

# Congenital Heart Disease Services

**We are changing the way care is delivered across the North West of England, North Wales and Isle of Man for people living with congenital heart disease.**

**Please read below to see how this may affect you.**

## Why is it changing?

In 2017 NHS England reviewed congenital heart disease services across the country and announced a series of changes to the way care is delivered in the North West of England, North Wales and The Isle of Man. The review looked at services from before birth, right through to old age and including end of life care. Its aim is to ensure that no matter where you live you can expect to receive high quality services that are of a consistent standard across the country and delivered as close to home as possible.

## What is changing?

Children's services will remain unchanged. Changes will only affect the adult service, and how people move from the children's to the adult service.

In November 2017 NHS England decided that the specialist adult congenital heart disease (ACHD) service that provided surgery and specialist procedures in Manchester, needed to move to Liverpool. This was to enable robust, safe and sustainable rotas to be developed between the children's and adult teams who need to be able to work more closely together.

There will still be a specialist ACHD cardiology service at Manchester Royal Infirmary, including maternity care for mothers with ACHD, outpatients and some interventions - but it will no longer be providing ACHD surgery.

## When will these changes take place?

Changes like this need careful planning. Specialist ACHD surgical services are expected to start gradually at Liverpool in September 2018, allowing the clinical team some time to establish the new ways of working ahead of the service being fully up and running by January 2019.

## What will happen to my care until then?

### What if I am waiting for an operation or a procedure?

The Liverpool service needs time to grow and develop. There are interim arrangements in place at the moment which have been agreed with NHS England. These arrangements will ensure that if you require an operation or a procedure now, this happens at the right time for you.

In the North of England, this may mean that you need to travel to another specialist ACHD centre in Leeds or Newcastle for your treatment. If you live in North Wales, you may need to travel to Birmingham.

## **What about travel costs while the interim arrangements continue?**

If you incur extra costs as a result of having to travel out of the North West area for your care, you can claim these back. Each individual case will be assessed and all reasonable costs reimbursed.

You should receive a 'travel pack' with information about the centre you have been referred to and details of how to make a claim. Once the service is fully operational within the North West of England, North Wales and Isle of Man, this process will no longer apply.

We have been trying to make sure that these arrangements are in place for as short a time as possible. The ACHD specialist nursing team will be available to discuss how this affects you as an individual.

## **What about my outpatient appointment?**

We are still providing some outpatient clinics across the North West of England but you may have noticed that you haven't been seen as expected, or you may have had your appointment cancelled. We have prioritised patients who are not feeling as well or who are worried about their health.

We want to reassure you that whilst you might not have had your appointment as planned, we know about every patient and you are not 'lost' in the system. We will be able to provide more routine outpatient appointments after September 2018 as we recruit more doctors who are trained in congenital heart disease. It will take us some time to get through the current backlog.

If you are worried about your health in the meantime, please call the North West ACHD advice line on 0151 254 3333 so that we can ensure you are reviewed appropriately. Calls to the previously used 0161 276 7959 will receive an automated message advising of the new number.

We are confident that as new ACHD consultants join the team, this situation will further improve.

## **What will happen if I need to be admitted to hospital?**

If you need to be treated as an inpatient and require specialist ACHD care, your care will be coordinated by a North West team of ACHD cardiologists and specialist nurses and you may be admitted to Liverpool to receive treatment.

## **What will the new ACHD service look like for the North West of England, North Wales and Isle of Man?**

NHS England is responsible for ensuring a high quality service is delivered to everyone with congenital heart disease. This is an all age service and the following hospitals have been given the responsibility of providing this care. Each Trust will be contracted separately but is required to work under the governance arrangements of The North West Congenital Heart Disease Service. NHS England will directly commission its congenital heart disease services from the following hospitals:

1. Liverpool Heart and Chest NHS Foundation Trust

2. Alder Hey Children's Hospital NHS Foundation Trust
3. Manchester University Hospitals Foundation Trust.

### **Level 1 Specialist ACHD Surgical Centre**

This specialist ACHD service will now be delivered by the Liverpool Partnership This is where all surgery and complex procedures will be performed and complex inpatient care given. The ACHD team will be based in Liverpool to ensure that robust rotas can be provided 24hours a day.

### **Level 2 Specialist ACHD Cardiology Centre**

Manchester Royal infirmary will remain as a specialist ACHD cardiology centre. It will continue to run outpatient clinics and you will still be able to have your investigations done there. You may be treated as an inpatient in Manchester if you have simple or stable congenital heart disease. The cardiac maternity services will continue to run at St Mary's Hospital.

### **Level 3 ACHD outpatient services**

Outpatient services will continue to be run at Blackpool Victoria Hospital and Wrexham Maelor Hospital. You will also continue to be able to have most investigations performed locally.

### **The new Liverpool Partnership**

As part of this North West Congenital Heart Disease Service arrangement, those Trusts based in Liverpool work together in what is described locally as The Liverpool Partnership.

<b>The Liverpool Partnership</b>	<b>What will they deliver ?</b>
<b>Alder Hey Children's Hospital</b>	All surgery and procedures for babies, children and teenagers with congenital heart disease.
<b>Liverpool Heart and Chest Hospital</b>	All surgery and complex procedures for adults with congenital heart disease.
<b>The Royal Liverpool University Hospital</b>	Medical admissions, A&E services and non cardiac surgery for patients with congenital heart disease.
<b>Liverpool Women's Hospital</b>	For pregnant women with very complex ACHD, the North West team will decide on where a woman should deliver based on a multidisciplinary specialist assessment.

### **Who will look after me after September 2018?**

As part of this new model of care, the North West has been busy recruiting new ACHD doctors and nurses and the wider team members who are required to enable you to receive a comprehensive service. The team also includes specialist congenital heart surgeons and doctors who specialise in doing procedures in patients with congenital heart disease. They are experts in looking after people with congenital heart disease and will be responsible for delivering care across the North West of England, North Wales and the Isle of Man from September 2018.

This will mean that regardless of where you have your follow up appointments – you will be cared for by the same ACHD team.

The ACHD advice line will continue to be available as normal. This will mean that regardless of where your care is delivered you will always be able to access help, support and advice from the team of ACHD specialist nurses as before.

### **Will I have to be seen at a different hospital?**

We will be looking at every patient and where they live to see if they can be seen closer to home. This may mean that your appointment is at the specialist ACHD cardiology centre in Manchester, or in Blackpool or Wrexham.

However if you have complex congenital heart disease or if your heart problem has become more unstable then you may need to be seen in the new specialist ACHD centre at Liverpool, even if this means that you have to travel further.

### **Where will my operation or procedure be done after September 2018?**

From October 2018, some ACHD operations and procedures will start to be performed at Liverpool Heart and Chest Hospital. Some people may still have to travel to Leeds, Newcastle and Birmingham for a while as the service grows in Liverpool.

There is a commitment from NHS England that all procedures will eventually be in Liverpool as soon as possible.

### **What will happen if I need to be admitted to hospital?**

Patients who require specialist ACHD inpatient care may need to be transferred to Liverpool. If you have very simple congenital heart disease, you may be cared for at your local hospital.

If you become unwell you should seek medical help by arranging to see your GP, by calling 111, or in an emergency where you become acutely unwell by attending your local A+E.

**In all situations**, advice should be sought from the specialist ACHD team based in Liverpool to make sure that the care you receive is appropriate. The North West ACHD advice line is currently on 0151 254 3333. Calls to the previously used 0161 276 7959 will receive an automated message advising of the new number.

### **What will happen to the maternity services?**

The current cardiac maternity services will remain largely unchanged. The North West team will decide on where a woman should deliver based on a multidisciplinary specialist assessment.

### **I have high blood pressure in my lungs – will my care change?**

No, you will continue to attend the same outpatient appointments at Manchester Royal Infirmary. You will also continue to receive your medication in the same way from either Lloyds Pharmacy at Manchester Royal Infirmary or via healthcare@home services.

If you currently send a monthly blood sample to the ACHD team, please continue to do this as normal. If you become unwell and require an inpatient stay, you may need to be transferred to Liverpool for inpatient care.

## Help and advice

We appreciate that you may have individual concerns and questions about your care and how this is going to be delivered. We would encourage everyone to call the North West ACHD advice line on 0151 254 3333 if you have any questions about how this affects you directly or if you are worried about your health.

There is a large team of ACHD specialist nurses who will be able to respond to your queries on an individual basis.

## Further information

There will be a series of patient engagement events, providing an opportunity for congenital heart disease patients to visit Liverpool Heart and Chest and learn more from ACHD clinicians about how the new North West Service will work.

These are due to take place in Research Unit conference room at Liverpool Heart and Chest Hospital on:

- Saturday 15 September at 10.30am
- Wednesday 19 September at 10am
- Thursday 27 September at 6.30pm

This will include a tour of facilities, so space will be limited and anyone interested in attending is asked to register by contacting 0151 600 3019 or emailing Louise.McGarvey@lhch.nhs.uk