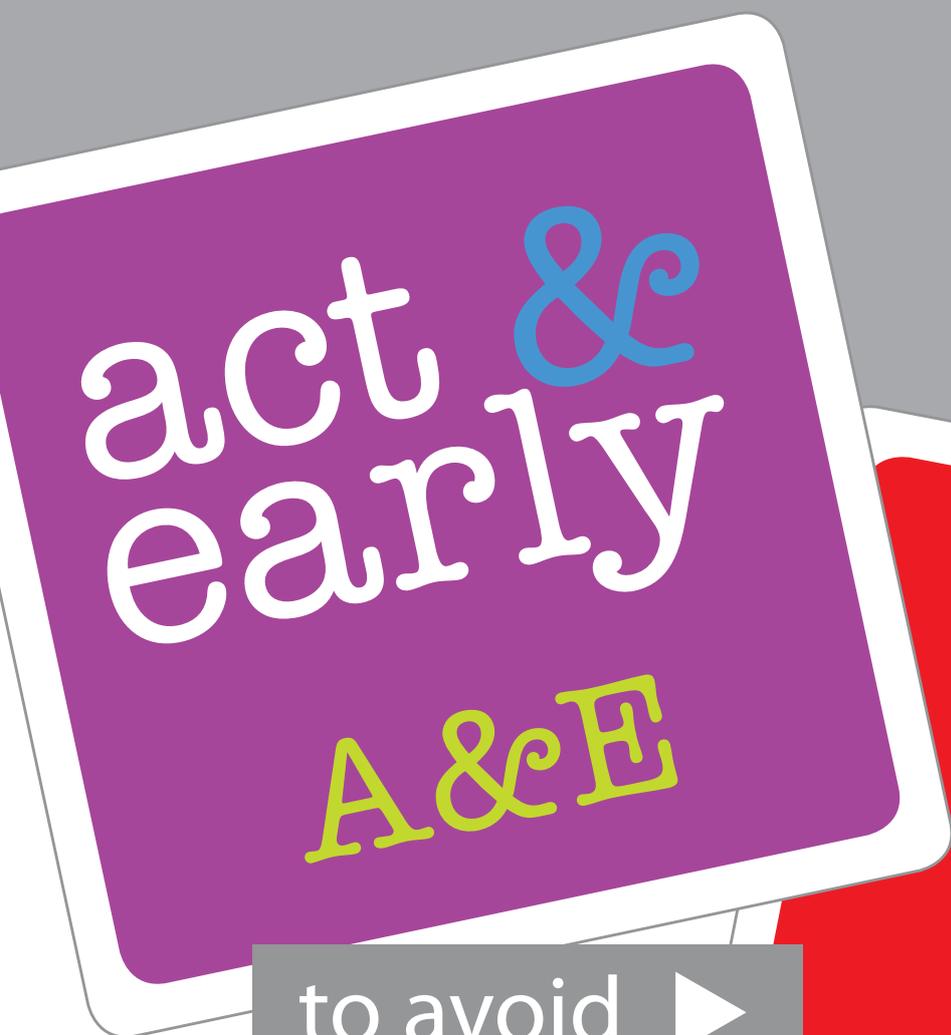


Commissioning End of Life Care



to avoid ▶



June 2011

initial actions for
new commissioners

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About...

THE NATIONAL COUNCIL FOR PALLIATIVE CARE

The National Council for Palliative Care

The National Council for Palliative Care (NCPC) is the umbrella charity for all those who are involved in providing, commissioning and using palliative care and hospice services in England, Wales & Northern Ireland. NCPC promotes the extension and improvement of palliative care services for all people with life threatening and life-limiting conditions. NCPC promotes palliative care in health and social care settings across all sectors to government, national and local policy makers. For further information or to subscribe to NCPC to receive publications free of charge and reduced rates at conferences visit www.ncpc.org.uk



Dying Matters

Dying Matters is a broad based and inclusive national coalition set up by the National Council for Palliative Care and is supported by the Department of Health. It aims to engage thousands of organisations across a range of sectors, generating, leading and supporting collective action to promote public awareness and debate on issues of death, dying and bereavement in England.



National End of Life Care Programme
Improving end of life care

The National End of Life Care Programme

The National End of Life Care Programme works with the health and social care workforce across all sectors in England to improve end of life care for adults, supporting the implementation of the Department of Health's End of Life Care Strategy.

The National End of Life Care Programme aims to:

- Promote high quality, person-centred care for all adults at the end of life in all care settings
- Enable more people nearing the end of life to choose where they live and die.



The National End of Life Care Intelligence Network

The National End of Life Care Intelligence Network which is part of the The National End of Life Care Programme aims to improve the collection and analysis of information about end of life care services provided by the NHS, social services and the third sector. Areas of research include quality, volume and costs of care provided to adults approaching the end of life. This intelligence will help drive improvements in the quality and productivity of services.

Introduction: why **act&early**

Who?

For the purposes of this guidance people are 'approaching the end of life' when they are likely to die within the next 12 months.

This includes people whose death is imminent (expected within a few hours or days) and those with:

- (a) advanced, progressive, incurable conditions
- (b) general frailty and co-existing conditions that mean they are expected to die within 12 months
- (c) existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- (d) life-threatening acute conditions caused by sudden catastrophic events.

For some people the appropriate start for end of life care might be at the time of diagnosis of a condition which usually carries a poor prognosis, for example motor neurone disease or advanced liver disease.

Adapted from Treatment and care towards the end of life: good practice in decision making, the General Medical Council 2010

What?

A Working Definition of 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 enables the supportive and palliative care needs of both patient 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.

Source: National Council for Palliative Care 2006
The End of Life Care Strategy 2008



- 1 <http://www.endoflifecareforadults.nhs.uk/publications/eolc-strategy>
- 2 <http://www.demos.co.uk/publications/dyingforchange/>
- 3 http://www.nao.org.uk/publications/0708/end_of_life_care.aspx
- 4 http://www.nao.org.uk/publications/0708/end_of_life_care.aspx
- 5 http://www.kingsfund.org.uk/multimedia/ten_priorities.html

Why?

The next two years provide a unique opportunity for new commissioning organisations to position themselves in the best clinical and financial position before they begin business as legal entities, for some at least as early as April 2013. By targeting end of life care, emergent commissioners can place themselves in a strong position for one of the major required areas of improving quality and safety of care; improving patient and carer experience and making care more cost/resource efficient.

Tackling end of life care early can offer a number of significant 'quick wins' in improving the quality of care in your locality. People should be supported to be cared for and to die in their preferred place of care, which is usually their home [End of Life Care Strategy 2008¹](#). **It may also include other community based settings such as a care home or sheltered housing.** This means commissioners should ensure there is planned 24/7 provision of community support, including care co-ordination, nursing and symptom control. In contrast, poor end of life care is rushed and unplanned often resulting in unnecessary, and expensive trips to Accident and Emergency with crisis admissions to hospital. These are distressing not only to individuals but can have a detrimental effect on those who have been bereaved.

- End of life care accounts for a high proportion of NHS spending. The [Demos²](#) think tank has estimated it as at least a fifth of NHS costs and a total of about £20 billion
- The [National Audit Office³](#) (NAO) found that 40% of end of life care patients had no medical need to be in hospital
- In the same report, the NAO found wide variations in end of life care provision across England. Spending by PCTs varied from £154 to over £1,600 per person
- The [King's Fund⁴](#) has identified improving primary care management of end of life care as one of the top 10 priorities for commissioners

- There is considerable scope for improvement using interventions such as early identification triggers, advance care planning, co-ordination of care and effective multi disciplinary team (MDT) working

End of life care is a national priority, following the [End of Life Care Strategy¹](#). It is one of the DH's Quality Innovation Productivity & Prevention (QIPP) priority areas and is included in the NHS Operating Framework for 2011/12. There has been some excellent progress made at local level over recent years but considerable variation in quality and efficiency remains across the country.

Aspects of end of life care are provided across the health and social care economy. District nurses, GPs and care assistants are fundamental to generalist palliative and end of life care needed by the majority of people at some stage. People may also receive elements of end of life care from their specialist community and secondary care teams, such as symptom management. A smaller proportion of people will need direct access to specialist palliative care teams. These might be based in a hospital, a hospice or the community. The majority of specialist palliative care services are managed by voluntary sector organisations, not the NHS, and their commissioning arrangements with the NHS have traditionally varied substantially. Hospices and other specialist palliative care providers, however, are vital not only to the care of people with complex needs but also to training and developing the wider workforce and providing access to specialist advice and support to other professionals.

The purpose of this briefing is to help you to identify the immediate priority actions to commission effective end of life care, focusing on steps which we believe will make the most difference initially and can be seen as 'quick wins'.

Key actions for act&early

Assessment & measurement

Assessment and measurement for end of life care commissioning must reflect the whole population's needs across the end of life care pathway.

Commissioning services to meet people's end of life care needs will require linking with planning for areas such as long term conditions care, care of the elderly, dementia care and carers support.

On average, 1% of people (20 people) on a GP's list, will die each year. Every practice should be encouraged to have an up to date and reviewed End of Life Care register. However, not everyone needing end of life care will be on an end of life care register. End of life care should be a significant aspect of the local Joint Strategic Needs Assessment (JSNA) process and population needs assessment should draw on data from health, social care, public health and housing, including the [National End of Life Care Intelligence Network](#)¹.

Monitoring for quality outcomes will be core to measuring service delivery. As part of the commissioning cycle, assessment and measurement should be combined with audit and review, including information gathered in organisations' Quality Accounts.

The [NHS Outcomes Framework](#)² for 2011/12 identifies improving the experience of care for people at the end of their lives as an improvement area, using surveys of bereaved relatives (VOICES) as a measure. NICE will be publishing a [quality standard for end of life care](#)³ in 2011/12

- 1 <http://www.endoflifecare-intelligence.org.uk/home.aspx>
- 2 http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_123138.pdf
- 3 <http://www.nice.org.uk/guidance/qualitystandards/indevelopment/endoflifecare.jsp>

Early recommendations for new commissioners:

- Ensure that each GP practice has a [mechanism](#)⁴ to identify people approaching the end of life and holds a register for all those identified as approaching the end of life. This needs to be in place to ensure the other commissioning steps can be implemented, for example communication and co-ordination of care
- All people on the end of life care register should receive a [holistic assessment](#)⁵ of their care and support needs, which includes their carers' needs assessment where appropriate
- Understand the implications of local population data on end of life care needs such as that available from the [ISNA](#)⁶ process, [National End of Life Care Intelligence Network](#)¹, Hospital Episode Statistics (HES), QOF and Care Quality Commission (CQC)
- Agree quality outcome markers for measuring provision of EoLC by different organisations, and ensure those are written into local service specifications and contracts. The national [End of Life Care Strategy Quality Markers and Measures for End of Life Care](#)⁷ and the End of Life Care Quality Assessment tool ([ELQUA](#)⁸) are available now to support quality benchmarking. The NHS Outcomes Framework and the NICE quality standard will also be able to support this.
- Monitor the reporting of end of life care complaints, such as collected by PALs, and reporting of serious untoward incidents to inform future service design and commissioning arrangements.

- 4 <http://www.goldstandardsframework.nhs.uk/OneStopCMS/Core/CrawlerResourceServer.aspx?resource=68FE53BA-A79B-4DBD-A32A-E76B40B-C7828&mode=link&guid=9d9423c7b38d49c9b74c02cdc95f1aa2>
- 5 <http://www.endoflifecareforadults.nhs.uk/publications/holisticcommonassessment>
- 6 <http://www.networks.nhs.uk/networks/news/joint-strategic-needs-assessment-toolkit-for-shadow-health-and-wellbeing-boards>
- 7 <http://www.endoflifecareforadults.nhs.uk/publications/qualitymarkers>
- 8 <http://www.elcqua.nhs.uk/faq.php>

Communication & co-ordination

Communication and co-ordination are fundamental to good end of life care both at a strategic level and at an individual care level. They require clinical leadership at both a cluster level and within individual shadow consortia.

Early recommendations for new commissioners:

- Ensure professionals know how to **initiate conversations**⁹ about end of life care and carry out **advance care planning**¹⁰, including DNACPR decisions, and that there are mechanisms to share the information with other services
- Ensure that people on the end of life care register have access to an identified **care co-ordinator**¹¹, linking across all services including social care and voluntary sector providers. Case studies can be found at the **National End of Life Care programme**¹² website. Local experience of GP triage systems may assist
- Develop and implement local systems to share information across providers, particularly out of hours services
- Develop/support implementation of a local unified policy for DNACPR. **The South Central SHA**¹³ unified DNACPR policy is a useful example to consider.

- 9 <http://www.endoflifecareforadults.nhs.uk/education-and-training/communication-skills>
- 10 <http://www.endoflifecareforadults.nhs.uk/news/all/neolcp-publishes-updated-guide-to-advance-care-planning>
- 11 http://www.eastmidlandscancernetwork.nhs.uk/_HealthProfessionals-ServiceImprovement-SupportiveandPalliativeCare-KeyWorker.aspx
- 12 <http://www.endoflifecareforadults.nhs.uk/>
- 13 <http://www.southcentral.nhs.uk/what-we-are-doing/end-of-life-care/>
- 14 <http://www.endoflifecareforadults.nhs.uk/commissioning/commissioning-for-people-with-specific-conditions/dementia>

Transitions

Transitions occur throughout the end of life care pathway, between providers and across sectors, and at both a formal and informal level. End of life care should be commissioned from a pathway approach which incorporates management of transitions and co-ordination between pathways including mental health, **dementia**¹⁴ care, **children and young adults**¹⁵ **long term conditions**¹⁶ and **carers**¹⁷.

Early recommendations for new commissioners:

- Learn from the **Map of Medicine**¹⁸ to develop and roll out local pathways for end of life care service arrangements
- Implement robust handover processes between primary and secondary care and with OOH and ambulance services
- Monitor implementation of above by auditing what proportion of patients on GP practice end of life care registers have had an OOH/ambulance handover form completed.

- 15 <http://www.act.org.uk/landing.asp?section=97§ionTitle=Care+pathways+for+babies%2C+children+and+young+people>
- 16 <http://www.endoflifecareforadults.nhs.uk/commissioning/commissioning-for-people-with-specific-conditions/neurological-conditions>
- 17 http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_122077
- 18 http://eng.mapofmedicine.com/evidence/map/end_of_life_care_in_adults1.html

& Who else?

There are many important contributors to end of life care and part of the role for new clinician-commissioners will be to provide the clinical leadership needed to pull the strands into a coherent and efficient service for patients and carers. Local authorities have a fundamental role given their oversight of the JSNA process, the management of social care services and of the emerging Health and Wellbeing Boards. The voluntary sector provides a wide range of services across the end of life care pathway from specialist hospice care to very local befriending support to patients and carers. Many of these will have strong understanding of patients and carers' preferences and needs, making them a very valuable resource for user involvement.

User involvement must be central. There are emerging statutory requirements on commissioners to work collaboratively and to incorporate user involvement in their planning; Health and Wellbeing Boards will be crucial to this. Involving people in planning end of life care will need creative thought to ensure the views of the different groups within a local population are included. NCPC's publication *Getting Started* can support this.

Early recommendations for new commissioners:

- Appoint a clinical commissioning board member to lead on end of life care
- Build early links with Local Authorities to identify opportunities for greater joint commissioning to improve efficiencies and quality of care
- Build an understanding of the current range of local voluntary sector providers as part of mapping processes
- Work with voluntary sector organisations and the emerging Health and Wellbeing Boards to develop user involvement which reflects the range of people using eolc services locally
- Build links with local care homes and community-based supported housing to ensure the needs of people living there are identified and met.

E ducation

There are three levels of education to consider:

- 1 Public health and population level on death and dying will help increase local communities' resilience and knowledge which will help people feel more confident at identifying and discussing their wishes and preferences.
- 2 Individuals - provision of information and training to enable people to make informed choices early in their end of life care planning. See for example, [NHS Choices end of life care information](#)¹
- 3 Workforce education. While the arrangements for this are still in an early stage of development, shadow consortia will need to work with providers to identify gaps in current workforce training which need to be addressed in order to deliver the locally agreed eolc priorities. Commissioners will need to recognise the role of specialist palliative care staff in providing education and support for their non-specialist colleagues.

Early recommendations for new commissioners:

- Work with providers of end of life care education to ensure education and development is available across the local workforce. Local hospices are likely to be key providers of local education and training and their role must be reflected in local plans and in their funding
- Clusters of consortia may wish to develop local End of Life Care Charters as part of public health education, learning from work by [NHS North East](#)², and consider the charter's role as a mechanism for kitemarking services
- Implement local action to raise public awareness of dying, death and bereavement and link to the national work being led by the [Dying Matters](#)³ coalition
- Begin to build links with new [workforce network structures](#)⁴ to ensure local education priorities reflect EoLC needs
- [Access e-learning for end of life care](#)⁵. About 135 sessions are currently free to access on this site for health and social care staff.

Acute care

A significant proportion of people will still die in hospitals and more will need acute care during their end of life phase. Arrangements with **acute sector**⁶ providers should therefore not just focus on enabling discharge processes but also on improving the quality of experience for people dying in hospital and their carers. Commissioners should support services to be compliant with the **NICE Guidance for Supportive and Palliative Care**⁷ and the Improving Outcomes Guidance for cancer, building in quality markers and measures into service contracts and supporting **Routes to Success in Acute Care**⁸

Early recommendations for new commissioners:

- Ensure that acute sector providers have a systematic approach to supporting the identification of people approaching the end of life, and providing a holistic needs assessment
- For those people in hospital who are identified as dying, ensuring they are placed on an EoLC pathway such as the **Liverpool Care Pathway**⁹
- Requiring hospitals to ensure their staff have received education and training in end of life care where necessary
- Ensure effective **discharge planning**¹⁰ and ensure access to fast track continuing healthcare where needed.

Realigning resources

Realigning resources away from unplanned acute care to planned community support will improve quality of care, meet patient choice and provide value for money. The **Palliative Care Funding Reviews**¹¹ interim report advised that a 'relatively small investment in community services now will enable commissioners to deliver improved outcomes for patients, as well as ensuring services are delivered in the most cost effective way'. This should include assessment, care co-ordination and 24/7 access to nursing and symptom control. Consortia should consider the **good practice examples**¹² collected for the end of life care QIPP pathway and by the National End of Life Care Programme. Commissioners should encourage models of integration between primary and acute services, working with their local voluntary sector providers. See, for example, **Transforming End of Life Care**⁶ from the Transforming Community Services series. Pooled budgets are vital to enabling more flexible services working across care domains.

Early recommendations for new commissioners:

- Agree local priorities for end of life care service improvement
- Ensure there is local monitoring of end of life care spend and an agreed end of life care budget
- Work with Local Authorities to develop use of pooled budgets to encourage integrated and flexible care.

1 <http://www.nhs.uk/Planners/end-of-life-care/Pages/End-of-life-care.aspx>
2 <http://www.agooddeath.co.uk/>
3 <http://www.dyingmatters.org/>
4 <http://www.cfwi.org.uk/about>
5 <http://www.e-lfh.org.uk/projects/e-elca/index.html>
6 <http://www.endoflifecareforadults.nhs.uk/publications/transformingendoflifecare>
7 <http://www.nice.org.uk/guidance/index.jsp?action=byID&r=true&o=10893>

8 <http://www.endoflifecareforadults.nhs.uk/publications/route-to-success-acute-hospitals>
9 <http://www.mcpcil.org.uk/liverpool-care-pathway/index.htm>
10 <http://www.endoflifecareforadults.nhs.uk/publications/rtssupportsheet14>
11 <http://palliativecarefunding.org.uk/>
12 <http://www.evidence.nhs.uk/qipp>

L

ife choices

People's choices are at the heart of good end of life care. Taking an Act + Early approach to end of life care will improve individuals' and carers' quality of care and their experiences. The end of life care pathway includes holistic care, spiritual care, bereavement care and carers' support and these may well be priorities for individuals and their families. Getting these right may improve people's experiences of end of life care and so reduce negative long term impact and number of complaints. Capacity building and education within the community and the provider market is needed to encourage service development responsive to people's choices.

Early recommendations for new commissioners:

- With Local Authorities, identify a process to develop capacity within the provider market to support wider choices of services in line with people's preferences and the personalisation agenda.

Y

our checklist of resources

National policy guidance

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_122944

The Outcomes Framework for the NHS 2011/12

<http://www.dh.gov.uk/>

The Operating Framework for the NHS in England 2011/12

<http://www.endoflifecareforadults.nhs.uk/>

The National End of Life Care Strategy and annual progress reports

http://www.nao.org.uk/publications/0708/end_of_life_care.aspx

End of Life Care, National Audit Office, 2008

<http://www.endoflifecareforadults.nhs.uk/publications/qualitymarkers>

End of Life Care Strategy Quality Markers and Measures for End of Life Care

<http://www.nice.org.uk/guidance/index.jsp?action=byID&r=true&o=10893>

Improving Supportive and Palliative Care for adults with cancer, NICE, 2004

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085345

Carer's strategy

http://www.dh.gov.uk/en/Aboutus/Features/DH_125045

Dementia strategy

Commissioning and costing EoLC

<http://www.improvement.nhs.uk>

NHS Improvement QIPP resources

http://www.kingsfund.org.uk/topics/endoflife_care/index.html

Implementing the End of Life Care Strategy: lessons from good practice, the King's Fund, 2010

<http://www.nuffieldtrust.org.uk/publications/>

Social care and hospital use at the end of life, The Nuffield Trust, 2010



Commissioning and costing EoLC (continued)

<http://www.palliativecarefunding.org.uk/>

Palliative Care Funding Review

<http://www.endoflifecareforadults.nhs.uk/publications/transformingendoflifecare>

Transforming Community Services: Ambition, Action and Achievement - Transforming End of Life Care, DH, NEOFPC, Housing 21, 2009

<http://www.endoflifecareforadults.nhs.uk/>

Information for Commissioning end of life care, NEOFPC, 2008

<http://www.ncpc.org.uk/>

Focus on Commissioning: End of Life Care - a commissioning perspective, NCPC, 2007
NICE Commissioning toolkits

<http://www.endoflifecareforadults.nhs.uk/publications/eolc-for-people-with-dementia-commissioning-guide>

Dementia

Working with the whole community

<http://www.crusebereavementcare.org.uk>

Cruse bereavement pathways project

<http://www.dyingmatters.org/>

Dying Matters online resources

<http://www.nhs.uk/Planners/end-of-life-care/Pages/End-of-life-care.aspx>

End of Life Care, NHS Choices

<http://www.ncpc.org.uk>

Getting started: involving people with personal experience, NCPC, 2010

<http://www.helpthehospices.org.uk/about-hospice-care/find-a-hospice/uk-hospice-and-palliative-care-services/>

Hospice and Palliative Care Directory, United Kingdom and Ireland, Help the Hospices

Data and measurement

<http://www.endoflifecare-intelligence.org.uk/home.aspx>

National End of Life Care Intelligence Network

<http://www.ncpc.org.uk/>

Population Based Needs Assessment for Palliative and End of Life Care, NCPC, 2008

<http://www.vodg.org.uk/JSNA-Resources.html>

Joint Strategic Needs Assessment, DH Strategic Partners Programme online resource

<http://www.ncpc.org.uk/>

10 questions to ask if you are scrutinising end of life care, NCPC & Centre for Public Scrutiny

Developing services and workforce

<http://www.endoflifecareforadults.nhs.uk/publications>

Routes to Success series, NEOFPC

<http://www.endoflifecareforadults.nhs.uk/publications/corecompetencesguide>

Common Core Competences and Principles: A guide for health and social care workers working with adults at the end of life

<http://www.e-lfh.org.uk/projects/e-elca/index.html>

End of Life Care for all e-learning resources, e-learning for health care, Association for Palliative Medicine, NEOFPC

<http://www.endoflifecareforadults.nhs.uk/education-and-training/communication-skills>

Communications skills online resource, NEOFPC

<http://www.mapofmedicine.com/newsandevents/news/2010/endoflife>

Map of Medicine for End of Life Care

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Help the Hospices
www.helpthehospices.org.uk



Macmillan Cancer Support
www.macmillan.org.uk



Marie Curie Cancer Care
www.mariecurie.org.uk



Sue Ryder
www.suerydercare.org



THE
NATIONAL
COUNCIL FOR
PALLIATIVE
CARE



This publication is available as a web-based resource and also as a download from the NCPC and National End of Life Care Programme websites:

www.ncpc.org.uk www.endoflifecareforadults.nhs.uk