



# LINDA'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.

Linda's story is about Linda McLeod. Linda was 63 when she was diagnosed with secondary breast cancer and aggressive cancer in her spine. Linda's daughter, Nicola, describes the challenges she encountered trying to care for her mother while looking after her own young children. She also describes how she wishes more had been done to help her mother to return home rather than remain in the hospital.

The key issues raised in this story include:

- The substantial costs that can be incurred by people at the end of life, and by their carers, including childcare, travel and funeral costs;
- How the physical environment of the home can be a barrier to home dying.

### 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 is also encouraged. Some examples are provided at the end of the toolkit.

#### *Pre-screening question*

What additional costs might be incurred by a person diagnosed with a terminal illness, and their carer(s)?

### 4. Watch the digital story

Length: 3 minutes

Language: English [subtitled version also available]

Linda'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 Nicola, Linda's daughter. The digital story is best viewed on a device with an internet connection and adequate playback volume.

Link to Linda's story: [https://youtu.be/STttA1o\\_a\\_U](https://youtu.be/STttA1o_a_U)

## 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 Linda's story? Did you find any elements of the story challenging? If so, what elements and why did you find them challenging?
2. Linda experienced anxiety about the cost of her funeral. What support are you aware of for people concerned about funeral costs?
3. Nicola was Linda's main carer. Affording travel and childcare proved particularly challenging for Nicola. What **hidden** costs could be incurred for a person with a terminal illness or their carer(s)?
4. Marie Curie<sup>1</sup> has proposed that terminally ill people of working age should be entitled to claim the state pension. What do you think of this proposal and what difference would it have made to Linda?
5. What challenges might be encountered when delivering end of life care in a setting such as a tenement or a tower block?
6. For health and social care professionals: In your practice have you encountered anybody who wished to die at home but was not able to because of financial considerations? Can you think of any additional financial barriers to dying at home?
7. Has the digital story made you think differently at all about the financial insecurity faced by people at the end of their life?

## 6. Additional commentary and background from Nicola, Linda's daughter

When my mum initially went to see the GP in 2019, she was told her pain was pulled muscles and was given painkillers. But she actually had stage three breast cancer and developed large lumps under both of her arms. When she was finally correctly diagnosed, she was too ill for chemo and radiotherapy. Two of the discs in her spine had been eaten away by cancer.

Nevertheless, the physio team would visit her in the hospital to try and encourage her to walk up two flights of stairs with her walking stick so that she could be discharged home. She needed to be able to walk up a flight of stairs to get to her flat on the fourteenth floor

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<sup>1</sup> Marie Curie is a national charity providing care and support for people living with any terminal illness, and their families.

because the lift only went up to the thirteenth. This gave us the false hope that she might be able to return home, where she wanted to be.

My mum's experience in the hospital was poor. She was hoisted out of bed, crying in agony because of the pain in her back. She had to use the commode on a mixed ward of six people. This was not dignified. In another incident my mum fell out of bed while trying to get to the toilet and hit her head – she was unable to reach the buzzer to call a nurse for help.

As time passed my mum became frailer. She was put in the day room so they could clean the ward. A Healthcare Assistant was trying to get her out of her seat to take her back and my mum repeatedly asked them to wait so she would slowly get herself up. Trying to help, the HCA lifted underneath her arms, and her collarbone broke. This was upsetting for us ... it felt like she wasn't being listened to.

A social worker came every day to organise my mum's discharge. However, because of the strong pain medication she was on, my mum was confused about what had been organised for her. The social work team tried to discharge her to sheltered housing accommodation on the opposite side of the city with no additional support and no in-house care. My uncle and I had to insist that the social worker wait until my mum had accompanying adults before they discussed her discharge.

We never once got to speak with my Mum's consultant directly, I didn't get a reply to any of my pleas for information. Once we were told she was terminal and she had around 3 weeks to live I was adamant she would not die in a mixed ward. I called the hospice every day for eight days until they had a space to take my Mum. After trying to get her to be transferred and repeatedly being told there was none available, I drove her there myself.

In the end, it felt like there was never a concrete care plan shared with us for how she was going to get back home. She wanted to be at home at the end of her life. Although she passed away five and a half weeks after first going into hospital, every single day was challenging. This was precious time I wanted to spend with mum. I didn't want to be chasing doctors and nurses. Although we were relieved when she finally got a room at the local hospice, it felt as if all the way through, we were never offered any choice or given clear communication on what was happening.

I felt so guilty that after everything my Mum had done for me I couldn't have her die at home. The home she had lived in for 30 years, her little safe haven. I need to live with that, that I let her down. I shared my mum's story so other people can avoid a similar experience.

## 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>