

A Patient Journey

The patient journey begins from the very first moment a cardiac anomaly has been suspected on ultrasound. It is often a difficult and challenging journey and this information will highlight some of the challenges and complexities patients will face along the way. Delivering unexpected news is the first hurdle for both the patient and the sonographer - it is important we get this right.

Informing the patient

- Inform the patient there may be a problem but advise that you don't diagnose and label the condition you suspect. There are often associated anomalies and these change the counselling, and often, the prognosis.
- There is now new national guidance to support sonographers on delivering unexpected news: https://www.bmus.org/static/uploads/resources/ASCKS_Framework_guidelines.pdf
- There is a FASP information leaflet you can give to the patient if you suspect a cardiac anomaly: <https://www.gov.uk/government/publications/congenital-heart-disease-description-in-brief/congenital-heart-disease-information-for-parents-html>
- Advise the patient not to Google (although we know that this is what the majority do).
- Describe what you see without making a diagnosis eg: 2 vessels in the 3 vessel view (maybe a TGA).
- Follow your hospital's protocol. Different units have different referral methods - some refer straight to the tertiary centre, some through a cardiac champion and some through their own Fetal Medicine Unit.
- The national standard is for the patient to be offered an appointment within three calendar days of the referral being accepted at the tertiary unit.

The first visit to fetal cardiac clinic

- The patient may have travelled a long way to her regional unit and have a long wait. Appointment times are lengthy and include a scan followed by counselling.
- There are many people who make up the fetal echo team. Here is a list of people the patient may come into contact with:

Consultant Paediatric Cardiologist

Consultant in Fetal-Maternal Medicine

Neonatologist

Specialist/Consultant Sonographer

Cardiac Physiologist

Cardiac Liaison Nurse

Midwives

Health care assistants

Medical students

Student midwives

Sub-specialists in fetal medicine

Depending on extracardiac involvement – genetics, General Surgeon,

Neurosurgeon, Urologist

Palliative care team

Cardiac Nurse Specialists

- The patient may be scanned by more than one person and there is often more than one health professional in the scan room.
- Sometimes, on-screen findings are discussed during the scan and there is often lots of medical terminology used.
- The patient is informed that everything will be explained to them at the end of the scan.

Counselling

- Once a diagnosis has been made, the patient is moved to a private room away from the waiting area (a quiet/counselling room).
- The Cardiologist and/or Obstetrician, Specialist Midwife and Cardiac Liaison Nurse should be present for the counselling.
- All patients will be given impartial and non-biased counselling.
- The patient will be given the diagnosis and explanation of the cardiac condition, often with the aid of a diagram. Depending upon the diagnosis, counselling may include discussion about:
 - Continuing with the pregnancy
 - Active surgical management (corrective surgery and palliative surgery)
 - Compassionate care (bereavement team involvement)
 - Termination (method dependent upon gestation)
 - Timing of delivery
 - Intrauterine death (higher risk in some cases)
 - Genetic testing – amniocentesis
- Any decisions the family wish to make do not have to be made on the same day.
- Amniocentesis may be offered the same day if the patient wishes or the patient can have this at their local hospital.
- The patient will be offered to look around the NICU and also visit Paediatric Surgical Unit (this is dependent upon the current guidelines in place due to the COVID pandemic).
- Contact details of the Cardiac Liaison Nurse Specialist will be given.
- A detailed written report of the scan findings, diagnosis and subsequent counselling will be given to the patient to take home including a copy of any diagrams used.

Delivery

- All aspects of the delivery will be discussed and planned according to the cardiac condition.
- The decision of where delivery will take place will depend upon local neonatal team preference, prostaglandin dependence, if immediate transfer to a surgical unit is required and also parental preference will be taken into consideration.
- It is better for delivery to take place as close to term as possible as prematurity and/or small size at birth can worsen the overall prognosis.
- Method and onset of labour and delivery, from induction /spontaneous labour to vaginal delivery and caesarean section can be decided closer to the time of birth.
- Maternal disease, multiple pregnancy and intrauterine growth restriction may all have an impact on the method and timing of delivery.

Postnatal

- A subset of associated cardiac anomalies depend on flow through the ductus arteriosus to maintain systemic/pulmonary blood flow, therefore intravenous access may need to be obtained immediately after birth and prostaglandin started to keep the duct open.
- In some cases, the baby may need immediate transfer to the nearest tertiary cardiac surgical unit meaning the mother and the baby are in different hospitals until the mother is discharged from the postnatal ward.
- Some conditions mean the baby will require stages of open heart surgery.
- Some babies may have a lengthy stay in hospital following complex surgery.
- Depending on the cardiac condition, some babies may be discharged home with the mother and have follow up outpatient appointments at the nearest cardiac unit.
- Some may be managed conservatively, while others may need surgery within the first year of life.

The future

- Babies and children with congenital heart disease (CHD) will need lifelong follow-up.
- Some will be on medicines for the rest of their lives.
- They will need repeat tests like echocardiogram, ECG and sometimes cardiac Magnetic Resonance Imaging (MRI) scans. The aim of these tests is to monitor their heart function so that any future heart problems are diagnosed and treated quickly.
- As complicated as these conditions can be, children are encouraged to be as active as they can and live as normal a life as possible.
- Babies and children who have had open heart surgery will have a scar down the middle of the chest. There may be small scars where drain tubes were used, but these will fade over time.

Tiny Tickers is here to help you and your family when you receive a diagnosis of congenital heart disease. Our website – www.tinytickers.org – has lots of information, advice and support for heart families.

Tiny Tickers improves the early detection and treatment of babies with serious heart conditions

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