



The Scottish Parliament
Pàrlamaid na h-Alba

Health and Sport Committee
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Dear Cabinet Secretary for Health and Sport,

PALLIATIVE AND END-OF-LIFE CARE

The previous Health Committee published its report *We need to talk about palliative care* in November 2015. A response was received from you in December 2015 in the form of a *Strategic Framework for Action on Palliative and End-of-life Care 2016-2021*. The vision set out in the Framework is that everyone in Scotland will have access to good quality person-centred palliative and end-of-life care by 2021.

The purpose in writing to you is to request an update on the implementation of the Strategic Framework and a review of what progress has been made against the inquiry's recommendations and the Government's vision for palliative care in the last year. It would also be helpful to understand what milestones you have established to measure progress against the 2021 target.

The previous Committee also commissioned Professor David Clark to carry out research on palliative care around the world which was discussed in his report *International comparisons in palliative care provisions: what can the indicators tell us?* The report highlighted that there was a dearth of available information as little data was collected. Can you advise:

- what work has been done to improve data collection and analysis as promised in Commitment 9 of the Framework
- when will a complete picture of palliative resource in Scotland be known
- how you will ascertain the palliative care need for Scotland
- how will quality of care be measured, reflecting a person-centred approach

One of the issues raised in the previous committee's report, and noted by yourself when giving oral evidence on 26 January 2016, was the need for action to address the changing needs for children and young adults as a result of more children with life-shortening conditions living into adulthood. This issue is identified as commitment 4 in your Strategic Framework. Professor Whyte noted in oral evidence that the Scottish Government was working in association with the Children's Hospice

Association Scotland to test out different models of respite care for young adults. Can you provide details of how this testing is progressing and if any recommendations have been made or any specific respite provisions put in place for young adults?

Another area of concern which was raised with the previous committee by numerous witnesses was access to and uptake of anticipatory care plans (ACPs) and the information put into key information summaries. Commitment 7 seems to acknowledge these concerns and looks at future systems to support sharing of ACPs. During oral evidence it was advised that NHS National Services Scotland had been commissioned to carry out a piece of work to make sure that the key information summary, in its current state, was being used and accessed. Can you advise if this work has now concluded and if so provide an update on the outcomes?

Education was also highlighted by the previous committee as an area that need to be improved on, with inconsistency to training and education in palliative care being a concern. You advised that NHS Education for Scotland was recruiting three regional practice education co-ordinators to work across the NHS and social care services on establishing an integrated and collaborative approach to palliative and end-of-life care education provision. Can you advise if these posts have now been filled and how the role is progressing and also how the new palliative and end-of-life care educational framework, as outlined in Commitment 3, is developing?

Commitment 2 states that the Government will provide strategic commissioning guidance on palliative and end of life care to Health and Social Care Partnerships. We are now well into the financial year and partnerships have no doubt at least begun commissioning services. Can you confirm that this guidance has been provided to the partnerships? How will the Scottish Government monitor the implementation and use of the guidance?

The Committee highlighted the need for greater public and personal discussions of death and dying whilst also acknowledging the success of previous campaigns in this area. Commitment 6 agrees to support this need partly through commissioning of work. Can you advise if any work has been commissioned to support this goal and if there are any further campaigns to be run on this topic?

The previous committee noted in its report that families and service users had an important role to play in providing feedback on the quality and timeliness of palliative care and end-of-life service provision and recommended that one of the ways that this could be delivered was through the use of the VOICES survey. The previous Minister for Sport, Health Improvement and Mental Health and yourself advised that you were looking at ways of extending VOICES so that it was Scotland wide. Can you advise if any progress has been made on achieving this and if any other options have been explored for including families and service users in the feedback process?

During the oral evidence session you and your officials advised of various other strands of work which were being undertaken to improve palliative and end-of-life care. These included:

- consultation looking at emergency care and treatment planning, including anticipatory care planning.
- request to Healthcare Improvement Scotland to submit a report describing how its existing work could support the commitments to palliative and end-of-

life care and how that links in with on-going work on the national care standards and the inspection process.

- agreement from three health and social care partnerships – Glasgow, East Ayrshire and Western Isles- to test out how the Commitments can be implemented
- review of hospice funding to address the disparity between adult and children's hospices and specifically the review of the funding agreement between NHS Tayside and Children's Hospice Association Scotland
- a mapping exercise of specialist palliative care services across Scotland carried out by Professor David Clark

The Framework also advises that a national implementation support group will provide an annual learning and improvement report. It would be helpful to know when this report will be published each year and I would be grateful if you would advise.

One of the areas covered in the previous committee's inquiry report was the range of different settings that palliative care could be provided in. One setting not covered in that report was prisons. We are aware that the responsibility for the health care of the prison population now falls with health boards and it would be helpful if you could advise what steps have been taken to ensure that all prisoners who need palliative care receive it; whether within the prison or on release to a hospital or hospice.

Whilst I have mentioned specific commitments and strands of work within this letter I would be grateful if you could update us in relation to all work that has been undertaken to implement the commitments in the strategic framework.

It would be much appreciated if you could provide a response to this letter by 7 December 2016.

Kind regards,

Neil Findlay MSP

Convener of the Health and Sport Committee