



University  
of Glasgow

# MONEY MATTERS AT THE END OF LIFE

HAVING OPEN CONVERSATIONS  
ABOUT FINANCIAL HARDSHIP AT  
THE END OF LIFE



# INTRODUCTION



This resource provides guidance for health and social care professionals on how to hold open conversations about financial hardship and deprivation with people approaching the end of life.

It has been developed as part of the [Dying in the Margins](#) (2019-2023) research project. The development of this resource was funded through an Economic and Social Research Council (ESRC) Impact Acceleration Account Award. Grant No: ES/T501918/1.

We have drawn on existing evidence in the poverty alleviation sector, interviews with health and social care professionals, and input from a community of practice event run in November 2022.

# WHY ARE THESE CONVERSATIONS IMPORTANT?



Talking about financial hardship and deprivation at the end of life is crucial for several reasons. We know that experiencing financial hardship and deprivation can have significant negative impacts throughout the life course, including during the final year of life. This can include a higher likelihood of experiencing complex comorbidities, increased incidences of severe pain and a lower likelihood of accessing specialist palliative care.

Financial hardship and deprivation also impact peoples end of life experiences in other significant ways. Some of these include housing insecurity, poorly maintained urban environments, and noise pollution. The home environment can also cause significant challenges where there is material deprivation such as mould, dampness, and lack of proper maintenance or repairs, or limited space to accommodate equipment and family members involved in caregiving. Additionally, it can be difficult for people experiencing financial hardship at the end of life to meet the expenses associated with heating and electricity for necessary equipment.

There is evidence to suggest that health and social care professionals can find it difficult to discuss people's financial circumstances with them. Conversations about money can be uncomfortable, as discussion of financial concerns may be seen as insensitive or intrusive. Additionally, people may be hesitant to disclose their financial struggles due to the associated stigma, which can make them feel embarrassed or ashamed.

In *Dying in the Margins*, we have found that some professionals prefer to use the physical environment of a person's home as an indicator of whether a person is experiencing financial hardship. While an empty fridge or a sparsely furnished house can provide clues about a person's financial circumstances, relying on physical indicators of deprivation in a person's home is insufficient. This is because financial hardship and deprivation are complex and multi-dimensional issues that cannot be accurately assessed solely based on visual cues. They can manifest in many ways that are not visible, such as a lack of access to healthcare or healthy food, transportation barriers, and social isolation.

# WHY ARE THESE CONVERSATIONS IMPORTANT?



Relying solely on visual cues to assess a person's financial circumstances can mean relying on pre-existing assumptions and potentially misjudgements of what it means to be experiencing various hardships. A seemingly awkward conversation may be avoided, but a person is not given the opportunity to talk about *if*, or *how*, they may be struggling. Facilitating upfront and open discussion gives people the chance to talk about how they feel and to describe *in their own words* how they may be struggling.

*People will tell you, 'No, I'm absolutely fine.' They don't want to bother you. They don't want to cause a fuss. But actually, it's about being aware and digging a bit deeper (Senior Palliative Care Nurse).*

Health and social care staff must be supported to engage in open and non-stigmatising conversations with people as this allows for a deeper understanding of their specific financial challenges and enhances their ability to provide appropriate support and resources. While some people may be reluctant to have these conversations, everyone should be offered the chance to engage in them. Open and non-stigmatising conversations about financial challenges can have a palliative effect by relieving people of the stress and anxiety associated with financial pain or bureaucratic pain. Financial pain and bureaucratic pain can exacerbate the emotional and psychological burden of terminal illness and can make it challenging for people to focus on their physical and emotional well-being.

# STRUCTURING A CONVERSATION



To develop this resource, we reviewed evidence from the poverty alleviation sector and facilitated a community of practice event bringing together palliative care clinicians and community link workers and invited [Dr Ruth Patrick](#), Senior Lecturer in Social Policy, to frame the session drawing on her experience of undertaking participatory research with low-income families.

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## INITIATE THE DISCUSSION IN A TIMELY WAY

It is recommended that a discussion of financial considerations begins at the onset of a chronic or terminal diagnosis. As a matter of routine, health professionals should ask *all* patients about financial matters to ensure inclusivity and prevent singling out individuals based on perceptions of need and financial status, which may be wrong. Furthermore, it is advised financial considerations are incorporated into advance care planning.

## NORMALISE THE CONVERSATION

Emphasise the significance of discussing financial matters and acknowledge that it is a common concern for many people. Normalising the conversation and using non-stigmatising language, such as 'money worries' or 'making ends meet', can help people feel more at ease when sharing their financial concerns.

*I say, "Have you got any financial worries or concerns?" or 'Have you got any money worries?' It depends on the level of the patient and the conversation you're having but, those are the things that I tend to say. (Palliative Care Doctor)*

## USE OPEN-ENDED QUESTIONS

Allow people to guide the conversation by asking open-ended questions, which can encourage them to express their thoughts and feelings more freely and provide insight into their specific circumstances. For example: How are you managing financially?

*I will ask open-ended things and if they're not managing, then I will ask the questions: 'What are you spending [money] on? how can we make this better? and where can we cut back to make sure that you have money for the necessities that you need or don't get into arrears with your gas and electric?' (Senior Community Links Practitioner)*

# STRUCTURING A CONVERSATION



## USE RIGHTS-BASED LANGUAGE

When facilitating conversations about money with people at the end of life, it is important to use language that emphasises their entitlement to support and resources. Using words like "rights", "dignity", and "fairness" can help to create a safe and non-judgmental space for people to discuss their financial concerns. It can also help to shift the conversation away from individual blame and towards a more systemic and structural understanding of poverty and financial hardship.

*When you're bringing it up with people, if you say "There might be benefits that you're entitled to, I don't know if anyone's ever raised that with you before?"  
(Palliative Care Consultant)*

## BE GUIDED BY THE INDIVIDUALS' RESPONSES

It is important not to formulate decisions around financial considerations as a binary choice i.e., addressing costs at the end of life versus ignoring costs at the end of life. A preferable approach might be to allow the individual to determine the extent to which they want to discuss their finances.

## PROVIDE PRACTICAL ADVICE AND SIGNPOST TO LOCAL SERVICES

Be familiar with what support is available within your area. Offer guidance on managing financial challenges and direct people to relevant local services or resources, such as the Citizens Advice Bureau or a social worker. Links to additional support and resources are included below.

## ENCOURAGE PEOPLE TO INVOLVE THEIR FAMILIES AND LOVED ONES

Suggest that people include their families or loved ones in discussions about financial hardship, and how it is affecting their mental state. This might increase the avenues for support and help collective decision-making.

By incorporating these strategies, we can start to create a safe and open space for people to discuss financial issues they may be experiencing. Having honest conversations about financial hardship, rather than relying solely on physical indicators of deprivation, is key to promoting equitable end of life care and ensuring that those who require support receive it.

# RESOURCES AND FURTHER READING



1. Citizens Advice Bureau. (2023).  
Citizens Advice Bureau webpage. <https://www.citizensadvice.org.uk/>

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2. End of Life Studies Group,  
University of Glasgow. (2023).  
Dying in the Margins. <https://www.gla.ac.uk/research/az/endoflifestudies/projects/dyinginthemargins/>

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3. Macmillan Cancer Support. (2023).  
Managing money at the End of Life. <https://www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/benefits-and-financial-support/financial-help-end-of-life>

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4. Marie Curie. (2023).  
Terminal illness benefits and finance. <https://www.mariecurie.org.uk/help/support/benefits-entitlements>

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5. Public Health Scotland. (2023). Challenging  
poverty and discrimination: free online training. <https://bit.ly/PublicHealthScotlandPovertyTraining>

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6. Public Health Scotland. (2019). A short film about  
how healthcare professionals can help address  
patients' money worries by introducing the  
principle of CARE – Consider, Ask, Refer, Engage. <https://bit.ly/MoneyWorriesInSicknessAndInHealth>

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7. Social Security Scotland. (2023).  
A guide to Social Security: Scotland's benefits. <https://www.socialsecurity.gov.scot/guidance-resources/resources/a-guide-to-our-benefits>

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8. Scottish Government. (2022).  
Cost of living support leaflet: Multiple languages. <https://www.gov.scot/publications/cost-of-living-support-leaflet/>

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9. Royal College of Paediatrics and Child Health  
(RCPCH). (2022). Health inequalities tool for  
developing clinical skills for talking to families. <https://www.rcpch.ac.uk/resources/health-inequalities-tool-2-develop-clinical-skills-talking-families>

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10. British Association of Social Workers (BASW).  
(2020). Social workers talking about poverty. <https://www.basw.co.uk/social-workers-talking-about-poverty>

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2. Donely, G. & Danis, M. (2013) Making the Case for Talking to Patients about the Costs of End-of-Life Care. The Journal of Law, Medicine & Ethics. <https://doi.org/10.1111%2Fj.1748-720X.2011.00587.x>

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3. Patrick, R. (2018). How to treat people on benefits with respect – a lesson from Scotland. <https://www.theguardian.com/society/2018/may/07/treat-people-benefits-respect-scotland-social-security-law>

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4. Patrick, R. (2016). Living with and responding to the 'scrounger' narrative in the UK: exploring everyday strategies of acceptance, resistance and deflection. Journal of Poverty and Social Justice. <https://doi.org/10.1332/175982716X14721954314887>

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5. Richards, N. (2022). The equity turn in palliative and end of life care research: Lessons from the poverty literature. Sociology Compass. <https://doi.org/10.1111/soc4.12969>

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6. Rowley, J., Richards, N., Carduff, E. & Gott, M. (2021). The impact of poverty and deprivation at the end of life: a critical review. Palliative Care and Social Practice. <https://doi.org/10.1177/26323524211033873>

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7. Quinn, S., Richards, N. & Gott, M. (2023). Dying at home for people experiencing financial hardship and deprivation: How health and social care professionals recognise and reflect on people' circumstances. Palliative Care and Social Practice. <https://doi.org/10.1177/26323524231164162>





If you would like more information on our research please visit our website:  
<https://www.gla.ac.uk/research/az/endoflifestudies/projects/dyinginthemargins/>

