



Children's Cardiac Nurse
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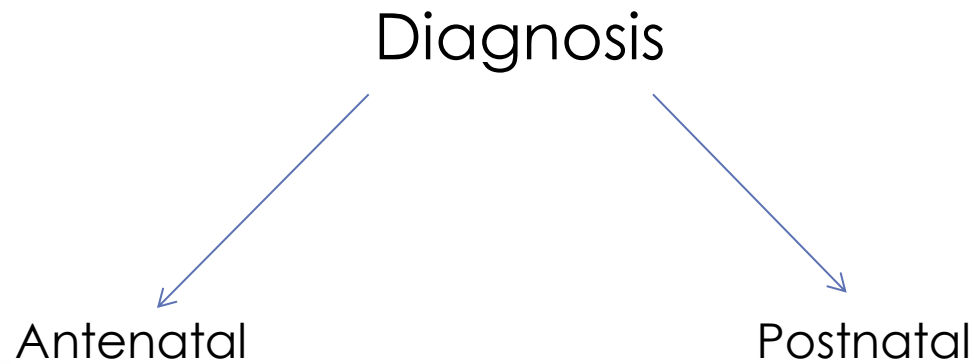
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Congenital heart disease (CHD) journey



Antenatal Suspicion of CHD?

- Detection can be as early as 13 weeks
- 20 week anomaly scan in local hospital
- Suspicion - referral to Fetal Medicine Unit, RVI, Newcastle.

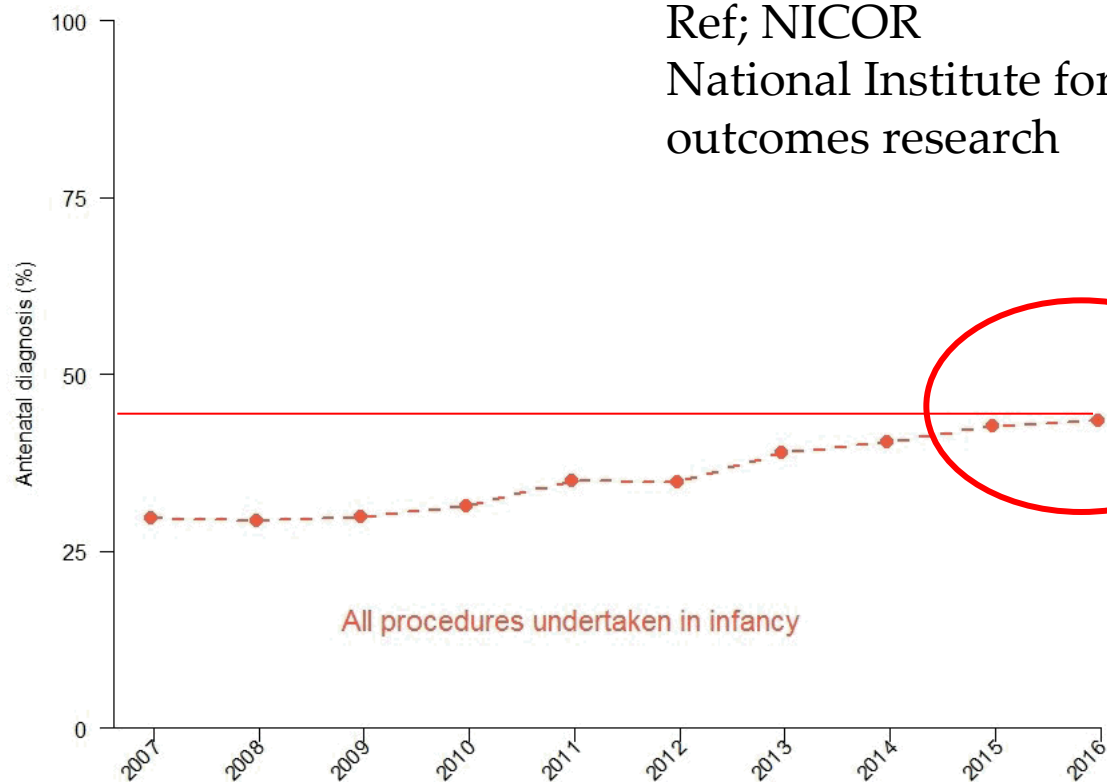


Results are averaged over a 3 year period and also shown for the most recent full year available.

Current analysis shows that the proportion of children with CHD who are diagnosed antenatally, who have a procedure in the first year of life, detection continues to improve as show in figure 4.

Figure 4

Ref; NICOR
National Institute for Cardiovascular
outcomes research



Correctable or palliative

Correctable

- VSD
- Fallots

Palliative

- Hypo plastic left heart – single ventricle

Choices

Termination, surgery, comfort care

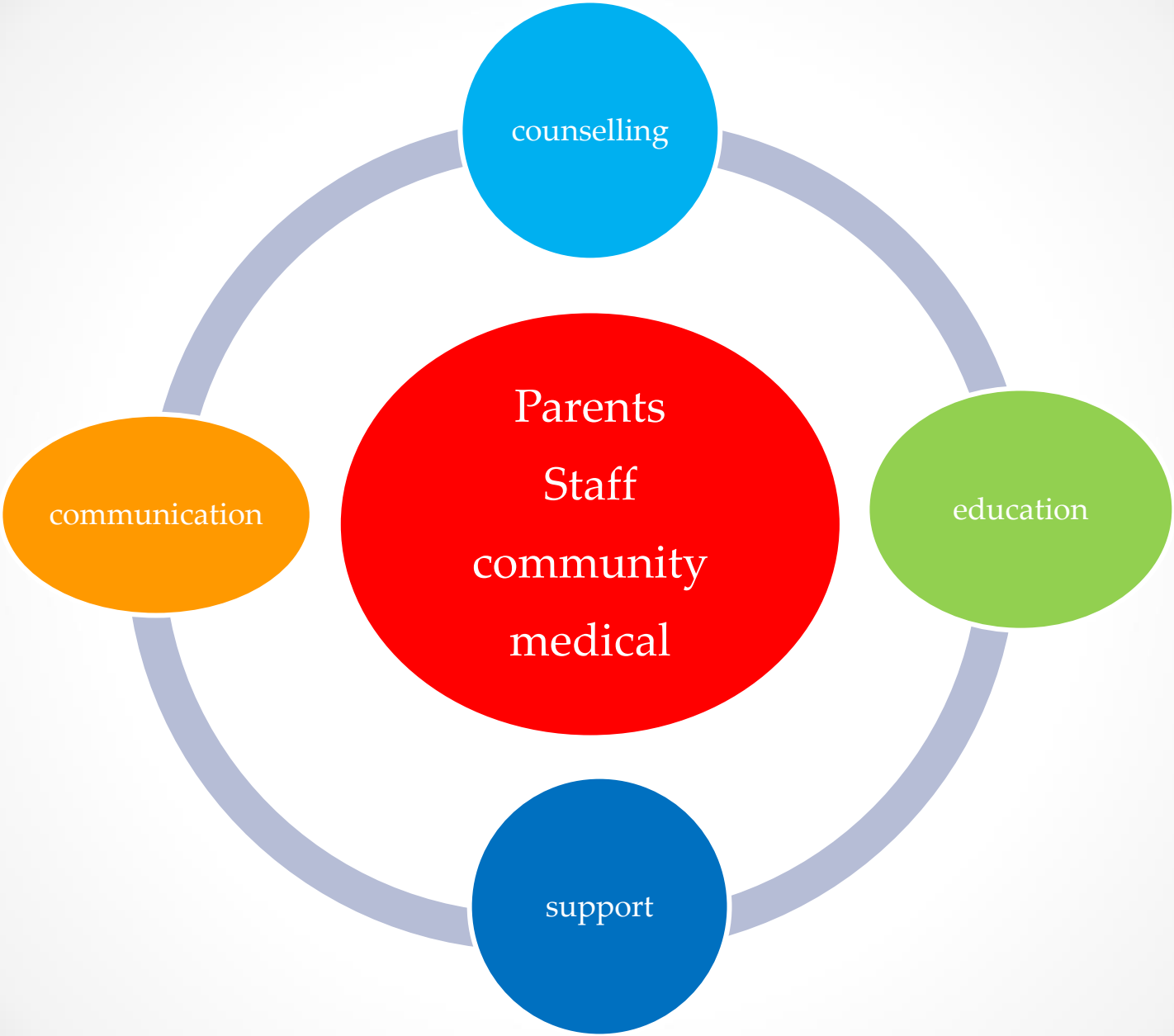
Role of Fetal cardiac nurse

Education

- Diagnosis
- Lifestyle
- Treatment options

Supportive

- Counsellor
- Information to empower parents – informed consent



counselling

Parents
Staff
community
medical

education

support

communication



British Heart Foundation
www.bhf.org.uk

The impact

- Relationship
- Long term hospitalisation
- Multiple hospital visits / clinics /admissions
- Financial implications
- Family support?
- Investigations/Surgery
- Family/siblings
- Deterioration
- New normal
- Death

Parents and families

- Shock
- Grief
- Anxiety and worry
- Isolation
- Guilt
- Confusion / lack of understanding

Postnatal Diagnosis

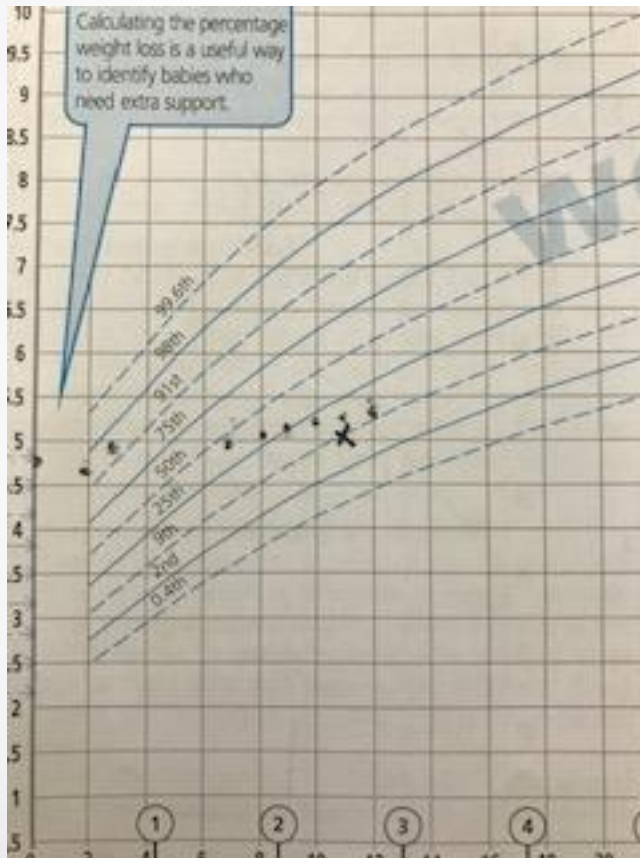
Hospital post birth

- Cyanosis - ECHO
- Weak femoral pulses -ECHO
- Murmur – follow up clinic

Community

- Critically unwell
- Faltering Growth

Faltering Growth



Date	Age	Wt (kg)	Wt (lb)	Other Measurements
1.5.19	13/7	4.56	10 lb.	
7.5.19	19/7	4.62	10 lb 2 oz	
14.5.19	3 ⁺ /52	4.78	10 lb 7 oz	
7.6.19	7/52	4.96	10.15	
13.6.19	8	5.03	11.1 oz	
19.6.19	9/52	5.08	11.3	
26.6.19	10/52	5.14	11.4	
3.7.19	11/52	5.18	11.6 1/2.	

Following diagnosis

- Shock
- Grief
- Anxiety and worry
- Guilt
- Confusion/lack of understanding
- Uncertainty
- Relief

Role of CCNS is to support, educate and collaboration

What happens next

Hospital stay

- Critically unwell and in PICU
- Cardiac surgery imminent

Discharged home

- Collaboration with community services essential
HV, CCN, Dieticians and local hospitals.
- Winter - palivizumab

Discharging families

Corrective surgery

- Liaise with HV and CCN teams
- Post op follow up call/clinic visit

Complex Cardiac, health or social needs

- Discharge planning meetings
- Home monitoring programme
- Emergency health care plan (EHCP)
- Education and CPR training
- Palliative care

Anticipated emergency(ies)

Sudden Collapse.

Respiratory infection or intercurrent illness

Low oxygen saturations

Vomiting/Diarrhoea

What to do

Dial 999

Full Cardiopulmonary resuscitation should be given.

Maintain OXYGEN SATURATIONS 75-85%

Full Ventilation as appropriate and ECMO

Please contact FREEMAN CARDIOLOGY TEAM.

Parents are trained in CPR

[REDACTED] has open access to the Paediatric unit at Carlisle Hospital. [REDACTED] should be assessed and discussed with a senior Paediatrician promptly. PLEASE INFORM THE FREEMAN HOSPITAL OF ADMISSION

If oxygen saturation below 70% consistently for more than 5-10 minutes please administer oxygen to keep saturations between 70-85% and inform FREEMAN CARDIOLOGY TEAM

If Vomiting or Diarrhoea:

[REDACTED] IS SHUNT DEPENDENT FOR PULMONARY BLOOD FLOW

Risk of Shunt blockage and circulatory collapse if she becomes dehydrated for a prolonged period.

Please maintain at least 120mls/kg/day of fluid/milk to prevent shunt blockage

If a DNACPR decision has been agreed, complete the regional DNACPR document

EHCP - Who?

- All Norwood, BT Shunt and Ductal Stent babies.
- Life threatening Arrhythmia
- Cardiomyopathies – where heart function is poor and at risk of sudden collapse
- Complex congenital and single ventricle circulations
- Ventilated and children with a tracheostomy
- Warfarin
- Palliation

Life long Support

Parental support

- Telephone and answering service
- Team email address
- Letters of support; school, DLA and housing
- Referral to other services

Community Support

- Education and training
- Collaboration

The good news

- cardiac centre with excellent outcomes
- 3 congenital cardiac surgeons
- Heart failure / transplant centre
- 'can do' attitude
- Professional practical and emotional support
 - CCNS, social workers, psychology team, nursing, medical.

Nutrition nurse specialist

Early intervention

- to prevent exacerbation of problems and repeated hospital admission

Regular monitoring

- complex cases - especially those requiring more than one surgery

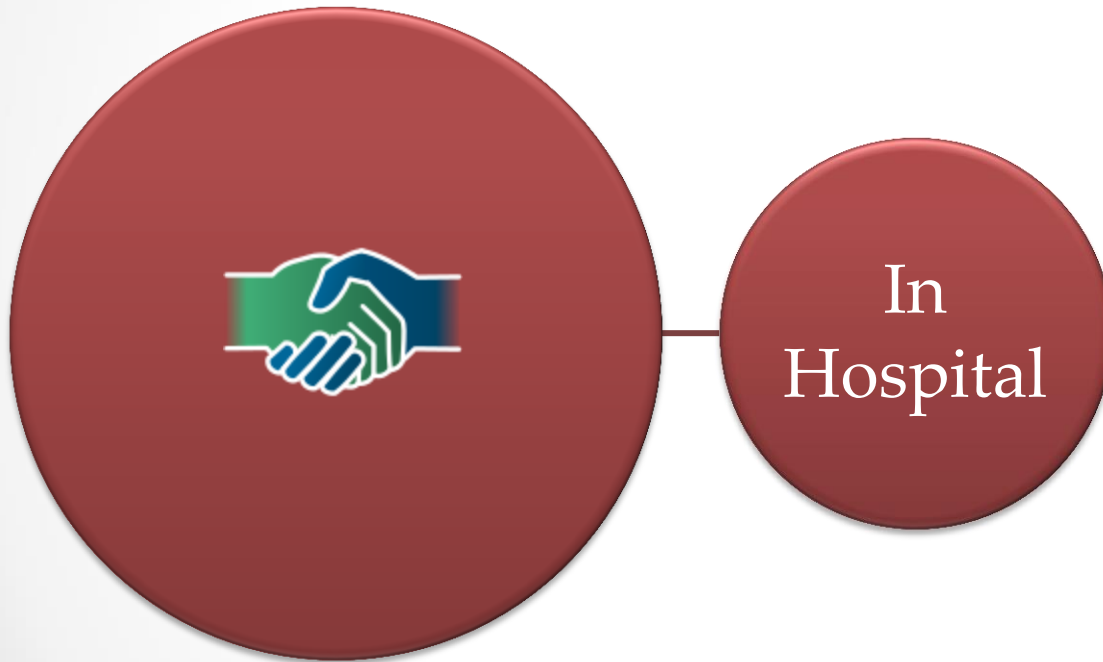
Support, advice and education

- To families and other professionals involved in care of the family

Facilitating early discharge



How is this achieved?



- Weekly ward rounds
- Attendance Gastro MDT's GNCH site
- Liaison between of all teams
- Competencies
- Streamlining gastrostomy surgery FRH site
- Telephone contact (Massive!)

Outreach?



Children's cardiac nurse specialist team

