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## Priorities for Dementia Care within the End of Life Care Strategy's Quality Markers and Measures for Commissioners

**Living well with dementia: A National Dementia Strategy** (DH, 2009) includes an objective of improved end of life care for people with dementia. It suggests that to meet that objective 'local work on end of life care needs to focus on the large numbers of people who will die with dementia' and makes reference to the **End of Life Care Strategy: delivering high quality care for adults at the end of life** (DH, 2008). This guide maps out some of the priorities for achieving high quality care for adults with dementia at the end of life.

**The End of Life Care Strategy: quality markers and measures for end of life care** (DH, 2009) was published to support commissioners and providers in delivering improvements in care. As with the Strategy they accompany, the markers and measures are generic and apply to care across end of life care. The end of life care quality markers already provide detailed structure and process markers and measures which will be relevant for end of life care for people with dementia. There are, however, particular points of consideration for end of life care for people affected by dementia. This document, therefore, aims to focus on dementia specific priorities which might otherwise be lost if looking at the quality markers from across the whole of end of life care. It does not offer alternative quality markers or measures but aims to support the implementation of the generic set in a manner that recognises issues arising from dementia.

We have taken the seven headings for quality markers for end of life care aimed at commissioners and mapped these against areas of priority from a dementia perspective. There are several resources already available which impact on some of the priorities for dementia and end of life care. We have included sources of further information or support to help bring together many of these relevant documents.

## Quality markers for dementia and end of life care

Quality marker for end of life care – Commissioners	Points of consideration for dementia	Sources of further information
<p><b>Public awareness</b></p>	<ul style="list-style-type: none"> <li>Public awareness around dementia care must not be separated from awareness rising for end of life care, particularly given the stigma associated with dementia. Commissioners should have ensured their strategies interlink to promote public awareness with regard to issues around dying with dementia.</li> </ul>	<ul style="list-style-type: none"> <li>The <b>National Dementia Strategy</b> promotes public awareness on dementia as its first objective</li> <li>The <b>Joint commissioning framework for dementia</b> includes advice on how to meet this objective: Both: <a href="http://www.dh.gov.uk/dementia">www.dh.gov.uk/dementia</a></li> <li>The <b>Dying Matters Coalition</b> set up as part of the End of Life Care Strategy to raise public awareness on death, dying and bereavement, will be a useful resource: <a href="http://www.dyingmatters.org">www.dyingmatters.org</a></li> </ul>
<p><b>Strategic planning</b></p>	<ul style="list-style-type: none"> <li>Commissioners should have understanding of the needs of the local population with regard to people with dementia at the end of life. Strategic planning should take into account these people's particular needs.</li> <li>They should take an active role in encouraging end of life care services to address the needs of people affected by dementia.</li> <li>Planning must include engagement with care homes and the wider housing sector: 17% of all deaths currently occur in care homes and between 50 and 60% of care home residents will have dementia.</li> <li>Planning should take into consideration the under diagnosis of people with dementia among Black Asian Minority Ethnic groups.</li> <li>Commissioners should encourage more accurate recording of diagnoses of dementia, particularly where dementia is contributing factor at the end of life. This would help improve understanding of access to end of life care services by people with dementia.</li> </ul>	<ul style="list-style-type: none"> <li><b>Dementia 2010</b> (University of Oxford / Alzheimer's Research Trust) : A very useful resource on the numbers of people affected by dementia and the current and anticipated costs: <a href="http://www.dementia2010.org">www.dementia2010.org</a></li> <li><b>Joint commissioning framework for dementia</b></li> <li><b>Evidence of under-diagnosis of dementia and poor access to treatment in BAME communities:</b>   <b>Shah, A (2008)</b>, Estimating the absolute number of cases of dementia and depression in the black and minority ethnic elderly population in the United Kingdom. <i>International Journal of Migration, Health and Social Care</i>, 4(2), October 2008, pp.4-15   <b>Purandare, N et al (2007)</b>, Knowledge of dementia among South Asian (Indian) older people in Manchester, UK. <i>International Journal of Geriatric Psychiatry</i>, 22(8), pp. 777 - 781</li> <li><b>Out of the Shadows: end of life care for people with dementia</b> (NCPC, 2009) includes the detailed findings</li> </ul>

		<p>from a survey of users and carers affected by dementia of their perspectives around end of life care priorities:  <a href="http://www.ncpc.org.uk">www.ncpc.org.uk</a></p> <ul style="list-style-type: none"> <li>• <b>Capacity to care: a data analysis and discussion of the capacity and function of care homes as providers of end of life care</b> (NCPC, 2008)</li> </ul>
<p><b>Identification, communication and care planning</b></p>	<ul style="list-style-type: none"> <li>• Commissioners should be ensuring that their providers are identifying people with dementia with end of life care needs;</li> <li>• that their care plans reflect both dementia and end of life care needs;</li> <li>• that advance care planning is a priority for people with dementia;</li> <li>• that the particular needs of carers of people with dementia are recognised and supported;</li> <li>• There should be a proactive approach to identifying people with dementia who live alone and may not self present to services.</li> </ul>	<ul style="list-style-type: none"> <li>• The <b>National Dementia Strategy</b> emphasises the importance of early assessment and early diagnosis of dementia, vital if people are to be given the opportunity to discuss their end of life wishes and preferences.</li> <li>• <b>Creative Partnerships: Improving quality of life at the end of life for people with dementia</b> (NCPC, 2008) provides examples of different approaches to meeting the needs of people with dementia at the end of life  <a href="http://www.ncpc.org.uk">www.ncpc.org.uk</a></li> <li>• <b>Out of the Shadows</b> gives information useful to share with providers on how to meet some of the needs of people with dementia at the end of life</li> </ul>
<p><b>Co-ordination of care across organisational boundaries</b></p>	<ul style="list-style-type: none"> <li>• Commissioners should ensure that there are mechanisms in place to coordinate individuals' care across dementia and end of life care services. These must include health (including mental health), social care and housing services.</li> <li>• PCTs and Local Authorities should agree a process for a central coordination process of people with dementia and their carers, similar to the Care Programme Approach in Mental Health</li> <li>• Registers identifying people at the end of life are linked with registers of people with dementia and that dementia registers are linked with carers registers to support care planning</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Power of Partnerships: palliative care and dementia</b> (NCPC, 2009) explores the importance of joint service provision by palliative and dementia care services. It gives examples of specific partnerships already working and tools to support the process <a href="http://www.ncpc.org.uk">www.ncpc.org.uk</a></li> <li>• <b>Refocusing the Care Programme Approach: policy and positive practice guidance</b> (Department of Health, 2008): <a href="http://www.dh.gov.uk">www.dh.gov.uk</a></li> </ul>

<p><b>Availability of services</b></p>	<ul style="list-style-type: none"> <li>• Commissioners should be ensuring services are available that meet the needs of people with dementia who live alone without close informal carer support.</li> <li>• Provision of specialist palliative care services must include availability of such services to people with dementia and complex palliative or end of life care needs. This may be a small number of people but they must have access to the services.</li> <li>• Services to support people to be discharged from hospital to their home or other community setting must work in partnership with dementia care services.</li> <li>• Carers of people with dementia may require bereavement service support early than carers in some other circumstances. This has implications for bereavement services' resourcing.</li> </ul>	<ul style="list-style-type: none"> <li>• <b>The Admiral Nursing model</b> demonstrates the benefits of supporting carers throughout the dementia programme: <a href="http://www.fordementia.org.uk">www.fordementia.org.uk</a></li> <li>• <b>Power of Partnerships</b> gives advice on when specialist palliative care input may be beneficial to a person with dementia</li> </ul>
<p><b>Care in the last days of life</b></p>	<ul style="list-style-type: none"> <li>• Commissioners should have an understanding of the numbers of people with dementia supported by tools for the last days, such as the Liverpool Care Pathway. While this is currently difficult to ascertain accurately given the under recording of dementia on death certificates, commissioners should be working with providers to address this.</li> <li>• Likewise, there should be reporting of the place of death of people with dementia and proportion of where this meets any stated preference.</li> </ul>	<ul style="list-style-type: none"> <li>• <b>The Liverpool Care Pathway:</b> <a href="http://www.liv.ac.uk/mcpcil/liverpool-care-pathway/index.htm">www.liv.ac.uk/mcpcil/liverpool-care-pathway/index.htm</a></li> </ul>

<p><b>Care in the days after death</b></p>	<ul style="list-style-type: none"> <li>Commissioners should there are bereavement services available to carers of people with dementia. Many of these carers will be used to having several people visiting their home a day prior to the individual's death and so may have particular need for support in the initial days after death.</li> </ul>	
<p><b>Workforce planning</b></p>	<ul style="list-style-type: none"> <li>The dementia care workforce, including those based in social care and housing, should be trained to have an understanding of and skills in delivering end of life care.</li> <li>Palliative and end of life care staff should equally be trained in understanding of needs of people with dementia.</li> <li>Commissioners should have an understanding of staff turnover levels in care homes and the implications for the local workforce.</li> </ul>	<ul style="list-style-type: none"> <li><b>Common Core Competencies and Principles for health and social care workers working with adults at the end of life</b> (Skills for Care, Skills for Health, End of Life Care Programme, 2009): <a href="http://www.endoflifecareforadults.nhs.uk">www.endoflifecareforadults.nhs.uk</a></li> <li><b>Care to Learn</b> (NCPC, 2009) is a training resource that provides introductory training on end of life care, particularly aimed at care home staff. An additional module is available on caring for people with dementia at the end of life: <a href="http://www.ncpc.org.uk">www.ncpc.org.uk</a></li> <li>The <b>Admiral Nursing competency framework</b> illustrates some of the skills required when working with carers of people with dementia: <a href="http://www.fordementia.org.uk">www.fordementia.org.uk</a></li> </ul>
<p><b>Monitoring</b></p>	<ul style="list-style-type: none"> <li>Ensure that there is a coordinated approach to data gathering and reporting for both dementia care and end of life care, including health, social care, housing and voluntary sector providers.</li> <li>Work with providers to improve recording of dementia at the end of life.</li> </ul>	<ul style="list-style-type: none"> <li><b>National Minimum Data Set for Social Care:</b> <a href="http://www.nmds-sc-online.org.uk/">http://www.nmds-sc-online.org.uk/</a></li> <li><b>Quality Outcomes Framework: online GP practice results database:</b> <a href="http://www.qof.ic.nhs.uk/">www.qof.ic.nhs.uk/</a></li> </ul>

## About the organisations

**The National Council for Palliative Care (NCPC)** is the umbrella charity for all those who are involved in providing, commissioning and using hospice, palliative and end of life care services in England, Wales & Northern Ireland. NCPC promotes the extension and improvement of hospice, palliative and end of life care services for all people with life-threatening and life-limiting conditions. It promotes palliative care in health and social care settings across all sectors to government, national and local policy makers. For more information visit [www.ncpc.org.uk](http://www.ncpc.org.uk), email [enquiries@ncpc.org.uk](mailto:enquiries@ncpc.org.uk) or telephone 020 7697 1520. (Registered charity no. 1005671).

**Dying Matters** is the national coalition led and supported by NCPC to promote public awareness of dying, death and bereavement. For more information visit [www.dyingmatters.org](http://www.dyingmatters.org)

**Anchor** is England's largest not-for-profit provider of housing and care for older people. Anchor's services include residential nursing and care homes, retirement housing and at home care. For more information visit [www.anchor.org.uk](http://www.anchor.org.uk)

**Alzheimer's Society** is the largest UK care and research charity for people with dementia, families and carers. It has 1800 staff and thousands of volunteers based throughout England, Wales and Northern Ireland. Dementia affects 700,000 people in the UK alone and 1 in 3 people over 65 will die with dementia. Alzheimer's Society provides information and support for those with any form of dementia and their carers. It advises professionals working in the field, funds research, run quality care services and campaigns for improved health and social care and greater public understanding of dementia. For more information visit [www.alzheimers.org.uk](http://www.alzheimers.org.uk), email [info@alzheimers.org.uk](mailto:info@alzheimers.org.uk) or telephone 020 7423 3500

**Dementia UK** (previously called 'for dementia') is a national charity committed to improving the quality of life for all people affected by dementia. It does this through the provision of Admiral Nurses, providing high quality, affordable training to care staff professionals and providing support through a network of carers, Uniting Carers for dementia. It also provides a helpline Admiral Nursing DIRECT, which is run by experienced Admiral Nurses, to provide practical advice and support to carers of people with dementia. For more information visit [www.dementiauk.org](http://www.dementiauk.org), email [info@dementiauk.org](mailto:info@dementiauk.org) or telephone 0845 257 9406 (Admiral Nursing DIRECT) or 020 7874 7210 (switchboard)

**National Care Forum (NCF)** was established in 2003, building on more than 10 years of the Care Forum, to promote quality outcomes for people receiving care services through the not-for-profit sector. For more information visit [www.nationalcareforum.org.uk](http://www.nationalcareforum.org.uk)

**St Christopher's Hospice** exists to promote end of life care through education, training, research and clinical practice. For more information visit [www.stchristophers.org.uk](http://www.stchristophers.org.uk)