

Heart transplantation

Heart Information Series Number 13



**British Heart
Foundation**

This is one of the booklets in the *Heart Information Series*. For a complete list of booklets, see page 45.

We welcome your comments on this booklet.
Please fill in the feedback form on page 57.

We update this booklet regularly. However, you may find more recent information on our website
bhf.org.uk.

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About this booklet

This booklet is for people who have had, or are waiting for 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 immediately after the operation.

It also describes:

- the drugs you will be given after the transplant
- life after a transplant
- the long-term outlook for heart transplant patients, and
- the possible complications.

This booklet is not a substitute for the advice your doctor or cardiologist (a doctor who specialises in heart disease) may give you based on his or her knowledge of your condition.

At the end of some sentences there are small numbers like this one.⁸ To find out where we got our information for what we say in that sentence, turn to page 49 and look up the number in the list of *References*.

Introduction

The first heart transplant was carried out in South Africa in 1967. In the UK, transplants are now carried out in six centres around the country – Royal Brompton and Harefield Hospital in London, Papworth near Cambridge, the Queen Elizabeth Hospital in Birmingham, Wythenshawe Hospital in Manchester, the Freeman Hospital in Newcastle, and the Royal Infirmary in Glasgow. Transplants for children are carried out at Great Ormond Street in London, and in Newcastle. Between 150 and 200 heart transplants are carried out in the UK each year.¹

A much smaller number of heart and lung transplants – about 20 – are carried out each year.¹ 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, see the British Heart Foundation information sheet *Heart lung transplants*, or contact the Transplant Support Network. (Their contact details are on page 47.)

Who needs a heart transplant?

Most heart transplants are carried out on people with severe heart failure. Heart failure is when the heart becomes less efficient at pumping blood around the body. The causes of heart failure can be a previous heart attack, coronary heart disease, or cardiomyopathy – which is a disease of the heart muscle. Heart failure may also be caused by severe high blood pressure or by a heart rate that is too fast, too slow, or very irregular. For more information on heart failure, see our booklet *Living with heart failure*.

In a very small number of cases, transplants are carried out on people who have abnormalities of the heart valves, or congenital abnormalities of the heart. (Congenital means that the abnormality was present from birth.)

However, not everyone who has these conditions is suitable for a transplant. And the number of transplants is still limited by the lack of available donors.

How are patients referred to a heart transplant centre?

If you have heart failure, you are probably under the care of a cardiologist. The cardiologist will try the full range of conventional treatment before considering referring you to a 'transplant centre' for a 'transplant assessment'. People are usually referred to the centre that's nearest to where they live.

What does the transplant assessment involve?

If you are referred for a heart transplant, you will need to have a 'transplant assessment'. This involves 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 tests
- urine tests
- tests to find out how well your lungs are working
- tests on the heart – an electrocardiogram (ECG), echocardiogram, coronary angiogram, thallium tests and a biopsy.

You may already have had some of these tests in the past. To find out more about them, see our booklet *Tests for heart conditions*.

The transplant assessment also gives you and your family the chance to meet the members of the transplant team, and to ask any questions. The team includes the transplant specialist or cardiologist, the surgeon, transplant nurses, physiotherapists and psychologists, and a transplant co-ordinator. You may also have the chance to talk to other people who have had a transplant.

Having a heart transplant carries significant risks and the transplant team needs to make sure that the benefits of the transplant outweigh the risks for each person. There may be a reason why a transplant is not suitable for you. The following are examples.

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

As the transplant is a big operation, having another serious condition could affect your recovery. Also, if you have an infection before the operation, it could cause serious complications after the transplant (see page 34).

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

Heart failure may have caused some damage to other organs, particularly the kidneys and the liver. The transplant team needs to find out how well your organs are working before the transplant, and how well they will be able to cope after the operation. It is particularly important that your kidneys work well because kidney damage is a possible side effect of the drug ciclosporin – a drug which helps reduce the risk of your body rejecting the transplanted heart.

Is the pressure in the pulmonary artery too high?

Over time, heart failure can cause a build-up of the pressure in the pulmonary arteries (the arteries that lead to the lungs). Your heart may have coped with this pressure, but a heart from a previously normal donor may have difficulty pumping blood at this higher pressure. During your assessment, the pressure in the pulmonary artery will be measured. If the pressure is too high, it means that a newly transplanted heart is less likely to succeed, and so you may not be accepted onto the transplant waiting list.

The results of the assessment

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

<ul style="list-style-type: none">• That you should go on to the active waiting list.	This means that you may be called for a transplant at any time.
<ul style="list-style-type: none">• That you may be acceptable for a transplant, but that you do not have severe heart failure at the moment.	This means that you will be reviewed regularly and if your condition gets worse, you will go onto the active waiting list.
<ul style="list-style-type: none">• That you need further investigations or treatment before a decision is made.	This may take a few weeks or maybe months.
<ul style="list-style-type: none">• That you are unsuitable for a heart transplant, even if you have heart failure.	This might be for one of the reasons given on pages 9-10. The staff at the transplant centre will give you a full explanation and offer you advice about other treatment options such as medicines or alternative heart surgery.
<ul style="list-style-type: none">• That you should be referred to another centre for a second opinion.	This doesn't often happen, as most transplant centres in the UK have very similar conditions for accepting patients for a heart transplant.

Waiting for a transplant

Once you are on the waiting list, the right heart for you may come along in a few days, or it may take many months or even years. The average waiting time for a heart in the UK is about six months.¹ Unfortunately, suitable hearts do not become available for everyone who is on the waiting list. However, about 7 people in every 10 people accepted onto the waiting list do receive a transplant.²

When you are on the waiting list it is important that you can be contacted at short notice. The transplant centre may give you a bleeper.

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 be very stressful and full of uncertainty. Some people may worry that they

may die if the transplant is not carried out. For advice and support during this time, talk to one of the transplant team or contact the Transplant Support Network. (For contact details see page 47.)

Most transplant centres will want to make sure that, before they do the transplant, you have been treated for any other medical conditions. You will also need to have a dental check-up, to make sure your teeth and gums are as healthy as possible. This is to reduce the risk of infection which could spread to your new heart.

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 has been done. Priority is often given to these patients, who are clearly in much more urgent need of a transplant. Some people may have to spend some of their waiting time in an intensive care unit, especially if drugs have to be used to support the heart.

Left ventricular assist device (LVAD)

Some people may need to have a mechanical pump, called a 'left ventricular assist device' or LVAD, inserted. This helps to support the heart and the

circulation while they are waiting for transplant surgery. The device is removed when the donor heart is transplanted.

Left ventricular assist devices have been developed over the last 30 years for cases where the left ventricle has become severely weakened by disease. There are several different types of ventricular assist devices. One type which is often used is a tiny battery-operated pump that is implanted in the left ventricle of the heart. A fine wire is guided up through the body and connected to a power socket fitted behind the ear. This is joined to a power lead and on to a rechargeable battery which you wear on a belt around your waist.

Having an LVAD inserted involves having surgery and a general anaesthetic. This is a high-risk operation, so it is not suitable for everyone.

Getting the call for a transplant

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 will 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.

When you are admitted to the centre you will be reassessed quickly. Some of the tests that you had at your first assessment may be done again. This is to make sure that nothing new has happened which may make a transplant less likely to be successful.

In the meantime, a separate surgical team will be examining the donor heart. Donor hearts may come from anywhere within the UK or, occasionally, from other countries in western Europe. Hearts coming from a distance are often brought by air. The team will try to reduce the time from removing the heart from the donor and transplanting it to the recipient, as much as possible. However, four to five hours is acceptable.

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, but unfortunately it is unavoidable.

What happens immediately after the operation?

The transplant operation usually takes between three and five hours. 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.

You will have a wound along your breastbone, as the surgeon has to make an incision (a cut) to get access to your chest. 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 medication through small tubes attached to your arms or neck.

Most patients wake the following morning – others take a little longer. You will usually be moved out of the intensive care unit as soon as you are in a stable condition. You may be moved to a high-dependency or a 'step-down' ward. Your visitors may be asked to wear gloves, masks and gowns if there is a particularly high risk of infection.

What drugs will I need to take after the transplant?

You will need to make a lifelong commitment to 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.

Immunosuppressants

All patients need to take immunosuppressant drugs after a heart transplant. These drugs suppress your immune system. (The immune system is the cells and proteins in the blood and tissues that help protect your body against attack from bacteria and viruses or any foreign substances.) You will usually receive the first dose of immunosuppressants during your operation and you will need to take them for the rest of your life. Without these drugs, your body would rapidly recognise the new heart as 'foreign' and attempt to 'reject' it. The immunosuppressant drugs control this rejection by reducing the strength of your immune system. However, they also reduce your body's defences against infection.

Almost all patients will need to take a few of the following immunosuppressant drugs – ciclosporin,

azathioprine, prednisolone, tacrolimus and mycophenolate mofetil. Rejection of the new heart is most likely to happen within the first months after a transplant and during this period you will be given quite a high dose of immunosuppressant drugs. It is during this time that the risk of infection is at its greatest. After this time, your doctors may be able to gradually reduce the dose of some of the medicines.

Ciclosporin

Ciclosporin helps to prevent the body rejecting the transplanted heart. You will need regular blood tests to check the levels of ciclosporin in your blood. The dose is then adjusted to suit you personally. It is important that you take the medicine exactly as instructed.

Possible side effects

Ciclosporin is likely to affect how well the kidneys work in most patients. The doctors will regularly monitor your kidneys by doing blood tests and will reduce your dose if necessary. Other side effects may include hand tremors, high blood pressure and sore gums. There is also a possibility that ciclosporin causes an increased growth of facial and body hair. However, women are advised not to use electrolysis for removing hair as this increases

the risk of infection. You can use hair-removing cream or cosmetic bleach instead.

People who take ciclosporin should not eat or drink grapefruit, as this can increase the level of ciclosporin in your blood. Always check with your doctor or pharmacist 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.

Tacrolimus

This drug is sometimes used instead of ciclosporin and works in a similar way. You will need to have regular blood tests to check the level of tacrolimus in your blood, and your doctors will gradually adjust your dose to suit you. If you are taking tacrolimus, it is important that you avoid eating grapefruit.

Possible side effects

You may get some of the same side effects as for ciclosporin (see page 19).

Azathioprine

Azathioprine is often used together with other immunosuppressants. Azathioprine reduces the

number of white cells that your bone marrow produces. (The white cells are one of the body's most important defence mechanisms against infection and foreign bodies.) Your doctors will monitor the effect of this medicine by measuring your blood-cell count, and will adjust the dose if necessary. This drug may also affect the liver, so you will have regular blood tests to check this.

Possible side effects

A side effect of azathioprine is that it may reduce the production of cells in the bone marrow by too much. This can increase the risk of infection or bleeding. You should report any unexpected bruising or bleeding to your doctor. In some people this medicine can cause nausea, vomiting, or stomach upsets. To help avoid this, take the medicine either with food or just after eating.

Mycophenolate mofetil

This medicine is often used instead of azathioprine. It acts in a similar way and possible side effects are similar. Tell your doctor if you have any unexpected bruising or bleeding. To avoid the risk of getting a stomach upset, take the medicine either with food or just after eating.

Prednisolone

Prednisolone is a steroid drug which is used as an immunosuppressant. This drug is used just before and immediately after the operation to prevent rejection. People usually need to take it for 6 to 12 months after the transplant operation, although some may need to take it for the rest of their life. The dose is gradually reduced over time to a low maintenance dose. Prednisolone is also used to treat acute rejection (see page 34).

Possible side effects

People who take prednisolone tend to gain weight, so it is important to eat a healthy balanced diet. Some people find that they may become 'fuller' in the face. However, this varies from person to person and usually becomes less of a problem when the dose is reduced. Other possible side effects are high blood pressure, swollen ankles (due to water retention), an increased risk of diabetes, mood swings and eye problems. Long-term treatment with steroids can lead to the bones and muscles becoming weak and poor skin healing. So if you need to take steroids for a long time, you may also be given other medicines to protect your bones. You must not stop taking prednisolone suddenly, so make sure you don't run out of tablets.

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. They may disappear with time, and some can be treated with other medicines.

Other drugs

Drugs to lower blood cholesterol

As narrowing of the arteries can affect the coronary arteries of the transplanted heart, it is important to take a cholesterol-lowering drug, even if your cholesterol level is normal. The main type of drug used to reduce cholesterol is a statin. Statins can reduce total cholesterol levels by over 20%.³ However, treatment must be decided together with the transplant team because some cholesterol-lowering drugs interact with some immunosuppressant medicines.

Antibiotics and antiviral drugs

Antibiotics 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 the antibiotic co-trimoxazole long-term to prevent certain types of infection. Your doctor may also prescribe antiviral drugs and other medication to prevent fungal infections of the mouth or throat.

Drugs to lower blood pressure

The combination of ciclosporin and steroids can often cause high blood pressure, so you may need to take drugs to lower your blood pressure.

Diuretics

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

General advice on medicines

- With some drugs it is important to avoid certain foods or drinks. Check the information leaflet that comes with the tablets, or check with your doctor or pharmacist before you start to take 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 medications may cause problems. Ask your pharmacist and transplant team if you have any questions about any herbal medicines.

Life after a transplant

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.

Most heart transplant patients leave hospital two or three weeks after the operation, but some people may need to stay in hospital for longer. For the first month or two after the operation, you will probably have to stay very close to the transplant centre – possibly in a hospital flat or similar accommodation. After this, you will need to go for weekly appointments at the outpatients' clinic. 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.

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 a longer time for you to recover.

It is important to build up your level of activity gradually, starting with walking at home or around

the garden, and then building up to short walks outside. You can do light housework, or light gardening, once you feel fit and able. However, in the first six weeks after your transplant you need to avoid doing any heavy lifting, twisting, pushing and pulling.

About six to eight weeks after the operation, you may be able to start doing things like light vacuuming or washing the car. But remember that your breastbone will not be fully healed until three to four months after surgery, so you still need to be careful.

You will be encouraged to take part in a rehabilitation programme. The aim of this is to get you as fit as possible. The programme will include visits to the gym and supervised exercise. It also offers advice about how to have a healthier lifestyle, and emotional support for you and your partner.

Exercise

Exercise is important to help your heart work better and to make it stronger. It will also help to improve your quality of life – reducing any symptoms you may still have, and helping you to feel better. Because of the surgery, your new heart will beat

faster than before. (It will beat about 110 times a minute, compared with about 70 times a minute before the transplant.) When you exercise, your heart will also respond more slowly than before, and your heart rate may not increase as quickly as before. The physiotherapist at your rehabilitation programme can give you advice about how much and what sort of exercise to do. You will be encouraged to do regular exercise, always starting with a slow warm-up period.

Most 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. However, you should avoid vigorous sports such as squash or weight-training.

Sex

Use the same common-sense approach to having sex again as you do to building up your other general physical activities. You will need to find a position which is comfortable for you, remembering not to put any stress on your chest wound. It helps if the room is warm, and your partner plays a more active role than you. It will also help if you and your partner are relaxed about having sex again.

Healthy eating

It is important that you eat a healthy, balanced diet. People who have had a transplant tend to put on weight, especially if they are taking steroids. Both healthy eating and physical activity will help control your weight. As long as your doctor agrees, it is safe for you to drink a moderate amount of alcohol. However, drinking heavily is not recommended as it could interfere with the absorption of your medication. For more on healthy eating, see our booklet *Eating for your heart*.

Driving

You will be advised not to drive for at least two months after your transplant, but this may vary depending on your condition, so discuss with your doctors exactly when you can return to driving. You don't need to contact the DVLA (Driver and Vehicle Licensing Agency) but you must let your car insurance company know that you have had a heart transplant.

If you drive a large goods vehicle (LGV) or passenger-carrying vehicle (PCV), there are special driving restrictions if you have had a transplant. Ask your doctor or the DVLA about this. Their address is DVLA, Swansea SA99 1TU. Phone: 0870 600 0301.

Holidays

It is generally not recommended to go abroad in the first few months after your transplant. When you are ready to go away, it is important to choose a country with high standards of food and hygiene, and where you will have access to medical treatment, in case you need it.

Vaccinations

It is not safe for you to have some vaccinations (live virus vaccines) because of the immunosuppressant drugs you will be taking. Check with your GP or transplant clinic. However, people who have had a heart transplant are strongly recommended to have vaccinations against flu and pneumococcal pneumonia.

Avoiding infection

Because you are taking immunosuppressant drugs, your body's defence against infection will be low. So it is important that you do your best to avoid infection. For more information on this, see page 38.

In the sunshine

Heart transplant patients have a higher risk of getting skin cancer (see page 41). 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.

Emotional support

Preparing to go home from hospital after a transplant can make you feel 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 often worried or your concerns start to affect your daily life. 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 have mood swings or disturbed sleep in the early days after a transplant. The cause of these might be the high doses of steroids. It is important to remember that the transplanted heart is no more than a

pump and that a transplant does not change your personality or behaviour.

If you have been ill for many years 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.

What is the long-term outlook?

For those people who have a transplant, the long-term outlook is now very good indeed. About 8 in every 10 transplant patients in the UK live for at least three years after the transplant, 7 in every 10 people are alive after five years, and 5 in every 10 are alive after 10 years.⁴

People usually have a good quality of life, especially if the side effects of the immunosuppressant drugs 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 your kidneys
- high blood pressure
- diabetes, and
- a higher risk of some forms of cancer.

Attempts to reject the new heart

Soon 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 18). And, you will need to have regular check-ups to see how well your new heart is performing. 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 drugs 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
- palpitation
- 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 or for signs that your immune system is not working properly 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. 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 within the first year after your transplant. If rejection has

been a particular problem, you would 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 assessment (see page 8).

Chronic rejection

This describes certain changes that develop in the transplanted heart – over a period of several months to many years – which cause a gradual deterioration in heart function and may lead to heart failure. Chronic rejection often affects the coronary arteries of the transplanted heart due to damage to the immune system. (The coronary arteries are the arteries that supply blood to the heart muscle.) The lining of these arteries gradually thickens and eventually the arteries may become narrowed. Transplant surgery removes the nerve supply of the new heart, so you may not get the chest pain (angina) that is a common symptom of coronary disease.

The most reliable way to detect chronic rejection is by coronary angiography – 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.

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

- Your doctors may give you stronger immunosuppressant drugs to try and slow down the process of the arteries narrowing.
- You may need to take aspirin or anticoagulants to reduce the risk of blood clotting.
- The doctors may give you treatment for risk factors such as high blood pressure and high cholesterol. The arteries narrow much faster in people who have high cholesterol and high blood pressure, so it is important to control these very carefully. For more information on how to do this, see our booklets *Reducing your blood cholesterol* and *Blood pressure*.
- You may need medical treatment for heart failure.
- 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 much higher risk than the first transplant.

Infection

Because you are taking immunosuppressant drugs, your body's defence against infection will be lower than normal. An infection could spread to your new heart, so it is important that you do what you can to avoid infection.

Your doctors will ask you to report any signs of infection, and you should contact the transplant centre if you have a temperature. If you do get an infection, you may need to take antibiotics but they should only be started after your doctor has tried to identify the cause of the infection. Some antibiotics interact with the immunosuppressants and in general they should only be given either by the transplant centre or after discussion with the staff at the transplant centre. As the years go by, the risk of rejection becomes much less 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.

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.

- If you need dental treatment, your dentist should give you antibiotics an hour before treatment. This applies to any treatment other than examinations and simple fillings. The dentist should check with your transplant centre which type of antibiotics to give you.
- 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 dietitian in the transplant team can give you more information on this.
- Do not 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.
- Women are advised not to have electrolysis to remove excess hair because of the possible risk of infection.

Problems with the kidneys

Many people who have had a transplant develop problems with their kidneys after the transplant. This may be because the kidneys are sensitive to changes in circulation and because they are

sensitive to some of the medicines that you need to take, such as ciclosporin.

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.

High blood pressure

Most people develop high blood pressure after having a heart transplant. It is thought that this is related to the drugs that you need to take. The transplant team (or your GP) 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 stress and anxiety or by drugs such as steroids. The transplant team will regularly check your blood glucose 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 immunosuppression is a higher risk of certain forms of cancer. About half of these are skin cancers which, if treated early, are easily dealt with and are rarely life-threatening.^{5,6} Skin cancer is more common in people with sun-damaged skin (skin that has suffered in the past from over-exposure to the sun). Another type of cancer linked to immunosuppressant drugs is cancer of the lymph node, or lymphoma. This accounts for a large percentage of cancers in people who have had a transplant.⁷ If you get either of these types of cancer, your doctors may need to reduce your dose of immunosuppressant drugs and you may need to have chemotherapy. Many of these tumours are curable.

The more common forms of cancer, such as cancer of the lung, bowel, or breast, may be slightly more common in heart-transplant patients than they are in the general population.

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 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 early detection of 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.

Your donor

Once you have recovered, it is normal to wonder about your donor and his or her family. Some people may want to write to the family while others prefer not to have any contact. This is a very personal decision. If you do decide you would like to write to the family, discuss it with your transplant team.

A fuller and more active life

Having a transplant can give you a fuller and more active life than before and allow you to benefit from many more good-quality years of life.

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

- If you smoke, stop smoking.
- Do regular physical activity.
- Eat a healthy balanced diet.
- Aim to control your blood cholesterol and blood pressure levels.

For more information

British Heart Foundation website

bhf.org.uk

For up-to-date information on the BHF and its services.

Heart Information Line • 08450 70 80 70

An information service for the public and health professionals on issues relating to heart health.

Publications and videos

The British Heart Foundation (BHF) also produces other educational materials that may interest you.

To find out about these, or to order your

Publications and videos catalogue, or to order publications, please go to **bhf.org.uk/publications**, call the **BHF Orderline on 0870 600 6566** or email **orderline@bhf.org.uk**. You can download many of our publications from **bhf.org.uk/publications**.

Our publications are free of charge, but we would welcome a donation.

Heart Information Series

This booklet is one of the booklets in the *Heart Information Series*. The other titles in the series are as follows.

- 1 Physical activity and your heart
- 2 Smoking and your heart
- 3 Reducing your blood cholesterol
- 4 Blood pressure
- 5 Eating for your heart
- 6 Angina
- 7 Heart attack and rehabilitation
- 8 Living with heart failure
- 9 Tests for heart conditions
- 10 Coronary angioplasty and coronary bypass surgery
- 11 Valvular heart disease
- 12 Having heart surgery
- 13 Heart transplantation
- 14 Palpitation
- 15 Pacemakers
- 16 Peripheral arterial disease
- 17 Medicines for the heart
- 18 The heart – technical terms explained
- 19 Implantable cardioverter defibrillators (ICDs)
- 20 Caring for someone with a heart problem
- 21 Returning to work with a heart condition
- 22 Diabetes and your heart

Heart health magazine

Heart health is a free magazine, produced by the British Heart Foundation especially for people with heart conditions. The magazine, which comes out four times a year, includes updates on treatment, medicines and research and looks at issues related to living with heart conditions, like healthy eating and physical activity. It also features articles on topics such as travel, insurance and benefits. To subscribe to this **free** magazine, call **0870 600 6566**.

Heartstart UK

For information about a free, two-hour course in emergency life support, visit our website at bhf.org.uk or contact Heartstart UK at the British Heart Foundation. The course teaches you to:

- recognise the warning signs of a heart attack
- help someone who is choking or bleeding
- deal with someone who is unconscious
- know what to do if someone collapses, and
- perform cardiopulmonary resuscitation (CPR) if someone has stopped breathing and his or her heart has stopped beating.

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. You may also find it helpful to join a heart support group. A heart support group gives you and your family or friends the chance to meet and talk to others who have gone through similar experiences. At the British Heart Foundation we keep an up-to-date list of all heart support groups in England and Wales which are linked to us. To find out the nearest one to you, call 020 7487 7110.

Transplant Patients' Trust of Great Britain

PO Box 44

Hexham, Northumberland NE47 0YX

Website:

<http://users.argonet.co.uk/body/rmrt/tptgb.html>

The trust aims to provide financial support to transplant patients and their families throughout the UK.

Transplant Support Network

The Temple Row Centre

23 Temple Row, Keighley BD21 2AH

Phone: 01535 210101

Website: www.transplantsupportnetwork.org.uk

The Transplant Support Network is a nationwide network of volunteer transplant patients and their carers, who provide support and information for others coping with transplants.

UK Transplant

Communications Directorate

Fox Den Road, Stoke Gifford

Bristol BS34 8RR

Phone: 0117 975 7575

Website: <http://www.uktransplant.org.uk>

UK Transplant is a special health authority within the NHS which provides support to transplantation 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 Donation Register

Phone: 0845 60 60 400

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

For information on cardiomyopathy

The Cardiomyopathy Association

40 The Metro Centre

Tolpits Lane, Watford

Hertfordshire WD1 8SB
Phone: 01923 249977
Freephone: 0800 018 1024
Website: www.cardiomyopathy.org

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- 6 From: 'Cardiac transplant experience with cyclosporine', by JK Patel and JA Kobashigawa. Published in 2004, in *Transplantation Proceedings*, volume 36/2, pages 323S-330S.
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About the British Heart Foundation

The British Heart Foundation (BHF) is the leading national charity fighting heart and circulatory disease – the UK's biggest killer. The BHF funds research, education and life-saving equipment and helps heart patients return to a full and active way of life.

We rely on donations to continue our vital work. If you would like to make a donation, please ring our **credit card hotline on 0870 606 3399**. Or fill in the form opposite.

We need your help. Please send a donation today.

Please accept my donation of:

£50 £25 £15 £12 Other £

If you are sending a cheque, please make it payable to
British Heart Foundation.

Or, you can ring our credit card hotline on **0870 606 3399.**

I want to donate using: MasterCard Visa CAF Card

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Signed

Date

Name (Mr/Mrs/Miss/Ms/other) _____
Address _____

Phone _____
E-mail _____

Postcode _____

7/2005

Your personal information

The British Heart Foundation will use your personal information for administration purposes, and to provide you with services, products and any information that you have asked for.

We greatly value your support and would like to keep you informed about our work through marketing literature to help us meet our charitable aims. We may contact you by phone or post for this purpose. Please tick the box if you would prefer **not** to hear from us in s this way.

We may want to share information with other organisations that we work with and who support our aims. Please tick the box if you would prefer us **not** to share your details. MP02

Please tick this box if you **would like to** receive e-mail communications about our future activities, at the e-mail address you have provided. MP07

Thank you for your support.

**Please send your donation to:
Supporter Services, British Heart
Foundation, 14 Fitzhardinge Street,
London W1H 6DH.**

Registered Charity Number 225971

Please turn over.

Please tick if you would like us to send you a Gift Aid form to make your donation work harder at no extra cost to you.



Please send me information about the following.

- BHF publications**
- Giving regular donations**
Regular donations through a standing order give us the long-term support we need. Just tick for information on how to set up a standing order.
- Remembering us in your Will**
Many people choose to leave a gift to their favourite charities in their Will. We can send you a useful information pack to tell you how to go about it.
- Local fundraising activities and sponsored events**
- Payroll giving**
How you and your work colleagues can donate from your salaries before tax.
- Buying BHF Christmas cards and gifts**
- Becoming a volunteer in a British Heart Foundation shop**

Please send your form to the British Heart Foundation. The address is over the page.

Technical terms

angiography	A test to show where the arteries are narrowed and how narrow they have become.
biopsy	A procedure in which a small specimen of tissue is taken for examination. The procedure is similar to angiography.
cardiologist	A doctor specialising in heart disease.
cardiomyopathy	A condition in which the muscle of the heart is abnormal, but with no apparent cause.
coronary heart disease	When the walls of the arteries become narrowed by a gradual build-up of fatty material called atheroma.
donor	The person whose heart is given to the transplant patient.
echocardiogram	An ultrasound picture of the heart, which shows the structure of the heart and how it is working.
heart failure	When the heart fails to pump enough blood around the body, either when the person is resting or when exercising.
immune system	A system made up of special cells and proteins in the blood and tissues that help protect the body against attack from infection.

immunosuppressant drugs	Drugs which suppress the body's immune system.
left ventricular assist device	A device used to support the heart and the circulation.
recipient	The person receiving the donor heart.

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Your comments please

We would be very interested to hear your views about this booklet.
Please fill in this form and send it to:

British Heart Foundation

FREEPOST WD513

LONDON W1E 1JZ.

1 How did you get this booklet?

I got it directly from the British Heart Foundation.

My GP or practice nurse gave it to me.

I got it from a display at my GP's surgery or health centre.

A nurse or doctor at the hospital gave it to me.

I got it from a display in a hospital.

A friend or relative gave it to me.

Other (Please give details.) _____

2 Do you find this booklet...

very helpful?

helpful?

not very helpful?

not at all helpful?

3 Do you find this booklet ...

very easy to understand?

easy to understand?

not very easy to understand?

4 What do you think of the design of the booklet (how it looks, the size of the text, the front cover, the size)?

Very good

Good

Not very good

Poor



5 Are there any issues that you need to know about that are not covered in this booklet? If so, what are they?

6 Do you have any other suggestions for how we could improve this booklet?

7 Are you...

...a patient with a heart condition?

...a carer (for example, a relative or friend of someone with a heart condition)?

Other (Please give details.) _____

Acknowledgements

The British Heart Foundation would like to thank all the cardiologists and health professionals who helped to develop the booklets in the *Heart Information Series*, and all the patients who commented on the text and design.

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Heart health is a free magazine produced by the British Heart Foundation especially for people with heart conditions. See page 46 for more information.

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Heart Information Line • 08450 70 80 70

(A local rate number.)

An information service for the public and health professionals on issues relating to heart health.