



Marie Curie briefing

Inequities in palliative care - Deprivation

Care and support
through terminal illness

11,000 people who need palliative care in Scotland each year are not accessing it. 1 in 4 people who die in Scotland miss out on the care they need. This isn't good enough and needs to change. We fully support the Scottish Government's Strategic Framework on Palliative and End of Life Care and the vision that everyone who needs palliative care has access to it by 2021.

Certain groups of people receive less palliative care than others with a comparable need. These are people who are over the age of 85, are from black, Asian and minority ethnic (BAME) backgrounds, identify as lesbian, gay, bisexual and transgender (LGBT), are from more deprived areas, are socially isolated or live alone, are homeless, have mental health needs, or are living in prisons.

Key points – Deprivation

- The most deprived people are more likely to die in hospital compared to the least deprived.
- Those living in the most deprived areas are 33% less likely to die at home and those in the second most deprived areas are 18% less likely compared to the least deprived¹.
- People from more affluent areas are more likely to die in a hospice than the most deprived. Home deaths are associated with higher income households for non-malignant conditions.
- People living in the most deprived parts of Scotland are likely to spend 26 days of their last six months of life in hospital compared to 24 days for those from the most affluent areas². This gap has grown significantly since 2010.
- There are significant differences in referral rates for people living different areas. Even where people had the same diagnosis, there were fewer referrals in areas with multiple and income deprivation³.
- Even after referral to specialist palliative care services, variation in place of death by deprivation persists. A study of all deaths from the last 5 years at our Glasgow Hospice found that patients from more deprived areas, who are known to the hospice, are still more likely to die in hospital than their more affluent counterparts, who are more likely to die in the hospice.

Evidence Base

Research undertaken by the London School of Economics (LSE) and commissioned by Marie Curie, found that there are inequities between those people living in the most and least deprived areas.

¹ <https://www.mariecurie.org.uk/globalassets/media/documents/policy/campaigns/equity-palliative-care-uk-report-full-lse.pdf>

² <http://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Publications/data-tables.asp?id=1721#1721>

³ <http://spcare.bmj.com/content/early/2016/12/01/bmjspcare-2016-001099.long>

Overall, people reported similar access to community-based support from nurses, social workers, hospice at home and rapid response teams. However, [those in more deprived areas were less likely than those in the least deprived areas to feel they had sufficient support to care for someone dying at home](#); they were less satisfied with the care they receive and more frequently died in hospital, than either home or a care home.

People living in Scotland's poorest communities die considerably younger than those from more affluent communities. In Glasgow, for example, people die up to 20 years younger and live in poor health for longer. They are more likely to die in hospital, more likely to need palliative care, and more likely to have numerous hospital admissions.

Recent research published in December 2016 in NHS Lothian⁴ shows that even after referral to specialist palliative care services variation in place of death by deprivation persists. [Greater deprivation is associated with increased likelihood of dying in hospital and decreased likelihood of dying in a hospice](#). No difference was noted for home deaths.

This may be due to a number of reasons: It may be that it is more challenging to engage patients from more deprived backgrounds in advanced care planning; people from deprived areas may be less willing to request hospice admission; lower healthcare literacy in more deprived patients may reduce people's understanding of palliative care and increase anxiety when hospice is discussed; [they may be less willing to engage with palliative care services](#); and local transport links may make it difficult for relatives and carers to attend hospices.

Further data from the VOICES survey in England found that people in the most deprived areas were less likely to rate care received by their family member or friend in the last days and weeks of life as outstanding or excellent compared to those in the least deprived areas. Carers for people living with a terminal illness in the most deprived areas were [less likely to report that their family member had always been treated with dignity and respect than those in more affluent areas](#). Carers were also less likely to feel that they had the right levels of support when caring for someone at home.

The research suggests that there may be a number of reasons for these differences. It may be that [housing in more deprived areas provides a less suitable environment for end of life care](#), or that people from more affluent areas can pay for additional support. There may also be differences in local resourcing decisions and spending on services.

VOICES collects information on bereaved peoples' views on the quality of care provided to a friend or relative in the last three months of life, for England. There is no VOICES or similar survey carried out in Scotland; however, we would expect to see similar findings. We look forward to the results of the VOICES pilot due to be carried out by NHS Lothian this year.

Marie Curie would like to see:

- More data to understand why people and their carers experience different standards of care in the least and most deprived areas.
- More research to understand access and barriers to palliative care in socially deprived communities.
- More work to understand the experiences that have affected people from socially deprived communities in order to build effective service responses and resources to maximise quality of life and death. This should include social support and public health messaging.
- More understanding of area-based differences, to inform effective policy that makes sure end of life care is delivered fairly and consistently across Scotland.

⁴ <http://spcare.bmj.com/content/early/2016/12/01/bmjspcare-2016-001099.long>

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