

INFORMATION MANUAL

for liver transplant recipients and their families



**AUSTRALIAN NATIONAL
LIVER TRANSPLANT UNIT**

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INTRODUCTION

Liver Transplantation

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 over 800 transplants. Over 2000 liver transplants have been performed altogether in Australia.

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, 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 hepatocellular cancer (primary liver cancer).

Liver transplantation is usually recommended when there is a progressive deterioration in your liver function. Liver failure is manifested by a number of physical and clinical symptoms e.g. 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 your blood results that suggest deteriorating liver function (e.g. low albumin, rising bilirubin and blood clotting abnormalities).

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 discolouration of the whites of the eyes and skin occurs because bile pigment can no longer be removed by the liver

SECTION 1

How the Liver Works

- 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 (impending coma) – 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 (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’)
- Treatment of encephalopathy includes use of specific medication such as lactulose syrup
- 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 (TIPPS)

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.

USE OF ALCOHOL & RECREATIONAL DRUGS IN PEOPLE WITH CIRRHOSIS

In many people with cirrhosis, alcohol has either caused or accelerated the disease process. Even small amounts of ongoing alcohol use can worsen liver function and lead to complications such as bleeding. People with cirrhosis awaiting transplantation should use no alcohol, and if alcohol has been a major factor in the disease should have used no alcohol for at least 6 months, and must continue lifelong abstinence.

Recreational or illicit drugs (amphetamines, marijuana, ecstasy, heroin, cocaine and other party drugs) can also adversely affect your physical and psychological health. The drugs can mask some of the symptoms of the liver disease making assessment of your health status much more difficult.

The ingredients and doses of these drugs are often unknown and this further increases the risk to your health. All recreational/illicit drugs should be ceased at least 6 months prior to transplant and life long abstinence is expected post transplanted.

Stopping use of alcohol or illicit/recreational drugs can be very difficult. If you are having difficulties with abstinence from alcohol or illicit/recreational drug use it is very important you discuss these issues with your doctor or nurse. Your doctor or nurse will arrange appropriate referral and support for you.

SECTION 2

Assessment

REFERRAL FOR TRANSPLANT

Ideally, patients with cirrhosis should be referred to the liver transplant unit when they develop evidence of deteriorating liver function, experience their first major complication e.g. ascites, variceal bleeding, spontaneous bacterial peritonitis (an infection that can develop in the abdominal fluid), encephalopathy or malnutrition.

Patients with hepatocellular cancer (primary liver cancer) and cirrhosis should be referred for assessment by the liver transplant team as soon as the tumour is discovered, so that optimal treatment can be decided.

TRANSPLANT ASSESSMENT

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:

1. Irreversible, progressive liver disease
2. The liver disease fails to respond to all other forms of medical and surgical treatment.
3. Absence of other major diseases
4. 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 7-10 days 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 urine collection to assess your renal 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

SECTION 2

Assessment

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 our 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 hepatologist, 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:

1. You are considered suitable for immediate transplant and your name is placed on the active waiting list
2. 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
3. There is may be 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 gets presented at a

SECTION 2

Assessment

meeting of the Liver Transplant Team. If the team are in agreement that there are no valid obstacles to your successful transplantation, you are formally placed onto the Active Waiting List to await a suitable donor organ becoming available for you.

MEMBERS OF THE TRANSPLANT TEAM AT RPAH

Physicians:

Professor Geoff McCaughan, Dr David Koorey, Dr Simone Strasser, Dr Robert Feller and Dr Nicholas Shackel

Surgeons:

Dr Deborah Verran, Dr James Gallagher and Dr Michael Crawford

Anaesthetist:

Dr Andrew Watts

Dietitians:

Helen Vidot and Joanne Heyman

Transplant Coordinators:

Graham Kyd, Nick Koutalistras and Ganson Govender

Social Worker:

Susan Clare

See page 47 for an outline of common liver tests performed in people with liver disease performed before or after the transplant.

Psychiatrist:

Dr Rob Gribble

Psychologist:

Ms Suzanne Roche

Drug and Alcohol Specialist:

A/Prof Paul Haber

Liver Transplant Nursing Staff:

Sr Margaret Gleeson CNC and Sr Fran Coble CNS

Theatre Sister:

Sr Jenny Watson CNC

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

Many patients with severe liver disease have lost a significant amount of their body fat stores and body protein stores by the time they are referred to the liver transplant unit. The most important nutritional goal whilst waiting for your transplant is to eat enough food to stop your body losing more fat and more protein. This may be difficult if your appetite is poor. You will really need to work very hard at eating and this job does not end until some months after the transplant. If you have been advised to restrict some foods, you will need to be more careful of the sorts of food that you eat but it is still important that you work very hard to keep up a high energy high protein intake.

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 doctors will discuss your individual requirements with you.

The most common restriction for people waiting for a liver transplant is a salt (sodium) restriction. If you have been advised to reduce your salt intake you will need to discuss this with one of the dietitians as salt occurs in many foods, both processed and naturally occurring. You will need some professional advice about reducing your salt intake at the same time as maintaining a high energy high protein intake. If you continue to eat foods with a high salt content it will be more difficult to control the fluid in your abdomen and legs.

Most people waiting for a liver transplant have an increased need for energy. People with significant liver disease also need to eat more protein. If you cannot eat enough to meet your body's increased energy and protein requirements you may be asked to use dietary supplements such as Ensure, Ensure Plus, Resource Plus, Polyjoule or Hepatamine or any combination of these.

SECTION 4

Social Support

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

People can require added assistance with practical concerns such as:

- Hospital procedures and documentation
- Financial concerns, such as Centrelink options
- Accommodation – in or near the hospital
- Travel issues e.g. IPTAAS (Isolated Patients' Travel and Accommodation Assistance Scheme)
- Provide education resources e.g. books, web pages about liver transplantation
- Lifestyle options such as recreation activities
- Organise interpreters and liaise with cultural community services
- Discharge planning e.g. community support referrals

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

You can contact the Social Worker through the Social Work Department telephone 9515 3787 or ask the staff of the liver transplant team to contact the social worker by page.

ACCOMMODATION

The hospital provides a limited amount of Patient/Relative accommodation for patients at RPAH and their relatives who normally live outside Sydney. This accommodation consists of a number of studio and 2 bedroomed units located at Carillon Ave., Camperdown. The cost is \$45 single and \$65 double per night. Accommodation bookings in the local area, can be made by contacting the RPA accommodation co-ordinator (Noeleen Franks) on 9515 9901. She will also be able to advise you regarding other accommodation options in the area.

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). It costs about \$30 per person per year.

TRAVEL AND ACCOMMODATION EXPENSES

You are responsible for your own travel and accommodation expenses. However, if you live more than 200 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.

SECTION 4

Social Support

NSW ISOLATED PATIENTS' TRAVEL AND ACCOMMODATION ASSISTANCE SCHEME (IPTAAS)

The Isolated Patients' Travel and Accommodation Assistance Scheme (IPTAAS) was established in the 1970s to provide financial assistance to people in isolated and remote rural areas of Australia who needed to travel more than 200km to access specialist medical treatment. The Scheme was transferred to each of the States in 1987 and apart from some minor changes, the eligibility criteria and levels of support established by the Commonwealth were largely retained in New South Wales.

NSW IPTAAS

The target population for IPTAAS in New South Wales is defined as people living in isolated remote areas of the State who:

- Are permanent residents of NSW;
- Need to travel more than 200kms one way to access specialist medical treatment or specialist oral health services not available at a local level;
- Have not received, or claimed by way of compensation, damages or other payment (e.g. Third Party) in respect of the illness or injury;
- Have not received benefits or claimed from a registered benefits organisation, such as private health funds; and/or
- Need to travel interstate to receive specialist medical treatment or specialist oral health service not available in NSW

To be eligible for financial assistance individuals must be referred by their GP to the nearest specialist in a particular speciality and live at least 200km one-way from the nearest specialist.

Assistance will not be granted where the medical service is available locally unless a valid medical reason is provided (Section A, Question 4).

AIR AND/OR UPGRADED TRAVEL ARRANGEMENTS

Approval for air travel must be obtained prior to travel by the referring GP or treating specialist from the IPTAAS office located within the Area Health Service in which a person lives. Medical reasons are the primary reason for approval of air travel. For example, where the individual's medical condition would be exacerbated by any other form of transport. Certification of the need for air travel and/or upgraded travel arrangements should be provided by the referring practitioner or treating specialist (in Part 6 of Section A of the IPTAAS claim form).

ACCOMMODATION BENEFITS

Benefits of up to \$30 per night are available towards commercial accommodation only when overnight stays are required during a period of treatment.

ESCORTS

Benefits may be paid in respect of an approved escort for patients who meet the conditions of eligibility for assistance under IPTAAS. Patients under 17 years of age are eligible for an escort. Where a patient is over 17 years of age, benefits for an escort will only be paid if the referring practitioner or treating specialist determines that it is medically necessary for an escort.

MANDATORY PATIENT CONTRIBUTION

IPTAAS is not a full reimbursement scheme. A mandatory patient contribution fee of up to \$40 is deducted from travel costs per claim. The mandatory contribution reflects the fact that other people living within the 200km limit also incur

SECTION 4

Social Support

travelling, meal and accommodation expenses in accessing specialist medical treatment, especially where frequent access is required.

VETERANS

Veterans, war widows and their carers may be eligible for assistance with travel expenses for treatment through the *Repatriation Transport Scheme* (Department of Veterans Affairs). If a veteran or war widow has claimed travelling expenses under the *Repatriation Transport Scheme*, they cannot also claim financial assistance for travel or accommodation expenses under IPTAAS.

A veteran or war widow will not be considered eligible for assistance under IPTAAS unless they have checked their eligibility for assistance under the *Repatriation Transport Scheme* first. If a veteran or war widow is not eligible for any assistance under the *Repatriation Transport Scheme*, they may be eligible to claim financial assistance under IPTAAS. To accurately establish eligibility to claim financial assistance through IPTAAS, veterans, war widows or their carers should telephone the nearest IPTAAS office (contact below) before making a claim.

REVIEW OF IPTAAS

A review of IPTAAS was undertaken in 1998 and a discussion on the review was issued for community comment in January 1999. After extensive consultation with peak professional and community groups, the recommendations of the review have been finalised and submitted to the NSW Minister for Health for his consideration.

HOW TO APPLY AND MAKING A CLAIM

Claims for assistance under IPTAAS are processed by the Health Service in the area where the patient lives. People interested in the scheme should contact their nearest IPTAAS Office

(see details below) to check their eligibility for financial assistance under IPTAAS before making travel arrangements.

An IPTAAS application form has three sections: one must be completed by the referred practitioner, another by the treating specialist and the other by the applicant. Application forms can be obtained from IPTAAS Offices as well as general practitioners, specialist and social work departments.

Claims for financial assistance under IPTAAS must be lodged within three months of treatment. Completed application forms should be sent to the nearest IPTAAS Office where the person permanently resides.

IPTAAS - Albury 02 6058 4455

IPTAAS - Bathurst 02 6339 5312

IPTAAS - Broken Hill 08 8080 1432

IPTAAS - Dubbo 02 6881 2264

IPTAAS - Goulburn 02 4823 7805

IPTAAS - Lismore 02 6620 2168

IPTAAS - Tamworth 02 6766 3946

IPTAAS - Taree* 02 6551 1229*

** People on the Mid North Coast who live outside the postcodes 2440 or 2443 – 2459 should contact Tamworth for those in the Lower North Coast and Lismore for those in the Macleay-Hastings region.*

(This information was provided by the NSW Department of Health.)

PARKING

Visitors may park in the car park behind KGV Hospital for \$5.00 per entry. A Temporary Parking Permit may be issued by the Parking Allocation Officer to resident patients and relatives. A charge of \$15.00 per week (minimum period one week) will apply. A deposit of \$20.00

SECTION 4

Social Support

(which is refundable) is required for a key card. Applications are processed at Transport Services between the hours of 7:30 am and 3:00 pm normal working days. Ask at the Enquiries counter of the Main Building for directions to the Transport Office.

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 +/- T-tube removal only. 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. 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 to 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:

1. www.tppp.netl/iver.html
2. www.cs.nsw.gov.au/gastro/livertransplant
3. www.gastro.net.au
4. www.transplant.org.au
5. www.myDr.com.au
6. www.hepatitisc.org.au
7. www.liverfoundation.org
8. www.nsw.health.nsw.gov.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
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.
6. Become thoroughly familiar with this book.
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 for you and your family to come and see him.

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)

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 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. He will 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 Margaret Gleeson or Fran Neveu-Coble at the AW Morrow Liver Centre,**
Monday to Friday: 8am-5pm
ph: 9515 7263 or 9515 7801
- **After hours:** Call Liver Registrar on-call
ph: 9515 6111
- **If you feel your illness is unrelated to your transplant or liver disease, you should see your local General Practitioner (GP)**

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. Only people who have died as a result of brain death are able to donate organs. Injuries or illnesses that result in brain death may include bleeding into the brain, accidents, infections or tumours. Potential organ donors must be brain dead, on a mechanical ventilator and in hospital (because without a supply of oxygen, organs would not be suitable for transplantation).

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 50%.

When consent for organ donation is obtained from the next of kin and following rigorous tests to confirm brain death, 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 will be allocated by matching the blood group, height and weight of the donor and the recipient.

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.

Many liver transplant units worldwide will offer a hepatitis C-positive donor liver (that does not have evidence of significant liver disease) to a recipient with chronic hepatitis C. In all patients with hepatitis C, the hepatitis C infection comes back after transplant, and there is no evidence that the course of the hepatitis C in the new liver is any different if the donor liver has hepatitis C as well. Such a liver will not be used in a recipient who does not already have hepatitis C.

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, called lamivudine) 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.

SECTION 6

The Right Donor for You

COMMUNICATION WITH THE DONOR FAMILY

The donor coordinator (the person who organises the donation) writes to the donor's family with information regarding which organs and tissues were transplanted and how the recipients are progressing. In accordance with the law, identifying information cannot be revealed to donor families or recipients. However, the donor family and the recipient may send anonymous letters to each other. For the family of an organ donor, receiving a card or letter of thanks from a transplant recipient is very special. If this is something that you would like to do at anytime following your transplant, we have set out some guidelines in order to maintain confidentiality. For information on how to write to the donor family, please contact the Liver 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.

Once the call has been received, you must commence fasting for surgery, that is, you must not have anything more to eat or drink.

When you arrive at the hospital, you should report to the Emergency Department. You should inform the staff that you have been called in to have a transplant.

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 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.

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. Cancellation is usually necessary when the donor liver has been found to be unsuitable, or the match between you and the donor is not compatible. These facts can 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

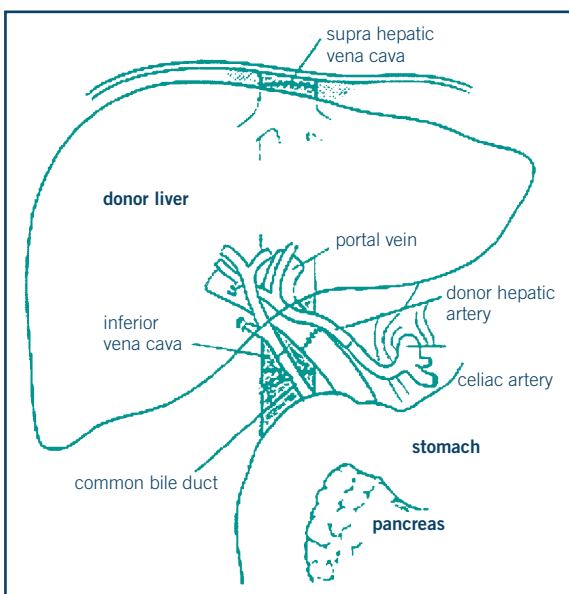
THE SURGICAL PROCEDURE

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 so-called “Mercedes-Benz” incision on the upper abdomen.

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

DIAGRAM OF THE OPERATION

Figure 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).

Figure 1

This is the conventional operation where your own inferior vena cava (IVC) is left in place. The donor IVC is “piggy-backed” onto your IVC.

The liver is attached to a number of vital structures, all of which have to be severed and rejoined. These are:

- The inferior vena cava (IVC), the major vein that drains into the heart, both above (suprahepatic) and below (infrahepatic) the liver;
- The portal vein, the vein that feeds blood from the intestines into the liver;
- The hepatic artery; and 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. Some of the saline will remain in the abdomen.

Three white drains called **Jackson Pratt** drains are inserted into your abdominal cavity. They will be attached to another suction container. The fluid (saline) which drains into them will be a little blood stained. This is quite normal. Your abdomen is closed in layers of muscle under the skin.

You will be transferred to ICU from theatre where the staff will observe the drainage and once it ceases the Jackson Pratt drains will be removed.

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.

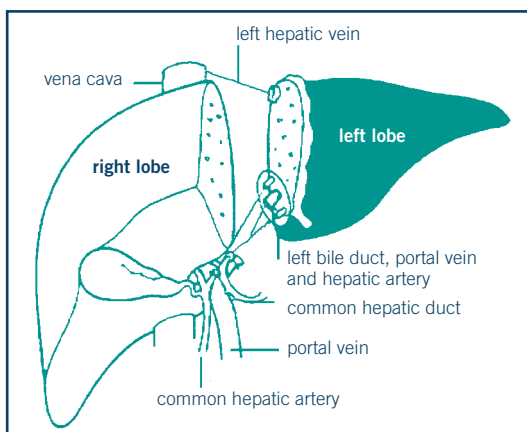
SECTION 8

The Transplant Itself

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 in 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.

Figure 2



Split liver transplantation. The left lobe is used for a child, and the right lobe is used for an adult.

TRANSPLANTATION FROM LIVING DONORS

Liver donation from living relatives to adult recipients is performed in many parts of the world, but is not currently offered in Australia. An adult recipient requires the right lobe of the liver, as the left lobe would be of insufficient size to sustain normal function. Severe complications and even death have been reported in living donors, and until the risks are reduced, it is unlikely that such a procedure will be offered routinely in Australia.

GALL BLADDER

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

SURVIVAL CHANCES

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

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 coming from your nose, a small tube to empty your bladder and a number of tubes draining fluid from your abdomen. Some patients will also have a soft rubber tube called a T-tube draining bile into a bile bag. 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 IV lines and drainage tubes will gradually be removed. All tubes should be able to be removed in the days following the operation although if you have a T-tube, this will not be removed until 6 to 8 weeks after the transplant.

THE TRANSPLANT WARD

After a short stay in the intensive care unit you will be transferred to the transplant ward on Level 9. Once in 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. Once the surgeons are happy that your bowel has recovered from the surgery, you will commence diet, fluids at first then on to a light diet and solid food.

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.

SECTION 9

After Surgery

RECOVERY TIME

The average stay in the Intensive Care Ward is 2 to 3 days. The average stay in hospital wards is 2 to 5 weeks, giving an average stay of 3 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 6 to 12 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 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.

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. Therefore, it is important that you be aware of signs and symptoms of 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
9. Flu-like symptoms – fever, joint and muscle pain

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 readjustment
- Intravenous steroids (IV methylprednisolone) (a 'pulse')
- Other immunosuppressive drugs such as Imuran, Cellcept or OKT3

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 DURING YOUR HOSPITAL STAY AFTER TRANSPLANTATION

Most patients do not start to eat until the second or third day after the transplant. Your first meal will usually consist of fluids and you will progress rapidly to a full ward diet.

By the end of the first week of eating you will find that the nursing staff, the doctors and the dietitian are all very concerned about how much food you are eating and you will receive constant inquiries about your food and fluid intake.

The reason for the concern is that most patients come to transplant in a malnourished state in spite of pushing themselves hard to eat. Many studies have shown that people who are poorly nourished take longer to recover and longer to heal their wounds after an operation and may be more susceptible to infections.

There are studies to show that liver transplant recipients need a high protein intake as well as a high-energy intake in the period after the operation. It also seems that liver transplant patients go through a period where they need lots of calories just to maintain their weight and in fact may lose weight rapidly even on a very high energy intake.

At this stage eating may seem to be one of the hardest things you have ever had to do. You will receive constant reminders from all the Transplant Team about eating enough food to help your wound to heal and to prevent further weight loss.

You will be asked to supplement your intake with high protein drinks such as Ensure Plus, Resource, Sustagen and milkshakes. You may find your drinks and canned fruit “spiked” with Polyjoule. Polyjoule is a form of glucose that does not have the sweetness of sugar or glucose.

You may receive large meals. You are not expected to eat all the food at one meal but rather to spread it out over the day, so that you spend your day grazing. Your family is encouraged to bring in some of your favourite home-prepared foods in an effort to increase your intake.

Occasionally it may be necessary to supplement a patient's intake with an overnight feeding through a fine tube which passes from the nose down the back of the throat and into the stomach. This happens when the team identifies that the patient is eating poorly, and not able to drink enough supplements in the presence of significant weight loss or poor wound healing.

The dietitian will monitor your weight and nutritional progress closely and you will constantly be pushed to increase your protein and energy intake. It will be reassuring for you to remember that these increased requirements do not last forever.

The dietitian will discuss your ideal or preferred weight with you. When you are nearing this goal you will need to reduce your food intake dramatically, as there is a great tendency to gain weight rapidly several months after transplant. Long-term weight control may 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 patients have high blood sugar levels after their transplant and this may be related to their medication doses. It is not necessary to go onto a special diet to control the blood sugar levels at this stage. Insulin is used to control blood sugar levels as it is much more important to eat enough foods rich in protein and energy or calories. As the medication is reduced the blood sugar levels often normalise.

SECTION 13

Nutrition Following Liver Transplantation

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

YOUR DIET WHEN YOU GO HOME AFTER TRANSPLANT

By the time most people leave hospital the emphasis on eating has changed. Some may have started to gain weight prior to leaving hospital. This weight gain will continue out of hospital with very little effort. At this time your taste buds may be returning to normal. Food is starting to taste as it should and you are able to enjoy your food with a renewed interest. Unfortunately this combined with the fact that you now have a liver that works and the high prednisone doses means that it is now all too easy to gain weight.

Prednisone has the effect of stimulating your appetite at the doses you are taking when you go home. Patients frequently say that they no longer know when they have eaten enough and that they are always hungry in the early days after discharge from hospital. They also say that this effect may last for years.

It is very important to reduce your food intake when you are within four to five kilograms of your goal or desired weight. You will gain the remaining weight without really trying.

Weight control is the most important nutritional issue when you are discharged after transplantation. Rapid excessive weight gain may affect your liver function tests. Regular exercise and a sensible eating plan will help to control your weight.

Your exercise program should start from the time you leave hospital even if you are still significantly underweight at this stage. Gentle regular exercise will not harm your new liver nor will it open up the scars.

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

- Try to eat regular meals
- Frequent snacking between meals will make it difficult 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 and are low in fat and calories
- High fat foods are high in calories or kilojoules. Try to choose the reduced fat alternatives at all times. These include lean meats, lean poultry, fish, reduced-fat spreads and low-fat or reduced-fat dairy products. Try to avoid fried foods and foods laden with oil or cream
- Fluids are important. Choose low calorie drinks such as iced water, tea or coffee without sugar, plain mineral water or soda water, diet soft drinks and diet cordial
- Vegetables, including potatoes and cereals such as bread, rice and pasta should provide the basis of your meals with smaller serves of lean meats, lean poultry, fish etc, rather than the other way around
- Choose fresh fruit or fresh fruit combinations to finish off a meal rather than the higher-calorie alternatives
- Sucking sweets or lollies or eating chocolates regularly makes it difficult to control your weight

Some patients may 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 will need to go on to a special diet to make it easier to control your blood sugar levels. Regular exercise also makes it easier to control your blood sugar levels.

SECTION 13

Nutrition Following Liver Transplantation

The dietitian will discuss your diet details with you and your family prior to discharge. 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 concentration of sugar.

You may find that your blood sugar levels normalise within twelve months after transplantation and that you are then able to eat an unrestricted diet. Remember, that if this does happen then you still have the ability to gain weight easily.

Fluid retention may be a problem even by the time you go home. Avoiding added salt and food with an obviously high salt content would assist in controlling this excess fluid. Many patients may have been on a salt restriction prior to transplantation. It is not necessary to limit your salt intake as severely after your transplant.

As transplanted patients are immunosuppressed it is important to be aware of the possibility of food poisoning. There are two bacteria in particular which may be a serious problem for patients who may be immunosuppressed. They are *Listeria monocytogenes* and *Vibrio vulnificans*.

Vibrio vulnificans is a bacterium that may be present in raw shellfish. It is particularly harmful in people with a suppressed immune system.

Although contamination with the bacteria is rare, all transplant patients are advised not to eat any raw shellfish.

Listeria monocytogenes is a bacterium that is more widespread in our food supply. It also loves to grow in the cold. Keeping foods in the refrigerator will not safeguard you from this “bug”. Careful handling of food and an awareness of possible contamination of specific foods will help prevent infection. You will receive a detailed brochure about this “bug” and its possible food sources from the dietitian when you have your transplant.

Finally, you always have access to the liver transplant dietitian. If you have any inquiries 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 – telephone number (02) 9515 8053. Alternatively you can ask the staff at the Liver Transplant clinic to contact the dietitian.

SECTION 14

Recurrence of Original Disease

Recurrence of your original disease may occur, particularly if your original disease is due to viral Hepatitis B or C. Hepatitis B recurrence after the transplant was previously fairly high risk without preventative treatment. Nowadays there is good preventative treatment available against recurrence, in the form of anti viral drugs that act against the Hepatitis B virus. Treatment is usually commenced in the pre-transplant phase and continues indefinitely post transplant in conjunction with regular monthly injections of Hepatitis B Immunoglobulin.

Recurrence of the Hepatitis C virus is universal following transplantation. The majority of patients will have a mild recurrence which will not cause significant problems for the first five years after transplant. Problems beyond this time may emerge. A small group of patients will develop a more severe recurrence with the development of cirrhosis within three to five years of transplantation.

Treatments are being developed to prevent and treat viral recurrence post transplant.

If you had a liver cancer in your old liver, there is a possibility this may recur after transplantation.

Your doctors will take all steps to minimise the chance of this occurring, but it is always a risk. Recurrence of liver cancer, may first be noticed in the bones or the lungs, rather than in the new liver. Your doctor will be constantly monitoring your condition.

Recurrence of primary biliary cirrhosis, autoimmune chronic active hepatitis and primary sclerosing cholangitis has been reported but seems very rare.

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.

LONG-TERM DRUGS

Life-long immunosuppression is necessary daily. Most patients have to 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.

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. 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 (FK506) (PROGRAF)

Stops special white cells (T-cells) from becoming active in your blood and attacking your transplanted liver.

Tacrolimus and cyclosporine 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:

- Impaired renal function (picked up on routine blood tests)
- Increase in blood pressure
- Neurological side effects that include headaches, mild tremors, insomnia, possible nightmares. Rarely patients may experience severe side effects including confusion, seizures and coma
- Raised blood sugar levels or diabetes.
- Increased risk of infection
- Raised potassium level
- Nausea and vomiting

CYCLOSPORIN (NEORAL)

Again 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:

- Impaired renal function (picked up on routine blood tests)
- High blood pressure

SECTION 15

Drugs Used in Transplantation

- Hot flushes or sweating
- Numbness or tingling in the hands, feet or mouth
- Shaking or trembling hands and feet, but this decreases with the reduction in dose over time
- Hair growth, most commonly noted on the face, arms and legs but this decreases with reduction in dose over time
- Overgrowth of gums, sometimes associated with soreness, swelling and redness, hence the need for regular mouth care
- Sinus drainage, “runny” or “stuffy” nose
- High risk of infection

HOW TO TAKE YOUR TACROLIMUS (PROGRAF) OR CYCLOSPORIN (NEORAL).

1. Tacrolimus/cyclosporin is given in two divided doses 12 hours apart usually taken at 10am and 10pm.
2. It is very important to take tacrolimus/cyclosporin regularly exactly as prescribed. You must not alter the dose or time taken without medical advice.
DO NOT RUN OUT OF CAPSULES.
3. Tacrolimus/cyclosporin is usually prescribed through hospital Pharmacies. In patients who are on stable doses, the medication may be available from your local pharmacy using an Authority Script.
4. 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.

PREDNISON

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:

- Stomach irritation that may occasionally cause stomach ulcers. Never take prednisone on an empty stomach so you should take it after breakfast each day
- Fluid retention, high blood pressure and swelling of the face, hands or ankles
- Weight gain due to an increase in your appetite and subsequent increase in food intake
- Increased risk of infection, especially in the first few months after transplantation while your prednisone dose is high
- 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
- Skin changes such as acne, rashes or bruising
- Mood changes that may swing from feeling “up” to feeling “down”

SECTION 15

Drugs Used in Transplantation

- Softening of the bones (osteoporosis) can be experienced after long-term use of steroids.

A diet high in calcium will help, although prednisone is reduced as soon as possible after transplant.

NEVER STOP OR REDUCE PREDNISONE WITHOUT MEDICAL ADVICE

IMURAN (AZATHIOPRINE)

Imuran 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 Imuran there is an increased risk of infection and an increased tendency for skin cancers.

Side effects include:

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

CELLCEPT (MYCOPHENOLATE MOFETIL)

One of the newer immunosuppressant medications similar to Imuran that may be added to some patients drug regime. It is taken twice a day 12 hours apart (as is Tacrolimus/cyclosporin).

Side effects include:

- Vomiting
- Diarrhoea
- Low white cell count

SIROLIMUS

Another of the newer generation of immunosuppressant drugs. It acts by stopping

special white cells (T-cells) from becoming active in your blood and attacking your transplanted liver. Unlike tacrolimus/cyclosporin this drug does not have any adverse effect on kidney function. It is taken once a day and the dose given is dependent on the level of the drug in your blood.

Side effects include:

- Hyperlipidemia (high cholesterol levels in the blood)
- Abdominal pain and diarrhoea
- Low red blood cell count (anaemia)
- Low white blood cell count
- Low platelet count (thrombocytopenia)
- Acne and rash

Caution: *If you are taking tacrolimus/cyclosporin, your Sirolimus should be taken 4 hours after your morning tacrolimus/cyclosporin dose to prevent absorption complications.*

OKT3

OKT3 is a specific antibody directed at cells in the immune process and is used for acute, severe rejection. OKT3 is one of the most powerful anti-rejection drugs and is used where other measures fail or a biopsy shows very severe rejection. It may be used to prevent rejection in very high risk patients. The first dose may cause acute flu-like symptoms.

VALACICLOVIR (VALTREX)

Valaciclovir is used for prevention and treatment for viruses known as herpes simplex (causing cold sores) and varicella zoster (which causes chicken pox). 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).

SECTION 15

Drugs Used in Transplantation

VALGANCICLOVIR (VALCYTE)

Valganciclovir is used to prevent CMV (cytomegalovirus) viral infection. This is a viral infection transplanted patients may be prone to because of their suppressed immune systems. It is given to all liver transplant patients for 3 months post transplant.

ANTIHYPERTENSIVES

Antihypertensives are drugs which lower 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.

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 (PCP) which immunosuppressed patients are sometimes prone to. This medication is continued for 12 months.

PENTAMIDINE

This is an alternative drug to Bactrim, which is used as preventative treatment for PCP, 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.

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.

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.

RANITIDINE (ZANTAC) OR OMEPRAZOLE (LOSEC)

These drugs help to prevent the possible 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 AVOID taking aspirin, as it may cause stomach irritation.

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.

SECTION 15

Drugs Used in Transplantation

Check with the Social Worker about this. As well, you will probably be able to take advantage of the Safety Net Scheme. Make sure you keep your Prescription Record up-to-date so that you will know when your safety net total is reached.

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 screened 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 pre-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 Sisters. Arrangements will be made for you to be followed by the RPAH Diabetes Centre or your own doctor.

CMV INFECTION

This is a viral infection which usually comes on about four weeks after transplant. If you are taking valganciclovir to prevent CMV, you may still develop infection after the medication is stopped (usually about 3 months after transplant). It may cause fevers, aches and pains or diarrhoea. It is important to promptly report any new fever or diarrhoea. If you get this infection, you will receive anti-viral treatment (Ganciclovir) intravenously for two weeks. This will require admission to hospital.

OTHER POSSIBLE POST OPERATIVE PROBLEMS

These include problems related to the flow of bile from your liver, either a possible bile leak or the development of a stricture (narrowing) in one of the bile ducts. 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.

SECTION 17

Other Post-transplant Problems

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. If this is a problem you may require treatment with antihypertensive medication or alteration in your drug dosage.

PCP (PNEUMOCYSTIS)

This is a lung infection that doesn't hurt healthy people even though 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. Calcium and Vitamin D is given to help 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.

T-TUBE CARE

Although not a routine procedure, some patients will have a T-tube placed at the time of transplant surgery. The T-tube is a flexible rubber tube that runs through the skin in your upper abdomen to the bile duct (the duct that carries bile from your liver to your intestine).

Prior to your discharge the T-tube will be clamped. It will remain in place for approximately six to eight weeks from the date of your surgery. The T-tube will be removed in the X-ray Department. It requires admission to hospital for at least two nights.

It is important that you observe the T-tube insertion site every day for any signs of infection such as redness or drainage. The site must be cleansed every day with Betadine and the T-tube strapped securely. If you feel the stitches holding the T-tube to the skin are breaking, you should notify the clinic, and arrangements will be made to have a couple of new stitches inserted.

SECTION 17

Other Post-transplant Problems

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 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:

- 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
- Do not take your morning dose of Cyclosporin/ Tacrolimus (Neoral) until **after** your blood has been taken
- Bring your medication card, so that it can be updated
- 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 surgeons in their Rooms at the Royal Prince Alfred Medical Centre within 2-4 weeks of discharge. On the same day you will need to have a Doppler Ultrasound of your liver performed on Level 2 of the Missenden Medical Centre, 54-60 Briggs Street, Camperdown (Phone 9550 4733). This appointment will also be made prior to discharge.

SECTION 19

Follow-up Medical Care

DENTIST

- Routine dental care should be maintained. However, gums may swell or bleed because of Cyclosporin therapy
- You should make your dentist aware of your medications, particularly of your Cyclosporin regime
- Cyclosporin may cause an overgrowth of your gums that will decrease when your dosage is reduced
- 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.

GYNAECOLOGIST

Women should continue to have regular pap smears and gynaecological examinations. Examine your breasts regularly, one week after your period and report to your doctor if any lumps develop.

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. Ensure you have enough supply of medications to last for the duration of your holiday. You should carry extra in case some are destroyed.
2. 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.
3. Carry identification at all times including a letter explaining your medical condition and listing your medications.
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. You might find it very difficult, if not impossible, to obtain such insurance coverage. 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.

ALWAYS REMEMBER TO PLAN AHEAD.

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
- MMR (mumps, measles and rubella)
- 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.

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 45 minutes of continuous exercise – 15-20 minutes 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;

Five minutes of each is encouraged to help prevent muscle tears and unnecessary soreness with exercise. Gentle stretching is also encouraged prior to exercising.

SECTION 22

After Discharge

SAMPLE OF PROGRAM PROGRESSION:

Week 1 walk 10 minutes 2 x day

Week 2 walk 15 minutes 2 x day

Week 3 walk 20 minutes 2 x day

Week 4 walk 30 minutes 2 x day

Week 5 walk 45 minutes 1 x day and thereafter

REMEMBER:

- Start slowly and progress gradually
- There is a physiotherapist available for further advice

ALCOHOL

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

BIRTH CONTROL

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 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.

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 that you notify us 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.

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

New medical guidelines for assessing a patient's fitness to drive came into effect on

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After Discharge

October 1st 2003. These guidelines apply throughout Australia and have been endorsed by all driver licensing authorities, the Royal Australian College of General Practitioners, the Australian Medical Association and other specialist bodies. These guidelines clearly outline the responsibilities of drivers, examining health professionals and licensing authorities in the licensing.

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 longterm 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 licence* may be granted. Further information can be obtained from the AUSTROADS website at [http: www.austroads.com.au](http://www.austroads.com.au).

Most people can resume driving about six weeks after the operation. Even if granted a *conditional licence*, 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 for 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

SECTION 22

After Discharge

“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 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. An Application Form to join the Liver Support Group is 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 SPF15 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. Contact sports should be avoided. The Australian Transplant Sports Association has “Come and try” days to encourage transplant recipients to try new and different sports. Ask at the clinic for more information.

TRANSPLANT SPORTS ASSOCIATION

The Transplant Sports Association is dedicated to the promotion of sport and recreation amongst organ transplant recipients. They cater for all levels of sporting abilities, from the “never

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After Discharge

played” to the highly competitive. Their activities include sports, social events and weekends away. Meetings are held monthly on a Sunday and usually consist of a social get together, BBQ and a sporting activity that may be a “COME & TRY” day. National Transplant Games are held every two years and the World Transplant Games are held every two years when the Nationals are not on. Contact Heather Edgell on (02) 9531 2589 or email feather4uidodo.com.au more information available on the Transplant Australia web site: www.transplant.org.au

WOUND CARE FOLLOWING DISCHARGE

If you are likely to need any wound dressings following your discharge home, arrangements will be made through the Discharge Liaison Sister for these to be undertaken by community nurses if necessary. This will be discussed with you as part of your discharge planning.

SECTION 23

Common Tests

COMMON TESTS PERFORMED IN PEOPLE WITH LIVER DISEASE (tests that may be performed on patients with liver disease before or after the 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

SECTION 23

Common Tests

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 bowel via the anus. 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 generally performed by a gastroenterology registrar or radiologist after an ultrasound. 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 inject 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.

Acyclovir: An anti-viral drug that works against the virus that causes cold sores.

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-feto Protein: 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.

Bile Salts: Sodium and potassium salts in bile acids. Produced in the liver, secreted into the bile and delivered to the intestine where they help the digestion and absorption of fats.

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.

APPENDIX A

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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 and 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 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 effect 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.

Cyclosporin (Neoral): A very important drug which virtually all transplant patients now receive. Its function is to prevent rejection of the liver by the body’s immune system.

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

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Defective Virus: A virus which needs the help of other viruses to grow, e.g. 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.

Ganciclovir: See CMV.

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.

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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).

Immunosuppressives: Drugs used to reduce the body's defence mechanism, the immune system. These drugs keep the body from rejecting the transplanted organ, but they also reduce the body's ability to fight off infection.

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 (or hepatocellular cancer) usually arises in a liver that is already damaged through cirrhosis.

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.

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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 above). 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.

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.

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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.

APPENDIX B

Australian National Liver Transplantation Unit



THE CHILDREN'S HOSPITAL
WESTMEAD



DEPARTMENT OF SURGERY
UNIVERSITY OF SYDNEY



ROYAL PRINCE ALFRED
HOSPITAL

In association with the RPAH Department of Upper Gastrointestinal Surgery and the AW Morrow Gastroenterology and Liver Centre

Director: Professor GW McCaughan

Surgeons: Dr PJ Gallagher, Dr DJ Verran, Dr GJ Stewart, Dr MD Crawford, Dr A Shun (Paed)

Hepatologists: Prof GW McCaughan, Dr D Koorey, Dr S Strasser, Dr M Stormon (Paed), Dr N Schackel

CONSENT FOR A LIVER TRANSPLANT OPERATION

request that a liver transplant operation be performed on me. The nature of the operation has been explained to me by Professor/Dr _____

The process of organ donor selection and retrieval has been explained to me. I am aware that the donor livers may not be entirely normal, but every effort has been made to screen the donor for transmittable disorders. There can be no guarantee that the donor does not have such a disorder (e.g. known or unknown at this time including infection or cancer). Donor livers can sometimes have fatty deposits or other abnormalities, not recognised before implantation, which can cause slow initial function and occasionally transplanted livers do not function adequately, which may necessitate the need for re-transplantation. I am aware that it is usual practice of the ANLTU to use organs from donors with primary tumours localised to the brain, as the risk of tumour transmission in these cases is extremely low. I am aware that in some circumstances I could be transplanted only a portion of a donor liver, if the organ has been thought suitable for a split procedure for use in a child as well as an adult.

The development of complications of the operation have been discussed with me, these include infection, bleeding, poor function and rejection of the liver.

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 projects.

I understand that signing this consent form does not interfere with my legal rights in the event of negligence.

SIGNED: _____

WITNESS: _____ **DATE:** _____



APPENDIX C

The Liver Support Group - Membership Application

Name: _____

Address: _____

City/Town: _____ State: _____ Postcode: _____

Phone: (home) _____ (work or mobile): _____

Email: _____

Transplant Date (if applicable): _____

NEWSLETTER

To enable us to produce a newsletter that is of both use and interest, please take a few moments to jot down some notes or questions that you may have.

For more information contact: Mark Rosser – President

The Liver Support Group, 4 Hickory Street, Woonona, NSW 2517

Phone/Fax: 02 4285 9901 **Mobile:** 0418 231 824 **Email:** rosserm@bigpond.com

APPENDIX C

The Liver Support Group



The Liver Support Group Inc was founded on the 10th of November 1992. It was established to aid transplantations patients with emotional support where possible. Over the past 11 years the group has grown to provide the following services.

THE GOAL OF THE GROUP TODAY IS TO:

- Provide peer support to liver patients and their families
- Demonstrate the quality of life that may be obtainable after a liver transplant
- Offering opportunities to talk and meet with others that have experienced what they are or will be experiencing
- Offering support to carers and their families
- Providing some financial assistance
- Moral support
- Practical support – many members have valuable expertise in various fields
- Raising funds to aid research projects
- Heighten the community's awareness of Transplantation within Australia
- Provide a regular Newsletter to keep people informed. Informal meetings, be it face to face or by phone or email
- The Liver Support Group Website is currently under construction and upon its completion will be a simple way for people to keep up to date and in contact with other people in the same position

HOW DO WE ACHIEVE THIS?

- Through various fundraising activities, such as raffles and the monthly stall
- Provide a regular Newsletter to keep people informed and informal meetings, be it face to face or by phone or email
- Canvass for Corporate sponsorship
- Assist in patient education schemes/days

COST OF MEMBERSHIP

The cost of membership is \$5.00 per family per calendar year (1st January to 31st December).

NOTE: *to be able to vote within the group it is necessary to be a financial member. Membership forms should be completed and cheques made to The Liver Support Group and forwarded to the address below.*

CONTACT DETAILS

If you would like further information on the group or becoming a member of the group, please contact:

Mark Rosser

President

Phone: 0418 231 824

Fax: 02 4285 9901

Address: 4 Hickory Street Woonona NSW 2517

Email: rosserm@bigpond.com

APPENDIX D

Contact Numbers

RPAH Switchboard:

Phone: 9515 6111

Liver Transplant Sisters:

Sr Margaret Gleeson

Monday to Friday: 8am-5pm

Voicemail: 9515 7263

Phone: 9515 6111 and page no 80883

Sr Fran Neveu-Coble

Monday to Friday: 8am-5pm

Voicemail: 9515 7801

Phone: 9515 6111 and page no 88984

Sr Jennifer Watson (Theatre Sister)

Phone: 9515 7275 and page no 86542

Liver Transplant Registrar:

Monday to Friday: 8am-5pm

Phone: 9515 6111 and page

Gastroenterology Registrar:

After hours and Weekends

Phone: 9515 6111 and page

Liver Transplant Physicians:

Phone: 9515 7268 or switch 9515 6111

Chaplain:

Phone: 9515 6111

Dietitians:

Ms Helen Vidot and Ms Joanne Heyman

Monday, Tuesday and Thursday

Phone: 9515 8053

Clinic Appointments:

Besmirela Berberovic

Phone: 9515 7268

Liver Transplant Administration Centre

Monday to Friday: 9am-5pm

Phone: 9515 7275

Nurse Unit Manager

Sr Fiona Burrell

Phone: 9515 7543

Psychiatrist

Dr Rob Gribble

Phone: 9515 6111 and page no 80135

Psychologist

Ms Suzanne Roche

Phone: 9515 7426

Social Worker

Susan Clare

Through Switch

Phone: 9515 6111

Transplant Coordinators:

Mr Graham Kyd, Mr Nick Koutalistras,

Mr Ganson Govender

Monday to Friday: 9am-5pm

Phone: 9515 7274 or 9515 6111

After hours and weekends

Phone: 9515 6111 and page

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ROYAL PRINCE ALFRED
HOSPITAL

A tradition of excellence since 1882

Missenden Road, Camperdown

Hospital Phone: 02 9515 6111