

TRANSITIONING TO ADULT CONGENITAL HEART DISEASE (ACHD)

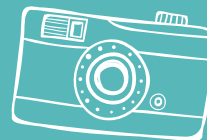


CHILDREN'S
HEARTBEAT
TRUST

Northern Ireland's
Children's Heart Charity

Charity no: NIC 102410

WHO'S WHO



Dr C Lockhart
ACHD Consultant



Dr P Brennan
ACHD Consultant



Dr A Sands
Paediatric Cardiology
Consultant



Dr B McCrossan
Paediatric Cardiology
Consultant

ACHD WORK CLOSELY WITH THE CHILDREN'S CARDIOLOGY TEAM SO YOU MAY EVEN MEET SOME FAMILIAR FACES IN OUR CLINICS!



Lynda Briggs
ACHD Nurse Specialist



Rebecca Reid
Paediatric Cardiac Liaison Nurse



Dr C Owens
Interventional Cardiologist



Mr C Austin
Cardiac Surgeon



Dr M Spence
Interventional Cardiologist



Ciara McStravick
Medical Secretary



Louise Dragonetti
Medical Secretary

OUTPATIENT CLINICS



**Appointments are held on level 9 in
the Cardiovascular and Respiratory
Outpatient Clinic, Critical Care Centre of
the main RVH building**



**YOU CAN DISCUSS ANY ISSUE AROUND
YOUR CONDITION WITH ACHD NURSE
SPECIALISTS. THESE ISSUES MIGHT INCLUDE
THE FUTURE, MEDICATIONS, CONTINUING
FURTHER EDUCATION, CAREER CHOICES,
EXERCISE, SMOKING, ALCOHOL, PREGNANCY
AND MUCH MORE**



Once you are 16, you can speak to any of the ACHD team on your own if you wish to do so.

You will have an ECG prior to your appointment in special investigations.

On occasions you may have an ECHO at your appointment.

They may ask for a blood sample. (It is important to let them know if you have a needle phobia.)

Don't be afraid to ask to speak to an ACHD nurse specialist if you have already seen your doctor.

All conversations you have with nurses are confidential unless they think you are a risk to yourself or others.

If you are unable to attend your appointment it is important to let ACHD know in advance so they can offer the time to others.

You will be reviewed by the Doctors and often one of the ACHD nurse specialists.

Contact Appointments on: 02890634700 to reschedule.



THERE ARE 2 ENTERTAINMENT
CONSOLES AVAILABLE WITH
DVDS AND PLAYSTATION
GAMES TO PASS THE TIME

INPATIENT STAYS

NETFLIX

During your admission a family member can stay with you if you are under 25.

There is a fold out chair bed for their comfort.



There are a number of wards you may be admitted to within adult cardiology on level 5 in the main building...

**WARD 5A
CARDIAC SURGERY**

Visiting times:
14.30 - 16.00 | 18.30 - 20.00

Contact numbers:
02890 632355 | 02890 633222

**WARD 5B
CARDIAC INVESTIGATIONS**

Visiting times:
14.30 - 16.00 | 18.30 - 20.00

Contact numbers:
02890 633306

**WARD 5C
CARDIOLOGY**

Visiting times:
14.30 - 16.00 | 18.30 - 20.00

Contact numbers:
02890 633272

**WARD 5D
CARDIOLOGY**

Visiting times:
14.30 - 16.00 | 18.30 - 20.30

Contact numbers:
02890 633603 | 02890 633229

ADVICE FOR TRANSITIONING TO ADULT SERVICES



Learn about your condition and medications.

Learn about important symptoms and when to seek help and advice.

Start to take responsibility for your medications: What they are called, what they are for, when to take them and how much to take.

Learn how and when to order new prescriptions.

Practise starting to ask and answer questions at your appointments.

Start to spend time talking to the ACHD team without your family present.

Talk to the ACHD nurse specialists if you have any worries about taking on this extra responsibility and independence. They are here to help you!





USUALLY, HAVING A CONGENITAL HEART
CONDITION WON'T STOP YOU LEARNING
HOW TO DRIVE. HOWEVER, WHEN
APPLYING FOR YOUR DRIVING LICENSE,
YOU MUST TELL THE DVLA.

DRIVING

Stop driving and always seek advice from your doctor immediately if you experience episodes of dizziness, fainting or blackouts.

Unfortunately, you may find your car insurance is higher because of your age and possibly also your heart condition.

You should always let your car insurance company know about your heart condition and any changes in your medication, including treatment that you've had. If you don't, your car insurance may not be valid.

If you can't walk far without getting breathless or tired, either because of your heart condition or any physical disabilities you may have, it's worth checking whether you're entitled to a blue badge.



FITNESS

Exercise strengthens your heart, improves your circulation and can give you more energy.

It can control your weight and reduce stress.

Working exercise into your day can make you fitter, stronger, happier and smarter – what's not to love!

Exercise should be fun! Find something you love doing!

Have a quick chat with your doctor to get their advice on your exercise plan.

Easy Ways To Get Active:

Walk on short journeys rather than getting a lift in the car.

Get off the bus a stop early and walk the rest.

Make the most of activity clubs offered at your school, college or uni.

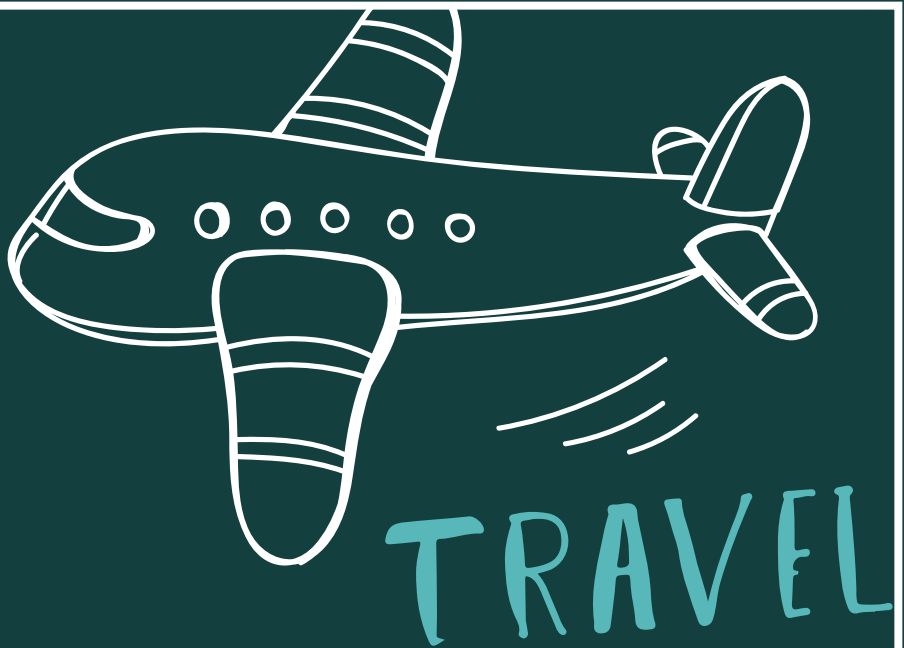
Encourage your family or friends to do something active together at the weekend.

If you can, get out of the lift a floor early and take those last few stairs.

Get moving by helping out with household chores – and get in the good books.

Do something active during TV ad breaks – or keep moving when you're watching your favourite show – if it's Strictly then dance yourself.

Advice about exercise will depend on your condition so make sure you speak to the ACHD team first.



You may need to take your heart condition into account when planning traveling. Extreme changes in temperature or humidity may affect you. High altitudes may make you breathless.

Before you travel make sure you write down your diagnosis & medications.

Make sure you have enough medications for the whole trip including some extra to allow for any travel delays or cancellations.

You may need to pay more for travel insurance due to your heart condition. It is important to be honest as an insurer can refuse to pay, even for an unrelated injury, if they did not have your full health history.

**IF YOU HAVE ANY QUERIES SPEAK TO
THE ACHD TEAM PRIOR TO BOOKING.**

CAREER CHOICES

It can take a long time to decide what job you want, many people even change their career later in life.



You may have already decided what you want to do for a career, but don't worry if you haven't.

If you decide to leave home to attend university or work in another part of the UK, or another country, let the ACHD team know so they can put together an information pack for you with recent clinic letters and test results etc.

For most people with a heart condition they will be able to pursue any career they like.

For some, certain careers may not be advised due to strict fitness tests, such as the armed forces or an airline pilot.

Speak to your ACHD team for any further advice or guidance.

Teenage years and young adult life can be hard.

Stress might be triggered by school work, exams, bullying, relationships or problems with friends or family.

Stress can make you feel sad, irritable and distracted.

Heart Health with Stress

Being stressed could cause you problems because you are more likely to make choices which can be bad for your health: Eating unhealthy foods, smoking or drinking too much alcohol.

STRESS

TALK TO THE TEAM WHO CAN ADVISE YOU ON HOW TO
MANAGE STRESS AND GET FURTHER SUPPORT.

Signs you might be stressed

You feel tired, weak, and have trouble sleeping.

Loss of appetite, or eating much more than normal.

Find it difficult to concentrate.

You have tight, knotty feelings in your stomach.

Avoiding relationships or going out.

How to help

Small changes can make a really big difference:

Talk things through with someone you trust.

Find something that relaxes you – maybe sketching or painting, a hot bath, or listening to music.

Eating well.

Doing regular physical activity that you enjoy.

Asking your doctor for help and further information.

* SMOKING *

EVERYONE KNOWS THAT SMOKING IS NOT A GOOD IDEA, THE YOUNGER YOU START, THE WORSE THE IMPACT ON YOUR BODY.

Smoking tobacco in cigarettes, roll ups, a pipe or in any way at all:

Damages the lining of your arteries, leading to a build-up of fatty material. This makes them narrower and harder to get blood through.

Reduces the amount of oxygen in your blood.

Nicotine makes your heart beat faster and raises your blood pressure.

Causes your blood to clot more easily.

Smoking Facts

Smoking kills someone every 6.5 seconds.

The average smoker spends £28 a week, or £90,000 in a lifetime.

Gives you bad breath by drying out your supply of saliva.

Turns your fingers and teeth yellow and makes your gums more prone to bleeding.

Gives you early wrinkles making you look older.

Smoking increases your chances of getting cancer.



For advice and support on stopping smoking talk to your ACHD team, G.P. or local pharmacy.

ALCOHOL

It is illegal to purchase alcohol before the age of 18 in the UK.

Current guidelines are that men and women should drink no more than 14 units per week, spread over the week.

Alcohol can cause abnormal heart rhythms, high blood pressure, damage to your heart muscle and other diseases such as stroke, liver problems and some cancers.

Alcohol is high in calories so it can lead to weight gain.

Alcohol lowers your inhibitions.

If you are taking medication (especially Warfarin), check with the ACHD nurses about alcohol effects.

Know your limits and don't be influenced by peer pressure.



Most importantly STAY SAFE!

Only drink alcohol with people you trust.

Always plan how you are going to get home before you start your night out.



DRUGS



Drugs that can put a strain on your heart causing irregular heartbeats, heart attacks and strokes are:

- LSD (acid, blotter, liquid acid, micro dot, smilies, tabs, trips)
- Cocaine (coke, charlie, crack, snow, blow, spanky, bingo dust, marching powder, bongo, devils dandruff, nose bomb)
- Amphetamines (speed, fet, base, billy, whizz)
- Ketamine (Special K, K, ket)
- Crystal meth (Ice, glass, Christine, Tina)
- Mephedrone (meow meow, miaow miaow, MCAT, meph)
- Cannabis (hash, weed, grass, skunk, marijuana, dope, puff, ganja, pot, joint, reefer, kazoo, blunt, zoot)

Drugs that slow your breathing and can possibly stop your heart are:

- GHB (GBH, liquid ecstasy)
- Heroin (brown, skag, smack, gear, H)
- Poppers (amyl nitrate, butyl nitrite, ram, thrust, liquid gold)

Drugs that can cause a pulmonary oedema (when fluid flows back into your lungs causing extreme shortness of breath) are:

- Amphetamines
- Heroin


Endocarditis is a life-threatening heart condition caused by injecting drugs like:

- Amphetamines
- Heroin
- Cocaine

Sniffing solvents such as glue can cause irregular heartbeats and blackouts. This can possibly cause sudden death.

Legal highs can also cause many of the effects described above. Just because they're not illegal doesn't mean they're not dangerous. All drugs have many other side effects and affect everybody differently.





Remember:
Everything
you tell the
ACHD team is
confidential!

When it comes to sex and relationships, everyone is different. The important thing is that you are happy with the choices you are making.

Your heart condition shouldn't prevent you from having a healthy sex life but if you have concerns about sex and the effects on your heart just speak to a nurse specialist.

Sex should always be agreed by both people and be something you feel ready for. Remember in the UK the age of consent is 16 years old.

Don't feel embarrassed to ask the ACHD team about sex. They are used to talking about it and can offer you advice and support.

It is important for both partners to practise safe sex – it is not just one person's responsibility.

There are lots of types of contraception to choose from. Different methods will suit different people.

ACHD team can talk about the safest contraception for you to use. Some medications can have effect on some forms of female contraception.

If you think you may be pregnant, or are planning pregnancy, speak to the ACHD team. This is so both you and your baby can be monitored to make sure you are both safe and healthy.



MENTAL HEALTH

WE ALL NEED A LITTLE HELP SOMETIMES. SOMETIMES WE NEED SOMEONE TO TALK TO, SOMEONE TO LISTEN AND SOMEONE TO CARE... HERE IS OUR THREE STEPS TO FOLLOW WHEN LOOKING FOR SOMEONE TO HELP!

Step 1: Family & Friends

Sometimes speaking to a close friend or a member of your family can help a lot with your mental health. Sharing a problem can help you see things in perspective but also helps to know those around you really do care for you.



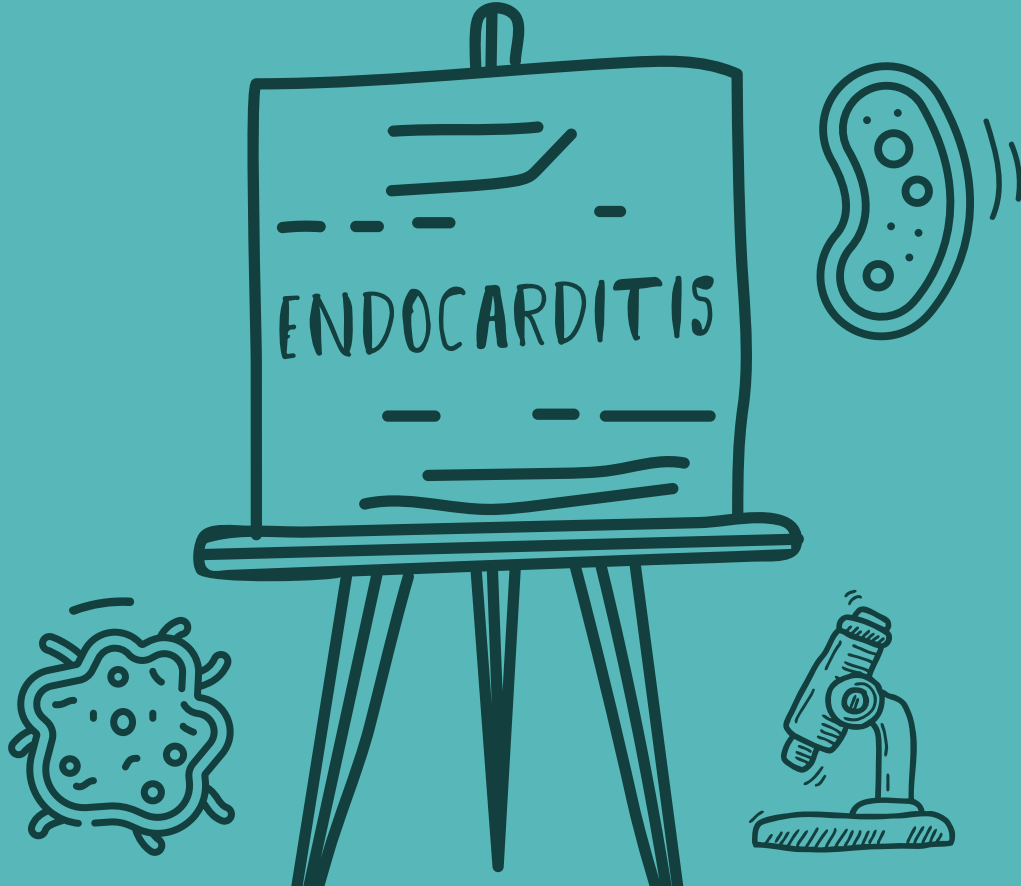
Step 2: Children's Heartbeat Trust Team

We are always here to listen and to offer whatever help and advice we can. You don't have to make an appointment just lift the phone and we can listen and help direct you to some support.



Step 3: Medical Team

Sometimes it's best to get help from those who know the most. If your worried about your mental health then speak to a medical professional and they can get you the best help available.



Endocarditis is caused by bacteria in the bloodstream multiplying and spreading across the inner lining of your heart (endocardium)

The endocardium becomes inflamed, causing damage to your heart valves.

It is a serious condition which usually requires 6-8 weeks in hospital with antibiotics. Some people also require surgery. For a small amount of people it can be fatal.

Anyone with a congenital heart defect has a greater chance of developing endocarditis.

It is not possible to prevent all bacteria from getting into the bloodstream, but there are steps you can take to reduce your risk of endocarditis:

- Keep your teeth clean and attend regular dental check ups. (Most people no longer require antibiotic cover for routine dental work.)
- Avoid tattoos.
- Avoid piercings.

MEDICAL BRACELETS

Nobody ever wants to be involved in an accident or to get injured while out and about! If this does happen though it's really important to get your medical information to the relevant emergency services as fast as possible.

Some people wear medical jewellery but there are also loads of different alternatives:

- Bracelets
- Necklaces
- Helmet Straps
- Seatbelt straps
- Keyrings
- Wallet Cards



TEENBEATZ + ☁️ TRIBE

TEENBEATZ

Teen Beatz: This is for anyone aged 12-16!

Being a teenager is tough and living with CHD isn't always easy but we know when we work together we can get through anything.



TRIBE: This is our Young Adults group for anyone aged 17-21.

We love to hang out but also give back through our volunteering and supporting other parts of the charity.

To find out more about any of these groups check out the dedicated youth section of www.childrensheartbeattrust.org



APPOINTMENT LOG



DATE:

WHAT WE DISCUSSED:

WHAT I WANT TO ASK NEXT TIME:

DATE:

WHAT WE DISCUSSED:

WHAT I WANT TO ASK NEXT TIME:



Use the white space to write down any questions you have for your next clinic review.

**For information, advice or
support contact:**

Lynda Briggs
Transition / ACHD Clinical
Nurse Specialist

Tel/Text: 07525 212801

Email:

lynda.briggs@belfasttrust.hscni.net

Rebecca Reid
Paediatric Cardiac
Liaison Nurse

Tel/Text: 07710 709321

Email:

rebecca.reid@belfasttrust.hscni.net

Children's Heartbeat Trust

www.childrensheartbeattrust.org

 Children's Heartbeat Trust

 @Chldns_hrtbeat

 childrensheartbeattrust

For more information or support for young people living
with CHD please call David on 07483130853 or
familysupport@childrensheartbeattrust.org



Other Resource Charities:

British Heart Foundation: www.bhf.org.uk

Heartbeat NI: www.heartbeatni.com

Bravehearts: www.braveheartsni.com



**CHILDREN'S
HEARTBEAT
TRUST**

Northern Ireland's
Children's Heart Charity

Charity no: NIC 102410