Marie Curie data briefing
Poverty at the end of life in the UK: A survey of Marie Curie community nurses

March 2022

INTRODUCTION

The current cost of living crisis is having devastating consequences for households across the U.K., but those impacted by terminal illnesses have been largely ignored in the public policy debate on this issue. That is despite evidence showing that, even in ordinary circumstances, those at the end of life may be particularly at-risk of slipping into poverty – owing to the high costs associated with their declining health, the barriers they face to accessing welfare support and their inability to engage in paid employment. [1]

We already know that living in poverty has a cruel impact on people who are terminally ill. It robs them of a decent quality of life before they die, creates extra stress and anxiety, exacerbates their physical symptoms and, in the worse cases, may even hasten their death. [2]

This data briefing provides fresh evidence on the effects of poverty at the end of life. Based on a new survey on poverty and terminal illness from the perspective of Marie Curie's community nurses, it shows that a significant proportion of dying people in the U.K. are struggling to afford the daily cost of living and household essentials like heating and food.

With costs continuing to spiral and another increase in the energy price cap expected in April 2022, the briefing also serves as a warning – showing that even more terminally ill people will face misery, suffering and quicker deaths in the months ahead without urgent government action on the cost of living crisis.

METHODOLOGY

The Marie Curie community nurse survey was conducted during December 2021-January 2022. The survey was hosted online using Microsoft Forums and was completed by 139 nurses, with the number of responses in each jurisdiction as follows:

Jurisdiction	**No. survey responses**
England	105
Wales	11
Scotland	15
N. Ireland	8
Total	**139**

KEY SURVEY FINDINGS

Marie Curie's community nurses provide care to dying people in their own homes across the U.K. every day. They see patients at their best and worst – and are ideally placed to identify the impact that poverty can have on a dying person's health, wellbeing and quality of life.

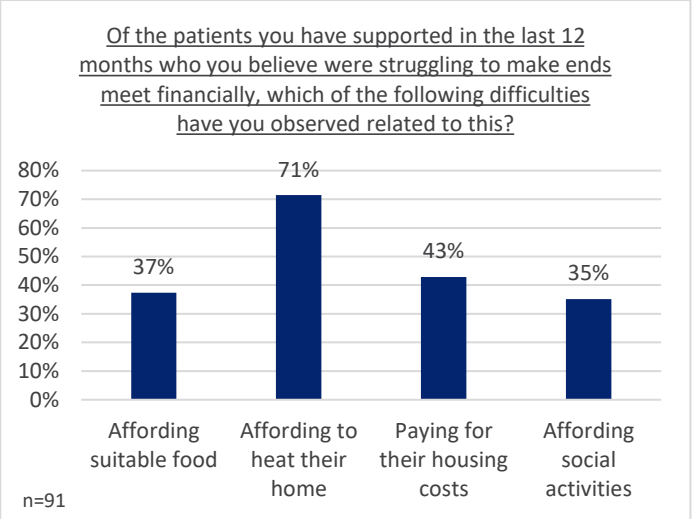
Our survey found:

- **65%** of Marie Curie community nurses believed that some, many or all/almost all of the patients they had supported during the previous 12 months were struggling to make ends meet financially.

[1] Marie Curie (2019). The cost of dying: The financial impact of terminal illness.
[2] Marie Curie (2020). The vicious cycle of fuel poverty at terminal illness.

Among those nurses:

- **71%** said they had observed patients having difficulty affording to heat their home.
- **43%** said they had observed patients having difficulty paying for housing costs like mortgage or rent payments and other utilities.
- **37%** said they had observed patients having difficulty affording suitable food.
- **35%** said they had observed patients having difficulty affording to take part in social activities.



The challenges facing people who struggled to afford the costs of heating were particularly predominant. One nurse spoke of a household where:

"Concerns about heating bills prevented a patient putting the heater up to a reasonable level. The house was cold and a family member bought an electric heater into the bedroom. It was warmer outside." – Marie Curie Nurse

Our nurses also highlighted that problems related to poverty at the end of life were becoming more common – as one nurse put it:

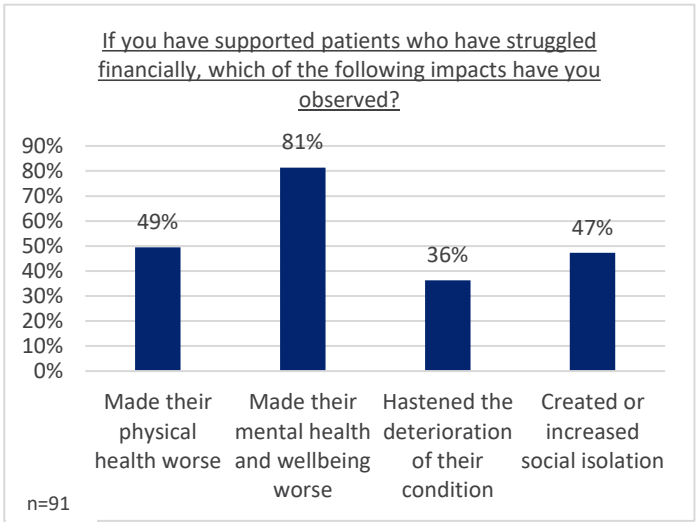
"We are supporting more and more people who are under retirement age and still have jobs and are on reduced wages because of their illness. This impacts on paying household bills and some partners look as if they are on the verge of a breakdown trying to juggle losing a loved one and wondering how the next bill is going to be paid." – Marie Curie Nurse

Another reported:

"One patient we have been going to has heart failure and his wife has her own health problems. They were on pensions and couldn't afford to have the heating on all the time. Their concern was that I was warm enough on their visit. Such selfless lovely people who were always grateful for our visits." – Marie Curie Nurse

We also asked about the impacts that poverty has on people at the end of life. Among those nurses who had cared for dying patients who were struggling to make ends meet:

- **81%** said it made the patient's mental health and wellbeing worse.
- **49%** said it made the patient's physical health worse.
- **47%** said it created or increased social isolation for the patient.
- **36%** said it hastened the deterioration of the patient's condition.



It was clear that many nurses working with terminally ill people saw the profound impact that poverty could have on every area of their life – from affecting their mental health and wellbeing, to increasing their social isolation and even hastening the deterioration of their condition. As one nurse put it:

"One family I went to had the bare minimum. They were in a farm cottage with little or no heating as the lady could not cut the logs for the fire. They had no family and relied on one neighbour to give them food for 4 months as they had no money to pay for the food or repairs in their small cottage. The house was so cold and damp. They had the bare minimum in the fridge. When I made the lady a cup of tea, she shared with me that, due to her husband's illness, they had used all their savings." – Marie Curie Nurse

RECOMMENDATIONS

To help address the cost of living crisis among people at the end of life and ensure they can afford heating and other household essentials, Marie Curie is calling for:

- Universal implementation of the recommendations in NICE guideline NG6 – *Excess winter deaths and illness and the health risks associated with cold homes* – across England and Wales.
- Prompt delivery of reform to the Special Rules for Terminal Illness in social security law for all relevant welfare benefits.
- Automatic entitlement to energy bill discounts for terminally ill people, such as through the Warm Home Discount or equivalent schemes.

ABOUT MARIE CURIE

Marie Curie is the UK's leading end of life charity. We provide frontline nursing and hospice care, a free support line and a wealth of information and support on all aspects of dying, death and bereavement.

For more information contact:

Craig Harrison
Policy Manager, Marie Curie
craig.harrison@mariecurie.org.uk