



University
of Glasgow



Marie
Curie



DYING IN THE MARGINS

The Cost of Dying Exhibition

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



Economic
and Social
Research Council

The Cost of Dying

This exhibition contemplates research findings on experiences of dying at home for people facing financial hardship and deprivation in Scotland.

The imagery and testimonies encountered here lay bare end-of-life experiences which are not always considered. Firstly, not everyone pictured in this room looks as if they are dying. Despite serious illness, pain, and discomfort, many people included in the study continued to go about their daily lives. This included continuing to care for their children, grandchildren, and partners. That the dying are still carers, or still live alongside us in our communities, passing us in the stairwell, the library, or on the bus, is not always recognised.

The twelve stories represented depict people who were weighed down by the heavy financial costs of dying. Some of these individuals also lacked a material environment or a care package conducive to a dignified end of life experience. For those who had struggled on a low income their entire lives, terminal illness only plunged them further into hardship. For others just about getting by, terminal illness brought new and unanticipated hardship.

While the state offers a partial safety net in such cases, there are questions over whether this is sufficient to meet the needs for a comfortable end of life.

The exhibition comprises three different approaches to aid a deeper understanding of the issues. The photovoice images, made by participants themselves, frame their experiences from the inside demonstrating their resilience as well as their isolation. The digital stories give the perspectives of bereaved loved ones. Margaret Mitchell's images speak to each individual's strengths as well as their vulnerabilities.

As you view this exhibition, we ask you to think about what the NHS, housing associations, social work, and the third sector, as well as communities in general, should and could offer people who perhaps haven't had the best chances in life.

What could be designed or distributed differently to ease people's distress in the final months of their lives?

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 disadvantages 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

Amandeep, age 22

“Things are changing hour by hour; one day I can be okay and then the next minute I can be not so well ... it’s scary because I don’t know what’s going to happen.”

Amandeep lives with his mum and two of his siblings in a three-bedroom flat. He has lived with the symptoms of Duchenne muscular dystrophy for much of life. His mum is his full-time carer. Amandeep feels a great deal of uncertainty about his future in terms of how they will both manage. Months on end spent shielding from Covid has made him more reliant on his mum than ever. His world has been his bedroom: “I can’t even get out to the back garden because there’s stairs.” A shortage of professional carers and an inability to leave his house has meant his mobility has taken a serious dip.

In the close-up image Margaret took of Amandeep (far left), we can see his resilience and strength coming through. Amandeep feels that he has had to fight for many of the supports he has in place, and for the equipment and technology which are his lifeline. He relies heavily on electronic medical devices like his wheelchair, hoist, and ventilator to stay at home.

During the study, Amandeep was assisted to take his own photovoice images. Here you can see his hoist and his room at home, full of medical equipment and supplies.



Amandeep's Photovoice

When a crisis results in Amandeep being admitted to hospital for extended periods, he and his mum find it really challenging and he struggles to sleep - “nothing beats your own bed”.

He wants to stay at home, but that means paying considerable heating costs, and the costs of running all his equipment – up to £400 a month. These have spiralled recently, causing significant financial strain for the family.

“Do we heat our house up or do we eat food? It’s very much getting to that point now.”

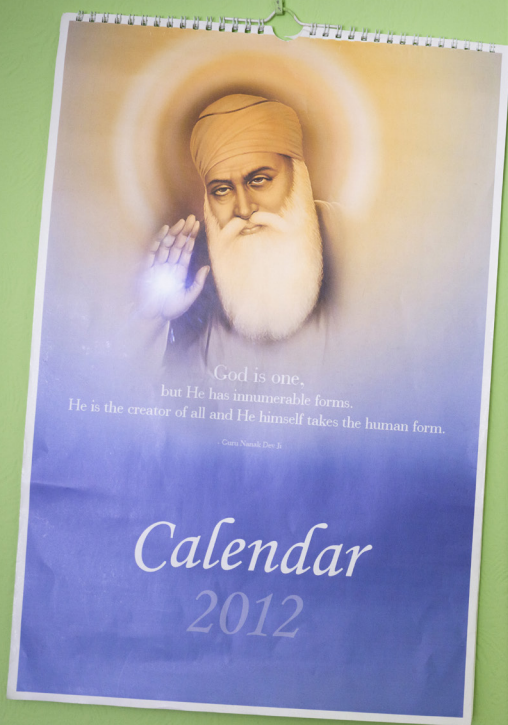
Margaret’s image of the 2012 calendar on Amandeep’s bedroom wall reflects the year his health started to decline, a commentary on a stillness and lost time. It’s hard for Amandeep to be living alongside his brothers and sister who have a sense of freedom that he has never had. Covid brought an abrupt end to the limited freedom he did have: “I can’t do anything, I can’t go anywhere, I can’t see the world.”

Margaret’s image of Amandeep in bed at the hospice shows a more spacious environment than his home. The environment is also less busy and calmer. Thinking of the future, Amandeep has said that when the time comes, he would like to die in the hospice – “it’s like a hotel ... I get treated like a king.”



Amandeep's Photovoice







Photographs by Margaret Mitchell

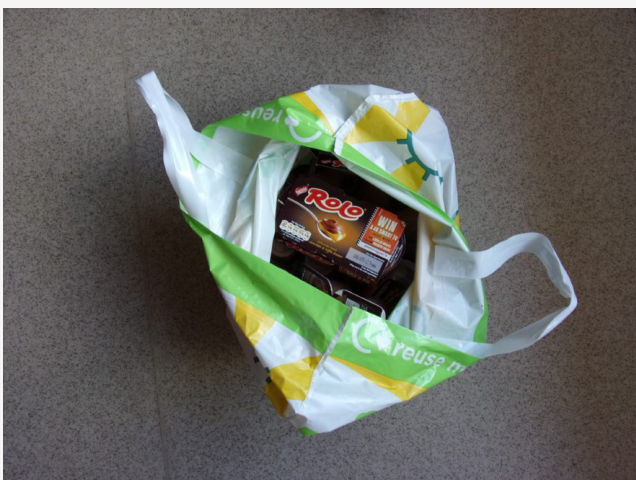
Andy, age 53



Project Diary: Margaret Mitchell

When Andy first arrived at the hospice in Glasgow, he was in a bad way and was simply waiting to die. His throat cancer made it hard from him to communicate and to be understood. He was estranged from his family, and he was worried about naming them on his hospice forms in case they were then burdened with paying for his funeral.

Over several admissions, the hospice staff were able to help Andy reconnect with members of his family, including his daughter and his granddaughter, whom he had never met. When Margaret met Andy in the hospice during the first lockdown of the pandemic, she noticed a closed jar containing an unopened sticky notes pad and was intrigued by it, reflecting that it was somehow significant. On her next visit, Margaret saw that the jar now included some written notes and Andy told her that he was writing them to leave to his granddaughter. The image on the far left shows Andy proudly and tenderly holding this jar.



Andy's Photovoice



Project Diary: Margaret Mitchell

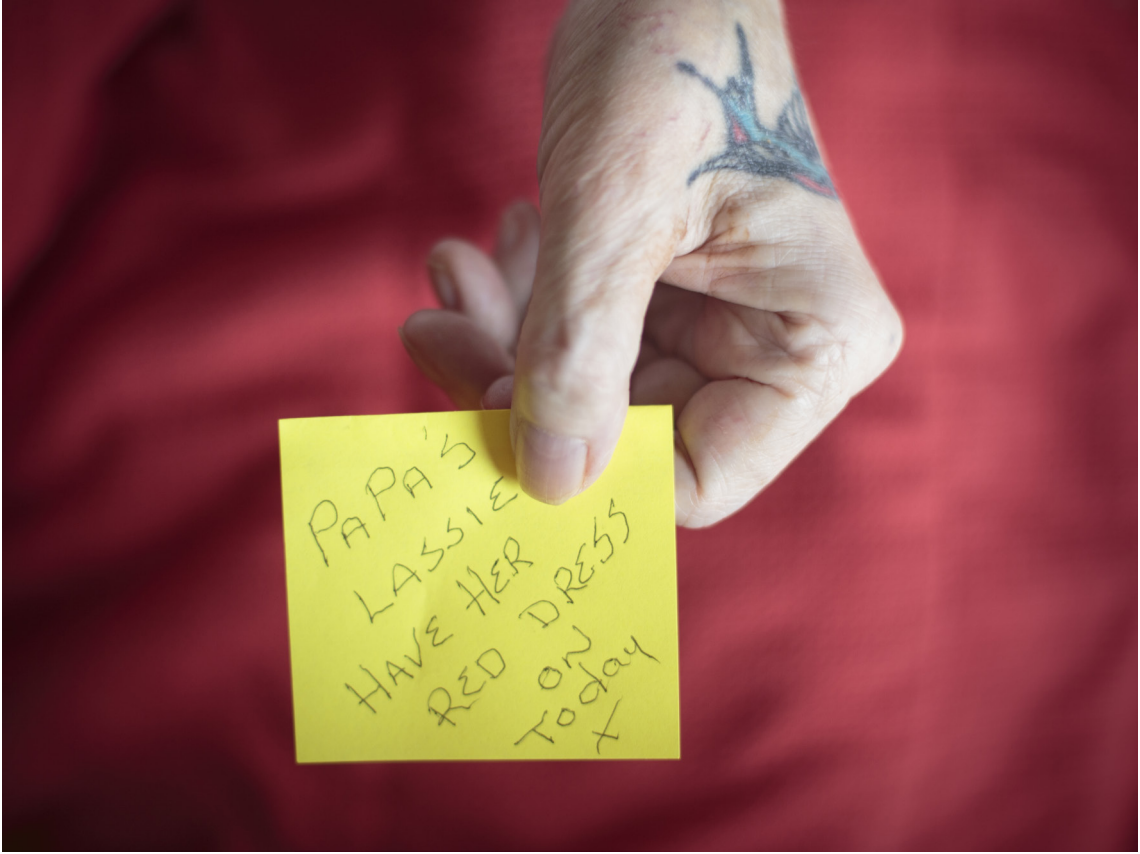
Andy experienced hardship from a young age and throughout his life. There were aspects of his past that he expressed regret about. He had no choice but to spend his final weeks in the hospice, as his flat had been broken into and he had nowhere else to go.

Andy's photovoice images show the bags of food his daughter brought him which were the only things he was able to eat due to his cancer. They also show the sparseness of his belongings in the hospice. The jar of notes was the main thing he left for his granddaughter.



Andy's Photovoice







Photographs by Margaret Mitchell

Donna, age 56

Donna has experienced multiple hardships throughout her life, financial insecurity being just one. She is a single parent with caring responsibilities. She has experienced a series of bereavements over the last decade, including the sudden death of her son.

“I don’t think I could be hurt any more than I have been hurt.”

Donna lives with multiple chronic conditions, some of which, like COPD, she has had for many years, while others are new. Together, her conditions cause her a lot of pain and breathlessness and she has low energy: “I struggle to leave the house, to get dressed.” Because she is housebound much of the time, she struggles with isolation: “I feel like a prisoner in my home. I really feel like that. Nobody to go and see, I just need to sit here, basically.”

She has a wee dog for company, but she can’t take him for walks anymore: “as my pain has grown and become unbearable ... the [dog lead] has become redundant.”

Because she has so many different conditions, Donna’s care isn’t joined up and she struggles to get doctors to sort out her medications and get on top of her symptoms. She spends a lot of her time seeing different doctors for her different illnesses, and going in and out of hospital, which she says she hates, “because sometimes I wonder whether I’m going to come back out again.”



Donna’s Photovoice



Project Diary: Margaret Mitchell

Donna has had support from her Community Link Worker to try to join up her care, but there are things she feels she hasn’t been told by medical professionals, mainly about what she can expect in the future:

“I was thinking the other day, maybe if they actually sat down and told me how ... about my liver and then my pancreas and all that, they’ve not really explained how my illness will go on, if you know what I mean? I would like somebody to sit down.”

Seeing the photographs which Margaret took, Donna had mixed feelings. She could see in the photographs how her illness had changed her in a short space of time. To look at a surface that you don’t always recognise yourself can take bravery, which Donna did with grace as she faced her own fragility.







Photographs by Margaret Mitchell

Liz, age 73

The photographs of Liz capture both her vulnerability and creative flair. Liz knew outsiders might see her flat as 'cluttered' or an inappropriate place to deliver care, but she liked being there, and in her neighbourhood, because it was home to her.



Liz's Photovoice

When she was diagnosed with terminal lung cancer, Liz struggled to get support. She was estranged from most of her family and lived alone as her partner lived separately. Her partner also has her own care needs. Liz spoke a lot about being alone, not knowing what would happen when she reached the final stage of her illness, and her concern for what would happen to her partner after she died. She wondered if her care and support was impacted by her living in a poorer neighbourhood, known for its high crime rates:

"What if I lived in Milngavie and was surrounded by loving sons and daughters that have done really well and had a beautiful house, blah, blah, was a professional person. I suspect my care would be different."

Liz fully embraced the photo-voice element of the study. She took photos of the problems she was facing in her flat – the black mould, which was right next to her bed, the leak from the flat above, the fire alarm which kept going off in the middle of the night. She also had to contend with noise pollution coming from outside her flat: "Because of where I live, they're always doing road works, the noise is terrible."



Liz's Photovoice

At times she really despaired. She clung to her faith to give her strength: "I've survived with using the radio. When I can't get to church, I listen to this ... it's a big help to me when I can't get, or don't feel, safe." She also absorbed herself in dress-making and her love of fashion design. She visited charity shops and vintage clothes shops, for the conversation and the warmth as much as for buying clothes.



Liz's Photovoice

The Mitchell Library was also a place she found warmth, away from her flat. It was there that she researched her condition and local neighbourhood, and where she spoke to the project researcher, Sam, and showed him her photographs.



Liz's Photovoice - The Mitchell Library

In the last weeks of her life, Liz tried to remain at home. The care package she was offered from a home care provider initially involved half an hour's care, twice a day. But this was quickly dropped to half an hour, once a day, reportedly due to staff shortages. This package didn't meet Liz's needs, so when she was offered a hospice bed, she took it. Although Liz was happy to be looked after in the hospice, any real choice about where she wanted to be at the end of her life had been taken away from her.







Photographs by Margaret Mitchell

Margaret, age 64

“Even though her whole world was ending, she was still a strong person, and you can still see the fight in her.”



Photograph by Margaret Mitchell

Margaret thought her cancer was caused by pollution - growing up in an industrial city, living on a busy, polluted road, and working above a bus station for many years: “we went to school in the peasouper. You were all holding onto each other, it was so thick. You couldn't see anything.” In her neighbourhood, Margaret knew lots of other people who had also got cancer – “and that's only people who I know.”



Project Diary: Margaret Mitchell

Margaret's main worry as she neared the end of her life was ensuring her teenage daughter would be secure financially after her death. Margaret had been careful with money her whole life and had been self-sufficient from a young age, leaving home at 16 and being steadily employed.



Project Diary: Margaret Mitchell

She worked with the hospice social worker to check she had got all the benefits she was entitled to. She was upset when she found out she wouldn't be able to access her pension which she had worked so hard for: “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.”



Project Diary: Margaret Mitchell







Photographs by Margaret Mitchell

Marie, age 46

“I gave my children a loving, happy home where they are safe and nurtured to go on and accomplish an even better life for themselves.”



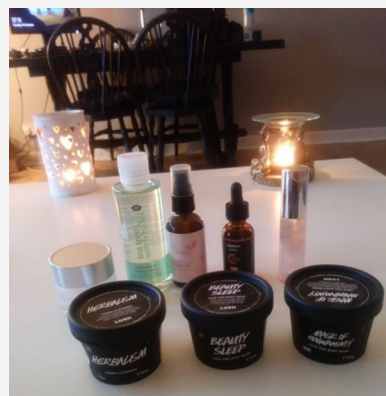
Marie's Photovoice

Marie was a very calm, positive, and resilient woman. She managed to escape her own childhood experiences of severe hardship and homelessness and gave her kids a different start in life. She was proud of being self-sufficient and of what she had achieved.

Marie was living with a rare form of cancer, but despite her symptoms and the uncertainty she experienced, she always tried to make the best of things. As a single parent, she made ends meet, partly through support she received from the Welfare Rights team at the Council who helped maximise her entitlement to state support. Marie didn't like being dependent on state support, but she wasn't able to work: “Sometimes it feels like begging for money as I have always been fiercely independent with money and never ask anyone for handouts, but my needs now mean I must swallow my pride and apply.”

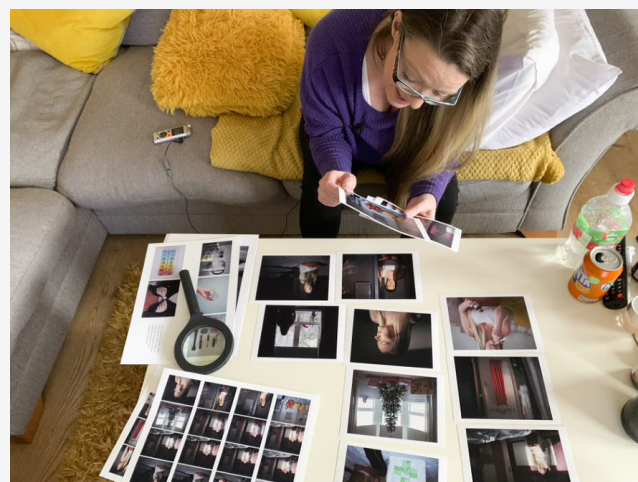
Taxis were the biggest expense for Marie; getting to and from hospital appointments could be up to £100 per week: “I'm unable to walk and wait on a bus. I feel a combination of dizziness and weak legs, so going to a bus stop and waiting, then the bus journey itself amongst people during a pandemic is too much for me.” Other costs she had to meet included heating, electricity, and the cost of clothes because her weight fluctuated dramatically as a result of her illness.

Although Marie was able to keep a roof over her head and kept up with her bills, there was very little left for anything else except small treats. She took photos of these small acts of indulgence; the pampering sessions with her daughter as a way to spend precious time together and “put a smile on my face on weeks that I lack energy and feel low.”



Marie's Photovoice

Marie enjoyed the photovoice element of the study in the first few months, writing a diary to accompany her photographs. But as her world became smaller, more 'boring' and limited to the house, she felt the photos she was able to take became repetitive. Margaret was able to show a different side to her, perhaps a more contemplative side: “with Margaret's side [of the project], I think she's trying to capture like an essence of how I'm feeling, where [in the photovoice] I've got this smiley, happy picture, she's giving you ... atmospherics.”



Project Diary: Margaret Mitchell







Photographs by Margaret Mitchell

Max, age 65

Max wanted to remain in his local community at the end of his life, to be with his friends and his dog Lily. He was an army veteran with prior experience of homelessness and trauma, and he felt trapped by institutions: "I prefer being at home. No one wants to be in a hospital. I want to do my own thing."

But being at home was not always easy. There were four flights of stairs to manage, plus his front steps. This meant he was essentially housebound and not able to get outside: "You see about the stairs, right, the stairs are a big, big problem."



Project Diary: Margaret Mitchell

The bath was also a problem as he couldn't get in and out of it to take a shower. His local housing association didn't appear to prioritise the adaptations he needed, or the maintenance issues he experienced in his final few months. Max wasn't well enough to keep things clean or tidy and it's possible that carers visiting him at home would have judged his environment 'unsuitable'.

Each time Max's cancer symptoms became too severe, or his carers could no longer manage, he was admitted to the hospice. He told Margaret that the title of his life story would be: "From hell to heaven and back to hell again."



Max's Photovoice

Being in the hospice wasn't easy for Max either. He missed Lily terribly. In the photo below, you can see a china replica of Lily which accompanied him to the hospice when the real Lily couldn't be there with him.



Project Diary: Margaret Mitchell

At one point, Max made a 'great escape' from the hospice. As his friend said afterwards – "he did a runner from the hospice basically to get back to his dog." Max found the hospice environment and policies too restrictive and walked off on his own, despite being in considerable pain and having difficulties walking. From then on, his care team took a trauma-informed approach to his care, which was more flexible to his needs.

Max was supported at home until the final week of his life, when he asked to be moved into the hospice because his symptoms were worsening. This provided some relief for his friends who had been caring for him.

When Margaret was photographing him, Max talked about his spirituality, which incorporated elements of Christianity and Paganism. The day before he died, his friends arranged for a Pagan celebrant to visit him in the hospice.



Max's Photovoice







Photographs by Margaret Mitchell

Stacey, age 39

Stacey explored every avenue possible to treat her condition and extend her life. She lived with a rare hereditary genetic condition called Li-Fraumeni syndrome, which makes a person highly susceptible to developing cancer. She lived with her partner and her mother in a one-bedroom flat in inner city Glasgow. They supported her at home, as she tried to cope with her symptoms and manage her pain. Margaret's photograph on the left shows all the pills Stacey took over the course of a single day.



Project Diary: Margaret Mitchell

Her extensive medical regime to treat her cancer and her symptoms meant that Stacey needed to frequently travel back and forth to the hospital. This involved paying for a lot of taxi fares: "I'm in the Health Centre for blood Monday, that's £20. Then to get injections Tuesday (£25). Then to see my surgeon on Thursday at the hospital (£20)." It also meant having to go up and down the stairs in her tower block as the lifts often malfunctioned: "I almost missed my appointment yesterday as the lifts weren't working again."



Stacey's Photovoice

Space was a big issue for Stacey and her family. Her mum slept on the sofa bed which took up most of the living room, while her and her partner took the bedroom. But it was cramped with little privacy and there was not enough hot water for them all. Stacey was also trapped inside most of the time because of all the stairs. If she did make it outside, there were very few places to sit and no garden or parks to speak of: "I'm in this overcrowded house and there are road works outside blasting away and I've 2 brain tumours."



Project Diary: Margaret Mitchell

Stacey and her partner made several attempts to move. These included using their initiative and lobbying their local MSP. "I really need to move. I've been messaging the housing and phoning and phoning constantly trying to get out of here. My landlord is like 'Oh, there's no houses.'" After a year of trying unsuccessfully to move, they finally secured a two-bedroom ground-floor property. But Stacey had barely moved in when her symptoms were so bad that she was hospitalised and then moved into a hospice, where she spent her final few weeks of life.

Stacey O Sunday
Hi there, I'm messaging about a housin...

MSP Sarwar A 12:25
To: Stacey O >

RE: Housing

Good afternoon, Stacey

Thank you for your email to Anas Sarwar MSP.

Anas was concerned to hear about your health issues, and understands how depressing and frustrating it can be waiting for a move to a more suitable home.

If you would like to let me know your current full address, Anas would be pleased to make representations on your behalf to Glasgow West and Queen's

My bid preference

Advert no.	qx2375
Address	Northbank and Crosswell Terrace Glasgow
Closing date	02/11/2022
Total bids	168
	2
Advert no.	qx7342
Address	Street Glasgow
Closing date	02/11/2022
Total bids	177

Stacey's Photovoice







Photographs by Margaret Mitchell

Digital Stories

We have worked with bereaved carers to create short digital stories - 2-3 minute videos using images, music and voice-over. Each digital story shares a part of a bereaved carer's experience and the experiences of those they cared for, using their own words.

Our digital stories are free to access and use.

We want them to be used as widely as possible to educate and inform health and social care professionals, volunteers, as well as individuals in our communities who are carers or may become carers in the future. Each video also includes an accompanying toolkit to be used by trainers and educators and provides additional context, learning objectives and suggested discussion points.

Linda McLeod's Story as told by her daughter Nicola

My mum, Linda McLeod, was born in Edinburgh and lived in Dundee. My Mum was 63 when in June 2019, she was diagnosed with secondary breast cancer and aggressive cancer in her spine.

As soon as she told me, I rushed home from London in the car at 2am with my three young children.

My mum knew she had terminal cancer and that she was going to die, but she also knew that she didn't have any money to pay for anything - including her funeral. Because my mum didn't have a financial safety net, there was no income when she was diagnosed. It was really difficult for us to manage as a family.



I would drive to Scotland with the children and stay for five days while my husband was at work. If we'd had more money, we could have arranged childcare. The cost of the travel, flights and looking after my mum in the hospital was huge.

Before the oncology team realised how quickly she would pass away there was talk of her being sent home. Sadly, it never materialised and they didn't communicate with us. She wasn't given any choice about where she could stay.

My mum lived on the fourteenth floor of a tower block. The lift only went to the thirteenth floor. Moving back home with all the equipment she needed would have been practically impossible. The space would have been too small for me, my mum and three children and we couldn't afford childcare to allow me to focus on caring for her.

In the end, she was transferred to a hospice ten days before she died. The hospice was brilliant, and I'm so glad she didn't die in hospital, but I know she would have wanted to be at home. I just couldn't do that for her with what we were offered.

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.

Steven Thompson's Story as told by his brother John

My brother Steven was diagnosed with slow-growing stomach cancer in 2015. He was told he had about 10 years before the cancer became terminal. We hoped that new curative treatments would be developed in that period.

After his diagnosis, Steven became anxious and withdrawn. He worked on a zero-hour contract and lost his job due to his ill health. He sought advice from the Citizens Advice Bureau who suggested that he apply for Personal Independence Payment – a benefit for people living with long term conditions.

He applied for the benefit and was eventually awarded it in August 2019.

For reasons unknown to me, Steven had to make a new claim for the same benefit in May 2021. This time it was turned down.

I question how someone with a long term, ultimately terminal condition can be eligible for a benefit one day, yet two years later not be eligible for the same benefit.



This was the point where Steven simply gave up fighting - he was exhausted. His cancer rapidly went downhill. He died in a hospice two months later.

I am convinced that Steven would have succeeded in his claim if he had help from local services. He struggled to articulate the physical and mental challenges he was facing when he filled in the forms alone.

In the last week of his life, Steven had a review appointment with his consultant. The hospital was a 30-minute car journey from his home. However, Steven could not drive so he used public transport to go to the hospital. A 90-minute journey.

Our younger brother accompanied him. He was concerned Steven would not manage the journey alone. At the end of the journey, there is a walk from the Metro to the hospital. This normally takes 6 minutes. However, due to Steven's breathlessness, infirmity, and pain, this journey took twenty minutes.

On seeing him, Steven's consultant immediately admitted him to the hospital for tests. After 72 hours he was transferred to a hospice. Within 72 further hours he was dead.

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.

Barry Armstrong' Story as told by his wife Jo

My husband, Barry, was an incredible person who lived an incredible life. He was a humanitarian aid worker who thought hard and fought hard to improve the lives of people affected by war or natural disasters. He worked across the globe in Africa, Asia, and the Middle East and was awarded an MBE in recognition of his humanitarian work.

In Easter of 2019, aged 46, Barry was diagnosed with an aggressive type of brain cancer. Our boys were 10 and 12. We have always been an active family. By 2020 and 3 operations later, Barry was told that options for active treatment had been exhausted.

Despite anticipating this it still felt like a heavy blow. With Covid-19 restrictions, what was important to us was time with Barry at home, where friends and family could freely visit. This would not have been possible in a hospice, and the option of a care home felt unacceptable. However, I could not cope with helping Barry to move alone, as he had developed a left-sided paralysis.



The first care package we were given was not fit for purpose and did not consider our needs as a family. I had taken leave from work to care for Barry, but needed help to move him, wash him etc, while also needing to keep up normal family routines.

Barry needed someone with him constantly. Support was not forthcoming from the care funder. I was forced to consider buying in private care, but this would have left me unable to pay my mortgage and left us with nothing once Barry had died.

Eventually, I had to draw on my clinical background as a clinical physiotherapist, I had to argue repeatedly on the telephone, and I had to complain. Only then did I secure an adequate care package. Thanks to our amazing live-in carer, I could take my children to school and know that Barry was not alone. This helped me to cope and keep some normality for our family.

Barry died at home with his family around him in November 2020. Only by fighting every step of the way was Barry able to stay at home. My clinical background, support of friends, and my ability to argue helped us to secure the care that Barry needed. I'm concerned that others in our situation might not know how to access the necessary resources to support dying at home.

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.

Franks Story as told by his daughter

My dad, Frank, was 58 years old and had multiple health conditions, including COPD and epilepsy. In June 2020, my dad was diagnosed with lung cancer. This was in the very middle of the COVID-19 pandemic.

My dad was at risk due to COVID and spent a lot of time shielding in his flat. When he did try and leave, his symptoms made him unsteady on his feet and he couldn't go down the stairs in his block. There was also no lift he could use. He became very isolated, and I was his main carer. My time was split between trying to look after my dad and my two young children. Having to support both my dad and my young family meant I had to leave my cleaning job. I received £69 a week in carers allowance, but at the end of the month, £300 would be taken off my Universal Credit. This meant that I was effectively losing money because I had taken on caring responsibilities.

For eight months I tried my best to support dad at his home but at times it was a nightmare because I didn't have any extra support – it was just me, my dad, and my children. It was hard work – both physically and emotionally draining. I wish I could have had a visiting carer to just do a quick meal for dad or help him out of the house. However, I was the only person he wanted to care for him, and the doctor told me there was nothing they could do as it was his decision.



I also had to help him out with the cost of living. His main expense was his energy bills as he wasn't leaving his flat. Sometimes I would need to be at home with the children but wanted to make sure my dad had eaten, so I would order him food online, to be delivered to his flat. However, this would quickly add up and become expensive. We were able to pay our bills and just get by, but it meant cutting back on activities. It would have been nice to afford a few little treats for the kids during a really difficult time.

He was at home until February 2021 when he had a stroke and was admitted to the hospital. He was very unwell and the visitation restrictions at the hospital were strict. I had to communicate with him on facetime, but he could barely speak after having his stroke.

Dad told me he wanted to be at home at the end – I had mentioned this to the Macmillan nurse who visited dad at his flat. When the time came, the doctor told me that his condition was too serious for him to be moved home, instead they transferred him to the onsite palliative care unit. He didn't have a good experience there – there was an incident where they found him out of his bed, collapsed on the floor – Why was no one watching him? I felt so helpless when that happened, and not in control of his care as I would have been if he'd been at home.

At the very end, I was contacted by the ward and told that he had taken a turn for the worse. I went up as quickly as I could but had just ten minutes with him before he died. It wasn't enough time and I just wish he could have stayed at home.

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.

Participatory Visual Methods

Photovoice

Photovoice has been used extensively in social research to explore people's experiences of structural disadvantage. This method involves giving participants cameras to take their own images in order to tell their own story. Photovoice has hardly ever been used with people who are nearing the end of their life.

People taking part in the study were asked to take images of 'the things and experiences that are important to you, the things you are finding helpful, as well as those you may be worrying about.' Some people only managed a few images taken from their hospital bed, while other took hundreds of photos over several months.

Taking the pictures contributed to legacy-building and meaning making for some people in the study. Some also found that the photovoice method gave them a focus and a chance to express themselves in a way which they might otherwise have struggled to do.

If you are interested in reading more about our methods, we have an open access article available to read:



Digital Storytelling

Digital Storytelling involves producing a short 2–3-minute film highlighting a small aspect of somebody's life story.

The scripts for our stories were developed collaboratively between bereaved relatives and the research team, using the bereaved relative's words wherever possible. They were then recorded reading their script and this voice recording was edited together with music and photos chosen by them. Due to contact restrictions during the pandemic, we commissioned visual artist and filmmaker Lucas Chih-Peng Kao to help edit and give shape to each film.

These digital stories are publicly available, along with accompanying toolkits for use in education and research:



About Margaret Mitchell

Margaret Mitchell is a Scottish photographer living in Glasgow. With a focus on ethical and engaged documentary, her work ranges from exploring communities and children's worlds to long-term projects on social inequality. Bridging both psychological and social issues, her practice often explores complexities in people's lives with an emphasis on place and belonging. She has exhibited widely, and her work is held in the permanent collection of the National Galleries of Scotland.

Notes from Margaret on her practice:

In my long-term work, I try to bridge both emotional and social aspects of those I photograph. That what is happening on the inside, in people's minds, is just as important to represent as what is happening in their physical, tangible world. It is this approach and background that I brought with me when starting this project, seeking out the individual experience of a person and their situation.

Working on this has been both challenging and rewarding. Challenging because of the deep responsibility inherent in the telling of part of a person's story at end-of-life. Rewarding, because of the hours spent over repeated visits getting to understand each person and taking images, which hopefully convey part of their story for both them and a wider audience.

For being a photographer is a most privileged position where you are invited into people's lives, allowed an insight into a life experienced, with the aim of sharing that with as much depth of feeling as possible. For lives are never simple, experiences not one-directional, and hopefully these images allow a measure of nuance and complexity to emerge.

My photographic practice comes from a place of listening to thoughts, concerns, and histories, and observing each person, their location, and circumstances. Yet, a photograph can only allow a modest insight into a person, into the fabric of who they are. What a person shares might be what is uppermost in their thoughts at that time, the aspects that have become prominent. In this work, many people reflected on their connections and reconnections with family and friends. Others on their isolation, or sorrow, or difficulties. That is what shaped these images: photographs of a life being lived, in the situation that they were in, with the knowledge that time was limited.

It has been the utmost privilege to have been invited into people's lives, to spend time with them. I am deeply grateful to all those who allowed me into their lives, for the hours shared, and the stories recounted.

Margaret Mitchell
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Acknowledgements

This exhibition is an output of a research project called:

Dying in the Margins: uncovering the reasons for unequal access to home dying for people experiencing socio-economic deprivation (2019-2023)

This is a visual methods study based in Scotland and funded by the Economic and Social Research Council and the UKRI.

We applied for this funding in 2018, commencing our research in September 2019. This was shortly before the seismic economic and social consequences of the Covid-19 pandemic and the cost of living crisis hit the country. The situation for people living on low incomes and nearing the end of their lives is far harder now, in 2023, than at the start of this research. We believe the project has become more relevant as a result.

Recruitment to the study was incredibly challenging from the outset. Understandably, health and social care providers had other priorities during the pandemic. The interests of people who are dying are sometimes fiercely protected by the professionals caring for them. The benefits of taking part in research are not always obvious. There was also some reluctance to recruit to a study which involved photography, for fear that it might be exposing.

We quickly discovered that the stigma and shame associated with experiences of hardship and financial precarity can sometimes prevent open discussion or acknowledgment of people's circumstances. This can impede people from accessing the help they are entitled to.

In the end, a few key individuals supported and championed this study. It is down to them that we managed to get the referrals which made the study viable. They gave us confidence in the visual methods chosen, as they reported the benefits they observed in participants. And, of course, they saw the dignity conveyed in Margaret Mitchell's portraits, which inspired further conviction in the research.

We want to thank all of these supporters for their commitment to the study and for recruiting for us and advising us throughout. Particular thanks go to the staff at the Marie Curie Glasgow Hospice and the Prince and Princess of Wales Hospice, the Glasgow Community Link Workers who supported the study, and to the members of our Steering Groups in Dumfries & Galloway and Glasgow for their advice throughout.

Our final and most important thanks go to all of our participants who contributed their time and energy to the project and who trusted us with their stories.

Research Team:

Principal Investigator: Dr Naomi Richards, University of Glasgow, UK

Post-Doctoral Research Associate: Dr Sam Quinn, University of Glasgow, UK

Co-Investigator: Professor Merryn Gott, University of Auckland, New Zealand

Co-Investigator: Dr Emma Carduff, Head of Research and Innovation, Marie Curie UK

Photographer: Margaret Mitchell, Glasgow, UK

Exhibition producer: Oona Dooley, UK



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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