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Department of Health

National Service Framework for Children,
Young People and Maternity Services

Commissioning Children's and Young People's Palliative Care Services

Every Child Matters - Change for Children

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For recipient's use

COMMISSIONING CHILDREN'S AND YOUNG PEOPLE'S PALLIATIVE CARE SERVICES

A PRACTICAL GUIDE FOR PRIMARY CARE TRUSTS AND PRACTICE-BASED COMMISSIONERS

Palliative care for children and young people with life-limiting conditions is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite and care through death and bereavement.

(A Guide to the Development of Children's Palliative Care Services: Report of a Joint Working Party of ACT and the Royal College of Paediatrics and Child Health) (2003)

Endorsements

“As children and young people with life-limiting conditions live longer, the importance of commissioning appropriate palliative care services for them and their families is increasing all the time. The Royal College of Nursing welcomes this guide for commissioners on children’s and young people’s palliative care.”

Fiona Smith
Advisor in Children’s and Young People’s Nursing
Royal College of Nursing

"We are delighted that the Department of Health has assembled these multiple sources of information. This will aid commissioners in their duty to bring a range of providers together, to create a seamless network for this vulnerable group of children, young people and families."

Professor Sir Alan Craft
President
Royal College of Paediatrics and Child Health

“ACT welcomes this guide from the Department of Health. It provides much needed national guidance which will help to raise awareness of the needs of life-limited or life-threatened children and provide information for commissioners on how best to meet the needs of this often overlooked group of children and families.”

Lizzie Chambers
Chief Executive
ACT (Association for Children with Life-threatening or Terminal Conditions and their Families)

“ACH welcomes the publication of this new document. This is an important step forward for the children’s hospice movement and those organisations providing children’s palliative care. It’s vital that those responsible for commissioning children’s care services understand the importance of children’s hospice services and the role they play in our society.”

Barbara Gelb
Chief Executive
The Association of Children’s Hospices

Why this document is needed

1. Improving the quality of palliative care for children, young people and their families is an important aspect of the Children, Young People and Maternity Services National Service Framework (Children's NSF). Evidence suggests that there is scope for these needs to be met more systematically: "Voices for Change" a survey by the Association for Children with Life-threatening or Terminal Conditions and their Families (ACT).

2. The process of commissioning plays a vital role in identifying local palliative care needs and models of effective delivery. It also enables transparency and agreements on levels of investment to meet those needs. The Children's NSF requires the framework, which commissioners are putting into place for this, to be of a calibre that ensures that all children or young people needing palliative care are able to access it at a high level of quality. This guide therefore aims to support commissioners in their role, increasingly through children's trust arrangements, joint commissioning and the use of pooled budgets.

3. This guide should also be read in the light of the manifesto commitment to increase funding to improve end of life care, giving more people the choice to die at home, whether from cancer or any other life-threatening condition. Funding the commitment is expected to be covered in the White Paper, which will follow consultation on "Your Health, Your Care, Your Say".

4. The guide aims to support healthcare organisations in their work with local authorities and other partners to develop children's palliative care services. It will help commissioners of health services to apply the Children's NSF in their strategic development and delivery of children's palliative care. Practical examples of palliative care service delivery are available on the Children's NSF website and the Department of Health has developed a web-based emerging practice database that contains over 180 case studies exemplifying how the NSF is being implemented locally (http://www.childrensnsfcasestudies.dh.gov.uk/children/nsfcasestudies.nsf).

5. This guide complements "A Guide to the Development of Children's Palliative Care Services, 2nd edition", which was jointly produced by ACT and the RCPCH and is commended to commissioners.

The Policy and Legislative Context

6. The Children's NSF forms the health and social care developmental standards for services to children and young people by 2014, however, the child protection element of Safeguarding Children are core, under "Standards for Better Health" (2004). In effect, the 2005 manifesto commitment to double funding for end of life care, so that more people, including children, could have the choice to die at home, brings implementation of palliative care standards much further forward than 2014. A number of other related policies impact on delivering this commitment. These include the public service agreement targets for long-term conditions, access to services, and patient and user experience as set out in "Improvement, Expansion and Reform : The Next Three Years' Priorities and Planning Framework, 2003-2006 (2004)", the NSF for Long-term Conditions and the forthcoming White Paper on out of hospital care.

7. Building on the five key outcomes that are set out in "Every Child Matters: Change for Children" (2004) and the Children Act 2004. Standard 8 of the Children's NSF expects high quality palliative care to be available to all children and young people who need it. It is to be co-ordinated by a network of agencies including the NHS, children hospices, the voluntary sector, social care and education. PCTs, NHS Trusts and local authorities are required to ensure provision takes account of the child or young person's and their family's physical, emotional, cultural and practical needs in a way that promotes choice, independence, creativity and quality of life.

8. Collaborative commissioning arrangements are vital to meeting the needs of children and young people for palliative care. PCTs should take account of their duty under Sections 26/27 of the Health Act 1999 to co-operate with each other and other NHS bodies in exercising their respective functions. That duty also extends to their co-operation with local authorities in order to secure and advance the health and welfare of their population. PCTs should also take account of the specific requirements under Section 10 of the Children Act 2004 of their duty to co-operate with local authorities and a number of 'relevant partners' to improve the five "Every Child Matters" outcomes for children.

The Demand for Palliative Care for Children and Young People

9. In order to commission effective palliative care for children and young people, it is important to understand the nature of the life-threatening and life-limiting conditions which may affect them and the ways in which their palliative care needs differ from palliative care of adults.

10. A range of different medical conditions with different manifestations can give rise to the need for palliative care in children and young people but in some cases a precise diagnosis may not be possible. Four broad definitions of groups of children and young people requiring palliative care are described in "A Guide to the Development of Children's Palliative Care Services":

    > Children with life-threatening conditions where cure is possible but can fail, for example cancer;

    > Conditions which, though treated intensively over a period of time, inevitably lead to early death, such as cystic fibrosis;

    > Progressive conditions where treatment is palliative and often over many years, for example muscular dystrophy; and

    > Irreversible but non-progressive conditions giving rise to severe disability and sometimes premature death.

11. The number of children and young people dying is small but their need for palliative care involves much longer term provision, often intermittently throughout their lives. Depending on the underlying disease or condition the care pathway can be complex. There is no single source of data on numbers and for the purpose of this guide, the demand for children and young people's palliative care is estimated from death data and disease prevalence.

12. Excluding neonatal deaths and stillbirths, the number of deaths in young people aged between 0 and 30 years has steadily risen in the four years from 2000/01-2004, totalling 32,449 deaths. Of this four-year total, just under half (14,935) were deaths in children and young people aged up to 19 years. The most recent annual figure (for 2004) shows 3,914 deaths in this age group. (Table 1: Column A).

13. Analysis of cause of death of those between the ages of 0 and 30 years, from causes that were likely to have required palliative care totalled 7,055 over the period 2000/01-2004. They therefore made up 22% of all causes of deaths. These deaths rose steadily from the age of 10 years until 30 years, reaffirming the importance of providing good transitional care for young people, which continues well into young adulthood (Table 1: Column B). A further analysis of the conditions causing deaths where palliative care would have been required, showed about half to be cancer-related (Table 2). No data is available on how long palliative care may be needed before death.

14. The data at Table 3 show that choice of place of death is restricted. Only 30% of children and young people aged 0-19 years died at home in the four-year period to 2004; 62% died in NHS hospitals and 6% died in hospices (5% in non-NHS hospices and 1% in NHS hospices). It is likely that, given the proper and full back-up of services, more children and young people, with the support of their families, may choose not to die in hospital.

Commissioning High Quality Palliative Care for Children and Young People

PCT Commissioning

15. Commissioners should be guided by the model on pages 16 and 17 in considering how best to ensure sustained and effective delivery of palliative care to children and young people with life-limiting or life-threatening illnesses. At all times, community-led palliative care, available locally, should be at the heart of all the provision to children and young people. It should be supported by the following:

> Disease-specific care either where the hospital team with the expertise in treating the underlying condition also provides the palliative care (for example oncology and cardiac) or specialist palliative care where more scarce resources are drawn upon, usually regionally, to address complex management issues such as pain, nutrition, tissue viability or mental health problems;

> Residential and hospice outreach care;

> Access to acute hospital care;

> Local authority social services, education and voluntary sector provision;

> Community paediatrics; and

> Primary care.

16. The National Definitions Set currently states "the definitions identify the activity that should be regarded as specialised and therefore subject to collaborative commissioning arrangements". Commissioners should employ existing collaborative commissioning arrangements, currently at the following levels:

> PCTs, in partnership with other local commissioning agencies, including children's trusts;

> Local Specialised Commissioning Groups (LSCGs) at a population of 1-2 million;

> Specialised Commissioning Groups (SCGs) at a population of 3-5 million; and

> The National Specialised Commissioning Advisory Group (NSCAG) with top sliced funding from PCTs, nationally commissions 33 services of which at least 10 concern children, including heart, lung and liver transplants, retinoblastoma and bone tumours.

17. Except for voluntary hospice provision, it is therefore recommended that community-led palliative care is commissioned at the first level of collaborative commissioning, that is at PCT/Children's Trust level. The larger configurations of PCTs/Children's Trusts and their anticipated increased coterminosity with local authorities expected from "Commissioning a Patient Led NHS" would commend this approach to commissioning. In this context, delegation by PCTs/Children's Trusts to practice-based commissioners could further enhance the availability of more localised and therefore accessible community-led palliative care provision.

Specialised Commissioning

18. It is further recommended that disease-specific or specialist palliative care, which is for fewer children who require expertise that can be scarce, is dealt with through LSCGs or SCGs. The "Specialised Services National Definitions Set (2nd Edition)" currently describes 35 Specialised Services for Children - see Definition No. 23. Although palliative care is not currently mentioned this does not prevent its specialised commissioning in population terms. The RCPCH document "Commissioning Tertiary and Specialised Services for Children and Young People" (March 2004) referred to the same services as the National Definitions Set, and highlighted the need for palliative care within particular services, such as neuro-disability and cystic fibrosis. Arrangements for commissioning specialised services, of which specialist palliative care is one, are being looked at by the current Ministerial Review into Commissioning Arrangements for Specialised Services.

19. For the reasons set out below, and pending the outcomes of the specialised services review, the model recommended is not prescriptive about the level of specialised commissioning (LSCG or SCG) at which disease specific or specialist palliative care services should be commissioned because:

> conditions requiring different kinds of palliative care occur at different frequencies;

> different components of palliative care provision for a child or young person can be more or less specialised; and

> geographical considerations can influence both providing and commissioning arrangements.

20. However, the following general observations are offered:

> For neuro-disability, the needs of the child and family are multiple and chronic. The frequency of neuro-disability, and the close interface with paediatric community services, implies that this service should be commissioned at PCT /Children's Trust level;

> For cystic fibrosis and muscular dystrophy, most of the care, including terminal care, may be delivered by the specialist respiratory and neurology teams respectively. Whilst these teams frequently need to work closely with local community-based colleagues, their services tend to be commissioned by specialised services commissioners;

> Management of pain is an integral part of paediatric care commissioned by PCTs. However, severe chronic pain may in some circumstances require a high degree of expertise and skill, for example in epidural or other regional analgesia. These specialised pain teams are likely to be commissioned at SCG level; and

> Commissioning palliative care for cancer in children and young people will be a component of specialised commissioning of oncology.

21. It is clear that commissioning voluntary children's hospice provision at PCT/Children's Trust level leaves many hospices struggling to manage the process with several Trusts. Voluntary children's hospice services should be planned and commissioned at LSCG level or above. It will ease the burden of negotiation and management on individual children's hospices, which are by nature quite small and serving large catchment areas.

Planning Principles

22. The following planning principles set out in "National Standards, Local Action" apply to commissioning palliative care services:

> Population needs;

> Local service gaps;

> Equity;

> Evidence based;

> Partnerships; and

> Value for money.

23. There is a variety of resources on how to assess palliative care needs and provision in a local area. They include the ACT publication “Assessment of Children with Life-limiting Conditions & their Families: A Guide to Effective Care Planning” and ACT/RCPCH's "Guide to the Development of Children's Palliative Care Services". More on the specific requirements for palliative care is provided in the ACT guidance "Integrated Multi-agency Care Pathways for Children with Life-threatening and Life-limiting Conditions”. Funded by the Department of Health, the document is also endorsed by the Royal College of Nursing and the RCPCH. There is also the quality assurance package “Are We Getting it Right?” from the Association of Children’s Hospices (ACH) and “Palliative Care for Children - Joint Briefing No.1” by the National Council for Palliative Care jointly with ACT and ACH. The ACH guide “The Children’s Hospice Service Toolkit” (November 2005) provides information around the planning and establishment of children’s palliative care services in the voluntary sector.

24. Population needs assessment and addressing palliative care service gaps may be further informed by benchmarking existing statutory and voluntary sector services against Children’s NSF standards and the choices made by children, young people, parents and carers. The use of a matrix, care pathways and local users’ surveys will help commissioners to examine service strengths, gaps and relationships in order to plan and integrate palliative care provision to enhance the experience of children and their families. Where service need is small, commissioners may consider making joint provision arrangements with other local partners so that a critical mass of service is viable and available. From summer 2006, PCTs will be able to use palliative care services information available from the National Child Health Mapping project to evaluate current patterns of service provision and benchmark against other providers.
The project website is: http://www.childhealthmapping.org.uk

25. Local health equity audits and equality impact assessments are helpful in ensuring equity of access. By tracking the experience of users, they can provide useful information for refining services.

26. In commissioning palliative care for children and young people, PCTs, LSCGs and SCGs should use the children and maternity services managed networks. The advantages of these in developing the local partnership arrangements necessary for integrated and multi-agency services are set out in “A Guide to Promote a Shared Understanding of the Benefits of Managed Local Networks”. For further information please refer to: http://www.dh.gov.uk/publications. The Care Services Improvement Partnership – Change for Children Programme is supporting local development of these networks. For further information please refer to: http://www.csip.org.uk.

Funding and Value for Money

27. In their funding decisions, commissioners will be ensuring value for money including opportunities to maximise impact through ventures with local authority partners where pooled budgets could be used to achieve a more integrated service. In addition to the baseline allocations to PCTs, there is a number of funding streams for children's palliative care, which include the following:

> On 29 January 2003, the New Opportunities Fund (now The Big Lottery) announced the award of £48m over 3 years to 135 children's palliative care projects in England. The money was allocated to community based palliative care teams, bereavement teams and hospices to sustain or develop their provision. The length of the funding period gives an opportunity for voluntary organisations and PCTs to engage with local partners on the future of these services and their integration into local commissioning arrangements and mainstream funding. Further information is available from www.nof.org.uk

> Local authorities have an equal interest in the provision of services for these children, for example to ensure flexibility by supporting short breaks. The Carers and Disabled Children Act (2000) strengthens the rights of carers to an assessment of their own needs as carers. It gives local councils mandatory duties to support carers and young disabled people as well as providing Direct Payments for carers' services. This increases carers' choices, options and control over their own lives, but uptake has been rather low and needs to be encouraged.

> The Carers Grant, introduced in 1999, provides breaks for carers. It is worth £125 million in 2004/05, rising to £185 million in 2005/06 and will remain at this level until at least 2008: "Carers Grant 2005-06". Ring fencing has been removed for three star rated local authorities. Feedback indicates that they have continued to support the carers fully in their community through the grant. The grant remains targeted, meaning that the funding is still labelled for carers up to 2005/06.

> The Social Care Institute for Excellence is developing a practice guide and will be using the evidence from its current knowledge review on the participation of carers in changing and improving social care. The practice guide will include advice on how to implement the Carers (Equal Opportunities) Act 2004 and will be developed in consultation with key stakeholders. Further information is available at www.scie.org.uk/publications

> Voluntary sector funding supports a significant range of children's palliative care services that may be available from local children's hospices. This may range from day and night breaks with professional support (that is specialist breaks in the child's own home or at the hospice) to access to education, 24hour support lines, social activities and bereavement counselling. These are just some of a range of core services that voluntary sector providers including children's hospices can provide. PCTs seeking or holding contracts with children's hospices need to be aware of the large number of other similar bodies that a single hospice may be dealing with and therefore, where possible, may seek to designate a lead PCT/Children's Trust or other health care commissioner to conduct service and finance negotiations on their behalf. In their palliative care service proposals, commissioners would wish to consider carefully how their development decisions could affect local hospices and involve them early in their discussions. It would be helpful for healthcare commissioners, with their local authority social service partners, to engage early with prospective developers of a new hospice, or an expansion to existing facilities, to discuss and influence its fit with the direction of travel in statutory services provision for local children. The ACH guide to setting up a children's hospice "The Children's Hospice Service Toolkit" (November 2005) clearly sets out the need to collaborate actively with other organisations and services.

> Many of the specific condition charities have local and regional services which parents regularly access e.g. information, face-to-face support, home-based care, befriending, counselling etc. Hospices are a vital part of this pattern of provision and commissioners should enable the voluntary sector as a whole, to work with the statutory agencies to ensure there is continuity of care and support. The ACH estimated in 2000 that only about 5% of children's hospice funding is from the statutory sector. The pathway of this funding flow and how referrals are made is not always clear.

28. Commissioners need to be aware of HM Treasury's 2002 Cross Cutting Review on the Role of the Voluntary and Community Sector in Service Delivery, a key theme of which was the funding relationship between the statutory and voluntary sectors. The Review identified a strong view within the voluntary and community sectors that commissioners are often unwilling to finance the fixed and overhead costs that they incur.

29. The Review recommended that commissioners should recognise that it is legitimate for voluntary and community sector (VCS) providers to include the relevant element of overheads in their cost estimates for providing a given service under a contract or service agreement. The intention of full cost recovery is that the Government will meet the full costs – i.e. including the relevant element of overhead costs - of any VCS services it commissions by April 2006. In the context of hospice care, this does not mean the full costs of the hospice, but rather those services provided by the hospice that are commissioned by the PCT. Prior to implementation of Payment by Results for services provided by the VCS, the NHS and the VCS should be working towards agreed volumes of service, ensuring that the price for the agreed volume of service reflects the full cost of the service to be provided including the legitimate portion of overhead costs. Local compacts provide a framework for partnership working between the NHS and VCS.

30. The "Compact Code of Good Practice on Funding and Procurement" (Compact Working Group and the Home Office, March 2005) aims to influence and strengthen the financial relationship between the statutory sector and the VCS. It sets out the principles for full cost recovery in line with the conclusions of the Cross Cutting Review. The introduction of Payment by Results for specialist palliative care will ensure that, in future, all providers – across all sectors – are paid on a transparent basis for the services that meet patients' needs and could, in effect, provide the basis for the full cost recovery as recommended by the Cross Cutting Review, for those services provided by the voluntary sector that are commissioned by the NHS. However, Payment by Results does not necessarily mean an individual provider will be paid the full cost for providing a service, as prices are fixed under a National Tariff. As a result, individual providers – whether NHS, commercial independent sector or VCS – may not be able to recover the full costs of service provision where the costs of the service they provide are, for whatever reason, greater than the National Tariff. The emphasis will, therefore, be on effective negotiation between contracting partners as contracts and service level agreements come up for renewal. Work to develop Healthcare Resource Groups and Payment by Results in specialist palliative care is still ongoing.

What Should be Provided?

31. The need for palliative care begins as soon as it is clear that a child or young person has a life-threatening or life-limiting illness. Whether community-led, disease-specific or specialist, active individually titrated palliative care approaches support children, young people and families to lead as normal lives as possible. They include:

- Partnerships between the child, young person, family, carers and professionals to listen and identify and meet needs in an individualised and flexible way;
- Delivering care where the child, young person and family want it to be, e.g. in the home, hospital or hospice, school or nursery;
- Individually planned pain and symptom management with access to 24 hour advice;
- Psychological and social support including formal counselling and therapy;
- Attention to cultural, spiritual and practical needs – further details about these are set out in the Children's NSF hospital standard, paragraph 3.4;
- Services appropriate to the age and development of the child or young person, integrated and reflecting the longer-term continuing care pathway required by an increasing number of children and young people;
- Multi-professional and multi-agency teamwork and partnerships;
- Supporting children, young people, their families and education professionals to enable children and young people to continue to access education; and
- Provision of information and advice about services such as play, leisure, housing adaptations, childcare, aids, equipment and transport; some minority groups may need extra assistance to enable this to happen, including translation services.

32. For severely disabled children and those with multiple disabilities, recent studies indicate a particular need for co-ordination if services are to be improved. For example, parental experience of services when their child requires long-term ventilation raised the following issues: significant delays in hospital discharge; organisational fragmentation in commissioning services; problems with supply and maintenance of equipment; significant social morbidity - reduced family incomes; housing and social isolation; difficulties with access to short breaks; loss of employment; and problems with access to education.[1]

33. It may not be practical or possible to provide children, young people and their families with a complete choice of locally available specialist palliative care providers. There may be a need to refer to regional or sub-national specialised services or to consult the forthcoming national network for children's palliative care telephone advice (see the service examples at http://www.childrensnsfcasestudies.dh.gov.uk/children/nsfcasestudies.nsf

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[1] Margolan H, Fraser J, Lenton S. Parental experience of services when their child requires long-term ventilation. Implications for commissioning and providing services. Child Care Health Dev. 2004 May; 30(3):257-64.

PCT Commissioning

A child or young person may e
> either as a step change from
> or as a continuum of previous s

Single multidiscip

Multiprofession
> Identified lead
> Key worker
> Support work

Primary care

> GP informed, involved in treatment decisions, meeting needs of rest of family
> Other members of primary care team including school nurses
> NHS Direct
> 24 hour support available
> Ambulance service
> Out of hospital service
> Walk-in centres

Community Paediatrics

Other agencies

Local authority social services, education and voluntary agencies
> Equipment and aids
> School liaison
> Leisure
> Allowances and benefits
> Short term breaks
> Support services (e.g. Contact a Family, Barnardos, Wellchild)
> Bereavement care
> Faith support

Community-led
Multidisciplinary culturally-
> Written
> Children and parents involved a
choices in
> Choice to be at hon
> Early transi
> Prospective discussion a
> Specific end of life care in
Care delivered by Children's Nursi
children's nurses, and special

supported by appro

Access to acute care
> Agreed future strategy for a
(e.g. resuscitation plan, desi
> Care plans held by family
> Local A&E and paediatric un
prevent hasty decisions by s
> Open access policy to ward
(e.g. severe fits)
> Optimal communication cha
community and hospice

Specialised Commissioning

enter a phase of palliative care:
a curative phase e.g. malignancy
supportive care e.g. Batten's Disease

linary assessment.

al team:
d professional

ers

'Disease-specific' Specialist Team e.g.

- > Cystic fibrosis (e.g. managing respiratory problems)
- > Cardiac
- > Neurology (e.g. seizures, contractures)
- > Oncology / haematology
(e.g. may give cytotoxics, radiotherapy for palliation)

The teams involved in the curative or chronic phases retain involvement at the end stages of the child's life.

d Palliative Care
sensitive tailored packages:
care plan
nd supported in making informed
care decisions
ne as much as possible
tion planning
about end of life decisions
cluding resuscitation choices
ng Teams including CCNs, generic
ist outreach children's nurses;

priate medical input

Specialist palliative care e.g.

- > Complex pain management
- > Mental health support
- > Nutrition services
- > Tissue viability services

cute deterioration
red place of death)

it knowledgeable about child to
taff
for repeated needs

nnels between hospital,

Residential & outreach hospice care

- > Elective planning
- > Emergency bed accessibility
- > Choice of site & services
- > Recognised part of the continuum of care
- > Clinical governance
- > Partnership working with specialist services
- > Expertise of hospice staff made available to community team
- > Short term breaks (respite)
- > Specific end of life care
- > Bereavement care

34. In addition to health needs, the child or young person often has many other complex needs for social support and formal education. Their family also needs to be supported effectively. Palliative care services are therefore provided by a network of agencies in addition to care carried out by family members themselves. PCTs commissioning for choice to deliver the Children's NSF standards are likely to consider the diverse range of potential services and, in collaboration with their local authorities, a mix of provision within both the statutory and voluntary sectors. In addition to medical care, packages of care range from help with complex nursing care and therapy in the home to opportunities for short breaks, education and play and leisure provision to help to maintain the mental, physical and social health and well-being of all the family members.

35. Local authorities play a key part in funding the provision of short breaks, practical and emotional support. Practical support can include help with the cost of housing adaptations through Disabled Facilities Grants. This can enable the child or young person to participate in activities such as leisure and education where backed by good quality healthcare. The provision of the service should be seamless and integrated around the child's needs.

36. Standard 8 of the Children's NSF highlights the importance of the role of a named key worker. Research has shown the benefits of having a key worker, commissioned jointly to work with families, who can:

> Provide information and advice;
> Identify and address needs;
> Improve access to services;
> Improve co-ordination of services;
> Provide emotional support; and
> Act as an advocate.

More information on standards for key workers is available online from Care Co-ordination UK (http://www.ccnuk.org.uk).

37. The need for palliative care for children with complex disabilities or life-threatening long-term conditions may be recurrent and is often unpredictable. A continuing care approach provides reviewable personalised care plans, helping to improve the flexibility of care and co-ordination of services to these children, for whom the application of time limits on care is quite inappropriate. As set out in the NSF, children requiring NHS continuing care should receive co-ordinated multi-agency packages of care according to their individual need. Further details are included in Health Service Circular/Local Authority Circular HSC 2001/015: LAC (2001)18.

38. Involvement in education not only helps children and young people to maintain achievement but also to sustain friendships and enjoy life with their peers. The child and family should continue educational input for as long as possible whilst an illness is progressing. Local authorities are responsible for arranging to provide suitable education at school or elsewhere for children of school age who because of illness may not otherwise receive appropriate education. Education of pupils who are not able to attend school because of medical needs can be provided in a variety of ways, for example through the provision of a hospital school service, home teaching or an integrated hospital/home education service; more frequent reviews of educational provision may be needed for pupils receiving palliative care.

39. Health professionals liaising closely with the local authority, hospital and home teaching services can make it possible for the child to receive some continuing education. Well-informed teachers, learning support assistants and other school staff are well placed to support the child or young person and enable them to have as "normal" a life as possible by involvement in educational activities. Attention to pain management and symptom control services are primary considerations in order to help maximise the child's quality of life and the confidence of the family, schools and other providers. Services to provide appropriate advice and support to schools and other community services with regard to the administration of medication, management of personal care, counselling and risk management are further elements for consideration in commissioning and may be delivered by trained generic workers.

40. Commissioners may find the provision of local directories of children's services a useful resource for parents and children to help them make informed choices about services available. From summer 2006, the National Child Health Mapping Project will facilitate the production of such directories. A range of information is available from local voluntary agencies and their national bodies.

41. The importance of effective provision in the transition to adult services was identified both in the Health Select Committee Report on Palliative Care, the Children's NSF and the Long-term Conditions NSF. A young person with a life-threatening or life-limiting illness or complex needs requires specific attention when managing their health service provision in the challenging period between childhood and young adulthood. As the young person leaves children's services and enters the adult care system, special consideration needs to be given to their developmental and psychological needs, which are specific and different from adults'. Smooth transition to adult services requires careful follow-up where there is an underlying life-threatening illness within a framework of early co-operative planning and delivery across health, social care and education services which is supportive without compromising the need for the young person's increasing independence. A Department of Health Policy Collaborative project is under way with local stakeholders to develop and profile the work of champions who are making headway in local medical provision of transitional services to young people with disability and complex needs.

42. Adult palliative care services are available to a small number of 'older' children and young people with cancer and a few adult hospices provide specialist short breaks for young people with palliative care needs. It is important that, whether in the voluntary or statutory sector, services should be appropriate to the age and development of the children or young people served. Some children's hospices include separate facilities for young people.

What the Child or Young Person and their Family Should Expect

43. Every child or young person and their family should be able to access services that:

- Promote their quality of life by managing pain, adverse symptoms and specialist palliative care needs;
- Integrate multi-agency assessment of his/her needs, involving them and their families as much as they want in decisions about how their needs could be met in a choice of settings including home, hospital or hospice;
- Are co-ordinated at the point of delivery across health, social services and education;
- Respond to their changing needs as they move from children's services;
- Are delivered by competent staff;
- Are planned in partnership and provided by a network of agencies, including the statutory and voluntary sector (please refer to the model illustrated on pages 16 and 17); and
- Information in appropriate formats and language about services and the child or young person's condition and treatment.

44. Children and families want an integrated, multi-agency assessment of the needs of the child or young person, their parents, carers and siblings, resulting in packages of care reflecting choice of where they want services delivered, rather than multiple assessments by different agencies and a standard package of care. The "Framework for the Assessment of Children in Need and their Families" provides this and further important aspects of multi-agency assessments are set out in standard 8 of the Children's NSF. Many children who need palliative care will be likely to have continuing care needs, which should result in co-ordinated multi-agency packages of care referred to in paragraph 34.

Workforce Implications

45. A workforce fit for purpose is critical to the delivery of quality palliative care to children and young people. Workforce Development Directorates need to consider the retention, recruitment, education and training needs of all members of the palliative care team that will include a variety of staff from different professional and non-professional groups and backgrounds. The existing workforce in voluntary hospices should also be taken into account. The Children's NSF recommends that training should be based on the "National Workforce Competence Framework for Children's Services" developed by Skills for Health and the "Common Core of Skills and Knowledge for the Children's Workforce" (Department for Education and Skills) (see www.everychildmatters.gov.uk).

46. To enable workforce development the NHS Modernisation Agency Changing Workforce Programme (CWP) developed a number of tools and methodologies that can help with local role and service redesign. Rapid roll out programmes developed by the CWP and subsequently NHS Employers' Large Scale Workforce Change Team have shown the benefits of developing workers such as assistant and advanced practitioners and administrative and clerical workers in increasing the capacity and flexibility of the workforce.

47. Working differently and role redesign can play a further part in enabling more creative re-balancing of the skills mix of the palliative care team to include a range of workers such as professional staff, nursery nurses, generic workers and volunteers all of whom play a part in the different stages of the child's care pathway. Such developments often have best effect when undertaken in the context of service redesign.

48. A service-wide partnership approach to local workforce development, including the voluntary sector and the voices of children, young people and parents, helps to ensure the availability of staff with the right range of skills and competencies across a choice of services. There is a need to consider how such workforce development relates to the workforce elements of the Children and Young People's Plans that are to be developed by Directors of Children's Services. Disability awareness training can go a long way towards increasing understanding in staff of the rights and needs of those in their care.

Table 1:

England: Deaths of children and young adults (0-30 years) from all causes and from causes likely to have required palliative care, by age, 2000/01-2004
Source: ONS Mortality Database

	Column A				
	All causes of death				
Age (yrs)	2001	2002	2003	2004	All years
<1	1,033	1,058	1,031	1,119	4,241
1 - 4	554	588	569	601	2,312
5 - 9	314	362	358	390	1,424
10 - 14	424	472	490	491	1,877
15 - 19	1,243	1,222	1,303	1,313	5,081
0 - 19	3,568	3,702	3,751	3,914	14,935
20 - 24	1,751	1,833	1,777	1,748	7,109
25 - 30	2,415	2,568	2,670	2,752	10,405
Age 0-30	7,734	8,103	8,198	8,414	32,449

	Column B				
	Causes of death likely to have required palliative care				
Age (yrs)	2001	2002	2003	2004	All years
<1	141	123	109	105	478
1 - 4	180	171	180	157	688
5 - 9	166	153	155	142	616
10 - 14	196	196	187	169	748
15 - 19	297	305	308	281	1,191
0 - 19	980	948	939	854	3,721
20 - 24	314	298	328	369	1,309
25 - 30	552	493	488	492	2,025
Age 0-30	1,846	1,739	1,755	1,715	7,055

	Column C				
	% of deaths in age group likely to have required palliative care				
Age (yrs)	2001	2002	2003	2004	All years
<1	14%	12%	11%	9%	11%
1 - 4	32%	29%	32%	26%	30%
5 - 9	53%	42%	43%	36%	43%
10 - 14	46%	42%	38%	34%	40%
15 - 19	24%	25%	24%	21%	23%
0 - 19	27%	26%	25%	22%	25%
20 - 24	18%	16%	18%	21%	18%
25 - 30	23%	19%	18%	18%	19%
Age 0-30	24%	21%	21%	20%	22%

Table 2:

England: Deaths of children and young adults (0-30 years) from causes likely to have required palliative care (2000/01-2004) Source: ONS Mortality Database

	AGES			
Cause of death	<1	1-4	5-9	10-14
Malignant neoplasms	40	316	374	419
Epilepsy	37	95	75	88
Cerebral palsy & other paralytic conditions	35	142	120	153
Congenital malformations of the circulatory system	218	65	24	31
Cystic fibrosis	10	5	8	24
Congenital malformations of the nervous system	98	87	33	31
Primary disorders of muscles	34	13	9	29
Chronic renal failure	11	8	3	7
Disorders of psychological development	1	10	10	7
Mental retardation	0	3	3	4
Other myopathies	6	1	1	1
Juvenile arthritis	0	1	1	3
TOTAL	490	746	661	797

AGES			
15-19	20-24	25-30	Total
585	704	1,308	3,746
177	200	272	944
173	126	110	859
48	39	56	481
90	131	112	380
31	35	54	369
121	68	52	326
22	31	91	173
11	4	8	51
3	4	9	26
1	1	2	13
0	1	1	7
1262	1344	2075	7375[1]

[1] The total number of deaths in Table 2 is higher than the total in Table 1, as each death is only counted once in Table 1, whereas in Table 2 the same death may be recorded against more than one cause. The ONS mortality database records the original underlying cause of death, original secondary cause of death, and original mentions of cause of death (up to 8 occurrences).

Table 3:

England: Deaths of children and young people aged 0 - 30 years from causes likely to have required palliative care, by place of death (2000/01-2004)

Source: ONS Mortality Database

	2001		2002		2003	
Place of death	0 - 19	20 - 30	0 - 19	20 - 30	0 - 19	20 - 30
Home	289	209	298	187	284	218
NHS Multi-function site[1]	204	210	224	204	174	177
NHS Hospital or other communal establishment[2]	416	302	360	268	393	281
NHS Psychiatric hospital or other NHS psychiatric establishment	0	1	0	0	0	2
NHS Hospice[3]	1	10	0	10	1	10
Non-NHS Hospice	34	81	35	75	57	71
Non-NHS hospitals and other non-NHS establishments[4]	17	15	16	12	9	14
Non-NHS Multi-function site	0	1	1	0	0	1
Non-NHS Psychiatric establishment	4	3	1	7	0	3
Elsewhere[5]	15	34	13	28	21	39
TOTAL	980	866	948	791	939	816

[1] Multi-function site are almost all NHS hospitals, providing treatment for more than one group of patients, including maternity, non-psychiatric as well as psychiatric (the hospital may have a Maternity Unit and/or a Mental Health Unit for example). Examples include: Southend Hospital, Stoke Mandeville Hospital, Chelsea & Westminster Hospital, Wythenshawe Hospital (Manchester), Addenbrookes Hospital (Cambridge). There are a very small number of non-NHS multi-function sites, e.g. the Royal Hospital for Neuro-disability, Putney

[2] NHS hospitals and communal establishments for the care of the sick cover nursing homes, general hospitals, convalescent homes, hospitals and units for the elderly, establishments for the chronic sick, homes or hostels for people with learning disabilities, maternity hospitals, and multi-function sites such as large hospitals.

2004		2001-04 totals		2001-04 %'s	
0 - 19	20 - 30	0 - 19	20 - 30	0 - 19	20 - 30
260	205	1,131	819	30%	25%
163	197	765	788	21%	24%
364	304	1,533	1,155	41%	35%
0	0	0	3	0%	0.1%
1	9	3	39	0.1%	1%
43	96	169	323	5%	10%
9	20	51	61	1%	2%
0	0	1	2	0.03%	0.1%
1	4	6	17	0.2%	1%
13	26	62	127	2%	4%
854	861	3,721	3,334	100%	100%

[3] NHS Hospices are owned and run by the NHS. Examples include Pembridge Palliative Care Centre, Kensington, St Benedicts Hospice, Sunderland and Duchess of Kent House, Reading

[4] Non-NHS hospitals and non-NHS establishments include private nursing homes, drug abuse units, holiday homes and hostels, local authority and private residential homes, boarding and day schools, prisons, student halls of residence, YMCA.

[5] Elsewhere covers anywhere that is not a communal establishment, for example deaths in private homes other than the deceased's own home, deaths in the street including road traffic accidents, the railway, the cinema, in a sports centre or football ground etc

Useful documents and resources

Organisation/Author	Name of Publication	Website
Association of Children's Hospices	A Guide to Children's Hospice Services (2004)	http://www.childhospice.org.uk
	Guidelines for Good Practice in a Children's Hospice (2001)	
	The Children's Hospice Service Toolkit (2005)	
	Are We Getting it Right? (2004)	
Association for Children with Life-threatening Illnesses or Terminal Conditions and their Families (ACT)	A Framework for the Development of Integrated Multi-agency Care Pathways for Children with Life-threatening and Life-limiting Conditions (2004)	http://www.act.org.uk
	Assessment of Children with Life-limiting Conditions and their Families: A Guide to Effective Care Planning (2003)	
	Voices for Change: current perception of services for children with palliative care needs and their families (2003)	
	A Guide to the Development of Children's Palliative Care Services: Report of a Joint Working Party of ACT and the Royal College of Paediatrics and Child Health (2003)	
	Palliative Care for Young People, 13-24: Report of the Joint Working Party of ACT, National Council for Hospice and Specialist Palliative Care Services and Scottish Partnership Agency for Palliative and Cancer Care (2001)	

Organisation/Author	Name of Publication	Website
Department for Education and Skills	Every Child Matters: Change for Children (2004)	http://www.everychildmatters.gov.uk
	Every Child Matters: Next Steps (2004)	
	Every Child Matters (2003) (Government Green Paper)	
	Removing the Barriers to Achievement: The Government's Strategy for Special Education Needs (2004)	http://www.dfes.gov.uk/rsgateway
	Early Support: Professional Guidance (2004)	http://www.dfes.gov.uk
Department of Health and Department for Education and Skills	Managing Medicines in Schools and Early Years Settings (2005)	http://www.dh.gov.uk
	Every Child Matters: Change for Children in Health Services. Supporting Local Delivery (2004)	
	National Service Framework for Children, Young People and Maternity Services (2004)	
Department of Health	The NHS Improvement Plan (2004)	http://www.dh.gov.uk
	National Standards Local Action: Health and Social Care Standards and Planning Framework 2005/06–2007/08. (2004)	

Organisation/Author	Name of Publication	Website
	Government Response to the Health Select Committee Report on Palliative Care (2004)	
	Letter to SHA Chief Executives. Resource and cash limit adjustment in respect of the Working Time Directive Strategic Change Fund. (25 June 2004)	
	Continuing Care: NHS and local councils' responsibilities HSC 2001/015, LAC (2001) 18	
Council for Disabled Children	Direct Experience: A Guide for Councils on the Implementation of Direct Payments in Children's Services (2004)	http://www.ncb.org.uk/cdc/
	The Dignity of Risk (2004)	
Social Policy Research Unit University of York	V. Greco, P. Sloper and K. Barton Care Co-ordination and Key Worker Services for Disabled Children in the UK (2004)	http://www.york.ac.uk/inst/spru
Blackwell Publishing	D. Wray and S. Wray Andrew: A Journey - A Parent's Perspective in Child: Care, Health and Development May 2004/ Vol 30/ No. 3	http://www.blackwellpublishing.com/
Contact a Family	Parent Participation (2004)	http://www.cafamily.org.uk

Possible Sources of Useful Data

Source	Website
Children in Need census	http://www.dh.gov.uk
Disabled children's registers	See individual local authority websites
Chronic disease registers in primary care	Held locally. See article in the Journal of Epidemiology and Community Health at: http://jech.bmjjournals.com/cgi/content/abstract/43/1/25
Special Educational Needs partnership information	http://www.teachernet.gov.uk/wholeschool/sen/regional/
Mortality and prevalence data national and local	http://www.statistics.gov.uk
National Child Health Services Mapping planned for 2006	http://www.childhealthmapping.org.uk

Other Useful Websites

Title	Address
New Opportunities Fund	http://www.nof.org.uk
Early Support Programme DfES	http://www.earlysupport.org.uk
Care Co-ordination Network UK	http://www.ccnuk.org.uk

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