

End of Life Clinical Working Group:

This report, written by Steve Dewar, Cyril Chantler, Penny Dash and Rob George on behalf of the End of Life Clinical Working Group (see Appendix 1) is not a systematic review of the literature on good practice. It is however, a considered collation of opinion and evidence from an experienced group of stakeholders seeking to lay out areas of general consensus about how End of Life Care might be improved in the Capital.

We want to start by thanking the group for their extraordinary commitment to the task and the time and energy that they gave over a very short timespan. In particular we want to acknowledge that this report has drawn substantially and significantly upon the national work being undertaken by Professor Michael Richards and others developing the end of life strategy for the Department of Health. The group met three times during early 2007 and discussed four main questions which we have adopted and used as chapter headings.

- What is meant by end of life care?
- Current issues in end of life care
- Understanding the end of life
- What would good practice look like?

1. DEFINITIONS OF END OF LIFE CARE

It was agreed that the scope of end of life care expressed in the DH working paper¹ on end of life care should be adopted. This states that end of life care should encompass:

- Adults with any advanced, progressive, incurable illness (e.g. advanced cancer, heart failure, COPD, stroke, chronic neurological conditions, dementia).
- Care given in all settings (e.g. home, acute hospital, residential/care home, nursing home, hospice, community hospital, prison or other institution).

¹ End of Life Care Strategy Working Paper. Department of Health, September 2006.

- Care given in the last year(s) of life.
- Patients, carers and family members (including care given after bereavement).

The work excludes care given outside the current legal framework (e.g. assisted suicide or voluntary euthanasia).

We recognise that other specialist reviews of children's palliative care needs are being undertaken elsewhere and proposals in relation to children's care needs should be based on this work. However, we did reach the conclusion that it would require a compelling argument not to locate the commissioning of children's palliative care services, as a specialist commissioning activity, at the SHA level.

2. CURRENT ISSUES IN END OF LIFE

The group has highlighted five key issues in end of life care:

Issue One: There is a lack of discussion in society about death and dying

Death is a taboo subject for many people, with little active discussion in society about what constitutes a "good death". There are widespread misconceptions about the process of dying and polarised debates about euthanasia impede rational discussion.

Only around one third of the general public have discussed with anyone how they would like to die². In a poll of 1, 027 people conducted by ICM research for Endemol UK, 67% of people over 65 years had prepared a will, while only 51% had discussed how they would like to die². Another study by Catt et al reported that 70% of those aged 75 or more had prepared a will³.

Nearly four out of five people say that they would wish to be told when they were dying² but it is not clear how many actually are told. In the ICM poll, only 34% of the general public reported that they had discussed their wishes for how they would like to die. Even among those over 65 years, the figure was only 51%. Further, 42% of bereaved relatives did not know the patient's preferred place of dying while 66% had never discussed death with the patient. Only 21% had discussed death before the patient was ill and a further 13% during the illness.

² ICM/Endemol/BBC Poll (2005) – General Public: 1027 participants: 45% male; 55% female: Broad age span (16 years and above): Broad social mix: England, Scotland and Wales.

³ Catt et al. Older adults' attitudes to death, palliative treatment and hospice care. *Palliative Medicine*, 2005; 19:402-10.

However, a different survey carried out in Norfolk and Waveney⁴ found that 73% of respondents had discussed their own death, with those under the age of 25 being the least likely to have done so. Two thirds of respondents to the Norfolk and Waveney survey felt that as a society, we do not discuss death enough, with women being more likely than men to hold this view. In a Marie Curie survey, 79% of respondents felt that death is a taboo subject for the majority of people⁵.

Issue Two: Inadequate planning for individuals at the end of their lives

Inadequate planning on behalf of the health and social care system is an unacceptable reality in relation to both the individual and the system of care. We address the latter problem under Issue Five (below).

Across England, including in London, there are inconsistent approaches to supporting individuals to state their preferences for end of life care. This is due to many factors including:

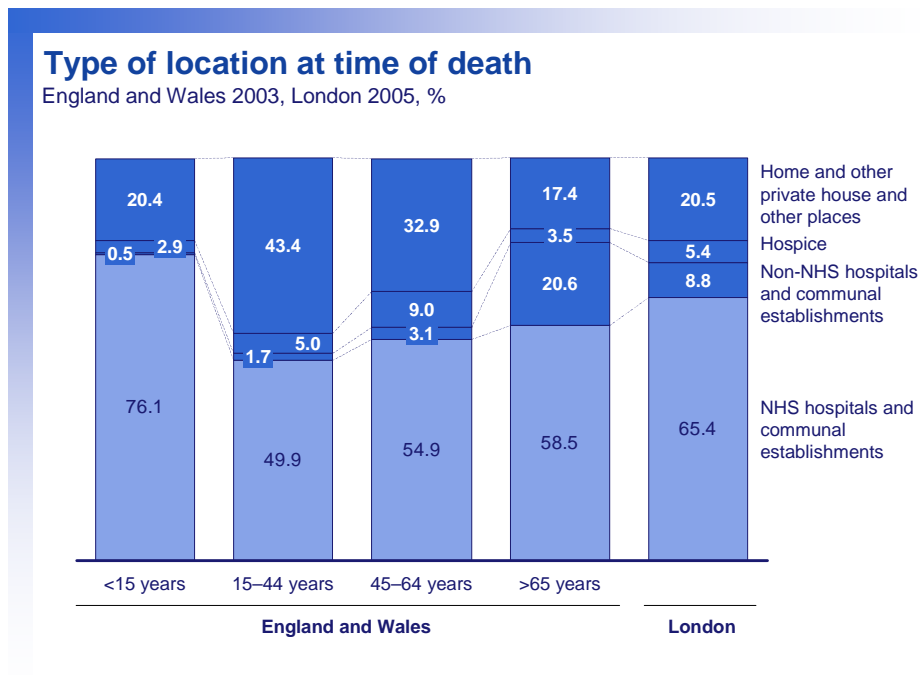
- Lack of skills amongst healthcare professionals to appropriately discuss death and the process of dying
- Insufficient information to support individuals and their carers
- Lack of designated responsibility for documenting preferences
- No consistent system for recording preferences
- No consistent approaches for updating preferences
- No system for ensuring preferences are communicated to all professionals coming into contact with patient (and their carers) e.g. ambulance, care home staff, social care
- Preferences are often driven by circumstance – and individuals' choices may change depending on the circumstances e.g. availability and awareness of facilities available

⁴ Attitudes to death and dying and palliative care: A survey of people living in Norfolk County and Waveney. Norfolk County Overview and Scrutiny Committee, September 2005. Questionnaire sent to 1,101 members of the general public. 524 responses. 72% over 45; 52% female. Referred to in Mike Richards paper.

⁵ Survey of general public conducted on behalf of Marie Curie. Online questionnaire with 2,543 respondents in Great Britain.

Issue Three: Most people are dying in hospital when they would rather die at home (including in their care home) or in a hospice

Across England and Wales the majority of people, particularly the very young and the very old, die in hospital. We acknowledge that there are major issues about the need to consider care homes as peoples' homes and we address this further in Issue Four (below).



Source: National statistics 2003, London Health Observatory 2005

Repeated surveys of the general public have shown that the first preference for most people (56-74%) would be to die at home⁶. In three of the surveys, hospices emerged as the next commonest first preference (10%-24%), the exception being the ICM/Endemol/BBC poll in which only 3% selected hospice as a first choice. In a study of bereaved relatives 82% of those who knew the patient's preference reported that it was home⁷.

⁶ ICM survey, Norfolk survey and Marie Curie surveys as above. Also see... Higginson: Priorities and preferences for end of life care. National Council for Palliative care. 2003. Telephone interviews with 1,000 adults (46% male) across England, Wales and Scotland. Broad age range and social background.

⁷ ICM research for Endemol UK. 2005. Survey of 500 people who had suffered a significant bereavement in the previous 5 years. 41% male. Partner/spouse (10%); other family member (80%); friend (10%). England, Scotland and Wales.

However, when questioned in more depth, many people (and especially older people) express concerns about dying at home⁸. These concerns relate particularly to not having an informal carer at home and not wanting to be a burden on family and friends.

A study of 256 Londoners shows a slightly different picture with hospice care being first preference for place of care in older and younger age groups. In the younger age group (55-74), home was the second preference with hospital being third. Among those over 75, hospital was the second preference with home being third⁹.

Individuals' preferences for place of care may change over time. One study found that a small number of patients and family members change their preferences as a result of negative experiences and because of progression of illness¹⁰.

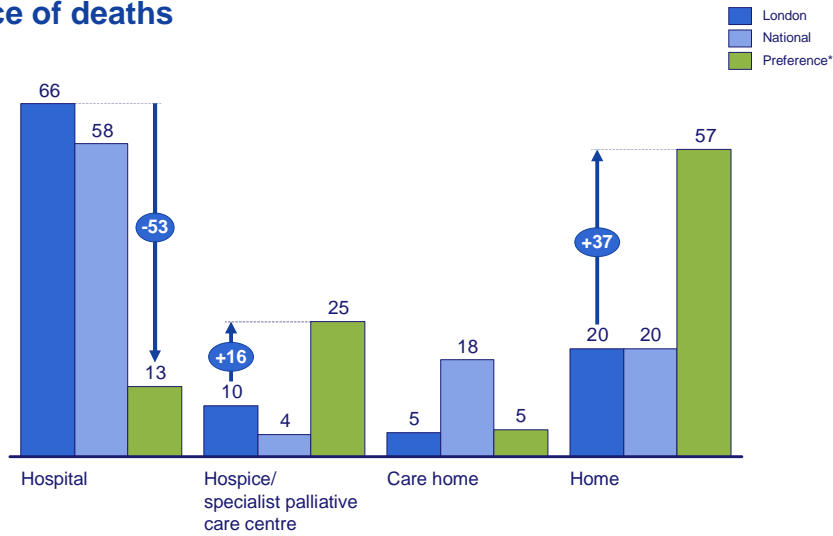
In practice only 20% of deaths nationally, and in London, occur at home with 58% of deaths nationally (66% in London) occurring in hospital. There are far fewer deaths in care homes in London than in other parts of the country – this may be due to the lower number of care home spaces in London, or may be due to specific issues relating to care home staff being less able to manage patients towards the end of their life; or may be due to a broader range of factors which deter care homes from supporting individuals to die there (for example concerns that a high death rate might lead to investigations into poor care provision). The data is shown below:

⁸ Gott et al. Older people's views about home as a place of care at the end of life. *Palliative Medicine* 2004; 18:460-467. Interviews with 45 older people in Sheffield, 2004.

⁹ Catt et al. Older adults' attitudes to death, palliative treatment and hospice care. *Palliative Medicine*, 2005; 19:402-410. 129 people aged 55-74 years and 127 aged 75 years or more.

¹⁰ Higginson and Sen-Gupta. Place of care in advance cancer: a qualitative systematic review of patient preferences. *Journal of Palliative Medicine* 2000; 3:287-300.

Difference between preferred and actual place of deaths



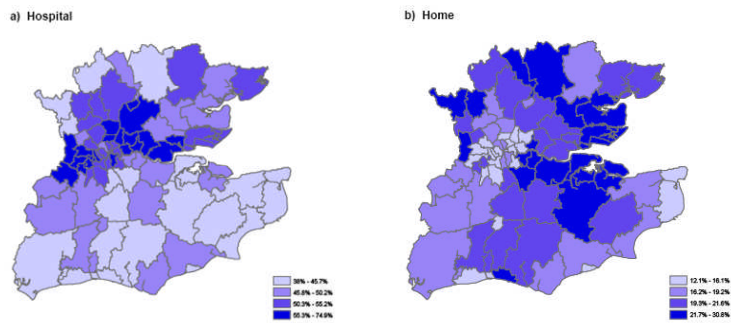
Source: England, Wales and Scotland (2000); Telephone survey; Priorities and preferences for end of life care in England, Wales and Scotland (2003) Telephone Survey NCHPCS/ Cicely Saunders Foundation; National statistics 2003, London Health Observatory 2005

Too many people die in hospital in London

Proportion of cancer patients dying at home or in hospital, %

Londoners rely on hospitals for end of life care ...

While comparatively fewer die at home



Source: Thames Cancer Registry, 2002-2004

A study into cancer deaths found wide variations in the percentage of cancer deaths at home in different electoral wards¹¹. Social factors were found to be inversely correlated with home cancer death and may explain part of the variation. However, recent research collating data from over 1.5m patients found three main factors to be important for cancer patients¹²:

- Patient characteristics e.g. haematological cancers were less likely to result in a home death than other forms of cancer
- Socio-demographics of the patient – in London, age is negatively correlated with death at home, as is social deprivation
- Living arrangements and family support and the services received, especially the availability and intensity of home care

Issue Four: The quality of end of life care provided is highly variable

A high proportion of bereaved relatives report that they are satisfied with the care given to a loved one. In the ICM poll of the general public, 77% of people who had experienced the death of a loved one in the last 5 years were fairly or very satisfied with the care given. Within the survey of bereaved relatives, 74% were satisfied with care received in the last few hours of life. This varied depending on location with 74% of those whose relative died in hospital being satisfied, compared to 68% of those dying at home and 97% of those dying in a hospice. We consider the generic challenges for quality as well as those that are specific to different settings below.

Generic challenges

We recognise that quantitative satisfaction surveys do not necessarily give the full picture. For example a post bereavement survey of people who registered a cancer death in inner London found that when comments could be added, negative comments were often made even when the care had been rated as “good” or

¹¹ Higginson, Jarman et al. Do social factors affect where patients die: an analysis of 10 years of cancer deaths in England. *Journal of Public Health Medicine*. 1999. 21; 22-28.

¹² Gomez and Higginson. Factors influencing death at home in terminally ill patients with cancer: systematic review. *BMJ*, Mar 2006; 332: 515 - 521

“excellent”¹³. Dissatisfaction centred around communication, information, personal care, bureaucracy, late diagnosis of condition and the hospital environment.

‘Choice and control’ emerged as one of seven key themes in relation to dying well in a study of terminally ill patients, bereaved relatives and professionals. Other key themes were: symptom control, dignity, quality of life, preparation, relationships and coordination / continuity¹⁴.

Hospitals

In contrast to this, a high proportion of hospital complaints are related to end of life care – of all complaints about hospitals received by the healthcare commission, 54% of them were about end of life care¹⁵. This equates to a quarter of all healthcare complaints.

Care homes

Members of the group reported that a number of data sources indicate worrisome variations in care given towards the end of life in care homes. In contrast care given in hospices and community hospitals is often highly rated. Further points highlighted in the literature^{16,17} and supported by the group included:

- patients are taken to hospital to die because their carers and professionals “panic” at the final stages
- Little/inconsistent support for death at home, or in a care/residential home
- Lack of palliative care facilities
- Individual’s preferences not communicated to all staff (as above)
- We are aware of less care home provision in London, which may have an impact on the proportion of Hospital deaths in London (see the earlier graph on page 6).

¹³ Rogers A, Karlsen S, Addington-Hall J “All the services were excellent. It is when the human element comes in that things go wrong”: Dissatisfaction with hospital care in the last year of life. *Journal of Advanced Nursing* 2000; 31:768-774

¹⁴ Aspinall et al. What is important to measure in the last months and weeks of life? *International Journal of Nursing Studies* 2006; 43:393-403.

¹⁵ Spotlight on Complaints : a report on second-stage complaints about the NHS in England. London - Healthcare Commission 2007

¹⁶ Hockley J, Clark D (eds). *Palliative Care for older People in Care Homes*. Buckingham, Open University Press 2002

¹⁷ Froggatt K. Palliative care and nursing homes: where next?. *Palliative Medicine* 2001; 15:42-48

There is an anxiety that it may be likely that a wish to improve the quality of care at end of life in care homes will inevitably lead to a higher death rate within care homes. We acknowledge that this may lead to investigation or a negative impression of the home. We are worried that this may inhibit a drive to improve care at end of life in care homes and we recommend that ways are sought to address the culture that leads to such potentially unwarranted perceptions.

Primary and Community health care

The key policy document “Building on the Best; Choice, Responsiveness and Equity¹⁸” commits the Department of Health to putting in place training programmes for staff to ensure that all adult patients experience quality end of life care and live and die in the place of their choice. A total of £12m was committed, over three years, from November 2004 to specifically support the implementation of the Gold Standards Framework (GSF)¹⁹, Liverpool care pathway for the Dying (LCP)²⁰ and the Preferred Place of Care (PPC)²¹ end of life tools²². While these are examples of high quality care they are not the only examples. Indeed, across London, there are many examples of good practice care being put into place, though it should be noted that these have not been formally evaluated. Examples of these are in Appendix 3. But these are not consistently applied across all sectors.

By June 2006, 50% of all GP practices across England were adopting one or more of these tools, though in some instances only for people dying of cancer, not other conditions. However, there is considerable variation with performance in London being particularly poor. For example, over 90% of GP practices have adopted one or more tools in Cumbria & Lancashire and Cheshire & Merseyside SHAs, but fewer than 50% in SW London SHA and fewer than 20% in the other four London SHAs. The group recognise the importance of further enabling General Practices to gain the appropriate skills to deliver end of life care. The group remain concerned about the inconsistent provision of out of hours services and the impact that this may have on the consistency and co-ordination of services.

A similar picture exists for usage of the tools in acute Trusts with 100% uptake of one or more tools in many SHAs, including North Central London, but the other four London SHAs achieving between 40 and 65% uptake. Even within the Trusts

¹⁸ Building on the best: choice, responsiveness and equity in the NHS. Great Britain - Department of Health, 2003.

¹⁹ Gold Standards Framework. See www.goldstandardsframework.nhs.uk

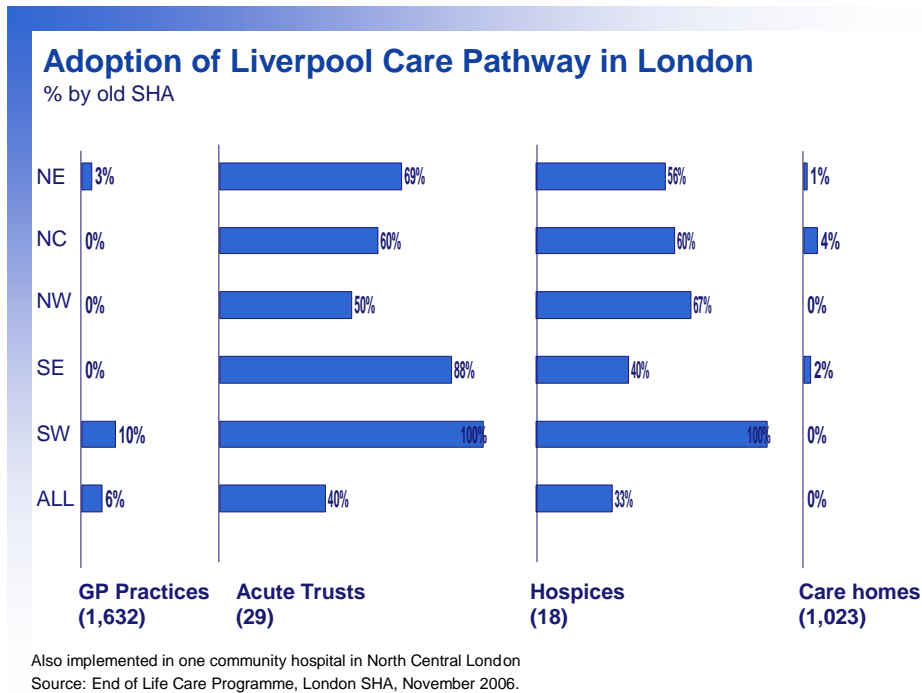
²⁰ Liverpool care pathway for the dying patient (LCP). See www.lcp-mariecurie.org

²¹ See www.cancerlancashire.org.uk/ppc.html

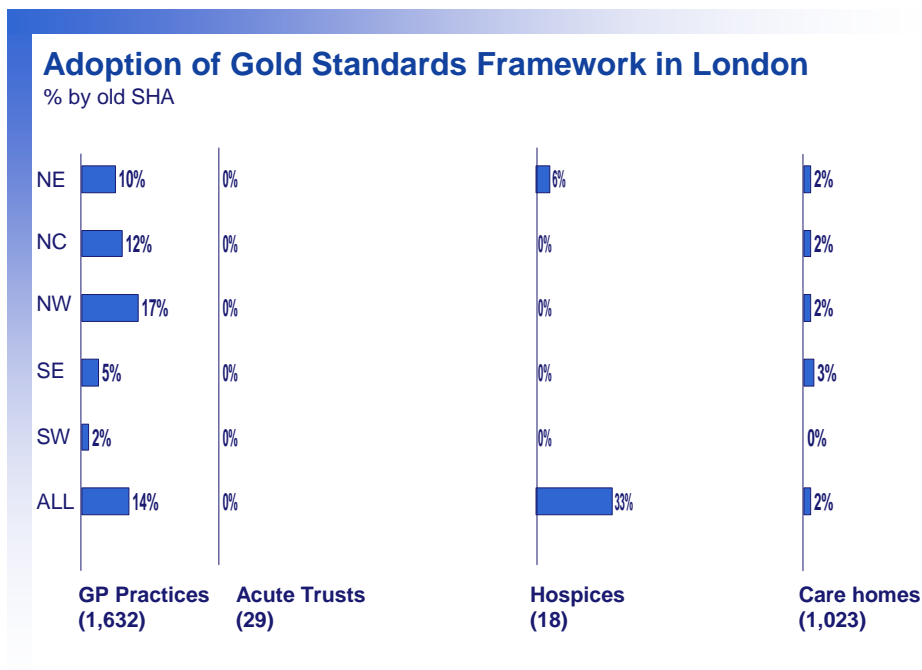
²² See www.endoflifecare.nhs.uk/eolc

using the tools, uptake may only apply to one or two wards within a hospital. Across the country, there are only 9% of acute Trusts (16 in total) who have rolled out the Liverpool care pathway to all their wards. Uptake of tools in care homes has been limited to date.

The diagram below shows the uptake of the Liverpool Care Pathway tool across London:



The diagram below shows the uptake of the Gold Standards Framework across London:



Many services and organisations use elements within the Preferred Place of Care tool to establish patients' wishes, and their choice on where they would like to be cared for, at the end of life, for example, 30% (45) of Care Homes within NW London ask and document preferred place of care.

Issue five : Inadequate planning at the system level: resources, responsibility and co-ordination

At a system level we do not believe that end of life care has received the priority that it should. Because of the lack of strategic attention on this aspect of care the health and social care system is not in a position to understand the value and the shortcomings of the current system. We do not know how much is spent on end of life care or use data to consider and refine the system of care.

The consequence of this lack of understanding is that we are unable to specify or commission services with intelligence. Indeed we believe that there is little evidence or experience of specialist commissioning in the area of end of life care that has re-shaped and integrated services to better meet the needs of users.

Because we are unable to reflect on intelligent commissioning we can not marshal the necessary and detailed arguments for appropriate resourcing, we can not truly understand how best to integrate or reshape services and we can not recognise or

systematically address the undoubted staff training deficits that we suspect are limiting the effectiveness and adaptability of the system.

Lack of clear responsibilities

Good end of life care can be complex in its delivery, often requiring the use of multiple resources and the skills of a wide range of healthcare professionals to meet the needs of the patients and carers. It also requires good communication pathways and good co-ordination

A key barrier to change seems to be the lack of clarity of roles. Clinical care, as a person nears the end of their life, is often delivered by more than one health care professional or team. It is not clear what the responsibilities are especially in respect to the co-ordination of care and the communication between other health care professionals involved in the delivery of care.

This is confusing for patients and their carers, and for healthcare and social care staff.

Lack of overall co-ordinator role

The working group highlighted one of the most significant barriers to improving services as the lack of anyone with dedicated responsibility for end of life care. Some felt this should be the role of the GP – but it is clear that while some GPs play this role, by no means all do. In the Lincolnshire Marie Curie delivering choice programme site, only 4 out of 745 referrals (0.6%) to the Rapid Response Service came from GPs. The overwhelming majority came from patients or carers (53%).

There appears to be a lack of consistency across the country, and in London, for taking responsibility for ensuring high quality end of life care is in place.

Lack of commissioning responsibility

Underpinning concerns about the quality of end of life care is the lack of a clear responsibility for commissioning high quality services. PCTs are responsible for allocating monies on behalf of their population, and ensuring that these monies are spent on high quality services.

In many cases in London, it is not clear who within PCTs is responsible for ensuring high quality end of life care, if anyone. Further, the current fragmented commissioning arrangements in London (with 31 commissioners) make it especially difficult to commission care – the skills and capabilities required are spread too thinly.

We recognise that there is a need to shape policy in a way that seeks to avoid the risk of cost shifting. It is clear that we should move away from a situation that creates positive incentives for people to be directed to hospital for the last days of their life (regardless of their wishes) because it may be considered as a ‘free’ option to one provider where otherwise dying at home (if it were in line with the individuals wishes) might incur substantial unaccounted for costs to the providers of the key enabling services.

We consider this to be partly a problem arising from the lack of, or the immense difficulty in establishing joint commissioning systems between health and social care.

Perceived lack of resources

As well as not ensuring high quality services, there is concern that PCTs are not ensuring resources for end of life care are spent as well as possible. There is often a perception that dedicated facilities e.g. palliative care or hospices, cost more money than current services. But analysis from Marie Curie and elsewhere shows that high quality palliative care can be cost neutral or possibly offer financial savings from transferring costs of care away from “high-tech” hospital based care towards home based, “human” care.

Failure to prioritise end of life care

There appears to be a failure to prioritise end of life care over other health care services at a PCT level. This is partly related to the areas identified above – i.e. a lack of skills and expertise in PCTs to appropriately commission end of life care and a perception that high quality end of life care will be expensive. But there also seems to be a lack of willingness to ensure sufficient resources and time are allocated to end of life care, compared to other healthcare services.

At an individual carer level, this can also be true. For example, GPs may struggle to prioritise time and energy for end of life care – perhaps not surprising when they may only see a few patients a year.

Lack of skills and training in the workforce

Underpinning all the above barriers is a lack of training and education in end of life care in all health and social care staff. This relates to a lack of training in communication skills, to end of life care not being a core part of training for all health professionals/generalists and a general reluctance in society to discuss death and dying.

3. UNDERSTANDING THE END OF LIFE

Patterns of progression for fatal illnesses in the last months and years of life

On face value, dying entails a body deteriorating and failing to sustain the person that inhabits it. However, a person is more than flesh and blood; much, arguably all, of human identity, sense of meaning and purpose finds form in one's relationships. From these, people feel dignified or worthless, and through them their suffering also may be relieved. Dying is therefore an extremely complex and unique social event involving those who have been part of a life. Hence, good end of life care is complex and multidisciplinary. Practically and operationally, though, managing uncertainty is a central challenge in end of life care, both in terms of the time that a person has left and the fluctuating impact that the disease may have on them and their families. Unpredictability is no respecter of pathology.

Understanding that there are patterns of progression for fatal illnesses, allows a flexible foundation to care, upon which disease specific services can be added²³. There are four overall patterns of 'chronic dying'.

1. Slowly but relentlessly progressive diseases (see Cameo 1 and 2: Appendix A) that disable and kill over months to years in which the trajectory of the disease journey is to all intent and purpose linear. They are complicated by challenging and variable levels of disability. Neurodisabilities such as Motor neurone disease, MS and Dementia fall into this category. The following case illustrates that appropriate and timely involvement of specialist palliative care in the care of people severely affected by multiple sclerosis can

- Reduce the length of stay in an acute hospital
- Prevent unnecessary, unwanted admissions to an acute hospital
- Facilitate patient choice and advance planning
- Deliver effective end of life care in a patient's preferred place of care.

In addition, in more advanced illness, increased support at home reduces length of stay and prevents admission.

²³ George, R. Palliation in AIDS - where do we draw the line? *Genitourinary Medicine*, 1991: 67(2) 85.

2. *Progressive diseases punctuated by serious or life-threatening episodes*, any of which may kill. Historically, this was exemplified by HIV disease; chronic ischaemic heart failure (see Cameo 3: Appendix A) or chronic obstructive pulmonary disease are examples. Again the overall trajectory may span many years. The challenges of judging the balance between aggressive, curative and palliative approaches are prominent here;

3. Malignant diseases are *relatively rapid and predictably fatal diseases* in this scheme, but again, punctuations with life threatening episodes or iatrogenic crises may introduce unexpected uncertainties in care.

Finally,

4. Some diseases have *trajectories that vary with the success of their management*, co-morbidities, or where continued life depends on specific maintenance, the removal of which leads to death in a rapid and predictable way. Dialysis-dependent Chronic Renal failure and diabetes are examples.

The focus of care should always be to facilitate the patient and family in addressing tasks, relationships and personal resolution in a timely and effective way that reflect as far as possible the likely pattern of clinical deterioration and the trajectory that seems to be emerging. A helpful concept is to see the purpose of care, symptom control and therapeutics always to be the creation of '*Decision Space*' – ie the best chance to make choices and changes with the opportunity to live rather than to suffer or survive until death²⁴.

Terminal events and 'letting go' - the last days or hours

Terminal events also follow typical patterns. Any chronic dying patterns may end in these ways. Understanding these is important in managing patients' preferred places of death say with emergency discharges to die at home, or in ensuring that there are no inappropriate admissions to A&E, but equally that life-prolonging measures are available should there be a realistic need to "buy time", for example in assisting the family to orchestrate visits or the arrival of key people. It is essential to know that these processes can range from hours to weeks and the time is surprisingly elastic.

²⁴ George R, Martin J. Non-physical Pain: suffering in action. In: The Effective Management of Cancer Pain 3rd Ed UK Key Advances in Clinical Practice Series 2003 Eds Miles A, Finlay I, editors. Aesculapius Press 2003.

1. *'Acute death'*: sudden, 'unexpected' deterioration and death. This may be the first presentation of cerebrovascular or cardiac diseases (see Cameo 4: Appendix A). Contrary to popular belief, patients with Motor Neurone Disease characteristically develop fatal respiratory failure in this way with very little in the way of breathlessness.
2. *'Fading away'*; A relatively predictable steady fading of life with the patient taking to their bed, ceasing to eat and drink and then slipping into unconsciousness (see Cameo 5: Appendix A).
3. *'Practice runs'*: A sporadic course during which the patient draws back repeatedly from the brink of death and changes hour to hour or day to day.
4. *'Prolonged death'*: patients, whilst clearly in an active dying phase, may plateau for a variable period and seem to pause before they die. This is usually indicative of a wait for something such as a key person, anniversary, permission, spiritual intervention or some internal process of resolution²⁵. The challenge here is to support family (see Cameo 6: Appendix A).

In situations 2-4, the patient may well let go very suddenly, especially if they have been waiting for some critical event or person. This is one reason why it is so important to elicit comprehensive emotional and spiritual histories so that family or the patient can understand and engage the dying process and any suffering fruitfully.

²⁵ Dein S, George R. Commentary: A Time to Die; *Mortality*, 2001, 6: 203 – 211.

4. WHAT WOULD GOOD PRACTICE LOOK LIKE

Four proposals for the development of good practice

We present four proposals for the development of good practice. These proposals should in our view shape good practice for all those approaching end of life.

Proposal One - A strong 'sector' wide specialist commissioning function

Central to our approach is the need for a strong specialist commissioning of end of life care.

We believe that there are good arguments for locating this commissioning of adult end of life care at the sector 'SHA' level (areas co-terminus with the old five London SHAs). Commissioning at this level would enable meaningful community engagement and a degree of diversity from which we could learn. It may also enable patients to exercise choice within their area between two or more ***End of Life Service Providers*** (ELSPs).

The PBC or PCT level seems too small for the right skills and capabilities to reasonably develop in each area and would lead to an unnecessary duplication and variability in such complex and specialist commissioning.

We reiterate our belief that subject to the forthcoming specialist analysis and review being undertaken by others that children's palliative care needs should be considered separately and commissioned at a SHA level²⁶.

Commissioning of adult end of life care should be based on a detailed specification and should enable a variety of managed networks across providers to bid for the contract to provide end of life care services. Those bidding for the contract should be offering an integrated and comprehensive service that includes community nursing, GP organisations, specialist palliative care teams, local authorities, the voluntary sector, and acute care providers.

We appreciate that what we propose will require the co-ordination of services as part of a contract with PCTs to be delivered across the public, private and voluntary

²⁶ The Children's palliative Care Review Team is due to report its conclusions, by way of a published report in May 2007.

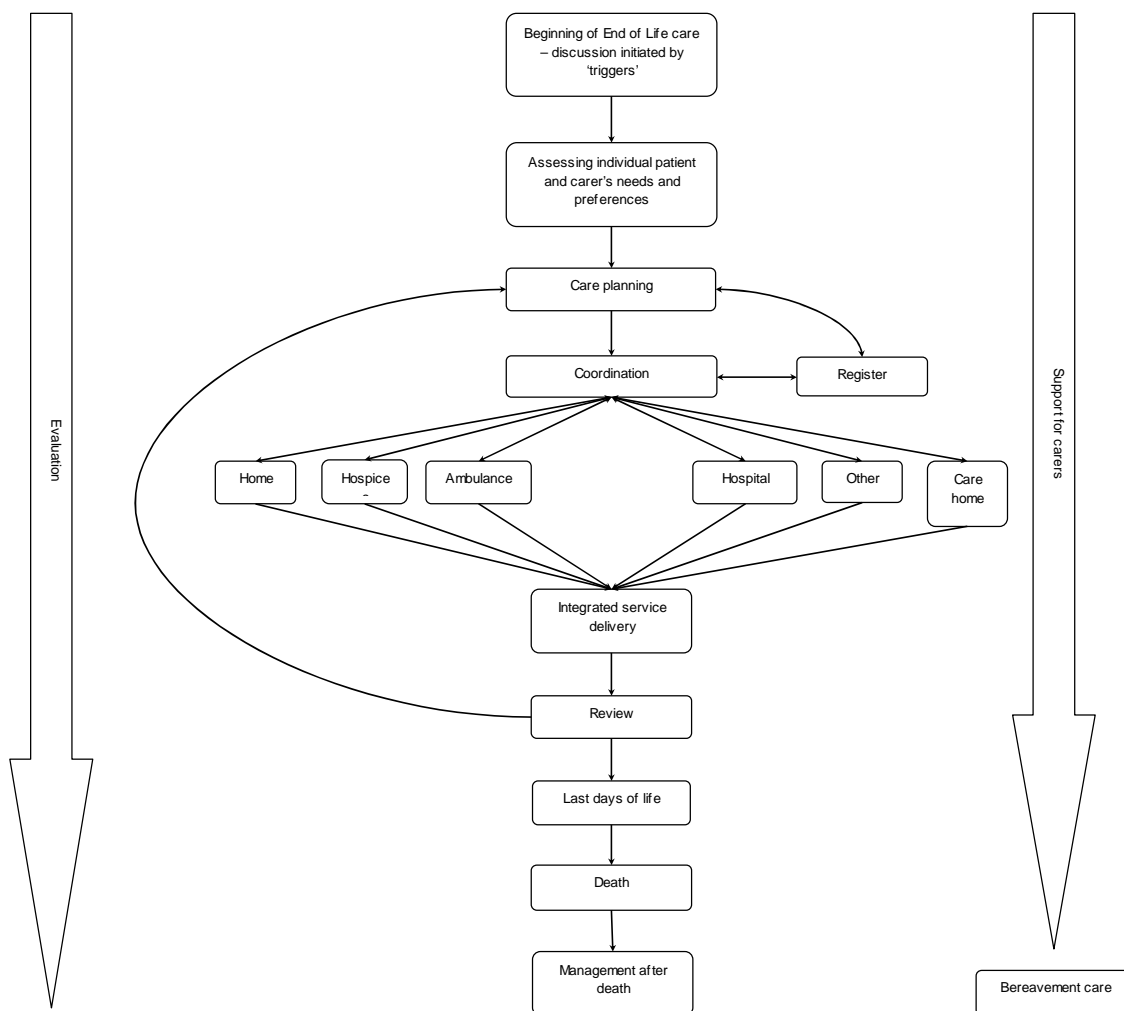
sectors. We understand the difficulties but nevertheless believe it is important and legitimate to challenge PCTs and Local Authorities (LAs - on a sector basis) to find a way to come together in this commissioning process to commission appropriate integrated specialist services.

We note that under the Operating Framework for 2007/2008 PCTs are under an obligation to undertake a baseline service review of end of life care. We are also aware that further guidance on the structure and content of this review will be available shortly. We expect that these reviews may inform and help shape the potential implementation of this proposal. We also suggest that PCTs across London sectors would benefit from working together to undertake this review on a sector wide basis.

We envisage this commissioning process (see the diagram below) being clearly based upon a care pathway for end of life patients and delivered through a managed network of providers. We expect PCTs to have a clear financial envelope identified for this purpose and we believe it is important for work to be undertaken to identify clear performance metrics to monitor the contract and drive up quality. Our aim is for a sophisticated commissioning function that can assist in assuring an appropriate managed network of clinical services delivers managed care to each and every individual who needs it.



A proposed care pathway for end of life care²⁷



Proposal Two - An integrated managed care system at the end of life: the responsibilities of ELSPs

We believe that the commissioning for an integrated managed care system at end of life needs to include three new and specific requirements that will form the future cornerstones of high quality end of life care. We will outline these three

²⁷ Kindly shared by Professor Michael Richards from the work of the Department of Health End of Life Strategy Group

requirements in turn: the end of life register; the recording of preferences; and the end of life care plan.

The Care at the End of Life Register

When it is clear that you have an advanced progressive illness which is likely to shorten your life, the ELSP should systematically offer you the opportunity to join a Care at the End of Life register.

Placement on this register would come with entitlements. Placement on the register would bring with it a commitment on behalf of the health system to a systematic assessment of needs and the co-ordination of appropriate services. It may also bring access to a wide range of services from free parking to dedicated support services provided by providers across the statutory and voluntary sectors.

We propose that these entitlements should be viewed in a similar light to the entitlements of those with a statement concerning their educational needs, although we do not propose a similar legal basis for this initiative. We certainly intend to imply that such entitlements should have a similar importance and impact.

The process of systematically identifying those that should be on this register would entail applying a range of ‘triggers’ for different conditions designed to identify the high potential of death from the disease in the following months. We would look to others to help engage in the specialist work necessary to identify these triggers for inclusion on the register.

Eliciting and recording preferences

Using the register would introduce a clear and we suspect for many, a first opportunity for a structured conversation about preferences, support and anticipatory planning for end of life.

We believe that all individuals should be supported to express their preferences when it is clear that they have an advanced progressive illness which is likely to shorten their life, alongside access to a range of appropriate entitlements for end of life patients. However, this should not restrict individuals to expressing a preference at other stages of their life, e.g. at retirement, or when making a will, even if at that stage formal entitlements to end of life services were not appropriate.

One of the entitlements to flow from inclusion on the Care at the End of Life Register would be access to comprehensive, locally tailored, information about

what services and support are available locally for individuals and their carers to inform preferences as well as access to advocacy, potentially provided by local voluntary sector providers. One of the requirements on the health system would be the use of clear, consistent documentation of preferences.

As part of the contract for end of life care the ELSP would be required to take on the responsibility for initiating and recording preferences for all patients on the end of life register. In practice this responsibility would rest with senior health professionals, named and charged with the task. These people should be in primary care (part of the GP practice) or associated with designated end of life providers. It would be important to specify the appropriate competences for such a role and establish a process for ensuring compliance with this personal competence profile.

We accept that the best way of ensuring that this information (and the care plan described below) could be shared across the multi-professional and cross-organisational teams involved in providing end of life care might, for now, be through a hand held record. However, depending on the location and the pace of electronic development we imagine that information on preferences should, very shortly, be held as part of the electronic health record and accessible to patient in user form, electronic form or on healthspace²⁸.

Individuals could change their record of preferences by working with a competent health professional meeting the competence requirements for discussing and adapting preferences - these competences would ensure the discussion was informed by clear clinical knowledge as well as personal choices.

Ensuring a systematic and tailored care plan

We believe that the development of an appropriate care plan for the individual must be informed by effective models for the management of chronic disease, and for this reason should, in many occasions, be undertaken in primary care (part of the GP practice) or associated with the designated ELSP. It will become the responsibility of those who hold the contract for end of life care in any one area, to ensure that this care plan is in place.

The managers responsible for the end of life contract would need to have absolute responsibility and accountability for ensuring the development of a care plan for all

²⁸ Proposal for core health records to be stored in national "health space". See Chantler, Clarke and Granger. Information Technology in the English National Health Service. JAMA, November 8, 2006 - Vol 296, No. 18 2255-2258.

end of life registered patients, as well as taking on the responsibility for co-ordinating services as a result, including bereavement and support for family and carers.

We envisage that managers representing the ELSP will be able to access and use resources at their place of work calling upon a range of services that might be co-located, housed and integrated by the ELSP. They would also be able to use service agreements with other providers to provide care. They would link in with services provided by social services, primary care and the voluntary and community sector, as well as potentially being able to provide resources for individuals to use themselves.

Part of the ELSP managers' responsibility may be to ensure that there are sufficient resources to enable providers in their network to deliver integrated care. They may have the use of a small enabling resource to do things like providing financial incentives to reward Care Homes in their management of end of life patients who wish to die in their care home.

The clinical working group believes that high quality end of life care requires:

- Clear ownership of responsibility for maintaining Care at the End of Life Registers, developing care plans, and ensuring appropriate care is provided.
- The integration of primary care, acute trust provision, ambulance services, hospice care, social care, and other voluntary and community sector provision.
- The identification of responsibility and accountability with the contract holder for the delivery of a highly specified contract.
- The provider of services to also ensure a single point of contact for patient/carers/health professionals – e.g. via 0800 number

Many of these aspects of care are already being implemented in some parts of the country as part of the Marie Curie Delivering Choice programme²⁹. This programme is aimed at improving services which allow all palliative and end of life patients – regardless of diagnosis – to be cared for and to die in the place of their choice. The programme aims to achieve this through working in partnership with local organisations to improve the planning coordination and uptake of existing local services.

²⁹ See www.deliveringchoiceprogramme.org.uk/

Proposal Three: A system of triple assurance for a co-ordinated and integrated approach

At the heart of our approach is the need to establish mechanisms for ensuring a systematic approach is taken to ensuring that all patients approaching end of life are identified, that they receive appropriate assessment and care planning, that their preferences are recorded and that integrated services are delivered.

We propose that there should be a system of assurance to ensure that this all important co-ordination and integration occurs.

First, it is crucial that those holding the ELSP contract are able to appropriately assess named clinical professionals against the competences necessary to undertake registration, the eliciting and recording of preferences and the necessary care planning activities. The responsibilities subsequently placed upon these professionals needs to be clear, both to them and to each patient who must know the named profession undertaking this role in relation to their care.

Second, within the ELSP there must be a named lead for the managed *network* delivering end of the life care services. This person must be held to account by the commissioner for the services delivered. A process of regular audit and review must be in place to ensure that there is evidence of the systematic and comprehensive adoption of the register and respect for preferences, as well as the delivery of a recorded multi-disciplinary care plan.

And finally, within the commissioning function we propose a new Guardian role in relation to the end of life contract. This Guardian has the formal task of ensuring and assuring that service providers are effective in identifying people for an end of life register, are able to ensure that they are aware of the entitlements that follow, that they receive an appropriate tailored assessment and have a care plan that amongst other things records their preferences for end of life care. Indeed, across one sector PCTs may need a number of Guardians to ensure a strong and effective audit and assurance system.

Proposal Four – putting in place a strong underpinning and supportive framework

First, let us say that it is crucial to work with the Voluntary and Community sector and the enormous numbers of carers across the capital if we are to engage in a real collaborative effort to improve the quality of end of life care. The NHS needs to understand and appreciate the fundamental role of both if it is to succeed in delivering its aspirations.

The SHA must enter into dialogue with the Voluntary and Community sector and bring funding and commitment to the table, if they are to ensure a partnership that does all that it can to improve the quality of care not only in this area but across the range of out of hospital services. We hope that all the work being done to think about health care in London helps to bring this about.

We believe that the geographical base for the ELSP could sit alongside a range of end of life and chronic disease management services. We believe that bringing these services together opens the way for a more integrated location where staff can train and learn together about how best to meet the needs of their users. We envisage such a centre as also being important for those voluntary and community organisations providing services or providing key connections to support networks and wider community resources. This vision might be aligned with local community hospitals, polyclinics or out of hospital care centres.

In order to provide high quality care, a number of additional areas need to be considered:

- First, all staff need to be trained in communication skills. Many healthcare professionals remain nervous of discussing death and dying with patients and their relatives. One of the biggest barriers to implementing an integrated care pathway in nursing homes is education and training of the staff³⁰
- Second, all staff working in end of life care need appropriate training. It is particularly important that patients and their carers feel safe in their care, wherever it takes place
- Thirdly, care at end of life needs to be co-ordinated with other aspects of healthcare services, in particular for those with long term conditions
- Fourth, these services need to apply to all end of life patients, irrespective of place of care, place of dying, cause of death (including dementia³¹), co-morbidities or socio-demographic factors.

³⁰ Watson et al, *International Journal of Palliative Nursing*, 2006;12(5):234-240.

³¹ Recommendations from the Alzheimer's Society to Professor Mike Richards, August 2006.

