



EDUCATING CHILDREN WITH CARDIAC CONDITIONS

Information for Teachers

by

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and
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Principal Sponsor



**We dedicate this book to all those special children
with cardiac conditions.**

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INTRODUCTION

This booklet has been written by Teresa Kedzlie, teacher in the paediatric cardiology unit at Green Lane Hospital and Mary Crosbie, a parent of a child with a cardiac condition.

It is aimed to help teachers of children with cardiac conditions.

The information is presented in general terms because the implications of treatment and side effects will vary with individuals.

Children with cardiac conditions like to feel that they are no different from their classmates and as far as possible, should be treated the same as their peers. However, their condition may have some impact on their schooling. If the condition is minor they will be no different from their class mates, however a major condition will have some impact. A major cardiac condition can be an “invisible” disability.

CONGENITAL HEART DEFECTS

The word “congenital” means that the condition is present from birth.

In New Zealand almost one baby in 100 has a congenital heart defect. It is therefore one of the more common congenital conditions.

About half the children who have congenital heart disorders will require surgery to correct the problem. Some congenital heart defects correct themselves with time, and others are so minor they do not need any active treatment. Children with minor defects are able to lead an entirely unrestricted life.

TYPES OF CONGENITAL HEART DEFECTS

There is a wide range of congenital heart conditions which means

that no child can be expected to be treated in the same way as another.

A hole in the heart is the most common type of congenital heart defect. In some forms of congenital heart defects arterial blood (red) mixes with venous blood (blue) through a hole in the wall which divides the left side of the heart from the right side. This wall is called a septum. A hole in the wall between the two upper chambers of the heart is called an atrial septal defect (ASD). A hole in the wall between the two main pumping chambers in the heart is called a ventricular septal defect (VSD). Because pressures on the arterial side of the heart are higher, blood passes through the hole to the venous side producing a high flow through the lungs. Where the hole is large this will make the patient breathless. On the other hand, if there is some obstruction in the pathway to the lungs, blue blood will pass through the hole to the arterial side and the patient will appear blue in the lips, tongue and skin.

Some congenital heart disorders occur when the valves between the upper and lower chambers in the heart are defective. Other valves at the outlet of the main pumping chambers may also be incorrectly formed or even absent.

Some of the defects can be so complex that surgical correction is not possible. These can involve abnormal connections of arteries with chambers or underdevelopment of one side of the heart.

OUTLOOK AND MANAGEMENT

Many children with severe heart conditions will have had corrective surgery well before they start school.

Some congenital heart conditions require a series of operations over several years and this series may not be completed by the time the child starts school. Most children with cardiac conditions will limit their own activity and there is no need for restraint from an adult.

However there are some patients in whom vigorous exercise may have an adverse effect, even though these children may appear outwardly normal. The cardiologist will always alert the parent/caregiver of these children, to any dangers from exercise. Children with major congenital cardiac conditions, which have not been surgically corrected, are likely to tire more quickly than other children. Many of these children will become breathless more quickly and in some, their lips and skin will become blue. They should then be allowed to rest.

Parents/caregivers are always advised that children should not be allowed to grow up believing themselves to be more delicate and therefore different from others. Most of these children can lead ordinary childhood lives and attend ordinary schools. Teachers are often worried about how much these children should be allowed to do in the way of exercise, games etc. Children with cardiac conditions are sensible and can be allowed, almost always, to limit their own activity without restraint from an adult. There are very few conditions when the child will be advised not to be too active. Swimming and cycling are both acceptable, with the normal precautions for any child.

In cold weather, children with major heart conditions will get breathless more quickly. As they cannot run around for long periods to keep warm, they may need to be given the opportunity to stay in a warm place during break and lunch time periods. This usually needs to be an unobtrusive arrangement, so that the child does not feel singled out as being different to others. Parents/caregivers will know how much cold weather their child can tolerate. The inconvenience of arranging for a child to stay inside school during some of the break times, seems a small price to pay for giving a child, who in every other respect is "normal", the opportunity to attend a normal school. It is important to note that common illnesses such as colds will possibly be more severe for a child with a major cardiac condition.

If due to illness, a child is absent from school for a significant length of time, provide work and encouragement and have children or a staff member keep contact with them. Provide class news and

information from school.

While some congenital heart conditions are associated with other conditions like Downs Syndrome which may affect learning ability, in most cases there is no medical reason why children with heart conditions should not progress at the same pace as their peers. However, because children with serious problems tend to tire more quickly, some may seem to have problems concentrating and therefore appear to be slower. This may become particularly apparent just before a child is due to have an operation. What is perhaps most remarkable is the difference in children **AFTER** a successful operation.

However, each child is different and will progress at a different rate. Some children can have a full repair, but others may only be able to have palliative surgery and still have physical limitations. It is not possible to judge how a child will behave from the experience of another whose condition appears similar. It is important to find out what each child can do by consulting with the parent/caregiver or, with their consent, the doctors. It is also important to be aware of the impact that hospitalisation has on the child. Children can react quite differently to stressful experiences such as hospital visits, surgery and blood tests.

The Particular Problems of a Child after an Operation

A child after an operation will quickly look and feel much better as the heart will now be able to supply enough blood to the body. Convalescence usually takes two to four weeks before a child will be able to return to school, initially for half days.

Sport and Physical Education

Children may be particularly sensitive about their surgical scar and consideration needs to be given to this at times like swimming and other sports. The teacher may find it worthwhile to discuss with the parent/caregiver how best to handle this problem, especially if the

child is exceptionally shy about undressing with other children. It may be necessary to prepare the other children in the class and talk about the reasons for the scar.

As it takes about six weeks for the sternum or breast bone to heal, children should not jump on trampolines, ride bikes or climb to great heights during that time.

After corrective heart surgery, many children will have normal exercise capacity and can participate in all activities. Children who have had palliative surgery or incomplete repairs may not be as active as their peers and participation in some activities like cross country running, may not be possible. Teachers should encourage children to participate in activities up to their own level but not force them to do more than they can manage comfortably. In other words, participation in sporting activities should be for fun rather than to win. After major heart surgery, parents/caregivers will have been told to steer their children away from competitive sports.

For about two months after surgery it is important that care is taken to protect the child from any knocks to their wound area.

The Risk of the Child Suddenly Collapsing with a "Heart Attack"

This is probably the teacher's greatest, if unvoiced, concern about a child with a heart condition in their class. There is a very small chance (about 1%) of a major, sometime fatal sudden collapse, after some types of major heart surgery in childhood. If the risk is thought by the heart specialist to be higher than this, then specific exercise restriction will have been recommended. Examples include children awaiting heart surgery for "aortic stenosis" or children with "prolonged QT syndrome", a very rare condition prone to rapid heart beat (arrhythmia) induced by exercise.

Heart attacks occur in adults when insufficient blood gets to the heart muscle, because the coronary arteries are narrowed or get blocked. Children with heart conditions are not at risk of these types of heart attacks.

Some children have heart conditions with a very slow pulse or very fast pulse, which can cause them to faint. This may be corrected with a pacemaker - a tiny battery powered machine which stimulates the heart to beat faster and which is sewn in under the skin of the chest. It is however, important that teachers update their CPR certificate and are therefore prepared in the event of an emergency.

The most likely condition that a teacher will have to cope with, is a child who becomes very breathless and blue, greyish or pale with stress or exercise. The first treatment is to allow the child to rest, lying down or sitting up if they are more comfortable that way, until they improve. If these simple measures do not alleviate the problem then medical help should be sought.

"Heart Failure" is a term that is bandied around and many lay people, including parents/caregivers, think that this is synonymous with "heart attack". In fact, it means no more than the heart is unable to fulfil the demands made on it by the body, and a child may be in "heart failure" if they are very breathless. The immediate treatment again involves reducing the body's demands on the heart by allowing the child to rest.

It is important that the school has contact telephone numbers for the child's parent/caregiver and G.P.

Where To Go for More Information

Because there is such a variety of congenital heart disorders, G.P.'s, Public Health Nurses and School Nurses may not have met many children with these conditions and indeed may have common misconceptions about their care and needs. The best people to provide information about the child are the parents/caregivers themselves. They have been living with the child's condition for at least five years and may have seen them through an operation or different investigations and treatment.

If teachers feel they need further information about the child they should seek the parent/caregiver's permission to contact the general practitioner or the cardiologist. From time to time, seminars are held at Green Lane Hospital for educators of children with cardiac conditions. Contact the teacher, Ward Nine, Green Lane Hospital for further information.

ACQUIRED HEART DISEASE

Acquired heart disease can have symptoms similar to congenital heart defects, including breathlessness and tiredness.

Rheumatic Fever

There is an old saying that rheumatic fever licks the joints but bites the heart.

It is primarily a disease of children between the ages of 7 and 14, although cases can occur much younger and also into the 20's. It starts as a throat infection due to a particular class of bacteria, the **STREPTOCOCCUS**. Most streptococcal throat infections respond quickly to penicillin and do not affect other organs, but a few children are sensitive to the organism and a more generalised disease, rheumatic fever, follows a week or more later. The organism is still confined to the throat but its effects are felt elsewhere.

Rheumatic fever causes the membrane around the joints and heart valves to become swollen and inflamed. Joint pains may be very severe but after a while the swelling goes down and the joints recover completely. Characteristic skin rashes and uncontrolled jerking movements may also be present. Abnormal noises (murmurs) may be heard from the heart valves. Some persist once the disease is finished, and when the valve inflammation is severe, the valves may be permanently damaged. A period of rest in hospital, sometimes three months or more, is required to settle the

inflammation. Occasionally, emergency surgery is required for a very bad attack.

Long term treatment with penicillin is required to ensure that there is no further infection with a streptococcus, as this may cause further rheumatic fever with very high risk of further valve damage. Usually, this means a penicillin injection every 28 days for many years. The District Nurse often administers the injection and it is important that she be advised of any change of address or school.

Rheumatic fever with cardiac involvement can affect the child's level of physical activity. If the valve disease is serious it means no competitive sport or strenuous physical activity. Children can still be involved in activities by being assigned the tasks of time keeper, recorder or even holding the finishing ribbon, and moderate rather than extreme exercise, is still encouraged.

There can be dietary restrictions for children with cardiac conditions such as low fat/low salt diets.

Again, it is important to communicate with the parent/caregiver as to what physical activity the child can do and also if there are any special dietary requirements.

Endocarditis

A child with congenital disease, or a child whose heart has been damaged by rheumatic fever, and sometimes a child who has had an operation to correct a heart defect, may be at risk from endocarditis.

Endocarditis is an infection sited inside the heart, usually on a faulty valve or other defect. It usually starts as a flu-like illness but it is serious and requires many weeks of treatment with antibiotics.

Endocarditis can be caused by bacteria entering the blood stream through the teeth or gums. Good dental hygiene and antibiotic cover for dental treatment is vital. It is important that the School Dental

Nurse and Dentist know about any child's heart problem.

WHEN A SCHOOL CHILD IS IN HOSPITAL

The Role of the Hospital School

The Green Lane Hospital Class is based in Ward 9. It is a unit attached to Cornwall Park School. The school provides an education service for children who are in hospital. Special arrangements can be made for siblings to attend, if this is of assistance to the family. When in hospital, a child may receive educational assistance in either the classroom or in the ward.

Children come from all over New Zealand and the South West Pacific.

While school-aged children are in hospital, educational support contributes to their care and assists in recovery. It may be necessary to continue this support after the child is discharged and is being treated as an outpatient.

The teacher of the Green Lane Hospital Class is experienced with the range of conditions treated at Green Lane Hospital, and is able to support children and assist teachers in the transition from hospital to their usual school. The liaison with schools is in response to the demonstrated needs of the children who are served by the hospital, and is not restricted by area boundaries.

Green Lane Hospital School features:

- * children from New Entrants to Form 7
- * individualised programmes
- * hours to suit child's condition, medical treatments and hospital routines
- * liaison with the child's home school

- * support for parents/caregivers and teachers (conferences, school visits and publications)
- * liaison with medical personnel and allied health professionals
- * professional development activities for education personnel about cardiac conditions
- * enrolment, when necessary, into Correspondence School

The Role of the Hospital Teacher

The hospital teacher of the child with a cardiac condition has an important role:

- * as a link to the world outside the hospital
- * as a friend
- * to provide a therapeutic programme aiming to alleviate anxieties about hospitalisation
- * to act as a distraction away from illness
- * to provide continuity in their schooling
- * to pick up on and remediate any weak areas or extend any strengths
- * as a source of support and reassurance
- * as the one who will arrange re-entry into the home school

School is important for children in hospital. It is a link to “normality”. It is important that they continue with schoolwork taking into account their medical condition.

When a Child is in Hospital

Hospital schooling exists to enable children to cope with ongoing education and to endeavour to fill some of the gaps which otherwise occur. When a child is due to come into hospital for a heart operation, it is a good idea for the child’s teacher to provide some school work. This enables the hospital’s teacher to gain an idea of the stage reached by the child.

Children with cardiac conditions often have a very real fear of getting behind with their school work and not understanding what is going on when they get back to school.

When they leave hospital they may be at home convalescing for a while and this needs to be borne in mind when planning work.

You can expect communication from the hospital school if the child with a cardiac condition is to be in hospital more than a couple of weeks, so that a realistic programme can be developed to meet special needs at the time. With the information provided by the home school and suitable assessment by the Hospital Teacher, an Individual Education Plan (IEP) will be designed for the child. The Hospital Teacher tries as much as possible to plan a programme similar to the usual school one.

If convalescence at home is to be long term, or the child is of secondary school age, the medical team may advise enrolment with the Correspondence School. The hospital school may organise this and liaise with both the home school and Correspondence School to set up a suitable programme. It is possible that the programme be reduced as the child may be unlikely to handle a full one.

Keeping In Touch

Good communication between the child, family and the home school is vital to the child's happiness and success. It is recommended that this be co-ordinated by the school guidance department or class teacher as they can take a broad view of the child's needs. It may be felt that peer support would be enhanced by full understanding of cardiac conditions, by other children in the class.

It is very important that a child in hospital is not forgotten by their classmates back at school. Some simple ideas for maintaining the link are:

- ⇒ photographs - a class photo, photocopied and enlarged

- ⇒ notices about class/school events
- ⇒ a small souvenir from a school trip
- ⇒ a large card with contributions from everyone
- ⇒ a newspaper clipping about school events
- ⇒ the current best classroom jokes
- ⇒ a video the class has enjoyed
- ⇒ a class made video
- ⇒ class news items recorded on a tape
- ⇒ letters and cards

In writing this booklet we found some of the ideas from the school re-entry programme, by the Child Cancer Foundation, to be excellent (see bibliography).

Telephone and fax messages are always welcome:-

Green Lane Hospital Ward 9 Fax number is: (09) 630 9792

Green Lane Hospital Class phone number is: (09) 638 9909
ext.4351

Visiting

It can be overwhelming if too many visitors arrive at once, so spread the visits. It is important for classmates to contact the family to arrange visiting rosters and to make sure visiting is allowed and appreciated. Visits do provide very important social contact for the sick child.

Visits to the child in hospital should be encouraged to maintain links and contacts. Teachers are encouraged to visit the child both in hospital and at home. By visiting with news or school work, emotional and social support is provided. This expression of care is to the advantage of the child and family. A visit close to discharge is particularly helpful in re-establishing contact before the child returns to the home school.

***People with colds or any other infectious illness
must not visit the ward.***

SCHOOL RE-ENTRY

The main problem of re-entry is the possibility of an academic lag. Children, especially in secondary school, will need to return with expectations which are realistic and goals which are attainable and within their limitations. Counselling should always be ongoing and available when the child needs it. Forward planning by hospital, parents/caregivers and school staff can facilitate a successful school re-entry for the child.

Re-entry can be enhanced by providing the school with correct information about the child. There may be concern on the part of the school, or specific teachers, in having a child with a cardiac condition back into the school. This is generally the result of the teacher not being sure about what to do. The teacher may not be fully informed about the child's condition, treatment, and prognosis.

This is best given to school staff by parents/caregivers or during the school visit and supported by educational seminars (run by Green Lane Hospital Paediatric Cardiology) and appropriate literature.

The Purpose of the School Re-entry Visit

When a child is in hospital for a substantial period the hospital teacher and other appropriate staff members such as the Hospital Social Work Counsellor may visit the Home School with the child, prior to return. Parents/caregivers may also attend. Parent/caregiver consent is obtained before the school visit and for any information to be shared.

It may be appropriate to discuss any or all of the following:

- * the needs of the child (medical, emotional and educational)
- * the diagnosis, treatment and any side effects the child may have
- * the physical capabilities of the child
- * any special requirements of the child
- * any dietary issues
- * ways to assist successful school re-entry
- * establish a liaison between the Green Lane Hospital and the home school
- * assistance to parents/caregivers who may be overwhelmed by the prospect of approaching the school
- * whether absence for medical reasons could occur
- * whether a medical crisis at school could occur
- * any concerns by answering questions
- * the most appropriate way to assist the child in continuing with their educational programme
- * providing education programmes while in hospital or at home
- * the academic needs of the child
- * the establishment of realistic goals that are attainable
- * alert staff to the needs of the siblings
- * provide counselling
- * if appropriate, discuss death and dying and provide supportive reading materials.
- * keep the school informed about any changes in the child's condition or treatment with parent/caregiver consent
- * discuss any issues with the school nurse or the staff member in charge of first aid
- * pass on any concerns expressed by the parent/caregiver or child
- * provide information on support groups e.g. Heart Children NZ Inc., Downs Association

BACK AT SCHOOL

When a child has been in hospital for a long time, the return to school

life can be difficult for them. They may be on medication, find it tiring and still be traumatised from the hospital experience. Here are some suggestions that may help you to assist the child:

- * start with half days until they recover their strength
- * photocopy any work the child has missed, to help alleviate any fears of not keeping up
- * make time if extra tuition is required
- * give the child work, at the correct level of difficulty, but in smaller amounts - for shorter time periods. It may be difficult to sustain concentration for longer periods
- * reduce the amount of homework and school projects
- * use of a computer if available, to draft written work
- * the programme should be the same overall but just modified to meet their needs.

Using the interview sheet in the appendix, you will be able to record any special requirements. (camps etc.)

SIBLINGS

Brothers and sisters also face special needs and challenges in having a sibling who has a cardiac condition. Like parents/caregivers they also need information about the condition of their brother or sister which is presented in a way they understand.

Sibling rivalry, feelings of anger, competition for parent/caregiver's attention, anxiety about the fear of "catching" the illness or disability, or guilt that they have caused it are a few of the issues children have to address where a sibling is chronically ill. They may be required to fulfil a role that does not allow them adequate opportunities to meet their own developmental needs and challenges. Again the professional should be able to provide guidance and support, so these needs are met. Liaison with the parent/caregiver is essential to ensure positive sibling support.

TERMINAL ILLNESS

The survival rate for children with cardiac conditions has improved considerably. However in some instances the condition cannot be controlled or repaired and is ultimately fatal. Some children spend a long period in a disabled state which cannot be relieved.

For them and those around them school can remain a rewarding experience. Often simple measures can help the child get the most from life.

Those who become too tired to attend school for a full day will often benefit from half a day or even only an hour's attendance.

When a child passes away, classmates may express their grief in a bewildering variety of ways. Some are quite open, while others may appear almost indifferent to the loss of their classmate. Such responses are all normal. The children may come to terms with the information about a death gradually, as they become more able to deal with the implications of the death.

Probably the most worthwhile method of helping children learn about death is allowing them to talk freely and ask their own questions. This is the same whether it is children who have not had a personal experience of death, or a bereaved or dying child. In an atmosphere of acceptance children can speculate and question and explore their own thoughts and fears.

It is important to find out what support/counselling the parents/caregivers of a terminally ill child have in place and what their understanding is of their child's knowledge about their condition. The hospital social work counsellor is an initial resource for information or ideas in dealing with these issues in a class environment.

In the event of a crisis/death, the Special Education Service has an intervention programme that they can implement within the child's school. This involves:

APPENDIX

Heart Diagrams

Teacher Interview Sheet

*Recommended Reading for
Children*

BIBLIOGRAPHY

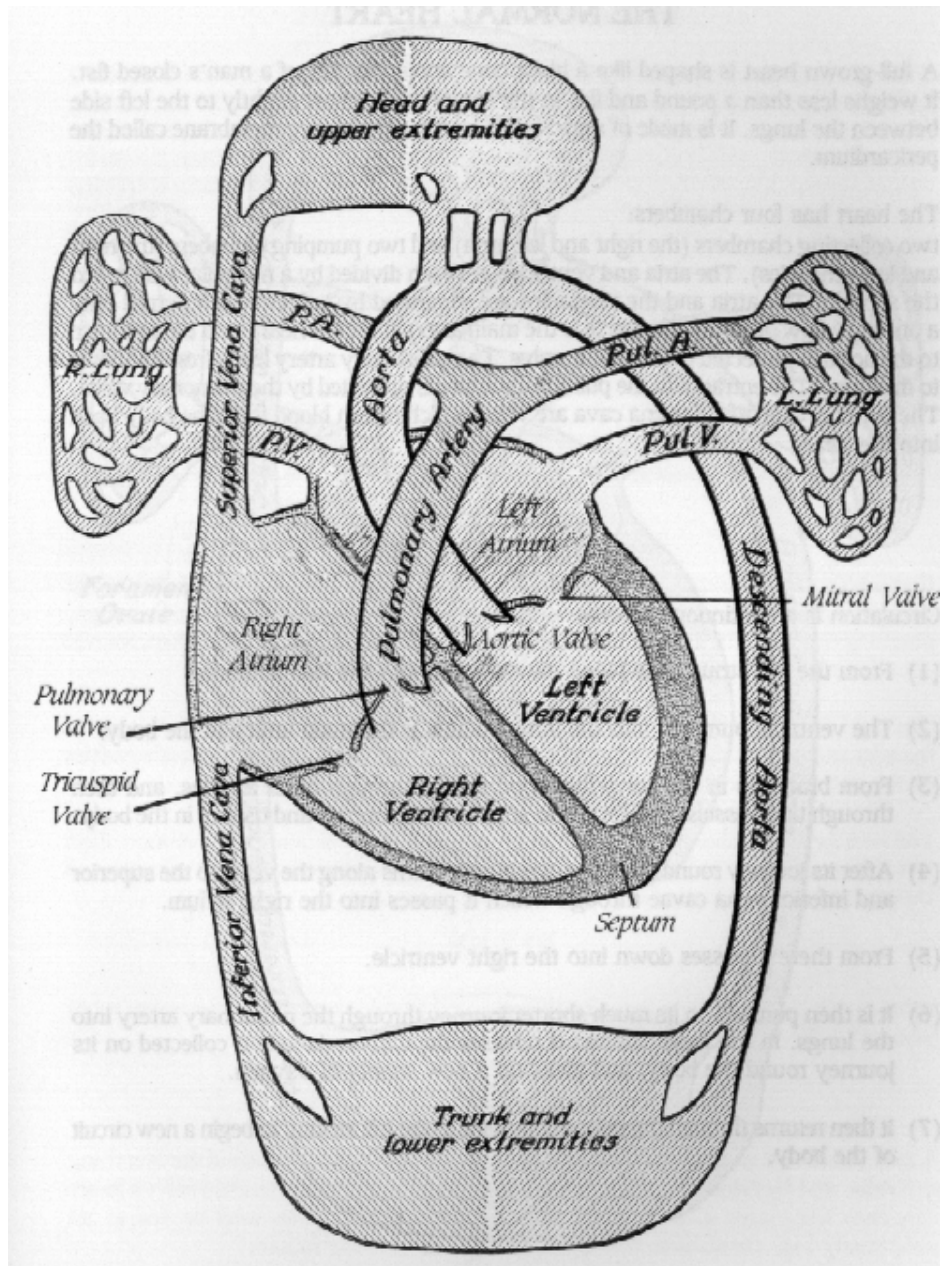
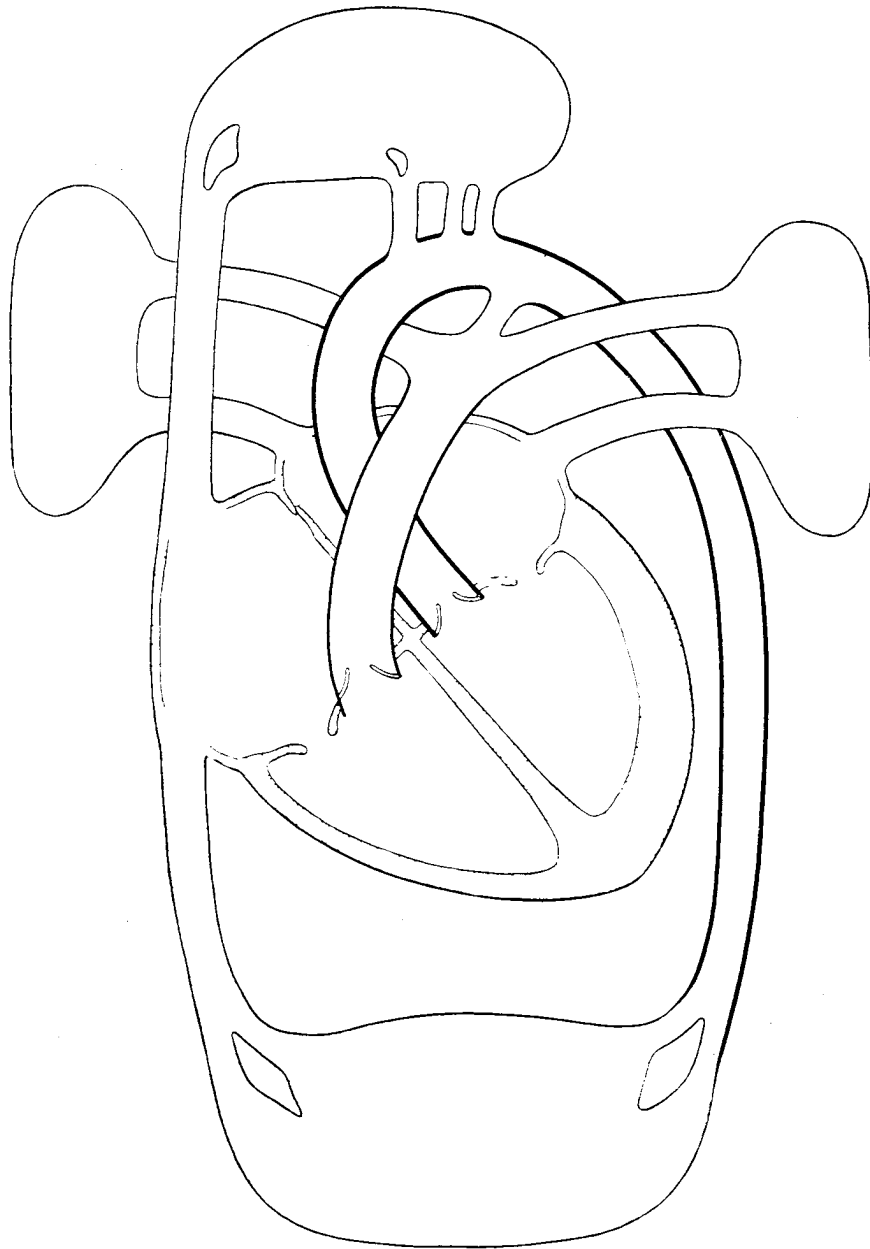


DIAGRAM OF NORMAL HEART (ref: Heart Children)



HEART DIAGRAM (ref: Heart Children)
For parents/caregivers to use in showing their child's defect

- how to tell the children, e.g. in smaller groups
- the proper words to use
- emphasising the importance of truth
- what reactions to expect from children
- support for the teacher and other people within the school involved in the crisis/death

There are excellent resources and books available to help children to understand death - some of these are mentioned in Appendix 2 of this booklet.

PARENT/CAREGIVER/TEACHER INTERVIEW SHEET

Notes for using Parent/Caregiver/Teacher Interview Sheet

The points on the sheet are by no means issues for every child with a cardiac conditions but may be triggers for a discussion. For a child who has spent a long period in hospital, it is recommended that teachers and parents/caregivers make a time for an interview after discharge and prior to the child's return to school. This is to make sure that the child has as easy a transition to school, as possible. It is also recommended that this sheet be dated and marked in pencil so alterations and amendments can be made at subsequent parent/caregiver /teacher interviews. This should then be placed in the child's personal file. One comment parents/caregivers frequently make is that it is difficult having to repeat the same information year after year. Hopefully such a system would enhance communication between families and schools.

PARENT/CAREGIVER TEACHER INTERVIEW GUIDELINES FOR ISSUES REQUIRING FOLLOW UP AT SCHOOL

MEDICAL CONSIDERATIONS

Current Medical Status

Limitations to Physical Activity

Other related Conditions

—

—

Potential "Emergencies"

Access to Toilet (diuretics) _____

Dehydration

Damage to Implants (eg, pacemakers) _____

Other Related Problems _____

TREATMENTS

Physiotherapy

Medication

Implants (eg, pacemaker)

Blood Tests

Monthly Penicillin Injections

Dental (antibiotic cover?)

INTAKE ISSUES

Quantity of Food

Types of Food

Need for Frequent Drinking

Salt

–
Fat

PSYCHO/SOCIAL ISSUES

Self-esteem

Peer Group Interaction

Teasing

Death and Dying

Compliance (ie, medication)

Parent/caregiver Concerns

Siblings

CURRICULUM ISSUES

Unwellness and Unavailability for Learning _____

–

Disrupted Attendance

Maintenance of Programmes

Evaluation of Child Work

Consideration of Double Set of Books _____

“Catching Up” Missed Schoolwork _____

Need for a Reduced or Modified Programme

Curriculum Choice

Vocation Counselling

Subjects with Contents that have Special Implications:

Disability

Growth and Development _____

Diet (including dietary guidelines) _____

Drugs and Drug Reaction _____

Reproduction and Pregnancy

Genealogy and "Family Trees" _____

Genetics

Lifestyles (and daily journals) _____

Death and Dying

Life Experiences

Expectations

—

Establishing Limits

Physical Education

SCHOOL/CLASSROOM MANAGEMENT

School Policies

Sick Room/Place to Retreat from Cold/to Rest

Emergency Procedures _____

Storage and Administration of Medicines _____

Assessment

Management of Child Behaviour _____

Lunchtime Supervision _____

Leaving of Classroom