

# Providing holistic, specialist palliative care services to children – one paediatrician's experience working in a children's hospice

Mark Hunter

## Abstract

The specialist provision of paediatric palliative care is a relatively new discipline. This article will review the epidemiology of paediatric palliative care and will discuss the current delivery of this care within the United Kingdom. The author will describe the nature of work within a children's hospice and in particular the role of a paediatrician working within this setting.

**Keywords** End of life; hospice; life limiting; life threatening; paediatric palliative care; symptom management

## Introduction

We are all born and we will all die. This is a truism but for most paediatricians our professional experience is very much with the former rather than the latter. Provisional figures for England and Wales in 2015 show nearly 698,000 births and approximately 4335 deaths of infants, children and young people under the age of 19. This review will discuss the nature of paediatric palliative care and the part that children's hospices play in its provision from the perspective of a consultant paediatrician working in a hospice.

## Paediatric palliative care

The World Health Organisation (WHO) offers a definition of children's palliative care (Box 1). The WHO also observes that the principles apply to other chronic paediatric disorders.

In the United Kingdom paediatric palliative care is generally regarded as care provided to children with a life limiting condition (LLC) and/or a life threatening condition (LTC) but it is difficult to find a succinct definition of either term. A more simple definition is that paediatric palliative care is care that aims to reduce suffering of whatever type for children, their families and the wider community.

## The size of the task

There have been two large epidemiological studies carried out in the UK in the last few years that have attempted to estimate the

## WHO definition of paediatric palliative care.

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.

## Box 1

numbers of children who have a LLC or LTC. These suggest that there are 49,000 children and young people living with a LLC or LTC and prevalence rates of 32/10,000 population in England, 44.6/10,000 in Wales, 27.8/10,000 in Northern Ireland and 41.4/10,000 in Scotland. These figures reflect the *hospital prevalence*, i.e. they are derived from statistics relating to hospital admissions. Estimates of prevalence including those children who have not received hospital treatment in the preceding year are much higher – in Scotland the estimate is 95.7/10,000 population. The prevalence is highest for children under a year of age and approximately 60% of those dying in childhood are infants.

## Children's hospices

The first hospices came into existence in the middle ages when they provided shelter and food for the sick and weary travellers. Dame Cicely Saunders developed the concept of palliative care as a speciality and founded the first 'modern' hospice, St Christopher's in London in 1967. The first hospice for children, Helen House in Oxford, opened in 1982 and since then the number of children's hospice services in the United Kingdom has increased to more than 40. Children's hospices are independent charitable organisations that rely upon fundraising and donations for much of their income with only 17% of running costs met by statutory services on average.

Every children's hospice is individual and provides a differing mix of services often in quite different ways although all will be broadly following the WHO principles referred to above. The discussion that follows is based on the authors experience working within a large children's hospice trust in the UK and although I hope my views and experience are widely transferrable there may be some differences when compared with the reader's local hospice.

## What do children's hospices do?

For many the word hospice conjures up images of places where care is provided for a short period before a person dies. Whilst this is a part of what is done the range of services is much larger than this. There are two main reasons for this. Firstly the trajectory of children's palliative care is frequently one of repeated

**Mark Hunter** MBBS MRCP (UK) FRCPCH DCH DCCH is Consultant Paediatrician, With Acorns Children's Hospices, Birmingham, UK. Conflict of interest: none declared.

episodes of deterioration and recovery over a variable period of time. Secondly paediatric palliative care places great emphasis on the care and support of the child's family, not just parents but other family members as well.

### **Psychosocial care**

This is care provided to the child and their family that aims to reduce the impact of the child's illness upon emotional health and social participation. This may focus on provision of support to parents around the time of diagnosis and at times of exacerbations or crises such as admission to intensive care. Often it will be concerned with helping the family deal with practical problems that can make social participation difficult – access to benefits and transport are common issues. This care is often provided by staff from a social care rather than healthcare background.

### **Respite and short breaks**

Much of the day to day life in children's hospices revolves around children who come for short breaks. Children may come with their parents and other family members or they may come alone – often described as a respite stay in which parents can have a break from the demands of caring or sometimes the child a break from the demands of the parents! Stays vary in length from a few hours up to several days. Increasingly hospices are offering home based respite with care staff and sometimes volunteers going to a child's home and providing care. This differs from psychosocial care in that the focus is on the child's direct needs although it will allow parents and the wider family to take a break from caring. This model of care is particularly helpful in situations in which hospice based care is less appropriate or possible such as for very young children or children recovering from surgery or serious illness.

### **Symptom management**

Hospices may offer expert advice on symptom management, especially but not exclusively the management of pain. This may be offered during a short break or as an outpatient. Doctors and nurses working within a hospice may offer advice on a consultancy basis to health service colleagues.

### **End of life care**

Yes, children's hospices do offer end of life care but not nearly as frequently as some might imagine. The organisation I work for has a total of 30 hospice beds (across three hospices) and serves a population of about 5.7 million. In 2014 there were 597 deaths in children and young people under the age of 19, 62 of these children were known to the hospices but only nine died with us. In a 'busy' year we will only see 20 deaths within the hospices although we do provide support and advice for other children dying at home. Many hospices are developing nurse led 'Hospice at Home' teams to support the delivery of care at the end of life. Over recent years we have seen a trend for end of life care to be provided to larger numbers of infants and for the duration of this care to become longer.

### **Care after death**

Many children's hospices offer cooled bedrooms providing an opportunity for children to stay in the hospice for several days after death. This allows time for families to remain in contact with

their child whilst coming to terms with the immediate impact of the death and making the necessary practical arrangements.

### **Bereavement care**

Children's hospices remain in contact with and available to families for as long as they wish after the death of their child. This contact may be quite intensive with counselling and support in dealing with grief but may also be infrequent such as attendance at memorial events or the opportunity to return and reflect within the hospice gardens.

### **Sibling and family care**

Siblings are often significantly affected by the serious illness or death of a brother or sister. Children's Hospices may offer 1:1 support or the opportunity to attend groups of peers which tend to mix activities and discussion. Children's hospices usually provide a stimulating environment and staff or volunteers to occupy and distract siblings if needed. In a similar way some hospices will also seek to cater for the needs of grandparents or other family members.

### **Medical care provided in children's hospices**

Children's hospices in the UK differ quite widely in the services they provide and the degree to which these services are medically managed. The model of medical provision used varies from hospice to hospice. It would be a generalisation, but a fair one, to observe that medical provision is gradually moving from a service delivered by general practitioners or paediatricians with a strong personal interest in palliative care to one delivered by specialist paediatricians with specific training in the discipline.

Historically, most children's hospices have functioned independently and alongside the NHS and tended to employ their own medical staff who either worked exclusively within the hospice, sometimes combining the role with another role in adult palliative care or sometimes if paediatricians, a completely different role within an NHS setting. Probably the most common model has been for a local general practitioner to split working in their practice with sessions in the hospice and often providing out of hours availability for long periods of time.

Over recent years some hospices have developed formalised joint consultant posts with neighbouring NHS units, some of these posts have responsibilities for paediatric palliative care within the NHS but others will work in differing disciplines within their NHS job.

### **One paediatrician's route into palliative care**

I trained as a paediatrician in the UK and decided early on to become a consultant in the relatively new specialism of community paediatrics (later to become community child health). Although my main interest was in the care of children with disability I had always had an interest as a trainee in the care of children and families facing death and bereavement most commonly on the neonatal unit or in the context of sudden infant death which occurred more frequently when I was trainee than it does now.

I think it is fair to say that the nature of community child health has changed in the nearly 30 years since I became a trainee in the speciality and I found my job changed gradually to

Download English Version:

<https://daneshyari.com/en/article/8813168>

Download Persian Version:

<https://daneshyari.com/article/8813168>

[Daneshyari.com](https://daneshyari.com)