

Renal Unit

Information for patients following a renal transplant

Introduction

We are delighted that you had a kidney transplant and are now recovering. This booklet gives you advice on living with your transplant, how to avoid problems and how to make the most of your new lease of life. This booklet aims to answer many of the common questions which patients ask. We hope that you find the information and guidelines useful. However, if you have any further questions however small they may seem, please do ask us and we will try to help.

Useful telephone numbers

Main Switchboard – University Hospitals of Coventry and Warwickshire	02476 964000
Ward 22 ECU –Transplant area	02476 966591
Ward 50	02476 968258/02476 968256
Ward 50 Day Unit	02476 967703
Patient transport services	01926 310312
Renal Social worker Balvinder Vraitch / Parmjeet Grewal	02476 968263/ 02476 968263
Renal Dietician	02476 966132/ 02476 966134
Renal Secretary (For appointment bookings and cancellations)	02476 968315/ 02476 968290/ 02476 968287/02476 968289/ 02476 968288/ 02476 968714
Pharmacy home care team	02476 966044/02476 966765 Email:pharmacy.homecare@uhcw.nhs.uk



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Team transplant

Mary Healey (Transplant Clinic Sister)	02476 967746 (Direct Line)
Esther Theophilus (Transplant Clinic Sister)	02476 967746
Cheryl Paczynski / Nora Skinner (Transplant Nurse)	02476 967745
Lynne Walsh (Transplant Healthcare Assistant) Laura Crozier (HealthCare Assistant)	02476 967748
Rufina Sanchez (Recipient Transplant Co-ordinator)	02476 967744
Sharon Timms (Recipient Transplant Co-Ordinator)	02476 96 7782
Yvonne Myers (Recipient Transplant Co-ordinator)	02476 96 6207
Laura Fraser(Live Transplant Co-ordinator)	02476 967750
Jane Reid (Live Transplant Co- Ordinator)	02476 967790
Louise Ford(Senior Transplant Administrator) Matthew Baggot (Transplant Administrator)	02476 967750

Quick reference

- Please do not take adoport /prograf/Ciclosporin before your clinic appointment. Bring it to clinic with you and take it after your blood test.
- Please bring your completed fluid input and output charts and the medication list to clinic.
- Please bring water to drink while waiting at the clinic. If you are on transport it is a good idea to bring something to eat as well in case you have a long wait for your transport home.
- If you have symptoms of cold, flu, diarrhoea or vomiting and rash please inform a nurse so that you can be isolated. Please do not sit with the other patients.
- If you are not feeling well during weekend/out of hours/bank holidays please ring the main switch board and ask for renal registrar oncall or a consultant for advice. Do not wait for your next appointment.

Medication

The Renal Pharmacist will visit you before your discharge in order to tell you about your medication. You will be given a list of the medicines that you will go home with and the times you have to take them. **Please bring this list with you to every clinic appointment.**

You will be given 4 week's supply of medication after which you can obtain further supplies from your GP (not all chemists will routinely stock the immunosuppressant drugs you are taking, but will order them for you so that you will have a regular supply). GP practices cannot prescribe your immunosuppressant drugs so they will be prescribed by your renal consultant. As your visits become less frequent we can arrange for **Pharmacy homecare team** to send you prescriptions just for the drugs your own GP cannot prescribe. The contact number is **0247696 6044/ 02476 966765** or email Pharmacy.homecare@uhcw.nhs.uk. Try not to let yourself run out of any

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medications that you are taking. However, if you have a real problem, do not hesitate to contact us.

Diet

The Renal Dietitian will give you advice on diet and food safety prior to discharge. She will provide you with a booklet on eating well after a transplant. It may be that for a while you have to continue your pre-transplant diet but once your kidney is working well and your blood creatinine and potassium levels fall to an acceptable level, then you will be able to relax restrictions and resume a normal diet.

Fluid Balance

After your transplant, you will be advised on how much fluid you will need to drink in a day. It is usually between 2 -3 litres, depending on how much urine you are passing. If however you pass more than 2 - 3 litres you will need to drink much more to compensate. For the first few weeks you will be asked to keep a record of your fluid intake and output when you leave hospital. You will be given fluid balance charts to take home with you. Urine can be measured in any clean container that is marked off in mls. Completed charts should be brought into clinic.

Transplantation – the early days

It is important to remember that the first 3 to 4 months after having your transplant can be quite an unsettling experience. Many people remark that they do not know whether to laugh or cry as the fear of losing the transplant is at the back of their mind. Clinic visits are frequent, but as time goes on these concerns will decrease and your confidence will grow. You may go home anytime from 7 days to several weeks following your operation. An exact time cannot be given as the date of discharge is determined by many factors. However, most people stay in hospital for 7-10 days. Generally, once your new kidney has started to function, the doctors are happy with your blood results, you have no raised temperature and are passing urine – they will send you home.

Outpatient follow-up

In the first few weeks after your transplant, while your body is adjusting to the new transplant, you will need to come for regular appointments. For the first 4 - 6 weeks, visits to the clinic will be three times a week. The frequency of your visits will gradually decrease as your body begins to stabilise. At approximately 6 months after your transplant, if your condition is stable your care will be handed back to your referring consultant renal physician.

The Clinic runs on Monday, Wednesday, and Friday between 08.30-11.45am at 5th floor, East wing, Renal Dialysis Reception. When you arrive to clinic book in with Reception Staff and weigh yourself and take a seat. The nurse will assess you first and blood tests will be taken. Then you will have to wait to see a doctor. After consulting with the doctor, return back to the reception for the time slots for the future follow up appointment.

- **Please take into consideration that clinics can be very busy and we do try to see everyone on time.**

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- **Please remember to bring your morning dose of adoport with you to your appointments to take it after your blood test. You must notify the nurse if you have mistakenly taken your morning dose as this will affect your blood tests.**
- If you are on **Ciclosporin**, we may ask you to take the medicine 2 hours before your blood test because a post dose level is usually more helpful. We will arrange a convenient time for you to do this.
- If you are unwell, extra tests will be carried out to check for infection. Urine samples may be checked for infection/abnormalities. If you have a temperature, blood cultures will be performed also to check for infection. If there are concerns about your kidney function, blood may be checked for antibodies.
- You may be asked to go for a scan of your transplanted kidney to look at the circulation of the blood to the kidney and to see if there is any evidence of bruising, infection or fluid collections. You may be asked to wait for the test results, as it is possible that you may need re-admission to hospital for further investigations and/or treatment.
- As clinic appointments can sometimes take up to 2 hours, it would be advisable for you to bring drinks in with you in order to keep up with your fluid requirements, and any medication that is due to be taken.
- Once the doctors have reviewed your results later in the day, the nurses will contact you if there is anything they are concerned about or any changes in your medications to be done.

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Many patients find it helpful and reassuring to be able to look at their blood results online. For more information about this speak to the one of the staff members who can give you a form to fill in.

Transport

For patients who have no other means of getting to their transplant clinic appointments and who meet the criteria, ambulance transport may be provided for the first 6 weeks only after transplantation. It is your responsibility to book it through the patient transport system -01926 310312.

About rejection

The purpose of the immune system is to identify and deal with invaders to the body. It has the ability to recognise what is part of the body and what is not. A rejection episode means that it has identified the transplanted kidney as an invader and will then attack and damage the new organ trying to **reject it** from the body. Rejection is a normal response of your body. Even when the new kidney is well matched, some degree of rejection is common.

Generally, giving you extra anti-rejection medication successfully treats episodes of rejection. You may also have a biopsy of the transplanted kidney in order to establish the type and amount of rejection that has occurred. Usually rejection causes no

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symptoms and is detected by routine blood tests. Doctors may suspect rejection if the blood creatinine level is not falling after a transplant or if it has started to fall and then remains stable or increases again.

Viral infection and your Transplant

There are 3 main viruses which can affect kidney transplant patients:

BK virus is a member of the polyoma family and it is latent or inactive in the kidney and urinary tract of the vast majority of adults. It can activate in kidney transplant patients and interfere with kidney function. There are often no symptoms apart from feeling “flu like” so it is usually discovered from blood tests when we check for all three viruses. The treatment is to lower the level of immunosuppression. This is usually sufficient to allow the body to fight the virus.

CMV Cytomegalovirus is one of the herpes families which can affect transplanted patients. CMV can affect any organ or tissue. Symptoms can be “flu like” temperature, aches and pains, diarrhoea, or indigestion. Occasionally it can cause visual disturbance, jaundice, or breathlessness.

EBV Epstein Barr virus is also a member of the Herpes family and is commonly associated with glandular fever. EBV also causes “flu like symptoms” and sometimes lumps can be felt. Once again, lowering the immunosuppression is normally enough to let the body fight the disease. If viral levels continue to be high a CT scan is performed to check for any abnormalities in the chest and abdomen because unchecked EBV can lead to a condition called post transplant lymphoproliferative disease or PTLN. This is normally cured by reducing the immunosuppression further and sometimes chemotherapy is used.

Information about your medicines

Drug therapy is essential to prevent your body from rejecting the transplanted kidney.

The main medicines which prevent rejection of your transplant are as follows:

- **Ciclosporin** (Neoral) or **Tacrolimus** (adoport) (envarsus)
- **Azathioprine** or **Mycophenolate**
- **Prednisolone**

The above drugs are known as immunosuppressives (anti-rejection drugs). They act by damping down the body’s immune system. You may be on all three or any combination of these medicines.

At times we may alter the doses according to your blood results, but we will keep you informed of any changes and they will be altered on your medication list. There is a fine balance between taking too little and risking rejection, or taking too much and risking side effects such as infection. Your treatment will be reviewed at each clinic visit. As your kidney stabilises and the doses of the drugs are reduced, the risk of infections is lowered and the side effects should become less apparent.

Neoral (Ciclosporin)

It is effective at suppressing the immune system. The blood test **is taken 12 hours after your last dose of Neoral**. It is important that you take your Neoral regularly at 12 hourly intervals. On clinic day mornings take advice from the clinic nurse who will

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probably want a **2 hour post dose level** so you will need blood taken at an allotted time.

Possible side effects:

- Tremor (shaking of the hands)
- Increase in hair growth on your face, hands, arms and legs
- Increase in blood pressure which may need to be controlled by medicines
- Nausea
- Swelling and tenderness of the gums, made worse by unhealthy teeth and gums and poor dental hygiene
- Numbness and tingling in the hands, feet and mouth
- Hot flushes

You may not experience any of these side effects, but if you do they usually improve as your dose of Neoral is monitored and gradually reduced over a period of time. Neoral capsules should always be kept in the foil packaging and stored at room temperature, not in the fridge. Also keep them out of direct sunlight and out of the reach of children.

Avoid taking grapefruit and grapefruit juice for one hour before taking Neoral.

Tacrolimus (adoport) (envarsus)

Adoport - taken every 12 hours

Envarsus - taken every 24 hours

It is very important that you make sure you are given the correct drug and dose when getting repeat prescriptions. Although it is the same drug ingredients, the release in the body is different because it is working over 24 hours.

On clinic days **do not take** your morning dose of adoport at home, but wait until your blood test has been taken in clinic. Bring your adoport to clinic with you so that you can take it as soon as possible after your blood is taken. **Avoid grapefruit and grapefruit juice for one hour before taking Prograf.**

Possible side effects:

- Tremors
- Stomach upset initially
- Sleep disturbance
- Increased blood sugar
- Impairment of taste

Prednisolone

This drug is a steroid hormone, similar to that which your body produces normally. It is effective in suppressing your immune system and reducing inflammation. The dose will be gradually reduced over a number of weeks to a minimal standard dose.

Possible side effects:

- Increased appetite- Try to adjust your eating habits to maintain a steady weight.
- Stomach upset/ indigestion
- Fluid retention resulting in swelling of the face, hands or ankles.

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- Skin changes – acne, thinner skin, stretch marks
- Osteoporosis(weak bones)
- Mood swings
- Fullness of face (moon face)

Long-term use:

- Bone thinning or damage
- An increase in blood sugar
- Diabetic patients will have to monitor their blood sugars closely and may need an adjustment to their treatment
- Eye problems.

Your eyes may become sore and in rare cases cataracts can form. Your eye focus can also change as the dose of Prednisolone is altered. **Do not** change your glasses until you have been on the same dose for several months. Regular tests by your optician will help to keep a check on your eyes and any problems can be dealt with at an early stage.

When you take Prednisolone for a long time your body will stop producing its own supply of this hormone. **Never** suddenly stop taking Prednisolone as your body will not have enough of its own steroid hormone and very serious side effects may result. You will be given a blue steroid card. It is important that you show this to anyone who is involved in your medical treatment or health care e.g. dentist, pharmacist etc.

Mycophenolate (MMF)

Mycophenolate is an anti-rejection medication. It is available as 250mg, 500mg and when necessary as a liquid (1g/5ml).

DO's

- Take mycophenolate twice a day, ideally every 12hrs.
- Take mycophenolate with food to minimize stomach upset.
- If you are planning to start a family it is very important that you discuss this with your transplant team first as we will need to change your medication. This applies to both male and female patient.

DONT's

- Never cut the tablets in half as doing this may create small amounts of dust that could cause side effects to you and those around you.
- Never take indigestion remedies at the same time as mycophenolate as they can reduce the absorption in your blood.

Side effects

- Drop in white cell count
- Upset stomach including diarrhoea nausea and vomiting

Azathioprine

This drug is also an anti-rejection medication. It is available as 25mg and 50mg. You should take this once a day (at the same time each day) with or just after a meal. Do not take allopurinol, a medicine used to prevent gout without discussing your transplant team.

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Side effects:

- Stomach upsets- taking it with or after meals will help.
- Can lower the white cell count in the blood and make you more susceptible to infections. Your blood count will therefore be monitored regularly in the clinic and we will advise you if your dose needs to be changed.

Other drugs commonly used following a transplant are:

Aspirin (75 mg soluble): To prevent blood clots. It is usually best taken with or just after food.

Co-Trimoxazole: To help prevent certain chest infections. This is given for the first six months after your transplant.

Omeprazole/Ranitidine: To protect the stomach from possible ulceration.

Nystatin Liquid: To prevent a mouth infection commonly known as thrush. This is given for the first six months after your transplant.

Pain killers:

- Do not take anti-inflammatory painkillers e.g. Ibuprofen, Diclofenac, Naproxen.
- You can take paracetamol based pain- killers e.g. paracetamol, co-codamol.

Antibiotics

Do not take erythromycin, clarithromycin, fluconazole as it may increase levels of tacrolimus in the blood.

New medicines:

Always check with the pharmacist/doctor if another healthcare professional prescribes a new medicine as they may interact with your anti-rejection medicines and cause problem with your transplant.

Please also note:

- If you have high blood pressure you may need drugs to reduce it.
- You may need to take drugs to correct your phosphate or calcium levels in your blood.
- If you are Asian or have a history of tuberculosis, then you will have to take anti-tuberculosis drugs for the first six months or so after your transplant.

Additional procedures

Kidney Biopsy

A biopsy is the removal of a tiny piece of kidney, which is carried out under the guidance of an ultrasound scan. If a rejection episode is suspected, then a biopsy of your transplanted kidney will usually be required in order to confirm the diagnosis. The procedure will be carried out under a local anaesthetic following which your blood pressure, pulse and biopsy site will be checked regularly to observe for signs of bleeding. You will also need to be on bed rest for 4 - 6 hours following the procedure. You may be able to go home the same day if the doctors are happy.

Removal of ureteric stent

During the transplant operation a stent will be inserted into the ureter in order to allow unobstructed drainage of urine. This will need to be removed at around 4 weeks following surgery. You will receive a letter from the Day Surgery Unit asking

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you to attend for the procedure called a cystoscopy. It is a short procedure, carried out under a local anaesthetic, following which you will be able to go home on the same day.

Removal of CAPD catheter/ vascular access

If you have a CAPD catheter/ dialysis line, this will remain in place until your blood results are stable. CAPD catheter should be “capped off” to prevent infection, but it will still need daily attention and dressings until it is removed. Dialysis line (tunnelled line) will require flushing every week. Once the kidney is functioning well and your blood results have stabilised, you will be asked to attend day unit for removal for CAPD catheter/dialysis line.

Dexa Scan

At 3-4 months post transplant you will be sent an appointment for a Dexa Scan. This is a quick non-invasive scan which is performed at Rugby St Cross Hospital. It checks the density of your bones and if they are found to be thinning (a condition called osteoporosis) the doctor will prescribe bone strengthening medication.

Transplantation – The long term

General health and General Practitioner

Your GP will receive details about your medical status and transplant. You should continue to see your GP about any health problems that comes up. Your GP will always phone us for advice if necessary. If you are prescribed any medications by your GP, make sure you or your GP checks with the transplant renal pharmacist as some drugs can interact with your anti-rejection medications.

It is recommended to have the ‘flu’ jab each year. However, there have been reports of occasional side effects. If you have had the jab previously and felt unwell afterwards you should discuss it with your doctor prior to having subsequent ‘flu’ vaccination. It is **not advisable** to have a flu vaccination **within the first 3 months of transplant**.

Urinary tract Infections (UTI)

As you are on medications to suppress your immune system, you will be at greater risk of developing infections. The most important sign of infection is raised temperature 37.5 C or above, stinging, burning when you pass urine or offensive or cloudy urine. Please telephone the Transplant Office/Ward if you have any of these problems so we can treat you as soon as possible.

Chest Infection

You are prone to certain types of chest infection immediately after your surgery; hence you are given certain medications to prevent those infections. If you have sore throat, productive cough it is important that you seek treatment promptly. This can be with your GP.

Diarrhoea and Vomiting

If you come in contact with anyone who has diarrhoea and vomiting make sure you wash your hands thoroughly. Use soap and water rather than alcohol based antibacterial hand gels. The alcohol hand rubs are not always effective in killing the bugs that are present in faeces and stools. Make sure that toilet sinks and door handles are disinfected and you wear gloves while doing this.

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Drink plenty of water if you have diarrhoea/vomiting, but if symptoms persist, particularly if you are unable to keep down your anti-rejection medications you should seek medical attention for intra-venous rehydration.

It is also sensible to avoid crowded spaces for the first three months of post-transplant E.g. Cinemas and supermarkets at busy times because you are at greater risk of picking up an infection in the early days.

Chicken pox and shingles

If you have been in contact with either chicken pox or shingles please contact us at the Transplant Office and we can do a blood test to check whether you have immunity to these infections. If however you suspect that you have the disease we will need to see you preferably when there are no other transplant patients around, so please contact us in the Transplant Office to arrange a time.

Foot care

If you suffer from in growing toe nails, corns etc. it is advisable to see a chiropodist rather than treating yourself.

Hair care

Your hair may appear thicker, but unfortunately, due to the effects of Prednisolone, the condition may not be so good. It will break more easily and therefore you should not use perming lotions, tints, dyes and bleaches until your immunosuppression is lowered. Tell your hairdresser that you are taking steroids and use a good conditioner.

Always perform a patch test first to check for any potential reaction.

Hair growth

Ciclosporin (Neoral) increases hair growth on legs, arms and the face. Excess hair growth is common in the first 6 – 12 months after a kidney transplant if you are on this drug. Fortunately, there is some improvement as the drug dose is lowered. Unwanted hair can be removed with any hair removal method that is cosmetically acceptable.

Dental / oral care

You must follow good oral hygiene following your renal transplant and inform your dentist that you had a transplant and you are on anti-rejection medications. Routine visits to the dentist should be avoided during the first three months following transplantation. After three months you should visit them regularly every six months.

Alcohol

Please check with the doctor in clinic before taking alcohol after your transplant. Generally, one or two pints of beer or one or two glasses of wine a day are acceptable as long as your blood pressure and blood sugar is well controlled. Be aware that alcohol can cause you to become dehydrated, so allow plenty of soft drinks or water to compensate for this.

Smoking

You should not smoke after a transplant. Smoking can cause lung damage leading to chest infections which, in the transplant patient can be life threatening. Smoking

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also causes a narrowing of blood vessels, which may affect the blood supply to the transplanted kidney.

Exercise

Exercise and physical activity are beneficial to your overall health and wellbeing in the immediate post-operative period. The healthy lifestyle will prolong the life of your transplant.

It is important to be up and about as soon as possible after a transplant, to prevent any complications. Start with some gentle walking and then gradually build this up over time. Don't do any heavy lifting or strenuous domestic tasks for the first 6-8 weeks.

Transplant patients must avoid any contact sports such as rugby, boxing and football. You may begin **swimming after three months** as long as all wounds are healed and you don't have any external tubes e.g. CAPD catheter. If you have one of these, you will need to wait until it has been removed and the skin has healed. If in doubt about any sport or hobby ask your doctor at the clinic.

Choose a form of exercise that you enjoy such as walking or gentle cycling, as this will encourage you to maintain your exercise programme. Make sure you take advice from the doctors before starting any new sporting activity. You should be able to drive a car again 6 weeks after the operation and to start work again 3 months after. However, it is advisable to discuss this first with your doctor.

Skin care

People who have had a renal transplant are more at risk of developing skin cancer because of the immunosuppressive drugs that are required to prevent their kidney from being rejected.

Having a suntan (but especially burnt skin) is a sign that your skin is damaged and is trying to protect itself from the sun's harmful rays. When transplanted, your immune system is depressed and your body finds it more difficult to repair itself from sun damage, which can lead to the development of skin cancer. You are also more prone to common viral warts. However, there are several things you can do to help protect yourself.

Remember: prevention is better than cure

From early May to the end of September in the UK (even on cloudy days) you should wear a sunscreen. Sun Protection Factor (SPF) 30+-50+ with at least a 3 star (***) rating. This protects you evenly from UVB and UVA rays. The sunscreen should be applied liberally every 2-3 hours to all exposed areas – not forgetting ears, hands and lips.

- Sun avoidance is even better. Avoid the sun between 11.00am and 3.00pm.
- Wear a wide brimmed hat and closely woven clothing.
- Use an umbrella or sunshade.
- Never sit in the sun or sunbathe.
- Never use a sun bed.
- Remember to wear sunglasses to protect your eyes.

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- Get to know your skin by checking it regularly. This will enable you to recognise any early signs of sun damage, which may be pre-cancerous.

Signs and symptoms of skin cancer

Skin cancers are most likely to appear on the face, neck and other sun-exposed areas but could also appear anywhere. Skin cancer may present in any of the following ways.

A small lump - smooth or waxy, bleed, develop a crust

A flat red spot - scaly and crusty

A firm red lump -Painless but growing

Changes in existing moles

- Increase in size
- Change in shape, irregular or ragged edge
- Change in colour, becoming inflamed or darker
- May become itchy, crusty or start to bleed

If you experience any of the above or any other suspicious changes in your skin that last more than 2 or 3 months, then discuss them with your transplant nurse or doctor. If skin cancers are treated early, then they shouldn't cause you any further problems.

Remember:

SLIP on a T-shirt

SLAP on a hat.

SLOP on the sunscreen.

Be sensible but enjoy life.

Women's Health

All women who have reached 18+ years of age should have:

- Routine PAP smear test (Papanicolaou's test) – to detect any abnormalities of the cervix as per national guidelines.
- Perform regular self breast examination on a monthly basis

Physicians may advise women who have a family history of breast cancer/ who have other risk factors to have mammogram before the age of 40 or more frequently.

Men's Health

Men should carry out regular testicular self examinations. The anti-rejection medications may increase the risk of cancer. Testicular cancer is almost always curable if detected early, so it is crucial that men examine themselves monthly. This will allow you to become familiar with the normal feel of your testicles and enable you to detect any changes. You must report any changes to a doctor.

Sexual health

Sexual activity may be resumed once you are feeling up to it. Some patients may find a previously suppressed libido returns after transplantation. For women menstrual periods will return and with them a renewed fertility. In men, a previously depleted sperm count may improve. **Contraception should therefore be considered and discussed with the transplant doctor.**

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Barrier methods (such as condoms or the diaphragm) are the safest forms of contraception post-transplant.

The Intra-uterine Device (I.U.D.) is not recommended due to an increased risk of infection.

Oral Contraception: Some types of contraceptive pills are not recommended for the post-transplant patient.

Planning a family- Women

It is generally advised that pregnancy should be avoided in the first one to two years following transplantation, as it can pose a risk to the new kidney. If you are considering pregnancy, please discuss it with your doctor as careful monitoring of renal function and drug levels will be required throughout. Some drugs may need to be changed because they may be harmful to the foetus. Ideally you should have good general health with good blood pressure control. Protein loss in the urine should be minimal, there should be no evidence of transplant rejection and serum creatinine should be stable at an acceptable level

Planning a family –Men

Men wishing to start a family after a transplant should discuss with the transplant team, as their medication may need to be changed. Each situation needs to be considered on an individual basis, looking at potential risks/benefits of continuing or switching medications. Birth defects have occurred with some medications taken by the father. It is recommended you wait at least one year before trying for a family.

It is also important to practice safe sex. You should use condoms if you are not in a long term monogamous relationship. This can prevent sexually transmitted diseases and pregnancy if used correctly.

Psychological problems

If you are worried or depressed about aspects of your transplant and would like to see a counsellor, please ask at clinic and we can refer you for an appointment.

Holidays

If you are thinking of going on overseas holiday, speak to your consultant first, who will advise you whether or not your blood results are stable enough for you to go away for any period of time.

The following are travel tips for all transplant patients:

- UK travel – 0-6 months post-transplant, European Travel- 6-12months post travel and worldwide travel- after 1 year.
- If you are flying, drink bottled water, take regular walks along the plane and do regular leg exercises.
- Take enough medication to last until you return plus one week. You may not be able to obtain same anti-rejection medications in other countries.
- Carry your medications in hand luggage, to ensure you have access to them at all times.
- It is advisable to take a letter with you explaining why you need your medication along with a summary of your medical condition and history in

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case there are any queries at customs. Ideally, you should ask your consultant if you are well enough to travel.

- Make sure that you have adequate insurance and the insurance company is aware of any pre-existing conditions.
- Make sure that you keep well hydrated in hot climates. Never drink untreated water. Only drink bottled water.
- Never have salads, ice cream or ice. Special care should be taken when buying food from the street sellers due to risk of food poisoning.
- It is also important to be careful with the hot sun. Please see the section on skin care for safe sun advice
- Please take the telephone number of the transplant team in case you need to ring for advice.

Vaccinations

You may require vaccines for travel. We suggest you confirm with your GP practice which vaccinations you require for the country you are travelling to. Please then contact the transplant pharmacist who can check that the vaccinations are suitable for you. You will **not be able to have live vaccines** as they may cause a very severe infection and can potentially be life threatening.

Social services

Having a kidney transplant is a life changing event for you and your family. Hopefully it will lead to you feeling fitter and better; certainly the Social Security Agency will assume so unless you tell them otherwise. So if you claim Disability Living Allowance or Attendance Allowance you will need to let them know, and unless you can demonstrate otherwise, the assumption will be that you no longer meet the criteria for these benefits. It is possible that you can no longer claim incapacity benefits or free prescriptions because you are now fit enough to work. It is advisable if you do have to pay for prescriptions to buy a prepayment prescription card.

If you have not been working or have to think about a change of job, the Employment Services have various schemes to help you with this. If you want any advice or information on these practical issues please contact the Renal Social Worker.

Donor information

Following your transplant, you may have lots of thoughts about the donor. It's important to remember that their gift to you was unconditional and freely given either directly or by carrying an organ donor card, or by the consent of family who wished this gifting process. You should not feel guilty about receiving a transplant as your donor didn't die for you, and no matter how long you were waiting for a transplant, you were the best match for this donor kidney. You are fortunate to receive such a precious gift.

One way of thanking these unknown donors and their family members who have lost a loved one, is to look after your new kidney as if it is your own. Enjoy your new life and new health to the full now that the restrictions of kidney failure have been lifted.

Other patients who have been successfully transplanted often enquire about their donor and want to thank the family of the donor personally. This is not usually

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possible as there is strict anonymity between recipients and their donor family, however, letters of thanks can be written to donor families. The details we are able to give you are age, sex, and some general information on the cause of their death. It is advisable to think carefully about this request, as this can be a very emotional piece of information. **You will not be told their name or address.**

What will my donor family know of me?

Within 14 days of the organ donation, donor family are written to by their local Transplant Co-ordinator, thanking them for their donation. In this letter relatives are usually given generalised information on recipients, including age, sex, if the recipient was married or single and if they have any children. They may also be told how long recipients had spent on the waiting list and where applicable, any goals recipients wish to achieve with their new kidney. Donor families are **not** informed of whereabouts in the country the recipients live, where they were transplanted or any other personal details that may identify a recipient. At this stage anonymity is paramount between donor family and recipient.

If requested to in the future by donor families, Transplant Co-ordinators will update donor families on a recipient's progress. We are honest and inform donor families if your transplant remains successful or has failed for any reason. Once again anonymity is maintained.

Useful websites and Contacts:

Walsgrave Hospital Kidney Patients Association formed by kidney patients

Contact: Vivienne Dodds Tel: 024 7638 4061

UK National Kidney Federation has a dedicated Helpline for kidney patients and their carers.

Tel: 0845 601 02 09 (charged at local call rate, UK only)

Email: helpline@kidney.org.uk or online www.kidney.org.uk/

Transplant Games www.transplantsport.org.uk – A charity that organises sports and social events for transplant recipients.

www.transplantliving.org- useful for Transplant information and resources

The Trust has access to interpreting and translation services. If you need this Information in another language or format please contact us and we will do our best to meet your needs.

The Trust operates a smoke free policy

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