

Post transplant and long term care



Hope Building
Transplant Specialist Team
0161 206 1295/2624



Introduction

This booklet is designed to give you an overview of the Transplant Service at Salford Royal NHS Foundation Trust and provide you with information which will help you care for yourself in the long term. If you have any questions or queries about the content please do not hesitate to contact us on the phone numbers listed on page 2.

The booklet is by no means a comprehensive account of all the advice and care you require, but is a supplement to advice which can be offered by the specialist team at Salford Royal.

The transplant team are here to help and support you in making a success of your transplant and future health. However, it is you who must play the major part in this.

The transplant nursing team are based in the Hope Building, within the renal outpatients department and consists of one senior specialist nurse, two specialist nurses and a transplant liaison nurse.



Transplant clinics

There are two transplant clinics per week at Salford Royal. These are held in the mornings. We will also be providing transplant clinics at premises in Bolton, Wigan and Oldham in the future, however your care will still remain under Salford Royal and you will see the same staff. In clinic you will see the consultant/registrars on a regular basis.

The specialist nursing team also run nurse led clinics and an annual review clinics alongside the medical team. The aim of the nurse led clinic is to offer extra support to patients that are perhaps changing their medication or require additional review. You will also see the specialist nurse on return after transplant, to introduce you to the service. Transplant clinics are always busy, therefore could you please ensure that you arrive on time, to try and avoid any delays. When a number of patients arrive late in any one session, it has a knock on effect to the rest of the clinic causing longer

waiting times. If you do arrive late, you may need to wait until the end of the clinic to be seen.

The consultant team will work on a rotational basis and we will endeavour to provide you with out patient appointments, under the care of the same consultant at future visits. Please ask at the reception on arrival if you would like to see the consultant. Alternatively if you have a preferred consultant please ensure when rebooking your next appointment you ask to be added to their clinic.

Each time you attend clinic we will take blood samples and will require a urine sample. Can you please ensure that you do not take your immunosuppression (as listed below) on the morning of clinic so we can check your levels.

Please see below for timings of medications before you attend clinic:

- Tacrolimus (Prograf)
- Ciclosporin (Neoral or sandimmun)

Please take last dose 12 HOURS before your clinic appointment

- Tacrolimus (Advagraf)
- Sirolimus (Rapamune)

Please take last dose 24 HOURS before your clinic appointment

All other medication can be taken as usual.

Your results will be checked and assessed at each hospital visit and you will be notified if any re checks or other actions are required.

You are able to view your results and clinic letters online via 'Renal Patient View'. Your GP will also have access to this up to date information. If you are interested in signing up, please ask at your next clinic visit.

If you are unwell or concerned about your health between visits or if you have any questions regarding your care or treatment, please contact the nursing team and we can advise you on an appropriate course of action. This may involve you attending the hospital for assessment.

Please note that we do not advise you to drop in to the renal unit, out patient clinic or to call the clinic if you are unwell or concerned about your health, as we have found this to be an unsafe practise. Please contact a member of the team on the numbers provided so that we can arrange your safe and timely assessment.

Useful contact numbers:

Transplant specialist nursing team:

Available Monday to Friday
8.30am - 6.00pm

Telephone: **0161-206-1295** or
0161-206-2624

Urgent queries: **07725 220346**

Email:
transplant.nurses@srft.nhs.uk
This is not for emergencies but for further information only

Weekends and out of these hours **ONLY** please telephone Ward H3 on **0161 206 4633** and ask to speak to the nurse co-ordinator.

Annual Review Clinics

Each year you will be sent an appointment to attend for a separate review by the transplant specialist nursing team. This is for purposes of health promotion, prevention and early intervention, aiming to promote your quality of life and increase longevity of your transplant. You could treat this as your yearly MOT. We will endeavour to make your appointment on the same day as your regular doctor appointment; however, it is also your responsibility to ensure you have an annual review.

Please ask at reception if you are unsure as to when your annual review is due.

Annual dermatology clinic

Transplant patients are at particular risk of developing some skin conditions, including skin cancer. You will be sent an appointment to see one of our dermatology consultants every year. It is important that you follow skin care advice but also that you attend this review, so that early detection of problems and treatment can occur.



Helping yourself

There are many factors which require monitoring in order to improve the longevity of your kidney Transplant and your general health and well being.

The main aim of your long term care is to help you to achieve and maintain a good quality of life.

For these reasons it is essential that you attend you're out patients appointments.

Factors to be aware of

- Long term medication and its side effects
- Monitoring of transplant function
- Infection risk
- Post transplant diabetes.
- Cardio vascular disease
- Cancer detection and prevention
- Oral care
- Keeping well
- Holiday care

Long term medication and its side effects

The medications you are prescribed to help your body stop rejecting your transplant are called "immunosuppressives". All of these may have side effects which you may experience in varying degrees.

If you feel you may be experiencing side effects it is important to share this information with a member of the transplant team.

We can then look at alternatives for you. If you feel you may stop or reduce your immunosuppression because of this, you must not do this before contacting a member of the transplant nursing team.

Every transplant centre is aware of patients who have lost their kidney because they have stopped their medications.

You may be prescribed other medications which can interact with your current drug therapy.

If you or your prescriber are unsure as to the effects this will have on your immunosuppressive treatment please contact the transplant team to discuss, we can always find out for you.

Please can you also check that you receive the same 'Brand' of immunosuppression from your pharmacy. Please contact us if you need to discuss this.

Also if you buy any over the counter medications including herbal and vitamin supplements, we would ask that you discuss this with us first before taking.



Monitoring of Transplant function

Your blood and urine results will be reviewed by the nursing and medical team each time you attend for your transplant clinic appointments. We may also ask you to attend your general practitioners for some monitoring.

When the transplant specialist nursing team have reviewed all your results they will contact you if further tests/visits are required. Sometimes this may be of an urgent nature and we would expect you to be able to attend at short notice. This will be explained to you fully at the time. In order to ensure that we can contact you easily at any time please keep the team informed of any change in your contact details, especially mobile telephone numbers. It would also be useful to ensure you have transport that can easily be accessed in these circumstances.

Infection risk

Your immunosuppressive drugs have an effect on your immune system which stops it from attacking your kidney transplant. This does however make your immune system less effective at fighting bacterial, viral and fungal infections.

Where possible avoid contact with people who have obvious infections. (For example colds, diarrhoea and /or vomiting illnesses)

Practice safe sex to prevent sexually transmitted diseases. Safe sex practices include:

- Having sex with only one partner (monogamy)
- Always use a condom with spermicide
- Avoid sex with anyone who has sores, a rash, or a foul discharge from their genitals
- Avoid anal sex.

Please ensure you have an annual flu vaccination via your general practice.

Cuts and abrasions need to be cleaned quickly and can be dabbed with a mild antiseptic.

Teeth should be cleaned a minimum of twice daily and you should attend your dentist for a check up every 6 months.

If you experience any of the following please contact the transplant nursing team, or if at the weekend use contact numbers provided in this booklet:

- Fever
- Diarrhoea and/or vomiting
- Sore throat
- Tenderness over transplanted kidney
- Pain in your native (old) kidneys
- Burning when you pass urine
- Frequent need to pass urine
- Coughing up yellow, green phlegm, persistent chest infection

- Shortness of breath
- New skin rash
- Night sweats
- New lumps or bumps

You will be advised by the transplant team as to the best course of action to take and what follow up you require.

Remember the best thing you can do is to keep hydrated and contact the team early on in the course of your illness.

If you experience any ongoing issues, please ensure that this is discussed at your clinic visits.

Post Transplant Diabetes

Diabetes is an illness that affects how your body makes and uses a hormone called Insulin. Diabetes occurs because either the pancreas does not produce enough insulin or the insulin that is produced is not used properly by the body.

Diabetes is one of the most common chronic diseases and has implications for those diagnosed.

Part of the screening of transplant recipients at this clinic is to look at individual risk factors for development of diabetes.

Some individuals are more at risk than others. These are:

- Those with a family history of diabetes
- Patients with Asian, African, Afro-Caribbean background
- Obesity
- Inactive life style
- Abnormal cholesterol levels
- Particular immunosuppressive drugs

Some of your risk factors cannot be changed. However some, with your co operation, can.

As a team we will look at these issues and plan interventions together.

Cardiovascular disease

Renal transplant recipients are at increased risk of cardiovascular complications including, heart disease and strokes.

The main risks factors are a raised cholesterol level, high blood pressure, smoking, diabetes, being overweight/obese and certain immunosuppressive medications.

These risk factors will be monitored when you attend clinics and it is important to listen to advice given. There are many ways in which we can try and reduce your individual risks and agencies such as the smoking cessation nurse and weight management service can be involved in your care.

The team can also look at how your medications including immunosuppressive therapy can be tailored according to your needs.

Cancer detection and prevention

Your immunosuppressive medication can increase your risk of malignancy and skin cancer.

As previously mentioned it is important for you to attend your dermatology out patient appointments and take precautions to protect your skin, particularly between the months of April and October when UV rays are at their strongest, but especially when on holiday in sunny environment.

A high factor sun cream (25 and over) is currently recommended in conjunction with use of hats and long sleeve tops. Most skin problems appear on the face, forearms and the back of hands.

Skin changes should be reported as soon as possible to the transplant team or your general practitioner.

Female patients should attend their general practice for a cervical as per guidance below from NHS Cervical Screening Programme:

- Commence smears at 25 yrs of age
- 3 yearly until 50 years of age
- 5 yearly until 64 years of age
- Over 65 years of age, smears only advised if recent abnormal screen

Female patients should follow the 5 point breast awareness code:

1. Know what is normal to you
2. Know what changes to look and feel for
3. Look and feel
4. Report any changes to your general practitioner or member of the transplant team
5. Attend for routine breast screening if you are aged 50 or over.

Some male patients may experience problems with their breast tissue. If you are concerned about this please contact the transplant nursing team to discuss.

Testicular cancer is very treatable. This however depends on early detection and treatment. Self examination of your testicles should occur at least every six months. Although you may find this embarrassing it may save your life. The principles of self examination are:

- Get to know what is normal for you
- Examine yourself just after a bath or shower as this allows the scrotal skin to relax.
- Look at your scrotum for its colour, feel and texture, noticing any swelling.
- Any abnormality in shape and feel, or any lumps or swelling should be investigated no matter how trivial it may seem.

For further advice on breast or testicular self examination please contact either the transplant nursing team, general practitioner or practice nurse.

Erectile dysfunction can occur in male transplant recipients. This can be due to medication effects, transplant operation, previous conditions or relationship problems. Please discuss this with us as we can refer you to local specialist services and offer advice.

If you experience the following in general, please either discuss with your general practitioner or telephone the transplant nursing team to discuss;

1. A lump or swelling anywhere in the body
2. Any abnormal bleeding from the mouth or rectum
3. Persistent indigestion or difficulty swallowing
4. Persistent cough or hoarseness
5. Change in normal bowel habits
6. Unexplained weight loss
7. Unexplained loss of appetite

Dental care

As you are now taking medications to suppress your immune system, you could have an increased risk of dental health problems.

It is recommended that you visit your dentist for regular check ups every 6 months and if you develop problems, every 3-4 months.

If problems occur as a result of side effects of your medication the transplant team will look at the possible adjustment of your medications and dose.

You should aim for healthy teeth, gums and mouth tissue with good oral hygiene. Here are some important guidelines for good dental health:

- Brush at least twice a day, particularly after meals and before bed
- Floss daily
- Use a toothbrush with a small head and soft bristles
- Brush for about 3 minutes
- Rinse with a mild mouth wash to help decrease bacteria
- Remind your dentist that you are a transplant patient.

Planning a pregnancy

Men and women with kidney disease who have been thinking of starting a family or who are actively trying to conceive are given a very real opportunity, with a functioning renal transplant, as fertility may return quickly.

It is possible for women to become pregnant within a few months of transplantation. It is wise however to wait for at least one year following transplantation, as this is a critical period for your transplanted kidney.

If you are planning a pregnancy please talk to the transplant nursing team or your consultant and we can plan your care with you and support you accordingly. Medication changes may be needed as some can be dangerous in pregnancy. If you have problems conceiving we can provide referrals to an obstetrician/gynaecologist.

When a female transplant patient becomes pregnant the transplant team will review medications and refer you to our joint renal/maternity clinic, where you will be closely monitored by the transplant consultant and the maternity team. There may be a few medication changes throughout pregnancy which will require regular blood monitoring.

Remember that most women who have a transplanted kidney, have no complications with the transplant and the risk of miscarriage is about the same as the general population, provided that the function of the kidney was stable and healthy prior to becoming pregnant.

Mental Wellbeing

We would hope that you feel very well after having a transplant, but for some this can be a trying time as you get used to a change in your health. We have a renal psychology service that can be offered to

all renal patients. If you feel that you would like to be seen, please ensure you discuss this with your doctor or transplant nursing team.

Keeping well

You should call your general practitioner or transplant specialist nursing team if you experience frequent watery stools (diarrhoea) and /or vomiting. An assessment will occur over the telephone as to the best course of action in your individual case. If diarrhoea or vomiting is severe you may require admission to your local hospital.

If you have a cold or flu you may take paracetamol, unless allergic to this, as directed on the packet. If symptoms persist or you begin to cough up green/discoloured sputum, please contact your general practitioner or transplant specialist nursing service.

If you are commenced on antibiotic treatment please inform the transplant specialist nursing team these may interact with your immunosuppression.

If you have a high temperature (e.g. 38 degrees centigrade and above) please contact the transplant nursing team.

Please drink lots of fluids as dehydration can occur rapidly, despite your best efforts. The transplant service would always recommend that you have blood samples to check your kidney transplant function and levels of immunosuppressive drugs, as these are absorbed through the gut and their levels can be altered in the case of diarrhoea and especially vomiting.

Holiday advice

The transplant service would always advise that holidays outside the UK be taken after you have had your transplant for over 12 months.

Please discuss with your consultant or member of the transplant nursing team prior to booking, as this can be different for the individual.

If you are going to countries where immunisations are recommended, please notify the transplant specialist nursing team, well in advance. We can then seek advice regarding the most appropriate and safe immunisations for you on an individual basis.

Previous advice regarding care when ill applies.

Please ensure that you have adequate health insurance and take your E111 with you. If you have problems gaining insurance or expense of premiums is a concern, please contact the transplant nursing team or kidney patients

association (KPA). A list of insurance companies who are recommended by the KPA can then be provided.

We will provide you with a letter to take with you on holiday. You can also take a copy of your last clinic letter with you. If you do not have a copy we can provide you with one.

All the points in this booklet are covered in your annual review clinics and annual dermatology review. Please attend.

Kidney transplantation leads to better health, increased activity and an improved quality of life for most recipients and their families. Now you have a transplant your goal and the goal of our service is to keep your transplanted organ functioning well, whilst working towards and maintaining a healthy life style, which will help you enjoy the benefits of your transplant.

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available in other languages
and formats upon request.

In accordance with the
Equality Act we will make
'reasonable adjustments'
to enable individuals with
disabilities, to access this
treatment / service.

If you need this interpreting please telephone

Polish

Jeżeli potrzebne jest Państwu tłumaczenie, proszę
zadzwoić pod numer.

Urdu

اگر آپ کو اس ترجمانی کی ضرورت ہے تو مہربانی کر کے فون کریں۔

Arabic

إذا كنتم بحاجة الى تفسير او ترجمة هذا الرجاء الاتصال

Chinese

如果需要翻译，请拨打电话

Farsi

اگر به ترجمه این نیاز دارید ، لطفاً تلفن کنید

☎ 0161 206 0224

Email: InterpretationandTrans@srft.nhs.uk

Under the Human Tissue Act 2004, consent will not be required
from living patients from whom tissue has been taken for
diagnosis or testing to use any left over tissue for the following
purposes: clinical audit, education or training relating to human
health, performance assessment, public health monitoring and
quality assurance.

If you object to your tissue being used for any of the above
purposes, please inform a member of staff immediately.

**Salford Royal
operates a
smoke-free policy.**

For advice on stopping
smoking contact
the Hospital Specialist
Stop Smoking Service
on 0161 206 1779

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