

Dying in the Margins submission of 9 August 2023

PE1956/F: Increase the provision of wheelchair accessible homes

The evidence below is from the University of Glasgow research study: [Dying in the Margins: Uncovering the Reasons for Unequal Access to Home Dying for the Socio-Economically Deprived](#), conducted in collaboration with Marie Curie and funded by the Economic and Social Research Council and UK Research and Innovation (grant no. ES/S014373/1). This was a qualitative, participatory and longitudinal study which involved in-depth research following a small number of people who were at the end of life over a long period of time, as well as interviewing bereaved relatives and health and social care professionals.

1. High Rise Flats

“You see about the stairs, right, the stairs are a big, big problem.”

Findings from our study show that for those approaching the end of life who live above ground level, there can be issues accessing outside space in the final months of life, resulting in not only physical but also social isolation and a sense of feeling “trapped”. It was challenging for these study participants to get any fresh air.

For some of our study participants, the lift in their block was unreliable and had been known to break down. This resulted in difficulties getting in and out of the flat, for example, to attend medical appointments:

“I almost missed my appointment yesterday as my lifts aren’t working again. The Uber left us and charged us for not coming. I’m trying to move house. I’ve had enough. This house isn’t suitable for me anymore.”

In one case, the individual lived on the 14th floor of her tower block in Dundee, but the lift stopped at the 13th floor. Her daughter is in no doubt that the inaccessibility of her flat meant she could not die at home as she wished. Living high up in a high-rise block also presented issues with

installing medical equipment for some of our participants e.g. a bed fitted with hydraulics, breathing apparatus. This situation could be compounded by a lack of space to accommodate both equipment and carers within flats themselves.

2. Inadequate Number of Plug Sockets

We conducted interviews with nurses providing care to people experiencing financial hardship at the end of life ([Quinn et al. 2022](#)). Several nurses raised the problem of being able to power electrical equipment. Some patients had an insufficient number of plug sockets to power the amount of equipment they needed to help support them to stay at home.

3. Moving too Late in Life

Some of our participants lived in newly built socially rented accommodation which had access to outside space and was wheelchair accessible. However, there were issues around: 1) new housing estates lacking local amenities and 2) people being moved into accessible accommodation either too late or outside/away from their community and their established networks of support. As one participant who had mobility issues and was nearing the end of her life commented:

“I feel like a prisoner in my own home. I really feel like that. Nobody to go and see, I just need to sit here, basically.”

Our findings show that there can be an issue of dislocation if someone is moved outside of their area very close to the end of life, as happened to the above participant. Participants who had no choice but to move to a hospice in the final weeks of life (due to housing issues) could also experience dislocation, because the hospice was usually not in their local area, and friends and relatives struggled to undertake, or afford to undertake, the long journey to visit them. This dislocation can leave people socially isolated as they are dying and in an unfamiliar setting.

This signals the importance of both planning and foresight, given a population which is ageing and where the number of people dying is also

rising dramatically. It should also be pointed out that the incidence of chronic multi-morbidity (and therefore mobility issues faced as a result) is higher in more deprived areas, so taking an equity-informed approach would mean prioritising such areas for the development of new housing, or retrofitting existing housing, which is suitable for the ageing-dying continuum.

Timely Adaptations

Findings from our study show that people can experience significant barriers and delays when it comes to necessary adaptations. Examples from the study include accessible baths or showers not being fitted in a timely way, or at all, prior to someone's death.

There was also evidence from professionals we interviewed that nurses were reluctant to refer to occupational therapy if their patient had a signed DS1500 (now BASRiS) form. This was because they felt that this would *deprioritize* them for adaptations such as stairlifts and wet rooms due to cost considerations. The 'Assessment Guidelines' for occupational therapists state that "OTs must think about the cost of an option so they can help as many people as possible with limited funding." If a person is nearing the end of their life, they may not use the adaptation for very long and this may be considered 'limited usage' and factored into a cost-benefit analysis. We also heard from professionals about concerns about the timeliness of adaptations when people's time is limited, and when patients' homes are not big enough to be adapted for wheelchair usage.

Some of our participants spent considerable time in the last months of their life lobbying their social housing provider to make the necessary adaptations, not always with success. There is no doubt that this caused them distress, and consumed limited time left. This is time that could have been better spent on existential questions or on relational and legacy work known to improve people's experiences of dying.

4. Disabling Urban Environment

While the focus of this consultation is on accessible homes, outside public spaces also need to be wheelchair and mobility scooter

accessible so that people who are nearing the end of their lives can continue to participate in society for as long as their illness allows. One of our participants could access the street from her house, but once on the street struggled to use her wheelchair on the poorly maintained pavement:

“The pavement’s sort of smashed to smithereens. I’ve got to go on the road.”

Once again, this is an equity issue as those people who are dying at home in more deprived neighbourhoods are more likely to become physically and socially isolated further in advance of death than those living in less deprived areas where the local environment is better maintained and has better wheelchair access.

Key Policy Recommendations

- 1. Scottish Government should take an equity-informed approach to its new Housing Standard and Scottish Accessible Homes Standard to reflect the needs of terminally ill people living with multi-morbidities for both existing and new homes. This should include a single definition of ‘accessible homes’ which is co-produced with people with lived experience of dying, death and bereavement, Local Authorities and Housing Providers.**
- 2. Scottish Government should provide ringfenced funding for social housing and local government to support building more accessible homes.**
- 3. Local authorities should use the BASRiS form to fast-track housing maintenance, adaptations and moving requests for terminally ill people, their families and carers.**