



Junior School

Key Stage 2
Education Booklet

Contents

Introduction	4
Preparation	5 - 6
Day-to-Day Challenges	
Medical Needs	7 - 11
When your child is unwell	
Medication	
Medic Alert bracelets	
Nutrition	
The physical effort of being at school	
Concentration	
Homework	
Physical Challenges	12 - 14
PE	
Physical activities	
Moving between classrooms	
Keeping warm	
Extra-Curricular Activities and School Trips	15 - 16
Hospital Visits	17
Developmental Delay	18
Psychological Effects of Congenital Heart Disease	19
Developing Independence	20
Communication	21 - 22
Transition to Senior School	23
Inclusion	24 - 25
Tools for Schooling	26 - 27
Key Terminology and People	28 - 29

Introduction

Going to school is such an important part of every child's life. The education gained during all the stages of school provides stepping stones to their eventual independence.

Ensuring that each child fulfils their personal potential takes thoughtful preparation by parents, guardians and teachers. If the child has a complex heart problem a great deal of research and planning is needed.

This booklet has been developed as one in a series of resources to help families positively face the challenges that single ventricle heart disease creates for children in school.

In this book we will concentrate on the middle years in school and explore the transition between Key Stage 2 (Years 3, 4, 5 and 6) and Key Stage 3 (senior school).

Preparation

Whenever a child moves between schools or changes class it is important to revisit the needs that the child will have in their new environment, and to think how those needs might change throughout the school year.

It is often useful to talk to current teaching staff to ascertain when they think that your child may have extra needs but it is also very important to stress what they are able to do.

Questions to ask yourself

- Does your child need help getting around the school?
- Do they need help or special provision at break-time?
- Do they need medication in school? Will their medications affect any part of their school life?
- How do they cope with physical exercise?
- How do they cope with homework?
- Do they have long periods away from school?
- Do they need to visit the toilet during class time?
- Do they have problems with concentration?

Compile a list of areas where you feel that your child may need added help and support and use it as the basis of conversations with teachers as you plan your child's move within school.

Teachers within junior and middle schools are usually very supportive of each individual child and will normally work with families to ensure that each child gets the most out of every day at school.

- **Who do I need to speak to in school and when do I need to see them?**

It is always useful to see the team that will be teaching and caring for your child in the term before they move class.

This team should include: the form teacher, Special Educational Needs Co-ordinator (SENCO), classroom assistants and any teachers who take the class for extra lessons. It is also important to ensure that lunchtime assistants and peripatetic tutors know about your child's needs. A meeting with the Head Teacher should also be arranged to ensure that all staff are aware of your child's condition and particular needs.

• What will the teacher want to know?

Most teaching staff are very concerned that each child will be safe in school. The mere mention of heart disease often causes staff to worry that a child will have a heart attack.

Ensure that you discuss what the risks are for your child and also clearly state what they are able to do and what signs there will be if they fall ill.

The following chapter will explore the day-to-day challenges that each child faces; use it as a guide for what you may like to tell the teaching staff.



Day-to-Day Challenges

This section explains how your child's heart condition may affect their Key Stage 2 school education and discusses potential problems and their possible solutions. Schooling should be a positive experience and so it is always a good idea to approach teaching staff in a positive way.

Medical Needs

When explaining your child's heart condition to a teacher it is important that they have a general understanding of:-

- the condition and treatments;
- the short and long-term medical effects of the condition, i.e. that your child will always have only half a heart;
- the day-to-day medical needs of the child, e.g. the effects of medication and how to treat breathlessness;
- the effects that the condition has on normal child development and on your child's ability to learn.

When your child is unwell

It is important that as parents you are always thoughtful about when to send your child to school.

There will be some days when you are unsure as to how well your child is. If you have any doubts that your child can cope with a day at school either arrange to speak with the school at midday to check their condition or keep them at home.

Although it is always important that your child is able to attend school as much as possible, it is very difficult for them to achieve if they are unwell and it is also difficult for the teacher to support them adequately in the classroom.

If your child has been missing a great deal of school because they are unwell, talk to the school about balancing their days and booking days out for recovery where small amounts of work can be done at home.

If long periods of absence from school are anticipated then it is important that home tuition is arranged. This will be initiated by the hospital or by the Local Authority.

Medication

Where possible, it is important that children take their medication whilst at home, but when a midday dose of medication is necessary it is important that you as parents talk to the school about their policy for giving medication.

Normally teachers do not administer medication, but either a school nurse or a classroom support member of staff may take on the responsibility to give the medication.

They will need clearly labelled bottles and clear instructions as to when the medication needs to be given.

It is often helpful to ask the doctor to make out a separate prescription that is available for school.

The government guidance "Managing Medicines in Schools and Early Years Settings" states the following:

Prescribers [should] consider providing two prescriptions, where appropriate and practicable, for a child's medicines: one for home and one for use in the school or setting, avoiding the need for repackaging or relabelling of medicines by parents

Teachers' conditions of employment do not include giving or supervising a pupil taking medicines. Schools should ensure that they have sufficient members of support staff who are employed and appropriately trained to manage medicines as part of their duties.

Any member of staff who agrees to accept responsibility for administering prescribed medicines to a child should have appropriate training and guidance. They should also be aware of possible side effects of the medicines and what to do if they occur. The type of training necessary will depend on the individual case.

The effects of medication during a school day

If your child is on medication that has any potential effects on their normal behaviour or may have an impact on how the teachers manage your child, it is vital you inform staff as they will need to know how to support the child correctly.

Diuretics

If your child is taking a diuretic, e.g. Furosemide, in the morning, they will need to be able to go to the toilet throughout a school morning. It is important that the teachers know that there will be some urgency for your child to go to the toilet and they need to be allowed to go when they ask to be excused. Some children use a card system to discreetly show their teacher that they need to go to the toilet

without drawing attention to themselves.

Anti-coagulation

Children on Warfarin are more susceptible to bruising and bleeding if they bump or cut themselves. Teachers, support workers and playground support need to be aware of the added risks to a child and understand the way to manage any bleeds. (See our leaflet on **Anti-coagulation**.)

It is also important to remember that your child may also have other conditions where school medication will be necessary such as inhalers for asthma.

Medic Alert bracelets

Most Cardiac Liaison Nurses and Anti-coagulant Nurses recommend Medic Alert bracelets for children with single ventricle heart conditions, especially if they are taking Warfarin. Children's designs on Velcro straps are available, which are very suitable for this age group.

As well as the obvious benefit in the case of any emergency, many parents report that the Medic Alert bracelet is a useful way of discreetly reminding teachers of your child's heart condition.

This bracelet must not be removed during a PE lesson as it is one of the high-risk activity times.

Nutrition

Children born with only half a functioning heart have a greater need for calories. Some calories are used to power their body, which works inefficiently, and some for growth. It takes energy to eat food, however. In order to ensure that each child can cope with an energy-filled day at school, it is important that they eat little and often.

Planned snacks should be available throughout the day. As many schools are now employing a healthy eating protocol, it is important to ensure that teachers see calorie-filled snacks as part of your child's treatment. Their school day will be far more productive if planned snacks are allowed.

It may be helpful if you provide the snacks each day. Bear in mind the healthy eating policy: dried fruit, peanut butter sandwiches and cereal bars are healthy but filled with calories.

Drinks

Some children need extra fluids; for example if they are taking diuretics (e.g. Furosemide), if they are prone to constipation, or if it has been advised by their Cardiologist to prevent the risk of blood clots.

If this is the case, it would be sensible to discuss with the school how they can

make sure your child drinks enough throughout the school day. Many schools now encourage all children to drink water from their water bottle throughout the day. Not all children do this in reality, however, so you may need to ask a named person to make sure your child is drinking enough to keep them well.

Lunch

As your child requires extra calories, eating plenty of lunch is very important. Many of the children have problems completing their lunch before going out to play. Lunchtime supervisors must encourage children to finish their lunch.

If children take a packed meal it is often helpful to ensure that it is filled with easy to eat food such as small sandwiches, pieces of cheese, cubed vegetables and pre-cut up fruit. Biscuits and chocolate may not be allowed but cereal bars and dried fruit should be.

The physical effort of being at school

Every day at school will present different physical challenges. These will be discussed in more detail below but it is important that teachers know how to deal with a child who has become exhausted at school.

They may show signs of breathlessness and cyanosis especially following exercise.

Allowing the children to rest until they regain their colour and their breath must be encouraged. If they still show no recovery after 15 minutes it will be important to get them assessed by a medical team. Calling an ambulance to come to the school means that treatment will start straight away rather than waiting for a parent.

It is important that teachers have permission to take a child to the local medical unit and they will need a card to ensure that they can take the right information about the child's medical care with them.

To help set out all medical needs and treatments, a full healthcare plan should form part of your child's school plan. (For further information on education plans look in the full *Education Pack*).

Concentration

Everyone needs energy to concentrate. Since our children have lower energy levels than their peers, they often have difficulties in concentrating, particularly towards the end of a school day or towards the end of a week. Some children show this difficulty in concentrating by fidgeting, which can make it hard for their teachers to understand the real problem, and it can be assessed as disruptive behaviour.

It is important to discuss this possibility with your child's school so that they can plan accordingly. If your child appears to be struggling, talk to the school about changing the way their classroom support works or ask about accessing support if it isn't already in place.

Homework

Children need to be encouraged to participate in as much of school life as possible. They also need the opportunity, however, to have a good rest each evening to be ready for the next day. There may be some evenings when your child is too tired to study or to complete a set task and it is important that you notify staff if this is the case.

Teachers should be open to varying the type of task your child needs to complete or to extending the time required. It is important to balance your child's educational development with their physical needs, so good communication between teacher, child and parent is essential.



Physical Challenges

Many children with single ventricle heart disease have some sort of restriction with their physical abilities in comparison with their peers. Having only one heart pump doing the job of two will restrict them, but it should not exclude them from taking part.

PE

Children with single ventricle heart conditions are usually able to participate in PE lessons, and should be encouraged to do so. However, their exercise tolerance will be lower than that of their peers and they may be unable to participate in a whole lesson.

Provision should be made to allow them a rest when they need one. At this age, the idea of children finding their own limits may need some support. Teachers may wish to remind all children at the beginning of a PE lesson that resting when they are tired is fine.

If PE is being played outside, provision to keep the children warm during times of inactivity must be made.

On some days, if they are particularly tired, they may need to do a different activity instead of the PE lesson, and the school should be prepared for this possibility. Explaining similarities with asthma can sometimes be helpful.

For more information refer to the **Sport and Exercise** information enclosed in the pack.



The government guidance "Managing Medicines in Schools and Early Years Settings" states the following:

Most children with medical conditions can participate in physical activities and extra-curricular sport. There should be sufficient flexibility for all children to follow in ways appropriate to their own abilities. For many, physical activity can benefit their overall social, mental and physical health and well-being. Any restrictions on a child's ability to participate in PE should be recorded in their individual healthcare plan. All adults should be aware of issues of privacy and dignity for children with particular needs.

Physical activities

Other physical activities may cause similar issues to PE, for example drama, dance or any task involving standing up for long periods. The same support considerations should be incorporated into every lesson.

"Our main problem all the way through has been Andrew's physical stamina and tiredness. This has gradually improved as he has grown up. As he matures he is learning his own physical limitations better and becoming less reliant on reminders to rest/stop to recharge."

Moving between classrooms

As children grow older and work their way through the school years they will be expected to move between classrooms, some of which may be upstairs.

A careful assessment of each child's ability must take place and thoughtful solutions to any problems sought. For example extra time can be allowed for children between lessons or classrooms can be changed around for lessons where stairs are a restriction.

Keeping warm

This can be a problem, especially during the winter months, but even in the summer on a cold damp day children get cold. It is useful to make sure your child and school staff understand how important keeping warm can be, and think of suitable extra layers e.g. vest, gloves, hat, warm coat. As your child grows older they will look at their peers and will not want to dress differently. Gradually they need to be encouraged to be independent and safe. This takes time and patience.

On particularly cold days, staying inside at break and lunchtime may be the most sensible solution. In these cases, the school should be encouraged to think about suitable indoor activities with a small number of peers. Your child should not be kept in by him or herself. It is important that adequate supervision is incorporated into the staffing plan for the occasions when a child needs to be inside.

Extra-Curricular Activities and School Trips

Extra-curricular activities

In many schools added activity in sport and games is offered after school or in the holidays. Although the added energy needed to take a part in school clubs may need to be balanced, many children can take part in music, drama, computer skills, literature, language, cookery, board games, writing (on a computer if necessary) Lego, puzzle clubs, etc, at some point.

School trips

Throughout a child's school experience there will be opportunities for trips away from the classroom.

It is important that the staff think about the needs of disabled children in their class as they plan such trips as it should always be possible to include them in these fun educational activities. This should be part of their normal risk assessment plan for the proposed activity and it is reasonable to ask for a specific risk assessment to be done for your child for each trip.

Questions to ask yourself

- Will extra staff be needed to support the child's physical needs e.g. pushing a wheelchair, accessing a toilet or time for rest?
- Will staff be informed of any special needs and treatments?
- What is the medical provision in the area of the visit?
- Will they be able to access all areas of the site to be visited?
- Will they need any medication whilst away?
- Will they be safe, especially if it involves any physical activity?
- Do they have any dietary needs?
- Will your child be warm enough?
- How far will your child have to walk?
- How can parents be contacted in the event of any problem?

Some trips involve an overnight stay, so it is important to ensure that children with special physical needs have help in coping with the particular challenges such a trip might entail. These could include: activity beyond the school day, a different diet, altered sleep patterns, the need for added concentration and the requirement to be more independent.

It is really helpful if parents can work with teachers and if necessary the staff at the venue booked for the visit to ensure that everyone knows what challenges the children might face and most importantly what can be done to get around potential problems. As previously mentioned, all trips are now risk assessed and the provision for disabled children **MUST** form part of the assessment.

Out of school activities should be a very positive experience for all children and your child should be as excited as their friends about the event.



Hospital Visits

Throughout your child's life they will need to be seen at the hospital for check-ups and possible treatment. It is important that all teaching and support staff understand that this is a normal part of your child's life. Their absence from school should not be questioned with them in class and they should be supported in catching up with any work missed.

If a longer stay in hospital is planned it is important also to plan the absence from school and the return to school.

In the weeks leading up to your child's absence it can be helpful to incorporate hospital learning into a school day. Ask staff about telling hospital stories, using hospital-based role play or watching television programmes about going into hospital. This can form an extension of the hospital admission preparation that you as a family are doing at home.

Support from class friends by way of cards and presents during treatment can really lift a child's spirits and if the hospital is close to home, so can visits from school friends once a child is on the road to recovery. In these days of digital communication some schools are filming DVD messages and songs that are then sent to the hospital.

Returning to school, especially after a long absence, needs careful planning with a slow introduction back into the classroom and an understanding that the hospital experience may have affected your child's confidence. Work with teachers to gradually build your child's confidence in being back in the school environment.

"Will coped well in hospital. We were home within a week and he was fine from a medical point of view. He did test our patience a number of times, being aggressive and extremely cheeky, with his poor little sister getting the brunt of it. A reassuring chat with Suzie put us right, making us realise it wasn't unusual, within a few weeks we were back to normal. Will was back to school after four weeks on a part-time basis and then two weeks later full-time.

Because his pacemaker is adult size, it sticks out of his abdomen a little bit. To start with, he was very concerned about getting knocked or pushed. He was also a little more reserved than normal and again at school he was a little self-conscious. He is now living life to the full again. For some reason, now he's got a pacemaker he thinks he's superman - but we wouldn't want it any other way!"

Developmental Delay

Repeated surgery, low oxygen levels and regular interruptions of normal family life for hospital appointments lead to varying degrees of developmental delay. There may be evidence of delay in the development of fine and/or gross motor skills.

If your child is having difficulty with a physical or mental activity that should be within the developmental range of their peers, it is important that they are offered the opportunity of a full educational assessment.

It is vital for parents and teachers to work in partnership to identify problem areas, and then to support your child in order to ensure that they reach their full potential.

It may be necessary to formalise the support structure through Individual Education Plans or further formal educational assessment.

If you feel that your child is not achieving their full educational potential or that their physical handicaps are holding back their schooling, seek information from their teacher and the school's Special Educational Needs Co-ordinator (SENCO) about the best way to take their problem forward. You can take this issue forward yourself if the school does not agree with your concerns. (For more information see the information on education plans and statementing in the full *Education Pack*).

"At Junior school it has become apparent that she is struggling more physically and academically, because although Joanna is doing well, her peers are getting stronger by comparison."

Psychological Effects of Congenital Heart Disease

It should never be underestimated how individual children are affected by the restrictions that their heart condition creates.

For some children every restriction is seen as a challenge and they are happy to work to solve any problems. For others the fact they are "different" to their peers is a problem especially if they are restricted in an area of school where their friends excel, e.g. sport.

As the children grow through school, differences may be magnified. Parents and teachers should encourage children to express their worries and woes and work with them to find solutions to their problems, always remembering that there may be issues where compromise is the only way through.

Encouraging each child to become confident in their areas of strength rather than always stressing their weaknesses will help to strengthen their worth and reduce their frustrations. (See *Extra-Curricular Activities*).

"From Will's point of view, his biggest concern has been psychological. He soon realised he couldn't run as fast as his classmates and for a while got really upset that he was always last. Will wants to be competitive, wants to be up there on a physical level with his mates. This has meant a great deal of work on our part to make him realise he has many other assets and focus him on them."

Developing Independence

One of the most important aims of education is to gradually build a child's independence and an ability to learn enough to support their independent life in adulthood.

Each child's ability to take on this independence is different. For some, the challenges of life at school are taken in their stride whilst for others it is more difficult. This is especially so if your child has already been reluctant to take on personal responsibilities such as taking themselves to the toilet, eating their lunch without help or simply sitting still.

These challenges need to be recognised and supported sensitively, so that your child can grow in independence at an appropriate rate. Children and parents should not be made to feel that these delays are inappropriate if the development is within the wide range of "normal" timings. It is important however for any ongoing problems to be identified and support offered.

"Edward was awarded 25 hours support which enabled him to remain in his peer group and to make progress educationally. He is able to participate in all aspects of school life, alongside his peer group, he is making progress and he is happy to go to school. We hope that he will leave school with the ability and skills to live an independent life."

Communication

The most important relationship in school should be between the child and their teacher/s. Teachers need to develop an understanding of the child's needs and the child and family need to understand the expectations of the educational aims of each term in school.

Good communication is essential not only at the beginning of each term but also throughout every week of school. Parents need to build a confident relationship with their child's teacher so that everyone is able to talk about how a child is coping with school life.

The use of a school diary can be a helpful communication tool as long as both teachers and parents read it on a daily basis.

Medical information should be made available in an easy to understand format with Cardiac Liaison Sisters linking with school to encourage an ongoing dialogue between the hospital and the school alongside the formation of a healthcare plan.

Healthcare Plans

These are documents held in school which table any areas of your child's education or physical ability that are affected by their heart condition.

To make the plan easier to use it is a good idea to go through a typical school day and write down every aspect of care which your child needs which is different to their peers in any way. This section needs to include all the common challenges for the children within their day at school: ability to exercise, need for energy-filled snacks, cold weather, concentration levels, homework, etc.

The plan should also include information on your child's diagnosis, treatment plans, medication (and effects) plus any specific limitations your child may have.

The plan should also set out the best course of action in the case of an emergency, for example:-

- if a child on anti-coagulation therapy should fall;
- if they become uncontrollably breathless;
- if they complain of chest pain.

⇒ What action should the school take?

⇒ Who should the school call?

It can be really helpful to have a laminated information card with a plan of the actions needed if a child falls ill in school. When displayed on the school office wall, the PE department, the staff room and in any relevant classroom it allows school staff easy access to the emergency information. It is also useful to have the child's medical information available to take to hospital in the case of an emergency.

If other health or social teams are involved with a child's care it is important that they are able to add to any health plans or education plans. For example a physiotherapist may have exercises that could be incorporated into a PE lesson. Or a psychologist may advise that a supportive approach to hospital should be introduced into the classroom.

The SENCO and/or the school nurse should be responsible for co-ordinating the care of a child with disabilities within school.

“Andrew had no extra help in his Primary school apart from his Healthcare Plan.”

Please contact Little Hearts Matter if you would like to see some examples of healthcare plans.

Transition to Senior School

Having established a good relationship with the teachers in a school it is always a bit daunting when it is time to think about the move to more senior education. Senior school is a major step, not only to more structured schooling, but also towards independent living. It should be seen as a very positive step for a child, even if they have challenges because of their heart condition.

Parents and children should start to think about a move to senior school in year 5 or if it is a move to or from middle school a little earlier. The aims of starting to think about this transition are:-

- to gain a good understanding of what schooling is available in your local area;
- to assess what sort of secondary education will help a child with half a heart achieve independent living;
- to find a school that will offer a good education but that will also support a child through their learning;
- to actively seek the educational support that might be needed to ensure that a child with a heart problem can succeed to their full potential.

For further information and guidance ask Little Hearts Matter for the *Transition to Senior School* booklet.

“We made sure that we spoke to the Special Needs/Learning Support department, PE department and Head of Year of Andrew's new school as early as we could to see what they would be able to do to help.”

Inclusion

Your child should be able to participate in the majority of school life. Many schools are very helpful, once they have an understanding of your child's condition, how it impacts on their education, and some useful solutions. If you find your child is being excluded from certain activities, which you and / or your child feel they should be able to join, it is important to know that all education settings have a statutory duty to include all children.

This section of the pack gives a brief overview of the most relevant elements of two key pieces of law, the Disability Discrimination Act and the Education Act. This is an enormous and complex topic, so further information can be found through the LHM website (www.lhm.org.uk) or by contacting the office.

Disability Discrimination Act

The Disability Discrimination Act (DDA) is a law to end discrimination against people with disabilities and set out their rights in employment, property, education and use of transport. The 1995 Act was amended by the Special Educational Needs and Disability Act (2002) which placed new duties on schools and early years settings. "A person has a disability ... if he has a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities." Children with single ventricle heart conditions clearly fall within this definition as they have a permanent physical impairment which has day-to-day implications.

Schools must not treat a disabled child less favourably than another child for "a reason related to their disability" without justification. Without intending to discriminate, some schools have blanket policies such as children needing to be toilet trained or teachers not giving medicines, which in fact could discriminate against disabled children.

Organisations including schools are required to make "reasonable adjustments" to ensure all children are appropriately included within all aspects of school life.

Some schools may not have come across children with complex health needs before, or may not have much experience in this field. In these cases, they may need support themselves to understand how to make "reasonable adjustments" without necessarily needing extra staff to support your child. Support for the school may come from the Local Authority's Inclusion and Access team.

For this age group, areas which sometimes cause problems relating to inclusion are participation in PE, management of your child's safety at break and lunch times, and how best to allow them to participate in school trips.

If you feel you are encountering problems about Inclusion, all schools have a representative with responsibility for Special Needs on the Board of Governors. Some schools also operate a School Council system, where again there should be a Special Needs representative.

Education Act

The Education Act 1996 states "Each local education authority shall make arrangements for the provision of suitable education at school or otherwise than at school for those children of compulsory school age who, by reason of illness, exclusion from school or otherwise, may not for any period receive suitable education unless such arrangements are made for them."

The majority of children with single ventricle heart conditions are educated in mainstream schools and do not need any separate provision such as home schooling. Most children will come across the hospital school from time to time. It is important to have a basic understanding of what the possibilities are, in case you ever need to access some of this special provision, for example if your child is often away from school, or if he or she has a long hospital stay.

The key responsibilities outlined in the Act are:

- Pupils should not be at home without access to education for more than 15 working days.
- Pupils who have an illness/diagnosis which indicates prolonged or recurring periods of absence from school, whether at home or in hospital, should have access to education from day one.
- Pupils should receive an education of similar quality to that available in school, including a broad and balanced curriculum.
- Pupils educated at home should receive a minimum entitlement of 5 hours teaching per week.

Tools For Schooling

There are a number of tools which can help with schooling, as well as sources of further information and advice. This information pack contains brief details about these tools. Our more detailed information booklet '*Statutory Assessment and Statementing*' contains further details and examples of these tools and other sources of information.

The main tools to help with schooling are:

Healthcare Plans

It is vital that children with single ventricle heart conditions have medical information that is easily accessible and understandable readily available in school. A healthcare plan is the best way of doing this. It is a document held in school identifying the level of support your child needs throughout the day, signs and symptoms to look out for and what to do in an emergency. It should be written in non-medical language which can be understood by a range of school staff. The government's recommended format for a healthcare plan is included at the end of this booklet. The healthcare plan should be used as a tool to help everyone to understand your child's needs. If there is a school nurse, he or she may use the healthcare plan to train the staff in how to support your child.

Individual Education Plans

These documents are key to helping any child with identified additional needs. They are developed in partnership between the school, parents and any relevant professionals, and should state a small number of key targets to help your child achieve overall educational progress. It should detail what the support is, how it is to be provided, and how often these additional or different activities are to take place. Ideally IEPs should be reviewed every term. It will help teaching staff to understand understand and meet your child's needs better, it will reassure you about what support is in place and what progress is being made, and it is vital to identify if different or additional support is needed in the future.

Statutory Assessment

Statutory assessment is the process which may result in a Statement of Special Educational Needs - the Local Authority looks at your child's needs (physical and educational) and decides what their additional needs are (if any) - it could be that they identify different teaching methods, or they could agree to provide support.

Statement of Special Educational Needs

A Statement of Special Educational Needs describes a child's learning difficulties and the special help they must be given, such as extra resources, specially trained

staff, equipment or special programmes of learning.

Some children with single ventricle heart conditions need a statement, many do not. Some children have additional needs related to their heart condition or possibly due to another diagnosis. A medical diagnosis does not automatically mean a child needs a statement, it is all about the impact their condition has on their ability to access learning.

There are a number of sources of further information and support.

Some key providers are:

Parent Partnership

A service which provides support and advice to parents, and gives accurate and neutral information on the options available. Their aim is to help parents make informed decisions about their child's education. Find your local contact point by visiting www.parentpartnership.org.uk

Advisory Centre for Education (ACE)

Independent charity offering advice to parents about state education in England and Wales.
Tel 0808 800 5793
www.ace-ed.org.uk

Independent Panel for Special Education Advice (IPSEA)

Free independent advice on all aspects of special education.
Tel 0800 018 4016
www.ipsea.org.uk

Please contact Little Hearts Matter for further advice, support and signposting if you need it.

Key Terminology and People

A more detailed glossary is available from Little Hearts Matter.

Key Stage 2

Covers school years 3, 4, 5 and 6, usually when your child is aged 7 - 11.

LA

Local Authority (previously Local Education Authority or LEA).

Healthcare Plan

A document held in school identifying the level of support your child needs throughout the day, signs and symptoms to look out for and what to do in an emergency.

IEP - Individual Education Plan

Details the additional or different activities your child may need.

Statutory Assessment

The process whereby the LA assesses your child's needs. It may or may not result in them issuing a Statement of Special Education Needs.

Statement (of Special Education Needs)

A legally binding document which states the needs of your child and the resources required to meet those needs.

Note in Lieu

An alternative outcome to the statutory assessment process.

SEN - Special Education Needs

Describe the extra or different help that a child with learning difficulties needs in school.

SENCO - Special Educational Needs Co-ordinator

Person responsible for the setting's/school's special educational needs policies and children.

School Nurse

Provides support for children's medical needs in school and will help you to draw up a healthcare plan.

Cardiac Liaison Nurse

A nurse based at your child's heart unit, who can help with many aspects of life at home, including education.

Ofsted

The government agency which inspects schools, early years settings and LAs in order to improve standards of education and childcare.

Every Child Matters

A government initiative changing the approach in all services to have better outcomes for children as their focus.

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