



BARRY'S STORY

DIGITAL STORIES TO SUPPORT
DISCUSSIONS ON FINANCIAL
BARRIERS TO DYING AT HOME:
A TOOLKIT FOR HEALTH AND
SOCIAL CARE PROFESSIONALS,
VOLUNTEERS, AND FAMILY CARERS

Notes for educators and facilitators

Research has identified a need to support health and social care professionals in responding to the financial concerns experienced by patients and their families. To this end, our team based at the University of Glasgow has worked with family carers to create a series of digital stories. With the permission of these family carers we have made these available for education and training purposes and have developed an accompanying toolkit to support educators.

The toolkit provides a suggested structure and approach for planning a training session. We provide questions that can be used pre- and post-viewing to encourage discussion of the digital story.

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1. Introduction to the toolkit

Our research project has explored barriers to home dying faced by people who are experiencing financial hardship. As part of the project, we have worked with bereaved families and friends to co-create digital stories about their loved one's experiences.

Each story is approximately three minutes long and is voiced by a family member or friend, accompanied by photographs, video and music. All the stories are available on [our project webpage](#) where you can also find the accompanying toolkit. Permission to share these stories was obtained from participating families.

This is intended to be a resource to help health and social care professionals, volunteers, family carers, and others supporting people with serious advanced illnesses. We aim to raise awareness of issues related to financial hardship at the end of life and advocate for change through the sharing of real-world examples.

Before starting the session, we recommend that you watch the digital story and read through the toolkit. This will help you to plan how it can be adapted to your specific educational context.

2. Learning outcomes

The aim of our digital stories is to raise awareness of the financial barriers experienced by patients and families to dying at home.

Barry's story is about Barry Armstrong, a senior humanitarian aid worker, who was diagnosed with aggressive brain cancer in 2020. Barry's wife Jo describes the difficulties she experienced while trying to support Barry to remain at home, with their two young boys, as his condition progressed.

The key issues raised in this story include:

- Challenging stereotypes about who experiences financial hardship at the end of life;
- Financial barriers to dying at home, such as the cost of private care;
- Resources that can help somebody with a serious advanced illness to die at home.

3. Pre-screening discussion

Welcome and scene-setting

In training settings, it can be helpful to agree on 'ground rules' collaboratively with the group, such as:

- Confidentiality: any reflections privately shared with the group are held in confidence afterwards.
- Respecting diversity in people's responses and providing space for quieter participants to contribute.
- Valuing all contributions, whether or not we agree.
- Care: creating a supportive environment where all participants feel able to express emotion or leave the room if needed. Additional signposting to appropriate support and resources are also encouraged. Some examples are provided at the end of the toolkit.

Pre-screening question

Do you think that the financial barriers to dying at home that are experienced by patients and families are given enough consideration?

4. Watch the digital story

Length: 3 minutes

Language: English [subtitled version also available]

Barry's story is a digital story. Digital storytelling combines digital elements (text, images, video, audio) within a narrative structure (a story). The script, images and voiceover for this story were provided by Jo Armstrong, Barry's wife. The digital story is best viewed on a device with an internet connection and adequate playback volume.

Link to Barry's story: https://www.youtube.com/watch?v=vnCQ_jHEaSk

5. Post-screening discussion

Immediately after the film, participants may wish to take a few quiet moments to reflect on what they have seen. The following questions can then be used for personal reflection or group discussion.

Post-screening questions

1. What are your reactions to watching Barry's story? Did you find any elements of the story challenging? If so, what elements and why did you find them challenging?
2. Is Barry somebody that you would assume would have financial concerns resulting from the costs associated with dying?
3. What are the costs associated with living with a serious advanced illness which might cause somebody to slip into financial hardship?
4. What resources were Barry and Jo able to draw upon to enable Barry to die at home? These might be resources not just of time and money, but of knowledge of the system, knowing who to speak to get a decision made, being aware of what one is entitled to, and an ability to articulate one's demands for support.
5. Most patients and families never manage to secure the high level of care which Barry and Jo were able to receive, and which they almost *didn't* receive. What might be the experiences of patients and families who aren't able to draw on the same resources and who don't get such a care package?
6. Did the story have any resonance with your personal and/or professional experience?
7. How might health and social care professionals and volunteers ascertain whether someone is experiencing financial hardship and deprivation at the end of life? How might questions be sensitively phrased? Are there other indications which might suggest someone is struggling to make ends meet?
8. For family carers/patients: How easy or difficult do you find it to discuss financial concerns with health and social care professionals? Are you aware of any resources that can help you understand and address any financial concerns you may have experienced, or anticipate experiencing?
9. Has the film made you think differently at all about financial concerns relating to dying at home?

6. Additional commentary and background from Jo, Barry's wife

My husband, Barry, died in November 2020, three and a half months after receiving an initial inadequate care package and only six weeks after receiving the right care package. Assessing his needs properly, listening to our needs as a family and acting on them would have produced a different outcome. We would have had the care we needed when we needed it. Then we could have used our energy on spending time with him. I will not get that time back. This has to change. I have worked with the End of Life Studies Group at the University of Glasgow to create a 3 minute digital story in order to raise awareness.

“I don’t want to know my prognosis, I just want to know what will be done about it.”

With those words my husband and I entered the consultation room, take away coffee in hand with a hastily packed pen and paper to make notes with.

We left reeling; an incurable brain tumour, proposed high risk surgery, radiotherapy, chemotherapy, all essentially palliative – prolonging time alive but no curative options on the table.

In that hour our sense of selves, family and future fissured. We had always seen our future selves going to work abroad again, leaving the UK for another adventure of cross-cultural living and working, just as soon as our boys finished school. Now we had to navigate how to tell them the terrible news, how to live when time frames become sharpened, unpredictable.

I had access to median survival times, Barry wisely chose not to know these. We chose to return to work. Barry had worked hard to develop a career in humanitarian aid and we drew on the Trades Union Congress’ Dying to Work campaign to ask his employer to support his return. Working was important in its occupation, it provided meaning and an income.

Each month brought deterioration, ineffective treatments, first, second and third line until the lines ran out. We were in Covid-19 times; the first lockdown. An oncologist explained by telephone rather than in person that deteriorating scans meant no more treatment options. We were cut loose into the uncharted waters of decline. The unknown and unknowable face of dying.

We had a supportive palliative care doctor and district nursing team. We chose to travel to see family during lockdown in Ireland. Through my work and our friends, we created a lending library of kit so we could live as fully as possible. Mobility scooters were borrowed, these were exchanged for wheelchairs, for temporary ramps, for supportive backrests. Our local community therapy team set up grab rails, a hospital bed and a hoist.

Barry had always taken our boys on a Dad’s camping trip each year, so when the first lockdown eased we went. Supported by two other dads, their sons and a lot of equipment we managed a short trip, to sit round a campfire, get to the sea and watch the boys play in a river and at a skatepark.

As Barry’s physical fragility progressed, I needed help. Our neighbours pitched in, sharing their swimming pool when our local day hospice felt that bathing Barry was too difficult, sitting up with Barry over night to enable me to sleep. I had to stop work and instead I worked to navigate the opaque process of securing Barry's care.

We were offered daily care call visits that failed to time their arrival to Barry’s needs. To die at home when physically dependent takes a team around the dying person. They need to be

supported through the long nights of darkness and distress, they need to be helped with all tasks; feeding, washing, dressing, accessing the garden. They need the opportunity to talk about dying, what they want and do not want, their funeral wishes, to weep and for their loved ones to walk this road with them, rather than sink under the unrelenting burden of shifting symptom management and the gruelling nature of 24-hour care.

Barry could not sleep due to his high steroid dosage. I needed a live-in carer and night carers so I could care for Barry, leave the house for the school run, host the continual flow of friends and family, and support our children. We did not want to be in a hospice, a 40-minute journey away with Covid-19 visiting restrictions, cumbersome personal protective equipment, and the chance that Barry would be alone through the night.

I am sad to write that this was a battle - of arguments, of care package reviews, of a failure to assess, of delays. Substantive stress on an already stressful situation.

Barry died at home in November 2020, his family beside him, he was 47 years old. His sons were 11 and 13.

7. Further information

This digital story was created as part of the four-year (2019-2023) Economic and Social Research Council-funded Dying in the Margins research project. The aim of this visual research project was to examine experiences of home dying for people experiencing poverty and deprivation in the UK in both urban (Glasgow) and rural (Dumfries & Galloway) locations. The Dying in the Margins project team includes [Dr Naomi Richards](#), [Dr Sam Quinn](#), [Dr Emma Carduff](#), and [Professor Merryn Gott](#).

The digital stories are a co-production between the bereaved family and friends, the research team and the filmmaker *Lucas Chih-Peng Kao*. Lucas is an award-winning short film director based in Edinburgh, Scotland.

<https://cplkao.myportfolio.com/>

8. Digital story toolkit feedback

Your feedback is important to us. If you have any comments on our digital stories, please [contact Dr Naomi Richards](#).

9. Links and resources

Project webpage:

<https://www.gla.ac.uk/research/az/endoflifestudies/projects/dyinginthemargins/>

Twitter: @Dying_Margins

Marie Curie's 2022 Dying in Poverty report:

<https://www.mariecurie.org.uk/policy/poverty/povertyreports>

The equity turn in palliative and end of life care research: Lessons from the poverty literature by Dr Naomi Richards (2022):

<https://compass.onlinelibrary.wiley.com/doi/full/10.1111/soc4.12969>

The impact of poverty and deprivation at the end of life: a critical review by Dr Jane Rowley, Dr Naomi Richards, Dr Emma Carduff and Professor Merryn Gott (2021):

<https://journals.sagepub.com/doi/full/10.1177/26323524211033873>