

# Transitioning to Adult Congenital Heart Disease services

Support Booklet



East Midlands  
Congenital Heart Network





# Transitioning to Adult Congenital Heart Disease services

Transition simply means a planned approach to moving your healthcare from children's services to adult services. This process will be designed to support you and help you feel comfortable with the adult congenital heart healthcare team.

Each person's transition journey may look slightly different based on individual needs.

This booklet has been created to support you and help you answer any questions you may have. It is important for you to feel fully prepared when facing any change.

Taking responsibility for your healthcare is another key step in your development to adulthood.

# Moving into adulthood when you have congenital heart disease

Conversations about your readiness to move your care to adult services may start at around 12 years old, and will continue right up until your first appointment with your new adult cardiologist.

Children's Cardiac Nurse Specialists will continue to support you throughout this journey.

Specialist Transition clinics are in place to support young people who may need additional time to prepare for this process. Appointments can be arranged by your Consultant or Specialist Nurse Team.



For more information about Adults Nurses **follow this QR code**



For more information about CCNS **follow this QR code**



# Lifestyle choices & health care needs

As you take more responsibility for your healthcare needs you will also learn about making positive lifestyle choices to help you stay well. There is lots of information to help you along the way and your doctor and specialist nursing team are happy to answer your questions and point you in the right direction.



NHS UK has some great advice on how to live well. Follow the QR code.

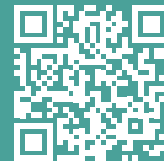




## Healthy eating

Your teenage years are an important time for growth and development. A healthy, balanced diet is essential to ensure that you receive all the energy and nutrients you need to feel good, stay healthy, concentrate at school, and take part in physical activities.

This means eating a wide variety of foods in the right proportions and consuming the right amount of food and drink to achieve and maintain a healthy body weight.



For information about eating a healthy diet **follow this QR code**

# Fitness

Exercise strengthens your heart, improves your circulation and can give you more energy. Exercise should be fun, so find something you love doing!

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

## Top tip

Easy Ways to get active:

- Walk for short journeys
- Make the most of clubs offered at school, college or university
- Encourage your family and friends to do something active at the weekend
- Take the stairs
- Get moving by helping with household chores
- Do something active during TV ad breaks



# Understanding Endocarditis

Endocarditis happens when bacteria or fungi enter your bloodstream. Anyone with a congenital heart defect has a greater chance of developing endocarditis

Infective endocarditis, also called bacterial endocarditis, is a rare but serious and potentially lifethreatening infection that affects the inner lining of the heart chambers (the endocardium) and valves.

It is a serious condition which usually requires 6-8 weeks of treatment with antibiotics, which may need to be given in hospital. Some people also require surgery.



For more information about symptoms of endocarditis follow this QR code

## What causes infective endocarditis?

Infective endocarditis is most commonly caused by bacteria (germs) entering the bloodstream and travelling to the heart

Bacteria can enter the bloodstream through:

- the mouth
- a pre-existing infection in the body
- cuts, accidental injury, piercing and tattoos

## How can I help reduce my risk of getting infective endocarditis?

It is not possible to prevent all bacteria from getting into your bloodstream, but there are some things you can do to reduce your risk of getting infective endocarditis.

### Good mouth and dental hygiene

- have regular dental check-ups
- brush your teeth twice a day for two minutes with fluoride toothpaste

If you are having Dental treatment (or are in need of treatment) please discuss this with your Specialist Nurses as you may need antibiotics prior to treatment.

### Piercings & tattoos

Individuals with congenital heart disease are encouraged to avoid having body piercings (particularly nose, mouth or belly button piercings) and tattoos, as these increase their risk of getting infective endocarditis.



For more information about symptoms of endocarditis follow this QR code

# Smoking & vaping

Smoking or vaping is not a good idea. The younger you start, the worse the impact on your body.

Smoking tobacco in any form damages the lining of your arteries and can lead to a buildup of fatty material. This makes them narrower and harder to get blood through. It reduces the oxygen in your blood.

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

For advice and support on stopping smoking talk to your GP or pharmacist.

# Drugs

Drugs and solvent abuse can put a strain on your heart, cause irregular heartbeats, cardiac arrest and strokes.

When someone takes drugs, there is always risk involved. Using alcohol or drugs affects our judgement and decision-making. This can increase the risk of getting into dangerous situations. There is also always a risk of poisoning, having a bad reaction, or drinking or taking too much.

If you are worried about drug addiction, please talk to your healthcare team.



For more information about getting help with drug addiction follow this QR code

# Alcohol

When you reach 18, you may decide to drink alcohol. Be mindful that alcohol can cause abnormal heart rhythms, high blood pressure, damage your heart muscle and other diseases such as stroke, liver problems and some cancers.

Alcohol can affect prescribed medications, especially Warfarin.

Know your limits and don't be influenced by peer pressure. The legal age for drinking alcohol is 18. Most importantly, **STAY SAFE!**

# Stress

Teenage years and young adult life can be hard. Stress might be triggered by school, work, exams, family or friend relationships or many other reasons. Stress can make you feel sad, irritable, angry or distracted.

## Signs you might be stressed

- You feel tired, weak or have trouble sleeping.
- Loss of appetite or eating more than normal.
- Finding it difficult to concentrate.
- You have a tight feeling in your stomach.
- Avoiding relationships or going out.

## Top tips

How to help manage your stress levels:

- Talk things through with someone you trust.
- Find something that relaxes you – maybe sketching or painting or listening to music.
- Eating well and doing regular physical activity that you enjoy.

# Access to psychology services

Sometimes, life can be tough, especially when you have a long term health condition. You might feel sad, anxious, or stressed about college, work, friends, or family. Psychology services can help you find ways to feel better and work through your feelings. They can also give you skills to manage on your own so you feel more confident and independent.

## How can I get referred to the psychology service?

Any member of your healthcare team involved in your care can refer you. A lot of young people can feel anxious about speaking with a psychologist, so there is no pressure to discuss anything that makes you uncomfortable. The psychologist may ask to briefly meet you first just to give you some information about the service and answer any questions you might have.



For more information about the psychology service follow this QR code



## Sex and relationships

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 relationship and sex life.

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

You can ask your healthcare team for advice and support around contraception and pregnancy planning.

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

## Career choices

You may have already decided what you want to do for a career, but don't worry if you haven't, you can speak to your healthcare team about how your condition may impact your career choices.

If you decide to leave home for university or work in another part of the UK or another country, let your healthcare team know so they can support you to continue to access the health care you may need.

Education or work place settings have a responsibility to support you and your heart condition. Don't be afraid to talk to them early if you wish to do so.



# Travel

You may need to consider your heart condition when planning travelling. Extreme changes in temperature, humidity and high altitudes may affect you.

Travel insurance is vital for any trip. It is important to be honest and disclose your full health history. This will ensure you can access healthcare if you did become unwell when travelling.

## Top tips

- Before you travel make sure you write down your diagnosis & medications. Make sure you have enough medications for your whole trip including some extra in case of any travel delays.
- It can be useful to carry a copy of your last clinic letter and ECG. Speak to your nursing team if you need help in accessing these.

# Driving

Usually, having a congenital heart condition won't stop you learning to drive. However, you must tell the DVLA that you have a heart condition when you apply for a driving license.

**Stop driving and seek medical advice if you experience dizziness, fainting or blackouts.**

You should inform the insurance company about your heart condition any treatment you have had and any medications you are taking. This will keep your insurance valid.

If you are unable to walk long distances without getting breathless or tired because of your heart or other physical disabilities, you may be entitled to a blue badge. This will enable you to park closer to your destination.



# Outpatient clinics

Appointments for ACHD clinics within the East Midlands Congenital Heart Centre are held at Glenfield Hospital. You may also be seen at your local hospital within the East Midlands.

## What will happen at outpatient clinic?

Once you arrive at the clinic you book into reception. You will see the nurses to take your observations such as height, weight, blood pressure, heart rate and oxygen saturations. You will often have investigations such as an electrocardiogram (ECG) and an echocardiogram (Echo). You will then go in to see a doctor. A specialist nurse may also be present.

The team will usually start by asking how you are and if there have been any changes to your health since your last clinic appointment. The doctors and nurses may also give you the results of any tests or procedures that you have had, so that you can be involved in the planning and management of your ongoing care.

Once you are 16 you can speak to any of the healthcare team on your own, or your parent, carer or relatives can attend the appointment with you. This choice will remain yours, but you are encouraged to start entering into the clinic room independently once you feel prepared to do so. This allows you the space to discuss healthcare topics and to build your confidence.

All conversations you have are confidential unless the team think that there is a risk to your safety.

You can discuss any issue around your condition with any of the team. These issues might include your medication, treatment options, your future education and career choices, exercise, alcohol, pregnancy and much more.

If you are unable to attend, tell us so we can cancel your appointment and offer you another date.

It is important that you attend appointments even if you feel well.

### Top tip

- It is helpful to have a basic understanding of your health condition and any medication you are taking. This can help you manage your condition and make positive lifestyle choices following the advice that is given to you by your healthcare team. Taking medication as prescribed, attending clinic appointments and maintaining a healthy lifestyle will be an important part of staying well.

# Staying at hospital for inpatient care

If you need to stay in hospital because you are unwell or need any treatment this will be provided at the Glenfield Hospital most of the time. There you can be looked after in a space which meets your needs as developing adult.

Friends and family will be able to visit you throughout your stay. Regular visiting times can be found in the ward information. If you feel you need additional support, please contact your specialist nurses to discuss your individual needs.

## Ward information

There are several wards you may be admitted to within adult cardiology. These are all at Glenfield Hospital which is part of the East Midlands Congenital Heart Centre.



Please follow this QR code for more information.



Please follow this QR code for more information on getting ready for procedures.



# Adult Congenital Heart Disease (ACHD) Nurse Specialist team

The Adult Congenital Heart Disease (ACHD) Nurse Specialist team is a dedicated team of adult nurses who provide ongoing support to adult patients with congenital heart disease and their families. They support patients in their lifelong journey with congenital heart disease.

## How can we help?

- Support at outpatient clinics and preparation for any hospital admissions
- Education for you and your family about diagnosis, treatment, lifestyle and medications, preparing you for procedures such as cardiac catheter or surgical procedures
- Supporting you in decision making and when having discussions with other members of the multi-disciplinary team
- Telephone advice for other health care professionals involved in your care in the community such as GP's, other specialist teams, community nurses, higher education
- Support for patients with Congenital Heart Disease through pregnancy



# Additional Resources

There are a number of different charities that offer support, advice and information around many different aspects of care. Their websites provide a wealth of information and a great additional resource.



For more information  
about these charities  
scan and follow this QR code



For more information about  
EMCHN  
scan and follow this QR code



**NHS**  
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