

# Briefing on the impacts of cost-of-living on people at the end of life

October 2023

Poverty and financial hardship are a stark reality for many at the end of life. This can be for a range of reasons; they may have to reduce their working hours or stop work altogether, and those close to them may have to do the same to provide care. As well as a reduced household income many also see an increase in their costs because of factors such as travelling to more medical appointments, running energy intensive medical equipment and keeping the home warmer.<sup>1</sup>

The cost-of-living crisis has hit UK households hard, with many having to make decisions about where to cut back, this is no different for people at the end of life who already face financial pressures and extra costs. To gain a better understanding of the impact of the cost-of-living crisis on people at the end of life, Sue Ryder commissioned polling of people who are receiving palliative and end-of-life care.<sup>2</sup>

## Key findings

### Preferred care setting

Almost all respondents told us that the cost-of-living crisis impacted where they would like to receive care. Everyone should have the right to receive end-of-life care in their preferred location and it is incredibly concerning that rising costs have affected people's decision about where they receive care.

### Preferred location to receive care

98% of respondents said rising costs have impacted where they would most like to receive end of life care.

There wasn't a particular sway of where people previously wanted to be cared for to where they now want to be cared for, but a varied mixture of changed preferences.

- Of those who wanted to be cared for in a hospice before cost of living increases, 40% now want to be cared for in their own home, 32% want to be cared for in someone else's home.
- Of those who wanted to be cared for in a hospital before cost of living increases 39% now want to be cared for in their own home.
- Of those who wanted to be cared for in their own home before cost of living increases 35% now want to be cared for in a hospice and 37% want to be cared for in a hospital.

### Factors affecting preferred location

A wide variety of factors led respondents to change where they would most like to receive end of life care, the most common were:

- Family working more hours to cover rising costs, so unavailable to provide care (31%)
- Additional pressure to family – increased costs (energy/food) of being cared for at home (29%)
- Cost of family needing to travel (including travel and accommodation) to visit (28%)
- Additional pressure to family – family member unable to work as caring for me (27%)
- Cost of travel to attend medical appointments/ therapies (22%).

### Running essential medical equipment

A significant majority of respondents told us that they have been unable to run essential medical equipment due to high energy costs. This is causing increased visits to healthcare services and visits from healthcare professionals, which means higher costs to health services in the long-term. This is something that was already incredibly costly, for example Marie Curie figures show that the total cost of emergency admissions for people in the last 12 months

<sup>1</sup> <https://www.mariecurie.org.uk/globalassets/media/documents/policy/dying-in-poverty/k406-povertyenergyreport-finalversion.pdf>

<sup>2</sup> In May 2023 Censuswide polled 201 people aged 18+ who are receiving palliative and end of life care in the UK.



of life were more than £1.2bn in 2018-19.<sup>3</sup> On top of this, government statistics also show that in 2021 63.5% of people had a least one emergency admission in their last 3 months of life.<sup>4</sup>

- 81% have been unable to run essential medical equipment due to high energy costs since the cost-of-living crisis, 40% said this has happened frequently.
- 48% said the impact of being unable to run essential medical equipment due to high energy costs is increased visits from healthcare professionals.
- 44% said the impact of being unable to run essential medical equipment due to high energy costs is needing emergency healthcare professional assistance.
- 36% said the impact of being unable to run essential medical equipment due to high energy costs is poor pain and symptom management.

## Attending medical appointments

Most people at the end of life will need to attend more medical appointments. Shockingly our polling found that many have been unable to do this due to cost concerns.

- 91% have been unable to attend medical or day centre therapy appointments due to increased costs since the start of the costs-of-living crisis, with 38% having been unable to attend frequently.
- 39% said the number one impact of not being able to attend medical or day centre therapy centre appointments – was increased visits from healthcare professionals.
- 40% said that concerns about the cost of any prescriptions that may result from their visit was a reason for not attending appointment.

## Next steps for Government

These findings demonstrate that people urgently need more financial support at the end of life, particularly in the context of the cost-of-living crisis. Whilst the sample size of this polling was relatively small due to the difficult nature of receiving responses from people who are in very poor health, it clearly identifies the main financial issues affecting people at the end of life. With an estimated 378,427 people receiving palliative care in England every year,<sup>5</sup> these issues are likely to be affecting people on a much wider scale.

The Government must review the financial support they provide to those at the end-of-life in the immediate and longer-term, to identify where there are gaps in support and where existing support is inadequate. These gaps must be urgently addressed to ensure that no-one faces poverty at the end of life and to reduce the NHS costs incurred by emergency admissions.

## About Sue Ryder

At Sue Ryder, we can't make life's most difficult moments easy, but we can carry some of the load. For more than 70 years, we have been a source of strength and support for anyone living with a life-limiting illness or grief. Dying and grief are universal experiences, but too many people face them alone. We are a safe and reassuring hand you can reach for. From providing care and support for someone at the end of their life to helping someone manage their grief, we know there is no one size fits all when it comes to how we cope and the help we need. We campaign for everyone who is approaching the end of their life or grieving to have access to the right support, at the right time. And we seek to break down the barriers to talking about dying and grief - so we can all be better prepared and better equipped to be there for each other.

We can make a positive difference during even the darkest of times. Whether in the last months, weeks or days of life, or living with grief, we help people live the best life they possibly can. We are there when it matters.

**For more information contact [campaigns@sue Ryder.org](mailto:campaigns@sue Ryder.org)**

<sup>3</sup> <https://www.mariecurie.org.uk/globalassets/media/images/policy/h408-in-and-out-of-hospital-emergency-admissions-v7.pdf>

<sup>4</sup> [https://fingertips.phe.org.uk/documents/peolc\\_patterns\\_of\\_care\\_factsheet\\_2021.html](https://fingertips.phe.org.uk/documents/peolc_patterns_of_care_factsheet_2021.html)

<sup>5</sup> <https://www.ohe.org/publications/unrelieved-pain-palliative-care-england/#:~:text=This%20study%20estimates%20that%20currently,care%20suffering%20from%20unrelieved%20pain.&text=Download%20publication-,In%20England%2C%20an%20estimated%20378%2C427%20people%20receive%20palliative%20care%20each,of%20specialised%20and%20generalised%20services.>

