

Helping your child with Congenital Heart Disease (CHD) stay healthy



Information for families

**Great Ormond Street Hospital
for Children NHS Foundation Trust**

Bringing up children is one of the hardest jobs in the world. Having a child with a congenital heart defect (CHD) can make this more challenging.

As parents, you want the best for your child so that they grow into adulthood as individuals who are able to participate fully in their community and society as a whole and be happy and healthy.

Children with CHD are, in the first instance, children and so have the same needs as any other child as well as facing similar challenges, such as making friends, understanding

their body as they grow, school, work and a place in society. A child with CHD has, in addition, the challenges their condition brings which can make ordinary growing up more difficult. Friendships, being active, taking part in group activities, keeping up with school work and staying healthy can all help to make any child happy and feel safe and secure in their life.

This booklet provides some information to help your heart child flourish. Other sources where more detailed information can be found are also given.

Six tips on helping your child stay healthy and well:

Teeth

Staying happy

Making friends

Keeping active

Growing

**Understanding
their condition**



Having strong healthy teeth encourages us to smile. When we smile and laugh we feel good about ourselves. We all look better with good teeth.

Keeping teeth and mouths healthy is more than cosmetic. When teeth and gums are not cared for infections can get into the blood stream. Individuals with CHD are at more risk than the general population of an infection affecting the inside of the heart and damaging the valves, leading to heart failure. This is called endocarditis¹. Although rare, it is a very serious condition, and can be life threatening.

The best way to avoid endocarditis is to look after teeth and gums. A healthy mouth and teeth are also thought to protect the body

Key Points:

- Healthy teeth and gums help to keep the body healthy
- Looking after teeth and gums helps prevent endocarditis
- Brush teeth twice a day with fluoride toothpaste
- Limit sweets and sugary drinks.
- See your dentist regularly



from other illnesses. Endocarditis and other infections can also occur after damage to or cutting the skin, such as having tattoos and piercings, so it is recommended these are avoided.

Brushing teeth² with fluoride toothpaste twice a day, once being before bedtime, is good practice as recommended by

¹ More information on endocarditis: www.nice.org.uk/guidance/cg64
see also back page for further resources

² More information resources about care of teeth:
Live Well NHS Choices: www.nhs.uk
www.nhs.uk/Livewell/dentalhealth
www.dentalhealth.org.uk
www.nhs.uk/conditions/dental-decay/pages/introduction.aspx

dentists. Children should be encouraged to spit out toothpaste but not to rinse with water.

Sugary foods and drinks are popular with children and avoiding them completely may be difficult – the alternative is to limit them to mealtimes. Sugary drinks when sipped frequently over a long period via a bottle can increase the risk of tooth decay as the mouth and teeth are covered with the sugary drink for longer. The bacteria build up on the teeth can produce acid that destroys the tooth.



Tooth decay in milk teeth can affect the adult teeth so it is important to look after children's teeth the moment they come through.

Activity Box

Now what?

- How might this information change how you look after your child's teeth?
- Discuss any concerns about teeth and gums with your child's dentist.
- Consider incorporating at least two of the recommendations from the Live Well NHS Choices website about dental care.



Staying happy & making friends

Happiness is a subjective and personal thing. Different things can make us unhappy; being unable to walk very far, having no friends, being unemployed, illness, feeling different and isolated.

The reverse is that being active, feeling well, having friends and family around, good work prospects and feeling positive about oneself and the future can help towards making individuals happy.

Research has identified that some children with CHD can feel lonely, that they feel different from their peers and so feel isolated. This can be exacerbated for those children who have frequent hospital visits and admission keeping them away from school.

Hospital admissions can also be stressful and frightening to young children and impact on how they continue accessing health care as they grow. If this is the case it may be worth speaking to your cardiac liaison nurse, cardiologist or GP about what psychological support and help might be available.¹

Key Points:

- Life long health conditions can affect children's well being
- Heart condition may make a child feel different to friends
- People with similar experiences can support one another



Having a life-long health condition can feel burdensome, as other people don't always understand what it is like. There are several organisations that help young people come to terms with their condition as well as sharing experiences with other young people who also have a life-long condition.

¹ www.gosh.nhs.uk/parents-and-visitors/advice-when-you-stay/coping-hospital-visit/helping-your-child-cope

The British Heart Foundation and Children’s Heart Federation also have away days and camps throughout the year where children and young people can meet others with similar conditions and try new activities under supervision.

For teenagers there are various websites where they can learn about others who have had a similar experience. The Children’s Heart Federation has “Brighthearts”, the British Heart Foundation has “yheart”²

Activity Box

Now what?

- Think how you might support your child to talk about their life-long condition and how it affects them.
- Are there any activities or groups that your child would enjoy being part of? This may be a way of making new friends, learning a new skill and keeping active.
- Consider taking part in one of the following:
 - British Heart Foundation away day
 - Children’s Heart Federation camps

² Websites for young people: Children’s Heart Federation: www.chfed.org.uk/how_we_help/brighthearts; British Heart Foundation: www.bhf.org.uk/heart-health/yheart; Corience: An independent European organization on congenital heart defects: www.corience.org

Keeping active

Exercise cannot only be fun but can also improve fitness levels, motor skills, help build friendships and improve quality of life.

Everyone can benefit from some form of regular exercise, such as walking, dancing, taking the dog out, playing a sport or flying a kite with friends. The newspapers and health professionals warn that a sedentary life style can lead to serious health problems such as obesity, poor heart function, joint problems and weak muscles and bones.



Key Points:

- Exercise is important even for individuals with a heart condition
- 60 minutes physical activity a day in 10 to 15 minute periods, for at least two days a week
- Check with your child's cardiologist about any limitations

It is important for those with a CHD to also take part in physical activities as this can help to preserve their fitness levels as well as improve quality of life.

Guidelines suggest that children should have about 60 minutes of exercise each day, this could be split into 10 to 15 minute intervals spread throughout the day. Children with CHD are likely to tire before their peers and should be supported when they want to take a rest or go at their own pace.

However, the level of physical activity may be restricted for some children, perhaps before the defect has been corrected or after surgery

where there is a residual defect. It is important to discuss with your child's cardiologist any limitations for them to take part in a sport or physical activity.

Remember to tell your child's school they may need to take regular breaks when doing physical activities or about any restrictions in taking part in sports.

Activity Box

Now What?

- How might you incorporate physical activities into your child's daily routine that they would find fun?
- Discuss with your child's cardiologist any limitations related to their condition about physical activities, particularly in undertaking any competitive sports or if your child is new to physical activities.
- Consider taking part in one of the British Heart Foundation or Children's Heart Federation weekend camps or away days.



More information about sports and congenital heart disease:

Corience: www.corience.org;
www.bhf.org.uk/publications/heart-conditions/keep-your-heart-healthy
Live Well NHS Choices:
www.nhs.uk/livewell/fitness/Pages/Fitnesshome.aspx

Many things are important in nurturing children and helping them grow and develop and learn. A healthy diet and a good night's sleep are important. Equally a poor diet and lack of sleep can have a detrimental effect on children's growth and ability to learn.

Key Points:

- A good night's sleep is important for a child's wellbeing.
- Balanced diet is ideal: a little of everything with the occasional sugary or salty snack for a treat



There are already many articles in the media advising about how to have a healthy diet.

Children with CHD may need extra calories when they are babies to help them thrive but after that a normal balanced diet is recommended.

Foods with a high salt, sugar and fat content, such as processed and pre-prepared foods and snacks can, over long periods of time, be damaging to our bodies. It can affect the heart and kidneys and may lead to diabetes and raised blood pressure which increases the risks of strokes and damage to the body's major organs.

Children should eat a variety of foods throughout the day so they have a selection of two or three from each food group, aiming for five portions of fruit and vegetables a day. Sugary foods, snacks and drinks should be limited to mealtimes or special occasions. For fussy eaters see resources below¹

Food Groups	
Cereals	Bread, potatoes, rice, pasta, breakfast cereals
Fruit and vegetables	Includes fruit juice, dried and fresh fruit
Milk	Cheese, yoghurt, milk
Meat, fish, other proteins	Fish, meat, nuts, pulses

¹ www.gosh.nhs.uk/medical-information/general-health-advice/food-and-diet/fussy-eaters Also consider speaking to your cardiac nurse specialist, cardiologist, paediatrician, health visitor, GP.



The amount of sleep children need depends on their age. Sleep is important for wellbeing and a lack of it can make concentration during the day difficult as well as affecting mood and lead to cravings for junk food.

Poor sleep has been related to the use of TVs and computers in bedrooms, particularly being used into the evening, as well as late nights¹.



¹ More advice on sleep: Live Well NHS Choices: www.nhs.uk/conditions/pregnancy-and-baby/pages/sleep-problems-in-children.aspx

Activity Box

Now What?

- Compare your child's actual sleep hours to the recommended amount. Could your child benefit from more sleep at night-time?
- How many portions of fruit and vegetables a day does your child have? Consider ways to increase them if currently having less than five portions.
- Consider whether your child regularly in a day eats from all four of the food groups. Talk to someone if you are worried or uncertain about your child's diet.

Understanding their heart condition

As parents you will teach and guide your child as they grow. At different stages in their life, they will start to understand more about their heart condition. Small bit of information can be given to them when they are young, with more complex information introduced as they get older.

Keeping a diary when they are young or a scrapbook can help to have a focus when talking to them about any hospital admissions and treatment they had when small.

There are many parent organisations and heart charities that can provide information to help you as a parent.

As your child grows they may enjoy exploring and finding out about how their body works, about their condition and finding out about other children who have similar conditions or experiences.

Key Points:

- Children with congenital heart disease survive into adulthood and most will need life-long follow up by an adult cardiologist.
- Children therefore need to:
 - understand their condition
 - learn to take on the responsibility of their own health needs as they move towards adulthood
 - be aware of "Transition", the gradual move to adults services usually from 14 years of age.

Some useful resources that might help when talking to your child about their condition. See also page 1:

Children's heart Federation:

- Brighthearts the teen forum
www.chfed.org.uk/how-we-help/brighthearts

British Heart Foundation:

- teenage website: www.bhf.org.uk/heart-health/yheart
- 7-11 website: www.yoobot.co.uk

Transition to adult services

Children as they move towards adulthood will be expected to take responsibility for their own health needs. Understanding their condition is one step towards being able to do this.

Another change will be that their care will be under a cardiologist who cares for adult patients only. The move to adult services usually starts when they are between 12 and 14 years old. We often refer to this as “transition”¹.

Parents and the child will meet their adult cardiologist, who specialise in congenital heart disease, alongside a paediatric cardiologist. This joint management continues until the child reaches 16 to 18 years of age when they move completely over to adult services.²

1 GOSH factsheet: Transition: getting ready to move to adult services www.gosh.nhs.uk/parents-and-visitors/advice-when-you-leave/transition-adult-services

2 There is a patient association to support young people and adults with congenital heart disease called the Somerville Foundation www.thesf.org.uk. The British Heart Foundation also has a section on it's website for teenagers.

Activity Box

Now what?

- How might you learn more about your child's condition in order to teach them?
- Think of one or two ways to regularly help your child understand their condition and how it relates to their body.
- What resources available from the various websites and heart charities might your child find useful and understand a little more about their heart condition?
- Consider keeping a diary or scrap book about the various stages of your child's treatment and hospital admissions to show your child as they grow up.
- Find out more about your child's condition and transition from their cardiologist or cardiac specialist nurse.

Further Resources

Useful organisations and websites easily found via internet search engine:

- British Heart Foundation
- British Dietetic Association
Has fact sheets and information about food
- Children's Heart Federation: [0808 808 5000 or www.chfed.org.uk]
Provides information about CHD & links to other organisations relating to heart disease and children. Also published "A guide to meeting the non-medical needs of children and young people with heart conditions"
- Corience: An independent European organisation on CHD
- Somerville Foundation: Adult Congenital Heart Disease information, contacts and support
- Live Well NHS Choices: Lots of articles about healthy living for adults and children

Some useful GOSH Factsheets

The following titles are available on the GOSH website.

You can also ask your cardiac nurse specialist, or PALS for copies:

- Coming into hospital: helping your child cope
- Leaving hospital after a heart operation
- Getting a good night's sleep
- Transition: getting ready to move to adult services

Notes

**If you have any questions, please contact your
Cardiac Nurse Specialist on 020 7405 9200 ext 5774**

Notes



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