

Palliative care for children in Poland

Anthea Hare reports on the impact of a dedicated palliative care programme at the Warsaw Children's Home Hospice on terminally ill children and their families

The Warsaw Children's Home Hospice is based at the National Research Institute of Mother and Child (NRIMC). Established in 1994, it was the first dedicated children's hospice programme in Europe outside the UK. It is registered as an independent association with the Polish Society of Palliative Care and is a non-governmental organisation.

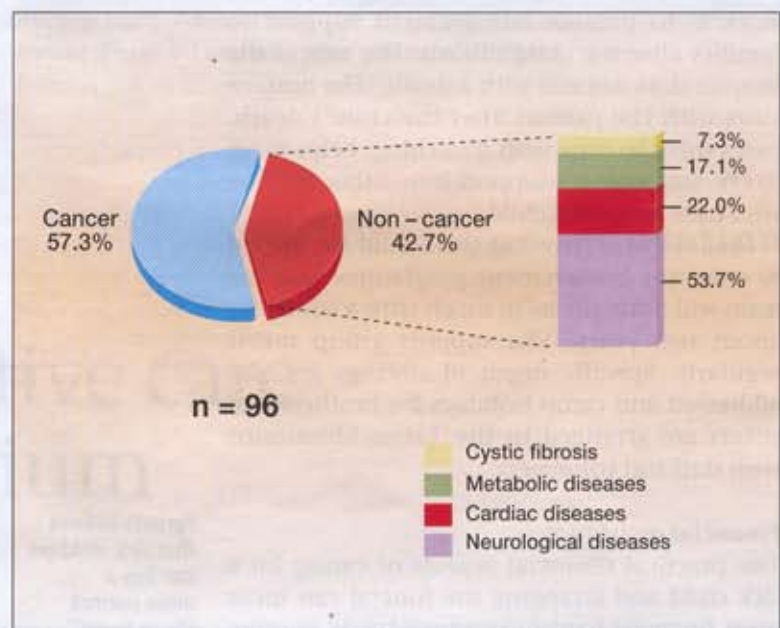
The catchment area for the hospice covers a population of approximately three million inhabitants in Warsaw and the surrounding districts. Children are referred from the Oncology Department of the NRIMC and by paediatricians from teaching hospitals.

The hospice team undertakes the care of children and young people with life-limiting and life-threatening illnesses, including cancers, heart disease, mucopolysaccharide diseases and neurodegenerative conditions (Figure 1). The team becomes involved with the child and family when parents and hospital doctors decide to stop curative treatment as it is no longer deemed appropriate.

Dr Tomasz Dangel is the founder and medical director of the hospice. His team consists of two doctors with experience in paediatric anaesthesia and pain control, five nurses experienced in the care of sick children, three social workers and a play therapist. In addition, there are about 30 volunteers who visit children and their families and offer friendship and support. The volunteers also assist with fundraising activities.

A chaplain works alongside the team to provide spiritual support to children, families and staff members. So far the hospice has cared for 96 children and currently there are 24 children under their care.

Each family has a primary nurse and a 24-hour service is provided with a nurse on call. All nurses and doctors drive cars and keep in contact with families using pagers and mobile phones.



The role of the hospice

What to tell the child

Perhaps the biggest challenge that any professional caring for a child with a life-threatening illness has to face is what to tell a child about their illness and its potential consequences. It is also one of the hardest questions that any family has to answer. The provision of home care for dying children allows for a greater intimacy between family members. Establishing a child's level of knowledge has to be a priority for the team if they are to support the child and the family to the best of their ability. This can be achieved by talking to both the child and their family and listening carefully to their responses, thereby discovering any misapprehensions that may exist about the sickness and the treatment.

Many families want to protect their child in the mistaken belief that this is in the child's best interests but children can feel lonely and isolated. Parents are helped by the team to

Figure 1. Patients categorised by diagnosis 1994-98

realise that avoiding answers or lying may be condemning their child to loneliness in the face of death.

The UK-based Association for Children with Life-threatening or Terminal Conditions and their Families' (ACT) *Charter for Children* states that: 'Information shall be provided for the parents, and for the child and the siblings according to age and understanding.'¹ The charter also states that: 'Every child shall be given the opportunity to participate in decisions affecting his or her care, according to age and understanding.'

Bereavement support

A very important aspect of the Warsaw team's work is to provide bereavement support to families after the child's death. The role of the hospice does not end with a death: 'The hospice stays with the parents after the child's death, helps them to cope with mourning, helps them to cry, and arranges support from other families who have also lost a child.'

Families who have lost their child are invited to enter the bereavement programme and the team will normally be in touch with a family for about two years. The support group meets regularly. Specific needs of siblings are also addressed and camp holidays for brothers and sisters are arranged in the Tatras Mountains with staff and volunteers.

Financial assistance

The practical financial aspects of caring for a sick child and arranging the funeral can incur great financial hardship and, so far, 18 families

Parents believe that sick children can live a more normal life at home

Box 1

Positive aspects of home care identified by parents

- Parents felt their child wanted to be at home and that once the child got home he/she felt better emotionally and physically.
- They believed that their children could live a more normal life at home and could achieve more control over that life by asking for and accepting personal care and involvement in family activities when they wanted it.
- Parents identified how disruptive the child's illness had been to the family and how home care helped to reverse that situation.

Negative aspects of home care identified by parents

- Home care is 'exhausting'.
- It is difficult to keep well-meaning visitors away.
- More follow-up and support with the management of medication is needed.

have been helped with these costs through the social workers within the team.

Domiciliary care

A central tenet of the philosophy of paediatric palliative care is that the home should remain the centre of caring wherever possible. There is evidence that parents prefer home care to institutional/hospital care.²

Children's Hospice International³ states that the hospice programme should provide a written evaluation tool for all recipients of services to document their satisfaction, or dissatisfaction, with the services received.³

Dr Dangel and his team believe that the last period of a child's life can be lived with dignity, without fear, separation and unnecessary procedures. The hospice team believe that they should provide companionship both in the bad times when anxiety, sadness and hopelessness predominate, and in the good times that happen as well.

The majority of parents known to the hospice decided to bring their child home because that was what the child wanted. Other motivating factors included the realisation that further hospital treatment and care was no longer beneficial to the child and because the whole family wanted to be together. Difficulties within the hospital environment were also identified. Some of the pros and cons of home care, as identified by parents, are outlined in Box 1.

The future of paediatric palliative care in Poland

Advances in medical technology allow for an increasing number of very sick children to enter



a cure-orientated, technology-based system of care that far too frequently creates more difficulties for families in terms of social, psychological and ethical dilemmas at a time when they are under great stress and suffering great distress. There is an enormous need to establish collaborative working between professional groups and to set standards, as there is still a lack of knowledge about the palliative care needs of children.

The hospice team in Warsaw are helping to develop their model of home-based palliative care in five other Polish cities and in paediatric haematology and oncology centres throughout the country. They are working at establishing standards of pain management and are setting up a scientific library on paediatric palliative care with Internet access. Much has already been achieved, and the hospice team is

working alongside other agencies in Canada, the Netherlands, Hungary and Belarussia to deal with some of the obstacles that are still interfering with the provision of paediatric palliative care.

The Warsaw team has demonstrated that children's palliative care should be a recognised specialty and given the status it rightly deserves.

The Warsaw team have demonstrated that children's palliative care should be recognised as a specialty

References

1. The Association for Children with Life-threatening or Terminal Conditions and their families. *The ACT charter for Children with Life-threatening Conditions and their families*. Bristol: ACT, 1993.
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