

# TRANSITIONING TO ADULT CONGENITAL HEART DISEASE (ACHD) SERVICE



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**

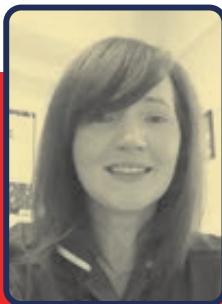


**Dr A Sands**  
**Paediatric Cardiology  
Consultant**

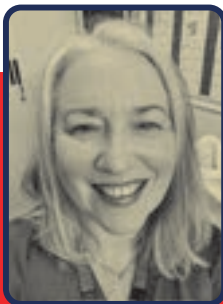


**Dr B McCrossan**  
**Paediatric Cardiology  
Consultant**

# **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



**Jan Gordon**  
ACHD Nurse Specialist



**Linda Eley**  
Paediatric Nurse  
Specialist



**Rebecca Reid**  
Paediatric Cardiac  
Liaison Nurse



**Dr C Owens**  
Interventional Cardiologist



**Mr C Austin**  
Cardiac Surgeon



**Dr M Spence**  
Interventional Cardiologist



**Seana Bunting**  
Medical Secretary



**Louise Dragonetti**  
Medical Secretary

# ATTENDING ADULT CARDIOLOGY APPOINTMENT

INFO-SHEETS

Appointments are held on level 9 in the  
Cardiovascular and Respiratory Outpatients Clinic,  
Critical Centre of the main RVH Building.

To reschedule appointments contact:  
**02890 634700**

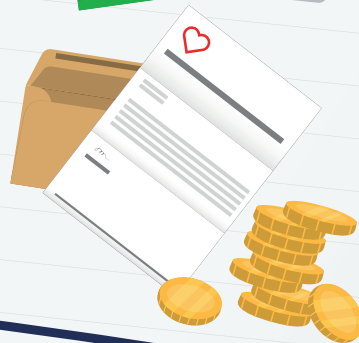
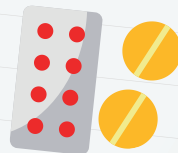


You can discuss any issues around your condition with the ACHD nurse specialists. These issues might include the future, medications, continuing further education, career choices, exercise, smoking, alcohol, pregnancy and much more.



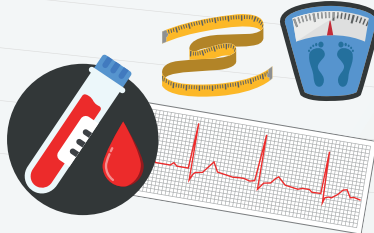
## WHAT DO I BRING?

- Hospital appointment letter.
- List of medication.
- Wear comfortable clothes.
- Money for the car park £1.60 for 4hrs.
- Leave extra time.



## WHAT IS MY APPOINTMENT FOR?

- Meet my Cardiologist / Talk to the Clinical Nurse Specialists.
- Height / Weight.
- Device check.
- ECHO / ECG.
- Blood Tests.



# WHERE DO I GO?



Walk down the Level 2 corridor.



Head up the escalator to Level 2.



Near the bottom of the corridor you'll see a sign to the left that says 'Level 9 Critical Care'. Take that left.

**Level 9 Critical Care**



Go past the Busy Bee Café to the escalator.



Walk to the lifts and go up to 'Level 9'



Royal Victoria Hospital:  
Head in the main entrance.

**START**



Head for Reception.

**ARRIVED**

**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.
- Practice 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 .

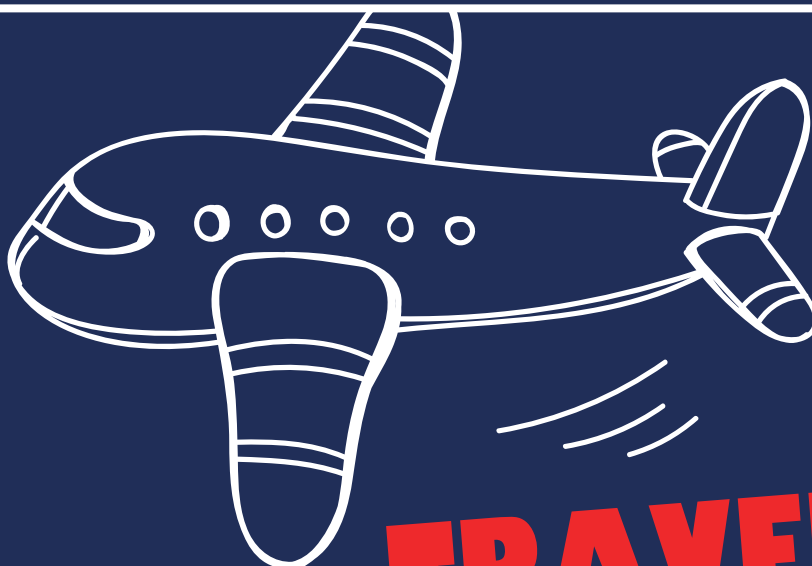
Encourage your family or friends to do something active together at the weekend.

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.



# TRAVEL

You may need to take your heart condition into account when planning travelling. 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.**

When it comes to vaping and e-cigarettes, it's important to understand that while they don't contain all the same toxic substances as traditional cigarettes, there is still a lot we don't know about their long-term effects. The research that exists so far has mostly involved small studies, which means the full impact on health is still unclear. Although e-cigarettes and vapes may seem like a safer alternative to smoking, they are not completely safe, and the potential long-term risks remain unknown.

# 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 ARE 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.



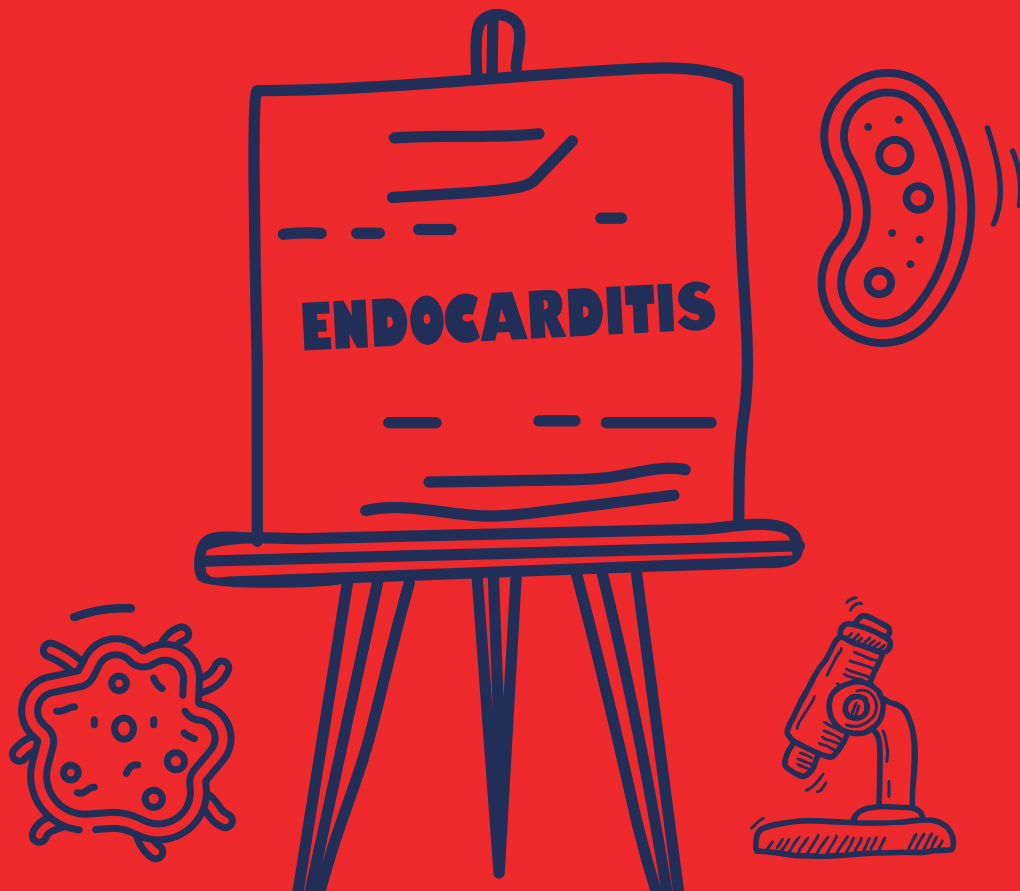
## Step 2: Medical Team

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



## Step 3: 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.



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.

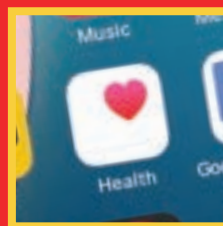
# MEDICAL ID ON YOUR PHONE



## IPHONE

### Step by step instructions:

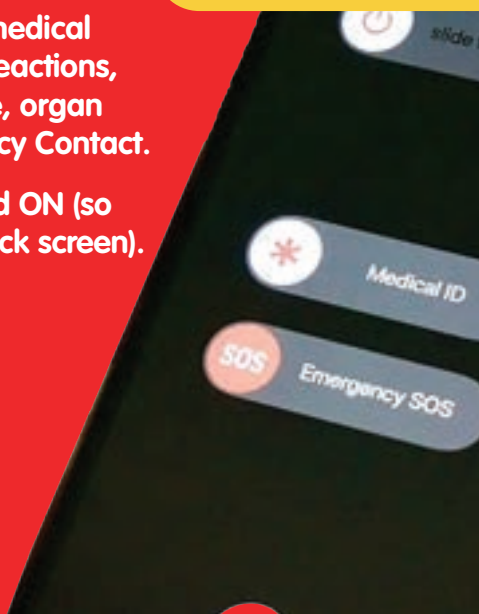
1. Open the Health app.
2. Tap your profile picture (top right) or the Medical ID tab (older iOS).
3. Tap Edit.
4. Fill in important fields: medical conditions, allergies & reactions, medications, blood type, organ donor, and an Emergency Contact.
5. Turn Show When Locked ON (so it's available from the lock screen).
6. Tap Done.



iPhone  
'Health' App

### How to view it from a locked iPhone:

- From the lock screen tap Emergency, then tap Medical ID.



# ANDROID

## Step by step instructions:

Android (general; menu names vary by phone)

Most Android phones have an emergency info / owner info setting. Steps are similar across brands:

1. Open Settings → search for Emergency info or Safety & emergency (or Lock screen → Owner info on some phones).
2. Tap Emergency info (or Edit emergency info).
3. Enter key items: medical conditions, allergies, medications, blood type, and an emergency contact.
4. Enable Show on lock screen (or similar option).
5. Save.

## How to view it from a locked Android:

- On the lock screen tap Emergency, then Emergency information (or Medical info).

Samsung example: Settings → Safety and emergency → Emergency contacts / Emergency message / Medical info → edit and enable show on lock screen.



# 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





# HEART

HEALTHY, EMPOWERED, ACTIVE, RESILIENT, TEENS

**AGE GROUP 14-17**



**This programme offers**

- Youth Council
- Transition Day
- Summer Blast
- Social Events
- Educational Workshops
- Peer Support

# VOLUNTEER PROGRAMME



**AGE GROUP 18-21**



**This programme offers**

- Volunteer Opportunities
- Youth Council
- Accredited Training
- Peer Support

For more information about HEART or Volunteering contact Katie:  
**07483130853** or [katie@childrensheartbeattrust.org](mailto:katie@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:**





**DATE:**

~~~~~  
**WHAT WE DISCUSSED:**

~~~~~  
**WHAT I WANT TO ASK NEXT TIME:**

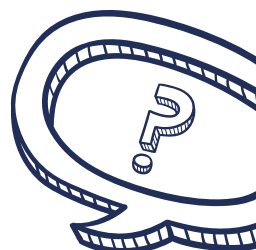
**DATE:**

~~~~~  
**WHAT WE DISCUSSED:**

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**WHAT I WANT TO ASK NEXT TIME:**



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



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](http://www.childrensheartbeattrust.org)**

 **Instagram: [childrensheartbeattrust](https://www.instagram.com/childrensheartbeattrust)**

 **Facebook: [childrens.h.trust](https://www.facebook.com/childrens.h.trust)**

 **LinkedIn: [children-s-heartbeat-trust](https://www.linkedin.com/company/children-s-heartbeat-trust)**

 **X: [@Chldns\\_Hrtbeat](https://twitter.com/Chldns_Hrtbeat)**

 **YouTube: [@childrensheartbeattrust](https://www.youtube.com/@childrensheartbeattrust)**

 **Spotify: Children's Heartbeat Trust**

**For more information or support for young people living with CHD  
please call Katie on **07483130853** or **[katie@childrensheartbeattrust.org](mailto:katie@childrensheartbeattrust.org)****

**Other Resource Charities:**

**British Heart Foundation: [www.bhf.org.uk](http://www.bhf.org.uk)**

**Heartbeat NI: [www.heartbeatni.com](http://www.heartbeatni.com)**

**Bravehearts: [www.braveheartsni.com](http://www.braveheartsni.com)**



**CHILDREN'S  
HEARTBEAT  
TRUST**

Northern Ireland's  
Children's Heart Charity

Charity no: NIC 102410