



Royal Papworth Hospital
NHS Foundation Trust

Temporary mechanical circulatory support

A patient's guide and
consent form



Temporary mechanical circulatory support (tMCS)

When you have a life-threatening form of heart failure called cardiogenic shock, we recommend the use of temporary mechanical circulatory support (tMCS). We believe this is the best way of keeping you alive and maintaining blood flow to your vital organs while we consider the next steps in your care.

It is possible that your heart will recover, and we can wean and remove tMCS. However, it is more likely that your heart will not recover, and either heart transplantation or a longer-term type of MCS is required. Sadly, it is also possible that adverse events in the coming days or weeks mean that we are unable to save your life and that palliative care will be more appropriate.

This is a serious situation and there are very significant risks associated with all forms of treatment, including a decision to continue with conservative treatment. We want to help you make the right decision, but time may be limited.

This booklet contains detailed information about tMCS and a consent form. The team will go through the consent form and ask you to sign it if you are willing to proceed. You will be given this booklet to keep and this includes a copy of the signed consent form.

If you are unable to give consent because you are unconscious or lack capacity to make complex decisions about your own treatment, then we will give a copy of this booklet to your next of kin. You can ask to talk with our team about your treatment at any point in the coming days, weeks or months.

Types of temporary MCS

There are several types of tMCS to support either the left side of the heart, the right side of the heart, or both sides of the heart. Some types of MCS can also support the function of the lungs. Most tMCS devices use a pump that sits outside the body which is connected to plastic pipes and which are placed inside your body. These pipes may be placed centrally into

the heart and into major blood vessels through an incision along the length of your breastbone. Alternatively, these pipes may be passed peripherally via large blood vessels at the top of your legs or upper chest.

Decisions about tMCS are complex and taken with a large multi-disciplinary team of cardiac surgeons, cardiologists, intensive care doctors and specialist nurses. We will explain the following types of tMCS which may be appropriate in your individual situation:

- **Veno-arterial extra-corporeal membrane oxygenation (VA-ECMO).** This form of tMCS supports both the heart and the lungs. The pipes may be placed centrally or peripherally. It is normally only used for days because of a high risk of adverse events during longer periods of support.
- **Temporary left, right or both/bi-ventricular assist device (LVAD, RVAD or BiVAD).** This form of tMCS supports one or both sides of the heart. The pipes are usually placed centrally but may be placed peripherally. It may be used for days, weeks or months.
- **Percutaneous left or right ventricular assist device (such as Impella®).** This is a miniaturised blood pump that is mounted on a catheter and placed inside the left side of the heart via a blood vessel in the upper body or leg. It may be used for days or weeks.

What are the benefits of temporary MCS?

In the sickest patients with cardiogenic shock, tMCS may be immediately life-saving. It maintains blood flow to your vital organs when your heart is unable to meet this demand. tMCS is not a treatment for heart failure, but is used to support your circulation while your heart recovers, or until a more definitive form of treatment is appropriate, such as having a heart transplant or long-term (implantable) LVAD.

The anaesthetic team

The anaesthetic team will meet you either in the critical care area (CCA) or 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. Ideally, you will meet a member of the anaesthetic team in the CCA before going to the operating department, but this is sometimes not possible due to the severity of your condition.

If you are awake, the anaesthetic team will ask you questions about previous anaesthetics, other medical problems, medications and allergies. They will ask you 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. It can be life-threatening if this preparation is not carried out.

Getting ready for the operation

Getting ready for the operation depends on your condition. Some patients will be awake as they arrive in the operating department. Other patients have already required sedation or mechanical ventilation in the CCA and will be unconscious when they arrive in the operating department.

You will lie down on the operating table and monitoring equipment will be applied. These include small ECG stickers on your 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. If needed, 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 venous cannula.

If you are awake at this stage, 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.

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 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 pressure.

A second CVC may be 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. 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 during the operation. 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 or 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).

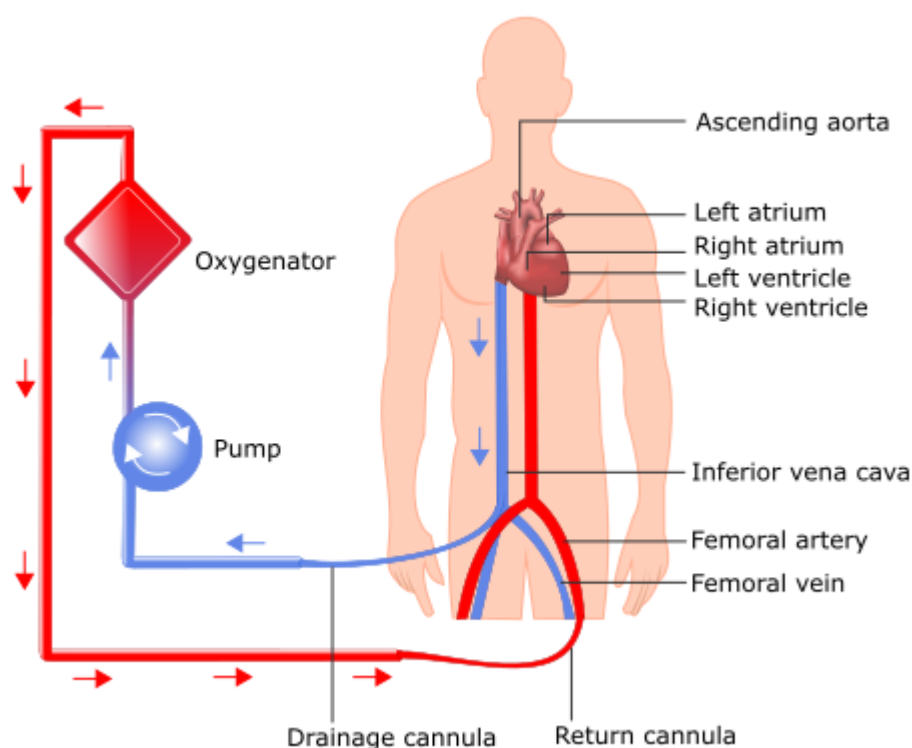
The temporary MCS operation

Once you are asleep and all the monitoring equipment is in place, then the surgeons start the operation. First your skin is cleaned, then you are given antibiotics and an anti-fungal medication for prophylaxis.

For central forms of tMCS, an incision is normally made along your breastbone to access the heart. This is called a sternotomy. The surgeons place large plastic tubes (cannulae) into large arteries and veins, or directly into heart chambers. These tubes are used to divert blood into a mechanical blood pump. The blood is returned, under pressure, into the arterial system.

The type and configuration of tMCS will depend on the side of the heart that is requiring support (right, left or both) and if there is an additional requirement to support the lungs with an oxygenator. An oxygenator is a device that can put oxygen into the blood and remove carbon dioxide from the blood when the lungs are unable to do this.

For peripheral forms of tMCS, such as peripheral VA ECMO or percutaneous LVAD, a sternotomy is not required. Instead, smaller



Peripheral VA ECMO

incisions are made at the top of the leg or the upper chest. Plastic tubes are passed into the blood vessels or heart chambers using X-ray and/or TOE guidance. In emergency situations, it is sometimes safest to start peripheral VA ECMO support in the CCA, rather than moving patients to the operating department.

Once your circulation is adequately supported and any bleeding is controlled, then the surgeons finish the operation. In central tMCS, the cannulae are usually tunnelled so that they exit your body beneath the sternum (at the top of the abdomen) through the skin. Several plastic tubes (drains) are placed around the heart and in the pleural spaces, to drain any blood or fluid that accumulates over the coming days. Fine pacing wires may be attached to the heart to regulate heart rhythm. If a sternotomy has been performed, then the sternum is usually joined together with wires and the wound closed with stitches. This will then be covered with a dressing.

What happens immediately after surgery?

Once the operation is completed, you will be transferred back to the CCA located opposite the operating department. CCA is a specialised area where we look after patients who are recovering from surgery. You will be looked after by a very large team of healthcare professionals. Once the CCA team is confident that you are stable, then the anaesthetic medications will be switched off to allow you to wake up. You will continue to be given painkilling medication.

You may feel disorientated and sleepy when you wake up. You will still be connected to monitoring equipment, which can be noisy, and have drips in your arm and neck. 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 by nodding or shaking your head. When the team caring for you 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 continued until after you wake up. Your nurse will regularly assess you to ensure you have adequate pain relief. Once you are awake, they can often be replaced by tablet painkillers.

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, please let your nurse know. It is important not to allow pain to continue after your operation as it can hinder deep breathing and rehabilitation.

Next steps in the critical care area

It is common to need additional organ support in the early days or weeks after starting temporary MCS. This might happen if there were problems with 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:

- **Ventilation:** used to support your breathing with a mechanical ventilator via a breathing tube. Most patients are sedated, but sedation is deliberately reduced at times. 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 and/or painkillers will be increased.
- **Tracheostomy:** if you require ventilation for a long time, then a tracheostomy may be performed. A tracheostomy involves creating a small hole in the front of the neck through which a breathing tube is passed into the windpipe. 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.

- **Arterial cannulae:** blood pressure is monitored through a fine plastic tube placed in an artery in your arm or leg. Arterial cannulae are removed when we are confident that your blood pressure can be measured non-invasively.
- **Venous cannulae:** venous cannulae are fine plastic tubes that are placed in a vein in your neck, leg or arm. They are used to administer medications and may be used to measure venous pressure. Central venous cannulae are changed regularly to reduce the risk of infection.
- **Nasogastric tube:** this is passed through the nose into the stomach to allow feeding. It is commonly used if you are sedated and cannot eat but is also sometimes used if you are finding it difficult to eat enough for your needs.
- **Temporary dialysis:** if your kidneys stop working, then a form of continuous dialysis called haemofiltration is used to support your kidneys. A tube will be placed in a central vein in your neck or groin. Blood is taken out of your body, passed through the haemofilter, and then returned to your body.

All patients with tMCS are treated with blood thinning (anti-coagulant) medications to reduce the risk of blood clot formation within the body, vascular cannulae and blood pumps. We typically use an intravenous medicine called heparin, once the immediate post-operative bleeding risk has settled. You may be switched to an oral medication called warfarin. All anticoagulant medications are associated with a risk of bleeding. You will be continually monitored for early signs of bleeding.

As you begin recovery from the tMCS operation, the priorities of treatment change. We will get you out of bed, into a chair and then onto your feet and walking around the

CCA. The CCA team will work with you daily and you will be regularly assessed by the physiotherapy team. We will encourage you to eat and drink, so that you are well nourished. We will offer you psychological support and talk to you about the next steps of your journey.

The possible outcomes from tMCS are:

- Weaning from temporary MCS
- Transplantation
- Conversion to durable LVAD
- Death

Over the last five years (2018-2023), we have supported almost one hundred patients with tMCS at Royal Papworth Hospital. Just over half of patients (52%) underwent heart transplantation. A small number of patients (3%) were converted to a durable LVAD and discharged from hospital. A larger number of patients (17%) recovered heart function and were weaned from tMCS. Sadly, just over one-quarter of patients (28%) died in hospital during tMCS.

Decisions to determine your best treatment path may take a long time. Since 2018, the average length of tMCS at Royal Papworth Hospital has been 27 days. However, the length of tMCS varies between patients. Half of patients are supported for between 10 days and 56 days. Sometimes patients are supported for much longer periods of time, many months or even up to one year, until a suitable donor heart is available.

It is important to understand that we do not know the outcome at the start of your treatment. In particular, we do not know whether you will recover sufficiently to be listed for transplantation. We would not list you for a transplant until the whole multidisciplinary team is confident that you are sufficiently strong to survive the transplant procedure.

Please affix patient label or complete details below.

Full name:

Hospital number:

NHS number:

DOB:

PIC 246: patient agreement to PI 246 - Temporary mechanical circulatory support

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:

- Reduce risk of death
- Preserve function of vital organs

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.....

Risks of a tMCS procedure

The potential risks of a tMCS procedure 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
- Return to operating theatre to manage complications
- Other procedure – please specify below:

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

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 later 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.
- 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 that any tissue removed as part of the procedure or treatment may be used for diagnosis, stored or disposed of appropriately and in a manner regulated by appropriate, ethical, legal and professional standards.



Please affix patient label or complete details below.

Full name:

Hospital number:

NHS number:

DOB:

- 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 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 which I do not wish to be carried out without further discussion:

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.....

.....

- 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

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):

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):

What are the risks with tMCS?

Temporary MCS is not successful for everyone. You may develop progressive failure of multiple organ systems despite tMCS and then it is very likely that you would die. You may experience adverse events during tMCS. Adverse events may be fatal or mean that heart transplantation is no longer appropriate. If you cannot move forwards to heart transplantation and your heart does not recover, then you would die.

Each patient is unique and will face different risks. It is our duty to explain the risks that an 'average' patient will face. Some risks are very individual, such as risks relating to previous heart surgery. It is important to recognise that we cannot describe every conceivable event that may occur. It is also important to understand that any of these adverse events could potentially result in death or prevent you from being suitable for a heart transplant.

Please remember that we will only recommend tMCS if we think that the benefits outweigh the risks for you. 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.

Very common risks

These affect more than 10 in 100 patients

- **Bleeding:** this may require insertion of a drain, blood transfusion or further surgery. Blood transfusion is safe but there are potential risks. Your team will offer you an information leaflet 'Receiving a transfusion.' (PI 10) royalpapworth.nhs.uk/download_file/7460/305
- **Acute kidney injury:** there are many potential causes of acute kidney injury with tMCS, including periods of low blood pressure, low blood flow, obstruction of blood flow due to blood clot or medications. This may require treatment

with temporary dialysis (haemofiltration). If kidney function does not recover, then this can prevent you from going on to receive a heart transplant.

- **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).
- **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.

Common risks

These affect between 1 in 100 and 10 in 100 patients

- **Stroke:** or other types of brain damage. If brain function does not recover, then this can prevent you from going on to receive a heart transplant.
- **Blood clots:** occur in the veins of the legs known as deep vein thrombosis (DVT), or lungs, known as pulmonary embolism (PE). You will receive blood thinning medication when this is appropriate to help prevent these. If a PE results in increased resistance to blood flow through the lungs, then this can prevent you from going on to receive a heart transplant.
- **Heart rhythm disturbances:** these may require treatment with rhythm-controlling drugs, or a procedure called cardioversion to correct the heart rhythm.
- **Partial obstruction of arteries or veins:** this can occur due to the presence of plastic pipes which can lead to bleeding and jeopardise blood flow to your arms, legs or other vital organs. This is termed ischaemia. Operations to remove a blood clot (embolectomy) or relieve pressure inside swollen muscle compartments (fasciotomy) may be required. In very severe situations, loss of your arm or leg (amputation) may be necessary to save your life. Limb swelling and pain may persist in the longer term.

Other risks

- **Stress ulceration of the stomach or bowel:** this can lead to bleeding from the area of ulceration. All patients receive antacid medication to help reduce this issue.
- **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 (ischaemia). Bowel ischaemia may require surgery to remove the affected bowel and this can be life-threatening.
- **Acute liver injury:** patients who are severely unwell may have periods of low blood flow or pressure which can affect liver function. Severe liver failure is life-threatening.
- **Heparin-induced thrombocytopenia (HIT):** this is an allergic reaction to an anticoagulant medication (heparin) that we use in patients with temporary MCS. HIT can lead to bleeding or blood clotting problems. We need to delay heart transplantation until HIT has resolved and this may take weeks or months.
- **Critical illness neuropathy:** severe weakness, muscle stiffness, joint pain or nerve injuries can result from being immobile for long periods.
- **Delirium:** this is not uncommon in the CCA. Features include difficulty focusing, sudden changes in behaviour and confusion but these get better with time. The experience can be distressing for you and your loved ones.
- **Mental health problems:** if problems such as anxiety, depression and post-traumatic stress were present before surgery, then they may get worse.
- **Severe allergic reactions:** (anaphylaxis) to medications used at the time of surgery are very rare. Most patients recover completely.
- **Difficulty swallowing:** this may require naso-gastric feeding to maintain nutrition during recovery.
- **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 mobile, then the CCA team will reposition you on a regular basis to help prevent pressure sores. Specialized dressings are used to reduce the risk of skin injury by medical devices, such as the plastic tubes that are used in temporary MCS.
- **Pancreatitis:** (inflammation of the pancreas) can be serious or even fatal.
- **Wound healing problems:** can result in a painful or cosmetically disfiguring scar.
- **Infection:** 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.

What are the consequences of not having temporary MCS?

The alternative to tMCS is conservative medical care with the expectation that you would be highly likely to die in the coming days to weeks. Managing your condition would focus on treating symptoms and maximising quality of life. We would recommend involving our supportive and palliative care team who can help address physical, psychological, social and spiritual needs.

If you decide not to proceed with tMCS, 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 before you receive temporary MCS. If you no longer wish to continue with tMCS, then we would talk to you about withdrawal of mechanical circulatory support, but we would ensure that you continue to receive supportive and palliative care.

Resources

[ics.ac.uk/Society/Patients_and_Relatives/A_Guide_to_ICU](https://www.ics.ac.uk/Society/Patients_and_Relatives/A_Guide_to_ICU)

[rcoa.ac.uk/patient-information/patient-information-resources/anaesthesia-risk](https://www.rcoa.ac.uk/patient-information/patient-information-resources/anaesthesia-risk)

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

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 includes a decision about whether cardiopulmonary resuscitation (CPR) should be attempted 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 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 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.

Royal Papworth Hospital NHS Foundation Trust

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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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