



The End of Life Pathway



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A good death

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This chapter (based on the work of the End of Life CPG – full report available at www.yorksandhumber.nhs.uk) sets out the action we should take to improve the care people receive at the end of their life.

2

The quality of care we provide to people nearing the end of their lives suffers as a result of a disinclination to talk about death and dying across society as a whole which is in turn reflected within our NHS organisations. There is often reluctance amongst health professionals to initiate discussions about people's preferences for end of life care.

The Case for Change

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Approximately 50,000 people die each year in Y&H - 56% of our deaths are in hospital which is close to the national average of 58%. In addition:

- Approximately 18% of patients die in care homes in England, in Y&H this is 19%.
- Just over 4% of patients across England die in hospices, in Y&H this is approximately 5%.
- On average in England around 18% of patients die at home, this is approximately the same in our region.
- There is significant variation across Y&H with regard to place of dying, possibly reflecting the nature of rural and urban localities and the distribution of services.

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We know that this does not reflect people's preferences:

- Almost 60% of our patients indicate a preference for dying at home.
- 24% of our patients would prefer to die in a hospice.
- Around 40% of our patients do not get their wish to die at home, and a further 19% do not get their wish to die in a hospice.
- Approximately 20% of our patients would prefer to die in a hospital or care home (or setting other than home or hospice); however approximately 70% die in such settings.

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Patients told us that the longer they can be at home the better.

"I do think it is more comforting and less stressful".

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As well as not meeting people's wishes at the end of their lives, there are other reasons for change. These include:

- Poor coordination, which leads to delay in setting up packages of care to meet people's health and social care needs.
- Suboptimal delivery of care in hospitals, care homes and the community when measured against known standards of good practice.
- Problems which can occur with verification and certification of death, viewing the body at mortuary and with return of the person's property to their family.



- Inadequate support for carers.
- Inadequate education and training and support.
- The low priority given to end of life care within the NHS and social care.
- The lack of robust measures to assess the quality and effectiveness of care.
- Inequalities in access to end of life. This is particularly relevant in parts of Y&H with diverse cultures and communities.

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There are a number of good practice protocols and tools that can significantly improve end of life care, and which have been recommended by NICE (Improving supportive and Palliative Care for Adults with Cancer) guidance in 2004. These include:

- The Gold Standards Framework (GSF) – has significantly improved care for people with advanced, progressive incurable illness in the primary care setting, enabling GPs to identify patients for inclusion on the palliative care register which attracts QOF points. It also helps primary care teams to work together in ensuring continuity of care, setting in place advance care planning, symptom control and patient, carer and staff support.
- The Liverpool Care Pathway (LCP) – This framework enables clinical staff to deliver high quality care as death approaches, providing guidance on comfort measures, anticipatory prescribing, psychological, spiritual care and family support. It is mainly used by staff in hospitals and hospices but is increasingly being adopted for use in other care settings.

- Preferred Priorities for Care (PPC) – This is a process for advance care planning. It is a patient held document designed to support patient choice, ensuring that the information is shared with all health and social care professionals involved in their care. The explicit recording of preferences and wishes of patient and carer helps to direct the planning and continuity of care and service delivery by the multidisciplinary team and other agencies.

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Yet these tools are not systematically applied across Y&H:

- Approximately 40% of GP Practices, and less than 2% of care homes make full use of the Gold Standards Framework in Y&H.
- Approximately 90% of acute trusts, 21% of GP Practices, 3% of care homes and 41% of community hospitals make full use of the Liverpool Care Pathway.
- Approximately 11% of GP Practices, and 0.2% of care homes make full use of the Preferred Priorities for Care process for advance care planning.
- Approximately 50% of GP practices in Y&H make use of one or more of these tools; the average for England is 70%.

Key Recommendations

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Clinicians have advised us of the key recommendations we should be taking forward to improve end of life services.

Culture shift

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There is a prevailing “live for ever” mindset amongst society at large and amongst the majority of health and social care professionals, which works against the normality of death and dying, and therefore hinders advanced planning for end of life and gets in the way of a good death in the place where patients choose to die.

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Significant work needs to be undertaken to challenge this through the use of social marketing techniques, public service broadcasting, education, and more visible dialogue and activity which breaks down taboos around death and dying.

End of life care as a core part of service planning and delivery

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Insufficient focus is placed on EoL Care such that the experience of patients and carers is not of the consistently high standard it should be.

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Our clinicians have recommended that EoL should be a priority in the Operating Framework, and EoL care standards should form part of HCC and CSCI assessments.

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A range of targets should be set nationally for EoL care as part of the developing national strategy, e.g. GSF, LCP etc to help drive forward improvements.

Effective strategic joint commissioning/contracting for the provision of End of Life services

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Driving up the quality and availability of appropriate EoL care which is responsive to patient’s needs and choices is a key role for PCTs. PCTs should put in place clear commissioning frameworks based on national minimum standards to be delivered across all settings, and consistent end of life care pathways across their area of responsibility which cover the following steps:

- Timely conversations about EoL.
- Assessment and care planning, coordination and registration.
- Integrated service delivery.
- Review.
- Last days of life.
- Care after death.
- Support for carers.

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These steps are shown in our pathway models explained in figures 40 and 41 overleaf.

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This should be combined with local flexibility in relation to how the pathway and standards are best delivered to suit local circumstances.



Use of commissioning to incentivise and improve access

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Commissioners need to specify clearly what needs to be in place to deliver good quality end of life care to their populations, and work to ensure that there is sufficient spread of care services providers available to deliver this, paying special attention to access to specialist palliative care services, hospice beds, bereavement services, pharmacy services, equipment, spiritual care and access to information. Attention is also required to out of hours services to maintain continuity of care 24/7.

Co-ordination of care, single end of life service provider in each area, supported by high quality information management system

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A single care co-ordinator is required to act as the End of Life Service Provider with the authority to broker and assure care and support from a range of "sub contractor providers" to patients and families.

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High quality communication systems between services are required with the effective use of IM&T, to support seamless care to ensure patient choices, DNR etc are known, shared and worked with.

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Every EoL patient should have access to an identified key worker, care coordinator at GP Practice level and have access to 24/7 advice and support through a dedicated telephone number.

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GPs, district nurses and hospital and social services staff should have access to 24/7 specialist palliative care advice.

Advanced care planning – shift in place of dying from hospital to home

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This needs to be undertaken in all settings for all individuals with diseases which are acknowledged as being incurable and progressive, with the aim of seeing a significant shift in achieving patients preferred place of dying.

Workforce development – mandatory education and training on EoL – palliative care as everyone's business

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Training and education on EoL should be part of core curriculums, professional CPD and revalidation tailored for the range of workforces involved in providing services at the end of life. Key skills would include communications, palliative care and advanced planning.

Research, audit, review and measurement of improvements in end of life care

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There should be a few key measures set nationally as part of the EoL Care strategy and incorporated into assessment processes by the HCC and CSCI. Commissioners should also ensure effective audit processes are built into contracting processes. Crucial to this is the collection of systematic feedback from patients, carers and families, and research to assess the impact upon the quality of care of a number of best practice EoL care tools.

Funding

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Identified funding to support the provision of EoL care, from pooled budgets across health and social services is needed to support joint commissioning and investment.

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Clear partnership arrangements with charities and other voluntary sector providers are needed to ensure the balance of resource investment is appropriate to ensure support across all areas.

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There is a need to ensure universal adoption of a consistent end of life care pathway.

End of life pathway

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The CPG recommended a model pathway to aid all providers and commissioners. This is explained in figures 38 and 39.

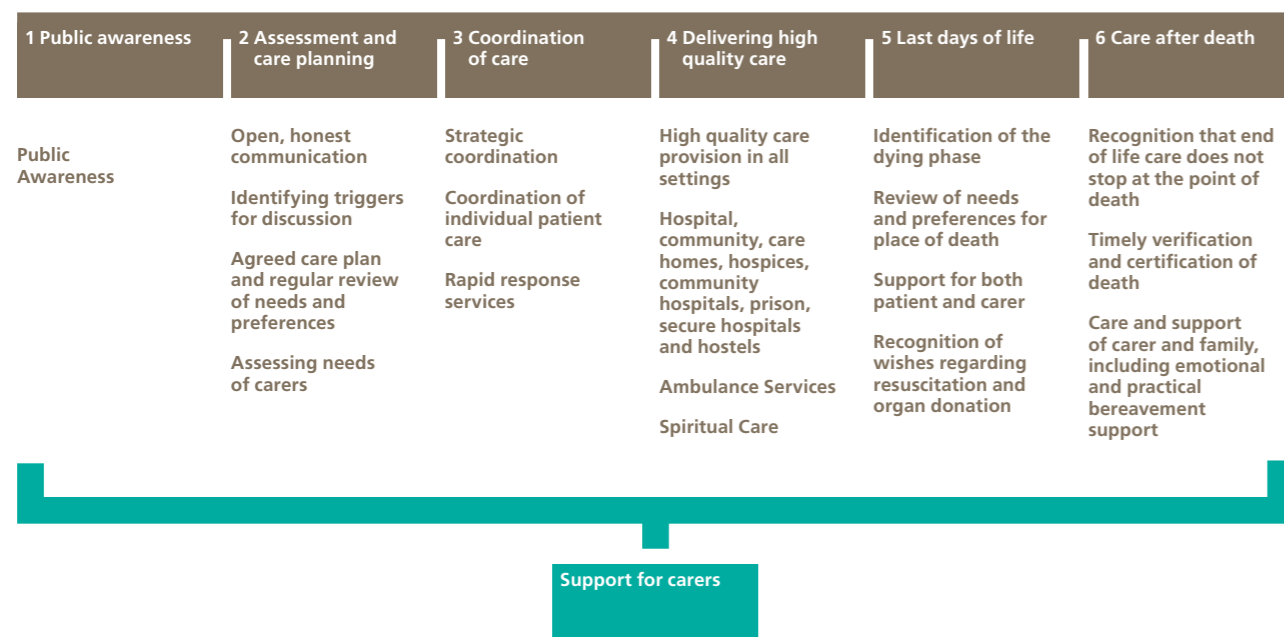
The Pathway in Practice

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To achieve the improvements we know to be necessary we propose to focus upon the following key elements of the pathway:

- The appropriate timing of the conversation about end of life care, early enough to ensure that patient preferences are recorded, communicated and available to all services involved in providing care. This includes preferred place of death, DNR, advanced directives etc.
- The recording and communication, and regular review of the patient and carer's care plan and inclusion on the end of life register.
- A single named contact/co-ordinator of care in general practice for patients entering end of life, responsible for ensuring access to services and support, communication across services and advice and support.
- Effective audit and evaluation to assure consistent quality of care in the last days of life in whatever setting an individual is being cared for.

Figure 38. End of Life Care Pathway - Addressing the Challenges / Source: Y&H End of Life CPG



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To support such an approach the CPG agreed the following were prerequisites:

- Sufficient investment in EoL care, with joint commissioning across health and social services.
- Clear partnership arrangements with charities and other voluntary sector providers to ensure appropriate support across all areas.
- A workforce adequate in numbers in all settings to plan and implement care, service provision driven by generalists with access to specialist palliative care advice and support, working with a single record and single point of access.
- Patients and carers who have access to good quality written and verbal advice, are confident that they will be supported in their choices, know who to contact, and who receive a prompt response to access good physical, psychosocial and spiritual care.
- Effective quality measures based upon a sensible range of key performance indicators, such as patient and carer satisfaction, preferred place of care, hospital admissions, place of death, registers, OOHs calls, and complaints.
- Good quality research into the impact of the implementation of good practice tools into the quality of care and experience of dying patients and their carers.
- Effective recognition and support for relatives who provide the main carer roles for individuals requiring EoL care, not only from health and social services, but from employers and others.

Barriers to Change

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Barriers to change in EoL care identified by the CPG are set out below.

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The identification of patients entering the end of life. This is a significant challenge, hampered by society's views in general about death and dying, and the difficulties which patients, families and clinicians have in planning for a good death. Some professionals still see death as failure and this can reinforce this challenge.

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A lack of clear joined up action to secure good end of life care, what needs to be available and support and equipment services to patients and families.

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Competing pressures for time and funding tend to drive out a focus upon end of life care for commissioners and mainstream providers. This, combined with the complex mix of funding arrangements and providers from health, social care, independent and private sectors makes EoL care vulnerable.

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The plurality of services can cause confusion amongst patients, carers and staff, and create challenges for ensuring consistently high standards, and ensuring the right person with the right skills is in the right place at the right time. Patients can often fall between services where there is lack of agreement about who provides what.

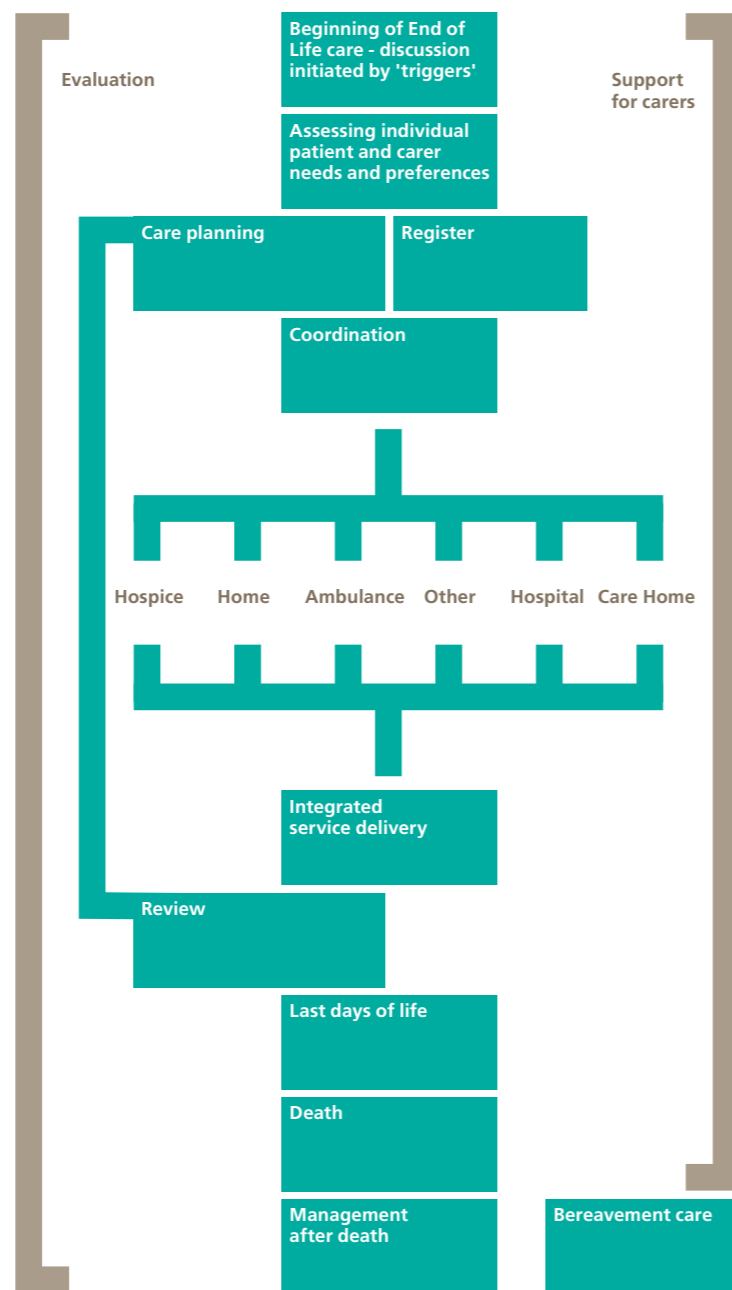
36 Language, terminology and differing expectations across the different sectors can also play their part in reducing quality of care. This is magnified where there is lack of coordination and communication, a lack of shared understanding of EoL pathway, and a lack of acceptance that good palliative care is everyone's business.

37 Professional education and training at present does not provide effective emphasis on the care of the dying.

38 The availability of services, and the pattern and distribution of such services can appear inconsistent, for example patients in certain areas have access to hospice care while others do not. This seems dependent upon local funding decisions, and priorities, and geographic considerations rather than any coherent strategic assessment.

39 There is a lack of protected funding to support end of life care, a reliance upon charitable organisations and voluntary and community services which whilst possessing relevant skills and expertise are often financially vulnerable.

Figure 39. Key elements of End of Life / Source: Y&H End of Life Pathway CPG



- 1** This chapter is based on the work of the Yorkshire and the Humber End of Life Clinical Pathway Group. Report available at www.yorksandhumber.nhs.uk.
- 2** NICE Improving supportive and Palliative Care for Adults with Cancer guidance in 2004
- 3** Healthcare Commission "spotlight on complaints, A report on second stage complaints about the NHS in England 2007"
- 4** Office for National Statistics, Mortality Statistics 2004
- 5** End of Life Care Strategy Working Paper, Department of Health, September 2007
- 6** ICM research for Endemol UK, Bereaved Carers, England, Scotland and Wales 2005
- 7** ICM /Endemol/ BBC Poll, General Public, England, Scotland and Wales 2005

Good Practice

We have several examples of good practice across our region – these include:

- An outreach Marie Curie evening service, operating from 6pm – 11pm, in East Riding PCT this is the first in the country.
- Drop in services and drop in bereavement services at hospices, which including a benefits advisor, complementary therapies etc.
- Preferred place of care document – audited and developed in Hull PCT.

Conclusion

40 The End of Life CPG have made clear recommendations which, if implemented, will lead to great improvements in the care people receive at the end of their lives. A key part of making these improvements will be the extent to which we can address our cultural reluctance to talk openly about death.

41 Our pledge in taking forward this pathway will be to double the number of people able to die at home rather than hospital.