

Patient information

Looking After Your Kidney Transplant in the Longer Term

Nephrology Speciality

Introduction

This leaflet is written and designed for patients who received a kidney transplant more than a year ago. It gives general information about the practicalities of longer term care and some information about how to ensure you look after your transplanted kidney in the longer term.

Not all the information will necessarily apply to every patient and if you're unsure or concerned you should discuss it with a healthcare professional when you next attend clinic, or your family doctor (GP).

Clinics

Clinics are run on a Monday morning. For patients who are stable we generally see people every three to four months. If for some reason an appointment hasn't come through in this timescale please do contact the secretaries so an appointment can be arranged.

Tel: 0151 706 3429 / 3475

Text phone number: 18001 0151 706 3429/ 3475

Please make sure you bring a urine sample with you to clinic.

Clinics are usually extremely busy. To avoid excessive waiting times, some patients with stable transplant function and satisfactory tacrolimus levels are given the opportunity to collect medications and blood forms and not wait to see a doctor or specialist nurse.

Medications

The transplant clinic is responsible for prescribing the immunosuppression medications Neoral, Prograf, Advagraf, Adoport, Sirolimus (Rapamune), Mycophenolate Mofetil, Myfortic, Azathioprine and steroids such as Prednisolone. In order to ensure we are giving you the correct doses of these it is essential we have up-to-date blood test results. These can best be done by you attending the Phlebotomy Department either at Broadgreen, Royal Liverpool or Garston hospitals, **two weeks before your appointment**. Please make sure you bring a urine sample when you have blood test as well.

When visiting the clinic you should be provided with blood test forms for this purpose. If for some reason this has not been done, or you have lost them please email transplantmeds@liverpoolFH.nhs.uk so these can be sent out.

For safety reasons, we can only issue a short supply of immunosuppression medicines without blood tests or clinic review in rare emergency situations. If this is needed please contact us using the transplant pharmacy number Tel: 0151 706 4354.
Text Phone Number: 18001 0151 706 4354

Please bring a full list of medications with you when you attend the clinic so these can be reviewed by the doctor. There are some medications which can interact with transplant drugs and it is important that whenever a doctor prescribes you a new medication they are aware you are taking these medications, so if necessary, a dose or drug can be changed accordingly.

Prograf, Adoport and Neoral are taken twice daily. It is important to try to take the dose as close as possible to 12 hours apart.

When you are having blood tests you should not take the morning dose of the medication until just after you have had the blood tests. The blood test should be as close as possible to 12 hours after the evening dose.

It would be advisable to plan to attend the phlebotomy department at least 30 minutes to one hour before the 12 hour post dose time.

Sirolimus and Advagraf are taken once daily, and again the tablet should be taken just after your blood tests which should be as close as possible to 24 hours after the previous dose.

There is a separate information leaflet about transplant immunosuppression medications which you should ask for if you have not already received it.

Patients taking Azathioprine should not take Allopurinol medication.

Infections

As a result of the transplant and the immunosuppressive drugs you are taking you are at increased risk of infections.

Antibiotics that should normally be avoided include:

- Trimethoprim.
- Nitrofurantoin.
- Erythromycin.
- Clarithromycin.
- Fluconazole.

The following are acceptable (if you are not allergic):

- Amoxicillin.
- Augmentin.
- Cephalexin.
- Ciprofloxacin.

If you are having frequent infections or suffer a severe one you may need to be referred to the specialist infectious diseases doctors.

Vaccinations

You should receive the annual flu vaccination each year. This can be done through your general practitioner. You should also receive the pneumovax vaccination once every five years, again through your GP.

You **must not** receive any live vaccinations and if you are unsure you should ask the healthcare professional you see about this.

If you come into contact with a person with chickenpox or shingles you should contact the transplant nephrology secretaries on 0151 706 3475 the next working day. **You should do this even if you have previously been told you are immune.**

Cancer Screening

All patients should take part in cancer screening routinely offered by the National Health Service including breast, cervical and colon cancer screening. Men should examine their testicles on a regular basis and inform the doctors if there is anything of concern.

Cancer is more common in patients who have had a transplant and if you develop new or concerning symptoms you should seek medical advice.

Skin Care

You should try to avoid excessive sun exposure by wearing a hat and long sleeves when it is sunny (whether it is warm or not). When sun exposure is inevitable you should use a high factor sun cream which is protective against both UVA and UVB light. You should not sun bathe or use a sunbed.

You should examine your skin on a monthly basis. This could easily be done by stripping to your underwear and using a mirror to examine your back and the back of your legs. Alternatively you could ask a partner to do this for you. If you develop any new skin lesions or these are changing you should inform either your general practitioner or the transplant doctor.

Cholesterol

There is some evidence transplant patients should possibly take a cholesterol tablet even if their blood cholesterol levels are normal. If you are not doing so, please discuss with the transplant doctor when you next visit.

Foreign Travel

Travel vaccinations, malaria tablets and other health measures are needed if you are travelling where particular infections are present. These include Africa, Central and South America, India and East Asia. If you are planning any trips to destinations outside Europe, you should consult your general practitioner or travel clinic about this **at least one month before you travel.**

As mentioned above you should not receive live vaccinations and if these are essential for the area you are travelling to, you should reconsider your plans to travel. Information about travel vaccinations can be found at <https://www.gov.uk/foreign-travel-advice>

If you require treatment to prevent malaria, this may interact with the transplant immunosuppression drugs and you should discuss this with the transplant doctors before starting to take these.

Pregnancy and Contraception

Women should avoid an unplanned pregnancy by using appropriate contraception if they are of child bearing age. Some drugs may be toxic to the baby during pregnancy and these will need to be changed. In particular, mycophenolate mofetil can harm a baby in the womb and it is recommended women use two forms of contraception if they are taking this. The combined oral contraception pill containing oestrogen may increase the risk of blood clots and you should discuss with your transplant doctor about taking this.

Alternative forms of contraception are preferred. If you are planning a pregnancy it is essential this is discussed at an early stage with a transplant doctor, ideally six months before conception so appropriate changes in medication can be given. In general a pregnancy should be delayed until one year after a transplant.

If you become pregnant you should inform the Nephrology/Transplant clinic as soon as possible.

Women contemplating In Vitro Fertilisation (IVF) should also discuss this with the transplant doctor before commencing this treatment.

If you are a man taking mycophenolate you must use condoms during treatment and for 90 days after stopping, and your partner must use highly effective contraception for the same time.

Patients who have a transplant are at a slightly increased risk of osteoporosis. However, transplant doctors don't have a specific expertise in this condition. If you are concerned you should discuss this with your GP.

Dental Health

You should register with a dentist and attend regularly for check-ups and treatment as required. Do inform your dentist and other health professionals that you have had a transplant. You do not need preventative antibiotics for dental work unless you were already requiring them for another, non-transplant health problem.

What to do when you are unwell?

You should make an appointment with your general practitioner, telephone NHS Direct or attend the Emergency Department (A&E) as appropriate. If the cause of your illness is a change in function of your kidney transplant we may need to arrange an earlier clinic appointment to see you or possibly admit you to the Nephrology ward at The Royal Liverpool Hospital.

Other causes for illness should be dealt with by either your GP or the appropriate specialist for that illness. However, it is important the doctor treating you is aware of the fact you have received a kidney transplant.

If you are admitted to hospital it would be appropriate for the doctors admitting you to inform us by contacting the Renal Registrar on call so we are aware of your admission.

Surgery

If you require surgery involving a general anaesthetic it may be additional measures are required with respect to your immunosuppression medications. Therefore, if surgery is planned, it is important we are informed so an appropriate plan can be agreed with the surgeon. If you are taking Sirolimus (Rapamune) this may need to be changed to a different medication.

Healthy Life Style

It especially important all patients adopt a healthy lifestyle. This includes totally avoiding smoking, ensuring you are a healthy weight, taking some exercise and consuming only a moderate amount of alcohol. You should have a healthy diet with plenty of fresh fruit and vegetables and not too much salt. If the function of your transplant reduces you may need to have some specific dietary advice from the dietician.

Women can reduce their risks of urinary tract infection 'cystitis' by ensuring they keep well hydrated, fully emptying their bladder when using the toilet and emptying their bladder before sexual intercourse. Cranberry products may also help but you should discuss with the transplant doctor or pharmacist before taking these.

Other advice

Psychological problems are common following a kidney transplant. Patients who are suffering from psychological problems can request to see the clinical psychologist at clinic. Please be aware the waiting time is approximately three months so if you feel you need help earlier than this, please consult your GP.

Sexual problems are also common following a kidney transplant. Please do not feel embarrassed to mention these to the doctor or specialist nurse who can refer you to a specialist for advice.

Patient View

All patients are encouraged to register with 'Patient View'. This allows patients to see their own blood test results on the internet. If you are not registered please ask about this when you attend clinic.

Feedback

Your feedback is important to us and helps us influence care in the future.

Following your discharge from hospital or attendance at your outpatient appointment you will receive a text asking if you would recommend our service to others. Please take the time to text back, you will not be charged for the text and can opt out at any point. Your co-operation is greatly appreciated.

Further information

Transplant secretaries – for advice about appointments

Tel: 0151 706 3429 / 3475

Text phone number: 18001 0151 706 3429/ 3475

Transplant pharmacy – for transplant medication queries – transplantmeds@rlbuht.nhs.uk,

Tel: 0151 706 4354

Text phone number: 18001 0151 706 4354

The British Kidney Patients Association.

www.britishkidney-pa.co.uk

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All Trust approved information is available on request in alternative formats, including other languages, easy read, large print, audio, Braille, moon and electronically.

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