



Early Years and Infant School

Education Booklet

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This pack is part of a series helping children with single ventricle heart conditions to make the most of their education, and covers Early Years and Infant School. Much of the information is also applicable to pre-school and childcare settings.

Education is such an important part of every child's life. It is a stepping stone to their eventual independence. Ensuring that each child fulfils their potential takes thoughtful preparation by all parents. It takes even more planning if that child has a complex medical condition. Following requests from parents, teachers and the children themselves Little Hearts Matter has created a series of information booklets to support families through the challenges of the education system. In general, teachers are 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.

For **parents**, we hope that the whole of the booklet will be useful. You may find it helpful to hear about other families' experiences, so we have included quotes from our members.

For **teachers**, the most relevant sections will be Development and Day-to-Day Challenges (pages 5-7 and 14-23). You may also wish to share this information with other members of school staff such as learning assistants, administrative staff or lunchtime supervisors.

The key aims of this pack are to make parents aware of what to do and when, what to expect / what to request, and to give them the tools and confidence to ensure their child is appropriately supported. In a recent membership questionnaire, one member commented "because the children look fine, they think you're a paranoid mother", - we hope this pack will help families to overcome this kind of reaction by explaining the help our children may need.

If any element of the booklet is not clear, please do not hesitate to contact the Little Hearts Matter office on 0121 455 8982. You are also very welcome to phone the office to discuss your child's individual circumstances. We can put you in contact with other parents to share experiences and solutions if you would find this helpful.

A brief glossary explaining key people and terminology is included at the end of the booklet.



Developmental delay

Repeated surgery, low oxygen levels and regular interruptions of normal family life for hospital appointments lead to varying degrees of developmental delay. Fine and gross motor skills are sometimes delayed, seen for example in co-ordination or balance problems. Language, social and emotional skills may also be affected. This should be addressed by individual plans, involving healthcare professionals where necessary.

Medical research shows that children with complex congenital heart disease do show some developmental delay, which can have a considerable impact on their education. A recent study looking at 5-10 year olds with these conditions (including single ventricle hearts) in the USA found that "a significant proportion of the children were at risk for inattention and hyperactivity", and nearly half were receiving additional support in school including 15% who were in full-time special education.

Developing independence

Some children experience a delay in being able to manage their own self-care needs. This needs to be recognised and supported sensitively, so that they grow in independence at an appropriate rate. Children and parents should not be made to feel that these delays are inappropriate as every child is different. Even without any additional needs of any sort, there is a wide range of "normal" timings.

Emotional needs

If you have any concerns about your child's emotional or psychological wellbeing, or if these emerge once he or she has started school, please talk to somebody such as the school, your GP or the health visitor / school nurse. You may wish to ask for a referral to the Educational Psychologist or another specialist. All of our children have gone through a lot by the time they reach the age of five e.g. some children are traumatised by time in hospital, needles or medications, and some deal with it in very different ways, including some ways which a school may not find acceptable or to which they may not know how best to respond. It is vital in these cases that you seek professional help so that the school have the understanding to help your child work through his or her issues, rather than labelling your child as 'naughty' because of the behaviour they are demonstrating.

"Matthew's long hospitalisation for his Fontan, plus the fact that he did not find school a particularly comfortable place to be meant that he was showing lots of difficult behaviour both at home and at school. The Educational Psychologist was the first person to recognise that there were good reasons for this behaviour, and to suggest initial strategies to help. We have since then had some excellent support from two Child Psychologists, and an amazing Special Support Assistant in school."

Social development

Many children are very articulate with adults, from having spent so much time in the company of adults, and possibly less unstructured time with their peer group, so the scale of any problems may initially be hard to understand.

Learning to interact appropriately with peers is a vital part of infant school education, and your child may need some support with this. Some ideas could be buddying systems, carefully arranged pair and group work, and discussions around friendship and other topics in circle time.

Awareness of own condition

Some children become aware of their own limitations during nursery or infant school. Even if you have always been open and honest with them about their condition, it is not until this sort of age that they will be able to understand, and may start to see their limitations compared to their peers.

School can play an important role in helping your family with this. By being aware

of and sensitive to your child's needs, school should ensure that they are not excluded from activities. They can help to nurture suitable friendships. They should be alert for any signs of your child feeling left out, or being made fun of (for not being able to keep up with others, or for wearing pull-ups still). For young children (nursery or reception age), the book "Rosie goes red, Violet goes blue" may be a useful tool for class discussion. There are also numerous other books about disability, difference and special needs written specifically for this age group, which could prove very useful tools in the classroom. Your school will likely be aware of or have some of these - ask them for help in this respect or refer to our **Further Information** section for some suggestions.

Conclusion

Children who have shown significant developmental difficulties will need a full assessment to identify their needs and put solutions in place. Our separate booklet '**Statutory Assessment and Statementing**' offers an explanation of the steps to follow. Please remember, however, that many children manage very well with some simple and thoughtful adjustments; formal assessment is by no means a foregone conclusion, nor is it necessarily a guaranteed solution to any problems you encounter.

Childcare and Pre-School

• How can I find suitable childcare?

Information about local childcare providers is available from your Children's Information Service, who will also provide details on which **settings** (including childminders) can support children with special needs. Childminders and day care nurseries are inspected by Ofsted. Some **settings** are actually keen to have children with special needs, as they can attract extra funding or fulfil certain criteria with their local council.

If you would like to discuss other parents' experiences of finding suitable childcare, please contact the Little Hearts Matter office.

Any extra help needed by children at this age is usually provided by voluntary agreement between different services. **Statements** are rare for children under two. If you feel that the help is not enough or not right, then you or any professionals involved can request a **statutory assessment**. The Local Authority must agree to conduct an assessment for this age group of children if it has been formally requested.

• Should my child go to pre-school?

Pre-schools and playgroups can be a very valuable experience for children with additional needs as they offer the opportunity to develop social skills with their peers (an experience which may have been limited due to medical needs), they start to get accustomed to school type routines, and they can be encouraged to develop some independence and self-care. Importantly, many children enjoy going, and it can give parents a small amount of very valuable time off. However it is crucially important that you feel your child will be safe in this type of setting.

Many pre-schools and playgroups are run by independent organisations or voluntary groups. This can be incredibly beneficial as it means they may be more flexible and able to access different funding sources which could meet your child's needs more quickly, without having to go through long paperwork exercises as sometimes happens when they are in full-time education.

As soon as you have decided whether you would like your child to go to a pre-school or playgroup, contact the leader of the group and arrange a meeting, together with other relevant contacts eg health visitor, any therapists involved, to discuss what help your child needs, and how it can be met. Each Local Authority will have different schemes available; in some areas it might be called a Support Scheme. Another term you may come across is Early Years Inclusion Officers.

The government is trying to develop a more co-ordinated approach to supporting families with young disabled children. This approach is called **Early Support**. If you have a child under five with a single ventricle heart condition, you should ask

about **Early Support** and co-ordinated working.

"Ethan started nursery just before his first birthday. I was far more nervous about returning to work and leaving him with other people than I had been with my daughter first time round.

The nursery had a settling in week, as they do for all their children and Ethan was assigned a keyworker who got to know him during this week as we built up his hours. During this week I was able to invite our community nurse to come in and meet the staff and talk a little about the condition and Ethan and her role in his care. This meant that they had a direct contact with her and failing being able to get hold of me they are able to contact her.

Communication has been crucial to our success so far. I felt the need for the staff to appreciate the complexity of Ethan's condition without making them so unduly nervous that they didn't treat him like a normal child. I therefore put together some key information about the condition and signs and symptoms to be aware of. I also showed them his nail beds to show them what is "normal blue" for him.

I have been very fortunate that the nursery manager and his keyworker have both listened carefully, taken things seriously but are unflappable. Ethan has also bonded so well with his keyworker which makes all the difference. So far we have had only one occasion where they have had to call me as he had a temperature and the system has worked well."

Before and after-school childcare

Many schools offer after-school clubs with wrap-around care for working parents. If you need this childcare provision, make sure you check where the club is situated (some are a short walk away from the school site, which may pose a problem after a full day at school). You should also check who runs the provision (they are often run by private nursery providers, not by the school).

If it is not run by the school itself, you should ensure that relevant staff are included in meetings about your child's needs. Any increase in staffing needed to properly support your child will come from a different funding source, not from the school. Some areas run a scheme called a Support Scheme, whereby they can increase the staffing in a setting or offer other support such as training. Your health visitor or school nurse should know about how to access this support.

Preparation for School

With some planning and preparation, the majority of children with single ventricle heart conditions do well at school. However, it is important that parents and schools discuss how best to ensure that children are able to access and participate in as much of school life as possible.

• How do I prepare for my child starting school?

It is vital to find somewhere which will meet all of your child's needs, including educational, social, communication and daily care needs. In order to do this, it could be worth spending some time thinking about what those needs are, and where they are different to the needs of other children of the same age. This may be difficult, as you grow accustomed to your child's needs, and for you they are 'normal'. It could be helpful to ask a friend, relative or someone like your health visitor to help you think this through.

You will need to find out about the provision in your area, and decide whether you would like your child to attend a nursery year which then feeds into the main infant school.

Throughout the years leading up to starting nursery or school, do not hesitate to talk to specialists about your child's needs and any concerns or worries you may have about his or her development in general. Identifying needs early on will help your child as you may be able to get professional help sooner, and it will also help when it comes to accessing suitable support in school, as your child is already 'known' or 'in the system'.

• When should I start to think about nursery / school?

Local Authorities (LAs) will ask you to apply for nursery and reception places around a year before your child is due to start. Even if your child has attended a school nursery, you will still have to apply for a reception place. Many schools will have open mornings at the beginning of the autumn term, which can be a useful time to visit schools; however you may also wish to request additional time with the school to discuss your child's particular needs.

If you would like your child to attend a nursery school, it may be advisable to request a morning place (there is sometimes a choice of five half-day sessions, either mornings or afternoons). Children with single ventricle heart conditions are often at their best in the morning, and may be tired by the afternoon. Some may still need a daytime sleep during their nursery year. Depending on their condition, if they are coming towards needing their Fontan (Stage Three) surgery, they may tire more as this year progresses. Most parents in general want a morning place, through personal preference, so please stress the medical reasons your child will be better with a morning place if this applies to you and if it's available.

Even if your child has had experience of childcare e.g. through a day care nursery, the experience of a school nursery is very different. The ratios of staff to children are different, and more importantly the staff think of themselves primarily as educators rather than care workers. This difference between childcare and a school nursery often takes parents by surprise, so please be prepared. Children who have coped very well in a childcare environment may need additional support when they start school nursery or reception.

• How do I find a school which will suit my child?

You will probably want to visit possible schools for your child well in advance of making their application. A list of possible questions to ask during a school visit is included at the back of this booklet. When you visit, you may find it helpful to explain your child's key problems first so that the staff start thinking about the implications themselves e.g. tiredness, breathlessness, cold, impact of anti-coagulants, need for food, etc.

Hopefully you will hear positive answers such as that the school will work in partnership with you and the healthcare professionals to put suitable plans in place, or they will help your child to be included in as many activities as possible. The key question to ask is whether your child will be welcome. You should also trust your instincts as a parent, and choose somewhere which gives you a good feeling.

Answers you hopefully won't hear include continued references to health and safety risks, them saying they don't think they can cope, or don't know how to deal with your child, or if their immediate answer is to keep your child separate from other children for example at break-times for his or her safety.

Some children's needs may best be met at a special school or a school with a specialist unit attached to it, in some areas this is called an ARB (Area Resource Base). This is likely to be the case for a child who has additional needs over and above their heart condition, it is by no means the expectation for our children.

Families sometimes meet a response which is unrealistically positive where the school assumes everything will be fine, possibly because the issues have not been understood or thought through. Other families are met with a negative 'we can't cope' response where no consideration has been given to how the child could successfully be included.

This pack aims to give parents the tools to address both these scenarios, and enable the school successfully and safely to include your child. Most schools do want your child to be happy and to achieve well whilst in their care; they may simply need some ideas about the best ways to do this.

• Once I have chosen a school, what should I do next?

It is important that you identify the key people at the school, who include your child's class teacher, the head teacher and the **SENCO (Special Educational Needs Co-ordinator)**. Full explanations of different people's roles are included in the '**Key Terminology and People**' section of this pack.

Around a year before your child starts school, it would be worth making a note to discuss this with your Cardiologist at your child's next outpatient's appointment.

Does your Cardiologist have any particular concerns or recommendations for your child? A phone call or chat with your Cardiac Liaison Nurse will also be helpful.

It would also be very valuable to organise a discussion between everyone involved with your child, such as your health visitor, your Cardiac Liaison Nurse, and representatives from whatever centre or childcare your child attends and from the school your child will attend. Any other healthcare professionals e.g. physiotherapist or speech therapist should also be invited. This will help you to jointly develop a plan regarding any support your child may need in school. An initial meeting well in advance of your child's start date, together with a more detailed planning meeting in the term before your child starts school would give a great opportunity to discuss your child's needs and make sure everything is in place for his or her first day at school. Ask for help from Little Hearts Matter if you would like to talk this through with another parent.

"I spoke to as many people as possible at his school and I asked the Cardiac Liaison Nurse to come and speak to them too."

Some schools will want to see your child in the school environment first, before making any decisions about whether they may need any extra support. In other cases, where you have already needed a lot of input from community healthcare professionals, the needs will be more apparent.

Many teachers' initial concern is that your child will collapse or have a heart attack in class. It is important to reassure them that this, in most cases (unless your Cardiologist has advised you otherwise), is unlikely to happen.

A brief description of the heart condition and the current surgery is helpful, together with any upcoming surgery, e.g. have they already had their Fontan?

Most importantly, the school will need to understand the implications of your child's heart condition plus any other additional needs they have. The section of this pack called '*Day-to-Day Challenges*' gives further detail on implications for school.

Regardless of whether your child appears to need extra support in school, he or she should have a **healthcare plan** in place when he or she starts school. This document could be drawn up at one of the meetings described above. One of the important areas to discuss is when your child is ill enough to consider it an emergency, and also when they are ill enough to be sent home. Over time, the teachers will get to know your child better, but you need some agreed understanding to start with, so that you know your child will be safe and so that they aren't being sent home too often. Further information about healthcare plans is included in the '*Communication*' section and the *Appendices* to the pack.

Depending on how well your child is when they start reception, you may need to consider reduced hours, for example mornings only. This could be necessary for a short period of time whilst they get used to the school routine, get through a period of cold weather or illness, or recover from surgery, or it could be a longer term measure. It may be necessary to review these types of arrangements on a

regular basis, for example every week, to check how your child is coping and how they feel about their school attendance.

• **If I feel my child needs extra support what should I do?**

Some children with single ventricle heart conditions need additional support through a Statement of Special Educational Needs, others do not. Some children have additional needs related to their heart condition or possibly due to another medical diagnosis. School and parents will jointly need to consider the impact their condition has on their ability to access education.

Please refer to our separate pack '*Statutory Assessment and Statementing*' for an explanation of the different options available, and how to go about seeking the support your child needs.

Many children may not need formal tools to support their education, they may manage very well with a few simple changes to the routine to accommodate their needs. Simple solutions can be very effective for some children - ideas are included in the '*Day-to-Day Challenges*' section of the pack. Other children may need support for a short period of time, and may then develop so that they can cope without support.

"To start with David found reading and maths difficult to grasp, but with a little extra support by the end of his first year he was greatly improved. He is now coming to the end of his second year and is doing extremely well. His reading, writing and maths is at the level of everyone else in his class, his teacher has even told us that his writing is so neat it's the best in the class! He has no extra support at all in the class now, and he loves school."

• **Should my child defer starting school?**

Some children with single ventricle heart conditions could benefit from starting school a year later, depending on their developmental stage and medical condition. The legal position in England is that parents of all children under five can defer their child's entry to school until later in the same school year, in fact some schools do a staggered intake anyway. It may be possible to discuss deferring further, i.e. into the next school year, on medical and / or developmental grounds. Admission authorities have the discretion to allow this, and would have to consider your request, if you felt it was right for your child. This could be an important topic to discuss at a planning meeting before your child starts school or at a review meeting during their nursery year, to decide whether or not they will be ready to enter reception. Please be aware that different areas of the country may have different policies.

A recent study in the USA of 5-10 year olds with complex congenital heart disease stated that 18% of the children had repeated a school year. This could be another possibility to consider for some children.

Day-to-Day Challenges



This section explains how your child's heart condition may impact on their infant school education, by describing some of the challenges they face and suggesting solutions. Within your child's **healthcare plan**, it can be a good idea to go through a typical infant school day and write down every aspect of care which your child needs which is different to their peers in any way. Many parents report that schools have difficulty understanding their child's condition, as there are no outward signs. We have tried to explain here why the children sometimes experience particular difficulties in order to help with this understanding.

Ongoing Medical Care and Treatment

Children with single ventricle heart conditions will have ongoing medical treatment for their whole lives. This will inevitably impact on school. Recording how medical care and treatment impacts on school for your child is the key purpose of the **healthcare plan**.

Use this tick list to help you prepare for a conversation with your school and to prepare your healthcare plan.

What this means for _____ (child's name) is (please tick as appropriate)

- he / she will become breathless easily
- he / she may go blue
- he / she will get tired during the school day, and will get increasingly tired towards the end of a week or term
- his / her ability to concentrate may be affected
- he / she is taking the following medications

Surgery

Depending on your child's cardiology plan of care, they may start nursery or infant school before they have had their Stage Three surgery. If this is the case, detailed planning should be carried out with the school to ensure your child's needs are met as well as possible. As hospitalisation for Stage Three surgery varies so much in time, convalescence will also vary for each child. Some schools find it difficult to understand that there is no way of knowing how long your child will be away. There can also be difficulties with understanding how major the surgery is, and how much time some children will still need at home before they are really well enough to be back at school.

Clearly, the most important factor at this time is helping your child through surgery and hospitalisation. Please don't worry about their education, as young children often catch up quickly with things they have missed, but may need extra support to do this. Ask your school to liaise with the hospital school, so that appropriate work can be covered whenever your child is well enough. Ask the school (or your child's teacher) whether they could incorporate hospital play into their activities at appropriate points (it doesn't have to be every week!), both before and after your child's hospitalisation. If the school is not sure about this, please feel free to contact Little Hearts Matter for suggestions. The rest of the class will enjoy this and benefit greatly, and sometimes it can give your child a chance to explain some of their experiences to their school friends. If your child has been in hospital for a long time, a gradual reintegration into school may be the best plan, with some weeks of part-time attendance, gradually building up to full-time attendance when they have convalesced fully.

Cardiac Tests

Various cardiac tests may be required during your child's time at nursery and infant school, some of which will require a hospital admission for some days, for example a cardiac catheter or a pacemaker check. Children may think of these as operations, as a hospital admission and general anaesthetic is required. The hospital will tell you how long the hospitalisation is expected to last and how long they advise the child to stay off school, together with any information the school needs to know when your child returns.

Some children will need to have a 24 hour ECG to monitor the electrical activity of the child's heart during their normal day-to-day life, to look for any rhythm problems. If this is the case, school will need to know, and to understand that the child should participate in everything as they normally do, although some (unexpected) difficulties may need addressing. For example, if your child is self-conscious about getting changed, is there somewhere s/he could get changed more privately? Is closer supervision needed whilst changing to limit the comments/open curiosity of others?

Medical Appointments

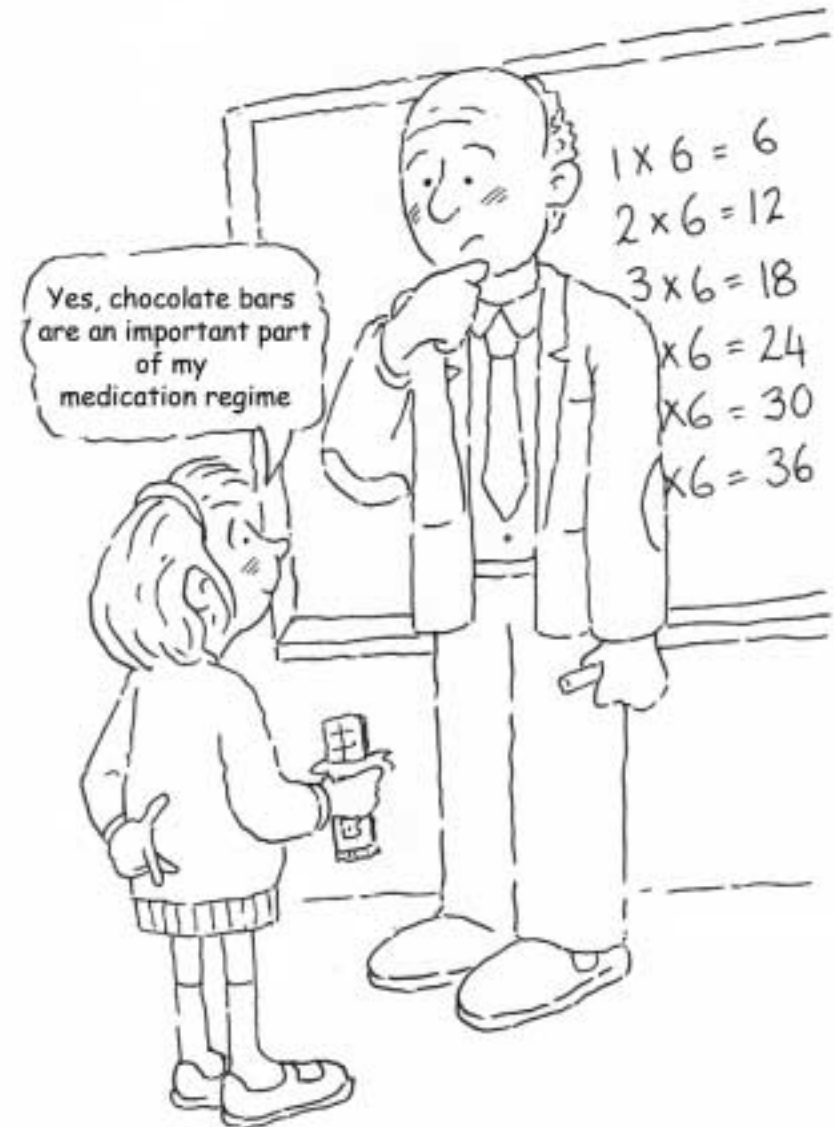
School will need to be made aware of your child's outpatient appointments. Most children will have six-monthly Cardiology appointments. Many will also see other specialists such as a paediatrician or physiotherapist. They will also need blood tests from time to time, and if they are taking Warfarin, will either need regular hospital visits to check their clotting (INR) levels or a six-monthly appointment if they are home testing.

Medications

Schools need to be made aware of the medications your child takes, and the impact these have. This information should be included in the **healthcare plan**.

Some children require medications during the school day eg Captopril (though it can be possible for some children to time three doses of medicine so that the middle dose is not required in school). This needs to be planned with school, so that

appropriate training for staff can be given. It may be useful to ask for a second prescription of Captopril that can be kept in school, so that it is kept in its original packaging and reduces the possibility of it being forgotten between home and school. Some extracts from the official government guidance "Managing Medicines in Schools and Early Years Settings" are included in the **Appendices** to this booklet.



Many of our children take Warfarin, which delays the blood clotting process to ensure that the blood flows freely through the passages in the heart. This means that they are vulnerable to prolonged bleeding or excessive bruising. All staff including lunchtime supervisors at your child's school must be made aware of this. They will need to understand the guidance that prompt attention is required to stop any bleeding by applying pressure to the bleeding point, and in the event of a bump to the head, a check at the local hospital may be needed as there could be a danger of internal bleeding. You will also need to make sure your child has some level of understanding, appropriate to their age. Warfarin can be a reason to suggest that your child needs some one-to-one support, to make sure they are safe during playtimes and physical activities within the curriculum.

Some schools have experience of children with haemophilia; others may have come across children with brittle bones. This may help inform their understanding of how to care for a child taking Warfarin.

Many children will take diuretics for some or all their time at infant school (e.g., Furosemide, Amiloride, Spironolactone). These medications increase the body's ability to pass out fluid, meaning more urine is made.

Some children with single ventricle heart conditions suffer from constipation. Again, the school should be made aware of this, especially relating to any medication your child is taking or any special dietary or fluid needs they have.

Toileting

If your child is not toilet trained when they are due to start pre-school, nursery school or reception, please do not worry about this. Talk to the school or pre-school and ensure that a proper plan is made. Many children without health problems are not toilet trained when they start pre-school, so pre-schools should have a very clear way of ensuring all children's needs are met. Nurseries and schools are not allowed to refuse admission to any child on the grounds of their toileting situation. They are also not allowed to insist that you, as a parent, come in to nursery or school to change your child's nappy or pull-ups.

As this is sometimes a difficult area for parents, the following are direct quotes from a government publication called "**Including Me**" (full details available from Little Hearts Matter).

"It is unacceptable to refuse admission to children who are delayed in achieving continence."

"Education providers have an obligation to meet the needs of children with delayed personal development in the same way as they would meet the individual needs of children with delayed language, or any other kind of delayed development."

"Asking parents of a child to come and change a child is likely to be a direct contravention of the DDA."

(DDA is the Disability Discrimination Act).

There are a number of reasons why your child may be slightly delayed with toilet training. They may be experiencing some delay due to the other complications in their life, or some of their medication making it difficult, or they may not even be genuinely delayed - you may just feel they are.

If your child is taking diuretics, it is important that staff have a good understanding of the impact of diuretics. It can be useful to ask if they have any relatives (often elderly relatives) taking "water tablets" and see if they are aware of the urgency which is experienced. Children must be allowed to go to the toilet whenever they need to. Systems may have to be put in place so that they are not embarrassed by this need, e.g. a card they can show the teacher. They may need to be encouraged to go to the toilet regularly throughout the day by a designated member of staff making sure they go at suitable times.

"My son made his own posters to go on the classroom door to remind him to go to the toilet at every break-time."

If toileting is a problem, ask the school nurse or community enuresis nurse to help you to agree a joint approach for home and school, making sure that positive actions are rewarded e.g. identifying a need to go to the toilet independently.

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.

Physical Challenges

Most 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.

"School has always been brilliant. She has a cosy corner where she can go during the day if she feels tired and wants to have a rest."

PE

Children with single ventricle heart conditions usually like 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 will rarely be able to keep going for long.

"He joins in PE but the teacher is aware that he may just need a 'breather' sometimes."

Physical activities

Other physical activities may cause similar issues to PE, for example drama, dance, and activities involving standing up for long periods.

Children should be encouraged to participate, but should also be made to feel that having a rest when they need one is completely acceptable. At this age, the idea of children finding their own limits may need some adult support. Teachers may wish to remind all children at the beginning of a PE lesson that resting when they are tired is fine. Your child may wish to have a special chair for resting during the lesson. On some days, if they are particularly tired, they may need an alternative activity instead of the PE lesson, and the school should be prepared for this possibility. Explaining similarities with asthma can sometimes be helpful.

"On May Day, Charlie was chosen to be the May King at playschool, and he was thrilled to bits. It was only when I was speaking to his teacher later on that she told me they had deliberately made him the May King so he would only have one little dance to do, and could then sit on his special 'throne' to watch all the other dancers. It was a perfect, thoughtful solution to what could have become a problem for Charlie - he was made to feel really special and involved in the whole event, but was able to avoid much of the dancing, which would have left him puffed out and unable to keep up."

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.

Concentration

Everyone needs energy to concentrate. Since our children have lower energy levels than their peers, they often have difficulties in keeping concentration, 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.

"When Matthew lies down on the carpet in the afternoons, is he being naughty or is he genuinely tired?"

It is important to discuss this possibility with your child's school so that they can plan accordingly. Core lessons are often held in the morning, for the benefit of all children in this age group - ask whether this is the case in your child's school. If your child appears to be struggling, talk to the school about either changing the way their classroom support works, or accessing support if it isn't already in place.

It is also worth considering the question of homework. Children need to be encouraged to participate in as much of school life as possible, however, they also need the opportunity to have a good rest each evening to be ready for the next day. Planning homework allows for normal school activity, but acknowledges that there may be some evenings when a child is too tired to study.

"Academically, he is the middle groups but at the top end. Reading is slightly higher. I have found that due to his tiredness you have to time it right when it comes to spellings, reading, etc, and that has always been the case. I have always let him sleep/rest if he needs it."

Nutrition

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

Snacks

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 these children's treatment. Cereal bars, dried fruit or peanut butter sandwiches may be a suitable idea. Make sure you discuss with the school who will give your child their snack, and who will ensure they have eaten it. Their school day will be far more productive if planned snacks are allowed.

Drinks

Some children need extra fluids, for example if they are taking diuretics, if they are prone to constipation, or if it has been advised by their Cardiologist to prevent the risk of blood clots. Please refer to the '**Medication**' section within this booklet for further detail.

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; however not all children do this in reality, so you may need to ask a named person to make sure your child is drinking enough to keep them well.

Lunch

As our children need extra calories, eating plenty of lunch is very important. They

need to have a balanced diet, but may find a higher-calorie pudding gives them more fuel than fruit. Many of the children have problems completing their lunch before going out to play. It's important to stress to the school that our children should be encouraged to finish their lunch, even if it takes a long time.

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



Safety in the Playground

Playground safety is a key area for this age group of children. As a parent, when you first see the playground and rough and tumble of break-times at 'big school', you are likely to be somewhat concerned, even if your child doesn't have any additional needs! If you then consider that your child is taking Warfarin, may have had recent surgery, or may have a pacemaker as well, this is clearly going to be a major area of concern.

Children should be allowed to join in with playground activities, but at a suitable and safe level. Extra supervision may be required. Your child should know who to go to in the case of feeling unwell, out of breath or cold (e.g. knowing where the designated first aid post is, knowing who they can go to). Some schools are introducing more structured playtime games e.g. through play leaders or members of support staff leading activities - this is likely to be a very useful solution for children with single ventricle heart conditions.

Keeping warm can be a problem, especially during the winter months. The children typically have poor circulation, and also cannot run around constantly to keep themselves warm. 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 (and you do need to think whether they can fasten it themselves - duffle coats are good for this - or you should get an agreement that an adult will fasten it for them). 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. Again, this can be a reason that the school would feel one-to-one support would be useful for your child. Some staff may have come across the condition Reynaud's disease where people have poor circulation in cold conditions - if they have, this can be a useful comparison.

Getting wet is just as much of a problem as getting cold. If children have got wet through water play, for example, they should be changed into dry clothes immediately.

Nursery and infant school age children need help to manage these physical needs. They do not want to be distracted from the serious business of playing, so are unlikely to notice that they are cold or tired until it is too late! Adult support can be very helpful.

"The head also said he could have someone to watch him during playtimes and they could take him indoors with a group of children (so he doesn't feel excluded) for quiet play if it's really cold or if he's really tired."

Communication

Good communication between everyone involved will make all the difference to your child's experience of school. Schooling should be a positive experience and so it is always a good idea to approach teaching staff in a positive way. There may be a number of professional involved in your child's care; at the very least, there are teaching staff, doctors, Cardiology staff plus the family involved. Some ideas to help are detailed below.



SENCO

The **Special Educational Needs Co-ordinator** or SENCO is the key link person at every school. The responsibilities of the SENCO are to identify children's needs and to make sure they are met. Any parent can request access to the SENCO - your child does not need a statement or to have any formal support in place for you to be able to talk to the SENCO.

Lead professional or key worker

This is an idea being developed through the government's **Early Support** programme, which is all about co-ordinating services across England for families with young disabled children. One person will help you with co-ordination of actions to meet your child's needs, and co-ordinating the different people involved. As part of their role, it is likely that they would suggest Team Around the Family or Team Around the Child meetings (sometimes known as Care Co-ordination), where everybody involved comes together to discuss the current issues for your child and how their needs can best be met. Education is a key element of these meetings.

Healthcare plan

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.

Review meetings

Asking for regular review meetings once your child has started school can be helpful. There may be a lot more ground to cover than a five or ten minute slot at parents evening would allow! Some parents have termly reviews together with a formal annual review, others may ask for an ad-hoc meeting when required. The **SENCO** (Special Educational Needs Co-ordinator) should be happy to arrange these for you. Before the meeting, think about who you would like to be there. You may feel some input from health service professionals would be useful, or you may wish to have a friend, relative or someone from an organisation such as Parent Partnership with you. A list of questions to help you prepare for these meetings is included at the back of this booklet.

Some children start off well in school, then encounter problems in Year 1 or 2. In these cases, a review meeting will be a vital tool to help try to establish the root of the problem and possible solutions. We know that many parents feel their children are bright, but that they struggle to access the learning in the way it is

presented. Identifying and discussing these needs, perhaps with input from an Educational Psychologist can be really useful. If you feel more formal assessment is needed, please refer to our booklet '*Statutory Assessment and Statementing*'.

Home School Link Book

These may be called a variety of different things, such as a 'Home School Liaison Book', a 'Communication Book' or a 'School Diary'.

Some families find this a very useful tool for keeping ongoing communication with the class teacher throughout the school term, provided everyone agrees to the system so the book is read and used properly. It can be a simple exercise book where the parent writes notes about their child e.g. a change of medication, whether they are particularly tired at the moment, forthcoming hospital appointments, etc. The teacher responds as appropriate and can also use the book to communicate positive and negative issues about the child's day. It is a particularly useful tool when coming up to reviewing your child's progress over a term.

Helping in school

Some parents find it helpful to go in to the child's class to help out either on a regular basis or just occasionally. This helps to develop good relationships with the teaching staff and gives them the opportunity to ask the parent any questions. Obviously this may not be possible if you have other children or work commitments. In these cases, you could try to become involved with other school activities such as the PTA. This type of involvement can allow you to have different (sometimes informal) communication opportunities.

Communication with other parents

As part of the overall experience of school, you will probably want to encourage your child to socialise with other children. It can be worrying to 'let go' of your child, and it may be hard to know what level of detail other parents would need to look after your child for a short time.

"We found it useful to talk openly to other parents about Andrew's heart condition when waiting outside the classroom at the end of the day. This helped them to understand and even meant Andrew was invited to friend's houses for tea/birthday parties without too much fear."

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.

It is good practice to allow all children to participate in school trips. Risk

assessments have to be carried out for all off-site activities; staff will have to also take account of your child's needs relating to the proposed activity.

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, 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.

The Next Step



There can be a need to prepare for change during every school year, as each subsequent year brings new challenges and a number of changes for your child. This need is far greater when your child changes school. If the infant school and junior school are separate, some careful planning will be required. If your area has a middle school system, you will also need to make sure you plan ahead. You and your child will need to visit the junior / middle school well in advance, armed with information about your child and a list of questions. It will be particularly important to discuss whether additional support will be needed due to the change in school, e.g. a different physical environment, moving about the school more, different teaching methods, more demanding lessons, a greater expectation of independence, etc. Inviting a representative from the new school (sometimes called the receiving school) to any meetings held during the final year at the infant school is very useful.

Please refer to the LHM Booklet on Junior School Education for further information about this next stage of your child's educational journey. If, at any transition point, it seems that your child may need additional support, please ask for our '**Statutory Assessment and Statementing**' booklet to help guide you through this process.

Further Information

We have tried to include some references to official guidance throughout this information booklet. Our full **Education Pack** contains sample copies of key parts of official publications. The LHM website (www.lhm.org.uk) contains links and contact details for obtaining your own copies of documents if you wish. Some documents are aimed at schools and LAs, others are specifically written for parents.

If you would like further information about education, you may wish to contact the LHM office in the first instance to ask for our full **Education Pack**. The detailed pack includes information on the statutory assessment process and how to access further help if your child needs it.

The report referenced on pages 5 and 13 is **Inattention, Hyperactivity and School Performance in a Population of School-Age Children with Complex Congenital Heart Disease**; Shillingford et al; *Pediatrics* 2008; 121; e759-e767.

Books about special needs, disability, etc

There are a large number of books written for this age group of children. Some ideas are below:

Don't Call Me Special: A First Look at Disability (First Look at Books)
by Pat Thomas

All Kinds of Bodies: a Lift-the-Flap Book (All Kinds of...)
by Emma Brownjohn

It's Ok to Be Me!: Just Like You, I Can Do Almost Anything! (Live and Learn Books)
by Jennifer Moore-Malinos

Accept and Value Each Person (Learn to Get Along)
by Cheri Meiners

I'm Special (Your Feelings)
by Jen Green

Rainbow of Friends
by P.K. Hallinan

Key Terminology and People

A more detailed glossary is available from Little Hearts Matter.

Early Years

The Early Years Foundation Stage (EYFS) covers birth to Aug 31st after a child's 5th birthday, which normally means the end of the Reception year. There are six broad areas of learning: Communication, Language and Literacy; Creative Development; Knowledge and Understanding of the World; Personal, Social and Emotional Development; Physical Development; Problem solving, Reasoning and Numeracy. Each topic (eg 'Ourselves & others') should have elements of learning from each area. Year 1 is the first year of Key Stage 1, although teachers will draw upon the Early Years curriculum to aid and support transition.

Foundation Key Stage (FS1 and FS2)

FS1 is the school nursery year, when your child is aged 3-4. FS2 is reception, ages 4-5, usually the start of 'proper' full-time school. This does differ in different parts of the country, so find out what the situation is where you live.

Key Stage 1

Is the next part of the formal education system and covers Years 1 and 2 (when your child is aged 5-7).

LA

Local Authority (previously Local Education Authority or LEA).

Setting

Where education takes place e.g. playgroup, nursery or school.

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 pre-school settings or 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.

Early Support

The government's recommended approach to co-ordinating services for families with young disabled children.

Every Child Matters

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

Additional Information Regarding Medication

The government guidance 'Managing Medicines in Schools and Early Years Settings' includes the following points.

It is helpful, where clinically appropriate, if medicines are prescribed in dose frequencies which enable it to be taken outside school hours. Parents could be encouraged to ask the prescriber about this. It is to be noted that medicines that need to be taken three times a day could be taken in the morning, after school hours and bedtime.

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.

Early Years Staff Giving Medicines

For registered daycare the conditions of employment are individual to each setting. It is therefore for the registered person to arrange who should administer medicines within a setting, either on a voluntary basis or as part of a contract of employment.

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