

# Palliative care for disabled children and young people

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## Abstract

Palliative care for disabled children and young people embraces holistic, high quality, evidence-based care, recognition and timely management of symptoms, recognition and discussion with the multidisciplinary team and with families about the possibility of dying and care and support through life, death and bereavement.

Systems are being piloted across the UK to collect data about who and where children and young people with palliative care needs are and to ensure robust funding mechanisms are established for provision of care in an equitable way.

Decision-making within a legal and ethical framework is paramount in this area of clinical practice, along with clinical networking within care pathways to ensure care delivered is of the highest standard.

**Keywords** best interests; child; clinical networks; decision-making; disability; disabled child; disabled young person; mental capacity act; palliative care

## Definitions & numbers

Palliative care for children is an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life to death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement. All disabled infants, children and young people require holistic, multidimensional, multidisciplinary and interagency care that accurately identifies and addresses their multifaceted needs. Thus the care of all disabled children and young people is concordant with the palliative care philosophy.

There are currently no robust data about how many disabled children and young people there are in the UK, nor how many children are at risk of early death or have palliative care needs. The UK's Chief Medical Officer in her special report 2013 focused on children and young people and dedicated a chapter to disabled children and young people: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/252659/33571\\_2901304\\_CMO\\_Chapter\\_9.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/252659/33571_2901304_CMO_Chapter_9.pdf). Many of the

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recommendations called for better data collection if we are to reach the goal of delivering needs-based services that bring the best outcome opportunities in an equitable way for all.

Disabled children and young people and those with long-term conditions are at highest risk of death in childhood of all children and young people. Some deaths are preventable with high quality management. A proactive palliative approach can afford greater opportunities for involvement of the child and family in decision-making about care including at end of life and ensure the best possible symptom control.

Where data are available from routinely collected Hospital Episode Statistics, the numbers of children and young people with life-limiting or life-threatening conditions have been found to be double those of previous estimates and are increasing year on year. Life-limiting conditions are especially prevalent amongst ethnic minority groups and in families with increasing levels of deprivation. As Hospital Episode Statistics only capture data from those receiving correctly coded in-patient care the actual prevalence in the wider community is likely to be higher.

## National policies, drivers and funding for paediatric palliative care Figure 1

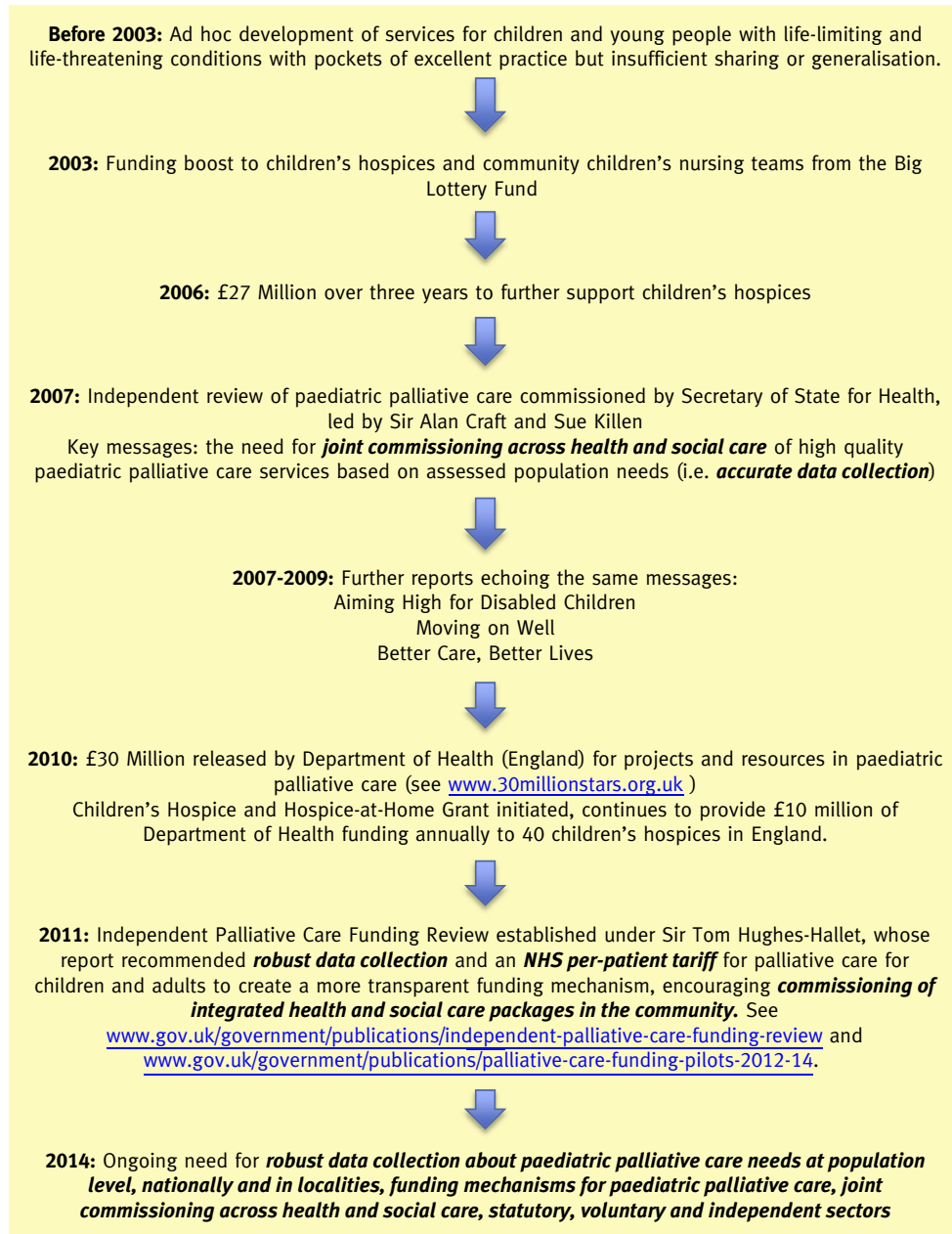
### Paediatric palliative care networks

The provision of children's and young people's palliative care via managed regional networks is being supported by Together for Short Lives (TfSL), the UK's leading charity supporting children with life-limiting and life-threatening conditions and all who care for them (formed by the merger of the 'Association for Children's Palliative Care' ('ACT') and 'Children's Hospices UK'). They define a palliative care network as: 'an interdisciplinary structured group representing providers and users of services over a defined geographical area, drawn together with the common aim of co-ordinating, strengthening and developing services for children and young people with life-limiting conditions'.

The East Midlands Children and Young People's Palliative Care Network (EMCYPPCN) for example, started in 2004 when members of the small children's palliative care teams from across the region began meeting at the local children's hospice to share knowledge, give mutual support and drive implementation of the 'ACT' Care Pathway. The Aiming High for Disabled Children regional board supported the network to develop governance arrangements and wider representation including commissioners. In 2010 the network supported local teams with 20 successful bids for the Department of Health £30 million funding, including development of a children's palliative care degree module at Nottingham university, a regional users and services mapping project, a directory of educational provision across the region, and several pilots including the rapid response respiratory physiotherapy service.

The network continues to serve an important role in bringing clinicians together for sharing knowledge and mutual support; the monitored work plan and short term working groups drive service developments and roll out good practice. User involvement has been problematic, but there are plans for a virtual reference group and links with the local Healthwatch.

The EMCYPPCN has now been adopted as a 'clinical advisory group' by the East Midlands Maternity and Children's Clinical Strategic Network. The latter will be supporting local commissioners to



**Figure 1** National policies and drivers for funding in paediatric palliative care.

collaborate with local authorities to commission 'core children's palliative care services' within the managed clinical network. These core services include children's community nursing teams, short breaks services, routine care by the children's hospice and other local community-based palliative care services.

A Guide for Clinical Commissioning Groups (CCGs) on commissioning children's palliative care in localities can be found at: [http://www.togetherforshortlives.org.uk/about/our\\_policy\\_work/186\\_commissioning\\_children\\_s\\_palliative\\_care\\_in\\_the\\_new\\_nhs](http://www.togetherforshortlives.org.uk/about/our_policy_work/186_commissioning_children_s_palliative_care_in_the_new_nhs).

Information about the 16 current UK regional networks can be found at: [http://www.togetherforshortlives.org.uk/professionals/service\\_planning/networks](http://www.togetherforshortlives.org.uk/professionals/service_planning/networks)

The West Midlands Network tool kit is a particularly useful resource.

### Specialist paediatric palliative care services

A service specification for specialist paediatric palliative care has been produced by NHS England for specialist commissioning: <http://www.england.nhs.uk/wp-content/uploads/2013/06/e03-paedi-med-pall.pdf>. However, despite initial proposals that each of the regional palliative care networks should have access to a specialist palliative care team for clinical, educational and strategic support there seem to be no immediate plans to extend the funding beyond the current small number of 'Highly Specialist Paediatric Palliative Care Centres'.

### Transition to adult services

Transition arrangements for young people with palliative care needs, despite a plethora of frameworks and guidance, are highly variable and generally unsatisfactory although there are

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