Patient Information
H09

NHS
Golden Jubilee

Advanced heart failure and transplant patients

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Version 2

About this booklet

This booklet provides you with advice and guidance on your heart transplant surgery.

Advanced heart failure and transplant patients

Advanced heart failure and transplant patients are cared for in the National Services Division (NSD) dedicated units located on level 2 and 3 of the Golden Jubilee University National Hospital (GJUNH).

Ward visiting times

We operate open visiting, at the discretion of the nurse in charge. The hour between 1.30pm and 2.30pm is normally set aside as a patient rest period, with meals served at the following times:

- Breakfast: 8am
- Lunch: 12.30pm
- Dinner: 5.30pm
- Supper: 8pm

We will endeavour to cater for all dietary requirements. Tea and coffee is provided in the main ward area and patients are encouraged to help themselves but please remember any fluid restrictions you may be following.

We aim to make your stay in the ward a pleasant one. If you have any questions or queries, please discuss these with the nurse in charge.

Who do I contact if I need advice?

If it is a medical emergency phone 999.

You can also contact the transplant coordinators and post-transplant nurse on the numbers below during office hours, Monday-Friday 8am-4pm.

Contact numbers

Transplant coordinators:	0141 951 5472 /5023 /5491 /5868
Post-Transplant Nurse:	0141 951 5489

For non-emergencies outside office hours, please contact the ward on: 0141 951 5340.

Transplant clinic

The advanced heart failure and post-transplant clinic is located on the second floor (Level 2) of the Hospital. You will meet with clinic staff prior to discharge from the ward following your transplant to discuss the clinic routine and to provide you with your clinic appointments. Following discharge, the post-transplant nurse will be your first port of call if you have any questions.

Remember!

- Your medication and your medication diary.
- Please bring a drink with you so you can take your medication after your blood tests.
- Your transplant team will give you specific instructions about taking your medication before clinic appointments.

Accommodation

Our Hotel offers a limited number of rooms for patients who live further from the Hospital and relatives of patients undergoing heart transplantation.

Due to the limited availability of rooms, if required, we ask that you book rooms as far in advance as possible.

Please note that availability of rooms may be subject to last minute change depending on transplant activity.

Accommodation is provided on a ‘room only’ basis, i.e. no meals are provided. Please note that any items charged to your room e.g. telephone calls, restaurant meals / drinks must be paid for by you prior to check out.

On occasions you may require to be outsourced to a nearby hotel due to demand or any renovations/ building works.

The hospital dining room is open to all and offers a variety of reasonably priced meals and snacks. Dining room opening times:

- Breakfast from 7.30am – 10am
- Lunch from 12pm – 2pm
- Dinner from 5pm – 7pm

Research

Transplant is a field of medicine in which many studies are currently in progress. During your hospital visits you may be asked by research physicians to participate in current trials. If you are asked, the purpose of research and what it would involve from you will be explained, you can then decide whether this is something you would be happy to take part in.

Getting here

Please refer to the following link for information on how to get to NHS Golden Jubilee:
https://hospital.nhsgoldenjubilee.co.uk/application/files/8715/7676/6060/GJNH_Travel_Guide.pdf

Section 1 – Heart Transplant Assessment

Please bring this booklet with you, along with any questions you may have.

What does it mean to come in for assessment?

Coming to the Hospital for your assessment means that your referring doctor believes you would benefit from other therapies which may include a transplant. The transplant team then invite you to the Hospital to assess your suitability for a possible operation.

No one is accepted onto the waiting list for a heart transplant until their condition has been assessed by the transplant team and reviewed in person by the transplant consultant.

The assessment to determine suitability for transplant usually takes place over 3 to 5 days, however you may be required to stay longer if further tests or treatments are required. Alternatively, you may be asked to return to the hospital for the day as an outpatient and there is also a possibility that tests could be carried out at your local hospital.

During your admission, you will undergo a variety of tests and investigations such as those listed overleaf.

The results are collated and each case is discussed at the regular Transplant Assessment Meeting where the decision is made whether to place patients on the list or to order more tests if this is appropriate. Sometimes alternative treatment may be recommended. If you are not given a decision on your suitability to be placed on the waiting list before you go home, a member of the transplant team will contact you following your discharge.

During your stay the transplant team will ensure that you have the opportunity to discuss the contents of this booklet. Not only does the information enable you to make an informed decision regarding transplantation, but it is also a reference for you and your relatives/carers as you go through the various stages of the transplant process.

The transplant coordinator/nurse will explain the tests as well as guide and support you and your family through the assessment process. They will also ensure that you have the opportunity to ask any questions, meet all the relevant transplant team members and discuss the outcomes of your test results and what they mean to you.

Transplantation is a procedure with significant risks. Everyone who is referred to a transplant unit will be given the same thorough physical and psychosocial assessments to ensure that the procedure is the best option for them. You will only be accepted onto the transplant waiting list if the benefits of surgery outweigh the risks. If you are not accepted, then the medical staff will give you a full explanation and advice on what to do next. In some cases, an adjunctive or alternative therapy may be considered e.g:

- further drug therapy
- cardiac surgery
- circulatory support, e.g. Ventricular Assist Device (VAD), Extracorporeal membrane oxygenation (ECMO) or Intra-aortic balloon pump (IABP).

If any of these are considered a suitable treatment option, you will be provided with further information by the transplant team.

If you are accepted on to the transplant waiting list, you will be reviewed regularly by the transplant team and/or your local hospital. If your condition deteriorates and other body systems, such as kidney function, start to decline you may be required to undergo further treatment to ensure you are fit and well for your transplant operation. If a change in your medical condition adversely affects the chance of transplantation being a success, you may need to be taken off the waiting list either temporarily or permanently.

The aims of the assessment process are:

- to promptly carry out tests and investigations that are required to assess your suitability for transplantation
- to consider alternatives to transplantation where appropriate
- to give you an opportunity to ask questions and gain support
- to help you understand the outcome of the tests and the decision regarding transplantation before discharge or as soon as all test results are available
- to let you know what follow-up arrangements have been made for you
- to let you know whom to contact if you have problems or queries

On occasions there may be an opportunity to meet a patient who has already had a transplant – please let your transplant team know if you think this may be of help to you. If following your assessment, transplantation is not deemed an appropriate option, you may be reconsidered in the future.

Tests and investigations during the assessment period

The transplant team will require the Name, Address and Telephone number of your current:
- NHS General Practitioner
- Referring consultant
- Family/carer contacts

You must be a resident in the UK, Ireland or the Channel Islands.

Below is a list of the tests and investigations that may be included in your assessment. You may have experienced many of these in the past.

The transplant team will explain any you are unfamiliar with:

- height
- weight
- clinical observations e.g. blood pressure
- bacterial swabs
- sputum and urine samples
- chest X-ray
- twelve lead electrocardiogram (ECG)
- echocardiogram (Echo)
- cardiopulmonary exercise tolerance test (CPET)

Blood tests include:

- full blood count
- biochemistry
- infectious diseases and viral screen
- clotting profile
- tissue typing and antibody screen
- blood group

You will be asked to consent to a blood test for HIV, Hep B and Hep C infection, unless this has been obtained previously at this hospital.

Additional tests may include:
- cardiac catheterisation (angiography) – left and/or right heart catheterisation
- endomyocardial (heart) biopsy
- cardiac MRI (magnetic resonance imaging)
- 24 hour ECG (Holter monitor)
- lung function tests
- dental assessment
- bone scan
- dopplers (ultrasound scans of blood vessels)

Remember!
You may have undergone some of these tests recently. It is not uncommon for the transplant team to repeat these for more up to date measurements. At the end of the assessment or soon after, you should know if a transplant is the best option for you and what happens next.

Please note: If you are taking blood thinners such as warfarin, it may need to be temporarily stopped prior to some of the tests. The doctors will give you specific advice. It is important that you follow the individual advice given to you and never stop taking your warfarin without medical guidance.

All patients will see a variety of members from the multidisciplinary team, these may include:

- transplant coordinator/transplant nurse
- nursing staff
- doctors/surgeon/anaesthetist
- dentist
- dietician
- physiotherapist
- occupational therapist

The transplant process can often be an emotional and sometimes difficult experience, as a result, you may see a psychologist as part of your assessment.

Orthotopic heart transplant (the standard operation)

An orthotopic heart transplant is the most common type of heart transplant performed in which the donor heart is put in place of the existing heart.

Survival after heart transplantation

Individual patient risk depends on their medical condition.

There is a continuing risk in the first year and each year thereafter, although, there is no absolute limit on survival.

The transplant team will inform you of the unit's survival figures and discuss your individual risks with you in detail.

The national 1-year survival rate of patients who have undergone heart transplantation can be found in research published by **NHS Blood and Transplant**. Available online at www.organdonations.nhs.uk

The most common causes of death during the first year after surgery are:

- poor function of the transplanted heart
- infection

In the long term, rejection and infection can still occur and there are additional risks caused by:

- chronic rejection of the heart
- kidney failure
- malignancy (cancer)

Please see Section 5: Complications following transplantation for more information.

Section 2 – Before the operation

The waiting list

An up to date list of all patients awaiting transplantation is kept by the transplant team. The length of time you will have to wait for your transplant is determined by the availability of suitable donor organs and relevant matching criteria.

Selection criteria for patients for the waiting list include:

- clinical condition
- specific factors affecting the suitability of a donor organ for you, e.g. blood group, size (height and weight), results of antibody tests and tissue typing.

Whilst you are on the transplant waiting list you will be asked to attend regular clinic reviews where your status on the list will be assessed.

Your referring doctor will still be responsible for your care during this period. If your condition changes, new treatment is started, or if you deteriorate between your visits, you and your referring doctor should keep the transplant team informed.

If there are any changes in your condition whilst you are on the list the doctors may need to re-evaluate your suitability for a transplant and if necessary, remove your name from the list, either temporarily (to allow for your treatment), or permanently. If this happens you will be informed and given an explanation and a follow up plan.

Unfortunately, suitable hearts do not become available in time for everyone on the waiting list. Therefore, some patients will pass away. Whilst this is a very sad reality, it is important that you and your relatives understand this as a possibility.

Coping with life on the waiting list

The transplant coordinators will provide you with an agreement form which will be discussed in depth with you and your loved ones. The agreement form provides specific information in relation to pre transplant, during the surgery and also post-transplant.

Once you have taken time to read the form at home or in the ward, you will then be required to sign it along with a member of your family/friend. The transplant coordinator and one of your doctors will also sign it. You will keep a copy of the agreement form at home which you can refer to at any time, a copy will also be kept in your medical notes.

Undergoing a transplant is a time of great emotional and practical upheaval and many patients experience issues of concern. Time spent on the waiting list is often part of the process patients find most difficult. Patients cope with life on the waiting list in very different ways, some of which can make this time easier for you and your family. Here are some suggestions that may help.

- Make plans for being called for a transplant from as soon as you are on the waiting list (it is never too soon to prepare).
- Whilst on the waiting list, stay as active and mobile as possible. This will help maintain a healthy weight and balanced diet in preparation for your transplant operation, and is more likely to lead to a successful outcome. (See Section 7: Lifestyle for more information on healthy living)
- Keep a bag packed and make clear plans with your family about transport to the hospital for when a donor organ becomes available. If someone is going to drive you, make sure you know their whereabouts and that they know the quickest route to the hospital. Upon listing, the transplant coordinator will discuss your specific travel needs with you.
- Live your life as normal. You should still participate in all your daily activities, whilst ensuring you are always contactable and ready with appropriate travel plans.
- Take time to think through what transplantation means to you and how you and your family will cope afterwards – and seek help if you need it before you receive a transplant.
- To make a Will at the time of transplantation is difficult so you may wish to consider preparing a Will beforehand.

To help the transplant coordinators, remember the following:

- They will need your home, work and mobile telephone numbers so you can be contacted at any time of day.
- If you are admitted to another hospital, make sure that a member of the hospital’s staff or a family member/friend makes the transplant team aware of this.
- Keep the transplant team updated on your condition, e.g. health, weight etc.
- You also need to inform the transplant team if you are away for the weekend or on holiday.

Remember!
As much as possible your life must go on as normal. You should make sure that daily activities continue, but also that you can be contacted 24 hours a day and that you have made appropriate travel plans when an organ becomes available.

Remember!
Whatever the problem, do not sit and worry about it. You can contact the transplant team for support and advice.

Admission for the transplant

When you receive the call from the transplant coordinator you will need to get to the hospital safely and in the shortest possible time. Therefore, it is important to discuss with the transplant coordinator what your travel arrangements are going to be during your assessment admission.

If you are called to come in for a transplant, these are the important things to remember.

- Do not eat or drink from the time of the call, unless otherwise advised.
- Bring all your current medicines, plus your partner’s if they are coming with you.
- Do not bring excess money, valuables or sentimental belongings with you.
- Bring a bag containing essential toiletries and overnight items, e.g. night clothes and light, comfortable shoes and clothing. It is a good idea to have this already packed in advance.

When you arrive at the hospital

This could be any time. The coordinator will tell you on the telephone which ward you are going to be admitted to, it is usually our NSD ward on level 3. After your operation you will go to our ICU Unit (ICU).

When you arrive on the ward

By the time the donor organ arrives at the hospital you need to be as prepared as possible so that the surgeons can proceed with minimal delay. Your arrival on the ward and transfer to theatre can feel rather hurried. This is normal but make sure you ask the transplant team if you have any questions or concerns. Your transplant coordinator and ward staff will keep you as up to date as possible throughout the journey.

A doctor will perform a physical examination and discuss any relevant or new medical problems. The doctor will discuss the operation again and then you will be asked to sign the consent form(s).

The nursing team will carry out a number of tasks including checking your:

- temperature, pulse and blood pressure readings and oxygen saturation
- MRSA screening
- urine/sputum sample
- height and weight
- blood samples
- chest x-ray and ECG
- shower and shave

You may also be seen by an anaesthetist and, if there is time, may be given a premedication to make you sleepy, this can make your mouth feel dry. You will then be started on immunosuppressant medicines (also called anti-rejection medicines).

Remember!
You will continue to take immunosuppressant medicines after your operation and this will need to be continued for the rest of your life.

Other issues

Cancellation of the transplant

Occasionally when the retrieval surgeons assess the heart at the donor hospital it can be found to be unsuitable. Although this is extremely distressing and disappointing, your operation may have to be cancelled and you should be prepared for this possibility. (Although very rare, you may even have been anaesthetised by this time). The transplant team only want to give you an organ that has a high chance of functioning well.

The transplant may also be cancelled if, on arrival at the hospital, you have a high temperature, or very abnormal blood results. If this happens the transplant team may keep you in hospital to treat or re-asses.

Section 3 – During and after the operation

Operating theatre

While you are in theatre you will be given a general anaesthetic and the team will start to prepare you for the operation, monitoring you carefully at all times.

Before your own heart is removed the surgeons will put you on a heart/lung bypass machine. This machine pumps oxygen rich blood to all your vital organs during the operation, taking over the work of your heart and lungs.

During your operation, support will be given to your family. The transplant coordinator/ ward nurse will be available to keep relatives updated during the operation.

Pain control

There are many ways to ensure that pain is controlled, such as administration of intravenous analgesia or oral medicine. Your pain control requirements will be constantly assessed and managed accordingly.

You will have an incision along the length of your sternum (breast bone) called a sternotomy. Your wound will be closed with surgical glue or sutures (stitches) and covered with a dressing. Your resulting scar should eventually look like a fine line.

On occasions some individuals may have problems with wound healing resulting in excessive scar tissue (known as keloid scarring). If this occurs the transplant team and tissue viability team will review the scarring regularly.

Possible complications during the operation

Unexpected poor function of new organ(s)

Although all organs to be transplanted are carefully checked by the team prior to transplant, in some cases the new organs do not perform as well as expected. There is not always a clear explanation for this. This can lead to serious complications, a prolonged stay in ICU, and in some cases patients do not survive.

Excessive bleeding

During the operation there is a risk of bleeding. There is a greater risk of bleeding if you have had previous chest surgery. In the event of excessive bleeding after your operation you may need to return to theatre for further surgery.

Remember!
If you would like to know more about the operative procedure, then please ask a member of the team.

The ICU Unit

After the operation you will be transferred to ICU. The transplant coordinator will advise your family of the best place to wait.

The ICU can be a busy and daunting place, but the nurses caring for you are specially trained and will do everything they can to make sure you are kept comfortable in the post-operative period.

The number of visitors is kept to a minimum to reduce the risk of infection and ideally one member of your family would be advised to organise this with the ICU staff to save a high volume of phone calls from various friends and family.

On your immediate return from theatre, you will be deeply asleep.

As you will be unable to breathe unaided at this time and will be supported by a breathing machine, called a ventilator. To connect you to a ventilator you will have a tube, called an endotracheal tube (ET tube), placed into your mouth and down your windpipe making you unable to talk. You will also be attached to a heart and blood pressure monitor.

All patients who have had a heart transplant will have a minimum of 2 chest drains that will remove any blood collected at the site of the operation. These are removed when the bleeding has subsided. Whilst you are unable to eat and drink, food and fluids will be provided through a feeding tube or an intravenous infusion (also called and IV or a ‘drip’). This may continue until you are able to eat and drink enough yourself. To assess your urine output, you will have a urinary catheter in place that will continuously drain urine from your bladder.

You will also have 4 ‘pacing’ wires in your chest, which may be connected to a ‘pacing box’. These are temporary wires that may be used in the early stages following the transplant to keep your new heart beating strongly and regularly. For some patients a permanent ‘pace-maker’ may need to be inserted.

When your condition is considered stable, the medical team will reduce the sedation that is keeping you asleep. This will allow you to wake up and breathe for yourself. When you are finally disconnected from the breathing machine, you will be able to speak and, in time, have a drink.

It is worth knowing that most people who have spent time in ICU do not remember much about this initial period. This is due to the medicines that you have been given to keep you asleep and free from pain. However, some people have vivid hallucinations, which can be distressing. This is not unusual, and the hallucinations reduce (in both intensity and frequency) with time. You may want to talk the nursing staff if this happens to you.

How long will I be in ICU?

The length of stay will vary for each patient ranging from days to weeks and sometimes even months depending on your condition. As your stay in ICU may be difficult to predict, your relatives should prepare themselves for this.

Physiotherapy

The physiotherapist will see you in the ICU to help you do breathing and leg exercises. Physiotherapy is a vital part of your rehabilitation and this will start from day one after the operation. When you are transferred to the transplant ward you will be encouraged to become progressively more mobile. You should be able to walk the length of the ward corridor and climb a flight of steps before discharge home.

Visitors

In ICU visitors are limited to immediate next of kin with a maximum of 2 visitors at a time. It is not recommended that babies and young children visit you in ICU. This is to protect you, and them, from the risk of infection. The staff will ask your visitors to wash their hands on entering and leaving the ward to reduce the risk of infection.

It is helpful to have 1 key person who will inform the rest of your family and friends about your progress to avoid you and the nursing staff being disturbed by frequent telephone calls.

Fresh flowers and plants are not allowed in ICU and are not recommended on the wards because of the risk of infection.

The ward

When you no longer require ICU, you will move to the NSD ward. Whilst most of the monitoring equipment will have been removed, you may still have a cardiac monitor and a urinary catheter, and may have chest drains and intravenous infusions (drips) that were mentioned earlier. Over the following days these will gradually be removed as your condition improves. You will be encouraged to eat, drink, move about and take care of your own needs as you progress.

Unlike ICU, the nurse who is looking after you will have other patients to care for as well. You may feel a little unsettled to begin with, but remember you would not have been moved to the ward unless your condition was progressing as expected.

Visiting may be restricted for the first week after the transplant. It is important that you understand this and discuss it with your family before you have your operation. The transplant coordinator and nursing staff will be happy to discuss this in more detail.

Your transplant team may like a close member of your family, a friend or your carer to be with you intermittently during your stay. This person will be encouraged to participate in your care so that by the time you go home you will both feel more confident about what to do and how to avoid and manage complications. Amongst other things, these will involve learning about how and when to administer your new medicines.

Remember!
You will need to take immunosuppressant medicines and other medicines for the rest of your life. These medicines will help prevent the risk of rejection and reduces the risk of complications. Taking immunosuppressant medicines helps to prevent your body from rejecting your new heart, and reduces the risk of complications.

It is usually not long before you will be up and dressed and feeling quite well. However, it is important not to overdo it, as you will feel tired. The nursing staff will discuss the need for rest periods with you.

If for whatever reason you are not feeling well, or are experiencing strange emotions and need to talk to someone about your feelings, please let the nursing staff/transplant team know.

Clinical Trials

A clinical trial is a research project, involving patients or healthy individuals, to test new or different types of treatment or medicine. Before new medicines are tested in clinical trials, they are thoroughly tested in a laboratory. It is only when this research shows that they are likely be effective and are not likely to cause serious side effects, or too many mild side effects, that they will progress to the stage of a clinical trial.

If a number of trials show a new treatment is better than those already available, it will become the new standard treatment. This may benefit you and future transplant patients.

Your unit may be taking part in a clinical trial. If appropriate, the transplant team may ask you if you want to take part. They will explain the details of the clinical trial and what it might mean for you. You should not feel under pressure to agree to take part. You will need to be fully informed and sign a consent form to be included in a trial.

Remember!
You have every right to refuse to take part and it will not affect the care you receive.

Section 4 – Your medicines

A lifetime commitment

Keeping yourself and your new heart healthy will require a life-long commitment. The transplant team will continue to give you information and support as they also have a commitment to you, but you will need to always keep your clinic appointments, exercise regularly, watch what you eat and drink, and never smoke.

Adherence to the drug treatment and follow up programme is essential to ensure the best chance of a successful transplant.

Remember!
Most importantly, you will need to take your medicines each and every day and in the exact way the doctors/nurses tell you. Never stop taking your medicines even if you feel well. You are always at risk of rejecting your transplant. To help prevent rejection you need to take the immunosuppressant medicines that have been prescribed for you every day and exactly as your transplant team have told you to.

Self-medication

Establishing a routine and taking your medicines exactly the way you are instructed is vital. Not taking your medicines at the right time and in the correct amount is 1 of the common reasons for transplant failure.

You are responsible for making sure you do not run out of your medicines. You can contact the transplant team for advice in an emergency.

To help you and your carer in the process of self-medicating, you may be given a book which is referred to as a ‘personal medication record’.

This is a diary where you should:

- record all your medicines, the dosage and times to take them
- record your daily temperature and weight, and
- record any concerns or anything significant that you feel needs to be recorded.

You will be taught about all the medicines and their side-effects, and you will learn to take them unsupervised whilst in hospital. You will then be able to continue this on discharge. Always bring your diary and medicines every time you go to the hospital.

In the interest of safety, your medicines must be locked in the boxes provided whilst you are in hospital.

What medicines will I take?

You will have to take medicines to keep you healthy and prevent infection. You must always take your medicines as you have been instructed. Here are some important points to remember about your medicines.

- The medicines and doses have been carefully selected for you. You must follow the instructions very carefully.
- Never miss a dose or change the amount you are taking unless you are instructed to by your transplant team.
- Not taking your medicines at the right time and at the correct dose can cause transplant failure.
- Certain food products can interfere with your drug therapy, e.g. grapefruit and grapefruit juice.
- Always make sure that anyone treating you is aware of all the medicines you take
- Make sure you get new supplies of medicines before they run out and if you are going abroad make sure you have extra supplies in case any unforeseen circumstances arise
- All medicines have side-effects, some minor and some more unpleasant. If you are troubled by side-effects talk to the transplant team
- You will be given a personal medication record, listing all the medicines you must take to provide an ongoing record of your treatment.

- Always ask the transplant team before taking any:
    - non-prescription medicines, such as aspirin and other pain killers
    - herbal remedies i.e. St John's Wort
    - medicines not prescribed by the transplant team (including your GP and local hospital)

Immunosuppressant (anti-rejection) medicines

Drug therapies change as new research is carried out. This section is not an exhaustive list of all drugs you will be taking but a guide to the main ones. The transplant team will explain additional information to you.

Your immune system is the body's main defence against disease and is composed of many different types of cells. Some of these cells attack and destroy bacteria and viruses that invade your body; other cells help your body become 'immune' (resistant to disease). Unfortunately, the body is unable to tell the difference between a 'foreign' virus and your newly transplanted heart. To try and stop your immune system from destroying the transplanted organs you will take immunosuppressant medicines for the rest of your life.

These medicines help to stop your body from rejecting your new organ, but also increase the risk of infections and may cause other side-effects. The risk of developing certain cancers may also be increased.

The increased risk of skin cancer can be reduced by avoiding sunlight exposure. Keep your skin covered as much as possible when in the sun and always use a lotion with a high sun protection factor. Report any changes in freckles or moles immediately. You are also advised against the use of sun beds.

There are a number of immunosuppression medicines – you will have to take about 3 of these. A combination will be chosen to suit you but will usually include: neoral or prograf, mycophenolate mofetil or azathioprine, and prednisolone.

Remember!
It is extremely important that you always take the same immunosuppressant medicine given to you by your transplant team. Take it at the exact dose and frequency as they have told you to. You should check with your transplant team if you are not sure of any details.

Only your transplant team should make changes to your immunosuppressant medicines (including the brand name, type and colour). If you are given an immunosuppressant medicine with a different brand name, you should ask why. You should tell your transplant team immediately about the change in your medicine and get their advice before you take it.

Listed below are some of the medicines you might be prescribed along with some of the side effects.

Prograf

Prograf is an immunosuppressive drug. It requires regular blood tests to check the level in your blood. The dose is then adjusted personally over a period of time and so it is important to take it exactly as you have been instructed.

There are several types of prograf available. It is very important that you do not change from one form to another unless a transplant doctor tells you to. Always tell your pharmacist which one you are taking.

Prograf should be taken on an empty stomach – either 1 hour before you eat or drink, or 2 to 3 hours afterwards – as food can reduce the amount of drug that is absorbed into your bloodstream. Be consistent.

Do not drink grapefruit juice or eat grapefruit while you are on prograf as it can increase prograf levels.

Some other medicines can increase or decrease your prograf levels and so put you at risk of rejection or side-effects. Always check with the transplant team before taking any new medicines, including anything bought over the counter!

Side-effects of prograf include:

- tremor (shakiness) in the hands and muscle cramps – drinking orange juice or tonic water can help reduce cramp pain
- upset stomach (initially)
- headaches
- sleep disturbance
- mood changes
- increase in blood pressure
- increase in blood sugar (diabetes) can also occur – this will be monitored via a blood or urine test
- increase in cholesterol
- hair loss
- decrease in kidney function – the dose is adjusted over time to minimise this problem
- gout (swollen, hot or painful joints)

Some of these side-effects will disappear with time and some can be treated with medicines.

Neoral

Neoral is also an immunosuppressive drug which requires regular blood tests to check the level in your blood. The dose is then adjusted to suit you personally over a period of time and it is important that you take it exactly as you have been instructed.

There are several types of neoral available. It is very important that you do **not** change from 1 form to another unless a transplant doctor tells you to. Always tell your pharmacist which one you are taking.

- The dose is taken twice daily at twelve hourly intervals, as directed.
- Neoral is available as capsules or liquid.
- Neoral capsules should not be removed from packaging until you are ready to take
- Do not drink grapefruit juice or eat grapefruit while you are on neoral as it can increase neoral levels in an unpredictable manner.

Herbal products are not tested for purity or potency and may cause problems, always check with a doctor or a pharmacist before taking e.g. St John’s Wort, as preparations can alter neoral levels in an unpredictable manner and hence should be avoided.

Some other medicines can increase or decrease your neoral levels and so put you at risk of rejection or side-effects. Always check with the transplant team before taking any new medicines, including anything bought over the counter.

Side-effects of neoral include:

- a slight shaking of the hands, and muscle cramps (drinking orange juice or tonic water can help reduce cramp pain);
- hot tingly hands and feet (usually during the first week of treatment);
- increased body hair. Women are NOT advised to use electrolysis or wax, as it can increase the risk of infection – use a hair removing cream or a cosmetic bleach;
- swollen or bleeding gums. Good oral hygiene may help to prevent this. You should also see a dentist regularly;
- nausea and vomiting;
- gout (swollen, hot or painful joints) – there are medicines to treat this;
- high blood pressure – can be treated with 'anti-hypertensive' medicines;
- decrease in kidney function – the dose is adjusted over time to minimise this problem; and
- increase in cholesterol.

Sirolimus

Sirolimus is an immunosuppressive drug used either as an additional immunosuppressant medicine in cases of persistent rejection or chronic rejection, or as an alternative to neoral or prograf, in cases of kidney impairment. It also requires regular blood tests to check the level in your blood. The dose is then adjusted personally over a period of time and so it is important to take it exactly as you have been instructed.

- Sirolimus is available in tablet form, and as a solution.
- The solution should be diluted with water or orange juice before drinking. No other liquids, including grapefruit juice, should be used.
- Sirolimus is taken once daily, at the same time each day. It should be taken consistently either with or without food. If you are still taking neoral the doses should be separated by 4 hours.

Side-effects of sirolimus include:

- abdominal pain, diarrhoea
- acne
- increase in cholesterol
- decrease in white blood cells and/or platelets which puts you at risk of infection and bleeding
- abnormalities in liver function tests, although these are usually mild

Mycophenolate mofetil/mycophenolic acid/mycophenolate sodium (MMF)

Mycophenolate mofetil is an immunosuppressive medicine. The dose is usually taken as a fixed dose.

- Mycophenolate is available as a liquid, capsules or tablets.
- Regular blood tests are undertaken and the dose of mycophenolate altered accordingly.
- The capsules and tablets should be swallowed whole, and taken as directed.
- Take with or after food to reduce the chance of stomach upset.

Side-effects of Mycophenolate mofetil/mycophenolic acid/mycophenolate sodium

include:

- upset stomach including diarrhoea, nausea and vomiting – minimised by taking with food
- mycophenolate can also cause blood disorders which puts you at risk of infection and bleeding. You should report any unexpected bruising or bleeding.

Azathioprine

Azathioprine is an immunosuppressive drug used as part of a combination regime. Regular blood tests are undertaken and the dose of azathioprine altered accordingly.

Immediately after transplantation it can be given either as an injection or as a liquid preparation, but may be changed to a tablet form as soon as possible.

It is usually taken once a day in the evening, with or after food to reduce the chance of stomach upset.

You should never try to break the tablets as the small amount of dust created can harm you and those around you.

A medicine used to prevent gout, called allopurinol, interacts with azathioprine and when used together your azathioprine dose will need to be reduced by your transplant team.

Side-effects of azathioprine include:

- nausea, vomiting and diarrhoea (minimised by taking with food)
- liver disorders – this is monitored by blood tests
- blood disorders which puts you at risk of infection and bleeding - this is monitored by blood tests. You should report any unexpected bruising or bleeding.
- rarely, rashes and hair loss can also occur

Steroids

Prednisolone, methylprednisolone and hydrocortisone are steroids which are each used as immunosuppressant's and are very different to the steroids used by bodybuilders.

- Methylprednisolone is usually used just before and immediately after the transplant to prevent early rejection.
- Methylprednisolone can also be used to treat acute rejection with daily injections on 3 consecutive days.
- Methylprednisolone is normally followed by a high dose of prednisolone tablets. The dose is gradually reduced over time to a low 'maintenance' dose. This is continued for at least six months after transplantation and forms part of the long term treatment programme for many patients.
- Prednisolone is available as tablets.
- Prednisolone is usually taken as a single dose in the morning with or after breakfast to reduce the risk of stomach irritation.
- You must never stop taking prednisolone abruptly and never run out of tablets.
- When you start taking prednisolone you may be given a 'steroid card' that has information about this medicine on it.
- Hydrocortisone is given as an injection and may be used as an alternative to prednisolone if patients are unable to take tablets by mouth.

Side-effects of steroids include:

- high blood pressure and swelling of the ankles and legs as water is retained
- muscle wasting
- osteoporosis (weak bones) – this can occur after a long time on steroids
- stomach upsets and indigestion – this can be reduced by taking the tablets with or after food
- fullness of the face – this varies from person to person and normally becomes less of a problem when the dosages are reduced
- increased appetite – watch your weight carefully and eat a healthy diet
- skin changes – healing of wounds may take longer than usual, skin may become thinner which can lead to bruising more easily and acne may occur
- increased blood sugar (diabetes) – this will be monitored via a blood or urine test
- mood swings may occur and you may experience periods of feeling depressed or tearful
- eye problems – if you notice any visual changes or have sore eyes let your doctor know, and
- increased risk of infection as signs and symptoms of infection may also be hidden by steroids.

Anti-infectives

The immunosuppressant medicines help to stop your body from rejecting your new organ but also make you less able to fight infections. To try to prevent various infections occurring a combination of anti-infective medicines may be used. Some are to fight off bacterial infections (antibiotics), some fight against viruses (antivirals), and some to fight fungal infections (antifungals).

Co-trimoxazole

Co-trimoxazole is an antibiotic. It is used at a very low dose to prevent a type of pneumonia called pneumocystis. It is taken once daily as directed.

Side-effects can occur even at low doses and can also include nausea, sickness and occasionally skin rashes. Co-trimoxazole can also cause blood disorders although this is rare. If co-trimoxazole is not tolerated then an alternative such as trimethoprim, pentamidine (nebulised), or dapsone may be used.

Ganciclovir/Valganciclovir

Ganciclovir/valganciclovir capsules are used to treat or prevent cytomegalovirus (CMV) infections in a number of susceptible patients. You may be prescribed either ganciclovir or valganciclovir depending on your clinical need.

Side-effects include blood disorders (these are monitored closely), suppression of fertility (in both men and women), nausea and vomiting, headaches, also abdominal pain and constipation have been reported.

Nystatin

Nystatin is an antifungal drug used to prevent fungal infections of the mouth and throat. It can be given as a lozenge or mouthwash.

Other medicines

Listed below are examples of medicines that may be prescribed but this is not an exhaustive list. Speak with your transplant team if you would like further information.

Anti-hypertensive medicines

These medicines are used to lower blood pressure.

Osteoporosis prophylaxis
There is a selection of medicines used to help prevent osteoporosis. Their use is particularly relevant to patients who have been, or are, on steroids. Some may be given as a tablet and some as an IV infusion. If these medicines are appropriate for you, you will be given more information.

Painkillers
Most patients experience some discomfort after the operation and there are a number of painkillers which can be used to help during this period.

Diuretic medicines (water tablets)
These medicines help your body get rid of excess water. You will pass extra urine after taking these tablets.

Lipid lowering medicines
These are used to lower cholesterol.

Anti-ulcer/reflux medicines
Prednisolone can increase the risk of developing stomach ulcers. These medicines reduce the amount of acid in the stomach and can help prevent and treat ulcers.

Anti-emetic (anti-sickness) medicines
Many medicines can cause nausea and vomiting. Some people also find they feel sick after an operation as well. This group of medicines can be used to relieve the sickness.

Miscellaneous

Allopurinol
Some immunosuppressant medicines and diuretic medicines can increase the risk of developing gout. Allopurinol may be used to help prevent gout.

Laxatives
Constipation can occur as a side-effect of other medicines, or if you are not as mobile as usual or if the amount of fluid you drink is restricted. Laxatives help relieve constipation but possible side-effects include stomach cramps.

Remember!
Many medicines interact with immunosuppressant medicines. You should always check with your transplant team to make sure it is safe to take other medicines as well as your immunosuppressants.

Medicines to avoid

Over the counter (OTC) medicines (medicines you can buy without a prescription)

There are a number of medicines and products that are available to patients without prescriptions which should be avoided. These include aspirin, and aspirin-like drugs: e.g. ibuprofen (also known as Nurofen, Cuprofen, Advil). These can cause a marked deterioration in your kidney function.

Remember!
It is important that you check that cold remedies and painkillers contain paracetamol instead of aspirin. It is also important not to exceed the maximum paracetamol dose per day.

You may have been given low dose aspirin (75-150mg daily) for thinning the blood. This low dose does not have any effect on your kidney function and so must be taken as prescribed for you by your doctor.

Always check with the transplant team before taking any products in case they contain any hidden aspirin or aspirin-like drugs.

Herbal medicines

Unlike conventional medicines herbal products are not usually tested for purity, some can cause problems. There is limited guidance on the interactions with herbal products, however, St John's Wort is a herbal remedy which has become increasingly popular as a remedy for mild depression. This has been shown to interact with some immunosuppressant medicines and **must be avoided.**

Remember!
Always check with the pharmacist and the transplant team before taking any non-prescription medicines or herbal remedies.

Other medicines (from your GP) e.g. Certain antibiotics

Because certain medicines can interact with your immunosuppressant medicines, it is important that new medicines are discussed with your transplant team. Your own doctor will be sent a list of the common drugs which can cause problems. However, you must contact the transplant team before taking any other medicines.

A number of other medicines may be used to treat individual problems. When you start on your transplant medicines you may have other questions. The transplant team will be happy to answer these for you.

Treatment and therapy will change over time as more is learned from research and as medical teams gain more experience. Having a transplant is uniquely individual to each patient. Your treatment and drug dosages may be quite different from another patient who has had the same operation as you.

Remember!
Always take the medicine that you have been prescribed and read any instructions carefully. Never take anything (even prescribed by your GP) before double checking with the transplant team.

If you obtain any of your medicines from the transplant unit, please ensure that at least 2 weeks' notice is given for repeat prescriptions.

Some medicines are available as a liquid suspension. Please ask the transplant team for advice.

Vaccination Requirements for Transplant Patients

Recommended post-transplant

- pneumococcal polysaccharide vaccine to help prevent pneumococcus infections such as pneumonia and septicaemia, and
- annual influenza vaccine to help prevent flu.

Not all vaccines can be given to transplant recipients and care needs to be taken to avoid the live vaccines.

Below is a list of vaccines which can and cannot be given to transplant recipients:

Vaccinations which **can** safely be administered:

- Cholera

- Diphtheria
- Inactivated Polio (IVP, SALK)
- Influenza
- Haemophilus Influenza Type B (Hib)
- Pneumococcal polysaccharide
- Hepatitis A
- Hepatitis B
- Normal Human Immunoglobulin
- Pertussis (gammaglobulin, kabiglobulin)
- Rabies
- Tetanus – absorbed
- Typhoid (typhoid/VacA – killed organism)
- Typhoid (Vi Polysaccharide – Typhim Vi)
- Meningococcal (C, and A&C)
- Meningococcal Polysaccharide
- Pertussis / whooping cough

Vaccinations which are unsafe and **cannot** be administered:

- BCG (Bacillis, Calmette-Geurin)
- MMR (measles, mumps, rubella)
- Measles
- Mumps
- Oral polio (OPV, SABIN) – including household contacts
- Oral typhoid (Vivotif)
- Rubella
- Smallpox
- Yellow Fever

Remember!
All vaccines (except ‘passive vaccination’ with immunoglobulin preparations) may be less effective in the immunosuppressed patient.

Oral polio vaccine should not be administered to household contacts (people you live with) as transmission of the live virus through faeces is possible (people you live with should use the SALK inactivated polio vaccine).

Family members can receive vaccination from the ‘unsafe’ list above, however, you must take care not to be exposed, for example through cleaning the toilet or changing nappies. If you need to change your baby’s nappies, you should wear protective gloves for at least six weeks after your transplant.

If you come into contact with chicken pox and you have not had it before, or are not sure if you have had it before, you should contact the transplant team as you may require treatment with immunoglobulin.

Section 5 – Complications following transplantation

This following section covers the most common complications following transplantation, how these are diagnosed and treated. If you wish to talk about these issues further, or about your progress in general, please speak to a member of the transplant team who will be pleased to answer your queries.

The most common complications include:

- rejection
- infection
- kidney problems
- heart dysfunction
- hypertension
- diabetes
- cholesterol problems

Rejection following heart transplantation

Rejection episodes are unpredictable in frequency and severity. Some will experience one or more episodes at some time after the operation. To minimise the risk, it is important that you take your medicines every day in the exact way you have been taught. Rejection can be classified as acute, chronic or antibody mediated.

Acute rejection following heart transplantation

Acute rejection episodes (when rejection comes on quickly) are common in the first year after transplantation and should be expected. Provided that you have been adhering to your medicines and the rejection is picked up early, most rejection episodes can be effectively treated.

Acute rejection must be detected and treated early to help prevent irreversible damage. Always contact the transplant team if you ever think that you are experiencing signs of rejection. Acute rejection occurs most frequently in the first year.

Warning signs of possible acute rejection include:

- ‘flu-like’ symptoms, chills and aches
- unexplained tiredness, or an inability to perform physical activity which was tolerated previously
- shortness of breath or difficulty breathing
- fluid retention - common signs of this is ’puffy ankles’, feeling bloated, sudden weight gain i.e. 2kg over 24 hours or a consistent rise in weight over a few days
- change in heart rhythms (palpitations)
- mildly raised temperature (above 37.5^{o}C)

Remember!
Acute rejection can come on suddenly. The sooner it’s spotted and treated the more likely it is that no permanent damage will be done to your heart.

Diagnosis of acute rejection

To detect rejection before you experience obvious symptoms, you will undergo a series of routine examinations and investigations at set intervals after the transplant, usually as an outpatient.

These may include:

- physical examination
- review and history of symptoms
- blood tests
- chest X-ray
- electrocardiogram (ECG)
- echocardiogram (Echo)
- endomyocardial (heart) biopsy

Endomyocardial (cardiac) biopsy

Biopsies are a routine part of medical follow-up after heart transplantation and the risk of a serious complication is small, however, as with any invasive procedure, problems can arise. Biopsies are performed because of the risk posed by rejection to the function of your transplanted heart, although other tests may give your transplant team clues that you are experiencing rejection, there is no satisfactory alternative to cardiac biopsy to make an early and definite diagnosis of rejection.

This procedure is carried out under X-ray control. After a local anaesthetic, the doctors will insert a small tube into a vein in your neck, or occasionally your groin. A sampling device (called a Bioptome) will be used to take samples of tissue (2-3mm) from your heart. Most patients find this procedure slightly uncomfortable, but not painful. If you are nervous or find this procedure uncomfortable then please discuss this with your nurse or doctor.

In the laboratory the tissue sample will be examined under the microscope and the results are usually available within 24 hours. The information gained enables your transplant team to detect rejection and ‘grade’ the level of rejection that you are experiencing. They can then select the most appropriate and effective treatment for you.

Other things to remember about the biopsy include:

- You do not routinely need to fast before this procedure (unless you are instructed to fast by the nursing/medical staff).
- The biopsy is usually undertaken as an outpatient once you have been discharged.
- Additional biopsies may be performed if you are clinically unwell following a course of anti-rejection therapy.
- You may require weekly cardiac biopsies for 4 to 6 weeks and thereafter according to your transplant unit’s protocol.
- After twelve months, biopsies are performed on the basis of individual need.

If you cannot have a biopsy via the vein in your neck, a vein in the groin is used. This biopsy may mean one to 2 hours bed rest following the procedure.

If you are taking blood thinning medication, you will be informed if you need to stop taking this before the biopsy.

Complications of cardiac biopsy

Complications that could occur include the following:

- Bruising/bleeding at the site where the Bioptome was introduced into the vein
- Damage to the blood vessel used for the procedure or adjacent nerves
- An air leak into the lining around the lung which may require a chest drain
- Bruising/bleeding into the lining around the heart or lungs
- Inadvertent damage to the heart muscle, blood vessels or valve caused by the sampling device.

Major complications of biopsy are infrequent but when they do occur, you may require admission to hospital for further treatment, which occasionally includes surgery.

Treatment for acute rejection

Treatment for rejection will depend on the following:

- how severe the rejection is (sometime referred to as a ‘grade’ of rejection)
- what your symptoms are and the effect on your heart function
- previous rejection episodes
- your current anti-rejection therapy

You may be given an intravenous injection of methylprednisolone once a day for 3 days. Patients may be admitted for this treatment. Alternatively, your dose of oral prednisolone may be increased.

If your rejection is severe, or ongoing, you may need to receive an additional, or alternative, immunosuppressant medicine. As each patient is different, if necessary, this will be discussed with you by the Transplant Team.

Remember!
Delay in treating rejection can lead to irreversible damage to the heart.

Chronic rejection

Chronic rejection describes certain changes that develop in the transplanted heart usually over a period of several months to many years. These changes can cause a gradual deterioration in the way the heart works. Chronic rejection often affects the arteries in the transplanted heart (the coronary arteries) which take blood to the heart muscle. Since transplant surgery cuts the nerve supply of the transplanted heart, the usual symptoms of coronary disease (chest pain) may not occur. The heart muscle may become stiffer than normal and the strength of the heart muscle deteriorates. This can sometimes lead to heart failure.

Coronary angiography and/or right heart catheterisation will reassess the function of your heart and is aimed at detecting any changes caused by chronic rejection as early as possible

Coronary angiography

You may need to undergo cardiac catheterisation (angiogram). This may be repeated as part of your follow-up care.

The procedure will re-assess function of your heart and is aimed at detecting any changes of chronic rejection as early as possible.

After you have given consent, the procedure is carried out in the Angio Department under a local anaesthetic. In this procedure, a small catheter is passed, usually via the blood vessels in the groin and advanced to the heart under X-ray control.

You may be 'nil-by-mouth' (not allowed to have any food or drink) for up to 4 hours before the angiogram and may be asked to shave your groin (usually the right side).

Afterwards you may be asked to stay in bed for between 2 and 6 hours and keep your leg straight. This is not a painful procedure, but can cause some discomfort. Angiography is a routine procedure and serious complications are unusual. The most common problem is bruising/bleeding around the point where the angiography catheter tube was inserted into the vessel. Following angiography patients must not drive for 24 hours afterwards. Patients with abnormal kidney function may need to be given intravenous fluids (a 'drip') before the procedure.

Uncommon but potentially serious complications of angiography include:

- heart damage (arteries or muscle)
- irregularity of the heart beat
- damage to blood vessels caused by the catheter
- kidney failure
- cardiac arrest

Right heart catheterisation

Right heart catheterisation is a procedure in which a long thin hollow tube is guided through the chambers of the heart and into the large blood vessels of the lungs. The catheter is left in place in a pulmonary (lung) artery. It is used to measure pressures in the heart and large blood vessels and checks how well the heart is working.

Treatment of chronic rejection

Although chronic rejection can be treated it cannot be cured. There are a number of treatments available that will be considered.

- stronger immunosuppressant medicines may slow down the process.
- treatment of other factors contributing to the damage of the blood vessels (e.g. cholesterol).
- medicines for heart failure.
- in some cases, narrowing of the coronary arteries can be treated by surgical interventions, e.g., angioplasty/coronary stenting or coronary bypass surgery.
- re-transplantation may be considered. However, a second transplant carries a much higher risk than the first operation and will only be considered as a last resort. Each person will be considered on an individual basis after a complete re-assessment. You may then be placed back on the waiting list. In practice, re-transplantation is rarely undertaken because medical complications of the first transplant may preclude a second operation.

Remember!
Chronic rejection may be controlled but not cured. To minimise the risk, it is important that you take your immunosuppressant medicines exactly as your transplant team have told you to.

Antibody mediated rejection

This is when your body produces antibodies to your transplanted heart. Antibodies are proteins made by your body to help fight infection or foreign substances.

Immunoadsorption (also known as plasmapheresis) is possible treatment for rejection if the rejection is caused by your body producing antibodies to the transplanted organ. This involves removing anti-bodies from the blood using a treatment similar to dialysis. Blood is withdrawn from the body, anti-coagulated (thinned), and then separated by a machine into red blood cells and plasma. Anti-bodies are found in the plasma, so when the plasma is passed through specialised equipment (called adsorption columns) the anti-bodies are removed. The ‘cleaned’ plasma is then mixed back together with your red blood cells and returned to your body.

Immunoadsorption is normally a painless treatment and usually causes few, if any, side effects. You should be able to eat and drink normally throughout the treatment, which may take 4 to 5 hours.

If immunoadsorption is a treatment that is appropriate for you, you will be given further information by your transplant team.

Infection

The immunosuppressant medicines that help prevent rejection will also make you more likely to develop certain infections. The first 3 months after the transplant are when you will be particularly at risk because you are taking your immunosuppressant medicines in high doses. However, there is a continuing risk of infection for all transplant patients.

Recurrent infection can lead to permanent damage to your transplant. It is important to know and report the warning signs so that treatment can be started early.

Infections are usually caused by the following:

- bacteria
- viruses
- fungi

Warning signs of infection may include:

- raised temperature (above 37.50C)
- change in sputum colour, quantity or consistency
- ‘flu like’ symptoms: chills, aches, tiredness, headaches, dizziness
- cough or shortness of breath
- nausea and vomiting
- diarrhoea
- pain or a burning feeling on passing urine, or a feeling you must pass urine constantly
- wounds or sores that will not heal and may be warm to the touch.

Bacterial infections can be treated with antibiotics. However, it is essential that a swab of the infected area or sputum sample, is taken before antibiotics are given to establish the exact type of infection and the most appropriate antibiotics. This will be decided by your transplant team.

Infection of wounds, drip sites or of the urinary tract is usually caused by bacteria. These usually respond well to antibiotic treatment although wound infection may require further surgery. Infection of the lungs may have a serious effect on your breathing and require vigorous treatment including antibiotics and physiotherapy.

Blood-borne infections (septicaemia) will usually make you feel very ill and can happen unexpectedly without the original cause being found. Rapid treatment with the correct antibiotics is needed, otherwise the condition may become very serious. Serious infection may need treatment in the ICU.

You are also at risk from food-borne infections. This can result in symptoms which appear between one hour to a week after eating infected food, but usually appear within 24 to 72 hours. You should contact the transplant team if this occurs. Please see Section 7: Lifestyle for information on handling food safely.

Cytomegalovirus

Cytomegalovirus (CMV) is the most common viral infection to affect patients after a transplant. CMV usually causes only a mild illness in healthy adults but can cause a serious illness in patients who are taking immunosuppressant medicines. Symptoms may vary from a mild fever and flu like symptoms to severe life threatening infection.

The most common organs to be affected are the lungs, but CMV can have an effect on the digestive tract, liver, heart, kidneys and eyes. If you develop CMV you may need to be admitted to hospital for treatment.

Blood tests may be taken regularly for the first 6 months following your transplant to monitor your susceptibility to the infection. This allows treatment to be given early. If you need to have a blood transfusion at any time following your transplant, the donated blood should also be CMV negative.

Drugs used to treat CMV are ganciclovir, administered intravenously, or valganciclovir, which is administered as tablets. Your transplant team will decide the most appropriate treatment option for you.

Aspergillus

The most common serious fungal infection to affect patients following transplantation is called aspergillus. This also affects the lungs and may cause similar symptoms to CMV. Minor infections are treated with medicines given via a nebuliser for 2 weeks, or oral medicines i.e. itraconazole or ketoconazole may also be used. Serious infections may need intravenous treatment which may result in hospital admission. To help minimize the risk of aspergillus infection, patients are recommended to avoid areas of building work and dusty environments.

Pneumocystis Carnii Pneumonia (PCP)

This is another common infection that affects the lungs. This is treated with a combination of drug therapy. However, to try to prevent this particular type of infection you may take a drug called co-trimoxazole every day as this is very effective in preventing this particular infection.

Other Problems

Kidney problems

The kidneys filter blood, remove waste products and regulate the fluid balance in your body. Your kidney function will be monitored by measuring levels of certain chemicals in your blood and urine. In some patients who have had a heart transplant the kidneys fail to work properly on their own.

In this situation the work of the kidneys may have to be taken over by a temporary dialysis machine. For many patients this is a short-term measure, while the kidneys recover. Occasionally, however, the kidneys do not recover and then dialysis will have to be a long-term treatment and a kidney transplant may be considered.

Kidney problems are often seen after transplantation and may be due to one of the following:

- The kidneys are very sensitive to changes in your circulation. Your transplant team monitor how they are working during and after the operation by measuring the amount of urine you are passing and the chemicals in your blood.

- The kidneys are also sensitive to some of the drugs you are given, especially neoral and prograf.

Your transplant team monitor how the kidneys are working during and after the operation by measuring the amount of urine you are passing and the chemicals in your blood. By doing this the risk of permanent damage to the kidneys is minimised.

Hypertension

Following transplantation some patients develop high blood pressure (also known and hypertension). This is thought to be partly related to the immunosuppression medicines. High blood pressure does not always cause symptoms and most people are unaware that they have it. Unfortunately, if it is left untreated for a long time it may lead to an increased risk of stroke, heart or kidney problems.

Your blood pressure will be monitored regularly and for many patients it will be necessary to start regular treatment to reduce their blood pressure.

Diabetes

Diabetes can occur following transplantation. This is sometimes temporary and is a result of stress and the medicines you are given, such as steroid therapy. The transplant team will monitor your blood glucose very carefully and will provide you with dietary advice, tablets or insulin if needed. Some patients develop permanent diabetes after their transplant. If this occurs you will be referred to an appropriate specialist.

If you are already diabetic, having a transplant may also upset your glucose levels and you may need your medicines and insulin adjusted accordingly.

Coronary artery disease

Your transplanted heart is at a greater risk of developing coronary artery disease therefore it is important that you follow a healthy lifestyle, exercise regularly, watch what you eat and drink and never smoke.

Coronary artery disease after transplantation may be due to one or more of the following:

- high blood pressure
- high cholesterol
- diabetes
- sedentary lifestyle, and
- poor diet

All of these will be monitored regularly and treated accordingly.

Less Common Complications

Less common complications after a transplant include:

- gout (painful swelling in a joint, especially the toes and feet)
- steroid related bone disease (osteoporosis)
- cancer
- post-transplant lymphoproliferative disease (PTLD)
- neurological problems, and
- problems related to the digestive system

The following section discusses some of these less common complications in more detail and their treatments. Although affecting only a small minority of patients these conditions can cause problems.

Cancer

Unfortunately, patients taking immunosuppressant medicines are more prone to certain types of cancer, especially of the skin and lymph nodes (lymphoma). Your transplant team will monitor you closely as part of your follow-up care.

All transplant patients are advised to avoid excessive sunlight exposure and particularly sunburn, which can increase the risk of cancer. Using a sunblock of at least SPF50 both at home and abroad is necessary. In certain circumstances sunblock may be available for you on prescription.

Female patients are advised to follow the usual screening procedures for the early detection of cervical and breast cancer via their GP. Male patients are advised to follow the usual screening procedures for testicular cancer via their GP.

Post-transplant lymphoproliferative disorder (PTLD (also referred to as LPD)

PTLD is the name given to a group lymphomas (cancers that begin in the lymphocytes of the immune system) that occur in immunosuppressed patients following organ transplantation.

A very small percentage of transplant patients may develop this condition which causes the lymph glands to become enlarged amongst other symptoms. A virus called Epstein-Barr, similar to glandular fever, can often cause this disorder to develop. PTLD is sometimes treated with a reduction in immunosuppressant therapy coupled with an increase in requirement for biopsies. It can also sometimes be treated with high dose antiviral therapy. PTLD can be treated with anti-cancer drugs (chemotherapy) and sometimes radiotherapy or surgery.

Gout

Some of the immunosuppressant medicines can cause gout (painful swelling in a joint, especially in the toes and feet). This can be quite painful but it can be treated with medicines, however, there are certain medicines that you may be unable to take for gout because of your immunosuppressant therapy. Please contact the transplant team before taking any treatment.

Osteoporosis

Osteoporosis, (a process by which bones become thinner and break more easily) is associated with long term steroid use, poor diet, post menopause or poor mobility. You may receive advice to help prevent this in the form of information on diet and exercise. Medicines may also be necessary in some patients.

Neurological Problems (problems with the brain and nerves)

Stroke (cerebrovascular accident)

Symptoms of a stroke include weakness down one side of the body, loss of sensation, and difficulty with speech or vision. This is a rare but serious complication of transplantation. If your circulation is being artificially supported during the transplant operation it is possible that there may be a reduced oxygen supply to the brain. This may cause some of the brain cells to die or become damaged. In some cases, the effect of this damage is temporary but in others it may be more permanent.

Fits and convulsions

Certain medicines or chemical changes in the body can cause fits. High levels of some immunosuppressants have been known to increase the risk of fits or convulsions in the early post-operative recovery period. By adjusting the level of medicines and correcting the chemical imbalance the fits should resolve. If you have had any sort of convulsion and are a car driver, you must report it to the Driver and Vehicle Licensing Authority and you may be unable to drive for up to one year following your last fit. Rarely, infections of the brain can cause problems including fits.

Problems related to the digestive system

Nausea (feeling sick) and vomiting (being sick) are the most common digestive problems that may occur.

Some patients also develop gallstones (hard lumps that form in the gall bladder) following transplantation due to drug interactions. This may be treated with medicines. However, some people may require surgery.

Constipation is a side-effect of some of the drugs you may take, so it is important that you drink plenty of fluids, eat foods that are high in fibre, and take laxatives if advised.

Another gastrointestinal problem is ulceration of the gullet (oesophagus) and the stomach, which may be caused by some medicines such as steroids, stress, or an infection.

Occasionally patients may experience serious problems with the digestive system such as bleeding or obstruction of the bowel which occasionally requires surgery.

Section 6 – Getting ready to go home

Everyone will respond differently after the transplant and this makes it difficult to predict how long you will be in hospital, especially if you were very unwell before the surgery. The length of time in hospital may vary but is on average about 4 weeks. As soon as you feel well enough, and the staff are happy with your progress, your discharge date will be planned.

The transplant team will give you and your relatives/carers information throughout your stay. By the time you go home you should be able to self-medicate, recognise the signs and symptoms of rejection and infection and know what action to take if these problems occur.

The team will give you advice on maintaining a healthy lifestyle. For further information, please see section 7: Lifestyle.

Waiting for and receiving a transplant has already caused many changes in your life. Your expectations for yourself may have changed which can cause a different range of emotions, from feeling happy and excited about the future to feeling stressed, confused and even frightened. It is important that you know that these feelings are normal and that there is someone available to help, when you feel you want to talk. Talking to your friends and family can be a good coping mechanism, after all they are having to adjust to your new way of life too and don't forget your transplant team will always be there to support you.

In preparation for going home, a discharge talk will be given to you and your carer by a member of the transplant team. The transplant clinic staff will answer any queries you may have about your follow-up. At this point you will be given your first outpatient appointment.

Transplant clinic

The clinic may be very busy but the staff will always aim to provide a quick and efficient service. However, occasionally delays do occur due to circumstances beyond their control. It is best to leave the whole day flexible when you go to the clinic, especially in the first few months after your transplant.

During the first six months, return visits for check-ups are frequent. If you live a long distance from the hospital you should think about the best way to organise your visits. Re-admission to hospital in the first few months can happen, even if you feel well as your test results may indicate a problem and you may also be required to wait overnight for a biopsy result. It is advisable to take an overnight bag to your appointments and you must also take a supply of all your current medicines along with your drug diary.

Overnight accommodation may be available at the hospital but you will need to book well in advance.

If you feel unwell or if you are concerned in any way it is important that you contact your transplant team straight away as complications can be treated more easily if they are discovered early.

Your transplant team will discuss with you how to contact them if you are unwell or are in need of advice, the contact numbers can be found on the front page of this leaflet.

Remember!
You will be followed up for life by the transplant team. Eventually your routine visits will become much less frequent and you may be able to have your blood tests done at your local hospital or GP.

Although you are encouraged to contact the transplant team at any time with problems or worries it is always preferable to contact them during office hours for general advice. However, do not delay in reporting any worrying signs or symptoms.

If you are unwell always ring and speak to a doctor or nurse before going to the clinic, by doing this, relevant tests can be organised in advance.

If you are admitted to another hospital, please ensure that a member of the hospital staff or a family member/friend informs the transplant team as soon as possible. Likewise, you should inform the transplant team when you are discharged.

Blood tests

Post-transplant you will need regular blood tests to check for side-effects of the immunosuppressant medicines and to make sure that you maintain adequate immunosuppressant levels to prevent rejection. Your medicines doses may change following your blood tests.

The level of immunosuppressant medicines in your blood goes up and down, depending on when you last took them. For this reason, your transplant team will give you specific instructions on how to take your medicines on the days you need to visit the clinic to have your blood levels measured.

Remember!
Follow the instructions given to you by your transplant team about taking your medicines on the days you need to visit the clinic to have your blood levels measured.

Transplant accommodation

Accommodation may be provided by the transplant unit as a ‘half-way house’ for patients who are not local but are well enough to be discharged. The accommodation is subject to availability. The accompanying carer may be asked to vacate the room if the patient is re-admitted to hospital.

Accommodation is limited and always in high demand however, the transplant unit will try to meet all of their patients’ needs. The accommodation may only be available for a limited time and this will be communicated to you via your transplant team.

All accommodation is strictly no smoking.

Transport home

It is your responsibility to organise your own transport to and from hospital. In some circumstances (due to medical reasons) the hospital may be able to arrange transport to take you home. However, the transplant team will need at least 2 days’ notice to arrange this. Your requirements will be discussed with you by the clinic staff. Travelling costs may be covered if you are receiving state benefits.

Medicines

Prior to your discharge you will be given a supply of medicines. As your GP and local pharmacist need to be informed of the medicines you are taking, a letter will be sent to your GP informing them of your medicines for future supplies.

It is extremely important that you always take the same immunosuppressant medicine given to you by your transplant team.

Only your transplant team should make changes to your immunosuppressant medicines (including the brand name, type and colour). If you are given an immunosuppressant medicine with a different brand name, ensure you should ask why. You should inform your transplant team immediately about any change in your medicine and get their advice before you take it.

If for some reason your GP is unable to provide you with a prescription, please contact your transplant centre immediately.

Section 7 – Lifestyle

Learning to adjust to change

You will need to be prepared to make changes in your lifestyle. Initially you may feel more tired and for the first few weeks it is a good idea to try and take short periods of rest every day as you did in hospital.

Being unwell prior to transplantation may have resulted in a loss of confidence. Planning short-term goals can help to boost your self-confidence, help you to feel more in control of your rehabilitation, and reduce your worries about your future health and going home. Establishing a daily routine and keeping mentally active will help this process.

Wound healing

It takes about 8 weeks for the incision down the centre of the breastbone to heal, and it will take 3 to 4 months to return to your normal strength however, you may still have generalised aches and pains for some time. If these pains are more than a mild ache, it is best to continue to take your pain relief, especially at night and in the morning.

Remember!
A healthy lifestyle and exercise are as important as taking your medicines in maintaining your wellbeing.

The first 6 weeks

Do	Do not
Avoid all heavy lifting, pushing and pulling.	Lift, push or pull anything heavy e.g., lift children, move furniture, clean your car, heavy housework such as vacuuming and heavy gardening such as mowing or digging.
Continue your walking exercise. Initially this may be around the garden. Build up gradually and keep the distance very comfortable.	Play any contact sports or other activities that may put pressure on your incision.
Continue your physiotherapy and breathing exercises daily.	Drive until you are told you may do so by your transplant doctor.
Eat well to promote wound healing.	Carry out any DIY that involves heavy lifting or stretching
Only take medicines and products that have been prescribed/recommended by the transplant team. Some OTC medicines and herbal preparations you can buy from a pharmacy can interact with your transplant medicines and damage your kidneys.	Overdo your exercises. Listen to what your body tells you.
	Take medicines which have not been prescribed by the transplant team. Please ask for advice.
	Actively try to lose weight at this stage

Remember!
Always check with the transplant team before taking any form of new medicine.

6 to 8 weeks onwards

Begin lighter activities first, such as vacuuming or washing the car, and build up gradually. Where heavy lifting, pushing, pulling or twisting are involved remember that the breast bone is not fully healed until 3 to 4 months after surgery.

Remember!
It is important to adopt a healthy lifestyle to protect you and your new heart. Your transplant team will be able to help if you need advice.

Heart rate following a heart transplant

After transplantation your resting heart rate (pulse) will often be faster than normal. This is because the nerve supply to the heart has been cut at the time of surgery and the heart rate can no longer be regulated by the nervous system. When you are exercising, hormones such as adrenaline will increase your heart rate. However, the speed with which the heart rate increases may be slower than normal. In some patients the nerve supply to the heart has been seen to regrow several years after surgery.

So what does this mean?

- You may have a resting heart rate of more than 100 beats per minute.
- This is normal for someone who has had a heart transplant.
- You will need to warm up and cool down before and after exercise to help the release of hormones. The physiotherapist will show you how to do this correctly.
- You cannot use your resting heart rate as a measure of your fitness.

Appetite

If you are underweight, or your appetite is poor, you may need to delay this and continue with the advice 'Eating for Healing', below.

If your appetite is good, this is the time to think about returning to a healthy diet; see section 'Eating for Health', below.

Eating for healing

It is important to eat a balanced diet with adequate energy and protein to promote wound healing, maintain muscle strength and speed recovery.

If you are underweight or your appetite was poor before your transplant, it is important to follow the advice below to improve your recovery. Your dietician may also provide you with additional information.

To increase your nutritional intake you should try to:

- eat little and often – include nourishing drinks, meals and snacks
- include in each meal or snack a high protein food such as meat, fish, eggs, cheese, milk, nuts and soya products
- have high energy foods such as cheese and dairy foods, fried foods, biscuits, cakes, chocolate and crisps. Choose full-fat products and avoid anything labelled as reduced or low fat
- add energy to food by adding extra cheese, butter or margarine, oil, mayonnaise, cream or milk powder, and
- include small portions of fruit and vegetables each day

If you continue to lose weight you should discuss this with your transplant team. They will be able to offer more advice and possible refer you to a dietician.

Eating for health

Eating for health is different to eating for recovery. To help maintain good health it is important to eat a healthy diet. Aim to achieve a healthy weight for your height and avoid gaining excess weight. Being overweight increases the risk of high blood pressure, coronary artery disease, raised cholesterol and diabetes. It can also limit mobility and can cause strain on weight-bearing joints such as hips and knees. Steroids may increase your appetite and lead to weight gain. This can be avoided by controlling your food intake and appetite.

The following suggestions will help you maintain a good weight.

- Eat a well-balanced diet including a wide variety of foods and enjoy your meals
- Meals should be eaten regularly and include starchy food. Aim for 3 meals per day, and have one serving of bread, potatoes, rice or pasta daily. Where possible try to have high fibre (brown) varieties.
- Fast food and take-away should be a treat; try not to have these too often
- Have at least 5 portions of fruit and vegetables per day. A portion is a piece of fruit, 3 tablespoons of vegetables or a small bowl of salad
- Have moderate portions of protein foods. These include meat, fish (especially oily fish such as mackerel or salmon), pulses, eggs, tofu, Quorn and soya mince. Ensure that the meat and poultry are lean.
- Milk and dairy products are excellent sources of calcium and help to protect bones. Try to include these daily and see that they are low fat or reduced fat varieties
- Only have high fat foods, sweet drinks and sugary food occasionally. Examples of these are chocolate, biscuits, cakes, pastries, ice cream, thick and creamy yoghurts, crisps, fried foods and cream sauces
- Avoid using too much salt. Only add small amounts if needed when cooking food. Do not add salt at the table and a salt substitute should be avoided. Try using other flavourings e.g. herbs and spices, black pepper or garlic
- Fluid – it is important to drink well to keep you from becoming dehydrated. However, you may have been advised to restrict your fluid intake by your doctor. If so, try to stick to this and be aware that there is fluid in soups, milkshakes and jellies

Osteoporosis

To help to improve the health of your bones it is important to include good sources of calcium in your diet, such as milk, yoghurts and cheese. Tinned fish with edible bones, tofu, green vegetables and nuts are other good sources of calcium. A dietician can discuss this with you in more detail.

Diabetes and diet

Following your transplant, you may have altered levels of blood sugars. If you are already diabetic your medicines may need to be adjusted and you will need to continue with previous dietary advice.

Your blood sugars may increase even if you were not diabetic before the transplant. If this happens you may need to change your diet and may be started on medicine.

Weight loss

If you are unwell or have a poor appetite, you may find that you lose weight. Rapid weight loss can result in fatigue and you may find that you take longer to recover from minor infections.

If you have a poor appetite and are losing weight then seek advice from your transplant team's dietician. You may discuss a referral to the dietician with the nursing staff in the transplant team.

Food safety

Due to your immunosuppressant therapy, you are at an increased risk of food poisoning (food-borne infections such as listeria or salmonella). In order to minimise your risk, it is recommended that you follow general food safety guidelines that would be recommended for other 'at risk' groups such as young children, pregnant women and the elderly.

Any symptoms you may experience such as vomiting and diarrhoea will not be any worse than for someone not on immunosuppressant medication but you could be at risk of rejection if you cannot absorb your tablets. Some foods are more likely to be a potential cause of food poisoning than others.

Take the following steps to ensure food is safe to eat:

Storage:

- Keep hot food hot and cold food cold.
- Make sure your fridge is at the correct temperature (0-5^{o}C). Your freezer should not be above -18^{o}C
- Do not leave food lying around and avoid storing food for long periods of time.
- Once opened, use within the recommended period, usually 3-5 days.
- Store raw foods at the bottom of the fridge, cooked foods at the top.
- Store all raw meats in a sealed container.

Preparation:

- Buy food in the best possible condition and stick to the ‘use by’ and ‘best before’ dates.
- Keep the kitchen clean and do not use dishcloths.
- Follow high standards of personal hygiene when preparing foods.
- Wash your hands before eating and touching food.
  - To wash hands, use warm water and soap. Work up a good lather and make sure you wash your wrist, hands, fingers, thumbs, fingernails and in between your fingers. Rinse the soap off your hands and dry them thoroughly.
  - This should be done before preparing food, after touching raw food, especially poultry and eggs, after touching animals, the rubbish bin and after using the toilet.
- Wash and peel fresh fruit, vegetables and salad before eating or cooking it. You should even wash ready-to-eat salads and vegetables before eating.
- Avoid cross contamination by using separate chopping boards and knives for raw and cooked foods and fresh vegetables.

Cooking
- Avoid buffets and food from uncovered counters.
- Cook all foods thoroughly, especially meats. These should be cooked until above 75^{0}c or piping hot throughout
- Only reheat food once and ensure it is thoroughly heated until piping hot all the way through.
- Ready meals should be pre-packed and follow manufacturer’s cooking instructions, particularly standing times when using microwaves.

	Low risk foods	High risk foods
Milk	Pasteurised, sterilised, tinned, dried and UHT milk. Pasteurised yoghurt and live (bio) yoghurt	Unpasteurized cow, sheep and goat's milk. Unpasteurized yoghurt
Cheese	Cheese made with pasteurised milk i.e. hard cheese such as cheddar and processed cheese such as Dairylea, Philadelphia and cottage cheese. Some cheese can now be made with pasteurised milk, e.g. parmesan, feta, mascarpone*.	'Blue'/mouldy cheese or 'soft' cheese made with unpasteurized milk e.g. brie, camembert, stilton, dolce latte, gorgonzola, Roquefort.
Eggs	Well cooked eggs, pasteurised, dried or liquid eggs. Tins and jars of mayonnaise but avoid deli style.	Raw or lightly cooked eggs or any food that contains raw or lightly cooked eggs e.g. tiramisu, homemade mayonnaise, homemade mousse. Never use eggs that have cracked in storage.
Meat and Fish	Well-cooked fresh, frozen, or tinned fish or prawns*. Packaged cooked meats.	Raw fish e.g. sushi. Shellfish e.g. oysters, mussels. Rare meats. Pate (meat, fish or vegetable). Cold smoked fish e.g. smoked salmon or trout. Rotisserie-cooked chicken and deli meats.
Fruit and Vegetables	Washed fresh fruit and vegetables. Tinned and frozen fruit and vegetables. Pre-packed coleslaw and potato salad.	Unwashed fruit and vegetables. Deli or self-service counter style salads (e.g. coleslaw or potato salad).
Other	Ice cream made with pasteurised milk	Soft ice creams

If in doubt look on the label or ask advice

* These foods may be considered higher risk if they are not prepared, cooked or stored carefully. They may also pose a higher risk at certain times, for example up to one year post-transplant or after a rejection episode. If you have any concerns then please discuss this with your transplant team.

Remember!
In the UK it is safe to drink tap water. If you plan to travel abroad, you should discuss this issue with the transplant team.

Pets

Household pets are a potential source of bacteria and infection. Ensure pets are kept healthy e.g. wormed regularly and vaccinated. Practice good standards of hygiene ,e.g. keep them out of the kitchen and never allow them near foods or on worktops. Prepare your animal's food on a surface and with utensils specially kept for that purpose.

Never use the utensils or the work surface for preparing food for human consumption. Avoid pets licking your face and discourage dogs and cats from sleeping on your bed.

- Be careful when changing cat litter trays. Thick rubber gloves should be worn and hands should be washed immediately afterwards. Cats can carry toxoplasmosis, an infection that can affect immunosuppressed patients.
- Medical staff have differing views on whether birds carry any risks to you. You will be given advice on this issue.

Smoking

It is strongly advised that you never smoke after the operation. If you are ever tempted to smoke, please ask your transplant team for help. Passive smoking can also have a detrimental effect on your health especially if you live with a smoker.

Alcohol

You should ask your transplant team for advice but generally alcohol may be taken in moderation, i.e. one or 2 units per day.

A unit of alcohol is equivalent to:
- ½ pint of beer or larger
- a single measure (25mls) of spirits
- 125ml glass of wine, or
- a small glass of sherry

Excessive alcohol is not recommended as it can interfere with the absorption of the immunosuppressant medicines you are taking.

Exercise

Lack of physical activity is linked with many health problems such as heart disease, osteoporosis, stroke, diabetes, high blood pressure, back pain and obesity. By maintaining an active lifestyle, the risk of developing these problems may be reduced. It is recommended that you gradually build up to thirty minutes of moderate intensity physical activity (activity that makes you mildly short of breath) each day. Your exercise programme will be discussed with you by the physiotherapist. Exercise is as important as taking your medicines to help keep you well.

Sexual activity

You can resume sexual activity as soon as you feel ready. Your transplant team can give you further advice on an individual basis.

Patients who have had problems or continue to have problems with sexual function should seek advice from the transplant team.

Contraception

It is advisable to practice safe sex so you should always use a condom. If you need birth control advice you need to see one of the transplant doctors, as certain contraceptives are more appropriate than others.

For women, the oral contraceptive pill may be a recommended method of contraception to help prevent pregnancy. The progesterone-only pill is preferable as this is less likely to affect your immunosuppressant blood levels. The combined pill may be used if the progesterone-only pill is not tolerated. The use of a coil is not recommended due to the risk of infection.

Liver and renal function, together with immunosuppressant blood levels should be checked for the first couple of months after starting the pill. Close monitoring ensures that any drug interactions can be detected early and should prevent problems arising.

Pregnancy

Pregnancy can have a serious impact on your health after a transplant. It is essential that you discuss your intention to become pregnant with the transplant team before you conceive, especially if you have been prone to rejection and/or infection. It is unwise to contemplate a pregnancy until your medical condition has stabilised and especially during the first year after transplantation.

Mycophenolate mofetil causes birth defects and miscarriages. This also applies to male patients wanting to conveive with their partner.

If you are considering becoming pregnant you must discuss this with the transplant team, so you can be fully informed of the risks involved. Some of the medicines used after transplantation could cause abnormality in the unborn child and the risks should be considered.

Due to exposure from X-rays you must inform the nursing/medical staff if you think that you may be pregnant.

If you suspect you may be pregnant, please discuss this with the transplant team as soon as possible. They will be happy to support and advise you.

Remember!
If you have any questions or concerns, please discuss this with your transplant team

Infertility

Some of the medicines can affect your fertility. If you are prescribed any medication that can affect fertility, your transplant team will discuss this with you.

Driving

You should not drive for 6 to 12 weeks after the transplant. The transplant team will decide when you are fit enough to recommence driving.

It is not necessary to contact the DVLA (Driver and Vehicle Licensing Agency), but you must inform your insurance company as your premium may be affected. The DVLA will send you information on appropriate insurance companies if requested.

If you require a class II (HGV/PSV) for work, special restrictions apply and you should contact the DLVA for advice.

Holidays

It is recommended that you do not travel abroad within the first year following your transplant. If you would like to plan any travel, please discuss your choice of location with the transplant team before you make any bookings. A trip to a country where standards of food and hygiene are poor, or where adequate medical treatment is hard to come by, may be particularly dangerous.

It is essential that you carry your immunosuppressant medicine in your hand luggage. You should also ensure that you have more medicines than you think you will need for your trip, and take a list of your medicines and the doses you take in case you need more in an emergency

When booking holiday insurance, please make sure the company is aware that you have had a transplant, otherwise your policy will be invalid. You can ask your transplant team for a list of suitable insurance companies.

It is advised you always insure your holiday against last minute cancellations due to medical problems, and make sure you can fly home immediately should you become unwell while you are out of the country.

Whilst you will already be aware that excessive sunlight can cause premature ageing and skin cancer, this is particularly important after transplantation. It is advised you avoid excessive exposure to sunlight and never let yourself become sunburnt . You can limit your risk by doing the following:

- using a sun protection factor (SPF) of at least 25 is recommended.
- keep your skin covered when possible, with long sleeves and trousers.
- wear a wide-brimmed hat and sunglasses which cut out 98% of ultraviolet light.
- avoid being in strong sunlight particularly between 11am and 3pm.
- avoid sunbathing and sunbeds – fake tan is a better alternative.

Remember!
There may be more risks to your health when you are abroad so you need to be fully prepared and never forget to pack your immunosuppressant medicines.

Care of teeth and gums

Some of the post-transplant medicines can cause overgrowth of the gums that in turn can cause discomfort and problems with eating. This can be controlled to some extent by maintaining a high standard of oral hygiene but sometimes the gums need to be treated by a dental surgeon. Oral thrush can also cause a sore mouth and if left untreated may result in a white, furry coating on the tongue and inside the cheeks. At this stage it can be very difficult and painful to eat. This can be treated with an antifungal drug.

The use of an electric toothbrush is therefore recommended as well as regular flossing and polishing.

After the first 3 months following your transplant, if you need treatment the dentist may give you antibiotic cover. The transplant team can advise if required.

Optician

Annual eye tests are recommended to screen patients for glaucoma and cataract development. Your eyesight may be affected temporarily following the transplant therefore it is not recommended to have an eye test for the first few months, unless you are experiencing major visual disturbance, in which case you should contact your transplant team.

Transplant rehabilitation

The rehabilitation process is intended to help you gain maximum benefit from your transplant and to ensure that you know how to keep yourself as fit and well as possible.

You will have already met the transplant team who will help plan your rehabilitation.

The aims of rehabilitation are:

1. to support you and your family through the lifestyle adjustments that you need to make.
2. for you and your family to learn how to identify and minimise the risk factors associated with poor health, and
3. to develop an exercise programme for you. The exercises will improve muscle tone and overall fitness. Being as fit as possible will ensure fewer health problems in the future. Although there may be times when your level of physical activity is reduced, problems are often worsened if you become inactive so it is always important to remain as active as your clinical condition allows. The transplant team will give you individual advice on activities and exercises. You should always check with a doctor before starting any vigorous sports e.g. squash, weight training or rugby.

It is difficult to predict your precise recovery after transplantation. This is influenced by many factors, including how well the new organ(s) function, how fit you were before the operation, and whether or not you have experienced post-operative problems.

Although you may be quite happy with just being able to walk again it is really important that you aim for more than this and follow your rehabilitation exercises and advice to achieve a healthy future.

Remember!
Anything is possible! Some heart transplant patients have completed the London Marathon and many have won medals at the Transplant Games.

Returning to work

Most patients should be able to consider returning to work 3 months after their transplant. Please discuss this with the transplant team and remember that when you go back to work you must still be able to attend your clinic appointments.

Other points to remember

- If possible, stay away from people who are sick with colds, flu or other signs of infection.
- Be careful with personal hygiene, bathe daily and check your skin for cuts, boils and bruises etc.
- Good oral hygiene is important – (see ‘Care of teeth and gums’ on page 41). Brush your teeth at least twice a day and check for bleeding or ulcers. You should also visit your dentist at least twice per year.
- You will be advised to avoid crowded areas, such as buses, tubes, trains, airports, theatres, pubs and restaurants etc., for a specific period of time. You should gradually increase your integration so that by 3 months you are socialising normally.
- When gardening, you should wear thick protective gloves especially when dealing with soil because of the infection risk.
- Avoid excessive exposure to sunlight, as your skin is more sensitive because of the medicines you are taking, putting you at more risk of skin cancer. Use a sunblock of at least SPF 25 and avoid sunburn as that may increase your risk.
- Due to an increased risk of air borne fungal infections, avoid areas of construction wherever possible e.g. building sites.

Section 8 – Further information

Emotional support after the transplant

After reading this booklet most of your questions should have been answered, however you may have started to worry about something that previously you had not thought about. This is a perfectly natural reaction, as you have had to understand and digest lots of new and difficult information. If you or your family require further support, please contact the transplant team.

Undergoing a transplant is a time of great emotional and practical upheaval with many patients experiencing worries and concerns. The transplant team are there to help you work through these issues, providing extra emotional support for patients and their families so that they can cope with life after a transplant and make the successful transition through rehabilitation. The transplant team are there to support the whole family. So, if you, your partner, family member or carer are feeling worried, low in mood or needing emotional support please get in contact with the team.

Support can be provided by:

- specialist transplant nurses
- social workers
- psychologists or counsellors

The team can help with problems including:

- anxiety, depression and fear about the transplantation process
- feelings of anger, frustration and guilt (‘why me?’)
- worries about the donor organ/family or rejection
- impairments in memory and concentration
- hallucinations and problems with sleeping
- managing fears and anxiety about rehabilitation and returning home
- social issues (financial concerns/welfare, employment, housing)
- worries about family problems (anxiety, coping, changes in roles) and other non-health related problems
- mood swings and low mood prior to and following transplantation
- developing confidence, independence and reducing health-related anxiety
- worries regarding managing your health and medicine
- personal care (if necessary)
- community support services

Being discharged from hospital is a time when most patients and their families can develop new worries or concerns. Some patients and their families find it difficult to adjust to new levels of independence post-transplant. Everybody copes differently after a transplant, however, there are support networks if these worries become too frequent or start to affect your everyday life. Please see the list of support organisations on page 44, or you can always contact your transplant team.

Spiritual Care support

Your hospital and transplant team are open to meet your spiritual, religious and cultural needs whilst in hospital. Please let your transplant team know if you would like a visit from a member of the spiritual care team.

Publicity

Transplantation is no longer headline news. However, your particular situation may attract media attention. If this is the case, and you are happy for the media to report your story, the Hospital Communications and Marketing Department may be in touch with you to discuss further details of this and assess your level of involvement.

Information about you will never be released without your consent. Any requests for media to come on site or speak to a member of staff must be cleared by the Communications and Marketing Department.

Your donor and their family

Once you have recovered from your transplant it is only natural that you might begin to wonder about your donor. Even more importantly you may begin to think about the family of your donor, and you may wish to find some way to thank the family.

Deciding to write to the family is a very personal decision. Some people simply send a thank you card and some wish to write a longer letter. There is no right or wrong thing to do or say. The letter should be sent to a member of the transplant team who will in turn forward it on appropriately.

Only very limited information will be given to you about your donor. Likewise, only general information will be given to the donor family about you.

You may not wish to know your donor's details for some time after the transplant or you may not want to know at all. This is a personal decision and you may get upset or feel sad when thinking about the donor, these are normal feelings and the transplant team will be there to support you.

Support organisations

British Heart Foundation Greater London House 180 Hampstead Road London NW1 7AW bhf.org.uk Tel: 020 7554 0000 Helpline: 0300 330 3311 (Monday to Friday 9am-6pm) Email: internet@bhf.org.uk	British Lung Foundation 73-75 Goswell Road London EC1 7ER lunguk.org Tel: 020 7688 5555 Helpline: 08458 50 50 20	British Organ Donor Society (BODY) Balsham Cambridge CB21 4DL body.orpheusweb.co.uk Tel: 01223 893636
CRUSE Bereavement Care Cruse Bereavement Care, PO Box 800, Richmond, Surrey, TW9 2RG crusebereavementcare.org.uk Tel: 020 8939 9530 Email:info@cruse.org.uk	Transplant Support Network 6 Kings Meadow Drive Wetherby West Yorkshire LS22 7FS transplantsupportnetwork.org.uk Tel: 0800 027 4490 or 0800 027 4491 Email: tsnetwork@tiscali.co.uk	The Transplant Trust Shaw House Pegler Way Crawley RH11 7AF thetransplanttrust.org.uk Telephone: 01293 763242

The Cardiomyopathy Association (CMA) Unit 10, Chiltern Court, Asheridge Road, Chesham, Bucks HP5 2PX cardiomyopathy.org Tel:01494 791224 Helpline :0800 018 1024 Email info@cardiomyopathy.org	Grown Up Congenital Heart **Patients’ Association** [**GUCH**] Saracen’s House 25 St Margaret’s Green Ipswich IP4 2BN guch.org.uk Tel/Helpline: 0800 854759 Email: admin@guch.org.uk	NHSBT (NHS Blood and Transplant, formerly known as UK Transplant) organdonation.nhs.uk NHS Donor Line on 0300 123 23 23
For information on benefits direct.gov.uk Helpline: 0800 882 200	To search for another charity charity-commission.gov.uk Tel: 0845 3000 218	

References

1. NHS Blood and Transplant Website. Transplant Activity in the UK 2008-2009; Section 8, Transplant Survival, page 55. Available online at: www.uktransplant.org.uk (Accessed January 2010).
2. NHS Blood and Transplant Website. Transplant Activity in the UK 2008-2009; Section 8, Transplant Survival, page 55. Available online at: www.uktransplant.org.uk (Accessed January 2010).

Glossary

Antibody screen	This is when a blood sample is screened for antibodies. Antibodies are substances that your immune system makes to attack anything it does not recognise as part of your body (for example, a transplanted organ).
Cardiac catheterisation (angiography)	A procedure which involves passing a catheter (a thin flexible tube) through a blood vessel to the heart.
Cataract	A painless clouding of the lens of the eye, which can eventually lead to blindness if left untreated.
Cystic fibrosis (CF)	Cystic fibrosis is a hereditary disease which affects the internal organs, especially the lungs and digestive system, by clogging them with thick sticky mucus. This makes it hard to breathe and digest food.
Cytomegalovirus (CMV)	A very common virus that causes symptoms similar to a mild cold. Once you’ve had the CMV virus, you carry it around in your body without it doing any harm. However, if you have had a transplant, you may develop a more serious form of illness from the transplanted organ if you haven’t had the virus before.
Dietician	Staff trained in nutrition to give you advice about diet and healthy eating.
Echocardiogram (Echo)	An echocardiogram is an ultrasound scan of the heart to monitor function of the heart muscle and/or heart valves.

Endomyocardial (heart) biopsy	The endocardium is a thin layer on the inside of the heart. The doctors may decide to take a small piece of this tissue to check for signs of rejection – this is called an endomyocardial biopsy.
Exercise tolerance test (ETT)	A diagnostic tool that involves measuring your heart function using tests such as an ECG while you are exercising.
Extracorporeal membrane oxygenation (ECMO)	ECMO is a temporary life support system used for people whose heart or lungs have stopped working properly. It is used for people who are very seriously ill and who have not responded to other measures. It can also be used for people whose hearts have been artificially stopped during heart surgery to help take the strain off their system after the operation. The ECMO machine is similar to a heart-lung bypass machine used for open heart surgery. Extracorporeal means 'outside the body' and a membrane oxygenator is a piece of equipment which delivers oxygen into the blood.
Gallstones	Solid lumps or stones that form in the gallbladder or bile duct. They are formed when some of the chemicals stored in the gallbladder harden into a mass. One large stone may develop or many smaller stones.
Glaucoma	Glaucoma is the name for a group of eye conditions where the optic nerve becomes damaged and vision deteriorates.
High blood pressure (hypertension)	Blood pressure is the pressure of blood in your arteries. It is recorded as 2 figures, e.g. 130/80 mmHg. This is said as '130 over 80'. The first number is the systolic pressure (pressure in the arteries when the heart contracts) and the second number is the diastolic pressure (pressure in the arteries when the heart rests between each heartbeat). High blood pressure is a blood pressure that is 140/90 mmHg or above each time it is taken. The higher the blood pressure, the greater the risk of developing heart disease, a stroke and other serious conditions. Hypotension is low blood pressure which causes dizziness or light-headedness.
	Medicines that help prevent your immune system from attacking (rejecting) a transplanted organ. They also make your body less effective at fighting off infections, but they are an important part of your therapy after transplantation. Anyone who has had a transplant will need to take immunosuppressant medicines every day for the rest of their life.
Intra-aortic balloon pump (IABP)	An intra-aortic balloon pump (IABP) is a device to help decrease the workload of the heart and increase blood flow to the heart and the rest of the body. Using local anaesthetic, the deflated balloon is inserted through the artery in the groin, and is threaded up into the aorta, the main artery leaving the heart. Here, it is inflated and deflated in a regular sequence synchronised to a person's heart rhythm to provide the needed pressure to circulate blood. An intra-aortic balloon pump is only used temporarily for emergency cardiac support conditions, such as after a heart attack, for severe heart failure, or while someone is waiting for heart surgery.
Intravenous infusion (also called IV or a 'drip')	This is when liquid substances (e.g. fluid or medicines) are administered to a patient via a vein.

MRSA screening	During an MRSA screening test a swab is wiped over part of your body to find out if you carry the MRSA bacterium. MRSA (Methicillin-resistant *Staphylococcus aureus*) is a bacterium responsible for many infections in humans that can be difficult to treat.
MUGA scan (multi-gated acquisition scan)	This is a technique used for carefully studying images of the heart in order to determine the efficiency of the individual chambers of the heart.
Nebulised medicines	Some medicines can be converted to a mist which is then inhaled into the lungs – these are called nebulised medicines. A nebuliser is the machine that converts the medicine to a mist.
NHSBT (NHS Blood and Transplant, formerly known as UK Transplant)	The organisation in the UK that keeps a database of patients waiting for a transplant. It also matches patients to organs when they are available.
Nil-by-mouth	This is the term used when a patient is not allowed to eat or drink anything before an operation or procedure.
Occupational therapist	Staff trained in helping people improve their ability to perform tasks in their daily living and working environments.
Oral thrush	A fungal infection in the mucous membranes of the mouth.
Pacemaker	A small device that is placed under the skin in the chest or abdomen to help control abnormal heart rhythms. A pacemaker is connected to the heart by pacing wires.
Pacing box	A pacing box is similar in function to a pacemaker but it is used externally, i.e. it is not placed under the skin. A pacing box is connected to the heart by pacing wires.
Pacing wires	Pacing wires connect the pacing box or pacemaker to the heart to provide electrical stimulation to help control abnormal heart rhythms.
Physiotherapist	Staff trained in treating patients with respiratory and physical difficulties resulting from surgery, illness, injury, disability or ageing.
Pulmonary hypertension	Pulmonary hypertension is an increase in blood pressure in the pulmonary artery, pulmonary vein or pulmonary capillaries, leading to a number of symptoms including shortness of breath, dizziness and fainting. Pulmonary hypertension can be a severe disease with a markedly decreased exercise tolerance and heart failure.
Sternotomy	A type of surgical procedure in which an incision is made along the length of your sternum (breast bone).
Stroke or cerebrovascular accident	The sudden and rapid loss of brain function(s) due to disturbance in the blood supply to the brain, caused by a blocked or burst blood vessel. In some cases, the effect of this damage is temporary but in others it may be more permanent.
Thallium scan	A thallium scan is a test using a special camera and a small amount of radioactive substance injected into the bloodstream to make an image of the blood flow to the heart.

Tissue typing	A procedure in which blood samples from a prospective donor and recipient are tested for compatibility prior to transplantation.
Transplant coordinator/ transplant nurse	A healthcare professional who will give you and your family the information and psychological support that you will need throughout the transplant process. They also take responsibility for coordinating the transplant process when suitable donor organs become available.
Twelve lead	A diagnostic tool that measures and records the electrical activity of the heart. A 12-lead ECG examines the electrical activity of the heart from 12 points of view.
Urinary catheter	A thin plastic tube that is that is gently inserted into a patient's bladder via the urethra. This is usually done by a doctor or nurse. The process is called catheterisation and it allows urine to drain freely from the bladder.
Ventilation/ perfusion scan (also called a V/Q lung scan)	This is a test that is used to evaluate the circulation of air and blood in the lungs.
Ventilator	A machine designed to mechanically move air into and out of the lungs to provide the mechanism of breathing for a patient who is physically unable to breathe, or is breathing insufficiently.
Ventricular assist device (VAD)	A specialised mechanical pump that is surgically implanted. It is used to partially or completely replace the function of a failing heart and helps to circulate blood around the body. Some VADs are intended for short term use, while others are intended for long term use (months to years and in some cases for life).
Viral screen	Tests to check if a patient is carrying any viral infections in their blood.

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