

## Patient perspectives

# Quality of care of the elderly towards the end of life

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A perusal of recent obituaries from local and national newspapers found the following:

Mrs Jane Brown age 92 enjoyed her usual breakfast and went to sit in the sun at the window to read the paper. She fell asleep and did not wake up.

Colonel Hugh Black age 88 was enjoying his twice weekly game of golf when he had a heart attack at the 12th hole and died instantly.

These notices are different from many obituaries in their content and tone. The first implies that the death was peaceful and the second that the deceased died doing what he enjoyed. While we cannot choose the manner in which we die, we should be confident about how we will be looked after towards the end of our life. In this paper, quality of care of the elderly towards the end of life is addressed.

Deaths at age 75 years and over in England and Wales comprised only 12% of all deaths at the beginning of the last century. They rose to 39% in 1951, and to 66% in 2006.<sup>4</sup> From population projections published by the Government Actuary's Department one can calculate that those will rise to 68% by 2020 and to 82% by 2056.<sup>4</sup>

In response to these demographic changes there have been substantial and rapid changes in the way social care is provided, involving the growth of independent services and increasingly important regulation, service commissioning and assessment. This has been paralleled by a substantial growth in the private funding of both domestic help and personal care in people's own homes. In addition, the support of family and informal carers to help elderly people remain at home cannot be underestimated.

## Background

The proportion of those aged over 65 years in the population is increasing, as is the proportion of those over the age of 80 years.<sup>1</sup> Many of the elderly will develop multiple problems, including physical, cognitive and sensory impairment. Two-thirds of patients in hospital are over 65 years, and that figure too is expected to rise. Most people, as they age, wish and do manage to remain in their own homes. Government policy aims to support them in this, although as people age, particularly after 85 years, greater proportions move to care homes. The majority of older people die in hospital or in care homes. In 2005 in England and Wales, approximately 80% of all deaths were in hospitals, hospices and other communal establishments, with only 20% at home or in other private houses.<sup>2</sup> And yet when patients in one geographical area were able to choose their end-of-life care, the numbers opting for their home environment doubled.<sup>3</sup>

## The problem

Over the last few years there have been many articles in the media highlighting problems in the care of the elderly. These articles have focused on a lack of understanding of the needs of the elderly, lack of dignity in their care, and an apparent inability to see the person as a whole.<sup>5-8</sup> These articles make uncomfortable reading with headings such as 'dignity is central', 'elderly dying undignified deaths', 'hospital care fails the elderly', 'no human rights for old in private care'.

There have been papers too in the professional press. A recent personal view in the *BMJ* described the disjointed and quite unacceptable standard of care given to the author's elderly mother with mental health problems.<sup>9</sup> Charities too are highlighting the extent of the problem and campaigning that dignity must be central.<sup>3</sup> Furthermore there is considerable unpublished anecdotal evidence from small voluntary organisations, community groups and individual

members of the public, all with similar stories to tell of undignified and indifferent care of the elderly by healthcare staff.

## Government response to setting standards

A recognition of the need to set standards for providers of care and support to older people in England resulted in *The National Service Framework for Older People* in 2001.<sup>10</sup> Key standards include rooting out age discrimination (standard 1), person-centred care (standard 2) and mental health in older people (standard 7). Legislation has been introduced to extend regulation to the area of private domiciliary care.<sup>11,12</sup> The introduction of Fair Access to Care Services in 2003 introduced criteria for eligibility for adult social care that aimed to target provision on those assessed to have priority need.<sup>13</sup> The Green Paper 2005 *Independence, Well-being and Choice*, followed by the White Paper 2006 *Our Health, Our Care, Our Say* has shifted the policy debate, by emphasising the importance of personalising care through which people are more involved in making choices about the type and level of support they need.<sup>14,15</sup> Furthermore, The Department of Health also launched in 2006 a Dignity in Care campaign, with dignity tests, and dignity champions.<sup>16</sup>

## Discussion

For many elderly patients, not only is the care that they receive poor but their preference as to where they wish to spend the last part of their life and how they wish to die, is not always discussed or known by their general practitioner (GP). Systems such as advanced care planning, a process by which people can think about their future healthcare choices, find out medical information relevant to their situation, and communicate wishes to family and GP,<sup>17</sup> is already being promoted in Australia, Canada and the United States. The 2006 UK GP contract established practice-based registers, including one for people who might benefit from supportive or palliative care and who might die within the next 12 months. Moreover, guidance has been developed through the Gold Standards Framework programme now used by over one-third of UK practices to identify and care for such patients.<sup>18</sup> The charity Help the Aged is campaigning for elderly people to be given more choice about how and where they are treated, and is supporting a campaign by Marie Curie Cancer Care for terminally ill people to be given support so that they can die at home.<sup>3</sup>

How can we ensure that primary care is offering a quality service for the elderly?

Scott Murray, Professor of Primary Palliative Care at St Columba's Hospice, Edinburgh has produced an advanced care planner for primary care.<sup>19</sup> This includes:

- identify patients who may be within 12 months of the end of life and adding them to the practice palliative care register. *I would add vulnerable patients*
- assess the present health and social needs of these patients
- raise issues of how and where patients would like to be looked after and any other preferences
- provide proactive, personalised care to be reviewed regularly with patient, family and carers
- I would also add *be clear who family carers are and what they are able to do.*

It may be very obvious, but it is also essential that there is a system within the practice to ensure that all staff are aware of these patients so that requests on their behalf may be dealt with expeditiously.

If such a system were generally adopted, it would help to ensure that patient preferences for their care towards the end of their life were adopted, and fewer elderly patients would spend the end of their days in acute hospitals. 'Adopted' means winning the hearts and minds of all those in general practice to initiate such a system, and requires inclusion in the education syllabus, both undergraduate and postgraduate, of medical and nursing staff. The 2001 UK National Service Framework did indeed recommend education and training for all professionals caring for older people, but no funds were allocated and such training has not yet happened.<sup>10</sup> And in 2003 the government announced that it was investing £12million over three years in its End of Life Care Programme, designed to provide better training for health professionals.

Hearts and minds of commissioners have also to be won to see such packages for the care of the elderly as a priority, and this fits very well into Graham Box's definition of people-based commissioning described in the August edition of this journal.<sup>20</sup> The recent description of world class commissioning by the Department of Health is adding 'life to years and years to life'. It is essential that this does not result in ignoring the large group of people who do not have years to live.

Whose responsibility is it to ensure that those elderly people towards the end of their life are treated with the respect, dignity and consideration of their preferences, aspects of care normally accorded to the rest of society? Who is accountable? The government has acknowledged the problem and introduced different initiatives, some of which have already been referred to. But GPs and other professionals in primary care must also take responsibility. UK general

practice has prided itself on looking after patients from 'the cradle to the grave' and GPs often say that they are advocates for their patients and that they know their patient population. While many GPs offer an exemplary standard of care to their patients, many still do not ascertain what is in the best interests of these elderly patients and are too quick to refer them to hospital to die. The elderly deserve respect that includes a professional and patient-centred approach to care towards the end of life. Without this, the good reputation of general practice and the trust that the public has had in this branch of medicine will be very badly damaged.

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