Cambridge Transplant Unit

Information for patients after a Pancreas transplant

This leaflet gives you important information on things to look out for and advice on how to care for yourself once you are home following pancreas transplant surgery. If you have had a kidney transplant at the same time you should read this along side the Kidney Transplant Guide booklet.

Outpatient clinics

You have been discharged from hospital because we no longer need to keep a daily check on you. However we still need to monitor your blood tests closely. You will need to come to the Transplant Clinic at Addenbrooke’s Hospital (held on clinic 12) every Monday and Thursday morning for a few weeks. At the clinic you will be formally reviewed by a doctor. There will also be a transplant specialist nurse and dietitian in the clinic who may see you too. We will check your blood tests to monitor your kidney and pancreas function. It is important that you remember not to take your dose of Adoport on the morning of your clinic as we need a blood test that shows us the level of this drug in your body before you take your tablet. Once you have had your blood taken you should take your Adoport. After the clinic when this blood level result has been reviewed, we will phone you to change your Adoport dose if necessary.

As your condition stabilises, your clinic visits will be reduced to one a week. In time they will reduce further. When you are very stable, those patients who originally came from other hospitals can return for follow up there.

If you need hospital transport we can arrange this for the first three months whilst you are not driving and are generally recovering from the transplant surgery. After this time you should make your own way to the clinics where possible.

Your wound care

When you go home, you may still have several dressings on your abdomen. If you have sutures or staples in your wounds, they need to stay in for three weeks, so if they were not removed while you were an inpatient we will take them out during one of your clinic visits. You may also have dressings covering the holes where the drains came out and we will also monitor and change these dressings at your clinics. If you need more frequent dressing changes then these can be done via your GP’s surgery.

Your white feeding tube was inserted during your operation in order to give you special feed to help you get enough nutrition during the early part of your recovery.
We do not need to use this tube to feed you now, but it must stay in place for 12 weeks.

This is so that your body can heal around where the tube goes into the bowel. After this time the tube can be safely removed and this can easily be done during one of your clinic visits. In the meantime it can be covered with a waterproof dressing so that you can shower.

**Medications**

Taking medications to suppress your immune system is essential after a pancreas and kidney transplant. Your body recognises the transplanted kidney and pancreas as foreign objects and tries to reject them. To prevent rejection, you must take your anti-rejection (immunosuppressant) medications each day as prescribed. You will probably go home with two anti-rejection drugs called Adoport and Mycophenolate Mofetil.

We have to monitor the level of Adoport in your blood every time you come to transplant clinic, so it is important you do not take this drug on the morning of your clinic until after your blood tests have been taken.

The pharmacist on the ward will have given you a list of all your medications. It is useful if you bring this list with you to clinic as we often make changes. Some of the doses of your drugs are changed by the doctors frequently in the first few weeks after your transplant. In time, some of the drugs will also be stopped but it is important to wait for your doctor to tell you when to stop a drug.

Please refer to the Kidney Transplant Guide booklet where more detailed information can be found on your medications.

**Rejection**

Rejection happens when your body recognises the transplanted pancreas as “foreign” and therefore attacks it, a process we call rejection. It is a common complication and usually can be treated successfully. If you have pancreas rejection, you may also have kidney rejection at the same time (see page 7 of the Kidney Transplant Guide), but sometimes only the kidney or the pancreas has rejection.

Symptoms of pancreas rejection include:

- increased levels of amylase and lipase in the blood
- pain in the lower abdomen
- increased blood glucose (a late sign of rejection)

If you do have raised amylase and lipase you may not have any pain and may not feel unwell. Your blood sugar levels may well be normal, but we would still need to investigate you for rejection. This will probably mean you will need a biopsy of the kidney as this is easier to biopsy than the pancreas.
A biopsy involves taking a very small sample of the transplanted kidney. You will be given local anaesthetic to numb the skin and a special needle will be inserted into the kidney to take some kidney tissue.

The sample is then sent to the laboratory where they look for signs of rejection through a microscope. Sometimes you may need to have a pancreas biopsy, which will be performed in the CT scanning department, or may require a short operation. If there are signs of rejection of the kidney or pancreas you would be given additional immunosuppression, as an inpatient. Treatment is usually successful, especially if the rejection episode is diagnosed quickly.

**Infection**

Infection is always a risk when you are taking anti-rejection tablets. Please refer to pages 9 and 10 of the Kidney Transplant Guide.

**Nutrition**

Now you have had a kidney and pancreas transplant you will not need to stick so rigidly to the renal or diabetic diets and you will not have to take insulin. It is likely that you will have lost some weight whilst being in hospital. The feed you were given through the tube will have stopped you losing even more weight. Whilst it is good that you put some of the weight you lost back on, it is still important to follow a healthy diet and guard against putting on a lot of weight.

We check your blood potassium levels every clinic visit. If the level of potassium in your blood is high we will advise you to cut down on some high potassium foods. Sometimes your medications themselves can increase your potassium level but this problem can be controlled when we are able to reduce your drug doses.

Please refer to pages 15-17 of the Kidney Transplant Guide for further information and advice.

**Blood sugar monitoring**

Your transplanted pancreas usually starts producing insulin straight away and you should have normal blood sugar levels soon after surgery. The ward nurses will have been checking your blood sugars frequently while you were an inpatient. When you first go home we would advise you to check your blood sugar level twice a day and at different times each day. Sometimes the sugars can be a little high. If you do get a reading around 10 then recheck your blood sugar level after about an hour. If your blood sugar level continues to rise, you should phone ward G5 for advice.

Your transplanted pancreas is in your lower abdomen and it therefore releases insulin into a different part of your blood circulation than your own pancreas did before you got diabetes. Because of this some people occasionally experience low blood sugar levels (around 3) and you can feel as if you are having a hypo.
Do not worry if this happens, but have something sweet to drink such as orange juice and recheck your sugar. Having small frequent meals rather than one big meal can also help maintain good sugar levels.

When you have had your transplant for a few months, you can reduce your blood sugar checks to a couple of times a week. Aim to check it a couple of hours after the biggest meal of the day.

As well as making insulin, the pancreas also secretes enzymes into your intestine that help digest the food you eat. Two of these enzymes are called amylase and lipase and we will check these levels in your blood at every clinic visit. If there is a rise in the level of amylase or lipase it can indicate that there is a problem with the pancreas and you may have to be admitted back into hospital for some further tests and extra treatment.

**Foot care**

Even though the transplanted pancreas should keep your blood glucose levels within a normal range it is very important to continue to keep a close check on the health of your feet. The years of diabetes leaves many people with less sensation and poor circulation to the feet meaning that pancreas transplant recipients are still at risk for foot problems including ulcers and infection. In time you may get improved sensation to your feet, but it will never become normal. Follow these guidelines to continue to take good care of your feet after your transplant.

- Wash your feet every day and dry them thoroughly, especially between the toes.
- Examine your feet carefully every day for cuts, scratches, blisters, ingrown toenails, puncture wounds or warts. Inform your doctor in clinic if you have any problems.
- Inform your clinic or doctor if you notice any signs of infection, burning, tingling, or numbness in your feet.
- Do not try to remove or treat corns or calluses by yourself. Make an appointment with a chiropodist or see your doctor to have them removed.
- Wear comfortable, well-cushioned shoes. Do not wear high heels and do not walk barefoot.
- Wear clean cotton socks to absorb moisture. Be sure to change your socks every day.

**Diabetic clinic**

Now you have been transplanted with a pancreas and have normal blood sugar control you should not need to attend a diabetic clinic as often as you have been. However we strongly advise that you arrange to have an annual review in your diabetic clinic so that they can keep a check on you. Even though you no longer have to inject insulin it is possible that you could encounter complications due to diabetes and the clinic can monitor you and keep a check on your feet and your eyes.
How will I feel when I go home?

Having a pancreas transplant can be a difficult time and when you go home you are very likely to need support with routine activities such as shopping, cooking and cleaning. It may well be a few weeks before you feel well enough to drive. It is also advisable to contact your insurers. We advise that you will need at least three months off work and when you do return it is often helpful to have a phased return so that you start off part time. Having said this, many people do make rapid progress and begin to feel better quickly once they are back at home.

If you have had a kidney transplant you will also have a stent protecting the join where the ureter joins your bladder. This will be removed in a minor operation in the Day Surgery about six weeks after you transplant (see page 6 of the Kidney Transplant Guide). Occasionally this tube is removed whilst you are an inpatient recovering from your transplant surgery.

Pregnancy

Women who are on dialysis or who have impaired kidney function often do not have periods and are not able to conceive or sustain a healthy pregnancy. Following a successful kidney transplant, fertility can return to normal very quickly. It is very important that contraception is planned and that pregnancy is avoided for at least the first year following kidney and pancreas transplantation.

Please do consult your transplant doctor in clinic if considering taking the contraceptive pill as some of these medications can increase the chance of blood clots which could affect the transplanted organs. Please avoid oestrogen containing pills.

When you want to start planning to become pregnant it is very important that you discuss this in your transplant clinic. Some of the transplant drugs you have been given would be very damaging to the unborn baby if you became pregnant and these drugs need to be swapped to different medications before you try to become pregnant.

It is important that you wait at least a year after your transplant before you plan to become pregnant so that your transplanted organs have settled down and your medications have been reduced.

Please refer to page 23 of the Kidney Transplant Guide for further information and guidance about sexual activity and general health.

Useful phone numbers

Ward G5: 01223 217711
Clinic 12: 01223 586918
Pancreas Transplant Coordinator: 01223 216536
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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Contact number 01223 216536
Publish/Review date March 2016/March 2019
File name PIN2466_Information_for_patients_after_a_pancreas_transplant_v3.doc
Version number/Ref 4/PIN2466