Living conditions and cultural needs towards the end of life: Patient and public reflections on census data for people who died in England and Wales

"With all the will in the world, everything that you want to do for them, you think 'we should give them more than we are able to provide in this house' and that is why they end up in hospital."

(PPI workshop participant)

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Cicely Saunders International
Better care at the end of life

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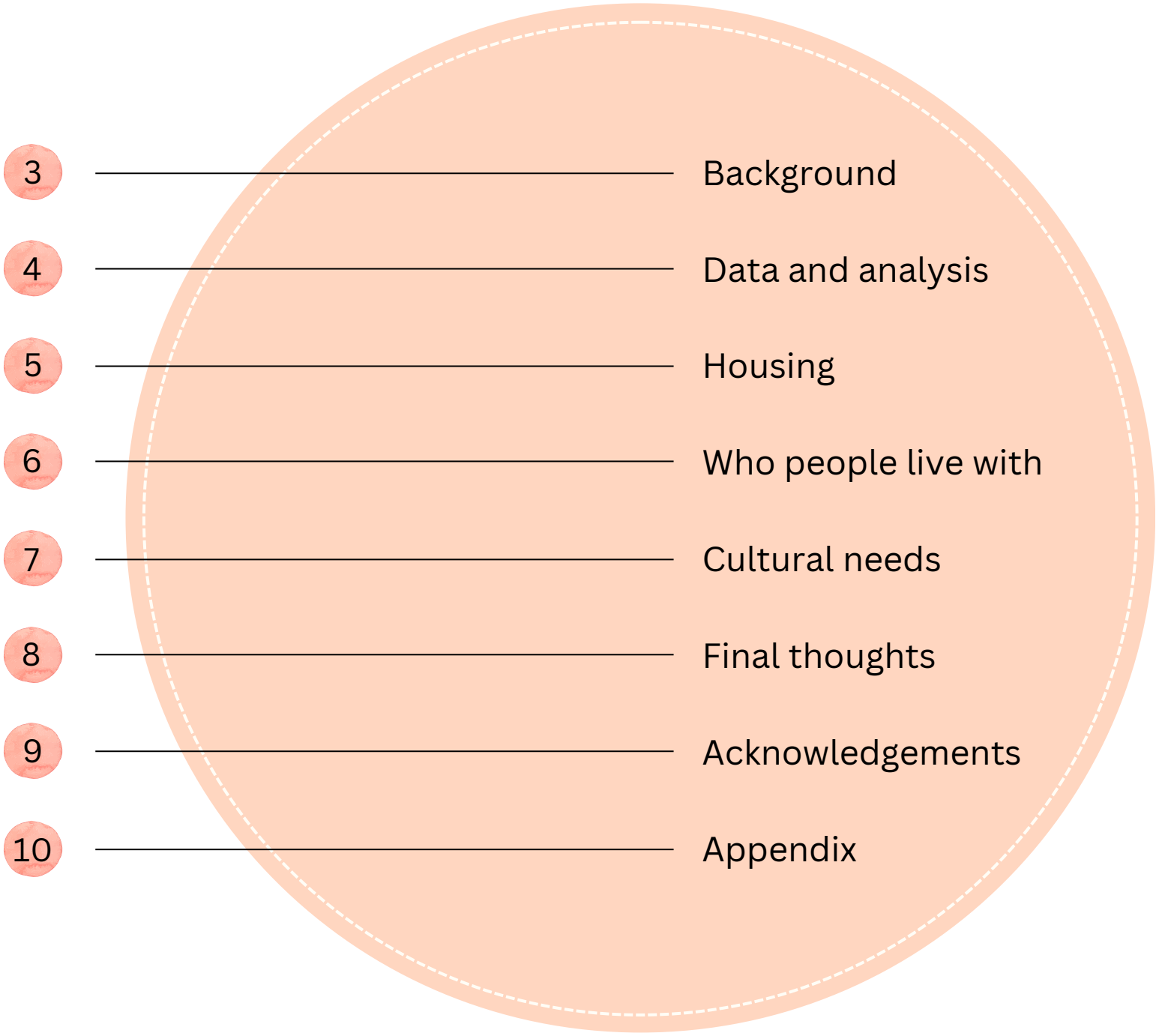


Background (from the PPI authors)

We are a diverse group of people with lived experience caring for family members with palliative and end of life care needs, either currently or in the past. We have experience of living with financial hardship and/or are from ethnic minority communities.

We have been supporting this project which is using data from the UK Census collected in 2011 to describe living conditions for people in the last year of life. We held online workshops in September and October 2023, where people living with life-limiting illnesses and informal carers were invited to share their experiences of how living conditions and cultural needs can shape experiences and preferences for care in the last months and weeks of life.

12 people (including authors of this report) attended the workshops; 11 were carers and 1 was a patient, 9 had experience of financial hardship, and 7 were from ethnic minorities.

This report presents some of the data that we discussed and shares reflections from the workshops, illustrated with quotes.

The report is organised into 3 themes: housing, who people live with, and cultural needs.

Statistical data and analysis (from the research team)

The statistical data in this report come from the Office for National Statistics Longitudinal Study (ONS LS). The ONS LS links data from the national censuses to life events data for a 1% sample of the population in England and Wales. For this report we have used data from the Census in 2011, linked to death certificates data for people who died in England and Wales.

For the data on housing and who people live with, the sample includes 3,976 people who were living at home when they completed the Census in 2011, and died in the 12 months following the Census. We haven't included people living in care or nursing homes because the data describes living conditions at home in the last year of life. We restricted the sample to people who died in the 12 months after they completed the Census to get a picture of living conditions in the last year of life, and because living conditions are more likely to change over longer periods of time.

For the data on cultural needs, the sample includes 34,935 people who were living either at home or in a care home or nursing home when they completed the Census in 2011, and died in the following years up until 2017.

For the section on cultural needs, we did not need to restrict the sample to people who died in the 12 months following the Census, because aspects of culture such as religion or language are usually more 'fixed' than living conditions. For the data on cultural needs, it was also important to include as large a sample as possible to ensure that minority groups are adequately represented in the data.

We estimate the number of people who die each year in England and Wales that are affected by the issues we report on. This estimation method takes the proportions in the sample of deceased people from the ONS Longitudinal Study and applies these to the number of people who died in 2019. More details on this method of estimation are in the Appendix.

The 2011 Census data was the most recent data available to us. The 2021 Census is expected to become available in the ONS LS at some point in 2024. We should keep in mind that living conditions and cultural needs for people who die in England and Wales may have changed since 2011, and that these changes are not captured in the data that we report.

Housing

In the workshops, participants discussed overcrowded homes. They expressed how a lack of space not only has negative effects on the person who is ill, but also on the people living with and caring for them.

"But when things come to the crunch, when mum and dad were really ill or you were really ill, if your house is not large enough, you become cramped. To look after a sick person in a very limited house is actually profoundly difficult."

"A house can soon resemble a sick bay when you are caring for a loved one."

Poor housing conditions, such as a lack of central heating, can lead to inadequate environments to live in, especially for those with heightened health needs. It can also impede family members from providing the care they desire.

"With all the will in the world, everything that you want to do for them, you think 'we should give them more than we are able to provide in this house' and that is why they end up in hospital."

The participants added that the cost of living crisis has worsened housing problems for people today.

"Even if they have heating provisions, they may not be able to afford it...my heating bill is £250 per month."

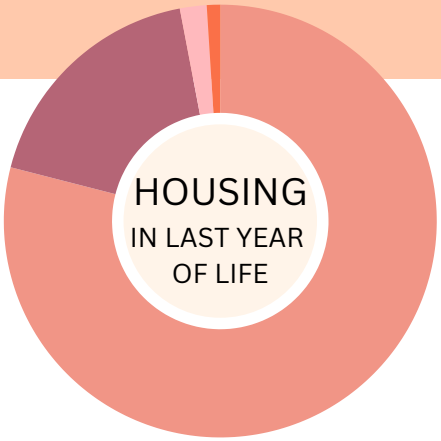
They also noted the importance of the type of accommodation people live in, and how this can ease or create problems for those who are approaching the end of life.

"I was in this two-storey house and I had breathlessness, so getting up the stairs, you know, if I had an attack of my illness, I would get to the top of the stairs and then collapse."

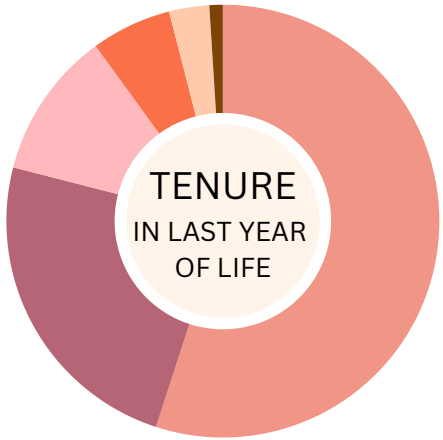
"I wish [my parents] had moved to a bungalow because it would have been easier all on the same floor, you know."

These experiences demonstrate the practical and emotional impacts that housing can have on people nearing the end of life and their family carers. They also draw attention to housing conditions that can exacerbate difficulties in the daily management of care.

DATA SOURCE: ONS LS



- HOUSE 79%
- FLAT / TENEMENT 18%
- SHARED 2%
- OTHER 1%

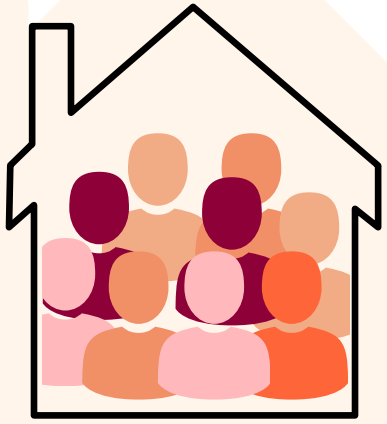


- OWN OUTRIGHT 55%
- SOCIAL RENTED 24%
- OWN WITH MORTGAGE 11%
- PRIVATE RENTED 6%
- LIVES RENT FREE 3%
- SHARED OWNERSHIP 1%

20,000 PEOPLE

DIE EACH YEAR LIVING IN OVERCROWDED ACCOMMODATION*

*A household is considered overcrowded if it has fewer bedrooms or rooms available than required, for example, a one person household is assumed to require three rooms - two common rooms and one bedroom.



14,000 PEOPLE

DIE EACH YEAR LIVING WITH NO CENTRAL HEATING

Who people live with

Participants discussed feeling a sense of duty around caring for their loved ones.

"I'd like to think that because I was there, I provided comfort. There's a question of duty. And on my parents' part, a question of dependence on me."

Whilst many people may be living with family towards the end of life, a large proportion are living alone. Participants highlighted geographical barriers or childcare responsibilities as contributing factors.

"We couldn't care for [him]. He lived alone and we were too far away. He had a sudden collapse and none of us were around, we were all in our different houses. He was rushed to hospital on his own."

Some people are unable to move closer to loved ones and/or professional care, due to lack of resource or the emotional comfort tied to where they have spent years calling home.

"Moving accommodation, that in itself would be a trauma. My sister is now 75, if she was to move after being used to living in this house for 40 years, that in itself could probably bring on her death."

Participants also discussed the trauma that some people who are living alone may have experienced, having themselves been bereaved.

"I've experienced the emotional pain of being bereaved on my own, it's a feeling of helplessness."

The data shows that an estimated 60,000 people who died had also been caring for someone else.

The participants discussed how looking after loved ones remains an important responsibility throughout the span of your life.

"Just because you're old or you're ill doesn't mean you don't have caring duties."

When reflecting on people living with dependent children in the last year of life, the participants noted that this can result in a much earlier onset of caring responsibilities.

"All of a sudden at the age of 12, I became an adult and took on all these responsibilities, including looking after mum and dad."

These experiences shed light on some of the reasons why people nearing the end of life may live alone and some of the motivations for caring for loved ones at home.

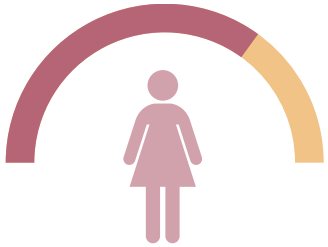
DATA SOURCE: ONS LS

41%

OF PEOPLE LIVE ALONE IN THEIR LAST YEAR OF LIFE

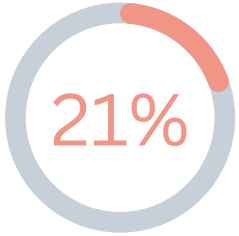
70%

OF WOMEN OVER AGE 85 LIVE ALONE IN THEIR LAST YEAR OF LIFE



20,000 PEOPLE

DIE EACH YEAR LIVING WITH DEPENDENT CHILDREN



OF WORKING AGE PEOPLE (18-64 YRS) WHO DIED WERE LIVING WITH DEPENDENT CHILDREN IN THEIR LAST YEAR OF LIFE

60,000 PEOPLE

WHO DIE EACH YEAR WERE PROVIDING CARE FOR SOMEONE ELSE IN THEIR LAST YEAR OF LIFE

Cultural needs

Language needs were highlighted as being important to receiving the right care. The participants described the detrimental impacts when patients cannot communicate effectively with healthcare professionals.

"When a person cannot communicate, that is being in locked-in syndrome. If you were desperately trying to say something that could save your life but you were gagged, imagine how you would feel. You're trying to scream and explain and explain. Lack of language completely isolates you."

They added that language can create problems for native English speakers too, in the form of health literacy or hearing impairments.

"Even the average UK citizen has trouble understanding medical jargon. And that then brings on all the power problems because you don't feel empowered."

"My uncle had a hearing impairment. This made communication difficult, particularly if a new doctor came out such as one from our local out of hours service."

One of the participants shared their experience of inadequate translator support within the care system for non-English speakers.

"Standard Gujarati words which my sister uttered, he didn't have a clue what she said. The interpreter is then asking me in front of her 'what is your sister saying?' And when he was interpreting, he was interpreting incorrectly."

Regarding religion, the participants expressed that spirituality may change towards the end of life, or have more importance to some people.

"When you get closer to the end, you need to feel comfort that there's something afterwards."

"[His] spirituality was personal and profound. His interaction with nature was lovely to witness. The joy of watching birds in his garden when he was confined to home I'm sure lifted both our spirits as he approached the end of life."

Cultural needs were also discussed in relation to feeling responsible for providing care at home for loved ones who are nearing the end of life.

"There's a feeling of guilt in my culture of putting anyone in a care home. If you're not in the same home, they might feel you've abandoned them."

DATA SOURCE: ONS LS

TOP 5 **NON-ENGLISH LANGUAGES** SPOKEN BY PEOPLE WHO DIED

- PANJABI
- GUJARATI
- URDU
- BENGALI
- POLISH

20,000 PEOPLE DID NOT HAVE ENGLISH OR WELSH AS THEIR MAIN LANGUAGE

RELIGION OF PEOPLE WHO DIED

CHRISTIAN 78.4%
NO RELIGION 9.5%
NOT STATED 8%
MUSLIM 1.5%
HINDU 0.9%
JEWISH 0.6%
SIKH 0.6%
OTHER 0.3%
BUDDHIST 0.2%

Final thoughts (from the PPI authors and the research team)

This report presents demographic data describing living conditions and cultural needs for people nearing the end of life. The characteristics of people who are nearing the end of life are different to those of the overall population. Using nationally representative Census data to describe this population can help to identify needs or areas of concern, such as highlighting the proportion of people living in inadequate housing, living alone, or with additional communication needs. As shown in the discussions we held in our PPI workshops, poorer living conditions and unmet cultural needs can have negative impacts on people living with life-limiting illness and the family and loved ones who are caring for them.

The reflections from our workshops provide a deeper understanding of the data by offering an insight into the experiences behind them. For instance, we can learn of the emotional pain associated with language barriers, or the sense of duty some family members feel to take care of loved ones who are nearing the end of life. These perspectives also help to uncover assumptions that may exist in the data. For example, in the context of language needs, whilst the majority of people who die speak English or Welsh as their first language, this may mask problems with poor health literacy. Or, a non-English speaker may be given access to a translator, but this service can be inaccurate and lack the necessary understanding of local dialects.

A final reflection that was prominent throughout our workshop discussions is a recognition of the complex intersection of social, cultural and economic factors that shape end of life experiences. It is important to consider how factors connect to each other. For example, in some cultures the expectation to live with and care for a family member who is unwell, can result in people living in inadequate or overcrowded accommodation. For others, living alone in unsuitable accommodation is the only option because relocating is feared to be a traumatic transition. Understanding the complex interplay of social factors is essential for providing good quality and tailored care for people towards the end of life.

This final quote helps to sum up this sentiment about the need to recognise that people and experiences are shaped by a multitude of factors:

“It is a contribution of multiple factors. You cannot isolate one factor because a human being is not made of one factor. He's made-up of housing, he's made-up of relations, he's made-up of economic deprivation, he's made-up of religion. And when you're very ill, they all come together, because that is you.”

Acknowledgements

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The permission of the Office for National Statistics to use the Longitudinal Study is gratefully acknowledged, as is the help provided by staff of the Centre for Longitudinal Study information and User Support (CeLSIUS). CeLSIUS is funded by the ESRC under project ES/V003488/1. The research team authors alone are responsible for the interpretation of the data.

The LS uses information from the 1971, 1981, 1991, 2001 and 2011 censuses; individuals census forms are linked; data is also linked to life events data (deaths, births and cancer registrations); individuals can enter the study by birth or immigration and being born on one of the four LS birthdays, and leave the study through emigration or death; and that the study contains data for over 1.1 million people.

Doi: https://doi.org/10.57906/z9xn-ng05

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Appendix

Population estimates method

To estimate the number of people who die in England and Wales each year that are affected by the issues we have reported, we applied the proportions from the sample of people in the ONS LS data to national data on the number of people who died in England and Wales in 2019. The proportions from the ONS LS and the national data on deaths in 2019 were split by sex (men and women) and by age group (18 to 64, 65 to 74, 75 to 84, and 85+), to account for changes between 2011/12 and 2019 in the age and sex structure of people who died.

For the population estimates on housing and who people live with, the ONS LS sample only included people living in their own homes (not people living in care or nursing homes), and so we excluded care or nursing home residents from the national data as well. For the population estimates on language needs, the ONS LS sample includes care or nursing home residents and so does the national data.

The method has 3 stages:

1. Derive the number of deaths (excluding or including deaths from care or nursing home residents, as appropriate) for men and women in 4 age-bands in England and Wales in 2019.
2. Derive the proportion from the ONS LS samples, for men and women in 4 age-bands.
3. Apply ONS LS percentages (stage 2) to the population in 2019 (stage 1), and sum the age and sex specific totals to give a total for the population.

The estimates have been rounded to the nearest 10,000 to acknowledge uncertainty in the estimation method.

Data sources

Age and sex specific number of deaths in 2019 – for England and Wales combined.
Local file name: ONS_deathEngWales2019(1).xlsx
Source: ONS
https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/deathsregisteredinenglandandwalesseriesdrreferencetables

Age and sex specific number of deaths of ‘care home residents’ (all places of death) in 2019 – for England and Wales separately.
Local file name: ONS_carehomeresident_deaths_2019.xlsx
Source: ONS
https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/deathsinthecaresectorenglandandwales