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Antenatal referral for hospice care: A New approach to pregnancy birth and beyond

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Paediatric and specifically neonatal palliative care has changed significantly over the past few years and is now integrated into the care of children and their families. This approach can begin before birth with palliative care for the family of a fetus with major abnormalities including Congenital Heart Disease (CHD).

When the diagnosis is made antenatally of severe CHD with a single ventricle circulation, several options for the antenatal and postnatal management are discussed. These include continuing the pregnancy and attempting to undertake palliative surgery, undergoing termination or opting for comfort care after delivery. Support from the hospice is discussed briefly at the time of diagnosis and at the follow up appointment, if the family wish, written information is given and a referral is made. It is stressed that referral to the hospice is primarily for support and does not commit the family to following the comfort care pathway. An initial visit to the hospice is arranged or a home visit if this better suits the family circumstances. A member of the hospice staff is the available to attend subsequent hospital appointments for support. They also provide regular counselling for parents, siblings and grandparents.

In the Yorkshire and Humber Fetal Cardiology department 54 antenatal diagnoses were made of a single ventricle anatomy between October 2015 and September 2016. Of these 20 were on-going within our service (29 TOP, 3 IUD and 2 chose referral to another centre). 8 declined hospice referral but 60% of the on-going pregnancies received antenatal and postnatal support.

If comfort care is chosen postnatally, redirection of care involving the hospice is seamless and if palliative surgery is chosen then respite care is offered.