Physical Activity

A guide for young people with a congenital heart condition and their families.

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Contents:

Introduction

Most of us know that being physically active is good for our health.

But what if you have a congenital heart condition?

It can be difficult to know which activities are suitable, which are best avoided and how much physical activity you should be doing. This can be frustrating and stressful!

Uncertainty about the safety of taking part can lead people to avoid many physical activities unnecessarily. On the other hand, a lack of understanding can result in people participating in physical activities that may harm their health.

The main aim of this booklet is to explain why some activities are good for you and others are best avoided.

Of course, everyone is unique and so you will still have to rely on your cardiologist for individual advice. However, we hope that this booklet will give you a better understanding of the reasons behind this advice. It will also help you to discuss physical activities with healthcare professionals so that you can be fully involved in making the right choices.

Who is this booklet for?

- Young people with a congenital heart condition
- Families and carers of someone with a congenital heart condition
- Teachers wishing to learn more about physical activities for people with congenital heart conditions

What are the aims of this booklet?

- to highlight the advantages of an active lifestyle
- to help you to understand which activities are most suitable
- to help you to know if you are doing the right amount of physical activity
- to explain why certain types of activity should be avoided by some people
- to explain the importance of a healthy diet and other lifestyle choices
- to help you to get all the information you need from your doctors and nurses

What this *booklet* does not do?

Everyone with a congenital heart condition is different. Therefore, it is essential that you get clear, individual advice from your cardiologist and other health care professionals.

This booklet cannot replace or override the advice of your cardiologist. They will have a detailed knowledge of your condition and your health needs.

However, this booklet should help you to understand how your heart condition affects your ability to exercise and your choice of physical activities.

Key definitions:

Physical activity
Any movement of the body produced by the muscles, which uses energy. This includes all sport and exercise, but also daily activities such as walking and playground games.

Exercise
Any form of 'physical activity' that is aimed at improving physical fitness. Exercise is usually a regular, planned activity.

Sedentary behaviour
Activities that use very little energy and take place whilst sitting or lying down. These include: watching TV, using laptops/computers, working at a desk, playing computer games.

Benefits of an active lifestyle

There is now a lot of scientific evidence that an active lifestyle makes us healthier, happier people. Physical activity is particularly important for young people, who are still growing and developing.

The benefits of regular physical activity for children include:

- Healthy growth & development
- Strengthens bones and joints
- Improves muscle strength and flexibility
- Improves cardiovascular (heart and blood vessel) health
- Reduces the risk of developing type II diabetes
- Improves psychological health (eg preventing depression)
- Develops good habits that can last a lifetime
- Promotes a healthy body weight
- Strengthens the immune system
- Improves concentration and memory
- Helps to develops social skills
- Develops coordination
- It's fun!!!

"If exercise were a pill, it would be one of the most cost-effective drugs ever invented" *Dr Nick Cavill*

The positive effects of physical activity can be enjoyed by everyone, including those with a heart condition. Indeed, exercise is now recognised as an important part of rehabilitation for adults who have developed a heart condition in later life!

Many people born with a heart condition can take part fully in all physical activities. For certain conditions there are some activities that should be avoided and other activities that may be particularly helpful. It is very important that you know which activities you should avoid. Your cardiologist, paediatrician or paediatric cardiac nurse specialist will be able to give you individual advice.

As well being good for our health and general wellbeing, physical activity is also a lot of fun!!!

The body's responses to exercise

'**Exercise**' means physical activity that is aimed at increasing physical fitness. This is usually done regularly and is structured and planned.

For those people who don't exercise regularly, it can feel like an ordeal! This is because our body is not used to it and we often try to do too much, too soon. It is really important to take things fairly easy for the first few weeks of a new exercise program, and then to increase the duration or intensity of exercise a little at a time.

Cardiovascular fitness

The higher the intensity of physical activity, the harder the muscles have to work and the more oxygen they need.

Cardiovascular fitness is largely determined by the ability of the heart and the blood vessels to supply the working muscles with enough oxygen.

Cardiovascular means 'to do with the heart and the blood vessels'.

Regular exercise improves our cardiovascular fitness in several ways:

- There is an increase in the number of capillaries in the muscles. This means that more oxygen-rich blood can flow to the muscles next time they are used.
- The heart becomes stronger. It is able to pump more blood every heart beat and can also pump the blood more forcefully.
- The muscles become stronger. You won't grow any extra muscle fibres, but the muscle fibres you already have will get bigger!
- The muscles become better at making use of oxygen to release energy. This means they can keep working for longer before getting tired or achy.

How much physical activity should I do?

Most young people with a congenital heart condition should follow the UK Physical Activity Guidelines. Ask your consultant or clinical nurse specialist if this is appropriate for you.

The UK Physical Activity Guidelines state that children and young people, aged 5-18, should be physically active for **at least 60minutes every day**. This does not have to be all in one go, but can be made up of shorter bouts of activity spread throughout the day.

This should be **moderate to vigorous intensity activity** and should include **muscle-strengthening** activities and **bone-strengthening** activities at least three days every week.

Visit the NHS webpages for physical activity at:
http://www.nhs.uk/Livewell/fitness/Pages/physical-activity-guidelines-for-young-people.aspx

Moderate physical activity will make you breathe harder and will make your heart beat faster. You will also feel warmer and start to sweat. You will still be able to carry on a conversation, but it will be difficult to sing without pausing to breathe.

Examples of moderate intensity activities:

 cycling at a comfortable speed on flat terrain

 dancing

 playing racket sports (without keeping score)

 playing outside

Vigorous physical activity will make you breathe much harder and will make your heart beat much faster. You will also feel a lot warmer and get sweaty. It will be very difficult to carry on a conversation, as you won't be able to say more than a few words without pausing to breathe.

Examples of vigorous intensity activities:

 running

 football

 swimming

 riding a bike fast or uphill

Muscle-strengthening activities

Having stronger muscles makes it easier to complete day-to-day tasks and improves endurance (the ability to keep going). It also helps us to achieve a healthy body weight.

Examples of muscle-strengthening activities:

 swimming

 walking uphill or up stairs

 playing sports such as hockey, football, tennis

 gymnastics

 climbing

Bone-strengthening activities

These are particularly important during the teenage years, when we are growing at our fastest. If you develop strong, healthy bones during adolescence it will reduce your risk of fractures and osteoporosis throughout your life.

Activities which help to increase the strength and density of our bones generally involve weight-bearing or moderate strain/impact forces.

Examples of bone-strengthening activities:

 walking, jogging and running

 jumping & skipping

 playing sports such as hockey, football, tennis

 gymnastics

Sedentary behaviour

Most of us spend a lot of time sat down being physically inactive e.g. watching television, using the internet and playing computer games.

It is now recognised that being sedentary for extended periods of time is linked with several health risks, including cardiovascular disease.

The National Guidelines recommend that we minimise the amount of time that we are sedentary, and try to break up sedentary time with some physical activity.

Is physical activity good for people with a congenital heart condition?

Leading a physically active life is good for almost everyone, whether they have a heart condition or not. There are very few people who are advised not to take part in any physical activities.

Of course, depending on the exact nature of the heart condition, some activities may be recommended, whilst other activities are best avoided. These will be discussed in the next section.

In a recent report for the European Society of Cardiology, a group of experts stated:
"In general, children with CHD should be advised to comply with public health recommendations of daily participation in 60 min or more of moderate-to-vigorous physical activity" (Takken *et al* 2011)

There are a number of reasons why being active is especially beneficial for youngsters with a heart condition:

Improved fitness (exercise capacity)

Studies have shown that, on average, young people with CHD have a lower level of fitness than their peers. Perhaps this is not surprising for more complex conditions. However, it has been found that even young people with relatively simple, mild conditions often have low levels of fitness. This can prevent them from participating fully in sports and other physical activities. It can also put young people off leading an active life-style, causing them to miss out on the many benefits (**see: 'Benefits of an active lifestyle', p3**).

Many studies have shown that, with appropriate training, young people with a congenital heart condition can increase their cardiovascular fitness. This means that they are able to exercise at a higher intensity and for a longer period of time. Improving cardiovascular fitness also makes it easier to participate at a particular level of physical activity.

Physical activity levels in young people

There are some concerns that many young people with a heart condition are less physically active than their peers. Reduced fitness or symptoms of the heart condition may cause people to be less active. However, uncertainty about which activities are safe, parental concern and a lack of self-belief may also lead to low levels of physical activity.

On average young people are much less physically active than they should be. According to a recent study of 4-15year olds in England, only 33% of boys and 21% of girls meet the National Guidelines for Physical Activity (Health Survey for England 2008). On average young people tend to become less and less active as they go through the teenage years. Boys are generally more active than girls! Both boys and girls tend to be more active on weekdays than at the weekend.

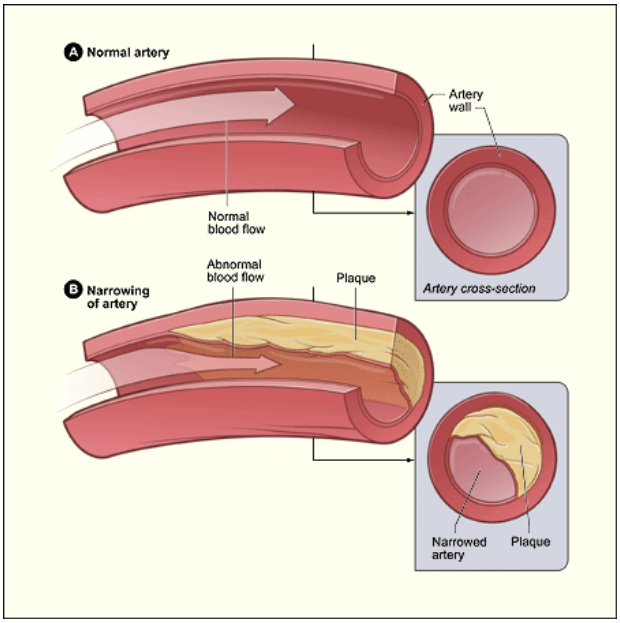
Improving cardiovascular health

Cardiovascular disease is one of the leading causes of ‘avoidable death’ in the UK.

As we get older our arteries lose some of their elasticity and become stiffer. This means that the heart has to work harder to pump blood. We also accumulate fatty deposits, called plaques, on the inner surface of the arteries. The formation of fatty plaques is termed **‘atherosclerosis’**. This often leads to cardiovascular disease, such as heart attacks and strokes, in later life.

There are several factors that increase the risk of developing atherosclerosis. These include:

- High blood pressure (hypertension)
- Family history
- Being overweight or obese
- Smoking
- **Leading a sedentary lifestyle, with little physical activity.**



Some congenital heart conditions may increase the risk of developing atherosclerosis at an earlier age than would normally be expected. Furthermore, people with a pre-existing heart condition may be more vulnerable and harder to treat if cardiovascular disease does occur in later life.

Clearly it makes good sense to reduce the risks of developing cardiovascular disease. Regular physical activity has been found to do just that.

There are several ways in which leading an active lifestyle, with plenty of moderate-intensity physical activity, improves our cardiovascular health:

- reduces high blood pressure
- prevents the arteries from losing their elasticity and becoming stiff
- helps to achieve or maintain a healthy body weight
- removes unhealthy fats from the blood

Which factors determine if an activity is suitable?

Key advice:

You should always **check with your doctor or clinical nurse specialist** before taking part in a new activity!!! They will be able to give you advice based on an understanding of the details of your medical condition.

There are many factors to consider when deciding if a particular activity is suitable for someone with a congenital heart condition. Obviously, the exact nature of the heart condition is a key consideration. Age and current fitness level may also affect recommendations.

When you are deciding whether or not an activity is suitable it is also important to consider the following factors:

- **Intensity**
- **Duration**
- **Type of activity (static vs dynamic)**
- **Competitive or recreational participation**
- **Risk of injury**
- **Medication (e.g. drugs to reduce blood pressure or prevent blood clots)**
- **Implanted devices to control or restore heart rhythm.**
- **Recent surgical or catheter-based procedures**

These factors will be explained in the next pages.

Intensity

'**Intensity'** means how hard you are working during an activity.

During physical activity your muscles need more oxygen. This oxygen is absorbed from the air by the lungs and is then carried to the muscles in the blood. The harder your muscles are working the more oxygen they need, so you breathe faster and your heart works harder.

We can rate 'intensity' as **low**, **moderate** or **vigorous:**

Low	No noticeable effect on breathing or heart rate. It is easy to carry on a conversation or sing a song without pausing for breath Feels very easy and you could keep going for a long time
Moderate	Breathing and heart rate are faster. Feeling a little warmer. You can carry on a conversation easily, but you can't sing the words to a song without having to keep pausing to get your breath back. Feels comfortable and you can keep going for a fairly long time.
Vigorous	Breathing much harder and faster. Heart rate much faster. Feeling warm & sweating. You can't carry on a conversation, because you have to keep pausing for breath. Feels very hard and you cannot keep going for very long.

Many people with a CHD can safely push themselves as hard as they can.

However, some congenital heart conditions limit the intensity of physical activity that can be done.

For these people, being physically active at a high intensity could:

- make them feel unwell
- cause dizziness or fainting
- make their heart condition worse

It is important to ask your cardiologist if there is a limit to the intensity of activity that is safe for you. You need to know - which intensity is appropriate: **Low**, **Moderate** or **Vigorous**?

Key advice:

The **'talking test'** – if you cannot carry on a conversation easily, because you have to keep pausing for breath, then you are working at a **'vigorous intensity'.**

This may be too much for some people with a congenital heart condition!

Duration

Often people with a heart condition find that they need to stop and rest during physical activity, usually because they are not getting enough oxygen to their muscles. This may be due directly to the heart condition, or it may be that they are simply unfit.

It is important to stop and take a break if:

- you feel unwell
- you are struggling to catch your breath
- you feel dizzy or faint
- your heart beat feels strange or very fast
- you become pale and clammy

When you are considering whether or not to take part in an activity, think about whether there will be opportunities to stop and rest. If you are taking part in organised activities, like team sports or PE lessons, then it is a good idea to make sure that the person organising the activity is aware of your heart condition. During team sports it may be possible to make regular substitutions so that you get a chance to rest and get your breath back.

The National Guidelines recommend that young people are physically active for **at least 60 minutes every day**. This does not have to be done all in one go! It is just as beneficial to do several short bouts of physical activity that add up to 1 hour or more.

For example: 30 minute PE lesson at school,
20 minutes of kicking a football around with friends
and 10 minutes of walking

Ask your cardiologist if you should be aiming to achieve the 60minutes a day recommended by the National Guidelines. Your cardiologist may give you a different target.

Hydration

Remember to drink enough when you are taking part in activities that last a long time. Especially in warm or humid conditions!

For example, if you are out cycling for over an hour on a hot, sunny day, make sure you take plenty of water to drink.

When we get hot we sweat more and if we don't replace lost fluids then we can quickly become dehydrated. When we are dehydrated our heart has to work harder. This is because the volume of blood decreases, so the heart beats faster to compensate.

Type of Activity (Static vs. Dynamic)

Different types of physical activity place different demands on the body.

In some activities lots of muscles are used to bring about movement. These are known as '**dynamic**' activities. Good examples of dynamic types of activity are jogging and racket sports. During dynamic activities the muscles are alternately relaxing and contracting (tensing).

Taking part in dynamic activities improves cardiovascular fitness. In general, dynamic activities are good for our health.

In some activities the muscles generate a large force, yet there is relatively little movement. These are known as '**static**' activities. A good example of a static type of activity is lifting heavy weights. Static activities cause a marked increase in blood pressure. This is potentially harmful for some people with a heart condition! Taking part in static activities may increase strength, but has not been shown to improve cardiovascular fitness.

Examples:

Static activities	Dynamic activities
Lifting heavy weights	Jogging & running
Rugby scrum	Racket sports (tennis, badminton etc)
Athletic throwing events (discus, shot-put etc)	Hockey
Arm-wrestling	Football
Rock-climbing	Swimming

The 'Valsalva manoeuvre'

Have you ever strained to lift or push an object and found yourself tensing up your whole body and holding your breath?

This is termed the 'Valsalva manoeuvre' – where the breathing muscles tense up as if trying to breath out, but the mouth and throat are closed off so that no air can come out.

We do this instinctively, but it may be harmful to health, particularly if you have a heart condition. This is because it causes sudden changes in heart rate and blood pressure. It can also cause dizziness or fainting, since it reduces blood flow to the brain.

Most activities are not entirely static or dynamic, but a mixture of the two.

When thinking about the suitability of an activity it may be useful to consider whether it is mainly static or dynamic. If there is not much movement involved, but a lot of muscular force is used, then it is probably a very static activity and may not be suitable.

Key advice:

In general, dynamic activities are better than static activities for people with a heart condition.

Competitive or Recreational?

When deciding if an activity is suitable for someone with a heart condition it is important to think about whether or not it will be competitive.

Most sporting activities can be enjoyed either at a recreational or a competitive level.

Recreational means that there is no pressure to play for a long time or at a high intensity. It is not important to keep score or time. It is not stressful and you can slow down or take a break whenever you like.

Competitive means that it is important to win or to do better than other people.

Examples:

Competitive	Recreational
Playing in a football match against another school/club	Kicking a football around with some friends
Running in a cross-country or athletics race	Running/jogging at your own pace
Playing in a hockey match against another school/club	Taking part in a hockey coaching session
Racing on mountain bike, bmx or road bike	Going on a bike ride with family or friends

Competitive sport is usually much more demanding than taking part at a recreational level. In a competitive situation people are likely to push themselves to a very high intensity. During competition there may be pressure from other participants, coaches or spectators. Often a competitor will put pressure on themself; this can be worse in team sports, when they may worry about letting down team-mates.

Training plays an important role in most competitive sports. Training often involves exercising at increasingly high intensities or for longer amounts of time, with the aim of increasing strength and/or cardiovascular fitness. However, care should be taken to avoid exceeding safe limits recommended by your cardiologist.

As well as being physically demanding, competition can also be emotionally stressful. This will have an additional effect on our breathing and heart rate.

Often the desire to be successful can make competitors ignore physical discomfort. This is potentially hazardous for some people with a heart condition! For this reason it is important to **discuss taking part in competitive sport with your doctor or clinical nurse specialist.**

It is very important to 'listen to your body' and to stop and rest when you need to. If competing makes this too difficult then it is better to enjoy the sport at a recreational level. **(see: 'Safety', p19)**

Key advice:
Before taking part in a competitive sport it is important to check with your doctor or clinical nurse specialist that it is suitable for you!

Risk of Injury

Assessing risk is all about using good judgment. Consideration should be given to how likely an incident is to happen and how serious the consequences might be. Often it is possible to take extra precautions or adapt activities to reduce the risks.

Physical Impact

Many activities have a risk of physical impact.

These include '**contact sports**', such as rugby and judo, where contact with other participant is expected.

In other activities a physical impact may not be intended, but it might be quite likely. For example football, skiing, skateboarding, cricket.

Physical impacts may be harmful if:

- You have a pacemaker or ICD. This is because the device may be damaged or the leads may be moved. In some activities these risks may be sufficiently reduced by wearing appropriate protective clothing.
- You have had recent surgery or a catheter-based procedure.
- You are taking anticoagulant drugs.
- You have a particular condition, such as mitral valve stenosis or Marfan syndrome.

Anticoagulants (risk of bleeding)

Anticoagulants are drugs that reduce the risk of blood clots forming. They are prescribed for lots of different congenital heart conditions. Warfarin, aspirin, dipyridamole and clopidogrel are commonly used anticoagulants.

If you are taking anticoagulant drugs then you may bleed for a longer time if you get cuts or scrapes. You may also bruise more easily.

People taking anticoagulant drugs are often advised to avoid contact sports. Activities with a high risk of cuts or scrapes may not be the best choice unless appropriate protective clothing is worn. For example: wearing elbow/knee pads, helmet and gloves when skateboarding reduces the likelihood of getting cuts and bruises.

Injury caused by loss of consciousness.

Some heart conditions can cause people to feel dizzy, or even to fall unconscious (loss of consciousness is sometimes referred to as '**syncope**').

Some activities are particularly dangerous if the participant becomes dizzy or unconscious. These include: swimming, climbing, kayaking, horse riding, cycling.

If there is a history of dizziness or fainting then it is important to think carefully about whether a particular activity is suitable.

Resistance Training

Resistance training is a way of improving muscular fitness by exercising the muscles against an opposing force e.g. weights, bodyweight, elastic resistance bands.

Nowadays lots of people have access to weights machines and free weights (dumbbells & barbells), either at home or at a gym/leisure centre. Whether or not resistance training is suitable for someone with a heart condition depends on how heavy the weights are and what type of training is being done.

Key advice:
Resistance training is not suitable for some heart conditions, including: aortic stenosis, uncontrolled hypertension, aortic dissection, Marfan syndrome.

Check with your cardiologist before taking part in any resistance training!

Benefits of improving muscular strength:

- Increased endurance (the ability to keep going)
- Makes completing physical tasks easier
- Helps with maintaining a healthy body weight
- Improves the flow of blood in the veins
  (this may be particularly beneficial for people with a Fontan circulation)

Is it safe?

Lifting very **heavy weights** for a small number of repetitions is used by bodybuilders and competitive weight lifters to increase the strength and size of their muscles. This is a highly **static** type of exercise and causes dramatic changes in blood pressure. For people with a heart conditions this is best avoided!
Training with very heavy weights can also cause a person to strain whilst holding their breath. This is known as the Valsalva manoeuvre and has been shown to cause very rapid changes in blood pressure (**see p12**).

In addition to placing strain on the heart, lifting very heavy weights is also likely to result in injury to the bones, joints or muscles; especially when poor technique is used. For these reasons young people and those with a heart condition have often been advised to avoid all strength training. However, over the last twenty years it has been recognised that appropriate strength training, using much lighter weights can be safe, enjoyable and beneficial. The American Heart Association and the American College of Sports Medicine have published guidelines for resistance training in cardiac patients.

Lifting fairly light weights (up to 50% of your maximum) for 10-15 repetitions is used to increase muscular strength and endurance (the ability to keep going).

This type of training has several health benefits (**see p13**), but does not cause a dramatic increase in blood pressure.

Key safety points:

- Check with your cardiologist before taking part in any resistance training program.
- Get instruction from a qualified professional.
- Children and adolescents should always be carefully supervised during training.
- Start out with easy weights and only increase the weight very gradually.
- Focus on breathing in and out smoothly. Never hold your breath when lifting weights!
- Always use good technique, lifting and lowering weights in a smooth controlled way.

Guidelines for cardiac patients:
The American Heart Association and the American College of Sports Medicine recommend using a program with 8-10 different exercises, to be completed 2-3 times a week. For each exercise 1 set of 10-15 repetitions should be performed.

If 10-15 repetitions cannot be completed then the weight is too high and should be reduced!

Other ways to increase strength

It is not necessary to go to a gym, unless this is something that you really enjoy and it has been approved by your cardiologist.

There are lots of fun ways to increase muscular strength, including:

- Swimming
- Climbing
- Football
- Hockey
- Kayaking
- Dancing
- Surfing
- Gymnastics
- Mountain biking
- Yoga
- Skipping
- Basketball

Other activities

Breath-holding activities

Breath-holding causes a sudden increase in blood pressure. This is best avoided by some people with a heart condition, since it can place the heart and blood vessels under strain.

We intentionally hold our breath when swimming under-water. But we may also breath-hold without realising it. For example, when we are stretching or lifting very heavy objects (**see p12**). Playing some wind or brass instruments may also cause a large increase in blood pressure.

Check with your cardiologist before taking up a wind/brass musical instrument or taking part in under-water activities.

Outdoor pursuits

Outdoor pursuits are becoming increasingly popular and some schools regularly organise trips to outdoor activity centres. Popular outdoor activities include: kayaking, rock-climbing, Duke of Edinburgh's Award, white-water rafting, hill walking and caving. Each planned activity must be considered separately and should be discussed with specialists in your cardiac centre before taking part.

Here are some of the key issues to think about and discuss:

- How physically demanding will the activity be?

  If necessary, could the activity be planned or adapted to make it easier for you to take part?

- How emotionally demanding will the activity be?

  Outdoor pursuits can be very exciting. Of course this is part of what makes such activities fun. However, intense excitement or anxiety can cause a substantial increase in blood pressure and heart rate. For some people with a heart condition, particularly those with a rhythm disorder, such activities might not be safe.

- If you are taking blood thinning/anticoagulant medication:

  Does the activity carry a high risk of cuts and scrapes? If so, can this risk be minimised with appropriate protective clothing?

- If you have an ICD/pacemaker:

  Is the activity likely to cause pressure or impact to the device? For example, the climbing harnesses used at adventure centres often have a chest strap which may press against the area where the device is implanted. A similar problem may occur with rucksacks, which are often needed for hiking.

  Activities such as potholing or caving may involve crawling on your front, potentially putting pressure in the area around the device.

Fairground/theme-park rides

A common question asked by young people with a heart condition is whether they can go on fairground rides, such as rollercoasters.

This is a very difficult question for healthcare professionals to answer because very little scientific research has been done in this area.

There are 2 main areas of concern:

1) Intense excitement/anxiety can dramatically increase heart rate and blood pressure.

   This, in addition to the ride's acceleration and rapid changes in direction, may place a stain on the heart and blood vessels.

2) Many fairground rides use powerful electromagnets. Strong electromagnetic fields can interfere with the functioning of ICDs/pacemakers. If you have been fitted with one of these devices then it is probably wise to avoid most fairground rides.

Most theme parks have notice boards at the entrance to rides, listing the medical conditions that prevent people from taking the ride. If the notice states that the ride is unsuitable for people with a heart condition then you should follow this advice.

Safety

What's normal?

It is important to know the difference between normal, healthy responses to activity and signs of physical distress. This can be a problem for people who are not used to being physical activity.

When we are physically active our body responds to supply more oxygen to the muscles and to cool us down.

Normal responses to physically activity:

- our heart beats faster,
- we breathe harder and faster
- we feel warm, start sweating and our skin looks more pink
- our muscles feel tired or achy

These are perfectly normal responses to activity and should not cause any concern.

Signs to look out for:

If someone with a heart condition is responding badly to an activity there are usually some obvious signs to look out for:

Signs/symptoms to look out for

- breathing too hard to be able to talk
- feeling dizzy or faint
- feeling extremely tired
- heart beat feels strange or very fast
- unusually pale and clammy skin
- skin becomes more blue (in cyanotic conditions)

If any of these signs occur then it is very important to stop and rest. The symptoms will usually disappear very quickly. However, if there is no improvement, or the symptoms get worse, then it is best to phone 999 and ask for an ambulance.

Warm-up and cool-down

Everyone should do a proper warm-up to prepare the body for moderate-vigorous activity, but it is particularly important for people with a heart condition. In many congenital heart conditions the heart takes longer to respond to increased activity.

Doing a good warm-up enables the body to slowly respond to the demands of physical activity. It allows the heart rate and breathing rate to gradually increase. It also gets the muscles gently working. This reduces the risk of injury and can also improve performance!

A good warm-up should:

- last for 10mins.
- begin at an easy, low intensity and gradually build.
- include some gently stretches, focusing on the muscles that will be used.

A cool-down allows the heart rate and breathing rate to gradually slow down to resting levels. It may also help to avoid muscle aches and stiffness from developing.

It is normal to experience some muscular soreness for 24-48 hours after being physically active at a vigorous-intensity or for a long duration. However, if this muscular discomfort does not disappear then you should speak to your GP.

Sudden cardiac death

When a young person dies suddenly and unexpectedly, it is shocking and devastating for their friends and family. Cases of sudden death are often reported in the news, especially when they involve young, fit, sporty people. Because of media interest in these events, we can be left believing that they are quite common. Naturally this may be worrying for the families of young people with a congenital heart condition. However, these are very rare events.

Sudden cardiac death is very rare in young people, affecting roughly 1 in 100,000 children. The majority of cases occur in young people who have not been diagnosed with any heart condition. Most cases of sudden cardiac death are caused by genetic diseases or by structural problems with the coronary arteries. These often do not cause any symptoms, so no one is aware of the problem until it’s too late.

If you have been diagnosed with a heart condition then cardiologists will have carefully studied the structure of your heart using echocardiograms or other scans. They will also have studied your heart’s rhythm and its electrical activity. If your cardiologist had any concerns you will have been given appropriate advice and treatment.

Recent surgical procedures

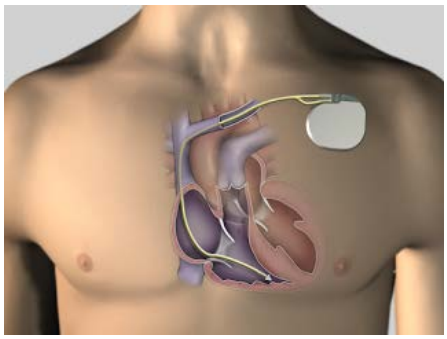
Following a surgical or catheter-based procedure your cardiologist, or a member of the specialist nursing team, will explain how this affects your participation in physical activities. A structured return to your normal level of activity is a key part of rehabilitation. It should be thought about and discussed before you leave hospital. You may find it useful to make a note of any questions you wish to ask. Think about all the activities you would usually do in a typical week and any other activities you anticipate doing in the next few months. Ask specific questions to make sure you understand what activity restrictions you have and how this will change during your recovery from the surgical procedure. If you have a '**Physical activity recommendations form**', make sure you get it updated before leaving hospital.

Sternotomy

During open heart surgery the breast bone (sternum) is divided to allow the surgeon access to the heart. This procedure is called a sternotomy. It usually takes approximately 12 weeks for the sternum to completely heal; however, this can vary between individuals.

For the first few weeks following the operation you will be advised to avoid activities that place any strain on the breastbone (sternum). Gradually, over a period of about 3 months, you will be able to return to active life. However, contact sports, where there is a likelihood of physical impacts, should be avoided for at least 3 months following surgery.

ICD/pacemaker fitting



ICDs and pacemakers are fitted to control abnormal heart rhythms (arrhythmia).

Which physical activities are appropriate for you depends upon the cause of your arrhythmia. It is therefore very important to get clear advice from your cardiologist.

It usually takes 4-6 weeks for the body to heal after an ICD or pacemaker has been implanted. You will be advised to avoid certain activities during this time, to ensure that the device's leads are not moved from their correct position.

Contact sports, where there is a likelihood of physical impacts, should be avoided if you have an ICD or pacemaker. This is to avoid damage or movement of the device's leads and to prevent injury to the area around the device. For some activities these risks may be reduced or eliminated by wearing appropriate protective clothing or padding. This must be discussed with you cardiologist first!

If you have an ICD then you should carry your 'ICD card' with you at all times, but especially when taking part in physical activities. It is also a good idea to be accompanied by someone who knows about your heart condition and is able to help in the unlikely event that your ICD delivers a shock.

If you have been diagnosed with an abnormal heart rhythm it is very important to make sure you do a proper warm-up and cool-down to reduce the risk of arrhythmia (**see p20**).

For more information on physical activity with a pacemaker/ICD visit the 'Arrhythmia Alliance' website: http://www.heartrhythmcharity.org.uk

Healthy eating & other lifestyle choices

In addition to leading a physically active life there are several other lifestyle choices that are important in keeping our hearts healthy:

- **Eating a healthy balanced diet**

The food we eat has a big influence on the health of our heart.

DO eat lots of fruit and vegetables.

DO eat foods high in monounsaturated fat and/or omega 3

AVOID saturated fats and trans-fats (hydrogenated vegetable oil).

AVOID eating too much salt (no more than 6g a day)

- **Not smoking**

As well as causing many types of cancer, smoking greatly increases the risk of cardiovascular disease. The chemicals in cigarette smoke are known to cause damage to the heart and the blood vessels.

Two thirds of smokers pick up the habit as children!

- **Avoiding drinking too much alcohol**

Drinking large amounts of alcohol causes high blood pressure and can cause abnormal heart rhythms. It also affects the blood clotting process; this may be particularly harmful in children taking anticoagulant medication, such as warfarin.

Many people begin to experiment with alcohol as teenagers and peer-pressure can lead youngsters to drink more than is safe.

Of course, this is good advice for everyone, with or without a congenital heart condition. However, for those born with a heart condition it is especially important to avoid things that are known to cause cardiovascular disease.

For more information on 'How to look after your heart' visit Heart Research UK's website: http://heartresearch.org.uk/

High calorie diets

Some infants with a congenital heart condition have difficulty feeding and putting on weight. Often they are put on high calorie diets containing lots of fat-rich food. This may be essential to help infants to catch up on growth and achieve a normal weight, particularly before an operation. However, it is important to avoid staying on this type of diet for longer than necessary. Ask your cardiologist or cardiac nurse specialist if a high calorie diet is still recommended. If this is no longer necessary then gradually change to a more balanced, healthy diet.

Useful questions to ask your cardiologist, clinical nurse specialist or paediatrician:

1) Should I follow the National Guidelines for physical activity (5-18years)?

   In other words, should I do at least 1hr of moderate-to-vigorous physical activity every day?

2) Is there a limit to how long I should be physically active for in one go?

3) Is there a limit to the intensity of physical activity that is safe?

   In other words, how hard can I push myself and how do I know when to stop?

4) Are there any physical activities that I should avoid?

5) Is it OK to take part at a competitive level?

   Remember, it may be OK to compete in some physical activities but not others.

   If you ask about competing then you must be very clear about which sport you intend to compete in.

6) Can I take part in activities where there is a risk of impact?

   In other words, does it matter if I get hit by a ball or collide with another player?

7) Can I take part in activities where there is a risk of cuts and scrapes?

Getting involved

You don't have to be super-sporty to gain the benefits of an active life-style.

3 golden rules to being more active:

1) **Find activities you really enjoy doing**.

   Lots of people struggle to get fit because they lose motivation. This is usually because they don't like the activity they've chosen, so it becomes a chore!

   There are so many sports and activities to choose from. It's just a case of finding the activities that are right for you!

2) **Steadily increase the amount of physical activity you do.**

   It takes a few weeks of increased activity before our fitness improves noticeably.

   Be patient! Don't try to do too much too soon. If you overdo it then you are likely to end up with aching muscles or injuries. This could be off-putting, making you less likely to be physically active in the future.

   For people with a heart condition it is particularly important to increase activity levels gradually. This gives the heart, lungs and muscles time to adapt.

3) **Take part with friends, family or a club.**

   Most people find sports and physical activities more fun when they take part with friends or family. If no one you know wants to take part in the same sport/activity as you, then find a local club. There are lots of great sports clubs about that welcome people of all abilities.

   Some days you might not be in the mood to go out and do something active. However, if you have a regular arrangement, such as attending a sports club or lesson, this can really help to motivate you. Soon the activity becomes a good, healthy habit which is hard to break.

Visit the 'NHS Choices' website to take a quick, fun test that could help you "Find the sport that's right for you".

There is also a search facility to help you find 'Sports and Fitness Services near you'.

http://www.nhs.uk/Livewell/fitness/Pages/physical-activity-guidelines-for-young-people.aspx#close

How can I encourage my child to be more active?

Under 10s

Young children (under 10yrs) tend to be fairly physically active. Often it's more difficult to get them to sit still for 5minutes! They usually prefer shorter activities that take the form of a game.

This is a great time for children to experiment with lots of different sports and physical activities. When they get older they may be less willing to try new things! The key thing is to make physical activities fun.

Top 5 tips:

1) Young children usually respond very positively to praise, so it's really important for parents/carers to give them encouragement.
2) Provide opportunities for your children to be active as often as you can. For example, by visiting parks, beaches, leisure centres etc.
3) Do something active as a family at least once a week. Weekends are usually the best time to get out and about as a family. Try playing Frisbee, football or French cricket in the garden, or at a park or a beach.
4) Set a good example! If you regularly take part in sporting activities then your child will grow up understanding that physical activity is a normal, fun part of life. This helps to create a positive attitude towards being active.
5) Help your child to keep a '**Physical Activity Record' (see Appendix B)**. This will help you to see it they are achieving the level of activity recommended by their cardiologist. It can also be a fun way of motivating your child to be more active!

11-18s

Many studies have shown that most young people do less and less physical activity as they go through the teenage years. This is especially true of girls, who tend to become more inactive with age. However, this is a time in our lives when physical activity is particularly important for our long-term health. **(See: Benefits of an active lifestyle, p3)**

Top 5 tips:

1) Help them to find activities that they really enjoy.
2) Encourage them to join after-school/weekend clubs. Most young people are more likely to participate in activities if it involves socialising with friends.
3) When discussing physical activity participation with their cardiologist and cardiac specialist nurses ensure that your child is involved. It's important that they get the opportunity to ask questions and to begin to become more involved in their health care.
4) Avoid nagging them. This may have unwanted results, making them think of physical activity as something to be avoided.
5) Remember to give them praise and encouragement. Teenagers may not always show that they appreciate this, but almost everyone responds positively to encouragement.

School

Informing the school

It is important that schools are fully informed about a pupil's heart condition. The school will have a policy in place that sets out how it provides for children with long-term medical conditions.

For a pupil with a heart condition is it usually appropriate for the school to develop an individual 'Health Care Plan'. This is the schools responsibility, but the parents/carers will usually play a key role in the process.

A Health Care Plan is a form which sets out:

- the details of a pupil's medical condition
- how medication will be managed/administered (if relevant)
- daily care requirements
- what to do in the event of a medical emergency
- contact details of the family and the clinic/hospital

The development of a Health Care Plan may require input from:

- the parents or carers
- the child (if appropriate)
- healthcare professionals (cardiologist/cardiac liaison nurse/cardiac nurse specialist, GP)
- the School Medical Officer and other medical centre staff
- school staff with pastoral responsibility (tutor/head of year/DMS child protection)

The Health Care Plan should be updated every year, or if there is a relevant change in the heart condition.

You may find it useful to provide the school with some general information on congenital heart conditions. Heart Research UK has produced a leaflet **'Congenital heart disease: a guide for schools' (see Appendix C).** This sets out the main considerations that school staff should be aware of.

PE and sports at school

It may be useful to consider how PE/Sports staff will be informed about your child's heart condition. This is particularly important if they have activity restrictions or difficulties in participating in some physical activities. Informing PE/Sports staff could be included in the Health Care Plan.

PE/Sports staff should be aware of:

- activity restrictions (activities that your cardiologist has advised you to avoid)
- symptoms that indicate that an activity should be discontinued
- symptoms that indicate that medical assistance is necessary

- the importance of allowing a child with a heart condition to rest when necessary
- the importance of respecting medical confidentiality and avoiding drawing attention to a child's heart condition

Physical activity information for specific conditions:

- **Tetralogy of Fallot**
- **Coarctation of the aorta (COA)**
- **Transposition of the great arteries (TGA) – corrected by arterial switch**
- **Fontan circulation**

Tetralogy of Fallot

Many congenital heart conditions are very complicated. It is important to discuss exercise with your consultant who will be able to give you individual advice.

Your doctor will regularly check your ability to exercise safely. This may involve an ECG, an echocardiogram or an exercise test. The results will help to determine what physical activities are best for you.

General recommendations:

- If you have no exercise restrictions then you should follow the national '**Physical activity guidelines**' (60 minutes of moderate to vigorous activity every day)
- If you have mild continuing heart problems your Doctor may recommend that you avoid high-intensity activities. However, you will still benefit from taking part in low-moderate intensity activities.
- If you have moderate continuing heart problems your Doctor may recommend that you stick to low intensity activities.
- If you have an implanted device (e.g. ICD) then you should avoid activities with a significant risk of impact e.g. rugby, martial arts (**see 'Risk of Injury', p14**).

Details:

Many children and adolescents born with tetralogy of Fallot (ToF) have a good exercise capacity and are able to lead physically active lives.

Recommendations for physical activity and exercise depend on whether you have any on-going heart problems. The two most common long-term problems are:

1) Pulmonary regurgitation/stenosis

   When the heart contracts, blood is pumped from the right side of the heart to the lungs, along a blood vessel called the pulmonary artery. In TOF the pulmonary artery is often very narrow. This is termed **'pulmonary stenosis'** and is usually corrected by surgery in early infancy. At the start of the pulmonary artery is a valve. This **pulmonary valve** stops blood flowing backwards when the heart relaxes. If this valve is not working well then some blood will flow back into the heart. This is called **'pulmonary regurgitation'** (also known as pulmonary insufficiency). This affects the amount of blood flowing to the lungs to pick up oxygen. It also means that the right side of the heart has to work harder.

2) Arrhythmia

   The heart is a complicated muscle. It contracts in a carefully controlled, precisely timed way. If the timing of contraction is wrong then the heart cannot pump blood efficiently. An abnormal heart rhythm is called '**arrhythmia**'. This may be treated with drugs or an ICD/pacemaker.

If you have no symptoms and your cardiologist confirms that you have no significant heart problems then you will be able to participate in all sports and physical activities.

Coarctation of the aorta (COA)

Also known as 'Aortic coarctation'

Many congenital heart conditions are very complicated. It is important to discuss exercise with your consultant who will be able to give you individual advice.

General recommendations:

- Do lots of low-intensity physical activities.
- Avoid activities which are very **static**, such as heavy lifting, pushing, pulling.
- Eat a balanced, healthy diet that is low in saturated fat and salt.
- Avoid becoming overweight.
- Don't smoke.

Details:

Most people born with coarctation of the aorta (COA) are diagnosed early in life and receive an operation to repair the structural defect. If there are no other problems with the heart then further surgery or medication may not be necessary. After leaving hospital a normal, healthy life can usually be enjoyed. However, there are some long-term health risks that may affect people with COA.

If you were born with COA then you are more likely to have high blood pressure throughout your life. This is because the aorta and other arteries are not quite as elastic as they should be. Often the blood pressure is normal at rest, but becomes unusually high during exercise.

Your doctor will regularly check your blood pressure. This may be done during an 'exercise test' on a treadmill or exercise bike. This will help to determine what physical activities are best for you.

'**Static activities**' are where there is not much movement, but the muscles exert a large force. (**see p12**) Examples include: lifting heavy weights, pull-ups, rugby scrums. Static activities can cause sudden increases in blood pressure that are thought to make the arteries less elastic. Therefore, it is recommended that you avoid these activities if you have COA.

'**Dynamic activities**', performed at low-moderate intensity, can improve the health of the arteries, making them more elastic. (**see p12**) Examples include: walking, jogging, racket sports, hockey.

Our diet can also affect our blood pressure. In particular, eating too much salt and drinking too much alcohol are known to increase blood pressure.

Visit the NHS website to learn more about salt in our diet.

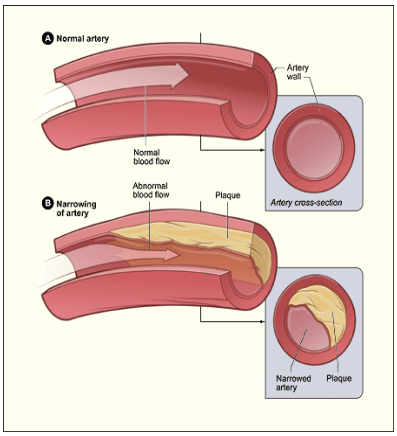
http://www.nhs.uk/Livewell/Goodfood/Pages/salt.aspx

People born with COA are thought to be at an increased risk of developing **atherosclerosis**.

Atherosclerosis is a build-up of fatty deposits on the lining of the arteries.

Atherosclerosis usually develops over many years. It causes a narrowing of the arteries, which slows down blood flow. This causes a range of health problems, collectively termed ‘cardiovascular disease.

Atherosclerosis affects most of us as we get older. If you were born with COA it is more likely that you will develop atherosclerosis at an earlier age than normal.



However, there are several things that we can all do to reduce our risk of cardiovascular disease in later life:

- Lead a physically active lifestyle.
  Regular, low-to-moderate intensity activity is known to be protective against atherosclerosis. It is also effective at reducing blood pressure.

- Eat a healthy balanced diet.
  Avoid eating too much food that is high in fat and salt.
  Visit Heart Research UK’s website and download a copy of the leaflet ‘Food for a healthy heart’. http://heartresearch.org.uk

- Don’t smoke.
  Smoking damages the blood vessels and increases your risk of cardiovascular disease.

- Maintain a healthy body weight.

Fontan circulation

The congenital heart conditions treated with ‘Fontan operations’ are varied and complicated. It is important to discuss physical activity with your consultant who will be able to give you individual advice.

The Fontan operations are used to help people with a range of congenital heart conditions. These include: Hypoplastic Left/Right Heart Syndrome, Tricuspid Atresia and Pulmonary Atresia.

Your capacity to exercise depends upon the exact nature of your heart condition and the surgical procedures used. It is important to talk with your doctor about physical activity to ensure that you get clear, individual advice. Ideally you will have a cardiopulmonary exercise test which will help to determine which physical activity and sports are best for you.

Research shows that most people with Fontan circulation do less physical activity than they should. For many people, a very inactive lifestyle makes them unfit and less able to participate in everyday activities.

General recommendations:

- Most people with Fontan circulation should follow the national guidelines (at least 60 minutes of moderate to vigorous exercise every day).

- Stop and rest when you need to.

  Typical signs that you need to stop and rest include:

  - getting very out of breath,
  - feeling faint / dizzy / lightheaded
  - nausea (feeling sick),
  - chest pain
  - palpitations (your heart feels like it is pounding or fluttering)

  Ask your cardiologist if there are any other symptoms that you should watch out for.

- Avoid situations where other people are likely to encourage/pressurise you to continue exercise even though you need to take a rest.

- If you have an implanted device (ICD/pacemaker) or are taking antithrombotic medication then you should avoid activities with a significant risk of impact or injury
  (see: ‘Risk of Injury’, p14)

Details:

Activities that strengthen the leg muscles may be particularly useful. Improved muscle tone has been shown to help blood return to the heart. Physical activities that strengthen the leg muscles include: cycling, walking, skipping and racket sports.

Transposition of the great arteries (TGA) – corrected by arterial switch

Many congenital heart conditions are very complicated. It is important to discuss exercise with your consultant who will be able to give you individual advice.

Your doctor will regularly check your blood pressure during exercise; usually on a treadmill or an exercise bike. This will help to determine what physical activities are best for you.

General recommendations:

- Do plenty of low-moderate intensity physical activity.
- If you have no continuing medical complications then you will be able to participate in all types of physical activity and sport. Check with your doctor!
- Avoid activities with both a **high static component** and a **high dynamic component**. (e.g. competitive rowing, competitive triathlon).
- Eat a balanced, healthy diet low in saturated fat. Fried food, crisps and ready meals often have high levels of saturated fat and should not be eaten too often.
- Don't smoke

Details:

Individuals with TGA are at increased risk of **atherosclerosis**. This is a build-up of fatty deposits on the lining of the arteries.

These conditions affect most of us as we get older. However, there are several precautions that we can all take to reduce our risk. These are important considerations for individuals with COA, since they are at greater risk of developing these conditions.

Precautions:

- Lead a physically active life-style,
- Don't smoke,
- Eat a healthy, balanced diet avoiding high amounts of saturated fat

  Visit Heart Research UK's website and download a copy of the leaflet 'Food for a healthy heart'. http://heartresearch.org.uk
- Try to minimise the time you spend on sedentary activities e.g. TV, computers

Understanding the circulatory system

Blood transports vital oxygen and nutrients to all parts of the body. On average adults have between 3½ and 5½ litres of blood. Of course, this varies depending on your size.

Blood vessels

Every drop of blood is contained within the cardiovascular system, which consists of the heart together with a network of blood vessels. Blood vessels are a bit like pipes, through which the blood travels.

> **cardio** means 'to do with the heart'.
>
> **vascular** means to 'do with the blood vessels'.

There are three main types of blood vessel: arteries, veins and capillaries. Arteries carry blood away from the heart. In our muscles and organs blood passed though the tiny capillaries. Veins carry blood towards the heart.

Arteries carry blood away from the heart. Every time the heart beats it pumps blood at high pressure along the arteries. To withstand this high pressure the arteries have thick elastic walls. We can feel the artery stretch with every heartbeat if we take our pulse by placing two fingers on the wrist. As we get older our arteries lose some of their elasticity. Low-moderate intensity, dynamic exercise helps to keep our arteries healthy and prevents them from becoming stiff.

The arteries branch into smaller and smaller vessels, which go to different parts of the body. Eventually they lead into tiny blood vessels called capillaries.

Capillaries are very delicate, microscopic blood vessels. They are only about 0.007mm wide – three times narrower than a fine human hair. However, there are a vast number of capillaries and they form a dense network throughout most of the body. If you get a minor cut or graze then you will bleed because you have damaged 100s of capillaries. Fortunately, they will soon grow back.

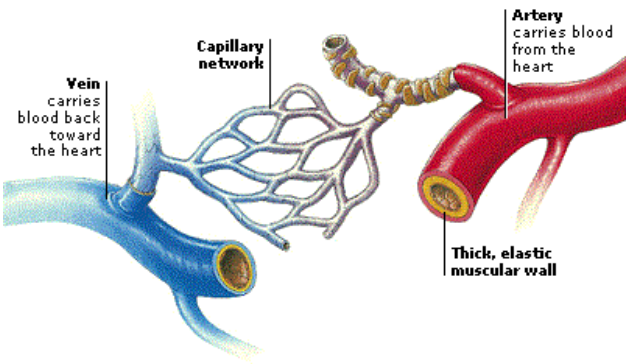
As it passes though the capillaries, blood releases most of the oxygen and nutrients it has been carrying, to be used in that part of the body. Waste products, such as carbon dioxide, pass from the surrounding cells into the blood to be taken away.

Capillaries converge to form larger blood vessels, eventually forming veins.

Veins

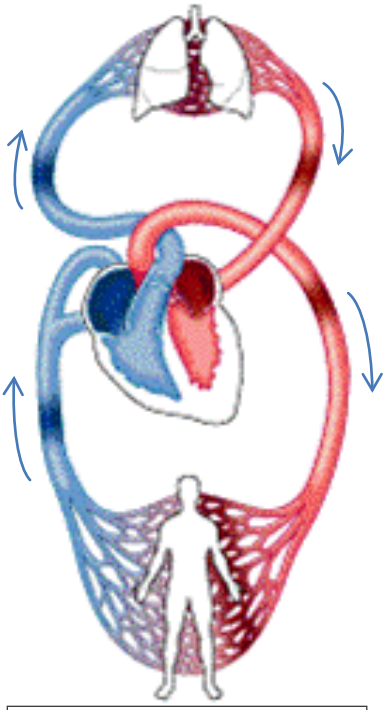
Veins return the oxygen-poor (deoxygenated) blood to the heart. The blood in the veins is at low pressure, so they don't have thick walls like the arteries.

Veins have valves to stop blood from flow back the wrong way. When our muscles are working they squeeze the veins, which helps to push the blood along towards the heart. Having good muscle tone, especially in the legs, improves the return of blood to the heart and can help us to be physically active at a higher intensity.



The circulation

There are two 'loops' to our circulatory system:



Simplified diagram of the circulatory system

From the heart to the lungs and back to the heart

Blood travels from the right side of the heart to the lungs.
Here it picks up vital oxygen.
Oxygen binds to haemoglobin, which is found in red blood cells.
Oxygen-rich blood flows from the lungs to the left side of the heart.

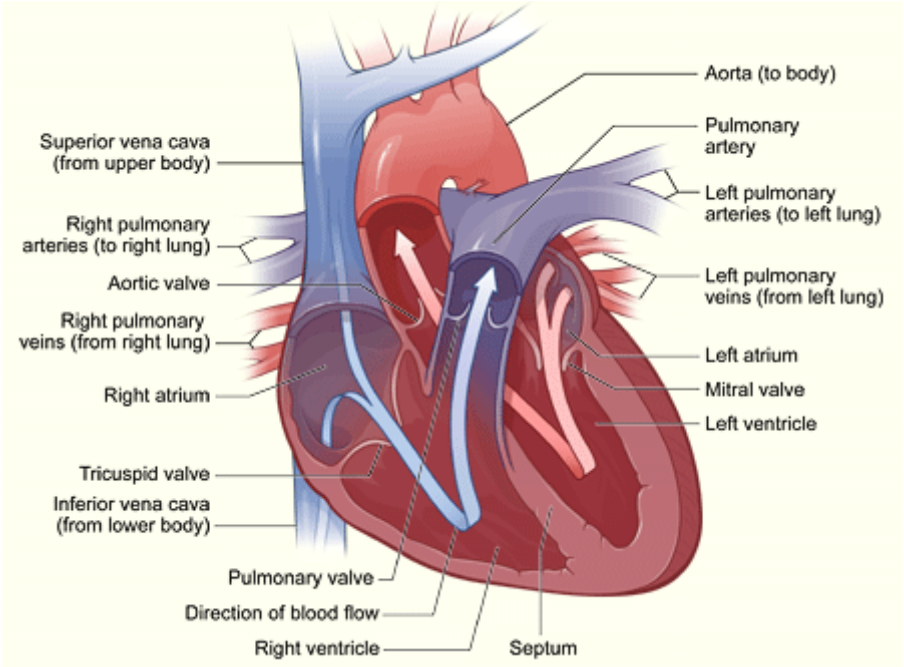
From the heart, around the body and back to the heart

Oxygen-rich blood travels out of the left side of the heart.
It flows to part of the body, delivering oxygen and nutrients.
Blood then returns to the right side heart.

The heart

The heart is mostly muscle. Every heart beat is a contraction of the heart muscle, which pumps blood. Your heart is roughly the size of your fist and beats about 60 times every minute (once every second).

There are normally four compartments, or chambers, in the heart. The upper two chambers are called the **atria**. The lower two chambers are called the **ventricles**. There are valves between the atria and the ventricles to stop blood flowing the wrong way. Two more valves prevent blood that has just been pumped out of the heart from flowing back in when the heart relaxes.



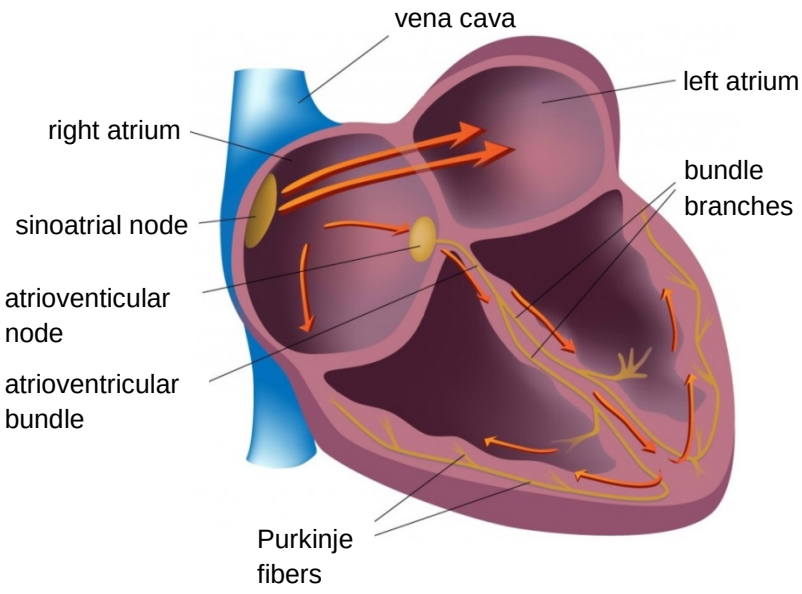
Muscles, including the heart, work by **contracting**. This means that the muscle uses energy to become shorter.

The heartbeat

The heart muscle does not all contract at the same time. The top chambers of the heart, the atria, contract first. This forces blood down through the valves and into the lower chambers, the ventricles. There is a slight delay to allow all the blood to pass from the atria into the ventricles. Then the ventricles contract pumping blood out of the heart.

The timing of the heart beat is very important. If the timing is wrong then the heart cannot work efficiently. This is controlled by special fibres in the heart, which allow an electrical impulse to travel to the correct parts of the heart at the correct time.

Conduction system



ECG

An ECG records the electrical activity of the heart and plots it as a graph. This enables doctors to check that your heart rhythm is normal. A normal heart rhythm is called '**sinus rhythm**'. If the heart's electrical rhythm is not normal then there may be a problem with timing of the heartbeat. This is call '**arrhythmia**' and, if necessary, can be treated with medication or an implanted device (pacemaker/ICD).

Glossary

arteries
The blood vessels that carry blood away from the heart.

atherosclerosis
The build-up of fatty deposits on the lining of the arteries.

atrium
One of the two upper chambers of the heart. (plural: atria)

arrhythmia
An abnormal heart rhythm

cardiopulmonary exercise test
A test in which the patient does exercise, usually on a treadmill or an exercise bike. A whole range of measurements can be taken to see how the body responds to exercise. These include: heart rate, blood pressure, ECG and oxygen uptake.

cardiovascular fitness
The ability of the heart and the blood vessels to supply the muscles with oxygen.

capillaries
The smallest of the blood vessels. It is at the capillaries that oxygen passes out of the blood and into the cells of the body nearby.

dynamic activities
Activities in which lots of muscles are used to bring about movement (e.g. jogging and racket sports). During dynamic activities the muscles are alternately relaxing and contracting (tensing).

exercise
A type of physical activity in which the aim is to improve cardiovascular fitness.

physical activity
Any movement of the body produced by the muscles, which uses energy.

regurgitation
Sometimes a heart valve does not shut perfectly. As the heart beats some blood flows in the wrong direction, back through the valve. This is known as regurgitation or insufficiency. When this happens the heart is less efficient – it has to work a bit harder to do its job.

resistance training
A method for improving muscular fitness by exercising the muscles against an opposing force.

sedentary behaviour
Activities that use very little energy and take place whilst sitting or lying down (e.g. watching TV, using laptops/computers, working at a desk, playing computer games)

static activities
Activities in which the muscles generate a large force, yet there is relatively little movement (e.g. lifting heavy weights).

syncope
Another word for fainting - the temporary loss of consciousness

Valsalva manoeuvre
Tensing up the breathing muscles, as if trying to breath out, while the mouth and throat are closed off so that no air can come out. This is often done instinctively when lifting a heavy object. It can cause large, rapid changes in blood pressure.

valve
The function of a valve is to ensure that blood only travels in the correct direction. In the heart there are several valves. They are soft and flap open and shut as the heart beats.

veins
The blood vessels that carry blood back to the heart.

ventricle
One of the two lower chambers of the heart.

Appendix A ……. Physical Activity Recommendation Form

Physical activity recommendations form for : ……

Name of condition: …… Date: ……

Intensity of exercise recommended:	(tick appropriate box)
Low (active, moving about, but no obvious change in breathing or heart rate)	
Moderate (get warmer, breathe harder, heart beats faster – but can still carry on a conversation)	
Vigorous (breathe much harder, heart beats much faster - difficult to carry on a conversation)	

Amount of physical activity recommended:	(tick appropriate box)
At least 60mins physical activity every day (National guidelines for 5-18 year olds)	
30 - 60mins physical activity every day	
Up to 30mins physical activity every day	

Types of exercise:	(circle as appropriate)
Dynamic (muscles work to produce movement e.g. running, swimming)	safe / best avoided
Static (muscles work hard but with little movement e.g. weightlifting, rugby scrum)	safe / best avoided

Activities to avoid:	(circle as appropriate box)
Activities with a high risk of impact (e.g. martial arts, hockey)	safe / best avoided
Activities with a high risk of injuries, such as cuts and grazes	safe / best avoided
Other:	

Competitive sport:	(tick appropriate box)
Avoid all competitive sports	
Participate in some competitive sports but rest when necessary	
Participate fully in all competitive sports	

Recommended activities:

Exercise capacity:	
Peak heart rate (bpm)	
VO_{2peak} (ml/kg/min)	
Six-minute walk test – distance (m)	

Other comments:

Authorised by: …… Valid for / review date……

Position: Paediatric consultant / cardiac liaison nurse / physiotherapist other: ……

Appendix B ……. Physical activity recording sheets

Physical Activity Record for …….. Start date ……...

	At school:	After school (e.g. clubs)	Total:
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			
Saturday			
Sunday			

Total for the week: _____

Physical Activity Record for …….……. Start date ……...

	At school:	After school (e.g. clubs)	Total:
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			
Saturday			
Sunday			

Total for the week: _____

Physical Activity Record for ……………………………………

Year …………. Month……………….

	Activity time:
Monday	
Tuesday	
Wednesday	
Thursday	
Friday	
Saturday	
Sunday	
Week's total:	

	Activity time:
Monday	
Tuesday	
Wednesday	
Thursday	
Friday	
Saturday	
Sunday	
Week's total:	

	Activity time:
Monday	
Tuesday	
Wednesday	
Thursday	
Friday	
Saturday	
Sunday	
Week's total:	

	Activity time:
Monday	
Tuesday	
Wednesday	
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Appendix C ……. Leaflet – ‘Congenital heart disease: a guide for schools’

Congenital heart disease: a guide for schools

About congenital heart disease (CHD)

Congenital heart diseases (CHD) are abnormalities of the heart that are present from birth. There are many types of CHD. Most CHDs are developmental and occur when the heart does not form correctly during the early stages of pregnancy. Some conditions are fairly simple and are unlikely to result in long-term health problems. Other conditions are more complex, requiring multiple operations and having a life-long impact on health. 1 in every 180 children born in the UK has a congenital heart condition, so most schools will have at least one affected pupil.

There is no need to feel anxious or alarmed if one of your pupils has CHD. Having a heart condition does not mean that a child is in any danger. Most people born with CHD will go on to lead a full and happy life, with few long-term problems. If a child's doctors considered that they were in any immediate danger they would not be allowed to attend school.

In *most* school situations children with a CHD should be treated the same as any other pupil. However, there are some important exceptions that you should be aware of. These are discussed below.

General considerations

- For most children with a heart condition it will be necessary to have a 'Health Care Plan'.
  (See 'Managing medicines in schools and early years settings', available at https://www.gov.uk/government/publications)
- Remember to respect the child's need for **confidentiality**. Most children with CHD consider their condition to be private information and wish to have control over disclosure to their peers. It is therefore important not to draw attention to a child's heart condition in front of their peers.
- **Getting around** school. Some children with complex heart conditions may need a little more time to get from one lesson to the next, especially if they have a lot of books to carry. If necessary, arrangements should be made to give them the option to leave lessons a few minutes early. It may also be useful to consider using a 'buddy' system, where friends help to carry books between lessons.
- Be vigilant for any **social problems**. Most children need to feel that they are a valued member of the school community. There is a risk that some aspects of their heart condition may single a child out as different, leading to social isolation or bullying. For example, there may be physical differences, such as small stature, surgical scars or a very pale complexion. Frequent or prolonged absence from school and inability to participate in team sports may also effect a child's social integration.

In the classroom

- Children with CHD are more likely to have academic, behavioural or coordination problems. Of course many children with CHD will have none of these problems. However, if you believe that a child may have an undiagnosed specific learning difficulty then you should follow the school's policy and consult with the SENCO.
- It is not uncommon for children with CHD to need further medical procedures. This will usually mean that he/she will be away from school for a few weeks. It may be necessary to provide addition support and materials to ensure that they do not fall behind and are able to catch up with work missed.
- Heart disease may be covered in science lessons or during PSHE lessons, in relation to healthy lifestyles. Teachers should be prepared to act with sensitivity, whilst ensuring that the need for confidentiality is respected.

During Games/PE

- It is very important that you are aware of any **activity restrictions**. This information will be provided to the school by the parents/carers or by the doctors or nurses working with the family. Activity restrictions depend upon the exact nature of the child's heart condition.

  The most common restrictions are:

  - Activities with a moderate-to-high risk of impact or injury / Contact sports
  - Competitive sports
  - Activities requiring strenuous exertion eg lifting heavy weights

  If in doubt, contact the parents/carer to ask if there are any activities that their child should avoid.

- Ensure that there are opportunities to rehydrate. Some children with a heart condition are more susceptible to dehydration. It may be useful for them to have a water bottle nearby during activities.
- Children with CHD should always be allowed to self-limit their activity. Always allow them to stop and take a rest if they need to.
- Be aware that a competitive nature or peer pressure could cause a child with CHD to push themself too hard. This is particularly likely during team sports.
- Wherever possible try to ensure that they are included. For example, when playing a team sport it may be useful to make regular substitutions to allow them sufficient time to rest and recover. If you need to adapt activities to allow a child to participate, try to do so without drawing attention to their heart condition.
- Where appropriate try to include a steady warm-up and cool-down in the activity.
- Don't assume that a child has limitations. Many children with CHD can safely participate without restrictions.
- Don't forget about them! Children with CHD usually don't like to draw attention to their heart condition and find it awkward to have to remind teachers about their condition.

Symptoms to watch out for:

- dizziness or feeling faint
- becoming so breathless that it is difficult speak
- palpitations (the heart feels like it is pounding, fluttering or beating irregularly)
- become very pale and clammy
- severe tiredness or fatigue,
- a blue tinge to the skin (if they have a cyanotic heart condition)

If a child with CHD develops any of these symptoms they should immediately stop the activity. If symptoms continue then seek medical assistance.

Medications

- Some children with a heart condition need to take daily medication. If medication needs to be taken during the school day then appropriate provision must be made.
- Some medications may have side-effects that staff should be aware of.

  Examples: Drugs to reduce blood pressure may cause dizziness or increased urinary urgency.

  Children on anticoagulant medication will usually bleed for a longer time following cuts and will bruise more easily.

For further information on specific conditions please visit the following website:

http://www.bhf.org.uk/heart-health/conditions/congenital-heart-disease.aspx