

Dying in the Margins; The Cost of Dying

The first research study in Scotland, and UK, to use visual methods to evidence circumstances of dying at home in financial hardship

Research undertaken by University of Glasgow and Marie Curie. The 'Dying in the Margins' study was funded by the Economic and Social Research Council (ESRC), part of UKRI (UK Research and Innovation).



Photograph by Margaret Mitchell

“I’ve never claimed unemployment benefits, ever. Talking about national insurance stamps, I’m fully booked up. I’m going to lose my old-age pension which I never, ever received.” - Margaret, 64



Photograph by Margaret Mitchell

"I prefer being at home. No one wants to be in a hospital. I want to do my own thing." Max's home was unfit for his needs, with four sets of stairs and a bath he could not climb into.

He was moved into a hospice by concerned carers but before long Max made "a great escape", according to his friends. "He did a runner from the hospice basically to get back to his dog." - Max, 65

What is Dying in the Margins?

Dying in the Margins examines barriers to, and experiences of, dying at home for terminally ill people, their families and carers living with financial hardship and deprivation.

The research is a longitudinal study which used participatory visual methods - photo-voice and digital storytelling – through which people directly experiencing poverty at the end of life were supported to tell their own story in their own words and images. In addition, award-winning Scottish photographer Margaret Mitchell was commissioned to create a body of work reflecting on participants' stories and emotions.

There are currently no images in Scottish or UK contemporary palliative care policy and literature which speak to the experience of dying in circumstances of socio-economic hardship, these are the first. The imagery and digital stories will inform public conversations around end of life care improvements, specifically for people experiencing poverty and marginalisation at the end of life.

There is an online gallery of a collection of exhibition images [here](#).

Research analysis of Dying in the Margins is still ongoing, but provisional themes and key findings from exhibition visitor feedback and a panel discussion are:

- 1. Equity-informed palliative and end of life support for people experiencing deprivation and financial hardship is not prioritised for those with the greatest needs at the end of life.** There are currently insufficient resources e.g. for social care and primary care, in areas of higher deprivation and for those experiencing, or at risk of, financial hardship
- 2. Existing housing stock (private, social and rented sectors) is often unsuitable for supporting terminally ill people's needs at home, and they experience significant barriers, delays and costs for housing maintenance and adaptations which they cannot afford.** This is particularly acute for people living with multi-morbidity (at least one terminal condition) whose needs vary and are often complex, as well as for their families and carers
- 3. Lack of compassion by immediately evicting relatives after a terminally ill person has died;** meaning relatives are being forced to vacate properties only two weeks after the death, often with no alternative accommodation in place
- 4. Lack of opportunities for professionals to undertake training on social determinants of health such as housing, financial circumstances and caring responsibility,** and how they impact end of life experience.
- 5. Insufficient independent advocacy for terminally ill people experiencing deprivation and financial hardship;** meaning they are lost in health and social care, social security and housing systems and do not get the support they need either while they are dying, or after death.

University of Glasgow and Marie Curie are calling for:

- 1. Scottish and nation-wide governments to commit to financial support specifically for terminally ill people, their families and carers experiencing poverty and multiple disadvantages, accompanied by a parallel public awareness campaign to ensure uptake**
- 2. Scottish Government's upcoming palliative care strategy and National Care Service to apply an intersectional lens, which acknowledges the complex and intersecting nature of multiple disadvantage across a person's life course, to ensure equity-informed end of life support**
- 3. Scottish Government's new Housing Standard and Scottish Accessible Homes Standard must reflect people living with multi-morbidity (at least one terminal condition) for both existing and new homes, and Scottish Government's Housing Bill must strengthen the rights of terminally ill tenants, their families and carers**
- 4. Local Government must commit to fast-tracking housing maintenance, adaptations, and moving requests for terminally ill people using the BASRiS form; Local Government and Housing Associations must extend eviction notices for bereaved co-inhabitants living in social housing for six months after the death**
- 5. Ring fenced funding from Scottish Government, Local Government and Health Boards to double the recruitment of advocacy professionals such as community link workers, as called for by GPs at the Deep End, with a parallel training programme in social determinants of health to empower and equip staff**
- 6. Local Government, public sector organisations and health and social care education providers to embed education on social determinants of health as a core aspect of curriculums, training and practice to build knowledge and confidence in trauma-informed practice for all professionals, including community link workers, as part of a continual professional development programme**

What is next for Dying in the Margins?

The **Dying in the Margins** exhibition ran from **Monday 24th April - Friday 5th May 2023** at the Advanced research Centre, University of Glasgow.

The **exhibition will also run from 19th June – 19th August 2023 at the Mitchell Library**, North Street, Glasgow, G3 7DN. **The exhibition is free to attend.**

As attendees view the exhibition, they will be asked to think about what the NHS, housing associations, social work, and the third sector, as well as local communities, should and could offer people who perhaps haven't had the best chances in life.

What could be designed or distributed differently to better support people in the final months of their life?

Change will require a whole-system approach, with collective responsibility for National and Local governments, policy makers, health and social care professionals and academics to take action.

About University of Glasgow

The University of Glasgow has been changing the world since 1451. We are a world top 100 university and a member of the prestigious Russell Group of leading UK research universities.

The University of Glasgow's End of Life Studies Group is based at the Crichton Campus, Dumfries. Our approach is to bring together the best ideas and perspectives from the social sciences, humanities, public health and clinical disciplines. We conduct interdisciplinary research collaborating with communities, policy-makers, practitioners and academics worldwide to address the challenges presented by dying, death and bereavement in a rapidly changing world.

In 2020-21, we launched our entirely [online MSc/PGDip/PGCert programme in End of Life Studies](#). This is a unique blend of bespoke courses which provide inspiration to students from around the world who, like us, are fascinated by the character and complexity of end-of-life issues.

About Marie Curie in Scotland

Marie Curie is here for people living with any terminal illness, their families and carers. We offer expert care and guidance through our two [Hospices](#) in Edinburgh and Glasgow, and [Marie Curie Nursing Service](#) in 31 out of 32 Local Authorities.

Our [volunteer-led Helper service](#) provides companionship and support to those affected by terminal illness and has a presence across all 32 Local Authorities, as well as our [Information and Support lines](#), including dedicated bereavement line, which provide emotional support and practical and clinical information about terminal illness. Marie Curie is also the biggest charitable funder of [palliative care research](#) across the UK.

In 2021-22, Marie Curie Scotland cared for 8,660 people at the end of life. With more and more people dying in the community throughout the pandemic, demand for our community nursing services has remained extremely high.

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