End of Life Papers

Promoting high quality care for all at the end of life: review of NHS National End of Life Care Programme 2004–2007 and implications for primary care

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Key messages

- End of life care has traditionally had a low profile in England. As a result many people do not die where they wish to.
- The creation of the End of Life Care programme and the launch of the National Strategy for End of Life Care has started to change that.
- Pockets of good practice show that excellence can be achieved. But it is now vital that the best is spread to the rest.
- Most end of life care is likely to take place in primary care. So success depends on what happens in the community.

Why this matters to us

End of life care is an experience we will all undergo in one form or another. So we must get it right. This article aims to demonstrate how the National End of Life Care Programme has helped to raise the profile of end of life care services. But it also shows that much more needs to be done. In particular, it seeks to alert primary care staff to the centrality of their role in establishing high quality, well-coordinated services.

ABSTRACT

Background Research shows most people want to die at home yet most in fact die in hospital. The underlying reason for this mismatch is that health and social care services struggle to respond satisfactorily to people's varying end of life care needs. The creation of the National End of Life Care Programme in 2004¹ and the launch of the End of Life Care Strategy in 2008² were designed to improve this situation.

Setting The National End of Life Care Programme was set up to offer patients nearing the end of their life high quality care and choices about where to die. Particular objectives were reducing the number of unnecessary emergency admissions and improving the skills of the workforce.

Question How effective has the National End of Life Care Programme been in its first three years? And given that an increasing proportion of end of life care services will take place in the community, what are the implications for primary care staff?

Methods The authors discuss an in-depth evaluation of the National End of Life Care Programme by Nottingham University.³ They also describe two Department of Health reports indicating how primary care services can improve the quality of end of life care services.^{4,5}

Results The Nottingham University evaluation shows that the National End of Life Care Programme is having an impact. SHAs with high uptake of end of life care tools tend to have higher rates of home

deaths. In addition staff who use the tools are more confident in broaching sensitive issues around dying. Meanwhile the DH reports provide a template for coordination of services and training of staff in the community.

Conclusion There are examples around the country of excellent end of life care. But it is essential that the best is spread to the rest. That success depends on

better organisation and collaboration, effective use of resources and good communication between commissioners and providers. Above all, care has to be focused on the individuals and their carers.

Keywords: end of life care, end of life care tools, national strategy, primary care, quality

Introduction

The pattern of dying in the UK has changed dramatically over the last century. In 1900 85% of the population died at home and 15% in institutions. By the start of the 21st century those figures had almost been reversed with 58% dying in hospitals, 21% in care homes and hospices and only 18% at home. If current trends continue it is predicted that fewer than one in ten will die at home by 2030.²

Those figures themselves hide wide variations depending on age, geography and condition. Home deaths are significantly higher among younger people and in some areas of the country. And while many people with cancer now die at home or in a hospice the vast majority of those with heart disease or pulmonary disease end their days in an acute hospital.

Yet what is clear is that most people wish to be cared for and to die in their own home. Research indicates that a majority of people – ranging from 56% to 74% depending on the survey – express a preference to die at home.

There are many reasons why this does not happen, including the taboos around discussing death and the fact that people may change their minds as death becomes more imminent. But the underlying reason is that our health and social care services still struggle to respond satisfactorily to people's varying needs in the months and days leading up to death.

High quality end of life care is a demanding and increasingly complex business. Around 500 000 people die each year in England of whom two thirds are over 75 and most following a period of chronic illness. And the proportion of elderly people in the population continues to grow. By 2032 it is projected that deaths in the UK will outnumber births.

All this requires close and effective coordination between a range of different organisations, possibly spanning both statutory and voluntary sectors, to provide effective care and support in the last days. Sadly, that is not always apparent.

It is also the case that until recently end of life care has had a relatively low profile within health and social care, tending to be seen as the province of the voluntary sector, especially the hospice and palliative care movements.

That is beginning to change. The *NHS Cancer Plan* in 2000⁶ unveiled plans to help patients with advanced cancer to be cared for at home for as long as possible and to die there if they wished. The *Building on the Best*⁷ strategy paper in 2003 set out to extend this choice to all those approaching the end of their life, not just those with cancer.

This was backed by a £12m funding initiative and led to the creation of the National End of Life Care Programme¹ in 2004 with the specific objectives of improving the quality of care for all and enabling more patients to die at home if they chose to do so.

National End of Life Care Programme, 2004–2007

The National End of Life Care Programme has encouraged a holistic and systematic approach to end of life care, involving pathways of care from identification all the way through to bereavement after the death (see Figure 1). This is especially important in an area of care where so many different services may be needed and the absence of the right service at the right time can mean people end up in hospital when they don't wish to.

Its principal objective during phase one of the programme 2004–2007 was to offer adult patients nearing the end of their life, and regardless of their diagnosis, access to high quality care and a choice about where they die. Specific aims included:

- a decrease in the number of unnecessary emergency admissions
- a decrease in the number of patients transferred from care homes to hospitals in the last weeks of life
- a workforce skilled in dealing with end of life care issues.

Between 2004 and 2007 the programme worked alongside a number of different organisations, including social and health care services as well as the voluntary and private sectors, to start making people's choices about their end of life care a reality. It also offered training in the principles of palliative care for general

NHS End of Life Care Programme. www.endoflifecareforadults.nhs.uk

Figure 1 The End of Life Care Pathway¹

staff across primary, acute and community settings and sought to disseminate examples of good practice.

In addition it helped to expand the use of end of life care planning tools, or models of care, to ensure high quality care across all settings. The three key tools, which were highlighted by NICE's *Guidance on Supportive and Palliative Care (2004)*,⁸ are: the Gold Standards Framework⁹, Liverpool Care Pathway¹⁰ and Preferred Priorities for Care¹¹ (previously Preferred Place of Care). Other similar tools have been developed locally.

The **Gold Standards Framework (GSF)**⁹ was designed in 2001 specifically to help improve care for patients nearing the end of their lives living in the community. It aims to optimise the organisation, communication and proactive planning for people in the last years of life. The GSF is now used by around two thirds of GP practices as well as in care homes and other settings.

The **Liverpool Care Pathway for the Dying Patient (LCP)**¹⁰ was developed to take the best of hospice care into care for people in hospital and other settings. It is used mainly to care for patients in the last days or hours of life once it is recognised someone is dying. The LCP involves promoting good communication with the patient and family, anticipatory planning including psychosocial and spiritual needs, symptom control, comfort care and care after death.

The **Preferred Priorities for Care (PPC)**¹¹ is a patient-held document that seeks to give patients greater choice and control over end of life issues. It

has space for patients' thoughts about their care and the choices they would like to make, including indicating where they wish to die. Information about the family can also be recorded. The document can be updated at any time and follows the patient through their entire care pathway. It provides a tool for documenting an advance care plan.

The last four years have seen a big increase in the use of these tools in all settings. By January 2008, for example, 75% of general practices were implementing one or other of these tools (compared to 23% in 2005). The proportion of community hospitals using them had risen from 9% to 47% in the same time while in care homes it increased from 0.3% to 7.6%. According to last year's National Audit Office report, both doctors and nurses say using these tools has increased their confidence in delivering end of life care (see Figure 2).

Evaluation

There is also growing evidence that using the tools is having a positive effect on outcomes. An in-depth evaluation of the programme carried out by Nottingham University between August 2006 and July 2007 suggests that those SHAs with higher uptake of end of life care tools also had higher rates of home deaths. In addition there was a positive association at PCT level between those practices achieving a high level of QOF

NHS End of Life Care Programme 2004-2007

	One or more tools		
	June 2005	Goal	Jan 2008
GP Practices	23%	60%	75%
Acute Trusts			
- 3+ wards	49%	80%	85%
- All appropriate wards	0%	4%	17%
Community Hospitals	9%	20%	47%
Care homes	0.3%	4%	7.6%
Hospices (LCP)	36%	-	75%

Figure 2 Uptake of end of life care tools, 2004–2007³

points for regular reviews of cancer patients and the proportion of cancer deaths taking place at home.

The evaluation also showed that most participants were enthusiastic about its impact, appreciating particularly the strong central support combined with freedom to innovate at local level. There were widespread accounts of changes in ways of thinking and practice about end of life care and a strong sense this was reducing unnecessary hospitalisation and increasing care at home.

Many said they had been able to develop policies that addressed long-standing and intractable problems such as DNAR policies and most appreciated the ability – through the programme's website – to share and learn about the good practice around the country. There was also greater enthusiasm for, and appreciation of, end of life care issues among generalist staff.

In addition many staff reported that using end of life care tools had increased their confidence to broach sensitive issues about dying. 'The impact on hospitals and the community is incredible,' reported one participant. 'Nurses have the confidence to care well for patients they were previously scared of.'

The evaluation team³ identified the following key factors in success:

- delegating decisions to a local level where possible
- the strength and leadership of the National Programme team
- a synergistic relationship between central direction and complementary local implementation
- a focus on implementing end of life care tools.

At the same time the authors point out that the overall picture remains patchy. Although there are many examples of excellent care, services within a small geographical area can be very variable. The overall proportion of home deaths remains low and it is still the case that cancer home deaths predominate.

A detailed examination of care in one locality over the last four weeks of life showed that people's care preferences were largely respected but also exposed a lack of systematic recording of advance care planning discussions, substantial variation in how they were recorded and some confusion about the process in care homes. More recently the National Audit Office report recommended further evaluation of the tools in relation to patient benefit.¹²

Department of Health End of Life Care Strategy

The DH National End of Life Care Strategy for England, published last year, does not duck these issues. 'Some people experience excellent care...but the reality is that many do not,' it says:

'Many people experience unnecessary pain and other symptoms. There are distressing reports of people not being treated with dignity and respect and many people do not die where they would choose to.'

The last few years have seen real progress in improved end of life care services.

'The challenge now is to extend this quality of care from the minority of patients (mainly those with cancer) who currently come into contact with hospices and specialist palliative services to all people who are approaching the end of life.'

The 10-year strategy stresses the importance of community services, for example through access to 24/7 community nursing services, and improving co-ordination between local authorities and PCTs. It will also be critical to develop specialist palliative care outreach services by encouraging PCTs and hospices to work together to provide appropriate support to everyone regardless of condition.

The strategy highlights the importance of listening to the needs and wishes of patients and carers and developing services that will meet those wishes. It is also vital to equip health and social care staff at all levels with the necessary skills to communicate with, and deliver care to, people approaching the end of their lives as well as their carers and family.

The National End of Life Care Programme has now further developed to support the implementation of all elements of the national strategy, in particular sharing and disseminating good practice.

Practical implications for primary care

So what does all this mean for primary care practitioners? As the strategy makes clear, an increasing proportion of end of life care services will need to be delivered in the community if patients' wishes to end their days at, or close to, home are to be respected.

Helpfully, two new reports demonstrate how community services can start to make this a reality. *Transforming Community Services: Ambition, Action, Achievement*⁴ is a practical guide for staff on improving end of life care produced as part of the Department of Health's Transforming Community Services (TCS) Programme (see Box 1).

The guide lists a number of high impact changes that experts agree have the greatest potential to improve care and improve quality. They include:

- identifying patients approaching the end of life at an early stage
- providing all patients with a care plan and a key worker or case manager
- ensuring care is available 24 hours a day
- using a systematic framework for delivering care such as the LCP or GSF to identify, assess and plan care

- where appropriate documenting patients' advance wishes and preferences for care.

At practice level this should involve setting up a local register with information on all those needing palliative care, individual and coordinated care for each individual, close involvement of families and carers and ensuring all those approaching the end of life have ready access to the medication and equipment they need.

The guide goes on to suggest that providers and practitioners should consider doing a 'stock take' of how well they measure against basic requirements and the high impact changes and then agreeing an action plan to take things forward.

It also encourages commissioners and providers to move away from 'valuing what we measure' to 'measuring what we value'. Some quality indicators for community services could include:

- the proportion of people who have an identified care plan and care manager
- the proportion who are on an end of care pathway
- the percentage of people dying in their preferred place of care.

Closely linked to this initiative are the Department of Health's quality markers (QMs)⁵ for care in the last stages of life. The markers cover ten groups ranging from commissioners to primary and acute providers, ambulance and out of hours services.

In future all providers will, among other things, be expected to identify those who are approaching the end of their life, offer a care plan, appoint a key worker, support carers and their families and meet staff training needs.

Within general practices it is suggested that multi-disciplinary teams should hold meetings, preferably at monthly but at a minimum quarterly intervals, to discuss the needs of those approaching the end of their

Box 1 Summary of high impact changes⁴

Familiarise yourself with the Quality End of Life Care markers (DH), SHA and PCT strategic end of life care plans in accordance with the national end of life care strategy and Next Stage Review.

Use an established systematic framework such as the Gold Standards Framework or Liverpool Care Pathway in order to optimise care delivery.

Ensure that all patients who are approaching the end of life are identified early and sensitive conversations are had about death and dying, choice and personalisation with patients, carers and families.

Provide all patients with a key worker/case manager and care plan and, where appropriate, document advance wishes and preferences for care. Make sure that all practitioners (including other relevant organisations) are aware of these preferences, subject to the consent of the patient.

Ensure that care for those approaching the end of life is accessible, responsive and available twenty-four hours a day.

Transforming Community Services: Ambition, Action, Achievement! Guide for Transforming Services for end of life care (2009) www.dh.gov.uk/tcs

lives as well as ensuring the timely transfer of information on all individuals to out of hours and ambulance services.

Meanwhile out of hours teams medical practitioners must be competent in providing general palliative care and should ensure they have up to date information about all individuals approaching the end of life, including the individual's preferred place of care and any advance care plans. They also need to know about the person's medication as well as having ready access to emergency drugs and equipment.

The overarching principle for all high quality care, says the QM document, is that services should be coordinated around the patient and their carers. And the key to delivering this patient-centred service is effective, speedy communication across all sectors.

Of course none of this will be possible without a well trained workforce that has the ability to handle the many delicate issues surrounding end of life care. It is particularly important that these skills extend to generalist staff whose central focus is not end of life care but who will nevertheless encounter people in the last days of life at some stage of their work.

In July Skills for Care and Skills for Health, working in partnership with the Department of Health and the NHS End of Life Care Programme, produced a common set of principles and competences for all generalist staff.¹³ The document suggests particular attention should be paid to those who find themselves initiating conversations about approaching the end of life.

As the TCS guide puts it: 'Many good initiatives flounder because insufficient attention is paid to the staff themselves and the actions needed to create the climate in which the desired attributes can ensure success.'

Conclusion

How we care for dying people is a litmus test for how services care for all sick and vulnerable people, says the National End of Life Care Strategy. And there is no doubt end of life care services will stand or fall on what happens in the community – whether in health, social care or the voluntary sector.

Success depends on better organisation and collaboration than has been evident in the past, effective use of resources and good communication between all providers and commissioners. Most importantly, care has to be focussed on the needs of individuals and their carers.

The pockets of excellent practice that already exist show it can be done. It is vital that the best is now spread to the rest. This is one experience we will all

undergo in one form or another. We must get it right – for ourselves and for everyone else.

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