

Physical Activity:

What if my child has a Congenital Heart Condition?



Advice for Parents / Carers

About this booklet

This booklet is for parents or carers of children and young people who are born with a heart condition. A congenital heart condition means that either there is a part of the heart which is abnormal, or a problem in the main blood vessels that are joined to the heart, which has been there since birth. It explains the benefits of physical activity for your child. It aims to make sure that your child exercises safely within the limitations of their condition, and is not discouraged from taking beneficial exercise because of unnecessary anxiety about their heart condition.

This booklet does not replace the advice that the health professionals involved in the care of your child may give, based on their knowledge of your child's condition.



Is it safe for my child to exercise?

Yes, there are very few children and young people who will be advised not to do any exercise at all. Your child's Paediatric Cardiac Liaison Nurse or Consultant Congenital Cardiologist will tell you what your child can do and if there is anything your child should avoid doing. Everyone is different so you must get individual advice about your child's heart condition.

How much exercise is recommended for children & young people?

Public health guidelines recommend that children and young people up to the age of 18 years should do at least 60 minutes of at least moderate-intensity physical activity a day, every day of the week. This recommendation applies to all children and young people, including those with medical conditions. The 60 minutes can be accumulated in 10-15 minute periods during the day.

What are the benefits of regular physical activity & exercise?

There is lots of evidence that regular physical activity benefits long-term health. This applies to everyone, including those with a congenital heart condition. These are some of the most important benefits of regular physical activity:

- ♥ The heart is a muscle, and regular exercise can improve the function of the heart and circulation.
- ♥ Regular physical activity may help children and young people to lose weight, or to control their weight, and helps improve their level of HDL blood cholesterol. (HDL is the protective type of cholesterol.)
- ♥ Physical activity boosts the immune system and improves the feeling of well-being.
- ♥ When first starting an exercise plan, some people feel more tired, but with time stamina and energy levels improve.
- ♥ Physical activity may help to reduce stress levels.
- ♥ It can help improve self-confidence.
- ♥ It can help improve concentration.
- ♥ It improves joint flexibility and general mobility and strengthens muscles and bones.
- ♥ It can help improve social interaction.
- ♥ Regular exercise at a young age tends to encourage more physical activity in adult life.

Where to get information about the exercise & activity your child can

do: It's important to get information about what exercise and activity your child can do, and if there is anything they should avoid doing. You can get this information from the Paediatric Cardiac Liaison Nurse or the Consultant Congenital Cardiologist based at the Specialist Cardiac Centre (rather than from the local hospital cardiac clinic which your child may attend).

Questions to ask the Paediatric Cardiac Liaison Nurse:

1. Are there any particular symptoms to look out for when my child is exercising?
2. Is my child taking regular medication for their heart condition? And if so, does this have any implications for the type or level of exercise or physical activity they can do?
3. Should my child be restricted with their exercise and activity?

You can also ask the Paediatric Cardiac Liaison Nurse for specific guidance about your child so that this can be passed on to your child's school. The school can then make sure that this information is accessible to all teachers and activity leaders, to help them plan appropriate activities for your child. The information should be updated at the start of each school year, and also if there is any medical change in your child's condition, for example, if he or she has surgery or another type of treatment.

What are the symptoms to look out for when my child is exercising?

It's OK and 'normal' for your child to feel warm, breathe harder, look 'flushed' and feel his or her heart beat faster during exercise.

Your child should stop to rest if they:

- ♥ say they feel dizzy or feel faint
- ♥ become so breathless they cannot speak
- ♥ say they have palpitations
- ♥ become very pale and clammy
- ♥ complain of severe tiredness or fatigue, or
- ♥ if they become extremely blue (if they have a cyanotic heart condition).

If you notice any of the above signs or symptoms:

- ♥ Get your child to stop and rest. Stay with them and reassure them.
- ♥ If they do not get better quickly (within 5-10 minutes), or if the symptoms become worse, call 999 for an ambulance (unless you have been specifically advised to act differently by your child's Paediatric Cardiac Liaison Nurse or Consultant Congenital Cardiologist).

In the very unlikely event that your child collapses, call 999 straight away and ask for an ambulance. Tell them it is for an unconscious child and whether they are breathing or not. If your child is breathing normally, place him or her in the recovery position. If he or she is not breathing normally, start cardiopulmonary resuscitation (CPR) and continue until medical help arrives.

If your child develops any new or unusual symptoms either during or immediately after an exercise session, you should report this to your child's GP and to the Paediatric Cardiac Liaison Nurse or Consultant Congenital Cardiologist.

What can I do to help?

- ♥ **Encourage your child to be active.** Everyone should try to do regular physical activity. If, as a result of their heart condition, your child has symptoms – such as breathlessness – that limit the amount of activity they can do, just let them do what they can but at their own pace and their own level.
 - How much your child can do depends on their particular heart condition and how well their heart functions during exercise. Your child's Consultant Congenital Cardiologist can tell you this.
 - Your child may need to think about how much effort they put into their activity. For example, they may need to take part at a lower level of intensity than other children or young people of their age, and stop to rest at regular intervals.
 - Most people can do more than they think, and being short of breath during exercise may be due to being unfit and may not have anything to do with the heart condition.

The 'talk test'

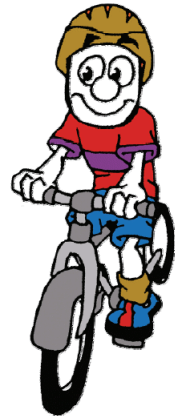
A simple guide to find out if your child is doing the appropriate level of activity is to use the 'talk test'. Your child should aim to feel warm and a bit 'puffed' but should still be able to talk in full sentences during an exercise session. If they are too breathless to talk, they are probably working too hard and need to slow down or stop to rest. They can usually resume the activity when their breathing is more controlled. If they have enough breath to be able to sing, they are not exercising hard enough to gain the benefits of exercise.

- ♥ **Try a range of activities.** Encourage your child to try a range of different activities to find out which ones they enjoy and which ones they can cope with better. See overleaf for some activity ideas.
- ♥ **Warm up and cool down.** Your child should always warm up for at least 10 minutes before doing an exercise or activity, and cool down for at least

10 minutes afterwards. Warming up means beginning the activity slowly and building up gradually. Cooling down means taking time to slow down and not stopping suddenly. This allows the heart rate to gradually rise at the start of the activity and then slowly return to normal at the end. This will help them pace themselves and control any breathlessness.

♥ **Always ask** your child's Consultant Congenital Cardiologist or Paediatric Cardiac Liaison Nurse for individual guidance and advice about your child. Remember that everyone is different and your child's heart condition may change with time. So always ask about exercise at clinic appointments, and if you have any queries in between appointments, phone or email the Paediatric Cardiac Liaison Nurse.

♥ **If your child is aged 13 to 19 ensure your child has a British Heart Foundation (BHF) card.** Your child can use this 'ID card' in situations where they need to prove they have a heart condition and to show what type of heart condition they have. This can help teachers and activity leaders to have a better understanding of what type of physical activity your child can and cannot do, although they will still need to know about your child's individual abilities and limitations. The card also gives additional information on what to do in the case of an emergency. The BHF card is only issued by cardiac specialists – ask your child's Consultant Congenital Cardiologist or Paediatric Cardiac Liaison Nurse for a BHF card at their next appointment.



Are some types of exercise better than others for people with heart conditions?

You may need to think about the type of physical activity that your child does, especially if they are very limited by their symptoms, because some activities are better than others for people with heart conditions.

Dynamic (isotonic) exercise such as walking, cycling, dancing and non-contact team games are generally better for children with congenital heart disease as these can be done at low impact, low intensity and intermittently.

The most important issue with taking part in sport exercise and physical activity is your child's level of participation in the activity, and their competitive spirit, rather than the particular sport or activity itself.

Here are some general points to consider:

♥ **Team games or sports**

Some children and young people with congenital heart conditions may struggle to complete a full team game of, for example, football, netball, hockey or basketball. However, they may be able to cope if they are allowed to take part in short sessions with rests in between. Playing in positions that need less movement around the field or pitch may be helpful. Take care to ensure that peer pressure or 'competitive spirit' does not make your child over-exert themselves, either because they don't want to let their team mates down, or out of a desire to 'do better'.

♥ **Racquet and net sports**

Activities such as tennis, badminton and volleyball are often suitable for children and young people with congenital heart conditions as they can be done at a lower intensity if necessary. Some children and young people, especially those with a cyanotic heart condition (which causes blueness), may find it difficult to complete a singles match but may cope better if



playing doubles, or if the activity is modified, or if a smaller playing area is used. The point about peer pressure or competitive spirit mentioned above also applies to racquet and net sports.

♥ **Striking and fielding games**

Activities such as cricket, rounders and softball may be suitable for children and young people with heart conditions, as they are all games where some players can be inactive while others may work intensively for short periods. To accommodate children and young people with congenital heart conditions, teachers or activity leaders need to adapt the activity. For example, if your child is batting in cricket, they may have someone who 'runs for them'.

♥ **Target games**

Activities such as golf, bowls, and pétanque are low-intensity activities which are ideal for children and young people who have reduced exercise tolerance due to their congenital heart condition.

♥ **Athletics and distance running**

Endurance activities such as distance running and cross-country may present problems for some children and young people with congenital heart conditions due to their lower exercise tolerance. These activities may need to be adapted for children and young people with heart conditions. For example, they may be able to take part but at a lower intensity or walking pace, or alternate jogging and walking, or complete a shorter course. Some care should be given to throwing and jumping activities that require a lot of short bursts of intense effort and may put stress on the body.

♥ **Gymnastics and dance activities**

Provided your child is allowed to pace their activity themselves, these activities are usually well tolerated as the level of participation can be controlled more easily and there is less of a competitive element.

Yoga, pilates and Tai Chi may be suitable activities for children and young people with congenital heart conditions.

♥ **Personal fitness programmes**

If your child wants to do a personal fitness training programme, before starting the programme you are advised to check with your child's Consultant Congenital Cardiologist or Paediatric Cardiac Liaison Nurse at the Specialist Cardiac Centre. This is particularly important if high-intensity activities or weight-training are planned as part of the programme.

♥ **Swimming**

Recreational swimming indoors is good exercise for most children and young people with congenital heart conditions as they can do it at their own pace. They should avoid breath-holding and surface diving activities such as searching for objects at the bottom of the pool. However, swimming is not suitable for any child or young person who has frequent

fainting or dizzy spells. Also, those with cyanotic (blue) conditions may not tolerate a very cold pool and may need extra time for changing and getting dressed, as they may get breathless and tired more easily. You should get individual advice about your child from the Specialist Cardiac Centre. For information about high-intensity activities such as swim training and competition-level swimming (see page 10).



♥ **Low-intensity activities**

Activities such as golf, yoga, archery and snooker can all be done at a low intensity. Find out what other children do in your area or try your local community sports centre for ideas.

♥ **Adventure and outdoor activities**

Many children and young people with a congenital heart condition may be able to attend outdoor activity centres and school trips and take part in, for example, water sports, rock climbing, hiking, skiing, orienteering, paintballing, mountain biking and Duke of Edinburgh challenges.



NOTE:

- ♥ **You should get individual advice from your child's Specialist Cardiac Centre** before your child takes part in any activity where the level of participation or the emotional stress involved is higher than their normal everyday or school activities.
- ♥ Some of the activities listed above may not be suitable for some children and young people with heart conditions.
- ♥ There are extra precautions for children and young people who:
 - Are taking the anticoagulant warfarin.
 - Have a pacemaker or an implantable cardioverter defibrillator (ICD).
 - Have a cyanotic heart condition.
 - Sometimes get dizziness **or fainting**

(see page 11).

Are there any exercises or activities people with heart conditions should avoid?

Ask your child's Consultant Congenital Cardiologist or Paediatric Cardiac Liaison Nurse if there are any activities that it would be better for your child to avoid. Everyone is different, and your child's heart conditions may change over time, so you need to make sure you always have up-to-date information. If you're not sure, check with your Specialist Cardiac Centre.

♥ **Weight-lifting.** As a general guide, heavy weight-lifting or body-building or any activity that causes intense static muscle work is probably better avoided in people with a heart condition. 'Intense static' means repeatedly needing to use lots of effort causing breath-holding. There is often a tendency to do this when lifting heavy weights, doing sit-ups, push-ups or chin-ups. It also includes playing some brass and woodwind instruments, and breath-holding during stretching exercises, and in swimming during breath-holding and surface diving activities such as searching for objects at the bottom of the pool. These types of activity may be harmful in some people with congenital heart conditions for the following reasons:



- It causes a sudden rise in blood pressure, which puts strain on the heart and major blood vessels.
- It increases the pressure in the lungs, which can affect blood flow from the body into the lungs.
- It often means there's more force on the chest wall. If your child has a surgical scar on their chest, this may become stretched or strained, particularly in the early months after surgery.



♥ High-intensity activities. Some children and young people with heart conditions may be advised to avoid high-intensity, sustained, dynamic activities such as basketball, triathlon, competitive-level swimming or cycling, distance running and competitive team sports. Your child's Paediatric Cardiac Liaison Nurse or Congenital Consultant Cardiologist will tell you if this applies to your child.

Important points to think about:

- ♥ **If your child sometimes gets symptoms such as dizziness or fainting**, they should avoid activities where a fall could be very harmful, such as water-based activities, horse riding, motor sports, climbing and skiing.
- ♥ **If your child takes warfarin, or if they have a pacemaker or an ICD**, it is better for them to avoid activities or contact sports with a repeatedly high risk of bodily collision – either with other people and/or hard surfaces or equipment – for example, hockey, rugby, football, judo, kick-boxing and gymnastic apparatus work. This is because there is a small risk of bleeding or bruising, or of damaging the leads of the pacemaker or ICD. If your child is taking warfarin, particular care should be taken with the head and abdomen.
- ♥ **Children who have a cyanotic heart condition (which causes blueness)** have a much lower exercise tolerance than other children of their age, but most can take part in physical activities provided they 'pace' themselves and stop to rest when they are tired. These are some ways you can help:
 - Make sure your child is appropriately dressed for exercise during very hot or very cold weather, or in very windy weather conditions, as these are not well tolerated.
 - Allow your child more time to carry out their activities – for example, getting changed for activities, or getting dry and dressed after swimming.
 - Avoid your child getting dehydrated at any time, to minimise the risk of headaches.

What about taking part in PE & sports at school?

- ♥ Taking part in physical activities at school is important for your child, both for their long-term health and well-being and their social integration into school life. Encourage your child to take part in PE and physical activity at school and in after-school clubs – at their own pace and within their own limitations.



- ♥ Make sure you keep your child's teachers and after-school club leaders fully informed about your child's heart condition. Give them detailed information about what type and level of activity your child can do, any restrictions they have, and what they should do if your child gets any symptoms. You can ask your child's Paediatric Cardiac Liaison Nurse for help with this.
- ♥ Talk to your child's teacher about how your child is coping with PE and other physical activities at school.

If you feel that your child's teachers or activity leaders are 'over-protecting' your child in terms of the amount of activity he or she is allowed to do, show them the report provided by the Paediatric Cardiac Liaison Nurse.

What else can I do to encourage my child to be active?

- ♥ Remember that your child does not have to be 'sporty' or join a team or a gym in order to take part in physical activity. Walking, or dancing to their favourite music, for example, are excellent forms of exercise and cost nothing.



- ♥ If your child enjoys sport, that is fine, but if they don't it really doesn't matter. Just find another way to keep them active doing something they enjoy.
- ♥ Any activity is better than none at all!
- ♥ Encourage the whole family to be more active and set a good example yourself. Try walking to school or to the shop and use the car less.
- ♥ Go for family walks, go to the park, and play games with your children.
- ♥ Encourage them to try new activities with friends and join local or after-school activity clubs.
- ♥ Limit the amount of time your child spends on sitting-down activities each day – for example, watching TV, being on the computer, or using games consoles.

What to do if someone has a cardiac arrest

If the person seems to be unconscious

Approach with care, making sure that you, the person and anybody nearby are safe. To find out if the person is conscious, gently shake him or her, and shout loudly, '**Are you all right?**' If there is no response, shout for help.

You will need to assess the casualty and take suitable action. Remember **ABC – Airway, Breathing, CPR.**

A Airway



Open the person's airway by tilting their head back and lifting the chin.

B Breathing

Check - Look, listen and feel for signs of normal breathing. Take no longer than 10 seconds to confirm normal breathing.

Action: Get help - If the person is unconscious and is either not breathing or not breathing normally, phone 999 for an ambulance.



C CPR

Action: Cardiopulmonary resuscitation (CPR)

Rescuers who have been taught adult basic life support, and have no specific knowledge of resuscitation of children should use the adult sequence given below.

Note: For children you must compress the chest by approximately one-third of its depth. Use one or two hands as necessary to achieve this.

1 Chest compression

Start chest compression.

Place the heel of one hand in the centre of their chest. If necessary, place the heel of your other hand on top of your first hand and interlock your fingers. Press down firmly and smoothly 30 times. Do this at a rate of about 100 times a minute – that's a little less than two each second.

2 Rescue breaths

After 30 compressions, open the airway again by tilting the head back and lifting the chin, and give two of your own breaths to the person. These are called rescue breaths.

To do this, pinch the person's nostrils closed using your index finger and thumb and blow into the person's mouth. Make sure that no air can leak out and that the chest rises and falls with each breath.

Then give another 30 chest compressions and then 2 rescue breaths.

3 Continue CPR

Keep doing the 30 chest compressions followed by 2 rescue breaths until:

- ♥ the casualty shows signs of life, or
- ♥ professional help arrives, or
- ♥ you become exhausted.

If you are not able, or are not willing, to give rescue breaths, give chest compressions only, as described in step 1. Keep doing the chest compressions – at a rate of 100 times a minute – until:

-
- ♥ the casualty starts breathing, or
 - ♥ professional help arrives, or
 - ♥ you become exhausted.

Note:

If you have been trained to do so, you can make the following modifications to the adult sequence to make it more suitable for use in children:

- ♥ Give 5 initial rescue breaths before starting chest compressions.
- ♥ If you are on your own, perform CPR for 1 minute before going for help.

For more information

British Heart Foundation

The British Heart Foundation (BHF) is the nation's heart charity, saving lives through pioneering research, patient care and vital information.

Heart Helpline

0300 330 3311 (a local rate number). For information and support on anything heart-related.

Websites:

The BHF's website for teenagers with heart conditions:

<http://www.yheart.net/meet>

For general information about heart disease: <http://www.bhf.org.uk>

The BHF's website for over-11s: <http://www.yheart.net/Over 11's>

The BHF's website for under-11s: <http://www.bhf.org.uk/Under 11's>

Children's Heart Federation

The leading children's heart charity and umbrella body for voluntary organisations, working to meet the needs of children and young people with heart conditions and their families.

Phone: 0808 808 5000.

<http://www.childrens-heart-fed.org.uk/>

Grown Up Congenital Heart Patients Association

Supports young people and adults born with heart conditions.

<http://www.guch.org.uk/>

BHF Publications

BHF Card

An 'ID card' for teenagers with heart conditions. It can be used in situations where a young person needs to prove they have a heart condition and to show what type of heart condition they have. This can help teachers and activity leaders to have a better understanding of what type of physical activity the person can and cannot do, although they will still need to know about the person's individual abilities and limitations. The card also gives additional information in the case of an emergency.

<http://www.bhf.org.uk/bhfcards>

Information sheets for young people with congenital heart disease

The following information sheets are designed to enable teenagers to understand more about their congenital heart condition as they start to take more responsibility for their own health:

- ♥ Aortic stenosis
- ♥ Coarctation of the aorta
- ♥ Large ventricular septal defect
- ♥ Pulmonary stenosis
- ♥ Tetralogy of Fallot
- ♥ Transposition of the great arteries

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