

ACT NOW

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The NSF: Focus on children's palliative care

The National Service Framework for Children, Young People and Maternity Services was published on 15 September. It aims to ensure fair, high-quality and integrated health and social care for children, from pregnancy through to adulthood.

The framework contains 11 national standards for health and social care services. This includes five standards that apply to the health and social well-being of all children, and six that are more specific, relating to, for example, children who are ill (standard 6) and disabled children (standard 8).

Full implementation of the NSF standards are not expected for up to 10 years, but the NHS and local authorities will be assessed on the quality of their services for children and how well they are progressing towards meeting the standards.

The NSF echoes many of the issues for which ACT has campaigned for the past 12 years. In particular, points in the more general standards about the need for services to be co-ordinated around the individual needs of each family, taking account of their views and recognising the central role and expertise that parents have in the care of their children.

The section that deals specifically with children's

palliative care (standard 8, 5.14 – 5.18) confirms there is a commitment to improving services for life-limited and life-threatened children and their families. ACT is delighted that children's palliative care is now recognised as a part of mainstream health and social care as reflected in the following phrase:

"High-quality palliative care services should be available for all children and young people who need them."

This section identifies the various agencies which provide support in children's palliative care, including the NHS, children's hospices, the voluntary sector and social care and education services.

There is a recognition of the fact that it is essential for these agencies to work together to provide an integrated service. There is mention also of the particular needs of young people as they make the transition to adult services.

The standards outlined within the NSF relating to children's palliative care state that:

Local Authorities, Primary Care Trusts and NHS Trusts should ensure that:

- Palliative care services provide high-quality, sensitive support that takes account of the physical, emotional and

practical needs of the child or young person and their family, including siblings. Services are sensitive to the cultural and spiritual needs of the child, young person and family.

- Services maximise choice, independence and creativity (access to preferred interests or activities) to promote quality of life.
- Services are delivered where the family want, for example in the home, hospital, hospice or other setting.
- Services include the prompt availability of equipment to support care, access to appropriate translation services and workers skilled in using communication aids.
- Palliative and terminal care services are regularly reviewed with parents or carers, children and young people, and gaps in provision identified and addressed.
- Short-term breaks, palliative and community health and social care services for children and young people with life-limiting conditions and/or complex health needs is planned in partnership with voluntary sector providers and children and young people's hospices in localities where these exist.
- Provision of services includes, where appropriate:
 - a) 24-hour access to

- expertise in paediatric and family care (often provided by local community children and young people's services to enable continuity of care) is available;
 - b) 24-hour expertise in paediatric palliative care (provided by those with specialist palliative care training) is available;
 - c) Pain and symptom control;
 - d) Psychological and social support;
 - e) Spiritual support which takes account of the needs of the whole family;
 - f) Where required, formal counselling or therapy;
 - g) Arrangements to avoid unnecessary emergency admission to hospital are in place;
 - h) Protocols for immediate access to hospital, if needed are in place;
 - i) A process for keeping the general practitioner informed.
- The care of children and young people with life-threatening diseases is informed by

evidence of best practice. The section on the death of a child contains the following standard:

Local Authorities, Primary Care Trusts and NHS Trusts should ensure that:

Following a bereavement parents and families are given the time, space and information to make practical arrangements and decisions, and receive ongoing support to cope with their loss.

All these points indicate that there is a move away from the concept of children's palliative care services being reliant on fundraising bids, to one where there is equity of provision, funded locally by the Strategic Health Authority from their existing budgets.

The standard makes it a requirement for children's palliative care to be prioritised in Local Development Plans. It is also encouraging to see that there is clear acknowledgement of the contribution of the voluntary sector, in particular

children's hospice services, and a commitment to including the voluntary sector in the planning process.

There is also a welcome recognition of the fact that families should have 24-hour access to professionals trained in children's palliative care. It will no longer be acceptable to propose that general children's community nursing teams are able to provide all the support that families need.

Whilst these aspirations are commendable, it is of concern that without ring-fenced government investment, they will not become a reality. While ACT is delighted to see government recognition of the needs of children with life-limiting conditions and their families, it remains the case that children's palliative care services are likely to remain inequitable, fragmented and under-resourced for some time to come.

The full NSF can be downloaded from the department of health website: www.dh.gov.uk

Noticeboard

The Disabled Children Team at the Department for Education and Skills

The disabled children's team, which moved from the DH to the DfES last year has launched a new area on the TeacherNet website. The disabled children's team works within the Special Educational Needs and Disability Division, which forms part of the Children, Young People & Families Directorate at DfES. The site provides information about the work of the team in developing social services policy relating to disabled children.

www.teachernet.gov.uk/wholeschool/sen/disabledchildren/
Contact the team: **Peter Smith on 0207 273 4852 or Raj Heer on 0207 273 4917. Alternatively, to: DfES, Area 4E, Caxton House, Tothill Street, London SW1H 9NS.**

Department of Health Voluntary Sector Partnership Agreement

This jointly developed agreement provides a framework for a new strategic partnership between the Department of Health, NHS & Social Care and the Voluntary and Community Sector. It aims to promote the increasing role of the VCS in contributing to health service planning and delivery. Further details available from:

www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4089515&chk=KvDHnR

Managed local children's clinical networks and managed maternity care networks – additional funding available

SHA chief executives were informed in June 2004 of a resource allocation of £90,000 in respect of the Working Time Directive Strategic Change Fund. This allocation is available to support the creation of managed local children's clinical networks and managed maternity care networks. SHA chief executives are asked to ensure that the money has been identified and is being made available for this purpose. Advice is available from the Modernisation Agency via Susanne Cox, 020 7210 5140. www.dh.gov.uk/PublicationsAndStatistics/LettersAndCirculars/DearColleagueLetters/DearColleagueLettersArticle/fs/en?CONTENT_ID=4091135&chk=%2BQ331R

PCT engagement on Supporting People

Supporting People is an Office of the Deputy Prime Minister (ODPM) initiative that spends £1.7bn annually on helping vulnerable people live at home. Local authorities distribute the money, but PCTs are required to be represented on a commissioning body that sets the overall priorities for spending the funds. Chief executives of PCTs are asked to ensure that their PCT is fully engaged on Supporting People and aware of the benefits it can bring in meeting key targets. www.dh.gov.uk/PublicationsAndStatistics/LettersAndCirculars/DearColleagueLetters/DearColleagueLettersArticle/fs/en?CONTENT_ID=4090979&chk=v2ETom

Books, reports and resources

Directgov

This government public service information website has recently launched a new section specifically targeted at disabled adults and children and their carers. Information is available under a variety of topic headings such as employment, health and well-being, home and community and learning.
<http://www.direct.gov.uk/Audiences/DisabledPeopleAndCarers/fs/en>

Guide to the Residential Special Schools Standards – National Children’s Bureau (NCB)

With government funding, the NCB has produced a series of guides to improve awareness of the Residential Special Schools Standards. Three guides are available: for young people, parents or staff. Also available in Braille or audio formats. Available at www.ncb-books.org.uk or call 020 7843 6029.

Medical Support at School – Tricia Nash & Anthea Asprey, Children’s Hospice South West Research Group, University of Exeter

This report, which explores the provision of medical and nursing support to life-limited children in school, found that parents were disappointed with the level of support their children received, both in mainstream and special schools. Copies of the report and an Executive Summary are available from: Tricia Nash, Senior Research Fellow, Department of Sociology, Amory Building, Rennes Drive, Exeter EX4 4RJ. Tel: 01392-263273, Email: P.T.S.Nash@exeter.ac.uk

Parent Participation – improving services for disabled children and their families – Contact a Family/Council for Disabled Children

The guides, one for parents of disabled children and one for professionals, outline the benefits of parent participation, flag up some common pitfalls and identify the key principles that underpin effective parental involvement. Available from Contact a Family on 020 7608 8700. The parents’ guide is free and the professional’s guide is £15. The parents’ guide is also available to download from www.cafamily.org.uk

Part of Us Forever – Wolf & Water Arts Company

The Wolf and Water Arts Company was approached to produce this video by a group of teenagers who have experienced cancer and leukaemia. It shares their experiences of their life-threatening illnesses and reflects their own individual reactions, senses of style and humour. It covers a range of issues including diagnosis, treatment and the impact on family and siblings. Wolf & Water Arts Co, The Beaford Centre, Beaford, Winkleigh, North Devon EX19 8LU. Tel: 01805 603 628. Email: w+w@eclipse.co.uk

Participation of Disabled Children and Young People in decision-making within Social Services – Social Policy Research Unit, York

This new addition to the Research Works series was funded by DH/DfES as part of the Government’s Quality Protects programme. A summary is available at www.york.ac.uk/inst/spru/pubs/rworks/aug2004-2.pdf

Relationships and Caring for a Disabled Child – Contact a Family and Relate

This free factsheet draws on the views of 2000 parents surveyed in 2003. It details the main issues faced by parents with disabled children, puts forward practical solutions and lists a wide range of helpful resources. To order a free copy, contact the CaF Helpline on 0808 808 3555 or email helpline@cafamily.org.uk

A Sure Start for Every Child and A Sure Start for Every Young Person – DfES

The government’s Sure Start Unit has produced two new leaflets for parents with disabled children. The leaflets include information on how to find the right childcare, how to pay for additional support and who to turn to for help or advice. www.surestart.gov.uk/ensuringquality/inclusion/inclusionnews

Team Around the Child and the Multi-Agency Keyworker – Peter Limbrick, Interconnections

In traditional approaches to children with complex needs, practitioners have worked separately, providing many families with a fragmented service. This manual addresses how to join these services together and argues that effective early support can only be achieved if key practitioners take time to establish better working relationships with parents and with each other. Tel: 01905 23255. Email: p.limbrick@virgin.net

DALE’S CHRISTMAS WISHES

Do you know someone who deserves a very special Christmas? They could be a child, parent, grandparent, family member, neighbour, teacher, friend or just someone who means something special to you. If so, Dale Winton and the BBC want to hear from you. Contact us with your stories and reasons why they should have an extra special Christmas this year. Have they shown exceptional kindness to you and others? Have they been brave and courageous? Remember to keep your story a secret as we wouldn’t want to spoil any potential surprises for them. Call us on: 08705 100 792 (calls charged at the national rate) or email: daleschristmaswishes@bbc.co.uk Fax: 0161 244 3606

BBC documentary

Each year, BBC Religion makes a documentary for BBC1 for Holy Week as part of our programmes for Easter. This year we are working on a programme about Christians who are enduring suffering.

The programme has a working title of *Suffering For A Reason*, and it reflects the view that many Christians hold that although they are enduring harsh times, God has a purpose for it. That’s not to say that they aren’t wrestling with big questions such as “Why me”? but their faith means that they believe that a loving God has a reason which they understand or may understand in the future.

For the majority of the BBC1 audience, such faith in action would be both intriguing and inspiring. For the subjects of the film, the answers to the questions about suffering may well come from the experience of Christ upon the cross, so the themes of Easter would be very much to the fore throughout.

If you are a Christian individual or family whose faith informs the way you are coping with a life-threatening or terminal illness, please e-mail: rob.cowling@bbc.co.uk or call 0161 244 3485.

Conferences & courses

Milton Keynes Bereavement Service Day Conference "Children Grieving 2004"
9 November, Central Milton Keynes. Cost: £50 waged, £25 unwaged. Contact: the Secretary, 01908 231292

St Christopher's Hospice: Schools and Bereavement
9 November, London. This day is aimed at promoting competence and confidence in responding positively to the needs of school-age children by colleagues in education and related services. Cost: £80. Contact: 020 8768 4656, education@stchristophers.org.uk

Acorns Children's Hospice: Asian Life-Limited Children and their Families; Working towards Equal, Accessible and Appropriate Services
11 November, Birmingham. Provides a unique opportunity to develop a greater understanding of the needs of Asian children and their families. Limited to four people per event. Cost: £76. Contact: 0121 248 4817

Acorns Children's Hospice: Loss, Grief & Bereavement
15 November, Birmingham. The facilitators will provide participants with a resource pack identifying key practice issues and a list of additional support services, which can be accessed. Cost: £76. Contact: 0121 248 4817

Carers UK – Carers and Their Rights
16 November, London. The last 10 years have seen major reform of the law as it relates to carers. This course examines how recent legislation fits in with the maze of other community care statutes, and what rights carers have as a consequence, both from social services and the NHS. Cost: £115 vol, £150 stat, £185 comm. Contact: Carers UK, 020 7566 7632, training@ukcarers.org, www.carersonline.org.uk

Child Bereavement Trust: Bereavement Advisor/Support Posts in NHS Trusts
17 & 18 November, 4 March 2005, 3 day workshop, West Wycombe, Bucks. Cost: £220. Contact: 01494 446648, training@childbereavement.org.uk

Neil Stewart Associates: Seamless Services for Children with Disabilities Improving Access, Integration and Quality
18 November, London. This one-day conference will

explore the latest policy developments in the field of children's mental and physical disabilities, as well as issues of accessibility stated in the Disability Discrimination Act (new provisions for 2004). Cost: full rate (commercial sector, govt depts etc) £399 + VAT; reduced rate (public sector, local authorities etc) £279 + VAT; supported rate (schools, voluntary organisations etc) £180 + VAT. Contact: 020 7324 4372, sarah.harbi@neilstewartassociates.co.uk

Acorns Children's Hospice: Communication with Families of a Dying Child: Talking about Death
19 November, Birmingham. This day will explore how to talk about death and dying with families of life-limited children, including taking a look at what children understand about death and dying. Cost: £76. Contact: 0121 248 4817

Pain Control Service Great Ormond Street for Children NHS Trust: 3rd Annual Paediatric Pain Symposium
19 November, London. A valuable day for nurses and health professionals working towards best practice in paediatric pain management. Cost: nurses/health professionals £125, students £110. Contact: 020 7829 8865, PaediatricPain@gosh.nhs.uk

Carers UK – Advocacy: Effective Skills
23 November, London. A one-day course giving participants an opportunity to develop, and to practice advocacy and negotiation skills in a safe and supportive environment. Cost: £115 vol, £150 stat, £185 comm. Contact: Carers UK, 020 7566 7632, training@ukcarers.org, www.carersonline.org.uk

Acorns Children's Hospice: Challenging Behaviour in the Palliative Care Setting
24 November, Birmingham. This workshop aims to encourage awareness of 'challenging behaviour' within a palliative care setting and to enable delegates to begin to develop positive approaches. Cost: £76. Contact: 0121 248 4817

Telephone Helplines Association AGM, Conference and Helpline Awards
24 November, London. Theme for conference and awards is confidentiality. Contact: 020 7089 6320 (fax), info@helplines.org.uk

ACH (Association of Children Hospices) Doctors & Head of Care Conference
25-26 November, Altrincham, Cheshire. Hosted by Francis House Children's Hospice. Cost: day delegate £75, residential delegate £165. Contact: 0161 434 4118, emma.leon@btinternet.com

Princess Alice Hospice 'An Introduction to Working with Bereaved Children'
2 December, Esher, Surrey. Day is based around children experiencing adult death. Cost: £40. Contact: 01372 461845, education@princess-alice-hospice.org.uk

University of Wales College of Medicine (UWCM)
2/3 December, Cardiff, Wales. 2nd International Cardiff Conference 2004 Paediatric Palliative Care. Cost: £180 (two days), £99 (one day). Reduced fee for nurses and equiv £110 & £65 respectively. Contact: 029 2087 5117, Cardiffconference@Cardiff.ac.uk

Carers UK – Carers' Rights Day
3 December. A day of action, co-ordinated under the umbrella of the Fair Deal for Carers campaign, to raise awareness of the benefits and services available to carers. Contact: 020 7490 8824, carersrightsday@ukcarersonline.org

Carers UK – Carers Awareness
8 December, London. A multi-disciplinary course aiming to raise participants' awareness of issues that affect carers. Cost: £115 vol, £150 stat, £185 comm. Contact: Carers UK, 020 7566 7632, training@ukcarers.org, www.carersonline.org.uk

Acorns Children's Hospice: Working with African Caribbean Children and Families
8 December, Birmingham. This short workshop will be beneficial to anyone providing health or social care services to African Caribbean children and families. Cost: £76. Contact: 0121 248 4817

Acorns Children's Hospice: Caring for Life-Limited Children in Special Schools
10 December, Birmingham. The workshop sets out to help participants gain greater insight into the valuable role schools and individuals teachers have in helping families cope with the fact that their child is dying. Cost: £76. Contact: 0121 248 4817

Study Centre Sir Michael Sobell House joint collaboration with Douglas House Respite: Difficult decisions in the palliative care of adolescents and young adults
15 December, Oxford. Provides an update on key issues and an opportunity to explore practice with speakers who have a wealth of experience. Cost: £75. Contact: 01865 225 886, ssc@orh.nhs.uk

Carers UK – Community Care Law: Recent Developments
16 December, London. Intensive half-day course aimed at those who already have a good knowledge of community care law and want to ensure that they are up to date with trends emerging from case-law and with new legislation and guidance. Cost: £115 vol, £150 stat, £185 comm. Contact: Carers UK, 020 7566 7632, training@ukcarers.org, www.carersonline.org.uk

Oxford Brookes University Palliative Care for Children and their Families
Commences January 2005 and includes 10 study days. In its sixth successful year, this two-module short course at degree and masters degree level is designed for health and social care professionals and aims to substantially develop the knowledge and skills of children's palliative care professionals. Cost: £1,070. Contact: Sue Castle-Miller, 01865 483765, Scastle-miller@brookes.ac.uk

Acorns Children's Hospice – Supporting the siblings of life-limited and dying children: Practical and Professional Issues
13 January 2005, Birmingham. This workshop is particularly designed to consider the practical and professional issues faced by workers when planning and organising projects and groups for siblings. Cost: £76. Contact: 0121 248 4817

Carers UK – Advocacy for Carers Introduction
26 January 2005, London. Community Care law has been described as a 'hotchpotch' of statutes. This one-day course is a basic starting point for anyone wanting to make sense of this complex area of law. Cost: £115 vol, £150 stat, £185 comm. Contact: Carers UK, 020 7566 7632, training@ukcarers.org, www.carersonline.org.uk

Find details of conferences, courses and events throughout the year at www.act.org.uk