

A Guide to Children's Palliative Care

Supporting babies, children and young people with life-limiting and life-threatening conditions and their families

Fourth edition 2018

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This publication will be reviewed on an annual basis and amended as needed, at our discretion.



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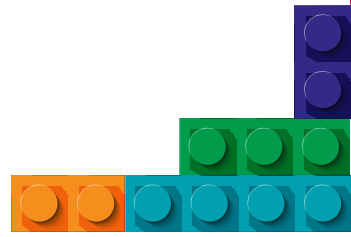
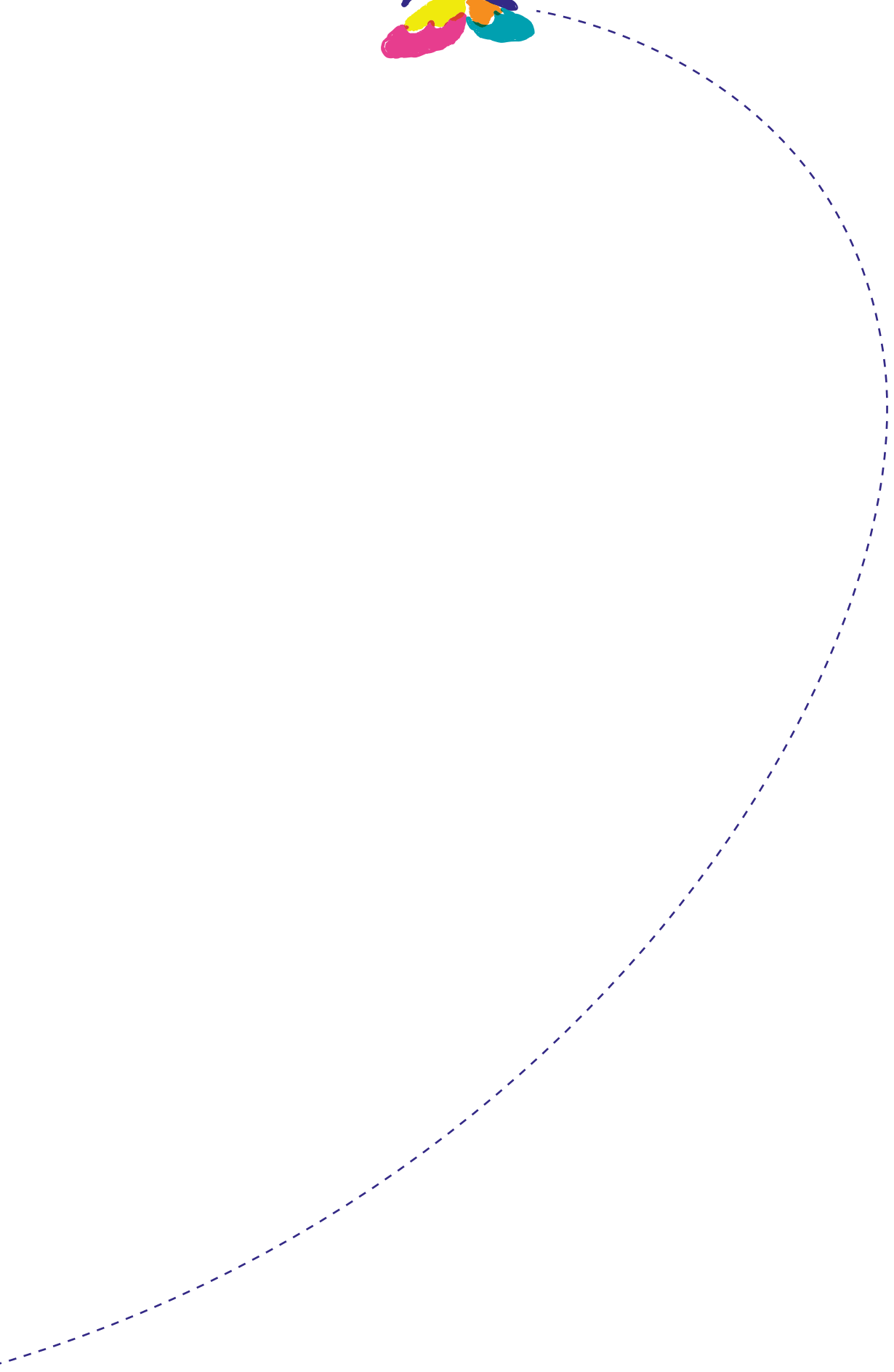
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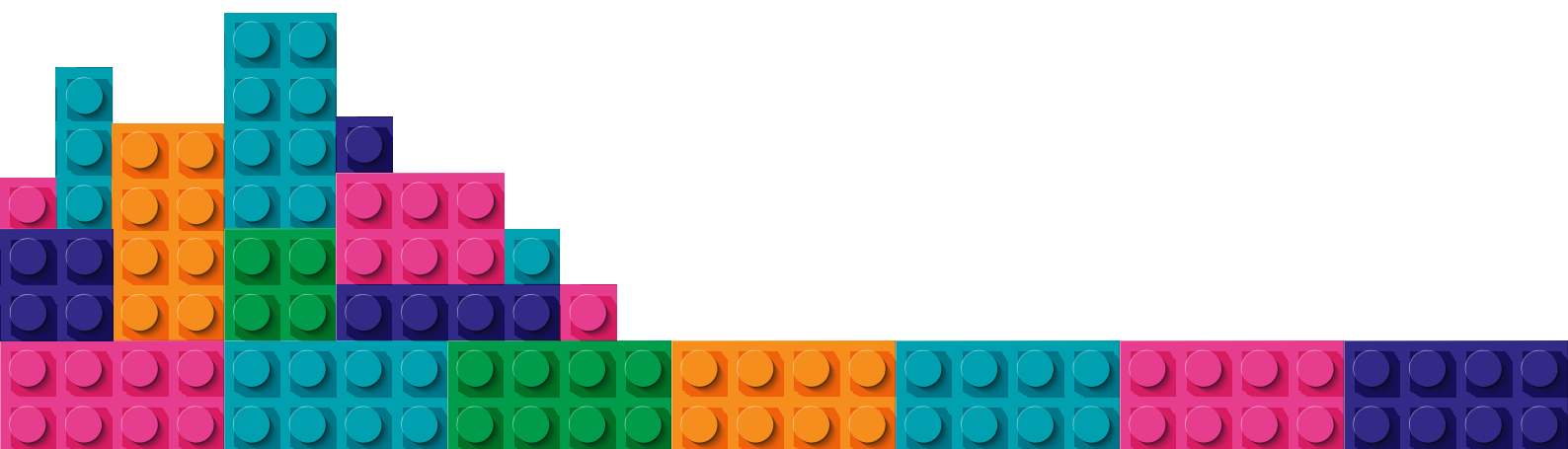
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1. *A Guide to Children's Palliative Care* is referred to as "The Guide" throughout.



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Foreword

There has been good progress in establishing palliative care for children since the publication of the earlier editions of *The Guide* and this new edition brings up to date information about where we are now and what is still needed.

Importantly, the most recent and rigorous epidemiology included tells us that we have been underestimating the numbers of babies, children and young people with life-limiting or life-threatening illnesses in the UK who could benefit from palliative care.

There is still a view among families and some clinicians that palliative care is a last resort and one of the strong themes in this edition is that of parallel planning. Planning for and offering palliative care alongside treatments aiming to cure or prolong life so that the child has as good a quality of life as possible, whilst also acknowledging the need to plan for a good death.

The value of partnership is another theme that has come to the forefront in this edition. Partnership of the clinical team with the sick child and their family will enable care to be tailored to their individual needs. Partnership and the formation of networks between clinicians will enable good practice to be shared and more joined up care to be delivered. Partnership between health and social care in commissioning will enhance services and be more economically effective.

The new and enhanced section on research acknowledges the need to expand the evidence base for children's palliative care. It offers guidance on priorities and addresses the barriers that have been holding back progress. As families themselves say they find it beneficial to take part in research this should be a spur to improving the situation in the future.

The UK has been a pioneer in the development of palliative care for children and the principles are now well established and recognised. However, there are still significant gaps in the provision for individual children and families in this country and the needs of children and families are even more profound in other countries around the world, especially those with less resources. I hope and believe this guide will be a valuable tool for those developing and planning care for children and families wherever they are.



Dr Ann Goldman



Introduction

The Guide to Children's Palliative Care provides information on children's palliative care: what it is, its principles, purpose and importance to the children, young people and families who need it. *The Guide* seeks to establish and realise a vision that ensures children and their families have access to and receive comprehensive, high quality, evidence-based services delivered by an appropriately trained and experienced workforce.

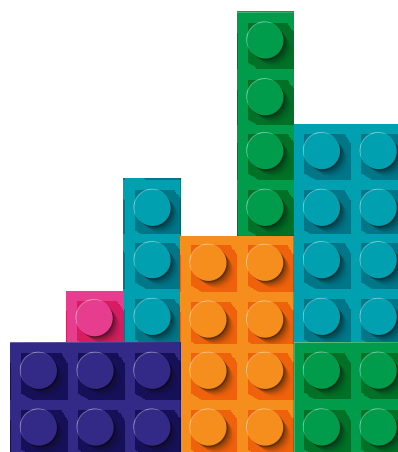
ACT² published the first edition of *A Guide to the Development of Children's Palliative Care Services* in 1997. It was the first time that the definitions of children's palliative care and the numbers and needs of life-limited and life-threatened children, young people and their families had been documented in the newly emerging field of children and young people's palliative care. A second edition was published in 2003 and a third edition in 2009.

This fourth edition comes as children's palliative care provision is relatively well established in the UK, with a recognised medical specialty. It describes the current state of the field and advocates for the next phase of its development, for example embedding the key principles and approach of children and young people's palliative care across all levels of service and in a variety of settings. These include neonatal units, hospital wards, hospices, community paediatrics, community children's nursing teams, social care teams, in adult services and in general practice as well as reaching out to members of the public to support families in their communities. It also advocates for an increase in research, as the evidence base has not kept pace with the developments in clinical provision and practice of children's palliative care.

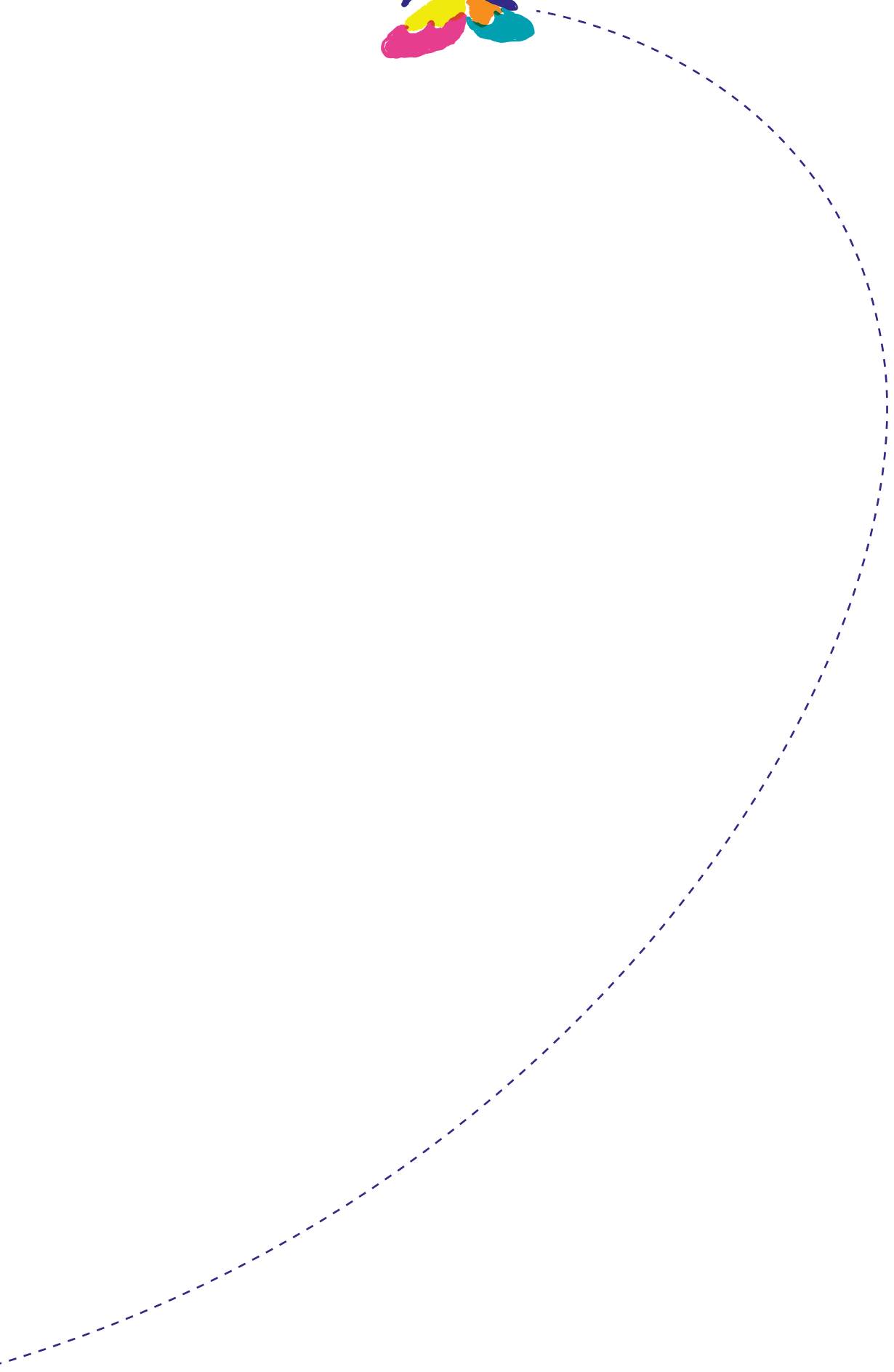
Since the last edition of *The Guide* we have seen an increase in the publication of national and international guidelines and standards relating to the planning and delivery of palliative and end of life care for children.

Integrated working practices, which were advocated in the first edition of *The Guide*, are now an accepted way of working. In the UK, there are informal children's palliative care networks established in almost all regions as forums for sharing of good practice, and there is now a move to establish more formally managed clinical networks to further enhance the planning and delivery of joined up care. Other approaches can also help with the integration of services, such as with other professional networks (for example, neonatal or adult palliative care) and the establishment of joint posts.

This new edition of *The Guide* seeks to cement these positive advances and to set out a vision for the future sustainable development of children's palliative care.



2. ACT (the Association for Children's Palliative Care) merged with Children's Hospices UK in 2012 to form Together for Short Lives.



Section 1

Essential information

Key points

- Palliative care for children and young people is an active and total approach to care, which begins from diagnosis or recognition and continues throughout the child's life and death.
- It is distinct from, but has much in common with, services for disabled children and with adult palliative care.
- Parallel planning is a key part of children's palliative care.
- The numbers of children with life-limiting or life-threatening conditions is rising.
- Children with life-limiting or life-threatening conditions, and their families, have many needs in common.
- Children's palliative care includes services provided at universal, core and specialist level from providers in the statutory and voluntary sectors.

1.1 Definition and philosophy of children and young people's palliative care

Palliative care for children and young people with life-limiting or life-threatening conditions is an active and total approach to care, from the point of diagnosis or recognition throughout the child's life and death. It embraces physical, emotional, social, and spiritual elements, and focuses on enhancement of quality of life for the child/young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.

The philosophy of children's palliative care is to promote the best possible quality of life and care for every child³ with a life-limiting or life-threatening condition and their family. Giving families real choice is key to this approach; choice of place of care, choice of place of death, choice of emotional

and bereavement support; and putting the child and family at the centre of decision making to produce a plan for care that is right for them. Parents often need support to understand the choices that are available to them from the outset and throughout their child's life.

Children's palliative care is an active and dynamic approach to care, from diagnosis through to death and in bereavement. Children should be free from distressing symptoms through anticipatory care, and children and families should receive support to reduce the emotional and psycho-social effects of the child's condition and to maximise their opportunities in life. This philosophy extends beyond childhood and includes the support young people need as they prepare for adulthood and settle into adult services, often at times of significant deterioration in health.

When a child is diagnosed with a life-limiting or life-threatening condition, their care is often provided by a wide range of professionals from different disciplines and specialties. These professionals include those who work regularly in children's palliative care and those providing more generalist

3. We use the term 'child' to mean baby, child or young person throughout, unless specified.

services. They will also receive informal support from friends, family members, faith and other community groups and these may be their first port of call.

All children with a life-limiting or life-threatening illness regardless of race, religion, age, diagnosis, gender or where they live, should have access to the sustainable, holistic, co-ordinated family-centred and high-quality care and support that they need. Commissioners and providers of services need to ensure that every child has the necessary services and support to live well and, when the time comes, die well.

1.1.2 Life-limiting conditions are those for which there is no reasonable hope of cure and from which children will die. Some conditions cause progressive deterioration, meaning that the child becomes increasingly dependent on parents and carers. **Life-threatening conditions** are those for which curative treatment may be feasible but may fail.

Other key terms are defined in the glossary on page 33.

1.1.3 Many children with life-limiting or life-threatening conditions need the same good quality universal services as **disabled children**. However, the increased likelihood or certainty of death in childhood or young adulthood for a child with a life-limiting or life-threatening condition adds a degree of complexity and urgency to the care that is needed for the child, and the increased support that is needed for the family. These children often need additional planning to meet their fluctuating, unpredictable and sometimes urgent need for dedicated children's palliative care services. There should be close working between services for children with life-limiting or life-threatening conditions and those for disabled children to achieve joined-up provision which enables them to maximise their potential and live life to the full.

1.1.4 Palliative care for children is different from **adult palliative care** in several ways:

- The number of children dying is small, compared with the number of adults.
- Many of the individual conditions are extremely rare with diagnoses specific to childhood or young adulthood.
- Many of the illnesses are familial. There may be more than one affected child in the family.
- Parents bear a heavy responsibility for personal and nursing care and siblings are especially vulnerable.

- A characteristic of childhood is continuing physiological, emotional and cognitive development. Children's palliative care providers need to understand and be responsive to the impact of a child's physiological development on handling of medications as well as each child's changing levels of communication and ability to comprehend their illness, treatments and prognosis.
- Provision of play for all children is essential and education is a legal entitlement.

However, there are many elements in common between children's and adults' palliative care, such as similar approaches to symptom management and the need for care to embrace the whole family. Providers should work together to enable a more seamless service for young people in transition.

1.2 Four groups of life-limiting and life-threatening conditions

Life-limiting or life-threatening conditions can be described in four broad groups (see Fig. 1 opposite). These groups are illustrative of the wide range of conditions likely to benefit from a palliative care approach and/or support from children's palliative care services. These examples are neither exclusive nor fixed; children may move between the groups or be in more than one group at any time. The groups are intended to be a helpful tool to illustrate the range of different conditions which may require palliative care.

1.3 Different patterns of children's palliative care

Palliative care can be seen as a thread that runs through the lives of children, often alongside other treatments. This is why the concept of **parallel planning** is important, where palliative care is offered in parallel with and alongside curative treatment, or treatment aimed at significantly prolonging life (see Fig. 2, opposite). The palliative care approach should be present from diagnosis or recognition that curative treatment is not an option or may fail.

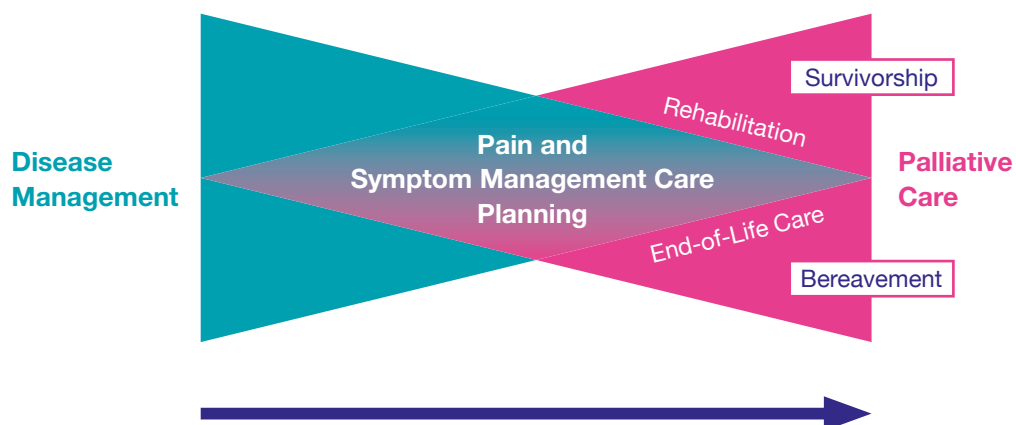
Palliative care needs to be dynamic and responsive to the changing needs of children and their families, who may dip in and out of using dedicated palliative care services as their condition fluctuates. As children become more vulnerable to complications, palliative care becomes a more active element of their support package. This is particularly relevant for the growing number of technology-dependent children and those who are receiving experimental treatments for which there is a high risk of unknown complications.

Fig. 1: Four groups of life-limiting and life-threatening conditions

Category 1	<p>Life-threatening conditions for which curative treatment may be feasible but can fail, where access to palliative care services may be necessary when treatment fails, irrespective of the duration of that threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services.</p> <p><i>Examples: cancer, organ failures of heart, liver, kidney, transplant and children on long-term ventilation.</i></p>
Category 2	<p>Conditions where premature death is inevitable, these may involve long periods of intensive disease-directed treatment aimed at prolonging life and allowing participation in normal activities. Children and young people in this category may be significantly disabled but have long periods of relatively good health.</p> <p><i>Examples: cystic fibrosis, Duchenne muscular dystrophy and SMA Type 1.</i></p>
Category 3	<p>Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years.</p> <p><i>Examples: Batten disease, mucopolysaccharidoses and other severe metabolic conditions.</i></p>
Category 4	<p>Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death. Palliative care may be required at any stage and there may be unpredictable and periodic episodes of care.</p> <p><i>Examples: severe cerebral palsy, complex disabilities such as following brain or spinal cord injury.</i></p>







In practice, there is still a tendency for families and some clinicians to view palliative care as an option to be taken up only when others have failed or been ruled out. This can result in families not accepting palliative care support that is offered at earlier stages in their child's disease or losing out on valuable care which could be available to them. It is important to have honest conversations and make decisions and plans in a timely way so that the children's palliative care approach is provided to help the child and family throughout their illness, and not introduced as a 'last resort' when a child is at end of life.

The need for a palliative care approach (whether or not from dedicated children's palliative care services) should always be assessed on an individual basis. It is also important to recognise that having a definitive diagnosis is only part of the identification of need and is not always necessary when deciding whether palliative care services are appropriate. The spectrum of disease, severity of disease, and subsequent complications as well as the needs of the individual child and family need to be taken into account when considering whether a palliative care approach is appropriate.

Fig. 2: Parallel planning for disease-directed alongside palliative care can be represented in the 'bow-tie' model⁴

4. Hawley, P. (2015). *The Bow Tie Model of 21st Century Palliative Care*. University of British Columbia.

Fig. 3: Examples of the relationship between palliative care and disease-directed care

	As the illness progresses the emphasis gradually shifts from disease-directed to palliative care (as in the 'bow-tie' model).
	Disease-directed treatments may be used both to prolong and improve quality of life alongside palliative care, each becoming dominant at different stages of the disease.
	It's recognised that disease-directed care will not provide a cure or prolong life and care is palliative from the time of diagnosis.
	At first it is not apparent that this will be a terminal illness and palliative care starts late in the illness.
Key:  disease-directed  palliative	

The relationship between palliative care and disease directed treatment can be complex and can vary for different conditions and situations. The diagrams above (Fig. 3) show examples of the relationship between palliative care and disease-directed treatments which are aimed at curing the condition. These can be helpful to conceptualise the different ways that palliative care can be provided in different circumstances.

1.4 Epidemiology

There were almost 3,000 child deaths in England in 2017 which were due to medical conditions, with 2,351 of these deaths due to a known life-limiting condition or a neonatal death.^{5, 6}

There is an emerging picture of the number of babies, children and young people living with a life-limiting or life-threatening condition in the UK. Research has estimated that there are 49,000 children and young people with a life-limiting or life-threatening condition in the UK aged 0-18 years.⁷ In addition, there are 55,000 young adults aged 18-40 living with a life-limiting or life-threatening condition in England, of which almost 13,000 are in the 18-25 age group.⁸

A more recent research project undertaken in Scotland⁹ used a different methodology (it analysed primary care data as well as Hospital Episode Statistics) and showed that the absolute numbers of children and young people aged 0-25 with life-limiting conditions had risen from 12,039 (2009/10) to 15,404 (2013/14). Prevalence had risen from 75 per 10,000 to 95.7 per 10,000 in the population of children living with a life-limiting condition.

In a survey of children's hospices in the UK,¹⁰ there were 7,638 children accessing the support of these children's palliative care services. It would seem likely that many children are missing out on having their needs assessed using a palliative care approach and from knowing about the support that is available from children's palliative care services. One way to achieve this is for children's palliative care professionals to develop strong links with neonatal and paediatric intensive care units. Tools have been developed to help identify and clinically assess babies, children and young people who would benefit from the support of a children's palliative care service.^{11, 12}

5. DfE Child Death Reviews; year ending 31 March 2017 SFR 36/2017, 13 July 2017.
 6. Sidebotham, P et al. (2014). Child death in high income countries 2: patterns of child death in England and Wales.
 7. Fraser, L et al. (2012). *Life-limiting and life-threatening conditions in children and young people in the United Kingdom*; final report for Together for Short Lives.
 8. Fraser, L et al. (2013). *Prevalence of life-limiting and life-threatening conditions in young adults in England 2000-2010*; final report for Together for Short Lives.
 9. Fraser, L et al. (2015). *Children in Scotland requiring palliative care: Identifying numbers and needs* (The ChiSP Study). University of York Social Policy Research Unit.
 10. Devaney, C et al. (2012). Count Me In: Children's Hospice Service Provision 2011-12 <https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/01/ProRes-Count-Me-In-Childrens-Hospice-Service-Provision.pdf>.
 11. Shaw, KL et al. (2014). *The Spectrum of Children's Palliative Care Needs: A classification framework for children with life-limiting or life-threatening conditions*. BMJ Support Palliat Care, Mar 5.
 12. Harrop, E and Edwards, C. (2013). *How and when to refer a child for specialist paediatric palliative care*. Arch Dis Child Educ Pract Ed, 98, 202-208.

Although there is evidence that the numbers of children affected by life-limiting or life-threatening illness is increasing, the overall numbers are relatively small compared to other populations, such as adults with cancer. This means that there is still a challenge to improve understanding of the numbers and needs of affected children and young people at local level. This understanding is critical to improve the effectiveness of planning, commissioning and delivery of services, including dedicated children's palliative care services.

1.5 Needs assessment for this population

Children with life-limiting or life-threatening conditions and their families have a range of specific needs, many of which are set out in the Together for Short Lives Charter.¹³ Considerable research has been carried out on the needs of families.^{14, 15} These show cross-cutting themes which may be transferred to most local situations, although local demographics or geographical issues should also be taken into account.

- **Pain and symptom management**

Management of pain and symptoms is a key element of children's palliative care. It includes management of a wide variety of complex symptoms and pain throughout the child's illness as well as at end of life. Management includes both pharmacological and non-pharmacological approaches.

- **The provision of accurate and relevant information**

All families should be signposted to relevant sources of local and national support.¹⁶ This may mean that written resources should be provided or that time needs to be set aside to discuss options with the family. Interpretation services and translated materials should be provided to those families whose first language is not English. Age and developmentally appropriate resources should be provided for children. Care should be taken that information is accurate, up-to-date and of good quality (for example, check that materials have the Information Standard kitemark). This is important given the range of information of variable quality available to families online.

Think about how to engage children and families more generally, for example including them in appropriate MDT meetings.

- **Where possible, children should be cared for in the place of the family's choice**

It is important to work to meet the family's wishes about where their child is cared for, although it is not always possible. For many, this is at home, but it may be in hospital (where they may feel safest and where the care team is familiar) or in a children's hospice. Regular open and honest communication is needed as families' choices may change over time and it is important to explain why it may not be possible or safe to provide care in their place of choice. Some children, particularly those with non-malignant conditions, may live away from the family home either in foster care or at school and will have additional carers and agencies involved. If it is suspected that a child may die soon, and they are not in their preferred place of death, think about whether rapid transfer is possible and in their best interest.

- **Emotional, psychological and spiritual support should be offered to the child and those close to him or her**

Emotional and spiritual¹⁷ support should be provided to the child and their family throughout the course of their illness and continued when the child has died. Support should be extended to include siblings, grandparents and wider family. Siblings should have their support needs addressed individually as well as through group activities with other siblings. It is important to take account of the beliefs and values of children and of their family and carers in all discussions with them. There should be awareness that while some children, young people and families find it reassuring to talk about their beliefs and values, others find it difficult, especially at end of life. There may also be disagreements between children, young people and parents or professionals about how beliefs or values should influence their care, in which case it can be helpful to involve chaplaincy services or other facilitators so that a mutually acceptable care plan can be developed. Although grief is a normal process and most families do not need specialist help, some families will require more specialist bereavement counselling and access to this should be available as part of the service provision pre and post death.

13. Together for Short Lives. (2012). *Charter for Children with Life-limiting or Life-threatening Conditions and their Families*. Together for Short Lives, Bristol.

14. Hunt, A. (2003). *Voices for Change: current perception of services for children with palliative care needs and their families*. ACT, Bristol.

15. Hunt, A, Coad, J et al. (2013). *The BIG Study for life-limited children and their families – Final research report*. Together for Short Lives, Bristol.

16. In England, law stipulates that all local authorities must publish a 'Local Offer' of all commissioned statutory and voluntary sector services providing support to disabled children and families.

17. Brown, E. (2012). 'Around the time of death: culture, religion, and ritual' in Goldman A., Hain R. and Liben S. (eds.) *Oxford Textbook of Palliative Care for Children*. Oxford: Oxford University Press.

- **Practical and social support**

Practical support is often a high priority for families who are caring round the clock for a sick child. For example, this may be support with accessing the right aids, equipment and adaptations for the home, moving to more suitable housing, help with transport or help with accessing benefits. Some families find it helpful to have practical support in the home, for example with cleaning, cooking, gardening or collecting children from school. This kind of support may be provided by social care organisations or through schemes working with volunteers in the local community.

- **Children should be given the opportunity to access education or employment that is right for them**

Life should be as normal as possible for children with life-limiting conditions. For many this will mean ensuring that they can attend a mainstream or special school, or if they are an older teenager or young adult, that they can attend college or university or have meaningful occupation.

- **The child and family's wishes concerning end of life care should be discussed and planned for well in advance**

A key element of children's palliative care is supporting children, young people and their families to develop Advance Care Plans (ACPs) which set out their wishes for current care and treatment in the future. These are often well received if they are introduced early as a plan for life, enabling the family to plan with professionals for their child's care during intermittent potentially reversible health deteriorations, preparing the way for decisions around irreversible changes at the end of life. ACPs should be regularly updated and shared with everyone involved each time they are updated. A parallel planning approach is very helpful to enable children and families to plan for hopes and wishes for life as well as advance plans for their end of life care.

- **Short breaks**

Short breaks have a hugely beneficial effect on children and their families.¹⁸ Short breaks not only give parents a break from their caring responsibilities but also provide an opportunity for a child to have a break from their parents or carers and for young people to spend time preparing for more independent living. Short breaks are provided in a variety of settings and can be in a residential unit or at home with in-reach support. Children's hospices, specialist psychosocial care services, and a range of other voluntary and statutory sector providers provide specialist short breaks for children with life-limiting conditions and their families, although it is recognised that not enough is available. Young people with a **personal budget** can choose to use this funding to purchase support for a short break that is appropriate for them.

- **Transition to adult services**

There is growing evidence of the unmet needs of an increasing number of young people living into adulthood with a life-limiting condition.¹⁹ It's important that planning for transition starts early, from age 14 at the latest, and that provision is individual and **personalised**.²⁰ Young people should be at the centre of planning for their care whilst also acknowledging the support and emotional needs of their families and the central role that they play, particularly when a young person has severe cognitive impairment.²¹ Planning should encompass the full range of a young person's needs: health, social care, education, meaningful occupation and independent living.²² Young adults can have complex, unpredictable and deteriorating health needs which make it difficult for them to achieve the independence they seek and achieve their goals as young adults. Health care must underpin the provision of all other services so that young people and their families feel confident that their medical and nursing needs will be met.

18. Mitchell, A. (2017). 'Can we fix it?!': Understanding the impact of children's hospice short breaks on parental relationships of life-limited and life-threatening children and young people. PhD Thesis. Bournemouth University, Faculty of Health and Social Sciences.

19. Fraser, L et al. (2013). *Prevalence of life-limiting and life-threatening conditions in young adults in England 2000-2010*; final report for Together for Short Lives.

20. Noyes, J et al. (2014). *Bridging the Gap: Using person-centred approaches and multi-agency liaison to incorporate palliative care needs in transition services: A guide for keyworkers and practitioners*.

21. Beresford, B et al. (2013). *Supporting health transitions for young people with life-limiting conditions: research positive practice* (The STEPP Project: Research Briefing and Practice Prompts).

22. Together for Short Lives. (2015). *Stepping Up: A Guide to enabling a good transition for young people with life-limiting and life-threatening conditions*. Together for Short Lives, Bristol.

1.6 An overview of current provision

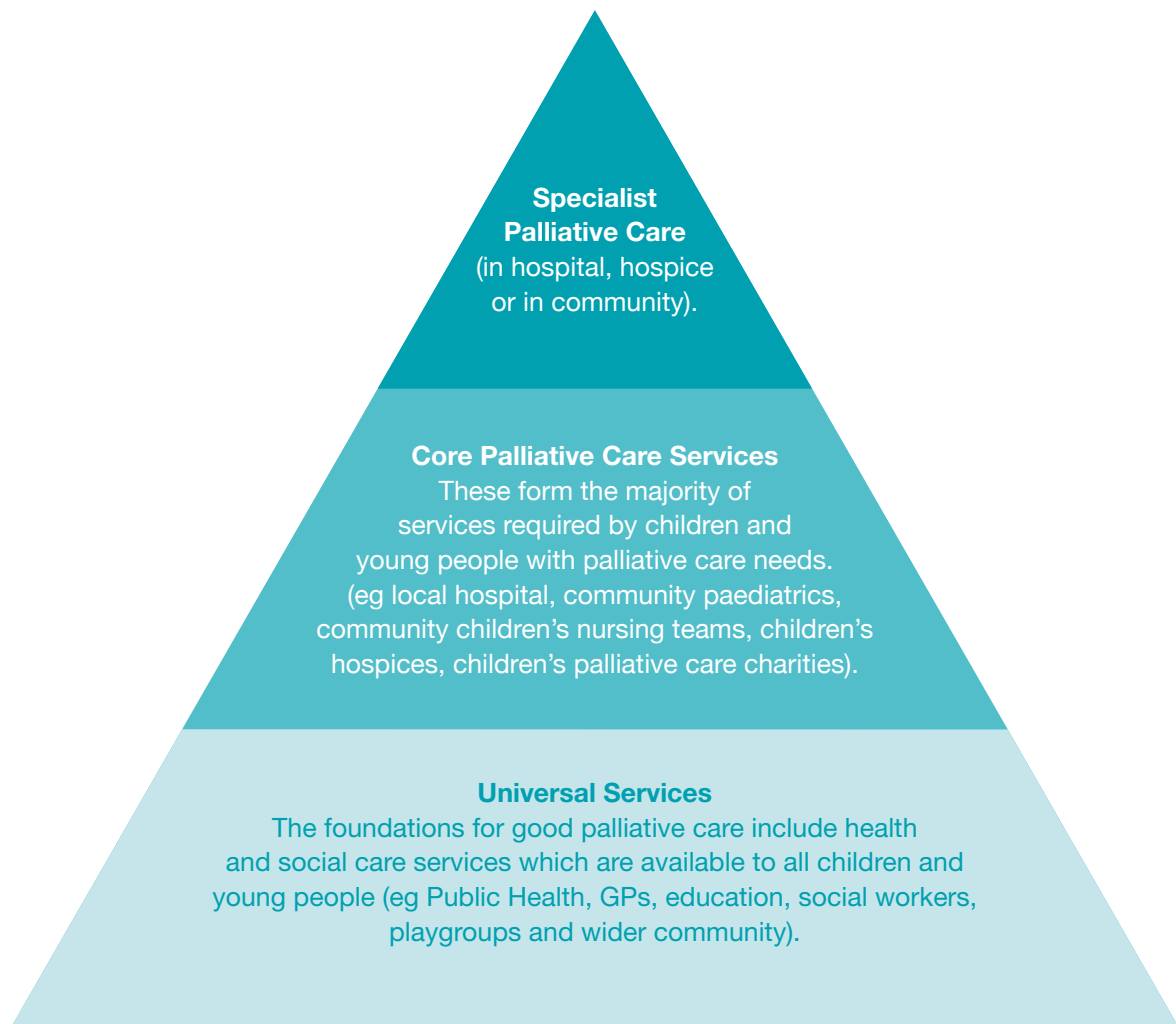
1.6.1 The co-ordination of care and support

There are a wide range of services from health, social care and education involved in the provision of children's palliative care which need to work together to provide more seamless care. One effective way to achieve more integrated working is through networks, which have the potential to bring together different organisations to share best practice and provide a structure through which providers and commissioners can strategically plan for service development and plan services effectively. They also offer potential for feeding in the voices of service users. These informal

children's palliative care networks are currently established in almost all regions and countries of the UK and are to varying degrees achieving this potential. There are also some networks operating at a more local level allowing for local operational planning and commissioning at point of delivery as opposed to more region-wide strategic planning.

One of the key recommendations of the National Institute for Health and Care Excellence (NICE) Guidelines²³ is the development of Managed Clinical Networks, which would have a more formal management structure to support the delivery of care, with defined objectives and a clear governance framework.^{24, 25} They can be a mechanism for services to develop and agree strategies and processes to support children who are approaching end of life and being cared for at home.

Fig. 4: Three levels of children's palliative care



23. National Institute for Clinical Excellence. (2016). *Resource impact report: End of life care for infants, children and young people with life-limiting conditions: planning and management* (NG61). NICE, London.

24. RCPCH. (2012). *Bringing Networks to Life – An RCPCH guide to implementing clinical networks*. RCPCH, London.

25. Baker, C & Lorimer, A. (2000). *Cardiology: the development of a managed clinical network*. *MJ*; 321:1152–3.

A truly integrated system should enable universal, core and specialist providers to work together in a co-ordinated way that enables accessible local support and management of everyday problems, and access to specialist services when needed (see Fig. 4). Integration of services is challenging, but the complexity of conditions and high level of care needs that many children live with, often over many years, mean that services do need to use their combined workforce and resources effectively, for example through integrated or co-located community children's nursing or multi-disciplinary children's palliative care teams.

An integrated children's palliative care service should include:

- Medical care including access to care from specialists in paediatric palliative care and specialists in the child's condition, including access to 24-hour medical expertise in symptom control, either as advice or direct delivery.
- 24-hour nursing care from competent hands-on carers with access to specialised children's palliative care nurses when required.
- Social care and practical support.
- Therapies such as physiotherapy, speech therapy, occupational therapy and play therapy.
- Short breaks provided by appropriately trained and competent staff.
- Educational, play and leisure opportunities.
- Emotional and bereavement support which is flexible and holistic.
- Spiritual support.

This range of support may be provided by services in the statutory or voluntary sectors, in hospital, the community and in children's hospices.

1.6.2 Equality of access

Care and support provision differs across the UK, often due to pressure on resources and the availability of specific services in a region.²⁶ There may be inequities in provision of children's palliative care due to factors such as the age of the child and their condition. There are also rising numbers of children requiring palliative care from diverse ethnic communities²⁷ and research has shown that they may not come forward for help and that their needs may be unmet.²⁸

1.6.3 A care pathway of provision

Together for Short Lives has published a series of care pathway documents which may be helpful to use within local networks as a planning tool to facilitate commissioning of the full range of services or to use with individual families to help to plan how best to meet their current and anticipated needs.^{29, 30, 31}

The elements of children's palliative care services provided along the care pathway will involve health, social care and education providers in the statutory and voluntary sectors and should be provided at all levels: universal, core and specialist (see Fig. 4 on the previous page).

Families will move between these levels of service provision throughout their child's illness and will need support to enable smooth transitions and handover between these different services, whether this is ensuring that there is good communication and join-up between different teams or providing appropriate transport between hospital and home. They may also need to recognise that their level of support may be reduced at times when their child is in relatively stable health.

1. Universal services

'Universal services' is the term applied to services to which all children and their families have access. This includes local district hospitals, primary care (for example, general practice or dental care), health visitors and education services. They are embedded in the communities that they serve and can play a key role in the development

26. Craft, A & Killen, S. (2007). *Palliative care services for children and young people in England: An independent review for the Secretary of State for Health*. DH England, London.

27. Fraser, L et al. (2012). *Life-limiting and life-threatening conditions in children and young people in the United Kingdom*; final report for Together for Short Lives.

28. Gatrad, R, Brown, E and Sheikh. (2008). *Palliative Care for South Asians – Muslims, Hindus, and Sikhs*. London: Quay Books.

29. Together for Short Lives. (2013). *A Core Care Pathway for Children with Life-limiting Conditions*, third edition. Together for Short Lives, Bristol.

30. Together for Short Lives. (2015). *Stepping Up: A Guide to enabling a good transition for young people with life-limiting and life-threatening conditions*. Together for Short Lives, Bristol.

31. Together for Short Lives. (2017). *A Perinatal Care Pathway for Babies with Palliative Care Needs*. Together for Short Lives, Bristol.

and promotion of public health palliative care approaches. GPs and the primary healthcare team can provide advice at times of intercurrent illness, routine health checks for certain long-term health conditions, continuous care during transition between services and support to the whole family in bereavement.

GPs can play a really important role in children's palliative care. They are well placed to inform families about palliative care provision locally, ensure continuity of care and work collaboratively with each other and with specialist colleagues. However, in reality the role of general practice in palliative care for children currently varies widely, from very little involvement to a much more proactive role in holistic care, with some GPs providing out-of-hours medical care or medical cover in children's hospices.³²

It may help to engage and empower GPs to have a more active role in supporting children with life-limiting conditions and their families if they are included more fully and at an earlier stage when a child is diagnosed with a life-limiting or life-threatening condition. Some specific practical approaches can foster closer links between families and their GP, such as carrying out joint home visits or appointments. At a national level, it would be helpful to increase the profile of children's palliative care in primary care, as well as increase the provision of education and training for GPs around early identification of children with palliative care needs.

Alongside the support provided by professionals and organisations, there is a growing move to involve members of the public in supporting families living in their community, whether this is through new family-focussed volunteering schemes or community-led approaches. This approach aims to make the support of children with life-limiting conditions everybody's business and can complement the statutory and voluntary sector professional service provision.^{33, 34}

2. Core services

The majority of children's palliative care will be provided at this level. Core children's palliative care services provide targeted and skilled support in a range of settings.

i) Hospital

Invariably families will receive the diagnosis or recognition of their child's condition following tests in hospital and their palliative care needs will need to be considered either prior, to, or after discharge from hospital to the community. Children may require multiple admissions to hospital and families may need support to prepare for this and the possibility of being cared for in different hospitals under different care teams. Children's hospitals may have dedicated children's palliative care or bereavement teams and will provide ongoing support to children and families.

ii) Community paediatrics

Paediatricians working in the community will be responsible for supporting the child's care at home, especially for children with long-term disabilities. They can enable the family to access medical support on a 24-hour basis and support local community children's nursing teams, GPs and multi-disciplinary children's palliative care teams to be able to provide flexible, high-quality and timely symptom management and care in the home.

iii) Children's nursing teams

There are several models of children's nursing services that provide the bedrock of children's palliative care in a family's home. Examples of such models include:

- **NHS community children's nursing teams**
Covering a wide spectrum of community children's nursing (CCN) activities including palliative care and continuing care. General CCN teams are often aligned with local authority children's teams.
- **Hospital specialist outreach teams**
Providing disease-specific or palliative care outreach to children at home.
- **Hospice at home teams**
Directly delivering nursing care or providing additional support to local CCN teams. These may be stand-alone services or part of a wider children's hospice provision.

32. Neilson, S, Gibson, F & Greenfield, S. (2015). *Pediatric oncology palliative care: Experiences of general practitioners and bereaved parents*. Paediatric Palliative Care and Medicine 5:214.

33. Sallnow, L et al. (2016). *The impact of a new public health approach to end-of-life care: A systematic review*. Pall Med, 2016 March, 30, 3, 200-11.

34. Kellehear, A. (2005). *Compassionate Cities: Public Health and End-of-Life Care*. Routledge.

iv) Children's hospices and other children's palliative care charities

There are currently 54 children's hospice services, providing support for children with life-limiting or life-threatening conditions and their whole family.

All children's hospices provide short break care, end of life care, specialist play, pre-bereavement and bereavement support. Some also provide day care facilities and home-based care services. Some children's hospice and children's palliative care charities have a specialist medical team and can support complex care such as long-term ventilation, others have a greater focus on social care. Some children's hospices, with their dedicated focus and facilities, are well placed to provide a hub for children's palliative care in their region.³⁵

There is no one single model of children's hospice care and a range of different age ranges are catered for. Children's hospices are independent organisations, which means that they vary in the type and level of care that can be provided. It can be problematic for those making referrals and for families who find it difficult to understand the differing eligibility criteria.

The provision of short breaks is a key part of this core service provision and there are a variety of models for providing this, including hospice inpatient, hospice at home, a range of charity short break opportunities, befriending services and short break fostering.

There are a wide range of other voluntary sector organisations involved in children's palliative care at local, regional and national levels (see www.togetherforshortlives.org.uk). These include charities that provide services directly to children and families, such as providing psychosocial support on an ongoing basis to families, and those working nationally to represent the needs of specific groups of children or types of service. It is valuable to include these organisations within children's palliative care networks so that they are part of the local planning process.

3. Specialist level support

The advancing edge of medicine means that many more babies are surviving the perinatal period, more children are surviving complex surgery and more young people are surviving in to their teenage years or early adulthood. This means that there are more babies, children and young people living with complex and long-term conditions which are life-limiting or life-threatening and who need specialist medical support. Children are now much more likely to be discharged home on ventilation and this increasing use of technology has implications for the level of medical and nursing support that is needed to support them in the community.³⁶ It also means that organisations such as children's hospices need to consider the appropriate level of specialist medical cover.

A specialist children's palliative care team is defined as one which is supported by a doctor with specialty training (a consultant) in paediatric palliative medicine.^{37, 38}

There are also specialist level nurses and specialist psychologists providing expert emotional support to children and families where it is needed, helping them to adjust to their child's prognosis, develop coping skills, build resilience and supporting them in bereavement.

1.6.4 Care for the team around the child

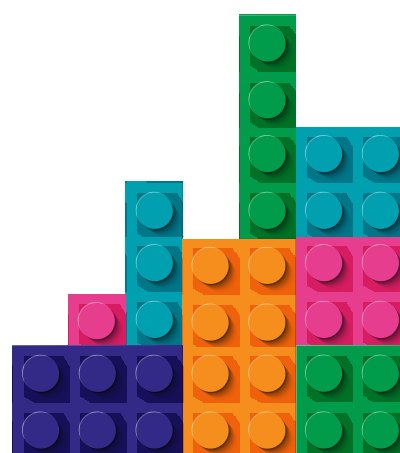
Everyone who is called upon to support the child and their wider family will at times find it emotionally challenging. Every member of the team around the child and family should receive support and an opportunity to feedback and discuss what is happening. Professionals as well as volunteers should have access to ongoing support and supervision.

35. Together for Short Lives. (2013). *The Future of Hospice Care: Implications for the children's hospice and palliative care sector*. Together for Short Lives, Bristol.

36. Mitchell, S. (2016). *Specialist paediatric palliative care services: what are the benefits?* Arch Dis Child, 10, 1136.

37. NHS England. (2013). E03/S/h. *NHS Standard Contract for paediatric medicine: palliative care particular, schedule 2 – the services, A – service specifications*.

38. National Institute for Health & Care Excellence. (2016). *Guideline on End of Life Care for infants, children and young people with life-limiting conditions: planning and management*. (N961)



Section 2

Service planning and delivery

Key points

- **Service planning and delivery should be based on local population numbers and knowledge of needs.**
- **It's important to have a joined-up approach between health and social care, children's and adult services and with services for disabled children.**
- **A care pathway approach can help to achieve this and support delivery of NICE guidelines.**
- **There are six key factors to consider when delivering children's palliative care.**



This section aims to provide the principles for planning and providing a comprehensive and co-ordinated overall children's palliative care service, based on local need and delivering the highest quality of care for individual families based on research evidence and with appropriate clinical governance.

The principles and standards of the Together for Short Lives' care pathways provide a simple framework for ensuring that children and their families are at the centre of joined-up planning and delivery of care. They can be used in conjunction with other standards and guidelines, such as the NICE *Guidelines on End of Life Care for Children*^{39, 40} and Quality Standard⁴¹ which is summarised in Appendix 2, or frameworks from other countries.⁴²

2.1 General principles in the delivery of children's palliative care

There are some overarching elements of good practice which should be considered for every child with a life-limiting condition. Many of these should apply to all children's care. (See Fig. 5 overleaf).

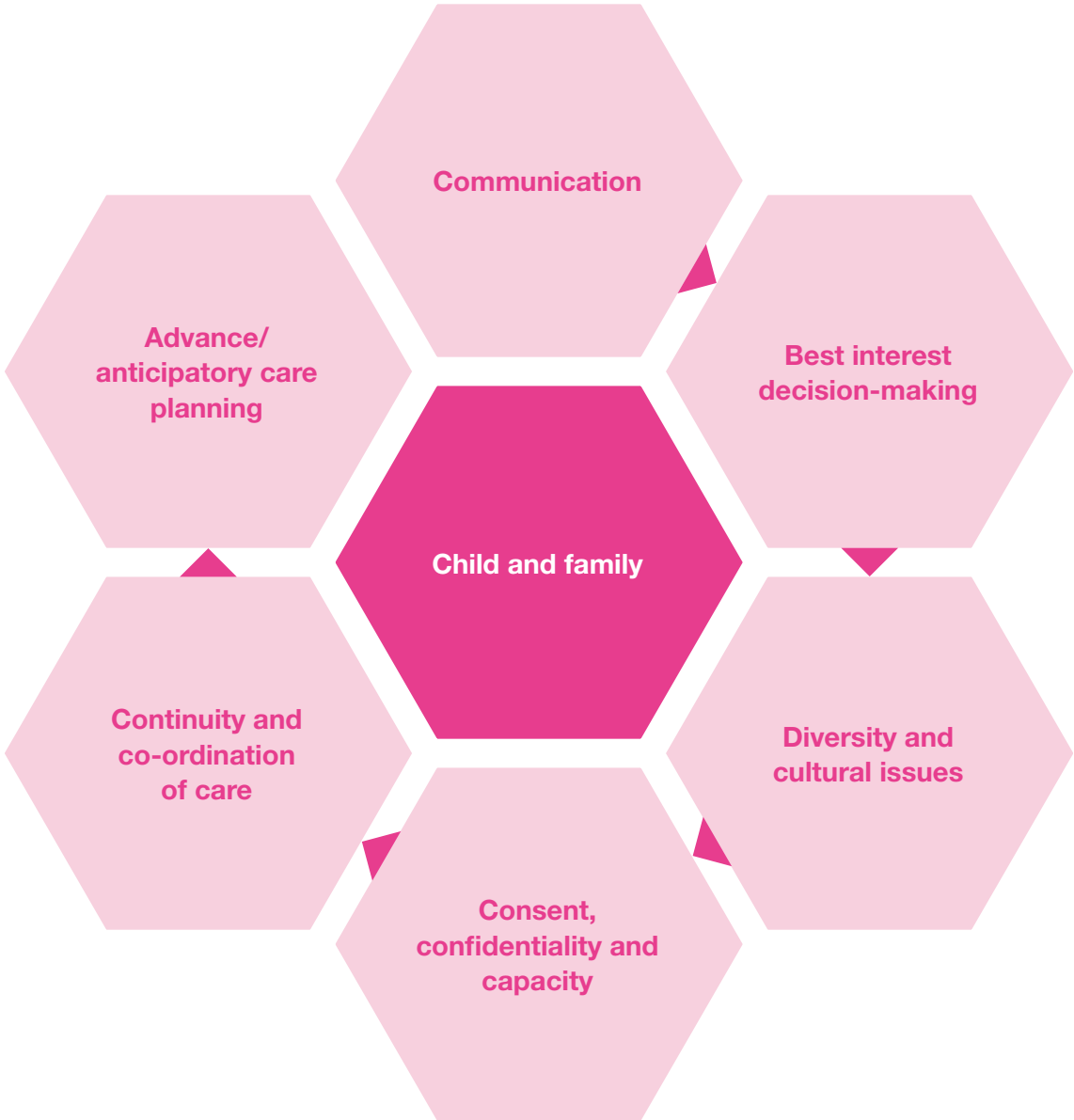
39. National Institute for Health and Care Excellence. (2016). *End of life care for infants, children and young people with life-limiting conditions: planning and management*. NICE, London. (N961)

40. Villaneuva, G et al. (2016). End of life care for infants, children and young people with life-limiting conditions: Summary of NICE guidance. *BMJ*, 355: 6385

41. National Institute for Health and Care Excellence. (2017). *End of life care for infants, children and young people: Quality standard (QS160)*. NICE, London.

42. Scottish Government. (2015). Strategic framework for action on palliative and end of life care.

Fig. 5: Six general principles to consider when delivering children’s palliative care



Communication

There should be an honest, open and timely approach to all communication with parents and carers throughout the child’s illness, from diagnosis to discussions about end of life and in bereavement. They should be consulted about other people important to them (such as friends, boyfriends or girlfriends, teachers or foster parents) and how they would like them to be involved. Good communication skills and the development of rapport between clinicians and families are essential in children’s palliative care. Different professionals may lead on communication at different stages, so it’s important to take account of their expertise and ability to discuss the topics that are relevant at that

time, their availability (for example, if discussions are needed over the course of an acute episode or at end of life). Children, young people and families should be consulted about which professional they would like to lead on communications with them. Consideration needs to be given to the different ways that people communicate (for example children might communicate through play activities), their level of understanding and the external factors that might impact on this. Consideration should also be given to whether any communication aids or interpreters may be needed to support the family. Communication between professionals, with a speedy flow of both clinical and social information between services is essential for the co-ordination and continuity of care.

Best interest decision-making

The overriding legal and ethical principle in the UK is that all treatment decisions must be taken in the child's best interest. Children and young people and their parents or carers should have a central role in decision-making. The nature of children's palliative care means that some very difficult decisions may need to be made about end of life care options and there needs to be sufficient time and space given to explore these complex ethical issues.⁴³

Diversity and cultural issues

Culturally appropriate care which respects diversity helps maintain a family centered approach. An awareness of the importance of cultural and religious practices around death, dying and bereavement is helpful and facilitates open conversations so that the individual needs of each family can be addressed.⁴⁴

Consent, confidentiality and capacity

Confidentiality, consent and capacity issues must be addressed throughout each child's care journey.^{45, 46}

- Ask which topics they feel are important and would particularly want information on.
- Ask whether there are topics they do not want detailed information on, and discuss their concerns.
- If appropriate, ask parents or carers whether they think their child understands their condition and its management, and which professional their child would like to talk to about it.
- If appropriate, ask parents or carers what they think their child should be told about their condition.

Continuity and co-ordination of care

Children with life-limiting conditions often experience multiple admissions to hospital and transfers to different care settings. Where possible, try to ensure that there are minimal changes to the members of the team supporting the child and family and that a named member of the care team takes the lead role in coordinating their care. This can help reduce the number of times that families have to repeat their story.

Advance Care Planning/Anticipatory Care Planning

Some children will have a very short life expectancy and things can change very quickly. Advance or Anticipatory Care Planning (ACP) is a process of discussion between the child and family with their care provider. Be aware that ACP discussions can be very distressing for children, young people and their families and they may find it difficult to discuss with professionals and with one another as end of life approaches. It is important to talk about dying and to support children and families to do this.

If there is an antenatal diagnosis, ACP discussions should start during the pregnancy and may involve obstetricians, midwives, neonatologists, condition specialists or members of the children's palliative care team. Parents often want to continue disease-directed care so a parallel planning approach can be helpful to facilitate conversations about planning in advance for withdrawal of treatment, alongside planning for ongoing care and supporting the best quality of life.⁴⁷

2.2 Together for Short Lives' care pathway standards and goals

The Together for Short Lives *Core Care Pathway* is designed to be a framework that can be adapted for implementation locally, according to available resources. The standards and key goals of the Core Care Pathway are set out in Fig. 6, together with a brief analysis of how they link to and can support delivery of the *NICE Guidelines*.⁴⁸

43. RCPCH. (2014). Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice. *Arch Dis Child*, 10, 1136.

44. Gandhi-Rhodes, K and Rose-Odogwu, C. (2009). *Diversity Toolkit*. Published by Children's Hospices UK, Bristol.

45. British Medical Association. (2016). *Consent Toolkit*. <https://www.bma.org.uk/advice/employment/ethics/consent/consent-tool-kit/7-children-and-young-people>

46. Rainbows Hospice. (2016). *My Adult Still My Child*. <http://myadultstillmychild.co.uk/>

47. Thomas, K and Lobo, B. (2017). Chapter 'Advance Care Planning' in End of Life Care, 2nd edition. Oxford University Press. Edited by Keri Thomas and Ben Lobo.

48. National Institute for Health and Care Excellence. (2016). *End of life care for infants, children and young people with life-limiting conditions: planning and management*. NICE, London.

Fig. 6: A comparison of Together for Short Lives Pathway standards and NICE Guideline recommendations

Together for Short Lives Core Care Pathway standards	Together for Short Lives Core Care Pathway goals	Links to recommendations in NICE Guidelines
<p>Standard 1</p> <p><i>Every family should receive the disclosure of their child's prognosis in a face-to-face discussion in privacy and should be treated with respect, honesty and sensitivity. Information should be provided for the child and the family in a form that they can understand.</i></p>	<p>Goals</p> <ol style="list-style-type: none"> 1. News should be shared in a face-to-face discussion in privacy. 2. Written information should be provided to support verbal communication. 3. Emotional support should be available to families when significant news is being shared. 4. Information conveyed should be available to families when significant news is being shared. 5. Parents should be treated with openness and honesty. 6. If possible, families should be together to receive the news. 	<p>NICE</p> <ul style="list-style-type: none"> • Communication (1.1.9 – 1.1.14) • Providing Information (1.1.15-1.1.20)
<p>Standard 2</p> <p><i>Every child and family diagnosed in the hospital setting should have an agreed transfer plan involving hospital, community services and the family, and should be provided with the resources they require before leaving hospital.</i></p>	<p>Goals</p> <ol style="list-style-type: none"> 1. Community services should be notified as soon as it is practical to do so. This may include children's hospice services. 2. There should be community in-reach to the family in hospital and outreach to primary care services. 3. Planning should begin as soon as possible and a clear plan for transfer should be agreed with the child, family, hospital and community services. 4. A lead community children's nurse should be agreed before transfer and the child's GP should be included. Clear plans should be in place for shared medical care. 5. Equipment and supplies should be provided before transfer. 6. Transport should be arranged. 7. Training should be provided for parents and carers prior to transfer. 8. Clear lines of communication should be agreed. 9. A home visit should be arranged within three days of transfer. 	<p>NICE</p> <ul style="list-style-type: none"> • Rapid transfer arrangements (1.5.8) • Care at home (1.5.9 – 1.5.11)

	<p>10. A 24-hour contact number should be provided to the family.</p> <p>11. If transfer to a children's hospice is planned, a member of the team should meet the family at the hospital before discharge where possible.</p>	
<p>Standard 3</p> <p><i>Every family should receive a child and family centred multi-disciplinary and multi-agency assessment of their needs as soon as possible after diagnosis or recognition and should have their needs reviewed at appropriate intervals.</i></p>	<p>Goals</p> <ol style="list-style-type: none"> 1. Those undertaking assessments should be skilled in the assessment of children with palliative care needs. 2. Children and families should have their strengths, needs and wishes assessed as soon as possible after diagnosis or recognition in partnership with the family. 3. A holistic, multi-disciplinary and multi-agency approach should be used to avoid the need for multiple assessments. 4. The child or young person should be the central focus of the assessment. 5. Care should be taken to include the strengths and needs of fathers, siblings and the wider family. 6. To enable shared assessment, consent needs to be gained and confidentiality assured. 7. Assessment information should be part of a family held document. 	<p>NICE</p> <ul style="list-style-type: none"> • General principles (1.1.1– 1.1.8) • Care planning and support throughout the child or young person's life (1.2.1 – 1.2.4)
<p>Standard 4</p> <p><i>Every child and family should have a multidisciplinary, multi-agency care plan, developed in partnership with them for the delivery of co-ordinated care to enhance family strengths and meet need. A multi-disciplinary and multi-agency team should be identified in agreement with the family and use key working principles. Wherever possible this should involve all agencies involved in supporting the child and family, including the child's community nursing team, allied health professionals, hospice, local acute and tertiary hospital services, education, social care and short break services.</i></p>	<p>Goals</p> <ol style="list-style-type: none"> 1. Every family should have a team that uses key working principles to co-ordinate the plan. 2. Relevant and timely information should be available for the child and family. 3. The plan should take account of the whole family's needs and wishes. 4. The plan should be comprehensive. 	<p>NICE</p> <ul style="list-style-type: none"> • A named medical specialist (1.2.2) • Managing transition to adult services (1.2.3) • Emotional and psychological support and interventions (1.2.22 – 1.2.27) • Social and practical support (1.2.28) • Religious, spiritual and cultural support (1.2.29 – 1.2.32) • Service delivery: Multidisciplinary team (1.5.1 – 1.5.7) • Care planning and support throughout the child or young person's life (2.3)

<p>Standard 5</p> <p><i>Every child and family should be helped to decide on an end of life plan and should be provided with care and support to achieve this.</i></p>	<p>Goals</p> <ol style="list-style-type: none"> 1. Professionals should be open and honest with families when the approach to end of life is recognised. 2. Joint planning with families and relevant professionals should take place as soon as possible. 3. A written plan of care should be agreed and shared with emergency services, including decision about methods of resuscitation. 4. Care plans should be reviewed and altered to take account of changes. 5. There should be 24-hour access to pain and symptom control including access to medication. 6. Those managing the control of symptoms should be suitably qualified and experienced. 7. Emotional and spiritual support should be available to the child and family. 8. Children and families should be supported in their choices and goals for quality of life to the end. 9. There needs to be clear understanding of the formal processes that are needed after death and the timing of these. 	<p>NICE</p> <ul style="list-style-type: none"> • Advance Care Planning (1.2.5 – 1.2.15) • Organ and tissue donation (1.2.16 – 1.2.21) • Care of the child or young person who is approaching end of life (1.3.1 – 1.3.8) • Preferred place of care and place of death (1.3.9 – 1.3.19) • Managing distressing symptoms, pain, agitation, seizures, respiratory distress, hydration, nutrition (1.3.20 – 1.3.55) • Recognising that a child or young person is likely to die within hours or days (1.3.56 – 1.3.70) • Care and support for parents, carers and healthcare professionals in relation to the death of a child or young person. • Practical arrangements (1.4.1)
<p>Standard 6</p> <p><i>Bereavement support should be provided along the care pathway and continue throughout the child's death and beyond.</i></p>	<p>Goals</p> <ol style="list-style-type: none"> 1. The family should be allowed time and privacy with their child. 2. Parents should feel in control of events before and after the death and be able to follow their own choices and wishes. 3. Families should all be offered bereavement support, and this offer should be repeated as it may not be heard or taken up in the first instance. 4. The bereavement needs of siblings should be recognised and supported. 	<p>NICE</p> <ul style="list-style-type: none"> • Bereavement support (1.4.2 – 1.4.6) • Support for professionals (1.4.7) • Informing other professionals (1.4.8 – 1.4.9)

2.3 Commissioning

Key points

- **Relatively small numbers and the specialist nature of children's palliative care means there is a need to create economies of scale.**
- **There should be a pathway approach to commissioning, across services and sectors, joining up health and social care in particular.**
- **It's helpful to create links with services for disabled children and with adult palliative care.**

The fact that there are relatively small numbers of children with life-limiting conditions, coupled with the specialist nature of children's palliative care services, points to the value of planning these services across a population of at least 1,000,000.⁴⁹ Given the considerable pressures on commissioning (for example, from elderly care and mental health), it is important to think about economies of scale, for example where CCN teams for all children with long-term or complex conditions are integrated with palliative care, it may be possible to commission an integrated but sustainable service. It may also be helpful for commissioners to work together to create the economies of scale necessary to commission services effectively. NICE has produced an economic modelling resource which may be a helpful tool for both commissioners and providers.⁵⁰

Commissioners will need to think about the full range of care and support that is needed for children and families and aim to establish joined-up care, with no gap as young people move from children's to adult services.^{51, 52} This pathway approach can be a helpful way of linking children and their families to community services, hospital-based services, social services, education, children's hospices and other voluntary providers in one, joined-up planning process.

Commissioning of children's palliative care should not be done in isolation. Ideally it should be considered in conjunction with services for disabled children to ensure a whole service approach. There is also a link between the morbidity of parents in caring roles which should be a consideration in the overall planning of services for the locality.

It is important for commissioners to work with providers to develop a shared understanding of what they want to achieve for children with life-limiting conditions and their families.⁵³ This can be achieved through engagement with regional children's palliative care networks and in supporting the establishment of more formally run Managed Clinical Networks.

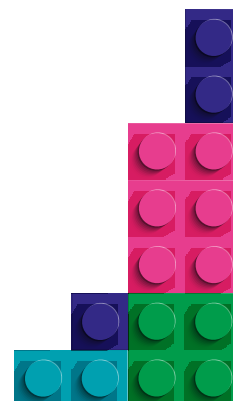
49. York Health Economics Consortium. (2007). *Palliative Care Statistics for Children and Young Adults*. DH, England.

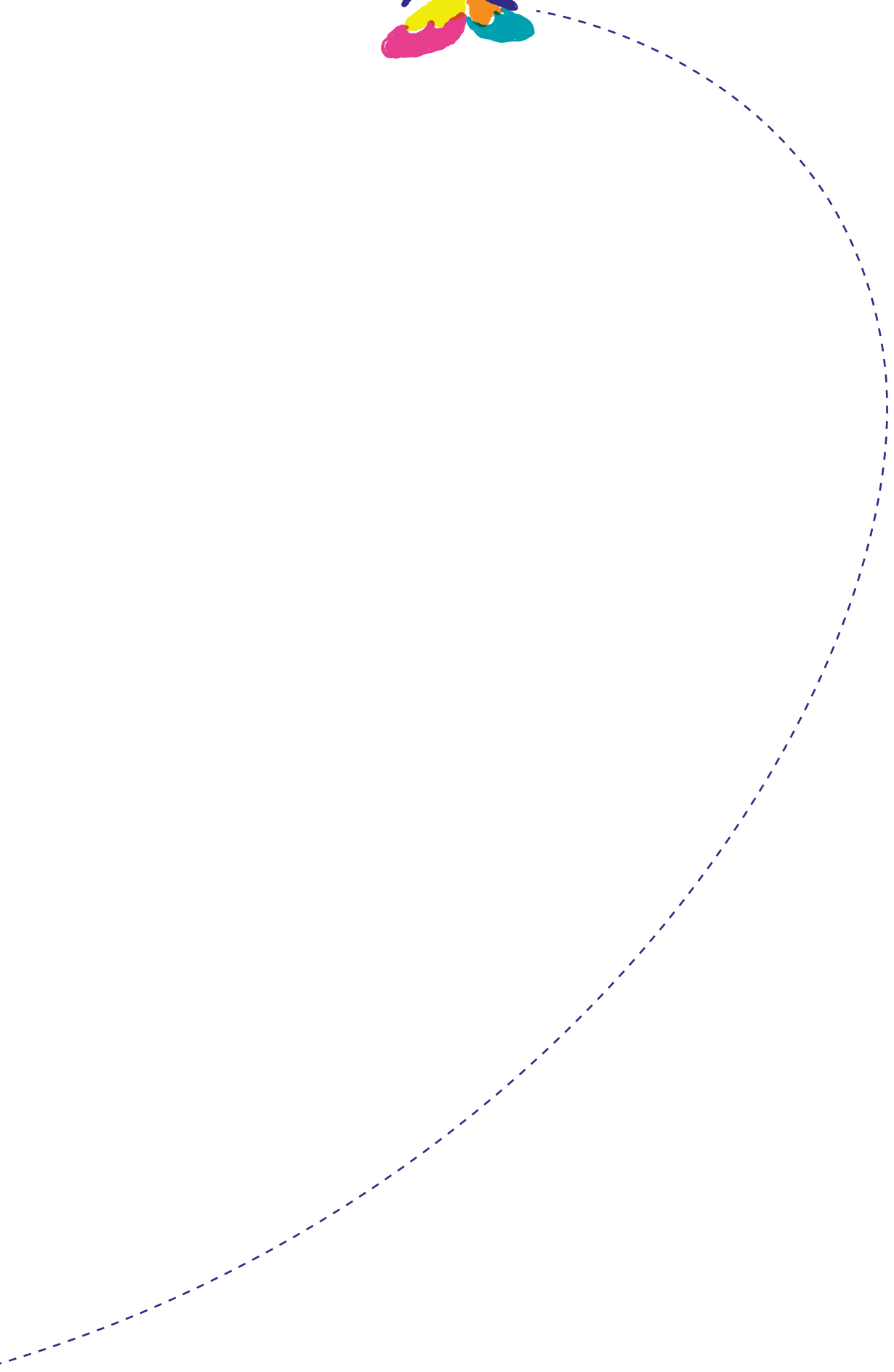
50. National Institute for Health & Care Excellence. (2016). *Resource impact report: End of life care for infants, children and young people with life-limiting conditions: planning and management (NG61)*. NICE, London.

51. Together for Short Lives. (2015). *Stepping Up: A Guide to enabling a good transition for young people with life-limiting and life-threatening conditions*. Together for Short Lives, Bristol.

52. Preparing for Adult. (2015). *Joint commissioning in action*. PFA, London.

53. Together for Short Lives. (2016). *Joint Commissioning Guide*. Together for Short Lives, Bristol.



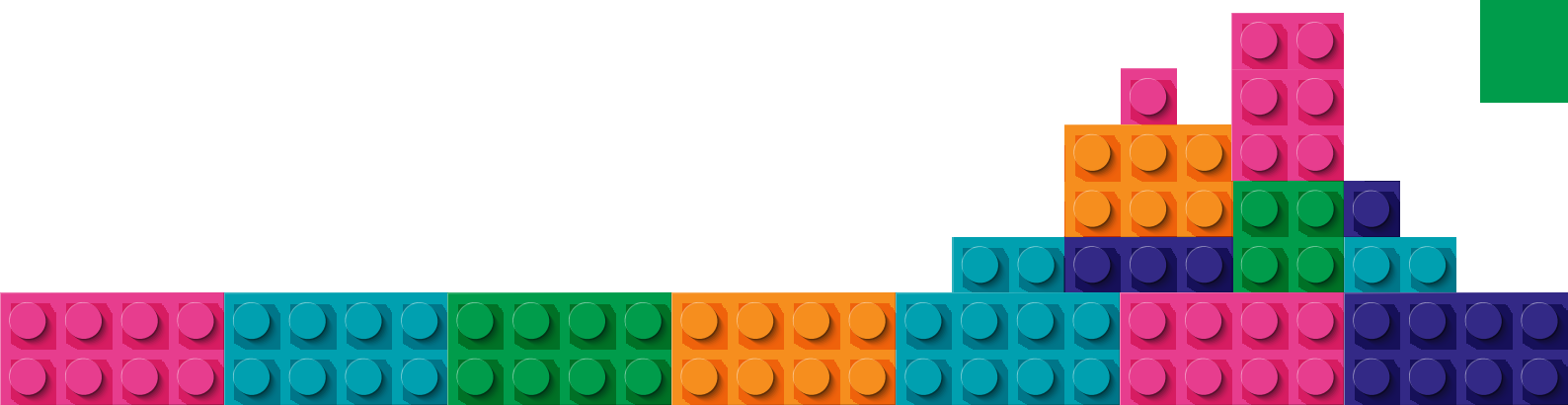


Section 3

Workforce, education and training

Key points

- There is a growing shortage of skilled professionals, despite recognition of paediatric palliative medicine as a sub-specialty and development of new nursing associate roles.
- There is need for a joined-up approach to education and learning.
- Innovative models for providing supervision and support for staff working in children's palliative care need to be developed.



3.1 Overview of key workforce challenges and opportunities

One of the key challenges for the children's palliative care sector is to achieve a workforce that has the capacity to provide palliative care to children that is safe, effective, high-quality and that is provided by competent and confident practitioners whether this is the general or specialist workforce.⁵⁴ This is difficult to achieve in the context of a growing shortage of skilled professionals, changing working patterns, new educational arrangements and the fact that a significant proportion of the children's hospice and palliative care workforce is due to retire in the next 10-15 years.⁵⁵

Children's palliative care is provided by a network of agencies including statutory (health, education and social care), voluntary and independent sector

providers. There is also a growing trend towards children's palliative care becoming 'everyone's business', with more community-led initiatives and volunteering schemes being developed to provide additional support to families. It is important to think about how to use this wide-ranging workforce to explore innovative models of care, such as new ways to provide short breaks in a flexible and sustainable way.

There is also a need for a joined-up approach to developing education and learning opportunities for all staff working with children with life-limiting conditions at all levels; in specialist, core and universal services.⁵⁶ A collaborative approach between different disciplines may be helpful, for example between children's palliative care and neonatal intensive care staff or between children's and adult's palliative care professionals in order to improve skills.

54. Together for Short Lives. (2016). *Workforce Signpost Guide*. Together for Short Lives, Bristol.

55. Hospice UK. (2013). *Future ambitions for hospice care: our mission and our opportunity*. The final report of the Commission into the Future of Hospice Care. Hospice UK, London.

56. Downing, J et al. (2014). EAPC White Paper on core competencies for education in paediatric palliative care. *EJPN*, 21, 5, p245-249.

3.2 The medical workforce

Doctors work in paediatric palliative care in a range of different roles and care settings. The Royal College of Paediatrics and Child Health's recognition of paediatric palliative medicine as a sub-specialty within paediatrics in 2008 has provided both acknowledgement and validity to the field. There is also a curriculum for doctors across all specialties and at all levels who encounter children with a life-limiting illness or who are dying.⁵⁷ There are an increasing number of training posts provided for doctors in children's palliative care settings.

3.3 The nursing workforce

Nurses play a key role in the delivery of children's palliative care within a diverse range of roles in hospital, in the community, schools and hospices. With new developments such as the 'Nursing Associate' role (which aims to provide basic care in primary, secondary, community and social care) and the new nursing degree apprenticeship programme (which aims to provide an opportunity to train flexibly for a career in nursing), there should be potential to create more flexible career progression routes into nursing. However, there is still a reported shortage of qualified nurses to provide children's palliative care.⁵⁸

3.4 The social care workforce

The social care workforce includes palliative care social workers and support workers who work directly with families. The British Association of Social Workers (BASW) has set standards for social work practice in palliative, end of life care and bereavement. In Scotland, the Scottish Social Services Council (SSSC) is the regulator for the health and social service workforce and provides a register of qualified social service workers, sets standards and supports their professional development. All support workers working in residential care and providing 'care at home' will need to apply to be on this register.

3.5 Supervision and support for staff

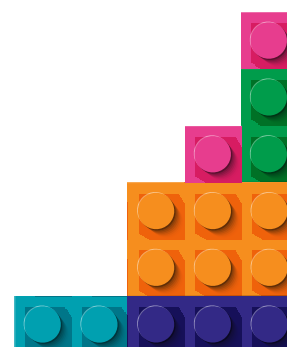
Working in children's palliative care can be stressful and have an emotional impact on staff. They should have access to a range of support such as clinical supervision, appraisals, mentoring and psychological support. Among the range of approaches to providing support and development opportunities to staff are 'Schwartz Rounds'; these are regular multi-professional team meetings where staff can reflect on the emotional impact of patient care⁵⁹ or an initiative called 'Project Echo' which is seeking to develop palliative care learning hubs.⁶⁰

57. RCPCH. (2015). *Curriculum in Paediatric Palliative Medicine Association for Paediatric Palliative Medicine Education Subgroup and Paediatric Palliative Medicine College Specialty Advisory Committee Royal College of Paediatrics and Child Health 2nd Edition 2015* <http://www.appm.org.uk/resources/PPM+Curriculum+2015.pdf>

58. Together for Short Lives. (2017). *The State of Children's Palliative Care Nursing in 2017*. Together for Short Lives, Bristol.

59. Lown, B and Manning, C. (2010). *The Schwartz Center Rounds: Evaluation of an interdisciplinary approach to enhancing patient-centred communication, teamwork, and provider support*. *Academic Medicine*, Vol 85, Issue 6, 1073-1081.

60. Arora, S et al. (2017). *Project ECHO: An effective means of increasing palliative care capacity*. *American Journal of Managed Care; Evidence Based Oncology* 23(7): S267-71.



Section 4

Evidence-based practice and research

Key points

- Children's palliative care service development has outstripped the evidence base.
- There's a need to prioritise the most important research questions.
- Research is needed that draws on views of children, young people, parents, clinicians and institutions, using a broad range of methodologies.
- It's important to synthesise existing research findings to inform practice guidelines.
- We need to address the barriers to research in children's palliative care: funding, research governance (ethics) and clinician gate keeping.
- Collaboration should be supported between clinicians and academic researchers.



This section has been contributed by the **Together for Short Lives and Association for Paediatric Palliative Medicine Joint Research Group**, chaired by **Professor Myra Bluebond-Langner**.⁶¹

4.1 Why research is important in children's palliative care

Children's palliative care is a relatively new field in which the development and delivery of services has outstripped the evidence base.⁶² More quality research is needed not only to identify and document the issues patients, families and professionals face and the circumstances in which

they arise, but also to guide the development and evaluation of interventions to address these issues. Such research is key to providing the best support for an ever increasing and diverse population of babies, children and young people with life-limiting and life-threatening conditions.

4.2 Research priorities

A number of research prioritisation exercises have been carried out since the last edition of *The Guide*.^{63, 64, 65, 66} Parents, patients, researchers and clinicians who have participated in these exercises have identified five areas where further research is needed:

61. Bluebond-Langner, M et al. (2016). Promoting high quality research with life-limited children and their families: Establishment of a joint Research Group between Together for Short Lives and the Association of Paediatric Palliative Care Medicine. Editorial, *J Adv Nursing*, Jan 2016. P283-285.
62. Bluebond-Langner, M et al. (2014). Pediatric palliative care in 2014: Much accomplished, much yet to be done. *J of Pall Care 30th Anniversary Thematic Issue*, 30,4,311-316.
63. Steele, R et al. (2008). Research priorities in pediatric palliative care: A Delphi study. *Journal of Palliative Care* 24(4): February 2008, 229-39.
64. Baker, J et al. (2015). Research priorities in paediatric palliative care. *J of Paediatrics*, Vol 167, Issue 2, Aug 2015, pp 467-470.
65. Downing et al. (2015). Priorities for global research into children's palliative care: results of an International Delphi Study. *BMC Palliative Care* 14:36 August 2015
66. Martin House. (2017). Research Prioritisation Exercise. <https://www.york.ac.uk/healthsciences/research/public-health/projects/martinhouse/projects/prior-exercise/>.

- The illness and bereavement experience
- Communication and decision-making
- Emotional, social, and psychological wellbeing
- Pain and symptom management
- Service development and delivery, including the development of outcome measures.

The illness and bereavement experience

There is a need for studies which will increase understanding of both the individual and the universal experiences of children and families over the entire course of the illness, covering the range of diagnoses on the palliative care spectrum⁶⁷. It is important to understand how children and families live with illness and cope with bereavement in order to ensure that services are developed which truly meet their needs. Studies are needed which will illuminate the lives of children and families as they manage complex care routines, set and reset priorities and hopes for the future and cope with loss, all in the context of trying to live as normal a life as possible.

Communication and decision-making

Assisting families in decision-making about their child's care, treatment and death is a core activity of children's palliative care. Communication is key. Yet there is very little evidence about how best to conduct these conversations and what support parents want and need in decision-making. What do parents and patients want to know? What do parents and patients have to say in conversations with health care professionals? What do they take away?

Emotional and psycho-social support

There is a need to understand more about the emotional and psychological needs of children and families and the impact on their mental health. We need to learn more not only to better understand what ill children and their siblings are thinking and feeling, but also how best to elicit their thoughts and feelings so that we can become more effective in talking with them and providing the social and emotional support they need.

Pain and symptom management

Pain and symptom management is currently based largely on experience, on trial and error.⁶⁸ Further research is needed that will lead to a stronger evidence-base about the efficacy of both pharmacological and non-pharmacological interventions and how these can be best delivered. Trials need to be conducted with larger populations to examine the effects of the drugs commonly used to treat pain.

Service development and delivery

There is also a need to know more about the best ways to deliver care to children and families and to explore the development of new service models, looking at whether such new models can be delivered within available financial resources. There needs to be evaluation of how best to deliver education and training on children's palliative care to reach the many different professionals and specialisms that could potentially engage in conversations with children and families facing a life-threatening condition. There is a pressing need to develop Patient Centred Outcome Measures to allow parents and children to identify what is important to them and to enable services to measure whether they are meeting these identified outcomes.

4.3 Doing research that makes a difference

Research in the context of children's palliative care is complex. It involves capturing the views of children and young people, parents, clinicians and the institutions of which they are a part and needs to reflect these views honestly and dispassionately, irrespective of whether they differ from those of the researcher or current clinical practices.

As a small field, it's important to involve a variety of partners in research who have a breadth and depth of expertise not just for the delivery of large multi-site studies, but also to facilitate the complex, robust studies that are needed to advance the evidence base for the children's palliative care sector as a whole.

67. Fraser, L et al. (2012). Life-limiting and life-threatening conditions in children and young people in the United Kingdom; final report for Together for Short Lives.

68. Beecham, E et al. (2015). Pharmacological interventions for pain in children and adolescents with life-limiting conditions. *Cochrane Database Systematic Review*, Mar,13, 3.

Researchers need a broad ranging methodological toolkit to ensure that the method used best fits the nature of the study being undertaken. For example, ethnographic and child and family-centred methods can be used to better capture the voices of children and families; observational studies can usefully draw on routinely collected clinical data to supplement data that is collected for research purposes. There is a need to do more prospective studies in order to focus on the reality of the situation being studied as it unfolds. It may be feasible to use randomised control trials to evaluate new pain management interventions and protocols versus existing approaches. Systematic reviews of the literature including Cochrane reviews are a useful first step in establishing what is known and where the gaps are on a given issue as well as in synthesising existing knowledge as we look to develop evidence-based guidance.

4.4 Barriers and opportunities to delivering high quality research in children's palliative care

As well as developing a wider programme of research questions, it is equally important to think about how to enable children and families and people working in the children's palliative care sector to become actively involved in carrying out research. There are three major barriers to conducting robust research in children's palliative care: (1) funding (2) research governance (3) clinician gate keeping.⁶⁹

There are significant barriers to securing research funding. Relatively small numbers, diverse illnesses and conditions make competing for and securing research funds difficult; a situation exacerbated by the limited number of funders both private and public. The children's palliative care research community can learn from what has worked well in other fields with small populations who have formed national, European and global research networks and consortia to pool numbers and expertise so that studies are more robust and have sufficient power to determine effects.

The difficulty of securing ethical approval to carry out research with children, young people and their families with life-limiting conditions has been a significant barrier and additional training for ethics committee members may be needed. There are positive signs that some NHS ethics

committees now put themselves forward as having specific expertise in children's studies and there is a growing awareness that children and families themselves want to participate in research studies, with a move towards co-design and co-research with service users.

A key step in enabling research participation is to give children with life-limiting conditions and their families the same right as anyone else to decide if they wish to participate in sensitively conducted research. Ethics committees now welcome 'patient' representatives to attend committee meetings with members of the research team. Hearing the child and family perspective can be very powerful in alleviating any concerns that the ethics committee may have about the importance of the question or the additional 'burden' that participation in a study may place on children and their families. Researchers in children's palliative care are also beginning to look at strategies such as 'opt out' which are successfully employed in other fields and settings (for example, emergency medicine, adult palliative care) for particular kinds of research.

Following a submission from the joint Together for Short Lives and Association for Paediatric Palliative Medicine Research Group, the latest RCPCH Guidance⁷⁰ on involving children in medical research includes a section on enabling research with particularly vulnerable children which states that:

"Children with life-threatening illnesses, looked-after children, their families, and bereaved families require a robust evidence base for both physical and psychosocial aspects of care. However, evidence remains limited and largely focused on aspects such as symptom relief. The fear of intruding on children who are especially vulnerable, and their families, and the perceived need to provide them with extra protection has led to reluctance to involve them in research. However, there is now considerable evidence that families and young people who participate in research find it beneficial rather than harmful, with opportunity to speak about illness and death, express painful emotions, and obtain release from isolation. There is also evidence of a 'maturational effect' of life-ending illnesses, where children and young people express a wish to benefit others and benefit themselves from such 'meaningful' encounters. Research in these sensitive areas, including qualitative studies, requires review by research ethics committees that have the necessary knowledge and expertise."

69. Beecham, E et al. (2016). *A call for increased paediatric palliative care research: Identifying barriers*. *Palliative Medicine*, 30,10 page 979-980.

70. Modi, N et al. (2014). *Guidance on clinical research involving infants, children and young people: an update for researchers and research ethics committees*. RCPCH page 6.

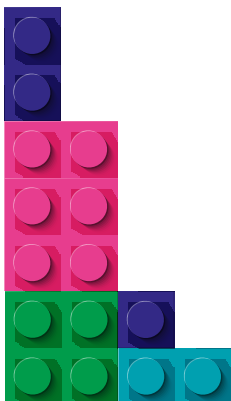
Other ways to reduce barriers to participation include: involving clinicians in the design and development at the outset, holding regular meetings to discuss the recruitment of participants, embedding researchers in clinical teams, and pressing for changes in research governance such that researchers can carry out invitation and recruitment themselves, rather than through clinicians.

4.5 Research capacity building

Quality research takes time and cannot easily be fitted in on top of an already packed clinical brief. This needs to be recognised so that the views of clinicians and those on the front line of service delivery can contribute in a timely way to research and be involved in grant applications and publications.

Collaboration is key between clinicians and service providers and with academic researchers. It's important that research questions are discussed early and framed in the context of what's most important for the sector. Such collaboration also contributes to the development of a research-ready workforce by building the capacity of professionals with sufficient skills and experience to conduct large scale and robust children's palliative care research. There is a pressing need to develop and support the next generation of researchers through graduate programmes, fellowships and academic posts.

Collaborations between clinicians and academics will contribute to a research ethos in children's palliative care in which not only the conduct of research, but also the findings from that research will find their way into practice. It will lead to a balance between eminence-based and evidence-based practice.



Appendices

Appendix one: Glossary of descriptions and definitions used in *The Guide*

Advance Care Plan/Anticipatory Care Plan

A formal care plan that includes details about the child or young person's condition, decisions made with them and their parents or carers (for example about managing symptoms), and their wishes and ambitions. The ACP is a core element of children's palliative care. The term 'Anticipatory Care Plan' is used in Scotland.

Care pathway

The Together for Short Lives' care pathways are an approach to working with babies, children or young people who have life-limiting or life-threatening conditions. They are a way of engaging with a child and their families' needs to ensure that everything is in place so that families have everything in place so that families have access to the appropriate support at the appropriate time.

Children

Throughout this document, the term 'children' is used to describe babies, children and young people up to their 19th birthday.

Children's palliative care

Children's palliative care is an active and total approach to care, from the point of diagnosis or recognition throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on enhancement of quality of life for the child/young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.

Children's hospice services

Children's hospice services provide palliative care for children with life-limiting conditions and their families. Delivered by a multi-disciplinary team and in partnership with other agencies, children's hospice services take a holistic approach to care, aiming to meet the needs of both child and family – physical, emotional, social and spiritual – through a range of services. Children's hospice services deliver this care in the home (commonly termed 'hospice at home service') and/or in a purpose-built building.

Commissioner

A person with responsibility for commissioning services from service providers in either the public, private or voluntary sector.

Commissioning

The process of improving outcomes and meeting the needs of the population within the local health community with the resources available.

Community services

Community services refer to a service that an individual or organisation performs within the local community. This might include community children's nurses (CCNs) who deliver nursing care and support within the local community including visiting a patient's home. Community services may also include some of the services delivered by the local council.

Complex care/continuing care

Complex care, sometimes known as continuing care, is an individualised package of care beyond what is available through standard health services. It is provided to children with highly complex health care needs or intense nursing care needs.

End of life

The end of life stage begins when a judgement is made that death is imminent. It may be the judgement of the health or social care team, but it is often the young person or their family who first recognises its beginning.

End of life care

End of life care is care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It focuses on preparing for an anticipated death and managing the end stage of a terminal medical condition. This includes care during and around the time of death and immediately afterwards. It enables the supportive and palliative care needs of both child/young person and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and the provision of psychological, social, spiritual and practical support.

Family

The term 'family' includes parents and other family members involved in the care of the young person, or other carers who are acting in the role of parents. It includes informal carers and all those who matter to the child or young person.

Hospice at home

Hospice at home is a term commonly used to describe a service which brings skilled, practical children's palliative care into the home environment. Hospice at home works in partnership with parents and families and other carers.

Key working

Key working or care co-ordination is an approach involving two or more co-ordinated agencies. It encompasses individual tailoring of services based on assessment of need, inter-agency collaboration at strategic and practice levels, and provision of a named key worker for the child and their family.

Life-limiting (life-shortening) conditions

Life-limiting conditions, sometimes referred to as life-shortening conditions, are those for which there is no reasonable hope of cure and from which children or young people will die. Some of these conditions cause progressive deterioration rendering the child increasingly dependent on parents and carers.

Life-threatening conditions

Life-threatening conditions are those for which curative treatment may be feasible but can fail, such as in children with cancer. Children in long-term remission or following successful curative treatment are not included.

Needs-led

Needs-led is the term used to describe services provided on the basis of the needs of the child and family, rather than as a result of assessing the resources that are available.

Outcomes

In health provision, this is the change in a patient's current and future health status that can be attributed to preceding health care.

Parents

The term "parents" has been used throughout the text, and it is used to mean any carer for a child whether that is a married or unmarried couple, a single parent, guardian or foster parent.

Personalisation

A social care approach which means that every person who receives support, whether provided by statutory services or funded by themselves, will have choice and control over the shape of that support in all care settings. Services are tailored to the needs of every individual, rather than delivered in a one-size-fits-all fashion.

Personal budget

A personal budget is an agreed amount of money that is allocated to an individual following an assessment of their care and support needs. A personal health budget includes their assessed health and wellbeing needs.

Primary healthcare team

Comprises of the general practitioner, practice nurse and community staff (such as community children's nurses or physiotherapists) who work with the practice staff.

Safeguarding and child protection

Safeguarding is defined by the Care Quality Commission as 'protecting people's health, wellbeing and human rights, and enabling them to live free from harm, abuse and neglect.' The term 'child protection' is used in Scotland.

Short breaks

Short breaks have three main functions:

- To provide the child or young person with an opportunity to enjoy social interaction and leisure facilities.
- To support the family in the care of their child so they have a break from caring.
- To provide opportunities for siblings to have fun and receive support.

Short breaks may offer the whole family an opportunity to be together and to be supported in the care of their child or it may offer care solely for the child or young person.

Specialist short break care

Specialist short break care provides additional care in an appropriate setting or programme for highly complex or technology dependent children who may otherwise be excluded from short breaks. Specialist short break care may take place in the child's home or in a setting outside of the home such as a hospital, long-term care facility or hospice. Specialist short breaks will often address some aspects of symptom management. They should also meet the functions described under general short breaks.

Stable condition

The child's symptoms and other concerns are well controlled and stable.

Supportive care

Supportive care is an 'umbrella' term for all services, both generalist and specialist, that may be required to support people who have a life-threatening illness. It is not a response to a particular disease or its stage but is based on an assumption that people have needs for supportive care from the time that the possibility of a life-threatening condition is raised.

Symptom management

Symptom management is the management of common symptoms associated with life-limiting conditions. It is often used to refer to symptoms that are primarily physical, but in palliative care symptom management also includes attention to psychosocial and spiritual aspects of symptoms where appropriate.

Technology-dependent children

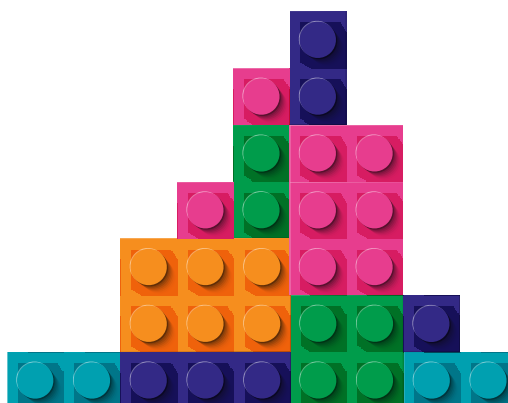
Children who need both a medical device to compensate for the loss of a vital bodily function and substantial and on-going nursing care to avert death or further disability.

Unstable condition

The child's symptoms and overall condition need regular review because they are unpredictable and at risk of worsening quickly.

Young adult

This term is used in this Guide to describe a person from their 19th-25th birthday.



Appendix two: NICE Guidelines and Quality Standard

NICE has developed the first Guidelines on *End of Life Care for Infants, Children and Young People* which set out recommendations based on published evidence (NICE, 2016). The Guidelines set out recommendations about what children and families should expect to receive from the point at which their needs are recognised until the end of their lives. The Guidelines are focussed on England, Wales and Northern Ireland, but the fundamental principles are relevant in other countries.

The associated NICE Quality Standard (NICE, 2017) consists of six quality statements and aims to help all who plan, fund or provide palliative care for children and their families to identify gaps and areas for improvement, measure the quality of care, understand how to improve care and demonstrate they are providing quality care.

NICE Quality Standard

1. Infants, children and young people with a life-limiting condition and their parents or carers are involved in developing an advance care plan.
2. Infants, children and young people with a life-limiting condition have a named medical specialist who leads and co-ordinates their care.
3. Infants, children and young people with a life-limiting condition and their parents or carers are given information about emotional and psychological support, including how to access it.
4. Infants, children and young people with a life-limiting condition are cared for by a multi-disciplinary team that includes members of the specialist paediatric palliative care team.
5. Parents or carers of infants, children and young people approaching the end of life are offered support for grief and loss when their child is nearing the end of their life and after their death.
6. Infants, children and young people approaching the end of life and being cared for at home have 24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care.

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A Guide to Children's Palliative Care (Fourth Edition)

The UK has been a pioneer in the development of palliative care for children and the principles are now well established and recognised. *The Guide to Children's Palliative Care*, has played a pivotal role in helping to drive this development, since it was first published in 1997.

The Guide to Children's Palliative Care is an essential must-read resource for all those with an interest in planning, commissioning and delivering services and care for babies, children and young people with life-limiting and life-threatening conditions and their families. Now in its fourth edition, The Guide, has earned the reputation as the cornerstone of children's palliative care planning and development, in the UK and internationally.

It provides a 360-degree insight into children's palliative care: what it is, its principles, purpose and importance to the children, young people and families who need it. *The Guide* seeks to establish and realise a vision that ensures children and their families have access to and receive comprehensive, high quality, evidence-based services delivered by an appropriately trained, experienced and integrated workforce.

This fourth edition comes as children's palliative care provision is relatively well established in the UK, with a recognised medical specialty. This new edition of *The Guide* seeks to cement the positive advances in children's palliative care since the last edition was published in 2009 and sets out a vision for the future sustainable development of children's palliative care. It includes a new and enhanced section on research, acknowledging the need to expand the evidence base for children's palliative care.



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