescope called an “endoscope”. This procedure is done using mild sedation injected into a vein and is usually not unpleasant. A similar device called a “colonoscope” is used for examining the large intestine.
endoscopy is commonly done before transplantation to check for the presence of varices, ulcers and cancer of the gastrointestinal tract. Your doctor will discuss the specific risks of an endoscopic procedure.

**Liver biopsy**

A liver biopsy involves collecting a small sample of tissue the size of half a matchstick from your liver by passing a needle through the skin into your liver. The sample is then examined under a microscope.

It is an important way that your doctor can determine the cause of a liver problem, and assess the severity of any damage. Liver biopsy usually requires admission to hospital for the day, and is performed by a radiologist during an ultrasound or CT scan. You lie flat on your back in bed as the doctor applies antiseptic to the skin over the right side of the rib cage then injects a local anaesthetic. The biopsy needle is then passed briefly through the skin and into the liver before being removed. The entire procedure takes a few minutes and generally causes only minor discomfort. Liver biopsy may occasionally be required prior to transplant, and is not uncommonly required after transplant if there is deterioration of liver blood tests. The biopsy is a critical test for assessing rejection, hepatitis, or other causes of liver disease.
Appendix A:

GLOSSARY

Acute: Occurring rapidly - commonly used by the public to convey seriousness or urgency. In medical terminology it only refers to the time course of a problem.

Acute hepatitis: Acute inflammation of the liver which is usually due to viral infection.

Albumin: One of the most important proteins made by the liver. Low albumin levels in the blood usually indicate poor liver function.

Alcoholic liver disease: Liver damage, caused by excessive consumption of alcohol, ranging from too much fat in the liver to cirrhosis.

Alpha-fetoprotein: A protein normally present in the foetus but occurring in high levels in primary liver cancer.

Alkaline phosphatase: An enzyme normally made by bile duct cells. If the bile duct is blocked, the level of alkaline phosphate in the blood rises.

Aminotransferase enzymes: Proteins that occur normally in liver cells which are released in increased amounts into the bloodstream when cells are damaged. Two of these enzymes - alanine aminotransferase (ALT) and aspartate aminotransferase (AST) - are commonly measured in liver function tests.

Anaemia: A condition in which the blood is deficient in red blood cells or oxygen-carrying proteins.

Antibody: Part of the immune system that helps the body fight infection and foreign substances.

Antigen: A substance foreign to the body (usually a protein) which causes the immune system to produce antibodies.

Anti-viral drugs: Drugs used to treat viral infections including viral hepatitis, CMV and herpes.

Ascites: Uncomfortable accumulation of fluid causing abdominal swelling. This occurs when the blood flow through the liver is obstructed. Ascites often occurs with cirrhosis of the liver. It may persist for some weeks after successful liver transplant.

Auto-immune: Immunity misdirected against the body instead of against an invading infection.

Auto-immune hepatitis: A form of chronic hepatitis which occurs when the body’s immune system attacks its own liver cells.

Autosomal recessive inheritance: An inherited problem which occurs only when a particular inherited gene is inherited from both parents.

Bile: Yellow-green fluid produced in the liver and stored in the gall bladder. Bile helps the body break down fats and digest fat-soluble vitamins.

Bile acids: Cholic and cheno deoxycholic acids made in the liver from cholesterol.

Bile ducts: Tubes which carry bile from liver cells to the gall bladder and duodenum.

Biliary atresia: Congenital condition in which bile from the liver cannot reach the intestine because the bile ducts have developed poorly or not at all.

Bilirubin: The breakdown product of old red blood cells excreted by the liver. Bilirubin is normally excreted in bile. If this does not occur, the concentration of bilirubin in the blood rises and leads to jaundice.

Blood pressure: The pressure of blood in the arteries. For blood to circulate through the body, the circulatory system must be under pressure to force blood through the system. When blood pressure is measured, the higher number, called the “systolic”, refers to blood pressure when the heart is contracting. The lower number, the “diastolic”, is when the heart muscle is relaxed.

Blood products: A general term for different components of blood which can be transfused into patients to replace various deficiencies.

Bone marrow cells: The cells in the bone where red & white cells and platelets are made.

Cholestasis: Failure of bile to flow from the liver through the bile ducts.
**Chronic:** Occurring over a long period of time. This term does not refer to the severity of a process, only its duration.

**Chronic active hepatitis:** Long-term liver injury due to inflammation of the liver.

**Chronic viral hepatitis:** Chronic infection of the liver due to the hepatitis viruses B and C.

**Cirrhosis:** The end stage of chronic liver disease from any cause. The liver is scarred and its function may be significantly impaired.

**Clotting factors/proteins:** Substances made mainly in the liver to help the normal clotting of blood. The ability of blood to clot is controlled by the presence of clotting proteins. Most of these proteins are made in the liver and exported into the blood. Declining liver function results in reduced clotting power. Patients with liver disease often have bleeding problems and lack of clotting factors is one of the reasons for this.

**Creatinine:** A product of muscle metabolism that is excreted by the kidneys. Creatinine level serves as a very good indicator of kidney function.

**Cross matching:** A test of compatibility between the potential donor’s and prospective recipient’s blood.

**Cytomegalovirus (CMV):** A very common virus that harmlessly infects many normal people. It causes lots of trouble in transplant patients because the drugs that prevent rejection of the liver allow this virus to be active. Virus activity can affect the liver, blood and eyes. It can be treated if necessary with a drug called Ganciclovir.

**Coma:** A state of drowsiness followed by loss of consciousness. May occur in liver failure.

**Computer Assisted Tomography (CT scan):** An X-ray technique using a computer reconstruction of multiple images of the body.

**Corticosteroids:** Drugs used to suppress inflammation, such as prednisolone, prednisone or hydrocortisone.

**Cryptogenic:** Literally means “unknown cause”. Some cases of liver cirrhosis have no known cause and are given the diagnosis “cryptogenic cirrhosis” to distinguish them from other known causes of cirrhosis such as alcoholic cirrhosis.

**Cytotoxic:** Damaging to cells, for example drugs used to destroy cancer cells.

**Defective virus:** A virus which needs the help of other viruses to grow, eg. hepatitis D.

**Dehydration:** Loss of water from body cells.

**Diabetes mellitus:** A condition of abnormal glucose metabolism. Blood glucose levels increase due to the lack of or low effectiveness of the hormone insulin. Also affects the way the body uses proteins and fats.

**Donor liver:** The liver provided to the recipient in a liver transplant operation.

**Donor:** Someone who provides an organ for transplantation.

**Doppler Ultrasound:** An easily performed, painless test that is often performed after liver transplantation and shows whether or not the blood flow to and from the liver is normal.

**Duodenum:** The first part of the small intestine joins the stomach to the jejunum.

**Electrolytes:** Minerals in solution in body fluids. The major electrolytes, sodium, potassium and chloride, influence the distribution of water in the body. Magnesium and calcium are also electrolytes.

**Encephalopathy:** Confusion or unconsciousness that can occur when someone has advanced liver failure or cirrhosis. It can be treated, but indicates that the liver disease is becoming severe.

**Endotracheal tube:** An airway tube inserted through the mouth leading to your windpipe to help you breathe during surgery.

**ERCP:** A special test for examining the bile ducts. An endoscope is passed down through the mouth and stomach and into the upper part of the small intestine. Fluid that shows up on X-ray is then injected into the opening of the main bile duct at the point where it drains into the small intestine. The resulting X-ray picture is used to diagnose certain diseases affecting the bile ducts.
Fatty liver: Excessive deposit of fat in the liver.

Fetor: A sweet smell on the breath of liver patients that results from an abnormal build up of certain chemicals in the blood.

Fibrinogen: A protein factor important in blood clotting.

Fibrosis: Formation of excess fibrous (scar) tissue in an organ such as the liver.

Flap: An uncontrollable jerking of the hands sometimes seen in advanced liver disease. A flap indicates poor liver function.

Foley catheter: A tube inserted into the bladder to drain urine.

Gastroenterologist: A physician who specialises in treating diseases of the digestive system and liver.

Glucose: A type of sugar found in the blood.

Graft: Your new liver.

Haematemesis: Vomiting up of blood. May result from bleeding from varices or a peptic ulcer (see below).

Haemochromatosis: Deposition of excess iron in the liver, skin, joints and pancreas. This is an inherited disease in which large amounts of iron are transported from the intestine, accumulate in the liver, and cannot be processed normally. Iron build up affects other areas of the body as well as the liver.

Haemoglobin: The red pigment in blood cells that carries oxygen to the tissues.

Hepatic: Referring to the liver.

Hepatic artery: The artery which carries blood to the liver. The portal vein is the other main source of blood flow to the liver.

Hepatic vein: The vein which drains blood from the liver towards the heart.

Hepatitis: Acute inflammation of the liver often caused by viruses, drugs, alcohol or toxins.

Hepatitis viruses: Viruses causing inflammation of the liver.

Hepatocytes: Liver cells.

Hepatologist: A physician who specialises in liver diseases.

Immune system: The body's natural system defending itself from viruses, infections or any foreign body (such as a new organ).

Immunosuppressive medication: A drug that suppresses the body's immune system. It helps prevent the recipient's own immune system from attacking and rejecting the new liver.

Imuran: Trade name for azathioprine (see above)

Inflammation: The end result of the reaction of the immune system to any foreign infection.

Interferon: A protein produced by the immune system to fight viral infection. It is given as an injection to treat chronic hepatitis C.

Intravenous (IV): The infusion of fluids, blood or drugs into a vein.

Jaundice: Yellow colour of the eyes and skin due to excess bilirubin in the blood. Usually occurs because the liver fails to excrete bilirubin in the normal manner due to liver failure or obstruction to bile flow.

Lipids: Another term for fats.

Liver: The largest organ inside the body with many functions, including manufacturing proteins and blood clotting factors, excreting bilirubin and storing iron.

Liver biopsy: The process of removing and inspecting a small sample of liver. A needle is inserted into the liver and a tiny piece removed to be inspected under a microscope.

Liver cancer: Malignant cells in the liver whether from a primary cancer (which originates in the liver), or, more commonly, a secondary cancer (which spreads from somewhere else in the body). Primary liver cancer usually arises in a liver that is already damaged through cirrhosis. Primary liver cancer may also be called hepatocellular carcinoma or hepatoma.
Liver failure: Failure of the liver to carry out its normal function. May result in jaundice, ascites or coma.

Liver function tests (LFTs): Blood tests to measure the function of the liver. These are blood tests that are ordered regularly by liver doctors. They give an indication of how well the liver is working and help sort out the type of problem that may be present. They are done daily immediately following transplantation. Abnormalities can indicate rejection, infection, side effects from drugs and many other things. Experience is required to determine what the results mean. Abnormal results do not necessarily imply that a serious problem is present.

Liver transplantation: The surgical removal of a diseased liver and its replacement by a donor liver.

Noncompliance: Failure to take medicine as prescribed or follow the advice of medical and nursing staff.

Obesity: Excess accumulation of body fat.

Oedema: Swelling of the ankles and legs due to an abnormal collection of fluid in the body and a deficiency of the blood protein albumin (see page 43). This is an effect of chronic liver disease.

Oesophagus: The tube between the mouth and stomach. Also known as the gullet.

Osteoporosis: A decrease in the density of bone associated with advanced liver disease and also with prolonged corticosteroid use. Bones with osteoporosis are more likely to fracture.

Platelets: Cells in the blood that help the blood to clot. Numbers may fall in cirrhosis.

Pneumonia: Inflammation of lung tissue (different from bronchitis).

Portal hypertension: High blood pressure in the portal venous system that carries blood from the intestine, spleen and pancreas to the liver. Portal hypertension can result in ascites or bleeding.

Portal vein: A large vein which carries the major blood supply to the liver from the intestine. Carries nutrients resulting from digestion of food.

Prednisone: A steroid hormone taken by most transplant recipients to help prevent rejection.

Prevalence: The number of people with a given disease at a given time.

Prophylaxis: The prevention of a problem. For example, antibiotics are often given to transplant patients in the first year after their operation to prevent Pneumocystis pneumonia - a complication of the anti-rejection drugs.

Red blood cells: Blood cells which carry oxygen attached to haemoglobin.

Small intestine: Part of the gastrointestinal tract that includes the duodenum, jejunum and ileum. The major site for digestion and absorption of food.

Spider naevi: Small red skin spots with spidery projections that indicate the presence of liver disease.

Spleen: An organ which breaks down ageing blood cells and is also an important part of the immune system.

Tacrolimus (Prograf, Advagraf XL): Most common immunosuppressive drug used after liver transplant.

Thrombosis: The formation or presence of a blood clot.

Tissue typing: A blood test done to evaluate the closeness of tissue match between organ donor and recipient (done before transplant).

Transfusion: Giving blood or blood products (such as platelets or plasma) through a vein.

Triglyceride: A type of body fat or oil made up of glycerol with three fatty acids attached. Triglyceride levels in blood rise after a meal, falling again as the fat is used for energy or stored as body fat. A continuing high level may occur with high alcohol intake or diabetes.
**Vaccination:** A technique to produce protective antibodies against an infection by exposing the immune system to a vaccine made of living or dead organisms.

**Valacyclovir (Valtrex):** An anti-viral drug that works against the virus that causes cold sores.

**Valganciclovir (Valcyte):** An anti-viral drug that works against a virus called CMV.

**Varices:** Large veins in the oesophagus which may develop due to portal hypertension, and which place the individual at significant risk of bleeding into the oesophagus or stomach.

**Viral hepatitis markers:** Antigens and antibodies measured by laboratory tests to indicate the presence or absence of viral infections that cause liver disease.

**White blood cells:** Elements of blood that fight infection.

**Wilson’s disease:** A disease due to excessive storage of copper in the liver and brain.
CONSENT FOR A LIVER TRANSPLANT OPERATION

I understand that liver transplantation is a treatment for liver failure and not a cure and that I will need to take drugs to suppress rejection indefinitely. These anti-rejection drugs have side effects specific for each drug and these have been explained to me. Patients treated long-term with these agents are at increased risk of infection and cancer development.

I understand there is a possibility (currently about 1 in 10) of death during the first year following the transplant operation. I am satisfied with the explanations regarding the risk of liver transplantation that I have received.

I have been informed that the details of my liver disease and of my transplant procedure will be discussed with relevant health professionals and that these details will be included on clinical databases run by the liver transplant unit, which will be used for clinical audit and research purposes. I am also aware that tissue taken from the organ at the time of the operation for clinical management reasons may also be utilised for research. I understand that signing this consent form does not interfere with my legal rights in the event of negligence.

SIGNED:........................................

WITNESS:......................................... DATE:..........................
Appendix C:

CONTACT NUMBERS

Liver Transplant Clinical Nurse Consultants: Sr Fiona Burrell
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Gastroenterology Registrar: After hours and Weekends. 9515 6111 and page

Chaplain
9515 6111

Dietitians
Ms Helen Vidot & Ms Joanne Heyman
9515 8053

Clinic appointments
9515 0056

Nurse Unit Manager
9515 7543 Sr Susan Virtue

Psychiatrist
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Transplantation Research at Royal Prince Alfred Hospital

The RPA Transplant Institute was established in 2006 to formally recognize the interdependence of best clinical practice and clinically based research at all levels. The scope of our research interests at RPA is as varied and as broad as our multi-disciplinary care team. Our central research theme is the provision of greater access to better and safer transplantation, and revolves around the shortcomings of the following two truths about current clinical transplant practice:

1. More people can benefit from transplantation than we have kidneys or livers to transplant.
2. The success of transplantation has been made possible by the combination of powerful drugs to control transplant rejection and our sophisticated ability to diagnose and treat the problems caused by those drugs.

Our Mission

The RPA Transplant Institute is the research heart of Transplantation Services at RPA. Our mission is to conduct high quality scientific and clinical research that will lead to cures for diseases and find solutions to one of the key challenges facing transplantation medicine, the need for immunosuppressant therapy and the side effects it brings.

We aim to advance the knowledge of transplant healthcare professionals and create treatments that will contribute to prolonged, improved health for all transplant patients. Through the education of patients, physicians and the wider community we will create a greater understanding of transplantation and the significance of transplantation as a critical means of prolonging life.

How can you help?

The RPA Transplant Institute has unparalleled clinical facilities and transplant results. Our challenging clinical service provides a stimulating environment for research. The endeavors of our productive clinical and laboratory research team require ongoing financial or equivalent support. Also, it is vital that we continue to grow and improve. Your donation will help us to attract and train the best and most enthusiastic young clinicians and scientists, just as we have done for the last 40 years.

For further information please call 9515 1965 or visit the website www.rpatransplantinstitute.com.au
Professional Websites

Please note that some of these websites are international sites. Organ allocation is country specific. For information on organ allocation in Australia please talk to your doctor or the Transplant Coordinator.

A. Liver Transplantation

Liver Transplantation: Medline Plus

Australia and New Zealand Liver Transplant Registry
www.anzitr.org

B. Liver Disease

Australian Liver Foundation
www.liver.org.au

Love Your Liver
www.loveyourliver.org.uk

American Liver Foundation
www.liverfoundation.org

Health Insite
www.healthinsite.gov.au/topics/Liver_Diseases

Canadian Liver Foundation
www.liver.ca

Children’s Liver Disease Foundation
www.childliverdisease.org
These medication stickers are provided as an educational teaching tool for transplant recipients and may not include specific medications, or generic equivalents, that your individual transplant team recommends or prescribes. Always follow the advice and training of your individual transplant team.

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