Guideline: Paediatric cardiology patients who should be offered contact with CHIPS

The paediatric cardiology population encompasses a diverse group of children and young people (CYP) whose disease trajectory can be difficult to predict. Palliative care input provides the most benefit to children who are at high risk of death, where a holistic approach, parallel planning and smooth transition to end-of-life care (if required) can be facilitated. This guideline is aimed to help staff identify which CYP are at high risk of death and therefore who may benefit from formal referral to the Childrens Holistic Integrated Palliative Care Service (CHIPS).

Defining the population of paediatric cardiology patients at high risk of death

In a study by Blume et al, clinicians aimed to define a cohort of cardiac children and young people with a 1 year mortality rate of 20%**.** Patients with advanced or serious cardiac lesions were defined by their diagnostic groups (below) and followed up for 1 year.

- Single ventricle
- Pulmonary vein Stenosis
- Pulmonary hypertension
- Ventricular Assist Device
- Congenital heart disease with one of the following;
  Hospitalised >30 days,
  Intubated >14 days,
  >3 admissions in the past year
  or referred for transplant

The definition proved valid as the cohort demonstrated an 18% mortality rate within the 1 year follow up period (1).

Based on the above, the following group of patients with 'Advanced heart disease' should be considered for referral to CHIPS.

- Single ventricle anatomy (including antenatal involvement if diagnosed within foetal medicine clinic and Comfort Care is being considered by family)
- Pulmonary vein Stenosis
- Pulmonary hypertension
- Any child/young person supported by Ventricular Assist Device technology
- Any child/young person with congenital heart disease with one of the following features;
  Hospitalised >30 days,
  Intubated >14 days,
  >3 admissions in the past year
- Children and young people being assessed for heart transplantation

Others: for example a patient who has had a prolonged ECMO run or one who has failed ECMO weaning who have limited or high-risk options

Intended benefits

There is good evidence that paediatric palliative care (PPC) provided by a separate specialist team in conjunction with PPC provided directly by the cardiology teams can improve patient and carer experiences and even those who do not die benefit from additional support.

Early PPC team involvement allows the team to build relationships with the family, be involved in decision making within MDT's and undertake advance care planning in a timely fashion.

Those with PPC team involvement have shorter hospital admissions and fewer invasive investigations, with fewer patients dying in ICU and during active resuscitation attempts.

Most cardiac deaths in paediatric patients with heart failure are not sudden and can be anticipated and therefore planned so that children and families have the greatest opportunity to express and enact their wishes (2).

How it will be done

1. If a patient is identified within one of the high-risk groups, referral to CHIPS should be discussed with the Consultant or team leading care, to decide on when, how and by whom the discussion about CHIPS will be had with the family.

2. There are a number of ways that introductions can be made, depending on the situation including

- The CHIPS booklet can be given to the family at a cardiology clinic appointment. CHIPS booklets are freely available in Clinic E
- CHIPS can be introduced by the VAD or congenital specialist nurse or by a senior medic to a PICU/ward patient and a leaflet given
- The CHIPS team can be introduced at transplant assessment

Families do not have to meet with CHIPS if it is not their wish. If they take away a leaflet, it will make it easier to request a meeting at a point in the future.

References

(1) Blume ED, Balkin EM, Aiyagari R, Ziniel S, Beke DM, Thiagarajan R, et al. Parental perspectives on suffering and quality of life at end-of-life in children with advanced heart disease. Pediatr Crit Care Med. 2014;15:336–342
(2) Morell E, Wolfe J, Scheurer M, et al. Patterns of care at end of life in children with advanced heart disease. Arch Pediatr Adolesc Med 2012;166(08):745–748