

Gillian Martin MSP
Convener, Health, Social Care and Sport Committee

16th January 2023

Dear Gillian

Follow-up to attendance at HSCS Committee 13th December 2022

Many thanks for the opportunity to give evidence to the committee before Christmas on palliative care and the National Care Service, and for your follow up letter of 14th December.

As requested the report *Every Story's Ending – proposals to improve experiences of living with serious illness, dying and bereavement in Scotland* can be accessed here (summary version and short film too) <https://www.palliativecarescotland.org.uk/content/everystorysending/>. Developed with stakeholders over 2 years the report identifies priorities and recommends actions that will make a positive difference. The report is comprehensive in scope and addresses issues covered in the evidence session including demographics, social care planning and delivery, inequalities, and measuring outcomes.

I have responded to the other follow up questions in your letter below.

Does the Bill as introduced take appropriate account of and appropriately support the changing demographic picture and the considerable and growing need for palliative care?

No. The Bill as introduced (and the accompanying Explanatory Notes and Policy Memorandum) make no reference to palliative and end of life care. Whilst understanding that this is an “enabling” or “framework” Bill it is a concern that the biggest single group of people receiving social care is not mentioned. The evidence papers accompanying the Bill which examine who uses social care, changing demographics and people’s experiences of social care also omit any reference to people approaching the end of life. Data analysis projecting significant growth in the numbers of people with palliative care need (and an increase in the complexity of need) has been produced by researchers at Edinburgh University and Kings College London. Updated projections are also being produced at the instigation of the SG team leading development of the forthcoming palliative and end of life care strategy, and these could usefully inform development of proposals for the NCS.

In addition, the language in the Bill used to describe the principles of the National Care Service does not easily encompass the provision of care for people who are approaching the end of their life. Examples that particularly stand out are:

1a ii) “enables people to thrive and fulfil their potential”

and

1c “services provided by the National Care Service are to be centred around early interventions that prevent or delay the development of care needs and reduce care needs that already exist”

SPPC has proposed alternative wording which clearly signal the importance of social care as part of palliative and end of life care. Words matter because the language used in these high level principles is vital in framing the thinking required to develop the details of the secondary legislation which will determine the NCS Charter and strategic planning and commissioning processes.

How should the NCS interact with community health and acute services at the end of life?

People with palliative care needs often need care and treatment from different parts of the health and care system, and sometimes need to move between settings. People are admitted to hospital more frequently as the end of life gets closer, particularly in the final 3 months.

One of the most vital steps in improving palliative and end of life care is the establishment of a **clearly identified locus of responsibility** for planning, commissioning, monitoring, evaluation, learning and improvement. The locus needs to take a population health approach and develop cross-agency collaboration between health and social care, primary care, acute services, voluntary sector and independent sectors.

The Bill is silent on where responsibility/accountability should lie for those elements of community health services which are of relevance to palliative and end of life care (for example general practice, district nursing, community pharmacy). It is also silent on palliative care provided in hospitals (currently the responsibility of IJBs). Around half of people die in hospital.

So, NCS “interaction” with community health and acute services should take place as part of a population health approach, with structures and processes which enable collective accountability and collaborative working.

How should the varying needs of all those at the end of life be considered in an equitable way?

At an individual level care and support discussions should inform person-centred planning, with plans regularly updated and shared across settings. Just as needs and preferences vary between individuals, they may also vary over time for any particular individual. For example people often express a wish to be cared for and to die at home. However, often people’s needs and priorities change as the realities and uncertainties of serious illness become manifest. Someone might wish to avoid feeling as though they are ‘burdening’ family members; to be sure of quick access to rapid treatment or to feel secure with experienced staff close – and so need and accept admission to hospital. This is why reviewing and updating plans is vital.

Needs should also be assessed at population level and understanding developed as to the different pathways and levels of care experienced by different groups. There is considerable variation depending on age, type of illness and personal characteristics and circumstance. Understanding and addressing such variation should be a key aim of local planning and commissioning processes. Currently such an approach is often absent, with no overall effective accountability and responsibility for outcomes in the final phases of life, or for equitable allocation of scarce resources. Current structures and systems largely fail to measure or account for outcomes towards the end of life.

What should a national care service ideally be seeking to achieve with respect to quality of care outcomes for people in receipt of palliative care, irrespective of where they are receiving that care? How should this be measured?

When faced with the reality of deteriorating health and death, people need many things from their friends, families and communities, the NHS, social care services and other formal services. What a person needs

depends on their personal circumstances and what is important to them. People value open and honest discussion, and opportunities to explore personal preferences and options. Supporting a sense of autonomy and control is often important. For many of us, our needs will include:

- relief from distressing symptoms
- reliable and consistent access to support and advice from healthcare and social care professionals who are compassionate, knowledgeable and competent
- information about what is happening, what is likely to happen next, the uncertainties that might be involved, and ideas of some ways of responding
- empathy and support in adjusting to coping with uncertainty and deteriorating health
- support to get the most out of whatever time is left with the people we care about
- time, space and support to discover and maintain a sense of meaning, purpose and spiritual wellbeing in new and changing circumstances
- access to short breaks/respite and other support for the people we care about who are caring for us
- support with financial, legal and other practical issues, including the 'little' things that can make a big difference, like mowing the lawn, or taking the dog for a walk
- understanding and support from family, friends, colleagues and communities when dealing with loss and bereavement, and access to more specialised support if bereavement becomes harder to cope with.

How should this be measured?

Chapter 10 of *Every Story's Ending* explores this complex subject in some depth. Amongst other recommendations we call for the development and implementation of a regular national survey of bereaved carers, asking about the experience of care of their loved one.

I hope this response is helpful. I am of course happy to provide clarification or more information which might be useful to the committee.

Best wishes

A handwritten signature in black ink that reads 'Mark Hazelwood'.

Mark

Mark Hazelwood
CEO
Scottish Partnership for Palliative Care