

Marie Curie data briefing

The Cost of Living: A survey of Marie Curie Caring Services Staff



Introduction

The ongoing cost of living crisis continues to hit UK households hard, with annual inflation having reached 9.2%¹ by the end of 2022 and families across the country struggling with the rising price of food, fuel and other daily essentials. Many of those living with terminal illness were already struggling to make ends meet long before recent rises to inflation, rises in prices have only exacerbated the financial insecurity they were facing.

Marie Curie's *Dying in Poverty* report, published in May 2022, found that 90,000² people died in poverty in the UK every year, even before the cost of living crisis, with one in every four people who dies in working age in the UK spending the last year of their lives in poverty. Lost income, added costs – such as travel to medical appointments, paying for medication and higher energy bills – and inadequate welfare benefits can, in many cases, push dying people below the poverty line.

The sharp rise in energy bills during the last year has been a particular concern for terminally ill people - our research has shown how terminally ill people are particularly at risk of fuel poverty, with the need to heat the home longer or to a higher temperature and to power specialist medical equipment seeing energy bills for some terminally ill people rising as much as 75% in the aftermath of their diagnosis³.

This data briefing, based upon a new survey of Marie Curie's Caring Services workforce, shows that the cost of living crisis has left even more people affected by terminal illness struggling financially than before, with many struggling to afford essentials like energy bills, food and housing costs, and with support provided to date by the UK Government not going far enough to meet the rising costs those at the end of life are facing. It underlines the urgency of Marie Curie's *Dying in Poverty* campaign, which calls upon the Government to provide further, targeted support to terminally ill people with the cost of living to prevent thousands of people spending the end of their lives in poverty.

Methodology

Marie Curie's community nurses, hospice staff, healthcare assistants and social workers provide frontline care for 50,000 people at the end of life each year across all four nations of the UK. They see patients at their best and at their worst and have a unique insight into how the ongoing cost of living crisis is affecting people living with terminal illness, their families and their carers.

¹ Office for National Statistics. [Consumer price inflation, UK: December 2022](#).

² Marie Curie. [Dying in Poverty: Exploring poverty at the end of life in the UK](#). May 2022.

³ Marie Curie. [Dying in Poverty: Improving financial support for terminally ill people with the cost of living](#). October 2022.

To better understand how the cost of living crisis is affecting families affected by terminal illness, and how this has changed across 2022, we conducted a survey of our Caring Services workforce in December 2022 and January 2023.

We received 335 responses from Marie Curie Caring Services staff across the four UK nations and from different health professions, with the number of responses in each nation as follows:

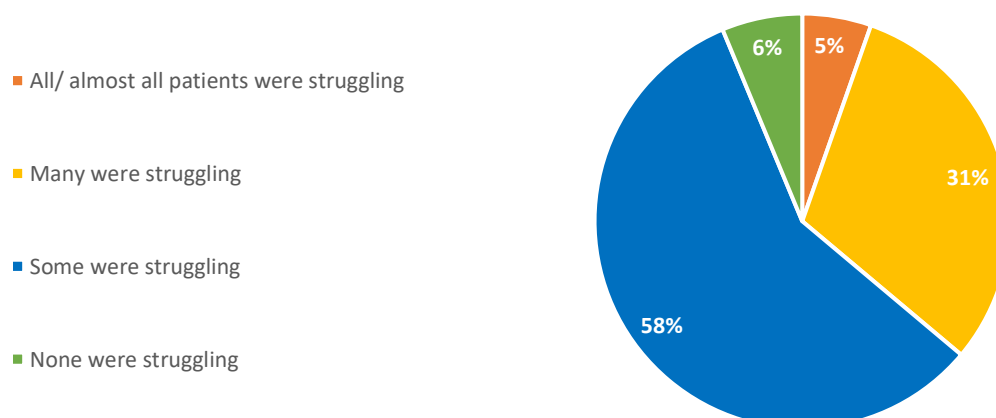
- England - 160
- Wales – 53
- Scotland – 63
- Northern Ireland – 59

Key findings

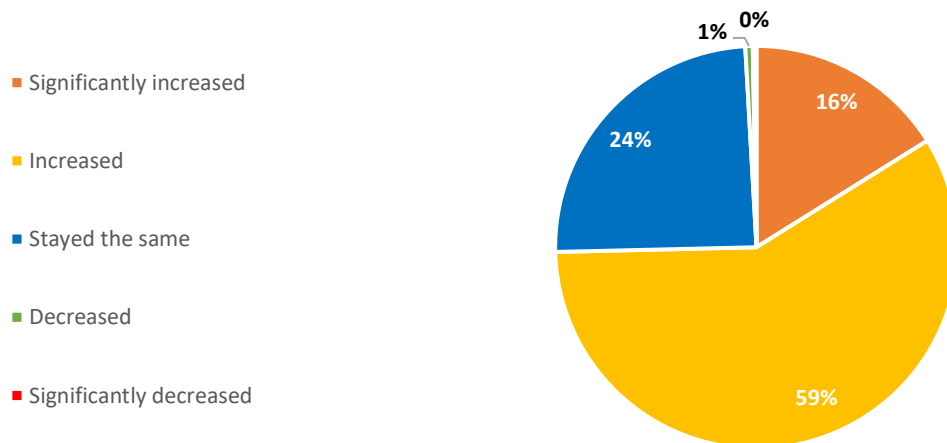
Overall, Marie Curie staff have seen more patients struggling with their finances during 2022, with many struggling to meet the cost of basic essentials. Our staff were very concerned about their patients' ability to keep their houses warm this winter owing to the rising cost of energy bills. Staff also observed that the financial struggles faced by their patients were linked to the further deterioration of patients' mental and physical wellbeing and the wellbeing of their family, friends and carers.

More terminally ill people are struggling financially

Over the last 12 months, 89% of Marie Curie staff have cared for patients who were struggling financially. A third (36%) reported that 'all/almost all' or 'many' patients were struggling and nearly two-thirds (58%) reporting that 'some were struggling'. Just 6% of those who responded to the survey said they had not cared for a patient who was not struggling financially in 2022.

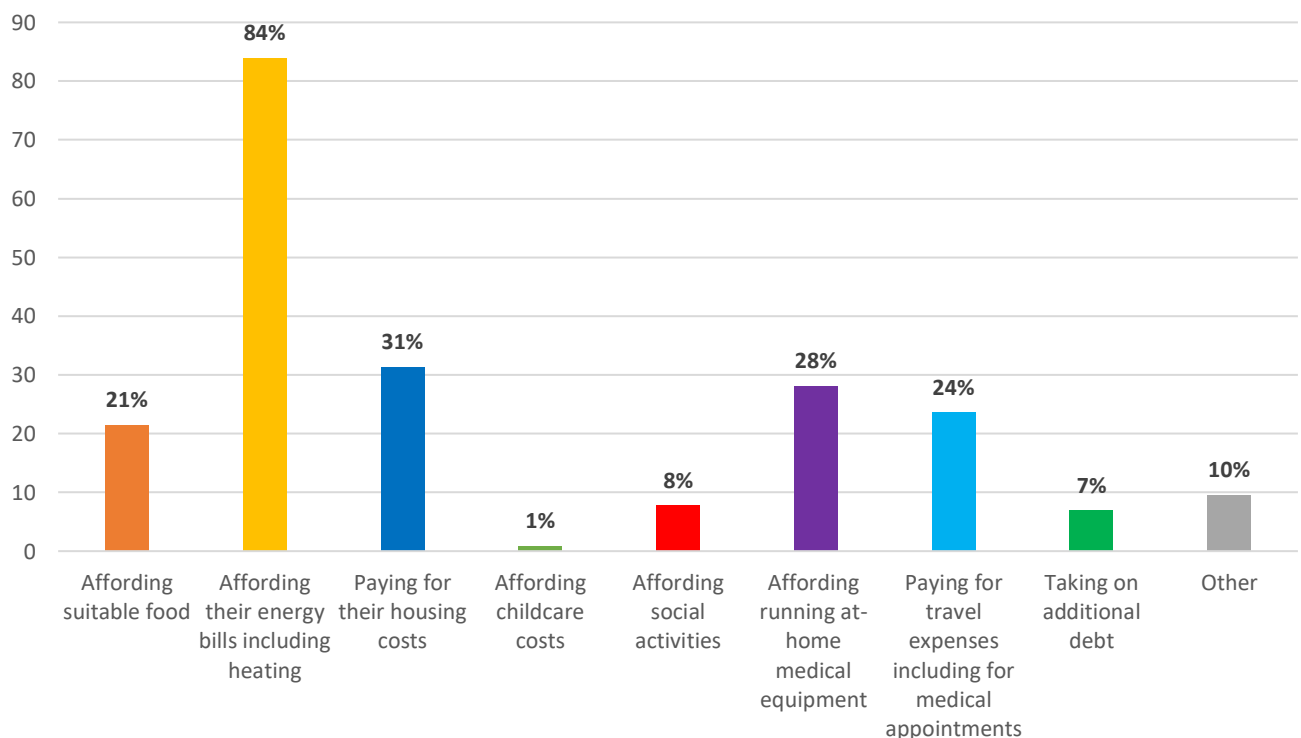


When asked if there has been a change in the number of patients, they cared for who were struggling financially since this time last year, overall 75% of Marie Curie staff reported that there had been an increase in the number of their patients who were struggling. Just 1% of Marie Curie staff reported that the number of their patients struggling financially had decreased since last year.



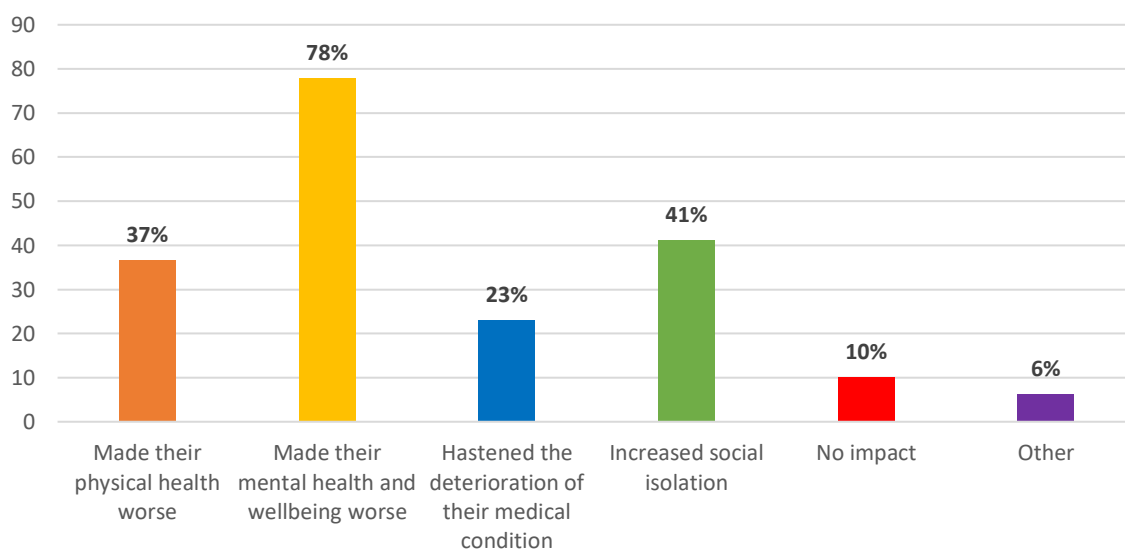
The impacts of financial insecurity at the end of life

Among the most significant financial impacts on patients observed by Marie Curie staff in 2022, 281 (84% of those who responded to the survey) said that they had observed patients struggling to afford their energy bills, with 105 (31%) also observing patients struggling to meet their housing costs, 94 (28%) reporting patients struggling to afford running at-home medical devices and 72 (21%) even reporting seeing patients struggling to afford suitable food.



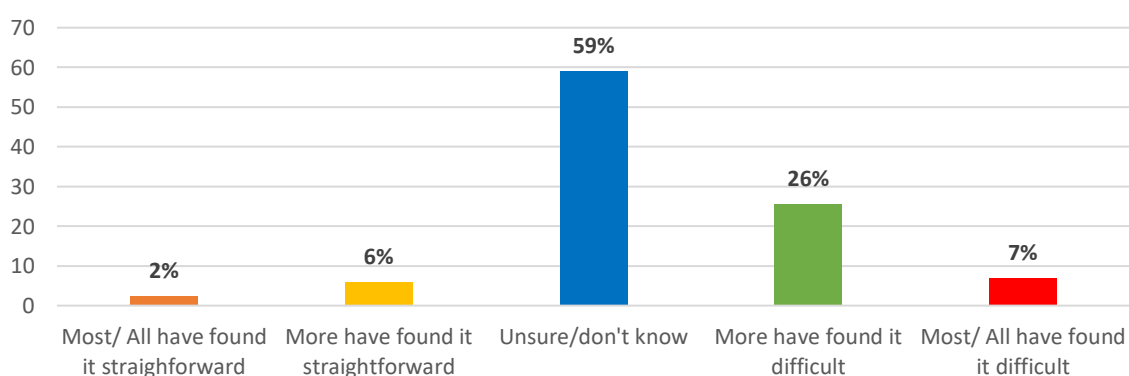
"I have been to patients that the fridge is bare, and the house is freezing, I went to one patient where she had so many blankets on her to keep warm because they could not afford to turn the heating on." Marie Curie staff member

In addition to the financial impact on patients, we know that financial insecurity can have significant negative impacts on the physical and mental well-being of terminally ill people and their families. 4 out of 5 Marie Curie staff (78%) observed that they had witnessed impacts on the mental health of their patients because of financial insecurity in 2022, with a third (37%) observing impacts on the physical health of patients and 41% observing an increase in patients' social isolation due to financial struggles. Shockingly, one in five (23%) of Marie Curie staff felt that financial insecurity had hastened the deterioration of some of their patients' conditions.

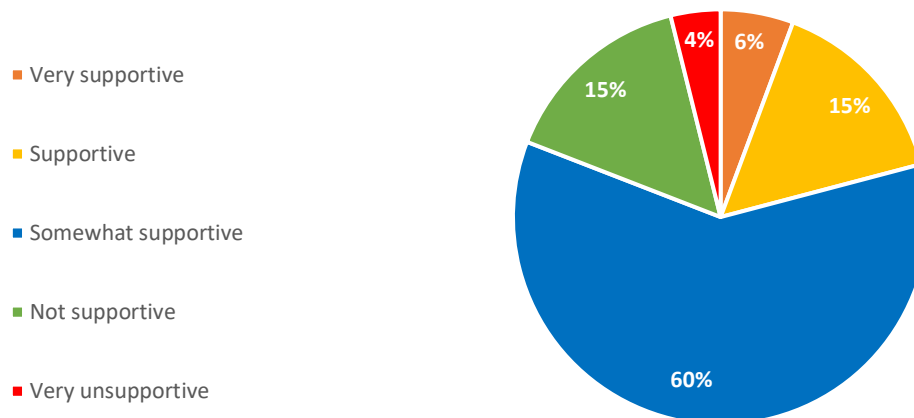


Accessing financial support

Only 2% of Marie Curie staff felt that a majority of their patients had found it straightforward to access financial support from the UK Government over the last year, with 26% saying that more of their patients had found it difficult to access support. Most (59%) Marie Curie staff, however, were unsure how difficult or straightforward their patients had found accessing financial support from the Government with the cost of living.

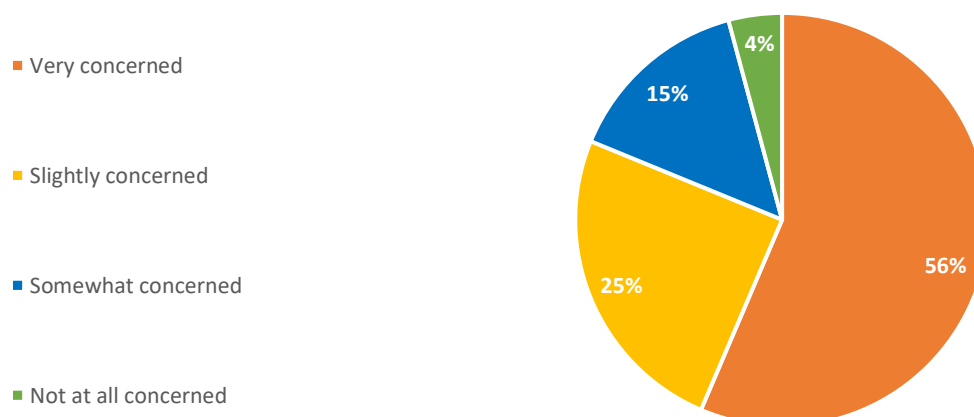


Around two-thirds (60%) of Marie Curie staff felt that financial support from the Government with the rising cost of energy in 2022 had been 'somewhat supportive' for their patients - but only 6% said they felt this had been very supportive. Concerningly, one in six (15%) felt that support from the government with energy bills had not been supportive for their patients.



Concern over patients' ability to heat their homes

Finally, we asked Marie Curie staff how concerned they were that their patients would be able to keep their homes warm over the winter. More than four in five Marie Curie staff (81%) reported that they were concerned or very concerned about this, with more than half (56%) reporting that they were 'very concerned' for their patients. Just 4% of staff reported that they had no concerns about their patients' ability to keep their homes warm over the winter.



Conclusions

Marie Curie's Caring Services staff provide frontline care to thousands of people at the end of life, their families and their carers, every year. In 2022, they witnessed a sharp increase in the number of patients struggling financially as the cost of living has risen – with significant impacts not only on their ability to make ends meet and pay for daily essentials like food and utility bills, but also on their health and wellbeing. More than four in five staff have witnessed patients struggling to pay their energy bills – a particular concern given the vulnerability of terminally ill people to fuel poverty and the importance to those living with terminal illness of staying warm, especially over the winter.

Support from the UK Government with the rising cost of living, and particularly with rising energy bills, is welcome and it is reassuring that our staff have seen some positive from this support. It is clear from the experience of our staff, however, that support provided to date has not fully met the rising costs patients are facing – and too many are struggling to access that support in practice.

The findings of this survey underline the urgency of Marie Curie's Dying in Poverty campaign. We are calling on Government to:

- 1. Give all dying people access to their State Pension, no matter their age**
- 2. Protect dying people from soaring energy bills**
- 3. Support dying parents with childcare costs**

It is clear from this survey that further, targeted support must be made available to terminally ill people and their families with the added costs and financial impacts they face due to their illness.

With more terminally ill people struggling than before, and Marie Curie's research having shown that one in four people who die in working age were spending their last year in poverty even before the cost of living crisis, access to the State Pension would be a lifeline for these families. It cannot be right that those who die in working age, and are most at risk of dying in poverty, miss out on this support after paying into the system all their lives – simply because their lives will be cut short.

This survey sharply underlines the particular vulnerability of terminally ill people to fuel poverty. Existing support with energy bills is welcome but will not go far enough to meet the added cost of energy terminally ill people face. Entitling all terminally ill people, regardless of age, to the Winter Fuel Payment and Warm Home Discount would prevent families from having to make the impossible choice between keeping their homes warm and eating or paying other bills.

Working age parents are more at risk of falling into poverty during a terminal illness than any other group. The UK already has the most expensive childcare system in the world and these costs do not go away after a terminal diagnosis. The Government must ensure that all terminally ill people can benefit from proposals in the 2023 Budget to support parents with the cost of childcare.

2022 saw the sharpest increase in the cost of living for a generation – with price rises expected to continue this year, it is vital that in 2023 the UK Government acts to ensure those nearing the end of their lives can afford to make ends meet, and to prevent people living with terminal illness from dying in poverty.