British Heart Foundation

A Heart transplant will transform my life

Vicky Small

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FOR EVERY
HEARTBEAT

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ABOUT THE BRITISH HEART FOUNDATION

As the nation's heart charity, we have been funding cutting-edge research that has made a big difference to people's lives.

But the landscape of cardiovascular disease is changing. More people survive a heart attack than ever before, and that means more people are now living with long-term heart conditions and need our help.

Our research is powered by your support. Every pound raised, every minute of your time and every donation to our shops will help make a difference to people's lives.

If you would like to make a donation, please:

- call our donation hotline on **0300 330 3322**
- visit **bhf.org.uk/donate** or
- post it to us at BHF Customer Services, Lyndon Place, 2096 Coventry Road, Birmingham B26 3YU.

For more information, see **bhf.org.uk**

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ABOUT THIS BOOKLET

This booklet is for anyone who may need a heart transplant, and for their family and friends. It explains:

- who is accepted for a heart transplant
- what happens when you go for an assessment at a transplant centre
- what happens if you are accepted for a transplant, and
- what happens after the operation.

It also describes life after a transplant, the long-term outlook for heart transplant patients, and the possible complications.

This booklet does not replace the advice that your doctor or the health professionals looking after you may give you, but it should help you to understand what they tell you.

INTRODUCTION

A heart transplant is a surgical operation to replace a person's diseased heart with a healthy heart from a human donor.

In the UK, heart transplants are now carried out in six centres around the country:

- Royal Brompton and Harefield Hospital in London and Middlesex
- Papworth Hospital near Cambridge
- the Queen Elizabeth Hospital in Birmingham
- Wythenshawe Hospital in Manchester
- the Freeman Hospital in Newcastle, and
- the Golden Jubilee National Hospital in Clydebank.

Heart transplants for children are carried out at:

- Great Ormond Street Hospital in London, and
- the Freeman Hospital in Newcastle.

As many as 200 heart transplants are carried out on adults in the UK each year.

A much smaller number of heart and lung transplants are carried out each year. These transplants are for people with lung disease, or people whose lungs have been damaged by heart abnormalities. For more information on heart and lung transplants, visit **www.nhs.uk**

WHO NEEDS A HEART TRANSPLANT?

Heart transplants are carried out for people with severe **heart failure**. Heart failure means that your heart is unable to pump as much blood and oxygen around your body as it should.

The most common causes of heart failure are:

- heart attack
- high blood pressure
- cardiomyopathies (diseases of the heart muscle), and
- heart valve disease.

Other causes include:

- arrhythmias (abnormal heart rhythms)
- some types of congenital heart disease (a heart problem you are born with)
- a viral infection affecting the heart muscle, and
- some chemotherapy medicines.

Not everyone who has heart failure – or one or more of the conditions above – is suitable for a transplant.

How are people referred to a heart transplant centre?

If you have heart failure, you are probably under the care of a cardiologist. If your condition is serious and other treatments have not managed to improve things or control your symptoms, your cardiologist may refer you to a heart transplant centre for a **transplant assessment**. This is to see if you may be suitable for a heart transplant.

NHS Organ Donor Register

Transplants are one of the greatest achievements of modern medicine. But they depend entirely on the generosity of donors who are willing to make this life-saving, or life-enhancing, gift to others. Joining the NHS Organ Donor Register records your agreement to the use of your organs and tissue for transplantation after your death. For more information, see page 71. Or visit **bhf.org.uk/jointheregister**

For more information on heart failure, see our booklet Living with heart failure.

The transplant assessment may be done in two parts. You may have an initial transplant assessment as an outpatient, and later on you will be admitted to hospital for two or three days for further assessment. The assessment involves having a range of tests and examinations to make sure that a transplant is the best option for you.

Some of the tests that may be carried out are:

- blood and urine tests
- tests to find out how well your lungs are working
- tests on the heart – such as an electrocardiogram (ECG), an exercise ECG, an echocardiogram (echo), a coronary angiogram, a myocardial perfusion scan, an MRI scan, and possibly a biopsy (which involves taking a small sample of the heart muscle), and
- a dental check-up.

You may already have had some of these tests in the past, but some tests may need to be repeated so that the transplant team has up-to-date information. To find out more about these tests, see our booklet *Tests*.

Having a transplant assessment also gives you and your family the chance to meet the members of the **transplant team**, to find out what is involved in having a transplant, and to ask any questions you may have. The transplant team includes the cardiologist (heart specialist), surgeon, transplant nurses, physiotherapists, a transplant co-ordinator and sometimes a psychologist. You may also have the chance to talk to other people who have had a heart transplant.

Having a heart transplant carries significant risks, and the transplant team needs to find out if you are sick enough to need the transplant but well enough to survive the surgery and recover afterwards. During the assessment, the team needs to find out answers to the following questions.

Do you have any other serious medical condition or any continuing infection?

If you have a medical condition that is likely to affect your short-term or long-term outcome after a heart transplant, you may not be accepted onto the transplant waiting list.

Will your kidneys and other organs be able to work well after the transplant?

Heart failure may have caused some damage to other organs, particularly your kidneys and your liver. The transplant team needs to find out how well your organs are working before the transplant, so that they can predict how well the organs will be able to cope after the operation. It's particularly important that your kidneys work well, because kidney problems are a possible side effect of some of the medicines that you will need to take after your transplant.

Is the pressure in your pulmonary artery too high?

Over time, heart failure can cause a build-up of the pressure in the pulmonary blood vessels (the vessels in your lungs). During your assessment, a catheter is inserted into a vein to measure the pressure in your pulmonary artery and heart. This procedure is called a 'catheterisation'. If the pressure is too high, it means that a newly transplanted heart is less likely to function satisfactorily, and so you may not be accepted onto the transplant waiting list.

THE RESULTS OF YOUR ASSESSMENT

After the assessment, the staff at the transplant centre will decide whether you need a transplant and if you are suitable for one. They may decide one of the following.

That you should go on the active waiting list.	This means that you may be called for a transplant at any time.
That you may be suitable for a transplant, but your condition is currently not severe enough.	This means that you will be reviewed regularly and, if your condition gets worse, you will go onto the active waiting list.
That you need further investigations or treatment.	This means that more information is needed before a decision can be made.
That you are not suitable for a heart transplant.	This might be for one of the reasons given on pages 08 and 09. The transplant team will explain why and discuss other treatment options and, if necessary, palliative care (the support and care of people whose illness cannot be cured).

Having a transplant assessment gives you the chance to meet the transplant team, find out what is involved in having a transplant, and ask any questions you may have.

VICKY'S STORY

Vicky, now 40, was born with a hole in her heart. When she was 12 she was told that the hole had closed up, but later she was found to have problems with one of her heart valves and began to experience severe episodes of atrial fibrillation (AF).

"Over the years I've had lots of treatment, but in 2012 the doctor advised me to go for a heart transplant assessment. I was told that my heart would only last a few more years. The transplant team told me about the benefits and the risks. It was scary to be told there was a high chance I would never wake up. We decided that I was not ready for transplantation at that stage.

Now, I feel so tired and out of breath all the time that I've had to give up my job and my condition is really affecting my quality of life. So I'm now focusing on the positives. I'm now feeling ready for a transplant."

Once you are on the transplant waiting list, a suitable donor heart may come along in a few days, or it may take many months or even years. The donor heart needs to come from someone with a compatible blood group to yours. How long you need to wait also depends on how many other people are on the waiting list, and how urgent their cases are. **Unfortunately, suitable hearts do not become available for everyone who is on the waiting list**. About half the people accepted onto the waiting list receive a transplant within three years.

When you are on the waiting list, it is important that you can be contacted easily. Make sure the transplant team have your up-to-date contact phone number, and that you tell them about any changes in your contact details.

The doctor who referred you to the transplant centre will be responsible for your care during this waiting time, although you will probably need to go for check-ups at the transplant centre as well. If your condition changes, you may need to have another assessment to make sure that you are still suitable for a transplant. Some people may have to be taken off the waiting list either temporarily or permanently.

The time while you are on the waiting list can be very difficult. It can feel hard trying to get on with life, and the uncertainty can be stressful.

Some people worry about what will happen if the transplant is not carried out, while at the same time they are anxious about having the operation if a donor becomes available.

For advice and support during this time, talk to one of the transplant team or contact one of the organisations listed on the NHS Blood and Transplant website **www.organdonation.nhs.uk** in the section on *Useful links*.

Most transplant centres will want to make sure that, before they do the transplant, you have been treated for any other medical conditions you may have. You will also need to have regular dental check-ups, to make sure your teeth and gums are as healthy as possible. This is to reduce your risk of getting an infection.

If you have to stay in hospital while you wait for a transplant

Some people on the transplant list will be too unwell to leave hospital and will have to stay in hospital until the transplant can be done. Their names go on a waiting list called the Urgent Heart Allocation Scheme. Priority is given to these patients.

Ventricular assist device (VAD)

If you are too ill to wait for an appropriate donor heart, you may need to be supported with a ventricular assist device – or **VAD** for short. A VAD is a mechanical pump that helps pump blood out of the ventricles to the rest of the body. Some pumps are meant for short-term support (a few days or weeks), while others allow discharge home and can be used for several months, or sometimes even years. This is known as a **'bridge to transplantation'**. This means that the device is intended to be used for a limited period and is removed when you receive a donor heart.

Sometimes the heart recovers when supported with a VAD, and the device can be removed without the need for a heart transplant. This is called a **'bridge to recovery'**. Unfortunately we cannot predict which patients will recover to this extent.

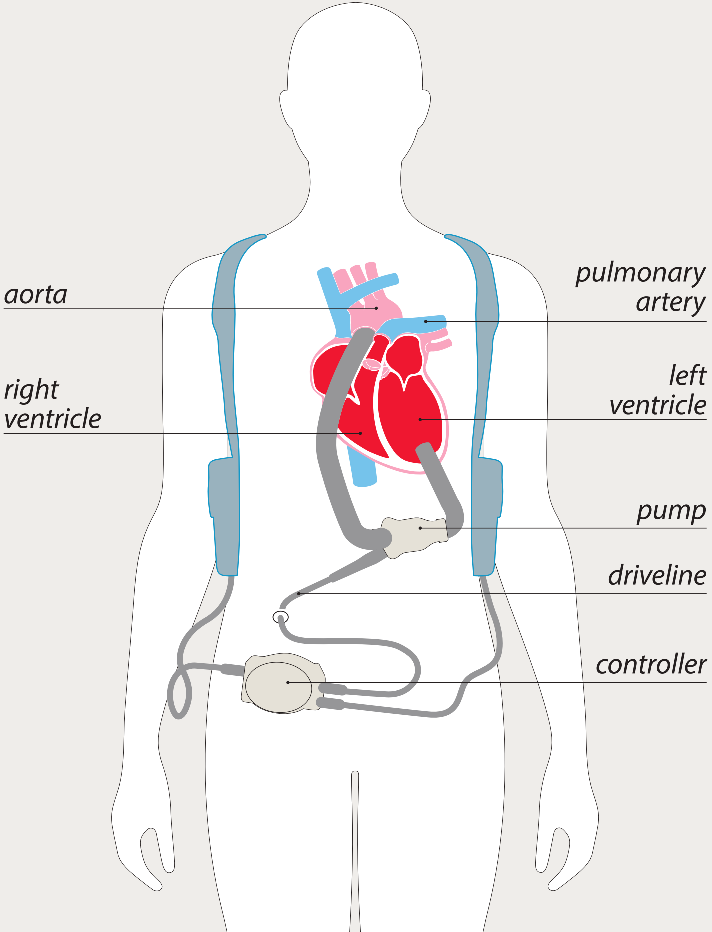
A VAD can be placed in the left, or right, or in both ventricles of your heart, but it is most commonly used to support the left ventricle (as shown in the diagram on the next page). When placed in the left ventricle it is called a left ventricular assist device – or LVAD.

Having a VAD inserted involves having open-heart surgery and usually the use of a heart-lung bypass machine (see page 25). It is a high-risk operation. Your doctor will be able to discuss whether a VAD is suitable for you and whether this is the best treatment option for you.

If you need a VAD, you will need to go to one of the designated heart transplant centres to have an operation to have the device inserted.

One end of the pump is attached to the ventricle (or ventricles). The other end is attached either to the aorta or to the pulmonary artery. (These are major blood vessels that lead off from the heart.) A driveline (an insulated wire attached to the pump) is guided through the body and out through your skin. It is then connected to a controller, which has rechargeable

Left ventricular assist device (LVAD)



batteries that provide the electrical power to make the pump work. You wear the controller on a belt around your waist, or carry it in a shoulder bag. Blood flows into the pump from the ventricles, and the device then pumps it out and into the aorta or pulmonary artery.

After the operation, you have to take an anticoagulant medicine called warfarin, to reduce the risk of blood clots forming in the pump. You will need to have regular blood tests to check that you are getting the right amount of this medicine. You will also need to take aspirin, or a medicine similar to aspirin, to work alongside the warfarin. To find out more, see our booklet *Medicines for your heart*.

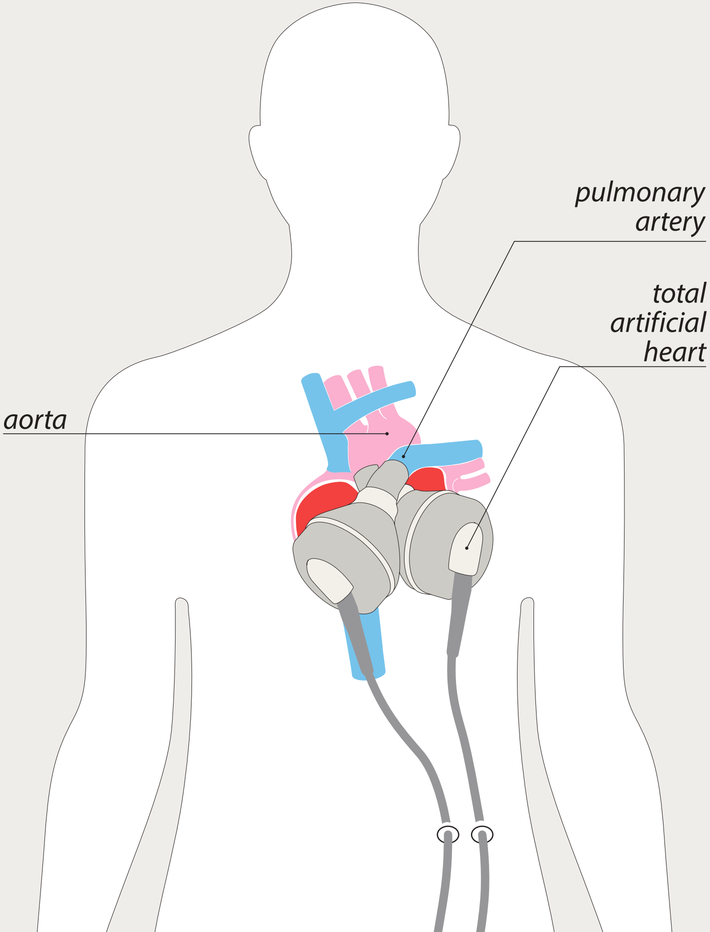
While you're in hospital, the staff will show you and your carer how to look after the device. You will also have to go back to the hospital for follow-up.

Total artificial heart

Another 'bridge to transplantation' method is the implantation of a total artificial heart. This is a relatively new procedure in the UK and is suitable for only a very small number of patients.

A total artificial heart can be used for selected patients who are critically ill with end-stage bi-ventricular failure (which means that both ventricles in the heart are failing). The person's ventricles and four heart valves are removed, and the artificial heart is attached to the aorta, the pulmonary artery and the remaining top part of the heart. The artificial heart is powered by a portable 'driver' which is carried in a backpack or shoulder bag.

The aim of the total artificial heart is to improve your condition while you're waiting for a donor heart to become available, so that you are in a better condition to have your transplant surgery.



The transplant centre will contact you when they find a donor heart which they think is suitable for you. They will ask you to go to the centre and may have made arrangements with the local ambulance service beforehand.

It is important to remember the following:

- Don’t eat or drink anything from the time you get the call from the transplant centre.
- Bring all your current medicines with you.
- Bring a bag with items for a hospital stay.

The transplant co-ordinator will advise you on all this and anything else you may need. When you are admitted to the centre, you will be re-assessed quickly and have blood tests, an ECG and a chest X-ray. This is to make sure that nothing new has happened that may make a successful transplant less likely.

Donor hearts may come from anywhere within the UK or, rarely, from other countries in western Europe. Hearts coming from a distance are often brought by air. The team will try to reduce, as much as possible, the amount of time between removing the heart from the donor and transplanting it into you, and will try and keep the time to under four hours.

While you are being admitted, the team will examine the donor heart to make sure it is in good condition and that it is suitable for you. If it is not, the transplant operation will not go ahead. This may be very distressing and upsetting for you and your family, but unfortunately it is unavoidable.

As many as 200 heart transplants are carried out on adults in the UK each year.

You will be given a general anaesthetic. The transplant operation usually takes between four and six hours. The surgeons will make an incision (a cut) in your breastbone to get access to your heart. You will then be connected to a heart-lung bypass machine. This machine makes the blood circulate around your body so that your body still gets the oxygen and nutrients it needs. Your surgeons then remove your failing heart and transplant the new heart.

Once the surgeons have finished the operation, they will start your heart beating again and slowly allow the blood to enter your heart from the heart-lung bypass machine. When the heart begins to take over pumping and your condition is stable, the heart-lung bypass machine is turned off. The surgeon will then close your breastbone securely with wires. These wires will stay there for the rest of your life.

WHAT HAPPENS AFTER THE OPERATION?

After the operation, you will be moved to the intensive care unit. You will be sedated and will breathe with the help of a ventilator machine until your condition is stable and you are able to breathe for yourself. This may be anything from a few hours to a few days after the operation.

You will have a wound along your breastbone and you will also have 'chest drains' – tubes which have been inserted in the chest area to drain fluid from your chest. You will be given fluids and medicines through small tubes attached to your arms or neck.

Most patients wake up the following day, while others take a little longer. Most people are moved out of the intensive care unit as soon as they are in a stable condition. You may be moved to a high-dependency unit or 'step-down' ward.

For more information on what happens after the operation, see our booklet Having heart surgery.

WHAT MEDICINES WILL I NEED TO TAKE AFTER THE TRANSPLANT?

It is important that you keep yourself and your new heart as healthy as possible. For your transplant to succeed, it's essential that you take your medicines correctly and at the right time. You will learn about your new medicines while you're still in hospital and will be taught how to take your medicines safely.

Immunosuppressants

These are also called **anti-rejection medicines**.

All patients need to take immunosuppressant medicines after a heart transplant. These medicines suppress your immune system, and help to stop your body from rejecting the new heart. (The immune system includes cells and chemicals in the blood and tissues that help to fight infection but also damage anything 'foreign' like a donor organ.)

You will probably receive the first dose of immunosuppressants before going for your operation, and you will need to take them for the rest of your life.

Rejection of the new heart is most likely to happen within the first months after a transplant. During this time you will be given quite a high dose of immunosuppressant medicines. It is during this time that the risk of infection is at its greatest. After this, your doctors may be able to gradually reduce the dose of some of the medicines. You will be taught how to recognise the signs of rejection and infection.

It is vital that you take your immunosuppressants **exactly as they have been prescribed**. You will be given a medicines diary to record every medicine you take, and when and how you take it.

Only your transplant team can make changes to your immunosuppressant medicines. If you are ever given a different brand of immunosuppressant when you collect your prescription, it is important that you check with the team before you start taking it.

You will need to take a combination of immunosuppressant medicines, which usually includes:

- **tacrolimus** or **ciclosporin**
- **mycophenolate mofetil (MMF)** or **azathioprine**, and
- **prednisolone**.

Another medicine which is sometimes used is **sirolimus.**

Tacrolimus or ciclosporin

You will need to have regular blood tests to check the level of tacrolimus or ciclosporin in your blood. The dose is then adjusted to suit you.

If you are taking either of these medicines, it is important that you don't eat grapefruit or drink grapefruit juice, as these can increase the level of tacrolimus or ciclosporin in your blood.

Possible side effects of tacrolimus

The side effects of tacrolimus may include:

- a decrease in kidney function
- high blood pressure
- an increase in blood sugar levels (increasing your risk of diabetes)
- tremors and muscle cramps
- gout (which causes swollen, hot or painful joints)
- hair loss.

Possible side effects of ciclosporin

You may get some of the same side effects as for tacrolimus, but instead of hair loss you may get an increase in hair growth on your face and body. (You can use hair-removal cream to remove the hair, or a cosmetic bleach, but **not** electrolysis.) Ciclosporin can also cause swollen and bleeding gums and increase cholesterol levels.

Always check with your transplant team before taking any new medicines or herbal remedies, as some can affect how ciclosporin works. For example, you should avoid using St John’s Wort, as this can affect the level of ciclosporin in your body.

Mycophenolate mofetil (MMF)

This medicine can affect the number of white blood cells and platelets in your blood. (The white cells are one of the body’s most important defence mechanisms against infection and foreign bodies.) You may need to have regular blood tests, and your doctors will adjust the dose if necessary.

Possible side effects

The side effects of MMF may include:

- blood disorders which put you at risk of infection and bleeding
- nausea, vomiting and diarrhoea. (It may help to take the medicine either with food or just after eating.)

Azathioprine

Azathioprine is sometimes used instead of MMF, together with other immunosuppressants. It acts in a similar way and can cause similar side effects. It can also affect how well your liver works, so you will need to have regular blood tests to check for this.

Prednisolone

Prednisolone is a steroid medicine which is used as an immunosuppressant. This medicine is used just before and immediately after the transplant operation, to prevent early rejection of the new heart. People usually need to take it for at least six months after the transplant operation and it forms part of the long-term treatment for many patients. The dose is gradually reduced over time to a low-maintenance dose. Prednisolone is also used to treat acute rejection (see page 56).

You must not stop taking prednisolone suddenly, so make sure you don't run out of tablets.

Possible side effects

The side effects of prednisolone may include:

- weight gain and a 'fuller' look to the face
- high blood pressure and fluid retention (particularly in the feet, ankles and legs)
- an increased risk of diabetes
- osteoporosis (weak bones)
- poor skin healing and thinning of the skin
- stomach upsets and indigestion.

Sirolimus

Sirolimus is sometimes used instead of ciclosporin or tacrolimus if the kidneys don't work as well as they should. It is also used as an immunosuppressant if there are signs that your body is continuing to reject the new heart even though you have taken other immunosuppressants to prevent this.

You will need to have regular blood tests to check the level of sirolimus in your blood. The dose is then adjusted to suit you.

Possible side effects

The side effects of sirolimus may include:

- pain in your abdomen
- an increase in cholesterol levels
- blood disorders which put you at risk of infection and bleeding
- acne (a common skin condition which usually affects the face).

Side effects of immunosuppressants

Not everyone will experience side effects when taking immunosuppressants. However, if you do get any side effects, it is important to let your doctor know about them. Some side effects may disappear with time, and some can be treated with other medicines. Your doctor can keep the side effects to a minimum by using the lowest effective doses.

Other medicines

Medicines to lower blood cholesterol

To help prevent the coronary arteries of the transplanted heart from becoming narrow, it is important to take a cholesterol-lowering medicine, even if your cholesterol level is normal. The main type of medicine used to reduce cholesterol is a statin.

Antibiotics and antiviral medicines

Antibiotics and antiviral medicines are given during and after the transplant and may be given from time to time if there is a threat of infection. Some people may need to take an antibiotic called co-trimoxazole long term, to prevent certain types of infection.

Medicines to lower blood pressure

The combination of ciclosporin or tacrolimus and steroids can sometimes cause high blood pressure, so you may need to take medicines to lower your blood pressure.

Diuretics

You may also retain fluid, so your transplant team may prescribe diuretics (water tablets) for you.

Anti-platelets

You may need to take an anti-platelet medicine – such as aspirin – to reduce the risk of blood clots forming in the vessels of the transplanted heart.

Medicines to prevent osteoporosis

You may need to take a medicine to reduce your risk of bone fractures, particularly if you are taking steroids, as these can cause weak bones.

General advice on medicines

- Always check with your transplant team before you start taking any new medicines, as some medicines can affect each other.
- With some medicines it’s important to avoid certain foods or drinks. Check the information leaflet that comes with your tablets, or check with your doctor, transplant team or pharmacist before you start taking them.
- The transplant team will send your GP a list of approved medicines you can take, including the types of antibiotics you can have.

- If you have any questions or concerns, contact the transplant team.

Medicines to avoid

- If you need to take painkillers, don't use ibuprofen-based ones, as ibuprofen can affect the kidneys. Always check with your doctor or pharmacist before buying painkillers.
- Some herbal remedies may cause problems. If you have any questions about any herbal medicines, ask your transplant team.

For those who have a heart transplant, the long-term outlook has now greatly improved. About 7 in every 10 transplant patients in the UK are alive after five years.

SIMON'S STORY

Simon, now 59, had a heart transplant when he was 46.

"My dad sadly died when I was a teenager, from a condition called dilated cardiomyopathy. I was checked out at the time and my heart was normal, but in 2002 I suddenly collapsed. I had inherited the same condition, and had severe heart failure. Over the next few years it got worse, and my consultant told me I had a life expectancy of about a year. It was a bombshell. I was assessed for a heart transplant at Papworth Hospital, and added to the waiting list.

It was 11pm on 30th June 2005 when the phone call came. By midnight I was actually going into the operating theatre. It was all quite surreal really. I knew what the odds were, and decided to take the gamble. The operation took eight hours.

After my transplant I retired. You get more of a hunger and an enthusiasm for life, and now I only do things I enjoy."

The first few months after the operation

Although you will be weak and tired after the operation, recovery can be very quick. However, if you were very unwell before your transplant operation, it may take longer for you to recover. Your transplant team will give you advice and information related to your needs after the transplant.

Most heart transplant patients leave hospital about three to four weeks after the operation, but some people may need to stay in hospital for longer. Before leaving, you will be seen by a member of the transplant team for a 'discharge talk', which will help to prepare you for going home.

During the first few months after a transplant, you may feel that your life is dominated by all the medicines you have to take, and the frequent visits you need to make to the hospital.

You will need to go for frequent appointments at the outpatients' clinic and you should keep the whole day free for these. You will gradually need to go for appointments less often, depending on your progress. Even years after a transplant, many people have two or more outpatient appointments a year at the transplant centre and you will have follow-up appointments there for the rest of your life.

Physical activity

A physiotherapist will see you every day while you're in hospital, and will discuss an exercise programme with you for when you go home. Before you leave hospital, you should ask about the type of activity you should be doing, how much you should do and how to gradually increase the amount you do.

It is important to build up your level of activity gradually, starting with walking around at home and then building up to short walks outside. You can do light housework, once you feel fit and able. However, in the weeks after your transplant you need to avoid doing any heavy lifting, twisting, pushing and pulling, or doing any heavy work, until your breastbone is healed, which will take three to four months.

You will be encouraged to take part in a **cardiac rehabilitation programme** in your local area. The aim of this programme is to help you recover as quickly as possible and to teach you how to exercise safely. The programme includes supervised exercise, advice about how to have a healthier lifestyle, and relaxation techniques. For more information, see our booklet *Cardiac rehabilitation*.

After the rehabilitation programme, try to do some regular physical activity each day. Exercise such as walking is ideal. Start slowly and build up gradually as you feel able. Always start with a slow warm-up period and, when you come to the end of your activity, take time to slow down and don't stop suddenly.

Regular physical activity helps to improve stamina and fitness, and helps keep your heart healthy.

Your new heart will have a resting heart rate which is faster than normal, because the new heart is not 'connected' to the nerves that control your heart rate. This means that you cannot use your heart rate as a measure of how fit you are. During exercise, your heart rate increases. So it is particularly important to make sure you warm up before any physical activity, and cool down afterwards.

After your heart transplant, regular physical activity helps to improve stamina and fitness, and helps keep your heart healthy.

Many people who have had a transplant are eventually able to take part in a wide range of activities and many are able to do sports. You may be advised to avoid some strenuous activities. Exercises such as press-ups and heavy weightlifting are not recommended. You may also be advised to avoid vigorous sports.

It is important to speak to your doctor, nurse or cardiac rehabilitation team before you start any new exercise or activity. They will be able to offer you advice about whether it is safe for you to do that activity.

Sex

Many people who have had a transplant can return to a normal sex life. Use the same common-sense approach to having sex again as you do to building up your other general physical activities.

People who have had an uncomplicated recovery after a heart transplant can usually start having sex again when they feel comfortable to do so. For some people this may be after a few weeks. For others it may be longer.

If you are not sure when you can start having sex, talk to your transplant team or your GP.

Healthy eating

Eating a healthy, balanced diet can help to keep your heart healthy. These are the main points to remember:

- **Eat plenty of fruit and vegetables.** Aim to eat at least five portions a day.
- **Choose healthier fats.** In particular, cut down on saturated fats. These are found in fatty meats and in dairy products such as cheese and cream.
- Aim to have two portions of fish a week. One of these portions should be **oily fish** – such as herring, mackerel, pilchards, sardines, salmon, trout or fresh tuna.
- **Cut down on salt** and don’t use low-sodium salt.

For more information on healthy eating, see our booklet *Eating well*.

Some people who have had a heart transplant tend to put on weight, especially if they are taking steroids. A combination of healthy eating and regular physical activity will help you control your weight. For more information, see our booklet *Facts not fads – Your simple guide to healthy weight loss.*

If you drink alcohol, check with your transplant team first before you start drinking again. However, drinking too much alcohol is not recommended. It is not good for your heart and general health, and could interfere with the way your medicines are absorbed into your body.

Driving

If you have an ordinary licence

You will usually be advised not to drive for about two months after your transplant. This may vary depending on your condition, so talk to your doctors about whether or not it is OK for you to drive.

If you have a licence to drive a bus, coach or lorry

If you have a licence to drive a bus, coach or lorry, special regulations apply. You will need to tell the DVLA about your heart transplant, and check with them whether you can continue to drive. Visit **www.direct.gov.uk/driverhealth**. Or call the DVLA on **0300 790 6806**, or write to them at DVLA, Swansea SA99 1TU.

Telling your motor insurance company about your heart transplant

Whatever sort of driving licence you have, you need to tell your motor insurance company that you have a heart condition and about any treatment that you have had for it. If you don't, your insurance may not be valid.

Returning to work

Most people can go back to work after having a heart transplant. When you can return will depend on your recovery and the type of work you do. Talk to your doctor about when you can go back to work. For more information, see our booklet *Returning to work*.

Holidays

Once you have recovered from your operation, and as long as your condition is stable, it should be OK for you to go on holiday. Talk to the transplant team about going away. They will be able to give you advice that is specific to you.

It is generally not recommended to go abroad in the first year after your transplant due to the number of follow-up appointments you need to have and the increased risk of complications.

If and when you are ready to go away, check with your doctor or specialist nurse that it is OK for you to go and that the place you are going to is suitable. It's a good idea to choose somewhere where you will have access to medical treatment if you need it.

Make sure you get travel insurance before you go abroad. You may be asked to provide a letter from your doctor stating that you are fit to travel. The BHF produces a list of insurance companies, including those offering travel insurance, based on the feedback received from heart patients. You can download a copy from our website **bhf.org.uk**, or call the BHF Heart Helpline on **0300 330 3311** to order a copy of the list, called *Insurance*.

Vaccinations

It is not safe for you to have some vaccinations (live virus vaccines) because of the immunosuppressant medicines you will be taking. Check with your transplant team. However, people who have had a heart transplant are strongly recommended to have vaccinations against flu (once a year) and pneumococcal pneumonia (once every three to five years).

Avoiding infection

Because you are taking immunosuppressant medicines, your body's defence against infection will be low. So it's important that you do everything you can to avoid infection. For more information on this, see page 61.

In the sunshine

Heart transplant patients have a higher risk of getting skin cancer (see page 63). To reduce this risk, stay out of strong sunshine, and always use a sunblock or a sunscreen with a sun protection factor (SPF) of 30 or more. Protect your skin as much as possible by wearing clothes with long sleeves, and use a sunhat.

A fuller and more active life

Having a transplant can give you a fuller and more active life than before and can give you many good-quality years of life. Many people notice a considerable improvement in their symptoms and are able to do much more.

To make sure that your heart transplant is as successful as possible, you may need to adjust your lifestyle.

- Don’t smoke.
- Do regular physical activity.
- Eat a healthy, balanced diet.
- Aim to control your blood cholesterol and blood pressure levels.

Preparing to go home from hospital after a transplant can be very emotional. You may feel excited, but also a bit worried about how you will manage. You may wonder how you are going to cope with daily life, or you may feel overwhelmed by the number of people wanting to visit you.

Every person reacts differently after a transplant. The important thing is to talk to someone you trust about how you feel. While you are in hospital you can talk to the specialist transplant nurse or other members of your transplant team. The staff at your transplant centre can give you details of who you can contact after you have left hospital in case you are worried or have concerns. Most transplant centres run outpatient support clinics which can help you and your family adjust to life after a heart transplant.

Most people who have had a transplant cope remarkably well emotionally. It is normal to feel low or to have mood swings or disturbed sleep in the early weeks after a transplant. It’s important to remember that the transplanted heart is no more than a pump and that it does not change your personality or behaviour.

If you have been ill before having the transplant, you may have become dependent on your partner. The independence you enjoy after recovering from the transplant may mean that you now need to adapt your relationship with each other.

i **For more information about the emotional aspects of having a heart condition, see our booklet Heart to heart. See page 67 for how to order a copy.**

If you care for someone who is going to have, or has had, a heart transplant

Caring for someone who is waiting for or has just had a heart transplant can be stressful and emotionally demanding, and you may experience a variety of emotions. If you are looking after someone, it is important that you look after your own health. Ask for support when you need it and make sure you get regular breaks. If you are finding things difficult, talking can be comforting and helpful. For more information, see our booklet *Caring for someone with a heart condition*.

> **Once you've recovered, it's normal to wonder about your donor and his or her family. If you'd like to write to the family, discuss it with your transplant team.**

WHAT IS THE LONG-TERM OUTLOOK?

Having a heart transplant aims to improve your quality of life and prolong your survival. For those people who have a transplant, the long-term outlook has now greatly improved. More than 8 in every 10 heart transplant patients in the UK are alive after one year and about 7 in every 10 people are alive after five years.

Many people have a good quality of life, especially if the side effects of the immunosuppressant medicines can be kept to a minimum.

You may be able to return to work – or go back to further education or school – and many people who have had a transplant can take part in sporting activities.

WHAT COMPLICATIONS MIGHT THERE BE?

It is important that you and your family know about the main complications that can happen after a heart transplant. The transplant team will be monitoring you closely, and most of the complications are manageable.

The most common complications are:

- attempts to reject the new heart – 'acute rejection' and 'chronic rejection'
- infection
- problems with the kidneys
- high blood pressure
- diabetes, and
- a higher risk of some forms of cancer.

Attempts to reject the new heart

After the transplant, the body tries hard to reject the new heart. You will need to take quite high doses of immunosuppressants to reduce the risk of rejection (see page 27). You will also need to have regular check-ups to check for signs of rejection and to see how well your new heart is working. The rejection can be either 'acute' or 'chronic'.

Acute rejection

Acute rejection is common in the first year after the transplant and should be expected. As long as you take your medicines and the signs of rejection are noticed early, most episodes can be treated.

Some warning signs of rejection are:

- flu-like symptoms
- tiredness
- nausea or vomiting
- breathlessness
- a high temperature
- palpitations
- putting on weight quickly
- swollen ankles.

If you get any of these warning signs, it is very important that you contact the transplant centre.

One of the best ways of checking for signs of rejection is for the doctor to take some small specimens of the heart muscle (a biopsy) at regular intervals and examine them under a microscope. You will be given a local anaesthetic for this. The doctor introduces a catheter (a fine, hollow tube) through a vein in your neck. Using X-ray screening, the catheter is passed through into the heart and small specimens of tissue are taken. You will probably need to have several biopsies in the first year after your transplant. If rejection has been a particular problem, you will have to have the biopsies done more frequently.

Another way of checking the transplanted heart is by carrying out some of the examinations you had at your transplant assessment (see page 07).

Chronic rejection

The term ‘chronic rejection’ describes certain changes that can develop in the arteries of the transplanted heart. This usually happens some years after the transplant, although in some cases it can happen much sooner. The coronary arteries (the arteries on the surface of the heart) can become narrower. This is known as **coronary heart disease**. These changes to the arteries are mainly due to damage done by your immune system, which tries to ‘attack’ the new heart. (For more information on the immune system, see page 27.)

A common symptom of coronary heart disease is **angina** (chest pain). However, some people who have had a transplant may develop coronary heart disease, but may not get angina. This is because transplant surgery removes the nerve supply of the new heart. For more information on coronary heart disease and angina, see our booklet *Angina*.

The most reliable way to detect chronic rejection is by having a **coronary angiogram** – a test which shows where the arteries are narrowed and how narrow they have become. People who have had a transplant usually need to have this test. The number of times you need to have it done varies from one person to another, depending on their condition.

For more information about coronary angiograms, see our booklet Tests.

Chronic rejection cannot be cured, but it can be treated in the following ways:

- Your doctor may need to change your immunosuppressant medicines.
- You may need to take aspirin or anticoagulants to reduce the risk of blood clots forming.
- The doctors may give you treatment for risk factors such as high blood pressure and high cholesterol levels. This is because the arteries become narrow much more quickly in people who have high cholesterol or high blood pressure. It's important to keep your cholesterol level and blood pressure under control. For more information on how to do this, see our booklets *Reducing your blood cholesterol* and *Blood pressure*.
- In a few people, narrowing of the coronary arteries can be treated with coronary angioplasty or coronary artery bypass surgery.
- In a very small number of people, a second transplant may be considered, but this carries a higher risk than the first transplant.

It is extremely important not to smoke, as coronary heart disease develops more quickly among smokers, and it increases the risk of heart attack and stroke.

Infection

Because you are taking immunosuppressant medicines, your body's defence against infection will be lower than normal. It is unlikely that an infection could spread to your new heart, but it is important that you do what you can to avoid getting an infection.

The transplant team will ask you to report any signs of infection. You can talk to your transplant centre about the signs to look out for. You should contact the transplant centre if you have a temperature. If you do get an infection, you may need to take antibiotics, but you should only start taking them after your doctor has tried to identify the cause of the infection. Some antibiotics can interact with your immunosuppressant medicines and they should only be given either by the transplant team or after your GP has discussed this with them.

As the years go by, the risk of rejection becomes much lower and your dose of immunosuppressant can be reduced. Your immune system will gradually become more effective again, but you will still be slightly more at risk of infection than other people.

What you can do to avoid infection

- As far as possible, avoid coming into contact with anyone who has an infectious illness.
- Be careful with personal hygiene, and hygiene of the mouth and teeth.
- Food hygiene is also very important. So be aware of the risk of food poisoning and try to avoid high-risk foods such as raw eggs, mayonnaise, raw or partially cooked meats, pâtés, unpasteurised milk and cheeses, and shellfish. The transplant team can give you more information on this.
- Don't change cat litter trays. (The infection toxoplasmosis is carried by cats.)
- Make sure you keep your pets healthy – wormed and vaccinated. Avoid keeping birds, because of the risk of infection.
- Always wash your hands after gardening or if you have been handling any pets.

Problems with the kidneys

Your kidneys remove waste products, minerals and excess fluids from the blood. These are then transferred to the bladder and leave the body as urine.

Many people who have had a transplant develop some problems with their kidney function after the transplant. This may be because the kidneys are sensitive to changes in blood circulation and to some of the medicines that you need to take, such as ciclosporin and tacrolimus.

The transplant team will monitor how well your kidneys are working and will work with kidney specialists if there is a problem. A small number of transplant patients may have severe long-term problems with their kidneys, and dialysis may be needed. (Dialysis is a treatment which filters your blood to remove waste, salt and extra water.)

High blood pressure

Many people develop high blood pressure after having a heart transplant. It is thought that this is related to the medicines that you need to take.

The transplant team (or your GP or nurse) will monitor your blood pressure and you may need to take medicines to lower your blood pressure.

Diabetes

After a heart transplant some people may develop diabetes. Sometimes this is only temporary and might be brought on by medicines such as steroids. The transplant team will regularly check your blood glucose level to find out if you have developed diabetes, and you will be given advice and treatment if necessary.

Increased risk of cancer

One of the potential complications of long-term use of immunosuppressants is a higher risk of certain forms of cancer. Skin cancer and lymphoma (cancer of the lymph nodes) are the most common, but other cancers can occur. Skin cancer is easily dealt with if treated early, and is rarely life-threatening. Skin cancer is more common in people with sun-damaged skin.

If you get either of these types of cancer, your doctors may need to reduce your dose of immunosuppressant medicines and you may need to have chemotherapy.

The more common forms of cancer – such as cancer of the lung, bowel or breast – are slightly more common in heart transplant patients than they are in other people.

What you can do

To reduce the risk of skin cancer, you should avoid being out in strong sunshine and getting sunburnt. Use a sun block or sunscreen with a sun protection factor (SPF) of 30 or more.

Tell your doctor or nurse about any changes to your skin, or any changes to moles, so that he or she can refer you for treatment if necessary.

Follow the usual guidelines for screening tests for cervical cancer and breast cancer (for women), and testicular cancer (for men).

Your doctors will monitor you very carefully for any signs of cancer. Early detection is very important as this makes it easier to treat the cancer.

For more information about skin cancer, contact Macmillan Cancer Support (phone 0808 808 0000 or website **www.macmillan.org.uk**), or Cancer Research UK (phone 0808 800 4040 or website **www.cancerresearchuk.org**).

British Heart Foundation website

bhf.org.uk
For up-to-date information on cardiovascular disease, the BHF and its services.

Genetic Information Service

0300 456 8383
(A similar cost to 01 or 02 numbers.)
For information and support on inherited heart conditions.

Online community

community.bhf.org.uk
Share your experiences, stories, tips and ideas with other people like you in our online community.

Heart Helpline

0300 330 3311
(A similar cost to 01 or 02 numbers.)
For information and support about your heart condition and keeping your heart healthy.

Twitter

@TheBHF
Get our latest news and views directly into your Twitter feed.

Facebook

facebook.com/bhf
Join the conversation and get our latest news and updates on Facebook.

Booklets and DVDs

To order our booklets or DVDs:

- call the BHF Orderline on **0870 600 6566**
- email **orderline@bhf.org.uk** or
- visit **bhf.org.uk/publications**

You can also download many of our publications from our website. For a list of resources available from the BHF, ask for a copy of our catalogue *Take heart*.

Our resources and services are free of charge, but we rely on donations to continue our vital work. If you'd like to make a donation, please call our donation hotline on **0300 330 3322** or visit our website at **bhf.org.uk/donate**

Heart Information Series

This booklet is part of the *Heart Information Series*. The booklets in this series are:

- Angina
- Atrial fibrillation (AF)
- Blood pressure
- Cardiac rehabilitation
- Caring for someone with a heart condition
- Coronary angioplasty
- Diabetes and your heart
- Having heart surgery
- Heart attack
- Heart rhythms
- Heart transplant
- Heart valve disease
- Implantable cardioverter defibrillators (ICDs)
- Keep your heart healthy
- Living with heart failure
- Medicines for your heart
- Pacemakers
- Peripheral arterial disease
- Primary angioplasty for a heart attack
- Reducing your blood cholesterol
- Returning to work
- Tests

Our services

For more information about any of our services, contact the BHF on **0300 330 3322** or visit **bhf.org.uk**

Nation of Lifesavers

This BHF campaign aims to help save an extra 5,000 lives each year by increasing knowledge of CPR (cardiopulmonary resuscitation) and how to use public access defibrillators (PADs) in an emergency. Join our Nation of Lifesavers at **bhf.org.uk/lifesavers**

- **Heartstart** is a free, two-hour course where you can learn CPR and other emergency life saving skills.
- Our **Call Push Rescue Training Kit** is available free to secondary schools and community groups, and for a small fee to workplaces. It has everything you need to learn CPR, including a training DVD.

Heart Matters

Heart Matters is the BHF's free, personalised service offering information to help you lead a heart-healthy lifestyle. Join today and enjoy the benefits, including Heart Matters magazine and access to online tools.

Call the **Heart Matters Helpline** on **0300 330 3300**, or join online at **bhf.org.uk/heartmatters**

Heart Support Groups

Local Heart Support Groups give you the chance to talk about your own experience with other heart patients and their carers. They may also include exercise classes, talks by guest speakers, and social get-togethers. To find out if there is a Heart Support Group in your area, contact the **Heart Helpline** on **0300 330 3311**.

Make yourself heard – Heart Voices

Heart Voices gives you the skills, confidence and knowledge you'll need to influence health services for the benefit of heart patients and their families across the UK. By signing up, you'll join a network of representatives that speak out on behalf of heart patients and their carers, and get opportunities to have your say. Visit **bhf.org.uk/heartvoices** for more information and to sign up.

For more information on heart transplants

Contact with other transplant patients

Some transplant centres may be able to put you in touch with patients who have had a transplant.

NHS Blood and Transplant

Website: www.organdonation.nhs.uk

Provides support to transplant services across the UK and makes sure that donated organs are matched and used in a fair way. It also provides information and statistics on transplants.

NHS Organ Donor Register

Phone: 0300 123 23 23
Website: www.organdonation.nhs.uk

A register for anyone who wants to donate their heart or other organs after their death.

For information on cardiomyopathy

Cardiomyopathy UK
Freephone: 0800 018 1024
Website: www.cardiomyopathy.org

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HAVE YOUR SAY

We would welcome your comments to help us produce the best information for you. Why not let us know what you think? Contact us through our website **bhf.org.uk/contact**. Or, write to us at:

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Lyndon Place
2096 Coventry Road
Birmingham B26 3YU.

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THANK YOU

This booklet is part of the *Heart Information Series*. We distributed 2 million booklets from this series last year. Without your hard work and support the British Heart Foundation wouldn't be able to provide this vital information for people with heart conditions.

Donate to the fight at **bhf.org.uk/donate**, or text **FIGHT** to **70080** to donate £3 to fund our life saving research.

British Heart
Foundation

For over 50 years we've pioneered research that has transformed the lives of millions of people living with cardiovascular disease. Our work has been central to the discoveries of vital treatments that are changing the fight against heart disease.

But cardiovascular disease still kills around one in four people in the UK, stealing them away from their families and loved ones.

From babies born with life-threatening heart problems, to the many mums, dads and grandparents who survive a heart attack and endure the daily battles of heart failure.

Join our fight for every heartbeat in the UK. Every pound raised, minute of your time and donation to our shops will help make a difference to people's lives.

Text FIGHT to 70080 to donate £3*

**FIGHT
FOR EVERY
HEARTBEAT**
bhf.org.uk

*This is a charity donation service for the BHF. Texts cost £3 + 1 standard rate msg. The BHF will receive 100% of your donation to fund our life saving research.

To opt out of calls and SMS text NOCOMMS BHF to 70060, or if you have any questions about your gift call 0203 282 7863.

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