Introduction

1. Marie Curie provides care and support for people living with a terminal illness and their families and carers. We provide support through our two hospices in Glasgow and Edinburgh, as well as our community nursing services across 31 local authority areas, and our six volunteer led Helper services. We also provide nationwide support through our information and support service including our national helpline.

2. Last year we provided care for 8,394 people living with a terminal illness, as well as their families and carers across Scotland.

3. Marie Curie’s vision is for a better life for people and their families living with a terminal illness. Our mission is to help people living with a terminal illness, their families and carers, make the most of the time they have together by delivering expert care, emotional support, research and guidance.

4. Socio-economic status impacts palliative and end of life care outcomes, as it does in many strands of health and public health. It can impact on health literacy which is an integral part of improving people’s choices and outcomes, especially around person-centred care and the application of the realistic medicine agenda. It can impact on the type of care people receive and where. It can impact on access to bereavement support for adults and children, and in turn, complex grief can also go on to affect people’s life chances.

The Consultation

5. Marie Curie welcomes the introduction of the Socio-Economic Duty in Scotland. We welcome the efforts that the Scottish Government is taking to ensure that public authorities consider the impact that their decisions will have on narrowing socio-economic inequalities.

6. However there are a number of areas associated with socio-economic deprivation and support toward the end of life that we believe are not currently represented in the consultation paper.

7. In terms of health and social care, the inequalities of outcome referenced on page 11 of the consultation refer primarily to impacts on healthy life expectancy. However, this does not adequately articulate or reflect all of the health impacts of socio-economic advantage.

8. The consultation goes on to link to a number of duties, already set out in legislation that has a socio-economic focus. Barring the duties set out in the Community Empowerment (Scotland) Act 2015, the majority of these are focused around childhood and early life experiences, setting out efforts to reduce child poverty and disadvantages resulting from being born and growing up with socio-economic disadvantage. There is no doubt that this
should be a significant focus on tackling and narrowing socio-economic inequalities. However, we are concerned that there is not due consideration in legislation to look at later life stages and focus on addressing socio-economic inequalities towards and at the end of life.

9. There is evidence that people and their carers living in areas of socio-economic deprivation have different experiences during an illness and at the end of life to their less deprived counterparts. There is also evidence to show that many people with complex conditions, multi-morbidities and terminal diagnoses can struggle both financially and socially.

10. We recognise that the consultation makes reference to duties of the Equality Act 2010 and human rights legislation in regard to socio-economic deprivation. However, we believe that in order to maximise impact of the new duty, there should be explicit links to other legislation, such as the Carers (Scotland) Act 2016, Public Bodies (Joint Working) (Scotland) Act 2014, Mental Health (Care and Treatment) (Scotland) Act 2003 (updated in 2015), and the Strategic Framework for Action on Palliative and End of Life Care. We believe it is important to ensure that public authorities connect this duty with decisions about people and carers who are living with terminal and life-limiting conditions and manage decisions effectively.

Evidence

11. Research\(^1\) undertaken by the London School of Economics (LSE) and commissioned by Marie Curie, found that there are inequities in access to palliative care services between those people living in the most and least deprived areas of Scotland. People living with socio-economic deprivation are:

- more likely to have numerous hospital admissions;
- more likely to need palliative care;
- less satisfied with the care they receive;
- less likely to feel they had sufficient support to care for someone dying at home, and;
- more likely to die in hospital than at home or in a care home.

Access to palliative care

12. Overall, people from different socio-economic backgrounds reported\(^2\) 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 received and more frequently died in hospital, than either home or a care home. 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

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compared to the least deprived\textsuperscript{3}. Home deaths are associated with higher income households for non-malignant conditions.

13. Recent research into the imminence of death among hospital inpatients\textsuperscript{4} looking at a hospital population on any given day, found that a disproportionate number of admissions belonged to the two most deprived quintiles (50.1\%) and that more deprived patients are likely to be hospitalised longer. People living in the most deprived parts of Scotland are also likely to spend 26 days of their last six months of life in hospital compared to 24 days for those from the most affluent areas\textsuperscript{5}. This gap has grown significantly since 2010.

14. There are significant differences in referral rates to specialist palliative care services, such as those Marie Curie provides, for people living in different areas. Even where people had the same diagnosis, there were fewer referrals in areas with multiple and income deprivation\textsuperscript{6}. However, it is important to note that referrals to specialist palliative care services are reliant on external sources. For example, referrals to Marie Curie are through healthcare professionals, such as district nurses, consultants and GPs.

15. However, recent research published in December 2016 in NHS Lothian\textsuperscript{7} shows that even after referral to specialist palliative care services variation in place of death by deprivation persists. Similarly a study of all deaths from the last five 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.

16. The research posits a number of reasons for this: 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; people from areas of deprivation 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.

17. There is sufficient evidence to suggest correlation between socio-economic deprivation and access to palliative care services, though not direct causation. Further research is needed to ascertain the level that deprivation impacts on access to care. If this can be confirmed, we can begin to explore reasons for this and how it can be addressed. It could also be that further education and awareness work is needed among health and social care professionals regarding referral to specialist palliative care services.

\textsuperscript{4} http://journals.sagepub.com/doi/full/10.1177/0269216314526443  
\textsuperscript{5} http://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Publications/data-tables.asp?id=1721#1721  
\textsuperscript{6} http://spcare.bmj.com/content/early/2016/12/01/bmjspcare-2016-001099.long  
\textsuperscript{7} http://spcare.bmj.com/content/early/2016/12/01/bmjspcare-2016-001099.long
Carers

18. Data from the National Survey of Bereaved People (VOICES) in England\(^8\) 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 are also 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\(^9\).

19. 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, strategic commissioning decisions and local spending on services.

20. 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 which is currently being carried out by NHS Lothian.

Bereavement

21. In Scotland over 200,000 people are significantly affected by the death of a loved one\(^10\). Research shows that carers for people living with a terminal illness can be in a very vulnerable position and highly exposed to psychological distress, both during caregiving and following the death of a loved one\(^11\). This distress can include depression, anxiety, complicated and prolonged grief. A study of family carers of patients with advanced cancer showed that more than 50% of the carers had depression scores approaching clinical depression.

22. Family carers also report high levels of mental health problems during bereavement. Research shows that 10-15% of the bereaved individuals suffer chronic distress and depression for years after the loss. While grief is seen as a normal experience after major loss, between 10-20% of bereaved persons experience prolonged grief, where a normal grief adjustment does not occur and the person experiences debilitating grief for a longer period. These people then also suffer from an increased risk of adverse health effects\(^12\).

23. Research from Robert Gordon University has mapped the socio-economic costs of bereavement in Scotland and its impact on people’s life chances\(^13\). As part of the socio-
economic duty in Scotland, public authorities must consider how decisions can improve people’s outcomes following bereavement.

**Figure 1. Aspects of socio-economic costs of bereavement**

24. Further research from Cruse Bereavement Care shows that, particularly in the case of children and young people, if they are culturally isolated or financially deprived this can increase the likelihood of complicated grief. If a bereaved child or young person is exposed to poor housing, substance misuse, domestic violence and poverty they can be at risk of complicated grief. Social networks and support systems need to be in place to support these people.

25. There is limited research and understanding about the picture of childhood bereavement and grief in Scotland. However, what does exist demonstrates potential for unanswered grief and bereavement to have a long term impact on children and young people and their life chances. For example:

- Children and young people report difficulties concentrating and learning after a parent dies. Young people bereaved of a parent experience GCSE scores half a grade lower than their non-bereaved peers on average. Girls bereaved of a sibling scored almost a full grade below their matched controls (Child Bereavement Network).

- Research carried out by the University of Strathclyde found that around 90% per cent of people at Polmont Young Offenders Institution had experienced a significant bereavement that has affected their lives. The study found that “the trajectory into offending starts very soon indeed after the bereavement. If there was better bereavement support, much earlier in childhood, maybe in the school system, then I think a lot fewer of them would end up here.”

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14 https://www.cruse.org.uk/children/complicated-grief
15 http://www.childhoodbereavementnetwork.org.uk/
26. Stephen et al\textsuperscript{17} estimate that the hidden effect of spousal bereavement on secondary healthcare provision costs NHS Scotland around £20 million annually. Similar projections are also needed in capturing the true impact in primary care, where the effects of bereavement are more hidden. There is currently insufficient data to establish a true picture of the cost of bereavement to people’s outcomes and the impact this has on socio-economic inequalities, where less deprived people are more likely to access health and social care services.

27. It is clear that a robust Scottish picture needs to be established. More research is needed to further address the socio-economic impacts of bereavement. Strong leadership is needed to bring services together, identify gaps and share good practice to ensure that everyone gets the support and help they need following a bereavement. Measures to monitor any interventions are also needed to show progress in tackling inequities.

Other factors

28. Similarly research has found that access to palliative care services is also inequitable for disadvantaged communities, such as refugees, prisoner populations, ethnic minorities and those that identify as lesbian, gay, bisexual and transgender. There is extremely limited research and evidence around these areas and the impacts of deprivation on these already marginalised groups and how they access services.

29. In the case of homelessness, we know that homeless people often die in crisis and with little or no advanced planning. For many homeless people it can be very difficult to identify their palliative needs. Many of the conditions which homeless people suffer from do not have a clear trajectory or pathway, making it difficult to assess when palliative care might be appropriate. The chaotic nature of a homeless lifestyle can also add another layer of complexity to providing palliative care\textsuperscript{18}.

30. Marie Curie is currently in the process of undertaking a joint piece of work with St Columba’s Hospice about linking in with the homeless GP practice in Edinburgh to look at addressing the needs of the homeless population. We are also in conversation with the prison service about caring for prisoners with a terminal illness.

Monitoring

31. We have concerns that the monitoring of the impact of the socio-economic duty, as set out in the consultation is not robust enough to meaningfully tackle long term inequalities.

32. Scotland does not currently collect and analyse enough data to show the impact of socio-economic deprivation across the country or how this affects people’s access to care, services and outcomes. Nor is there any way to show the progress we are making in improving people’s outcomes. The Scottish Government needs to be able to record and measure the current and future impact of socio-economic deprivation and the impact of the duty on addressing these.

33. As such, we agree with the consultation that states further work is needed to develop the analysis and understanding of inequalities of outcomes related to socio-economic disadvantage. However, we have concerns that many aspects of socio-economic inequity

\textsuperscript{17} http://www.artshealthandwellbeing.org.uk/sites/default/files/Socio-Economic%20Costs%20of%20Bereavement%20in%20Scotland.pdf
are not currently included in existing monitoring frameworks. We urge the Scottish Government to rethink processes and set in place a strong system to monitor and measure the impact of the socio-economic duty.

**Strategic Decision-making**

34. In terms of strategic decision-making and commissioning arrangements, we have concerns over how public authorities will meet requirements of the duty and the impact that may have on existing service level agreements with public authorities. Further clarification on how decisions may affect third-party commissioning agreements would be welcomed.

**Recommendations**

35. Any discussion around socio-economic deprivation is highly complex and multi-faceted. We believe that these issues can only be addressed in a meaningful way through strong leadership, dedicated and substantial resources and a commitment to affect fundamental change through clear legislated pathways that influence all parts of the system. The introduction of the socio-economic duty is a welcome start to this work. However, we believe that any duty should take into account the interplay of factors across all sectors. As such, we would like to see a wider recognition of the ways that deprivation can impact on people across the life course and when they are dying.

Marie Curie would like to see:

- Greater recognition of wider impacts of socio-economic deprivation reflected in the duty, particularly to highlight people in later life and those at the end of life.
- Links between the socio-economic duty and legislation that affects people accessing care services and their carers.
- 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.
- Measures to show the impacts of deprivation in Scotland and robust ways to show the progress we are making in improving people’s outcomes and the impact of the duty.
- Further clarification on how strategic decisions as part of the duty may affect third-party commissioning agreements.
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