



# A closer look at Perinatal Palliative Care

By Busi Nkosi

**P**erinatal palliative care refers to palliative care for the foetus, neonate or infant. The concepts are the same as for older children but certain areas require specific consideration.

[www.perinatalhospice.org](http://www.perinatalhospice.org) describes it as an approach that “walks with these families on their journey through pregnancy, birth, and death, honouring the baby as well as the baby’s family. It is a way of caring for the pregnant mother, the baby, the father, and all involved with dignity and love”<sup>1</sup>

## Why perinatal palliative care?

Many pregnant women now undergo prenatal testing which has led to increasing numbers of parents who are given devastating diagnoses before their babies are even born. More often than not, the ability to diagnose has outstripped the ability to provide appropriate care for the parents, the siblings and their babies. At times parents are often offered therapeutic termination of pregnancy and have to cope with this difficult decision and its consequences.

Further, a vast number of preterm babies are born each year. The WHO Global Action report, *Born too Soon* (2012)<sup>2</sup>, states that more than one in 10 of the world’s

babies born in 2010 were born prematurely. Of an estimated 15 million preterm births (defined as before 37 weeks of gestation), more than a million died as a result of their prematurity.<sup>3</sup> Prematurity is now the second-leading cause of death in children under five years and the single most important cause of death in the critical first month of life.<sup>4</sup> For the babies who survive, many face a lifetime of significant disability.

## Conditions that may require palliative care

There are five broad categories of babies that may require palliative care

1. Antenatal/postnatal diagnosis of a condition that is not compatible with long-term survival eg anencephaly.
2. Antenatal/postnatal diagnosis of a condition which carries a high risk of significant morbidity or death eg severe spina bifida
3. Babies born at the margins of viability where intensive care has been deemed inappropriate.
4. Postnatal conditions with a high likelihood of severe impairment of quality of life either when receiving life support or that may at some point require life support eg severe hypoxic ischaemic encephalopathy

5. Postnatal conditions which result in the baby experiencing “unbearable suffering” eg severe necrotising enterocolitis, where palliative care is in the baby’s best interests.

## Supporting families

Families in this situation will require support at many levels. They will have to cope with the knowledge that their baby has a life limiting condition or abnormality not compatible with life and go through the stress of labour/delivery with no “reward” of a healthy newborn. They will grieve the loss of a normal pregnancy and birth as well as the loss of hopes for the future. The stress of long hospital stays and supporting other children financially and emotionally is burdensome. There may also be fears around future pregnancies. All of this needs to be dealt with honestly and sensitively requiring good communication skills, compassion and sufficient time.

## Practicalities to consider

When speaking to families, always call the baby by its name, using gentle touch and tones in a private space. Ensure enough time is allowed for them to absorb what has been said and listen to them

carefully. This is a time of great anxiety; they cannot control the future or protect the child. The health professional should therefore give them choices and control whenever possible. Discuss how the baby is likely to die and where they feel would be best for this to happen. Too many children die in hospitals when they could be comfortable at home surrounded by those that love them. Many health practitioners use phrases such as “there is nothing more we can do” or “withdrawal of care” when referring to withdrawal of life sustaining interventions. The truth is there is always a great deal more to be done with respect to ensuring a baby’s comfort.

Offer spiritual support with appropriate referral and be aware that there may be religious rituals that a family wish to conduct. Consider the issue of mementos which will provide tangible evidence of the baby’s existence and the time they spent with him/her. These may include photos, hand or footprints on a card or locks of hair.

Do not forget about the mother’s health, post-partum care and lactation and ensure good communication between obstetric and neonatal teams. It is important to register the birth as soon as possible, as a baby cannot be registered as dead before it has been registered as alive. This can be very traumatic for families.

All staff should be aware of protocols for foetal/infant death and certification and as far as possible families should not have to wait to be assisted in this regard.

### Developing a Care Plan

The approach to the following issues should be discussed within the team and decisions made with the family:

- Resuscitation
- Nutrition
- Pain assessment and relief
- Symptom control
- Need for painful procedures, blood transfusions
- Antibiotics
- Place of care
- Place of death

### At the End of Life

Counsel the parents about the physical changes that are likely to occur as their baby dies. Parents

should be made aware that the time until death can vary from minutes to hours and sometimes days or longer.

### After Death

After the baby dies, allow adequate time for goodbyes with the body and allow the family to perform appropriate rituals. Consider the need for ongoing bereavement support and refer them to support organisations if available.

### Conclusion

Perinatal palliative care requires honesty, courage and compassion from the health care provider. We can make a difference to families experiencing the death of a child by providing accurate information, discussing both sides of all options and giving families time to make difficult decisions with our support. ■

### Additional Resources

Leuthner S, Jones EL, Fetal Concerns Program: a model for perinatal palliative care, *MCN Am J Matern Child Nurs.* 2007 Sep-Oct;32(5):272-8. [www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk) [www.icpcn.org.uk](http://www.icpcn.org.uk)

This article first appeared in *PedMed*, a South African magazine focusing on paediatric and adolescent medicine.

### About the author: Dr Julia

Ambler co-founded the organisation Umduduzi, Hospice Care for Children in December 2012. The mission of the organisation is to bring compassion, dignity, relevant care and relief from discomfort and pain to children diagnosed with a life threatening or life limiting illness within KZN. This is done through direct patient care, mentorship, empowerment of caregivers, training and advocacy. You can contact Julia via email at [julia@umduduzi.co.za](mailto:julia@umduduzi.co.za)

### References

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