A Guide to the Development of Children’s Palliative Care Services

THIRD EDITION 2009
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Foreword

This is the latest edition of ACT's *A Guide to the Development of Children's Palliative Care Services*. As with previous editions it sets out the background, the definitions and the need for children's palliative care and lays out the actions that commissioners and providers need to take to develop the highest quality, child and family-centred services.

The Guide has been updated to reflect the work and the research that has been undertaken since the second edition was published in 2003, in particular the new statistics and evidence that emerged as Sue Killen and I led the work on the *Independent Review of Children's Palliative Care Services* in England in 2007.

Parents know what they would like and professionals know what the children and families need, but it is up to commissioners and providers of services to ensure that every child and young person has the necessary services and support to make the most of the precious time that they have.

ACT continues to work tirelessly to cement into practice their vision for children's palliative care across the UK. With work on care pathways, mapping of the numbers of life-limited children and young people, and education and training, there is now an armoury of resources and tools to enable both providers and commissioners to develop sustainable services that are of the highest standard.

This Guide brings together all these elements to ensure that excellent models of good practice are shared and established throughout the UK. The vision is that every life-limited or life-threatened child or young person, regardless of race, religion, age, gender or where they live, should have access to the sustainable, holistic, family-centred and high quality palliative care and support that they need.

I recommend this Guide as an important tool in enabling this vision to become a reality.

Professor Sir Alan W. Craft
Introduction

ACT 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. The first edition of the Guide was an invaluable tool for all those who were working in the newly emerging field of children’s palliative care.

A second edition was published in 2003 to reflect the expansion that had taken place in the range and number of children’s palliative care services and the increased profile of the specialty.

Since 2003, there has been a rapid growth and recognition of the children’s palliative care sector with government policy in all UK countries, placing children’s palliative care higher up the agenda. New research is leading to a stronger evidence base to inform practice and a better understanding of the epidemiology. In addition, children’s palliative medicine has now become a recognised medical speciality.

Integrated working practices, which were advocated in the first edition of the Guide are now an accepted way of working. Children’s palliative care networks are recommended as the ideal way to enable multi-agency working and the use of the ACT Care Pathway as an approach to commissioning services with the needs of children/young people and their families at the centre of the planning process.

This new edition of the Guide seeks to cement these many positive advances and to set out ACT’s vision for the future sustainable development of children’s palliative care, ensuring that the best quality care is available to all the children, young people and families that need it. It aims to set out the definitions and evidence that will inform the development of children’s palliative care services and to raise awareness of the principles for providing and commissioning high quality and sustainable children’s palliative care services. It also seeks to establish a vision for establishing an appropriately trained workforce to deliver the highest standard of care.

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Executive Summary and Recommendations

1. Every life-limited or life-threatened child or young person, regardless of race, religion, age, gender or where they live should have access to the sustainable, holistic, family-centred and high quality palliative care and support that they need.

2. Palliative care for children and young people 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 the 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.

3. Life-limiting or life-shortening conditions are those for which there is no reasonable hope of cure and from which children or young people will die. Life-threatening conditions are those for which curative treatment may be feasible, but can fail.

4. There are four broad categories of illness trajectory which are useful for planning purposes, but each child’s need for palliative care will be different and should be assessed on an individual basis.

5. The number of children aged 0-19 (including neonates) likely to require access to palliative care services in the UK each year is 23,500 (i.e. 16 per 10,000). Further mapping is needed to collect real-time data on numbers of children needing palliative care support.

6. The needs of these children and young people as a whole have been well researched and include: continuity and co-ordination of care, symptom management, normalisation of life, psychological, social and spiritual support, assistance with practical and financial issues, short breaks, end of life care and bereavement care.

7. Current service provision is variable across the UK. This Guide recommends the further development of children’s palliative care networks to enable the many professionals and services from all agencies and sectors to work together and provide a forum which enables the user voice to be fed in.

8. Families from minority ethnic communities should have equal access to children’s palliative care services.

9. The ACT Care Pathway provides an ideal model to use within children’s palliative care networks as a tool to facilitate commissioning of the full range of services whilst keeping the needs of children, young people and families central to the planning process.

10. The core elements of children’s palliative care services include input from universal, core (targeted) and specialist
provision and include: medical care, 24 hour nursing care, social care, therapies, short breaks, education, play, leisure, emotional and bereavement support. There needs to be co-ordination of these services to enable seamless and holistic support for families.

11 Community children’s nursing (CCN) provides the bedrock for children’s palliative care services. There are many different models of CCN services. An increasingly popular model is that of a community based multi-disciplinary children’s palliative care team.

12 The voluntary sector provides a wide range of services at local, regional and national levels. Voluntary sector organisations, including children’s hospice services, should be included within children’s palliative care networks and be part of the local planning process.

13 Short breaks are provided in a variety of models and settings and include medically supported short breaks in the home or family-centred short breaks.

14 Transition to adult services is a growing problem as the number of young people with life-limiting conditions surviving into adulthood is increasing. The lack of short break care and 24 hour cover for these young people is a major issue. The ACT Transition Care Pathway provides a good model for improving early planning of transition.

15 Bereavement care and family support should be available to all families including siblings. All who work with life-limited or life-threatened children and families should have the skills to provide support and identify when specialist support is required.

16 Commissioners should work with providers and regulators to develop a shared understanding of what they want to achieve in developing children’s palliative care services.

17 Commissioners should carry out local assessments which identify the numbers of children requiring palliative care, the palliative care needs of these children, the services available (including service overlaps and gaps) and service costs.

18 Commissioners should ensure that community-led palliative care is at the heart of local children’s palliative care provision and that there is leadership and co-ordination of the overall service.

19 Providers should work in partnership with commissioners to identify, assess and review the children and young people who need palliative care and work within networks to ensure identification of local palliative care services.

20 Providers should develop leadership roles to ensure service co-ordination and the development of strong local and regional partnerships and networks.

21 Providers should plan and deliver co-ordinated services for each child and family, ensuring that each family has a named key worker and effective communication channels with the family and other professionals.

22 Providers should carry out risk assessments and provide clinical governance to ensure that high standards of care are maintained.

23 Providers from all disciplines should work to develop the research evidence base.

24 Providers should contribute to the development of regional workforce strategies.

25 Providers should work at developing long term relationships with local commissioners and building a robust business case to support the ongoing funding of their service.

26 Workforce plans are needed to ensure the development of children’s palliative care services. A multi-agency, collaborative approach to providing education and training is likely to be effective and more sustainable.

27 Education and training can be effectively commissioned along the ACT Care Pathway, addressing the needs of staff working in universal, targeted and specialist services and ensuring that the whole workforce can access appropriate learning and development opportunities.

28 All staff working in children’s palliative care will need to receive regular clinical and professional support and supervision.
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Section 1 – Essential Information

1.1 Philosophy of children’s palliative care

ACT’s aim for children’s palliative care is one of well co-ordinated services that enable, support and inform families so that they can exercise true choice relating to:

► Choice of place of care.
► Choice of social opportunities.
► Choice of place of death.
► Choice of emotional, psychological and bereavement support.

ACT believes that every life-limited or life-threatened child or young person, regardless of race, religion, age, gender or where they live, should have access to the sustainable, holistic, family-centred and high quality palliative care and support that they need. Children’s palliative care is an active and dynamic approach to care, from diagnosis through death and beyond. Services should aim to help children and their families achieve a ‘good’ life and a ‘good’ death1 and barriers should be removed to enable the child and family to lead as ‘ordinary’ a life as possible. Children should be free from distressing symptoms, and children and families should receive support to reduce the emotional and psychological effects of the child or young person’s condition.

All children with palliative care needs and their families should have access to specialist medical, social and psychological support from a range of professionals trained in children’s palliative care.

To ensure that children and families receive good quality and equitable palliative care, services should be commissioned and delivered along the ACT Care Pathway, and:

► Recognise that children are different from adults.
► Provide an early assessment, leading to specialist service provision when necessary.
► Enable families to access the right information at the right time.
► Provide a key worker to guide families through the maze.
► Enable families to access childcare and short breaks with appropriate medical and nursing input both in the home and in the community.
► Co-ordinate services at home if this is the family’s choice.
► Provide specialist equipment.
► Ensure effective management to reduce pain and other distressing symptoms.
► Provide access to 24 hour specialist advice and expertise.

1 “As a society, we fight shy of pondering on death, yet inherent in each of us is a deep desire, both for oneself and for those we love, for a ‘good’ death. It would be absurd to try to describe that concept more fully beyond saying that everyone in this case knows what it means: not under anaesthetic, not in the course of painful and futile treatment, but peacefully in the arms of those who love them most.” – Mr Justice Hedley, High Court Ruling on the Charlotte Wyatt case, 7 October 2004.

1.2 ACT definition of children’s palliative care

Palliative care for children and young people with life-limiting conditions 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 the 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.

1.2.1 ACT defines ‘children’ as children aged up to their 19th birthday and we include those whose diagnosis is made in childhood and who live unexpectedly beyond this age. The term young people is used to describe young adults from their 19th birthday.

1.2.2 Life-limiting or life-shortening conditions2 are those for which there is no reasonable hope of cure and from which children or young people will die. Some conditions cause progressive deterioration, rendering the child or young person increasingly dependent on parents and carers. Life-threatening conditions are those for which curative treatment may be feasible but can fail.

1.2.3 Palliative care for children is different to disabled children’s care in a number of ways. Many children and young people with palliative care needs are disabled however the risk of, or certainty of death in childhood or young adulthood adds a degree of complexity and urgency to their care and the support that is needed for the family. If the social and emotional needs of life-limited or life-threatened children are to be fully met, then these children and their families must be recognised as a discrete group and be supported to be fully integrated into their local communities.

This means that they should have equal access to universal services as well as access to the specialist services that they may require. Within this it should be recognised that due to the particular nature of the illness trajectory of life-limited and life-threatened children, their social, emotional and physical needs, and hence their need for services, do fluctuate.

1.2.4 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

2 The definitions of the terms life-limiting and life-threatening referred to in this document are current at the time of publishing (April 2009). However there is ongoing debate and a Delphi consultation in progress relating to them. We have included some blank pages at the back of the Guide so that the reader can update this information in due course. ACT will aim to contact all interested parties as and when these definitions change or develop.
diagnoses specific to childhood, although the child may survive into early adulthood (age 19 or over).

- The time scale of children’s illnesses is generally different from adults; palliative care may last only a few days or months, or extend over many years.
- Many of the illnesses are familial. There may be more than one affected child in the family.
- Care embraces the whole family. All family members may be vulnerable as they face the changes in life that the child’s diagnosis imposes on them. Parents and siblings are especially vulnerable and parents bear a heavy responsibility for personal and nursing care.
- A characteristic of childhood is continuing physical, emotional and cognitive development. Children’s palliative care providers need to be aware of and responsive to each child’s changing levels of communication and ability to understand their illness, treatments and prognosis. Children with life-limiting or life-threatening conditions face many periods of transition throughout their life.
- Provision of education and play when a child is sick is essential, and education is a legal entitlement. This introduces an additional dimension which adds to the complexity of care provision.

ACT has published a paper setting out the similarities and differences between adult and children’s palliative care which can be accessed at: http://www.act.org.uk/dmdocuments/Microsoft_Word_-_children_adult_pal_care_differences.pdf

1.2.5 The introduction of palliative care is not always clear cut. It is, of course, totally individual; one child may require palliative care from infancy, while another with the same condition may not be in need of such care for many years.

Families may also vary as to whether they wish to pursue treatments aimed at cure or significantly prolonging life. In practice, palliative care should be offered from diagnosis or recognition that curative treatment is not an option, however the changing face of children’s palliative care recognises that each situation is dynamic and changing and a range of support mechanisms are needed for each child and their family. The diagram (Fig. 1, above right) explores the relationships between palliative care and those treatments aimed at prolonging life.

1.3 Categories of life-limiting and life-threatening conditions

Four broad groups of life-threatening and life-limiting conditions may be delineated. Categorisation is not easy and the examples used are not exclusive. Diagnosis is only part of the process; the spectrum of disease, severity of disease and subsequent complications and the needs of and impact on the child and family need to be taken into account.

Category 1

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 or during an acute crisis, irrespective of the duration of that threat to life.

Category 2

Conditions where premature death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities.

Examples: cystic fibrosis, Duchenne muscular dystrophy.

Category 3

Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years.

Examples: Batten disease, mucopolysaccharidoses.

Category 4

Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death.

Examples: severe cerebral palsy, multiple disabilities such as following brain or spinal cord injury, complex health care needs and a high risk of an unpredictable life-threatening event or episode.
Fig. 2 Classification of children and young adults with life-threatening and life-limiting conditions

- Children diagnosed with a condition that can be fatal.
- Children living with the risk of dying (life-threatening conditions).
- Children living with a shortened life expectancy (life-limiting conditions), may live for many years. Will not necessarily have needs different to others with complex chronic but non life-threatening or life-limiting conditions for much of this time.
- Critically ill children for whom death is a possibility in weeks or days.
- Children who die.
- Children who recover and risk of dying is no greater than that of the general population.
These four categories outline the four types of illness trajectory which will require children’s palliative care provision. The categorisation is important for the purpose of planning and needs assessment. However, it is not suggested that all young people in these four groups need active palliative care throughout the trajectory of their disease or condition. Some, for example those in the second group, may have long periods of relatively good health and whilst being significantly disabled may not need active palliative care. Others in the group may need active palliative care from an early stage. The need for palliative care should therefore always be assessed on an individual basis.

Children, young people and families should be informed about what children’s palliative care support is available from the outset so that they can make choices about the elements of a service that they wish to access at different points in their care journey.

1.4 Statistics

1.4.1 Epidemiology

In the light of recent studies ACT believes that:

The annual number of children aged 0-19, including neonates, likely to require access to palliative care services in the UK is estimated to be 23,500 (i.e. 16 per 10,000 population). (Palliative Care Statistics for Children and Young Adults. Department of Health, 2007).

The number of neonates requiring access to palliative care services is estimated to be 1,473 (i.e. 1 per 10,000 population). (Palliative Care Statistics for Children and Young Adults. Department of Health, 2007).

It is estimated that 5,800 children and neonates (aged 0-19) die each year in England. Of these, 3,900 will have required palliative care, and 2,100 are neonates. (Palliative Care Statistics for Children and Young Adults. Department of Health, 2007).

A further 10,400 young adults aged 20-39, many of whom will have been diagnosed with a life-limiting condition in childhood, die per annum with life-limiting conditions. 4,200 of these young adults are likely to have required palliative care. (Palliative Care Statistics for Children and Young Adults. Department of Health, 2007).

Department of Health data analysis published in 2007 indicate that of those with conditions likely to require palliative care in England, around 7,000 (74%) of those under 20 years (excluding neonates) died in hospital; 1,800 (19%) died at home, and 390 (4%) died in hospices. It also identified that an estimated 63% of children and young people requiring palliative care have a need for social care services (i.e. 11,000 children/young people aged 0-19 years). (Palliative Care Statistics for Children and Young Adults, Department of Health, 2007.)

It is recognised that approximately two-thirds of children and young people with palliative care needs will also have a recognised disability. Research (McCulloch, 2007) recognises that 40% die from cancers and 60% die from non-malignant disease (e.g. metabolic, degenerative, cardiac conditions).

1.4.2 Need for locally-based data

‘One of the biggest challenges facing children’s palliative care commissioners, providers and service users is a lack of uniform, regular and accurate information about the nature of life-limiting conditions and the services available to support them. This means that it is difficult to effectively plan, commission and deliver services to children and families where they are most needed. Equally, without this source of information, it is impossible to predict need, track prevalence or spot trends.’

(Better Care, Better Lives, Department of Health (England) 2008)

The need for a UK-wide mapping initiative has been recognised as a priority for some time. Services for life-limited children, young people and their families are known to be patchy, but it is difficult to determine where the gaps in service provision lay. It has also been difficult to establish accurate data on the numbers of children who require palliative care, and where they live. This lack of robust regional and national information has led to services being developed in an ad hoc way. Families state that they do not know what is available to support them, whilst fragmented services are unable to develop integrated working practices.

The simplest method of collecting epidemiological data regarding children and young people with life-limiting and life-threatening conditions is by analysis of death certificate data. However this data is likely to underestimate children who do not receive a diagnosis, children who live unexpectedly into adulthood and children with life-limiting conditions who die from acute complications. Death certificate data cannot provide information on the prevalence of children and young people living with a life-threatening or life-limiting condition or with active palliative care needs. There are also practical difficulties identifying children with these conditions through cross sectional prevalence studies. These include a lack of recognition of children with life-limiting conditions, reluctance to label a child with a palliative care need and a lack of uniformity regarding the interpretation of a life-limiting or a life-threatening condition.

The Children’s Palliative Care Minimum Dataset (MDS) comprises 20 data items of epidemiological data relating to children and young people with palliative care needs. The data items enable the counting of children and young people who are diagnosed with a life-threatening or life-limiting condition. This approach is focused on collecting ‘real time’ data as opposed to retrospective, aggregate information which does not provide up-to-date prevalence figures. This information is collected when a child or young person is referred to a service and when a child dies who is already receiving care through a service.

1 The Mapping MDS and services questionnaires have been developed and piloted in Merseyside and Cheshire by a team from the Merseyside and Cheshire Children and Young People’s Palliative Care Clinical Network, led by Dr Lynda Brook. The Making Life-Limited Children Count Mapping Initiative has been facilitated by partnership working between ACT, Children’s Hospices UK and partners from within the NHS. For more information visit: www.act.org.uk/index.php/mapping.html
The MDS includes the following data items.

### When patients are referred to a children’s or young people’s palliative care service:

1. Service ID
2. NHS number
3. Date of birth
4. Gender
5. Ethnic group
6. Postcode
7. PCT code
8. Primary diagnosis (coded by WHO International Classification of Diseases 10 (ICD10), ACT group and organ system group)
9. Source of referral
10. Date of first assessment
11. Date of referral
12. Date of diagnosis
13. Life-threatening condition Y/N
14. Life-limiting condition Y/N
15. Date of recognition of life-limiting condition
16. If over 16 years whether living alone
17. Referral accepted by the service Y/N

### When a patient dies:

All as the above plus:

1. Date of death
2. Place of death
3. Cause of death

Alongside the MDS collection, there is a tool for mapping levels of local service provision to enable commissioners to more accurately plan services for the local population. The generic part of this service data collection is being integrated with the annual national child services mapping in England to ensure the two initiatives are complementary.

#### 1.4.3 Needs assessment for this population

Considerable research has been carried out on the needs of these families and the difficulties they experience. (Souther et al, 1994; Beresford, 2002; While et al, 1996a; Putt and McElhill, 1995; Dobson and Middleton, 1998; Dobson et al, 2001; Corden et al 2001; ACT, 2003b). Children with life-limiting conditions and their families have a range of specific needs, and services should be provided on a needs-led basis, not on the basis of resources available locally. From the studies cited the same needs are found to be duplicated and ACT believes that the findings can be transferred to most local situations and do not require further local validation, although there may be local influences that should be taken into account, such as cultural differences. Here we summarise the major needs that may influence the type and level of services commissioned or purchased.

- Identification of locally available services and arrangements for continuity and co-ordination of care.
- Symptom management.
- Normalisation of life.
- Support for the family (psychological, social and spiritual).

There should also be awareness that many life-limited children, particularly those with non-malignant conditions, may live away from the family home, either in foster care or at school and that they will have key individuals in their lives and additional agencies involved in their care.

#### 1.5 An overview of current provision

##### 1.5.1 The integrated landscape of children’s palliative care

There are a wide range of services from health, social care and education involved in the provision of children’s palliative care. It is widely recognised that these services need to work together in an integrated way to provide more seamless care to children and families. One very effective way to achieve this integrated working is through children’s palliative care networks, which have the potential to ensure the right agencies work together to share best practice and plan services effectively. They also offer potential for feeding in the voices of service users at a more strategic level and allow for services to join together more effectively, providing a focal point for more strategic planning and a route through which the voluntary sector, including children’s hospices, are able to engage more effectively with commissioners. We recognise that this is the ideal model of delivery of children’s palliative care and that this is being achieved to varying degrees across the UK.

##### 1.5.2 Equality of access

The numbers of children requiring palliative care from minority ethnic communities is rising and will continue to do so for the foreseeable future (Hatton et al, 2004). There is sometimes an assumption that the needs of these families are met by the resources within their own community, but evidence shows that although they often do not come forward for help, their needs are often unmet and they may struggle with little support (Hendry 2006; Irish, Lunquist and Nelson, 1999; Gatrad, Brown and Sheikh, 2008; NICE, 2003). The outcomes of research from Acorns Children’s Hospices have highlighted the stress that minority ethnic families experience when they care for a life-limited child (Brown, 2006; Brown, 2008). Traditional family structures are changing in the UK and there is an increased need for caring professionals to listen to the views of families so that policies and practice are not based on stereotypes and generalisations of what people need. Rather they should reflect the processes of change that individuals experience as they adapt to caring for a life-threatened or life-limited child.

##### 1.5.3 A care pathway approach

The ACT Care Pathway provides a comprehensive care pathway for children and young people with palliative care needs. It is designed to be used within networks as a tool to facilitate commissioning of the full range of services and to be used with individual children and families according to their needs.
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 both for the child and family in a language that they can understand.

Every child and family diagnosed in the hospital setting should have an agreed transfer plan involving the hospital, community services and the family, and should be provided with the resources they require before leaving hospital.

Every family should receive a multi-agency assessment of their needs as soon as possible after diagnosis or recognition and should have their needs reviewed at appropriate intervals. Every child and family should have a multi-agency care plan agreed with them for the delivery of co-ordinated care and support to meet their individual needs. A keyworker to assist with this should be identified and agreed with the family.

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 as closely as possible.

Bereavement support should be provided throughout the care pathway and continue through the child’s death and beyond.
The core elements of children’s palliative care services provided along the care pathway are:

1. **A truly integrated children’s palliative care service**

A system where universal, targeted and specialist provision work together in a co-ordinated way that enables both local accessibility for support and management of everyday problems, and access to first class specialist services for the management and care of more complex symptoms.

Services should include:
- Medical care including care from specialists in palliative care and specialists in the child’s condition.
- Access to 24 hour hands-on nursing care, from competent hands-on carers with access to specialist nursing input when required.
- Access to social care.
- Therapies such as music therapy, complementary therapy and art therapy.
- Short breaks provided by appropriately trained and competent staff.
- Education, play and leisure.
- Access to emotional and bereavement support which is flexible and holistic.

2. **Universal services**

All children and young people with palliative care needs are likely to be known to universal services, such as GPs, health visitors and education services. These services are ideally placed to inform children and their families about what they offer, ensure that support is accessible and work more effectively together. Early combined, multi-agency assessments and recognition of need by GPs and the rest of the primary healthcare team can ensure earlier referrals to specialist services. Many universal services will be in a good position to provide basic bereavement support to families.

3. **Targeted services**

Appropriate targeted support to avoid the potential problems of stressed families, physical and mental exhaustion, and relationship breakdown. If such support is offered at an early stage and can be accessed by families as they need it, many later stresses and strains can be reduced.

Such support should include:
- Emotional and psychological support, including bereavement support, provided by appropriately trained and supervised staff.
- Key workers.
- Short breaks.
- Provision of specialist equipment.
- Practical support.
- Transport.
- Co-ordination of services.

4. **Specialist support**

Children and young people with life-limiting conditions often require specialist support for their medical and nursing care, e.g. to access supported short break services, trained escorts for transport services etc. They may also need specialist social and practical support. Dietetics, occupational therapy, specialist play and physiotherapy are an integral part of paediatric palliative care. Professionals from psychological and emotional support services may also play a role in supporting children, young people and their families, and psychological support should be an ongoing element of professional supervision. Specialist psychosocial support should be available from diagnosis and through to the remission of a life-threatening condition, or through the child’s death and into bereavement support as an integral part of the work of the palliative care team.

Services should include:
- Access to 24 hour specialist advice and expertise.
- Effective management of symptoms to reduce pain and other distressing symptoms.
- Outreach or home-based care services.
- Expert children’s palliative care, support and advice should be available to the child and family 24 hours a day, 365 days a year.
- Access to psychosocial support on a 24 hour basis at times of crisis and when the child dies.

1.5.4 **The provision of care in the community**

Local multi-disciplinary palliative care teams are increasingly being established. These teams often include community children’s nurses (CCNs), paediatricians, children’s hospice staff, social workers, psychologists and therapists who deliver community-based care to children with both malignant and non-malignant life-limiting conditions. Community children’s nursing services are the bedrock for children’s palliative care services. A number of different models of CCN services that support the delivery of children’s palliative care have developed. These include:
- Single Primary Care Organisation (PCO) Teams covering a wide spectrum of CCN activities including palliative care. General CCN services are often aligned with local authority children’s teams, continuing care, acute care etc.
- Multiple PCO teams focusing on palliative care.
- Hospital specialist outreach teams providing all care to a diagnostically discrete group of children or supporting smaller locality teams within this group of children or young people.
- Hospice based palliative care/hospice at home teams: directly delivering care or supporting local CCN teams.
- Specialist outreach nurses: providing specialist advice and support to local primary care teams.

The choice of model should be informed by population density, local facilities such as hospices and specialist centres, and local palliative care pathways and children services plans.

1.5.5 **Role of the voluntary sector**

There are a wide range of voluntary sector organisations involved in children’s palliative care at local, regional and national levels. These include charities that provide services directly to children and families, such as charities that provide...
psychosocial support on an ongoing basis to families, and organisations working nationally to represent the needs of particular groups of children or types of service. It is vital that voluntary sector organisations are included within children’s palliative care networks and are part of the local planning process. To be able to reach and help all of the children, young people and their families who need support, there needs to be a good working relationship across all sectors to provide care through complementary and joined-up service delivery.

1.5.6 Children’s hospice services

There are a range of models of good practice among children’s hospice services. All provide end of life care, short break care, specialist play, pre-bereavement and bereavement support. Some also provide day care facilities and home-based care services. There are currently 44 children’s hospice services providing support for the whole family.

1.5.7 Short breaks

It is recognised that the availability of short breaks has a hugely beneficial effect on children, young people and their families. They provide both an opportunity for a child or young person to have a break from their parents/carers, but also to give parents respite from their caring responsibilities.

Short breaks are provided in a variety of settings as outlined in the table below and include specialist short breaks. Short breaks provision can be either in or close to home, via the extension of existing services or through the development of new ones. Children’s hospices, specialist psychosocial care service settings, and a range of other voluntary and statutory sector providers play an important role in providing specialist short breaks.

<table>
<thead>
<tr>
<th>Some examples of short break provision include:</th>
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<tbody>
<tr>
<td><strong>Hospice care/hospice at home</strong> – help families to have a break together or time to themselves in a home-from-home environment, or in a family’s own home.</td>
</tr>
<tr>
<td><strong>Statutory funded short breaks in the home</strong> – community children’s nurses and competent carers delivering short breaks in the home to children with medically complex needs, sometimes funded through continuing care.</td>
</tr>
<tr>
<td><strong>Sitting services</strong> – people who regularly visit the child in his or her own home, enabling parents to spend time with their other children, have an evening out, or just do routine things such as shopping.</td>
</tr>
<tr>
<td><strong>Befrienders/activity services</strong> – people who take the child out into the community, for example: to the cinema, swimming, to the park, shopping, and a wide variety of other activities.</td>
</tr>
<tr>
<td><strong>Short break fostering</strong> – people who look after the child in the carer’s own home, perhaps for one night, a weekend or longer, depending on the child’s needs.</td>
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<tr>
<td><strong>Community houses</strong> – where children and young people can have the opportunity to be creative with arts, crafts and take part in other activities within the community.</td>
</tr>
<tr>
<td><strong>Domiciliary care</strong> – care provided at home which gives help with the child’s personal care and domestic tasks.</td>
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1.5.8 Transition to adult services

There is growing evidence of the unmet needs of an increasing number of young people living with a life-limiting condition into adult years and of the poor outcomes for young people with complex and life-limiting conditions. ACT estimates that between 6,000 and 10,000 young people aged 13-24 in the UK are living with a life-limiting or life-threatening condition (ACT, Palliative Care for Young People aged 13-24, 2001).

It is acknowledged that there is wide variation in the availability of services across the UK. In particular, access to short break care that is appropriate for young people and to 24 hour cover in the home is patchy. ACT has developed a Transition Care Pathway to facilitate better planning for improving provision of these services and recommends a shift from family-centred care to young person-centred care. The needs and wishes of young people should be central to the planning process, whilst also acknowledging the support and emotional needs of families.

Young people should be empowered to take part in the planning of their care. A vital component of the transition pathway is to ensure that there is good co-ordination of the transition process between paediatric and adult services. This pathway recommends a new ‘key worker designate’ role within adult services to gradually take over the child’s key worker role so to ensure smooth transition.

1.5.9 Bereavement care and family support

Grief is a normal process and most families do not need specialist help. Ideally the professionals who have been working with the family should be able to provide pre-bereavement care and this support can then be continued into bereavement. They should be able to identify those families who require more specialist bereavement counselling. Befriending volunteers, who have been carefully selected and received appropriate training, may be helpful.

Access to bereavement counselling should be available as part of the service provision for those few bereaved families who require it, pre and post death, and extended to include grandparents and extended family. Siblings also need bereavement support and their needs should be addressed individually as well as through shared activities with other bereaved siblings. The support and training needs of those providing bereavement care should be considered.

1.5.10 Sibling support

Support for siblings of children and young people with palliative care needs should be available. Universal services, such as early years services and pastoral support teachers are key in supporting these children; identifying increased needs and enabling access to more specialised support when required. Most siblings, given the appropriate support, will cope with bereavement when the time comes. Bereavement support should be available for all children and young people who experience the death of a sibling.
Section 2 – For Commissioners

2.1 General commissioning principles

Before starting to develop children’s palliative care services, it is important for the commissioners, providers and regulators involved to have a shared understanding of what they want to achieve. The nature of children’s palliative care makes it both necessary and sometimes difficult to arrive at clear definitions, but it is important for commissioners to define what palliative care is and what the overall service aims to achieve.

From this shared definition, a children’s palliative care pathway can be developed and used to clarify:

- The children and families who might benefit.
- The likely problems the child and family may experience.
- The effective interventions.
- Referral criteria to the service.
- A model of service delivery.

Local assessments should identify:

- The number of children in need of palliative care and trend information to enable projections of numbers for the next five to 10 years.
- The palliative care needs of children and young people.
- Existing services available to children and young people with palliative care needs, including service overlaps and gaps.
- Service costs.

The commissioner sets the service specification, for example:

- Patients.
- Packages of care.
- Numbers.
- What services.
- Types of conditions.
- Frequency, length of contact.
- Transition to adult services.
- Provision and maintenance of supplies and equipment.
- Skill mix.

Commissioners should then consider the range of services available across the care pathway and invite organisations to tender.

Commissioners need to be mindful of following the child’s journey and providing an integrated and sustainable approach. The legal responsibilities of the different agencies should also be taken into consideration.

2.2 Commissioning across the children’s palliative care pathway

Universal, targeted and specialist support for children and young people with palliative care needs and their families is provided by a web of service providers within the statutory and voluntary sectors. All levels of service provision may be commissioned from the whole range of the statutory and voluntary sectors using collaborative commissioning arrangements. Commissioners should ensure sustained and effective delivery of palliative care to children and young people. At all times, locally available and community-led palliative care should be at the heart of provision to children and young people. This provision should be supported by:

- Sustainable community children’s nursing teams.
- Specialist medical input (e.g. medical consultants with expertise in the child’s condition).
- Disease specific care.
- Specialist palliative care providers.
- Hospice and residential care.
- Access to acute hospital care.
- Emotional and psychological support.
- Local authority children’s services (social care/education/housing/leisure).
- Community paediatrics.
- Primary care.

The challenge is to ensure that there is leadership and coordination to enable appropriate integration and availability of these services. The ACT Care Pathway is one way to enable children and their families to be linked with community services, hospital-based services, social services, education and the voluntary sector in one joined-up planning process.

There are three stages to the ACT Care Pathway: diagnosis or recognition that a child’s care is going to be palliative rather than curative; living with the condition; and end of life care. The following diagrams illustrate the different services that would be provided at each stage of the pathway at universal, core and specialist levels.
Services should provide specialist investigations to enable accurate diagnosis, or specialist services should be able to recognise when active treatment is no longer an option and refer appropriately to palliative care services. These are highly specialist services, involving the care and psychosocial support of patients with more complex needs. They require specialist expertise.

Secondary or tertiary health care services may be provided in a range of settings including the child’s home, or other community setting, hospice or hospital. There is a contribution from disease-specific voluntary sector agencies such as CLIC Sargent, Debra; local authority specialist children’s teams e.g. disability services; hospice and other voluntary organisations and specialist CCN services, and psychological services.

These services may include input from palliative care professionals (GPs/nurses with special interest), some aspects of provision from children’s hospice services and other voluntary sector agencies; paediatric services; public health nurses; CCN services; pathology services; psychological support; specialist education and Early Years programmes; interpreters; housing workers; bereavement services.

Primary health care services including GPs; health visiting; school nursing; midwifery; new born screening; leisure and play; housing; education; Surestart; Early Years programmes.

Fig 4 Diagnosis/recognition stage of the Care Pathway
Services should contribute specialist information to multi-agency assessments and reviews and may provide a key worker.

Specialist support such as supported short breaks provided by children’s hospice services and other voluntary sector agencies. Services may also include disease-specific specialists, specialist CCN services, specialist children’s teams such as disability services, specialist symptom management and psychosocial support teams/professionals.

Services should contribute to multi-agency assessments and reviews and may provide a key worker and offer ongoing emotional support to child and family.

Services may include paediatrics, pathology, psychological support, specialist education and Early Years programmes, interpreters, specialist housing workers, 24 hour advice on pain and symptom management, therapy services, CCN services, outreach services, continuing care packages, CAMHS, short breaks, specialist housing, social care, hospice and other voluntary organisations.

Services should contribute to multi-agency assessments and reviews and offer ongoing emotional support.

Services may include primary health care services including GPs, health visiting, school nursing, midwifery, new born screening, leisure and play services, housing, Surestart, education and Early Years programmes.
Services should provide 24 hour access to specialist ‘hands on’ care and advice as required by children, families and carers, including professional members of the care team. Services should be able to deal with complex grief and loss issues.

Services should provide day-to-day care of the child and family and should have access to 24 hour specialist advice through effective clinical networks.

Services should support the whole family emotionally and practically. Services to support the siblings of children and young people who are dying are an important part of supporting the whole family through the bereavement process.

Services may include: specialist palliative care teams/professionals, disease specific/specialist palliative care such as neuro-disability, cystic fibrosis and muscular dystrophy to enable effective psychosocial support and management of severe symptoms, chronic pain and other distressing symptoms. Specialist CCN services and bereavement services.

Services may include: specialist palliative care teams/professionals, disease specific/specialist palliative care such as neuro-disability, cystic fibrosis and muscular dystrophy to enable effective psychosocial support and management of severe symptoms, chronic pain and other distressing symptoms. Specialist CCN services and bereavement services.

Primary health care services including GP services, health visiting, school nursing, opticians, pharmacy, midwifery services, newborn screening, leisure and play services, housing, Surestart, Early Years programmes and education services.
Section 3 – For Providers

This section aims to provide the principles for establishing a comprehensive and co-ordinated overall children’s palliative care service. This service should be based on local need and deliver the highest quality of care for individual families based on research evidence and with appropriate clinical governance mechanisms.

Some elements of this section should be undertaken in partnership with commissioners, and there is a need for overall co-ordination of the total pathway of care to ensure that all needs are met.

There are seven basic components for service providers to consider when creating and co-ordinating their service.

1. A system for identifying, assessing and reviewing all the children and young people in need of palliative care.
2. Working within networks to ensure the identification and recognition of the local palliative care team.
3. Overall co-ordination of the service.
4. Individual planning and delivery of co-ordinated services for each family.
5. Risk assessment and clinical governance.
6. Evidence-based care and research.
7. Ensuring robust business strategies are in place to underpin financial sustainability.

3.1 Identifying, assessing and reviewing all the children and young people in need of palliative care

3.1.1 Four distinct groups of children and young people can be defined as described in Section 1.3. Children who have recently received curative or other regular acute secondary or tertiary intervention (e.g. children in category 1 and category 2) are usually in close contact with professionals and there may be a good system in place for keeping track of their needs. However they may leave the hospital in the terminal phase of their illness and need to be supported locally. Other children with longer term needs tend to have less contact with secondary and specialist services and are more difficult to identify (e.g. some of the category 2 children and categories 3 and 4). This is why it is important to establish robust databases of children with life-limiting conditions in partnership with commissioners as described in Section 1.4.

3.1.2 Use of the ACT Care Pathway will enable a team of professionals from all the agencies and sectors to work in partnership in a ‘team around the child’ approach (Limbrick, 2001). Empowering and enabling GPs to be actively involved in the care of these children and young people throughout their illness is essential. This facilitates the possibility of shared care in the terminal phase, and when they work within a small community they can ensure their role is effectively supporting the whole extended family.

3.2 Recognition of the local palliative care team

A large number of healthcare professionals from many disciplines may become involved, as well as staff from local authority children’s services, community and religious groups and the voluntary sector. For each family this team will be unique and preferably not too large, depending on individual circumstances. It is likely to be drawn from the following:

- A range of physicians, including paediatricians from the hospital and community, general practitioners, tertiary specialist paediatricians, children’s hospice doctors and palliative care physicians.
- Nurses from hospitals, community trusts, children’s hospice services and primary healthcare teams providing specialist, outreach, community nursing, health visiting and school health services.
- A range of professionals providing short break care, including staff from hospice and hospice at home services and continuing care professionals.
- Child and adolescent psychiatrists, clinical psychologists and other mental health professionals.
- Occupational therapists, physiotherapists, speech and language therapists, play therapists, music therapists, dieticians, complementary therapists, hydro-therapists, play specialists.
- Paediatric, hospital and community pharmacists.
- Social workers, family support workers (from both statutory and voluntary sectors).
- Teachers, care assistants and support staff in both mainstream and special schools, educational psychologists, hospital teachers and home tutors.
- Counsellors, clergy and spiritual leaders.
- Staff from the voluntary sector, including self-help support groups, parent-linking schemes and care for the carers.

3.3 Overall co-ordination of the service

Strong and visible leadership is needed across the whole sector, with key people responsible and accountable for effective and efficient service design and delivery. Strong local and regional partnerships and networks need to be established and maintained, based on a common understanding of the issues affecting children with life-limiting and life-threatening conditions, as well as those with disabilities and complex health needs. These partnerships and networks should lead and manage multi-agency and multi-disciplinary teams in children’s services.

This could be achieved by identifying a senior clinician with specialist skills, knowledge of and expertise in working with children and families with palliative care needs to provide strategic leadership for future service development. Given the relatively low numbers of children with life-limiting and life-threatening conditions, it is likely that this role would be most effective working across a cluster of primary care organisations or a regional or other geographical area. Some
areas may also consider developing local champions to take this work forward.

These multi-professional, multi-organisational networks could sit alongside the adult palliative care networks. This would promote and enable joint working in the provision of transition support from children's to adult services.

3.4 Planning and co-ordination of the service for individual families

3.4.1 Named key workers

Families should have a named key worker to co-ordinate services, provide some aspects of the child's care, ensure that all equipment is available, provide access to other resources and support them emotionally. The key worker must have a good working relationship with the child and be used by the family and all involved as the main referral point and channel for discussion and information. Families appreciate the continuity of a key worker, but where this is no longer possible, or appropriate, families need to be well prepared for the change and other team members need to be aware of the role so that the changeover is as seamless as possible for the family. (Mukherjee, 1999).

Care Co-ordination Network UK (CCnUK) defines key working as “…a system whereby services from different agencies are co-ordinated. It encompasses individual tailoring of services based on assessment of need, interagency collaboration at strategic and practice levels and a named key worker for the child and family.” (CCnUK, 2008).

CCnUK outlines the role of the key worker as:

1. Providing information.
2. Identifying and assessing the needs of all family members.
3. Providing emotional and practical support.
4. Assisting families in their dealings with agencies and acting as an advocate if required.

3.4.2 Communication

Good communication, with a speedy flow of both clinical and social information in both directions is essential for the co-ordination and continuity of care. This may be facilitated by:

- Early communication between services with advanced planning if support is to be available for families when they need it and/or want it.
- Appropriate training for professionals at all levels of service provision.
- The use of parent-held personal child health records, care and management plans.
- The use of a named key worker as a channel between the family and professionals.
- Improved links between services so that care is integrated and collaborative, for example between hospital and community services, children's hospices and local services. This should include face-to-face contact between professionals where possible.
- Improved communication and collaboration between healthcare professionals, with copies of letters to the parents, so that in an emergency the latest decisions on management are available to the clinician involved. (Thornes, 1993).
- Provision of information appropriate to age and cognitive level.

3.5 Risk assessment, clinical governance and evidence-based practice

3.5.1 Risk assessment is a valuable tool in supporting the assessment of options for care delivery and can be used to assess clinical or environmental risk. Children will receive care, support and education in a variety of settings, all of which pose potential risks. A risk assessment can be used to make informed decisions about staff, equipment and back up services. Organisations have a duty under the Disability Discrimination Act 2005 to overcome physical barriers and to take reasonable steps to change practices, policies or procedures, which make it impossible or unreasonably difficult for them to use a service. Children must also be provided with auxiliary aids or services, which make it easier for them to use a service.

Risk assessments that may influence eligibility or care package design fall into the following areas:

- Clinical risk.
- Staffing levels and managing staff risks, e.g. lone working or night driving.
- Moving and handling.
- Environment of care.

3.5.2 Clinical governance

Clinical governance provides a system through which organisations are accountable for continuously improving the quality of their services and safeguarding high standards of care by creating an environment in which clinical excellence will flourish.

3.6 Evidence-based practice and research

There has been a substantial expansion in the amount of research in the field of children's palliative care, but published evidence is still often insufficient on which to base practice or service development. Continuing research is needed to expand the evidence base with contributions from medicine, nursing, social work and other disciplines. The priority is to acquire data to facilitate evidence-based practice, particularly in relation to:

- Incidence, prevalence, morbidity and mortality from life-limiting conditions (especially through the establishment of local and national databases). A national minimum dataset
mapping exercise has been piloted and is soon to be rolled out across the UK.

- Development of relevant outcome and validation measures, particularly those that realistically assess quality of life among children with diverse life-limiting conditions.

- Evaluation of therapeutic approaches to symptom management so that new guidelines can be evidence-based, and existing ones can be modified as necessary.

- More focused needs analysis of different groups of children with life-limiting conditions and their families.

- Evaluation of methods for integrating assessment, care planning and reviewing procedures amongst and between disciplines and agencies involved in delivering children’s palliative care services.

- Evaluation of service delivery in the various settings of children’s palliative care such as home, hospice, hospital and other community settings.

- Educational needs analysis of the various professionals involved in children’s palliative care.

- Psychosocial and bereavement issues as well as medical research areas.

### 3.7 Ensuring robust business strategies are in place to underpin financial sustainability

The key to securing sustainable funding for a service is to develop a long term relationship with local commissioners. Once ongoing dialogue is established there will be a need for providers to build up their business case which should demonstrate how the service fits into the total picture of children’s palliative care locally and evidences the value of the service. Further details on building a business case are contained in *Making the Case for Children’s Palliative Care*, a guide published by ACT and Children’s Hospices UK in 2009.
Section 4 – Workforce, Education and Training

4.1 Planning and developing an effective and fit-for-purpose workforce

Workforce plans are needed to ensure the development of children's palliative care services. In commissioning for quality and choice there is likely to be a diverse range of potential services and a mix of approaches to provide palliative care services for children and their families. The workforce required to provide these services will probably be delivered by a network of agencies, including the NHS, children's hospices, the voluntary sector and social care and education services, in addition to that carried out by parents themselves.

Commissioners may need to consider making consortia arrangements with other local partners as the service need may be too small to contract for. Workforce development directorates need to consider the recruitment and training needs of the workforce required to deliver these services, in particular for children's community nurses and allied health professionals, general practitioners, paediatricians with specialist training in palliative care and the existing and predicted multi-professional workforce within the voluntary sector.

The advantages of collaborative approaches bring obvious benefits in terms of care provision and these benefits are mirrored in the field of education and training too. A collaborative approach recognises the diverse needs of individuals and enables education and training providers to accommodate these needs and promote exchange and ongoing development of knowledge and good practice. It is also recognised that a cross-sectoral approach enables solutions to the challenge for the provision of high quality education and training to be found beyond the immediate local children's palliative care sector, through the formation and strengthening of partnerships or working alliances between service providers, higher education institutions and commissioners.

There is a need for a workforce development strategy to ensure that the workforce providing children's palliative care:

- Is competent and confident.
- Inspires people to join and remain working in the sector.
- Develops their skills and builds satisfying and rewarding careers.
- Is recognised and transferable to other work settings.
- Instils confidence and trust in children, young people, parents and carers.

Services to date have developed in a largely ad hoc manner, often as funding has become available from different sources. Future developments must however take account of the need for structured workforce planning to provide equitable, effective, sustainable and safe care delivery. Inter-disciplinary teams bring a richness of talent to the benefit of children and families. All professionals working closely with families must be appropriately trained for the posts they hold and services they provide. They should have knowledge and skills in palliative care and training for work with children. Life experience and interpersonal skills can also be a valuable addition to formal training.

Staff working with children need the skills to:

- Comprehensively assess a family's needs in liaison with the child and family.
- Listen to and demonstrate an understanding of and respect for the family's (and where appropriate the child or young person's) knowledge, skills and choice.
- Deal with the specific problems of childhood illnesses and their management.
- Communicate with children and young people.
- Provide care and support for the whole family.
- Advocate on behalf of these families to secure services from other agencies.
- Work with families from different backgrounds, cultures, family structures and beliefs, acknowledging how each influences the care of children.
- Maximize the child's developmental potential.
- Proactively plan for likely problems in the near future.

A team of staff working in children's palliative care also need the skills to:

- Assess and manage symptoms of the particular illness, and those symptoms present at the end of life phase.
- Assess psychosocial needs of children with life-limiting conditions and their families and enable the family to manage these issues or facilitate referral to an appropriate agency.
- Assess the spiritual needs of children with life-limiting conditions and their families and facilitate referral to appropriate support as necessary.
- Have knowledge of the services and resources available and how families can access them.
- Work effectively as a member of a multi-disciplinary team.

There is still a need for a consistent and co-ordinated approach to leadership and career development that is accessible to all staff of all children's palliative care providers including hospices and other voluntary providers as well as those from within the statutory sector. This would include:

- National standards across the entire children's palliative care workforce.
- Core standards for curriculum development (including standardised learning outcomes) across different groups and levels.
- Ways of acquiring continuing professional development points.

The benefits of a systems-based, collaborative approach to children's palliative care education and training commissioning include:
Greater capacity to implement policies and priorities to improve both access to and the quality of children’s palliative care services.

Greater capacity to influence the factors that drive the care and education and training systems, determine education and training needs and share best practice.

Less costly duplication in planning activities, and better forecasting of service need.

Improved information sharing.

Better understanding of the wider workforce issues.

The availability of a workforce with the capacity to improve the quality and experience of palliative care services, to provide better access to therapies, and which supports effective transition to adult services underpins the development of palliative care services for children and young people. A service-wide partnership approach to local workforce development, including the voluntary sector helps to ensure the availability of staff with the right range of skills and competencies.

The workforce is key to developing a reliable, responsive and sustainable service, delivering the kind of support that children and families need, where and when they need it. The importance, contribution and value of a fit-for-purpose workforce are critical to ensuring high quality care and support for children, young people and families. As well as ensuring the necessary skills are developed within the existing workforce, it is important to consider succession planning to ensure sustainability. Workforce development offers opportunity for integration and effective and efficient use of skills, but also poses challenges for education, training and development.

A particular challenge will be a need for core services, ranging from universal through to specialist services, to include specialist palliative care knowledge and expertise, particularly for managing children approaching the end-of-life phase, including access to symptom control advice and bereavement support, available 24 hours a day, seven days a week. This knowledge and expertise will need to be clinically driven and developed in collaboration between commissioners, service providers (including education providers) and the Royal Colleges.

Knowledge and skills can be developed allied to the ACT Care Pathway and should aim to develop education and training for the following areas of workforce development:

- Specialist palliative care practitioners from all professional backgrounds, within any care setting.
- Non-specialist practitioners working within a palliative setting.
- Non-palliative care workforce who may or may not be specialists in their own field but who deliver palliative care within their own scope of practice. For example there is a need for commissioners to ensure a high level of palliative care skill and knowledge within community children’s nursing teams. Community children’s nurses are categorised as specialist practitioners in their own right, but as targeted services, some will be required to care for children with palliative care needs as part of their role.

It is recognised that it is difficult to categorise all individual practitioners and the services in which they work into the three categories above but it can be helpful to use these categories to ensure the whole workforce can access appropriate learning and development opportunities.

4.2 Education and training

It is essential that appropriately trained and skilled staff are available at each of the levels of service provision across the range of agencies and in a variety of settings, throughout the ACT Care Pathway. Commissioners should aim to increase capacity and flexibility through:

- Work in partnership with service and education providers to capture reliable information/data about numbers and trends. For example data which show that an increasing number of children and young people are surviving longer and requiring transition into adult services will help to influence and identify workforce planning needs so that services can respond to need in the future.

- Asking whether workforce requirements would be better considered across a wider geographical area.

- Mapping the current workforce in children and young people’s palliative care in collaboration with health and local authority children’s services and identifying areas for expansion within continuing professional development (CPD) and post-registration education commissioning.

- Ensuring user participation in the evaluation and development of all aspects of children’s palliative care services and also ensuring that networks have identified an education lead for children’s palliative care.

- Encouraging collaboration between workforce planning in PCTs and SHAs and children and young people’s plans within local authorities.

- Reviewing models of community children’s nursing (CCN) services and provision to enable 24/7 access to ‘hands on’ care, support and advice in situations where CCNs act as first line specialists.

- Identifying short and long term needs to enable service planning.

- Identifying skills, competencies and working models alongside workforce planning and providing a career framework for children and young people’s palliative care workers.

- Considering what types of worker and skill mix are needed and whether this is across the whole sector (health, education and social care, including statutory, independent and voluntary services).

- Using joint commissioning arrangements whenever possible.
4.2.1 An education and training framework

This section contains an overview of some of the key themes discussed in Right People, Right Place, Right Time: Planning and developing an effective and responsive workforce for children’s and young people’s palliative care* developed and published by ACT and Children’s Hospices UK in April 2009.

The workforce is the primary building block for developing reliable, responsive and sustainable services to enable the delivery of care and support that children and families need, delivered where, and when they need it. To achieve this there needs to be interlinking of:

- Care pathways.
- Education commissioning and provision.
- Service commissioning and provision.

Right People, Right Place, Right Time includes an education and training framework which aims to make this happen by drawing together the processes required to enable service and education providers and commissioners to plan and work together, and to support networks as they plan to develop an effective and responsive children’s palliative care workforce.

The framework is based on a recognition that universal and specialist support for children and young people with palliative care needs and their families is provided by a web of service providers from health, education and social care within the statutory, voluntary and independent sectors. It sets out what services need to be commissioned throughout the pathway and describes examples of who may provide the services. It recognises the need for workforce development with an emphasis on the importance of lifelong learning and continuous professional development and sets workforce development commissioners the challenge of ensuring a workforce with the capacity and skills to provide children’s palliative care that is safe, effective and of high quality and provided by competent and confident practitioners.

Developing Right People, Right Place, Right Time emerged from discussions within the children’s palliative care sector about the current and future workforce needed within children’s palliative care. It takes account of the numerous emerging policy and service developments within children’s services across the UK and provides guidance which recognises the dynamic, constantly changing processes required to enable service and education providers and commissioners to plan and work together flexibly to make this happen.

Right People, Right Place, Right Time includes a ‘skills pathway’ which introduces a tiered approach to learning and development, called the ‘Learning Cone’. This approach to learning anticipates that networks will encourage the development of a workforce with expertise at the highest level within the ‘Learning Cone’ in their sphere of practice, (for example nursing, counselling, psychology, medicine) and the delivery of education and training to those working in universal and targeted services. The key aspects of this tiered approach to learning and development are:

- Flexibility: the workforce can ‘hop on and off’ the pathway to suit personal and professional needs.
- Ability to enter a learning pathway at a relevant level through accreditation for prior experiential learning (APeL).

- Ability to ‘bank’ credits for learning including the development of a ‘common currency’ which is also valued in the wider academic community and fits with the education system.
- A range of accredited and non-accredited options at all levels.
- Evidence based learning strategies, including blended learning approaches.
- Opportunities for extensive work place learning.
- Four core learning areas which are interlinked: communication skills, assessment skills; complex care management; and role development.

4.2.3 The training of doctors

Training regulations currently mean that it is sometimes difficult for doctors training in paediatric palliative medicine to obtain the breadth of experience necessary. The development of a new joint curriculum in paediatric palliative medicine prepared by the educational sub group of the British Society of Paediatric Palliative Medicine (BSPPM) and the Association of Children’s Hospices Doctors (Hain R, Jassal S, Lapwood S, McCulloch R and Rajapakse D, 2008) provides all doctors who encounter dying children or those with a life-limiting illness with a framework for learning. This document aims to inform the training and assessment of doctors across all specialities (paediatrics, general practice and palliative medicine) and at differing levels of competency ranging from a newly qualified doctor to a specialist consultant in paediatric palliative medicine.

1. Paediatricians

The Royal College of Paediatrics and Child Health’s (RCPCH) recognition of paediatric palliative medicine as a sub-specialty within paediatrics in 2008 has provided both acknowledgement and validity to the field. In addition the recommendation from the 2007 Department of Health Independent Review of Children’s Palliative Care Services has encouraged medical service development, specifying that there should be a specialist paediatric palliative care consultant for each region and a doctor with a specialist interest in each locality.

There are currently two national training posts available for paediatricians wishing to specialise in paediatric palliative medicine, one in London and one in Cardiff. A minimal period of two years is required for specialist eligibility.

The newly named Association for Paediatric Palliative Medicine continues to represent the specialty within the RCPCH at a national level and now includes paediatricians, children’s hospice doctors, general practitioners and adult palliative care consultants working in the field.

* Right People, Right Place, Right Time: Planning and developing an effective and responsive workforce for children’s and young people’s palliative care, ACT and Children’s Hospices UK, (2009)
2. Children’s hospice doctors

A survey describing the educational and training needs of children’s hospice doctors (Amery and Lapwood, 2004) emphasised the broad range of skills needed, including symptom management and end of life care and highlighted the importance of team work, communications skills, conflict management and personal coping strategies, which are often not fully recognised. Some of the required competencies can be gained through vocational training, but additional training will be necessary. The new curriculum will provide a benchmark for learning and standards for medical education, training, accreditation and revalidation within the children’s hospices.

3. GPs with special interest

A small group of doctors providing children’s palliative care services in the UK are effectively working as GPs with Special Interest. Many of these doctors are providing medical support to children’s hospices and some are providing support and advice to other professionals working with children in the wider community.

4. Other general practitioners

Some general practitioners find themselves providing a key role for families, but may have little experience of working with dying children and will need support to meet the particular needs of an individual child and family. This supporting role is likely to continue to be a valuable service provided by consultants and GPs with a special interest in paediatric palliative medicine.

5. Adult palliative medicine

Adult palliative medicine is a well-established speciality and there are many lessons that paediatric palliative medicine can learn from it. There is a broad overlap of competencies between adult’s and children’s medicine, but many different experiences and competencies are required for each. The particular needs of adult palliative medicine physicians wanting to work with children need to be addressed in collaboration with the Royal College of Physicians. Specialist paediatricians in training are required to work alongside a specialist adult palliative care unit for a minimum of three months. The need for collaborative working and development of some crossover skills between children’s and adult’s palliative care doctors is important for effective transition to adult care.

4.2.4 The training of nurses

The education and training of nurses in the UK has undergone considerable change in recent years with a strong emphasis on post-qualifying courses and continuing professional development. The purpose of training and education should be to develop nursing practitioners who are competent to care for children and young people across a range of settings.

Nurses contribute significantly to the delivery of children’s palliative care within a diverse range of professional roles. These include community children’s nurses, school nurses, children’s hospice nurses, learning disability nurses and health visitors.

Children’s nurses who already have basic skills for working with children, young people and families are able to further develop their knowledge and professional practice in caring for children and young people with palliative care needs through flexible learning opportunities. Community children’s nursing degree courses often include foundation modules on palliative care nursing in the community. These modules include the skill set required to set up and sustain effective community nursing services.

Work is currently underway by the Royal College of Nursing to develop competences for nurses working in children’s palliative care, from healthcare assistants through to nurse consultant levels.

4.3 Supervision and psychological support for staff

Those working in children’s palliative care work in a highly stressful environment. They also have to cope with a heavy emotional and spiritual burden, generated by working with those who are suffering, dying and bereaved. They therefore need a diverse and strong armoury of personal coping strategies in order to deal with the demands of the job.

The needs of children with life-limiting conditions are broad, complex and ever changing. Experience suggests that good palliative care requires the input of a broad team, able to communicate effectively, understand team dynamics and work positively with fellow team-members, even in situations where the team is under pressure. Good inter-personal, intra-personal and team working skills are therefore essential.

The challenge for teachers and trainers is to become familiar with, and use tools to develop all of these skills. These tools include educational diary keeping, significant event analysis, mentoring, clinical supervision and personal supervision.

Experience and anecdotal evidence suggest that these are often considered luxuries rather than core needs in many institutions providing children’s palliative care services. Most of those working with children with life-limiting conditions and their families will not have ready access to clinical supervision, mentoring or psychological support, which can impact on the quality of care delivered to children and their families and this should be addressed as a priority.
References


Phtt, M. & McElhill., 1995. More needs than most... Dealing with the family's economic and practical needs when a child has a chronic, life-threatening or terminal condition. London: Whiting and Birch.


Thornes, R., 1993. (On behalf of Caring for Children in the Health Services.) Bridging the gaps; an exploratory study of the interfaces between primary and specialist care for children within the health services. London: Action for Sick Children.


care and support needs in the technology dependent child. Archives of Disease in Childhood 2006;91:458-460; doi:10.1136/adc.2006.095679.


Appendix 1 The ACT Charter

1 Every child/young person shall be treated with dignity and respect whatever their physical or intellectual ability.

2 Parents shall be acknowledged as the primary carers and involved as partners in all care and decisions involving their child.

3 Every child/young person shall be given the opportunity to participate in decisions affecting his or her care, according to their age and understanding.

4 An honest and open approach shall be the basis of all communication.

5 Information shall be provided for the parent, the child/young person, the siblings and other relatives, appropriate to their age and understanding.

6 The family home shall remain the centre of caring whenever possible with appropriate support provided to all the family. Care away from home shall be provided in a child-centred environment by staff trained in the care of children, young people and families.

7 Every family shall have access to a 24 hour multi-disciplinary children’s palliative care team for flexible hands-on care and support in the home, and be in the care of a local paediatrician.

8 Every child and family shall receive emotional, psychological and spiritual support to meet their needs. This shall begin at diagnosis and continue throughout the child’s lifetime, death and in bereavement.

9 Every family shall be entitled to a named key worker who will enable the family to build up and maintain access to an appropriate network of support.

10 Every family shall be given the opportunity of regular consultations with a paediatric specialist who has particular knowledge of the child’s condition.

11 Every family shall have access to suitable flexible short breaks (respite care) both in their own home and away from home, with appropriate children’s nursing and medical support.

12 Every child shall have access to education, extended school opportunities and other appropriate play and leisure activities.

13 The needs of adolescents and young people shall be addressed and planned for well in advance using a person-centred approach.

14 Every family shall have timely access to practical support, including clinical equipment, financial grants, suitable housing and domestic help.

Appendix 2 Glossary

Children’s palliative care definition
Palliative care for children and young people with life-limiting conditions is an active and total approach to care, from the point of diagnosis or recognition, embracing physical, emotional, social and spiritual elements through to death and beyond. It focuses on the enhancement of quality of life for the child/young person and support for the family and includes the management of distressing symptoms, provision of short breaks and care through death and bereavement. ACT (2008).

Care of the dying
Care of the dying is the care of the patient and family in the last hours and days of life. It incorporates four key domains of care: physical, psychological, social and spiritual, and supports the family at that time and into bereavement.

Child
A child is defined as a young person aged up to their 19th birthday.

Children’s hospice services
Children’s hospice services provide palliative care for children and young people 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. These include:

- 24 hour end of life care.
- Support for the entire family (including siblings, grandparents and the extended family).
- Bereavement support.
- 24 hour access to emergency care.
- Specialist short break care.
- 24 hour telephone support.
- Practical help, advice and information.
- Provision of specialist therapies, including physiotherapy as well as play and music therapy.
- Provision of information, support, education and training where needed to carers.

Children’s hospice services deliver this care in the home (commonly termed ‘hospice at home service’) and/or in a purpose built building.

Children’s palliative care networks
Children’s palliative care networks are linked groups of multi-agency professionals and organisations from primary, secondary and tertiary care, social services, education and other statutory and voluntary services working together in a co-ordinated manner. They provide the forum in which:

- Better integrated and more effective commissioning models can be developed and shared.
- Statutory and voluntary agencies will work together to provide an agreed and comprehensive range of services.
- Local needs can be assessed, through mapping of affected children and young people and available services (this
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 a service, involving two or more agencies that provide disabled children and young people and their families with a system whereby services from different agencies are co-ordinated. It encompasses individual tailoring of services based on assessment of need, inter-agency collaboration at strategic and practice levels and a named key worker for the child and their family. Families with disabled children should only have a key worker if they want one. (Care Co-ordination Network UK, 2006).

Needs-led
Need-led is the term used to describe how services should be provided on the basis of the needs of the patient and family and not as a result of assessing the resources that are available. To deliver a needs-led service it is important to assess and thoroughly understand the needs of the children, young people and families first.

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.

Primary care organisation
A primary care organisation is the NHS body responsible for providing primary health services and improving health within their local community through commissioning. Primary care organisations have taken on many of the responsibilities of planning and purchasing health services that were formerly undertaken by health authorities and in addition they can also provide services themselves e.g. Primary Care Trusts and Local Health Boards.

Primary healthcare team
A primary healthcare team comprises the general practitioner, practice nurse and community staff (such as community children’s nurses or physiotherapists) who work with the practice staff.

Service level agreement
A service level agreement is an agreement between the commissioner and any organisation providing a service. They specify standards to which the service should be provided, for what sum of money and for how long.

Short breaks
Short break care has three main functions:
- To provide the child or young person an opportunity to enjoy social interaction and leisure facilities.
- To support the family in the care of their child in the home or an alternative community environment such as a children’s hospice.
- To provide opportunities for siblings to have fun and receive support in their own right.

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.

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 provision of psychological, social, spiritual and practical support and support for the family into bereavement.

End of life care services
End of life care services are services to support those with advanced, progressive, incurable illness to live as well as possible until they die. These are services that enable the supportive end of life 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 provision of psychological, social, spiritual and practical support. This is not confined to discrete specialist services but includes those services provided as an integral part of the practice of any health or social care professional in any setting.

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

Hospice at Home
Hospice at Home is a term commonly used to describe a...
Specialist short break care

Specialist short break care refers to a setting of care, a programme of care or a service that provides additional care for highly complex or technology dependent children who may otherwise be excluded from short breaks provided by social care. It 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 break care provides the support required to meet the child's holistic care needs and enables children and families to be able access short break services. Specialist short breaks will often address some aspects of symptom management. Specialist short breaks should also meet the functions described under general short breaks.

Supportive care

Supportive care is an ‘umbrella’ term for all services, both generalist and specialist, that may be required to improve the quality of life for people with life-threatening illness. It recognises that people need some forms of care that are not directed towards cure 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

Technology dependent children are those 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 (Kirk and Glendinning 1999; Glendenning et al 2001).

Young adult

The term young adult describes a person from their 19th birthday.

Young person

The term young person describes a person from their 13th – 19th birthday.
A Guide to the Development of Children’s Palliative Care: notes and updates

(These pages have been left blank for your own personal notes and for any updates to the Guide.)
A Guide to the Development of Children’s Palliative Care: notes and updates

(These pages have been left blank for your own personal notes and for any updates to the Guide.)
A Guide to the Development of Children’s Palliative Care Services is a key resource for all organisations and professionals who have an interest in developing or supporting services for life-limited or life-threatened children and their families. It sets out ACT's vision for the future sustainable development of children's palliative care, ensuring that the best quality care and support is available to all the children, young people and families that need it.

Essential reading for all commissioners and providers of services with an interest in children's palliative care, disabled children or children with complex health care needs. This Guide will be of specific interest to children's and workforce development commissioners, PCT chairs and chief executives, clinicians working with children, heads of care, paediatricians, GPs, hospice managers, community nursing teams and all statutory and voluntary sector providers working with life-limited or disabled children.

Now in its third edition, the Guide sets out the evidence and definitions that will inform the development of children’s palliative care services and gives commissioners and providers the tools they need to plan, develop and deliver high quality and sustainable services across the UK.

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