Care homes as hospices: the problem with long-term care provision towards the end of life in England

*The people most likely to experience disadvantaged access to palliative care and unexpected death are those living at home and in care homes, writes **Diana Teggi**. She explains how the care sector can ensure proper and compassionate care, especially in the light of COVID-19.*

The coronavirus crisis has exposed clear and deep-rooted inequalities across society. These divisions are particularly stark in the disparities we see in funding and access to end of life care. That a large proportion of COVID-19 deaths in England and Wales has come from those living in care homes should thus come as little surprise: over a significant period, there has neither been the attention given, nor the resources allocated, to properly support the oldest and most disabled adults in our society.

Compared to people aged over-50 who receive long-term care, those aged 80+ and those living with severe disability, dementia or the effects of stroke, more often than not live and die in care homes as opposed to other long-term care settings such as hospices or at home. Dying from cancer is also provided for under the NHS and hospice sectors, but dying in very old age from dementia or chronic conditions is a social care remit, which is mostly subsidised by self-funders. So, while care homes are the new hospices for many, they also have far fewer resources to deal with end of life care when compared to hospices.

Those aged 85+, those with non-cancer diagnoses, and those with dementia are also under-represented in specialist palliative care services. Reflecting this, and as my research reveals, relatives are less likely to expect the deaths of family members aged 80+ as opposed to younger ones aged between 50 and 79. Further, deaths from non-Alzheimer's types of dementia, as well as the deaths of care home residents are similarly not expected by relatives, unlike deaths from cancer. Yet death expectation is essential to end of life care: it is not possible to care for someone's dying when the death is not anticipated.

How can the sector ensure proper and compassionate care, especially amidst a pandemic? Blatant mistakes such as the discharge of coronavirus-positive patients from hospitals to care homes, and the lack of timely guidance, testing and personal protective equipment must not be repeated again. Beyond this, structural reforms are needed if we are to correct the culture of institutional ageism at the root of the neglect of the social care sector. First, we need integrated health and social care which does not overly rely on families and private funding as this is inequitable and will not withstand demographic pressure. By 2035, the number of highly dependent adults in England is expected to increase by 36% in the over-65s and to almost double in the over-85s. As the Commission on the Future of Health and Social Care in England revealed, funding reforms are key to achieving the sort of integrated care able to provide equal support for equal need.

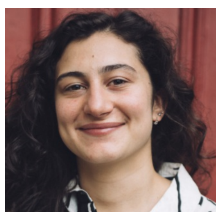
Specifically, the Commission advises a single, ring-fenced budget and a single local commissioner for health and social care as well as free access to social care when needs are high and at the end of life. This includes care home and domiciliary settings providing 24/7 supervision and care. Under the current funding model, local authorities cannot meet care home providers' costs, with self-funders paying on average 41% more for the same service to compensate for the loss. The scale of underfunding is also huge in the domiciliary care sector, with local authorities paying almost £2 per hour less than the minimum providers' price. An already strained market is now facing even more severe financial pressure as a result of significant extra costs and loss of income due to Covid-19. Government funding is thus key to ensure both the immediate recovery and long-term sustainability of the care market.

Second, we need policies that acknowledge the differences of dying in very old age. In particular, we need more research into dying in care homes that deals with issues of medicalisation and institutionalisation without evaluating care homes by hospice standards. Death and dying are not just medical events. So, we need to take care homes' knowledge and experience seriously as they are the ones caring for people dying in very old age over an extended period of time. This will lead to ad hoc policies and practice guidelines as opposed to the current one-size-fits-all approach to end of life care in every setting, featuring hospice and specialist palliative care agencies as the only contributors.

The situation is different in Australia and New Zeeland where the aged care and care home sectors contributed to policy design, and end of life care in old age reached satisfactory standards. This was the result of decades-long government investments in research and clinical education at the national level. Although the Care Quality Commission recognised end of life care as an area of improvement for care homes, this kind of initiative is still lacking in the UK. A first step in this direction could well be the creation of a linked dataset for care homes as an instrument to both monitor and coordinate action with healthcare settings. There is no shortage of data on care homes, much of which is held by providers themselves. What is lacking is a single, readily accessible dataset. Its absence was deeply felt early in the pandemic when the spread of COVID-19 in care homes was underestimated.

Third, we need to value the role of care work in our society and support care home staff beyond symbolic acts. This brings us back to funding issues and a cash-stricken industry which cannot afford to pay real living wages. Care workers are nothing but unskilled. Their caring and compassionate qualities demand adequate remuneration as much as social recognition. One of the silver linings of the pandemic has been the abundance of positive media coverage on a sector which has often been stigmatised or outright ignored by the press. COVID-19 has sensitised large swathes of the population to the reality of care homes and caring for our older people until the very end. The hope is that this will, at last, bring government action in line with the PM's promise to solve the social care crisis.

About the Author



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