

Senate Enquiry: Palliative Care in Australia

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**Perinatal and neonatal palliative care: Australian infants need palliative care too.**

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This enquiry has been asked to look into factors influencing access to palliative care for a number of groups who may be ignored or neglected by current models of palliative care provision, for example those from rural areas, those with disabilities, and children and adolescents. It is notable, however, that one neglected group is not mentioned in the terms of reference of the enquiry – the needs of infants or fetuses with life-limiting conditions. Perinatal and neonatal palliative care is all too often forgotten in discussions of end-of-life care.[1]

We are perhaps used to thinking about the deaths of adults and even of children. But babies die too. In Australia, approximately 4 out of every 1000 infants die before their first birthday.[2] This equates to almost 1200 deaths across Australia each year. Despite dramatic improvements in infant mortality in developed countries like Australia, infancy remains one of the most dangerous periods of human life. The death rate in the first year of life is only exceeded by those over the age of 55.[3] The rate of death in the first week or month of life is greater than at any other age until the 8<sup>th</sup> decade or later.

Newborn infants die in a number of different circumstances. A small number are born in unexpectedly poor condition, and die in the delivery room or operating theatre, unable to be resuscitated. However, the majority of infants who die are first admitted to neonatal intensive care units.[4] Studies of end-of-life care for such infants suggest that in Australia,[5] and overseas [6-8] most of these deaths are anticipated, and follow explicit decisions to limit life-prolonging treatment like artificial ventilation. However, only in the last decade has there been any academic attention to the potential needs of these children and their families.[1, 9-11] In some parts of the world, (eg the US), there have been attempts to develop specific neonatal palliative care teams.[10][11] Yet, compared to older children and adults, few infants are able to access hospice services, and very few deaths occur at home.[12] There have (to our knowledge), been no Australian studies of neonatal palliative care needs or provision. In our experience, while neonatal intensive care nurses and doctors provide generally high quality end-of-life care for infants, it is rare for palliative care specialists to be consulted or involved in the care of dying infants. Few Australian infants die at home, even if this would be technically possible.

The single largest cause of deaths of newborn infants is congenital abnormalities, responsible for about 1/3 of perinatal deaths.[3] Many of these abnormalities (for example major chromosomal abnormalities, or malformations of the brain, heart or lungs) are now able to be diagnosed before birth by ultrasound or other tests. Some of them are so severe that long-term survival is not possible, or is very unlikely, or would be associated with very severe impairment and illness. In such circumstances, women are generally offered a choice between continuing their pregnancy (in the knowledge that their baby is likely to die before or shortly after birth) or having a termination of pregnancy. For those who choose to have a termination there is a clear pathway of care and support within the public hospital system.

However, for those who may wish to continue their pregnancy the pathway is much less clear. Published accounts from Australian women who received a prenatal diagnosis of a life limiting condition indicate that women sometimes

face a striking lack of support from medical professionals and even pressure to terminate their pregnancy.[13][14] Data from two small projects in Victoria has revealed that the current care received in these circumstances is highly variable and sometimes unsatisfactory. There was strong support for a more structured program of care to provide palliative services for the pregnant woman and her family during pregnancy and before and after birth.[15] Such a program would support informed decision-making about termination or continuation of pregnancy. It would ensure that families receive appropriate multidisciplinary clinical, psychological, spiritual and social support,[16] and may allow advance planning of the management of infants after birth.[17, 18]

There is little evidence about perinatal palliative care provision in Australia. While there are more than 40 programs in the US, we recently surveyed paediatric palliative care specialists in Australia and found that there are no formal perinatal hospice or perinatal palliative care programs in Australia. This was also noted by Christine Campbell MP in a grievance recorded in the Victorian state parliament last year[19] There are paediatric and adult palliative care services who may be able to support pregnant women. However, our experience suggests that only a small proportion of women whose babies are diagnosed with a severe congenital malformation during pregnancy are referred to palliative care teams.

### **Conclusions**

There is an urgent need for more research into neonatal and perinatal palliative care in Australia. Attention needs to be paid to ensuring that palliative care is available in all major perinatal centres and neonatal intensive care units, and that women and infants are referred appropriately.

Palliative care in Australia currently provides very valuable support to many children and adults with life-limiting conditions.

Dying newborn infants and their families need support too.

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