



Little Hearts Matter



## Sport and exercise

when you have a single ventricle heart condition





# Contents

Introduction	Pages 4 - 7
Types of sport and exercise	Pages 8 - 17
School PE lessons	Pages 18 - 20
What to do if a child becomes ill during exercise or sport?	Pages 21 - 22
The bleep or multi-stage fitness test	Page 23
More challenging sports	Pages 24 - 25
Half a heart, half the energy project	Page 26
Inclusion	Page 27
Exercise chart	Page 28
Further support	Page 29
Acknowledgements	Page 30

# Introduction

We all know that exercise should be part of our lives. It helps us to stay fit and reduces the risks of short- and long-term health problems as we get older. But what about children with a complex congenital heart condition: how easy and safe is it for them to follow the same advice?

There is increasing evidence to support the need for most children and adults with a congenital heart problem to take some form of exercise. It can increase the effectiveness of their heart muscle and generally aid the circulation of blood around their body. It may also reduce the number of infections they catch as they become more generally fit and healthy.

Whilst it is crucial to remember that people living with only half a working 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 it is physically safe for them to do so.

This booklet is written for young people with half a heart, parents, teachers and club leaders. It aims to give overall guidance for leisure and school sport and exercise, and includes a chart which can be used by individuals to give an up-to-date personalised picture of what is safe for them.



## YOUTH MESSAGE

Exercising your muscles and increasing your heart activity can be really good for you, but you may need to be careful about what sort of sport you take up. Think about which sports you would like to get involved in and then talk to your heart doctor (cardiologist) about what is safe for you. It may not be the same as other children in your school or college but it will help to get you fitter and meet new people.



## GOLDEN RULE

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

It is important to pace any increase in activity so that the heart and lungs can gradually build up their ability to cope with a new demand on their energy levels. The activity needs to become part of the daily energy use but it is essential that the sport does not use up all of the daily energy available, leaving a young person short of energy for the other activities in the day. Balance is essential. For more information follow the link to the Half a Heart, Half the Energy information, [www.lhm.org.uk/youth-zone/lifestyle-information/half-heart-half-energy-2/](http://www.lhm.org.uk/youth-zone/lifestyle-information/half-heart-half-energy-2/)

### YOUTH MESSAGE

Don't throw yourself into an activity or sport. Assess what energy will be needed and slowly start to take part. Allow yourself time for breaks and a drink. Gradually as your fitness improves, the length of time you can take part will increase. You may never be able to play 45 minutes each way but you can take part.

## Exercise tolerance tests

Some children and young adults will be given an exercise tolerance test as part of their routine cardiac tests at the hospital.

They will walk or run on a treadmill or cycle whilst having an ECG and blood pressure tests. Occasionally they may have some breathing and oxygen level tests done as well.

These tests can tell the medical team how fit the heart is and

also indicate what exercise can be prescribed safely.

## Exercise prescription

Many units are now giving children a formal exercise 'prescription' in the same way as a drug might be prescribed. This recognises how important regular exercise is for children with heart conditions and also helps to ensure that the correct exercise is taken for their individual condition. If you have any areas of uncertainty, you could ask your consultant about this.

For more information about the exercise prescription toolkit, visit <https://chd.heartresearch.org.uk/adult-patient-resources/how-exercise-safely>

## Healthcare plans

Anyone in education aged 0 - 24 years with a long-term health condition should have a Healthcare Plan. Plans are written in partnership between parents, teachers and the pupil. They may also involve the school nurse and the hospital-based specialist team. Each Education Authority has their own plan so ask the school's Special Educational Needs Co-ordinator (SENCO) for a copy.

Safe inclusion in sport and exercise in school should be included in the plan. Use this booklet to help teachers understand how to keep a child safe whilst doing PE.

For more information on Healthcare Plans visit [www.lhm.org.uk](http://www.lhm.org.uk) and click on 'Information', 'Lifestyle information', 'Education'.





# 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 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 beginners table tennis or badminton, and the skills part of a football or netball lesson. It will require a gradual increase in involvement as a child becomes fitter.

### **GOLDEN RULE**

**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 the Duke of Edinburgh's (DofE) 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 wetsuit, and have a change of clothes ready to change into 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 be careful with 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.

## Examples of sport and exercise

Children with half a heart can often take part and really enjoy sport and exercise safely. Competition and personal achievement can be very important for children, especially as it helps them feel included.

Some sports may be more suited to a child's ability and energy levels. A conversation with their cardiologist will give you confidence to introduce a sport if you are worried about the level of safety.

### Running/athletics

Most children with half a heart will want to get involved in the activity going on around them. Running around the playground,



taking part in running in a PE lesson, hurdles, long jump and high jump can all be inclusive and can be very good exercise as long as a child is able to sit down when they are tired and they are not forced into a competitive running situation if they are not fit enough to do so.

## Swimming

Swimming can be a very good exercise for a child with a single ventricle heart to get involved in. The water takes some of the strain as it supports the weight of the body. Most schools encourage children to learn to swim.

Here are some helpful pointers when planning a swimming lesson.

Learning the different types of strokes is very good and building up the ability to keep safe in the water by swimming lengths and learning to tread water is good exercise. Taking part in races would come under the heading of competitive sport and should be avoided unless a doctor has said it is safe.

Children with half a working heart get very cold and very tired whilst swimming and when they get out of the pool.

A couple of useful tips include:



Wearing a simple wetsuit.



Ensuring that a dry towel is close to the edge of the pool.



Ensuring there is help so a child can swiftly get changed into dry clothes.



Having a snack available to boost used-up energy.

## Football

Football is played both competitively and for fun in school. Children love to be involved in a game of football in the playground. It can be a great way to keep warm in break time



as well as being a social game to play with friends.

As with all sports and PE lessons, learning the skills of the sport is a great thing for all children. More care may need to be taken when it comes to the competitive part of the game.

Some children are encouraged to take a position in goal as there is less activity. Care must be taken to ensure that they keep warm as there may be long periods with little activity. It is also important to remember that goalkeepers have to throw themselves around the goal to keep the ball out and this can lead to bruising if a child is on anticoagulation.

## Cycling

Some young people find cycling a good form of exercise because the pace can be set individually and the wheels help the activity and achievement. It has the added benefit that it also helps with getting around.

If a child is struggling with the activity an electric bike would give them some added support.

## Racket and bat sports

Racket or bat sports include tennis, table tennis and badminton. They are often at a lower intensity and can be played as doubles so the game can be shared but they provide competition and exercise. Once the game becomes more competitive it becomes more physical.

## Summer team games

Cricket and rounders encourage team activity and apart from the time when a player runs (a runner can be substituted if the running is difficult), the game is of a lower intensity.

## Dance and gymnastics

Both dance and gymnastics provide exercise and fun but can also help with the development of gross motor skills. Often children with a heart condition have delays in the development of

live to  
*Dance*



their gross motor skills, balance, co-ordination and perception.

If a child is prescribed anticoagulation, care is needed if they fall from equipment. If they have a pacemaker the position of the device, in the abdomen or chest, may restrict the type of equipment they can use.

## Martial arts

There are many types of martial arts and many children are attracted to them because of the kudos of the sports. Discipline, respect and personal control are all part of the activity which can be helpful for some children. Some martial arts expect physical contact early in the training, judo for example. Others restrict combat until later but it will be an expectation of the sport eventually. If a child is on anticoagulation, the physical contact will be an issue as it is a contact sport.

It is important to think about both the short-term and long-term implications of taking up a martial art. If a child becomes skilled in the sport and wants to take it up long-term, they may be disappointed because as the level of combat increases, they may need to be excluded for their safety.

## Lower-intensity activities

Sports such as golf, bowls and archery require precision and are very competitive but they require much lower levels of physical exertion. These sports may be attractive to young people with a low exercise tolerance.

## Active video/computer games

Activity based computer games are very popular with children and teenagers. As with any sports activity, care must be taken to follow the **GOLDEN RULE** when taking part. Regular breaks in activity should be encouraged.









# School PE lessons

It is important that children in school have an opportunity to take part in school PE lessons if possible. There is a statutory requirement for all pupils to be offered PE in school unless there is a specific medical reason why they should not be included.

## Primary school

In primary education the aims are to:

-  Master basic movements including running, jumping, throwing and catching, as well as developing balance, agility and co-ordination, and begin to apply these in a range of activities.
-  Participate in team games, developing simple tactics for attacking and defending.
-  Perform dances using simple movement patterns.
-  Swim competently, confidently and proficiently over a distance of at least 25 metres; learn how to keep safe in water.

Healthcare Plans (HCPs) are now a statutory requirement for any child with a long-term health condition. Information on what sport and exercise a child may take part in are an essential part of the plan, as is the medical response plan should a child become ill. Remember to include things like keeping warm after swimming and planning rests during a lesson if a child becomes breathless.

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 young people to take on this responsibility themselves as they get older so that they can build a greater understanding of what their body can or can't do.

## Secondary school

Most secondary school 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. 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.

### The 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. It is also important to put on an extra layer of clothes after a cool-down so that the muscles do not get cold, causing cramp.

## 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.
-  Make sure the children have a good drink after any activity. Dehydration makes it more difficult for a Fontan circulation to work well.

For more information on PE in the curriculum follow this link: [www.gov.uk/government/publications/national-curriculum-in-england-physical-education-programmes-of-study/national-curriculum-in-england-physical-education-programmes-of-study](http://www.gov.uk/government/publications/national-curriculum-in-england-physical-education-programmes-of-study/national-curriculum-in-england-physical-education-programmes-of-study)

# What to do if a child becomes ill during exercise or sport?

## Normal recovery after exercise

If a child follows the **GOLDEN RULE** set out on pages 6 and 9, that they should always be able to talk whilst they exercise, they may become a little breathless during activity but they should be able to recover quickly.

Just sit them down with their chest upright and gradually their breathing will settle.

## If they do not recover quickly

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.

## ACTION

- First 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 there is no improvement in their condition, initiate the school or sports club plan to obtain more professional help by calling for an ambulance. At the same time call parents or the school contact person. This will be written in a school Healthcare Plan.



**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 a 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. Everything should be included in a child's Healthcare Plan, and a copy should be held in the 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.

### YOUTH MESSAGE

It is important that you are responsible for stepping away from a game or exercise when you can feel that your heart and lungs are under strain. It is better to take a five-minute rest and then play again than to collapse because your heart and lungs cannot cope with the pressure you have put them under.

A copy of the school Healthcare Plan could be used at a club to ensure that club leaders have a good understanding of the response needed in an emergency.

# The bleep or multi-stage fitness test

Many schools encourage children to take part in the 20-metre multi-stage 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 20 metres 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.

Whilst the LHM team is very keen for children to get involved with as much activity as safely possible, this type of competitive exercise can pose a danger for children who do not listen to their heart or lungs.

The **GOLDEN RULE** when exercising is that you should always be able to talk whilst you walk or run. If you are too breathless to talk then 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 sports

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 touchdown 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. 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 sports 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 and this leaves them unable to take part in everyday activity 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 sports

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, usually 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 they can disturb the pacing box in the abdomen or chest. 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 your body pressure to take the added strain. This can create an added strain on the heart and should be avoided.

### Contact leisure activities

Some activities like paintballing or trampolining hold a potential risk of bruising or bleeding if a child is on anticoagulation, for example, 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.



#### YOUTH MESSAGE

If you want to take part in sport you should think about what type of sport, exercise or activity you are interested in and what is safe to do. You must consider not just the moment of the activity but what effect that activity will have on your energy levels for the rest of the week. It is all about personal responsibility (guided by parents and teachers when you are younger) 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.

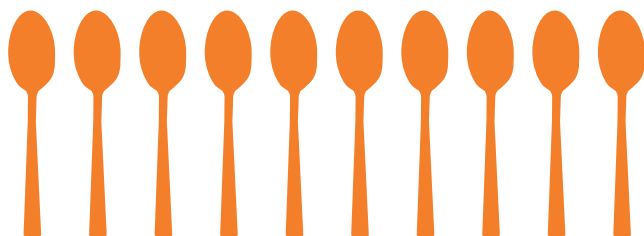
# Half a Heart, Half the Energy project

## Spoons that help you balance your life

Young people with half a working heart often find it difficult to balance all the things that they want to do in a day with their reduced energy levels. The Half a Heart, Half the Energy project can help them learn to balance the expectations in their day so that they maximise their inclusion.

Sport and exercise can help to gradually increase their fitness and allow them to gain better use of their limited energy levels.

To help children and teenagers learn how to manage their limited energy the LHM youth team have developed a way of using spoons to explain the use of energy each day.



For more information and the chance to watch the energy film, follow the link to the Half a Heart, Half the Energy project information: [www.lhm.org.uk/youth-zone/lifestyle-information/half-heart-half-energy-2/](http://www.lhm.org.uk/youth-zone/lifestyle-information/half-heart-half-energy-2/)

# Inclusion

It is important that every child is able to take part in all activities, if their heart condition will allow it. Ensuring that schools make provision for children to take part in PE, dance, drama and off-site activities is essential.

Each school and Local Authority will have an inclusion policy for you to refer to if there are any concerns about your child's inclusion.

# 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 heart doctor (cardiologist) to mark which sports you can play competitively [**C**], just for fun [**F**] or not at all [**X**]

Sport	C/F/X	C/F/X	C/F/X	C/F/X	C/F/X	C/F/X
Archery						
Golf						
Table tennis						
Badminton						
Cycling						
Gymnastics						
Athletics						
Swimming						
Yoga						
Cricket						
Basketball						
Tennis						
Hockey						
Ice skating						
Dance						
Football						
Martial arts						
Rugby						
Snooker/pool						
Netball						
Trampolining						
Skiing						

# Further support

## Activity Alliance

A national charity that enables organisations to support individual disabled people to be and stay active for life.

[www.activityalliance.org.uk](http://www.activityalliance.org.uk)

## Disability Sport Wales

[www.disabilitysportwales.com](http://www.disabilitysportwales.com)

## Scottish Disability Sport

[www.scottishdisabilitysport.com](http://www.scottishdisabilitysport.com)

## Disability Sport Northern Ireland

[www.dsni.co.uk](http://www.dsni.co.uk)

## Parasport

Provide information to disabled people who want to take up sport, either at a recreational or competitive level. They signpost people to disability sports that are available to them and where they can go to play them.

<https://parasport.org.uk>

## Wheelpower

This is the national disability sports organisation for wheelchair sports which aims to provide opportunities for disabled people to find a sport they enjoy from a broad range of possibilities. They offer a junior sport programme (information can be found in the 'Sport events' section of the website).

[www.wheelpower.org.uk](http://www.wheelpower.org.uk)

## PE National Curriculum

<https://www.gov.uk/government/publications/national-curriculum-in-england-physical-education-programmes-of-study>

# Acknowledgements

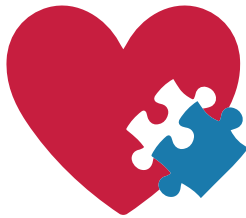
- Written by: Suzie Hutchinson RGN RSCN  
Chief Executive and Service Lead
- Medically verified by: Dr A G Stuart MBChB Cert Genomic  
Med Msc FRCPCH FRCP FESC  
Consultant Cardiologist
- Designed by: Deb Rahman  
Design and Information Administrator
- Proofed by: Isabel Baumber BA (Hons) DipM  
Parent Trustee  
David Beattie M.Phil. MITI
- Disclosure: Dr A G Stuart has no conflict of  
interest

We would like to thank members of our reader panel for reviewing this publication and sharing their experiences.

We are very grateful to our member families for sharing their experience and photos with us in this publication.

References are available from the LHM office on request.





**Little Hearts Matter**

**T:** 0121 455 8982 | **E:** [info@lhm.org.uk](mailto:info@lhm.org.uk) | **W:** [www.lhm.org.uk](http://www.lhm.org.uk)

© 2019 Little Hearts Matter

A company limited by guarantee, registered in England and Wales, number 06442071, registered office 75 Harborne Road, Edgbaston, Birmingham, West Midlands, B15 3BU, registered charity number 1123290.

LHM SEB 0319

Review date 0322