FRANK'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.

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.

Frank's story is about Frank, a 58 year old man, living with multiple health conditions during the COVID-19 pandemic. His story was told to us by his daughter, who wishes to remain anonymous. In it, she discusses the financial challenges of caring for a person with a terminal illness, particularly the cost of food and energy, and the difficulties of trying to provide care while raising a young family.

The key issues raised in this story include:

- How individuals may wish to remain at home, even if aspects of the environment, such as stairs, pose challenges to their care;
- The significant financial costs associated with caring for a person with a terminal illness, particularly food and energy bills, and the impact this can have on the wider family;
- The emotional impact on carers if they are unable to support their loved one 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 is 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]

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

Link to Frank's story:

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 Frank's story? Did you find any elements of the story challenging? If so, what elements and why did you find them challenging?
2. Frank's daughter was his main carer. Affording energy bills and food proved particularly challenging. What hidden costs could be incurred for a person with a terminal illness or their carer(s)?
3. What challenges might be encountered when delivering end of life care in a setting such as a tenement or a tower block?
4. Reflect on the importance of community and support networks in enabling individuals like Frank to receive the care they need. How can communities and organisations better collaborate to provide end of life care for people experiencing financial hardship?
5. Think about the role of communication in Franks's story. Are there instances where communication could have been improved? What should have been done differently?
6. Where a person expresses the desire to remain at home at the end of life but is unable to do so, what impact might this have on their bereaved carer?
7. 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?
8. Has the digital story made you think differently at all about the financial insecurity faced by people at the end of their life?

8. 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/

9. Digital story toolkit feedback

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

10. 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