

# Addressing poverty at the end of life



A guide for hospice and end of life care staff



PARTNERED WITH



Poverty Proofing®

# Introduction

In the UK, 111,000 people die in poverty each year, and 128,000 people die in fuel poverty. People living with a terminal illness can expect their household expenditure to rise by up to £16,000 each year.

There are currently 14.4 million people in the UK who live below the poverty line, with 3.8 million people living in destitution – unable to afford basics such as shelter, food, heating, light, toiletries, and appropriate clothing and shoes.

This guide was developed by Children North East and Marie Curie for anyone working in hospice or end of life care services, following a Poverty Proofing® review at the Marie Curie Hospice in Bradford. Poverty Proofing® as a methodology relies on the principles of voice and place to develop insights and solutions that are place-based.

This guide aims to help you start thinking about ways to adapt or develop your service to address poverty at the end of life. It's based on conversations with patients, their families and hospice staff. It's OK if not everything in this guide fits with your work – take what you need from it.

## Contents

The Poverty Proofing® approach	3
Understanding poverty-related barriers to accessing your services	5
How you can help people experiencing poverty	8
Thanks and acknowledgements	21

## The Poverty Proofing® approach

Poverty Proofing® Healthcare is a tool for identifying the barriers those living in poverty face to engaging fully with their health and care.

It focuses on listening to the voices and experiences of patients and their families. And it offers a pathway for services to address often unseen inequalities in their activities. By doing this, it helps them reduce stigma and break the link between health outcomes and financial background.

### Poverty Proofing® ethos

The Poverty Proofing® ethos is that no activity, or planned activity should identify, exclude, treat differently or make assumptions about those whose household resources are lower than others.

The Poverty Proofing® delivery model is founded on three core principles that underpin all Poverty Proofing® interventions:

1. **Voice.** To see real social change, the voices of those affected by poverty must be central to understanding and overcoming the barriers that they face.
2. **Place.** Alongside hearing from people, it's important to understand the context of the community and place being addressed. Recognising that poverty impacts places differently, and so understanding place is vital in responding. Being clear about why and how decisions are made is also essential.

3. **Structural inequalities.** While tackling poverty can feel like an impossible and unachievable goal, the knowledge that the root causes of poverty are structural give reason for hope. If poverty can be addressed, or at least alleviated, by making structural changes within society, it's important to consider the structural changes that can be made at an organisational level to eliminate the barriers that those in poverty may face.

This guide has been designed to help Marie Curie embed this ethos across all of its work. It might be useful if you work outside of Marie Curie too. The steps we talk through will hopefully be useful starting points to recognising barriers in your own hospice or service.

Want to learn more? Children North East have online training to help you spot and reduce the impact of poverty. Visit [academy.boost.org.uk/programmes/poverty-proofing](https://academy.boost.org.uk/programmes/poverty-proofing)

# Understanding poverty-related barriers to accessing your services

In this section, we explain what people at the Marie Curie Hospice in Bradford felt were poverty-related barriers to accessing services. Although the themes were often visibly related to financial resources, there were other 'hidden' financial and emotional costs that impacted people with the least resources.

You may find these barriers are happening within your service. And you may identify other barriers too. What's important is remembering each service and area will have its own unique challenges.

## Communication

Language and cultural barriers affect whether people can fully access services. Interpreters and interpretation services, although available, were not easy to access, which meant they were often underused. Instead, staff and patients relied on family members as interpreters during end of life care.

## Accessing and understanding appointments

People experiencing poverty can find themselves without the energy, capacity or time to easily navigate the care services they need.

During our conversations with patients, some were confused about the process of being referred into Marie Curie. Unclear, complicated and segregated referral processes and routes to engagement added to this confusion – with the responsibility being on the patients and families, rather than the services.

## Housing challenges

People are dying in houses that are cold, damp and unsuitable. This can also affect staff's ability to give overnight care in a dignified way. Issues with landlords, property condition, repairs, and timeliness of adaptive services, and affordability all affect home environments. See [pages 12-13](#) for suggestions on how to tackle this.

## Health costs

There are significant additional costs to managing care. For example, the cost of incontinence products, cost and availability of professional carers, and an increase in energy bills. See [pages 14-16](#) for ways to support patients and families.

## Patient empowerment

Financial concerns have a huge impact on how empowered patients feel during illness. The overly complex benefits system, as well as lack of knowledge about funding and grants, was a major hurdle for many people, who were not aware of what financial aid they were entitled to or how to access it. This often led to people experiencing poverty being unable to fully grieve, as they had to deal with financial complications rather than process their own emotions.

Several families we spoke with emphasised how this lack of empowerment particularly affected younger patients. These young people talked about being placed in residential care homes for the elderly, and how this made them feel out of place and disempowered.

## Travel costs

Hospice and community services are not always in areas that are easy to reach. Travelling to them can be a barrier for people experiencing financial hardship or poverty. Using public and patient transport can mean long waits, inaccessible travel options, and high costs. Relying on taxis or private transport is often the only option, and these are very expensive – especially if someone needs a wheelchair accessible taxi, which often have a premium fee.

## Staff awareness and support

Poverty awareness may be new to hospice and community staff, so knowledge and behaviour around the topic can vary. Staff may hold unconscious biases and preconceptions about poverty that stop them starting conversations about financial support.

Overall, patients value being offered as much support as possible. See [pages 11, 13, 15](#) and [17](#) for useful resources to share.

## How you can help people experiencing poverty

Here are our tips for supporting people experiencing poverty:

- Talk about poverty.
- Make your hospice or service accessible.
- Make care at home safe and comfortable.
- Be open about the additional costs of healthcare.
- Know what information and support is available.

Over the next few pages, we explain how you can master the tips above and make an impact.

### Talk about poverty

Talking about poverty may feel scary or daunting. Staff we spoke with shared feelings of:

- being afraid that patients will be offended
- worrying about not being in a position to help
- feeling uncomfortable because of the stigma around poverty.

Remember that having a holistic view of someone's circumstances, including challenges with finances, can lead to better health outcomes.

Acknowledging the additional costs of terminal illness for every patient is a good way of starting conversations about money. It also helps to remove stigma and, ultimately, can help patients access financial aid that they need but may not be aware of.

### Practical steps

It's important to start conversations about poverty as a universal and routine part of patient care. Having the conversation with everyone means no one feels singled out – and it will help to get rid of stigma. It'll also help you feel more comfortable talking about poverty.

Do not be afraid to broach the subject. People are more likely to tell you about their circumstances if it means they'll get help. You could try using phrases like:

- **'We want to make sure that everyone is able to access the service, so we're asking all our patients about their circumstances.'** or
- **'We ask everyone, just to make sure our service is accessible to everyone.'**

Consider screening every new patient for wider determinants of health.

Be aware of the stigma around poverty, and how it might affect people during these conversations.

**"Poverty is often rooted in structural and systemic inequalities that are beyond the control of the individual. Remember that it is the systems and government that hold the power to make structural changes, not the individuals."**

*Taken from **Structural Causes of Poverty: An In-depth Analysis in Sociology** (Edwards, 2024)*

## Useful resources

- WHAM (Wellbeing and Health Action Movement) has online tools for social determinant screening. Visit [whamproject.co.uk](https://whamproject.co.uk)
- The Joseph Rowntree Foundation has a downloadable toolkit on how to talk about poverty. Visit [jrf.org.uk](https://jrf.org.uk) and search for 'poverty toolkit'.

## Make your hospice or service accessible

You might assume hospices are the best place to hold activities like support groups and workshops, because they often have good facilities and staff. But people experiencing financial hardship may find it harder to access these activities – whether because of money or for health reasons. It's important to try to make your hospice or service, and the activities it offers, more visible to people in different communities.

## Practical steps

It's good practice to involve people using your services in these conversations. It helps you avoid making any assumptions and is another way to start conversations about poverty. You could develop patient participation groups in the community to improve communication and give more opportunity to share patient voice. This could be achieved through linking to the VCSE (Voluntary Community and Social Enterprise) Network in your area. If resources allow, you could consider appointing or seconding someone to look at community engagement and partnership working in your community.

## How you can help people experiencing poverty

- Try to work out how much it costs people to travel to your hospice or service – and any other possible costs.
- Explore what already exists in the community, and the feasibility of having more groups that are easily accessible for people to promote visibility in places where people live.
- Open your services to the wider community through groups and events. Advertise the hospice as a warm space in the colder months and provide free Wi-Fi.
- Consider working with schools, where there may be young carers who have family members with a terminal illness. The 2021 ONS census reported that there are around 120,000 young carers aged 5-18 in England, while the school census in 2023 suggested that there were 39,000 'known' young carers in the country.

## Useful resources

- GOV.UK allows you to search by postcode for community groups in your area. Visit [gov.uk/find-a-community-support-group-or-organisation](https://gov.uk/find-a-community-support-group-or-organisation)
- The Voluntary, Community and Social Enterprise (VCSE) Health and Wellbeing Alliance website has information and contact details for members. Most members operate across the UK. Visit [england.nhs.uk/hwalliance](https://england.nhs.uk/hwalliance)



## Make care at home safe and comfortable

Marie Curie, and other organisations, provide hospice care at home, meaning many people can continue to live and be cared for in a familiar environment. However, people being cared for at home who are experiencing poverty may live in cold, damp and uninhabitable conditions. They may also be unable to afford necessary home adaptations or be waiting for them due to lengthy council housing lists. This means staff may be exposed to these conditions, and are sometimes unable to stay because of risks to their own health and safety.

### Practical steps

- Try to do home visits and assessments of need early, in partnership with other stakeholders such as the local or housing authorities.
- Discuss short-term measures that can be put in place quickly with patients and community nursing staff. For example, portable heating equipment that can be charged in the hospice to take out to patient homes, warm clothing, and flasks for warm drinks.
- Work with local authorities housing, private rental and environmental health departments to improve conditions in housing.
- Partner with local social housing companies to help make sure safe homes are provided to patients with terminal illnesses. Explore what more can be done to prioritise this.

### How you can help people experiencing poverty

- Read, or have to hand, how housing quality is measured in your area. There is usually guidance about the responsibilities of landlords and property-related professionals:
  - o **England:** The Housing Health and Safety Rating System. Visit [GOV.UK](https://www.gov.uk) and search 'HHSRS'.
  - o **Scotland:** The Scottish Housing Quality Standard. Visit [gov.scot](https://www.gov.scot) and search 'SHQS'.
  - o **Wales:** Welsh Housing Quality Standard. Visit [gov.wales](https://www.gov.wales) and search 'housing quality guidance'.
  - o **Northern Ireland:** The Decent Homes standard. Visit [nidirect.gov.uk/decent-homes-standard](https://nidirect.gov.uk/decent-homes-standard)

### Useful resources

- Marie Curie has information about home adaptations, including costs and how to get them. Visit [mariecurie.org.uk/adaptations](https://mariecurie.org.uk/adaptations)
- Shelter has resources about tenants' rights, including guidance on dealing with hazardous homes. Visit [shelter.org.uk](https://shelter.org.uk)
- The Housing Ombudsman is an independent, impartial, and free service for social housing residents. It aims to settle disputes between tenants and landlords. Visit [housing-ombudsman.org.uk](https://housing-ombudsman.org.uk)



## Be open about the additional costs of healthcare

People living with a terminal illness, and those towards the end of life, have significant extra costs related to healthcare. These include medication, aids and adaptations, food and nutrition, energy bills, loss of earnings, and funerals.

Many people are unaware of these costs when they are diagnosed. And they may not be prepared for them. The costs can be an unwelcome surprise on top of other emotional and health demands. Doing more to educate on this proactively can help with budgeting and can ease the financial burden – another reason to have these conversations.

### Practical steps

#### Marie Curie's Energy Support Officers

Your patients can get free support over the phone, from anywhere in the UK, from our friendly Energy Support Officers. The team are here to help with questions and concerns about fuel poverty and energy bills, including provider-specific support and signposting. Share our Support Line number – **0800 090 2309\***.

- Consider having an information session about or including finances when people start to use your hospice or service. You could discuss how healthcare costs will impact their finances, break down any likely extra costs, and offer a list of resources where people can get help.

### How you can help people experiencing poverty

- Host information workshops in the community to educate people on what extra costs might look like.
- Try to form partnerships with suppliers, such as energy companies, producers of sanitary equipment or local authorities. This can help costs become more transparent. It may help people struggling to afford these basics, by giving them understanding and access.
- Use or develop posters or leaflets with information about extra costs and where to get help. These could be displayed in GP surgeries and hospitals.

### Useful resources

- Marie Curie's online information about help with energy bills – visit [mariecurie.org.uk/energy](https://mariecurie.org.uk/energy)
- Marie Curie's **Help with energy bills and the cost of living** booklet – visit [mariecurie.org.uk/publications](https://mariecurie.org.uk/publications) to order or download it.
- Marie Curie's 2019 report The cost of dying: The financial impact of terminal illness.
- If you're a Marie Curie professional or staff member, you can take our fuel poverty awareness course. Ask your manager or log into the Learn and Develop website and search 'fuel poverty'.

**“I would find her sitting in her pyjamas, a house coat and a blanket, worrying about putting her heating on. I would tell her it was important for her health to stay warm, but I soon realised the heating was off due to the cost.”**

**Gillian, who helped care for her mum**

## Know what information and support is available

Over £22 billion of benefits is unclaimed by eligible households every year. People may be eligible for support through benefits, including Personal Independence Payment, Disability Living Allowance or Attendance Allowance.

Many people having palliative or end of life care do not have the time, energy or capacity to navigate the complex benefits and grants system. Staff not being aware of available benefits support, or who feel confident in how to navigate the system, can make it even harder for people to access support.

### Practical steps

- Review and promote existing support in your hospice or service, such as Family Support Teams or Fuel Poverty Advisors.
- Make sure staff know the basics about benefits or where to signpost people for more information – like the free Marie Curie Support Line on **0800 090 2309\***.
- Promote the benefits calculator and UK-wide benefits information on the Marie Curie website. The calculator is free and can quickly let people know what benefits they may be eligible for (see [page 17](#)).
- Contact your local authority to find out what grants are available in your local area. Use, or signpost to, the Grants Search tool on the Turn2us website, which can quickly let people know which grants they're eligible for (see [page 17](#)).

- Consider creating a 'one stop shop' for money advice and support. For example, you could appoint a debt and money advice caseworker. This caseworker should have full benefits system and debt knowledge. Or you could partner with your local Citizens Advice Bureau or Welfare Rights Service and try to get someone seconded to your service on a regular basis.
- Understand what can be done locally to improve financial support for non-UK nationals, whose visa types will not allow them access to public funds. You could try linking in with local charities that offer support to people in this group.
- Research local charities who may be able to provide material aid or funding to people in need, but may not be nationally recognised.

### Useful resources

- Marie Curie's benefits calculator – visit [benefits-calculator.mariecurie.org.uk](https://benefits-calculator.mariecurie.org.uk)
- Marie Curie's online benefits information – visit [mariecurie.org.uk/benefits](https://mariecurie.org.uk/benefits)
- Turn2us Grants Search – visit [grants-search.turn2us.org.uk](https://grants-search.turn2us.org.uk)

## Putting it into practice

Now you've read our suggestions for things to think about and next steps, it's time to put it into practice. It might feel overwhelming, so here's a quick guide to how to get started.

### Ask

This is probably the most important thing that any service can do. Actively ask your patients what works for them and what they need. Sometimes patient participation groups are set up, but the people who cannot attend these groups may be living in poverty and their voices go unheard. If patients cannot attend, you could call them instead to ask their opinion. Try to do this regularly, as their needs may change depending on their condition.

### Listen

Really listen to what people have to say. Be aware that some people are not used to advocating for themselves, so show interest and ask follow up questions for deeper insight and clarification.

### Act

We sometimes think that there's nothing we can do without money and resources. This is often not the case – there's a lot we can do that does not cost much.

## Advocate

Sometimes we cannot make immediate changes. But, when this is the case, we can advocate for people. Look at data you currently collect, or start to collect it, and share it with your team – is the same thing coming up over and over again? If so, there's power in numbers. Take things to the next level and advocate for your patients. Wide-spread and profound changes can be made by the smallest actions.



Katy Kainton/ Marie Curie

## About our information

If you'd like the list of sources used to create this information, please email [review@mariecurie.org.uk](mailto:review@mariecurie.org.uk).

### Notice

The information in this publication is provided for the benefit and personal use of professionals involved in hospice and end of life care. This information is provided as general guidance for information purposes only. It should not be considered as medical or clinical advice, or used as a substitute for personalised or specific advice from a qualified practitioner. In respect of legal, financial or other matters covered by this information, you should also consider seeking specific professional advice about your personal circumstances. While we try to ensure that this information is accurate, we do not accept any liability arising from its use. Please refer to our website for our full terms and conditions.

## Thanks and acknowledgements

Between January and July 2024, Children North East worked alongside staff and patients at the Marie Curie Hospice in Bradford to 'poverty proof' the hospice and community services. We aimed to identify the barriers and challenges linked to financial hardship and poverty that patients face when accessing Marie Curie care.

As part of this work, 60 patients, their families and members of the community took part in consultations. Over 100 staff completed poverty awareness training and took part in consultations.

The compelling and heartbreaking stories we heard provided the Marie Curie Hospice in Bradford with insights into its care, and steps it could take to remove financial barriers and alleviate the impact of poverty for patients.

Our warmest thanks to all the staff at the Marie Curie Hospice in Bradford for their passion and cooperation, and to those patients, carers and families who allowed us to listen to their stories.

# Marie Curie



**Marie  
Curie**

Marie Curie is the UK's leading end of life charity. Whatever the illness, wherever you are, we're with you to the end.

**0800 090 2309\***

Marie Curie provides free support over the phone in over 200 languages, and via webchat, to anyone with an illness they're likely to die from and those close to them. Our team, including nurses and specialist Energy Support Officers, offers practical and emotional support on everything from symptom management and day-to-day care to financial information and bereavement support. Visit [mariecurie.org.uk/support](https://mariecurie.org.uk/support)

\*Calls are free from landlines and mobiles.  
Your call may be recorded for training and monitoring purposes.

# Children North East



Children North East understands that minimising the impact of poverty on healthcare provision is key to breaking the link between an individual's income and their opportunity to live a long, healthy life. Our Poverty Proofing<sup>®</sup> team experts can support healthcare teams to listen to the experiences of their patients, staff and stakeholders, then provide tailored guidance. For more information, contact [enquiries@children-ne.org.uk](mailto:enquiries@children-ne.org.uk)