

**Operating framework 2007/08:
PCT baseline review of services for end of life care**

**April 2007
Gateway reference 8116**

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Description	PCTs are required to undertake a baseline review of end of life care services in preparation for the End of Life Care Strategy. These questions are designed to provide all the information commissioners may need in order to develop stronger commissioning for end of life, working with a variety of service providers.
Cross Ref	None
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Contact Details	Robert Freeman End of Life Care Team 403 Wellington House 133-155 Waterloo Road London SE1 8UG 020 7972 3958
For Recipient's Use	

End of Life Care: Health and Social Care Service Review

1 Introduction

'*The NHS in England: the operating framework for 2007/08*' published in December 2006, set out local action for PCTs to begin to lay the foundations for future improvements. This included undertaking a local end of life care service baseline review in preparation for the End of Life Care Strategy due to be published in late 2007.

The strategy is in response to the Government commitment to increase choice at the end of life for all adults irrespective of the condition they are suffering from, to live and die in the place of their choice.

2 Purpose of review

The purpose of this review is to provide PCTs and Local Authorities with information that will enable them to:

- Assess the population need for end of life care services
- Map current provision including its quality
- Compare current provision with population need
- Identify where service improvements are needed
- Be prepared to respond to the end of life care strategy when published

To this end the attached guidance has been developed to help facilitate this local process. The questions set out in the guidance are designed to provide all the information commissioners may need in order to develop stronger commissioning working with a variety of service providers.

3 Conducting the review

Using the information from the review will enable PCTs and Local Authorities to assess current services, identify gaps or duplication and put in place a plan for development, as they consider appropriate, to deliver comprehensive end of life care services which will provide choice, quality, equity and value for money. Most data should be available from routine data sources such as ONS or HES. Public health departments will be able to assist in its collection and analysis. However, other data items may require local audit initiatives. In order to obtain local data the review can not be undertaken in isolation. It is suggested that PCTs and Local Authorities, working jointly, should bring together all relevant partners, users and carers, including the Private and Third Sector providers in reviewing current services. Where PCT and Local Authority boundaries are not co-terminous a lead should be identified.

4 Outputs of review

On completion of the joint review PCTs and Local Authorities may find it helpful to share the data with local partners and any gap analysis and plans for development

with the relevant SHA. PCTs are also invited, if they wish, to send the results to Professor Mike Richards, Chair of Advisory Board, End of Life Care Strategy [EOLC@dh.gsi.gov.uk] for information.

In the future, the Healthcare Commission may draw on information about end of life care services, including the baseline review, as part of its Annual Healthcheck.

5 Definition of end of life care services

By end of life care services it is meant services to support those with advanced, progressive, incurable illness to live as well as possible until they die. These are services that enable the supportive and end of life 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. This is not confined to discrete specialist services but includes those services provided as an integral part of the practice of any health or social care professional in any setting. Annex 1 provides a fuller working definition of End of Life Care.

6 Scope of review

The scope of this review should include services for adults with any advanced, progressive, incurable illness and in any setting (eg. Home, acute hospital, care home, extra housing, hospice, community hospital, hostels for homeless, prison or other institution). It should also include services for carers and family members during the illness and after bereavement.

PCTs and Local Authorities can decide whether or not to include children in this baseline review. However, it should be noted that the scope of the end of life care strategy relates specifically to adults and that parallel work has been commissioned by Department of Health to review end of life care services for children.

Definition of services (annex 1), a technical annex (annex 2), a list of useful resources (annex 3) and an extract from National Council for Palliative Care publication on needs assessment for people with dementia (annex 4) are attached. In particular PCTs/LAs will specifically benefit from referring to several National Council for Palliative Care publications on palliative and end of life care services. These are listed in annex 3.

Key questions for each PCT/Local Authority

Population-based needs assessment

1 Epidemiology of death / dying

1.1 How many people are dying each year in our population? i.e. average number of observed deaths for all underlying causes over the latest three year period for which data is available.

1.2 What conditions are they dying from?* See *technical annex for suggested definitions*.

1.3 What proportions are from BME groups and from socially deprived groups? What is the age and gender breakdown?

1.4 Where did they die? (Hospital, home, care home, hospice etc.)

1.5 What were their living arrangements prior to their final illness e.g. were they living alone, did they have an informal carer?

1.6 What are the likely trends in numbers of deaths and in place of death?

2 Place of care

2.1 Place of care in the last year of life. Comprehensive data may not be available but a retrospective survey could be undertaken of a sample of patients to look at the amount of time spent at home, in hospital, in care homes, in hospices or other institutions.

What end of life care services currently do we have?

3 Service mapping

3.1 What services are we providing for patients / families / carers as they approach the end of life? Are these services available to all patients?

For example:

- Specialist palliative care in-patient services in voluntary hospices and NHS managed units – bed numbers
- What are the local criteria under which such services:
 - a) Provide access to care
 - b) Are commissioned
- Outreach/hospice at home services including rapid response services/nursing agencies/marie curie nurses/domiciliary care/crossroads

- Acute hospitals - bed usage for end of life care
- Community hospitals / beds
- Care homes / beds for:
 - a) Personal care
 - b) Nursing care
- Respite for carers
- Hospital specialist palliative care support teams
- Community specialist palliative care teams
- Specialist palliative care day therapy/out patients
- Primary care medical and district nursing services for end of life care (including OOH availability)
- Social care end of life facilities (including home support, day care and equipment loan services)
- Ready access to medicines out-of-hours eg opioids
- Transport and Ambulance services for end of life care.
- Arrangements for coordinating EOLC across providers and care settings
- Partnership board or network for strategic planning of EOLC services

3.2 What plans do we have in place to improve the physical environment? E.g. quiet areas for speaking with families and patients, overnight accommodation, access to refreshments and sensitively appointed mortuary/ viewing rooms.

3.3 What services are we providing to support carers and families, including children, during the last phase of life of a loved one? Do they take account of the needs of BME, gay partners, different faiths, disability and other diverse groups?

3.4 What services are we providing to support carers and families, including children, during bereavement? Do they take account of the needs of BME, gay partners, different faiths, disability and other diverse groups?

3.5 For the services detailed in 3.1, 3.3 & 3.4 above how many people in the last year of life gained access to them and what percentage of all annual deaths does that represent?

3.6 For the services detailed in 3.1, 3.3 & 3.4 above how do patients/carers/family obtain access to the services (i.e. self referral, via GP, DN, Consultant etc)

4 Workforce and training

Specialist palliative care services

4.1 How many specialist palliative care staff do we have? (E.g. consultants, staff grades, junior medical staff, nurse specialists, hospice nurses, social workers, AHPs) And what are the priorities for workforce development for these staff?

Generalist end of life care

4.2 Which staff groups are regarded as key in providing generalist end of life care? (E.g. GPs, DNs, hospital ward staff, pharmacists, AHPs, care home staff, other social care providers)

4.3 What training / development programmes are we providing for these staff? (E.g. current engagement in Gold Standards Framework, Liverpool Care Pathway, Preferred Priorities in Care training or equivalent programmes).

4.4 What training is provided to social care staff?

4.5 What are our key priorities for workforce development?

4.6 What training and support are we providing for carers?

How well are the current services delivered?

5 Quality of care

5.1 What information do we have on the quality of care given to patients at the end of their lives (and to their families / carers)? What outcome measures are being employed?

5.2 What arrangements are in place to ensure systematic and comprehensive assessment of the supportive and end of life care needs of individual patients in the last phase of life?

5.3 What information do we routinely give to patients and their carers as part of an end of life care package? For example what do we tell them to do if circumstances change unexpectedly?

5.4 What active case management is in place for patients at the end of life?
a) For cancer patients
b) For all other terminal conditions

5.5 What % of all patients benefit from case management?

5.6 Does case management cover health or social care or both?

5.7 For each care setting and service provider, what is in place to ensure patients at the end of life do not receive inappropriate or unnecessary interventions/treatments (DNAR processes etc)?

6 Choice

6.1 What processes do we have in place to elicit patient and carers choices and preferences at end of life? For example:

i) Are patients being offered choices regarding service provider?

- ii) Are patients being offered choices regarding location of end of life care?
- iii) Are patients wishes regarding more or less intensive treatment being respected? If so by whom? How is this being done?
- iv) Are choices being recorded?
- v) How are choices communicated to other health and social care professionals?
- vi) Are the choices made by the patient reviewed with them at regular intervals?

6.2 How is information on choice of care and available services provided/communicated to patients and carers?

6.3 What % of patients achieved their preferred place of care?

6.4 How are the wishes of those patients who choose to put together their own package of care being respected?

7 Service coordination

7.1 What arrangements are in place for coordination of services?

- a) at organisational level and
- b) at individual patient level

7.2 Can patients at home, care home, hostel or other institution access the care they need 24/7? If so, how quickly?

7.3 How well coordinated are our services? (E.g. health / social care; ambulance service; hospital / community/ out-of-hours including access to medicines). What is the experience of individual patients and families?

8 Equity

8.1 Do our services provide equity of access? By age, disability, race, gender, religion/belief, sexual orientation, condition, social class etc.

8.2 Are services available across the whole PCT/LA area?

9 Research and Audit

9.1 What research into end of life care is currently being undertaken locally?

9.2 What audits of end of life care are currently being undertaken locally?

9.3 What investigation work is being carried out to identify end of life need in our community compared to provision of services?

9.4 What are our priorities for research and audit in the future?

How well are we using our current resources?

10 Use of resources

10.1 What is being spent in total on end of life care (including NHS, social services, voluntary and independent sectors)?

a) On specialist palliative care services (e.g. hospice beds, hospital and community teams etc)

b) On general health and social care at end of life. (E.g. GPs, district nurses, equipment, out-of-hours care including access to medicines, social services etc)

c) On the end of life care provided for all those whose death occurs in acute hospitals

10.2 For a), b) and c) above what % of the spend is funded by

- The NHS
- Local Authorities
- Voluntary sector providers

10.3 What was last year's Continuing Care spend on end of life care for patients?

a) at home

b) in a care home

10.4 Are resources being used as cost effectively and as appropriately as they might be?

11 Governance

11.1 Who has overall responsibility for end of life care across the PCT and within individual institutions / organisations?

11.2 What policies / guidelines are in place regarding end of life care and how is compliance monitored?

11.3 Is end of life care provision regularly reviewed at Board / Senior Management level in each relevant organisation?

From our review what are the greatest areas of need?

12 Areas of need

12.1 List in order of priority:

-
-
-
-
-

12.2 Which group within the local population have the most unmet need? E.g. People with diagnoses other than cancer, BME communities, homeless, travellers.

12.3 What services are least well developed? Eg community services, lack of respite care.

What are the priorities for action that we need to be put in place?

13 Strategy and proposed developments

13.1 Do we have an end of life strategy/plan?

If so:

- How was it developed?
- Who approved it?
- Is it comprehensive (i.e. does it cover all conditions and all locations of care)
- Is the voluntary sector involved?
- How are carers and users involved?

13.2 What developments in services would we plan to make to improve choice, quality of care, equity and value for money?

13.3 How do our proposed developments encompass the elements identified in the End of Life section of the White Paper 'Our health, our care, our say' in relation to:

- Choice for patients to be treated at home when they are dying
- Improved service coordination
- Identification of patients in need
- Bringing together primary care services, social care services, hospices, third sector providers, community based palliative care services as well as hospital services
- Building on the pilots being undertaken by Marie Curie Cancer Care.
- Ensuring that all staff who work with people who are dying and their carers, are properly trained to look after them.

13.4 Are these developments included in our LDP?

13.5 Has funding been allocated to implement these changes?

Annex 1

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.

Underpinning principles

End of life care is underpinned by:

- An active and compassionate approach to care that ensures respect for and dignity of the patient and family
- Partnership in care between patient, family and health and social care professionals
- Regular and systematic assessment of patient/carer needs incorporating patient consent at all times
- Anticipation and management of deterioration in the patient's state of health and well-being
- Advance care planning in accordance with patient preferences
- Patient choice about place of care and death
- Sensitivity to personal, cultural and spiritual beliefs and practices
- Effective coordination of care across all teams and providers of care (in statutory, voluntary and independent sectors) who are involved in the care of patient and family

Definition of key terms

End of life

The phase 'end of life' ends in death. Definition of its beginning is variable according to individual patient and professional perspectives. In some cases it may be the patient who first recognises its beginning. In other cases the principal factor may be the judgement of the health/social care professional/team responsible for the care of the patient. In all cases, subject to patient consent, the beginning is marked by a comprehensive assessment of supportive and palliative care needs.

Professional judgement may be informed by use of a range of indicators. They include:

1. **The surprise question.** Would you be surprised if this patient were to die in the next 12 months?
2. **Choice.** The patient with advanced disease makes a choice for comfort care only.

3. **Need.** The patient with advanced disease is in special need of supportive/palliative care
4. **Clinical indicators.** Specific indicators of advanced disease for each of the three main groups – people with cancer, organ failure, elderly frail/dementia

End of life does not normally begin earlier than one year before death and for most individuals it may come much later than that. However, in some cases discussions with individuals about end of life may start much earlier e.g. at the point of recognition of incurability.

Palliative care

Palliative care is the active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.

Supportive care

Supportive care is an 'umbrella' term for all services, both generalist and specialist, that may be required to support people with life-threatening illness. It is not a response to a particular disease or its stage, but is based on an assumption that people have needs for supportive care from the time that the possibility of a life-threatening condition is raised.

Care of the Dying

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

Family

Family includes informal carers and all those who matter to the patient.

NOTES:

1. The prognostic indicators have been derived from Guidance published in 2006 by the Gold Standards Framework Programme.
2. The definitions of palliative care, supportive care and care of the dying have been derived from the NICE Guidance on Improving Supportive and Palliative Care for Adults with Cancer.

Prepared by Peter Tebbit, National Policy Adviser, National Council for Palliative Care in association with Claire Henry, National Director, End of Life Care Programme.

Annex 2

Technical annex

Epidemiological/demographic/socio-economic data for those resident in each PCT population. Local public health departments will be able to collect and analyse the following data:

- Average number of observed deaths for all underlying causes over the latest 3 year period for which data is available
- Analysis of that number into each principal underlying cause i.e. neoplasms (ICD C00-D48), diabetes (ICD E10-E14), diseases of the nervous system (ICD G00-G99), diseases of the circulatory system (ICD I00-I99), ischaemic heart disease (ICD I20-I25), cerebrovascular disease (ICD I60-I69), diseases of the respiratory system (ICD J00-J99), bronchitis, emphysema and other COPD (ICD J40-J44)
- Analysis of the age and sex of those numbers
- Estimate of the prevalence of symptoms of dementia in those in the last year of life (for a possible approach see Table 5 in *Exploring Palliative Care Need for People with Dementia published by National Council for Palliative Care, August 2006*)
- Place of death (as per ONS Table 19 Deaths: area of usual residence and sex, by place of occurrence, numbers and percentages)
- Place of care in last year of life (comprehensive data may not be available but data could be collected from a representative sample of deaths)
- Economic/social deprivation as measured by the Index of Multiple Deprivation 2004 for local authorities, primary care trusts and Super Output Areas

Prepared by Peter Tebbit, National Policy Adviser, National Council for Palliative Care

Annex 3

References:

- 1 End of Life Care A Commissioning Perspective (2007) National Council for Palliative Care. enquiries@ncpc.org.uk
- 2 Population-Based Needs Assessment for Palliative Care – A Manual for Cancer Networks (2004) National Council for Palliative Care. enquiries@ncpc.org.uk
- 3 Population-Based Needs Assessment For End of Life Care – A Compendium of Data for SHAs and PCTs (2006), National Council for Palliative Care. enquiries@ncpc.org.uk
- 4 A new deal for carers in primary care (2006) The Princess Royal Trust for Carers. info@carers.org
- 5 Exploring Palliative Care for People with Dementia (2006), National Council for Palliative Care. enquiries@ncpc.org.uk
- 6 Improving Supportive and Palliative Care for Adults with Cancer (2004) National Institute for Clinical Excellence www.nice.org.uk
- 7 Our Health, our care, our say – a new direction for community services (2006) Department of Health www.tso.co.uk.uk/bookshop
- 8 Building on the Best, Choice , Responsiveness and Equity in the NHS (2003) Department of Health www.tso.co.uk.uk/bookshop
- 9 A New Ambition for Old Age (2006) Department of Health www.dh.gov.uk
- 10 Human rights: human lives (2006) Department for Constitutional Affairs www.humanrights.gov.uk
- 11 My Home Life (2006) Help the Aged www.helptheaged.org.uk
- 12 Widening access to hospice care (2006) Help the Hospices www.helpthehospices.org.uk
- 13 Advance Care Planning – a guide for health and social care staff (2007) NHS End of Life Care Programme and University of Nottingham www.endoflifecare.nhs.uk
- 14 Delivering the out-of hours Review: Securing proper access to medicines: Guidance for PCTs and organised providers (2004) Department of Health. www.mmnetwork.nhs.uk/med-out-home.php

Annex 4

Extract from National Council for Palliative Care publication.

Possible Approaches to Population-based Palliative Care Needs Assessment for people with dementia

One of the assumptions built into the methodology for assessment of the palliative care needs of people with cancer is that a good proxy measure of need is the annual incidence of deaths where cancer is the underlying cause. This is considered to be a reasonable assumption to make since most palliative care for people with cancer may be needed in the last year of life.

In the case of dementia there are relatively few deaths where the underlying cause of death is one that has caused the dementia (Vascular & Unspecified Dementia – 12,500 deaths; Alzheimers – 4,700 deaths). This means that dementia, given its very wide prevalence (over 650,000), is much more likely to be present in people whose deaths are due to other principal causes. If that can be considered to be a valid conclusion, then one approach to needs assessment for people with dementia would be to estimate the prevalence of dementia in the last year of life of those who are subject to the most common underlying causes of death i.e. cancer, diseases of the circulatory system, diseases of the respiratory system.

The Table overleaf provides such estimates. It shows that it can be expected that around 12% of people aged 45 and over will have symptoms of dementia in the last year of life. That would suggest that those who are providing the principal healthcare for those people e.g. cancer specialists, cardiologists, specialists in respiratory medicine, will need knowledge and skills relating to care of people with dementia, to know when to refer for specialist advice and to assess in what care setting the total care needed by the patient can best be delivered.

It is suggested that the Table below reveals a scale of the problem that would justify specific action to improve both individual patient and carer needs assessment as well as to provide education and training in the care of people with dementia for all those who have responsibility for end of life care.

National Council for Palliative Care

January 2006

Estimates of the Number of People with dementia in England in the last year of life where the underlying cause of death is cancer or diseases of the circulatory system or diseases of the respiratory system

Age Bands	45 to 54	55 to 64	65 to 74	75 to 84	85+	45+
Cancer						
Number of deaths	7496	18982	33305	43330	20474	123588
Number with dementia	7	19	977	3800	5951	10754
% with dementia	0.1%	0.1%	2.9%	8.8%	29.1%	8.7%
Circulatory						
Number of deaths	5211	12822	31548	71469	67962	189012
Number with dementia	5	13	941	6319	19992	27270
% with dementia	0.1%	0.1%	3.0%	8.8%	29.4%	14.4%
Respiratory						
Number of deaths	1068	3475	9615	21019	18239	53415
Number with dementia	2	4	283	1817	5224	7328
% with dementia	0.1%	0.1%	2.9%	8.6%	28.6%	13.7%

Notes to the Table:

1. Numbers of deaths: These have been derived from ONS Population Series DH1 no.36 (Table 2: Estimated resident population as at June 2003: sex and age-group by area) and ONS Age Sex and Marital Status Series DH1 no. 36 (Table 7: Death rates per million population; age-group and sex, infant mortality rates and SMR ratios for selected underlying causes, 2003)

2. Numbers with dementia: These have been derived by use of the estimated prevalence of people with dementia contained in Table 2 of the article entitled 'Dementia in People aged 65 years and older: a growing problem?' in Population Trends (Summer 1998). This Table makes use of the findings of the EURODEM study published in 1991 in the International Journal of Epidemiology.

3. The estimate of the numbers with dementia is based on an assumption that the prevalence of dementia among those in the last year of life is similar to the prevalence of dementia in the population as a whole.