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A fitting end

Quality palliative care in care homes needs to be delivered on a wider scale, find **Clare Connell** and **Henry Hunt** of Connell Consulting

The problem with palliative care in care homes is simply that it is not widespread enough. While there are shining examples of palliative care in homes across the United Kingdom that are quite capable of providing a 'good death', there are too many that do not have the systems in place that consistently support satisfactory mortality.

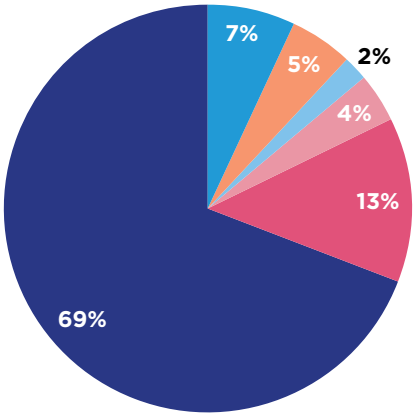
But what does a good death mean? According to a 2012 NatCen report on 'British social attitudes to dying', across ages 18 to over 75, there are three top priorities: to be pain free, to retain dignity, and to be with family and friends. Two thirds of respondents hope to achieve these outcomes in their own home.

Sue Ryder, a charity offering hospice care, in a report on end of life care from 2013, found similar priorities and similar preferred destinations. 63% of the UK population want to die at home with 78% of respondents hoping to be free of pain and discomfort, 71% hope to be surrounded by loved ones, 53% want privacy and dignity and 45% want familiar surroundings that are calm and peaceful. Sue Ryder suggests, and possibly overstates the preference for hospice services (28% compared to 5% in the NatCen report), but both reports figure that fewer than one in 40 hope to pass away in care homes.

But, if you look at where people actually end up dying, preferences are hardly being accommodated. According to data from the various statistical bodies of the United Kingdom,

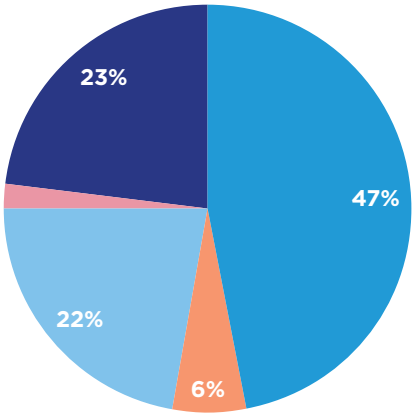
FIGURE 1: WHERE PEOPLE WANT TO DIE

Preferred place of death according to 'British social attitudes to dying' report, 2012



- In a hospital
- In a hospice
- In a care home
- Somewhere else
- Don't mind
- At home

Actual place of death, England, 2016/17



- In a hospital
- In a hospice
- In a care home
- Somewhere else
- At home

- 69% of British people hope that when they die they are able to do so in their own home
- Only 2% of people would choose to die in a care home
- However, in England, of all people who died in 2016-17, 47% end up dying in hospitals and about 22% died in care homes
- Clearly there needs to be increased receptiveness to dying in care homes, and a reduction in the number of people who die in hospital wards
- Both can be achieved by improving the palliative packages on offer in care homes.

Source: 'British social attitudes to dying'; ONS

about 55% end up dying in hospital and roughly 18% of people die in care homes. If one looks at just people aged over 75, the data is even more stark. In 2015, of 341,470 deaths, 30% occurred in care homes. Only 19% of people aged 75 and over died in their own home but over 46% died in hospitals.

The reasons for this gap between preferences and actuality are myriad and some are less susceptible to change than others. Many people over 75 cannot die in their own homes because it's likely that they were too highly dependent on personal, and medical support to realistically live at home in the years and months leading up to their deaths – it's important to note that in the 'British social attitudes to dying' survey, 60% of people who had said they wanted to die in their own homes would change their mind if they were doing so without support.

What could change most drastically is attitudes to death in care homes, as well as a reduction in the number of older people who die in hospitals when only 7-8% of people seek them out. Both may be improved by a more open discussion around mortality, as well as formalising the development of a palliative care plan upon admission into a care home.

The 'British social attitudes to dying' survey highlights a contradiction in our willingness to discuss death in the abstract, and our willingness to actually have that conversation in reference to our own mortality.

68% of British people are comfortable talking about death yet only 31% have discussed end-of-life issues with someone. This proportion rises to 45% when looking at those over 75, but this is still nowhere near the clear majority it should be. While comfortability of talking about death amongst the general public is widely reported, this has not translated into actual discussions. Reticence is worrying as a growing body of research, as well as intuition and anecdotes, suggests that talking about the end of life – also called 'advance care planning' – leads to 'better quality' deaths.

Why is it that people aren't talking about death and how they want to die? The reasons shift with age; for 18-34 year olds, 44% feel like it's a long way off. That's reasonable given that just over two thirds of deaths in the England & Wales were amongst those over 75 in 2016. If you include over 65s, the aged make up 84% of all deaths. Worryingly, 23% of those over 75 cite the same reason as adults under 35; they anticipate living for a good while longer. It is easy to overstate the homogeneity of the elderly and chronological age does not correlate perfectly with biological health, but this head in the sand attitude is probably not helpful in improving quality of death. Even if one appears spritely at 84, they should still be having a common-sense discussion about what they want from the end of their lives.

The work of charities like Dying Matters is steadily increasing engagement with the concept of death, which hopefully will decrease the number of those postponing a discussion of their own death. But, worryingly, the 'British social attitudes to dying' survey also found that for those over 75, even if they had wanted to discuss their deaths, 28% said that other people don't want to talk about it. Their preferences and priorities were not being heeded, presumably because the discussion was too uncomfortably close to reality.

For care home providers, the task is relatively simple; ensure that on arrival at the home there is a frank discussion about end-of-life care. A home doesn't need to be a specialist in palliative care, or to actively market toward the high acuity, potentially terminal cohort to understand that the risk of death is great enough to warrant a discussion of what is to be expected and what can be delivered.

Care homes, especially nursing homes, should be relatively well-prepared to shift to palliative care when the time comes. And this is the perception of the general public.

According to Sue Ryder the two characteristics most associated with residential or nursing homes are that there are "trained carers nearby to help you and your family" (76%), with ▶

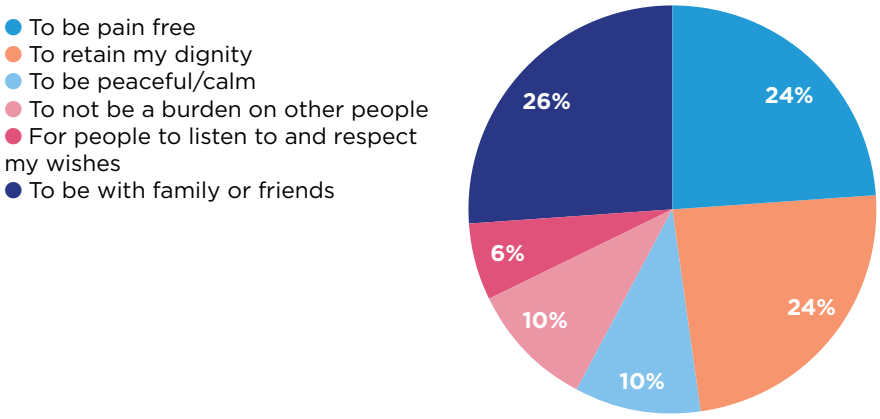
FIGURE 2: MATCHING PRIORITIES IN DYING AND CARE HOMES

Associations of residential or nursing homes in 'British social attitudes to dying' report: Dying, 2012

What factors do you associate with dying in a residential or nursing home?	
Professional medical support on standby for emergencies	75%
Trained carers nearby to help you & your family	69%
Being pain free/condition managed with medication	52%
Having privacy & dignity	8%
Feeling in control of your environment & the support you get	8%
Having your religious, cultural or spiritual needs met	6%

- Care homes are heavily associated with clinical professionalism
- However, there are shortfalls in the perceived ability to deliver agency, dignity and meet religious, cultural and spiritual needs
- These shortcomings can be mitigated by effective advance care planning.

First priority when dying according to 'British social attitudes to dying' report, 2012



- When made to choose a number one priority in death, to be with family or friends, to be pain free, and to retain dignity were of roughly equal importance
- Care homes are already considered to be good at delivering good pain management
- With an adequate advanced care plan, there is no reason why all of these needs cannot be met in a care home setting.

Source: 'British social attitudes to dying'

"professional medical support on standby" (56%) which gives the opportunity to be "pain free" or "to have a condition managed" (48%).

Given that for many people the priority is to be pain-free, care homes should be good options. But, more must be done to meet other priorities that are not traditionally associated with care homes, but are still important to residents. Scoring low in ▶ association with care homes is "access to privacy and retaining dignity" (9%), "feeling in control of your environment and support" (8%), and "having religious, cultural or spiritual needs met" (6%). When you ask people who have some experience of care homes the same question, the association falls further: 6%, 2% and 3% respectively.

But these problems are easily addressed within an advance care plan. There is nothing stopping care homes being able to ask the questions that allow people to feel in control of their environment, have choice over their support, and have their various non-physical needs met.

There is no doubt that a care plan that takes into account preferences in death would also reduce the number of people who are rushed to hospital just before they die for emergency treatment. As we know, only a small proportion want to die in the hyper-clinical setting of a hospital ward. But, this is where they end up because care plans do not include explicit instructions on what is to happen in the last few days or hours of life. Because the elderly resident has not voiced their preferences the care providers who would most likely feel an order to keep an individual in the home is right, do not feel empowered to withhold a hospital's support.

As a result, no one is happy. The carers see their residents abruptly taken to hospital, and away from the place they have called home for however long (the average is 30 months for residential homes and 16 for nursing). The hospitals now have an obligation to provide life-sustaining care from extremely tightly budgeted resources, and elderly people eventually die, without privacy, surrounded by clinicians.

Why is the provision of good quality palliative care not more widespread? A cynical answer could be that care homes deliberately underplay their capacity to cater for terminal residents. Stockton-on-Tees' strategic commissioning manager said: "Some homes do pick up a significant number of palliative packages of care from the local hospitals following discharge; however, this means that those homes will have a relatively high turnover of service users, just because of the nature of the support that they are offering, and the life span of that person when they are coming out of hospital." A high level of 'churn' impacts the top line, as it means empty beds for longer. But it also increases administrative costs associated with the admission of new residents. These costs are fixed for each new resident and the longer someone stays in a care home, the greater the revenue with which to cover initial outlay. If a home gains a reputation for excellent palliative care, they may well find that they begin receiving residents and referrals on the way out, with negative consequences for their viability.

The other risk may be to staffing. Retention might be more difficult in a care home where death is a more regular occurrence. A carer or nurse may

decide to move elsewhere if their job satisfaction is improved by longer lasting relationships with residents. Moreover, carers may have their own difficulties with talking about death; staff quoted in a report by the National End of Life Care Programme have said that they didn't talk about death because "it frightens me" or through a need to "protect" residents so as to not cause "upset".

Additionally, such a familiarity with death requires additional robust support and training that some care homes just don't have the cash for. It may mean counselling to address the emotional effects of end-of-life care work or courses on the more technical procedures and medications. Either way, some hardnosed care providers might see an opportunity to shift the responsibility to hospitals who will then pick up the pieces.

However, going forward, the choice to pass on palliative responsibility will have a significant impact to the operation of care homes. Apart from the ethics of hindering resident's dignity in death, care homes will be incentivised when they see referrals and recommendations falter if they do not put in place adequate advanced care plans. As commissioners increasingly push for the use of domiciliary care and extra care, when people eventually do go to care homes, they do so with needs of greater complexity and tend to not live as long. Increasingly, a move to a care home becomes the last move an older person makes, whereas historically they may have eventually been transferred to specialist care provision for palliative care. Such moves are disruptive and are being phased out; commissioners, relatives, and residents want to see their accommodation 'future-proofed' against such upheaval. In some parts of the county, such as Islington, they are "talking about potentially more need for palliative care." A care home that is unwilling to offer a robust palliative care package will not be considered adequate under these criteria and will be passed over in favour of one that does.

The best bet for care homes, is to begin to more consistently have discussions with residents and families about end-of-life care. Eventually all care homes will be the 'last stop' for residents who will be more receptive and appreciative of advance care planning. It will pay to be ahead of the curve and make end-of-life planning a priority in admission and in on-going care plans. ■

Clare Connell is managing director at Connell Consulting, a strategy consultancy specialising in the health, social care and education markets.
020 7371 8142 / clare@connell-consulting.com

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