

Healthcare Plans for Children and Young People with a Single Ventricle Heart Condition



Little Hearts Matter
Half a heart, not half a life

Every child with a single ventricle heart condition will have added needs within the school environment, although each individual's needs will be different. Most of these needs will be related to their reduced energy levels, but they may also have additional needs relating to other medical conditions or their ability to learn.

This booklet has been created to support parents/carers and young people to achieve a greater understanding of their needs within the school environment and to support the creation of an Individual Healthcare Plan or Management Plan to be used in school to support a safe learning experience.

School Guidance

In September 2014 a new set of guidance was created to support children with long-term medical conditions in school. A copy of the guidance forms part of this pack. In brief, the guidance sets out the school's responsibility to offer support to a child disabled by their long-term health condition ensuring that the school and external learning environments and teaching are offered in a safe and inclusive way.







Who decides that a child has a long-term medical condition?

Current information states that the final decision that a child has a long-term medical condition lies with the head of the school. It is very clear that children born with half a working heart have a long-term condition but schools may require a letter from the child's cardiac team to confirm the diagnosis and the needs of the child.



What is a Healthcare Plan?

A school Healthcare Plan is a plan for teachers and school support staff that sets out the needs of a child with a long-term medical condition.

It should include:

-  A photo identifying the child with their name and their preferred name.
-  Details and explanations of their medical condition.
-  A brief explanation of how the condition affects them on a day-to-day basis.
-  What is normal and OK on a day-to-day basis e.g. they may naturally get a little breathless or cyanosed (blue).
-  Which parts of a school day or the environment will be challenging, e.g. a PE lesson, walking between classrooms, getting cold in the playground.
-  A clear plan for what support has been put in place to solve the issues identified. For example, a child being able to stay in with a friend at playtime when the weather is cold and wet, being able to leave a classroom early so that they have time to move from class to class, or highlighting the golden rule for PE teachers.

If you become so breathless that you can't talk... STOP.

-  Signs to watch out for that indicate when a child's condition is deteriorating together with clearly set down response processes, for example increased breathlessness that does not get better.
-  A list of contact points and when to call them.

Who writes the Healthcare Plan?

Key to the school's understanding of the child's needs is the creation of strong positive links between the school's Special Educational Needs Co-ordinator (SENCO), parents, older children themselves, and specialist nurses. In some cases it will also be important for the school nursing service to become involved on a more local support level.

The plan needs to be written in collaboration between all of the identified people above but in reality it is often parents who take a lead and so it can be useful to create a draft Healthcare Plan to be used as the basis for any conversations with the school. See the example on the following page.

Who needs to know about the Healthcare Plan?

Having agreed which areas of each child's school day will require added support and having established who their key educational and support team will be, it is essential that everyone meets together to ensure a good understanding of the child's needs. It is also important that other members of staff learn about the plans for each individual child.

In many schools it is seen as good practice to have photographs of any pupil with a health need up in the staff room, medical room and perhaps in a tutor's office and/or department office. Although details of a child's condition and a response plan for concerns should be in every classroom it is not seen as advisable to put a photograph of any individual child on public display.




Moving forward, the Healthcare Plan will need to be reviewed yearly unless there are any changes to the child's medical condition or new challenges are recognised.

Every time there is a change in teaching staff or the child moves classes, the team need to revisit the plan and make sure that everyone is up-to-date with the child's needs in school.

What do we do if the school refuses to create a Healthcare Plan?

Most schools will be more than willing to set out a plan to ensure that a child can be kept safe within school. They are responsible for a child during the school day and they will want to make sure that all of the school team have a good awareness of the child's medical challenges.

In the rare case where there is a dispute about a child's needs there are a number of approaches to resolving the issue.

-  Arrange to have a private meeting with the head of the school and the SENCO.
-  Ask the hospital medical team to write a letter to the head of school explaining the added needs.
-  If the head of the school will not take the issues forward contact the chair of the governing body at the school. The new guidance (enclosed with this pack) sets out the governors' responsibility for the support of a child with a long-term medical condition within school.

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It can be really helpful to identify a member of school staff that you can relate to and who will work positively with you to forward the support needed for your child. This might be the SENCO, dedicated support staff or form teacher or tutor.

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Example Healthcare Plan

Healthcare Plan for Pupil with Medical Needs

Name: [Name]
Class:
Date of birth:
Condition: Hypoplastic Left Heart Syndrome
Cardiac Pacemaker
Medication: Sotalol 40mg BD
Lisinopril 5mg BD
Warfarin (current dose 4mg daily)
Date: [Add date]
Review date: [Add date to be reviewed]

Contact Information

Family Contact 1

Name: (e.g. Mum)
Phone: Home:
Mobile:
Work:

Family Contact 2

Name: (e.g. Dad)
Phone: Home:
Mobile:
Work:

Medical Contact 1

Name: Dr Local (GP)
Address: Local Surgery
Some Road
Some Town
Postcode
Phone: GP Phone Number

Medical Contact 2

Name: Dr YYY (Consultant)
Address: YYY Hospital
Some Road
Some Town
Postcode
Phone: Hospital Phone Number
Hospital No: YYYYYYYYYY

Describe condition and give details of pupil's symptoms

[Name] has had all three stages of the Norwood Surgical Procedure and has a Fontan circulation. This means his heart has only one pumping chamber. As a result, [Name] tires easily. He finds it difficult to do any physical activity quickly or for any length of time, even standing for long periods can be difficult. [Name] may go blue around the lips, finger tips and ear lobes when doing strenuous activity. As a result of being on Warfarin, [Name] will bruise easily and should avoid contact sports.

Daily care requirements (e.g. for sport/lunchtimes)

[Name] should be encouraged to and allowed to rest when needed during physical activity. He should not be expected to compete at the same level as other children.

[Name] gets cold very quickly during the winter months and should be allowed to go indoors to warm up if needed.

If [Name] says he feels unwell, he usually is and this should be acted upon.

[Name] should avoid contact sports. If falls or bumps occur, monitor closely. If a blow to the head, please notify parents.

Magnets should not be placed directly over [Name]'s pacemaker. Using small magnets at arms length is fine.

Describe what constitutes a medical problem/emergency for the pupil and describe the action to be taken if this occurs.

Symptom	Action
Dizziness, pale colour	Phone family contact
Arrhythmias - [Name] will say that his heart is beating in a 'funny rhythm'	Phone family contact
Blue in colour, especially lips, finger tips and ear lobes	Phone family contact
Blow to head/hard collision	Monitor for bruising and phone family contact
Increased sweatiness	Phone family contact
Increased breathlessness at rest	Phone family contact
Chest pains (especially left side)	Phone 999 and family contact
Loss of consciousness	Phone 999 and family contact

[Name] carries a pack of additional information in his school bag at all times. This includes his Pacemaker identification card, anticoagulation record, MedicAlert details and a copy of the consultant's letter from his last hospital appointment.

Who is responsible in an emergency situation at school

School time: Form Tutor / Head of Year - [Form Tutor Name] / [Head of Year Name]

Lunch time: Senior Middy Assistant - [Senior Middy Name]

School trips: Designated helper / teacher

Form copies to

Parents

Form Tutor / Head of Year - [Form Teacher Name] / [Head of Year Name]

Senior midday assistant - [Senior Middy Name]

SEN Coordinator - [SENCO Name]

School Office

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Disclosure: Emma Canetti has no conflict of interest

References are available from the LHM office on request