

Islet cell transplantation

What do I need to know?

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1. Tacrolimus (also called Prograf® or Advagraf®)	26
2. Mycophenolate	28
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Preventative medication. Usually all of these will be offered to you:	30
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General information about islet cell transplantation

1.1 What are islets cells?

People develop type I diabetes because they are unable to make insulin. As you may know, insulin is made by an internal organ called the pancreas. The cells within the pancreas that make insulin are found in groups of cells called the Islets of Langerhans (or simply 'islets'). A picture of an islet is shown in the pink area in the picture below (Figure 1). The cells that make insulin are called 'beta cells'

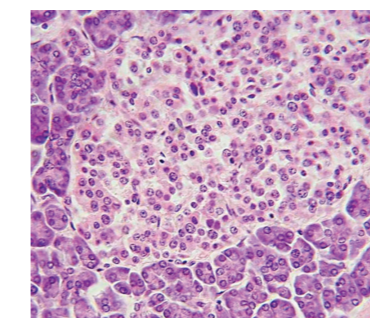


Figure 1: An islet (the pink area) surrounded by normal pancreas tissue

Islet cells produce insulin when the glucose (sugar) levels in the body are high. This insulin brings the blood glucose down again. Importantly, the islets stop producing insulin when the glucose level is low.

1.2 What is islet cell transplantation?

When someone dies and they have given consent for their organs to be used for transplantation, their pancreas may be used for islet cell transplantation. When this happens, the islets are extracted from the donor's pancreas. If this process produces a suitable number of good quality islets, then they can be offered to someone in need of a transplant.

Islet cell transplantation involves injecting the donor islets into a vein within the liver (the portal vein). After a period of two-six weeks or so, the islets start to work. At this time, the person will become aware that their blood glucose is easier to manage. Many people require two transplants (involving two hospital admissions) to get the maximum benefit from the procedure. Further details of the procedure and the hospital stay are given in the sections below.

At the time of the transplant, anti-rejection drugs are needed to make sure that your immune system does not reject the newly transplanted islet cells. These drugs are needed for the rest of the person's life. Anti-rejection drugs have known side-effects, which are discussed in detail in the appendix section.

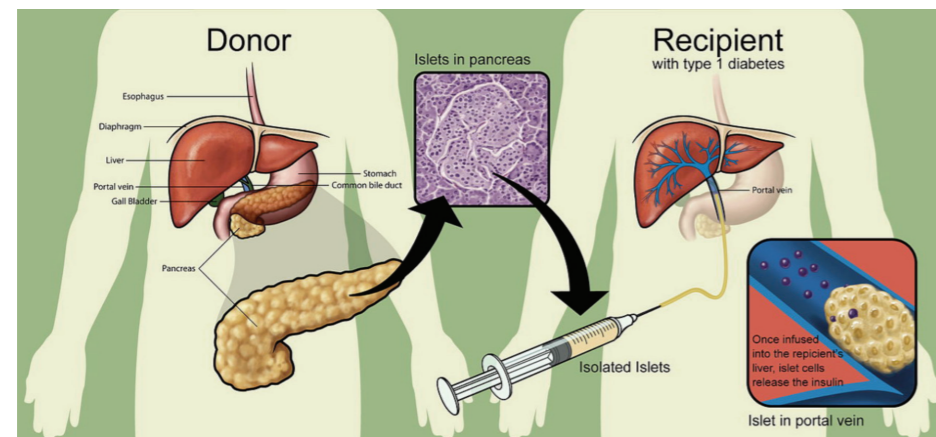


Figure 2: An islet cell transplant

1.3 What are the goals and likely benefits of islet cell transplantation?

The goals of transplantation are to reduce the frequency of severe hypoglycaemia, improve awareness of hypoglycaemia, improve quality of life, reduce fear of hypoglycaemia, and reduce the risk of long-term complications of diabetes. The goal of treatment is NOT to eliminate the need for insulin injections. However, this can be a great bonus when this happens. In some cases, people will have freedom from insulin injections for up to one year and very occasionally for more than five years. Others will need to continue with some level of injected insulin from the start.

1.4 Is an islet cell transplant suitable for me?

Some people with type I diabetes find it very hard to manage their blood glucose even though they make great efforts with their diet, their lifestyle and take multiple insulin injections or use an insulin pump. These people find that their blood glucose varies erratically from high to low levels in an unpredictable fashion. They have frequent episodes of severe hypoglycaemia (hypos that require help from other people), and very often they have no symptoms or warning when their blood glucose is low (impaired awareness of hypoglycaemia). This can be very dangerous, and often has adverse effects on their quality of life and the lives of their families.

If you think that the above is a good description of you, then an islet cell transplant might be a suitable option for you. Severe hypoglycaemia, awareness of hypoglycaemia, overall blood glucose levels and quality of life are all likely to improve following the procedure.

The main reason to have an islet transplant is recurrent, severe, disabling hypoglycaemia despite the best medical therapy, which may include a trial of insulin pump therapy.

Islet cell transplantation works best in people who are using less than 60 units of insulin per day. If you are on higher doses of insulin, then this could mean that other treatments might work better for you. Your medical team will discuss this with you in more detail.

Islet cell transplantation may NOT be suitable for:

- people who have moderate or severe problems with their kidney function. Anti-rejection medication can worsen kidney function, and your medical team will assess this pre-transplant.
- people who are very insulin-resistant
- people taking more than 60 units of insulin per day
- women and men planning a pregnancy, because we are not certain of the long term effects of some anti-rejection drugs on the unborn baby
- other less common reasons - your medical team will discuss these with you.

Islet cell transplantation may be particularly appropriate for patients with type 1 diabetes with hypoglycaemia, poor glucose control or hypoglycaemia unawareness, who have a functioning kidney transplant. If you are in this group, please discuss this with your diabetes team.

1.5 Will I have to take insulin after an islet cell transplant?

For most people, the simple answer is 'yes'. Our experience in the UK so far has shown that the majority of people have to continue with insulin but their dose is usually around half of that used before their first transplant. We have shown that around one in every three people is able to stop insulin injections a few weeks following their second islet cell transplant.

However, it is important to know that this welcome 'bonus' of treatment lasts for only 1-2 years in most people, at which time insulin is restarted in small doses. Five years after islet cell transplantation, around nine out of 10 people will need insulin by pump or by injection. Therefore, it is important to understand that islet cell transplantation is not an effective treatment for those people whose main interest is in stopping insulin therapy.

1.6 Understanding the risks and benefits of your treatment options

At this stage, it is important that you have sufficient information to help you make a decision about the procedure. Before you embark on the full clinical workup, you should be familiar with the risks and benefits of this therapy (please see Table 1 and section 4.3.3.) and of the other available therapies (see Table 1).

2. What are main treatment options for patients with type 1 diabetes and recurrent severe hypoglycaemia?

Several treatment options are available (see Table 1). These are listed here in order of increasing complexity:

- a) revision of your insulin regimen and overall diabetes management
- b) an insulin pump
- c) an islet cell transplant or a whole organ pancreas transplant.

For a full discussion of these options please see the document, 'Treatment options for patients with type 1 diabetes and recurrent severe hypoglycaemia.'

3. How do I get referred for islet cell transplantation?

You will require a referral to the transplant team by your diabetes specialist or renal specialist. Your diabetes team will need to confirm that all possible options have been explored to help you achieve stable blood glucose levels, and to avoid severe hypoglycaemia.

Table 1: Risks and benefits of islet cell transplantation, whole organ pancreas transplant and insulin pump therapy

Risks and benefits	Islet cell transplant	Pancreas transplant	Insulin pump
Death due to the operation or procedure	Less than 1 patient in 100	3 patients in 100	close to zero
Operation to open the tummy	2 patients in 100	All patients	0
Repeat operation on the tummy	close to zero	30 patients in 100	0
Serious surgical complications including colostomy	close to zero	30 patients in 100	0
When treatment starts to work	After 3-12 weeks	Straight away	Straight away
Any infection over 6 years	17 patients in 100	17 patients in 100	Not applicable
Life-threatening infection with long-term clinical effects over 6 years	2 patients in 100	2 patients in 100	0
Death due to infection over 6 years	1 patient in 300	1 patient in 300	Not applicable
Cancer, potentially life-threatening, over 6 years (except skin cancer)	< 2 patients in 100#	4 patients in 100	0
Skin cancer including melanoma (often treatable) over six years	8 patients in 100	8 patients in 100	0

Risks and benefits	Islet cell transplant	Pancreas transplant	Insulin pump
Severe reduction in kidney function due to anti-rejection medication	Sometimes	Sometimes	Not applicable
Freedom from insulin injections at 1 year	30-70 patients in 100*	80-90 patients in 100	Not applicable
Freedom from insulin injections at 5 years	10-30 patients in 100	50-60 patients in 100	Not applicable
Major reduction in severe 'hypos' at 18 months	75-95 patients out of 100	75-85 patients out of 100	See below**
Reduced risk of severe 'hypos' at 5 years	50-70 patients in 100	50-70 patients in 100	75 patients in 100
Improved HbA1c at 5 years	50-70 patients in 100	50-70 patients in 100	50 patients in 100
Improved diabetes complications	Likely	Proven	Likely

3.1 What happens next?

Once we receive the referral, we will contact you and provide you with some information. We may also send you some questionnaires about your 'hypos' to complete and return to us. This information will help us to assess whether you may be suitable for the procedure. We will then contact you and arrange an outpatient appointment where you will meet the medical and nursing staff. We will assess the severity of your diabetes in more detail and give you further information about the procedure. We may also perform some blood tests to help us assess whether you might be suitable.

4. What happens if I decide to go ahead with islet cell transplantation?

If you are keen to go ahead, and the initial blood tests are OK, further check-ups will be arranged. We will try to minimise the number of hospital visits but you need to be prepared for at least two additional visits to the hospital during this phase of the work-up. Your hospital visits will include the following:

General tests - including a chest x-ray, an electrical recording of your heart (ECG), and some blood tests to assess your tissue type and blood group. We will also test whether you have had previous viral infections such as HIV/AIDS, chickenpox or hepatitis, which could flare up if you were to receive anti-rejection therapy. We may also perform a 24-hour urine collection for protein, a blood test for kidney function, and we will check a midstream specimen of urine for infection. Some women will be asked to have cervical screening (a 'smear'), a mammogram and a pregnancy test.

The anti-rejection drugs used in transplantation can reduce kidney function. Therefore, we generally avoid the procedure in people who have poor kidney function, as it could lead to kidney failure.

We may arrange a heart scan to assess whether you have any important narrowing of the arteries that supply the heart with blood (the coronary arteries). If we find that you have coronary artery disease, then this may influence some aspects of your treatment but it is unlikely to prevent you from going ahead with the procedure. This test can take up to five hours to perform, and you may have to attend on two separate days. This test involves an injection in your arm of a radioactive dye. You may be asked to exercise, or your medical team may decide to simulate exercise using drugs that speed up your heart for a few minutes during the test. This is a safe procedure. The Nuclear Medicine Department at the hospital will explain the details of this test and will explain that the dose of radiation given to you is low.

We will also arrange an ultrasound scan of your liver, which will help to identify any problems that you might have with the islet cell transplant procedure itself.

It may be appropriate to refer you to other specialties for further tests if necessary.

Psychological assessment - we may arrange for you to have a meeting with our clinical psychiatrist. This will help us to identify people who are likely to require extra psychological support during or after the transplant. It is unlikely that the psychological assessment will influence the decision about transplantation.

Continuous glucose monitoring - we will be interested to know how your blood glucose changes over time. Therefore we will arrange for you to be fitted with a small monitor that will record your blood glucose every five minutes for six days. The monitor involves having a small plastic tube placed under the skin of your tummy (lower abdomen), which is inserted using a needle. The monitor can be fitted in around 20 minutes, and then you will be able to go home with it for a week or so. You will be asked to check your blood glucose frequently while you are wearing the monitor (up to seven times daily). You will be asked to return to the hospital after one week so that the monitor can be removed (this takes about 20 minutes), after which you'll be able to go home again. Your medical team will discuss the results with you.

Dental and eye records - we will also obtain information about your retinal screening results and your dental history.

If the results of the above tests are OK, then your name may be added to the waiting list.

4.1 What happens when I am on the waiting list for an islet transplant?

It is difficult to predict how long individuals wait as this depends on a number of factors.

While on the waiting list, it is important that you contact the transplant team if:

- a) there is any change in your general health
- b) you have any hospital admissions
- c) there is any change in your telephone numbers or address
- d) you decide to go abroad (for holiday or work).

This is important so that we know how and where we can contact you and so that we can suspend your name from the waiting list temporarily (while you are abroad or in hospital). Do not worry – you will re-join the list where you left it and your temporary suspension will not affect your chances of getting a donor.

While on the waiting list, you will be required to provide a monthly blood sample for tissue typing. These blood samples can be taken at your diabetes clinic or at your family doctor's surgery.

4.2 What happens when I'm called in for a transplant?

We will telephone you to let you know that a suitable donor pancreas has become available. We will ask about your general health and if you still wish to go ahead.

For example, if you have an infection when we call you, then we may be unable to go ahead because of the risk of causing a more severe infection with the anti-rejection drugs.

If all is well, you will be admitted to hospital for three to six days. When admitted, you will be seen and examined by your medical team and you will have a series of blood tests.

For a few hours before the transplant, you will be asked to stop all short acting insulin injections such as Novorapid - and to stop eating and drinking ('nil by mouth').

At this time, a small plastic tube (intravenous drip) will be inserted into a vein in your arm (in rare situations, this may be inserted in your neck – just above your collar bone). Insulin and fluids containing sugar will be given through this tube in carefully adjusted doses to keep the blood glucose as close to normal as possible.

If your glucose level goes low, this will be treated by giving more glucose through your vein and stopping the insulin drip until your glucose level goes up. Hypos are unlikely to happen because your glucose will be checked at least every hour and the insulin dose will be reviewed and adjusted every hour too. You will be able to take glucose tablets or Lucozade in an emergency situation, but this is unlikely to be required. We usually keep this drip running for the first 48 hours after the transplant to help achieve near-normal glucose levels while the islets settle into their new environment.

Anti-rejection drugs will be given once the medical team has final confirmation that the transplant will be going ahead. These drugs are either given through a vein, or sometimes by an injection under the skin.

4.3 What does the transplant procedure involve?

The transplant procedure will usually take place in the x-ray department. Before the procedure starts you will be given drugs through the drip to help you relax, and also some pain-relieving drugs. When the procedure starts, we would expect that you would be feeling sleepy, but awake, and aware of what is happening during the procedure. However, you may find that later your memory of the procedure is limited because of the sedative drugs given to you.

You will be given a local anaesthetic injection to numb a small area of skin on the right side of your chest. The radiologist will use ultrasound and x-rays to identify your portal vein, which is located within the liver. Using a needle, the radiologist

will insert a plastic tube (a catheter) through your liver and into the portal vein. The islets are then injected slowly into the portal vein over a period of 15 to 30 minutes.

4.3.1 Can I have a general anaesthetic routinely?

One of the advantages of islet cell transplantation is that it is a fairly minor surgical procedure with small risks associated with it. A general anaesthetic involves additional risks, which are best avoided. Some patients may prefer to have a general anaesthetic (be put to sleep) for the duration of the transplant, and sometimes this may be recommended to you by your medical team. This will be discussed with you before you are listed.

4.3.2 When is a larger operation and a general anaesthetic necessary?

There are two situations when you may be offered a general anaesthetic routinely:

- In about 5 out of every 100 people treated, it is impossible for the radiologist to insert a tube into the portal vein. If this happens, then you will be offered an operation on the tummy. Your surgeons will aim to locate a vein on the surface of your bowel, and inject the islets into this vein, which is connected to the portal vein. The consent that you give before you are sedated will cover this possibility, just in case it is necessary to go ahead with this larger procedure.
- If you find that it is very uncomfortable for you to have the islets given under a local anaesthetic, a general anaesthetic will be offered if this can be arranged immediately.

4.3.3 Are there additional risks not listed in Table 1?

Islet cell transplantation is generally considered to be a low-risk procedure, but there can be complications that are not listed in Table 1, and these are listed here:

- Pain:** Tummy pain is common, and some pain should be expected. It is usually mild, but it can be severe and require strong painkillers such as morphine. This pain would be expected to settle within a few hours.
- Bleeding:** You will be given a medication called heparin to thin your blood. This is given to protect you from developing a clot in the portal vein where the islets are given. The heparin is given with the islets and later as a drip or by subcutaneous injections. Bleeding inside the tummy, and sometimes from the skin where the islet infusion needle goes in, is rare. Bleeding or bruising is usually minor and it stops without treatment. However, it can be more severe and may require an operation on the tummy to stop it.

- Clots (thrombosis) in the portal vein** is rare. These have not been known to cause any important problems, and they are usually prevented and treated with a blood-thinning medicine (heparin as above). A clot affecting the whole of the portal vein is a potentially life-threatening complication but this has not been seen in any patient treated worldwide (more than 1000 people).
- Damage to other organs:** A small number of people (less than 1 in 50) have had damage to the gall bladder, liver or other parts of the tummy and this may require surgical operation under general anaesthetic.
- Infection** can occur as a result of the procedure. This is usually mild and can be treated easily with antibiotics.
- Abnormal changes in the liver blood tests** develop in nearly half the people treated, but this does not usually cause important symptoms or any long-term harm.

4.3.4 What are the other risks?

The main risks relate to rejection and the potential risks of anti-rejection therapy:

- Rejection:** This means that your new islets stop producing insulin. Although this can occur at any time after your transplant, complete failure of the islets is uncommon. For example, five years after transplantation, it is expected that approximately seven out of every 10 people will continue to have clinical benefit from their transplant in terms of fewer severe hypoglycaemic episodes, better control of their diabetes and better quality of life.
- Side-effects of anti-rejection drugs:** This medication can cause a range of side-effects, which include worsening of your kidney function (occasionally severe), mouth ulcers, nausea, diarrhoea, constipation, acne, joint aches, hand shaking and ankle swelling. Some of these side-effects can be severe enough to warrant a change in therapy, but this occurs in less than 1 in 20 people treated. These drugs can also cause elevation in blood fats (cholesterol) and blood pressure, but these changes can usually be addressed by prescribing additional medication. Further details are given at the end of this document.
- Infection:** The anti-rejection medication increases the risk of infection. It is difficult to put figures on the risk of infection. However, severe infections such as pneumonia occur in approximately three out of every 100 people treated. Most infections can be treated and the risk of dying due to infection is probably less than two people in every 100 treated over six years with immunosuppressant medication. Some of these are discussed in the next section.
- Cancer:** The anti-rejection drugs used in islet cell transplantation increase the risk of some cancers. The likelihood of developing a serious cancer with anti-rejection drugs is difficult to work out from the small number of people around the world who have received an islet cell transplant

- e) Overall risk of cancer (except skin cancer): Over six years, fewer than two out of every 100 people receiving anti-rejection drugs for islet cell transplantation are likely to develop cancer as a direct result of the therapy. A larger number of people would be expected to develop cancer even if they had not received this medication. Most of these cancers are likely to be treatable, but sadly, some of these will be fatal (less than 1 in every 100 people treated over six years). These figures exclude skin cancer, which is more common (see below). The fact that you will be monitored closely after your transplant will mean that most cancers, if they develop, will be picked up at an early and potentially treatable stage.

Note: Women are advised to have cervical screening (a 'smear') once a year, as the risk of cervical cancer is higher after a transplant. Cervical cancers may not be serious if they are picked up early. Women are also advised to have ultrasound scans of their ovaries after a transplant, as they may also be at higher risk of developing ovarian cysts if taking one of the anti-rejection drugs (sirolimus).

- Skin cancer: Over six years, approximately eight out of every 100 islet cell transplant patients treated is likely to develop skin cancer. Almost all of these cancers will be treatable and they are unlikely to be fatal. Fewer than two out of every 1000 people treated with anti-rejection drugs will develop the most serious skin cancer - melanoma. The risk of skin cancer can be reduced by having regular skin examinations (arranged routinely for all patients), by using the highest factor sun-block (which is available on prescription) and by covering up in the sun. You will be encouraged to examine your skin on a monthly basis and let your medical team know about any changes, or unusual lumps or bumps.

If you would like to know more on the subject of cancer and anti-rejection medication, you may like to read the following papers which are available on the internet or through your medical team: Kasiske BL et al. Am J Transplant. 2004; 4: 905-913 (<http://www.ncbi.nlm.nih.gov/pubmed/15147424>) and Engels EA et al. JAMA. 2011 Nov 2;306(17):1891-901 <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3310893/?tool=pubmed>

4.3.5 How can I prevent infection, and how might I know that I have an infection?

In general, the risk of infection can be reduced by taking simple precautions such as hand-washing, avoiding people with infections, avoiding eating out in places where the kitchen hygiene is uncertain, and practising safe sex.

We encourage you to remain as fit and healthy as possible, take light to moderate exercise, eat healthily, to have regular dental checkups and to take good care of your teeth. We recommend an annual flu jab and, if you currently smoke, we encourage you to stop. These precautions will help to minimise risk of infection and help your body fight any infections that do occur.

Transplant patients who develop symptoms of infection are encouraged to contact their transplant team at an early stage. These symptoms include:

- High temperature, chills and shivering
- Pain, swelling, redness or heat in any area of the body
- Excessive tiredness with aching muscles or joints
- Vomiting or diarrhoea
- Pain when passing urine or passing urine frequently
- Coughing up green phlegm
- Cold sores.

If you develop an infection that causes you to be unable to take or absorb your anti-rejection drugs, you will be advised to contact your transplant team immediately. For example, if you develop vomiting or diarrhoea we would like to know about this immediately.

4.3.6 What specific types of infections are common?

There are several infections that are commonly seen in people who have had a transplant:

- Thrush: This is caused by a fungal infection. It commonly affects the mouth and, less often, the chest or water works. In the mouth, thrush can cause discomfort, difficulty swallowing and a white film may be seen on the tongue and throat. In women, thrush can cause vaginal discharge and itching. It is important that you let your medical team know if you think you might have this infection - it can be treated with medication.
- Cytomegalovirus (CMV): Most adults have been exposed to this virus when they were younger, but when people receive drugs that suppress the immune system the virus can sometimes become active. Symptoms of this are tiredness, fever, sweating (especially at night), aching joints and headaches. If you develop the symptoms, particularly in the first few weeks after having your transplant, you need to inform your medical team because you may need to be admitted to hospital for treatment.

- c) Cold sores (herpes virus): Like cytomegalovirus, most adults have been exposed to the herpes virus, and it can become active when people have a transplant. If you develop painful blisters in the mouth or in the genital area then you should inform your medical team. The virus can be treated (but not cured) by medical therapy.
- d) Shingles (herpes zoster): If you develop a rash or small water blisters on the side of your face, chest or tummy, please call your medical team so that you can receive treatment as soon as possible.
- e) Chickenpox: If you have not previously had this infection in childhood, and you are exposed to someone with chickenpox or shingles, you need to contact your medical team immediately. You may require treatment to prevent you from becoming unwell.
- f) Pneumocystis: This infection can cause a chest infection or pneumonia. Please contact your medical team if you have a cold or flu-like symptoms that do not go away, or if you become breathless for no obvious reason. This infection can be treated with antibiotics.

4.4 What happens after the procedure?

After the transplant, you will be transferred back to the transplant ward where you will be closely monitored. This will include hourly checks of your blood glucose, and checks for signs of bleeding. Your blood glucose will be controlled by an insulin and glucose drip, aiming to keep your glucose levels as close to normal as possible. You will be able to eat and drink after four hours. You will choose from a specific Islet transplant menu. The dietitian will have discussed this with you before your admission to hospital. Your insulin doses will be discussed with you by the islet transplant team once you are off your insulin and glucose drip.

The day after your transplant, you will have an ultrasound scan of your liver to check for any signs of bleeding or clots within the portal vein. You will have additional blood tests on a daily basis to monitor your kidney, liver, blood count and the levels of the anti-rejection drugs.

We would expect you to stay in hospital for about three days after the transplant, but occasionally, the hospital stay might be longer. For example, you may need to stay for longer than a week if you require an operation on the tummy, or if there are bleeding problems.

During your hospital stay, you will be seen frequently by members of the islet transplant team, and by the pharmacist, who will help to explain the details of your medication including the important anti-rejection drugs.

4.4.1 Will I go home taking insulin?

Yes. It may take six to 12 weeks before your islets work properly and therefore it is likely that there will be no major change to your usual insulin doses when you are discharged. However, some patients start to see a reduction in their insulin requirements 10 days - three weeks after the procedure. You will be asked to monitor your blood glucose seven times a day and to keep in close contact with your medical team. We would expect your insulin requirement to come down by $\frac{1}{4}$ or $\frac{1}{2}$ during the first three months after the transplant.

After your first islet cell transplantation we would not expect you to stop insulin. However, as discussed above, after your second transplant it is possible that you may be able to stop insulin and stay off it for a few months (we expect to see three in every 10 people to be insulin-free after 18 months). However, most people stay on a small amount of insulin - usually about half the dose that they were taking before their first transplant. At five years, we would expect no more than one in every 10 patients to remain off insulin. Taking a small dose of insulin following an islet cell transplant may be beneficial to the transplant and extend the length of time that it continues to work.

4.5 What medications will I need?

4.5.1 What drugs will I need at the time of the transplant procedure

People receiving islet cell transplants are required to take many different tablets and this may seem very confusing. Your transplant team and the transplant pharmacist will be ready to help and we hope that the information provided here will be useful too. At the time of discharge from hospital, we encourage you to have a good understanding of your medication. Here are some general suggestions:

- Get to know:
 - the name of, and reason for taking each medication
 - what time of the day to take each medication
 - how long to take each medication
 - the main side-effects of each medication
 - what to do if you forget to take a dose.
- Please make sure that you never run out of your medications, because missing doses of the anti-rejection therapy could cause you to lose your transplant through rejection. Please make sure that you always have at least a two week supply of medication prescribed by your transplant team or by your family doctor.

- Please keep an up-to-date list of your medication and bring this with you to every clinic appointment.
- Please store your medicines safely. Most medicines are packaged to protect them from moisture and light. So keep your medicines in the original container, and only remove them when you are about to take them. Medicines should be stored in a cool dry place and out of direct sunlight. Please keep them out of the reach of children, and in a locked cupboard if necessary.
- Please develop a good relationship with your pharmacist and let them know when you have had a transplant. They will be able to advise you on what over-the-counter medication is safe for you. In general, simple painkillers such as paracetamol and simple cough mixtures are safe. Before you start any new medication you need to discuss how safe this will be for you with your pharmacist or transplant team. Some medication cannot be taken safely with your anti-rejection therapy. This also applies to herbal, flower or Chinese remedies. Please discuss this with your pharmacist if necessary.

4.5.2 What drugs will I take on discharge?

The medication given to individual patients will vary according to the transplant centre, and therefore only the commonly used medications are discussed here. If you are prescribed drugs that are not listed here, please ask your clinical team for further information.

The medicines you will take after a transplant can be split into three main types:

- Anti-rejection medications (or immunosuppressants) - these will be the most important of your new medicines. These help your new transplant to be accepted by your body. They will have to be taken as long as your transplant is working (which could be life-long). It is vital that you take your medication exactly as recommended, or you could put your transplant at risk.
- Preventative medications - these help to prevent the side-effects of anti-rejection medication. These are generally prescribed to prevent infection and are usually taken for three to six months after the transplant.
- Other medicines - these are likely to include insulin, blood pressure and cholesterol-lowering medication.

4.5.3 Anti-rejection drugs - general information

The immune system is your body's natural defence mechanism. It is there to find and destroy anything that is "foreign" in your body, including germs that cause infection. Your transplant will be seen as "foreign" by your immune system, and to prevent it from attacking your transplant, you will be prescribed anti-rejection medication (also known as immunosuppressants). These medications dampen down your immune system just enough to prevent you from rejecting your transplant, while still keeping it active enough to fight infections.

For some anti-rejection tablets, it is important that you know which brand you are taking. If your medicines look different from your previous prescription, always check with your transplant team before taking them. This is discussed in more detail below.

The dose of these medicines will need to be finely tuned as too little may lead to rejection, and too much may lead to side-effects. In the first few weeks after your transplant, the risk of rejection is higher, so the doses of anti-rejection therapy are higher than in later months. The results of regular blood tests will guide your medical team regarding your ideal dose of these medications.

Some people experience side-effects with these tablets. If you think you may be experiencing side-effects do not stop taking any of these medicines. Contact your transplant team immediately to discuss this, as there may be a simple solution. Side-effects should get better as the dose of your tablets is reduced - after the first few months.

For women only: if you become pregnant, treatment with some of these drugs may increase the risk of your baby having a birth defect. If you're thinking about having children, then you are strongly advised to discuss this with your medical team.

For men only: there is a small risk that your medication could cause a birth defect in any children that you father. If you plan to have children, you are advised to discuss the risks with your medical team.

4.5.4 Which anti-rejection drugs will I be given?

A few hours before your transplant you will be given an anti-rejection drug that works quickly. The drugs in this class (induction agents) include Alemtuzumab, ATG and Basiliximab. It is usual for only one or two doses of one of these drugs to be given to each patient undergoing a transplant.

In the first few days after your transplant, you will start taking long-term (or maintenance) anti-rejection medication. It is usual to take two of these drugs together and the most commonly used combination is Tacrolimus and Mycophenolate. Another drug in this class is Sirolimus, which is sometimes used in combination with one of the others.

In the section at the end of this document, we give you some detailed information about the commonly used drugs. We would like you to read all of this information so that you are aware of the potential side-effects. If you require further information, please discuss this with your transplant team.

4.6 After your transplant

4.6.1 What information can I expect at the time of discharge?

At the time of discharge your medical team will inform your GP by phone and letter, and provide you with written information about:

- Your insulin regimen
- Your medication card, including your anti-rejection drugs
- Your clinic appointments
- Food safety
- Advice about vaccination and travel
- Contact numbers and follow up visits.

4.6.2 How often will I need to attend the clinic?

Your medical team will need to see you very often for the first few weeks, and we understand that this can be very demanding for some people. These visits are needed because your medication, including insulin, will need to be changed frequently in the early stages. The following is a guide to how often you will need to be seen, but this will vary depending on individual circumstances:

- Weeks 1 – 3: twice a week
- Weeks 3 – 6: once a week
- Weeks 7 – 18: once every two weeks
- Weeks 19 – 52: arranged on individual needs
- After the first year: once every three months.

Visits are likely to take between 30-90 minutes, including blood testing. Please talk with your team about local parking arrangements and help available towards parking fees and travelling expenses.

On the days when you plan to attend the transplant clinic, do not take your Tacrolimus or Sirolimus tablets until after your blood tests have been taken in the clinic. It will be helpful to take your tablets with you to the clinic, and then take them as soon as your blood test has been done.

4.6.3 How often will I need to check my blood glucose after my transplant?

High glucose levels could harm your transplant, and therefore we will work hard with you to keep your glucose levels as close to normal as possible after your transplant. To help you to achieve this, for the first few weeks we will ask you to check your blood glucose levels seven times a day: before every meal, two hours after your meals and also at bedtime. After several weeks, the number of blood glucose checks per day can be reduced as your glucose levels improve, and your insulin dose is reduced. We will ask you to keep a written record of your glucose and insulin doses, and it will be helpful to take this record to every clinic visit.

4.6.4 How will I know if my transplant is working?

After one to two months, we would expect your transplant to start working, and then your blood glucose levels will improve and your insulin doses reduce. Until this happens, it can be difficult to be sure that your transplant is working.

Your medical team will check your blood and possibly your urine to find out how much insulin your transplant is producing. Another way that we can assess this is by giving you a test meal (like a milk shake) and then measuring the amount of insulin produced in your blood. This so-called 'meal tolerance test' is performed routinely at one month, at three months and six months after your transplant. This will normally take around four hours.

However, it is unusual to get the results of these tests immediately, and therefore we might not be sure that your transplant is working for a few weeks.

Fortunately, only a small proportion of people (fewer than 1 in 20) find that their transplant does not work at all after three months. If this happens to you, your medical team will discuss with you the value of continuing with anti-rejection medication.

If it becomes clear that your transplant has failed, this may be because your body has rejected it. Fortunately, this does not happen very often, but you need to be aware that this can happen at any time, even if you take your anti-rejection tablets regularly.

4.6.5 What can I do to prevent rejection?

The most important things that you can do are:

- take your anti-rejection medication as prescribed
- attend all of your follow-up visits at the hospital so that your medical team can give you the best possible care.

You can also look after your islets by keeping your glucose levels as normal as possible through eating sensibly and taking insulin as advised by your medical team.

Clearly it is important that you do what you can, but do not become overly concerned. If your body rejects your transplant, or it fails for other reasons, it is unlikely to be the result of anything you did or did not do.

4.6.6 How long will I be off work?

In the weeks after your transplant, you will need to attend the outpatient clinic very frequently (see Section 4.6.2). Therefore even if all goes very well, return to work is usually not practical before two months. Most people will be off work for about two to three months. You will receive a medical certificate to pass on to your employer (if needed).

4.6.7 When will I be called in for my second transplant?

This varies quite a bit between individuals. Some people are offered their second transplant within three months of the first, while others may have to wait for more than a year. This is because of the limited number of organs donated for transplantation in the UK.

Occasionally, when a person has an excellent response from their first transplant, they may be advised by their medical team to hold off having a second transplant until there are signs that this is required. This will be determined from the control of blood glucose levels (particularly 'hypos'), the insulin requirement and the results of blood and urine tests. A small number of patients never need a second transplant.

4.6.8 How long will my transplants work?

Currently, we expect that at least half the transplants given will work for six years or longer. Some patients continue to have clinical benefit from working transplants given more than 10 years ago. The long-term outcome from islet transplantation continues to improve as we improve the way the islets are prepared at the time of donation and with ongoing developments in anti-rejection medication.

4.6.9 What happens if my transplants fail?

Unfortunately, it is not possible to identify which patients will have long-term benefit from their transplant, and which patients will sadly lose their transplant soon after it is given (fortunately a rare event). If your islet cell transplant were to fail, then you would find that your blood glucose levels and insulin requirements would return to pre-transplant levels, and sadly your risk of severe hypos would likely return. Loss of the transplant would be confirmed by the medical team using blood and urine tests, and the anti-rejection medication would be stopped unless another transplant was planned.

4.6.10 If my transplants fail, can I have another?

Most patients in the UK programme will have two transplants, but if these fail we don't normally offer more because third and fourth transplants do not tend to work well for reasons that are unclear.

4.7 Will I be involved in research?

The islet transplant procedure has been researched thoroughly, is safe and is now part of routine NHS care. However, there are several ongoing research projects that you may be invited to take part in. The main purpose of these projects is to improve the care that we give to you and future islet cell transplant patients. Although we would be interested to involve you in these projects, you should not feel obliged to take part. Not taking part in research will not affect the clinical care you receive or the speed with which you receive a transplant.

5. Further information

If you have internet access and would like additional information, the following reputable websites may be of some interest:

- Information on islet cell transplantation from the UK's National Institute for Health and Clinical Excellence (NICE) <http://www.nice.org.uk/nicemedia/pdf/IPG257Guidance.pdf>
- Information on islet cell transplantation from Edmonton in Canada where our procedure was developed: <http://www.islet.ca/procedure>
- Information on islet cell transplantation from the American National Institutes of Health: <http://diabetes.niddk.nih.gov/dm/pubs/pancreaticislet/>
- Information on the outcome after islet cell transplantation from the International Collaborative Islet Transplant Registry <http://www.citregistry.org>
- Information on insulin pumps from Diabetes UK: http://www.diabetes.org.uk/Guide-to-diabetes/Treatments/Insulin/Insulin_pumps/
- Information on insulin pumps – input (with other useful links) <http://www.input.me.uk/>
- NHS information on insulin pumps <http://www.ntac.nhs.uk/HowToWhyToGuides/ContinuousSubcutaneousInsulinInfusion/Insulin-Infusion-Executive-Summary.aspx>
- Information on many aspect of diabetes care from Diabetes UK www.diabetes.org.uk
- Information on free advice on legal matters relating to chronic health problems. www.gov.uk/community-legal-advice Their phone number is 0845 3454345.
- Facts and figures on general transplantation in the UK www.uktransplant.org.uk
- Information on finding a local NHS dentist www.nhs.uk/scotland/Dentists or you can contact NHS Direct on 0845 4647

Appendix 1: Details of medication usually taken by islet cell transplant patients

First immunosuppressant drugs given (induction agents). Only one of the three drugs listed here will be offered to you:

1. Alemtuzumab (also called Campath®)

What is Alemtuzumab?

Alemtuzumab is an antibody that will help protect you from rejecting your islet cell transplant by reducing the number of white cells in your blood.

Why is it used, and how has it given?

Alemtuzumab works quickly to suppress your immune system. It is given a few hours before you receive your islet cell transplant, usually as a single injection under your skin. Your medical team may decide to give you a second dose approximately 24 hours after your islet cell transplant.

What are the side-effects of Alemtuzumab?

Alemtuzumab does not normally cause side-effects when it is first given. However, in fewer than 1 in 100 people treated, allergic reactions can occur. This can be a serious side-effect causing skin swelling (hives); difficulty breathing; swelling of the face, lips, tongue, or throat; and very rarely serious heart problems, including death.

Less severe side-effects at the time of the injection include feeling dizzy, hot or cold, nauseated, light-headed, sweaty, itchy, or having a fast heartbeat, or chest tightness.

Approximately 12 hours after receiving Alemtuzumab, it is quite common to experience flu-like symptoms such as feeling generally unwell, fever, chills, body aches and light-headedness. These symptoms usually settle after a few hours and often respond to paracetamol.

More serious side-effects occurring later include developing viral illnesses such as cytomegalovirus (CMV), and it may increase the chance of conditions brought on by antibodies such as anaemia or conditions such as an overactive thyroid gland. You will be monitored for these conditions. In general, they are treatable but very occasionally they can be severe and life-threatening. The drug may also increase the risk of cancer and other severe infections like other drugs used to suppress the immune system (as explained above).

Is there anything else I should know?

Alemtuzumab is not currently licensed in the UK for people receiving an islet cell transplant; though it is licensed for other conditions, and it is commonly used in most transplant centres (UK, USA and in Europe). Your transplant centre has approved its use through its official committees having carefully reviewed the evidence in the medical literature. In this situation, your medical team will be required to secure your agreement to give the drug and document this in your medical notes.

2. Etanercept**What is Etanercept?**

Etanercept (trade name Enbrel) is a drug that inhibits tumour necrosis factor (TNF: a soluble inflammatory cytokine). Biological medicines like Etanercept are sometimes called cytokine modulators, or monoclonal antibodies.

Why is it used, and how is it given?

Etanercept is given by an injection (subcutaneous) under your skin on day three, day seven and day 10 after the transplant. It is used to reduce inflammation following islet transplantation and may reduce inflammation and promote survival of infused islets.

What are the risks of Etanercept?

There is an increased risk of infection. A reaction at the site of the injection (such as bleeding, bruising, redness, itching, pain, and swelling) may occur and allergic-type reactions, such as an itchy skin rash may occur. Let your doctor know if you develop any of these symptoms. Contact your doctor straightaway if you develop a fever, sore throat, or any unexplained bruising or bleeding.

3. Antithymocyte Globulin (also called ATG)**What is Antithymocyte Globulin?**

This is an antibody-based drug that helps prevent rejection by reducing the number of white cells in the blood.

Why is it used, and how has it given?

ATG is given intravenously through a drip put in your upper chest or neck. One or two doses are given each day over several hours for five days.

What are the risks of Antithymocyte Globulin?

When the drug is first given it can often cause flu-like symptoms, such as feeling generally unwell, fever, chills, headache and muscle aches. Occasionally it can cause severe allergic reactions that can be life-threatening.

Like other drugs that are used to prevent rejection, it can increase the risk of severe infections and cancer. It can also increase the risk of bleeding and anaemia.

4. Basiliximab (also called Simulect®)**What is Basiliximab?**

This is an anti-rejection drug.

How is Basiliximab given?

The drug is given intravenously as a drip immediately before your transplant and then usually repeated a few days after.

What are the risks of Basiliximab?

This is generally a safe drug, but it can cause constipation, stomach upset, headache or swelling of the feet and hands.

**Second immunosuppressant drugs given (maintenance agents).
Usually two of the three listed here will be offered to you:**

1. Tacrolimus (also called Prograf® or Advagraf®)

Prograf® (also called standard release tacrolimus) is the most commonly used brand. It is available in three different strengths: 0.5mg capsule (yellow), 1mg capsule (white), 5mg capsule (greyish-red).

Advagraf® (also called Tacrolimus MR) is occasionally used and is available in three different strengths: 0.5mg capsule (yellow), 1mg capsule (white), 5mg capsule (greyish-red).

These brands are not the same, and you should not change brand unless you have detailed advice to do this from your transplant team.

It is important that you check your prescriptions and supplies carefully to make sure you have the correct product. If in doubt contact your transplant team.

Tacrolimus may be used alone or in combination with azathioprine, mycophenolate or prednisolone. Tacrolimus is never used with ciclosporin.

When do I take Tacrolimus?

Prograf® is taken twice daily allowing around 12 hours between each dose.

Advagraf® is taken once daily half an hour before your breakfast in the morning.

Both Prograf® and Advagraf® are taken on an empty stomach (one hour before or two hours after food). If you forget to take a dose or take an extra one by mistake, tell your medical team when you come to clinic as this may affect how your blood tests are interpreted.

How is the dose of Tacrolimus decided?

The amount of Tacrolimus in your blood is important because too little Tacrolimus can lead to rejection and too much Tacrolimus can also be harmful to your islet cell transplant and to your kidneys. Blood levels need to be checked on a regular basis so your medical team can decide what dose of Tacrolimus is right for you. On the day you attend the transplant, do not take a dose of Tacrolimus at home but bring it with you. Once you have had your blood taken you can take your usual dose of Tacrolimus.

What are the side-effects of Tacrolimus?

Tacrolimus is a very good drug but it can cause side-effects in some people, for example: trembling, "pins and needles" in the arms or legs, blurred vision, headache, indigestion and feeling sick. You need to inform your medical team if you experience any of these symptoms. Tacrolimus may also cause high blood pressure or high blood sugar but these can usually be managed by reducing the dose or by using other medication (though only on the advice of your medical team).

What do I do if I forget a dose or take too much?

If you forget to take a dose, take it as soon as you remember. If it is almost time for your next dose, miss it out and continue as normal and inform your transplant team. If you accidentally take a larger dose than recommended, inform your medical team straightaway.

Can I take other medicines with Tacrolimus?

Some other medicines can affect the amount of Tacrolimus in the blood. Examples of some medicines that can do that include: Aspirin and products containing Aspirin for pain relief (low-dose aspirin for the blood is safe), Ibuprofen (also known as ibuprofen) and products containing this drug such as Advil and Nurofen, anti-migraine preparations such as Migril and Cafegot, Cimetidine (also called Tagamet), Erythromycin, Clarithromycin, Fluconazole and Rifampicin. This is not a full list so be sure to check with your medical team or pharmacist before taking other medicines alongside Tacrolimus, including herbal remedies.

Can I drink Grapefruit juice with Tacrolimus?

Grapefruit juice can affect the level of Tacrolimus in your blood and therefore this is best avoided, especially within three hours of taking your Tacrolimus medication.

2. Mycophenolate

Mycophenolate is an immunosuppressant and is available as two different brands so it is important that you know which brand you are taking:

1. Mycophenolate Mofetil or (also called Cellcept®) is available in two strengths: 250mg capsules (blue/brown) and 500mg tablets (lavender). Cellcept is the brand of choice in most transplant units.
2. Mycophenolate sodium (also called Myfortic®) is available in two strengths: 180mg tablets (lime-green) and 360mg tablets (pale-orange). Myfortic is usually prescribed for people who experience side-effects with Cellcept.

Both of the brands above are as effective as each other so do not worry if your medical team suggests switching brands. Mycophenolate is usually used together with tacrolimus or ciclosporin with or without prednisolone. Mycophenolate is never used with azathioprine. Mycophenolate should not be taken at the same time of day as indigestion remedies as these may reduce the effectiveness of mycophenolate.

When do I take mycophenolate?

Mycophenolate is taken twice daily allowing around 12 hours between each dose. If you suffer side-effects such as stomach upset or diarrhoea your medical team may advise you to split the dose so you take it three or four times daily. If this is the case you should take them evenly spaced through the day, for example: morning, midday, evening (tea-time) and night-time. Tablets and capsules should be swallowed whole with a glass of water.

How is the dose of mycophenolate decided?

You will usually start mycophenolate with the brand Cellcept at a dose of 1gram twice daily though this may be reduced if you experience side-effects. If you are started on the similar drug called Myfortic, your starting dose will be 720mg twice daily.

What are the side-effects of mycophenolate?

Mycophenolate may cause side-effects in some people including bloating, heartburn, diarrhoea, and feeling sick. Less commonly, mycophenolate can cause a low white blood cell count which can increase your risk of infection. Your medical team will monitor your blood tests closely and if your white blood cells drop your medical team will reduce your dose or stop the drug.

What should I do if I miss a dose?

If you forget a dose, take it as soon as you remember. If it is almost time for your next dose, miss out the forgotten dose and continue as normal. Please inform your medical team at your next clinic appointment if you miss a dose or accidentally take a larger dose than prescribed.

Can I take other medicines with mycophenolate?

You should not take antacids at the same time of day as mycophenolate as this may reduce its effectiveness.

3. Sirolimus (also called Rapamune®)

Sirolimus is available in two strengths: 1 mg tablets (white triangle) and 2mg tablets (white/beige triangle). Sirolimus can be used in combination with Tacrolimus or Mycophenolate.

When do I take Sirolimus?

Sirolimus is taken once daily in 30 to 60 minutes before food with a glass of water.

How is the dose of Sirolimus decided?

The dose of sirolimus is adjusted according to the amount in your blood. On the day that you attend the transplant clinic do not take a dose of sirolimus at home, but bring a dose with you. Once you've had your blood taken, you can take your usual dose of sirolimus.

What are the side-effects of Sirolimus?

Sirolimus can cause diarrhoea, stomach cramps, feeling sick, sore mouth, mouth ulcers and increased cholesterol levels. If you experience any side-effects, please contact your transplant team before you make any change to your medication.

Can I take other medicines with Sirolimus?

Some other medicines can affect the amount of sirolimus in the blood. For example: rifampicin, erythromycin and fluconazole. Also avoid Ibuprofen and some antihistamines and some medicines used for heart problems including diltiazem. Always check with your medical team or pharmacist before taking other medicines, including those that can be bought over the counter and herbal remedies.

Can I drink Grapefruit juice with Sirolimus?

Grapefruit juice can affect the level of Sirolimus in your blood and therefore this is best avoided, especially within three hours of taking your Sirolimus medication.

Preventative medication. Usually all of these will be offered to you:

Anti-rejection tablets are essential in protecting your new transplant rejection, but they do have side-effects, some of which can be prevented by other medication. Following your transplant, you are likely to be prescribed the following:

1. Co-trimoxazole (also called Septrin® or Bactrim®)

This antibiotic is given for six months to prevent urine and chest infections, and in particular, a chest infection known as Pneumocystis (see above). The usual dose is 480 mg (one tablet) taken once daily in the morning.

What are the side-effects of co-trimoxazole?

This drug can cause nausea, diarrhoea and sensitivity (rash) to sunlight. Very rarely, it can cause a drop in the white blood cells, and if this happens, your medical team may reduce or stop this medicine. Some people are allergic to this drug and are prescribed alternative called dapsone.

What should I do if I miss a dose?

Take it as soon as you remember. However, if it is almost time for your next dose, miss out the forgotten dose and continue as normal. There will be no need to inform your medical team.

2. Valganciclovir (also called Valcyte®)

This drug may be given to prevent a virus infection called cytomegalovirus or CMV. The drug is given for six months if either you or your organ donor has had this infection in the past. Many people carry this virus without it ever causing problems, however, and in people who receive anti-rejection therapy, the virus can become active. This infection can be serious and can affect your lungs, your tummy and your eyes.

Valganciclovir comes in oval pink tablets, and this should be swallowed with a glass of water after food. The dose varies between two tablets daily to as little as one tablet twice per week depending on how well your kidneys are working.

What are the side-effects of Valganciclovir?

This drug can cause stomach upset, diarrhoea, headaches and confusion. Occasionally it can cause a drop in some blood cells leading to tiredness, signs of infection or bruising. If this occurs, tell your medical team, who will most likely reduce or stop this medicine.

What are the side-effects of Valganciclovir in relation to pregnancy?

It is important that you do not become pregnant while taking this drug because it may damage an unborn baby. Women should use contraception, and men should use a condom while taking the drug and for three months after they stop it.

What should I do if I miss a dose?

If you forget to take a dose, this probably will not cause any problems but please inform your transplant team at your next clinic appointment.

3. Isoniazid and Pyridoxine

If you have had tuberculosis (TB), or have had contact with people that have had TB, then you'll be advised to take isoniazid alongside the vitamin, pyridoxine, for six months after your transplant. This will reduce the risk of you developing TB, while taking anti-rejection therapy. Isoniazid is taken in a dose of 300 mg once daily. Pyridoxine is taken in a dose of 10 mg or once daily.

What are the side-effects of Isoniazid and Pyridoxine?

Isoniazid can sometimes cause liver problems, but your medical team will monitor your blood test to detect this early and stop the drug if necessary. Isoniazid can cause numbness or tingling in the hands and feet, which is why you will be given pyridoxine to reduce the likelihood of this occurring.

4. Lansoprazole (also called Zoton®) and omeprazole (also called Losec®)

These medicines reduce the production of acid by your stomach. They may be prescribed to prevent or to treat heartburn or stomach ulcers. They are given either once or twice daily and you should preferably take them at around the same time each day.

What are the side-effects of lansoprazole?

These tablets can occasionally cause feelings of sickness, diarrhoea and headaches.

5. Aspirin

Aspirin works by making blood less "sticky" which helps prevent blood clots. It can help reduce the risk of heart attacks and strokes in people who are at risk.

How should I take aspirin?

Aspirin is taken on a low dose of 75 mg once daily. It is best to take this after food such as after breakfast.

What are the side-effects of aspirin?

Aspirin can cause stomach irritation. Occasionally people can be allergic to it and may develop rashes or wheezing if they have asthma. If you are allergic to aspirin you may be prescribed medicine called clopidogrel instead which works in a similar way as aspirin.

6 Other medicines

Medicines for conditions not related to your transplant will almost certainly be continued, such as medicines for epilepsy, gout and high cholesterol.

7 Holiday/travel vaccinations

The immunosuppressants you are taking to protect your transplant make it unsafe for you to have some vaccinations. The vaccines you can and cannot have are listed below:

Vaccines which you CAN have include:	Vaccines which you must NOT have are the "LIVE" vaccines and these include:
<ul style="list-style-type: none"> • Diphtheria • Hepatitis A • Hepatitis B • Immunoglobulins • Influenza • Meningococcus • Pertussis (whooping cough) • Inactivated polio injection ('special order only') • Pneumococcal • Rabies • Tetanus • Typhoid injection • Swine flu 	<ul style="list-style-type: none"> • BCG • Measles, mumps and rubella • Oral polio • Oral typhoid • Yellow fever • Rubella

Frequently asked questions about medication

Q: Why are there lots of names for the same medicine?

A: Each medicine has an approved name and it is this name which will appear on the label of the box medication. You may hear other names or abbreviations used for the same medicine, for example, Tacrolimus is sometimes called Prograf (the brand name) or "tac" (an abbreviation often used by hospital staff). If you are unsure or confused by different names always ask. We encourage all our staff to use the approved names of medicines to avoid confusion.

Q: Will I have to take tablets forever?

A: Some medicines you take after transplant are needed for only a short time and can be stopped after a few months. Others, including the immunosuppressant medication, must be taken as long as the transplant continues to work.

Q: What happens if I forget to take my tablets?

A: As mentioned above, if you accidentally miss a dose of your medicines, do not worry. For medicines taken three or four times a day, miss the dose and take the next dose at the correct time. For medicines taken once or twice daily, if you remember within a few hours, take the dose as usual and take the next dose at the correct time. If, however, it is closer to when the next dose is due, miss the dose and take the next dose at the correct time.

Missing doses of anti-rejection tablets on a regular basis increases the risk of you rejecting your transplant. Taking the tablets an hour or two later than normal occasionally will not cause any harm, but it is advisable to stick to a regular routine.

Q: Will I experience all the side-effects listed in the leaflet?

A: No. You may experience one or two, but most people experience none of them. Most medicines you receive will contain a leaflet of detailed information (more detail than is given in this booklet), including a long list of possible side-effects. The intention is to inform you. It is not intended to discourage you from taking your medicines, though the list can be concerning for some people. Do not alter the dose or stop taking any of your medicines without discussing it with your medical team first, even if you feel well. If you have any concerns about side-effects, please discuss them with your medical team or pharmacist.

Q: Can I drink alcohol with my medication?

A: Alcohol can increase the side-effects of some medications. In general, small amounts of alcohol are okay. The safe limit alcohol intake at:

- 21 units* per week for men
- 14 units* per week for women

* One unit is the same as half a pint of beer, one small glass of wine or one pub measure of spirits.

It is important that you avoid binge drinking as this may reduce the levels of immunosuppressants in your body and increase the risk of rejection. We suggest that you alternate alcoholic drinks with soft drinks or water to reduce the risk of dehydration.

Q: If I become pregnant, will my medicines affect my baby?

A: Having a transplant increases your chances of becoming pregnant. It is not advisable to become pregnant within a year of having a transplant, so it is important to take extra precautions during this time. Some immunosuppressants and other drugs used at the time of a transplant cannot be used during pregnancy, so if you're planning a pregnancy, or you think you may be pregnant, you must let your medical team know so that they can ensure that you are on the safest medicines for you and your baby.

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Several of our patients have commented on this document and I will be pleased to receive further feedback for future revisions.

I have had an islet cell transplant

Name: _____ Hospital Number: _____

- I take the following immunosuppressants: [Please tick]:

Mycophenolate mofetil (Cellcept)

Prograf [Tacrolimus standard release]

Advagraf [Tacrolimus modified release]

Mycophenolate sodium (Myfortic)

Sirolimus

- I must stay on the same brand of immunosuppressants
- I may have kidney impairment so please check my eGFR before prescribing any medicines.

For problems with supply please contact:

Prograf/ Advagraf Astellas
01784 419 615

SirolimusWyeth
0845 850 5544

MyforticNovartis
0845 741 9442

Cellcept Roche
0800 731 5711

