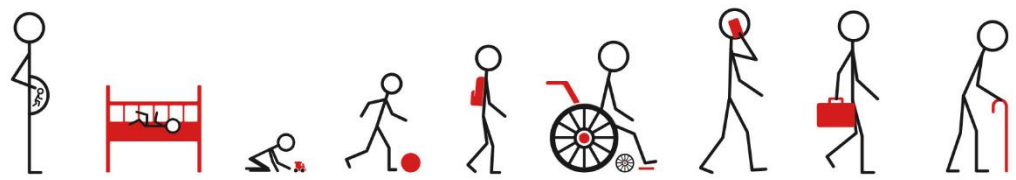
Information for families following a postnatal diagnosis of congenital heart disease

27th July 2026



Information for families following a postnatal diagnosis of congenital heart disease

We understand that learning your baby has a heart condition after they have been born can be very distressing, and you may feel that this has been 'missed' during your scans whilst you were pregnant. The heart is looked at during the 20-week screening scan; it is not routinely examined at every scan, for example, it is not typically assessed during growth scans.

The 20-week screening scan includes five views of the fetal heart in 2D black and white imaging therefore not all heart conditions can be detected on this type of assessment. It is currently not mandatory that images of the heart are stored as part of this examination.

Examples of conditions that are difficult to detect include:

- Small holes in the heart, even if they later require surgery
- Narrowed vessels or valves, which may not be apparent during pregnancy or may develop later in pregnancy, after the final scan, or even after birth.
- Congenital heart disease in a baby where there is a late presentation of being pregnant
- Situations where scans are limited due to baby's position or unclear views
- Atrial septal defect (ASD) / Patent Foramen Ovale (PFO) - hole between the top collecting chambers- and ductus arteriosus (PDA) -vessel between the body and lung artery - are structures that are normal before birth and close only after delivery.
- Heart muscle and heart rhythm conditions

When a heart condition is undetected antenatally, we can ask your local team for a review of your anomaly scan (usually performed between 18 and 22 weeks of pregnancy) or any fetal echocardiogram that was carried out.

We offer this review for two reasons:

- To help provide you with answers
- To identify any potential training or learning needs for the scanning team

If you are happy to consent to us contacting the unit where your pregnancy scans were performed, we will need:

- Your full name
- Your date of birth
- Your NHS number
- The name of the hospital where your scans were done
- Your consent for us to input your information into Microsoft Forms for this review

How we will update you
The review process can take several weeks, and in some cases a few months. We will share the outcome with you either:

- By phone, or
- During a clinic appointment with your cardiologist

If you have not heard from us after some time, please feel free to contact us for an update:

Alder Hey Children's Hospital Cardiac Nurse Specialists 0151 252 5291 (Mon-Fri)

Manchester Children's Hospital Cardiac Nurse Specialists 0161 701 0664 (Mon-Fri)

Additional Information

For further information on antenatal screening for congenital heart disease and fetal anomaly detection, the following resources may be helpful:

- **NHS England/ Office for Health Improvement &Disparities guidance document: 11 physical conditions (20-week scan)**
- **NHS England document: NHS Fetal Anomaly Screening Programme (FASP)**
- **tiny tickers charity – a better start for tiny hearts**