

Heart transplant

A patient's guide and
consent form



You have advanced heart failure. We have recommended that you go onto the waiting list for a heart transplant. We believe that heart transplantation has the potential to offer you a longer life and a better quality of life.

This booklet contains detailed information about heart transplantation and a consent form. The team will go through the consent form and ask you to sign if you are willing to proceed. You will be given this booklet to keep and this includes a copy of the signed consent form. This document should be read along with other information given to you by our team.

Detailed information about heart transplantation, benefits and risks, waiting for a transplant, and living with a transplant is also available on the NHSBT website and can be accessed via:
nhsbt.nhs.uk/organ-transplantation

What are the benefits of a heart transplant?

In carefully selected patients with advanced heart failure, a heart transplant can provide benefits which include:

- You are likely to notice a considerable improvement in the symptoms that were caused by heart failure.
- You are likely to have a better quality of life, including being able to cope with everyday activities, return to work and go on holiday.
- You are likely to live longer.

Waiting for a heart transplant

We have no way of knowing how long you will wait for a heart transplant. There are more people waiting for transplants than there are suitable donor hearts. The average waiting time depends on many factors including your size, blood group and whether you have antibodies to potential donors.

In addition, organs are preferentially allocated to the most unwell patients who are at the greatest risk of death. These patients are on the 'urgent' or 'super-urgent' waiting list for heart transplantation. Waiting times vary from days to years, depending on your individual situation.

You will be asked if you are willing to accept a heart from certain categories of donor when you are listed for a transplant. These include donors with a current or previous cancer with low risk of transmission, donors older than 60 years, donors with small chance of transmitting infection due to lifestyle and donors after circulatory death. This information is covered in a separate booklet called '**Donor choices in heart transplantation (PI 106)**'.

We ask you to make these decisions in advance because there will be very little time to make decisions when a donor heart becomes available. Restricting donor choices may increase your waiting time for a heart transplant and therefore increase your risk of deterioration while waiting. We will discuss donor choices to help you make an informed decision.

Being placed on the waiting list does not guarantee you will receive a heart transplant. Unfortunately, some patients die while they are on the waiting list or have to be removed from the waiting list because they are too sick to survive an operation.

You will be reviewed regularly while you are on the waiting list to identify any deterioration. Some patients require mechanical circulatory support with a left ventricular assist device (LVAD) or another type of mechanical pump while they are waiting for a transplant.

You must tell the transplant co-ordinators immediately if you become unwell whilst on the waiting list, particularly if you need treatment with antibiotics or steroids or are admitted to hospital.

This is important because some illnesses and treatments can affect your surgery or affect

the function of the transplanted heart. It may be necessary to place you 'on hold' from the transplant waiting list until you are well enough to have the operation.

Very occasionally, some patients improve while they are on the waiting list and no longer require a heart transplant.

What happens when a potential donor heart is found?

The transplant co-ordinators will let you know that we may have a suitable donor heart. They will arrange for you to be brought to Royal Papworth Hospital. Some patients will already be in our hospital if they are on the 'urgent' or 'super-urgent' waiting list. You will be reviewed by a member of the transplant team to make sure that you are well enough to proceed. There is a waiting period while the donor heart is thoroughly assessed. If there is a problem with the donor heart such as coronary artery disease, then we cannot proceed with the heart transplant. This is called a 'false alarm'. If we are certain that the donor heart is good, then you will be moved to the operating department.

The anaesthetic team

The anaesthetic team will meet you in the operating department. The team is led by a consultant anaesthetist and may include junior anaesthetic doctors, operating department practitioners (ODP) and anaesthetic nurse-specialists.

They will ask questions about previous anaesthetics, other medical problems, medications and allergies. They will ask about any fragile dental work, mouth opening or neck mobility issues and swallowing difficulties. They will answer any questions that you have about the anaesthetic, the lines that will need to be inserted and pain relief after the operation.

It is particularly important to let us know if a rare condition called malignant hyperpyrexia runs in your family as this requires special preparation prior to an anaesthetic and can be life-threatening if this preparation is not carried out.

Getting ready for the operation

You will be helped to lie down on the operating table. Monitoring equipment will be applied. These include small sticky pads (ECG dots) on the skin and a peg on your finger or earlobe to monitor your heart rate and oxygen levels. Any dentures will be removed and you may be given oxygen to breathe.

The anaesthetist will insert a thin plastic tube (cannula) into a vein on the back of your hand or forearm. You will usually be given a small dose of a sedative medication which may make you feel relaxed. A second cannula will be inserted into an artery, usually in your wrist or arm crease. This is used to measure blood pressure and allows blood tests to be taken. Local anaesthetic will be used to numb the skin before insertion of the arterial cannula and may also be used for the vein cannula.

Your anaesthetist will then slowly inject anaesthetic drugs. These will render you unconscious and you should not be aware of anything else until you are waking up on the intensive care unit after the operation is finished.

The risk of awareness (not being properly asleep) during the operation is extremely rare (around 1 in 20,000 procedures from a national audit). Your anaesthetic team will be present the whole time and will monitor you carefully. If you are worried about this, please ask your anaesthetist. There is a link to further information in the resources section at the end of this booklet.

Once you are asleep, the anaesthetic team will place a breathing tube through your mouth and into your windpipe. A ventilator is then used to blow a mixture of oxygen, air and anaesthetic gases into your lungs.

A specialised cannula, called a central venous catheter (CVC), will be inserted into a large vein in your neck. This is used to give fluid and medications and measure venous blood pressure.

A second CVC is usually inserted in the same vein. This is used to pass a pulmonary artery catheter (PAC) which measures blood pressure in the lungs and monitors the function of the heart.

Sometimes additional lines are placed into the groin either for monitoring, to administer fluids or medications or to provide mechanical support for the heart. Most of these lines stay in for a few days after surgery.

A transoesophageal echocardiography (TOE) probe will be passed through your mouth and into your food pipe (oesophagus). It is used to take ultrasound pictures of the heart during the operation and is essential for assessing the function of the new heart. The risk of injury from this probe is low (around 1 in 1,300 procedures from a national audit).

These injuries can be serious, may result in further operations being required and can result in death. It is important to tell the anaesthetist if you have had surgery previously on your throat, food pipe or stomach, have any difficulties swallowing or have been told that you have a pharyngeal pouch, a hiatus hernia or problems with your food pipe.

A temperature probe will be inserted into your nose or mouth to continuously monitor your temperature during the operation. Occasionally it can cause bleeding from the nose. Let your anaesthetist know if you have had problems with nosebleeds in the past as this probe can be put in a different place if needed.

A tube (catheter) will be passed into your bladder to drain urine and monitor how much urine is being produced by the kidneys. This will be inserted whilst you are asleep and will stay in after the operation for a few days. Occasionally this can cause infection, some bruising or bleeding. Let

your anaesthetist know if you have an enlarged prostate (men) or have previously experienced problems with these catheters.

Occasionally it is necessary to insert this through the front wall of the lower abdomen into the bladder(a suprapubic catheter).

The heart transplant operation

Once you are asleep and all the monitoring equipment is in place, then the surgeons start the heart transplant operation. You are given antibiotics and medications to suppress the immune system.

An incision will be made along the length of your breastbone (sternum) to access the heart. This is called a sternotomy. The surgeons place large plastic tubes (cannulae) into large arteries and veins. These tubes are used to divert blood from the heart and lungs into a heart-lung bypass machine. This machine pumps oxygen-rich blood to all your vital organs during the operation, taking over the work of your heart and lungs while you are having the heart transplant.

Once you are safely supported by the heart-lung bypass machine, then the surgeons will remove your failing heart. If you have a pacemaker, implantable cardioverter-defibrillator (ICD) or a left ventricular assist device (LVAD), then this is removed at the same time. Small remnants of pacemaker or ICD leads are occasionally left behind if these cannot be safely removed. Your old heart is sent to our pathologists for examination. For some patients, this allows us to tell you more about the cause of your heart failure.

The transplant co-ordinators ensure that the new donor heart arrives at Royal Papworth Hospital at this exact moment, to minimise the time that the donor heart is outside your body. The new donor heart is immediately implanted by the surgeons.

Fine temporary pacing wires are attached to the outside surface of the heart. These allow the heart rhythm to be controlled. Once this

process is complete, then you will be weaned from the heart-lung bypass machine and the donor heart is allowed to pump blood around your body.

It is normal for the transplanted heart to need support with medications at this stage. These medications are called inotropes. They are used to increase the pumping function of the heart and regulate blood pressure.

Mechanical circulatory support may be needed if the transplanted heart is struggling to pump blood around the body. This is discussed later in this booklet. It is extremely common to need a blood transfusion at the time of heart transplantation.

Once the surgeons are satisfied with you and your transplanted heart, then they finish the operation. Several plastic tubes (drains) are placed around the heart and in the pleural space, to drain any blood that accumulates over the subsequent days. The sternum is joined together with wires and the wound closed with stitches. This will then be covered with a dressing.

The resulting scar in most people will eventually look like a fine line. The stitches dissolve over time and the dressing may be removed after a few days.

What happens immediately after surgery?

Once the operation is completed, you will be transferred to the intensive care unit (ICU). This is also known as the critical care area (CCA) and is located opposite the operating department. ICU is a specialised ward where we look after patients who are recovering from surgery.

You will meet a very large team of healthcare professionals on the ICU. Once the ICU team is confident that you are stable and your transplanted heart is working well, then the anaesthetic medications will be switched off to allow you to wake up. You will feel disorientated and groggy when you wake up. You will still be connected to monitoring equipment, which can be noisy, and

have drips and infusions in your arm and neck. You may also have cannulas in your groin. There will be drains and pacing wires in place.

At first you will still have the breathing tube in your mouth, and because this passes through your voice box you will not be able to speak. You will still be able to answer 'yes, no' questions from your nurse if you wish to by nodding or shaking your head.

When your nurse and medical team are confident that your breathing is stable and the anaesthetic has sufficiently worn off, the breathing tube will be removed and replaced with an oxygen mask. It is unusual to be fully awake and have the breathing tube in place for a long period of time. Many patients do not remember waking up with the tube still in place.

Strong painkillers will be given to you through a vein as part of your anaesthetic and are usually continued until after you wake up. Once you are awake, they can often be replaced by tablet painkillers. Some patients occasionally require ongoing intravenous pain relief, and this can be provided using a patient-controlled analgesia (PCA) machine. A PCA allows you to give yourself a small dose of strong painkiller by pressing a button.

If you are in any discomfort or pain after surgery, then you must let your nurse know. It is important not to allow pain to continue after your operation as it can hinder coughing and mobilisation.

Most patients recover quickly after heart transplantation and can leave the ICU. The average length of stay on the ICU after a heart transplant at Royal Papworth Hospital is six days. However, one-third of our patients stay on the ICU for longer than one week after a heart transplant and patients occasionally spend months on the ICU after a heart transplant.

Recommended summary plan for emergency care and treatment (ReSPECT)

What is ReSPECT?

ReSPECT stands for 'Recommended summary plan for emergency care and treatment'. It is a process that helps people to think about what treatment is suitable in an emergency, should they be unable to make decisions at the time.

Why is it important?

We know that, when people are very unwell, they are often unable to think clearly about what treatment they may or may not want because their brain and body are overwhelmed by the illness. It is also normal for people to feel anxious about what is happening when they are sick and in hospital, and this can also make it difficult to think clearly. This is why we think it is a good idea, where possible, for decisions about medical treatment to be made in advance – before there is an emergency situation or crisis.

How does it work?

The ReSPECT process is designed to help conversations between you and your healthcare professionals: they need to make sure you understand your health problems and which treatments may or may not benefit you. You need to make sure the healthcare professionals understand what matters most to you and whether there is anything you are particularly worried about or would want to avoid.

This conversation is used to complete a ReSPECT form that records a person's health problems, their preferences and which medical treatments may or may not be suggested. The original form should stay with the patient, though it is extremely helpful to have a record of the content of the form on their electronic patient record.

A ReSPECT form is NOT a legally binding document and can be changed or withdrawn at any point.

The ReSPECT form is often used to indicate treatments that someone may not want and/or treatments that their healthcare professionals consider would no longer be of benefit to them.

If people are getting worse from progressive conditions, it may be helpful to consider in advance about things such as whether they would wish to go back into hospital and, if in hospital, what sort of treatments might or might not be helpful for them.

This often includes a decision on whether or not they should have attempted cardiopulmonary resuscitation (CPR) if their heart was to stop.

Who is it for / is this relevant for me?

This process has increasing relevance for people who have complex health needs, people who may be nearing the end of their lives and those who are at risk of sudden deterioration or cardiac arrest.

However, many people come to Royal Papworth to have major procedures or surgery with the intention of curing a progressive disease or with the intention of substantially prolonging their life and, if that is you, you may wonder how a ReSPECT discussion applies to you and others like you. One of the key things to understand about the ReSPECT process is that it can be used simply to document a person's wishes and priorities, without setting any limitations on what treatment they should have.

This is important because all the procedures and operations we do here come with the risk of complications. In the unlikely event that things do not go as planned, it is really helpful to have some idea about a person's preferences and about their fears, worries and hopes.

Once again, the document is not legally binding, but it can help those looking after you to know what you might want if you weren't able to say for yourself.

The ReSPECT form is a separate document.

It is possible that your clinical team will start a conversation about the ReSPECT process with you. Equally you can ask any member of your medical team if you would like to start this conversation yourself.

Longer stays on the intensive care unit

You may need to stay longer on the ICU following your heart transplant if supportive treatment is needed that can only be provided there. This might happen if there were serious problems with the function of the transplanted heart or other vital organs such as the lungs, kidneys, liver or brain, or issues with infection. Treatments that may be needed include but are not limited to:

A ventilator to provide breathing support via a breathing tube:

Most patients are sedated but sedation is deliberately reduced at times. This reduces problems with over-sedation which include delirium and post-traumatic stress disorder.

When sedation is lightened, you may be able to hear what is going on and respond to questions with head or limb movements. If you are uncomfortable, then sedation will be increased.

Tracheostomy:

If you require ventilation for a long time, then a tracheostomy may be performed. This is a breathing tube passed into the windpipe through a hole in the front of the neck.

It will leave a scar and comes with its own risks but has significant benefits for recovery and avoids problems caused by breathing tubes passed through the mouth.

Monitoring of heart function:

If lines are needed for a prolonged period of time, they may need to be changed to reduce the risk of infection.

Nasogastric tube:

This is passed through the nose into the stomach to allow feeding. It is commonly used when people are sedated and cannot eat. It is sometimes used to give additional nutrition if someone who is unwell is finding it difficult to eat enough for their needs.

Temporary dialysis:

Kidneys may stop working after a heart transplant and a form of continuous dialysis called haemofiltration is used for support.

A tube will be placed in a large central vein in the neck or groin to allow blood to be taken out of the body, passed through a machine, and replaced back into the body.

Mechanical circulatory support:

This is a machine to pump blood around the body. It may be required if the transplanted heart is struggling to support the circulation at the time of surgery.

Different types of mechanical circulatory support may be used, depending on the situation. These devices are used to allow time for the transplanted heart to recover or, in very rare circumstances, as a bridge to re-transplantation.

- **Intra-aortic balloon pumps** are balloon devices that are placed in the aorta and inflate/deflate in time with the heart beat. Balloon inflation improves blood flow around the body and balloon deflation helps the heart eject.
- **VA ECMO** (veno-arterial extracorporeal membrane oxygenation) is a more invasive form of support which takes over the function of the heart and lungs in a similar way to a heart-lung bypass machine.
- **Temporary ventricular assist device (VAD)** is a machine that supports either the left or right sides of the heart.

Moving to the ward and preparing for discharge

Once you have recovered sufficiently to leave the ICU, then you will be moved to the cardiac surgical ward. This is on the fifth floor of the hospital. As you recover, remaining lines and drains will be removed.

You will be encouraged to get out of bed each morning, get dressed and to participate in physiotherapy.

Please affix patient label or complete details below.

Full name:

Hospital number:

NHS number:

DOB:

PIC 231: patient agreement to PI 231 - Heart transplant

Intended procedure/surgery

Statement of healthcare professional

(To be filled in by healthcare professional with appropriate knowledge of proposed procedure, as specified in consent policy).

I have explained the procedure to the patient. In particular I have explained:

The intended benefits:

- Improved heart failure symptoms
- Increase survival

The potential risks of heart transplant have been detailed in this document (pages 13 - 17).

Additional, significant or unavoidable risks include the following:

.....
.....

Any extra procedures, which may become necessary during the procedure:

- Blood transfusion
- Return to operating theatre to manage complications
- Other procedure - please specify below:
.....

I have also discussed what the procedure is likely to involve, the benefits and risks of any available alternative treatments (including no treatment) and any particular concerns of this patient.

This procedure will involve general anaesthesia.

Healthcare professional

Signed:

Date:

Name (PRINT):

Job title:

Contact details

.....
.....

Has a ReSPECT form been considered and, if relevant, appended to this form? (See page 7 for further details on ReSPECT)

Yes No

Statement of patient

Please read the patient information and this form carefully. If the treatment has been planned in advance, you should already have your own copy of which describes the benefits and risks of the proposed treatment. If not, you will be offered a copy now. If you have any further questions, do ask - we are here to help you. You have the right to change your mind at any time, including after you have signed this form.

Yes No

I agree to the procedure or course of treatment described on this form and have read this information leaflet on heart transplant (PI 231) and had the opportunity to ask questions.

I agree to the procedure or course of treatment described on this form. I have read the written information provided to me including: nhsbt.nhs.uk/organ-transplantation and had the opportunity to ask questions.

Please affix patient label or complete details below.

Full name:

Hospital number:

NHS number:

DOB:

I agree to the use of photography for the purpose of diagnosis and treatment and I agree to photographs being used for medical teaching and education.

- **I understand** what the procedure is and I know why it is being done, including the risks and benefits.
- **I understand** that any tissue removed as part of the procedure or treatment may be used for diagnosis, stored or disposed of as appropriate and in a manner regulated by appropriate, ethical, legal and professional standards.
- **I understand** that any procedure in addition to those described on this form will be carried out only if necessary to save my life or to prevent serious harm to my health.
- I have listed below any procedures **which I do not wish to be carried out** without further discussion:

.....
.....
.....
.....
.....

I have been told in the past by Public Health that I am at increased risk of CJD (Creutzfeldt Jakob disease) or vCJD (variant Creutzfeldt Jacob disease).

Yes No

(Where patient indicates 'yes' health professional to refer to Trust CJD procedure DN092)

Statement of interpreter (where appropriate)

If an interpreter was present to support this consent, please state the name and number of the interpreter present:

Date:

Interpreter's number:

Name (PRINT):

Interpreter PIN:

Top copy to be filed in medical notes, carbon copy to be retained in booklet for patient.



Royal Papworth Hospital NHS Foundation Trust

If a telephone / video service has been used, please document the name of the interpreter and company below

.....
.....

Patient

Patient signature:

Date:

Name (PRINT):

Confirmation of consent

(To be completed by a health professional when the patient is admitted for the procedure, if the patient has signed the form in advance).

On behalf of the team treating the patient, I have confirmed with the patient that they have no further questions and wish the procedure to go ahead.

Signed:

Date:

Name (PRINT):

Job title:

Important notes (tick if applicable).

Patient has advance decision to refuse treatment

Patient has withdrawn consent (ask patient to sign/date here)

Patient signature:

Date:

Name (PRINT):

Please use and attach Consent form C for a young person who is not Gillick competent.

You will be established on different tablet treatments, including your immunosuppression which will be continued life-long. A series of 10-12 biopsies will be performed during the first year after transplantation to ensure that your immunosuppression is adequate and there is no evidence of rejection of your transplanted heart.

You will be discharged once you are independent with self-care, confident with your medications and the transplant team think you are well enough to leave Royal Papworth Hospital. The average length of stay in hospital after a heart transplant is three weeks.

Heart transplant patients are seen regularly in the outpatient department after discharge. You should expect to be seen 10-12 times in the first year after heart transplantation, three times in the second year after heart transplantation and then twice per year for the rest of your life. We have a life-long responsibility to look after you.

What are the risks with a heart transplant?

Heart transplantation is not successful for everyone. The greatest risk is that the transplanted heart does not work well enough to support the circulation. If this happened and the transplanted heart did not recover, then it is likely that you would die.

If 100 patients underwent a heart transplant in the United Kingdom today, then we would expect 92 patients to be alive after 90 days and 88 patients to be alive after one year.

In the longer term, the main risks of heart transplantation relate to the interaction between your immune system, the donor heart and immunosuppressive medications. These are required to stop your body rejecting the transplanted heart. These medications have many side effects. However, your immune system may damage the transplanted heart despite these

medications. On average, a patient will survive 14 years after a heart transplant.

Each patient is unique and will face different risks. We have a duty to explain the risks that an 'average' patient will face after heart transplantation. Some risks are very individual, such as risks relating to previous heart surgery. We have categorised risks as very common, common, uncommon or rare.

It is important to recognise that we cannot describe every conceivable event that may occur after heart transplantation. It is also important to understand that any adverse event could potentially result in death.

Please remember that we will only recommend a heart transplant if we think that the benefits outweigh the risks. We will discuss your individual risks with you.

Please ask a member of the transplant team if you have further questions or concerns about the procedure.

Early risks in the days or weeks after a heart transplant

Very common early risks

These affect more than 10 in 100 patients

- **Nausea and vomiting:** anti-sickness medications are usually given at the time of surgery to reduce the risk and can be given as needed after surgery.
- **Bleeding:** this may require insertion of a drain, blood transfusion or further surgery. Blood transfusion is safe but there are potential risks. You will be offered an information leaflet: '**Receiving a transfusion (PI 10)**'
- **Primary graft dysfunction (PGD):** this occurs when the transplanted heart does not function adequately. If the transplanted heart requires mechanical circulatory support, then this is called severe PGD. Severe PGD affects approximately 20 out of 100 patients and is the most common cause of early death after heart transplantation.

- **Infection may occur** in the surgical wound, around the drains or elsewhere in the body such as your lungs, urine or blood (also known as septicaemia).
- **Kidney failure:** this may require treatment with a blood filter (similar to dialysis). In rare cases, kidney function does not recover and long-term dialysis is needed.
- **High blood sugar:** this may require treatment with insulin or other medications. If the problem lasts more than three months, then this is called post-transplant diabetes mellitus. If you have pre-existing diabetes mellitus, then your blood sugar may be more difficult to control.

Common early risks

These affect between 1 in 100 and 10 in 100 patients

- **Stroke or other types of brain damage** due to bleeding or problems with blood flow to the brain
- **Blood clots** in the veins of the legs known as deep vein thrombosis (DVT), or lungs pulmonary embolism (PE). You will receive blood thinning medication when this is appropriate to help prevent these.
- **Fast heart rhythm- disturbances** such as atrial flutter or fibrillation may require treatment with rhythm-controlling drugs or a procedure called cardioversion.
- **Slow heart rhythm disturbances** may require implantation of a permanent pacemaker.

Rare early risks

These affect fewer than 1 in 1,000 patients

- **Transmission of cancer from donor:** this is very rare. Every effort is made to ensure that a donor does not have a cancer that could be passed on to you.

- **Transmission of a serious infection from donor** such as hepatitis B, C or HIV despite donor screening is very rare. Treatments for hepatitis C have improved and it is now possible to cure nearly all infected patients. You may be asked whether you would accept a heart transplant from a hepatitis C positive donor. You will be given a separate information leaflet 'Transplantation of heart from hepatitis C positive organ donors (PI 211)' to help you decide.

Other early risks

- **Damage to arteries or veins** at the time of surgery can lead to bleeding and jeopardise blood flow to your arms, legs or other vital organs. In very severe situations, loss of your arm or leg (amputation) may be necessary to save your life. Limb swelling may persist in the longer term.
- **Severe allergic reactions (anaphylaxis)** to medications used at the time of surgery are very rare. Most patients recover completely. If this occurs before surgery, then you may be woken up and your transplant postponed until you have seen an allergy specialist.
- **Sore throat or hoarse voice:** this may occur due to the breathing tube and TOE probe used at the time of surgery.
- **Eye abrasions:** sedated patients do not blink, so the surface of the eye can become dry. If you are sedated for a long period, then your ICU nurse will lubricate your eyes regularly to help prevent this. In rare cases abrasions and infections can lead to vision loss.
- **Pressure sores:** if you are not able to be mobile your ICU nurse will reposition you on a regular basis to help prevent pressure sores.
- **Critical illness neuropathy:** severe weakness, muscle stiffness, joint pain or nerve injuries can result of being immobile for long periods.

- **Difficulty swallowing:** this may require naso-gastric feeding to maintain nutrition during recovery.
- **Stress ulceration:** this can cause bleeding from the stomach or bowel. All patients receive antacid medications to reduce the risk of this problem.
- **Altered bowel function:** bowel function may be slow to normalise after surgery, leading to constipation or diarrhoea. Rarely bowel perforation may occur and this would require additional surgery.
- **Bowel ischaemia:** patients who are severely unwell may suffer from disruption of the blood supply to the bowel. Bowel ischaemia may require surgery to remove the affected bowel and this can be life-threatening.
- **Pancreatitis** (inflammation of the pancreas) can be serious or even fatal.
- **Narrowing of the anastomosis** (connection) between your new heart and the main blood vessels. This may require further surgery.
- **Rejection of the transplanted heart** requiring more intensive immunosuppression.
- **Delirium** is common on the ICU. Features include difficulty focusing, sudden changes in behaviour and confusion but these get better with time. The experience is distressing for patients and their loved ones.
- **Mental health problems**, such as anxiety and depression and post-traumatic stress disorder. If these problems were present before surgery, then they may get worse.
- **Visual disturbance** can be a side effect of high dose steroids.
- **Wound healing problems** that result in a painful or cosmetically disfiguring scar.

- **Infection by a bacterium called *Mycobacterium chimaera*** can be associated with heart-lung bypass machines. The risk of infection is extremely small affecting approximately 1 in 10,000 patients. You will be offered a separate information leaflet about this problem.

Longer-term risks (in the months or years after a heart transplant)

Some complications may only become apparent months or years after a heart transplant. Each patient is unique and long-term risks differ between patients.

Very common longer-term risks

These affect more than 10 in 100 patients

- **Rejection:** acute cellular rejection is the most common type and happens when white blood cells attack muscle cells of your new heart. It occurs most often in the first year after heart transplant and affects around 20 out of 100 patients.

Antibody mediated rejection is less common. It can develop early after a transplant (within weeks) but can also happen months or years later. It is caused by antibodies that your body may form and which can damage your transplanted heart.

You will be monitored for rejection with around 10-12 heart biopsies over the first year when the risk is greatest.

Treatment for acute cellular rejection includes high dose steroids and changes to other immunosuppressive medications. Antibody mediated rejection can be harder to treat and usually involves a treatment called plasma exchange to remove harmful antibodies.

- **Infections are more common** following heart transplantation because your immune system will be suppressed. Different types of infection may occur.

- **Cytomegalovirus (CMV)** is dormant in two-thirds of adults. CMV can be activated by immunosuppression and cause infection. You can also acquire CMV from the donor heart.

We use preventative anti-viral treatment in patients at risk of CMV acquisition or reactivation. CMV is most common in the first year after a transplant. It is usually easy to diagnose and treat.

- **Pneumocystis Jirovecii:** is a fungus that can cause lung infection. It is rare because we use preventative antibiotics in the first year after a transplant.
- **Herpes virus infections** can cause cold sores or shingles after transplantation. These infections can be treated with anti-viral medications.
- **Bacteria or fungi:** can cause infections after a heart transplant. These infections can usually be successfully treated with antibiotics but some patients require further surgery.
- **High blood pressure:** is a common side effect of immunosuppressive medications. Most patients need to take medication to control blood pressure after a heart transplant.
- **Cardiac allograft vasculopathy (CAV):** occurs when blood vessels supplying the heart muscle become narrowed and eventually blocked.

We think this is caused by an interaction between the body's immune system and the transplanted heart.

Non-immune factors such as high blood pressure, high cholesterol and diabetes may also contribute.

All patients are offered screening for CAV after heart transplantation. CAV affects around half (50 in 100) of patients within the first 10 years after a transplant. Sadly, CAV may lead to failure of the transplanted heart and is the most

common long-term cause of death after heart transplantation.

- **Skin cancers:** occur in 15 to 20 in every 100 patients. SCC (squamous cell carcinoma) of skin is reported in around 10 out of 100 of five-year survivors and 18 out of 100 of 10-year survivors.

Common longer-term risks

These affect between 1 in 100 and 10 in 100 patients

- **Sternal malunion:** the breastbone does not heal as expected, leading to discomfort in about 1 in 100 patients. This may need re-wiring of the sternum under general anaesthetic.
- **Chronic kidney disease:** some immunosuppressive drugs adversely affect kidney function, especially if drug levels are high. Of those patients who are alive at 10 years after a heart transplant, 20 out of 100 have developed severe kidney dysfunction. Some may require dialysis (6 out of 100) or renal transplant (less than 5 out of 100).
- **Post-transplant lymphoproliferative disorder (PTLD):** this is a type of lymphoma (white blood cell cancer) that affects transplant patients. Between 3 to 9 in 100 patients will develop PTLD over ten years.

In most patients, this is caused by an increase in dormant virus levels. Decreasing dose of immunosuppression is sometimes enough to control PTLD but most patients will require chemotherapy.

- **Osteoporosis (brittle bones)** resulting in a risk of fracture. This risk can be reduced by regular exercise, and adequate calcium and vitamin D intake. You will be given calcium and vitamin D supplements and a bisphosphonate infusion to maintain bone density and reduce fracture risk.

You may need bone density scans after transplant to guide the need for ongoing treatment.

Other longer-term risks

- **Medication side effects:** you may experience side effects from medications that are prescribed after transplantation, such as a tremor.
- **Other cancers:** transplant recipients are at a higher risk for all types of cancer. The risks of skin cancers and PTLD have already been presented. Around 10 out of 100 patients develop other types of cancer by ten years after receiving a heart transplant. Participation in national cancer screening programmes is important.
- **Heart rhythm problems:** atrial flutter and atrial fibrillation can develop many years after a heart transplant. Some patients may benefit from a catheter ablation procedure. Slow heart rhythms can also develop in the years after a heart transplant and may require a permanent pacemaker.
- **Weight gain** is associated with adverse outcomes after heart transplantation
- **High cholesterol:** some immunosuppressive medications contribute to high blood levels of cholesterol and other lipids. All heart transplant patients are offered a statin to reduce cholesterol.
- **Mycobacterium abscessus** is a non-tuberculous mycobacteria that is ubiquitous in the environment and has been identified in the Royal Papworth Hospital water supply. Exposure to this organism via hospital water is believed to have contributed to *M.abscessus* acquisition in a small number of vulnerable patients but no heart transplant patients have been affected.

Following a comprehensive investigation, the hospital has implemented a number of effective measures. Some patients who acquire *M.abscessus* need no treatment at all, for some treatment can be effective, while for others it can be very difficult to treat and have serious effects on quality of life, health and survival.

- **Some immunosuppressive medications can cause abnormalities in the unborn child** and need to be stopped before you try to conceive. This applies to both male and female patients. If you are considering pregnancy, then you must discuss this with your team. It is recommended that pregnancy is avoided during the first one to two years after transplant. Reliable contraception is strongly recommended.

What are the consequences of not having a heart transplant?

The alternative to transplant is continued medical care with your local team. Managing your heart condition should focus on symptoms and quality of life. We would recommend involving your local supportive and palliative care team who can help address physical, psychological, social and spiritual needs.

If you decide not to proceed with transplant, this will not affect the relationship you have with the medical team who referred you to Royal Papworth Hospital. If you choose not to have the procedure, you do not have to sign the consent form. If you have signed a consent form, you have the right to withdraw your consent at any time.

Resources

nhsbt.nhs.uk/organ-transplantation/heart/

[bhf.org.uk/informationsupport/treatments/
heart-transplant](http://bhf.org.uk/informationsupport/treatments/heart-transplant)

[pumpingmarvellous.org/heart-failure-guide/
heart-transplant/](http://pumpingmarvellous.org/heart-failure-guide/heart-transplant/)

ics.ac.uk/Society/Patients_and_Relatives/A_Guide_to_ICU

rcoa.ac.uk/patient-information/patient-information-resources/anaesthesia-risk

nationalauditprojects.org.uk/downloads/PI-RISK08-AWARENESS-2015_0.pdf

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