



## Palliative care beyond cancer

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## SPOTLIGHT SUPPORTERS



The British Heart Foundation (BHF) has a long term commitment to improve the quality of care available for all patients with cardiac problems. Since 2002, our investment in the management of heart failure has focused largely on funding heart failure specialist nurses. Visiting patients in the clinic and at home, the nurses—who today number 269—provide a continuity of care that was previously lacking.

But in 2004, an evaluation of this service highlighted that patients with heart failure did not have access to palliative care services, and that some specialist nurses found it difficult to broach and discuss end of life issues and options.

In response, the BHF joined forces with Marie Curie Cancer Care (MCCC). We've been working together since to understand the issues facing patients at the end of life, and to pilot innovative models of care to address these needs. In our Better Together project, BHF and MCCC nurses together visited heart failure patients in their homes. Patients received valuable advice and medical support along with vital physical and psychological care. The evaluation reported that 79% of patients who took part in the pilot died in their place of choice.

Today, there are eight BHF palliative care specialist nurses in the UK. And with MCCC and NHS, we are

developing integrated models of palliative care in the Greater Glasgow and Clyde Health Board area, with the intention of providing lessons for the wider NHS.

The articles in this Spotlight address some of the key issues raised by the BHF and MCCC projects. The natural history of heart failure is not the same as that of cancer, so the cancer care model is inappropriate. The prognosis for heart failure classified as New York Heart Association III and IV is poor, although in recent years it has been improved by better drug treatments and the use of implantable devices (such as resynchronisation therapy). There is no clear transition into the end of life phase of heart failure. However, our experience suggests that specialist and district nurses, who have developed a working relationship with patients, can identify those nearing the final months of their life.

Conversations about a patient's choices at the end of life remain an area of anxiety for healthcare professionals, and tackling the spiritual aspects of care is a pressing issue.

The BHF welcomes this first edition of Spotlight on Palliative Care Beyond Cancer. We hope that it will catalyse this vital debate among doctors and enable them to respond to the recent General Medical Council guidance on end of life care, for the benefit of their patients. The Department of Health's end of life care strategy must provide better services for all people at the end of life, including those with heart failure.



The National Council for Palliative Care (NCPC) is the umbrella charity for all those involved in providing, commissioning, and using palliative and end of life care services in England, Wales, and

Northern Ireland. Since 2004 we have been a leader in the development of palliative care for people with a range of conditions, and we are delighted by the growing recognition of the need for this work. The End of Life Care Strategy for England (2008) was a very welcome acknowledgement of the part palliative and end of life care can play regardless of diagnosis. Through the strategy, NCPC has also been charged with leading the Dying Matters coalition, raising public awareness of death, dying, and bereavement.

Working in partnership is central to good palliative and end of life care. It is also fundamental to NCPC's priority in developing practical guidance for all who need it. We work with people who have personal experience of living with a terminal condition or of caring for somebody approaching the end of life, as well as with clinicians from a range of specialties, social care staff, housing staff, academics, and policy makers. Together we produce a wide range of resources to support the development of palliative care for people with chronic respiratory disease, heart failure, multiple sclerosis, and motor neurone disease, as well as for frail older people with multiple conditions, including

dementia. NCPC undertakes the only data collection and analysis of specialist palliative care activity for England, Wales, and Northern Ireland. Recent trends from these data show a slow but steady increase in access to specialist palliative care by people with primary conditions other than cancer. This is progress, but more still needs to be done.

Extending palliative care beyond cancer means reaching people in a wider range of settings. We work closely with national care home organisations to ensure residents receive high quality care until they die, and our Care to Learn training pack provides an introductory guide for staff working with people approaching the end of life. A particularly exciting area for us has been our dementia project. We have worked extensively to scope the provision of palliative and end of life care for people with dementia and to identify and disseminate solutions and best practice. Through national events and guidance we have helped ensure that the palliative care needs of people with dementia are increasingly recognised.

The Dying Matters coalition, led by NCPC, is a powerful force in continuing to drive improvements to palliative care for all who need it. With over 10 000 members from across the NHS and the voluntary and independent health and care sectors the coalition is raising awareness on dying, death, and bereavement. By encouraging and supporting people to discuss and plan for the end of their lives earlier in life we can equip them to help shape services to suit their needs, regardless of their diagnosis.



## We're all going to die. Deal with it

Eventually, everyone dies—many more of us after gradual physical and mental decline than cancer

In the years since Cicely Saunders opened St Christopher's Hospice in 1967, palliative care has blossomed into one of the glories of British medicine. Although much has been learnt about caring for cancer patients at the end of their lives, these lessons have been inadequately appreciated by doctors treating patients dying from causes other than cancer. The series of specially commissioned reviews in this inaugural *BMJ* Spotlight is intended to help remedy that.

Eventually, everyone dies—many more of us after gradual physical and mental decline than cancer. Early recognition of those patients with advancing illness who would benefit from supportive and palliative care is the key to good management.<sup>1</sup> A positive answer to the question: "Would I be surprised if this patient died within the next year?" is one trigger indicating that such care should begin.

After that decision come the difficult conversations. Not everyone will want to talk about the end of their life, but "the right conversations with the right people at the right time can enable a patient and their loved ones to make the best use of the time that is left and prepare for what lies ahead."<sup>2</sup>

The obstacles to plain speaking, and clear thinking, about death are legion. We live in a culture in which people are uncomfortable with their own mortality.<sup>3</sup> This needs to change, as the *Dying Matters* coalition argues, "so that dying, death and bereavement will be accepted as a natural part of everybody's life cycle." Doctors seem to find that message harder to accept than others, with some of them regarding any death as a failure. In a doomed attempt to stave off the inevitable, typically more money is spent on health care during a patient's last year of life than in any other year.

But it must be an encouraging sign that "palliative care beyond cancer" topped a recent *BMJ* poll of topics respondents wanted to read more about. Similarly encouraging are initiatives of organisations such as the British Heart Foundation to start thinking about palliative as well as curative care.

Earlier this year, the UK's General Medical Council published *Treatment and Care Towards*

*the End of Life*, recommending that death should become an explicit discussion point when patients are likely to die within 12 months.<sup>4 5</sup> Its guidance is in keeping with a raft of end of life reports and UK national strategies. For the time being at least, all parties seem to be on the same page.

Frank discussion of the topic throws up many challenges. We have room for only two of them here—the related issues of where patients want to die and who should provide their palliative care,<sup>6</sup> and a recognition of the spiritual needs of patients facing death.<sup>7</sup> But more is coming. The *BMJ* Group will launch *BMJ Supportive and Palliative Care* next April with Bill Noble as editor. This peer reviewed journal will publish original research as well as education, debate, commentary, and news with the aim of improving supportive and palliative care for patients with many kinds of illness.

We all have much work to do.

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- 2 Barclay S, Maher J. Having the difficult conversations about the end of life. *BMJ* 2010;341:c4862.
- 3 Seymour JE, French J, Richardson E. Dying matters: let's talk about it. *BMJ* 2010;341:c4860.
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- 6 Ellershaw J, Dewar S, Murphy D. Achieving a good death for all. *BMJ* 2010;341:c4861.
- 7 Grant L, Murray SA, Sheikh A. Spiritual dimensions of dying in pluralist societies. *BMJ* 2010;341:c4859.

Tony Delamothe deputy editor *BMJ*, London  
tdelamothe@bmj.com

Mike Knapton associate medical director  
British Heart Foundation, London

Eve Richardson chief executive, National Council for  
Palliative Care and Dying Matters coalition, London  
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► Mike Knapton talks about the shift towards palliative care for non-cancer conditions in a *BMJ* podcast coinciding with this Spotlight. Find out more at [bmj.com/podcasts](http://bmj.com/podcasts)

# Dying matters: let's talk about it

Jane E Seymour,<sup>1</sup> Jeff French,<sup>2</sup> Eve Richardson<sup>3</sup>

As death has become less common in our daily lives, it has become harder to consider our own mortality or that of those close to us. Lack of openness about death has negative consequences for the quality of care provided to the dying and bereaved. Eradicating ignorance about what can be achieved with modern palliative care and encouraging dialogue about end of life care issues are important means of changing attitudes

Awareness of our own mortality is a human characteristic. Arguably, life would have little meaning without our knowledge and experience of inevitable loss, death, and bereavement. But while in some ways our society is obsessed with death—with reports of violent, sudden, and unexpected death paraded across our media every day—it is still very difficult to talk about this one shared certainty in terms that relate to our own deaths or those of people close to us. Across the past century there has been a movement away from using the “sacred canopy” of religion<sup>1</sup> to make sense of death and to embrace its presence in life. Instead, the defence of health, youth, and vigour against the enemy of death has become a “lifelong labour”<sup>2</sup> for many. On the rare occasions when death and dying are discussed, the language used is most often rooted in the discourse of individualism and control of personal destiny. This perspective does not fit well with the needs and daily experiences of people approaching the end of life, such as those in advanced old age, who may find they wish or need to entrust their care to others. Nor does it reflect the finely balanced dilemmas patients, families, and clinicians face in dealing with the physical, ethical, emotional, and existential problems of serious illness. The increasingly rare designation of any illness as terminal complicates matters and perhaps explains why complaints about lack of preparation and communication surrounding death are common among the bereaved.<sup>3</sup>

## Consequences of not talking about and planning for death

Strategic plans for end of life care in England<sup>4</sup> and Scotland<sup>5</sup> argue that a lack of public openness about death may have negative consequences for quality of care at the end of life, including fear of the process of dying, lack of knowledge about how to request and access services, lack of openness between close family members, and isolation of the bereaved. A new national coalition<sup>6</sup> with the same name as this article aims to raise public awareness and change behaviour associated with death, dying, and bereavement as one means of addressing these consequences. The work of the coalition is based in part on a comprehensive review of published research evidence,<sup>7</sup> together with new market research about the concerns, needs, and beliefs of the general public about these issues and ways to raise public awareness.

## Evidence about public attitudes

The review shows a preponderance of research about views on euthanasia and physician assisted suicide, often funded by “right to die” movements, but also featuring in large scale public opinion polls.<sup>8,9</sup> These findings suggest public support for euthanasia has hovered between 60% and 80% since the mid 1970s on both sides of the Atlantic, with similar levels of support emerging for physician assisted suicide. A report of the 2005 British Social Attitude Survey<sup>10</sup> shows that people make clear distinctions between the acceptability of assisted dying in different circumstances; 80% of respondents agreed that the law should allow voluntary euthanasia to be carried out by a doctor for someone with a painful, incurable, and terminal condition, but less than 50% agreed for cases where the illness is painful, but not terminal. Very few respondents supported family assisted suicide.<sup>9</sup> In the United States, differences in response rates of more than 30% have been reported<sup>11</sup> dependent on how questions are framed. Such nuances are not visible in surveys that present respondents with limited options for responses (such as yes or no) to short hypothetical scenarios.

The simple and high visibility messages of support for assisted dying could obscure the very considerable, but perhaps less sexy, findings about attitudes to other issues. Results of cross sectional surveys indicate that dying at “home” is a strong preference (whether this is the person’s home, a retirement complex, or care home), although hedged by worries about burden on care givers<sup>12</sup> and by fears of dying alone.<sup>13</sup> At the same time, most people are worried about how they would cope practically with caring for a close relative who was dying at home.<sup>14</sup> A majority of people seem to welcome clinicians who are willing to start discussions in advance about place of care or medical treatment at the end of life.<sup>15</sup> Interesting and persistent differences according to sociodemographic characteristics are found in survey data from many different countries. For example, some studies show that older people are less likely than younger ones to favour death at home, while women are more likely than men to prioritise quality over length of life.<sup>15</sup> Other findings suggest that ethnic minority groups in Western countries tend to be less supportive of withdrawing or withholding life prolonging medical treatment at the end of life.<sup>16</sup> These findings point to the effect of structural inequalities on experiences that shape attitudes.

Perhaps unsurprisingly, fairly uniform opinions are found about the elements comprising quality of care at the end of life, with relief from pain and other symptoms at the forefront, reflecting widespread concerns about the process of dying.<sup>17</sup> A 2006 survey of the UK public suggested that a minority of people (34%) have talked to their friends or families about these issues or made any type of advance statement to inform their own end of life care.<sup>18</sup> A survey of a representative sample of the general public in England,

<sup>1</sup>Sue Ryder Care professor of palliative and end of life studies, School of Nursing, Midwifery, and Physiotherapy, University of Nottingham, Nottingham NG7 2HA

<sup>2</sup>professor of social marketing and chief executive, Strategic Social Marketing, Liphook, Guildford GU30 7QW

<sup>3</sup>chief executive, National Council for Palliative Care, London N7 9AS

Correspondence to: Jane Seymour  
jane.seymour@nottingham.ac.uk

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Ron Mueck "Dead Dad," 1996-97. Mixed media; 20 x 38 x 102 cm, Stefan T Edlis Collection, Chicago

## When death is managed badly it leaves a scar that runs deep

Wales, and Scotland<sup>19</sup> commissioned by the National Coalition, repeated some aspects of the 2006 survey and had very similar findings. Although they were not talking about end of life care issues themselves, a substantial majority of respondents (88%) would favour the open disclosure by a clinician of a terminal prognosis. The most prevalent reason given by all respondents for not discussing issues, including a fifth of people aged over 75, was that "death seems a long way off."

Qualitative research provides at least partial explanations of the trends seen in the quantitative research. For example, an interview study<sup>20</sup> among older adults in the UK reports how older men and women tend to conform to gender stereotypes when discussing the issue of caregiver burden in end of life care. Older women are more likely to be concerned about burdening others during a final illness, while men express more self oriented views, including the desire to live longer. Qualitative research shows that attitudes about death develop against a backdrop of varied cultural and historical influences, are deeply affected by biographical and experiential influences, and are likely to change with time and across age groups.<sup>21</sup>

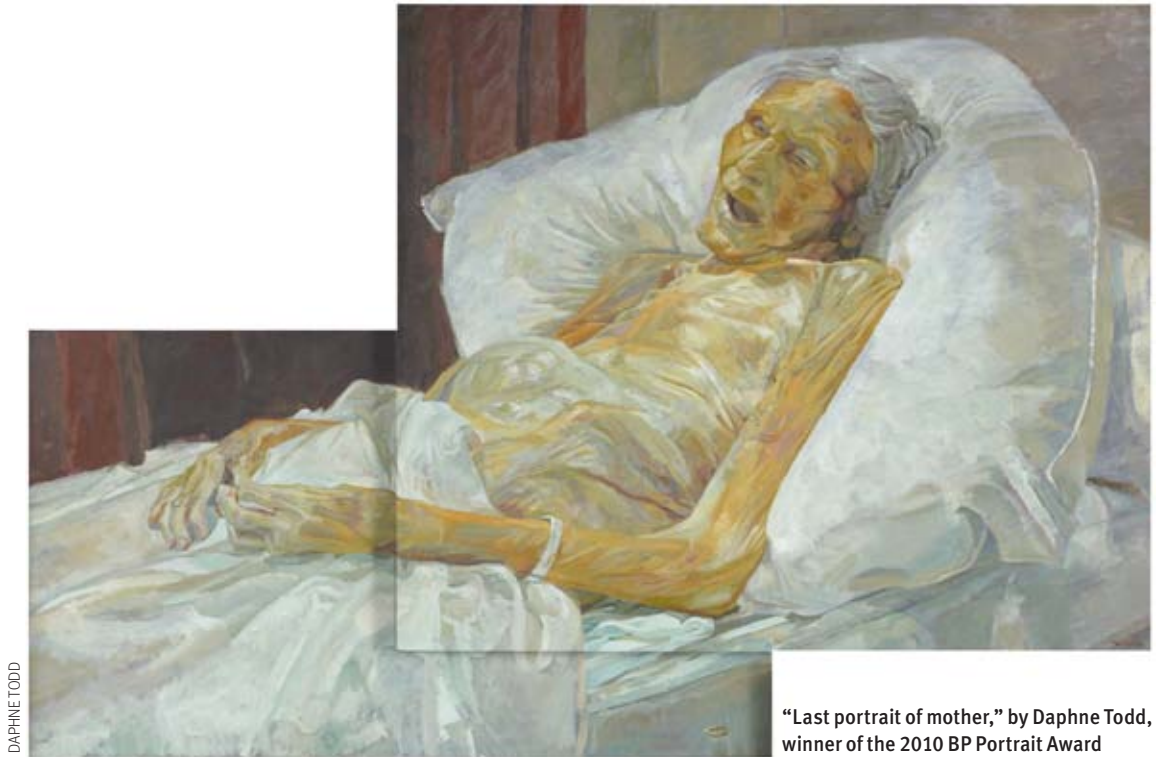
### Ways of raising awareness and public involvement

Evidence from social marketing shows that "bottom up" approaches focusing on value to the user may provide a framework for designing programmes to raise public awareness of issues related to death and change behaviours.<sup>22</sup> Another approach is to mobilise community involvement

in end of life care projects as a matter of public health.<sup>23</sup> In the United States, the Project on Death in America, a large scale programme to change the culture and character of dying, was funded by George Soros and located in the Open Society Institute between 1994 and 2003.<sup>24</sup> It supported not only a conventional research and practice development programme but also arts projects to identify and convey meaning in facing illness, disability, and death, and community initiatives about bereavement and grief. Many of these involved thousands of people and have reportedly had a substantial lasting value although the effect is difficult to measure. From the outset of the project, raising public awareness was regarded as just as vital as the policy and practice developments needed to address seemingly intractable problems in the care of the dying in the United States.

### Challenges for the future

For many of the 56 million people who die each year worldwide, death is associated with substantial but preventable suffering. When death is managed badly it leaves a scar that runs deep in our collective psyche and reinforces the tendency to turn away from any reminder of death. Shifting attitudinal barriers to the provision of excellent end of life care means eradicating ignorance among clinicians, patients, and the public about what can be achieved with modern palliative care and with careful proactive planning. Raising public knowledge of issues surrounding death, dying, and bereavement risks raising expectations we cannot yet meet or sending an unrealistic message that



DAPHNE TODD

“Last portrait of mother,” by Daphne Todd, winner of the 2010 BP Portrait Award

death can always be managed well. But such activity is a vital part of generating a sense of wider responsibility for the dying and promoting social justice for all those living towards the end of their life.

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# Recognising and managing key transitions in end of life care

Kirsty Boyd,<sup>1</sup> Scott A Murray<sup>2</sup>

Prognostic paralysis may delay a change in gear for too long. Being alert to the possibility that a patient might benefit from supportive and palliative care is central to delivering better end of life care

Palliative care is being introduced earlier in the trajectory of illness, often in parallel with disease modifying treatment. A care pathway that starts with the identification of people approaching the end of life and initiating discussions about their preferences is central to the end of life care strategy in England.<sup>1</sup> The Scottish government action plan also advocates a person centred approach based not on diagnosis or prognosis, but on the needs of patients and carers in all care settings—home, care home, and hospital.<sup>2</sup> These needs include information about the illness and prognosis, symptom control, attention to psychological and spiritual concerns, continuity of care, and practical support. In view of the increasing numbers of people who could benefit, the emphasis of the UK strategies is on improving end of life care delivered by primary care teams, hospital staff, and social care services. Specialist palliative care should be available to people in any care setting who need additional expertise, and it serves most effectively as a resource to support ongoing care by other clinical teams.<sup>3</sup>

In economically developed countries, most people now die from one or more complex long term conditions.<sup>4</sup> End of life care encompasses three overlapping phases of illness (figure). In this article we offer guidance about recognising end of life transitions. We also consider the challenge of changing the goals of care in patients with slowly progressive or fluctuating long term conditions.

## Transition 1: would my patient benefit from supportive and palliative care?

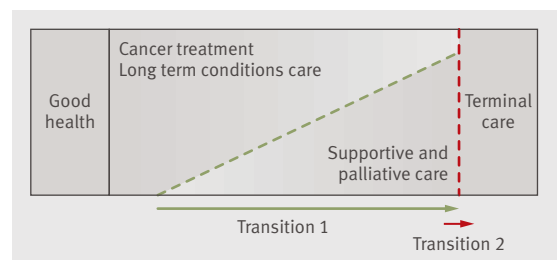
Managing the transition to supportive and palliative care is arguably more of a challenge than identifying people who are in the last days of life.<sup>5</sup> Doing so earlier can affect how, and potentially where, people die, but what constitutes “end of life care” is not uniformly understood and opinions vary as to who is a “palliative care” patient. Judging prognosis is particularly difficult for non-cancer patients.<sup>6</sup> Identification of people with a life limiting illness when they are starting to need a change in their goals of care contributes to end of life care planning and can aid communication with patients and families. It depends on clinical judgment and weighing up a complex mix of pathology, clinical findings, therapeutic response, comorbidities, psychosocial factors, and rate of decline.<sup>7</sup> UK primary care teams are now expected to decide which

patients should be included in their supportive and palliative care registers and when. We have reviewed two types of prognostic tools as the basis for a pragmatic approach to identifying candidates for palliative care needs assessment in primary and secondary care.

Disease specific prognostic tools use statistical models to predict the risks of individuals dying from conditions such as heart failure, chronic obstructive pulmonary disease, or liver disease. These tools tend to be used in clinical trials or when selecting patients for treatments like transplantation, but less often in end of life care.<sup>8-10</sup> Prognostic models were not found to be specific or sensitive enough when used to estimate survival of six months or less in older people with a range of non-cancerous illnesses.<sup>11</sup> Such survival data have limited meaning for individual patients who are “sick enough to die.” In advanced heart failure, prognostic data suggested that an average patient had a 50% chance of living for six months on the day before their death.<sup>4</sup>

Performance status is strongly associated with survival time in patients with advanced illness, regardless of the diagnosis. This factor therefore forms the basis of the palliative performance scale, which is used in several countries to aid referral to hospice and specialist palliative care services.<sup>12</sup> A similar tool, the palliative prognostic index, adds the symptoms of anorexia, breathlessness, and delirium to functional status.<sup>13</sup> Such tools will identify most (though not all) patients who are likely to die within weeks, but are much less reliable for patients with supportive and palliative care needs who may still have 6-12 months to live.<sup>12,13</sup>

An alternative to prognostic tools is the use of criteria based on the clinical features of different advanced illnesses. The National Hospice and Palliative Care Organisation tool is used to decide eligibility for hospice care in the United States, where many services will only enrol patients with a prognosis of less than six months.<sup>4</sup> These US clinical indicators were updated in 2001. They formed the basis of the prognostic indicator guidance tool that is used in the UK Gold Standards Framework for palliative



Key phases in end of life care

<sup>1</sup> consultant in palliative medicine  
<sup>2</sup> St Columba's Hospice professor of primary palliative care  
Primary Palliative Care Research Group, Centre for Population Health Sciences, University of Edinburgh, Edinburgh

Correspondence to: K Boyd  
Kirsty.Boyd@luht.scot.nhs.uk

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**Box 1 | Supportive and palliative care indicators tool****(1) Ask**

Does this patient have an advanced long term condition, a new diagnosis of a progressive life limiting illness, or both? (Yes)

Would you be surprised if this patient died in the next 6-12 months? (No)

**(2) Look for one or more general clinical indicators**

Performance status poor (limited self care; in bed or chair over 50% of the day) or deteriorating

Progressive weight loss (>10%) over the past 6 months

Two or more unplanned admissions in the past 6 months

Patient is in a nursing care home or continuing care unit, or needs more care at home

**(3) Now look for two or more disease related indicators****HEART DISEASE**

NYHA class IV heart failure, severe valve disease, or extensive coronary artery disease

Breathless or chest pain at rest or on minimal exertion

Persistent symptoms despite optimal tolerated therapy

Renal impairment (eGFR <30 ml/min)

Systolic blood pressure <100 mm Hg and/or pulse rate >100

Cardiac cachexia

Two or more acute episodes needing intravenous treatment in past 6 months

**KIDNEY DISEASE**

Stage 5 chronic kidney disease (eGFR <15 ml/min)

Conservative kidney management due to multi-morbidity

Deteriorating on renal replacement therapy; persistent symptoms and/or increasing dependency

Not starting dialysis following failure of a renal transplant

New life limiting condition or kidney failure as a complication of another condition or treatment

**RESPIRATORY DISEASE**

Severe airways obstruction (FEV<sub>1</sub> <30%) or restrictive deficit (vital capacity <60%, transfer factor <40%)

Meets criteria for long term oxygen therapy (PaO<sub>2</sub> <7.3)

Breathless at rest or on minimal exertion between exacerbations

Persistent severe symptoms despite optimal tolerated therapy

Symptomatic heart failure

Body mass index <21

Increased emergency admissions for infective exacerbations and/or respiratory failure

**LIVER DISEASE**

Advanced cirrhosis with one or more complications: intractable ascites, hepatic encephalopathy, hepatorenal syndrome, bacterial peritonitis, recurrent variceal bleeds

Serum albumin <25 g/l, and prothrombin time raised or INR prolonged

Hepatocellular carcinoma

**CANCER**

Performance status deteriorating due to metastatic cancer and/or comorbidities

Persistent symptoms despite optimal palliative oncology treatment or too frail for oncology treatment

**NEUROLOGICAL DISEASE**

Progressive deterioration in physical and/or cognitive function despite optimal therapy

Symptoms that are complex and difficult to control

Speech problems; increasing difficulty communicating; progressive dysphagia

Recurrent aspiration pneumonia; breathless or respiratory failure

**DEMENTIA**

Unable to dress, walk, or eat without assistance; unable to communicate meaningfully

Increasing eating problems; receiving pureed/soft diet or supplements or tube feeding

Recurrent febrile episodes or infections; aspiration pneumonia

Urinary and faecal incontinence

NYHA=New York Heart Association. eGFR=estimated glomerular filtration rate. FEV<sub>1</sub>=forced expiratory volume in 1 second. PaO<sub>2</sub>=pulmonary artery oxygen content. INR=international normalised ratio.

care in the community.<sup>14</sup> Both tools have good face validity and are widely used, but formal validation studies have been limited.

**Using clinical indicators to identify patients for supportive and palliative care assessment**

Our review of the prognostic models and guidelines leads us to propose a small group of readily identifiable indicators that can be used by professional carers in both primary and secondary care. Instead of seeking to refine prognostic accuracy, we propose that clinical judgment informed by evidence can improve care.

Box 1 describes how to identify patients for a supportive and palliative care assessment. If a patient has an advanced long term condition or a new diagnosis of a progressive, life limiting illness, or both, then ask the question, "Would you be surprised if this patient died in the next 6-12 months?" If the answer is no, look for one or more general clinical indicators that suggest this patient is at risk of dying and should be assessed for unmet needs. Some people who may benefit from supportive and palliative care have slowly progressive or fluctuating long term conditions. Concerns about deciding which of these patients should have additional assessment and structured end of life care planning are common, as are worries about discussing dying "too soon." We suggest that a shortlist of disease related clinical indicators drawn from prognostic models and existing palliative prognostic guides be used to support clinical decision making.

Rapid decline in the last weeks or months of life is often associated with progressive cancer, although other diseases sometimes follow this course and cancer can progress more slowly. Patients receiving palliative treatment for cancer may want to focus on fighting their illness, but supportive care, coordinated in primary care, should run in parallel with treatment. It should come to the fore as the patient starts to deteriorate and treatment, except for symptom control, is stopped.<sup>15</sup> Advanced cancer at presentation or a poor performance status usually means that the patient would benefit from early supportive and palliative care in line with the general indicators in box 1.

A patient whose illness is associated with acute exacerbations followed by partial recovery may have been receiving health and social care for some time with the emphasis on optimal disease management, personalised care planning, and supported self management (see Resources). This situation is typically seen in those with heart failure, coronary artery disease, chronic lung disease, or end stage liver disease. Too much emphasis on prognostic accuracy in these fluctuating illnesses can hinder a positive focus on reasonable, patient centred goals at the end of life.<sup>16</sup> Variables identified in disease specific prognostic models are particularly useful as additional indicators in this group.

A prolonged, slow decline, sometimes punctuated with more acute episodes, is generally associated with multi-morbidity, advanced dementia, and progressive neurological diseases. Such patients comprise the largest group in economically developed countries, and they typically need long periods of supportive and palliative



## The ability to make an accurate and timely diagnosis of dying is a core clinical skill

care.<sup>4,17</sup> The offer of early advance care planning is important because many patients will lose capacity to consent or express preferences about care.<sup>18</sup> Many patients in this group can be identified from general clinical indicators, but additional triggers such as recurrent febrile episodes and eating problems suggest advanced cognitive and functional deterioration indicative of a substantial change in an otherwise gradual decline.<sup>19</sup>

### Transition 2: Is my patient reaching the last days of life?

Appropriate use of clinical pathways such as the UK Liverpool Care Pathway for the Dying (see Resources) can help to optimise care in the last days of life, but a timely diagnosis of dying is essential. Patients on such pathways are reviewed regularly, medication is prescribed in line with good practice guidelines, and the holistic needs of the patient and family are addressed. Entry on to an end of life care pathway depends on clinicians being alert to the possibility that the patient may be dying and is based on clinical judgment after careful assessment.<sup>20</sup>

Diagnosis of dying can be problematic for a range of reasons including a lack of continuity of care in the

community and in hospitals. In the community, anticipatory care planning should ensure that sufficient care and support are in place to enable most patients who are expected to die soon to remain at home or in their care home. However, any potentially reversible causes of deterioration must be excluded in a patient who might still benefit from appropriate treatment. Such treatment should be started on the basis of clear, agreed goals, including a plan for review. Patients in hospital often continue to receive treatment of their underlying illnesses and complications until close to death. The decision to withdraw active treatment at the right time is important but will remain challenging if the outcome is uncertain and if the patient has recovered previously, particularly if earlier discussions about end of life preferences have not been possible.<sup>21</sup>

### Using clinical indicators to identify patients in the last days of life

To improve the transition to terminal care, the care team should ask if a patient's deterioration was expected, find out if the patient or a healthcare proxy wants further interventions, and exclude all potentially reversible causes (box 2).

#### Box 2 | Clinical indicators for terminal care

##### Q1 Could this patient be in the last days of life?

Clinical indicators of dying may include:

- Confined to bed or chair and unable to self care
- Having difficulty taking oral fluids or not tolerating artificial feeding/hydration
- No longer able to take oral medication
- Increasingly drowsy

##### Q2 Was this patient's condition expected to deteriorate in this way?

##### Q3 Is further life-prolonging treatment inappropriate?

Further treatment is likely to be ineffective or too burdensome.

Patient has refused further treatment.

Patient has made a valid advance decision to refuse treatment.

A healthcare proxy has refused further treatment on the patient's behalf.

##### Q4 Have potentially reversible causes of deterioration been excluded?

These may include:

- Infection (eg, urine, chest, cholangitis, peritonitis, neutropenia)
- Dehydration
- Biochemical disorder (calcium, sodium, blood sugar)
- Drug toxicity (eg, opioids, sedatives, alcohol)
- Intracranial event or head injury
- Bleeding or severe anaemia
- Hypoxia or respiratory failure
- Acute renal impairment
- Delirium
- Severe constipation
- Depression

If the diagnosis of dying is in doubt, give treatment and review within 24 hours.

If the answer to all four questions is "Yes", plan care for a dying patient.

### Conclusions

Primary care teams are well placed to use computerised disease registers and multidisciplinary review meetings to identify patients using pragmatic clinical criteria. Many more patients stand to benefit from better identification, assessment, and structured end of life care planning. Such improvements will enable professionals to address morbidity related to progressive disease and offer patients and their families opportunities to talk about living well with advanced illness.

Hospital specialists see many patients in the last year of life, often on multiple occasions, so can make an important contribution to identifying the need for additional supportive care, as well as optimising disease modifying treatments that will contribute to quality of life. Specialists can suggest when these patients may be suitable for supportive and palliative care in the community in discharge and outpatient letters, and primary care teams can ensure that such patients going to hospital are clearly identified.

The ability to make an accurate and timely diagnosis of dying is a core clinical skill based on careful assessment that could be done better in all care settings. Education and training of staff are central to the success of end of life policies in the UK.<sup>1,2</sup>

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**Contributors and sources:** This review was written by KB, a consultant in palliative medicine who has worked in hospital, community and hospice settings, in collaboration with SAM, leader of an international primary palliative care research group. We reviewed key policy documents, prognostic tools, and papers from international experts in care planning drawn from a 10 year Medline search and sought the views of colleagues in primary and secondary care. We are grateful for the opinions and papers contributed by W MacNee, P Reid (respiratory medicine); M Denvir (cardiology); P Cantley (geriatric medicine); M Young (general medicine); A Sheikh, E Paterson (general practice); F Downs, J Welsh (palliative medicine). KB is guarantor.

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## RESOURCES

## PALLIATIVE AND END OF LIFE CARE

NHS Department of Health. *National End of Life Care Programme*. [www.endoflifecareforadults.nhs.uk/eolc](http://www.endoflifecareforadults.nhs.uk/eolc)

Scottish Government Health Department: *Living and Dying Well: A National Action Plan for Palliative and End of Life Care in Scotland*. [www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell](http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell)

Gold Standards Framework. [www.goldstandardsframework.nhs.uk](http://www.goldstandardsframework.nhs.uk)

Gold Standards Framework Scotland. [www.gsfs.scot.nhs.uk](http://www.gsfs.scot.nhs.uk)

Liverpool Care Pathway for the Dying Patient. [www.endoflifecareforadults.nhs.uk/eolc/lcp.htm](http://www.endoflifecareforadults.nhs.uk/eolc/lcp.htm)

## LONG TERM CONDITIONS

NHS Department of Health Long Term Conditions website. [www.dh.gov.uk/en/Healthcare/Longtermconditions/index.htm](http://www.dh.gov.uk/en/Healthcare/Longtermconditions/index.htm)

## CANCER

National Institute for Clinical Excellence: *Improving Supportive and Palliative Care for Adults with Cancer*. 2003 [www.nice.org.uk/guidance/index.jsp?action=download&r=true&o=28800](http://www.nice.org.uk/guidance/index.jsp?action=download&r=true&o=28800)

## HEART FAILURE

NHS Heart Improvement Programme. *Supportive and Palliative Care in Heart Failure—A Resource Kit for Cardiac Networks*. 2006. [www.heart.nhs.uk/endoflifecare](http://www.heart.nhs.uk/endoflifecare)

Scottish Partnership for Palliative Care. *Living and Dying with Advanced Heart Failure: a Palliative Care Approach*. 2008. [www.palliativecarescotland.org.uk/publications/sppc-publications/living-and-dying-with-advanced-heart-failure](http://www.palliativecarescotland.org.uk/publications/sppc-publications/living-and-dying-with-advanced-heart-failure)

## CHRONIC LUNG DISEASE

National Institute for Clinical Excellence. *Chronic Obstructive Pulmonary Disease. National Clinical Guideline on Management of Chronic Obstructive Pulmonary Disease in Adults in Primary and Secondary Care*. 2004 <http://guidance.nice.org.uk/CG12>

## CHRONIC KIDNEY DISEASE

NHS Department of Health. *End of Life Care in Advanced Kidney Disease: A Framework for Implementation* [www.endoflifecareforadults.nhs.uk/eolc/kidney.htm](http://www.endoflifecareforadults.nhs.uk/eolc/kidney.htm).

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# Having the difficult conversations about the end of life

Stephen Barclay,<sup>1</sup> Jane Maher<sup>2</sup>

Clinicians need to create repeated opportunities for patients to talk about their future and end of life care, guided by the patient as to timing, pace, and content of such talks, and respecting the wishes of those who do not want to discuss such matters

More than half a million people die each year in Britain—36% from cardiovascular disease, 27% from cancer, and 14% from respiratory disease; and 58% of all deaths occur in hospital,<sup>1</sup> a proportion that has increased in recent years. While some deaths are sudden and unpredictable, many patients go through a period of illness when death becomes increasingly probable.

Recent General Medical Council guidance on good practice in decision making in treatment and care towards the end of life states that “patients whose death from their current condition is a foreseeable possibility are likely to want the opportunity to decide what arrangements should be made to manage their final illness” but also cautions that “you must approach all such discussions sensitively, as some patients may not be ready to think about their future care or may find the prospect of doing so too distressing.”

Some may not wish to talk with their clinicians or their family about the end of life, but others may greatly benefit from such conversations. The right conversations with the right people at the right time can enable patients and their loved ones to make the best use of the time that is left and prepare for what lies ahead.

In this article, some of our comments arise from our experience as clinicians in general practice and oncology, and others from the research evidence in this area, which is limited. We seek to stimulate discussion and debate: we focus mainly on issues that make these conversations difficult for patients and clinicians, and invite readers to expand on our suggestions of practical ways forward.

## The difficulty of knowing what lies ahead

Uncertainty about prognosis creates anxieties for doctors when discussing end of life care, with patients and their families often expecting greater prognostic certainty than is possible. Cancer patients have traditionally been viewed as having an identifiable dying trajectory,<sup>2</sup> but health professionals’ estimates of their prognoses are frequently inaccurate and over-optimistic,<sup>3,4</sup> with deterioration and death coming sooner than expected by all concerned. In illnesses other than cancer, recurrent hospital admissions and interventions give rise to an unpredictable dying trajectory and a “prognostic paralysis,”<sup>5</sup> in which the difficulty of prognostication results in failure to consider or raise end of life issues until death is very close and the patient too unwell for meaningful conversations. End of life discussions are particularly challenging with patients who

have heart failure: up to half of deaths are sudden, particularly in the less severe stages.<sup>6</sup> Many older patients have multiple comorbidities, each of which is potentially life limiting.

## Changing illness trajectories

Therapeutic and healthcare advances are changing care at the end of life. Patients with cancer are increasingly receiving active treatment into their last weeks of life and their dying trajectories are becoming more akin to those of patients with non-malignant chronic illnesses. In exacerbations of non-cancer illnesses, patients and clinicians often see acute admission and active treatment as appropriate: “you never know what they might be able to do in the hospital.” Public and professional attitudes have not kept up with this increasing medical activism: end of life discussions are still often linked in their thinking with the stopping of active treatment and the close proximity of death. In modern health care, such cessation of treatment often takes place far too late for effective end of life care planning to happen, if it takes place at all.

## Keeping in the frame of “curative change agent”

The communication of a poor prognosis is a most difficult conversation for doctor and patient and is a source of considerable physician stress.<sup>7,8</sup> Doctors are often reluctant to discuss poor prognosis and treatment options,<sup>9,10</sup> and when such conversations do occur, they frequently avoid the words “death” or “dying,” preferring euphemisms such as “time is getting short” that are intended to soften the shock but may also confuse or mislead.<sup>11</sup> Patients with cancer frequently misunderstand the aim of their treatment, seeing therapy aimed to palliate disease as having curative potential.<sup>12</sup> Patients view the option of supportive care without continued disease modifying treatment as the clinical team “giving up”: they value their doctors’ expertise in up

<sup>1</sup>general practitioner and Macmillan Postdoctoral Research Fellow, General Practice and Primary Care Research Unit, Institute of Public Health, Cambridge CB2 2SR

<sup>2</sup>consultant clinical oncologist and chief medical officer, Macmillan Cancer Support Mount Vernon Cancer Centre, London

Correspondence to: S Barclay sigb2@medschl.cam.ac.uk

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## Imposing open discussions on all patients may destroy hope and cause considerable harm

to date active interventions and prefer them to remain in the role of curative agent.<sup>13</sup>

### Coping with uncertainty and maintaining hope

Professionals often prefer to wait for patients to approach them to talk about the end of life, whereas patients often wait for the doctor to broach the subject.<sup>14</sup> Conversations are thus avoided until disease is advanced and prognosis is more certain, and this delay is a common cause of late referrals to palliative care, unplanned hospital admissions, and inappropriate interventions when crises develop.<sup>15</sup> Doctors are often uncomfortable with the inherently uncertain nature of prognostic estimates and find patients' expectations of clarity and certainty impossible to meet.<sup>8</sup> They struggle to bring that uncertainty into the open for themselves, the clinical team, and the patient.<sup>16</sup>

Maintaining hope during and after difficult conversations is challenging. Some patients would like open communication about their illness and its progress: others are more ambivalent, wanting to be told but not wanting to know, or having a compartmentalised awareness in which they acknowledge that their illness is terminal while retaining a sense of hope.<sup>17</sup> Evidence suggests that open discussion is beneficial for those who desire it, with less inappropriate medical treatment, lower risk of depression, and better adjustment of care givers to bereavement.<sup>18</sup> However, to impose such open discussions on all patients, irrespective of their wishes, may destroy hope and cause considerable harm. Denial is an important ego defence mechanism that must not be broken down.

### Understanding patients and carers' perspectives

Patients' fears may underlie their reluctance to discuss the end of life: fear of treatment withdrawal, of loss of the managing team, of uncontrolled symptoms, to name but a few. They may have cognitive impairment or low health literacy, and misunderstand or selectively retain information given. They may be protecting their families, using coping strategies such as denial, or they may simply not wish to address the issues at this time. Many, however, have information needs that could be addressed by sensitive, patient led conversations.

### The financial impact of failure to start end of life conversations

Failure to discuss the end of life may have a substantial financial impact. In the UK, patients with a terminal prognosis (defined as six months or less to live) are entitled to both the higher rate disability living and attendance allowances, which are fast tracked on completion of form DS1500: over half of people who die from cancer receive neither allowance.<sup>19</sup> In the United States, Medicare funded patients have to make a choice between home hospice care and hospital active treatment: in the absence of early end of life discussions, most continue with active treatment and are referred for hospice care very late in their illness.<sup>15</sup>

### What are the organisational incentives?

Studies of the Gold Standards Framework for Palliative Care in primary care suggest that timely end of life conversations can trigger the introduction of processes that are associated with improvements in care.<sup>20</sup> The current details of palliative care indicators for primary care in the Quality and Outcomes Framework are insufficient, and there are no organisational

incentives in secondary care to encourage the appropriate initiation of end of life discussions. Tariffs for chemotherapy and radiotherapy do not include auditable communication or support elements, and end of life needs are rarely addressed in multidisciplinary team meetings. Hospitals do not routinely identify patients approaching the end of life, other than when very close to death when the Liverpool Care Pathway for the Dying is used. Nor do they have codes for end of life assessment and care planning.

### Possible triggers for starting the conversation

Many triggers have been suggested for clinicians to consider opening up conversations about the end of life: poor control of symptoms, changing care needs, deteriorating function, withdrawal of active cancer treatment, diagnosis of incurable advanced disease, admission to hospital, or entry into a nursing or care home, among others. Recognition is growing that prognostic precision is rarely achievable and it may be better to identify patients who are "sick enough that dying within the next year would not be a surprise."<sup>21</sup> Those identified by this "surprise question" might be sensitively approached for end of life conversations and be put onto general practice palliative care registers. However, for many patients the proximity of death is not clear until very close to the end of life. For them, an approach of "hoping for the best and planning for the worst" may be the best way forward.

### Initiating and holding the conversation

Hospital specialists, including oncologists, rarely initiate discussions about the end of life during active treatment, and hospital team care rarely permits the personal continuity that facilitates these difficult conversations. Primary care may be a better setting, where patients and families may have established and trusting relationships with their general practitioner, although personal continuity has declined in general practice over recent years. However, general practitioners may feel that they lack the specialist knowledge required and wait for a signal from the specialist team before opening up conversations. Patients may expect such information to come from their specialist, but disease specific specialist nurses often do not see these discussions as part of their role, and hospital palliative care teams are involved with a minority of dying patients.<sup>22</sup> The consequence is that no professional





takes responsibility for starting these conversations and the patient and family are left uncertain and confused about the future and their care options.

Discussions about the end of life require good communication skills and great sensitivity and respect for individual wishes.<sup>23-25</sup> The crucial task is to ascertain *which* patient wants *what* information at *this* time—a judgment that doctors find very difficult to make.<sup>26,27</sup> Some patients do want their doctors to talk in a straightforward and sensitive way when they judge the patient to be ready, listening and encouraging questions, and striking a balance between honesty and hope.<sup>28</sup> Others may not want to talk *now*, not with *that* particular health professional, or *not at all*. Each patient's care needs to be handled in the way they prefer, even if to do so creates untidiness and uncertainty for care providers. A patient's preference for silence should be respected.<sup>29</sup>

### Conclusion

In 1769 Samuel Bard wrote that “To buoy up a dying man with groundless expectations of recovery is really cruel” and could lead to “overlooking the important concerns of futurity, and involve families in confusion and distress.” Such practice is still very familiar 250 years on. In response, a conventional wisdom is developing that open awareness and communication about death and dying is the best option for everyone. Since patients' preferences are varied and complex, such a “one size fits all” approach needs to be questioned: a patient's preference not to hold such conversations must be respected.

Death is not a medical failure: it comes to all of our patients, and to all of us. It is part of our duty as doctors to provide optimal end of life care for our patients, a key part of which is the offer of timely, sensitive, patient-led conversations about the end of life.

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**Contributors and sources:** SB has been a general practitioner for 25 years. He is honorary consultant in palliative medicine at the Cambridge Hospice and Macmillan post-doctoral research fellow in the University of Cambridge General Practice and Primary Care Research Unit. He leads the End of Life research team of the NIHR CLAHRC for Cambridgeshire and Peterborough (Collaborations for Applied Health Research and Care). JM has been a consultant clinical oncologist at Mount Vernon Cancer Centre and Hillingdon Hospital for 20 years. She is senior clinical lecturer at University College London, visiting professor in cancer and supportive care at the Centre for Complexity Management at Hertfordshire University, and chief medical officer

for Macmillan Cancer Support. Both authors are members of the Macmillan Palliative and Cancer Care Research Collaborative (MacPaCC), a group of clinical academics whose research has informed this paper, and whose contribution and support is acknowledged with gratitude. SB is guarantor.

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▶ Jane Maher talks about the importance of end of life care in a *BMJ* podcast coinciding with this Spotlight. Find out more at [bmj.com/podcasts](http://bmj.com/podcasts)

# Achieving a good death for all

John Ellershaw,<sup>1</sup> Steve Dewar,<sup>2</sup> Deborah Murphy<sup>1</sup>

A good death for all is now recognised as a priority at societal and political levels. To achieve this goal we need a fundamental shift of emphasis: to train and educate healthcare professionals, to ensure rigorous assessment of new end of life care services that aim to improve quality and choice, and to explore best use of resources

“How people die remains in the memory of those who live on.”

Dame Cicely Saunders<sup>1</sup>

The importance of high quality care for patients in the final hours and days of life has received national recognition in recent years.<sup>2,3</sup> Increasingly the need to establish this element of care in the core business of hospitals and other care settings is acknowledged. Providing high quality care for the dying is a marker of our commitment to the delivery of care to all. As Mike Richards, national clinical director for end of life care in the UK, remarked in the foreword of the first National Care of the Dying Audit of Hospitals in England in 2007,<sup>4</sup> “How we care for the dying must surely be an indicator of how we care for all our sick and vulnerable patients.” The growing proportion of elderly people in the developed world will have consequences for the economies and healthcare systems of these countries. The elderly are “more likely to have highly complex problems and disabilities, and need packages of care that require partnership and collaboration between different groups and

across many settings.”<sup>5</sup> The number of deaths in England and Wales is set to increase by 17% between 2012 and 2030<sup>6</sup> and WHO<sup>5</sup> suggests that provision of palliative care and, more specifically, services to deliver care for the dying, need to be enhanced and made available in all care settings to make this situation “manageable.”

## Where do people die?

Currently, the majority of deaths in England (56%) occur in NHS hospitals and institutions.<sup>7</sup> All healthcare professionals in this setting need to have the appropriate skills and knowledge to provide optimum care for dying patients and their relatives and carers. Despite care of the dying being a core clinical activity, many professionals do not receive specific preparation in this area during their initial training, and few receive any ongoing training. This issue lay at the heart of much of the media disquiet over the variable degree of care taken in the implementation of care for the dying. Mike Richards remarked recently that “there are 1.3 million people working in the NHS and almost all of them have roles in end of life care . . . we train all clinicians in resuscitation though relatively few will use this skill in any one year. I would like to see a similar approach so that all staff are trained in end of life care.”<sup>8</sup>

## Liverpool care pathway

One programme aimed at improving care of the imminently dying is the Liverpool care pathway for the dying patient (LCP), led by the Marie Curie Palliative Care Institute Liverpool.<sup>9</sup> The initiative has been supported and recommended by the Department of Health<sup>2,3</sup> as a means to translate the key principles of the hospice model of care (box) into general healthcare settings, including hospitals, care homes, and patients’ own homes. The LCP is an integrated care pathway that supports clinicians in making important decisions about care for the dying. Importantly, use of the document is reinforced through continuous education and training for doctors, nurses, and other healthcare professionals. A systematic, ten step implementation process within a four phased service improvement model underpins the programme.<sup>10</sup> The document, like any integrated care pathway, continues to evolve, taking into account developments in evidence based medicine and clinical practice. Version 12 strengthens the guidance on initiating the LCP and consideration of clinically assisted (artificial) hydration.<sup>11</sup>

The research evidence for improvement in care of the dying based on the LCP continues to emerge in the UK and internationally. Qualitative evidence has shown that it improves the confidence of nurses and doctors in delivering care to imminently dying patients.<sup>13,14</sup> A before and after study in hospitals and nursing homes in the Netherlands showed a fall in the burden of symptoms and improvements in documentation of care.<sup>15</sup> The results of a questionnaire study of bereaved relatives in the hospital

### Best practice in the last hours and days of life

- Current drugs are assessed and non-essential ones discontinued
- “As required” subcutaneous medication is prescribed according to an agreed protocol to manage pain, agitation, nausea and vomiting and respiratory tract secretions
- Decisions are taken to discontinue inappropriate interventions
- The ability of the patient, family, and carers to communicate is assessed
- The insights of the patient, family, and carers into the patient’s condition are identified
- Religious and spiritual needs of the patient, family, and carers are assessed
- Means of informing family and carers of the patient’s impending death are identified
- Family and carers are given appropriate written information
- The general practitioner is made aware of the patient’s condition
- A plan of care is explained and discussed with the patient, family, and carers

From National Institute for Health and Clinical Excellence, 2004.<sup>12</sup>

<sup>1</sup> professor of palliative medicine

<sup>2</sup> director of research and innovation, Marie Curie Cancer Care, London SE1 7TP

<sup>1</sup> associate director

Marie Curie Palliative Care Institute, University of Liverpool, Liverpool L69 3BX

Correspondence to:  
John Ellershaw  
j.e.ellershaw@liv.ac.uk

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## Up to a third of all people who died in hospital could have been looked after at home

setting showed that those relatives of patients being cared for on the LCP perceived a higher quality of care than the relatives of those who were not cared for on the pathway.<sup>16</sup> In the care home environment, Hockley and colleagues reported improved anticipatory prescribing of medication for five key symptoms and an improvement in multidisciplinary team working.<sup>17</sup>

### National care of the dying audit

Specifically in the hospital setting, round 2 of the National Care of the Dying Audit of Hospitals in England has provided evidence of the care delivered for 155 hospitals using data from 3893 patients whose care was supported by the LCP at the end of life.<sup>18</sup> The audit was led by the Marie Curie Palliative Care Institute Liverpool, in collaboration with the Royal College of Physicians, supported by Marie Curie Cancer Care and the Department of Health End of Life Programme. Significantly, the proportion of patients in the audit with a diagnosis other than cancer increased from 55% in round 1 (2006/7) to 65% in round 2 (2008/9), which supports the use of the LCP for all patients irrespective of diagnosis and illustrates the multi-professional recognition of its wider applicability. For the majority of patients, drugs were prescribed in anticipation of five physical symptoms known to be common at the end of life (pain, agitation, respiratory tract secretions, nausea and vomiting, and dyspnoea). For more than 70% of up to 16 475 assessments made at four hourly intervals in the last 24 hours of life, patients were reported to be free from these symptoms, which illustrates that good quality care can be delivered in this environment. However, the audit did identify some areas for improvement, including communication, assessment of spiritual and religious needs, and care after death.

### Where do people want to die?

Central to a good death is respect for the patient's wishes about their preferred place of care. In recent years the choice to die at home has become a central tenet of public policy based on the well documented preference to die at home—between 56% and 74% of the population of Great Britain report such a preference.<sup>19</sup> However between 1974 and 2003 the proportion of home deaths in England and Wales fell from 31.1% to 18%.<sup>6</sup> Undoubtedly, more insight is needed into the factors that shape these expressed choices and how they may alter according to illness or the imminence of death. Nonetheless the gap between espoused and actual home deaths is, for many, evidence of the need to enhance support in the community, to provide choice for patients and avoid inappropriate admission.

What is the evidence that more patients could or should die in the community? The National Audit Office's case note review of all patients who died in a month in one UK city identified 40% whose medical needs at the point of admission had not required them to be in hospital and who could have been cared for elsewhere.<sup>20</sup> These 80 patients used 1500 bed days in acute hospitals. Further evidence was provided by a systematic audit of deaths that occurred in a year in one UK hospital; its conclusion was that up to a third of all people who died in hospital could have been looked after at home if excellent end of life services had been in place.<sup>21</sup> A recent systematic review that assessed the effect of enhanced community services on the use of acute inpatient services<sup>22</sup> found that "in comparison with usual services, palliative home care reduced general health service use, inpatient mortality, and increased patient and family satisfaction with care." However, the methodological quality of the included studies was far from robust. A descriptive analysis of the Marie Curie Cancer Care delivering choice programme in Lincolnshire showed an increased rate of home deaths and lower rate of hospital admissions for those who received a rapid response intervention.<sup>23</sup> But this analysis was not able to assess the effect against any comparative group or establish whether such findings could have been caused, at least in part, by the self selecting nature of the sample.

### Resource implications

The argument for how better quality end of life care may come cheaper is well put by the National Audit Office: "reducing hospital utilisation by people at the end of life has the potential to improve patient care by transferring patients to their preferred care setting whilst releasing resources to be used to deliver care outside of hospital."<sup>21</sup> But many commissioners may question the ease with which saved admissions can be converted to realisable savings that can be invested in the necessary community services required to deliver the shift. The apparent universality of supply induced demand in health care means that many trusts will remain sceptical of whether reduced admissions will translate to savings or be replaced by other activity.

Providing care for patients in the last hours and days of life in the care home sector is another potential mechanism for reducing inappropriate admission to the acute hospital sector and delivering choice. Again the evidence is persuasive without being compelling. The NAO audit work suggested the proportion of care home residents dying in their care home "could have been increased from 61% to 80% if alternative





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care pathways had been followed, thereby avoiding inappropriate hospital admissions.”<sup>21</sup> Similarly, the audit of deaths in one hospital suggested that “69% of those admitted from nursing homes could have stayed in the nursing home to die.”<sup>21</sup> Regardless of the cost implications, the imperative to make a good death a reality in the patient’s own home and in care homes is paramount. The LCP is currently being used by trained community healthcare professionals in some homes and care homes, which may be part of the answer to building capacity. However, a key challenge for care homes might be the establishment of a culture that enables achieving a “good death” as a marketable and welcome characteristic. A national project is under way to implement the LCP in the care home environment. This implementation process is underpinned by a model of education and training specifically created for this environment which is subject to ongoing review and development as part of the process. At the end of the project, a sustainable model of implementation, education, and training will be available for wider use.

### Conclusion

In view of the changing demographics of death, the changing pattern of dying, and the policy and financial imperatives, many new service configurations are likely to be tried. To deepen our understanding of what works and why, we will need to hone our measurements of effect and support further research and evaluation. However, an even more radical shift may be necessary. Given a future of fewer carers, fewer resources, and a dramatic increase in chronic disease and comorbidities, we may need to consider whether communities, rather than health services, need to take on more of the burden of care at the end of life.

In the meantime, we must strive to ensure that a good death is the expectation rather than the exception in all settings. Mandatory training in care of the dying alongside the LCP programme potentially provides an effective mechanism for the delivery of high quality care to achieve a good death for all.

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**Contributors and sources:** The authors of this paper have considerable complementary experience in the area of improving care for dying patients and support for their relatives and carers. JE (guarantor for the paper) is professor of palliative medicine at the University of Liverpool; director of the Marie Curie Palliative Care Institute Liverpool, the main aim of which is

to improve care of the dying; national clinical lead for the LCP; and national deputy clinical director for end of life care for the Department of Health. SD is director of Research and Innovation for Marie Curie Cancer Care, with expertise in evaluation of service redesign and delivery. DM is associate director of Marie Curie Palliative Care Institute Liverpool and national lead nurse for the LCP.

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# Spiritual dimensions of dying in pluralist societies

Liz Grant,<sup>1</sup> Scott A Murray,<sup>2</sup> Aziz Sheikh<sup>3</sup>

Despite the decline of formal religion many people still regard the idea of spirituality as essential to their sense of self, especially at times of inner turbulence. We explore how the spiritual needs of dying patients can be understood and met in pluralist and secular societies

“Man is not destroyed by suffering; he is destroyed by suffering without meaning.”

VE Frankl<sup>1</sup>

Palliative care is about helping people die well, but how do we know how to “die well”? In all cultures, sacred stories, proverbs, and rituals around death exist to help people prepare to die. Death and dying were keystones of the grand narrative of religion. But religions, in Western cultures, are disappearing, and grand narratives have been replaced by worldviews driven by individual success that are not so much death denying as blind to death.

In this article, we reflect on the spiritual needs of the dying and on how these needs can best be understood

and met in pluralist societies. An assumption underpinning our approach is that the core aspects of spirituality are common to all people, although the external manifestations of spirituality and spiritual need are many and varied. Where appropriate, key issues are illustrated with data from our qualitative studies investigating the end of life experiences of patients and their social and professional carers in a range of populations.<sup>2-4</sup>

## Understanding spirituality

Cecily Saunders proposed the concept of “total pain” to capture the complex effects of physical, emotional, and spiritual pain experienced by patients with advanced illnesses, thus introducing the idea of spiritual distress and suffering to the palliative care discourse. Spirituality, in the context of end of life care, is now incorporated into international health policies, clinical guidelines, cultural training initiatives, and quality of life measures.<sup>5</sup> Recognition is increasing among health professionals that spiritual issues and needs may affect the likelihood of achieving a good death, and should therefore be met if possible. Often less clear is how these needs should be met and by whom.



Purepecha woman paying homage during “Day of the Dead”

<sup>1</sup>senior lecturer

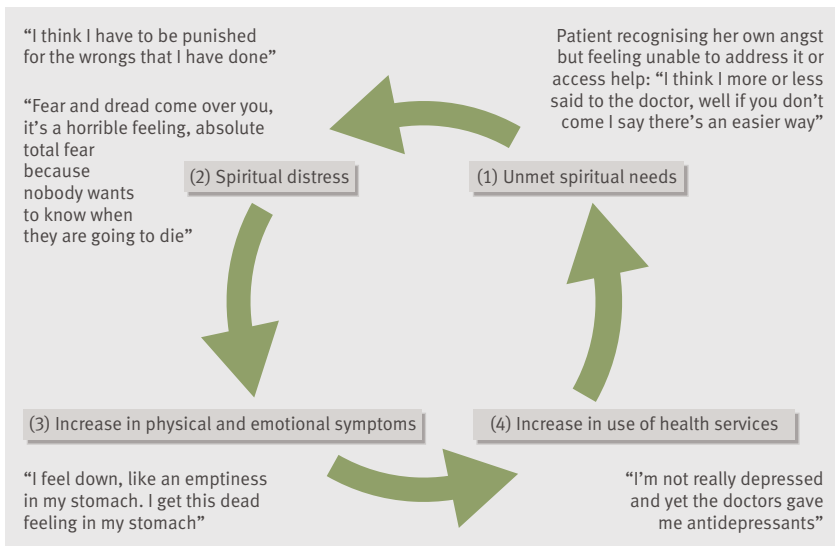
<sup>2</sup>St Columba's Hospice professor of primary palliative care

<sup>3</sup>professor of primary care research and development

Primary Palliative Care Research Group, Centre for Population Health Sciences, University of Edinburgh, Edinburgh

Correspondence to: A Sheikh  
aziz.sheikh@ed.ac.uk





**Fig 1 | Unmet spiritual need cycle may result in increased demand and service use<sup>3</sup>**

Understanding what spirituality is, especially in relation to religious beliefs, remains problematic with many diverse definitions.<sup>6-9</sup> Religions are understood as systems of belief, often relating to deities or spirits, that connect people together into communities through structures, worldviews, and rituals. Spirituality, though commonly practised within the framework of religion, can also be experienced outside formal religious structures.

Spirituality is multidimensional and relational, encompassing meaning and purpose, self reflection, hope, faith, beliefs, and a sense of sacredness and separateness. Common to all expressions of spiritual need among those facing end of life issues is a search for meaning. Spiritual needs are about the need to be valued, to repent and be forgiven, to achieve self integrity, and to face and accept death. Spiritual resolution is frequently about the ability to affirm and value relationships with one's self, with family, with community, and with the "other"—whether that is a deity, unseen spirits, nature, humanity, or the unknown. Spiritual needs can be seen as different from psychological needs in that they are embedded in a sense of the sacredness of life.<sup>10</sup>

**Box 1 | Common spiritual concerns**

- Searching for meaning: "What was the purpose of my life?"
- Searching for validation: "Was my life worth living and did I live it well enough?"
- Asking for forgiveness for mistakes: "Can I be forgiven and absolved of the past?"
- Searching for a sense of redemption, and restoration to wholeness
- Searching for reconciliation of memories, and of broken relationships, for reunion and community of spirit among all relations
- The quest for peacefulness and searching to make peace with others and with self
- Asking for permission to leave this world

**Why does spirituality matter in end of life care?**

A sense of wellbeing is one of the main predictor variables in the will to live among patients in the last year of life.<sup>11</sup> Religious and spiritual beliefs often affect patients' decision making towards death. Those who believe that the span of their life is in the hands of a deity greater than them, who knows their time and who cares for their future, are often more able to accept an end to futile treatment and exude a sense of calm and dignity as they await death.<sup>12</sup> As noted by Breitbart, "Palliative care informed by spiritual attentiveness allows both the patient and the provider to give up illusions of therapeutic entitlement to cure and at the same time honor the privilege of intentional and reverent caring for the dying."<sup>13</sup>

Conversely, unmet spiritual need can negatively affect a person's sense of wellbeing and their capacity to cope with pain and suffering.<sup>3</sup> Spiritual distress has been identified as a factor in depression, demoralisation, and end of life despair.<sup>14-16</sup> Patients can be at their most vulnerable when expressing their spiritual needs, an experience that can be cathartic if patients feel that they have been listened to; if they are not listened to, it can leave them feeling empty, rejected, and hopeless.<sup>17</sup>

Patients often struggle to explain their spiritual needs. In developed countries, this generation's loss of a spiritual language coupled with the tension of traversing two different discourses—medical and spiritual—can result in increased angst about unresolved issues, uncertainty, lack of self confidence, and vulnerability, which in turn can further heighten spiritual distress. This distress can affect patients' ability to sleep and their capacity to cope with pain. Figure 1 illustrates the cycle of spiritual distress. Health professionals may tend to deal with the symptoms as presented—for example, resorting to prescribing medication. As a patient remarked: "I am not really depressed, but the doctors gave me antidepressants."<sup>3</sup>

For those with religious beliefs, being able to fulfil traditions and rituals around death is important and can have a considerable effect on how a patient dies and how their family copes with the bereavement. Ancient religious rites emerged in cultures and contexts very different from the 21st century hospital wards where 60% of people now die in the UK. Although the need to facilitate rites is recognised within hospital spiritual care strategies, there are still gaps in provision of the space and place for these needs to be met.<sup>18</sup>

**Identifying spiritual distress and delivering spiritual care**

**Key time points**

Qualitative longitudinal research in people with lung cancer and their carers has revealed four key times when people may be spiritually distressed (fig 2)<sup>4 19</sup>—at diagnosis; at home after their initial treatment; at disease progression or recurrence; and in the terminal phase. Murray and colleagues note that: "When people with life threatening illnesses and their carers ask about prognosis ('How long have I got?'), they are often doing more than simply enquiring about life expectancy."<sup>20</sup> They may be asking about the probable course of events until they die and have a number of existential issues

**Box 2 | Possible questions to guide spiritual exploration in people with advanced illnesses<sup>19</sup>**

- What's the most important issue in your life right now?
- What helps you keep going?
- How do you see the future?
- What is your greatest worry or concern?
- Are there ever times when you feel down?
- Is religion or faith important to you?

**Box 3 | Common religious traditions and rites around death**

- Prayers
- Confessions
- Final family blessings
- Washing and cleansing
- Last rites
- Covering the body and placing it in the right position and direction
- Funeral routines
- Pouring libations

and questions in mind (box 1). Medicine has traditionally relied on knowing the heart of the person in order to effect healing, but in busy clinical settings the therapeutic power of the relationship between doctor and patient can be overlooked or subsumed by technology. Yet as a GP explained in one of our studies, "Respect is a core value of general practice, it means valuing their soul qualities—it's impossible to practise appropriately without caring for the spirit."<sup>21</sup>

**Challenges in offering spiritual care**

Offering spiritual care can be challenging. As Sloan argues, "Between the extremes of ignoring the role of religion within health and actively promoting it, there lies a vast uncharted territory in which guidelines for appropriate behaviour are needed urgently."<sup>22</sup> The current General Medical Council consultation on end of life treatment and care states that doctors should be able to diagnose spiritual distress.<sup>23</sup> Yet fear of causing offence, of misunderstanding, or of crossing unspoken cultural barriers, along with a lack of training and knowledge, can lead to freezing of action.<sup>24</sup> Health professionals also sometimes fear that they will be seen to be proselytising. Encouragingly, however, the National Institute for Health and Clinical Excellence (NICE) has made clear that spiritual care is the responsibility of all clinicians,<sup>25</sup> a view that is echoed in Marie Curie's religious and spiritual competency framework.<sup>26</sup>

**Available resources**

Key to offering spiritual care is an awareness of what resources are available and what is required. While providers have looked to a product or a tool to give spiritual care, patients frequently identify that spiritual care is more about giving a person permission to speak and be heard, and about people relating to their essential "inner self" rather than their weakening physical "outer self."<sup>27</sup>

"My doctor, the most important thing that he does—well he assures me that I'm not away yet. He always listens."<sup>3</sup>

This patient centred approach is, as with other dimensions of health care, best delivered by a community of workers. As Meador argues, "The best spiritual care for the dying patient is most likely to be delivered in the same way other types of care are best provided, through partnerships within the team of persons caring for the patient."<sup>28</sup> Supporting people within their own world-views while allowing expression of fear and doubt may help patients in their search for meaning and purpose and prevent spiritual concerns escalating into disabling distress. Allowing patients to raise spiritual and religious concerns may furthermore be therapeutic; the use of a gentle prompt, such as, "You seem fine today, but do you ever feel down or a bit low?" may in this respect prove helpful (see box 2 for further suggested prompts). Most people with advanced illness have already "brushed with death" and may have competing private and public accounts of their illness in their minds.<sup>1</sup>

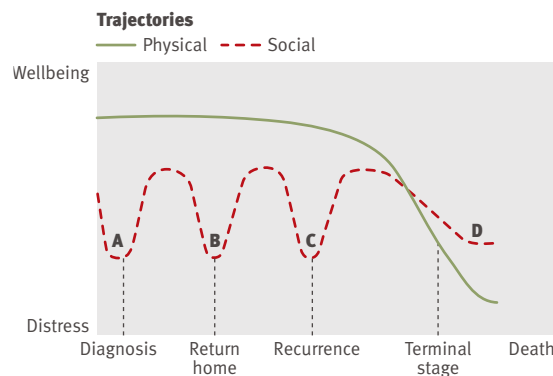
But alongside a patient centred approach, which everyone can offer, lies a role that may require another sort of expertise, that of being able to help articulate the sacred. Chaplaincy teams, increasingly staffed by multi-faith members, are trained to meet the needs of people of all faiths (and none) and can provide such expertise. This may involve conducting a ceremony (for example, a naming, a blessing, or a baptism for a baby that has died), listening to a final confession or testimony of faith, performing a marriage, creating a safe space for family and personal reconciliation, and providing an opportunity for final cleansing rites (box 3).

Patients and families who have felt that their religious and spiritual needs have been met often speak of the sensitivity and understanding shown by healthcare staff in listening to them and respecting the motivation and need of patients and families to carry out their rituals.

**Conclusions**

To meet spiritual and religious needs, healthcare workers have to be aware that such needs might be present, differentiate such needs from other needs, and assess if they are causing distress. This awareness involves listening to patients, their carers and families, and others in the wider healthcare system with knowledge and understanding of the nuances of religious and cultural traditions. As Gatrads et al have noted, "Understanding each other's narratives of what constitutes a good death offers us the possibility of improving the quality of care we deliver."<sup>29</sup> It also involves knowing what our health and referral system structures already provide and what they could provide better, such as time to listen and to meet the specific spiritual and religious traditions that are important to patients and those dealing with death.<sup>30</sup>

Expressions of religious beliefs are manifold in our diverse society, as are expressions of secular spirituality, but underpinning all these expressions are a similar set of questions relating to the past, the present, and the future, and fundamentally about being at peace with ourselves, with our family, and with the physical and metaphysical world around us.



- A** "When I was first told, that was the first thing through my head – how long? It's been like going through hell and back"
- B** "I'm not really depressed and yet the doctor gave me antidepressants"
- C** "Well I got the results back, he said 'I'm afraid it's terminal.' I got such a shock – we were just absolutely gobsmacked"
- D** "I'll say, God just let me die tonight. There must be something that's better than this"

**Fig 2 | Pattern of spiritual distress at the end of life in patients with lung cancer<sup>4,19</sup>**

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## BMJ GROUP RESOURCES

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### BMJ Learning modules

Advance decisions <http://learning.bmj.com/learning/search-result.html?moduleId=5004469>

Breaking bad news to patients and relatives <http://learning.bmj.com/learning/search-result.html?moduleId=5001101>

Palliative care in the community <http://learning.bmj.com/learning/search-result.html?moduleId=5004331>

### Best Practice

End-of-life care <http://bestpractice.bmj.com/best-practice/monograph/1020.html>