



LIFESTYLE ISSUES

This leaflet is designed to provide you with advice on some lifestyle issues.

It is not meant to tell you what to do and what not to do but to provide you with information so you can take the decisions for yourself.

We hope by doing so the decision you take will be the most sensible one for you and your condition.

It is not however designed to either replace or alter any advice that you might or should get from your medical professionals and if you are in doubt, like with most things, it is best to check with them.

ENDOCARDITIS

Bacterial (infective) endocarditis is a serious infection where one of the four heart valves becomes infected with bacteria introduced into your bloodstream. This may occur during procedures including routine dental work, tattoos, body piercing, acupuncture, minor surgery and for females, placement of the coil.

Symptoms include fever, skin rash, breathlessness and tiredness, but it can be weeks before a diagnosis is made. You can also develop blood in your urine, anaemia, and/or an additional heart murmur.

It is therefore sensible to avoid any unnecessary procedure that may introduce bacteria into your blood stream.

It is REALLY IMPORTANT that you start taking antibiotic cover BEFORE having any procedure carried out. Your GP or dentist will prescribe them for you and if they forget, always ask. You should take responsibility for your own health.

It is also important sometimes NOT to take antibiotics. For example if you feel unwell and go to a doctor with symptoms including fever and feeling unwell without an obvious cause, a blood test (including blood cultures) should be taken before you start on antibiotics as they may well mask the real cause.

HEALTHY EATING

Much has been talked about regarding healthy eating, so here is some basic information relating to your heart and circulation.

Eating at least 5 portions of fruit and veg per day will help to keep your heart healthy by reducing the risk of your arteries furring up and possibly precipitating a heart attack. Green leafy vegetables, pumpkins and sweet potatoes are especially good for you.

Here is an example of what is meant by a portion.

- Vegetables - Two large tablespoons
- Mixed salad - One small bowl
- Tomatoes - One medium size
- Fresh fruit - One banana or pear or apple or orange one slice of melon, grapefruit, 12 grapes, 12 cherries, 2 kiwi fruits, 7 strawberries
- Fruit juice - One small glass
- Tinned fruit - Three tablespoons

By reducing the amount of fats you eat - e.g. red meat, peanuts, fried food, crisps, chocolate, you can help to improve the amount of 'good' or non-harmful cholesterol in your blood. This will then help to reduce the risk of heart damage.

'Oily' fish (herring, fresh tuna, salmon, sardines and pilchards) are really good for you.

Salt - try not to add salt when you are cooking, and try to not have any with your meal. This will help to keep your blood pressure down. However, if you are in a very hot climate and are sweating a lot you may need to take extra salt.

WEIGHT

If you keep your weight to the average for your height and not go too far over the average, you will reduce the workload on your heart.

ALCOHOL

There is a lot of publicity about the effects of alcohol and you need to use your common sense as to how much you have. One to two alcoholic drinks (singles) are the most you should have each day, especially if you are on warfarin or any heart drugs. Alcohol can interfere with the absorption of the drugs or prevent them from working effectively and may lead to rhythm upsets.

It is really important that you don't binge drink – i.e. go out one or two nights a week and get drunk. It has loads of very harmful effects - your liver can't cope, you may vomit a large amount and not absorb your medication, your heart beats rapidly, it increases the risk of blood clots, it affects the electrics of your heart and seriously raises blood pressure. Binge drinking can lead to accidents, violence, poor social behaviour, 'lost' days, unsafe sex and bad skin.

STIMULANT DRINKS

Although these are usually non-alcoholic, they are especially dangerous for GUCHs to drink as they can cause an instant rise in blood pressure and heart rate, which could be fatal. (Examples of these include Red Bull.)

TRAVEL

It is important to be aware that travelling to different climates or by air might have an effect on you. Air travel, particularly long haul, can take its toll on a lot of people and you should bear in mind that it might make you retain water a bit more than normal. Hot climates can have a similar effect and you may get breathless or dizzy if you get too cold or go somewhere that has a high altitude. For example Mexico City is the highest capital city in the world and the altitude can even affect people without a heart condition. If you are planning on going somewhere with a high altitude or with either a very hot or very cold climate it is best to check with your consultant before you book. Bear in mind that high altitude has particularly bad effects on people with high pressure in their lung arteries (Pulmonary Hypertension).

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 just to check whether anything is likely to have an adverse affect on you. E.g. Bungee jumping is a definite no-no for those on warfarin or those of you who have an electrical device implanted. Some GUCHs may want to scuba dive, ski, parachute jump etc. but it does need to be discussed with your consultant first.

THEME PARK RIDES

These will increase your heart rate and blood pressure as well as putting a lot of strain on your neck and back. Rides that use G force for a thrill will really put your heart under strain. If you are on a ride with positive G force (you experience a sudden upward velocity) your weight increases and your blood will be pushed towards your feet. It will resist your hearts attempt to pump it around, therefore your heart pumps even harder – a vicious cycle. 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.

However if you want to take the risk of anything adverse happening it is up to you – but you cannot blame the ride company if it does! Also the harness they strap you in with may press on an operation scar and hurt. Those of you on warfarin may bruise and the general effects may make you pass out, those who have an implanted electrical device may also have severe problems and should think carefully before going on these rides.

INVASIVE PROCEDURES

There are necessary procedures e.g. dental work, and unnecessary procedures e.g. tattoos, body piercing and acupuncture. It is much safer to avoid the unnecessary procedures and not risk endocarditis. However it is your choice and the information given will help you reduce the risk to your health and make an informed decision as to whether to go ahead or not.

TATTOOS

It may be necessary for you to take antibiotic cover before you have it done and you will be able to get this from your GP. If in doubt, check with your cardiologist or liaison nurse before you have it done.

Good hygiene is vital. Keep the area clean with a skin disinfectant containing alcohol or chlorhexidine before the procedure.

Before you decide where to have it done visit a couple of places and note that:

- The work areas are clean;
- There is good lighting;
- There are consent forms for you to sign agreeing to have the procedure done;
- They use pre-packed sterilised needles only once and then throw them away;
- The practitioner uses sterile gloves only once and then throws them away;
- Leftover ink is thrown away.

PIERCING

It will be necessary for you to take antibiotic cover before you have it done and you will be able to get this from your GP. If in doubt, check with your cardiologist or liaison nurse before you have it done.

Good hygiene is vital. Keep the area clean with a skin disinfectant containing alcohol or chlorhexidine before and after the procedure and until the wound is healed.

Navel piercing carries an increased risk of endocarditis both at the time of piercing and afterwards if the area becomes infected, so meticulous attention to skin hygiene is vital.

Never have your genital area pierced. This is unsafe for GUCHs, even with antibiotic cover. The area can be very easily infected well after the procedure is carried out and antibiotic cover has finished.

Before you decide where to have it done visit a couple of places and note that:

- The work areas are clean;
- There is good lighting;
- There are consent forms for you to sign agreeing to have the procedure done;
- They use pre-packed sterilised needles only once and then throw them away and that they do not use a piercing gun;
- The practitioner uses sterile gloves only once and then throws them away;
- The jewellery used is made from non-corrosive metal such as surgical stainless steel, titanium, niobium or 9k gold. These are the only metals that are safe for new piercings, silver or gold plate should never be used.

ACUPUNCTURE

It may be necessary for you to take antibiotic cover before you have it done. If you have been told to take antibiotics before going to the dentist then you should also do so for acupuncture. If in doubt, check with your cardiologist or liaison nurse before you have it done.

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 with a congenital 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 please be aware that sauna and heated spa pools can lower your blood pressure and increase your heart rate so follow the advice at the centre regarding the length of time you may safely stay in them.

TANNING BOOTHS

As well as the normal concerns that anyone should take into account as they use ultra-violet rays, from a GUCH point of view they can lower your pulse and blood pressure and have an adverse effect on scars. The tan they produce DOES NOT give you protection on the beach, you will still have to use a skin protection or sun blocker.

SMOKING

Much has been written about the detrimental effects of smoking. The simple fact for GUCHs is that it will have a more profound effect on your heart and lungs compared to a non-GUCH.

Smoking will:

- Increase your heart rate and put it under severe strain;
- Decrease your oxygen uptake and therefore increase breathlessness;
- Reduce your arterial function which will increase your blood pressure;
- Introduce poisons into your body;
- 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.

Cigarette smoke appears to damage the inside of the artery and also reduces the amount of oxygen the blood can carry around the body. It is also 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.

These along with all the other effects of smoking can be fatal - DON'T START

RECREATIONAL DRUGS

There is a huge amount of literature available regarding the use of these drugs. The normal risks to health are high enough, but to a GUCH the risks are increased to a level dangerous to your health and your life.

The following information just shows the main side effects these drugs have on you.

AMPHETAMINES / METAMORPHINES

(Speed, Whiz, Uppers, Amph, Billy, Sulphate)

Speed is the most impure drug in the UK.

The effects of taking amphetamines, which are stimulants, can last for up to 12 hours. Side effects include increased heartbeat and breathing, convulsions, dangerously high body temperature, stroke (blood clot on the brain), cardiac arrest (heart stops beating), cardiac arrhythmias (uneven and missed beats of your heart), stomach cramps, shaking, increased blood pressure, anxiety and panic attacks, insomnia, confusion and depression.

ALKYL NITRATES

(Poppers, Ram, Thrust, Rock Hard, Kix, TNT, Liquid Gold)

Blood vessels enlarge and you get a flushed face and neck, you get a surge of blood through your heart and brain, you usually get a headache after using it, problems around mouth and nose, poppers may be fatal if swallowed, can lead to death for those suffering from heart or breathing problems.

ECSTASY

(E, MDMA, Doves, Fantasy, Mitsibushis)

A drug derived from amphetamine and common side effects of ecstasy include increased heart rate, nausea, dizziness high temperature and jaw tension. Taking it can lead to sudden death.

GASES, GLUES AND AEROSOLS

These can cause instant death – even if you have used them before. They may cause your body to produce fluid in your lungs, which can be fatal. Nausea, vomiting, blackouts and fatal heart problems can also be caused by inhaling these substances.

CANNABIS

(Marijuana, Draw, Ganja, Weed, Blow, Hash)

Side effects include increased heart rate and blood pressure when only taking a little, slow heart rate and low blood pressure when taking higher doses. Symptoms of bronchitis with coughing and phlegm, frequent respiratory infections, impaired memory and learning ability, anxiety and panic attacks, abnormal functioning of the lungs.

COCAINE

(C, Charlie, Coke, Snow)

Side effects include restlessness, anxiety and paranoia, high temperatures, fits and tremors, increased risk of blood clotting (which can cause a heart attack), abnormal heart rhythms that can lead to sudden death. Long term or repeated cocaine use on the heart muscle may cause cardiomyopathy, which is a disease of the heart muscle that can lead to heart failure.

MAGIC MUSHROOMS

(Mushies, Shrooms)

Side effects include panic attacks, sickness, diarrhoea, stomach pains and they can impair your judgement. You can have a bad trip on magic mushrooms.

SEX AND CONTRACEPTION

There is loads of information on this subject around, all of which is also relevant to GUCHs, so it will not be repeated here.

Unprotected sex can lead to all sorts of diseases, which will make your heart condition even worse, besides an unwanted pregnancy. Not only do you risk getting AIDS, but gonorrhoea, syphilis, genital warts and a whole load of other nasty conditions are around and waiting to infect you. Be sensible. If you think you may have sex carry a condom (unexpired) with you. If you decide to have sex, use it.

There are many different types of contraception available today, and lots of places where you can get information about them. It is best to talk to a specialist about them, especially if you are female. It is essential that a female with a congenital heart problem has protected sex, as a pregnancy may have disastrous consequences for certain conditions. Your consultant will advise you on various forms of contraception that will be suitable for you. If you don't want to talk to them about it, please talk to the Cardiac Liaison Nurse, who will ask on your behalf, or our Helpline who can also help.

The taking of Viagra should be all right unless you also have coronary disease, are on nitrates or have had a recent stroke. It might not be very pleasant for you if you have very low blood pressure.

REGULAR QUESTIONS ON SEX:

Will I die if I have a climax? Is masturbation safe for my heart?

In both cases your heart will beat faster and your blood pressure will raise but it is very unlikely indeed that you will collapse. If you feel uncomfortable, slow down and wait for your heart to settle a bit. You will soon get to know and get used to handling any limits.

DRIVING

There is no reason why you should not be able to drive if you are well.

There are conditions about which you need to inform the DVLA or to stop driving until they have been sorted and these are noted in the DVLA's website www.dvla.gov.uk or you can telephone 0870 240 0009.

These are currently listed in terms of heart conditions as, "angina (heart pain) brought on by driving, implanted pacemaker, disturbance of heart rhythm significant to cause dizziness, collapse or loss of consciousness, defibrillator implanted or any other heart condition".

The DVLA do not usually need to be notified unless you have had a pacemaker or an implantable cardioverter defibrillator (ICD) fitted.

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 as they were not informed of a material fact that might have affected your driving.

HELPFUL HINTS

- If you are leaving home and going to college or university, try to get a place to live nearby, as you will probably be late some mornings and have to run!
- When you travel abroad, put a complete set of medication in BOTH your hand luggage and suitcase in case either piece of luggage gets lost.
- When travelling, remember to get a letter from your doctor about your medications and condition, a recent ECG recording and the GUCH PA Health Passport explaining what is wrong with your heart. It is also a good idea to find out the nearest GUCH unit to where you are going.
- Travel Insurance information can be obtained from GUCH PA.
- GUCH Helpline 0800 854 759 - we will endeavour to answer your questions, and if we can't we usually know who can!
- GUCH PA website – www.guch.org.uk loads of information, articles and a fantastic message board.



Supporting young people and adults born with a heart condition

Helpline: 0800 854759

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