



STEVEN'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 (Rowley et al, 2021). 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.

Steven's story is about Steven Thompson, who was diagnosed with slow growing stomach cancer in 2015. Steven's brother John describes the difficulties that Steven faced in accessing disability benefits and the severe impact that this had on his mental and physical health.

The key issues raised in this story include:

- The complexity of the benefits system;
- The role of local support agencies in advocating for people with serious advanced illness;
- The cost of transport to healthcare appointments for people at the end of life.

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 benefits/social welfare system provides appropriate support for people who have a terminal illness?

4. Watch the digital story

Length: 3 minutes

Language: English [subtitled version also available]

Steven'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 Steven's story: <https://youtu.be/Z3MYkTgh3dQ>

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 Steven's story? Did you find any elements of the story challenging? If so, what elements and why did you find them challenging?
2. What were the main causes of the financial insecurity Steven experienced?
3. How do you think Steven's financial concerns impacted on his mental and physical health? What would have made a difference to Steven?
4. The Citizens Advice Bureau¹ played a major role in helping Steven to access the benefits he was entitled to. Do you have any professional experience of referring people to this advice service? Are there other advice services you have found helpful on matters related to benefits?
5. The cost of transport was a major issue for Steven towards the end of his life. Can you identify any issues around transport/travel to healthcare appointments in the area you are based? How might the experiences of people living in urban and rural areas differ?
6. If you encountered a person in Steven's circumstances, what, if any agencies you could signpost/refer them to and how might you go about this?
7. If a person with a terminal illness is struggling with travel and transport, what options and support might be available to them?
8. Has the digital story made you think differently at all about the financial insecurity faced by people with terminal illnesses?

6. Additional commentary and background from John, Steven's brother

It is my firm belief that the benefits system hastened the death of my brother, Steven Thompson.

He had a slow growing cancer which he fought for a number of years. He lost his zero hour job mainly due to attending a number of medical appointments which meant he was not available for work at short notice. As he was on zero hours contract he had no working rights such as time off for medical appointments.

He was advised by The Citizens Advice Bureau to apply for [Personal Independence Payment](#) (PIP), a state benefit for people living with a disability. He was initially turned down, and

¹ The Citizens Advice Bureau is a network of independent charities throughout the UK that give free information and advice to assist people with money, legal, consumer, and other problems.

again refused on appeal. With the help of a local advisory service he eventually won an award at a legal tribunal.

Two years later, the PIP award was stopped and he had to apply again. He was again refused. He did not have the mental or physical strength to mount an appeal

At this point he gave up fighting and died six weeks later.

My question is: How can someone with a slow growing cancer be eligible for PIP at one point and yet two years later be refused?

The Department for Work and Pensions (DWP) would have received a report from the GP stating that the cancer was not any better and the award should have been made automatically.

Steven's final journey was to the hospital for a routine check-up. The hospital was 12 miles away, a 30 minute car journey. However, neither Steven nor any family member drove a car, so the journey had to be made via public transport; a 90 minute journey ending with a '6 minute' walk to the hospital. This walk took 20 minutes due to the severity of Steven's illness. He never made the return journey.

Perhaps if he had some extra financial support via PIP he might have taken a taxi to the hospital.

I made a complaint to the DWP but was assured that from their point of view all the boxes were ticked and the computer said 'no'. This may be true, but if so then the system is not only wrong it is cruelly wrong. People's hopes are destroyed when they are at their lowest point.

It is my aspiration that the system is fine-tuned so no one finds their hopes destroyed as Steven did. This is why I am sharing his story.

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>