Kidney Transplant Guide

Information for patients after a kidney transplant
Introduction

This booklet has been written for patients who have received a kidney transplant at Addenbrooke’s Hospital. It provides information about the kidney transplant operation and the recovery period. The aim is to help you and your family/carer to become more aware of what to do to keep yourself and your transplanted kidney in good health, and also what to do if you think you have a problem.

Below is a list of useful contact numbers for the Cambridge Transplant Centre.

09:00–17:00 Monday to Friday:
Renal transplant specialist nurse team 01223 274637 or 01223 348031
E-mail: renaltransplantcoordinators@addenbrookes.nhs.uk

Pancreas transplant coordinator 01223 216536
E-mail: pancreas@addenbrookes.nhs.uk

17:00–09:00 and weekends for urgent telephone advice only:
Transplant Ward, Addenbrooke’s Hospital, Cambridge 01223 217711

Outpatient clinic enquiries:
Clinic 12: Telephone: 01223 217452 or e-mail: clinic12@addenbrookes.nhs.uk

Clinic 5: Telephone: 01223 216217 or e-mail: clinic5@addenbrookes.nhs.uk

Transplant Pharmacy team: Telephone: 07580 364118
or e-mail: transplant.pharmacy@addenbrookes.nhs.uk

Addenbrooke’s Hospital switchboard: 01223 245151

www.cuh.org.uk/transplant
The kidney transplant operation

The transplanted kidney is usually placed in either the right or left groin area, as illustrated. It is placed here as it is close to your bladder. Normally your own kidneys are not removed unless there is a reason to do so. As a result, you will end up with three kidneys (your own ‘native’ kidneys and the transplanted one).

The operation requires the surgeon to join up your blood vessels to those of the transplanted kidney. The urine tube (ureter) that will drain the urine from the transplanted kidney will be connected to your bladder.

If you have a peritoneal dialysis catheter this will be removed at the time of the transplant operation.
After the operation

After the kidney transplant has been carried out you will usually return to the transplant ward. Sometimes it may be necessary for you to be looked after in the intensive care unit or high dependency unit for a day or two, depending on your recovery from the operation. The nursing staff will make sure that you are comfortable and will monitor your transplanted kidney to make sure it is working well.

When you wake up you will notice that you have a number of different plastic tubes in your body, the most common ones will be:

A **tube in your neck** to help us to give you fluids and give you temporary dialysis if required.

A **small tube in your hand or arm** to give you medications and pain relief.

A **plastic drain tube in your abdomen** to help drain away any blood and fluid from the operation.

A **urinary catheter**, a tube which passes up your urethra into the bladder, to help us monitor your urine output.

Most of these tubes should be removed after two to three days. The urinary catheter will remain for five days to allow the sutures to heal.

During the transplant you will also have a small plastic tube (ureteric stent) placed between your transplanted kidney and your bladder to help maintain the flow of urine. The stent will be removed after six weeks as a day case procedure using a local anaesthetic.
Recovering from the operation

Eating and drinking is usually encouraged as little as six hours after the operation. Whilst you are in hospital, your transplant nurse will encourage you to record everything you drink and measure the urine you pass, even after your urinary catheter has been removed. This will help us to check how well your transplanted kidney is working.

On the first day after your operation your nurses or physiotherapist will help you out to your chair for a few hours where you will be taught how to carry out deep breathing exercises. You will be encouraged to be mobile around the ward as soon as possible as this will help speed up your recovery and reduce your chances of getting a chest infection or a blood clot in the leg. You are likely to be in hospital for six to ten days following a kidney transplant. However this could be longer depending on your condition and your recovery.

Following discharge you will be seen in the outpatient clinic very regularly, twice a week to start with.

Although you should be able to take a shower after your operation the specialist nurse in clinic will advise you about when you are able to resume taking baths and the use of creams/oils to aid healing.

Wound care

There are three different ways used to close the wound after your transplant operation:

- **Staples:** these will be removed in clinic three weeks after your operation.
- **Glue:** this will eventually dissolve. For the first few weeks, try and keep the wound area as dry as possible when showering and avoid long hot baths.
- **Stitching:** your surgeon will advise you if these are dissolvable or require removing in clinic.

One of the transplant specialist nurses will look at your wound when you come to your clinic appointment to ensure that it is healing.
Complications associated with kidney transplantation

Although kidney transplantation is a very successful treatment for kidney failure, complications can occur. Your transplant team will do their best to reduce your chance of having any complications and to treat any arising problems straight away. You can minimise the risk of complications by following the advice we give to you carefully and keeping your transplant team informed of any problems that occur.

Problems associated with kidney transplantation:

About half of all transplanted kidneys will not work immediately; this is called delayed graft function. It may take several days for your transplanted kidney to start working and you may need haemodialysis during this time. If your kidney takes more than a few days to start working properly, or temporarily stops, your doctors may take a tissue sample (biopsy) of the transplanted kidney to see if your body is rejecting the transplanted kidney.

Failing to drink enough may lead to dehydration which can damage your transplanted kidney. You might find it difficult to drink plenty of fluid after your kidney transplant, especially if you had previously been restricting your fluid intake. To help prevent complications associated with dehydration you should aim to drink between two and three litres of fluids a day unless we have told you otherwise. If you start to develop diarrhoea and vomiting it is essential to increase your fluid intake to prevent yourself from becoming dehydrated. If you are unable to keep your fluids and transplant medications down then you should contact your GP or transplant team for advice.

High blood pressure is very common following a kidney transplant, particularly during the early months. After a kidney transplant many people require blood pressure lowering medication. It is vital to control high blood pressure as, if left untreated, you could be at risk of heart disease or a stroke and it can damage your transplanted kidney.

Roughly 30 in 100 patients will experience acute rejection within the first six months of their transplant. Your body will recognise that your transplanted kidney is ‘foreign’ and the natural response is to attack and reject it. You will have been given anti-rejection medication to reduce the chance of this happening; these medications will need to be taken for the life of your
After a kidney transplant. Rejection is treated by changing the dose of your anti-rejection medication and / or by prescribing a new medication in addition. As rejection can be detected following one of your regular blood tests it is critical that you attend your clinic appointments regularly. Rejection does not necessarily mean loss of your transplanted kidney. The signs of rejection can include:

- pain or tenderness over your transplanted kidney
- fever
- fatigue/weakness
- reduced urine output
- flu like symptoms
- sudden weight gain
- swelling in hands or feet
- a rise in blood pressure.

Some patients will experience anxiety and mood swings as the transplant operation can put a lot of stress on you and your family. It is very common for patients or relatives to have anxieties. There are counselling services to help you adjust to life at home. Please ask your transplant team for more information about these services.

Problems associated with the medication taken after transplantation:

There is a small chance that you could develop diabetes (raised blood glucose) as a side effect of your anti-rejection medication. It can affect any transplant recipient, but those with a higher weight (or body mass index, BMI) are at increased risk. Diabetes is a serious disease that is associated with many health problems. During your clinic visits, the transplant team will be regularly checking your blood glucose level. If your blood glucose is raised, you may be asked to have a further blood test, to confirm the diagnosis. Treatment for diabetes can include some or all of the following:

- a simple change to your anti-rejection medication
- changes in diet (low sugar diet)
- changes in lifestyle such as increased exercise and losing weight
- taking tablets or injecting insulin.

You are twice as likely to develop cancer if you are on anti-rejection medication compared with the general population who aren’t taking anti-rejection medication. In particular you will be more prone to developing skin
cancers. For this reason we encourage you to protect yourself from the sun by using powerful sun screens and avoiding direct exposure to the sun.

**The anti-rejection medication will make you more likely to develop infections.** The risk is greater in the early stages after your transplant because the doses of your anti-rejection medication will be higher. It is important that you inform your transplant team if you think you have an infection. If you know family or friends who have a serious infection it is a good idea if you avoid visiting them while they are unwell.

The majority of infections for example wound, urinary and chest infections are caused by common bacteria, which can be treated with antibiotics. However, because of your anti-rejection medications you are also at risk of other infections that can usually be prevented or treated. With time the increased risk of infection lessens but never goes away completely. The following are some of the most common infections:

**Fungal infections:**

**Thrush** – is caused by a fungus called candida. It can infect your wound, mouth, eyes, respiratory and urinary tract. In the mouth, thrush can cause soreness, a white film on the tongue and difficulty in swallowing. It can also infect the oesophagus or gullet, (the tube from your mouth to the stomach). In women, thrush can also infect the vagina, causing an abnormal discharge and itching. Severe fungal infections may require you to come into hospital for treatment.

**Viral infections:**

Three quarters of the UK population have had **cytomegalovirus** (CMV), the symptoms are similar to a cold or flu. If you have not had a CMV infection prior to your transplant then it can be passed onto you through the transplanted kidney. If you have had the virus in the past it can become re-activated after your transplant. In order to prevent a CMV infection, we give you tablets (valganciclovir) for the first few months after your transplant, when you are most at risk of developing a CMV infection. As CMV can still occur once these tablets have been stopped, we regularly test for it in your blood when you come to clinic. Signs of CMV infection include fatigue, fever, sweating (especially at night), aching joints and headaches. If you are unwell with CMV, you may need to be admitted to hospital for treatment.
After a kidney transplant

Most adults have had a **BK virus** infection without knowing it. Following your transplant, BK virus can re-activate. This will not make you feel unwell but it can damage your transplanted kidney. Treatment of BK virus involves reducing your anti-rejection medication in order to allow your body’s immune system to clear the virus. We regularly test for the virus in your blood when you come to clinic and occasionally we will need to take a biopsy (tissue sample) of your transplanted kidney to make sure that the virus is not causing inflammation.

**Cold sores** (herpes-simplex virus (HSV) types 1 and 2) generally infect the skin around the mouth causing painful blisters, they can also turn up in other areas of your body including the eyes, lungs and genitals. Herpes can be treated, but not cured, by using creams and medication available from your GP or local pharmacist.

**Shingles** (herpes zoster) appears as a rash or small blisters usually on the side of the face, chest, abdomen or back. The rash may not be painful and only occurs in people who have had chicken pox in the past. **Call your GP or transplant team immediately** if you think you have shingles as you will need treatment.

**Chicken pox** (varicella) may appear as a rash or small blisters. Chicken pox usually occurs in childhood. If you have been exposed to someone with chicken pox or shingles and you do not think you have had chicken pox, **please contact your GP or transplant team immediately**, do not wait to see if you are going to be sick.

**Other infections:**

**Pneumocystis** is a germ that is normally found in the lung. After your transplant you will be given tablets (Co-trimoxazole) to prevent you from catching this. Symptoms can include breathlessness and a cold or flu that does not go away.

**It is important that you contact your transplant team if you think you have any of the above infections.**
Going home

Below is a checklist of items you need to take home with you:

• A supply of your prescribed medication. This will be arranged by the transplant pharmacy team before you leave.
• A list of your medication including their names, doses and how often they should be taken.
• A discharge letter to pass on to your GP as soon as possible.
• A clinic appointment (ensure you have transport booked if required).
• A white topped urine specimen bottle labelled with your name and hospital number, to bring to your next appointment.
• Wound dressings for the first dressing change by your practice/district nurse or for you to change yourself.

When you get home

Once you have been discharged home it is important that you are aware when you should seek medical advice. You should contact your transplant team or the ward for urgent medical advice if you think you have suddenly developed one of the following in the first few weeks after your transplant:

• abdominal pain that is not controlled by your pain relief
• reduced urine output
• blood in your urine
• bleeding
• fevers or a raised temperature of 38°C or above
• diarrhoea and/or vomiting for more than 24 hours
• chest pain
• difficulty breathing
• swelling in the face, stomach or legs.

If you are unsure and cannot get over the phone advice, please phone NHS Emergency and Urgent Care Services on 111 or attend your local Accident and Emergency Department.
Medications after transplant

Before you are discharged from hospital the transplant pharmacy team will go through your new medications with you, giving you information on what to take, when to take it and why you need to take it. If you require any advice or have a concern about your new medications you can contact the transplant pharmacy team on: 07580 364118 or transplant.pharmacy@addenbrookes.nhs.uk

Non-prescribed medication

Ideally you should avoid using non-prescribed medication, such as recreational drugs, herbal medicines or remedies, diet and beauty pills/medicines, and body building drugs. These types of medicines have been known to cause irreversible kidney damage. However, if you do wish to take them, please be honest with your transplant team. We need to try and keep you safe.

Clinic arrangements

Following discharge from hospital you need to attend regular transplant clinics in the outpatients department at Addenbrooke’s Hospital. For the first few weeks it is very important that we see you twice a week to make sure both you and your transplanted kidney are OK. Over time these clinic appointments will become less frequent. Before you leave hospital the ward will make your first clinic appointment for you. When attending clinics please remember:

- Do not take your morning dose of ciclosporin, tacrolimus or sirolimus on your clinic days until you have had your blood test. Ensure that you bring the dose with you to clinic so that you don’t miss it.
- Bring an up to date list of your medications with you.
- Make sure you have an appointment for your next clinic before you leave.

If you are unable to attend the clinic for any reason, please inform clinics using the contact information at the front of this booklet.

If you were referred from the dialysis centres in Ipswich, Norwich, Stevenage (Lister), Peterborough or Chelmsford (Broomfield) you will normally be referred back to your local hospital three to six months after your transplant operation.
We encourage you to arrange your own transport to and from clinic as strict rules apply to determine whether hospital transport can be provided for you. For advice on public transport and parking at Addenbrooke's, please contact:

Addenbrooke’s travel helpline: **01223 586655** or [www.cuh.org.uk](http://www.cuh.org.uk)

**Education group**

In the first few weeks after your transplant you will be invited to attend a kidney transplant patient education group. The group is held once a month, usually on a Thursday after your clinic appointment. At the group you will receive extra education and advice on how to look after yourself and your transplanted kidney. You will also have a chance to ask the pharmacy and dietitian teams any questions you may have.

**Stent removal**

During the transplant operation a small plastic tube (ureteric stent) will have been placed between your transplanted kidney and your bladder, to help maintain the flow of urine while the sutures joining the ureter and the bladder heal. To prevent infection this **stent needs to be removed after your transplant**. About six weeks after your transplant you will receive a day case appointment to attend Addenbrooke’s for your stent removal. It is a simple procedure performed using a local anaesthetic.

During the stent removal, the transplant surgeon will gently insert a local anaesthetic jelly into your urethra. This will numb and lubricate the area enabling the smooth passage of the cystoscope (bladder telescope). The stent will then be removed, during which you may briefly feel some discomfort or pressure. The procedure takes about 15 minutes. Make sure that you drink plenty of water afterwards, as this helps to flush out the bladder. If you have any questions or want to discuss the procedure further, then talk to the transplant nurse or doctors before you are discharged.
Your health after a kidney transplant

Feel fit and enjoy life!

Before your transplant you may have felt too weak and tired to exercise. Many transplant patients find that after they have recovered from the surgery, they have more energy and are eager to increase their level of activity. Once you have been discharged from hospital we encourage you to gradually increase the amount of exercise you take without allowing yourself to become too tired. To avoid developing potential complications please follow the following advice carefully:

- Avoid lifting heavy weights for at least six weeks, gradually increasing the weight you can carry.
- Avoid repetitive tasks such as vacuuming or mowing the lawn for the first six weeks.
- Avoid the temptation to become stooped over your wound, worsening your posture and increasing the risk of back pain.
- Gradually improve your exercise tolerance in order to avoid the complications associated with poor levels of fitness.
- Extreme athletic exercise should be avoided for twelve weeks.
- The only sports to avoid are those where you might get a direct blow to the kidney, for example rugby, boxing or martial arts.

Although your ability to exercise will depend on you as an individual, regular exercise is important for your general health and wellbeing. Incorporating 30 minutes of physical activity in your daily routine will:

- lower your risk of developing diabetes following a transplant
- help to keep your weight down
- help prevent other health problems, such as high blood pressure and heart disease.

Exercise classes and gym memberships can provide a structured environment to exercise, however daily activity does not need to be expensive. Consider simple things that you can do every day:

- try parking further away from work or other destinations to increase the distance you need to walk
- cycle to work, rather than drive
- climb the stairs instead of taking the lift.

Remember – all activity counts!
Returning to work
As a guide, you should anticipate being off work for at least six weeks, but this will depend on how you are doing and the job that you do. When you feel you are ready to return to work please speak with one of the transplant team for advice.

Stop smoking
Smoking is harmful to your health and will reduce the life of your transplanted kidney! Smoking will also increase your chances of developing cancers and chest infections because of the anti-rejection medication you will be taking. We strongly advise that you give up smoking as soon as you can, more advice on stopping smoking can be provided by your GP or by visiting the following website: www.nhs.uk

Skin care
Skin cancer – You are twice as likely to develop skin cancer if you are on anti-rejection medication compared with the general population who aren’t taking anti-rejection medication. Skin cancer is a result of damaged skin caused by the ultraviolet (UV) radiation rays from the sun or tanning bed. Careful avoidance of sun exposure and daily use of sunscreens, SPF 30 and above, will help reduce the risk to the skin. You should regularly inspect your skin for signs of skin cancers, the pictures below give examples of the commonest types of skins cancers:

![Basal Cell Carcinoma](image1)
![Squamous Cell Carcinoma](image2)
![Melanoma](image3)

You should discuss any new or concerning moles/blemishes when you are next in clinic with the transplant team, alternatively you can seek advice from your GP.
Dry skin – If you are having problems with dry skin, use a mild soap and put on a body lotion after showering. If you have cuts or scratches ensure that you clean them. For larger cuts contact your GP. If you discover any unusual skin growth, rash or discoloration, contact your GP.

Tattoos and piercings – Tattoos and piercings bring a risk of viral and bacterial infections. We advise you to wait six months after your transplant before getting a new tattoo or piercing. Then only use a licensed studio.

Body image
The way we see ourselves is complex and has many contributing factors. These are all unique to every one of us. Scars left behind from surgery, intravenous lines and drains can alter your body image. These will become less visible in time. There are also some side effects from certain anti-rejection medication which may contribute to a negative body image. These may include weight gain and excessive hair growth. These symptoms are likely to diminish as the doses of your medication are reduced over time. If you are very concerned, please speak to the doctor when you see them in the transplant clinic – it may well be that some alteration in medication will improve things. If you have any particular worries regarding how you feel about your body after transplantation you can speak to one of the transplant team for advice.

Hair care
Illness and steroid treatment may change the condition of your hair. Permanent hair dyes, tints, wave lotions and bleach may cause your hair to become brittle and break. It is recommended that you wait until your steroid (prednisolone) dosage is lower than 10mg a day before perming or colouring your hair. If you notice that your hair becomes thinner, this will usually recover spontaneously but may take several months. If the problem persists please discuss this with the transplant team.

Dental care
Make sure that your dentist knows that you have had a kidney transplant and what medication you are taking. It is advisable to have routine dental checks every six months and maintain good dental hygiene. Non-healing mouth ulcers could be a sign of oral cancer and should be investigated by your GP.
Eye care
You should wait until your medications have been reduced before purchasing new glasses/contact lenses (usually about six months after your transplant), as your vision can alter in the first few months. It is important to have an eye test (at least every two years), to ensure an early detection of any eye problems.

Sexual activity
You can resume sexual activity as soon as you feel well enough to as it will not harm your transplanted kidney. Sexual functioning can be affected by dialysis, transplantation and some medications. If you have any concerns, please feel free to discuss them with one of the transplant team. If you are sexually active and do not have a steady sexual partner, you should use condoms to reduce the risk of sexually transmitted diseases. You should also use contraception to avoid an unplanned pregnancy.

Pregnancy and contraception
Having a kidney transplant doesn’t mean you can’t have a baby. However, due to the medication you will be on we advise you to avoid becoming pregnant for at least one year following a kidney transplant. If you are planning on or have recently become pregnant then it is essential to discuss your plans with the transplant team as it may be necessary to change some of your medication to make your treatment safe for you and your unborn child.

Vaccines
The table below outlines some of the vaccines you can and can’t have. For vaccines not covered below please speak to the transplant team before getting them.

<table>
<thead>
<tr>
<th>Vaccines that are SAFE to have:</th>
<th>Vaccines you should NOT have:</th>
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<tbody>
<tr>
<td>• influenza vaccine</td>
<td>• MMR vaccine</td>
</tr>
<tr>
<td>(recommended yearly)</td>
<td>• poliomyelitis vaccine live – oral (Sabin type)</td>
</tr>
<tr>
<td>• inactivated poliomyelitis vaccine (Salk type)</td>
<td>• oral typhoid vaccine (vivotif)</td>
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<tr>
<td>• pneumococcal vaccine</td>
<td>• BCG for tuberculosis</td>
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<tr>
<td>• tetanus toxoid vaccine</td>
<td>• smallpox vaccine</td>
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<tr>
<td>• polysaccharide typhoid vaccine (Typhum Vi)</td>
<td>• yellow fever vaccine</td>
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<td></td>
<td>• shingles vaccine – Zostavax</td>
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Health care for women
Your anti-rejection medication will increase your risk of developing cancers such as cervical, breast and bowel cancer. We recommend that you routinely check your breasts for lumps and speak with your GP for advice on screening programmes such as cervical smears, mammograms and bowel screening tests.

Health care for men
Your anti-rejection medication will increase your risk of developing cancers such as testicular and bowel cancer. We recommend that you routinely check your testicles for lumps and speak with your GP for advice on screening programmes such as bowel screening tests.

Foreign travel
If you are planning on travelling abroad it is essential that you follow our advice to minimise the risk to yourself and your transplanted kidney.

Infections
Your anti-rejection medication will make you more prone to picking up infections while abroad. You can reduce the risk of getting these infections by following simple advice such as:

• avoiding drinking tap water
• increasing your daily fluid intake
• ensuring the food that you eat is cooked properly
• avoiding salads and other raw fruits and vegetables that have been washed in tap water
• avoiding swimming in areas, such as rivers or seas, that do not have their water quality checked regularly or are known to have waterborne diseases/parasites.
• When planning a trip abroad you need to check well in advance which vaccinations are required, as you should not receive live vaccines whilst taking anti-rejection medication.
Malaria
You should speak to the transplant team if you are planning to travel to an area affected by malaria as some anti-malarial treatments can affect the levels of anti-rejection medication in your blood. When travelling to areas that are affected by malaria, you should try and minimise the risk of being bitten as contracting malaria whilst on anti-rejection medication can be very dangerous.

Insurance
It is very important to get adequate travel insurance before travelling abroad. You should ensure your insurer has full details of your condition. For European travel you need a European Health Insurance Card, which is available free online via the NHS website: www.nhs.uk

Transplant medication and travel
Obtaining supplies of your transplant medication whilst away from home can be very difficult or very expensive. You should always take more supplies than you will need for the trip; ensuring that you spread your supplies evenly between hand luggage and your suitcase in case one gets lost or stolen.

Dietary advice following your kidney transplant
While you are in hospital or during your clinic visits you will be seen by a dietitian who will advise you on your specific dietary needs. One of the great benefits of a successful kidney transplant is that you can enjoy a more varied diet. However, during the early stages after the transplant operation you may be advised to continue restricting certain foods until your new kidney is working properly.

Food hygiene – It is important that during the first three to six months after a transplant, whilst you are on higher doses of anti-rejection medication, that you avoid eating foods that may cause food borne infections such as listeria, salmonella and E. coli, for example, unpasteurised cheese, milk or yoghurt, and raw/undercooked meats, fish and eggs. Your dietitian will go through this in more detail with you and discuss any dietary specific questions that you have.
Salt – You should continue to follow a no added salt diet to help prevent high blood pressure.

Grapefruit – You should avoid having grapefruit/grapefruit juice because it interferes with the level of anti-rejection medication in your blood. If you cannot resist the temptation, you should wait until three hours after taking anti-rejection medication and always discuss this first with your doctor or pharmacist.

Calcium and vitamin D – Transplant patients can be at a higher risk of developing weak bones (osteoporosis) which can break more easily than normal. Adequate vitamin D and calcium in your diet can help lower the risks of breaks (fractures). Good sources of calcium include dairy products such as milk, cheese and yogurts; fish with bones, eg. sardines or tinned salmon; green leafy vegetables, for example broccoli; and dried fruit, nuts and seeds. Exposure to sunlight is our main source of vitamin D, but as a transplant patient you are recommended to take protection from the sun. Instead try to include good dietary sources of vitamin D, such as oily fish, eg. sardines or mackerel; cooked eggs, margarines, and fortified breakfast cereals.

Healthy diet and weight gain in the long term – You should now be able to enjoy a much greater variety of foods since you no longer have the dietary restrictions needed when you were on dialysis. After you have recovered from your transplant the advice is to follow a general healthy eating diet for good weight control and overall health, which is the same as the rest of the population. Your dietitian will cover this in more detail if you are concerned about your weight and will discuss your dietary needs on a more individual basis.

Further information
If you have any queries, please do not hesitate to contact your dietitian in the Department of Nutrition and Dietetics on: 01223 216655
Thanking your donor family

You may wish to find out a little bit about your donor. To ensure confidentiality of the donor family is maintained we are only able to tell you their approximate age and gender. In time, you may wish to write a letter to your donor’s family. The decision to write to your donor’s family is a personal choice. It may be the most difficult letter you have had to write. However, it may help you to know that nearly all donor families express appreciation for the cards and letters that they receive from recipients and their families, and occasionally they will write a reply. If you do decide to write a letter or card the following suggestions may help you:

• use your first name only
• mention your family or friends
• mention your hobbies or interests
• write about how your lifestyle was affected by kidney failure and its treatment
• say how long you waited for your transplant
• explain the benefit of transplantation for your lifestyle and health
• show how much this means to you and your family or friends
• you may wish to thank your donor’s family for the unique gift they have given you
• try to keep the language simple and sincere
• be aware that your donor’s family freely decided to donate their loved one’s organs to benefit others
• **do not** mention what area you live in or your hospital
• All letters should be sent to your recipient transplant coordinator for forwarding to the donor family. This is a confidential service.
Advice and Support

Following your kidney transplant, you may find the following support services offered by Addenbrooke’s Hospital useful:

**Young Adult Transplant Service (YATS)**
A service aimed at supporting patients aged between 16 and 30 who have had a kidney transplant and are under the care of Addenbrooke’s Hospital. The main aim of the service is to encourage peer support through the meeting of other young kidney transplant recipients at dedicated YATS clinics throughout the year. You can contact the YATS on: **07736 379570** or **youngadultstransplantservice@addenbrookes.nhs.uk**

**Addenbrooke’s Renal Counsellors:**
Our renal counsellor team are available to offer help and support to those in need of emotional and psychological support when coming to terms with renal failure and kidney transplantation. They can be contacted on: **01223 274544**

**Addenbrooke’s Renal Social Care Practitioner:**
The renal social care practitioner can offer advice on benefits, financial support and housing issues after kidney transplantation. They can be contacted on: **01223 274269** or via e-mail: **renalsocialsupport@addenbrookes.nhs.uk**

**Addenbrooke’s Patient Advice and Liaison Service (PALS):**
The PALS holds regular sessions with the Citizens Advice Bureau. For further information you can contact the PALS office on: **01223 216756 / 257257** or e-mail: **pals@addenbrookes.nhs.uk**

**Transplant unit patient support group**
This is an opportunity for patients to get together and learn from one another by sharing experiences. It takes place most weeks in the day room on the Transplant Ward. The patient support group is open to all inpatients and relatives. More information can be obtained from: **Addenbrooke’s Chaplaincy and Multi-Faith Community, Telephone: 01223 217769**
Other external support groups that you may find useful include:

**Addenbrooke’s Kidney Patients Association (AKPA)**

**Who are we?**
We have members from all over East Anglia including dialysis and transplant patients, relatives, friends, nursing and medical staff. The charity’s trustees are elected each year at the AGM and are all volunteers. We are affiliated to the National Kidney Federation who promote issues affecting kidney patients at a national level.

**What do we do?**
The main purposes of the AKPA are to help people suffering from kidney disease and to inform the public of our patients’ needs. You can find out more information at: [www.akpa.org.uk](http://www.akpa.org.uk)

**The transplant games**
If you enjoy sport you can enter the British Transplant Games. Although athletics and swimming predominate the games there is a range of other pursuits including darts, golf, archery, bowls, snooker, squash, badminton, tennis, table tennis, walking, cycling, volleyball, fishing and a mini marathon. When competing in the games you may be offered the chance to represent the United Kingdom in the World Transplant Games. Further information about the British Transplant Games and how to enter can be found at: [www.transplantsport.org.uk](http://www.transplantsport.org.uk)

British Kidney Patients Association Facebook page via: [www.britishkidney-pa.co.uk](http://www.britishkidney-pa.co.uk)

Transplant Patients’ Trust of Great Britain
[www.transplantpatientstrust.org.uk](http://www.transplantpatientstrust.org.uk)

National Kidney Patients’ Federation
[www.kidney.org.uk](http://www.kidney.org.uk)
After a kidney transplant

Privacy and dignity

Same sex bays and bathrooms are offered in all wards except critical care and theatre recovery areas where the use of high-tech equipment and / or specialist one to one care is required.

We are now a smoke-free site: smoking will not be allowed anywhere on the hospital site. For advice and support in quitting, contact your GP or the free NHS stop smoking helpline on 0800 169 0 169.

Other formats

If you would like this information in another language, large print or audio, please ask the department where you are being treated, to contact the patient information team: patient.information@addenbrookes.nhs.uk

Please note: we do not currently hold many leaflets in other languages; written translation requests are funded and agreed by the department who has authored the leaflet.

Document history

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