



TheAlfred

TRANSPLANT PATIENT EDUCATION MANUAL

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INTRODUCTION

This transplant resource file has been specifically designed for transplant recipients, because we understand that you have specific, ongoing needs.

It will help measure your progress and the health of your transplanted organ and also provide you with general information relevant to all transplant recipients.

In addition, this simple format will enable you to share your progress with your healthcare professionals, including your transplant team, GP, pharmacist, dietician and dentist, at each visit.

Important information regarding you and your transplant can be recorded in the diary, such as your contact details, medication details, test results and appointments.

Your transplant team will provide you with specific instructions and therapies for your type of transplant, as all transplants are different. This information and relevant documents can be stored within this file for easy access and safety and we encourage you to customise this folder to suit your individual needs.

Please note, whilst the information within this file is accurate at the time of printing, it is to be used as a guide only and is not intended to replace any advice given to you by your transplant unit and treating doctor. It is also recommended that you consult with your transplant doctor and/or transplant unit before altering any therapy or treatment.

Good luck as you embark on your transplant journey!

POST TRANSPLANT ISSUES

After a transplant some medical problems may arise and the most common are outlined below.

Infection

One of the effects of taking anti-rejection medication is that it reduces the body's ability to fight infection because it dampens your immune response. Infections are common in transplant patients, and can include bacterial, viral and fungal infections. It is recommended that you avoid sources of known infection. This includes people who have a cold or a viral illness such as chicken pox, measles or mumps. Your doctor may recommend that you get a flu vaccination each year to help protect you from an influenza related illness.

You will be susceptible to other viruses such as Epstein-Barr Virus (EBV) which causes glandular fever, and Cytomegalovirus (CMV). CMV is generally harmless and many people in the community have been exposed and carry the virus in their system. However, in an immuno-suppressed person active disease may develop at any time, but is more prevalent during the first 6-12 weeks after transplant or after being treated for an episode of rejection. Symptoms may include a high temperature and flu-like illness. **It is important to report any of these symptoms to your transplant team.**

If you are CMV positive on blood tests, a course of antiviral treatment will be required. The Herpes viruses that cause cold sores (Herpes Simplex Virus; HSV) and chicken pox (Varicella Zoster; VZV) can be dormant in the body for years without symptoms. However, immunosuppressive medication and stress following surgery means that your immune system will become weakened and thus these viruses may become activated. You may experience cold sores (due to HSV) or shingles (due to VZV) and genital herpes may also be reactivated. Antiviral medication will be needed and your doctor will give you either a cream for the lesions or a course of oral or intravenous medication. Please refer to the information in "Preventing Infection" in The Caring for Myself section.

High Blood Pressure (Hypertension)

Hypertension is very common after transplantation. This is in part due to the anti-rejection medications Cyclosporin and Tacrolimus. Early recognition and treatment is important in preventing long-term vascular problems. You may be required to regularly monitor your own blood pressure or your doctor can monitor your blood pressure at each visit. Hypertension may be difficult to control and may require several different medications to achieve good control. Be aware that some antihypertensive medications can interact with your anti-rejection drugs, so check with your transplant unit or GP before commencing on them.

Some simple steps to assist the maintenance of good blood pressure control include:

- Regular exercise
- Balanced diet -avoid excessive dietary salt and weight gain

- Compliance with anti-hypertensive medication

Kidney (Renal) Function

Some of your immunosuppressive drugs (eg. cyclosporin and tacrolimus) can damage the kidneys and regular blood tests will help to monitor your kidney function (i.e. urea, creatinine and electrolytes). If you have a pre-existing kidney dysfunction from your original illness, which may worsen with these medications, your transplant team will adjust your medications to minimise the risk to your kidney function. Other drugs can increase the levels of cyclosporin and tacrolimus and can cause kidney function to deteriorate. Please refer to the list of immunosuppressant drug interactions in the section “my medication”. **You should never take any non prescribed health products or medications, such as herbal remedies, without consulting your transplant doctor first.**

It is important to remain well-hydrated, paying particular attention to your fluid intake at all times, especially in summer. You should drink 2 litres or more of water a day unless you are told to restrict your fluid intake. If you experience problems with diarrhoea or vomiting seek medical advice, as dehydration may increase the concentration of cyclosporin/tacrolimus in your blood, increasing the risk of kidney dysfunction.

Increased levels of cholesterol (Hyperlipidaemia)¹

Hyperlipidaemia is a common problem after organ transplantation. Other risk factors which may influence the development of hyperlipidaemia include: age, diabetes, smoking, obesity and hypertension. Reduction of a high blood cholesterol level with diet, exercise and medication, as recommended by your doctor, is essential in those at risk. Consulting a dietician, either at your transplant centre or on medical referral, will assist you with dietary changes. If this is unsuccessful, a cholesterol lowering medication may be required, or your doctor may modify your immunosuppressive regimen. Be aware that some medications may interact with your immunosuppressive medication and affect your liver function tests or precipitate muscle damage. Please discuss any concerns with your doctor.

1. Cupples SA, Ohler L. Transplantation Nursing Secrets. Philadelphia, Pa: Hanley and Belfus; 2003; p 275

Onset of Diabetes After Transplant

Following transplantation, some people may develop diabetes (high blood sugar levels). It can be related to the immunosuppressive drugs you are taking, although you may have pre-existing risk factors that contribute to the development of diabetes after transplant. You will be taught to monitor your blood sugar levels frequently, in the early months of transplant. If you have consistently high blood sugar levels, you may need a dietician review and you may have to take medication to lower your blood sugar levels.

Diabetic medication may be in the form of tablets (oral hypoglycaemics) or if your body is resistant to these tablets you may have to have insulin injections. If you are already

insulin dependent, changes in dose may be required frequently. Your transplant team will assist you with your diabetes management. You will need to have further information and education from a diabetes nurse educator and possibly a diabetic specialist. You can help reduce your chance of getting diabetes by exercising, eating healthy foods and maintaining your weight.

Poorly controlled diabetes can affect health in the following ways:

- Kidneys – decreased function
- Eyes – Retinopathy
- Vascular disease – Poor circulation to lower limbs and heart disease.²
- Neuropathy – nerve damage

Monitoring Diabetes

It is **essential** you monitor your blood sugar levels at home for the rest of your life. Your transplant nurse or diabetes nurse will educate and teach you how to do this. Ask for a referral to Diabetes Australia so you can purchase your own machine and equipment at a government funded price. Often blood sugar levels (BSL's) can become uncontrollable during an illness. **It is essential to remember to bring to your appointments your blood sugar diary, so your results can be reviewed.**

Metabolic Bone Disease (Osteopaenia / Osteoporosis)

Bone mineral density (or thickness) decreases during the first 3 months after transplant due to the high dose of immunosuppressive medication required to prevent rejection. With dose reduction of medication over the first year, bone density should return to near pre-transplant levels.

2. New-onset diabetes after transplantation:2003 international consensus guidelines
Davidson J, Wilkinson A, Dantal J, Dotta F, Haller H, Hernandez D, Kasiske B, Kiberd B, Krentz A, Legendre C, Marchetti P, Markell M, Woude F, and Wheeler D. *TRANSPLANTATION* Vol 75, SS3-SS24, No 10, May 2003

Patients on long term prednisolone may be monitored by a DEXA scan (like an X-Ray but with less radiation) to assess bone density. Your transplant doctor will recommend how often you need to get it done. Your doctor may reduce or cease your prednisolone or treat persistent bone thinning (osteopaenia) with bone strengthening agents.

Nerve (neurologic) Disorders

Many patients experience some form of neurological complication particularly in the early post transplant period. Headache, tremor, pains in the limbs, numbness or prickle sensations in the feet and heightened sensitivity in the skin or hair follicles is often related to drug levels. Please discuss these symptoms with your doctor or transplant nurse. Often they will abate when your medication is adjusted.

Blood Cell (Haematological) Problems

After your transplant, a low red cell count (anaemia), low white cell count (leukopaenia) or low platelet count (thrombocytopaenia) may be related to chronic disease before your transplant or to some transplant medications. In addition, in solid organ transplantation a low platelet count may be caused by viral infection, in particular Cytomegalovirus (CMV). Your blood cell levels can be monitored by regular blood tests and, if necessary, your doctor can recommend the best treatment options for you.

Cancer (Malignancy)

Patients who take immunosuppressant drugs are at an increased risk of developing skin cancers (most commonly) or malignant disease such as lymphoma and solid organ tumours. Men must remember to do monthly testicular self-examination, and women should examine breasts monthly and have a yearly PAP smear. **All transplant recipients must be especially vigilant in examining their skin for suspicious spots and lesions.** Some lesions include: solar keratoses (sun spots), squamous cell carcinoma (SCC) and basal cell carcinoma (BCC). By surgically removing a suspected skin cancer, it can be sent for testing to check its type and whether it has been completely removed. Transplant units recommend a yearly review by a dermatologist, or more frequently if required. In the transplant setting cancers can spread to other areas of the body rapidly, however regular examinations can help prevent this occurring. These examinations and skin cancer precautions are discussed in the section “Caring For Myself” and the following changes should be reported immediately:

- Bleeding from the bowel
- Breast / testicular lumps
- Suspicious or changing skin lesions

MY MEDICATION₃

Anti-Rejection (Immunosuppressive) Medications

The normal function of the immune system is to protect the body against infections and cancers. It does this by recognising the organisms that cause infection as foreign, releasing chemical signals that bring other white blood cells to the area and then destroying them. This is known as the “immune response”. Unfortunately, your immune system also recognises your transplanted organ or tissue as not belonging to you and may try to destroy it as well. This is called **rejection**. The purpose of anti-rejection medication is to prevent this from happening. The time at which you are at highest risk for this happening is in the first few months after transplantation, with the risk reducing over time. However the risk of developing rejection always remains. Rejection may be acute (quick) or chronic (over a long period of time) and may be classified from mild to severe. It is essential that you always take your medication as prescribed, and on time, to reduce the chances of rejection developing.

Immunosuppression therapy protects your new organ from rejection, and missed doses of these drugs may expose you to the risk of rejection of your transplanted organ. Symptoms of rejection vary in different types of transplants, and you may even be symptom free, with the diagnosis of rejection identified on tissue biopsy or blood test results. It is important to continue regular blood tests to monitor both transplant function and the levels of immunosuppressive drugs in the blood. Rejection is usually always treatable. You may require a short stay in hospital for a biopsy and intravenous medication, and your current medication regime may require dose adjustment. At times an alternative medication may be introduced.

A variety of new, as well as tried and true immunosuppressive medications have been developed over many years, to become very specific in their actions in preventing rejection. Each transplant unit will tailor these medications to your individual requirements.

As with all medications, there are things you need to be aware of such as drug interactions and side effects. Before you take any new medications (including over the counter and naturopath medications) or alter your current medication, you must consult with your transplant doctor first. This is vitally important as any changes may seriously harm the health of your transplanted organ. Each of the following drugs works in a different way to prevent rejection. You may be on as many as three different immunosuppressive medications in the early phase after your transplant, or as little as one in the long term. These will be prescribed on an individual basis, taking into consideration type of transplant and other current medical concerns such as poor kidney function, blood counts, hypertension and previous rejection episodes.

3. © 2004 Australian Medicines Handbook Pty Ltd.

AZATHIOPRINE

(Imuran→, Thioprine→, Azamun→, Azahexal→, GenRx Azathioprine→)

Action: Acts on the bone marrow by decreasing the production of blood cells that can attack your transplanted organ (will affect red and white cells and platelets).

Dose: The dose will vary according to your white cell count.

This medication is usually given in the evening, a few hours after the evening meal, as some patients experience heartburn.

Side Effects: Heart burn (dyspepsia)

Low red blood cell count (anaemia)

Low white blood cell count (leukopenia)

Low platelet count (thrombocytopenia)

Nausea and vomiting

Sun exposure

These side effects settle quickly when medication is adjusted.

CYCLOSPORIN (Neoral)

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

Dose: Taken twice a day, 12 hours apart, at the same time each day.

The dose is variable and will be adjusted according to the level of drug in your blood.

To assess the concentration of cyclosporin in the blood the following tests will be done:

Trough (or C0 levels) – a blood sample will be collected before you take your morning dose, approximately 12 hours after your evening dose. Some transplant units monitor the cyclosporin level at this time and adjust the dose on the trough level of cyclosporine in the blood.

Peak (or C2 levels) – a blood sample will be collected 2 hours after taking cyclosporin, as this is when the drug reaches its highest concentration in the blood. Some transplant units monitor the cyclosporin level at this time and adjust the dose on the peak level of cyclosporin in the blood.

Side effects: Increased hair growth (hirsutism)

Swelling or overgrowth of the gums (gum hyperplasia)

High blood pressure (hypertension)

Diabetes

Impaired kidney function

High cholesterol in the blood (hyperlipidaemia)

Hand tremor

Headaches / blurred vision

Nausea, vomiting, diarrhoea

Burning sensation in the hands and feet

Bone disease

Acne

MYCOPHENOLATE MOFETIL (Cellcept)

Action: Acts on the bone marrow by decreasing the production of blood cells that will attack your transplanted organ. Similar to Azathioprine but uses a different method of suppressing your immune system.

Dose: Taken twice daily, 12 hours apart, at the same time each day.
Should be swallowed whole with a glass of water and can be taken with or without food.

Side effects: Vomiting
Diarrhoea
Low white cell count (leukopenia)

MYCOPHENOLATE SODIUM (Myfortic)

Action: Acts on the bone marrow by decreasing the production of blood cells that will attack your transplanted organ. Similar to Azathioprine but uses a different method of suppressing your immune system.

Dose: Taken twice daily, 12 hours apart, at the same time each day.
Swallow whole, with a full glass of water.
If you take it with food, always take it with food.
If you take it without food, always take it without food.

Side effects: Vomiting
Diarrhoea
Constipation
Nausea
Indigestion
Low white cell count (leukopenia)

SIROLIMUS (Rapamune)

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

Dose: Taken once a day, at the same time each day.
The dose is variable and will be adjusted depending on the level of drug in your blood.
To assess the concentration of sirolimus in the blood, a blood sample should be collected just before you take your daily dose, approximately 24 hours after your last dose.

Side effects: Hyperlipidaemia (high cholesterol levels in the blood)
Abdominal pain and diarrhoea
Low red blood cell count (anaemia)
Low white blood cell count (leukopenia)
Low platelet count (thrombocytopenia)
Acne and rash

EVEROLIMUS (Certican)

Action: Similar to Sirolimus, when taken in combination with Cyclosporin it will reduce the dose of cyclosporin required.

Dose: Taken once a day, at the same time each day.

The dose is variable and will be adjusted depending on the level of drug in your blood. To assess the concentration of Everolimus in the blood, a blood sample should be collected just before you take your daily dose, approximately 24 hours after your last dose.

Side effects: Hyperlipidaemia (high cholesterol levels in the blood)

Abdominal pain and diarrhoea

Low red blood cell count (anaemia)

Low white blood cell count (leukopenia)

Low platelet count (thrombocytopenia)

Acne and rash

The dose should be taken at the same time as cyclosporin.

4. Certican Approved Product Information, Novartis Pharmaceuticals Australia Pty Ltd, 15 February 2005. Seradyn Inc. (2003) "Innofluor® Certican Control Product Insert", Seradyn Inc Indianapolis.

STEROIDS

(Prednisolone / Methylprednisolone / Hydrocortisone)

Action: Reduces the number of circulating white cells in the blood and dampens down the inflammatory response.

Dose: The dose is variable and will depend on the protocol of your transplant unit.

Side effects: Mood swings / difficult sleeping

Increased appetite

Weight gain / roundness of face

Acne

May cause increased blood sugar levels –

For better sugar control diabetics may be advised to:

- check your blood sugar levels more frequently
- split your prednisolone dose eg. ½ with breakfast and ½ with your evening meal
- adjust your diabetic medication

Osteoporosis

Refer to the section on Metabolic Bone Disease for information on steroid effects on bones.

TACROLIMUS (Prograf)

Action: Stops special white cells (T-cells) from becoming active in your blood and attacking your transplanted organ. This drug is similar to cyclosporin in the way it works, but has some different side effects.

Dose: Taken twice a day, 12 hours apart, at the same time each day.

It should be taken 1 hour before food or 2 hours after (i.e. on an empty stomach).

The dose is variable and will be adjusted according to the level of drug in your blood.

To assess the concentration of tacrolimus in the blood: a blood sample should be collected just before you take your morning dose, approximately 12 hours after your evening dose.

Side effects: Impaired kidney function
High blood pressure (hypertension)
Diabetes
Burning sensation in the hands and feet
Headache
Nausea
Diarrhoea
Vomiting
Bone disease
Hair loss (alopecia)

These are just some of the medications that your transplant unit may prescribe for you. Information regarding these and other medications you may be required to take will be provided by your transplant unit and can be added to this section.

Drug Interactions

Many drugs have the potential to interact with your transplant medications. Please consult your transplant doctor or pharmacist if you are unsure about any new medication you are taking.

Some medications that are available “over the counter” without prescription including herbal medication, can interact with your prescribed medication, or may be harmful to your transplanted organ. Please check with your pharmacist or transplant team before taking such medication. Patients with Cystic Fibrosis should take a snack dose of pancreatic enzyme supplement with medication to ensure maximum absorption of anti-rejection medications.

CARING FOR MYSELF

Preventing Infection^{5/6}

Infection as a complication of your transplant is discussed in the section “Post Transplant Issues”. **A high temperature is likely to be a sign of infection.** Your transplant co-ordinator/nurse will give you instructions about monitoring your temperature at home, and when to contact the transplant unit.

Other signs of infection include but are not limited to:

- Chills or shaking
- Redness / swelling or pain in your eyes, ears, throat, skin, joints or abdomen
- Rash / sores or blisters on the body
- Diarrhoea / vomiting
- Burning or blood when passing urine, or passing urine more frequently
- New or persistent cough / shortness of breath / wheezing or chest discomfort.

There are some simple precautions you can take to help minimise the risk of acquiring an infection:

- Take your temperature regularly and particularly if you feel unwell
- Talk to your doctor about having a flu vaccination each year
- Avoid close contact with people who are unwell
- Maintain your personal hygiene, including washing your hands after using the bathroom, after patting pets, and before eating
- Always wear gloves when gardening and a face mask if using potting mix.

5. Cupples SA Ohler L. Transplantation Nursing Secrets. Philadelphia, Pa: Hanley and Belfus; 2003; pp 247-270

6. Randlops, Sxholz K. Self Care guidelines: Finding Common Ground. Journal of Transplant Coordination 1999;9 (3): 156-160

Dental Care

After an organ transplant you are more likely to have problems with your teeth, including infection and gum overgrowth caused by your immunosuppressive medications. Good oral hygiene is very important.

In order to minimise dental complications:

- Brush your teeth regularly with a soft toothbrush
- Visit your dentist every six months
- Check with your transplant unit before any dental procedures – you may need antibiotic cover
- See your doctor or dentist immediately if you have swollen, tender or red gums

Skin Care

People after an organ transplant are often more likely to have problems with their skin including skin cancer.

In order to minimise skin complications:

- See a dermatologist at least yearly for a skin cancer screen
- Report any suspicious looking skin lesions immediately

- Avoid direct exposure to the sun, remember to wear protective clothing, sunscreen and a hat - **SLIP, SLOP, SLAP!**

Vaccinations⁷

Transplant recipients **should not** receive any “live” vaccines including:

- Measles, mumps, rubella
- Polio Sabin (oral)
- B.C.G
- Yellow Fever Vaccine
- Varicella Zoster (chicken pox)
- Typhoid (Typh-vax oral)

Check with your transplant unit which vaccinations you should or should not have. Please note that transplant recipients should avoid intimate contact with other people who have received live vaccines for 48 hours after immunisation occurs.

7. Australian Technical Advisory Group on Immunisations (for National Health & Medical Research Council).

The Australian Immunisation Handbook. 8th Edition. 2003. Available at <http://www.health.gov.au/immhandbook>. Accessed June 17, 2005

Nutrition

Dietary requirements after transplantation will vary depending on the type of transplant you have had, your medical condition, and transplant unit practices. Please check with your transplant unit dietician and doctor regarding any special dietary instructions you may require.

General guidelines for healthy eating include:

- Eat foods that are low in fat (particularly low in saturated fats), sugar, salt and use salt sparingly.
- Drink adequate fluids, especially water
- Ensure good food hygiene is maintained

Drinking alcohol may lead to dehydration and decreased blood flow to your new organ.

Smoking

Smoking is not recommended whilst waiting for and following your transplant. Every year, thousands of Australians die as a result of smoking. Cigarettes are full of poisons that can have serious effects on your health, including shortening your life. Other good reasons not to smoke include reducing your fitness, reducing fertility, your skin appearance and effects on your family including children. For information regarding giving up smoking call the QUIT line in your State.

Exercise^{8/9}

Exercise is an important part of post transplant recovery, and helps improve your overall sense of well being, fitness levels and weight control. The level and type of exercise you can undertake will vary depending on the individual, and their clinical condition. Please check with your transplant physiotherapist and doctor regarding safe

exercise practices for you. Water activities such as swimming should be discussed with your transplant doctor or nurse before undertaking them, due to the potential risk of infection.

General guidelines for exercise after your transplant include:

- Introduce regular, gentle exercise (such as walking or cycling) into your lifestyle
- Gradually build your fitness level by increasing the time and intensity of your exercise activity
- Avoid contact sports (such as football)
- Care should be taken by heart transplant recipients when exercising due to the physiological effects of cardiac denervation.
- Check with your transplant team regarding weight restrictions with regards to lifting.

Consider joining Transplant Australia and you will have the opportunity to participate in social activities, “Come and try” days, recreational and sporting activities, National Transplant Games, World Transplant Games. See www.transplant.org.au for more details.

8. Bahruth, AJ. What every patient should know: pretransplantation and post transplantation. *Critical Care Nursing Quarterly*. 2004 27:31-61

9. Cupples SA Ohler L. *Transplantation Nursing Secrets*. Philadelphia, Pa: Hanley and Belfus; 2003; pp 247-270

Sexual Health

Resumption of sexual activity post transplant is very much an individual issue. Your transplant unit should provide you with education about resuming sexual activity in your current physical condition. It is not uncommon for males and females to experience some loss of libido and /or sexual dysfunction after an organ transplant. There may be several reasons for this, and we encourage you to discuss any sexual problems you may be experiencing with your doctor, transplant coordinator or nurse. Be assured, more often than not the problem can be resolved.

If you have multiple sexual partners, we encourage you to practice safe sex, to minimise the risk of acquiring a sexually transmitted disease or an unplanned pregnancy.

Women’s Health Issues¹⁰

Women should remember to continue or improve your previous health maintenance routines. You should have yearly pelvic examinations and PAP smears. Women over the age of 40 (particularly if there is a family history of breast cancer) should have a yearly mammogram. Your GP can help you enrol in a screening programme.

Female transplant recipients, who ceased menstruation due to their illness before transplantation, may find that their menstrual cycle resumes after their transplant. Be aware that prednisolone may stop menstrual flow, but ovulation will continue and therefore pregnancy can occur. If you are considering pregnancy, please discuss this with your transplant doctor or transplant coordinator. Your doctor will also be able to help you decide which form of contraception is safest and most effective for you.

Men's Health Issues¹¹

Screening for testicular and prostate cancer should be undertaken after your transplant. Early detection is vital in the treatment of these cancers. Your GP can perform a regular testicular and prostate examination, and men over the age of 50 years (or 40 years for those with a family history of prostate cancer) should have a prostate specific antigen (PSA) blood test every two years. Also, young males need to know the importance of storing sperm should complications occur. For both male and female patients who have ureteric stenting, you will require a cystoscopy (look into the bladder) at the time of stent removal.

10. Cupples SA Ohler L. Transplantation Nursing Secrets. Philadelphia, Pa: Hanley and Belfi ns; 2003; pp 279-280

11. Prostate Cancer Foundation of Australia. Available at: <http://www.prostate.org.au/BAM-DL.htm>. Accessed July 2006.

Fertility & Pregnancy¹²

Successful pregnancy is possible post transplant. However, most transplant units will advise that becoming pregnant or fathering a child should not be considered until your health and transplanted organ are stable. Transplant recipients should always discuss plans for pregnancy with their transplant team to ensure the safety of the mother and baby. **Some medications may reduce fertility or pose an increased risk to the mother or baby if taken during pregnancy.** The risk of rejection of the transplant organ and the effects of pregnancy on the transplant recipient's health must be considered.

Driving

Transplant recipients need to check with their local statutory authority as to any restrictions that may be in place regarding people who have undergone an organ transplant. Your transplant unit will be able to give you an indication as to when you can expect to resume driving a motor vehicle. Please be aware of any physical or mental limitations that may make it unsafe for you to drive.

Returning To Work

Resuming your previous job or commencing a new one is an important goal for many transplant recipients. Consult with your transplant unit regarding the timing of this. It is usually recommended that a transplant recipient waits for approximately 3 months before returning to work (or school). This is due to the fact that the risk of infection is significant and medical follow up is intensive, during this time. Your medical condition and any physical limitations should be taken into consideration, and if possible, try returning to work or school on a part-time basis until energy levels improve.

12. Coscia L. *et al.* Pregnancy and Parenthood after Transplant. Pittsburgh, PA. International Transplant Nurses Society, 2005.

Travel Information

Some issues to consider:

- Choose your destination carefully taking into consideration your current health, physical limitations and the sanitary conditions in the country you will be travelling. Find out where the nearest medical assistance would be should you become unwell.
- Consider travel insurance. You may have to shop around to find a company who will provide insurance for someone who has undergone an organ transplant.
- Ask your doctor for a letter outlining the medications you are taking and a brief medical history. Medic Alert tags are also a good idea.
- Discuss vaccination with your doctor.
- Make sure you pack more medication than you need.
- Seal your medication in an airtight container protected from heat and light.
- Carry some of your medication in your hand luggage and some in your suitcase, in case either is lost.
- Take your transplant team contact numbers and obtain contact details for hospitals/transplant units in the area you are travelling to.
- Take a basic medical kit with a thermometer, and medicine to treat cuts, bruises, nausea and diarrhoea.
- Take your medicine at the time that you normally would in Australia. You will need to convert this to local time in the city you are visiting (eg if you take your medicine at 8pm Australian time, you should take it at midday if you are travelling in the UK, or 5pm if you are travelling in Thailand).
- Ask your transplant coordinator / nurse for assistance if you need help adjusting your medication times.

Donor / Recipient Correspondence

You have received your transplanted organ or tissue through an unconditional gift from your donor and their family. By law, transplant units are not allowed to pass on any information which may reveal the identity of your donor or their family.

This is to ensure both their privacy and yours. Should you wish to say thank you to your donor family, this can be done by way of an anonymous letter or card. Your transplant coordinator or nurse can provide you with guidelines to assist you in writing a letter, and they will facilitate the process of sending it to your donor family.

Please speak to your transplant coordinator / nurse for more information.

Psychological / Social Issues

by Cathy Martin, Social Worker, Princess Alexandra Hospital, QLD

Receiving a transplant is something which many people with end-stage organ disease look forward to, and yet when the transplant occurs patients describe a large variety of emotional responses. Some of these emotions are ones which patients and families report as being exactly what they expected, whilst there can be other feelings that somewhat surprise them.

These feelings can include:

- Joy

- Elation
- Relief
- Hope for the future
- Fear
- Frustration
- Pain
- Feelings of grief for the donor family (if a deceased donor transplant)
- Guilt that a donor family is grieving when the patient and family are celebrating a new transplant
- Anxiety about accommodation, finances or work matters which might need to be attended to quickly
- Worry for the future
- Excitement for the future
- Anxiety about the transplanted organ rejecting or failing altogether, either now or in the future
- If the new transplant is a kidney transplant, there could be guilt that others at the dialysis unit have not got their transplant yet, or may not even be on the waiting list hence will never have the opportunity to experience freedom from dialysis
- Other feelings not identified in this list so far.

Feelings are normal and are our way of processing our experiences and the ways we respond to things. The type and extent of feelings experienced are sometimes an amplification of the usual feelings one has. For example, if someone often feels “flat” they might feel even more “flat” after the surgery. Or if someone is more naturally exuberant or outgoing they might feel even more so for a while after the transplant. Also, different medications can affect your mood. There is no such thing as an “abnormal” feeling after the transplant. The feeling is simply a barometer of what you are trying to process and make sense of. Without feelings or thoughts, we would all be unresponsive to anything, be unable to make judgements and would have no idea what to do next. Feelings enable us to get in touch with what the mind is processing, help us to identify what aspects of our life and psyche need more support, and to identify which aspects of us are doing well. Often people will say that they should not express their feelings or should try and suppress them altogether. Many people don’t want to seem “silly” or to “waste the time” of others by expressing their own feelings. Sometimes people think it is a sign of weakness to express their feelings. Whereas the expression of feeling and even asking for help is in fact a sign of strength, maturity and willingness to move on. Feelings are normal. What is **not normal** is when sad, negative, despairing, destructive, abusive or suicidal feelings dominate your thought patterns. When there is a sense that things are just not right, it is vital that you take responsibility for obtaining help and support.

How do you go about getting help?

You can obtain help in several ways:

1. Ask your transplant unit doctor or nurse to contact one of the transplant unit social workers or the psychiatrist.

2. Discuss your concerns with your GP, who in turn could refer you either to the above mentioned social worker or psychiatrist; or who could refer you to a local private or community-based counselling service.
3. You can phone your Hospital Social Work Department directly, leave your name and details; and one of the transplant unit social worker's will return your call and arrange your first appointment.

Cost of help?

There is no cost to see a social worker or psychiatrist at a public hospital. If you choose to see a private practitioner, there is likely to be a cost, but you would be advised about these at the time of your appointment or when you make a booking.