

What do patients say about perinatal hospice care?

Albert Balaguer et al.¹⁶ investigated four clinical studies which initiated perinatal hospice programmes in five different centres in the United States and Britain to examine the benefits of perinatal hospice care. In these four studies, 37% to 87% of women decided to continue their pregnancies and opted for perinatal hospice care.¹⁷ Those who opted for perinatal hospice care gave positive feedback about their decision and the care provided.¹⁸ Participants appreciated consultations and sought guidance in creating a plan of care following discussion with specialised providers who explained the benefits of palliative care.¹⁹

REFERENCES:

1 Charlotte Wool, 'Clinician Confidence and Comfort in Providing Perinatal Palliative Care' (2013) 42(1) Journal of Obstetric, Gynecologic and Neonatal Nursing 48, 49. **2** Amy Kuebelbeck and Deborah L. Davis, A Gift of Time: Continuing Your Pregnancy When Your Baby's Life is Expected to Be Brief (Johns Hopkins University Press, 2011). **3** Nathan Hoeldtke and Byron Calhoun, 'Perinatal Hospice' (2001) 185(3) American Journal of Obstetrics and Gynecology 525, 526. **4** Byron Calhoun and Nathan Hoeldtke, 'The Perinatal Hospice: Hope for the Helpless' (2002) 17(2) Association for Interdisciplinary Research in Values and Social Change 1, 2. **5** English NK and Hessler KL, 'Prenatal Birth Planning for Families of the Imperilled Newborn' (2013) 42(3) Journal of Obstetric, Gynecologic and Neonatal Nursing 390, 393. **6** Steven Leuthner and Emilie Lamberg Jones, 'Fetal Concerns Program: A Model for Perinatal Palliative Care' (2007) 32(5) American Journal of Maternal Child Nursing 272, 276. **7** English and Hessler (2013) 395. **8** *ibid* 396. The neonatologist or neonatal nurse who is familiar with palliative care for newborn children assists with orders that include: breast milk or formula if the newborn child expresses hunger; the cardiac/respiratory resuscitation status; and management of the newborn child's symptoms such as respiratory distress by nasal or oral suctioning, oxygen via cannula or opioids given sublingually. **9** English and Hessler (2013) 395. **10** As desired, nurses assist the family in orally feeding, bathing, and dressing the baby, taking photos and videos, and introducing the baby to the extended family. Leuthner and Jones (2007) 276. **11** Calhoun and Hoeldtke (2002) 3. **12** Hoeldtke and Calhoun (2001) 528. **13** Catlin and Carter (2002) 193. **14** Anthony Lathrop and Leona VandeVusse, 'Continuity and Change in Mothers' Narratives of Perinatal Hospice' (2011) 25(1) Journal of Perinatal and Neonatal Nursing 21, 24. **15** <http://www.perinatalhospice.org/> **16** Albert Balaguer et al., 'The Model of Palliative Care in the Perinatal Setting: A Review of the Literature' (2012) 12(25) BioMed Central Pediatrics 1. **17** Balaguer et al. (2012) 5. **18** *ibid* 5. **19** (Calhoun et al. 2003).



This leaflet was researched and compiled by **Every Life Counts**, an all-Ireland support network for parents whose unborn children have been diagnosed with life-limiting disabilities. This leaflet was first presented at **The Perinatal Hospice Care Conference in Belfast, September 2016**.

This information in this leaflet has been approved by **Dr Byron Calhoun**, Professor and Vice-Chair of Obstetrics and Gynaecology in West Virginia University and pioneer of perinatal hospice care in the United States.

Dr Calhoun's expertise includes prenatal diagnosis and care of all high-risk pregnancy conditions. He is the author of 57 published peer review articles, has presented over 75 scientific papers, and lectures extensively on perinatal hospice care.

Other helpful resources:

www.everylifecounts.org.uk • www.perinatalhospice.org

For more copies of this leaflet, or for further information, please email:
info@everylifecounts.org.uk



What is Perinatal Hospice Care?



What is perinatal hospice care?

Perinatal hospice is an emerging specialty¹ in healthcare. It is not a physical place, but a model of care; an extra layer of support that can easily be incorporated into standard pregnancy and birth care.²

It is an interdisciplinary approach to providing a continuum of support for parents from the moment of prenatal diagnosis, through the pregnancy, during and after the birth of their baby, and during the period of bereavement.³

What does perinatal hospice care include as a healthcare service?

The aspects of perinatal hospice care can be divided into ante-partum, intra-partum, and post-partum care:

Ante-partum care

Parents receive counselling with sensitive and accurate information regarding the diagnosis and prognosis of their unborn baby's condition, their anticipatory grief, and the preparation of a birth plan.⁴

The Birth Plan

A consultation with the parents initiates the discussion of important decisions and treatment options for the mother and child, which will include:

- Management of the pregnancy until birth;
- The possibility of preterm birth;
- Labour considerations and mode of birth;
- Immediate newborn care; and
- Special touches for the birth experience and immediate postnatal period.⁵

Who is involved?

A dedicated nurse coordinator becomes the single point of contact for the parents and families. The nurse is someone the family trusts to 'know their story' and to prepare the written birth plan, with recommendations from other team members and the parents' preferences for care.^{6,7}

The neonatologist offers information regarding the unborn child's diagnosis and guidance concerning the prognosis and palliative care options.⁸

The mother's primary prenatal care provider (obstetrician, midwife, or maternal foetal medicine specialist) guides decisions regarding how the pregnancy is managed, such as foetal monitoring and mode of delivery.⁹

Who is involved? (cont'd)

Intra-partum care

Extensive support is provided in labour by the nursing staff and pain relief administered by the anaesthesia service.

Method of delivery is advised based on obstetrical indications. The newborn child is handed immediately to the mother and father to share in their child's life, no matter how brief that time may be.¹⁰

Chaplains or social services provide key spiritual and emotional support as needed.¹¹

Post-partum care

The healthcare team helps the parents make arrangements for a funeral or memorial service.¹²

A member of the team should be designated to be the follow-up connection with planned visits and phone calls.

Parents and families can be assisted by establishing contact with a chaplain, social worker or grief counsellor prior to discharge, facilitating their introduction to a formal bereavement support group and inviting them to a group memorial service held by the hospital or hospice centre.¹³

The importance of grief-counselling should not be underestimated. Explaining various phases, such as ongoing heartache and grief that will never go away but will decrease in intensity over time, will provide helpful guidance for bereaved mothers and fathers and help them anticipate and understand their grieving experiences.¹⁴

Who is eligible for perinatal hospice care?

Any patient with her family who has received the news that her unborn child has been diagnosed with a life-limiting disability, meaning that her child is not expected to survive to term or live very long after birth.

What are the benefits of perinatal hospice care?

- Loving supportive care for an unborn baby with a life-limiting diagnosis and his or her mother, father, and family
- The Gift of Time¹⁵ for the mother, father and family to spend with their baby until his or her natural death.