Royal Papworth Hospital
NHS Foundation Trust

Lung transplantation and combined heart-lung transplantation

A patient's guide and consent form

Compassion
Excellence
Collaboration

We have recommended that you go onto the waiting list for a lung or combined heart-lung transplant. We believe that transplantation has the potential to offer you a longer life, a better quality of life, and the prospect of a return to work and travel.

This booklet contains information about lung and combined heart-lung transplantation and a consent form. The transplant 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 consent form. This document should be read along with the other information given to you by the transplant team.

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

What are the benefits of a lung or combined heart-lung transplant?

In carefully selected patients, a lung transplant or a combined heart-lung transplant can provide a better quality of life and longer survival. Other benefits include:

- You are likely to have extra energy and be more able to cope with everyday activities.
- You are more likely to be able to work and go on holiday.

Time on the transplant waiting list

We have no way of knowing how long you will be on the waiting list for a transplant. There are more people waiting for transplants than there are donors.

The average waiting time for a donor match 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. Waiting times vary from days (in the most urgent situation) to several years. Heart-lung candidates need both organs from the same donor and because of this, may experience longer waiting times.

When you are listed for a transplant, you will be asked if you are willing to accept organs from certain categories of donor. This information is covered in a separate booklet called **'Donor choices in lung transplantation'**, that you will be given.

We ask you to make these decisions in advance because there will be very little time to make decisions when a donor becomes available. Restricting your donor choices may increase your waiting time for a 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 lung or a combined heart-lung transplant. Unfortunately, some patients die while they are on the waiting list or have to be removed from the waiting list because they become too sick to survive an operation. You will be reviewed regularly while you are on the waiting list to identify any deterioration. Very occasionally, patients improve while they are on the waiting list and no longer require a transplant.

What happens when a potential donor lung / combined heart-lung is found?

The transplant co-ordinators will let you know that we may have suitable donor organs. They will arrange for you to be brought to Royal Papworth Hospital. Some patients remain in hospital while they await donor organs. 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 is thoroughly assessed. If there is a problem such as poor quality or function of the lungs, then we cannot proceed with the transplant. This is called a 'false alarm'. If we are certain that the donor organ 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 your 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. The equipment will 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 supplemental oxygen. 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 wake up on the intensive care unit (ICU) after the operation is finished.

The risk of awareness (not being properly asleep) during the operation is extremely low (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.

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. 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 your heart during the operation and is essential for assessing the function of your heart during the lung transplantation operation and for assessing the function of a new donor heart if you are receiving a combined heart-lung transplant. The risk of injury from this probe is low (around 1 in 1300 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 transplant operation

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

A cut (incision) will be made in your chest so that the surgeon can remove your diseased organ(s) and replace them with your donor organ(s).

The surgeon will select an incision according to the transplant you are having:

- **Thoracotomy:** a cut on one side of the chest for a single lung transplant (may be performed on both sides of the chest for a bilateral lung transplant).
- **Sternotomy:** an incision down the middle of the sternum (breastbone) for a bilateral lung or combined heart-lung transplant.
- **Clamshell:** an incision across the chest below the breasts for a bilateral lung transplant.

The surgeon may put you on a heart-lung (cardiopulmonary) bypass machine during the operation. This machine pumps oxygen-rich blood to all your vital organs during the operation, taking over the work of your heart and lungs.

Extracorporeal membrane oxygenation (ECMO) is a longer-term version of heart-lung bypass which may be used before, during and after transplant surgery. ECMO is discussed further later in this booklet.

Once the surgeons are satisfied with you and your transplanted organs, they will complete the operation. Several plastic tubes (drains) are placed into your chest to drain fluid, air or any blood that may accumulate over the coming days.

If needed, a feeding tube will be placed into your stomach. Your chest incision will be closed with stitches and then 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 organs are 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.

Pain relief after lung transplantation and combined heart-lung transplantation

The options available for pain relief after lung or heart-lung transplantation will depend largely on the type of incision that the surgeon judges is needed in order to be able to safely do the operation.

If you require a sternotomy incision for the operation, then 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, which 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.

If your operation is a single lung transplant and can be performed through a thoracotomy incision then it is likely that local anaesthetic injected into your chest or back at the time of the operation will help with pain relief afterwards.

If your operation is a bilateral lung transplant and can be performed through a clamshell incision then an epidural may be recommended for pain relief afterwards. This can often be performed whilst you are still asleep.

The different options for local anaesthetic administration include but are not limited to:

- Local anaesthetic infiltration into the skin incision
- Intercostal nerve blocks
- Serratus plane block/Erector spinae block
- Paravertebral block

All of these methods of local anaesthetic injection carry a small risk of bruising at the site, injection of local anaesthetic into a blood vessel (3-4% risk), infection, or puncture of the lining around the lung (pneumothorax – 0.5 to 1% risk) which may need a temporary drain to be inserted.

There is a small risk of some permanent numbness or pins and needles in the area where local anaesthetic is injected. These methods will only be used if it is felt that they will provide useful pain relief for you. Please ask your anaesthetist about these if you are worried.

Epidural catheter insertion:
An epidural is the most effective form of local anaesthetic administration as it provides pain relief to both sides of the chest at the same time. It is often used after a bilateral lung transplant with clamshell or thoracotomy incisions.

The risk of an epidural not working properly and a different form of pain relief needing to be used is about 10% (1 in 10). There is likely to be some bruising in the back around the site of insertion which should get better after a few days. There is a small risk of developing a blood clot in the epidural space or abscess from infection, both of which may require another operation specifically to treat.

The risk of permanent harm from this is between 1 in 24,000 and 1 in 54,000. The risk of paraplegia or death from an epidural is between 1 in 50,000 and 1 in 140,000. It is because of the small but present risk of serious harm that you may decide you would prefer not have an epidural, in which case we would use alternative methods of pain relief as detailed above.

It will only be offered to you if the team feels the benefit outweighs the potential risks. Please discuss with your anaesthetist if you have any questions or a strong preference for or against any of these pain relief options.

Moving to the ward and preparing for discharge

Once you have recovered sufficiently to leave the ICU, then you will be moved to the 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.

You will be established on different tablet treatments, including your immunosuppression which will be continued life-long. A series of bronchoscopy procedures will be performed to ensure that your airways are free from secretions and healing well and to ensure there is no evidence of rejection of your transplanted organ(s).

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

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 lung or heart-lung transplant is three weeks. Lung and heart-lung transplant patients are seen regularly in the outpatient department after discharge, and we will continue to see you in clinic for the rest of your life. We have a life-long responsibility to look after you.

Longer stays on the intensive care unit

You may need to stay longer on the ICU following your lung or heart-lung transplant if supportive treatment is needed that can only be provided there. This might happen if there are serious problems with the function of the transplanted organs or other vital organs such as your 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 reduced to the lowest level required to keep you comfortable. 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.

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.

A tracheostomy is better tolerated than a tube into your mouth, meaning you can be awake and able to perform rehabilitation. You may progress to being able to speak with the tracheostomy in situ. It will leave a scar.

Monitoring of heart function:
If lines are needed for invasive monitoring 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 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 returned to the body.

Mechanical circulatory support:
This may be required if the 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, with ECMO being the most commonly used.

If you would like further information about the treatments provided in an ICU please see the website of the Intensive Care Society, UK: ics.ac.uk/about-icu.html

What are the common and significant risks associated with a lung/combined heart-lung transplant?

Transplantation is a complex medical intervention with a high risk of complications. Many complications are minor and get better on their own, but others are serious enough to require another surgery or medical procedure and some complications can be fatal.

Some complications are related to the operation itself. Others are related to the medications you need to take after transplant. There may also be risks specific to your individual condition and circumstances.

There may be a delay in the function of your transplanted organ(s) and it is possible that the transplanted organ(s) will not work well enough for you to breathe unaided or maintain your circulation without support. You may continue to require supplemental oxygen after transplant.

When a new organ is transplanted, your immune system treats it as a threat which can lead to organ rejection. You will be given immunosuppression medication, which you will need to take for the rest of your life. Immunosuppression is used to reduce the risk of your body rejecting your transplanted organ(s).

The risk of acute rejection is highest in the first few months after a transplant. In the longer term, despite immunosuppression, your immune system may damage the transplanted organ(s) leading to loss of lung function over time. As immunosuppressants weaken your immune system, you will be more vulnerable to infections, including bacterial, fungal and viral infections. Any minor infection is more likely to progress to a major infection.

Immunosuppressants also increase the risk of health conditions including blood count abnormalities, diabetes mellitus, high blood pressure, numbness and pain in the feet (neuropathy), chronic kidney disease (which may progress to the stage where long term dialysis or renal transplantation is required), osteoporosis (weak bones and fractures) and weight gain.

People who have received a transplant have an increased risk of developing cancer. The most common cancers seen after transplant are skin cancer, lung cancer, liver cancer, kidney cancer, and lymphoma (known as post-transplantation lymphoproliferative disorder or PTLD).

It is not possible to document all potential risks in this consent document. Some additional very common, common, uncommon and rare risks are listed below.

For further information we recommend you visit the NHSBT webpage 'Benefits and Risks of a Lung Transplant' or the NHS webpage below:

nhsbt.nhs.uk/organ-transplantation/lung/benefits-and-risks-of-a-lung-transplant/

nhs.uk/conditions/lung-transplant/risks/

It is important to remember that the transplant team only recommend transplantation if they think that the benefits outweigh the risks to you as an individual. Your team will discuss your personal risks with you.

Very common risks
These affect more than 10 in 100 patients

- **Pain:** following the operation, you may experience pain and discomfort. This will be carefully monitored so you can receive appropriate pain medication. Most patients experience a gradual reduction in pain over two-three weeks after surgery.

- **Bleeding** may require insertion of a drain, blood transfusion or further surgery. Bleeding is more common if you have been taking blood thinning drugs. Blood transfusion is safe but there are potential risks. Your team will offer you an information leaflet **'Will I need a blood transfusion? Patient information'.**

- **Elevated blood sugar readings:** steroid medication used for immunosuppression can cause high blood sugar levels requiring treatment with insulin or other medications. If you have diabetes mellitus prior to transplant, then your blood sugars may become more difficult to control.

- **Infections: i**nfection may occur at your surgical wound sites, around the drains or elsewhere in the body such as your lungs, urine or blood (also known as septicaemia).

  Cytomegalovirus (CMV) is dormant in about two thirds of adults. CMV can be activated by immunosuppression and cause infection. You can also acquire CMV from your donor organ(s).

  Prolonged treatment with tablet, nebulised and intravenous antibiotics, anti-fungal and anti-viral medication may be required.

- **Rejection of the transplanted organ(s):** acute cellular rejection is very common early post-transplant and the risk diminishes over time. Antibody mediated rejection is less common. It can develop early after transplant (within weeks) but can also happen months or years later. It is caused by antibodies formed against your new organ(s) which cause damage to the transplanted organ(s).

  You will be monitored closely for rejection. You can expect to undergo at least three lung biopsy procedures via bronchoscopy over the first year, when the risk of rejection is greatest.

  Treatment depends on the type and

severity of rejection but usually involves more intensive immunosuppression

- **Nerve damage:** injury to the vagus nerve causes poor stomach emptying (known as gastroparesis). This may need to be managed with diet modification, for example by changing to a liquid/semi-solid diet, or naso-gastric feeding (see above).

  Injury to the nerve supplying the diaphragm (phrenic nerve) may lead to lung collapse and breathing difficulties.

  Injury to the recurrent laryngeal nerve may lead to poor function of the voice box, with impairment of swallowing and a hoarse voice.

  Nerve injuries can recover but in rare cases they can last for an extended period or become permanent.

- **Altered bowel function:** bowel function may be slow to normalise after surgery, leading to constipation or diarrhoea. Rarely bowel perforation may occur and this requires surgical management.

Common risks
These affect between 1 in 100 and 10 in 100 patients

- **Primary graft dysfunction:** the function of the transplanted organ(s) may be poor or delayed, requiring prolonged support on a ventilator or the use of ECMO to support the transplanted organ(s).

  If you need prolonged support, the team may recommend you have a tracheostomy (a breathing tube inserted via the front of the neck, connected to a ventilator).

  The use of ECMO may be complicated by bleeding, infection, blood clotting and poor blood supply to the limbs, causing problems with function of the limb in the short or long-term and, very rarely, loss of limb(s) and death may occur.

- **Blood clots** may form in your veins (deep vein thrombosis) and cause pain and swelling. Rarely, fragments of clot may break off and travel in the circulation to the lungs (pulmonary embolism).

- **Circulation problems:** disturbance of the heart rhythm may be fast (such as atrial flutter or fibrillation) or slow and may require treatment with medication or a procedure called cardioversion. Disturbance of blood flow to the brain caused by small blood clots (cerebral microemboli) may affect short term memory, concentration and thinking processes.

- **Reduced kidney function:** early post-transplant, treatment with a blood filter (similar to dialysis, see above) may be required. In rare cases, kidney function does not recover and long-term dialysis is needed.

- **Gastro-intestinal issues:** difficulty swallowing may require feeding via a tube to maintain nutrition during recovery. Gastro-oesophageal reflux may contribute to infection and rejection of the transplanted lung(s).

  Treatment for reflux with a keyhole operation called 'Laparoscopic Fundoplication' may be recommended after transplant.

- **Problems with wound healing:** the anastomosis (where your new lung joins your own airways) may narrow with scar tissue, become floppy and collapse, or breakdown, causing an air leak requiring further surgery or stent placement.

  There may also be issues with narrowing or leakage of the surgical connections between the blood vessels in your new organs and your own blood vessels.

  Infection or separation of the breastbone may require further surgery. In some people, wound healing may result in painful, thickened or cosmetically disfiguring (keloid) scarring.

Uncommon risks
These affect between 1 in 1,000 and 1 in 100 patients

- **Circulation problems:** heart attacks or strokes that are severe enough to cause disability are uncommon. A stroke may occur during or after surgery, when blood flow to the brain is affected by a blood clot or bleeding event. Strokes are more common in older patients, and in those who have had a stroke before.

Rare risks
These affect fewer than 1 in 1,000 patients

- **Serious infection from the donated organ(s):** the spread of viral infections such as hepatitis B, hepatitis C or HIV or other serious infectious diseases from the donor lung(s), or from blood transfusion, is extremely rare. Most transmitted infections are easy to diagnose, treat and monitor.

Other risks

- **Risks associated with anaesthesia:** these have been discussed throughout this booklet. For further information please see the website of the Royal College of Anaesthetists:
  rcoa.ac.uk/patient-information/patient-information-resources/anaesthesia-risk

- **Risks associated with non-tuberculous mycobacterium (NTM) infection:** mycobacterium chimaera is a non-tuberculous mycobacterium (NTM) which is a recognised cause of infection in patients who have undergone cardiothoracic surgery and can be transmitted from heater-cooler units, which are part of the heart-lung bypass equipment. The risk of infection is extremely low, affecting approximately 1 in 10,000 patients.

  Further information is available via the following link:
  gov.uk/government/collections/mycobacterial-infections-associated-with-heater-cooler-unitsMycobacterium abscessus (M. abscessus) is a non-tuberculous mycobacterium (NTM) 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, including lung transplant recipients.

  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.

  Following a comprehensive investigation, the hospital has implemented a number of effective measures. However, to further reduce your risk of any potential water borne infection, we strongly suggest that you avoid drinking tap water or showering.

  Oral care and cleaning of inhaled medical equipment such as nebulisers must be done with bottled water, which will be supplied to you. Tap water can still be used for hand washing and is actively encouraged. With these measures in place, we believe that your risk of M.abscessus acquisition is low.

- **Risks associated with conception and pregnancy:** 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. A reliable method of contraception is
  recommended after transplantation.

Outcomes after lung transplantation and combined heart-lung transplantation

Each patient is unique and will face different risks. Your risk of dying during or after transplant surgery will vary depending on your age, and the nature and severity of your illness prior to transplant.

The transplant team will be able to help you understand your personal risk. We have a duty to explain the risks that an 'average' patient will face after lung and heart-lung transplantation.

If 100 patients underwent a lung transplant in the United Kingdom today, then we would expect:

- **90 patients to be alive after 90 days**
- **81 patients to be alive after one year**

If 100 patients underwent a heart-lung transplant in the United Kingdom today, then we would expect:

- **81 patients to be alive after 90 days**
- **70 patients to be alive after one year**

In the longer term, the main risks of lung and heart-lung transplantation relate to the interaction between your immune system, the donor organ(s) and immunosuppressant medications.

- On average, a patient will survive six years after a lung transplant and 4.5 years after a heart-lung transplant.

In the longer term, the main risks of lung and heart-lung transplantation relate to the interaction between your immune system, the donor organ(s) and immunosuppressant medications.

For further information we recommend you visit the webpage for the 'NHSBT Annual Report on Cardiothoracic Organ Transplantation': odt.nhs.uk/statisics-and-reports/organ-specific-reports/

What are the consequences of not having a lung or heart-lung transplant?

The alternative to transplantation is continued medical care with your local team. Medical management of your condition without transplant 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 transplantation, this will not affect the relationship you have with your local team.

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.

What is ReSPECT?

ReSPECT stands for 'Recommended summary plan for emergency care and treatment'. It is a process which 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 which someone may not want and/or treatments which their healthcare professionals think would no longer benefit 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 incudes a decision on whether or not they should have attempted cardiopulmonary resuscitation (CPR) if their heart was to stop.

Who is it for? Is it 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 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 a 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.

Please affix patient label or complete details below.

Full name:

Hospital number:

NHS number:

DOB:

PIC 232: patient agreement to PI 232 - lung/heart-lung transplant

Intended procedure/surgery

____

____

____

Statement of health professional
(To be filled in by health 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:

☐ Improve symptoms
☐ Increase survival

....

....

Risks of a heart/heart-lung transplant
The potential risks of a lung/heart-lung transplant are detailed in this document. Additional significant or unavoidable risks include the following:

....

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....

....

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

☐ Blood transfusion
☐ Heart-lung (cardiopulmonary) bypass support
☐ Extracorporeal membrane oxygenation support
☐ Other procedure – please specify below:

....

....

....

....

I have discussed what the procedure is likely to involve, the benefits and risks of any available alternative treatments (including no treatment), all complications of the operation that have a material impact upon the outcome and any particular concerns of this patient.

Consultant/Performer

Signed: ....

Date: ....

Name (PRINT): ....

Job title: ....

Contact details
If you require further information at a late date, please contact switchboard on 01223 638000 and ask to speak to your consultant's secretary.

Statement of patient
Please read the patient information and this form carefully.

If you have any further questions please 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.

- **I understand** what the procedure is and I know why it is being offered, including the risks and benefits.
- **I understand** that the procedure requires a general anaesthetic and have read the information leaflet called 'Your anaesthetic for major surgery' (PI 170) 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
  - ☐ nhs.uk/conditions/lung-transplant/risks/
  - ☐ odt.nhs.uk/statistics-and-reports/organ-specific-reports/
- **I have** had the opportunity to ask questions.
- **I agree** to the use of photography for the purpose of diagnosis and treatment and I agree to photographs being used for medical

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

Please affix patient label or complete details below.

Full name:

Hospital number:

NHS number:

DOB:

teaching and education.

- **I understand** that any tissue removed as part of the procedure or treatment may be used for diagnosis, stored or dispose 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 our only if necessary to save my life or to prevent serious harm to my health.
- **I understand** that sometimes planned procedures described on this form are not performed if it is not possible to do so safely or deemed not to be necessary during the course of the operation.
- I have listed below any procedures t**hat 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-Jakob disease).
  - ☐ Yes (Health professional to refer to Trust CJD procedure DN92)
  - ☐ No

Patient

Patient signature: ....

Date: ....

Name (PRINT): ....

Statement of interpreter (where appropriate).
I have interpreted the information above to the patient to the best of my ability and in a way which I believe he/she can understand.

Signed: ....

Date: ....

Name (PRINT): ....

A witness should sign below if the patient is unable to sign but has indicated his or her consent. Young people/children may also like a parent to sign here (see notes).

Signed: ....

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): ....

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Large print copies and alternative language versions of this leaflet can be made available on request.

View a digital version of this leaflet by scanning the QR code.

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