

# **Your Renal Transplant Looking Towards the Future**

## **South West Transplant Centre**

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## **The future**

Most people with a kidney transplant are able to stay free from dialysis for the long term and use this



opportunity to take up new hobbies or re-start old ones they weren't able to do before due to ill health or the restrictions of dialysis.

Our kidney survival rate from a deceased donor in Plymouth is currently 88% at one year, which compares to the national average of 86% (2011-2015).

## **Annual review**

Following kidney transplantation you will require lifelong follow-up to monitor the function of your kidney. In addition to your routine transplant outpatient clinic, you will be invited for a 45 minute "Annual Review"



appointment around the anniversary of your transplant. The purpose of this clinic is to provide screening for potential long term problems, identify risks and through health education allow you to make your own healthy lifestyle changes.

Apart from the regular checks we will also undertake a number of blood tests. In addition, lifestyle factors relating to heart disease, sun care and male and female health.

## **Healthy lifestyle**

It is important that you try and stay as healthy as possible after your transplant as this will keep your transplant healthy for longer.

It is a good idea to be active after your kidney transplant, we suggest you start with short walks and then build up over time.

Transplant patients can drink alcohol and should follow the recommended limits. Currently the government recommends no more than 14 units of alcohol over the course of a week for both men and women. These should be spread over several days with at least two alcohol-free days per week.

Drinking to excess or 'binge' drinking can cause vomiting which reduces the amount of transplant medication you absorb. Excess alcohol can damage your liver which can affect your transplant medication levels. Please have a chat with the transplant team if you are unclear about how much alcohol is safe to drink.

## A healthy diet



Before you had a transplant you may have been on a special diet, for example low potassium, phosphate, or fluid.

Once your transplant is working well you will be able to relax these restrictions and can enjoy a much wider range of food and drink.

You may find you have a larger appetite because the transplant medications can make you feel hungrier. Taking care about what you eat is still important to help avoid unwanted weight gain and control your blood cholesterol and sugar levels.

Eating a healthy diet and taking regular exercise will reduce your risk of heart disease and keep you healthier for longer.

Good food hygiene and hand washing when preparing, cooking and chilling food is also essential. This is because your reduced immune system function will leave you vulnerable to food poisoning and other stomach bugs.

Some foods carry a higher risk of food poisoning so should be avoided. Examples include unpasteurised dairy products, mould-ripened soft cheeses, pate and raw eggs. Special care should be taken when eating out

or when abroad. There is more information in the booklet provided by the dietitians.

Some foods and drink interact with your medication so should be avoided. These include grapefruit, pomelo and their juices, and star fruit. It is best to avoid taking any 'alternative' medicines or high dose vitamins without discussing with the transplant team first.

Looking after your bones is important after a transplant because some of your medications can weaken bones. Eating plenty of calcium and vitamin D rich foods can help to keep your bones strong. Examples include dairy products, fortified non-dairy products, tinned fish, fortified breakfast cereals and eggs.

Safe sun exposure is the best source of vitamin D. Keeping to a healthy weight and doing weight bearing exercise can also have a positive effect on your bone health.

Please ask the dietitian if you need further advice about any aspects of your diet or food safety.

## **Long term problems after kidney transplantation**

Although kidney transplantation helps to prevent the many problems that come from being on long term dialysis it does have its own set of problems.

These include sun sensitivity and infections, both bacterial and viral, but also high blood pressure, diabetes, high cholesterol, osteoporosis or even cancer.

You will have had an opportunity to discuss this with your consultant prior to transplantation but we will provide further information here.

## Infections



The medication you take to prevent your body from rejecting your kidney stops the immune system from working properly. This protects your kidney but also reduces your natural protection against infection and means you are more likely to suffer from them.

Common infections that can develop after transplant can range from urine infections to stomach bugs (diarrhoea or vomiting), thrush (mouth, groin or genitals) or simply a cold or flu.



Lots of people would develop these infections anyway but transplant patients can suffer from them more frequently, it may take longer to recover from them or may suffer from them more often.

All transplant patients receive an antibiotic called co-trimoxazole (or an alternative if you are allergic) for the first three months following your transplant (or longer depending on what other treatment you might have had). This helps prevent against some common infections.

## **Chicken pox**

Chicken pox is a viral infection that people often contract as a child. When your body starts to clear the infection the virus hides in your nerves and goes to sleep. This can re-activate at times of stress or lowered immunity and cause shingles. You cannot catch shingles, but you can catch chicken pox if you come into contact with shingles.

If you have had chicken pox in the past (even if it was when you were a small baby) you are unlikely to have any problems.

If you are not sure or have not had it before then contact the transplant nurses as they can check to see if you are at risk as we test your immunity to this virus at the time of transplant.

If you are vulnerable then the transplant nurses can arrange for you to come to outpatients for some preventative treatment.

Shingles can be more serious in transplant patients than in other people. If you develop shingles, then contact the transplant team for advice as you may need specific treatment.

## **Cytomegalovirus (CMV)**

CMV is a member of a group of viruses called herpes viruses and is very common. Probably about 80% of the population is infected.

In healthy people it lives in harmony with our body and rarely causes any problems, most people do not even realise they have been infected with it. This is called a

“latent infection” and although it is present in the body the immune system prevents it getting out of control.

Since the transplant medication weakens the immune system to prevent the new kidney from being rejected, the CMV can become active again and start to cause problems.

This can make people ill as well as damaging the kidney so we monitor the blood levels and give preventative medication if we are concerned you might be at increased risk.

We check to see if you have been exposed to CMV prior to your transplant as well as whether your new kidney is from a donor who has been exposed to CMV.

The highest risk time period is in the first few months after transplant when your immune system is very low. Even if you are not in the highest risk group we will still monitor your CMV levels in clinic.

If you have never been exposed to CMV and are receiving a kidney from a donor who has been exposed to CMV we know you are at risk of developing harmful CMV. In this case you will be given an anti-viral medication that reduces your chances of developing a harmful CMV infection (valganciclovir).

We can check your CMV levels with a blood test taken at your clinic appointment. If your level climbs we know you are at risk of a harmful infection and will start you on valganciclovir to treat this.

The symptoms of CMV infection often feel like any other viral infection, a high temperature, feeling tired and aches and pains.

Sometimes CMV can affect one part of the body in particular which causes symptoms related to that area. If it affects the lungs it can cause breathlessness, but it can also affect the liver, eyes or bowels. Fortunately these problems are less likely with kidney transplants than other types of transplant.

## **High blood pressure (Hypertension)**



Many patients with kidney problems develop high blood pressure. High blood pressure itself can also cause kidney disease so it's really important that your blood pressure is well controlled.

Unfortunately some of the medications we use to prevent rejection have a side effect of causing your blood pressure to rise so we keep a very close eye on it at clinic.

It's essential that your blood pressure is as well controlled as possible to prevent problems such as heart disease, strokes, blood vessel damage and even loss of your transplant. Reducing your salt intake will help to control your blood pressure.

## **Diabetes**

Our bodies constantly adjust themselves to ensure things stay stable. When we eat a meal the pancreas produces hormones that work to keep the sugar in the blood at a steady level.

One hormone helps to store sugar when the blood level is high (such as after a meal) and this is called insulin. Another hormone is called glucagon and releases sugar when the level is low (such as when a meal is missed).

In diabetes the pancreas does not work as well as it should and the body can become resistant to the effects of the hormones. This means sugar levels in the blood start to rise; if they rise above a certain level we call it diabetes.

Transplant patients are at risk of developing new diabetes after their transplant because of the medication used to suppress the immune system. Both tacrolimus and prednisolone increase the chances of developing diabetes.

We estimate that around 8-14% of people may go on to develop diabetes after their transplant and those who already have diabetes can find their sugars are more difficult to control.

Post-transplant diabetes is most likely to be diagnosed early on after the transplant (in the first 4 months).

We check blood sugar levels at every transplant clinic appointment and if we find an abnormal level you may need to have a further blood test.

Diabetes can cause symptoms such as thirst, increased frequency of passing urine or thrush. Let your transplant nurse or doctor know if you have any of these symptoms or are worried.

If you are diagnosed with diabetes you will be referred to the dietitian for advice as modifying your diet can reduce your chance of needing medication or reduce the amount of medication you might need to take.

You may also be given tablets or injections (insulin) to control your blood sugars, the choice will depend on your individual circumstances. It is important to control your diabetes well to reduce your risk of strokes, circulation problems and heart attacks.

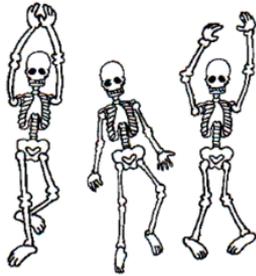
### **High cholesterol (Hypercholesterolaemia)**

Some of the transplant medications that suppress your immune system can also cause an increase in your cholesterol level.

We check your cholesterol level at intervals during your visits to clinic. This means it is important to attend your follow up appointments and have your blood tests.

Cholesterol is easy to control with medication but high cholesterol is strongly associated with developing heart disease. Eating a healthy diet will help to control your cholesterol level.

## **Osteoporosis (Thinning of the bones)**



Osteoporosis is where the usual structure of bones becomes thinner and they become weaker and are easier to break.

Steroids and tacrolimus can both lead to weakening of the bone which increases the chances of broken bones and back problems.

Eating plenty of calcium rich foods such as dairy products, bony tinned fish and fortified cereals will help to protect your bones. Vitamin D helps you to absorb calcium from your food and is found in fortified cereals and spreads, oily fish and eggs.

Some patients can be treated with weekly tablets to try and strengthen the bones (called bisphosphonates) but others just need calcium or vitamin D supplementation. The choice of treatment depends on individual circumstances.

## **Cancer**

As well as fighting against infections, our immune system helps prevent us from developing cancer.

Cancer is very common in the general population, around 1 person in 3 will develop cancer over the course of their lifetime.

It is slightly more common after having a transplant due to the medication needed to suppress the immune system. However, the benefits of having a transplant and taking the medication far outweighs the potential risk of developing cancer.

The most common type of cancer after a transplant is skin cancer and the chances of developing it are greatly increased by sun exposure.

## **Keeping safe in the sun**



Some of the medicines you take to prevent your body rejecting your kidney will make your skin more vulnerable in the sun. This means that your skin will burn faster, easier and to a greater extent than before your transplant.

We suggest that you use factor 50 SPF sunscreen with 4 star UVA protection, avoid the midday sun and cover up by wearing a broad brimmed hat, long sleeves and long trousers.

Transplant patients are also at a three times higher risk of developing skin cancer due to the medication you take. This means that it is really important to avoid the sun and cover up when it is unavoidable.

You should also keep an eye on any moles/skin lesions and contact your GP if you are worried about any of them.



All patients are seen in the Dermatology Department one year after their transplant to look at the risk of developing skin problems. If the department are happy you will be discharged and the transplant nurses will review your skin annually. If there are any concerns we will re-refer you back to dermatology within two weeks.

## **Epstein-Barr virus (EBV)**

The Epstein-Barr virus causes glandular fever and most people have been exposed to it by the time they reach adulthood.

As with other infections transplant patients are vulnerable to infections by the Epstein-Barr virus unless they have previously been exposed to it and become immune.

If you have not been exposed before you may be at risk if you receive a kidney from a donor who has previously been exposed and if you do develop it, the illness may be more severe.

EBV can also cause an extremely rare cancer of the white blood cells (part of your immune system). This is called Post-Transplant Lymphoproliferative Disorder

(PTLD) and only occurs in 1-2% of all kidney transplant recipients.

If you do develop this you may only need your immunosuppression medication reducing but some people can require chemotherapy.

## **Sexual health and family planning**

Sexual libido often improves after a transplant but it is not guaranteed as medication and diabetes can also affect sexual function.

Women should use contraception after their transplant and avoid pregnancy for at least the first year. This means you will be taking less medication, your renal



function will be stable and you will be completely recovered from the operation.

Pregnancy can put a lot of stress on your body and your kidney so it is really important to plan ahead.

Speaking to your transplant consultant early will mean the necessary changes can be made and you can be monitored closely.

Some of the medication you will be given after your transplant could potentially be toxic to your unborn baby and cause birth defects so you must discuss with the transplant team if you think you might have become pregnant or are planning to have a baby.

It is not only women who need to have their medication reviewed prior to starting a family. There is a potential

low risk that the medication could also affect sperm and so men should also discuss with their transplant doctor if they intend to start a family.

Although there is a risk to the unborn child of taking these medications there is also a risk of rejecting your kidney and renal failure can be a risk to unborn children as well.

Your transplant doctor will be able to have a frank discussion with you about the various risks and benefits of changes to medication as well as timings of any pregnancy in order to support you in any way we can.

If you wish to avoid pregnancy then barrier contraception is the most reliable method. The oral contraceptive pill is safe to be prescribed in most cases but care should be taken if you develop severe diarrhoea as this can mean the pill is not absorbed and thus could leave you vulnerable to becoming pregnant.

Some men have an improvement in their sexual function after transplantation.

However some men can suffer from impotence and struggle getting or maintaining an erection, this can be the result of medication, diabetes or a hormonal problem. Please mention it to your transplant doctor as there are tests that could detect a specific problem and different types of medication that can be prescribed to help.

## Going on holiday



One of the great advantages of having a kidney transplant rather than dialysis is the freedom to travel and enjoy holidays.

We advise that you start small and holiday in the UK for the first year after your transplant in case you develop problems. It is important you are medically stable before you travel, even in the UK.

You need to ensure you take enough medication with you to last the whole of your holiday and take an accurate list of medication with you. If you became unwell, or lose your medication you might need to go to a local hospital for help.

If you are travelling abroad always check whether you require any extra vaccinations.

You can get further information on the NHS Choices website or the fit for travel website:

- [www.fitfortravel.nhs.uk/home.aspx](http://www.fitfortravel.nhs.uk/home.aspx)
- [www.nhs.uk](http://www.nhs.uk)

If you are travelling to a country that requires vaccines, please check with your GP or the transplant team that they are safe for you.

**Transplant patients must not have any “live vaccines” as these could make you ill instead of protecting you.**

For example yellow fever and certain types of polio vaccine are not safe for transplant patients.

If you are travelling to a country that has malaria, talk to one of the transplant doctors or pharmacist about anti-malarial treatment as this can affect your immunosuppression levels.

It is especially important to be careful with food safety when eating abroad. Avoid tap water (or boil first), ice cubes and foods which may have been washed in tap water (such as salads or fruit). Select fruits and vegetables which can be peeled. Avoid high risk foods, and ensure food is always piping hot. The booklet from the dietitians provides more information.

## **Vaccinations**

The winter flu vaccine and the pneumococcal (pneumonia) vaccine are not live vaccines and are safe. We highly recommend both of them.

**Always have your winter flu vaccine!**



## Transplant games

One of the things that people often re-start after transplant is sports that they have not been able to play whilst they were unwell. Some people also start a new sport that they have never tried before.

Sport is an excellent way of staying healthy and we really encourage it after transplant.

The British Transplant Games is a four day sporting event held at various locations throughout the UK with the main aim of raising awareness of organ donation and what can be achieved post-transplant.

Over the four days transplantees of all ages (2 to 80+) and all abilities compete against each other in activities such as golf, darts, snooker, swimming, athletics, ten pin bowling, tennis, badminton, bowls and many more.

Please note you do not have to be a sports person before or after your transplant as there are events to suit everyone and every day.



Both Plymouth and Exeter have teams and there is the potential for competitors to go on to compete in the World Transplant Games.



**This leaflet is available in large print and other  
formats and languages.  
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