

Interim service arrangements for patients with congenital heart disease

Background

The Adult Congenital Heart Disease service in the North West of England is currently experiencing staffing pressures and there is no longer a Manchester-based surgeon for this service. Temporary arrangements have been put in place to ensure that patients with congenital heart disease continue to receive high quality, safe care appropriate to their needs. The questions and answers set out below may be of help in explaining what these temporary arrangements are and how they will affect patients and families dependent on these important services.

You will be aware that a decision is expected imminently from NHS England following the national public consultation on how it will put in place new standards for hospitals providing congenital heart disease services in England.

You may already know that as part of this process, NHS England published a plan in June 2016 that they were minded to remove the adult congenital cardiac surgery service from Manchester Heart Centre at Manchester Royal Infirmary (not including maternity services) and transfer them to Liverpool.

The uncertainty surrounding the future of the services in Manchester has resulted in a number of senior doctors leaving the service. This means that the ACHD service in Manchester can no longer be provided in the same way as before and interim arrangements have been put in place to support the current service.

The specialist ACHD centres in Leeds and Newcastle, together with the Pulmonary Hypertension Service in Sheffield, are working with Manchester Heart Centre to try and reduce the impact on patients as much as possible and ensure that patients continue to be seen and treated appropriately.

Local hospitals and emergency department across the North West as well as GPs have been made aware of the interim arrangements. The clinical team at Manchester Heart Centre will continue to provide support and advice to local hospitals and clinicians.

The outcome of the national consultation is expected in autumn 2017 - this will include a decision about the future shape of the ACHD service in the North West.

Your questions answered

1. ***What services are now provided in Manchester?***

Manchester Heart Centre at Manchester Royal Infirmary continues to provide:

- A dedicated ACHD clinical nurse specialist service and support on site
- Most outpatient services including some diagnostic tests
- Non-cardiac surgery for adults and children with ACHD in all of our hospitals including the Royal Manchester Children's Hospital, Saint Mary's Hospital, Manchester Royal Eye Hospital, University Dental Hospital of Manchester, and Manchester Royal Infirmary (MRI)
- Maternity care for women with ACHD and pre-conception counselling.

Doctors and nurses at Manchester Heart Centre will continue to provide advice and support about the care of ACHD patients to the doctors and nurses in other local hospitals, if required.

2. ***What services are provided by other specialist ACHD centres?***

Manchester Heart Centre is working with the specialist ACHD centres in Leeds and Newcastle, together with the Pulmonary Hypertension Service in Sheffield, as part of the interim arrangements. This may mean that patients receive care on the Manchester site from a specialist doctor from any of these three centres or it may mean that patients have to travel for expert care to one of these centres, particularly for a heart operation. The location of where any further treatment will be provided will form part of a clinical discussion taking into consideration individual patient preferences.

These interim arrangements have been agreed with NHS England and include provision for the following:

- Patients who require a planned heart operation or emergency heart surgery
- Patients who need an ACHD cardiology procedure
- ACHD patients who need to be admitted to hospital
- ACHD patients who need to attend an outpatient appointment.

The arrangements in place with Leeds and Newcastle will ensure continuity of care for all patients transferring there for treatment. The doctors and nurses at these specialist centres will have access to patients' hospital records. The specialist nurses at Manchester Heart Centre continue to be available to provide support to patients on an on-going basis.

3. *I have a future appointment but I haven't been contacted about it. Will this still go ahead?*

If you have a planned appointment anywhere in the North West (or at another hospital outside the North West), please attend unless you are contacted directly and advised otherwise. Patients are reviewed on a continual basis so that they can be seen urgently where necessary.

If your symptoms change or you become unwell while you are waiting to be seen, you can contact the specialist nurse team at Manchester Heart Centre on 0161 276 7959 for advice.

4. *What happens if I need a heart operation or other complex heart procedure?*

Manchester Heart Centre is continuing to run multi-disciplinary team meetings where doctors and nurses with expertise in congenital heart disease review patients who may need an operation. These meetings are now supported by the clinical teams from the specialist ACHD centres in Leeds and Newcastle.

If, following discussion at these meetings, it is decided that you need a complex heart operation or procedure, this will most likely be undertaken at the specialist centre in Leeds or Newcastle.

If this happens, you will be contacted by the relevant team at Leeds or Newcastle who will also provide practical information such as directions, parking, accommodation options, and how to claim back travel costs.

5. *What happens if I need emergency care for a heart-related problem and have to attend A&E?*

Most emergency hospital care will continue to be provided at local hospitals and at Manchester Royal Infirmary.

If you become unwell with a heart-related problem and need to attend your local emergency department (A&E), you should tell the doctor and nurses assessing you that you are a congenital heart disease patient under the care of Manchester Heart Centre (or another hospital if appropriate). They should contact the clinical team at Manchester Heart Centre for advice in the first instance – the Specialist Registrar on call for Cardiology is available 24 hours a day and can be contacted via the hospital switchboard. The Specialist Registrar will be able to offer advice and ensure that the ACHD team at Leeds or Newcastle is contacted for further advice and support if required.

An ACHD on-call team in Leeds and Newcastle is available at all times to provide advice and support. If necessary, a referral and transfer will be made to Leeds or Newcastle.

6. *What happens if I need emergency care or an operation for something that is not related to my heart, such as a broken ankle?*

If you are taken to the emergency department of your local hospital, you should tell the doctor and nurses assessing you that you are a congenital heart disease patient under the care of Manchester Heart Centre (or another hospital if appropriate). Should they want to speak to a member of the clinical team at Manchester Heart Centre urgently, they should contact the Specialist Registrar on call for Cardiology who is available 24 hours a day via the hospital switchboard. Any non-urgent queries should be directed to the ACHD specialist nurses on 0161 276 7959.

7. *Could I be sent to Leeds or Newcastle for a check-up, or would this only be for an operation or treatment?*

The interim arrangements with the teams in Leeds and Newcastle provide the option for both outpatient appointments and operations or procedures. Complex heart operations or procedures will most likely be undertaken in Leeds or Newcastle. Outpatients will continue to be provided in the North West but some appointments will also be provided in Leeds and Newcastle.

8. *I am being referred for treatment to Leeds/Newcastle? Can I get any support with travel costs?*

Yes, support is available for patients who have to travel to Leeds or Newcastle for treatment. Requests for reimbursement must be reasonable and will be considered on an individual basis. Travel information packs will be sent out with appointment letters by the relevant team to any patients due to have treatment at these specialist centres. These packs provide useful advice on travel arrangements, parking, accommodation options and how to claim travel costs, as well as contact information. If you do not receive a pack, please contact the helpline on 0161 276 7959 during office hours Monday – Friday.

9. *What happens if my appointment is cancelled or I don't have an appointment? How long will I have to wait?*

The clinical team at Manchester Heart Centre continues to run clinics and review patients. Appointments are arranged in priority order so that patients requiring treatment or review can be seen first. If you have any concerns about your care, please contact the specialist nurse team on 0161 276 7959 during office hours Monday – Friday.

10. *My child is due to transfer from the children's service at Alder Hey Hospital to the adult service next year. What will happen to them?*

Supporting any child with the transition from the children's service to the adult service needs careful planning over a period of time, involving both their current and future doctors and specialist nurses. Each patient in this position will be considered individually. The clinical team will do all they can to minimise any disruption or anxiety for your child and your family. Given the current position, this may mean that your child remains temporarily under the care of their current clinician.

11. *Will I continue to get specialist medicines for the high blood pressure in my lung arteries?*

If you are currently receiving specialist treatment from the pulmonary hypertension service at Manchester Royal Infirmary, this will continue as normal - there will be no interruption to the delivery of your medicines.

12. *Are there plans to fill any of the vacant posts at Manchester Heart Centre?*

Work is underway to recruit to the following vacant posts which will contribute to the delivery of ACHD services as part of a North West clinical network:

- 1 adult congenital heart disease consultant surgeon
- 2 adult congenital heart disease consultant cardiologists
- 1 adult congenital heart disease specialist nurse.

13. *How long will the interim arrangements be in place for?*

The interim arrangements with Leeds and Newcastle are temporary until a decision is taken on the new service model for the North West as part of the outcome of the national consultation on congenital heart disease services which closed on 17th July 2017.

Once the decision is made, it will then be some time before the new service model in the North West is fully functional. In the meantime, work will start on the recruitment process to fill the vacant posts to help stabilise a regional North West service.

14. *Will there be any further updates or meetings for patients to attend?*

Any further developments or updates regarding the ACHD service at Manchester Heart Centre (MHC) will be published on social media and associated patient forums. They will also be made available on the Manchester Heart Centre section of the Manchester University Foundation Trust website at:

<http://www.cmft.nhs.uk/royal-infirmary/our-services/manchester-heart-centre>.

With regard to meetings, the aim is to run drop-in events in Blackpool, North Wales and Liverpool in the next couple of months to provide an opportunity for patients to discuss the impact of the interim arrangements on their care with members of the ACHD team.

15. *What if I have any concerns about my care?*

If any ACHD patient has concerns about his/her care, please speak to your doctor or nurse or contact one of the specialist nurses at Manchester Heart Centre on 0161 276 7959 during office hours Monday – Friday.

If you become unwell and need urgent advice at night or at the weekend, you should contact your GP out-of-hours service or attend your nearest emergency department.

16. *What if I have any feedback or concerns about the service provided by Manchester Heart Centre?*

If you feel that you would like to provide additional feedback or raise concerns about your experience at Manchester Heart Centre, you can contact the Patient Advice and Liaison Service (also known as PALS). The PALS team can explain the options available to you, including the process for complaints. To contact PALS, call 0161 276 8686 or e-mail: pals@cmft.nhs.uk.

17. *What if I have any comments to make regarding the future ACHD service in the North West?*

Please note that the national consultation closed on 17th July 2017 and NHS England is expected to make a decision on the outcome in autumn 2017. This will include a decision about the future shape of the ACHD service in the North West.