

How can we improve our support for people facing financial hardship?

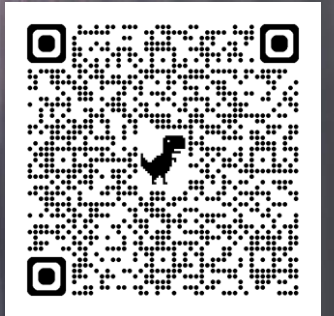
Big Conversation
Tuesday 14 January 2025

Agenda

14:00	Welcome and Introduction	Katie Reade , Head of Policy & Public Affairs, Hospice UK
14:05	Hospice UK's policy work in this area	Katie Reade , Head of Policy & Public Affairs, Hospice UK
14:10	Poverty Proofing © in the Hospice Sector	Ailbhe Cashman Poverty Proofing Co-Ordinator. Children Northeast
14:25	Ardgowan Hospice - Transport Service - Financial Advice in collaboration with Inverclyde HSCP & Macmillan Cancer Support	Vivienne McCarlie , Data & Patient Systems Lead Ardgowan Hospice
14:40	Q&A	All
14:50	Breakout Rooms	All
15:05	Discussion	All
15:25 – 15:30	Close	Katie Reade , Head of Policy & Public Affairs, Hospice UK

**"It's a nightmare scenario":
death, dying and financial hardship**

Scan me



"It's a nightmare scenario": death, dying and financial hardship



Policy report informed by the views and expertise of those with lived and professional experience, including many hospice workers

"You may have never claimed benefits because you've always had a job but then suddenly you're unable to work and you have no income or savings to fall back on."

"If you're trying to work to keep your head above water you have two problems. You should be at work but you're needed at home. Your loved one needs you and you can't be there."

"They will be coming to our funerals, before we go to theirs. We're knackered. We're done. The money is going down. I'm trying to keep working but all I'm thinking about is how can I earn another £50 this week."

"I didn't know there was (financial) help out there. Nobody offered it to me."

"It's a nightmare scenario": death, dying and financial hardship



Findings included the value of:

- financial advice and social worker support from the third sector
- asking patients about money worries
- valuing holistic needs
- raising awareness of social security support and hospice services
- improving the physical accessibility of services
- collaborating with services that support those facing financial hardship
- examining who is being supported by your service

Poverty Proofing © in the Hospice Sector

Ailbhe Cashman

Poverty Proofing Co-ordinator

Twitter: [@povertyproofcne](https://twitter.com/povertyproofcne) | www.children-ne.org.uk



Presentation Outline

- What is Poverty Proofing©?
- Poverty Proofing© Marie Curie
- Main barriers in healthcare access
- Fundamentals of poverty-informed services
- Useful resources

What is Poverty Proofing? ©

A brief introduction

‘No activity or planned activity should identify, exclude, treat differently or make assumptions about those babies, children, young people and families whose household income or resources are lower than others.’

Poverty Proofing© Principles

People

Place

**Structural
Inequalities**

Poverty Proofing in Practice

Training and initial
staff consultations

Scoping

Patient
Consultations

Community
Consultations

Feedback, report &
recommendations

Review

Poverty Proofing © in the Marie Curie Hospice, Bradford

In the Marie Curie hospice, we...

- Delivered a 2 hour training session to over 100 staff
- Spoke to 43 people who either used the service or were family/ carers of someone who did
- Spoke to 17 people in the wider community

Key Considerations



The dedication and passion of staff was vital to the success of the project



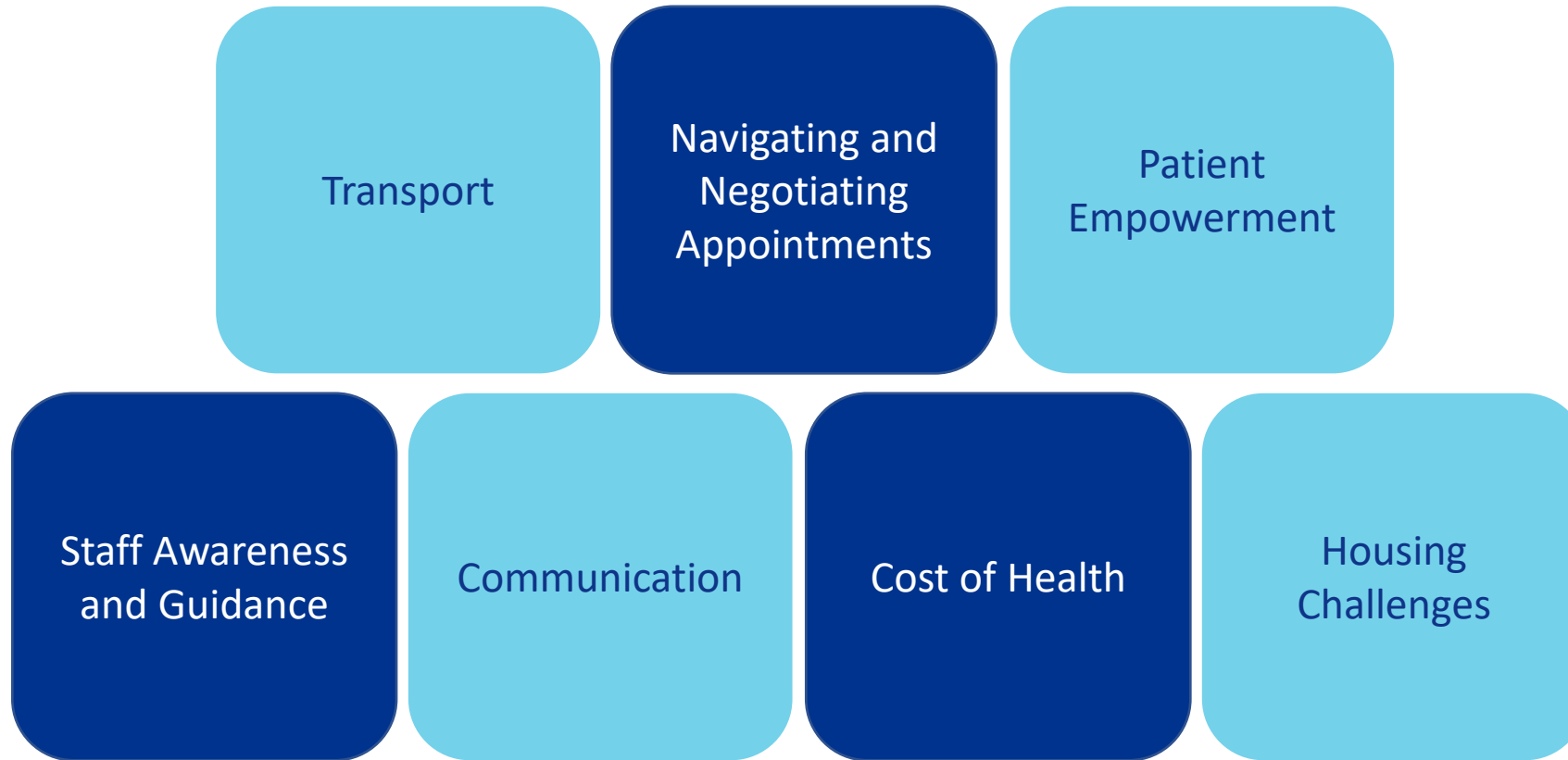
A collaborative and safe training space increased awareness and addressed biases



Effective community engagement is challenging, but provides invaluable insight

Poverty Informed Care Approach

Barriers to Access

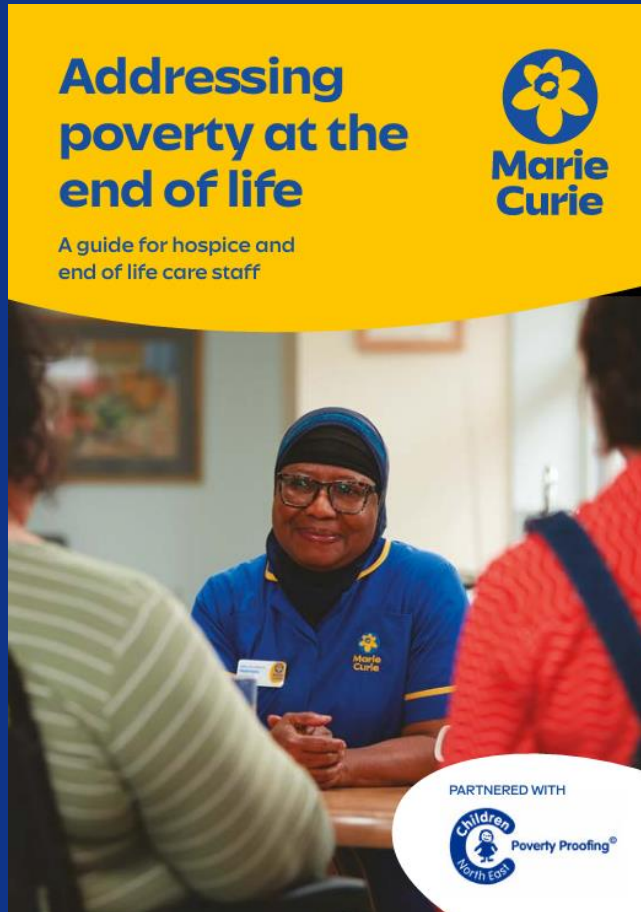


Fundamentals of Poverty Informed Services



Resources

Resources



- Workforce guide can be downloaded in a PDF version or ordered as hard copies for teams

Resources

Children North East offer

- Free online 1 hour Poverty Awareness training on training.meccgateway.co.uk
- Half day training and workshops
- Poverty Proofing intervention
- Delivery Partner model

**For more information, contact
enquiries@children-ne.org.uk**

Vivienne McCarlie,
Data & Patient Systems Lead
Ardgowan Hospice



Hospice UK, Financial Hardship - The Big Conversation 14th Jan 2024

- Who - are we
- What - is the service about
- Where - does it all happen
- When - does the service run
- Why - do we do it

Between April 2023 and March 2024, the service enabled:

- 399 passengers to use the service
 - 1479 appointments were attended, at a total of 10 various hospitals
 - 1174 driver runs were completed. Occasionally the journeys can be shared with other passengers who have similar appointments times at the same hospitals, to keep running costs to a minimum.
 - 61,844 mileage was recorded for the period
-
- The Value of financial advice from the third sector



Transport Service

Ardgowan Hospice is situated in an area of high poverty and deprivation on the west coast of Scotland. Many people living with a life-limiting illness in Inverclyde and neighbouring islands, cannot afford to pay for trains/taxis or buses to attend numerous hospital appointments. Whether in Inverclyde or at a Glasgow hospital, travelling via public transport isn't always feasible for people who are often so unwell.

In response to this Ardgowan Hospice offers a **free** and personalised Transport Service. This service is co-funded by the Hospice and Strathclyde Partnership for Transport (SPT), which provides an annual grant of £30,000. The service costs £75,000 a year to run, with the remaining £45,000 provided by the Hospice. This service is supported by a manager, a coordinator who are both part-time along with a volunteer coordinator and currently 24 volunteer drivers who support our passengers with their journeys to hospital.

This service is for any individuals who reside within the Inverclyde Area or neighbouring islands. Passengers do not have to be actively having treatment at the Hospice to be able to use the service. Passengers from neighbouring islands have to be able to make their own way to their local ferry but will be collected from the mainland ferry port by the volunteer drivers.



Anyone with the following criteria can access the service:

- Anyone receiving treatment for a life-limiting illness at a hospital within or outwith the Inverclyde area, who does not have access to transport from family and friends.
- People who are able to travel unaided and do not use oxygen or require an escort, although this can be accommodated for first visits or if going to receive results of tests. Passengers must be able to sit, stand from a low seat, walk and take stairs unaided.

Once accepted by the service and all hospital appointments are logged, passengers are picked up at a convenient time from their own homes by volunteer drivers and returned home again immediately after their appointments have finished. Volunteer drivers use their own cars for this service and checks are done to make sure that they have clean driving licences, appropriate insurance, cars are road worthy and that they complete shadow shifts with an establish driver to get to know what is required for the role. Volunteer drivers are provided with hospice branded uniforms to make sure they are easily identifiable to passengers, along with photographic identity badges and car identity badges which can aid with parking at hospitals. They are also provided with an infection control kit, drivers handbook and supported daily by the office team. They also have access to an inhouse counsellor for 'how to deal with difficult conversations' if required. They are reimbursed for fuel using the HMRC rate of 45p per mile and this is paid directly into their bank accounts.

We could not run this service without these dedicated volunteer drivers who provide their time, empathy and compassion to help care for others.

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- 1174 driver runs were completed. Occasionally the journeys can be shared with other passengers who have similar appointments times at the same hospitals, to keep running costs to a minimum.
- 61,844 mileage was recorded for the period

Challenges/Moving forward

- It can be challenging to recruit volunteer drivers as their days are long and require a significant commitment. The hospice would like to have enough volunteer drivers to allow for them to undertake one way trips instead of waiting for someone's treatment to finish.
- SPT recognises the importance of providing transport to enable people with palliative care needs to attend appointments but we are reliant on their annual grant to help aid our service. In this financial crisis we can only hope for their continued support.

The majority of the service is funded through donations from the local community. Some families who have used the service will donate to show how grateful they are for the support and we cannot thank them enough.



Examples of feedback for this wonderful service that have been received.



"There is no way to improve the standards of your service. I am unbelievably blessed to have your service available, otherwise I wouldn't be able to attend the Beatson [West of Scotland Cancer Centre] for my consultations.

Your drivers give up so much time and they are amazing and your staff are friendly and helpful."

Service user



"The transport service has been a life saver for me over the last 3 and a half years. From the drivers to the co-coordinators, everyone has been so supportive. Sometimes [they were] the only person I had spoken to between treatments."

Service user

Collaboration is key



Strathclyde Partnership
for Transport

Contact

Please do not hesitate to get in touch should you have any questions

Address



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Scotland, PA15 1TS

Contact Details



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Financial Advice in collaboration with Inverclyde HSCP & Macmillan
Cancer Support

Here at Ardgowan Hospice we work very closely with our local Senior Macmillan Cancer Support Advice Worker, who is funded by Inverclyde Health and Social Care Partnership and her team. They come into the Hospice regularly and hold a drop-in clinic in our Access Building. This allows them to meet not only our patients/carers but anyone else in the community who would benefit from their vast knowledge in an informal and comfortable setting to chat over a cup of tea or coffee. We find that this service is a wonderful addition and compliments our other services.

People with a cancer diagnosis face all sorts of hardships, with health, family concerns, worries, work and finances. When we talk to people and referrals arrive the main issue relates to money concerns and every time a HNA (holistic needs assessment) is carried out, concerns about money come top of the list just under health implications and worry about having a cancer diagnosis.

Money worries infiltrate peoples and families lives in profoundly deep ways. The financial hardship is far reaching and affects the person with health issues and their family. Immediate concerns can centre around how will the mortgage or rent costs be paid, how council tax costs and other bills will be paid. This is because many people move straight from full wages per week or month to SSP (Statutory Sick Pay) which is only £116.75 per week meaning earnings can typically drop to a third/quarter of their usual earnings.



Due to the increased price of heating the home, gas/electricity bills price rises, there is serious concern about how to manage and juggle finances at the best of times, but when someone must take time off from work it can be a “scary” outlook financially.

As we all know the price of food, price of fuel-to-fuel cars or transport costs used to get to work or take children to school or help elderly parents are all increasing. Compound this with additional costs of transport to attend appointments, heat a home when someone is usually out all day at work, buy more healthier food etc we have a picture of the financial hardship suffered by many people with cancer or other long term life limiting health conditions.

There is real fear and anxiety about how people can cope, with fear about being able to stay in their home, about losing their job and about getting into debt. In addition many people have never had to explore help from DWP (Dept for Work and pensions)/SSS (Scotland Social Security). They can find the benefits system confusing and slow to respond when they are in time of need. Our Service helps and supports people to navigate both DWP and SSS benefits and access any relevant benefits in their individual circumstances.

There are non-means tested and means tested benefits, various grant schemes and other resources we can map in to help and support people and families.



Macmillan Benefits Service Inverclyde Our Report Jan 24 till Dec 24

- 512 people and families were assisted by Macmillan Benefits Service during Jan 24 -Dec 24.
- 168 people were terminally ill from 512 new referrals.
- £2.5 million has been generated in Inverclyde by the Macmillan Benefits Service for people and families affected by cancer
This total is from a range of benefits and grants applied for by our team to assist clients and their families. We assist and support anyone affected by cancer, the person, their partner, sister/ brother, friend / relative, parent, child etc. The grants can be Macmillan Cancer Support Grants and a range of other grants to help for example with heating costs .We assist people getting back to work after illness and assist bereaved families with applications for Bereavement Support Payment and Funeral Support Payment, where relevant. People are concerned about funeral costs. People are also concerned about their income at state pension age and losing their entitlement to state pension after contributing if they are end of life. Financial concerns are wide ranging and diverse.
- We meet people in person, at their home, at hospital, Ardgowan Hospice or our main office. We are reactive to what is best to ensure a positive outcomes is reached for people. If there are existing debt issues or concerns about being unable to pay existing payments eg credit cards, bank /car loans etc we refer to our inhouse Money Advice Team within HSCP Inverclyde.
- Our Service has been supporting people in Inverclyde since 2008.
- Our workers are skilled and knowledgeable in the various aspects of DWP/SSS benefits systems that are in operation. We take part in regular updates and training about changes in benefit Law and Regulations. We provide advice within the National Standards quality provision.
- Money and concerns about living costs remains the number one concern for people. The concerns about money and coping financially are as **raw** and **scary** as they have always have been.



Thank You

Any questions?

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jamie.thunder@mariecurie.org.uk

Questions for discussion

- 1) What are the barriers people experiencing financial hardship face in your area?
- 2) What do you already do as a hospice to reduce these barriers?
- 3) What more can you do? What are the steps you need to take?

Time to feedback

- 1) What are the barriers people experiencing financial hardship face in your area?
- 2) What do you already do as a hospice to reduce these barriers?
- 3) What more can you do? What are the steps you need to take?

In the chat:

What is the one thing you will commit to doing in the next three months following this workshop?

Feedback Survey

How can we improve our support
for people facing financial hardships?
14th January 2025



Please consider sparing a few minutes to answer this survey, so that we can continue to improve future Big Conversations events:

<https://forms.office.com/e/vqjHH6dKDi>

Big Conversations

The Big Conversations series comprises webinars, workshops, and roundtables that enable our members to:

- learn more about key issues
- share knowledge and experience to inform our work
- discuss problems and solutions with peers
- get practical guidance to move work forward

We invite you to continue engaging with us in the months ahead, as we explore a range of important topics. Upcoming events:

- Employment Law Changes: impact on hospices – 11th February
- C-POS (Children's Palliative care Outcome Scale) – 13th February

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Hospice UK Technology Leaders Conference

- For the first time, Hospice UK will bring hospice tech leaders together for a one-day conference dedicated to exploring key challenges and opportunities in the technological and digital development space.
- Join us in Manchester on **4th February 2025**, to develop your strategic thinking, share good practice and learn about trends in the sector and beyond.

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Stay up to date



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Our [Member Update page](#) is updated regularly so you can keep up with our key work and priorities from week to week.

The page is hidden from the public and will not come up in web searches, so we'd recommend bookmarking it!