



Sport and Exercise

for children with single ventricle heart conditions.



Little Hearts Matter
Half a heart... not half a life

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Introduction

There is ever increasing encouragement to keep fit, eat a healthy diet and pressure to remain slim. Every GP's waiting room encourages a healthy lifestyle full of exercise and low fat diets to ensure that our hearts stay healthy. But what about children with a complex congenital heart condition, how easy and safe is it for them to follow the national trend?

Whilst it is very important to remember that people living with only half a heart do not have the energy levels of their peers, most children and young adults can take part in some sort of exercise. It is important that every young person has the opportunity to explore and participate in exercise where physically safe.



Using your arms and legs and increasing your heart activity a little is good for you. And remember that you need to ask your cardiac team about what is safe for you. It may not be the same as every child in your school or college but equally it may not be the same as another heart child.

But there is a golden rule...



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

This booklet is written primarily for parents, but it will also be useful for young people with single ventricle heart conditions. It aims to give overall guidance for leisure and school sports and exercise, and includes a chart which can be used by individual families to give an up-to-date personalised picture of what is safe for them.

It aims to help families to understand the principle that everyone should exercise within safe limits.

Types of sport and exercise

Exercise

Exercise is any sport or activity that makes your muscles work harder than if you were just sitting down. It makes you feel warm and, in some cases, breathless. The exercise can include swimming for fun, riding a bicycle, playing football in the garden or going to a dance class. It should be fun and gradually anyone taking part regularly should be able to increase the length of time that they can take part whilst still being able to talk to the other people around them.

Activity

Activity is an experience that keeps you active but may not include exercise. Going fishing, joining a drama group, singing in a choir or joining a chess club are all activities where you can meet other people, join in and have fun but they do not exercise your heart or other muscles.

Sport

This is a game, match or physical activity where there is an element of competition, either with yourself or against other people. Some competition can be safe, for example golf, archery, cycling or beginner's table tennis or badminton, and the skills part of a football or netball lesson. A gradual increase in involvement as a child becomes fitter is fine,

but the golden rule always applies...



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

Outdoor pursuits

There are also more adventurous outdoor pursuits, such as hillwalking, climbing, abseiling, zip wire, canoeing, etc. These are the type of activities often undertaken on school residentials, with

organisations such as cubs and scouts, or as part of a Duke of Edinburgh (D of E) Award programme.



You should seek advice from your cardiologist about these types of activity. You must also discuss your condition with the instructors / activity leaders in advance to ensure you can participate as much as possible, but within safe limits. Always follow all safety instructions and wear the correct safety gear. Many of these activities will be safe for you, but there may need to be some small adaptations. For example, for water sports such as canoeing, you may need to wear a wet suit, and have a change of clothes ready to change straight afterwards. Or for climbing, you may need to agree a height limit with the instructors in advance, so that you do not push yourself too hard. With an activity such as zip wire, you will need to be careful if there is a hard impact at the other end of the wire. You may need to take care of the type of harnesses used, if any of them put pressure on your chest. Activities such as hillwalking will probably need a more substantial adjustment, depending on how far you are able to walk, and whether you are able to safely carry anything.

“Before Matthew’s Year 6 residential, we did a detailed plan for the week with a teacher who had run the programme many times. We considered each activity in turn and looked at the possible risks, and whether Matthew could take part safely. As it was, he had a fantastic week, and took part in every activity except the disco, with only a few modifications, such as a shorter walk and extra rest time.”

Cycling

Some young people find cycling a good form of exercise with the added benefit that it also helps them to get around.

School PE lessons

It is important that children in school have an opportunity to take part in school PE lessons if possible. Most PE teachers are grateful if parents explain what a child can or can't do at the beginning of each school year. It is also important for the child to take on this responsibility as they get older so that they can build a greater understanding of what their body can or can't do.

Most PE lessons are split into four sections.

The warm up

This section of the lesson warms up the muscles ready to play sport. As long as there is no running laps around the sports field, a little bit of a jog will warm up the legs.

Rules and skills

Within every PE lesson the teacher will demonstrate the skills and rules needed to play that sport and will get the students to practise those skills. As long as the skills test does not expect too much chasing around it is a good way to learn about the sport and get involved.

The game

This is the part of the lesson where you put the skills learnt into practice. If the sport is very competitive or physically demanding this is the section of the lesson that anyone with a complex heart condition may need to avoid. Learning about the game by watching, taking part in the refereeing or choosing a different activity may be the best way to cope with difficult sports.

And it is often a problem to keep warm if you have to sit out this section.

Schools may have a choice of sports that can be played during PE; lower endurance sports may be the best choice.

Cool down

It is very important to cool down correctly and stretch out the muscles at the end of a lesson, as it helps prevent pulled muscles. It is safe to join in with this part of the lesson.

Further tips

- Children should wear their MedicAlert bracelet during PE lessons as these are high risk times. This may need planning as the wearing of jewellery is not usually allowed during sports lessons. Velcro MedicAlert bracelets are often safer.
- Make sure your child has appropriate clothing for PE lessons e.g. the full tracksuit for outdoor games. Added layers are helpful if the weather changes.

Current government guidance around PE provision in both primary and secondary schools states that individual schools are free to develop their own curriculums for PE that best meet the needs of their pupils (see www.education.gov.uk). This is in anticipation of the new National Curriculum which is due to be introduced in September 2014.

PE should be a fun, safe, useful activity that does not tire out any class member or isolate them from their peer group unnecessarily. The best sessions are inclusive, creative and supportive of all abilities. Teachers and support staff should be aware of the heart child's limitations and have a series of agreed strategies about how and when to intervene, remembering that preparation and recovery time are of optimum importance, especially if students are going on to other lessons or activities.

What should parents or teachers do if a child becomes ill during exercise or sport?

If a child follows the Golden Rule set out on page 5 that they should always be able to talk whilst they exercise, they may be a little breathless after exercise but they will be able to recover quickly. Just sit them down with their chests upright and gradually their breathing will settle.

If a child pushes their activity too far they will become so breathless that they will not be able to talk. They will be unlikely to be able to breathe effectively for some time. Their colour may change becoming pale with very red cheeks and increasingly blue lips. Their chests will heave up and down and they will be very sweaty but often they have cold hands and feet. Their heart rate will be very fast and may be erratic.

- ✓ Firstly calm them down as they will be frightened that they can't breathe properly.
- ✓ Sit the child upright to allow for good lung expansion.
- ✓ Encourage them to breathe in a slow rhythm, this will make each breath more effective.
- ✓ Seek first aid help.
- ✓ If after ten minutes there is no improvement in their condition initiate the school or sports club plan to gain more professional help by calling for an ambulance, at the same time call parents or the school contact person.
- ✗ Do not put the child in a car to drive them to seek help.

It is important that the expertise comes to the child as the ambulance team can start treatment as soon as they arrive: they have oxygen on board, they can record the heart rhythm and oxygen saturation rates and can ring through to the hospital for advice. If you put the child in the car their condition can deteriorate and you will be unable to provide the necessary treatment if you are driving them.

Teachers need to have all the medical information about a child to

hand to take to the hospital with them should it be needed. A laminated sheet with all of their details on it is a safe way to ensure the information is easily found. Copies should be kept in the school office and PE department.

It is important not to stop your child taking part in exercise as it is a great way to feel included in school life. Exercise just needs to be approached positively and sensibly to keep a child or young adult safe.

Medical information sheet

Below is an example of a medical information care plan, information included will change dependent on your child.

[CHILD'S NAME] - MEDICAL INFORMATION

DATE OF BIRTH: ___ / ___ / ___

DIAGNOSIS:

e.g. Complex congenital heart disease consisting of Hypoplastic Left Heart Syndrome (HLHS)/Tricuspid Atresia/Complex Pulmonary Atresia/Univentricular Heart. *Write down your child's exact diagnosis here.*



**Child's
Photo**

MEDICAL HISTORY:

e.g. Norwood Procedure, BT shunt, PA banding, Cavo-pulmonary shunt. Cardiac catheterisation.

Fontan (internal or external, fenestrated or non-fenestrated)

Include dates of procedures and any detail you can - take it from clinic letters.

MEDICATION: e.g. Warfarin/Aspirin, Furosemide, Enalapril.

List all the medications your child takes.

SUPPORT NEEDS:

Encouragement with eating and drinking (high calorie needs, high fluid needs), supervision to minimise the chance of traumatic injury especially during unstructured times, support required to self-limit appropriately.

Make this section relevant for your child - what do they need help with to keep safe and well?

CONTACT INFORMATION:

Parents [names]; [telephone numbers]

The bleep test

Many schools encourage children to take part in the 20 metre multistage fitness test or bleep test. This is a fitness test that tests the fitness of children or young adults taking part in PE. It is also used by some sports clubs and other organisations such as cubs and scouts. The test starts slowly with a child running between posts or stages 20m apart with a bleep sound setting off the next run. The time between each bleep gets shorter and shorter with children running more and more quickly between each stage. In theory, children can stop when they get tired and so some children with only half a heart like to be included in the early stage of the test, stepping away when they get a bit breathless, or at a pre-agreed limit.

But LHM would like to put out a warning. This is a competitive activity. Children may be put into teams or just race themselves against the clock.

Recently one of LHM's young members collapsed whilst undergoing the bleep test at school because she pushed herself to keep up with her friends beyond what was safe for her heart. She is now OK but was rushed by ambulance to hospital and was still off school nearly a week later.

The LHM team is very keen for children to get involved with as much activity as possible but competitive exercise can pose a danger for children who do not listen to their heart or lungs.



The golden rule when taking part in any exercise is that you should always be able to have a conversation whilst you walk or run. If you are too breathless to talk you are doing too much.



More challenging sports

There are some activities that are less safe for children with single ventricle heart conditions.

Serious competitive sport

These are sports where you have to race to beat someone else. In a football match it would be racing with the ball to score a goal or a touch down in rugby, in a running race you would be trying to be the first to cross the line, in the swimming pool you would race for the finish, and you would race the bleep in the exercise tolerance bleep test (see page 12 for an explanation of the bleep test). The very nature of competition is to push yourself to win so you try to make your heart and lungs work harder to get there first.

Why should competitive sports be avoided?

In a competitive environment, children and adults push themselves to win. They fail to listen to their body when they become too breathless to talk and they demand more activity than their heart can manage. Competitive sport also uses up all of the energy stores collected around the body so a child may run and win a race but they may take days to recover their energy stores which leaves them unable to take part in everyday action for two to three days.

Research conducted by Professor Gewillig from Belgium suggests that children with normally functioning hearts will have an energy level of 100% at rest which can rise to 500% when they exercise. Children with a Fontan circulation have energy levels between 50 and 70% at rest and can only raise the level to 200% on exercise.

Contact sport

This is where you have a risk of bumping into someone or where physical activity is part of the game, for example, in rugby you tackle the opposition, in judo you get thrown to the floor. It is not a good idea to do any of this type of sport for two reasons.

1. Most children who have had a Fontan procedure are on anticoagulation, either Aspirin or Warfarin. These medications slow down clotting so a bump, knock or kick will cause a huge amount of bruising or a cut will bleed more than an average cut.

2. Bumps to the body can cause problems if you have a pacemaker as it can disturb the pacing box in the abdomen. If a child has recently had surgery a bump to the chest can disturb the sternum as it heals.

Static weights/resistance exercise

When using weights or when pushing against a resistance you raise up your body pressure to take the added strain. This can create an added strain on the heart and should be avoided.

So if the children want to take part in sport they should think about what type of sport, exercise or activity they are interested in and what they are safe to do. They must consider not just the moment of the activity but what effect that activity will have on their energy levels for the rest of the week.

It is all about personal responsibility (guided by parents and teachers when the child is small) and finding a lifestyle balance that includes as much fun and games as possible, whilst also leaving enough energy to learn in school or take part in a job.

Contact leisure activities

Some activities like paintballing or trampolining hold a potential risk of bruising or bleeding if a child is on anticoagulation e.g. Warfarin or Aspirin. If children like to bounce make sure that they are supervised and alone on the trampoline so that they do not get knocked.

We believe the real key is balance; we have allowed our son to go paintballing. We discussed his condition with the centre; who were very understanding and accommodating and provided him with extra protection. As a cautionary measure his dad went along as well. Our son did get an extra bruise or two however we did not let this probability restrict his enjoyment on the day.

Exercise Chart



Below is a chart of different types of exercise. Take it to your doctor each time you have a check-up at the hospital and then they can tell you which sports or activities are possible for you. There are some blanks for any sport/activity not listed.

Ask your cardiac doctor to mark which sports you can play competitively [C] just for fun [F] or not at all [X].

SPORT	Date C/F	Date C/F	Date C/F	Date C/F	Date C/F	Date C/F	Date C/F	Date C/F
Archery								
Golf								
Table Tennis								
Badminton								
Trampolining								
Gymnastics								
Athletics								
Winter Sports								
Yoga								
Cricket								
Basketball								
Tennis								
Hockey								
Swimming								
Dance								
Football								
Martial Arts								
Rugby								
Snooker/Pool								
Netball								
Cycling								

Further Support

English Federation of Disability Sport

www.efds.co.uk

This is the national body for disabled people in sport and physical activity throughout England. The charity aims to increase opportunities at all levels of participation.

Disability Sport Wales

www.disabilitysportwales.org

Scottish Disability Sport

www.scottishdisabilitysport.com

Disability Sports Northern Ireland

www.dsni.co.uk

Parasport

www.parasport.org.uk

This organisation has been designed to inspire, educate, inform and signpost disabled people, and those interested in disability sport to high quality opportunities.

Find sports clubs in your area for many disability sports

www.parasport.org.uk/clubfinder

Wheelpower

www.wheelpower.org.uk

This is the national disability sports organisation for wheelchair sports but it is broader than just wheelchair sports. The website has a junior sport section.

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References are available from the LHM office on request.



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