# Lifestyle Issues

Somerville Heart Foundation

## Adult Congenital Heart Disease

## ACHD




For young people and adults born with a heart condition

This leaflet is designed to provide you with advice on lifestyle choices and issues that may be related to your heart condition. The aim of the leaflet is to provide you with information so you can make informed decisions for yourself. It is not however designed to either replace or alter any advice that you may have received from your ACHD specialist team.

A list of ACHD Specialist Centres is available on the Somerville Heart Foundation website www.sfhearts.org.uk. Every adult born with a heart condition is entitled to see an expert from a specialist centre at least once and have a written care plan.

## Healthy Eating & Weight Control

There are often a number of reasons why we put on weight, but excess weight for people born with a heart problem can put extra strain on the heart. The best advice is to follow a healthy lifestyle, which includes both healthy eating and plenty of exercise.

### Did you know being overweight can:

- Be a common cause of breathlessness
- Increase your chances of having a heart attack
- Cause high blood pressure
- Put additional strain on your heart
- Increase the risk of stroke and type 2 diabetes
- Give you sleep apnoea and daytime tiredness

### And can also cause:



- Difficulty in walking
- Arthritis
- Back pain
- Sleeping difficulties
- Low self-esteem and poor body image

## Current guidance suggests:

- Eating at least 5 portions of fruit and vegetables per day
- The following are examples of a portion: 1 medium apple, 3 celery sticks, half a large courgette, 1 leek, 2 broccoli florets, 1 medium banana, 2 small satsumas (visit nhs.uk/5aday for more information)
- Eating starchy foods like wholemeal bread, wholegrain pasta, brown rice and potato
- Reducing the amount of fats you eat (e.g. red meat, peanuts, fried food, crisps, chocolate), to help improve the amount of 'good' or non-harmful cholesterol in your blood
- Using cooking methods that reduce fat such as grilling and steaming
- Drinking less alcohol
- Cutting out fizzy, sugary drinks and drinking water instead
- Eating at least 2 portions of fish a week, one being oily fish (fresh tuna, salmon, sardines)
- Reducing your salt intake to no more than 6g a day



## How to get help:

If you feel you need some help losing weight, then find out what's on offer in your area.

There are a number of people/services that may be able to help:

- Your GP/Practice Nurse
- Dietician
- Local weight management classes

Everyone is different, and there will be people or services you feel more comfortable talking to than others.

# Exercise & Sport

Regular exercise has beneficial effects on physical and psychological health.

The majority of people born with heart problems can lead a full and active life and do not need to restrict their physical activity. A wide variety of activities can be enjoyed such as walking, swimming, cycling and tennis for example.

Physical fitness is important in reducing the risk of both coronary heart disease and obesity.



You can still improve your fitness level even if your exercise capacity is reduced.

## Effects of exercise:

Certain types of exercise produce different effects on the heart. There are two types of exercise:

- Isotonic (also called dynamic or cardiovascular exercise) e.g. jogging and swimming
- Isometric (also called static) e.g. weight-lifting and some gym-based exercise

Most forms of physical activity are part isotonic and part isometric.

## What does this mean?

Your Cardiologist or Specialist Nurse may advise against certain intense physical activities which include competitive or contact sports.

For example, weightlifting (isometric exercise) can increase the pressure within the heart and cause a sudden increase of blood pressure. It should be avoided if you have moderate to severe coarctation of the aorta, severe aortic stenosis or diseases of the aorta.



## General recommendations:

- Be realistic, set your own achievable goals
- Aim for 30 minutes of moderately intensive activity, such as brisk walking at least 5 times a week
- Physical activity is effective even when broken down into 10-minute chunks
- Increase exercise as part of daily living, activities such as walking to work and taking the stairs can be as beneficial as gym-based exercise
- Have a warm-up period before you start and give your body a chance to recover
- Avoid becoming dehydrated, drink water
- People who take anticoagulants are advised to avoid participation in contact sports
- Some medication (e.g. beta-blockers) affect heart rate response to exercise. This, in turn, is likely to affect the level of exercise that can be achieved

It is important to request individualised advice from your Cardiologist or Specialist Nurse about what is safe for you.

## Endocarditis

Endocarditis is an infection of the inner wall of the heart and/or the heart valves caused by bacteria that enter the bloodstream. It is serious and needs prompt treatment. It is not a common infection, but people with a heart condition are at greater risk of developing it than those with a normal heart. You can get endocarditis more than once.

Symptoms can develop gradually and may be vague at first. The most typical characteristic is a fever lasting more than 5 days, shivering and sweating at night and 'flu-like' symptoms. You tend to feel generally unwell with aches, pains and tiredness. If you develop an unexplained fever, it is important to have a blood test to determine whether infection is present in the blood before any antibiotics are considered.

The following factors can contribute to the onset of endocarditis:



- Contaminated needles
- Bacteria from skin infections
- Tooth abscesses
- Poor nail and skin care
- Body piercing and tattoos

Antibiotic cover is no longer offered routinely before invasive dental work, this includes a scale and polish or before interventional procedures (NICE (2016) Prophylaxis Against Infective Endocarditis in Adults and Children Undergoing Interventional Procedures. Clinical guideline No 64. NICE. London). However, people with mechanical heart valves and those with a previous history of endocarditis DO require antibiotic prophylaxis to reduce the risk of infective endocarditis. Advice on this should be sought from your Cardiologist or Specialist Nurse if you are in any doubt. Most ACHD Centres have their own independent guidelines. Further info about this can be found at: www.nice.org.uk/CG064.

There are things you can do to prevent infection. The most important is to make sure your teeth and gums are clean and healthy. Brush your teeth twice a day, use dental floss and visit the dentist once a year for check-ups. If you require urgent dental care and do not have a dentist, call the NHS on 111.

## Piercings & Tattoos

All tattoos and piercing carry some risk and most cardiologists and health professionals recommend that you avoid tattoos and piercing altogether. Any procedure which breaks the skin carries a risk of introducing bugs into the blood stream. These bugs can settle on the heart causing endocarditis (see previous page).

Piercing which involves the nose, lip, tongue, genitalia or belly button carries more risk than piercing of ears, eyebrows or nipples. However, the decision to get a piercing or tattoo is yours, and if you choose to proceed, the following will help you to make the procedure as safe as possible:

- Visit a reputable place that follows rigorous hygiene guidelines
- Good hygiene is vital. Keep the area clean with a skin disinfectant containing alcohol or chlorhexidine before and after the procedure, until the wound is healed
- Make sure pre-packed sterilised needles are used only once and then thrown away
- If the piercing becomes red and sore, you should remove the ring/stud and seek medical attention
- If you need to remove the ring/stud because of infection, you should not replace it until the infection is completely cleared



## Sex

Your heart condition should not prevent you from enjoying sex. Some medication used in the treatment of cardiac conditions can potentially cause specific difficulties, including erectile dysfunction. You may want to discuss any concerns with your Cardiologist or ACHD Specialist Nurse. The use of condoms can help protect against sexually transmitted diseases.

Detailed advice about different types of contraception can be found in our separate contraception leaflet. Online copies can be downloaded from our website at www.sfhearts.org.uk.



## Alcohol

One to two alcoholic drinks (singles) is the current recommended maximum daily intake, especially if you take warfarin, as alcohol can interact with this medication.

Alcohol can interfere with the absorption of some medications or prevent them from working effectively, and may lead to heart rhythm abnormalities. It is advisable not to binge drink – i.e. go out one or two nights a week, consume large amounts of alcohol and get drunk. It has many harmful effects – your liver may not cope; you may vomit a large amount and not absorb your medication. Large amounts of alcohol can cause your heart to beat rapidly or abnormally and it can increase the risk of blood clots. Binge drinking can contribute to accidents, violence, poor social behaviour, 'lost' days and unsafe sex.

## Tips for staying safe



- Work out where you stand on issues like alcohol. Knowing your own mind makes it easier to stay true to yourself
- Trust your own judgement – don't be swayed by peer pressure
- Eat a substantial meal before going out; a full stomach absorbs alcohol more slowly
- Plan how to get home safely, keep money for taxis separate, keep a fully charged mobile phone with you, have a plan B (friend or relative to phone if things go wrong)
- Decide on a drink limit and stick to it
- Stick with friends that you trust

- If you decide to drink, then drink in moderation and stick to lower-alcohol options. Some lagers can have up to 5.2% alcohol by volume, whilst some beers are as low as 2.8% abv. Stronger beers will take effect much more quickly

## Stimulant Drinks

Although these are usually non-alcoholic (e.g. Red Bull), they can have an effect on the heart as they can cause an instant rise in blood pressure and heart rate, which could be detrimental to your health.



## Smoking

Much has been written about the detrimental effects of smoking, and the general advice is not to start smoking or try to give up as early as possible in life, to prevent long-term complications. If you are waiting for heart surgery it's even more important that you give up, as smoking around the time of an operation seriously increases your risks of complications. Vaping/E-cigarettes are not harm-free and have also been associated with risks to health.



## Smoking can:

- Increase your heart rate and put it under strain
- Decrease your oxygen uptake and therefore increase breathlessness
- Increase your blood pressure
- Damage your arteries
- Increase the risk of heart attack or stroke. In general, people who smoke cigarettes have about twice as great a risk of a heart attack as people who don't
- Be associated with the formation of blood clots in the coronary arteries, chronic bronchitis, emphysema and different types of cancer such as lung, mouth and stomach cancer



## How to get help:

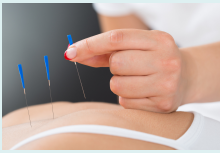
There is lots of support available to help you stop smoking – see your GP or Practice Nurse based in the local health centre for advice and support or visit www.nhs.uk/smokefree.

## Recreational Drugs

Drugs are powerful chemicals that can change how you think, feel and behave. Some recreational drugs are particularly dangerous for a person with a heart condition, especially stimulant drugs such as Ecstasy and Speed as these can cause heart rhythm irregularities. Intravenous drug usage puts you at increased risk of endocarditis.

For free and confidential advice call FRANK on 0300 123 6600 or visit talktofrank.com





## Acupuncture

Most people born with a heart condition are safe to have acupuncture, but if you are unsure about your particular heart condition contact your Cardiologist or ACHD Specialist Nurse. Good hygiene is vital and it is important that disposable needles are used. Keep the area clean with a skin disinfectant containing alcohol or chlorhexidine before and after the procedure.



## Spa Treatments

There is no reason why most of the treatments offered at spas should produce any greater degree of risk to someone born with a heart condition. These include body massages (either Swedish or pressure point), mud wraps (full body), hydro baths and alternative therapies of Shiatsu massage and reflexology. However, be aware that saunas and heated spa pools can lower your blood pressure and increase your heart rate, so follow the advice at the spa regarding the length of time you may safely stay in them.



## Sun Protection

It is important to use sunscreen and avoid prolonged exposure to the sun, particularly during the hottest part of the day. Extra care may be necessary with some medication, for example amiodarone which can make the skin more sensitive to sunlight.



## Extreme Sports

Your heart condition may not be the deciding factor if you attempt these, just your general fitness and fear factor! It is best to check with your Cardiologist or ACHD Specialist Nurse whether anything is likely to have an adverse effect on you.

Bungee jumping, for example, is dangerous for people on warfarin or for those who have an electrical device implanted. It is important to be aware that travelling to areas of high altitude can also have an effect on the cardiovascular system. Some adult congenital patients may want to scuba dive, ski, parachute jump etc. but it is sensible to understand fully the risks first by discussing with your Cardiologist or ACHD Specialist Nurse.





## Theme Park Rides

There have been some reported cases where specific rides have caused symptoms such as vomiting, dizziness and arrhythmia, so if you have complex congenital heart disease or an ICD, ask your cardiologist for advice if you are planning a trip.

There are some points that you should consider:

- Some rides may increase your heart rate and blood pressure as well as put a lot of strain on your neck and back
- The harness they strap you in with may press on an operation scar and hurt

- If you are on a ride with positive G force (where you experience a sudden upward velocity), your weight increases and your blood will be pushed towards your feet. It will resist your heart's attempt to pump it around, therefore your heart pumps even harder
- If the ride has a negative G force (where you experience a sudden drop), your weight lessens and your blood goes to your head and could rupture the blood vessels in your eyes – especially dangerous for those on warfarin or other anticoagulants
- People with implanted defibrillators or pacemakers should avoid the dodgems due to the large magnets on this ride



## Driving



There is no reason why you should not be able to drive if you are well. There have been a number of changes made by the DVLA over the past few years; visit the DVLA's website for more information or contact your Specialist Nurse for advice.

If the DVLA need to be informed, it is also sensible to tell your insurance company, as in the event of a claim they might refuse to pay out if they were not informed of a material fact that might have affected your driving.

## Careers & Employment Options

It is important that you know where to get the right career advice and appropriate information about jobs and your employment options.

Jobs that require rigorous fitness tests such as the armed forces or police may not be an option. However, that does not mean the right job isn't out there for you.

## Where to get help:

For those under 19 years of age, the National Careers Service is a useful source of information for further education courses and career choices. For more information call 0800 100900 or visit www.gov.uk/careers-helpline-for-teenagers.

Disability Employment Advisors are based in every job centre and can help you find suitable employment or help in practical ways to enable you to work. These employment specialists can also advise you about work-related benefits; visit www.direct.gov.uk for further information. If you require a medical letter relating to your condition, please contact your ACHD Specialist Nurse, or ask your Cardiologist when you next attend the clinic.

## Disability Discrimination:

Unfortunately some employers do unfairly discriminate against people who have heart conditions. If you feel that you have been discriminated against whilst applying for work or when you are in employment, Somerville Heart Foundation may be able to help. Call the office on 01473 252007 and ask about Employment Advice.

## Where to get further information & support

Somerville Heart Foundation offers practical help and advice to anyone born with a heart condition, as well as friends, family, colleagues and carers. There may be occasions when you feel down and find it difficult to cope. These feelings can be triggered if there is a change or deterioration in your health. People deal with stress in different ways; sometimes it helps to speak with someone outside of the family or who has been through a similar experience. If you have any concerns around emotional and mental health issues, members can access our mental health and wellbeing services.

## About Somerville Heart Foundation

Congenital heart disease (CHD) describes a heart condition or defect that developed in the womb. The term 'congenital' means the condition is present from birth. CHD is one of the most common types of congenital disability, affecting up to eight in every 1,000 babies. Today, there are an estimated 250,000+ adults living with CHD in the UK and there are now more adults than children living with the condition. We provide support in many ways, including mental health and wellbeing counselling, assistance in applying for grants, providing relevant information and access to resources. We aim to ensure that everyone with CHD receives the medical care, support and advice they need to lead happy and healthy lives.

### We exist to:

- Provide all congenital heart patients with accurate information and advice, allowing informed decisions and help make positive lifestyle choices
- Combat isolation and poverty for congenital heart patients and their families
- Enable congenital heart patients to share and learn from experiences and support each other

## Further Information, Support & Membership

You never know when you may need some extra help or advice. It's free to join Somerville Heart Foundation at www.sfhearts.org.uk/sign-up/

Join now to access our newsletters, mental health & wellbeing services, peer support and more.

*We are a registered charity, reliant on donations, fundraising and legacies. It's free to join but not free to run - your donations ensure the future of ACHD support for years to come.*

Somerville Heart Foundation

## Contact us...


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