Marie Curie Response

Scottish Parliament Health, Social Care and Sport Committee - National Care Service (Scotland) Bill

About Marie Curie

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 volunteer led services.

We also provide nationwide support through our information and support service including our national helpline. Marie Curie is also the biggest charitable funder of palliative care research in the UK. In 2020/21, we provided care for over 9,000 people living with a terminal illness, as well as their families and carers across Scotland; our highest ever since the charity was established in 1948.

Our vision is for a better life for people living with a terminal illness, their families and carers. 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.

General Questions

1. **The Policy Memorandum accompanying the Bill describes its purpose as being "to improve the quality and consistency of social work and social care services in Scotland". Will the Bill, as introduced, be successful in achieving this purpose? If not, why not?**

1.1. The Bill itself will not achieve this purpose on its own. Achievement of the stated purpose will be dependent on the successful development of secondary legislation and regulations that the Bill will enable.

1.2. Increased funding for social care delivery is also essential to improving social work and social care in Scotland. This is outwith the scope of the Bill or the proposed related secondary legislation.

1.3. It is imperative that the complex, concurrent processes developing the National Care Service, including this legislation, address the risk of the National Care Service increasing the existing integration gap through its sole focus of improving social care. Health and social care are less integrated than was hoped when the Public Bodies (Joint Working) Act was passed in 2016. We believe this has limited the potential for palliative care services to innovate, change and grow to better meet the needs of local populations and support the shift in care from acute to community settings. Some of these issues have been exacerbated by the pandemic.

1.4. The NCS and Community Health and Social Care Boards offer an opportunity to address these concerns, but this will only be possible if there is a genuine and strong commitment to working with all sectors and partners including health and social care, the third and independent sectors, as well service users and carers. This will require strong leadership to implement this approach, alongside key learnings from IJBs, to achieve success. Crucially, this must also include the rectification of corporate governance and accountability issues which have been long-standing problems on IJBs.

2. Is the Bill the best way to improve the quality and consistency of social work and social care services? If not, what alternative approach should be taken?

2.1 The Bill enables structural changes which have the potential, to enable a radical transformation of social care and health services in Scotland to improve people's lives for the better, including their experiences of dying, death and bereavement.

2.2 However, the structural changes enabled by this legislation need to be accompanied by further change from Scottish Government and beyond.

2.3 A cultural shift towards greater openness about dying among both health and social care professionals and the general public, along with increased access to support for Anticipatory Care Planning (ACP), will enable care to be more planned and less reactive especially for people in the last year of their lives, when they are more likely to use both health and social care services than the rest of the population.

2.4 ACP allows patients and healthcare teams to discuss treatment and care options, as well as preferences of place of care and where a person would prefer to die. It also allows spiritual and social preferences to be captured, as well as help identify family carers.

2.5 Having an ACP in place can reduce the amount of time a person spends in hospital, including reducing the number of unnecessary hospital admissions, reduce the likelihood of having to go to A&E, and make it more likely that a person will die in their preferred place of choice.

2.6 Marie Curie led research shows that 69% of people in Scotland have a Key Information Summary (KIS) in place at the time of death, created on average 10 months before death[1]. However, there needs to be continual progress especially around recording carer information.

2.7 Increased funding for social care delivery is also essential to improving social work and social care in Scotland. This is outwith the scope of the Bill or the proposed related secondary legislation. The increasing numbers over the coming years of people with palliative care needs means that review is also required of the funding for palliative care provision beyond social care; the voluntary sector plays a significant role in palliative care provision and associated information and support provision for people experiencing dying, death and bereavement in Scotland so it is imperative that the need to fund this sustainably is addressed as the National Care Service is defined and established.

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[1] Finucane. A et al: Electronic are coordination systems for people with advanced progressive illness: a mixed-methods evaluation in primary care. British Journal of General Practice https://bjgp.org/content/70/690/e20

3. Are there any specific aspects of the Bill which you disagree with or that you would like to see amended?

3.1 In 2020-21, there were over 63,000 deaths registered in Scotland[2]; around 90% of those (56,700) had a palliative care need. Palliative and end of life care supports people who have a terminal illness. By terminal illness, we mean a disease or condition which will likely result in the person's death. Someone can live for years, months, weeks or days with a terminal illness following their diagnosis.

3.2 Palliative care can be provided in different settings, including in hospital, a hospice, care or nursing homes and a person's own home. Palliative care aims to support a person to have a good quality of life – this includes being as well and active as possible in the time they have left. It can involve:

- managing physical symptoms such as pain
- emotional, spiritual and psychological support
- social care, including help with things like washing, dressing or eating
- support for family and friends

3.3 Scotland's ageing population means more people will be dying in the years to come. **Marie Curie research** projects over 60,000 people will die with palliative care needs, 10,000 more per year, by 2040, with over 85s accounting for 45% of all deaths[3].

3.4 Marie Curie research projects that by 2040, **nearly two-thirds of all deaths in Scotland will take place in care homes, people's own homes or hospices**. This represents a significant, continuing increase in demand for community-based palliative care services, including social care, for terminally ill people with complex needs which will continue to increase.

3.5 Covid-19 has shown the distressing impact dying, death and bereavement can have on anyone at any time, and the importance of easily accessible integrated health and social care services, including palliative care, when they are needed most.

3.6 Long-standing issues with health and social care integration, care co-ordination and lack of sustained national and local investment in community palliative care services, as well as social care, have been exacerbated by the pandemic and in part due to a rapid shift towards community care. There has been a significant physical, emotional and financial impact on patients, their families and carers, and health and social care professionals which will be long-lasting for years to come.

3.7 The Bill as it stands contains no recognition of the fact that such a high proportion of the people who will use both the social care and health services that the National Care Service may provide will be close to death and that these services will be palliative.

3.8 The principles set out in Section 1 refer to people who are enabled to "thrive" and services that "prevent or delay the development of care needs and reduce care needs that already exist". While these principles are important for many people with disabilities and long-term health conditions, they exclude and therefore deprioritise the high proportion of people who have a terminal illness or who are otherwise approaching death. They, too, continue to have rights which must be upheld by our health and care system.

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[2] NRS Vital Events Reference Table 2020-21

[3] Finucane, A.M., Bone, A.E., Evans, C.J. et al. The impact of population ageing on end-of-life care in Scotland: projections of place of death and recommendations for future service provision. BMC Palliative Care 18, 112 (2019)

3.9 The principles underpinning the National Care Service must explicitly recognise this and commit to supporting people who are dying to have the best possible end of life experience which reflects what is most important to them.

4. Is there anything additional that you would like to see included in the Bill and is anything missing?

4.1 We set out in answer to the previous section a clear rationale for explicit inclusion in the Bill of support for people who are dying to have the best possible end of life experience which reflects what is most important to them. This should be set out in the Bill in the principles of the National Care Service, and in Clause 11 describing what the National Care Service charter should include.

4.2 Further to this, the Bill creates a power for Scottish Ministers to designate as a National Care Service function any function of a Health Board or a Special Health Board. Even the Policy Memorandum refers only incidentally to the Scottish Government's intent that community health services should become part of the National Care Service. If the Scottish Government's intention remains that only certain health services will be transferred to the National Care Service, this Clause in the Bill must be defined, and explained in the Policy Memorandum.

4.3 The Bill does not refer to the Public Bodies (Joint Working) Act 2016. It may be that there is no need to do so in the Bill itself, but even in that case, an explanation in the Policy Memorandum is required to describe when and how the Integration Authorities created by that Act will cease to exist.

5. The Scottish Government proposes that the details of many aspects of the proposed National Care Service will be outlined in future secondary legislation rather than being included in the Bill itself. Do you have any comments on this approach? Are there any aspects of the Bill where you would like to have seen more detail in the Bill itself?

5.1 The Policy Memorandum states that much of the detail - secondary legislation, regulations, and related action (for example, the Structure of Standards and Processes) - will be created by 'co-design'. No information is available about how co-design for the National Care Service will happen. While we strongly welcome the recognition of the importance of involving people who use services in determining what those services look like and the structures within which they operate, there are important questions to be answered about how this co-design process will work:

- Who will decide, and how, who is to be involved in the co-design process? How can the co-design process ensure it is inclusive of the full range of people who use social work and social care services, and the health services that may be included in the National Care Service? How will it include people who would benefit from these services but are not currently able to access them? In particular, how will people who are seriously and/or terminally ill, and people who have been caring for people who have recently died, be included in the co-design processes?
- Will the co-design process also involve the staff and volunteers who deliver the services involved?
- How will the co-design process ensure that participation is meaningful, given the complexity and wide-ranging implications of the changes involved – including for people whose involvement time or capacity may be limited due to their circumstances?

- How could the co-designed proposals be amended if there was a need either due to legal issues arising during the process of putting the proposals into regulations, or due to future events?

5.2 Deprivation, geography, gender, religion, ethnicity, sexuality, learning disability, diagnosis and age are all biological and social determinants that can have an impact on whether someone gets the care and support they need at the end of life.

5.3 Many of these inequalities have been exacerbated during the pandemic and could have led to considerably worse outcomes for patients, including poor quality of care and experience at the end of life.

5.4 Recent Marie Curie and Loughborough University research[4] found that 8,200 people die in poverty every year in Scotland, equating to one in four working age people in one in eight pensioners. There were also clear overlaps between the most deprived areas in Scotland and poverty at the end of life, yet these issues are often considered separately.

5.5 People with protected characteristics are most likely to experience poverty throughout their lives, this increased risk persists to – and is magnified by – reaching the end of life, which when coupled with the current cost of living crisis, results in a vicious cycle that can become impossible to break.

5.6 Terminal illness is not the cause of these inequalities, but exacerbates their impact – contributing to a significantly higher risk of falling into poverty, or deeper into poverty, at the end of life.

5.7 It is vital that palliative and end of life support can be accessed by these communities; this includes, physical, emotional and financial support to help those affected by dying, death and bereavement to have an end of life experience which reflects what is most important to them.

5.8 The question remains as to how the co-design process will acknowledge and address these inequalities.

5.9 Transparency is needed about how all the co-design referred to in the Policy Memorandum will happen, how it will encompass diversity and address unmet need and what the triggers and processes are for implementation and review of the resulting proposals.

5.10 People who have a terminal illness or who are otherwise approaching death have rights which must be upheld by our health and care system. The principles underpinning the National Care Service must explicitly recognise this and commit to supporting people who are dying to have the best possible end of life experience which reflects what is most important to them.

5.11 The rights and needs of people who have a terminal illness or who are otherwise approaching death must also have explicit reference in Clause 11 describing what the National Care Service charter should include. Otherwise, there is a high risk that these rights and needs are ignored, as they currently are in the

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[4] https://www.mariecurie.org.uk/globalassets/media/documents/policy/dying-in-poverty/h420-dying-in-poverty-5th-pp.pdf

proposed principles of the National Care Service.

5.12 Clause 2 of the Bill states that the National Care Service shall be “designed to secure the wellbeing of the people of Scotland” and that this should “reflect the National Care Service principles”. The proposed principles describe how the National Care Service will operate, but not it will deliver. In order to future proof the Bill and to make it clear what the National Care Service is for, ‘wellbeing’ must be carefully and inclusively defined. This definition must include those who are dying and those who are supporting people who are dying, recognising that they should have the best possible experience of dying, death and bereavement which reflects what is most important to them.

6. The Bill proposes to give Scottish Ministers powers to transfer a broad range of social care, social work and community health functions to the National Care Service using future secondary legislation. Do you have any views about the services that may or may not be included in the National Care Service, either now or in the future?

6.1 The lack of definition of ‘wellbeing’ in Clause 2, allied to the very general nature of the proposed National Care principles that focus on how the National Care Service will operate, mean that there is very little contained in the Bill itself about what the National Care Service will deliver.

6.2 The Policy Memorandum states that the Bill’s purpose is “to improve the quality and consistency of social work and social care services in Scotland”. Clause 28 of the Bill, however, allows for Health Board functions to be transferred to the National Care Service.

6.3 Nowhere in the Bill or the Policy Memorandum is it defined which health services should be included in the National Care Service. Marie Curie has longstanding support for more integrated planning and delivery of health and social care in Scotland and we welcome the apparent intention to deliver this. However, the Bill as it stands leaves gaping uncertainties about not only how health and social care services will be integrated and delivered in practice, but also where the accountability and governance will rest for health services transferred to the National Care Service.

6.4 Palliative care can be provided in different places, including in a person’s home, in hospital, in a care home or nursing home, and in a hospice. It can be delivered by general health and social care professionals, such as GPs, District Nurses and social care teams, as part of the day-to-day care they provide. A person may also receive support from specialist palliative care professionals who might be involved in managing more complex care needs. They will often work in partnership with other professionals to provide co-ordinated and personalised care[5].

6.5 The Policy memorandum refers to ‘community health services’ with no definition, so it is not clear which services the Scottish Government intend to transfer to the National Care Service. In any case, the Bill as it stands would allow any future government to transfer health services beyond the realm of what might be considered ‘community health services’.

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[5] https://www.mariecurie.org.uk/help/support/diagnosed/recent-diagnosis/palliative-care-end-of-life-care#what

6.6 In order to provide people using palliative care services with the most integrated possible experience, Marie Curie would be supportive of consideration of all palliative care services being commissioned by the National Care Service, including those delivered in hospital, not normally described as ‘community’ health services.

7. Do you have any general comments on financial implications of the Bill and the proposed creation of a National Care Service, either now or in the future?

7.1 Increased funding for social care delivery is also essential to improving social work and social care in Scotland. This is outwith the scope of the Bill or the proposed related secondary legislation.

7.2 The increasing numbers over the coming years of people with palliative care needs means that review is also required of the funding for palliative care provision beyond social care; the voluntary sector plays a significant role in palliative care provision and associated information and support provision for people experiencing dying, death and bereavement in Scotland so it is imperative that the need to fund this sustainably is addressed as the National Care Service is defined and established

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