

Having a simultaneous pancreas-kidney (SPK) transplant

This leaflet explains more about having a simultaneous pancreas-kidney (SPK) transplant, 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 SPK transplant programme.

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

What is a simultaneous pancreas-kidney transplant?

A SPK transplant is a treatment for patients with kidney failure and insulin-dependent diabetes. The kidney and pancreas are 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, and these enzymes flow into your gut.

There are alternative treatments, but a SPK transplant is often the best treatment for kidney failure patients with insulin-dependent diabetes who are fit enough for the operation. A SPK transplant is not a 'cure', and has risks as well as benefits. SPK transplantation is major surgery and should be considered carefully.

Why should I have a SPK transplant?

For most patients having a SPK transplant leads to a better quality of life and a longer life. This is because they no longer have to rely on dialysis; they have more freedom to travel, work, and they can eat and drink more freely. Most people say they have more energy and feel more able to cope with everyday activities.

Your sex life and fertility are likely to improve. If you are a woman of childbearing age you will usually be able to conceive after a transplant, although we suggest you wait one year before trying for a baby.

Blood sugar control is usually very good, and the recipient does not need to inject insulin or check their blood sugars regularly. Dangerously low blood sugars ('hypos') 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 stabilise after SPK transplantation. Sometimes these diseases get better.

What are the risks?

As with any medical procedure there are risks associated with SPK transplantation 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 SPK transplant. 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, and two to three out of 100 kidney 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 blood clots within the pancreas, or inflammation of the pancreas. Occasionally the pancreas may be working, but might have to be removed due to infection or leakage of enzymes.

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

Delayed kidney function

About 75 out of 100 kidney transplants from deceased donors start to work within a few hours of surgery. If this doesn't happen, (called 'delayed graft function' and sometimes referred to as 'sleepy kidney'), you will need dialysis until the new kidney starts working. This may be a few days or sometimes a few weeks. You will need regular ultrasound scans of the kidney and a once weekly kidney biopsy (where a tiny piece of tissue is removed from your kidney with a needle and examined under a microscope) to make sure that there are no other problems with the kidney.

Infection

After a SPK transplant 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 SPK transplant patients need a blood transfusion after surgery. Between ten and 15 of these patients might need a further operation to stop the bleeding. If you are taking blood-thinning medications such as warfarin, you are more likely to need a blood transfusion and to need another operation.

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 SPK patients need more surgery after the transplant. Between ten and 15 out of 100 patients may develop a hernia or 'rupture' in the transplant scar and may need an operation to repair this.

Between four and six weeks after the transplant the plastic tube (stent) that has been placed between the new kidney and your bladder will be removed in the operating theatre as a day procedure. Occasionally more surgery is needed months or years later if complications occur.

Rejection

Sometimes your body may recognise the new kidney and/or 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 SPK transplant will have an episode of rejection during the first year. Rejection is diagnosed by taking a sample of kidney or pancreas tissue to look at under the microscope (a biopsy). Most episodes of rejection can be treated by increased doses of immunosuppressant medication.

Risks of immunosuppressant medications

You will need to take medication to suppress the immune system during the whole time that the SPK transplant lasts. This medication has side effects including an increased risk of infection and, in the longer term, cancer, particularly skin cancer. Other side effects include a higher risk of high blood pressure, and high cholesterol (a fatty substance found in the body that can cause narrowing of the blood vessels). 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 SPK 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 SPK transplantation. Heart attacks or strokes occur in between three and five of every 100 patients after transplantation.

Very rarely, the blood supply to the spinal cord or legs is damaged as a result of the SPK 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 to it. If the surgeon feels that it is unsafe to try to repair your intestines, they will need to bring your intestine out to your tummy wall. This is called a stoma. This happens in two to four out of 100 patients after having an SPK transplant. Faecal 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.

Survival

Sadly, between four to six out of 100 patients will not survive the first year after SPK transplant surgery. This is due to complications from the surgery, complications from the immunosuppressant medications or other health issues.

Are there any alternatives?

If you have kidney failure you must have specialist treatment to keep you alive. Your kidney care team at your local renal centre will have discussed the different types of treatment with you and will have given you information to read. You may also wish to visit our website www.mykidney.org.uk for further information. Apart from SPK transplantation, the other treatment options are:

- Live donor kidney transplant – a kidney transplant from a live donor is a very good option, as they tend to work straight away, and usually work for longer than a kidney from a deceased donor. This is a smaller operation (two to four hours) with less chance of bleeding, needing further surgery, and other major complications. However for many kidney patients finding a suitable live donor can be difficult. Without a pancreas transplant you will still have diabetes, and the tablets that you need to take for the kidney transplant may make your blood sugar control worse.
- Live donor kidney transplant followed by a pancreas transplant – a pancreas transplant from a deceased donor can take place 12 to 18 months after a live donor kidney transplant. Because the transplanted pancreas and kidney come from different donors, the risks of rejection occurring in the pancreas are higher. The average survival of a pancreas transplanted after a live donor kidney transplant is three to five years. This is less than a pancreas transplanted as part of an SPK transplant (10 to 12 years).
- Deceased donor kidney transplant – a kidney transplant from a deceased donor, without a pancreas transplant. This is a smaller operation (two to four hours) with less chance of bleeding, needing further surgery, and other major complications. The average waiting time is two to four years.
- Dialysis – an artificial process by which the toxic waste products of food and excess water are removed from your body. Although dialysis will keep you alive, long-term dialysis can result in problems such as hardening of the arteries and thickening of the heart muscle. Dialysis can be either haemodialysis (HD) or peritoneal dialysis (PD). The main complications of HD are associated with getting access to your blood. This is done via a fistula (where an artery and vein are joined in a small operation), graft (a small piece of plastic connecting your artery and vein) or dialysis line (a small plastic tube in your neck) and this may become more difficult with time. The main complication associated with PD is infection in the abdomen (tummy). Rarely, PD patients can develop thickening and scarring of the lining of the abdomen; this is thought to be related to staying on PD for many years.

- **Conservative management** – managing the symptoms of kidney failure without the use of dialysis or choosing not to have dialysis or a kidney transplant, but receiving support from the healthcare team. This option is for those with a limited life expectancy due to other serious health conditions. If you have been referred to a surgeon for possible SPK transplantation, this is not likely to be a good option for you.

What happens while I'm waiting for a SPK transplant?

If, after discussion with the kidney doctors and surgeons, you decide that a SPK transplant 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 SPK transplant waiting pool. Most people wait for between nine to 15 months before they receive an SPK 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. If you dialyse abroad in a country where blood-borne infections are common you will be suspended from the transplant list for two months. This is because the transplant medications can be dangerous for people with recently acquired infections.

You will need to stay as fit as possible to prepare for your SPK transplant by dialysing regularly (if you have already started dialysis) and 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 and kidney become 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 (parents, friends etc).

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 SPK transplant?

Most people are called in for the SPK transplant late at night. You will be asked 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.

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 SPK transplant, but the transplant does not go ahead. This happens for about one in three patients and is often due to problems with the pancreas, kidney, or your blood tests. We understand that this can be very upsetting for you and your family.

What happens during a SPK transplant?

The operation is carried out under general anaesthetic. Please refer to our leaflet 'Having an anaesthetic' for more information about this. A large incision (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 tummy. 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.

Through the same cut, the artery and vein of the donated kidney are sewn into your artery and vein in the left hand side of your lower tummy. The tube carrying urine from the kidney (ureter) is sewn into your bladder. A small soft piece of plastic tubing (a stent) is placed inside the ureter to help it heal.

The operation usually takes between six to eight hours. Your own kidneys and pancreas are left in place (if they are still there).

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 simultaneous pancreas-kidney transplant?

For the first few days after the SPK 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 tummy (drains), and a tube in the neck to give fluids into your veins. You will have an ultrasound scan to check the blood flow to the kidney. Your blood sugars, urine output, and blood tests will be carefully monitored to check the function of the transplanted pancreas and kidney.

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

Most people are in hospital for between ten to twenty days after the transplant. If you need more surgery, or there is a problem with the SPK 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 kidney and pancreas transplants are 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.

How long will my simultaneous pancreas-kidney transplant last?

Between 85 and 90 out of 100 pancreas transplants and 93 to 95 kidney transplants are still working one year after SPK transplantation. On average, pancreas transplants last for between 10 and 12 years and kidney transplants last for 10 to 15 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 SPK 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.mykidney.org

Guy's Hospital and King's College Hospital kidney information website - describes the different stages of kidney disease and explains the treatment options and support available.

www.organdonation.nhs.uk

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

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

Guy's and St Thomas' website, transplant section - includes information on pancreas transplantation, live donor kidney transplantation, and surgery to form access for haemodialysis.

<http://www.guysandstthomas.nhs.uk/our-services/kidney/overview.aspx>

Guy's and St Thomas' website, kidney section - all of our kidney and transplant information leaflets are listed here and can be read online or downloaded.

Your Guide to Kidney Transplantation booklet – an in depth guide on kidney transplantation from Guy's Hospital and King's College Hospital, includes detailed information on all aspects of kidney transplantation including transplant medications and their side effects. If you do not already have a copy please ask us for one.

Renal clinical psychologists Tel: 020 7188 5969

Renal social workers Tel: 020 7188 5684/4023

National Kidney Patient Helpline Tel: 0845 601 02 09

Contact us

For further information, please contact the kidney/pancreas transplant recipient co-ordinator on 020 7188 5969 (Monday to Friday, 9am to 5pm). Alternatively, call the hospital switchboard on 020 7188 7188 and ask for the bleep desk. Ask for bleep 2063 and wait for a response. This will connect you to the transplant pool recipient co-ordinator 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

Leaflet number: 4227/VER1

Date published: March 2016

Review date: March 2019

© 2016 Guy's and St Thomas' NHS Foundation Trust