

Having a pancreas transplant alone (PTA)

This leaflet explains more about having a pancreas transplant alone (PTA), including the benefits, risks, alternatives, and what you can expect at the time of the transplant. The figures we quote in this leaflet relate to the Guy's PTA programme.

If you have any further questions, please speak to a doctor or nurse caring for you.

What is a pancreas transplant alone (PTA)?

A PTA is a treatment for patients with insulin-dependent diabetes mellitus (a condition in which there is too much sugar in the blood, often referred to as "diabetes") who frequently get life-threatening low blood sugars ("hypos"). The pancreas is removed from a person who has died (the deceased donor) and given to another person (the recipient).

The transplanted pancreas produces the insulin that the recipient needs and it responds to the recipient's own blood sugar levels. The pancreas also produces enzymes (chemicals that break down tissues) that your body doesn't need. The transplanted pancreas is joined to your blood vessels and intestines.

There are alternative treatments, but a PTA may be the best treatment for some patients with severe insulin-dependent diabetes who are fit enough for the operation. A PTA has risks as well as benefits. Pancreas transplantation is major surgery and should be considered carefully.

Why should I have a PTA?

For most patients having a PTA leads to a better quality of life and a longer life. This is because they no longer have to rely on injecting insulin and don't have to worry about low blood sugars.

Blood sugar control is usually very good, and dangerously low blood sugars do not occur. Complications of diabetes such as eye disease (diabetic retinopathy), gut disease (diabetic gastroparesis), nerve disease (diabetic neuropathy), and heart and blood vessel diseases often become stable after PTA. Sometimes these diseases get better.

What are the risks?

As with any medical procedure there are risks associated with having a PTA and it is important to understand these. Some deceased donors will have had long-term health problems before their death. Where relevant we will discuss these with you before your transplant. Some of this information may be worrying, but we believe it is better for you to understand the potential risks as well as the potential benefits of having a PTA. Everyone's situation is different and we will talk to you about your individual risks and benefits before a decision is made about adding your name to the national transplant pool.

Primary non-function and pancreas failure

Sometimes the transplanted organs never work (we call this 'primary non-function'). This happens in between three to five out of 100 pancreas transplants. The failed transplant will then need to be removed by the surgeon.

Sometimes the pancreas may work for a few days or weeks, but then stop working. This may be due to a blood clot within the pancreas, or other reasons. Occasionally the pancreas may be working but might have to be removed due to infection or leakage of enzymes.

Overall, about 10 out of 100 transplanted pancreases need to be removed within the first year after the transplant.

Infection

After a PTA you may get an infection in your chest, surgical wound, abdomen (tummy), or urine. These infections can usually be treated with antibiotics, but sometimes another operation is needed.

Bleeding

Between 50 and 60 out of 100 PTA patients need a blood transfusion after surgery.

More surgery

A further operation may be needed for bleeding, infection, or to rule out any problems with the first operation. Between 30 and 40 out of 100 PTA patients need more surgery after the transplant. Between ten and 15 out of 100 patients may develop a hernia or 'weakness' in the transplant scar and may need an operation to repair this. Occasionally more surgery is needed months or years later if complications occur.

Rejection

Sometimes your body may recognise the new pancreas as foreign and start to attack it. This process is called rejection. Between 10 and 20 out of 100 patients who have had a PTA will have an episode of rejection during the first year. Rejection is diagnosed by taking a sample of pancreas tissue to look at under the microscope (a biopsy). Pancreas rejection can be difficult to diagnose and treat, but some episodes of rejection can be treated by increased doses of immunosuppressant medication. We recommend that all PTA recipients have a biopsy six weeks after the transplant.

Risks of immunosuppressant medications

You will need to take medication to suppress the immune system during the whole time that the pancreas transplant lasts. This medication has side effects including an increased risk of infection and, in the longer term, cancer, particularly skin cancer. While you are in hospital the transplant pharmacist will talk to you about these possible side effects and how to monitor and manage them. For example, using sun protection creams to reduce the risk of skin cancers. At your transplant follow-up clinics we will check your blood pressure, cholesterol and blood sugar.

Diseases passed on from the donor

In rare cases, the transplanted organs may unknowingly carry diseases such as cancer or infection. All deceased donors are tested for viral infections such as HIV (human immunodeficiency virus, which attacks the immune system), hepatitis B, and hepatitis C (viruses that can cause liver damage). All organs are inspected carefully for signs of cancer.

Overall, less than one in 1000 transplanted organs will unknowingly carry a cancer or a serious viral infection like HIV, hepatitis B or C. If we know that the donor had a history of cancer or had a higher than average risk of HIV or hepatitis B or C, your doctors will discuss this with you before the transplant. If you think that the risks are too high you can decide not to go ahead with the transplant. This will not affect the rest of your treatment and you will not lose your place in the transplant pool.

Other infections, for example with cytomegalovirus (CMV), are very common in the community and are commonly caught from transplanted organs, but cause little or no long-term harm. You may need to take medication to reduce the risk of these milder infections, and we will discuss this with you at the time of your operation.

Other risks

Between one and two patients out of 100 may develop a blood clot in the legs or lungs after pancreas transplantation. Heart attacks or strokes occur in between three and five of every 100 patients after transplantation. In the long term, your risks of heart attacks or strokes are likely to be reduced by having the transplant.

Very rarely, the blood supply to the spinal cord or legs is damaged as a result of the transplant operation. If the blood supply to the legs is very bad, amputation (removal) of the leg may be needed. Amputation is more likely if you already have poor blood supply to your legs before the transplant. Between one and two in 100 patients have this problem. Problems with the blood supply to the spinal cord are very rare (about one in 500 patients), but could lead to paralysis of the legs.

If the transplanted pancreas needs to be removed, your own intestines will need to be repaired at the site where the transplanted pancreas was attached. If the surgeon feels that it is unsafe to try to repair your intestines, they will need to bring your intestine out to your abdomen wall. This is called a stoma. This happens in two to four out of 100 patients after having a pancreas transplant. Intestine fluid will be emptied into a bag stuck to your tummy wall. This is not permanent, and more surgery will be needed four to six months later to remove the stoma and re-connect your intestines.

Sometimes the anaesthetic, the surgery, or the immunosuppressant medications can damage your kidneys. It is important that you have good kidney function before the PTA operation. Blood tests will be done to check this.

Survival

Sadly, between 2 and 4 out of 100 patients will not survive the first year after pancreas transplant surgery. This may be due to complications from the surgery, complications from the immunosuppressant medications or other health issues.

Are there any alternatives?

If you have diabetes that is poorly controlled you must have specialist treatment to try to improve it. You should have seen a specialist diabetes doctor for advice. Apart from pancreas transplantation, the other treatment options may include:

- Insulin pump – a steady infusion of insulin with a special mini-pump, and careful dietary advice can improve the diabetic control of many patients, and avoid the risks of severely low blood sugars. You may need referral to a specialist diabetes team to consider this treatment.

- Islet transplantation – a different type of pancreas transplant. The donated pancreas is broken down into the clumps of the cells that produce insulin. These clumps (islets) are then injected through your abdomen skin, into the main vein leading into the liver. The clumps stay in the liver and produce insulin. This will have been discussed with you as part of your assessment.
- Simultaneous pancreas-kidney (SPK) transplantation – if your kidney function is poor, you may be suitable for transplantation of both a kidney and a pancreas. The pancreas surgeons will check your kidney function to see if this is necessary.

What happens while I'm waiting for a PTA?

If, after discussion with the kidney doctors and surgeons, you decide that a PTA is your best option, your case will be discussed in a meeting of the pancreas transplant team. If the team agrees, then your name will be placed in the national pancreas transplant waiting pool. Most people wait about one year before they receive a pancreas transplant. Some patients have shorter or longer waiting times depending on their tissue type, blood group, age, and whether they have antibodies in their blood against other tissue types. If you become unwell while you are waiting, you may need to be temporarily removed (suspended) until you're well enough to be put back into the pool.

You will need to stay as fit as possible to prepare for your transplant by taking all your medications. Make sure you attend all of your booked clinic appointments so that we can monitor your health. Keep to a healthy diet, take regular exercise, and don't smoke. Stay out of the sun and use a high protection sun block to reduce your risk of developing skin cancers.

You must make sure that we have your contact details up to date so that we can call you if a pancreas becomes available. If you have a mobile phone keep it on, and with you at all times, if not give us additional phone numbers where we may be able to get in touch with you.

If you have not received a pancreas transplant within 12 months of being in the waiting pool, we will see you again in the pancreas clinic to make sure you're as fit as possible and to answer any questions you might have. You might need more tests to make sure that you're still fit enough for the operation.

What happens when I am called in for a PTA?

Most people are called in for the transplant late at night. We will ask you to come to Richard Bright ward, on level 6, Borough Wing, Guy's Hospital, where you will have blood tests and be checked by the transplant team and anaesthetists. Do not eat or drink anything unless you need to manage your blood sugar.

You can be told the approximate age of the donor, their sex, and the cause of death (as long as this does not harm the donor's confidentiality). You may also be given some information about the donor's medical history (e.g. history of cancer, or whether they have an increased risk of an infectious disease), if this is relevant. We will talk to you about your individual risks and benefits, especially in relation to the deceased donor.

We want to involve you in decisions about your care and treatment. If you decide to go ahead with the transplant, you will be asked to sign a consent form. This states that you agree to have the treatment and you understand what it involves.

It is common for patients to be called in for a pancreas transplant, but the transplant does not go ahead. This happens in about one in three patients and is often due to problems with the

pancreas, or your blood tests. We understand that this can be very upsetting for you and your family.

What happens during a PTA?

The operation is carried out under general anaesthetic. Please refer to our leaflet 'Having an anaesthetic' for more information about this. A large cut is made in your abdomen. The artery and vein of the pancreas are sewn into your artery and vein in the right hand side of your lower abdomen. The intestine that comes attached to the pancreas is sewn into your intestine. The pancreas usually starts producing insulin a few hours after the transplant.

The operation usually takes between three to four hours. Your own pancreas is left in place.

Will I feel any pain?

You will feel some pain after the operation, but this will be controlled with strong painkillers given into your vein. You will control the amount of painkiller you receive by pushing a button (patient-controlled analgesia – PCA). Most patients feel comfortable within hours of the operation.

Sometimes the anaesthetists decide to insert a narrow tube into your back to help with pain relief. This is called an epidural catheter. The anaesthetist will talk to you about this before the transplant.

What happens after a PTA?

For the first few days after the transplant, you will be cared for in the intensive care unit (Guy's Critical Care Unit – GCCU). You will have a catheter (a hollow, flexible tube) to drain urine from your bladder. You will also have tubes coming out of your abdomen (drains), and a tube in the neck to give fluids into your veins. Your blood sugars, urine output, and blood tests will be carefully monitored to check the function of the transplanted pancreas.

When you are well enough, you will be moved to Richard Bright ward. The catheter will be removed three to five days after the operation. Most patients can eat and drink within the first few days after the operation.

Most people are in hospital for about two weeks after the transplant. If you need more surgery, or there is a problem with the transplant, you may need to be in hospital for longer.

What do I need to do after I go home?

Before you go home the pharmacist will go through all of your medications and tell you what they are for and how to take them. You will also be given information about how long to rest, removal of dressings, and pain relief. To start with, you will be seen three times a week in the transplant clinic to make sure that the pancreas transplant is working well, and that you are getting better as expected.

A few months after the transplant you will be sent an appointment to come back to Guy's to have a special test to see how well your pancreas is working. This is called a mixed meal tolerance test. This involves drinking a mixture of protein, fat and carbohydrate that tastes like a milkshake. Blood tests will be taken to see how much insulin the transplanted pancreas is producing.

You are recommended to have a pancreas biopsy (where a tiny piece of tissue is removed from the pancreas and examined under a microscope) to make sure that there is no rejection of the transplanted pancreas.

How long will my PTA last?

Between 70 and 80 out of 100 pancreas transplants are still working one year later. On average, this type of pancreas transplant last for between three and five years. For some patients the transplants last much longer and for others they may only last a short time. The length of time that the transplants last depends on the age of the donor, other medical problems that the donor may have, and many other factors.

Can I have another transplant if it fails?

Most people can have another pancreas transplant if this happens. The success rate for second transplants is generally as good as for the first. However, you are likely to wait longer. You will also need to go through the same tests again to make sure you are healthy enough to have another transplant.

Useful sources of information

www.organdonation.nhs.uk

NHS Blood and Transplant website – describes the national policies on pancreas transplantation, transplant statistics, and how recipients are chosen for deceased donor pancreases.

www.guysandstthomas.nhs.uk/our-services/transplant/overview.aspx

Guy's and St Thomas' website, transplant section - includes information on pancreas transplantation.

www.drwf.org.uk/sites/default/files/ISLET%20BROCHURE%20UK%20webfinal2.pdf

Diabetes Research and Wellness Foundation website – information on islet transplantation.

Contact us

If you have any questions or concerns about having a pancreas transplant alone (PTA), please contact the transplant pool recipient coordinator on 020 7188 9391 (Monday to Friday, 9am to 5pm). Alternatively, call the hospital switchboard on 020 7188 7188 and ask for the bleep desk. Ask for bleep 1521 and wait for a response. This will connect you to the transplant pool recipient coordinator directly.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.guysandstthomas.nhs.uk/leaflets

Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

t: 020 7188 8748 9am to 5pm, Monday to Friday

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) e: pals@gstt.nhs.uk
t: 020 7188 3514 (complaints) e: complaints2@gstt.nhs.uk

Language Support Services

If you need an interpreter or information about your care in a different language or format, please get in touch:

t: 020 7188 8815 e: languagesupport@gstt.nhs.uk

NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

t: 111

NHS Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

w: www.nhs.uk

Get involved and have your say: become a member of the Trust

Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, and to become a member:

t: 0800 731 0319 e: members@gstt.nhs.uk w: www.guysandstthomas.nhs.uk/membership

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