Dying In The Margins:

How financial insecurity shapes the end of life experience.

Jon Antoniazzi – Associate Director
Ailsa Chambers – Strategic Partnerships

Marie Curie: The UK's leading end of life care provider

- Provides a better end of life for more people, whatever the illness and support for their families
- We provide expert, hands-on care round the clock in peoples' homes and in our hospices.
- A source of free information and support for all.
- At the forefront of improving end of life care for the UK

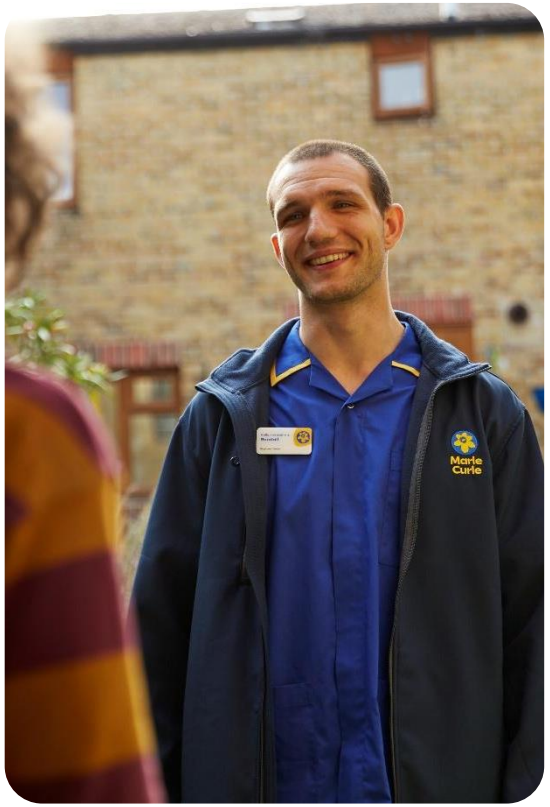
Every three minutes, someone, somewhere in the UK dies without the care and support they need.

Our Strategy and Vulnerability focus

- **Almost 1 in 4 people miss out** on the care they need at end of life
- Demand is rising - the gap will grow without action
- Disadvantaged communities crisis
- **Closing** the gap in end of life care
- We support people at the **most acute points of vulnerability**

Learning Points

- True cost of end of life with a terminal illness
- Financial stress overwhelms every-day life
- Who is really affected
- Lived experiences supporting vulnerable journeys

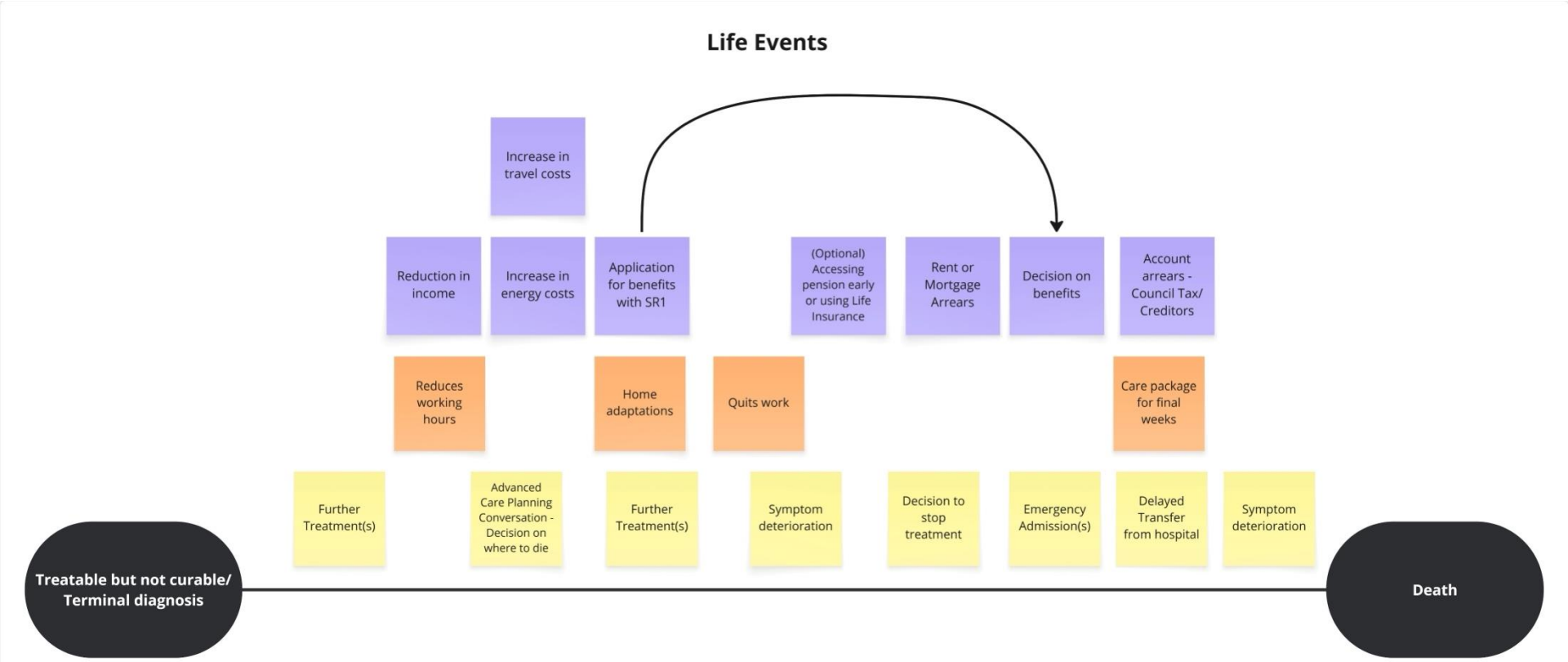


Dying in the margins

Marie Curie

Linda

The cost of dying



The hidden cost of dying – for people and families

People on low incomes are more likely to face financial hardship, rely on hospital care, and experience long-term poverty after bereavement.

For the person who is ill

- **Income loss** as illness limits ability to work
- **Higher day-to-day costs**
  Heating, transport, food, equipment, adaptations
- **Care costs aren't always covered**
  Social care and support are often means-tested

For families and carers

- **Lost earnings**
  Cutting hours, unpaid leave, or leaving work to provide care
- **Out-of-pocket expenses**
  Travel, parking, energy bills, care supplies
- **Financial insecurity**
  Caring is linked to higher risk of hardship during and after caring

After death

- **Immediate costs**
  Average funeral costs **£4,000–£4,700**, often paid upfront
- **Ongoing financial impact**
  Delays in benefits, debt, housing insecurity for bereaved families

111,000 people die in poverty each year in the UK
That's **more than 300 people every day.**

At least 128,000 people die in fuel poverty each year
This is the **first time fuel poverty at the end of life has been quantified.**

Working-age adults are significantly more likely to die in poverty than pension-age adults.
Across the UK nations, **around a quarter to three in ten working-age people** die in poverty
Compared with **around one in six pension-age people** in their last year of life

Marie Curie

Most people want to die at home – but many can't

There is a persistent gap between what people want and what the system delivers.

56% of people in the UK say they would prefer to die at home

Among people with a terminal illness, **42% say home is their preferred place of death**

What actually happens: In England, **only 28.4% of people died at home in 2023**

42.8% died in hospital, making it the most common place of death

Why people don't die where they want to
Despite most people wanting to die at home, many cannot because:

Unequal home circumstances
- Poor or overcrowded housing, lack of downstairs bathrooms or space for equipment
- Unsafe, cold, or unsuitable homes make care at home impractical (Home death is much less feasible in poorer housing stock)

Financial disadvantage
- Lower-income households are less able to absorb:
    - Loss of earnings
    - Extra energy and care-related costs
    - Private or supplementary care
- Financial strain increases reliance on crisis hospital care

Dependence on unpaid carers
- Dying at home often relies on family carers providing intensive support
- Carers may be older, unwell, working, or financially stretched
- When carers reach breaking point, hospital becomes the default option

Marie Curie

Impact on unpaid caregivers – The hidden workforce

Marie Curie's research estimates that up to 762,000 people across the UK provide unpaid care for someone with a terminal illness each year (2025)

Financial

- Being a caregiver might lead to decisions to reduce working hours or quit.
- Carers allowance does not supplement likely income decline.
- Cost of travel to appointments, shopping and other tasks might fall upon them.

Psychological

- Experiences of pre-bereavement, knowing their loved one will die.
- Post-bereavement support access depends on location and often self-referral.
- High levels of carer fatigue, exhaustion and ability to carry out administrative tasks.
- Social isolation due to care responsibilities
- High levels of stress and anxiety

Practical

- Lack of time for routine selfcare – going to the gym, going for a walk.
- Difficulty making their own routine appointments.
- High levels of responsibility in administering complex medications and supporting loved one with social life.

Thank you and discussion

Marie Curie