



Thames Valley Perinatal Palliative Care Pathway

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Thames Valley Pathway



- Guiding principles
- To provide **timely** support tailored to the needs of families
- To provide **multidisciplinary** support for patient choice and values.
- To facilitate **delivery close to the family's home**
- To provide **specialist input and advice to support local teams** within the region to provide PPC to families delivering in local unit
- To provide **training and support for staff locally** and in regional units providing PPC to enable confidence to care for the baby at birth to engage in parallel planning and to deliver a supportive end-of-life care plan.

Royal Berkshire Hospital, Stoke Mandeville Hospital, Wexham Park,
Milton Keynes, Swindon, Northampton.

Planning: the art of the possible

Baby Ali (Milton Keynes)

- Baby Ali had antenatally diagnosed congenital heart disease paperwork a progressive neurological disorder.
- His mother was counselled virtually on two occasions jointly by NICU and PPC.
- Emails were exchanged with links for virtual tours of both local hospices.
- Baby was born in his local DGH and died a few hours later:

'Thankyou for your condolences. Burial process happened yesterday after all the paper work and just because we knew about the disease and we had the after birth plan we got some time to spend with him. Thankyou again.'

Baby Lily (Oxford)

- Diagnosed with hypoplastic left heart
- Preferred home birth - risk assessed
- Antenatal paly therapy for siblings
- MDT including CCN, NICU, Midwifery, hospice
- Born at home in a birthing pool
- Lived for 10 days at home
- Frequent visits & calls
- In House bereavement care after death
- Siblings involved at every step



Learning from Experience

What we needed to succeed

- Collaborative working between neonatology, obstetrics / foetal medicine, and palliative care (since 2014)
- Adapting how we work during COVID – virtual meetings / MDTs
- Support from the ICB via the matched funding money from NHS E
- Hospice buy-in to seconding prescribing midwife for 2 years
- Good working relationships with DGH teams / community nursing teams

Problems to overcome

- Attitudes of some staff who feel that termination should be offered more proactively
- Shared electronic records are not in place for the whole region (only for Oxford)
- Knowing when the babies are born in a timely way (particularly out of hours and at weekends)
- Availability of specialist staff for the consultations (Nurse, MW, Doctors)
- Being able to prescribe anticipatory medication for unborn babies
- Having a simple referral process



The Specialist Midwife Post

Advocate for women by providing comprehensive support and care, especially in uncertain outcomes.

- **My responsibilities include:**
- Networking and collaborative working with MDT's, aiming to break down barriers and promote hospice services and support for women and their families.
- Frequent support and communications
- Forward planning
- Birth planning
- CYPACP
- Memory making
- Postnatal care and preparation for home.

Take Home Messages

PRACTICE



WHAT YOUR PATIENT IS THINKING

Palliative care is not just for those who are dying

Ana Todorovic reflects on the things that helped her when facing the death of her unborn daughter Nadia



PALLIATIVE
MEDICINE

Case Report

Facilitating home birth in perinatal palliative care: A case report

Sophie Bertaud^{1,2,3}, Rachel Kirven⁴, Thomas Kirven⁴, Emily Harrop^{5,6}, Amanda Crudgington⁷ and Dominic Wilkinson^{1,6,8,9,10}

Palliative Medicine

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- Listen to family's feedback
- Keep an open mind (homebirth?)
- Work as a network
- Shared electronic records would be the gold standard
- Detailed birth plans open many doors
- Anticipatory symptom management plans
- Advanced care plans (inc. antenatal)
- Parallel planning
- Bereavement care planning
- Share your learning