

Welcome to the Adult Congenital Heart Disease Service

Information for patients



Contact details for your information

Consultant Congenital Cardiologists

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Consultant Interventional Cardiologists

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Visit the Teen or Adult section of our website for more information about your specific heart condition and implications to your lifestyle.

www.leedscongenitalhearts.com

This information has been produced to benefit you and other healthcare professionals involved in your care. We recommend that you keep all your medical information together in a folder as this should help improve communication in the following circumstances:

- **Admission to hospital, planned or emergency.** It will provide useful information to the ward staff.
- **Outpatient appointment.** New information or any change in medication can be documented.
- **Take on holiday.** We recommend you take your last clinic letter on holiday or a photograph of it on your phone and ECG if appropriate.
- **Use it as a personal record for yourself.** You will receive a copy of the clinic letter sent to your GP. Keeping your clinic letters together in a folder can be useful in certain circumstances, such as leaving home for University.

- What is my heart condition called?

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- What are my normal oxygen levels?

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- Do I have a copy of my ECG?

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- What medication do I take?

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- Anything else I need to know?

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Endocarditis

Because you have a heart condition, you may be at increased risk of developing a serious condition called **Endocarditis**.

Endocarditis is an illness where infection develops on the heart valves or other heart tissues. This infection is extremely difficult to cure. It usually requires at least six weeks in hospital, being treated with antibiotics given via a drip. Patients who develop endocarditis can become extremely unwell, sometimes require heart surgery to cure the problem, and sometimes even die.

What are the symptoms of endocarditis

Patients with endocarditis develop a temperature and feel generally unwell, often with symptoms similar to having flu, such as:

- High temperature
- Shivering or chills
- Fatigue
- Night sweats
- Loss of appetite and weight loss

Flu is very common and usually resolves after about 7-10 days.

Symptoms which persist for longer than this should be reported to your GP as well as your heart team.

Dental health

The most common source of the bugs which cause endocarditis is from the mouth. Everyone's mouth carries bugs but if your teeth and gums are in poor condition the risk is increased.

When you have any dental work carried out and bleeding occurs, bugs from your mouth can enter the blood and make their way to your heart.

We therefore recommend:

1. You brush your teeth thoroughly twice a day
2. You see your dentist every 6-12 months
3. In line with the ESC Guidelines (2015) we would advise antibiotic prophylaxis in the event of any dental procedures requiring manipulation of the gingival or peri-apical region of the teeth or perforation of the oral mucosa if you fall into any of the following categories:



- Previous endocarditis
- A prosthetic valve replacement
- Cyanotic heart disease
- Implantation of prosthetic material for repair within the last 6 months

If you have difficulties finding a dentist visit the NHS website which keeps a directory of local services: www.nhs.uk

If you require urgent dental care and do not have a dentist then call **NHS 111**

Body art: tattoos and piercings

You should be aware that all tattoos, piercing and cosmetic procedures carry some risk and we recommend that you **avoid tattoos and piercings altogether**. Any procedures that break the skin such as tattooing, body piercing and cosmetic treatments, including microblading eyebrows, botox and dermal fillers can introduce bugs into the blood stream. These bugs can settle on the heart causing endocarditis. Piercing which involves the nose, lip, tongue, genitalia or navel (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 points will help you to make the procedure as safe as possible.

- Good hygiene is vital. Follow the cleaning guidelines from the practitioner until the wound is fully healed.
- 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 and seriously consider whether you should leave it out altogether.

‘Diet and Exercise’

We encourage our patients to maintain a healthy body weight, through eating a well balanced diet and taking part in regular exercise.

The NHS recommend adults complete 150 minutes of moderate intensity exercise a week, this includes activities such as walking and swimming.

The majority of patients with a congenital heart condition can exercise, and we encourage all patients to take part in cardiovascular exercise. Speak to one of the ACHD team if you require further information.

You can include weight lifting in your exercise routine. We would advise against lifting heavy weights, particularly if your heart condition involves aortic complications. Please speak to one of the ACHD team about this if you need more information.

It is important everyone maintains a healthy body weight. If needed, diet tips and recipe ideas are accessible on the NHS website. An ideal body mass index (BMI) is 18.5 to 24.9, this can be calculated for you when you come to clinic, or you can use the NHS website.

Sex, contraception and pregnancy for women and men with congenital heart disease

Sex

This information is provided to help make sure you enjoy a safe and healthy sex life. In most circumstances, your heart defect won't physically stop you from having sex, nor will sex itself be dangerous to you, as your body will tell you when to stop or slow down.

Some people with severe or complicated heart disease may find sex makes them particularly tired or breathless. Usually these symptoms can be avoided by encouraging your partner to do more of the work!

Pregnancy

Although plenty of women with congenital heart disease have normal pregnancies, deliveries, and happy healthy children, certain congenital cardiac conditions can make pregnancy a risky time for both Mum and baby.

If you have a congenital heart defect, your cardiologist will usually discuss the issues surrounding possible future pregnancies with you during your first visits to the clinic, so you don't get any unfortunate surprises! If you are thinking about starting a family and you haven't discussed it with your cardiologist, its best to contact us first so any potential problems can be discussed.

For women with straightforward heart problems care can often take place in your local midwifery unit. For those with more complex problems, we sometimes suggest that maternity care and delivery take place either in your local Adult Congenital Heart Disease (ACHD) centre (Hull or Sheffield) or in the ACHD specialist centre in Leeds.

IVF and other fertility treatments can have significant effects on the heart. It is best to discuss these with your cardiologist prior to embarking on any course of treatment.

Risk to your unborn baby

The chances of having a baby born with congenital heart disease are slightly increased from the general population if you have congenital heart disease yourself. The risk is generally quoted as being about 2-4%, compared to 1% for



the general population, but it may be as high as 50% with certain heart conditions that are more inheritable. Your cardiologist can discuss this with you in clinic prior to planning a family. We can offer a specialised scan of your unborn baby's heart at 18-20 weeks, which can detect any major abnormality of the heart.

Contraception

We will usually discuss contraception with you during your first visit to the adult clinic. There are many different methods of contraception. Not all of them are suitable for people with congenital heart disease. The important thing is to find a method which can be used in your particular condition, which you are comfortable with and which gives you the required protection.

We will be happy to advise you which methods are safe for you to use. If you or your family doctor has a query about whether a certain type of contraceptive is OK for you, please ask your doctor or contact your cardiologist or nurse specialist based at the centre.

Career and employment advice

It is important that you know where to get the right career advice and information about appropriate jobs, as you need to be realistic about your career options. Those jobs that require rigorous fitness tests such as the armed forces or police may not be an option. However that is not to say that there is not the right job out there for you. We hope the following agencies are able to help you.

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. If you require a medical letter relating to your condition, please contact the Nurse Specialists based at Leeds General Infirmary - **Tel. 0113 392 8154.**

Visit www.direct.gov.uk for further information

For those under 19 years of age Connexions Direct is a useful source of information for further education courses and career choices.

Visit www.direct.gov.uk/en/YoungPeople/index.htm, or **Tel. 080 800 13219**



Benefits

Your local Citizens Advice Bureau can advise you about benefits as well as helping you to complete benefit and other forms. Ring and make an appointment with your local centre or see their website www.citizensadvice.org.uk

Scope, the disability equality charity in England and Wales (www.scope.org.uk) provide information and advice on all aspects of living with a disability including:

- Welfare benefits
- Equipment
- Discrimination Community care
- Mobility & transport
- Independent living
- Holidays

Disability Helpline: **0808 800 3333**

Benefits available

Here is a brief overview of the main benefits that you may be eligible for:

Statutory sick pay

You are eligible for statutory sick pay (SSP) if you are employed but are too ill to work. SSP can be paid for up to 28 weeks from when you stop work because of illness or disability. You can claim £109.40 per week (2023)

Employment and support allowance

You can claim employment and support allowance (ESA) if you have an illness or disability that prevents you from working. It is available to women aged 16–59 years and men aged 16–64 years. You can start claiming ESA if your SSP has ended or if you were not eligible for SSP.

To be eligible for ESA, you will need to have a 'capacity to work' assessment. This involves a medical review to assess what type of work you could do. You will then be placed into one of two groups:

- Work-related activity group (you receive support to return to suitable work)
- Support group (you are not expected to work)

There are three types of ESA:

- 1. New style ESA.** To apply for the new style ESA, you must have paid a certain amount of National Insurance contributions, and you can't be getting the Severe Disability Premium.
- 2. Contribution-based ESA.** Similarly to new style ESA, you must have made a certain number of National Insurance contributions and you must meet the eligibility criteria. However, you can still receive contribution-based ESA if you get the Severe Disability Premium.
- 3. Income-based ESA.** You may be eligible for this if you've not met the criteria for National Insurance contributions in the last two to three years. You must also be entitled to the Severe Disability Premium.

Find out which type of ESA you could be eligible for on the GOV.UK website.

Personal independence payment (PIP) and Disability Living Allowance (DLA)

Disability Living Allowance (DLA) is a benefit for people who have a physical or mental disability, need help to care for themselves, or need someone to supervise them. You have to be under the age of 16 to make a new claim and is gradually being replaced with Personal Independence Payment (PIP). PIP can help with some of the costs of a long-term illness for people who are below State Pension age. It isn't means tested, so it's not affected by your earnings, savings or other income

PIP has two parts – a daily living component and a mobility component. You can get money from one or both of these. Each component has a standard rate and an enhanced (higher) rate.

In England, Wales and Scotland, start your claim by phoning the Department of Work and Pensions (DWP) on **0800 917 2222** (textphone **0800 917 7777**).

Carers allowance

Carer's Allowance is for people who spend at least 35 hours a week caring for someone who needs 'substantial and regular' care, therefore meaning they wouldn't be able to manage everyday tasks without your help.

The person you care for must be claiming one of these benefits:

- The middle or highest rate of the Disability Living Allowance care component
- Personal Independence Payment daily living component
- Attendance Allowance

- Armed Forces Independence Payment.

You'll also need to meet these conditions:

- You earn less than certain amount per week after tax, national insurance and expenses.
- You must be 16 or over.
- You're not in full-time education (21 hours a week or more).
- You must have lived in England, Scotland, Wales or Northern Ireland for two out of the last three years.
- You normally live in England, Scotland or Wales or Northern Ireland, or you live abroad as a member of the armed forces.
- You must meet certain immigration conditions

Claiming benefits

In addition to the benefits detailed here, there may be other benefits that you may be eligible for. These may include a community care grant, a free bus pass, a disabled person's rail card and help with travel costs to hospital. To check which benefits you may be entitled to, visit the benefits section of the direct.gov website - www.gov.uk/browse/benefits. Alternatively, your specialist nursing team may be able to put you in touch with a social worker or welfare officer who can advise you regarding which benefits you may be able to claim.

The Somerville Heart Foundation

The Somerville Heart Foundation can help with advice around employment, pensions, estate planning, will writing, power of attorney, benefits and can sometimes provide financial support for people in financial hardship. They also have a counselling service. Sign up as a 'friend' on their website to access their benefits <http://www.sfhearts.org.uk>.

Travel

The majority of people with congenital heart disease can and do fly/travel long distances around the world. If you are unsure ask at your Outpatient appointment or contact the Nurse Specialist. The most important thing to remember is to declare your heart condition when booking travel insurance. Any omissions or mistakes made in relation to your medical condition can be used as grounds to refuse your claim if made.

If necessary, we can provide a medical letter, but the majority of companies do not require this. Up to date insurance companies can be provided by the Nurse Specialist or via the patients association.

The Somerville Heart Foundation <http://www.sfhearts.org.uk>.

Some patients will require oxygen to be available for flights, particularly long haul. Ask your cardiologist or Specialist Nurse if you are not sure about needing oxygen in flight prior to booking your holiday. The Pulmonary Hypertension Association can provide you with information about the oxygen policy for specific airlines, as some airlines charge for the use of oxygen in flight.

www.phassociation.org or Tel: 0800 3898 156.

Life insurance

It can be difficult for some people who have congenital heart disease to get insurance. This is often because companies do not always have the medical knowledge relating to specific congenital heart conditions, or there is a lack of long-term survival data available. This can cause problems when trying to buy a house or get life insurance.

The best advice is to shop around, as there can be marked differences between companies. It is important that you inform the insurance company of your medical condition, to ensure you are fully covered. There are some more sympathetic insurers who can be identified and contacted through the patients association The Somerville Heart Foundation <http://www.sfhearts.org.uk>.

Monitoring of results at the Leeds General Infirmary

Here at Leeds Teaching Hospital we take our responsibilities to you as a patient very seriously. We continually monitor the performance of the unit in different ways, and take early action if we notice any changes which may indicate a problem.

Every week we discuss how best to manage patients, in a multi-disciplinary team meeting which involves all of the cardiologists and surgeons, alongside the nurses, echo staff and other individuals who are important in the care you receive. In particular, we review each of the cases who are due to have surgery over the following week to ensure that all concerned are fully aware of the details of each case, including any changes which may have occurred since the patient was initially listed.

Once a month we have a Clinical Governance and Audit meeting. In this meeting the whole team come together to discuss in detail, any cases where complications have occurred. We aim to learn as much as we can from these events so that we can continually make improvements to the quality of the care we provide. We regularly audit areas of our practice, for instance wound infections, post-operative complications, and hospital acquired infections to ensure that any significant increase in the rate of these is dealt with promptly. In these monthly meetings we also review the surgical mortality (death rates) over the last 12 months, in comparison with the national standard. The Trust management also monitor performance of the Congenital Heart Disease department through analysis of national statistics which are produced for all hospitals.

In addition, Leeds General Infirmary, along with all centres performing surgical or interventional procedures in patients with congenital heart disease submit data regarding all procedures to a national database. This database is hosted by NICOR (National Institute for Cardiovascular Outcomes Research), and analysed data can be accessed by the public at www.nicor.org.uk. The data is used to monitor unit activity and help the NHS plan how to improve your care.

The website allows you to examine the numbers of procedures performed, and the 30 day and 12 month outcomes for each centre and for each specific procedure. You may find this data useful, particularly if you are waiting for surgery or an interventional procedure. If you have any questions about how to interpret the data on the national database, please don't hesitate to contact the specialist nursing team who will be able to help you.

Finally, the Trust submits 'dashboard' data on a quarterly basis to the commissioners of the service. These data include various performance measures, such as hospital acquired infections, rates of cancellation of operations and the results of patient surveys. This allows any weaknesses in the service to be spotted early and acted upon.

Second opinion

Everyone has the right to be given the best possible care. If you have any concerns about the care or treatment you are receiving, you may want to get a second opinion.

Why ask for a second opinion?

Reasons for asking for a second opinion include:

- wanting another cardiologist to confirm the initial diagnosis
- wanting another cardiologist's opinion on your treatment
- having an operation by a surgeon who works at a different unit
- having concerns about some aspect of the care or treatment you are currently receiving

Your right to a second opinion

Whatever your reason, the NHS entitles you to ask for a second opinion. In Leeds we have no problem at all with you seeking a second opinion. Indeed, you will sometimes find that your cardiologist or surgeon will want to seek a second opinion on your behalf, particularly if your case is especially complicated.

How to get a second opinion

There are two main routes for getting a second opinion:

1. Ask your GP to arrange an appointment with a cardiologist at a different congenital cardiac unit. Your GP will then contact the centre to arrange for up to date information about your care.
2. Ask your cardiologist. The cardiologists will be happy to help you get a second opinion and will often suggest another cardiologist you can see.

Please do not feel uncomfortable talking to us about this subject. The most important thing is to make sure you are getting the best possible care. Please make sure that the cardiologist or surgeon you are planning to see is from another specialist congenital heart disease unit in England. We are happy to give you advice regarding this.

For more information, or any advice, please contact the Adult Congenital Nurse Specialists based at Leeds General Infirmary on **0113 392 8154**.

The Adult Congenital Nurse Specialists



Jo Birkett



Angela Leeper



Hannah Swift



Sarah Gardner

How we may be able to help you:

- Explain and help you understand your condition and treatments
- Provide a link to medical staff and other healthcare teams
- Discuss health education - dental advice, weight management, smoking, exercise
- Discuss contraception and family planning
- Help prepare you for heart surgery or intervention (keyhole procedures) admission
- Assess and refer you for counselling, psychology and physiotherapy as well as other outside agencies
- Provide benefits information and career advice and where to go for further help and support
- Support you and your family when given unexpected or bad news
- Provide letters of support for college, university and employment
- Liaise with the district hospitals and community teams
- Support you during your outpatient clinic appointment with the cardiologist or surgeon

We provide a telephone and email advice service during the working week (Mon-Fri 8am to 4pm) and we can also see you on a one to one basis either in hospital or in your home.

Please contact the Leeds Adult Congenital Nurse Specialists:

Email: leedsth-tr.achdnurse@nhs.net **Tel:** 0113 392 8154

www.leedscongenitalhearts.com

**LEEDS CONGENITAL
HEARTS**



What did you think of your care?

Scan the QR code or visit bit.ly/nhsleedsfft

Your views matter



© The Leeds Teaching Hospitals NHS Trust • 3rd edition (Ver 2)
Developed by: The Adult Congenital Nurse Team
Produced by: Medical Illustration Services • MID code: 20231019_012/RC

LN004651
Publication date
10/2023
Review date
10/2026