



**Antenatal/Perinatal Palliative Care in Partnership with
Children's Hospices.**

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Why Refer Antenatally?

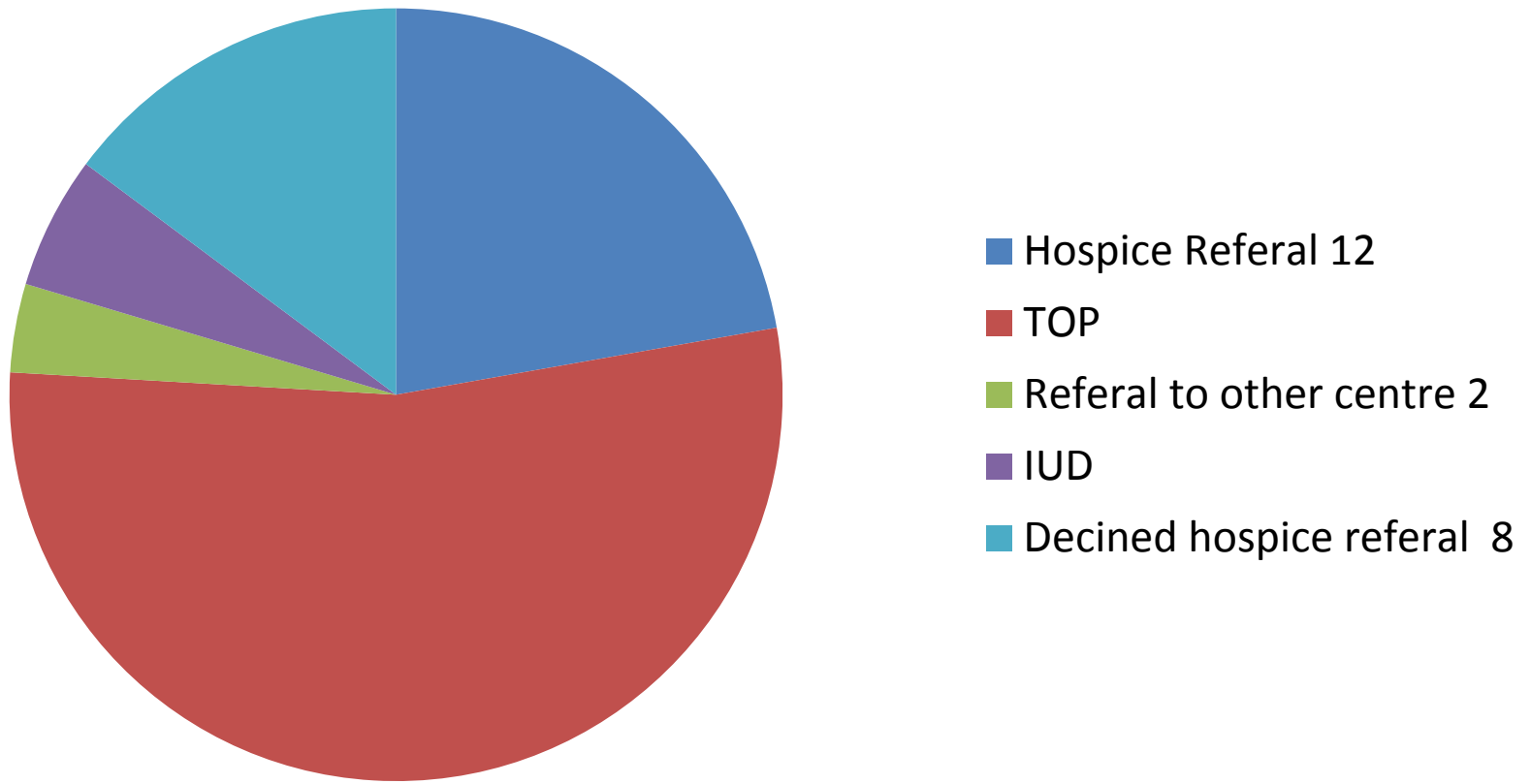
- In 2014 Leeds starting offering first stage surgery for HLHS. Previously all antenatal diagnosis had been referred to either Birmingham or The Evalina and all their care was then transferred.
- We now had to support these families through their pregnancies and prepare them for very high risk surgery and significantly reduced life expectancy.

First Hospice referrals

- In 2014, Emma Bleasedale was appointed as The Neonatal Palliative Care Inreach Coordinator at Forget Me Not Hospice in Huddersfield.
- Discussed antenatal support for continuing pregnancies and plan put in place.
- 4 children's hospices in Yorkshire and Humber region and all happy to be involved with ante natal/ongonig post natal support.

Diagnosis of Single Ventricle Anatomy Oct 15-Sept16

Sales



Ante natal Support

- Initial diagnosis made at 20/40 and hospice care briefly discussed as one of their options.
- Discussed again at 28/40 follow up, written information given and referral made.
- Initial visit to their local hospice of home visit.
- Member of hospice staff available to attend subsequent hospital appointments for support.
- Regular counselling for parents, siblings and grandparents.
- Available at time of delivery.

Post natal Support

Respite if prolonged hospital stay following surgery.

Quicker discharge if used as step down care.

Respite for family in Hospice or Hospice at home.

On going counselling.

Sibling support groups.

Mother and Baby groups.

Grandparent support groups.

Complimentary therapies.

Referral for older children

- We are now making an increasing number of referrals for families whose children have had completion of Fontan circulation.
- No more surgery is available and parents particularly struggle with the finality of this. Often they feel they are waiting for their child's condition to deteriorate.
- On going counselling support is then put in place for these parents/families.
- Hospices have adolescent units and can sometimes support children into their 30's.

End of Life Care

- This transition is much easier if the family are already involved with their local hospice.
- Families can stay at the hospice with their child until the funeral.
- IUD can deliver and transfer to the hospice.
- Re orientation of care, compassionate extubation can take place at the hospice or at home with hospice support.
- Transfer to the hospice can happen following a death either at the hospital or at home.
- 1st referral can be made after death, even following post mortem/organ donation.
- Better facilities following death.
- Families will then be given on going bereavement support.

Moving Forward

- We first discussed our links with the local hospices at The National Fetal Cardiology Group in April. As far as we know other center's do not offer anything like this presently.
- We are planning to standardise the antenatal/perinatal care pathway so it can then be considered nationally.