

## **We need to talk about Palliative Care**

### **Age Scotland**

#### ***Introduction***

Age Scotland welcomes the opportunity to give evidence to the Health and Sport Committee's inquiry on palliative and end-of-life care. In particular, we welcome the broad scope of the inquiry, not related to a specific policy measure such as a Bill. This enables a broader and more contextualised view to be taken, as well as addressing the specific aspects which the Committee has highlighted. Our submission seeks to reflect this context. We are content for our response to be published.

#### ***1. Age Scotland's approach***

Age Scotland is the national charity for older people, their rights and interests. We work towards the empowerment of older people, their improved health and wellbeing, their participation in and engagement with communities, which in turn become stronger, more inclusive and resilient. But most significantly of all we work to change and improve the perception of later life and older age.

The perceptions that poor health, degenerative decline and debilitation are inevitable in old age are wrong and damaging. Most people remain active and in sufficient health in their older age to have good, productive and enjoyable lives. However, any perception that in later years people become "as good as dead already"<sup>1</sup> devalues later life and can make poor or inadequate service provision seem more acceptable.

Palliative care developed around the same time as geriatric medicine and they have numerous similarities which are distinct from other disciplines. Both focus on the control of symptoms as much as or more so than finding a cure, and limit or advise against aggressive treatments or invasive procedures; both have pioneered community-based and multidisciplinary models of care; and by focusing on the individual and their family, arguably both have led the way in making modern care person-centred, enabling patient dignity, autonomy and quality of life. Age Scotland were delighted to see these concepts given enhanced recognition in the revised Standards of Care in Hospitals for Older People published by Healthcare Improvement Scotland in June, to which we contributed. We are also represented on the Scottish Government's Stakeholder Group which is advising on the development of a national framework for palliative and end-of-life care.

We adopt the view of palliative care adopted by the World Health Organisation – that it should provide relief from pain and distress, neither hasten nor postpone death, support dying people to live as actively as possible until death, and support families to cope during illness and bereavement. In particular, we agree that palliative care affirms life and dying as a normal process, and can be applicable early in the course of illness and should not be simply about final weeks, days or hours.

Age Scotland is a member of the *Good Life, Good Death, Good Grief alliance*.<sup>ii</sup> We appreciate that many people have had difficult experiences with loss and grief over the course of their lives, and death anxiety is common. However, since death is inevitable for everyone at some stage, we believe that dealing with death, dying, bereavement and loss in a healthy and constructive way should be seen as part of ordinary life. Lack of exposure to death may actually increase fear, anxiety and depression about mortality.<sup>iii</sup>

In 1999, our predecessor charity, Age Concern, created an Age, Health and Care Study Group, chaired by Baroness (then Rabbi) Julia Neuberger. They held a Millennium Debate in 2000, from which twelve principles were identified that epitomise a “good death”: to know when death is coming and to understand what can be expected; to be able to retain control of what happens; to be afforded dignity and privacy; to have control over pain relief and other symptom control; to have choice and control over where death occurs (whether at home or elsewhere); to have access to information and expertise of whatever kind is necessary; to have access to any spiritual or emotional support required; to have access to hospice care in any location, not just in hospital; to have control over who is present and who shares the end; to be able to issue advance directives to ensure wishes are respected; to have time to say goodbye and control other aspects of timing; and to be able to leave when it is time to go and not to have life prolonged pointlessly. We endorse these principles, which have gained wide currency. We also believe that the public, health and social care staff and volunteers should have awareness of these issues and the many ways in which communities and individuals can support each other.

## **2. *The context and need for palliative and end-of-life care***

Most people who are sick and need care turn firstly to their families and households for help. Informal care for people who are dying or with terminal conditions saves the public purse billions of pounds. However, changing family structures mean families are smaller and older people are less likely to continue to live with their children once the latter have grown up (unlike in some other societies around the world). The increasing number of households where older people live alone not only increases loneliness and isolation, but also means that informal care within the family might be impractical (if other relatives live long distances away or cannot combine caring responsibilities with work or caring for their own children) or places a heavy burden on someone who may also be older and who may therefore struggle with their own health, mobility or capacity to care for a spouse or partner. People in these categories are the most likely to need formal support or institutional care.

Recent research published on behalf of Marie Curie Cancer Care emphasised that around 11,000 people - mostly older - who would benefit from palliative care in Scotland do not receive it, and subtle or indirect ageism may be one factor in the causes of this.

Around the world, populations are ageing. One aspect causing this is increased longevity. As people live longer, death becomes a much more

common experience in older or very old age. This has profound consequences for the types of terminal conditions people develop and how older physical bodies are affected by them.

People are much more likely to survive long enough to develop multiple and complex chronic conditions which must be managed rather than cured. Chronic conditions associated with older age – such as heart and cardiovascular disease, strokes, diabetes, osteoporosis, arthritis and cognitive disorders (including dementia, Alzheimer’s disease, and Parkinson’s disease) – have replaced infectious diseases and accidents as the leading causes of mortality, along with cancer. This phenomenon demonstrates a much increased need for palliative care.

However, many older people also experience more than one chronic condition, suffering from long periods of illness, along with disability, frailty, and other mental and physical problems. Some of these may also become harder to detect and treat as people age, and as prognosis becomes more unclear alongside common symptoms of ageing. Palliative care is therefore becoming more complex.

This trend also has impacts on how we live and how we die. A century ago most people died quickly after contracting a communicable disease, and died at home, or died after accidents which could not be effectively treated. Few could afford medical treatment and those who could often found it rudimentary and of limited use.

When asked, most people still express a desire to die at home. However, nowadays many more people die in hospitals or in hospices, though older people are less likely to have access to hospice care. Deaths in hospital often occur because we are able to tackle many life-threatening conditions and/or acute events. It is a natural impulse to seek to do so whenever possible and to focus on moderate recovery, rather than looking too far into the future. Consequently, the majority of time most people spend in a hospital will be in their final year of life. But questions are now being asked whether this approach - referred to as the “medicalisation” of dying - is the best.<sup>iv</sup> A constant focus on the immediate and on recovery may preclude the physician from having to discuss death with the patient, but it deprives the patient from understanding or adjusting emotionally to their situation. As the editor of the *British Medical Journal* put it:

***“modern medicine may ... have had the hubris to suggest implicitly, if not explicitly, that it could cheat death. If death is seen as a failure rather than as an important part of life, then individuals are diverted from preparing for it and medicine does not give the attention it should to helping people die a good death.”<sup>v</sup>***

Different conditions have different effects on morbidity and mortality, and their differential effects on functioning and ultimately death can be traced over time. For example, diseases such as cancer may initially have few impacts on wellbeing, but sufferers can experience rapid decline and thereafter often a swift death. Heart disease and respiratory complaints may limit function and

also cause serious incidents, some of which may be survived, but one incident may cause death. Cognitive decline, however, especially associated with frailty, may lead to prolonged deterioration. These trajectories are clearly identifiable for a single, isolated illness. However, many people experience multiple conditions, which interact in unpredictable and unknown ways. This makes it necessary to research and apply better knowledge about maintaining quality of life as conditions are managed.

This context informs our responses to the Committee's specific questions, which follow. We also agree with the submission of the Health and Social Care ALLIANCE.<sup>vi</sup>

### **3. Access to palliative and end-of-life care services**

The increased prevalence and complexity of long-term conditions (LTCs) also places greater strain on services. Palliative care, especially as undertaken by hospices, was seen as a specialism involving intensive support, including emotional support for people with terminal conditions and their families, and pain management. The growth of LTCs makes a reliance on such a model unsustainable. Different people will need different levels of support along a spectrum, and these must be more widely available than being confined to the hospice movement.

Similarly, the public perception of palliative care has been closely aligned with cancer. People with other degenerative and terminal conditions, such as progressive multiple sclerosis or motor neurone disease, have struggled to access palliative care because of perceptions within the health system that it is not for them. Marie Curie highlighted earlier this year that less than one-fifth of people diagnosed with dementia are offered palliative care at any time, as opposed to three-quarters of cancer sufferers.<sup>vii</sup> If cognitive impairments develop among people who are already suffering from a different life-threatening or shortening condition, these may challenge their ability to self-manage their condition, follow medicine programmes, especially complex regimens, and worsen their condition.

We believe that these perceptions of what palliative and end-of-life care (PELC) is, and what it is for, are the chief causes (alongside the difference between demand for and available supply of resource) of differential access to palliative and end-of-life care services. A commonly agreed and widely accepted definition of what constitutes PELC, and appropriate training to embed this, would seem to be a significant help. To obtain the necessary buy-in from the professions, some of whom have previously been reluctant to recommend PELC, consideration may need to be given to a strong recommendation from their professional bodies backed by a professional practice rule, or giving the forthcoming framework a legislative basis.

Age Scotland have previously called for more support for anticipatory care planning (ACP). People who adopt this approach are more likely to live with a greater sense of control, a degree more happiness, and in some instances live longer, than people who do not. They are also far more likely to die at home, which is also likely to be consistent with their expressed wishes.

Supporting the ability to die safely and comfortably at home (or in a homely setting, where appropriate) is, for us, one of the key tenets of good palliative care. This should also be more affordable for public bodies since it avoids the high cost of hospitalisation or hospice care.

People who are experiencing cognitive difficulties, and those supporting them, may find it difficult to have important conversations about options for palliative care, including place of care, unless tools such as welfare guardianship or power of attorney, which enable decisions to be made and followed through, are known about and used. Age Scotland ran a power of attorney campaign during 2014 and 2015 to increase awareness of the POA option and highlight ways in which it was and was not being used, which identified early diagnosis and support as a common theme.

The final barrier worth mentioning, and the one most likely to be addressed, is the uneasy boundary between health and social care. Palliative care contains elements of both healthcare (such as pain management) and social care (such as personal and nursing care, as well as accommodation/living costs). Patients have reported that delays in arranging palliative care may be caused or exacerbated by the dislocation between health and social care services. This factor has caused problems elsewhere for other people, but seems more pressing when time is short and recognisably finite. Integration should set as one of its chief outcomes ensuring that the processes for identifying who needs palliative care and arranging all aspects of it is smooth and comforting.

We understand the argument for having a named healthcare professional for palliative care patients and their families. This is similar to the well-known point about consistency of care which applies in GPs' practices. People, especially older people, much prefer having a doctor whom they identify as their own and whom they consult most of the time, and that this bond can improve wellbeing even where it may delay access to any GP.

However, the phrase "named person" is redolent of the Scottish Government's named person policy for all children and young people. Despite the Scottish Government's intentions, this remains highly controversial and is subject to legal challenge. There would seem to be little apparent benefit to importing this negative association to the palliative care arena, especially if it is ultimately proved to breach human rights.

Worst of all, if people who need palliative care are equated in the public mind with children then there is a further perception risk that they will be infantilised by the sense that they need to be not simply looked after but also watched over. The problems of perception of old age and competence were discussed earlier in this response, and we would be against any move which accentuates that factor, however well intended.

We would prefer if there was a lead service - such as the Health and Social Care Partnership - rather than an individual for everyone who needed palliative care and that they in fact ensured that there was a personalised high-quality service to those in need without having an artifice which suggests that they do.

#### **4. Initial conversations about PELC**

The initial conversation about the need for palliative care is the very definition of sensitive discussion, alongside the diagnosis itself of a terminal condition. People receiving the diagnosis, and their families, often face a very strong initial reluctance to accept that death is approaching; there will typically also be a degree of uncertainty, depending upon the prognosis and progression of any condition, about the amount of time a person will have left, although that is often one of the most critical pieces of information a diagnosed person will want to know. The initial conversation about PELC becomes even more important where it is known that a person's condition means that their cognition will deteriorate over time. In our view, the subject of initial conversations should also form part of not only the revised guidance on caring for people in the last days and hours of life,<sup>viii</sup> but also the specialist training for professionals engaged with palliative care patients.

The phasing out of the Liverpool Care Pathway by December 2014 in Scotland followed a great deal of controversy about its intentions and methods. Our view is that the pathway itself was not inherently flawed, but that some of the ways it was being implemented were not satisfactory. The replacement of this with guidance based on four key principles seems to be a better approach, although we would like to see a stronger emphasis within the principles that people are encouraged to make their own choices at an early stage. At the moment, the principles point to decisions being made by multi-disciplinary teams.

We recommend wider sharing and internalisation of the lessons drawn from the Institute for Healthcare Improvement's "Conversation Ready" project at the test sites in Grampian, Lanarkshire and Lothian. As well as giving tools for healthcare professionals to use, this highlights a number of useful facts about end-of-life care in particular which could help to debunk some myths among the professional health and care communities (e.g. from an American study in 2013, before entering hospital, over three-quarters of older people with a terminal condition have considered their end-of-life care needs and options, but fewer than 12% opt for life-prolonging care). The first principle of the Conversation Ready model is to engage with patients and their families to find out from them what is most important to them in end-of-life care. This is consistent with the patient-centred care strand of the 2020 Vision for Health and Social Care and the revised Standards of Care for Older People in Hospitals.

We agree that carers and families should be involved in discussions about end-of-life care; not doing so may be harmful to the patient's outcomes and contrary to their wishes, even if legal tools such as power of attorney and welfare guardianship are not employed, especially if the patient has cognitive or sensory difficulties which impair their capacity either to understand or communicate. There could also be unexpected instances of reduced capacity, such as incidences of delirium, in a health or care environment, where the input of relatives and representatives could be crucial. We note that the fourth principle in the current guidance on caring for people in the final hours and

days of life is to consider the needs of relatives and the prospects for bereavement support, which seems appropriate to us.

### **5. Indicators and international comparisons**

We are not able to assist the Committee with detailed knowledge of which indicators measuring PELC are adopted worldwide and which are the most revealing. We agree, as the Committee proposes, that some research into this area would be advantageous.

However, we are aware that international comparisons should bear in mind different cultural and organisational models. In Japan, for example, rates of older people living alone are considerably lower than in Western Europe. Although it is a developed country with comparable economic activity and standards of living, we would expect to see that palliative and end-of-life care (however described) there would be more likely to be provided at home within families, but this could be a reflection of cultural norms about family units rather than quality or type of service provision. Similarly, we know that rates of dying in hospitals in the United States of America are also lower than here. Although the USA does not have a universal publicly-funded system of healthcare, it is broadly available through the Medicare programme for older people ('seniors', as they describe it), so cost disincentive is not likely to be a significant factor. It would therefore be valuable to discover why they seem to have more success to this extent.

### **6. About us**

Age Scotland aims to help Scotland's people enjoy a better later life. We believe that everyone should have the opportunity to make the most of later life, whatever their circumstances, wants and needs.

That's why we work to make later life the best it can be. We think Scotland can and should inspire, engage, enable and support older people to change their later lives for the better and ensure there is support for those who are struggling as they live longer to achieve better, happier and healthier lives. We work in partnership with other charities within the Age Network – Age UK, Age Cymru and Age NI – to pursue these aims across the UK.

## **Age Scotland**

<sup>i</sup> See, for example, "Dementia and the phenomenon of social death", Helen Sweeting and Mary Gilhooly, *Sociology of Health & Illness* (1997, vol 19, no 1), pp. 93-117. See <http://j.mp/DemSocialDeath>.

<sup>ii</sup> See [www.goodlifedeathgrief.org.uk](http://www.goodlifedeathgrief.org.uk)

<sup>iii</sup> e.g. "Should ward nurses hide death from other patients?", Liz Bryan, *End of Life Care* (2007, vol 1 no 1), p. 79. See [http://endoflifecare.co.uk/journal/0101\\_hide.pdf](http://endoflifecare.co.uk/journal/0101_hide.pdf).

<sup>iv</sup> See, for example, *Being Mortal*, Atul Gawande (2014) (also <http://atulgawande.com/book/being-mortal>).

<sup>v</sup> "A good death", *BMJ* (2000) 320 (15 January 2000). See also <http://dx.doi.org/10.1136/bmj.320.7228.129>

<sup>vi</sup> See [www.alliance-scotland.org.uk/download/library/lib\\_55cb256382db7](http://www.alliance-scotland.org.uk/download/library/lib_55cb256382db7)

- 
- vii “Dementia patients suffer due to lack of end-of-life care, says charity”, *The Herald*  
(Stephen Naysmith), 3 February 2015: see <http://j.mp/1JWV733>
- viii see [www.gov.scot/Publications/2014/12/6639/0](http://www.gov.scot/Publications/2014/12/6639/0)