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STRUCTURAL INEQUALITIES AND DYING AT HOME DURING COVID-19

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The [social determinants of health](#) have been laid bare by the coronavirus (COVID-19) pandemic. Official statistics show that [people living in poorer areas in Scotland are more likely to die of COVID-19](#) than people living in more affluent areas. The reason for this is that people living in these areas are more likely to have an underlying health condition, and indeed are [likely to have more than one](#). This increases their risk of contracting COVID-19 and of dying from it. People living in poverty are generally experiencing higher rates of infection. One of the reasons for this is that poorer areas tend to be more densely populated and properties overcrowded, making social distancing nigh on impossible. There is also a greater proportion of people living in these areas who are still going out to work and therefore are at heightened risk of being infected. These are the cleaners, carers, delivery drivers and supermarket workers who cannot afford not to work. They are also the essential workers keeping our society going during the crisis as many of us shelter at home, reliant on their service.

That people living in poorer areas have lower life expectancy is not exactly a revelation. The [Marmot Review](#) revealed the social reasons behind this stark inequality in 2010 and confirmed that health inequalities had worsened by 2020 in a report published just before the COVID-19 crisis. Reports of higher death rates in more deprived areas is therefore not so much surprising as it is depressingly predictable. [Our own research](#) is on inequalities in experiences of dying in Scotland; specifically, how experiencing poverty or living in a deprived area affects a person's experiences when dying at home. This has been the focus of our research since before the pandemic hit. It has become even more important since we have discovered the extent to which those living in deprived areas across Scotland are being disproportionately impacted by COVID-19.

Our research – Dying in the Margins

We are partnering in our research with the [Deep End Group](#), a network of GP surgeries serving the 100 most deprived areas in Scotland. We are united in our goal of finding out about the conditions at home for people dying in deprived areas. [Existing research](#) shows that people from more socio-economically deprived areas are less likely to die at home compared to people from higher socio-economic areas. They are also less likely to die in a hospice or receive specialist palliative care. And they are more likely to be admitted to hospital in the last three months of their life. All of these issues are related to the [‘inverse care law’](#) which expresses the idea that the

availability of good medical or social care, including end of life care in our case, tends to vary inversely with the needs of the population served. The overall aim of our research is to help people with direct experience of poverty and marginalisation to articulate, on their own terms, gaps in current support and potential strategies to improve end of life care for their communities.

Home dying for those experiencing poverty

Dying at home has long been viewed as a cultural marker of a 'good death'. In [policy terms](#) it is seen as an indicator of 'quality dying.' This is because home is often seen to fulfil the ideals of intimacy, comfort, privacy, and autonomy. It is a place of familiarity, where people supposedly feel most secure. Yet there are some obvious assumptions embedded in these policy mantras in terms of what home looks and feels like. Even in media reporting of the UK's 'lock down', we have noticed a middle-class bias in terms of how the home is represented. How home is experienced is likely to be quite different for people experiencing poverty.

In more deprived areas, housing is often poor quality. There can be issues with damp and mould from poorly constructed and poorly insulated properties. Homeowners

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picture which challenges the ideal of what dying well at home might be like for those living in these areas.

The social relations which facilitate dying at home are even more important than the issues relating to the physical infrastructure. A pre-requisite for dying at home is having a family member or support person who is able to help care for you. Without this and without an ability to pay for a professional carer it is much more difficult to die at home. Yet for people experiencing poverty, there is a high chance that their family members, and other potential support people in their life, are also experiencing poverty. They may not have the flexibility in their jobs to step away from

paid work to undertake a significant caring role. For example, they might not have the kinds of jobs which have carers' leave built into the terms and conditions.

COVID-19 has exacerbated financial hardship

Before the lockdown, one in 10 people suffered from [food insecurity in Scotland](#) and one in 10 older people died from [malnutrition](#) either because of poverty or lack of access to food. The sharp rise in unemployment caused by the lockdown has made things even worse with estimates that it has [quadrupled food insecurity for adults](#). Food banks have also been struggling to operate in the lockdown. At the end of life, going hungry or living with people who are hungry because they cannot afford food is not something which is reckoned with in policy terms. Hunger does not feature in our images of dying at home.

Access to financial assistance at this time in a person's life is hugely important. The [DS1500 form](#) exists as a way to fast-track a range of benefits for people with a terminal diagnosis who have less than six months left to live. This does not always work. Scotland is ahead of the rest of the UK in its commitment to designing a simpler form in an attempt to overcome issues around prognostication, following the [#scrap6months campaign](#). The Benefits Assistance under Special Rules in Scotland (BASRis) form removes the requirement for clinicians to apply a timeframe for the end of life, but this has yet to be introduced. Anecdotal evidence suggests that during the pandemic, there has been a decline in the number of people filling out DS1500 forms. We speculate that this could be because people who are already at the end of life are having less contact with clinicians and so there are fewer opportunities for them to sign the form. Ultimately, this means that benefits designed for people who are dying might never be claimed.

COVID-19 has [increased rates of dying](#). The government's lockdown measures have increased rates of poverty. People living in more socio-economically deprived areas had less access to a 'good death' than those in more affluent areas before the pandemic. Now their prospects have significantly worsened, both in terms of contracting and surviving the virus, but also in terms of timely access to appropriate healthcare. The pandemic has exposed and exacerbated existing health and social inequities, including those at the end of life. The increased visibility of these inequities right now should be used as a way of keeping it high on the political and research

agenda. The [King's Fund](#) suggests we should return to a national health inequality strategy. We certainly need to find out how to make dying better for people who are experiencing poverty, both in the new COVID-19 context and beyond it.

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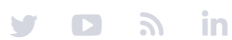
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