

Important information about changes to adult congenital heart disease services

New patient advice line: 0151 254 3333

As you may be aware, the provision of specialist surgical and interventional (Level 1) service for adult patients with congenital heart disease (ACHD) recently transferred from Manchester to Liverpool. This move followed an extensive review process and public consultation with the aim to bring paediatric and adult congenital cardiac services together in order to provide the highest quality of care for patients across the North West.

What does this mean for patients?

For the vast majority of patients, you will notice very little change. We will continue to provide outpatient appointments at Liverpool Heart and Chest, Manchester Royal Infirmary, Blackpool Victoria Hospital and Wrexham Maelor Hospital. These appointments will be provided by the existing ACHD cardiologist and specialist nurses, together with the newly appointed staff working across the North West as a single clinical team. The aim is that wherever possible, outpatient appointments will be offered as close to home as possible.

However if you require a cardiac intervention or a cardiac surgery, you will be referred to the adult congenital multi-disciplinary team meeting, where your case will be discussed in detail and a decision made on the most appropriate treatment option. All congenital cardiac surgical procedures performed in the North West, will be done at the Liverpool Heart and Chest Hospital. In addition all complex cardiac interventions will also be performed at Liverpool Heart and Chest Hospital but some simpler cardiac interventions may be performed at Manchester Royal Infirmary. The cardiac maternity service at St Mary's will continue to provide care for patients and this service will remain largely unchanged. Those patients with complex ACHD may need to transfer to Liverpool if it is felt that congenital surgery or intervention may be required around the time of delivery.

As is the case across the United Kingdom, some patients who require very rare or complex procedures may be transferred to other centres in the country. If this is being considered this will be discussed in detail by the doctors in charge of your care.

If you become unwell or require emergency care you would continue to access this in the usual way. Depending on the severity of your condition you can dial 999, attend your local A&E or attend your GP. However, as a result of a significant expansion in staff, there is now access to specialist advice from the ACHD cardiologist 24 hours a day, 7 days a week. Following discussion with the ACHD cardiologist, you may be cared for at your local hospital or transferred to either Liverpool or Manchester for ongoing care.

In addition, you can contact the ACHD specialist nursing team by calling a dedicated patient advice line on **0151 254 3333**. This new Liverpool number replaces the previous number and as before you will need to leave a message. There is now a large team of ACHD nurses who will make sure that every call is responded to within normal working hours Monday to Friday. If you are calling out of hours you will be directed to

call the hospital co-ordinators at Liverpool Heart and Chest who will be able to respond to any urgent queries.

We are aware that this has been a difficult time for patients with congenital heart disease and that due to critically low staffing levels many of you have not received routine appointments over the last 12-18 months. We have significantly increased the number of medical and surgical staff and are working through the list of patients that have not been seen recently as quickly as possible. We are doing this based on the clinical urgency of the patients being seen rather than those waiting the longest and hope to offer most patients an appointment over the next 6-12 months.

We hope that you find the information set out in this letter helpful. A launch event will be organised for the service in the New Year and further details for patients interested in attending will be shared on our hospital website. There are other ways for you to keep up to date with the latest news about North West congenital heart disease services. Further information and frequently asked questions are available in the congenital heart disease services section on Manchester University NHS Foundation Trust website:

https://mft.nhs.uk/mri/services/manchester-heart-centre/adult-congenital-heart-disease-service/

Yours sincerely

Professor Jane Eddleston Joint Medical Director

Miss Toli Onon Joint Medical Director

Please show this to any health care professional that is involved in your care.

I am an ACHD patient under the care of the North West ACHD team. If you are a clinician and need the advice of the ACHD consultant team, they can be contacted 24/7 by telephoning Liverpool Heart and Chest Hospital main switchboard on **0151 600 1616**. Please ask for the ACHD cardiologist on call.

You can also contact the ACHD patient advice line on 0151 254 3333.