Paediatric Heart Transplant

Patient Information Booklet

Heart Transplant Patient Information Booklet

An information and reference booklet for parents of children undergoing assessment for possible heart transplantation.

The information in this booklet reflects current practice (Summer 2007) and will be subject to change with time.

Each patient situation is unique and so the information given here is a general guide that complements, but cannot replace, information given to you by the transplant team.

This booklet aims to give you the information you need to understand what a transplant means to your child, you and your family. It is important that you read this information now. No one expects you to read this in one go; it is more useful to read it in sections. This way you will absorb the information better. Why not discuss sections as you read them, with other members of your family and / or your child and list any questions that you or your child may want to ask when you come to the hospital.

Contents

Section 1: Heart Transplant Assessment

Section 2: Before the Operation

Section 3: The Operation and Afterwards

Section 4: Drug Treatment

Section 5: Complications

Section 6: Getting Ready to Go Home

Section 7: Lifestyle

Section 8: Support Networks

Section 9: Information for Adolescents

Section 10: Personal Perspectives on Transplantation

Section 11: Support Organisations

Introduction

This booklet gives you important information related to heart transplantation and attempts to answer some of the questions you and your child may have.

It is also intended to be used as a reference and to help lead you and your child through from the assessment stage to life after transplant.

You and your child will receive a lot of information during your child's assessment. You may feel overwhelmed and anxious because of this. These are normal feelings and the medical and nursing staff will be there to provide you and your child with information and support.

A transplant is a serious operation and is not without risk. A transplant can be an effective treatment for certain serious heart conditions but is not a cure. In many situations transplantation can lead to an extension of life with improved quality.

Everyone will respond to a transplant in a different way. There are of course associated risks with transplantation, and whilst the early survival rates after the transplant are good there can be no guarantees that any particular transplant will be a success.

Once your child has undergone their transplant they will have to take immunosuppressive (anti-rejection) medication every day, for the rest of their life. This medication prevents the body from rejecting your child's new heart.

Keeping your child and their new heart healthy is a team effort. The team consists of you, your child, your family, nurses, doctors, psychologists and other members of the hospital staff.

About Great Ormond Street Hospital

Great Ormond Street Hospital (GOSH) opened to the public in 1852 with only a few inpatient beds. In the 150 years since then, the hospital has expanded to have around 350 beds on 28 wards. We see about 90,000 patients each year, of whom 11,500 have an inpatient stay ranging from a few days to weeks or longer.

Online Information

Visit our website at www.goshfamilies.nhs.uk

Children and young people can visit the Children First for Health website for information about life in hospital and their health www.childrenfirst.nhs.uk

Cardiothoracic Transplantation at GOSH

The Cardiothoracic Transplant Unit at GOSH has been established since 1988 when the first heart transplant at GOSH was performed. Currently the Cardiothoracic Transplant Unit at GOSH is the biggest paediatric heart transplant centre in Europe performing around 20 to 30 transplants per year. There is a full time team of 12 medical and nursing staff who will look after you and your child.

The Cardiothoracic Transplant Unit

The transplant unit is situated in the Cardiac Wing of the Hospital. The main areas your child will visit throughout the assessment, transplant and post transplant care will be ladybird ward, cardiac day ward and cardiac intensive care. Your child will be nursed straight from their transplant operation in one of three transplant isolation suites on level 4 of the Cardiac Wing (CCC4). Each suite has its own TV/video.

Once out of intensive care your child will be moved to Ladybird ward on Level 5 of the Cardiac Wing where they will have their own cubicle. Each cubicle has its own phone, TV/video and cupboards. Your child will stay here until they are well enough to be discharged to the transplant family accommodation - Italian Wing. The Italian Wing allows you time to get use to giving/taking medication prior to going home, you have the comfort of knowing the hospital staff are only a short walk away if you have any concerns.

Outpatients

Transplant Outpatients is situated on Level 2 of the Frontage Building. You and your child will visit clinic prior to their discharge to familiarise yourselves with the staff and routine of clinic.

Contact Numbers

Hospital Switchboard	020 7405 9200
Cardiothoracic Transplant Office	020 7813 8563

Postal Address

Cardiothoracic Transplant Team
Level 6 Main Nurses Home, Room E6032
Great Ormond Street Hospital
Great Ormond Street
London
WC1N 3JH

heart transplant
Assessment

Heart Transplantation Assessment

You may have received this booklet with a letter before your child's outpatient appointment or assessment admission. If so, we strongly advise you to read it before you come to the hospital and please bring it with you. We will also take you and your child through this information during your admission. There is space left at the end of each section for you to write down questions that can be answered by the transplant team. Bear in mind that it is common for people to forget questions that they want to ask. If you write them down you won't forget.

Your referring doctor thinks that your child may benefit from a transplant. We would like to see you and your child so that we can assess your child's suitability for a possible operation. No child can be accepted onto the waiting list for a heart transplant without having been reviewed usually in person, by members of the transplant team, which includes a paediatric transplant consultant.

Assessment for the transplant usually takes place over three to five days. Further tests or treatment may be required and involve a longer stay. Your child may need to come back for the day as an outpatient, or be re-admitted for further tests.

When you and your child arrive the first contact you will have is with the transplant specialist nurses. Your child will also be seen and examined by a doctor.

During the next few days your child will undergo a variety of tests and investigations such as those listed overleaf. These are usually completed in three to four days. The results are collated and your child's case will be discussed at the regular transplant assessment meeting, also known as the joint cardiac conference (JCC). This is a multidisciplinary meeting where the decision is made to place patients on the list or to order more tests where appropriate. In some cases to ensure your child is receiving maximum therapy, alternative treatment may be recommended. If you are not given a decision on your child's suitability to be placed on the waiting list before you go home, a member of the transplant team will contact you following your child's discharge.

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

You and your child will be involved in all decision making about going onto the Transplant List.

At the beginning of your child's assessment we will not know for certain if your child will need a transplant, or if there are any reasons why transplantation would not be an option for your child. We will be able to provide you and your child with this information at the end of the assessment or soon afterwards.

The transplant specialist nurse will explain the tests and provide support and guidance to you and your child throughout the assessment process. We will ensure that both you and your child have the opportunity to meet all of the relevant transplant team members and are aware of the test results and what they mean.

Transplantation is a procedure with significant risks. Every child referred to us will be given the same thorough physical and psychosocial assessments to ensure that the procedure is the best option for them. Your child will be accepted onto the list only if the benefits of surgery outweigh the risks. If your child is not accepted then the medical staff will give you a full explanation and advice on what to do next. In some cases an alternative treatment may be considered preferable. For example:

- Further drug therapy/medical management
- Other cardiac surgery

If your child is accepted onto the transplant waiting list they will be reviewed regularly by the transplant team and/or your local hospital. If your child's condition deteriorates and their other body systems, such as kidney function, start to decline your child may require further interventions to optimise their general health prior the transplant operation. If a change in your child's medical condition adversely affects the chance of transplantation being a success, your child may need to be taken off the list either temporarily or permanently.

The aims of the team during this assessment admission include:

- Tests and investigations that are required to assess your child's suitability for transplantation.
- When appropriate, alternatives to transplantation are considered.
- You and your child have the opportunity to ask questions and gain support
- You and your child have an opportunity to meet other parents and children who have already had a transplant
- You know the outcome of the tests and the decision regarding transplantation before discharge or when all test results are available.
- You know whom to contact if you have problems or queries.

Following transplant assessment, transplant may not be an appropriate option but for some patients this may be reconsidered in the future.

Tests and Investigations During the Assessment Period

We will require the following information about your child

Name, address and telephone number of your child's:
- NHS General Practitioner (GP)
- Referring consultant
- Family contacts

We will also require your child's NHS number.

Here is a list of the tests/investigations your child may have. Your child may have had many of these in the past. We will explain any unfamiliar ones to you and your child.

- Height
- Weight
- Clinical observations such as blood pressure, heart rate, respiratory rate
- Bacterial swabs
- Sputum and urine samples
- Chest X-ray
- Exercise test & walk test (if possible)
- Twelve lead electrocardiogram (ECG)
- Echocardiogram (ultrasound of the heart)
- Blood tests

It is important we take your child's blood to screen for infectious diseases and viruses and to determine blood group. If you child has had any previous surgeries or blood transfusions we may also do tissue typing tests.

Additional tests may include:
- Cardiac catheterisation (angio) - not always required
- 24 hour ECG monitor (Holter Monitor)
- Abdominal ultrasound

If you require further information regarding these tests prior to your child's admission, please contact the transplant team. Your child may have undergone some of these tests recently. It is not uncommon for us to repeat these for more up to date measurements.

You and your child may see a variety of members from the multidisciplinary team, these may include:

- A transplant nurse specialist
- A paediatric transplant consultant
- Doctors (junior doctors)
- Psychologist
- Dentist
- Play specialist

Psychological assessment: During your stay you and your child will also see a psychologist as part of the transplant assessment. This is because we recognise that undergoing a transplant can be an emotional and sometimes difficult experience and we want children and their families to be informed and fully prepared. Speaking to a psychologist may be a new experience for you and your child and it is something that you should not be worried about. Often the psychologist will speak to the parents and the child separately.

Types of Transplant

Orthotopic Heart Transplant (the standard operation)

An orthotopic heart transplant is the most common type of heart transplant performed. Orthotopic simply means 'in the normal place'. During the operation your child's heart will be removed and the donor heart replaced in the same position.

Heterotopic Heart Transplant

Heterotopic transplant - with this type of transplant your child's own heart is not removed. The donor heart is positioned so that the chambers and blood vessels of both hearts can be joined. You can think of it as adding a "backup battery" to your child's heart to cut down on the amount of work it has to do. This procedure follows the same basic steps as the orthotopic operation. However, this type of transplant is very rarely used, largely because the outcome following this operation is significantly worse than the outcome following orthotopic heart transplant.

ABO Mismatch Transplant

Usually, your child would receive a heart from a donor whose blood group matches your child's. This is called an ABO compatible transplant. A discovery was made at the Hospital for Sick Children (Toronto) as part of a research study led by Dr. Lori West, a cardiologist and transplant immunologist, which allows very young children to receive a transplant from a donor of a different blood group. This is called an ABO mismatch transplant.

In very young children their immune system has not yet matured, this allows them to accept an organ from a different blood group without any greater risk. As heart transplant waiting lists are long and organs are few, an ABO mismatch transplant can increase the chance of your child receiving a suitable donor heart.

At Great Ormond Street Hospital we will test your child for ABO mismatch suitability if they are under the age of four years. All children's immunity will develop at different stages and so although your child may be very young they may not be suitable for ABO mismatch transplant. The transplant team will discuss this further at your child's assessment.

Survival After Heart Transplantation

During the early years of the heart transplant programme at Great Ormond Street Hospital approximately half of the children who received a heart transplant survived for 10 years.

Success following heart transplantation has been made possible by the advancement of surgical technique, effective immunosuppressive therapy, post operative intensive care management and advances in post transplant medical knowledge therefore patients transplanted in recent years have had a significant improvement in survival, with over 80% survival to 5 years.

In the current era, children who receive a heart transplant could potentially survive more than 15 years and perhaps even half could survive more than 20 years.

The risk for an individual patient may be more or less than the average depending on their medical condition.

The commonest causes of death during the first year after transplant are:

- Poor function of the transplanted heart
- Acute rejection of the heart
- Infection

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

- Chronic rejection of the heart causing coronary artery disease
- Kidney impairment
- Malignancy (cancer)

This will be explained in more detail later in the booklet (section 5).

Ask the Team

Please use this space to record any questions you may wish to ask your team.

....

....

....

....

....

....

....

....

....

....

....

....

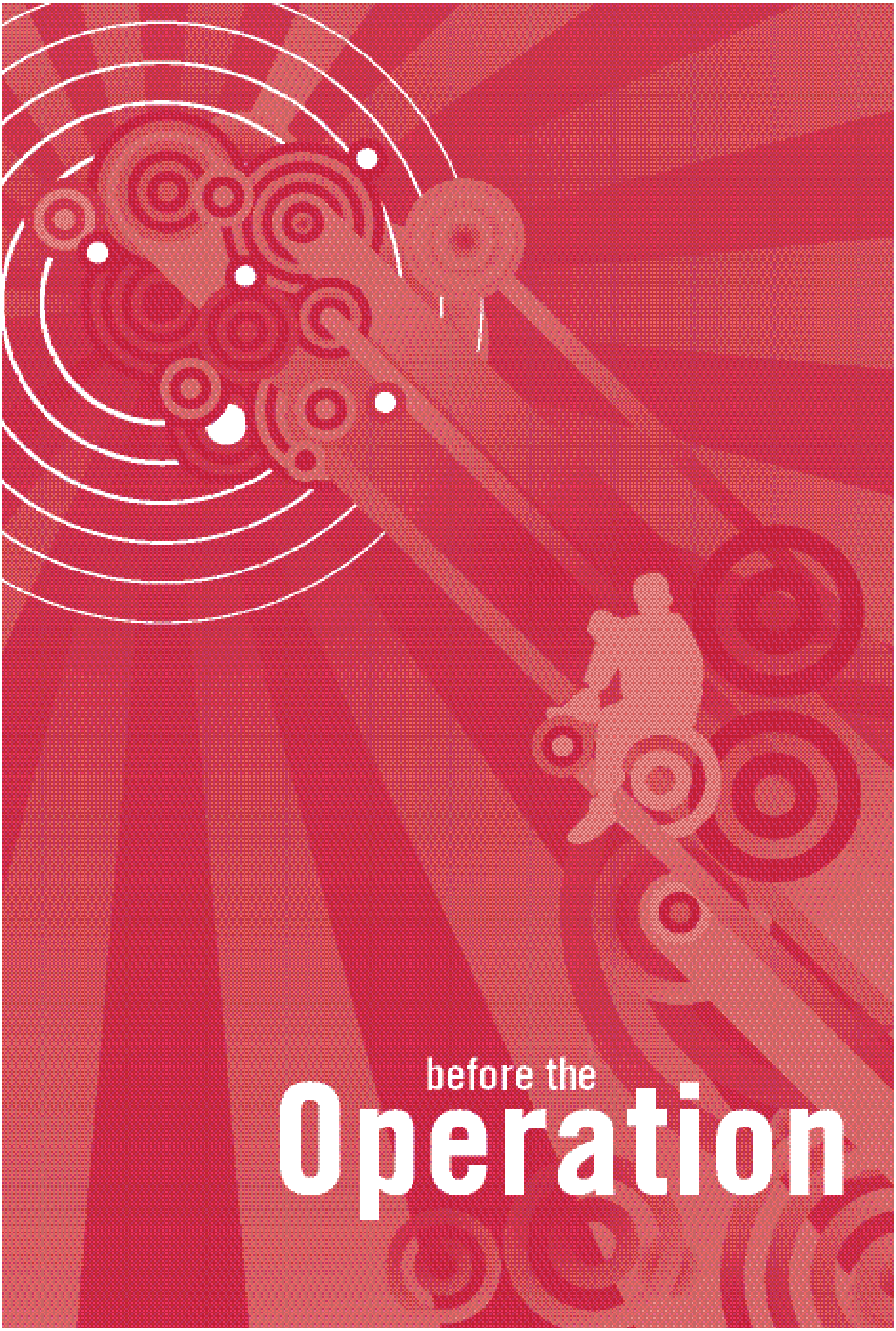
....

....

....

....

....



before the Operation

The Waiting List

An up to date list of all paediatric patients awaiting transplantation is kept by the transplant team. We cannot predict how long your child will have to wait for a transplant, this is determined by availability of suitable donor organs and not by the length of time that your child has been waiting.

Selection of recipients (child waiting for a transplant) is based mainly on:

- Clinical condition
- Specific factors affecting the suitability of a donor organ for your child - for example: blood group, weight, results of antibody tests and tissue typing.

Once your child is on the waiting list a suitable organ may become available in just a few days but it can take many months or even years. During the waiting period your child will remain under the care of the referring cardiologist. However, we will request that you and your child return for reviews at Great Ormond Street Hospital. If your child's condition changes, new treatment is started, or if they deteriorate between visits, you and your child's referring doctor should keep us informed.

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

Unfortunately suitable hearts do not become available in time for everybody who has been put on the waiting list. Some children therefore die whilst on the waiting list. This is a very sad reality that you, your child and your relatives should understand.

Coping with Life on the Waiting List

Undergoing a transplant is a time of great emotional and practical upheaval with many parents and children experiencing issues of concern. One particular area families can find difficult is the time on the waiting list. All families cope with life on the waiting list in very different ways. Here are some points that may help:

- Make plans about being called for a transplant from day one on the waiting list (it is never too soon to prepare).

- Please keep a bag packed and make clear plans with your family/friends to take care of other children.

- Remember life must go on as normal - make sure that daily activities/visits continue, whilst ensuring that you and your child are always contactable with appropriate travel plans in place. Upon listing, the transplant co-ordinator will discuss your specific travel needs with you.

- Take time to think through what transplantation means. If your child is old enough it is important that you take the time to talk with them about what transplantation will mean to them. If you or your child have any concerns or require further information please contact the transplant team.

To help the transplant co-ordinators, remember the following:

- We will need all home, school, work and mobile telephone numbers.

- If your child is admitted to another hospital, please ensure that the transplant co-ordinators are informed. Likewise when you child is discharged.

- Keep the co-ordinators updated on major changes in your child's health.

- You also need to inform the co-ordinators if you and/or your child are away for the weekend or on holiday, as this can affect the travel time to Great Ormond Street Hospital and needs to be accounted for.

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

Admission for the Transplant

When you receive the call from the transplant co-ordinator your child will need to travel to the hospital safely and in the shortest possible time. The transplant co-ordinator will organise transport for your child. We advise that a maximum of two adults only can travel with your child. Transport will not be delayed to wait for a second accompanying adult.

If your child is called to come in for transplant, these are the important things to remember:

- Do not allow your child eat or drink from the time of the call, unless otherwise advised.
- Bring all your child's current medication and your own medication if you are on any.
- Bring your child's favourite toy/DVD/music
- Bring a bag containing essential toilet items - night clothes, comfortable shoes and clothing. It is a good idea to have this already packed in advance.
- Do not bring excess money or other valuables with you.
- Please clearly label all belongings

When You and Your Child Arrive at the Hospital

This is usually late evening or during the night as this is when most transplants take place. The co-ordinator will tell you on the telephone which ward your child is going to be admitted to.

When You and Your Child Arrive on the Ward

You and your child will need to be as prepared as possible so that when the heart arrives the surgeons can proceed with minimal delay. Your child's arrival on the ward and transfer to theatre can be rather hurried. Your child will be prepared and in the operating theatre for when the new heart arrives. We hope that by notifying you and your child in advance of what to expect, you will feel less worried.

Given sufficient time many of the following may be carried out:

- Temperature, pulse and blood pressure readings
- Bacterial swabs
- Your child will need to have a shower/bath (if there is time and they are well enough)
- Urine sample
- Measure your child's height and weight.
- Blood samples will be taken
- Chest x-ray

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 and your child (where appropriate) will be asked to sign the consent form.

Your child will also be seen by an anaesthetist and, if there is time, given a premedication to make them sleepy. First dose of immunosuppression (anti-rejection) medication may also be given at this stage.

NB: Your child will continue to take immunosuppression medications after the operation and this will need to be continued for life.

Other Issues

Cancellation of Your Child's Transplant Operation

Occasionally when the surgeons arrive at the donor hospital to retrieve the organs they are found to be unsuitable. Although this is extremely distressing and disappointing, we will have to cancel the operation. You and your child should be prepared that this may happen. Although very rare, your child may have been anaesthetised by this time. You may find it helpful to discuss this with the transplant team. If this decision is taken it is only because we want to give your child an organ that has the best chance of functioning well.

Your child's transplant may also be cancelled if, on arrival to the hospital, your child has a high temperature or very abnormal blood results. Your child may then be kept in hospital for treatment, observation or re-assessment.

Ask the Team

Please use this space to record any questions you may wish to ask your team.

....

....

....

....

....

....

....

....

....

....

....

....

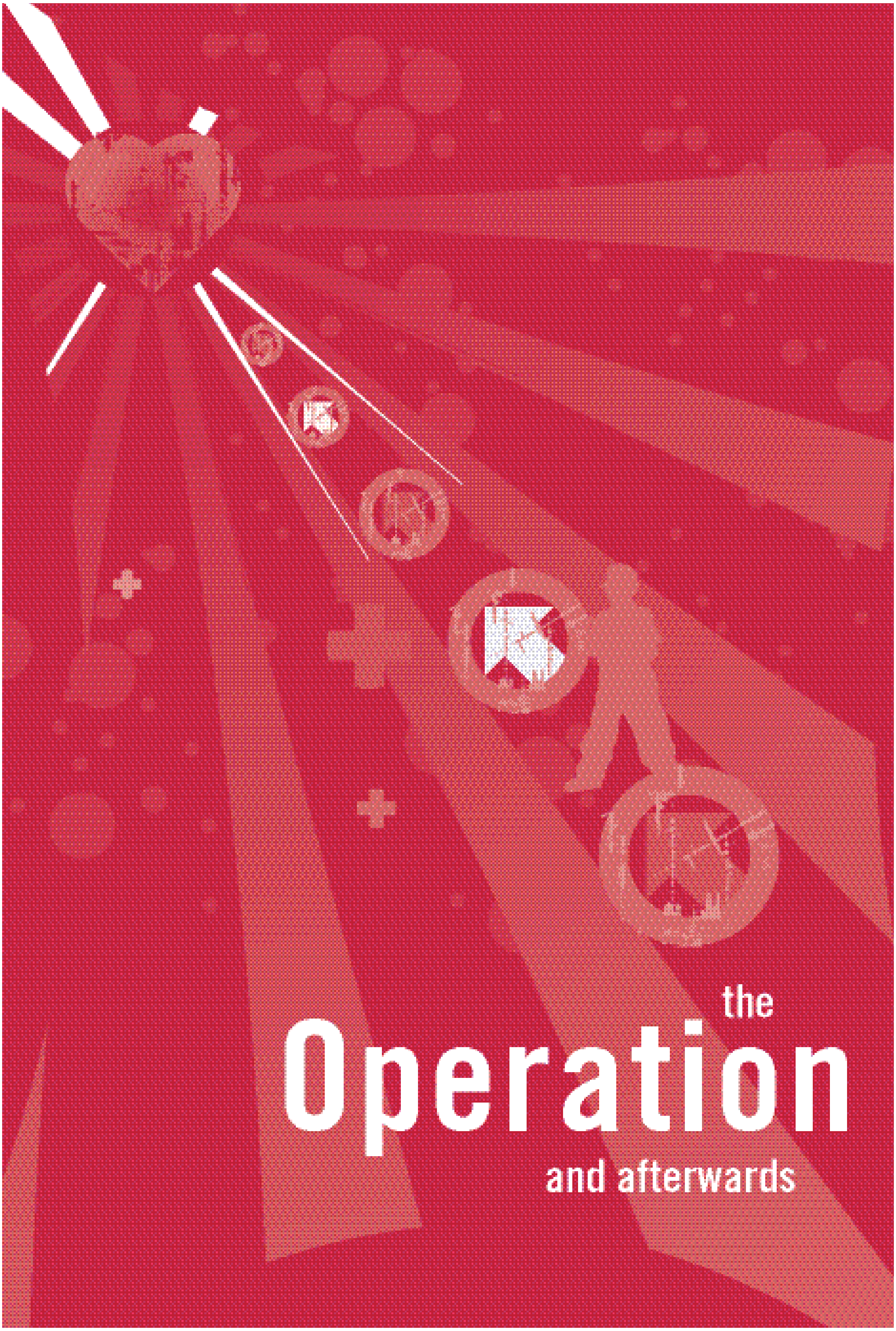
....

....

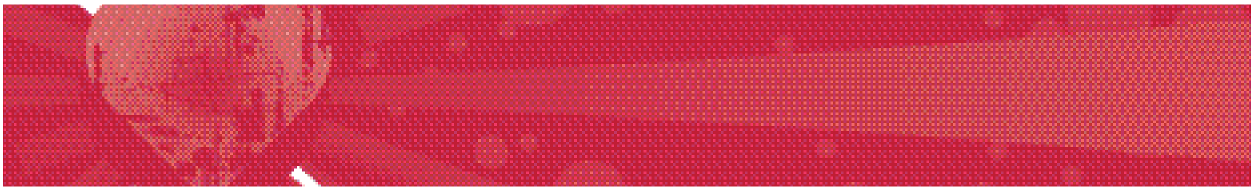
....

....

....



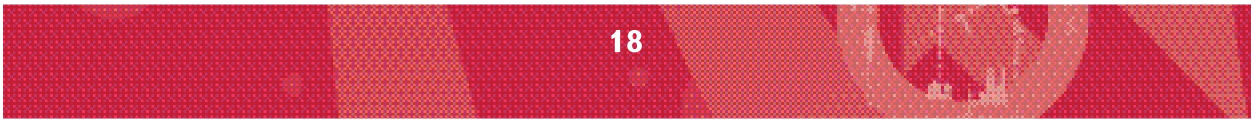
the Operation and afterwards

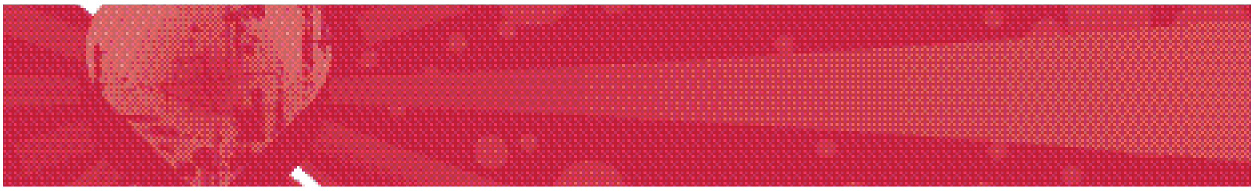


Theatre

The team will start to prepare your child for the operation: if you feel comfortable you can accompany your child to the anaesthetic bay where your child will be anaesthetised and carefully monitored at all times. Once your child is asleep you will be asked to leave and shown a comfortable place to wait for your child to return from theatre.

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

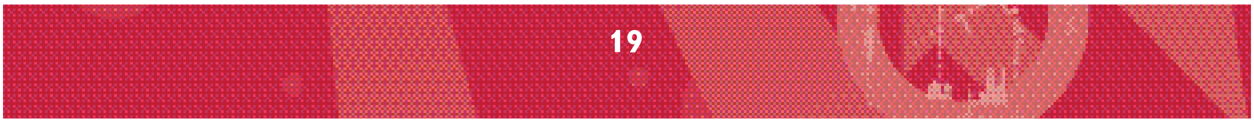


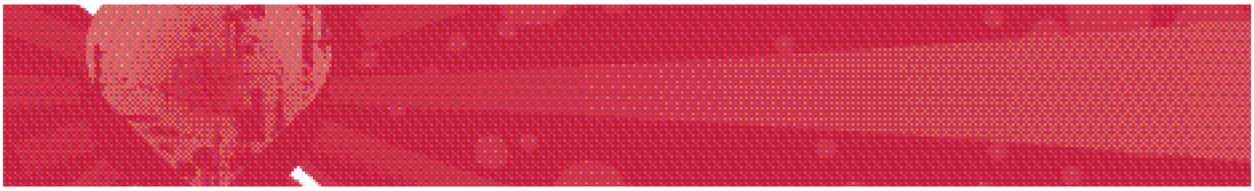


Unexpected Poor Function of New Organs

Although all organs to be transplanted are carefully checked by the team prior to transplant, in some cases following transplant the new organ does 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 intensive care, and in some extreme cases patients do not survive this period.

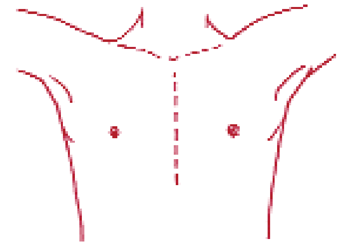
The transplant co-ordinator will keep you updated throughout your child's operation.





Incisions

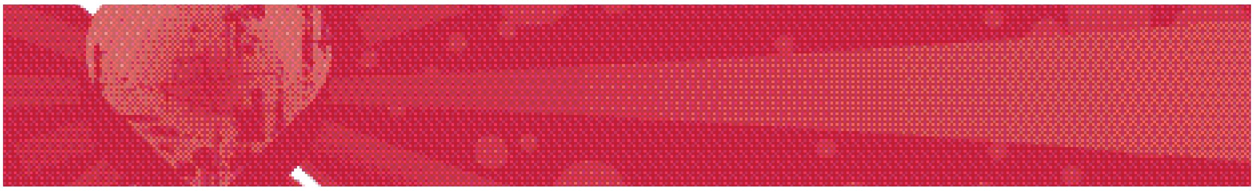
The diagram below shows the incisions that the surgeon will make.



- Sternotomy, an incision along the length of the sternum (breast bone)

The resulting scar should eventually look like a fine line. After two or three days your child's dressing will be removed. Some children may have problems with their wound with excessive scar tissue (known as keloid scarring). Where necessary this can be addressed at a later date.

After the operation your child will be transferred to Intensive Care Unit. The staff will require approximately 30 minutes to settle your child into the intensive care unit, after this time you will be able to join your child.



The Intensive Care Unit (CCC4)

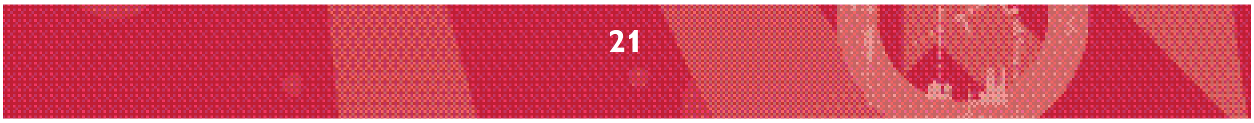
Intensive care can be a busy and daunting place, but the staff caring for your child are specially trained and will do everything they can to make sure they are kept comfortable.

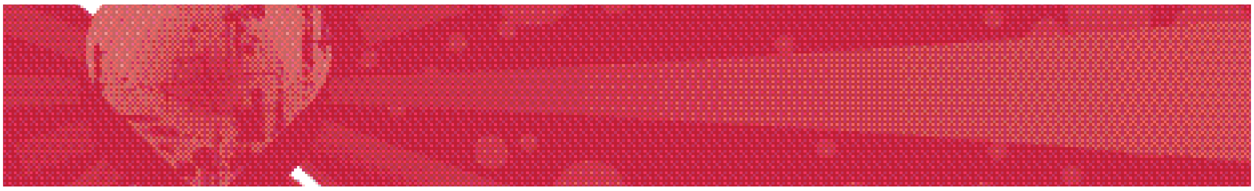
On your child's immediate return from theatre they will be deeply asleep. As your child will be unable to breathe without help at this time, a breathing machine called a ventilator will take over your child's breathing until your child is more awake and able to breathe on their own. To connect your child to a ventilator they will have a tube, called an endotracheal tube, placed into the mouth (or nose if very small child) and down the windpipe making them unable to talk. They will also be attached to a heart and blood pressure monitor.

During the operation there is a risk of bleeding. There is a greater risk of bleeding if your child has had previous chest surgery. In the event of the bleeding being excessive after your child's operation, your child may need to be returned to the theatre for further surgery.

Your child will have an incision along the length of the sternum (breastbone) called a 'sternotomy'. This wound will be closed with a subcutaneous stitch (under the skin) and covered with a dressing. The resulting scar should usually look like a fine line. The stitch is not removed; it dissolves over time. After two or three days the dressing will be removed and left off. Some children may have problems with their wound with excessive scar tissue (known as keloid scarring). Where necessary this can be addressed at a later date.

All patients who have had a heart transplant will have a minimum of two chest drains that will remove any blood and air that has collected at the site of the operation. These are removed when the bleeding has subsided. As your child will still be asleep or very drowsy at this time, fluids and nutrition will be provided via intravenous infusions (drips) in one of the large veins in their neck or groin. To assess your child's urine output, your child will have a urinary catheter in place that will drain urine from their bladder continuously. Your child will have four 'pacing' wires through the 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 the new heart beating regularly.

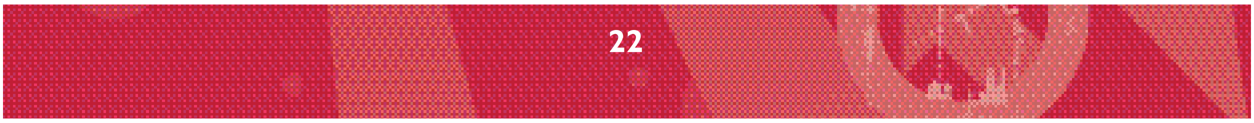


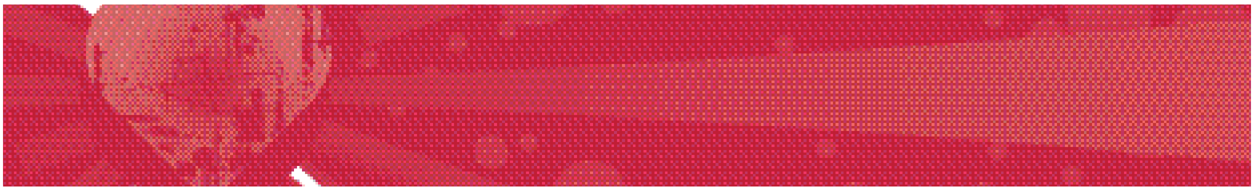


When your child's condition is considered stable, the medical team will reduce the sedation that is keeping them asleep. This will allow your child to wake up and breathe for themselves. When your child is finally disconnected from the breathing machine, they will be able to speak and, in time, have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

Children's experiences of their time spent in intensive care can be varied and depend on the individual child and the length of their stay. Some children do experience vivid hallucinations, which can be distressing both to your child and yourself. This is thought to be due to a withdrawal reaction from the medications that are given to keep them asleep and free from pain. In time the hallucinations will reduce in both intensity and frequency. You and your child may wish to speak to someone if this happens.

The length of stay will vary from child to child from hours, to days or even weeks depending on their condition. As their stay in Intensive Care may be variable, you should prepare yourself for this.





Possible Complications Early After Heart Transplant

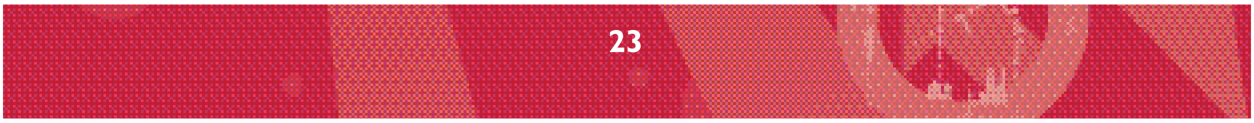
Poor kidney function and low urine output is common after a heart transplant. This will usually resolve over a week or so. Sometimes kidney support is needed (haemofiltration) using a type of kidney machine.

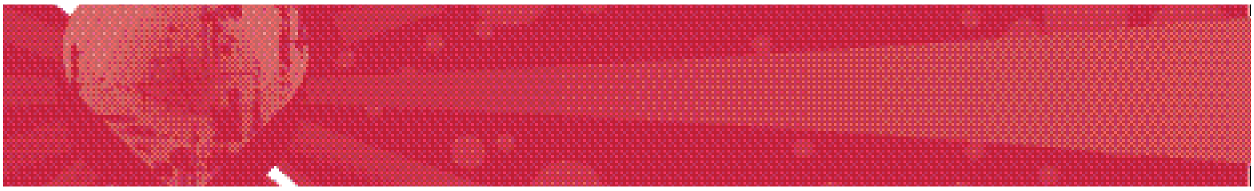
Infection is very common, but usually responds quickly to treatment.

Diaphragm Palsy is caused by bruising and/or damage to the nerves and usually resolves over a few weeks. It does not cause symptoms in older children, young infants may require an operation to tighten the diaphragm (a breathing muscle located in the lower chest).

Hoarse Voice is caused by bruising of the nerves / swelling of the windpipe and usually resolves over a few weeks.

Neurological Problems such as fits/ convulsions/ headaches are common in the first week after transplant. Brain damage from the operation is rare and occurs in less than 1% of transplant children. However, if a cardiac arrest occurs (the heart stops beating, requiring resuscitation) before or after the operation there is a risk of brain damage, which fortunately is rare.





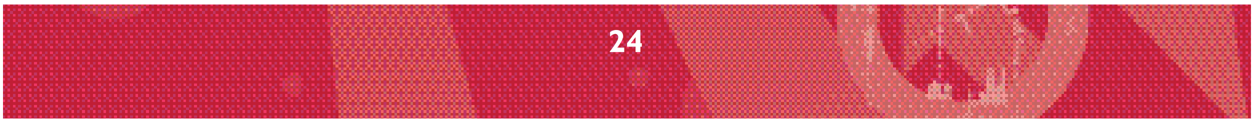
Visitors

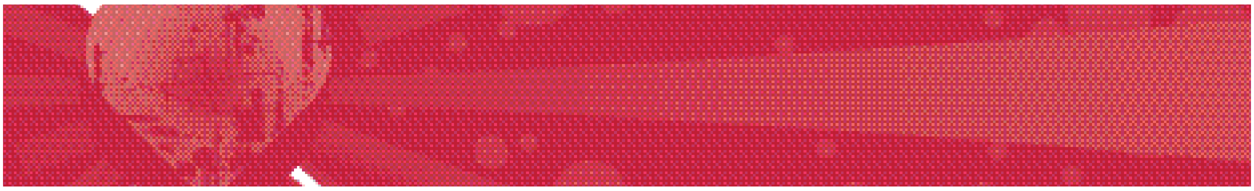
Visiting is restricted for the first week after the transplant. It is important that you, your child and other relatives understand this.

In intensive care visitors are limited to immediate next of kin, a maximum of two visitors at a time. To help prevent infection these need to be the same two people. We do not recommend that babies and young children visit in Intensive care. This is to protect your child from the risk of infection. The staff will ask you and your child's visitors to thoroughly wash their hands on entering and leaving the unit. To protect your child from infection we advise that you do not bring any material (fluffy) toys and thoroughly clean any plastic toys before giving to your child.

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

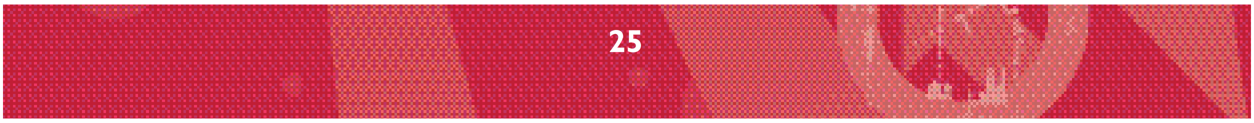
Fresh flowers and plants are not allowed in intensive care, and are not recommended on the transplant wards because of the risk of infection.

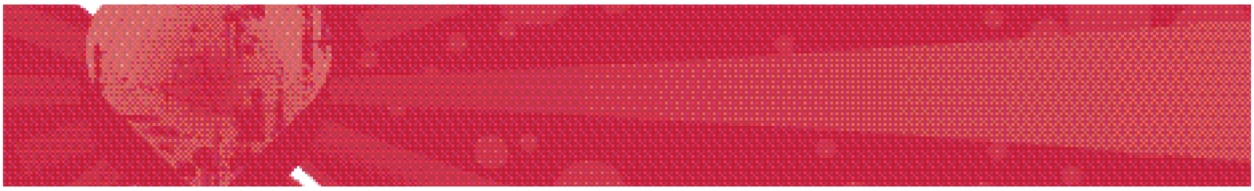




Pain Control

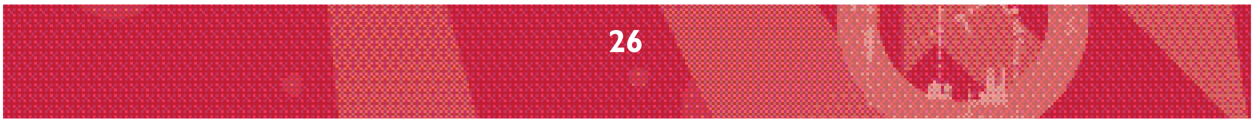
There are many ways to ensure that your child's pain is controlled, such as administration of intravenous (IV), epidural or oral medication. Your child's pain control requirements will be assessed and managed accordingly by the medical and nursing staff. Alongside medication management of pain control there are also non - medical methods, which can be used in the control of your child's pain. This will often involve the play specialists.

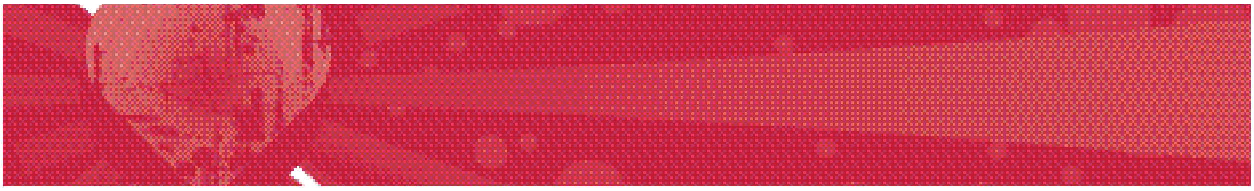




Physiotherapy

The physiotherapist will see your child in the intensive care to help them do breathing and leg exercises. When your child is transferred to the ward they will be encouraged to become progressively more mobile. If your child is of walking age they should be able to walk the length of the ward corridor and climb a flight of steps before discharge.





The Ward (Ladybird Ward)

When your child no longer requires intensive care, they will be moved to the ward. Whilst most of the monitoring equipment will have been removed, your child may still have chest drains and intravenous infusions, which were mentioned earlier. Over the following days, these will gradually be removed as your childs condition improves. You should play a role in encouraging your child to eat, drink and move about. If your child is old enough you should also encourage them to gradually take care of their own needs.

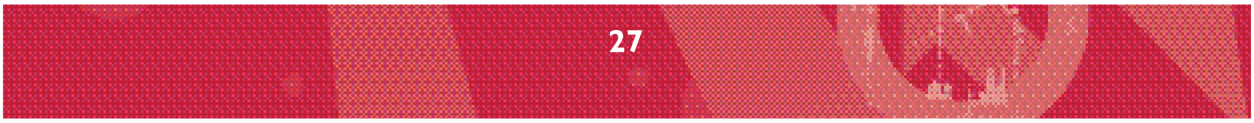
Unlike intensive care, the nurse who is looking after your child will also have other patients to care for. You and your child may feel a little unsettled to begin with, but remember your child would not have been moved to the ward unless their condition was progressing as expected.

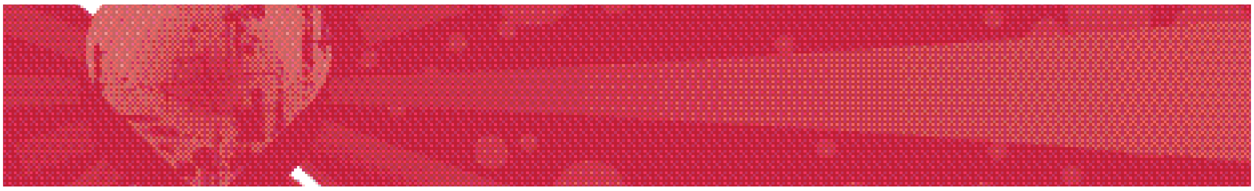
If it is possible we would like you to be with your child regularly during their recovery. Accommodation can be provided - please speak to the transplant co-ordinators. You will be encouraged to participate in your child's care so that by the time they go home you will all feel more confident about what to do and how to avoid and manage complications. Amongst other things, this will involve learning about how and when to administer your child's new medications.

The physiotherapists and nurses will start to mobilise your child and they will become more independent. This is when you and your child if they are old enough, will start to learn about your child's medications and also about the main complications your child may experience post-transplantation, particularly:

- Rejection
- Infection

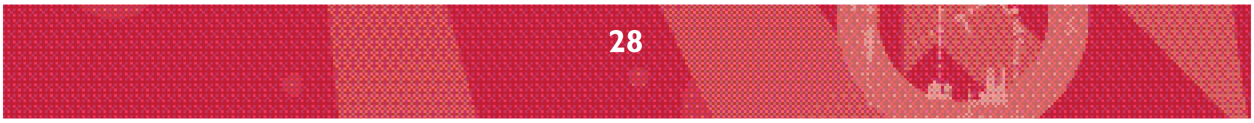
These and other complications will be explained in Section 5 of the booklet.

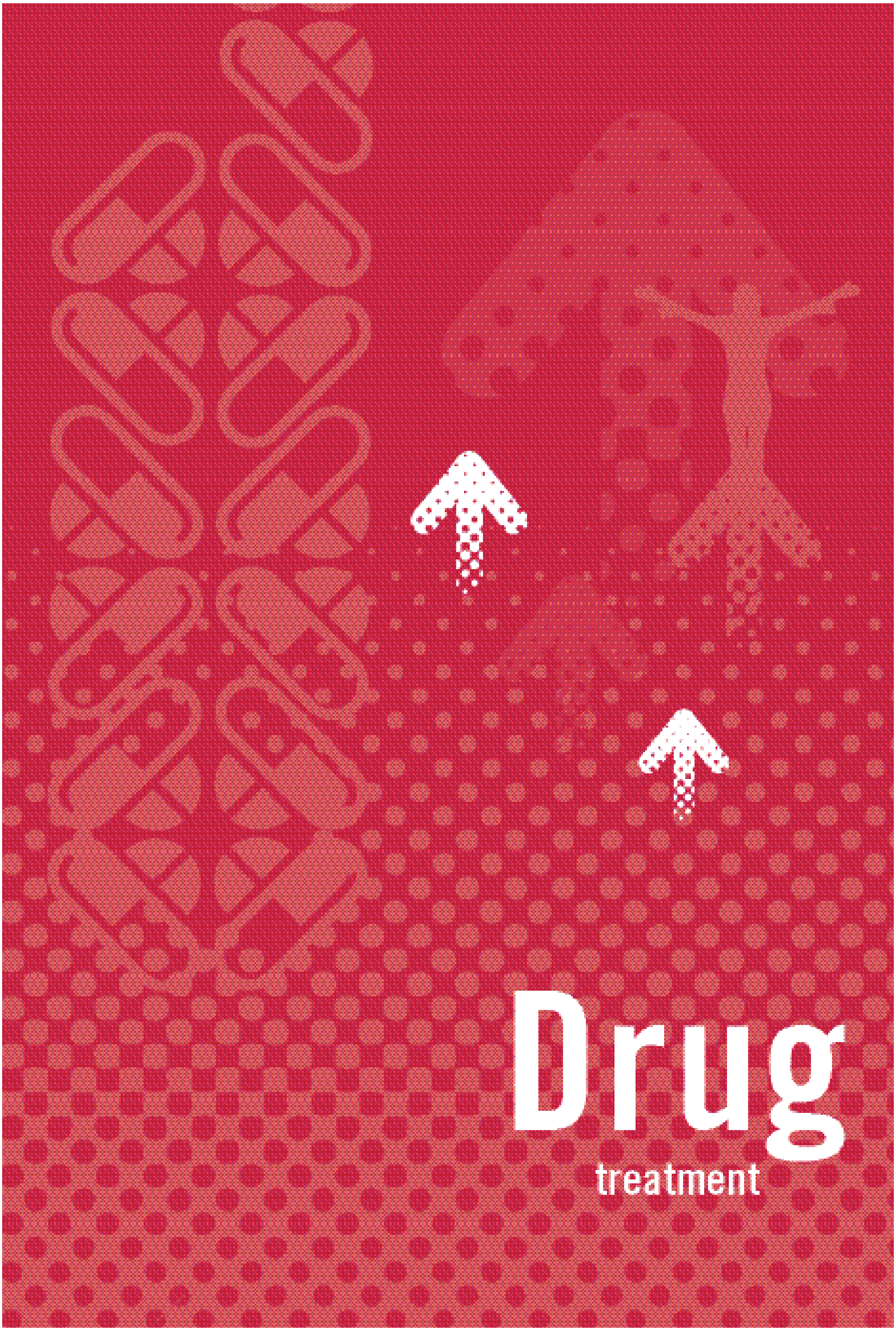




Ask the Team

Please use this space to record any questions you may wish to ask your team.





Drug
treatment

A Lifetime Commitment

Staying well post-transplant requires a life-long commitment to working with the transplant team. We expect families and patients to communicate with the team about any illnesses or planned holidays, to keep clinic appointments, and take their medication correctly. The transplant team is committed to caring for families and children pre and post transplant with the aim of maintaining health, and achieving as normal life as possible.

Although your child may be very well following transplant he/she will require specialist follow up care by the transplant team. This will require a commitment from you as parents to attend transplant outpatient clinics in London, which are currently held on Wednesdays.

After the transplant, a number of medications are prescribed to prevent rejection and infection. Your child will be on medication for the rest of their lives. Failure to take medication correctly can cause rejection, unwanted side effects or even death. It is important to communicate any problems with medication to the transplant team so that this can be avoided.

Medication Diary

To keep track of medications and any medication changes, we will give you a medication diary. The diary should hold a current account of the following

- current medications, the dosage and times to take them
- echocardiography (ECHO) results from local centres
- blood tests and results of those tests carried out by your GP or local hospital
- anything else that you want to raise with the transplant team

Always bring your child's medication diary and medications with you every time you come to the hospital. Whilst in hospital, all medication must be stored in a locked box or drug cupboard.

What Medicines will be Prescribed?

After the transplant, your child will be prescribed a number of medicines to prevent rejection and infection. Broadly there are three groups of medicines

- **anti-rejection** medicines or immunosuppressants to prevent rejection
- **anti-infective** medicines which include antibiotics, anti-viral and anti-fungal medicines to prevent infection
- **others** - these include medicines that are needed in the early post-op period to help recovery, but are not necessarily needed long term

There is more detailed information about each medication in the next section.

The combination of medicines and the dose (how much to give) is adjusted according to your child's needs. It is important to always take the medications as prescribed by your doctor, and to keep your medication diary up to date.

Usually after three months, some of the medications can be stopped. The transplant team will advise you how and when to do this.

Prior to leaving hospital, you will be shown how to administer the medication. You will have the opportunity to learn what the different drugs do and the common side effects.

IMMUNOSUPPRESSANT MEDICINES

The immunosuppressant, 'anti-rejection' medicines that we may use are

- Tacrolimus
- Mycophenolate mofetil (MMF)
- Methylprednisolone / Prednisolone
- Sirolimus

The drugs work on different pathways in cells of the immune system. They are given in combination to enhance the immunosuppression effect. Post transplant your child will be on a combination of three drugs, tacrolimus, mycophenolate mofetil (MMF) and prednisolone.

Tacrolimus (Prograf®)

Tacrolimus is an immunosuppressant drug that blocks stimulation of immune T cells. It is given orally twice a day either as capsules or as oral liquid. The concentration (amount per unit of volume) of tacrolimus in the blood indicates whether enough has been absorbed from the stomach to prevent rejection. It also indicates when too much has been absorbed. Different people absorb and metabolise (process) tacrolimus differently. Therefore, regular blood tests are necessary to measure the blood concentration to ensure enough has been absorbed to prevent rejection. The dose (amount given) may have to be adjusted frequently in the beginning until the blood concentration is in the right range. As time passes, the blood tests will become less frequent. High concentrations can be associated with seizures (fits) and kidney damage. The blood tests are important to get the dose correct.

Some medicines can increase or decrease tacrolimus blood levels by interfering with how the body processes them. This can lead to low levels and risk of rejection, or high levels and risk of side effects.

Common interactions with tacrolimus include;
- Erythromycin and other antibiotics of this type that end in 'mycin'
- Anticonvulsants (medicines taken to control epilepsy)
- Antifungals
- Antimalarials
- Contraceptive pill
- Anti-inflammatory medicines (pain killers) such as indomethacin

Always check with the transplant team or the pharmacist before starting your child on any new medicines, including anything bought over the counter.

Some herbal or alternative medicinal remedies may also interact with tacrolimus. For example St John's Wart increases the tacrolimus blood level. **Always ask the transplant team if it is safe to start a herbal or alternative medicine.**

Grapefruit juice and grapefruit can increase tacrolimus levels in an unpredictable manner. **It is best to avoid grapefruit and food/drinks containing grapefruit when taking these medicines.**

Food reduces the absorption of tacrolimus from the stomach, and so ideally, both these medicines should be taken on an empty stomach. This can be difficult to achieve for some children especially if they have been sick for some time and need to eat to increase their weight. Some transplant teams insist on administering these medicines on an empty stomach. We ask that you are consistent with the way the medication is given with respect to food, and the dose is adjusted according to the blood levels.

Side effects of tacrolimus include

- Kidney toxicity
- Nerve toxicity such as seizures (fits) or tremor of hands. These are reversible.
- Elevated blood glucose
- Stomach upset
- High blood pressure
- Elevated blood lipids (rare)
- Infection
- Increase risk of malignancy

Tacrolimus is available as a licensed product called Prograf®. It comes as capsules. An oral liquid is available as an unlicensed product from some specials manufacturers.

Mycophenolate Mofetil (MMF)

Mycophenolate mofetil (also shortened to MMF) is a medicine from the class called antimetabolites. These work by interfering with how white cells reproduce and function. They are prescribed together with tacrolimus.

Mycophenolate mofetil can be given intravenously or by mouth. It is given twice a day before or after food. The common side effects of mycophenolate mofetil are gastrointestinal pain and diarrhoea, low white cell count and infection. Gastrointestinal symptoms (such as diarrhoea) may be alleviated by taking MMF with food or giving smaller does three times a day. Mycophenolate mofetil is available as a licensed product. It comes as an oral liquid, tablets and capsules.

Steroids

'Steroids' is a general term for a class of compounds that have different physiological affects on the body. Our bodies produce natural steroids, such as cortisone and aldosterone, and many other hormones are 'steroids'. These work on different parts of the body to promote growth, to regulate blood pressure, to control carbohydrate, fat and protein metabolism, and to maintain the body's water balance. When steroids are given therapeutically, that is by a doctor to treat a disease, it is the glucocorticoid group of steroids that is being used for their specific anti-inflammatory and immunosuppressant effects on the white blood cells. Anabolic steroids, or androgens, used by athletes and body builders are not used.

The glucocorticoids used in transplantation medicine are prednisolone and methylprednisolone. Specifically these steroids reduce the number of white cells in the blood initially, and also block their function. The white blood cells are the body's immune 'defence' cells that are important for responding to tissue inflammation, and fighting infection.

Methylprednisolone is given intravenously only. Prednisolone is given by mouth only. It is usually given once a day in the morning after food. The presence of food in the stomach before taking prednisolone can reduce the chance of stomach pain and developing a stomach ulcer.

Methylprednisolone and prednisolone are prescribed in combination with tacrolimus and mycophenolate mofetil.

The dose of prednisolone is adjusted according to the child's specific need. Usually doses are higher to start with and slowly reduced over a period of weeks. The doctors will specify how to do this. It is important not to stop taking prednisolone suddenly or to run out of tablets. This is because when prednisolone is given as medication, the body's natural supply becomes diminished. When the dose is reduced gradually it allows time for the body's store to replenish.

Side effects of prednisolone and methlyprednisolone include
- High blood pressure
- Elevated blood lipids
- Elevated blood glucose
- Stomach ulcer
- Fluid retention
- Altered fat distribution on face and back
- Cataracts
- Depressed mood or confusion
- Osteoporosis
- Muscle wasting

- Growth retardation
- Thinning of skin and poor wound healing
- Easy bruising
- Infection

Some of these side effects occur only after long term use. Others occur early on when the dose is high, and disappear as the dose is reduced. Methylprednisolone and prednisolone are important immunosuppressant medications to prevent rejection. At this time, it is not possible to avoid taking steroids post transplant. If you are concerned about taking steroids, or the other immunosuppressant medications, discuss this with your transplant team. In most cases steroids are reduced and stopped by six months after transplant unless there has been concern about rejection.

NEW IMMUNOSUPPRESSANTS

Sirolimus (Rapamune®)

Sirolimus is a new immunosuppressant medication that became available commercially in 2004. Although it has a similar sounding name to tacrolimus, it works on different pathways inside T cells to block their function.

The role of sirolimus in heart and lung transplantation is not yet clear. Sirolimus may be useful when there is kidney impairment, or if there is persistent rejection while on tacrolimus. However, sirolimus is usually not given in the early post transplant period.

Sirolimus is given by mouth once a day. Similar to tacrolimus, blood tests are necessary to measure the blood concentration to ensure enough drug has been absorbed to prevent rejection. Sirolimus blood levels can be altered by other drugs, similar to tacrolimus. Always ask the transplant team or a pharmacist if it is safe to take any new medicines, including medicine bought over the counter or herbal or alternative remedies.

Sirolimus is available as a licensed product called Rapamune®. It is available in tablets and an oral liquid.

The common side effects of sirolimus include

- Elevated blood cholesterol
- Infection

- Acne
- Mouth ulcers
- Poor wound healing
- Pneumonitis / Lung inflammation -
  if this occurs Sirolimus may need to be stopped
- Stomach pains and diarrhoea
- Low white cell counts

Statins

These are medicines commonly used to reduce high cholesterol. In transplantation medicine, they also have an effect on the immune cells. Studies have indicated that the risk of chronic rejection in heart transplant patients and some lung transplant patients is lower if a statin is prescribed. Statins are normally given to patients following heart/lung transplant.

There are a number of different statins available. The common ones prescribed post-transplant are simvastatin, pravastatin, or atorvastatin. They are given once a day at night.

The common side effects are;

- Muscle pain and weakness
- Liver dysfunction
- Stomach pains.

A combination of the above drugs will be necessary for the rest of your child's life. The combination of medicines and the doses will be adjusted according to risk of rejection, and to minimise the chance of side effects. It is important to take the medications at the right times and at the right doses. Medication errors or forgetting to take immunosuppressant medication is a common cause for being admitted to hospital for poor heart or lung function. If you have any concerns about any of these medicines, please ask your transplant team.

ANTI-INFECTIVES

Anti-infective medicines include antibiotics, anti-viral and anti-fungal agents. Given that immunosuppression medication decreases the body's ability to fight infection, these medicines are needed to prevent infection in the early months post-transplant.

Co-trimoxazole (Septrin®)

Co-trimoxazole is an antibiotic. It is prescribed to prevent the bacterial infection, pneumocystis jiroveci pneumonia or PJP. It is usually given by mouth twice a day for three days per week, but can also be given intravenously.

The common side effects are;

- nausea
- vomiting
- skin rash
- low white cell count.

Aciclovir

Aciclovir is prescribed to treat and prevent Herpes Simplex virus and Varicella Zoster virus infection. These viruses can cause cold sores, shingles and chicken pox. After transplant it is given by mouth for prevention of infection. If an infection occurs, Aciclovir can be given intravenously for treatment.

Common side effects include;

- Light-headedness
- Nausea
- Vomiting
- Stomach pain
- Kidney impairment

Ganciclovir/Valganciclovir

Ganciclovir is prescribed for the treatment or prevention of cytomegalovirus (CMV) infection. It is usually administered intravenously. Valganciclovir is a drug that is converted to ganciclovir in the body. It is available as a tablet. Only those at risk of CMV infection need to take gancicolvir or valganciclovir.

The most common side effect is low white cell count.

Nystatin

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

OTHER MEDICINES

These are medicines that may be prescribed in the early post-transplant period to aid recovery or prevent side effects of other drugs. As time passes and your child recovers from the surgery, many of these medicines may no longer be required.

Painkillers or Analgesia.

Most children experience some discomfort after the operation. Immediately after surgery your child will be on a pain killing medicine, called morphine via a drip. As soon as they can eat and drink this will be changed to tablets or liquid, and then stopped. Paracetamol is the preferred medicine to relieve mild to moderate pain.

Anti-hypertensive (Blood Pressure) Medicines

There are two classes of medicines commonly used following heart and lung transplantation to lower the blood pressure.

These are ACE inhibitors and calcium channel blockers. These medicines work on different cell receptors and pathways to cause the blood vessels to dilate.

Examples of ACE inhibitors include captopril, enalapril, lisinopril and ramipril. The common side effects of ACE inhibitors are:

- Dry cough
- Rash
- Taste disturbance
- Nausea and vomiting
- Swollen lips and difficulty breathing is a rare side effect

Examples of calcium channel blockers include nifedipine and amlodipine. The common side effects are:

- Increase heart rate
- Swollen ankles
- Flushing of the face
- Overgrowth of gums.

Diuretics or Water Tablets

These medicines work in the kidney to increase the volume of urine produced. This prevents excess fluid accumulating in the body early after transplant.

Furosemide is the common diuretic used. It comes as an oral liquid and as a tablet. The dose is adjusted according to specific need. Furosemide is generally well tolerated.

The common side effects are:

- Abnormal blood electrolytes (salts)
- Rash

Anti-reflux Medicines

These medicines reduce the amount of acid produced in the stomach and are prescribed to prevent and treat stomach ulcers. They are routinely given to anybody having major surgery since during that time and immediately after surgery, they are unable to eat. When your child is eating and drinking it is most likely that these medicines can be stopped.

The main medicines used are ranitidine, omeprazole or lansoprazole.

Anti-emetic (Anti-sickness) Medicines

Medicines to prevent nausea and vomiting are prescribed immediately post-op. In nearly all cases, these are stopped by the time you are ready to go home from hospital.

Some examples of anti-sickness medicines are ondansetron, prochlorperazine, cyclizine and domperidone.

Laxatives

Constipation is not unusual following major surgery. Lactulose or senna may be given to get the bowel moving again. It is not usually needed long term.

Some Important Points to Remember About Your Child's Medicines

- Always take the medications as prescribed by the doctor. The type of medication, and the dose (how much to give) is individually tailored to your child's needs. Keep your medication diary up to date.

- Medication errors can cause rejection or side effects. If you are unsure about any changes please ask us.

- Missed doses of immunosuppressant medicines can lead to eventual damage of heart muscle. It is important to establish a routine for taking medicines. Teenagers can become complacent about their medicines and forget. They may need extra encouragement and reminders to take their medicines. If you are concerned, contact the transplant team.

Some non-prescription medication and herbal remedies can interact with the transplant medicines. Always check with the transplant team or the pharmacist if it is safe, before taking new medicines or herbal products.

- Always make sure that anyone treating your child is aware of all the medicines they take so that adverse interactions can be avoided. As well as doctors and surgeons, this includes nurses, dentists and pharmacists.

- Repeat prescriptions of medications will be your responsibility. Arrangements are made with your local GP or hospital to continue prescribing the medication. Make sure you allow at least two weeks for repeat prescriptions to be written and your local pharmacy to order the medication if necessary.

- All medicines have potential side-effects, although not everyone experiences side effects. If you are concerned about the side effects of the medication, please contact the transplant team to discuss possible alternatives. Don't stop taking the medication without advice.

Vaccination Requirements for Transplant Patients

Live vaccines cannot be given to transplant patients. Vaccinations with no living viruses are safe.

Vaccines are potentially less effective when given to people taking immunosuppressants.

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

Recommended post transplant
- Pneumovax
- Annual influenza vaccine

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

Vaccines that SHOULD NOT be Administered

- BCG (Bacillus, Calmette-Geurin)
- MMR (measles, mumps, rubella)
- Measles
- Mumps
- Oral polio (OPV, SABIN) - household contacts, such as family members, should also avoid this vaccine. The inactivated polio vaccine can be given.
- Oral typhoid (Vivotif)
- Rubella
- Smallpox
- Yellow Fever

Remember - after transplant children
should NOT receive any LIVE VACCINES

Ask the Team

Please use this space to record any questions you may wish to ask your team.

....

....

....

....

....

....

....

....

....

....

....

....

....

....

....

....

....

Complications

which may arise

Complications

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

The most common complications:
- Rejection acute
- Cardiac allograft vasculopathy (coronary artery disease)
- Infection
- Kidney problems
- Hypertension (High Blood Pressure)
- Diabetes
- High Cholesterol

Rejection

Rejection Following Heart Tansplantation

Acute rejection episodes are most common in the first year after transplantation. Provided that your child has been adhering to their drug treatment and the rejection is picked up early, most rejection episodes can be effectively treated.

Your child's immune system is the body's main defence against disease and is composed of many different types of cells. Some of these attack and destroy bacteria and viruses that invade your child's 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 child's newly transplanted heart. To try and stop the immune system from damaging the transplanted heart your child will be given immunosuppressive medication. The medications mentioned below reduce the reactivity of their immune system and reduce the risk of rejection.

- Mycophenolate mofetil (Cellcept®)
- Prednisolone
- Tacrolimus (Prograf®)
- Sirolimus, (Rapamune®)

Rejection episodes are unpredictable in frequency and severity. To minimise the risk it is important that your child takes their medication every day as advised by medical/nursing staff.

Acute Rejection Following Heart Transplantation

Acute rejection must be detected and treated early to help prevent irreversible damage. Always contact the transplant team if you ever think that your child is experiencing signs of rejection. Rejection occurs most frequently in the first year. If your child has any of the following symptoms inform the transplant team at Great Ormond Street Hospital as soon as possible.

Warning signs of possible rejection (usually a combination of some of these)
- 'Flu-like' symptoms/chills/aches
- Unexplained tiredness, inability to perform physical activity, which was tolerated previously

- Shortness of breath
- Fluid retention/weight gain such as 2kg over 24 hours/'puffy ankles'/feeling bloated, or a consistent rise in weight over a few days
- Change in heart rhythms (palpitations)
- Mildly raised temperature (above 37.5˚C)
- Abdominal pain

DELAY IN TREATING REJECTION CAN LEAD TO IRREVERSIBLE DAMAGE TO THE HEART.

Treatment

Rejection is usually determined by cardiac biopsy. Treatment for rejection will depend on the following:

- How severe the rejection is (what 'grade' of rejection)
- What your child's symptoms are and the effect on their heart function
- Previous rejection episodes
- Your child's current anti-rejection therapy

Your child may be given an intravenous injection of methylprednisolone once a day for three days. Children are generally admitted for this treatment. Alternatively your child's dose of oral prednisolone may be increased.

If your child's rejection is more severe, they may need to receive an additional anti-rejection drug. The transplant team will then discuss this with you and your child.

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

These may include a combination of the following:
- Review of symptoms
- Physical examination
- ECG
- Echocardiogram
- Blood tests
- Cardiac biopsy
- Chest x-ray

Cardiac Allograft Vasculopathy (Coronary Artery Disease)

Coronary artery disease describes certain changes that develop in the transplanted heart over a period of several months to many years. These changes can cause a gradual deterioration in the way the heart works. Coronary artery disease affects the arteries in the transplanted heart, 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.

To detect this disease (and assess what treatment is possible) coronary angiography and or intravascular ultrasound (IVUS) may be performed.

Treatment

Although this condition can be treated it cannot be cured. There are a number of treatments available that will be considered:

- Different immunosuppressive drugs may slow down the process
- Treatment of other factors contributing to the damage of the blood vessels (for example - treating high cholesterol with higher doses of statins)
- In some cases narrowing of the coronary arteries can be treated by surgical intervention (for example - angioplasty/coronary stenting, coronary bypass surgery)
- Medication for heart failure
- Re-transplantation may be considered. Each person will be considered on an individual basis after a complete re-assessment. Your child may then be placed back on the waiting list. Sometimes, re-transplantation cannot be undertaken because medical complications of the first transplant may preclude a second operation

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 and there is a small chance of serious damage to the heart during this procedure. Biopsies are performed because of the risk posed by rejection to the function of your childs transplanted heart. Although other tests may give us clues that your child is 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 general anaesthetic (local anaesthetic for older children), the doctors will insert a small tube into a vein in the neck, or occasionally the groin. A sampling device (called a bioptome) will be used to take samples of tissue (2 to 3mm) from your childs heart. Most patients find this procedure slightly uncomfortable, but not painful. If your child is nervous about having this procedure please discuss this with the transplant 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 us to detect rejection and 'grade' the level of rejection that your child is experiencing. We can then select the most appropriate and effective treatment for them.

Remember

- The biopsies are usually undertaken as a day case once you have been discharged.
- Additional biopsies may be performed if your child is clinically unwell following a course of anti-rejection therapy
- Your child will require three cardiac biopsies in the first year. These biopsies are performed at 1 month (or before discharge home), 3 months and 6 months after transplant. Each child is treated on an individual basis, and in some cases their cardiac biopsies may be performed earlier or later than expected. This is done for clinical reasons that will be explained to you and your child at the time.

- After 12 months, biopsies are performed on the basis of individual and clinical need.

Complications of Cardiac Biopsy

Complications that could occur include:

- 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 your child will require admission to hospital for further treatment, which occasionally includes surgery. The risk of death is very low (less than 1% risk).

Angiography

Before you go home after a heart transplant, your child may need to undergo cardiac catheterisation (angiogram). This may be repeated as part of your child's follow-up care.

The procedure will re-assess function of your child's heart and is aimed at detecting any changes in the coronary arteries as early as possible.

After you have given consent, the procedure is carried out in the angiography department under a general anaesthetic (older children can request to have this under local anaesthetic) and a small catheter is passed, usually via the blood vessels in the groin and advanced to the heart under X-ray control.

In older children intravascular ultrasound (IVUS) is sometimes performed. This is an ultrasound of the inside of the artery. It is a very sensitive test and due to the equipment size required the test can usually only be performed on children over the age of 9 years.

Your child will be required to be 'nil-by-mouth' for up to six hours before the angiogram.

Afterwards your child will be required to stay in bed for four hours keeping their leg relatively still. This is not a painful procedure, but can cause some discomfort at the site of catheter insertion. Angiography is a routine procedure and serious complications are unusual. The commonest problem is bruising/bleeding around the point where the angiography catheter tube was inserted into the vessel.

Uncommon but potentially serious complications of angiography include:
- Heart damage (arteries or muscle)
- Irregularity of the heartbeat
- Damage to blood vessels caused by the catheter
- Kidney failure
- Cardiac arrest
- Death is very rare (less than 1%)

Infection

The immunosuppressive drugs that help prevent rejection will also make your child more likely to develop certain infections. The first three months after the transplant is when your child will be particularly at risk because they are taking immunosuppressive drugs in high doses. However, there is a continuing risk of infection for all transplant children.

Infections are usually caused by the following:
- Bacteria
- Viruses
- Fungi
- Protozoa

Warning signs of infection may include:
- Raised temperature
- Discoloured sputum production
- 'Flu like' symptoms, chills, aches, tiredness, headaches, dizziness
- Cough or shortness of breath
- Nausea and vomiting
- Diarrhoea
- Pain or burning on passing urine, increased frequency in passing urine, change in urine odour.
- Wounds or sores that will not heal and may be warm to the touch.

Bacterial infections can be treated with antibiotics. Usually 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.

It is important that you alert the transplant team if your child is commenced on antibiotics by your general practioner or any other health professional.

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 necessitate further surgery. Infection of the lungs may have a serious effect on your child's breathing and require vigorous treatment including antibiotics and physiotherapy. Blood-borne infections (septicaemia) will usually make your child 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 intensive care unit.

Cytomegalovirus

Cytomegalovirus (CMV) is the most common viral infection to affect patients after a transplant. CMV usually causes only a mild illness in healthy children but can cause a serious illness in patients who are immunosuppressed. 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 your child develops CMV infection they may need to be admitted to hospital for treatment.

Blood tests may be taken regularly for the first few months, following your child's transplant, to monitor their susceptibility to the infection. This allows treatment to be given early. If your child needs to have a blood transfusion at anytime following their transplant, the blood should be CMV negative, if they are CMV negative.

Aspergillus

Although rarely seen the most common serious fungal infection to affect patients following transplantation is called aspergillus. This also affects the lungs and can be a serious infection. Minor infections are treated with medication given via a nebuliser for two weeks, or oral medications such as itraconazole may also be used. Serious infections may need intravenous treatment with amphotericin.

Pneumocystis Jiroveci Pneumonia (PJP)

Another rare but serious infection that affects the lungs is PJP. This is treated with antibiotics.

Other Problems

Kidney Problems

The kidneys filter blood, remove waste products and regulate the fluid balance in your child's body. We monitor your child's kidney function by measuring levels of certain chemicals in the blood and urine.

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. We monitor how they are working during and after the operation by measuring the amount of urine your child is passing and the chemicals in their blood.

- The kidneys are also sensitive to some of the drugs your child is given, especially tacrolimus.

In some children a brief period of poor kidney function is common after the transplant operation. Usually this recovers quite quickly. In some patients kidney problems are also seen late after transplant (usually from tacrolimus toxicity). In these cases dialysis may be required in a few cases kidney transplant is undertaken.

Hypertension

Following transplantation many children develop high blood pressure. This is thought to be partly related to the immunosuppressive drugs. 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 child's blood pressure will be monitored regularly. For many children 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 medications your child is given, such as steroid therapy. The team will monitor your child's blood glucose and will provide you and your child with dietary advice, tablets or insulin, if needed. Although rare some children develop permanent diabetes after their transplant.

If your child is already diabetic, having a transplant may also upset their glucose levels and they may need their medication/insulin adjusted accordingly.

Lifestyle Issues

It is important that your child follow a healthy lifestyle after their transplant. This will benefit both their present and future medical status. Your child's medicines may make them prone to;

- High blood pressure
- High cholesterol
- Diabetes

Less Common Complications

The following section discusses some of the more rare complications associated with transplantation which, although affecting only a small minority of patients, can cause problems.

Gout

Some of the immunosuppressive medications can cause gout. This can be quite painful but it can be treated with medications. There are certain medications that your child may be unable to take for gout because of their immunosuppressive therapy. Please contact the transplant team before giving your child any treatment.

Osteoporosis

Osteoporosis, the bone thinning process, is associated with long term steroid use, poor diet and poor mobility. Your child may reduce the risk of osteoporosis by leading a healthy lifestyle after transplant this includes a healthy diet and plenty of exercise. Medication may also be necessary in some patients.

Cancer

Unfortunately immunosuppressed children are more prone to certain types of cancer, especially of the skin and lymph nodes (lymphoma). We will monitor your child as part of their follow-up care.

We advise all transplant children to avoid excessive sunlight exposure and particularly sunburn, which can increase the risk of cancer. Using a sunblock of at least SPF25 both at home and abroad is necessary.

Post transplant Lymphoproliferative Disorder - PTLD (also referred to as LPD)

A very small percentage of transplant children may develop this condition, which causes the lymph glands to become enlarged. A virus called Ebstein-Barr, similar to glandular fever, can often cause this. This is sometimes treated with a reduction in immunosuppressive therapy coupled with an increase in requirement for biopsies. PTLD can be treated with anti-cancer drugs (chemotherapy) and sometimes radiotherapy or surgery. Please contact your transplant team if you would like further information.

Neurological Problems (the brain and nerves)

Stroke (cerebrovascular accident)

This is a rare but serious complication of transplantation. While your child's 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. Brain damage can also occur if a child suffers a cardiac arrest (the heart stops, requiring resuscitation) before of after their transplant. It can be a while before the degree and extent of the damage is known. In some cases the effect of this damage is temporary but is some cases may be more permanent. Symptoms of a stroke include weakness down one side of the body, loss of sensation, difficulty with speech or vision.

Fits/convulsions

Certain drugs and chemical changes in the body can cause fits. High levels of tacrolimus have been known to cause fits in the early post-operative recovery period. By adjusting the level of medication and correcting the chemical imbalance the fits should resolve.

Rarely, infections of the brain can also cause problems including fits and so it is important to report any fits that your child may have.

Digestive Disorders

Constipation may occur as a side-effect of some of the drugs your child takes. It is important that your child drinks plenty of fluids, eats foods that are high in fibre, and takes laxatives if advised by a doctor.

Your child may develop gallstones following transplantation due to drug interactions. These may be treated with medications. However, rarely some children may require surgery.

Less commonly your child may develop an ulcer in their stomach. This may be caused by drug therapy, stress and/or infection. Many children are on preventative therapy to reduce the risk of this occurring.

Rarely children may experience serious problems such as bleeding or obstruction of the bowel.

Ask the Team

Please use this space to record any questions you may wish to ask your team.

……………………………………………………………………………………………

……………………………………………………………………………………………

……………………………………………………………………………………………

……………………………………………………………………………………………

……………………………………………………………………………………………

……………………………………………………………………………………………

……………………………………………………………………………………………

……………………………………………………………………………………………

……………………………………………………………………………………………

……………………………………………………………………………………………

……………………………………………………………………………………………

……………………………………………………………………………………………

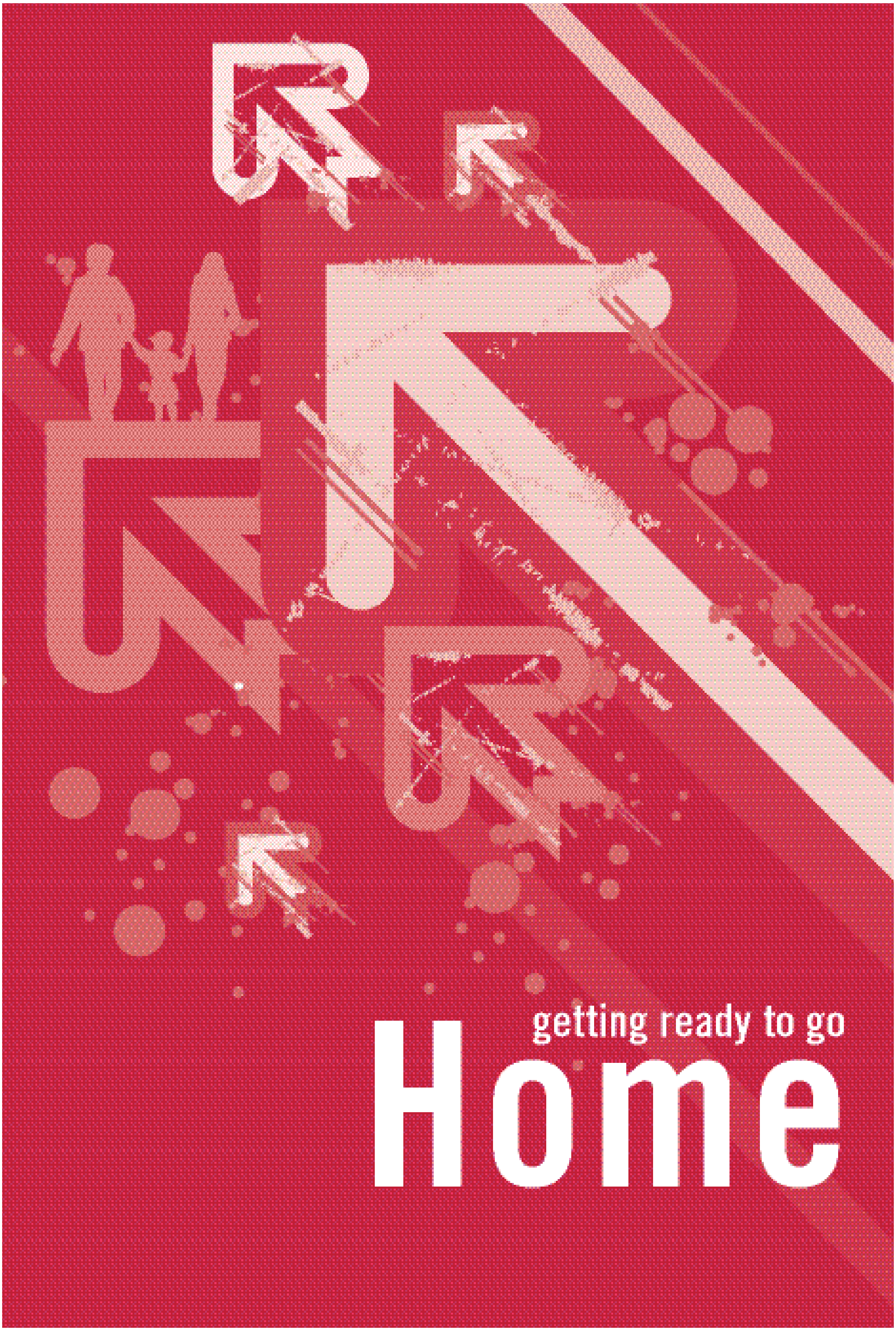
……………………………………………………………………………………………

……………………………………………………………………………………………

……………………………………………………………………………………………

……………………………………………………………………………………………

……………………………………………………………………………………………



getting ready to go
Home

Getting Ready to go Home

Everyone will respond differently after the transplant and this makes it difficult to predict how long your child will be in hospital, especially if they were very unwell before the surgery. As soon as your child feels well enough, and the staff are happy with your child's progress, your discharge date will be planned.

The transplant team will give you information throughout your child's stay. By the time your child is ready to go home you (and your child, if they are old enough) should be able to manage medications prescribed. You should also be able to recognise the signs and symptoms of rejection and infection and know what action to take if these problems occur.

Receiving a transplant will have already caused many changes in the life of you and your child. Your child may have altered expectations of themselves and may feel excited and happy, you will also likely have altered expectations of your child's abilities following the operation. However, on the other hand you and your child may feel stressed, confused, and even frightened. These are all perfectly normal feelings. It is important that you know that these feelings are normal and that there is someone from the team available to help, when you feel you want to talk.

During your child's admission the transplant team will be preparing you and your child for discharge home. The transplant team will answer any queries you may have about your child's follow-up. At this point you will be given your child's first outpatient appointment. You will also be given the transplant teams contact details.

Transplant Outpatients Clinic

During the first six months, return visits for check-ups are frequent (weekly then reducing to fortnightly, monthly and so on) and will include, ECHO, ECG and blood tests. If you live a long distance from the hospital you should think about how you will organise your visits. While you are getting used to medication strengths and dosages it is advisable to bring all of your child's medicines with you for clinic appointments. Also always bring your child's medication diary when you come for any hospital appointment.

- If you live a long distance from the hospital overnight accommodation may be available, but priority is given to children and families on the ward.

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

We will discuss with you how to contact us if your child is unwell or you are in need of advice, the contact numbers can be found at the front of this booklet.

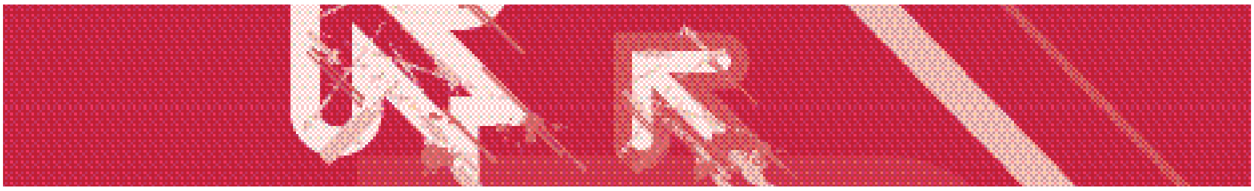
Remember

- You will be followed up for life by a transplant team. Eventually your child's routine visits will become much less frequent and you may be able to have 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 the transplant team during office hours. However, do not delay in reporting symptoms, there is always someone at the hospital to give you advice 24 hours a day seven days a week.

If your child is unwell always ring and speak to a doctor or nurse before coming to the clinic/hospital. By doing this, relevant tests can be organised in advanced.

The clinic may be very busy and we aim to provide a quick and efficient service, however, occasionally delays do occur due to circumstances beyond our control. It is best to leave the whole day flexible when you come to the clinic, especially in the first few months after your child's transplant.

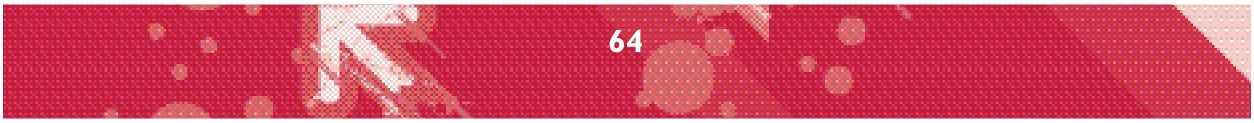


Blood Tests

Post-transplant your child will need regular blood tests to monitor for side-effects of the immunosuppressive therapy and to make sure that they maintain adequate immunosuppression to prevent rejection. Your child's medication doses may change following their blood tests. Tacrolimus blood levels are taken 12 hours from your child's last dose, therefore you will be asked not to give the morning dose

REMEMBER

Never run out of your transplant medication.
Do not give your child their immunosuppressive medications until aftertheir blood test. Bring them with you to give to your child afterwards.



Transplant Flats

Transplant flats are provided as a 'half-way house' for children and their parents who are not local but are well enough to be discharged from the hospital ward.

The flats are subject to availability.

All our accommodation and flats are limited and always in high demand however we try to meet all of our patients' needs as best we can. You may be asked to change accommodation from time to time although this may be unsettling we would appreciate your co-operation.

The flats are strictly no smoking zones.

Transport Home

It is important to consider how you will organise your own transport to and from hospital. Only in extreme circumstances the hospital will arrange transport to get you home, we need at least two days' notice to arrange this. You and your child's travel costs may be covered if you are receiving state benefits.

Medications

Prior to your child's discharge you will be given a supply of your child's medication. Your child's GP and local pharmacist need to be informed of the medication your child is taking on discharge. A letter will be sent to your child's GP informing him of your child's medications, for future supplies. Most GP's will supply the medications for you, but a few decline in which case the local hospital will usually supply them.

Ask the Team

Please use this space to record any questions you may wish to ask your team.

....

....

....

....

....

....

....

....

....

....

....

....

....

....

....

....

....

your Lifestyle

Learning to Adjust to Change

You will need to be prepared to make changes to your child's lifestyle. Initially your child may feel more tired, and it is a good idea to encourage your child to have short periods of rest every day, as they did in hospital for the first few weeks.

Being unwell prior to transplantation may have resulted in a loss of your child's confidence, and you may have lost some of your own confidence in parenting. Planning short-term goals may help to boost levels of confidence. This will help you and your child to feel more in control of rehabilitation. Getting into a routine again will help you to reduce your worries about your child's future health and going home. Keeping your child and yourself mentally active will help this process.

Wound Healing

It takes about eight weeks for the incision down the centre of the breastbone to heal, and it will take three to four months for your child to return to their normal strength. Your child may experience generalised aches and pains for some time.

A healthy lifestyle and exercise are as important as giving your child their medication to aid their full recovery.

The First Six Weeks

Do NOT

Play any contact sports or other activities that may put pressure on your child's incision.

Give your child medications, which have not been prescribed by the transplant team.

Children should avoid heavy lifting, pushing, pulling and over stretching.

Heart Rate Following a Heart Transplant

After transplantation your child's heart rate will be faster at rest. 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.

So What Does This Mean?

- Your child may have a resting heart rate of more than 100 beats per minute. This is normal.
- Your child cannot use their resting pulse rate as a measure of their fitness.

Appetite

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

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

Eating for Healing

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

If your child is underweight or your child's appetite was poor before their transplant, a higher calorie diet may be required. The hospital dietician may also provide additional information.

Eating for Health

To help your child maintain good health it is important for them to eat a healthy diet. Encourage your child to achieve a healthy weight for their height and try to prevent your child from gaining excess weight. Being overweight will increase your child's risk of high blood pressure, coronary artery disease, raised cholesterol and diabetes. Steroids may increase your child's appetite and lead to weight gain. This can be avoided by controlling your child's food intake and appetite. If your child has a good appetite, follow the advice given below.

- Provide your child with a well balanced diet which includes a wide variety of foods
- Your child should eat regularly. Aim for three meals per day
- Allow your child at least five portions of fruit and vegetables per day. A portion is a piece of fruit, three tablespoons of vegetables or a small bowl of salad
- Include starchy food at each meal. This includes bread, potatoes, rice or pasta.
- Give your child moderate portions of protein foods. These include meat, fish, 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 in your child's daily diet and see that they are low fat or reduced fat varieties

- Only give your child 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
- Fast food and take-aways should be a treat; try not to have these too often
- Avoid using too much salt. Only add small amounts if needed when cooking food. Do not allow your child to add salt at the table. A salt substitute should also be avoided. Try using other flavourings such as herbs and spices, black pepper or garlic
- Fluid - it is important for your child to drink well to keep them from becoming dehydrated.

Food Safety

Due to your child's immunosuppressive therapy your child is at an increased risk of food poisoning (food-borne infection). You can minimize your child's risk by following general food safety guidelines that would also be recommended for other 'at risk' groups. If your child is on immunosuppressive therapy, symptoms such as vomiting and diarrhoea will not be more severe. However, these symptoms may reduce the absorption of your child's immunosuppressive therapy, and therefore may increase your child's risk of rejection.

Take the following steps to make sure that food is safe to eat:

Shopping

- Check that packaging is intact and observe 'use-by' dates

Storing

- Keep your fridge at 0-50C. Your freezer should not be above -180C
- Store raw foods and cooked foods separately
- Observe 'best before' and 'use-by' dates
- Once opened use within the recommended period, usually three to five days

Preparation

- Ensure that hands are washed well

The whole family should do this before preparing food, after touching raw food, especially poultry and eggs, after touching animals, the rubbish bin and after using the toilet.

- Avoid cross-contamination by using separate chopping boards and knives for raw and cooked foods
- Keep your kitchen clean
- Do not use dishcloths

Cooking

- Cook all foods thoroughly, including meats. These should be cooked until above 750C or piping hot throughout
- For packed ready meals follow manufacturer's cooking instructions, particularly standing times when using microwaves
- Only reheat foods once. Ensure that it is piping hot all the way through.

	LOW RISK FOODS	HIGH RISK FOODS
Milk	Pasteurized, sterilized, tinned, dried, UHT milk. Pasteurized yoghurt, live (bio) yoghurt.	Unpasteurized cow, sheep and goat's milk. Unpasteurized yoghurt.
Cheese	Those made with pasteurized milk e.g. Austrian smoked, Babybel, Caerphilly, Cheddar, Cheshire, Derby, Edam, Emmental. Feta. Gloucester, Gouda, Gruyere, Halloumi, Leicester, Mozzarella, Paneer, cottage cheese, Boursin, cheese spreads, cream cheeses, Marscarpone, Ricotta. Other hard cheese e.g. Parmesan.*	'Blue'/ mouldy cheese or made with unpasteurized milk e.g. Brie, Camembert, Stilton, Cambazola, Lymeswold, Dolcelatte, Gorgonzola, Romano, Roquefort. If in doubt look on the label.
Eggs	Well cooked eggs, pasteurised, dried or liquid eggs. Mayonnaise. If you are in doubt - ask.	Raw or lightly cooked eggs or any food that contains raw or lightly cooked eggs e.g. tiramisu, home made mayonnaise, home made mousse.
Meat & Fish	Well cooked fresh/frozen /tinned fish, 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.

	LOW RISK FOODS	HIGH RISK FOODS
Fruit & Vegetables	Washed fresh fruit and vegetables. Tinned/frozen fruit and vegetables. Pre-packed coleslaw and potato salad.	Unwashed fruit and vegetables. Deli shop bought salads (e.g. coleslaw) Self service counters.
Other	Ice cream made with pasteurised milk	Soft ice creams

* 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.

- In the UK it is safe to drink tap water. If you plan to take your child abroad, you should discuss this issue with the Transplant Team.

Osteoporosis

To help to improve the health of your child's bones it is important to include good sources of calcium in your child's 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 child's transplant your child may have altered blood sugar levels. If your child is already diabetic your child's medications may need to be adjusted and you will need to continue with previous dietary advice for your child.

Your child's blood sugars may increase even if they were not diabetic before their transplant. If this happens you may need to change your child's diet and may be started on medication.

Smoking

Passive smoking can have a detrimental effect to your child's health especially if your child lives with a smoker. There are many sources of support for you to give up smoking to protect your child's health. Talk to the transplant team for advice. When your child is older they should never smoke.

Care of Teeth and Gums

For the first three months following your child' transplant, the dentist may give your child antibiotic cover if they need treatment. The transplant team can advise if required.

Oral thrush can 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 recommended as well as regular scaling and polishing.

Skin Care

Some of the medications your child is taking may leave them more susceptible to sunburn than other children. This increased susceptibility increases the risk of your child developing skin cancers. It is therefore important that your child wears a sun protection factor (SPF) of at least 25+ and avoids excessive exposure to strong sunlight. It is advised that your child refrains from deliberately sunbathing and using sun beds.

Optician

As with all children, we recommended that you take your child for an annual eye test.

Infertility

Some of the medications, such as valganciclovir and ganciclovir, can affect your child's fertility. Please talk to the medical staff for further information.

Holidays

We recommend that you do not travel abroad with your child within the first year following your child's transplant. Please discuss with the transplant team your choice of location in advance, as 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.

Prior to a journey, you may be asked to produce a medical letter for insurance purposes, stating that your child is fit to travel. Please give as much notice as possible for these requests (at least three weeks). It may be necessary to have a clinic visit before this is issued.

Additional vaccinations may be required for transplant children who plan to travel abroad. The transplant team may refer you to a 'travel clinic' for further advice. Always remember children who have had a transplant should NOT be given live vaccines

It is essential that you carry your child's immunosuppressive medications in your hand luggage. Ensure that you have more medication than you think your child will need for your trip.

When booking holiday insurance, please make sure the company is aware that your child has had a transplant; otherwise your policy will be invalid. Please ask for a list of suitable companies.

We would advise you to always insure your and your child's holiday's against last minute cancellations due to medical problems, and to make sure that you can fly home immediately should your child become unwell while you are out of the country.

We advise that your child avoid excessive exposure to sunlight. Never let your child become sun burnt after transplantation. Using a sun protection factor of at least SPF25 is recommended. Remember the risks - at home and abroad. The suns rays are often stronger in other countries.

Pets

Household pets are a potential source of bacteria and infection. Ensure that pets are kept healthy, for example wormed regularly and vaccinated. Practise good standards of hygiene. Keep them out of the kitchen and never allow them near foods or on worktops. Prepare your animal's food on a separate surface and with utensils specially kept for that purpose. Never use the same utensils or the same work surface for preparing food for human consumption. Avoid pets from licking your child's face and DO NOT allow dogs and cats in your child's bed. Encourage your child to wash their hands following each contact with a pet. Ideally pets should be kept outside the house.

- If possible DO NOT allow your child to clean out litter trays, but if necessary follow these instructions. Be careful when changing cat litter trays. Wood derived litter should not be used. Thick rubber gloves should be worn and hands should be washed immediately afterwards. Cats can carry toxoplasmosis, an infection that can affect immunosuppressed children.
- Medical staff have differing views on whether birds carry any risks to your child. In general birds are best avoided as pets. You will be given advice on this issue.

Transplant Rehabilitation

The rehabilitation process is geared to help your child gain maximum benefit from their transplant and ensure they maintain a healthy lifestyle.

The aims of rehabilitation are:

- To support you and your child through the lifestyle adjustments that you need to make.
- For you and your child to learn how to identify and minimise the risk factors associated with poor health.
- To develop an exercise programme for your child. The exercises will improve muscle tone and overall fitness. Many children find it easier to exercise as they often have more energy after their transplant. It is best to avoid contact sports for the first six months. After this time it is important that your child join in with school sport activities as they feel fit to. Being as fit as possible will ensure fewer health problems in the future.

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

Remember that anything is possible, some of our patients have completed the London Marathon and many have won medals at the Transplant Games.

A transplant doctor should see your child before starting any vigorous sports such as trampolining, squash, weight training or rugby.

Returning to School

The aim of transplant is to improve your child's quality of life and therefore we would expect that he/she should be able to return to full-time school by approximately 2-3 months after transplant. Children are individual in their needs, some children can cope with resuming full time schooling and some may require a more gradual approach such as half days to begin with. Your child is no longer considered to be unwell and so returning to school is considered a positive step towards adjusting to life post transplant.

It is always important to remember that your child may have missed a lot of schooling while they were unwell and may require time to catch up. If a significant period of schooling has been missed, your child may be given additional support at school to allow them to catch up with their year group. In some cases, although rare your child's school may request he/she repeat a year.

It is important for your child's physical and psychological well-being to encourage him/her to join in with physical activities at school. However we do suggest that contact sports, such as rugby, hockey, cricket and football, be avoided until approximately 6 months after transplant.

Prior to your child's return to school, a member of the transplant team will be happy to contact your child's school to discuss their return and allay any fears they may have about supporting your child's return to school. The process of returning to school can be an anxious time for you and your child; this may be the first time that your child has been well enough to attend school in months or even years. The transplant team will support you to manage this process in whatever way we can.

Other Points to Remember

- If possible keep your child away from people who are obviously sick with colds, chickenpox (unless immune) or other signs of infection.

- Be particular with your child's personal hygiene and check your child's skin for cuts, boils, bruises and so on.

- Good oral hygiene is important - (see 'Care of teeth and gums') - encourage your child to brush their teeth at least twice a day, check for bleeding or ulcers. Ensure your child visits a dentist at least twice per year.

- You will be advised that your child should avoid very crowded areas initially. Your child should gradually increase their integration so that by three months your child is socialising normally. Public transport is often necessary to attend hospital visits.

- If your child likes to dig in the garden, please ensure they wear thick protective gloves especially when dealing with soil because of the infection risk. it is advised not to work with manure and/or compost.

- Avoid excessive exposure of your child's skin to sunlight, as your child's skin is more sensitive because of the medications they are taking, this will put your child at more risk of skin cancer. Use a sunblock of at least SPF 25 for your child and avoid the possibility of sunburn.

- Due to an increased risk of air borne fungal infection avoid areas of construction wherever possible such as building sites.

Ask the Team

Please use this space to record any questions you may wish to ask your team.

....

....

....

....

....

....

....

....

....

....

....

....

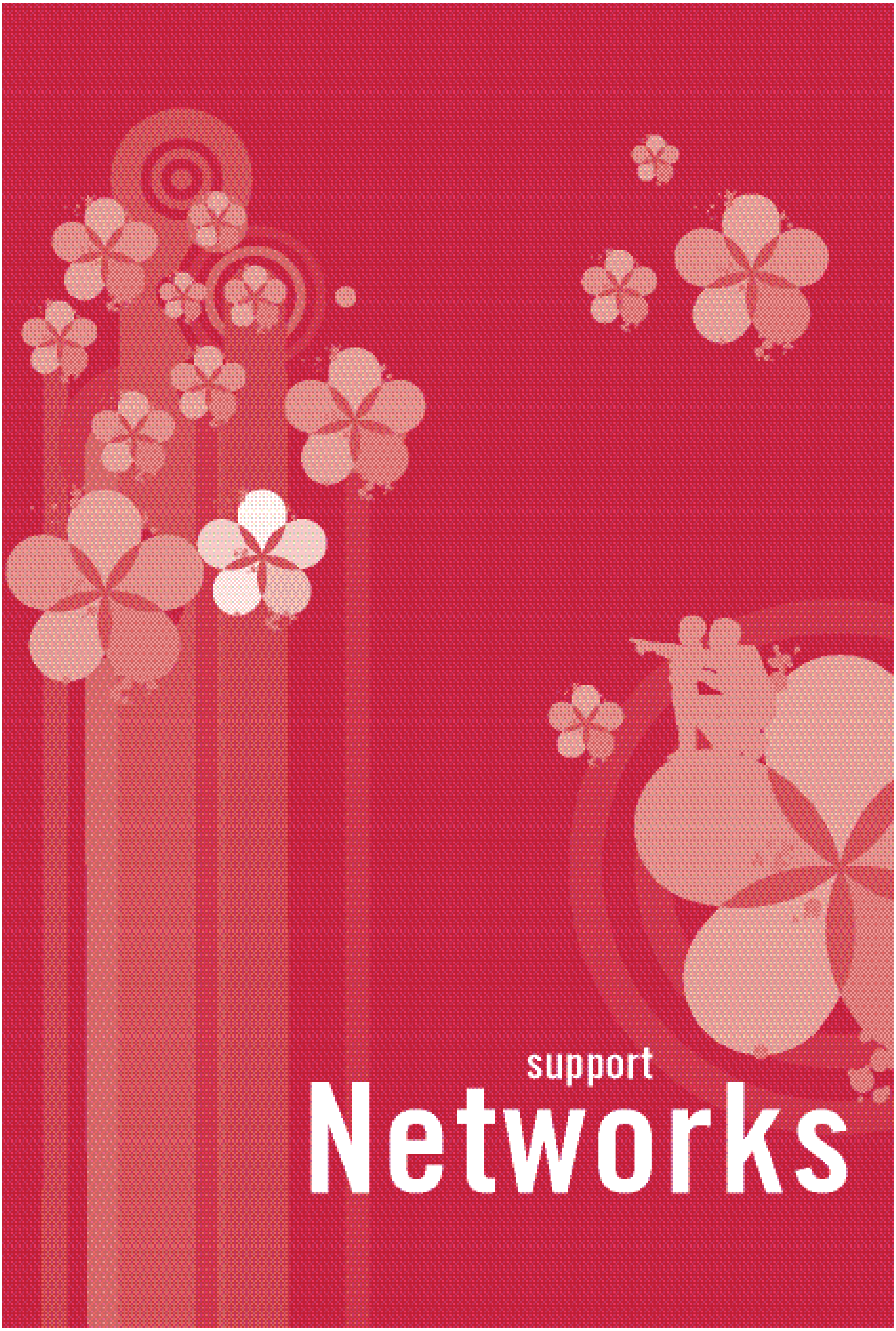
....

....

....

....

....



support Networks

Emotional Support After The Transplant

Undergoing a transplant is a time of great emotional and practical upheaval for children and their families, it is not unusual to experience worries and concerns of your own, and to observe similar in your child. The transplant team are here to help work through these issues, providing extra emotional support for your child, you and your family. The transplant team are here to support the whole family so that they can help your child cope with their life after transplant and help your child make a successful transition through their rehabilitation. So if your child, you or other family members are feeling worried, low in mood or needing emotional support at any time then please get in contact with us.

Support can be provided by
- Psychologists/ counsellors
- Specialist transplant nurses
- Social worker at referral centre or hospital

Religious Support

We endeavour to meet you and your child's religious, spiritual and cultural needs whilst in hospital. The local priest /minister regularly visits the ward. Great Ormond Street Hospital has a multi faith chapel located on level two.

Publicity

Many parents wish to contact the media to raise awareness of organ donation and therefore increase donation rates. However this does not necessarily follow hand in hand. Transplant can be an extremely trying period; this is why your transplant team may advise against media involvement at the time of transplant. Many families find that contacting the media at a later date (approximately three months after transplant) is a more appropriate and less stressful solution. To protect the donor family's privacy we ask that you do not mention the date of your child's transplant to the media.

Permission for media personnel to enter the hospital must be obtained from hospital management and your transplant team.

If at any time you are approached by media personnel the transplant team along with the hospitals press office can advise you on the best action.

The Donor Family

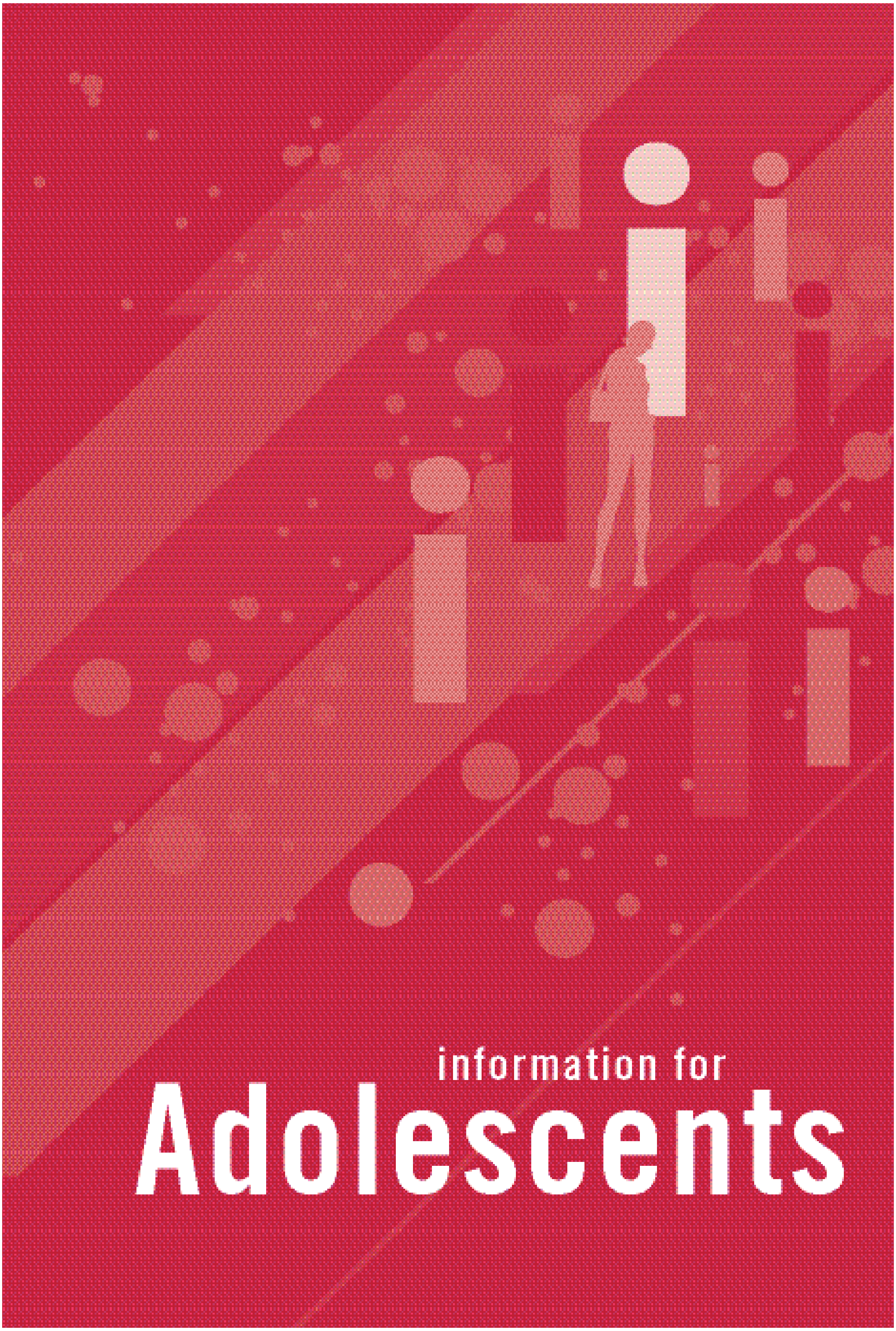
Once your child has recovered from their transplant it is only natural that you and your child might begin to wonder about the donor. You may also begin to think about the family of your child's donor. At some stage following your child's transplant, you may wish to find some way to thank this family.

Deciding to write to the donor family is a very personal decision. Some families simply send a thank you card. Some wish to write a longer letter. There is no right or wrong thing to do or say. We do however recommend that only first names be used in the letter. The letter should be sent to a member of the transplant team who will in turn forward it on appropriately. Only very limited general information will be given to you about your child's donor. Likewise only general information will be given to the donor family about you and your child.

You may not wish to know your child's donor details for some time after the transplant. You may not want to know at all. This to is a personal decision. You may get upset or feel sad when dealing with the donor information. This is normal and the transplant team will support you in your decisions.

Ask the Team

Please use this space to record any questions you may wish to ask your team.



information for
Adolescents

Smoking

We strongly advise you never smoke after transplantation. Passive smoking can also have a detrimental effect on your health especially if a parent or friend smokes in the house or car.

Alcohol (over 18 years of age)

Alcohol may be taken in moderation, one or two units per day.

A unit of alcohol is equivalent to:

- 1/2 pint of beer
- Single measure of spirits
- 125ml glass of wine

Excessive alcohol is not recommended as it can interfere with the absorption of the immunosuppressive drugs 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 build up to 30 minutes of moderate intensity physical activity (activity that makes you mildly short of breath) each day. If you require information regarding exercise please contact the transplant team, the transplant physiotherapist will be able to give you some suggestions.

Contraception

The oral contraceptive pill is the recommended method of contraception. The Progesterone-only pill is preferable as this is less likely to affect your immunosuppression 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. Please refer to your transplant team for advice.

Liver and renal function, together with immunosuppression 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.

Your immunosuppression medication may make the oral contraceptive pill less effective in preventing pregnancy, therefore we suggest you also use a barrier method such as a condom.

Remember the oral contraceptive pill will not prevent sexually transmitted diseases, it is advisable to always use barrier method such as a condom to prevent transmission of sexually transmitted diseases.

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.

If you are considering becoming pregnant you must discuss this with one of the transplant team, so that you can be fully informed of the risks involved and plan the best way to manage your pregnancy. Some of the drugs used after transplantation can cause abnormality in the unborn child and these risks should be considered.

Due to exposure from X-rays, post-transplant, you must inform the nursing/medical staff if you think, or have any suspicion, that you may be pregnant as soon as possible.

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

Infertility

Some of the medications, such as gancyclovir, can affect your fertility. Please talk to the transplant team for further information.

Driving

You will be unable to drive for at least six to twelve weeks after a transplant. The transplant doctors will decide when you are fit enough to recommence driving.

It is not necessary to inform the DVLA that you have had a transplant, 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 will apply.

Adherence

Teenagers tend to lead a busy life and may inadvertently just forget medications.

- If you find it hard to remember to take your medicines speak to the transplant team who can offer you suggestions that will help you to keep up with your medication routine.

Some teenagers find that moving from secondary school to college/work upsets usual medication routines and subsequently may miss some doses of their immunosuppressive medications.

- It is important that your medications remain an important part of your daily routine, and that medicines are taken at regular intervals.

Some teenagers who had their transplant when they were very young may not fully appreciate the importance of their immunosuppressive medicines. They may therefore feel well and stop taking their medicines.

- Ensure you are medically aware of what your transplant means to you.
- Never stop taking your immunosuppressive medications, even if you feel well.

It is important that you as a teenager are allowed to take guided responsibility for your medications, eventually leading to full independence. This will aid the transition from child services to adult services.

Not adhering to your medication regimen can compromise the health of your transplanted organ. This can result in death.

Transition

Young adults who have undergone a heart transplant, as a child will have to transfer to an adult centre prior to turning 18 for their continuing specialist care. Transition is a gradual, planned process, not a one off event. Doctors and other members of the paediatric transplant team will take time with the other team to ensure that young adolescents are fully prepared and ready for the move to an adult centre.

As a young adolescent you will need to become more involved in decisions about your care and treatment. This will start as early as possible in the paediatric unit, with informal discussions at about 13 to 14 years of age, with active preparations beginning around 16 years of age. The transplant doctors will begin by allowing an outpatient consultation to be directed more to you than to your parents. You will have the opportunity to talk to your consultant by yourself. You will be provided with the opportunity to ask questions and be given plenty of time to think around the issue of transition.

Eventually you will have to balance the demands of health and treatment with conflicting demands of education, career, social life and relationships. It is important to remember the transplant team are there to support you to explore and understand your feelings, opinions and attitudes towards your health and treatment. You may find comfort in with the knowledge that this will be done within a supportive and familiar paediatric team before your transition to an adult centre is completed.

Ask the Team

Please use this space to record any questions you may wish to ask your team.

....

....

....

....

....

....

....

....

....

....

....

....

....

....

....

....

....

personal Perspectives

Patients Perspective

“Hi, I'm Olivia and I had my transplant when I was 12 years old. My cardiomyopathy began in May 2002, just after my brother's birthday. What I remember of the 5 months I was ill is that I was always really tired even though I didn't do anything. Moreover, I was always vomiting, even if I ate a small piece of food. I could only really drink water and even this, in small sips. It got to the point when I felt I was completely helpless.

When my mum got the phone call that a heart was found for me I was sure that I did not want the transplant, despite all the pain I was suffering. I knew I was on the waiting list but I never thought I would be found a heart, because the thought that I would have a transplant seemed so surreal. Panic was all around me as my mum dashed up and down the stairs getting clothes and other things ready. My brother was shouting asking what was going on. I remember feeling so shocked and scared that I couldn't say anything and was completely numb. I just curled up in a ball on the sofa shaking. (I may also have been extremely worried because it was Friday 13th!!)

At the hospital tension increased as a whole host of doctors and other important people filed into the ward and towards the bed where I was sitting. Strangely I became calmer after a while, playing a game on the TV and talking to relatives who had decided to come and visit helped. I don't remember what happened after this, but after the operation I remember waking up slowly and feeling as though I was screaming at the top of my lungs asking if it was over, before hearing the much-awaited 'Yes!' from my mum…

My recovery was smooth and welcoming. Even though I was in hospital for about 5 weeks and had to learn to walk again. I couldn't believe how much better I felt after the operation. Early on after the operation I was always waiting to vomit or complain that I was tired but this time never came and it was such a relief for my parents and me. During recovery I listened to a lot of songs with the themes of motivation and determination, sounds cheesy I know but it really helped to give me encouragement and be a positive person. Even throughout my illness I can honestly say I generally had a positive attitude and I believe that seeing things in an optimistic light is very important when things are not going as planned.

Now I only go to the hospital every 3 months and am on very little medication, which I have to have for the rest of my life, but I would rather this than go back to the life I had before the operation. I am now 16 years old, in year 12 and studying for my AS levels in Chemistry, Biology, English, German and Critical Thinking.

So remember to be positive, never give up, keep listening to Enrique Iglesias and I promise you will reach the end of the tunnel and get better. There is always going to be some fear and apprehension in the back of your mind but try not to let it get the better of you. Having a heart transplant is always going to be scary but the results are remarkable and you'll notice that immediately and life again becomes loads more interesting and enjoyable. ”

Parents Perspective

“My daughter was admitted to Great Ormond Street Hospital suffering from cardiomyopathy. From the onset of her stay there I knew she was in the best place. I never felt I was on my own and was supported throughout by the transplant team who explained to us the procedure, facts and treatment my daughter was going to receive. As a result of heart failure her body had become puffy as her tissues were filling with water. She was put on diuretics and other drugs to regulate her blood pressure.

As a mother it is a harrowing experience to see your child strapped to all types of medical equipment and monitors bleeping all the time. The consultant treating her told us that her heart wasn't pumping efficiently and that there was the likelihood that she would need a transplant. She was given three months to see if there was any improvement in her condition. She was very lethargic and still suffered from bouts of nausea and vomiting. It was a struggle to maintain her weight, and it was increasingly stressful and painful to see my daughter literally becoming a skeleton.

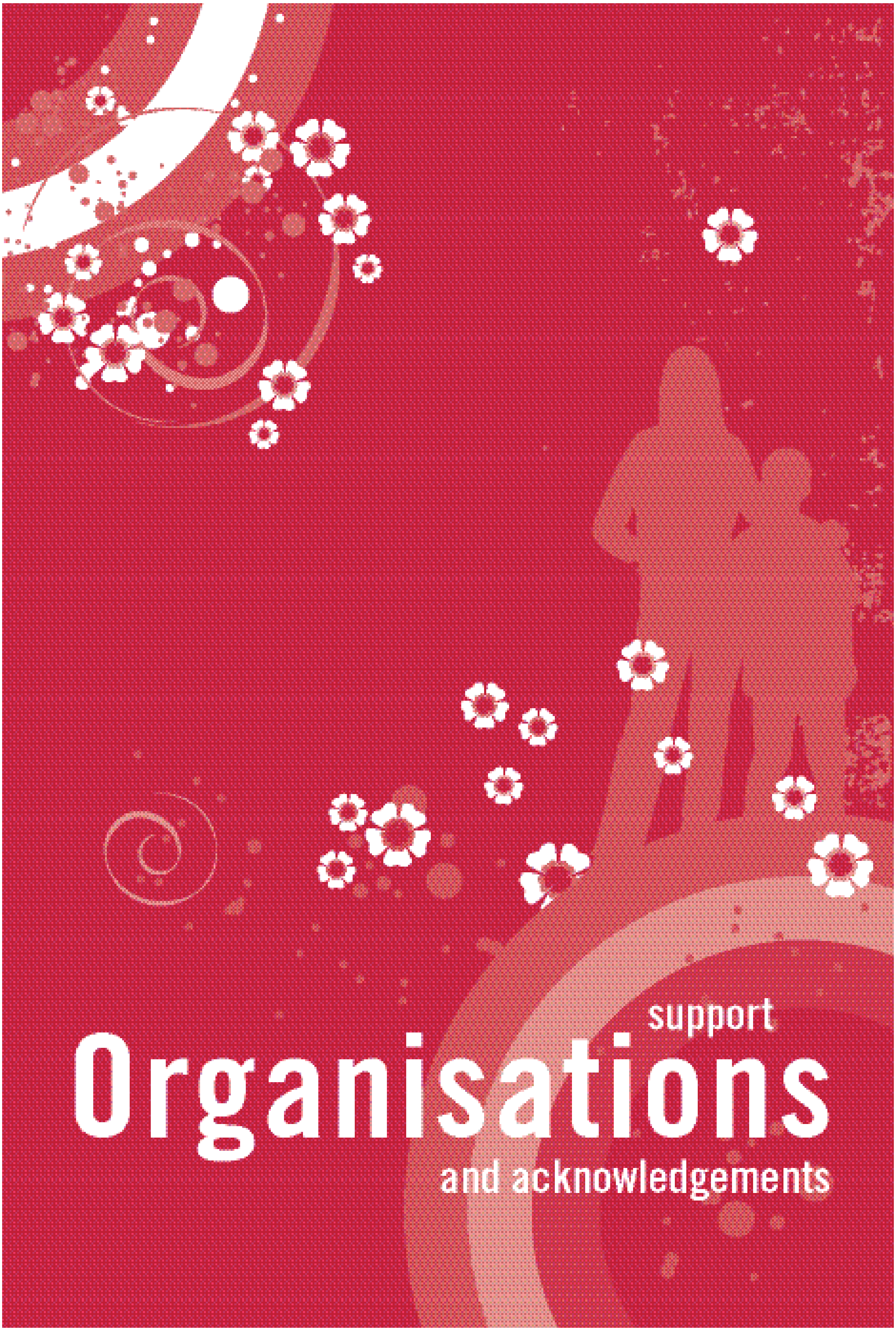
Towards the end of the three months my daughter was quite ill and was monitored regularly. Then the consultants gave us the news we dreaded: that she would definitely need a transplant. Your life just stops - here was my beautiful, gifted daughter who loved playing the piano and writing lovely poetry, who was now suddenly on the brink of death. It took days for me to accept this news and I went through a lot of soul-searching and also a lot of anger as to why it was happening to our daughter and us. But somehow you find the strength to carry on and you can only hope that things will get better.

I found it ironic that somebody's death meant life for someone else. I had never before thought of becoming a donor and had I not been put in this situation I probably never would have. I think that it is the pain and suffering you yourself experience that actually makes you understand the suffering of other people. This has made us more humble and we see life through a different perspective.

God answered our prayers and within a week a heart was found. It was a scary moment because although you are happy you are also afraid of the outcome. My daughter had an eight-hour operation and was in intensive care for about one week. She was looked after by a brilliant Team. I will be forever indebted to these wonderful people who looked after and monitored my daughter day and night.

When my daughter came out of intensive care she made good progress on the ward. She learnt to walk again and gradually built up her strength. She was put on many different drugs and it took me a while to get to know all the different medicines and how they worked. I never thought I would be able to manage without the nurses' constant guidance, although it is amazing how you learn to cope.

My daughter has just completed her GCSE's with flying colours, even though she missed six months of schoolwork. She goes to hospital every three months for a daylong check-up and has a yearly review. I would tell every parent to be positive, even though it is very hard, but believe me there is always light at the end of the tunnel - my daughter is proof of this. ”



support Organisations and acknowledgements

Support Organisations

NHS Donor Register
Freepost SWB 1474
Patchway
Bristol
BS34 8ZZ
Tel: 0845 6060400
www.uktransplant.org.uk

British Heart Foundation
14 Fitzhardinge Street
London
W1H 6DH
Tel: 020 7935 0185
www.bhf.org.uk

British Lung Foundation
73-75 Goswell Road
London
EC1 7ER
Tel: 020 7688 5555
www.britishheartfoundation.com

National Kidney Foundation
6 Stanley Street
Worksop North
Nottingham
S81 7HX
Tel: 01909 487 795
www.kidney.org.uk

United Kingdom Transplant
Fox Den Road
Stoke Gifford
Bristol
BS34 8RR
Tel: 0117 975 7575
www.uktransplant.org.uk

National Transplant Information Service
P.O. Box 326
Richmond
Surrey
TW9 1FY
Tel: 020 8332 2536

British Organ Donor Society (BODY)
Balsham
Cambridge
CB1 6DL
Tel: 01223 893 636
www.argonet.co.uk/body

Transplants in Mind (TIME)
Fox Den Road
Stoke Gifford
Bristol
BS34 8RR
Tel: 0117 931 4638
www.timeinmind.org.uk

Cystic Fibrosis Trust
11 London Road
Bromley
Kent
BR1 1BY
Tel: 020 8464 7211
www.cftrust.org.uk

The Cardiomyopathy Association
40 The Metro Centre
Tolpits Lane
Watford
Herts
WD18 9SB
Freephone: 0800 018 1024
www.cardiomyopathy.org

Children's Heart Federation
52 Kennington Oval
London
SE11 5SW
Freephone 0808 808 5000
www.childrens-heart-fed.org.uk

GUCH Patients Association
75 Tuddenham Avenue
Ipswich
Suffolk
IP4 2HG
Helpline: 0800 854759
www.guch.org.uk

Contact a Family
209-211 City Road
London
EC1V 1JN
Tel: (020) 7608 8700
www.cafamily.org.uk

GIFT - the children's transplant charity
(Formally - Heart Transplant Families Together)
36 Guildford Road
Worthing
West Sussex
BN14 7LL
Tel: 08450945810
Fax: 01903606826
www.htft.org.uk

Transplant Support Network (TSN)
6 Kings Meadow Drive
Wetherby
West Yorkshire
LS22 7FS
Tel: 01937585434
Helpline: 0800 027 4490/1
Email: tsnetwork@tiscali.co.uk
www.transplantsupportnetwork.org.uk

CRUSE Bereavement
CRUSE House
126 Sheen Road
Richmond
Surrey
TW9 1UR
Tel: 020 8939 9530
Helpline: 0870 167 1677
www.crusebereavementcare.org.uk

Association of Children's Hospices
First Floor
Canningford House
38 Victoria Street
Bristol
BS1 6BY
Tel: 0117 989 7820
www.childhospice.org.uk

Child Death Helpline
Great Ormond Street Hospital
Great Ormond Street
London
WC1N 3JH
Tel: 020 7813 8551
www.childdeathhelpline.org.uk

Transplant Adventure Camps for Kids
TACKERS
Case Postale12
1972 Anzere
Switzerland
Tel: 0207 871 0098
www.tackers.org

Transplant Sports Association
TSUK
Highcroft
Romsey Road
Winchester
SO22 5DH
Tel 01962 865030
email: tsagb@tsagb.org

Transplant Kids
www.transplantkids.co.uk
info@transplantkids.co.uk

Department for Work and Pensions
www.dwp.gov.uk
Freephone Benefits Helpline
Tel: 0800 052 3266

The Experience Journal
Boston Childrens Hospital
www.experiencejournal.com
An excellent information resource
for children and their parents

Gingerbread
307 Borough Highstreet
London
SE1 1JH
Tel: 020 7403 9500
www.gingerbread.org.uk

Acknowledgements

The transplant team would like to thank those families who have shared their personal experiences of transplant in order to help other families in similar circumstances.

This booklet has been a collaborative venture between the members of the transplant team, other health professionals and families.

Some of the information and diagrams have been adapted from the adult heart transplant information booklet. The Great Ormond Street Hospital cardiothoracic transplant team wish to acknowledge the role of the adult transplant centres.

This document was produced with an unrestricted educational grant provided by Astellas Pharma Limited.