



Information for patients who have had a kidney transplant

A kidney transplant is a major operation so naturally there will be lots of things you have to remember and you may want to ask several questions. This booklet will give you lots of advice and information about your recovery following a kidney transplant, and hopefully will answer any questions you may have.

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Leaving hospital

When you leave hospital you will be given a supply of your medicines. If you have any problems getting medicines, let us know straight away.

Medicine for life

Now you have been given your new kidney you will be taking medicines for life. This will stop your body attacking your new kidney (anti-rejection medication). Initially you will be on a combination of 3 of the following anti-rejection medicines: Tacrolimus, Cyclosporin, Mycophenolate Mofetil, Mycophenolate sodium, Prednisolone, Azathioprine. **You must never stop taking these medications, as not taking them will result in you losing your kidney.**

It is very important that you do not forget to take a dose.

Sometimes for different reasons you may be changed from one medicine to another – for example, ciclosporin to tacrolimus or vice versa. This will normally be done under the supervision of the doctor.

Never ever change or stop your medicine unless you have been told to do so by your doctor or nurse. You may be asked by the hospital to do this, because your blood levels of the medication may be too high or too low. We monitor certain medications that you are taking by a timed blood test. It is important that you follow the instructions you are given so that we can get your dose correct.

The section at the back of this pack gives you information about anti-rejection medicines. It is important that you always read the leaflet and instructions given with your medicine.

If you need any more information or advice, ask your transplant doctor, nurse or pharmacist.

Should I take my medicine before I have my blood checked?

If you are taking tacrolimus or ciclosporin you will need to take your medication 12 hours before your blood test is due. Therefore if your appointment is 10:00, take your medicine at 22:00 the night before. Please do not take your tacrolimus or ciclosporin on the morning of your clinic appointment. You will need to bring the tacrolimus or ciclosporin medication with you, so once you have had your blood test done you can then take your medication.

What if I forget to take my medication or I am being sick?

If you have forgotten to take a dose, continue to take your medicine as normal. You do not take twice the usual amount when it is time for your next dose. Let your doctor, nurse or pharmacist know if you forget to take a dose.

If you have been sick or have been having diarrhoea within two hours of taking your medication, they may not be working. Call your hospital nurse and they will advise you further.

Other medicines you may be asked to take

You may also be asked to take all or some of the following:

Co-Trimoxazole – an antibiotic taken every other day to prevent bacterial infection. You will be on this tablet for around 12 months.

Nystatin – an anti-fungal liquid, to prevent mouth infections. You will take this liquid for around 3 months.

Ranitidine or Lansoprazole – an anti-indigestion tablet, to prevent an increase in stomach acid. You will take this tablet for around 3 months.

Valganciclovir – an anti-viral medication, (this is only needed in some patients) to prevent you from developing active viral infections. You will take this tablet for 100 days.

Fluvastatin – this may be started to lower cholesterol levels in your body. It is the only cholesterol lowering medicine that has been tested with kidney transplant patients, and we know does not interact with any of your anti-rejection medication.

Calcium and Vitamin D3 – this is a calcium supplement that you may have taken previously as a phosphate binder. However you do not take it with food it should be taken on its own as a supplement to help your bones.

Alfacalcidol or bisphosphonate – to provide additional protection for your bones.

Isoniazid and Pyridoxine – This may be given for the first 12 months post transplant to prevent TB infections.

You may still need to take some other medications, for example to lower your blood pressure; your transplant nurse or doctor will advise you on this. Good blood pressure control is vital to maintain good function of your transplanted kidney.

What happens at the clinic?

In order to monitor your progress we will:

- Weigh you
- Check a “mid-stream” sample of your urine for infection and protein
- Take some blood to check your kidney function, sugar level, liver and bone, red and white blood cells and your tacrolimus or ciclosporin levels
- Check your blood pressure

If you have any questions, the nurses are always in the clinic. As time goes by, you will not need to come to the clinic so often, but still will be seen on a regular basis for the rest of your life. It is vital that you attend your clinic appointments.

Infections

All anti-rejection medicines will reduce your natural defenses to infection. You should be particularly careful to avoid contact with anyone with chickenpox if you may not have had yourself. Tell your transplant nurse or doctor immediately if you come into contact with anyone with chickenpox.

Look out for:

- Temperatures
- Rash on back or stomach
- Pain and tenderness over your scar
- Flu like symptoms
- Night sweating
- Burning when passing urine
- Cloudy or smelly urine
- Nausea vomiting
- Shortness of breath

If you experience any of these symptoms please contact your doctor.

It is very important that we keep a check on you once you are home. In the early days you will need to come back to the hospital at least two or three times a week.

You must not miss any appointments.

Rejection of the new kidney

Rejection is the body's immune system recognizing your kidney as foreign and attacking it, and can happen even though you are taking anti rejection medicines to stop your body fighting your new kidney. This is more likely to happen in the first three months. Many people suffer one episode of rejection, and there are a variety of medicines available to treat it.

How will you know if your kidney is being rejected?

We check your blood regularly and do other special tests to monitor how your new kidney is being received. You can help by telling us if any of the following happens:

- You pass smaller amounts of urine
- High temperature (over 38°)
- You put on weight very quickly
- Your ankles become swollen
- Tenderness or pain over the transplanted kidney
- Increase in serum creatinine (monitored through blood tests)

What will happen?

Most times rejection is reversible and your new kidney will function normally, but it is important that you inform the hospital immediately if you notice any of these changes.

If we think your kidney is being rejected you will need to come to hospital. Your kidney will be scanned and you may need to have a biopsy. We may give you high doses of steroid or stronger medicines if they do not work.

Very occasionally the body's natural defenses are too strong which may mean that you have to go back to dialysis. However, the final outcome will depend on your individual circumstances.

A healthy eating plan

You will probably feel hungrier now that you have a new kidney. This may be just because you feel healthier or as a result of the Prednisolone you are taking. Please continue to eat sensibly and maintain a healthy weight. Here are some tips:

Eat more fiber: eat 5 portions of fruit and vegetables each day and eat wholegrain bread and wholegrain cereals.

Eat less fat: foods labeled ‘reduced fat’ or ‘low in calories’ can have hidden fats (and sugar), so make sure you read the label first. Choose products that contain less than 3g of fat, of which less than 1g per portion (100g) is saturated fat. Reduce your fat intake by grilling rather than frying and use unsaturated fats, such as sunflower or olive oil rather than saturated fats like butter when cooking. Dairy products can contain a lot of fat, so choose skimmed, or semi-skimmed milk instead of full fat, and opt for the low-fat versions of cheese and yoghurts.

Eat less sugar: use “sweeteners” and sugar-free products. Try to avoid fizzy drinks, cakes and sugary breakfast cereals.

Eat less salt: a person should have no more than 6g of salt per day. Swap snacks such as crisps to fruit and add herbs or spices to your food instead of salt for flavour. This will help to lower your salt intake.

Make sure that food is properly cooked and avoid raw food. Remember that you should always wash your hands before handling food and after using the toilet.

A healthy drinking plan

While you are in hospital the nurse will check how much fluid you drink and how much urine you pass.

You may need to keep an eye on this when you are at home; you do not need to measure how much you are drinking or how much urine you are passing. We would also like you to weigh yourself each morning.

Let us know straight away if:

- You have rapid weight loss
- You always feel thirsty
- Your skin feels dry
- You feel dizzy or light headed on standing
- You stop passing urine

If we know these things, we can tell you what to do to keep your new kidney healthy. To avoid becoming dehydrated remember to drink plenty of fluids especially during the summer. Remember if you are feeling thirsty you are already becoming dehydrated.

Your fitness

When you feel well enough you can start to take more walks and go swimming. It is important to stay fit and healthy and have a regular fitness regime. There is no reason why you cannot have an active life, though you should avoid contact sports like rugby or karate.

Your mouth

Some of your medicines can affect your gums therefore you need to keep your teeth and gums healthy. Tell your dentist about your new kidney and what medicines you are taking. You should also tell your dentist if you have any allergies.

You may need to take antibiotics if you are going to be treated. This decision lies with your dentist to make. It is important to visit your dentist every 12 months.

Your skin

Due to your medication you may develop acne, which may require you to be seen by a skin doctor for treatment. You are also more at risk of skin cancer. Make sure you cover up, wear a hat and use a sunscreen that blocks both UVA and UVB rays (factor 30 or more). You should also do this on cloudy days, as the sun's rays can still damage your skin. You can still enjoy the sunshine but be sensible and avoid the midday sun.

You should examine your skin regularly looking for any changes to existing moles and blemishes. If you are concerned that your skin has changed please speak to the transplant nurse or doctor.

Hair loss or growth – some of the medicines you are taking may cause you to grow more hair on your body and face or may cause hair loss. This is a normal reaction. Speak to the nurses or doctors at

the clinic for advice, as it may be possible to alter your medication. As we reduce your medicine dose, there should be fewer problems with this.

Scar tissue – some people worry about their scar. Your scar will fade over time as your body heals. Don't forget to put sun cream on your scar if it is exposed to the sun.

Alcohol

Drinking alcohol in moderation is ok. It is recommended that you do not drink more than 21 units per week for men (and no more than four units in any one day) and women should not exceed 14 units per week (no more than three units in any day).

Your feelings

The early months after you get your new kidney can be very emotional and you may find that some days you are not sure if you want to laugh or cry. This can be for many reasons, and is entirely normal.

Sometimes "getting back to normal" is harder than you think. Your new kidney may not have worked straight away or you may be still experiencing some problems with it. You may be missing dialysis or the friends you made there, or you may be having feelings of guilt because you do not feel as happy as you expected to feel.

Sometimes it can be difficult to explain these feelings to your family. Remember that your doctors, nurses, relatives and friends are all there to talk to you.

Driving

We recommend that you do not drive for at least 6 weeks following your transplant.

Going to work

You will be able to go back to work. Some people go back to work sooner than others. There is no set time that you need to remain off work, this depends on your physical recovery and the sort of job you have. Ask your nurse or doctor for advice.

Getting out and about

It is important that you return to your normal day-to-day activities, and enjoy your new transplant.

Remember, due to your medicines you are more likely to get an infection. Be sensible and try to avoid people that you know to have an infectious illness, including anyone with chickenpox.

Going on holiday

We do not recommend that you travel abroad for at least 8-12 months after your operation.

Before booking any overseas holidays, always check that you are fit to travel with the transplant clinic.

For some holiday destinations you may need a vaccination. You should never have a "live vaccine". Some countries also require you to take malaria prevention tablets, check with the transplant team which ones are safe. You should also ask the clinic staff if there are any problems with where you want to go. Remember always check with your hospital, and plan ahead.

The transplant clinic will provide you with a letter for customs to cover your medication. You will need to take your medication in your hand luggage if you are travelling on a plane. Make sure you have enough medication to cover you for the

time you are away. Also don't forget to take some extra medication to cover you for any unexpected delays.

What about sex?

The answer is yes! You may have experienced some problems when you were on dialysis e.g. lack of libido or impotence. Hopefully you are now feeling fitter but if your sex drive has not returned please don't be embarrassed to discuss this with your transplant nurse or doctor. Sometimes symptoms such as impotence can continue but don't worry, they can be treated. Patients often worry that they will squash or harm the kidney during sex. Don't worry – having sex will not damage your new kidney. You may be having some concerns about your body or appearance, try talking to your partner about this.

Pregnancy

With a well functioning transplanted kidney the chance of a successful pregnancy is improved. However, if you are planning to become pregnant then please discuss this with your doctor. We advise against pregnancy during the first year after your transplant. If you want a baby then wait at least a year. Having a baby may put a strain on your kidney and there may be drugs that could affect the baby. Women can become fertile again before their periods return therefore we would recommend that you use contraception to prevent pregnancy.

It is a good idea to ask your doctor or nurse to make sure there are no problems before trying to start a family. You may need changes to be made to your medication before you get pregnant.

Contraception

You want your choice of contraception to be safe and secure. Most forms of contraception are safe to use after a transplant.

The combined pill is safe for most women, but it may increase your blood pressure. This should be monitored very carefully and this type of contraception should be avoided if you have a past history of blood clots (thrombosis).

The progesterone only mini pill is safe and effective. Your drug levels must be monitored after starting either types of the pill and you will need to make an appointment for a blood test 2 weeks after starting the pill. Remember to seek advice if you miss any type of pill.

The Mirena intrauterine device (coil) is safe and effective; however you may prefer to have an implant or a contraceptive (Depo-Provera) injection.

Condoms are safe and protect you from sexually transmitted diseases but are not always reliable, so should ideally be used in addition to another method of contraception.

Advice for women

Due to the medication you are taking it is recommended that you have yearly smear tests.

It is important that you carry out regular self-breast examination. This should be carried out monthly at a different time to your period. You are checking for swelling, lumps, and discharge from your nipple, and remember to check under your arms as well. If you are sexually active you should also be using condoms to protect yourself against sexually transmitted diseases.

Advice for men

Due to the medication you are taking it is recommended that you that you examine yourselves for any swelling or lumps in your testicles.

If you are sexually active you should also be using condoms to protect yourself against sexually transmitted diseases.

If you discover anything you are worried about please consult your GP, or transplant clinic.