Long Term Conditions Strategy Consultation

Scottish Government
Riaghaltas na h-Alba

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Full name or organisation's name

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x☐ Yes

☐ No

Questionnaire

1.   Do you agree that Scottish Government should move from a condition-specific policy approach to one that has a balance of cross-cutting improvement work for long term conditions alongside condition-specific work?

Yes Why do you say this?

Please give reasons for your answer.

SPPC supports the intention to balance cross-cutting improvement work alongside condition-specific work for two main reasons.

Firstly, palliative care primarily relates to a phase of life and related challenges rather than the specifics of a particular condition. The Scottish Palliative Care Guidelines, whose development was led by SPPC, are not condition-specific. Instead they relate to common symptoms and other issues which can occur across a range of specific conditions. Though more specific definitions can be helpful, one way of thinking about 'palliative care' is to talk in terms of providing 'good care' to people whose health is in irreversible decline or whose lives are coming to an inevitable close. Perhaps what differentiates 'palliative care' from 'just good care' is the awareness that a person's mortality has started to influence clinical and/or personal decision-making.   However, palliative care is not synonymous with death – it is about life, about the care of someone who is alive, someone who still has hours, days, months, or years remaining in their life, and about optimising wellbeing in those circumstances.

Secondly, changing demographics mean that most people will experience the final chapters of life with multiple long term conditions. In 2021, 23,900 people died with multimorbidity (38% of all deaths). The number of people dying with multimorbidity is projected to increase by 60% to 38,147 by 2040, accounting for 54% of all deaths. If current trends continue, it is projected that by 2040, 64% of people aged 85 and over could be expected to die with multiple health conditions and will be living with these in the years before they die.

SPPC welcomes the First Minister's recent statement of his personal and governmental commitment to improving palliative care:

"But what I take from that is that I as First Minister have an obligation to ensure people are supported during end of life care to the greatest extent possible in order to alleviate that suffering. Whether this legislation [the Assisted Dying Bill] ultimately passes or not, that is an obligation I take incredibly seriously and it's a matter my government will take forward in whatever circumstances we face."

2.   Are there any improvements in prevention, care or support you have seen in a long term condition you have, or provide care and support for, that would benefit people with other long term conditions?

Please give reasons for your answer.

Early and consistent receipt of palliative care improves outcomes for people with long term conditions and their families. However, for complex reasons people with some long term conditions are much less likely to receive the palliative care which they need. For example, people with cancer are more likely to receive palliative care than people with neurological conditions. Many people in Scotland with LTCs do not receive the care they need towards the end of life. Because palliative care and its benefits are often misunderstood by professionals people only receive palliative care at a very belated stage. People miss out on care and support which would have significantly improved the quality of life in their last years.

In addition to service improvements there are interventions around health literacy and community capacity which can improve experiences and these are covered under other questions.

There is a strong case for improving the experiences, care and outcomes of people with long term conditions as they approach the end of life. Here are 6 reasons why the new framework should have a clear and explicit focus on this domain:

1. Universal Relevance – everyone reaches the end of life and most people will do so with palliative care needs and multiple health conditions.
2. Improved Experiences – palliative care has been proven repeatedly to improve people's experiences of living with serious illness, dying and bereavement.
3. Inevitability – SPPC welcomes efforts to slow the progress of LTCs and to support maintenance of health and independence. However, regardless of these efforts the final phases of life will always be reached eventually – end of life may be postponable, but it is not preventable. A framework which fails to explicitly address living with serious illness, dying and bereavement is necessarily inadequate.
4. Prevention – whilst living with serious illness and dying is inevitable it is not immutable. Good palliative care can: manage difficult symptoms; support shared decision making; promote dignity and independence; provide family support; avoid burdensome/futile investigations and treatments; enable a focus on "what matters to you" in whatever time remains; improve outcomes in bereavement (because the way in which someone dies impacts on those left behind).
5. Efficiency in a Time of Scarcity – 1 in 3 acute hospital beds are occupied by people in their last year of their life (and most of these people have multiple long term conditions). A recent study has shown that Scotland spends £1.7billion on health and social care for people in the last year of life. The bulk of this expenditure is on unplanned acute admissions. A greater focus on the final phase of life can positively impact the reform and renewal challenges facing NHS Scotland. Acute capacity and flow, unscheduled care, delayed discharge and shifting the balance of care can all be valuably analysed, understood and addressed as final year of life issues. To date such analysis and framing has been conspicuously absent in policy making.
6. A Genuine Win Win! There is potential to improve outcomes for people and families whilst also making more efficient use of limited resources. There is real potential to deliver better value-based care and to operationalise at greater scale the principles of Realistic Medicine.

3.   Do you have any thoughts about how areas for condition-specific work should be selected?

Please give reasons for your answer.

4.   What would help people with a long term condition find relevant information and services more easily?

Please give reasons for your answer.

There is a need to sensitively integrate information about the final phases of life into public information offerings from NHS Inform. For example, if I access NHS Inform's page on Heart Failure there is no link or signposting to any information relating to palliative care. The page states "For some people with severe heart failure, a heart transplant may be recommended", which is true, but many more people with heart failure will benefit from palliative care than from a heart transplant yet there is no signposting to palliative care information. This pattern is typically replicated in other long term conditions. For example the pages on COPD mention treatments for advanced disease such as non-invasive ventilation and home oxygen but no link to information on palliative care.

NHS Inform has some good information on palliative care but it is hidden away. TO find this information people need to have prior knowledge about palliative care (yet we know that palliative care is not well understood), and that their condition may be (or become) serious.

This situation could be fixed relatively easily with some appropriate, sensitive cross- linkage and signposting.

5.   What would help people to access care and support for long term conditions more easily?

Please give reasons for your answer.

The following would improve people's access to care and support towards the end of life:
- Less restrictive eligibility criteria for social care
- Better information and public education about what care and support is available which might be of benefit to them, backed up with clear standards of care
- Open and honest conversations and earlier referral by health and care professionals
- 24/7 Helpline to provide advice and support to people and family carers who are supporting someone at home towards the end of life.
- Obviously the overstretched capacity in existing services is a major barrier and may negate the previous suggestions (though public information/education and access to 24/7 telephone support which prevents crisis could reduce service pressures).

6.   How could the sharing of health information/data between medical professionals be improved?

Please give reasons for your answer.

More rapid progress with digital health and care records and plans.

7.   What services outside of medical care do you think are helpful in managing long term condition(s)? You may wish to comment on how these services prevent condition(s) from getting worse.

Please give reasons for your answer.

Social care is a key support for many people with long term conditions, particularly towards the end of life.

In terms of prevention, rapid and responsive social care support can be key to enabling someone to remain in their home towards the end of life. Carer crisis is a key risk factor for unscheduled admission towards the end of life and often results from inadequate social care support. There is clear evidence that admission to hospital can impact negatively on people's general health and wellbeing and therefore should be avoided except where clinically justified. (see also reference to informal community supports in response to Q15)

8.   What barriers, if any, do you think people face accessing these (non-medical) services?

Please give reasons for your answer.

Eligibility criteria to access social care supports have tightened over the years reducing access. Restricted access undermines preventative approaches as support becomes limited to situations of severe need or crisis.

The Independent Review of Adult Social Care (The "Feeley Report" 2021) articulates the major deficiencies in adult social care and sets out a comprehensive set of measures for reform and improvement. This territory was exhaustively explored during the National Care Service consultations.

9. What should we know about the challenges of managing one or more long term conditions?

Please give reasons for your answer.

The research highlighted below, with people with LTCs and their families, conducted by Edinburgh University, provides useful insights.

'My body's falling apart.' Understanding the experiences of patients with advanced multimorbidity to improve care: serial interviews with patients and carers" BMJ Support Palliat Care. 2016 Mar;6(1):60-5

The abstract reports:

"We analysed 87 interviews with 37 patients and 17 carers. They struggled with multiple changing medications, multiple services better aligned with single conditions such as cancer, and a lack of coordination and continuity of care. Family carers spoke of physical, mental and emotional exhaustion and feeling undervalued by professionals. Patients and carers frequently saw deteriorating health as part of 'growing old'. Many used a 'day-to-day' approach to self-management that hindered engagement with advance care planning and open discussions about future care. 'Palliative care' and 'dying soon' were closely related concepts for many patients, carers and professionals, so rarely discussed.

Conclusions: Patients with advanced multimorbidity received less care than their illness burden would appear to merit. Some people did restrict their interactions with care providers to preserve autonomy, but many had a limited understanding of their multiple conditions, medications and available services, and found accessing support impersonal and challenging. Greater awareness of the needs associated with advanced multimorbidity and the coping strategies adopted by these patients and carers is necessary, together with more straightforward access to appropriate care."

10. What would strengthen good communication and relationships between professionals who provide care and support and people with long-term condition(s)?

Please give reasons for your answer

There are particular challenges in good communication towards the end of life. Many health and social care professionals find conversations about mortality challenging. In addition professionals, people and their families are frequently navigating high degrees of uncertainty where the efficacy of different interventions, and timescales for deterioration are difficult to predict.

Research shows that the public generally expect health and care professionals to share information about prognosis (including uncertainty). However professionals may sometimes feel that talking about end of life may be harmful e.g. "destroy hope". There is evidence that important conversations about mortality are often avoided by professionals. This can be exacerbated by "specific condition" approaches in which the focus is on fixing specific clinical issues in isolation and in the short term. In this context seemingly obvious longer trajectories of decline can be overlooked by multiple different actors. The result is that important and meaningful conversations don't take place until very late on.

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There is a need for more training and education for health and care professionals. Public education and measures to improve "death literacy" can better equip the public to ask questions and initiate conversations.

The use of triggers to routinely prompt future care planning conversations could strengthen communication.

11.   What digital tools or resources provide support to people with long-term conditions?

Please give reasons for your answer.

12.   What new digital tools or resources do you think are needed to support people with long-term conditions?

Please give reasons for your answer.

13.   How do you think long-term conditions can be detected earlier more easily?

Please give reasons for your answer.

14.   What barriers do people face making healthy decisions in preventing or slowing the progress of long-term condition(s)?

Please give reasons for your answer.

15.   Is there anything currently working well within your community to prevent or slow progression of long term conditions?

Please give reasons for your answer.

Many people with long term conditions rely primarily on family, friends, neighbours and other community members for support.

Planners and commissions can play a valuable role in nurturing and strengthening this vital informal capacity for care and support.

Many third sector organisations work to support and strengthen community connections and informal networks, but are often the first to experience cuts as budgets tighten. Many hospices have befriending or compassionate neighbour schemes though which informal community support is provided.

Public education can play an important role. An End of Life Aid Skills for Everyone (EASE) course has been developed by SPPC and is being delivered by community volunteers within communities across Scotland. EASE brings people together in four weekly 2-hour sessions, to learn about and share experiences of death, dying, loss and care. Through peer learning and expert input, participants grow confidence and knowledge around these issues, learn how to look after themselves and others, and find out where to go for further information and support. EASE won the Self Management Resource of the Year award.

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16.   How can the Scottish Government involve communities in preventing or slowing the progress of long term conditions?

Please give reasons for your answer.

Provide sustainable multi-year funding to the type of work described in the response to Q15.

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17.   Are there additional important considerations for people with long term conditions:
  o **who live in deprived areas and rural and/or island areas?**
  o **with protected characteristics e.g. race, disability (see paragraph 84 above)?**
  o **who are in inclusion health groups e.g. homelessness?**
  o **who experience stigma due to perceptions of their long term condition e.g. people with dementia?**

Death is not "the great leveller". People who have experienced deprivation and discrimination earlier in life tend to have worse experiences and outcomes at the end of life.

Whilst not all people dying prematurely will have palliative care needs, levels of multi-morbidity increase with deprivation, and multi-morbidity and palliative care need are closely linked.

People living in deprived areas have different patterns of service use/ access. They are less likely to access specialist palliative care, they are more likely to spend time in hospital during the last 3 months of life, more likely to die in hospital and less likely to die at home or in a hospice. Even when people living in deprived areas access specialist palliative care they are less likely to die in a hospice and more likely to die in a hospital than those from affluent areas . People from the most deprived areas are less likely to report that they received sufficient support from health and social services to care for someone at home .

The Ritchie Report on Out of Hours (SG 2015) highlights how primary care resources are maldistributed by health care needs, according to socio-economic status and the fact that levels of multi-morbidity increase with increasing deprivation.
The impact of type of housing, material environment, and poverty on end of life experiences are not well understood. The Dying in the Margins project is explored these issues in deprived communities in urban and rural areas in Scotland .
Serious illness and caring for someone with a serious illness are themselves causes of poverty. A over a decade of austerity has left an increasing number of people in Scotland facing funeral poverty.

SPPC's report "Every Story's Ending – proposals to improve experiences of living with serious illness, dying and bereavement in Scotland" contains numerous specific recommendations on improving inequities towards the end of life.

**18.	Given that racism and discrimination are key drivers of inequalities, what specific actions are necessary to address racism and discrimination in healthcare?**

Please give reasons for your answer.

See answer to Q17

19.   Is there anything else you would like to raise that was not covered elsewhere in the consultation paper?

SPPC supports the broad approach to the new framework, with an emphasis on cross cutting themes.

Our experience over the past 15 years is that the final phases of life are very often omitted from relevant policy documents and consultations. Recent examples include the National Care Service work (including the supporting data analyses) and this LTC consultation. We find that unless a policy explicitly mentions terms such as "death", "dying", "bereavement", "end of life" and "palliative care" this domain of life will tend to be ignored in practice. The reasons for this seem multiple and complex. There remains a strong strand of clinical culture which experiences death as professional failure, and perhaps subconsciously avoids explicit engagement with this crucial area. People in all walks of life can find consideration of mortality uncomfortable and again avoidance can be a very human and understandable response. There is also a tendency to think that because end of life is inevitable there is nothing much which can be done to improve it – "you just have to get through it". Of course there is much which can be done which makes an enormous positive difference to people and their families. People can be enabled and supported to live as well as possible in their last years, months and hours. And people can be supported to remain the authors of their lives as they navigate final chapters of uncertain length.

For this reason we would be interested to discuss and understand better how the framework might best achieve an effective and explicit focus on the final phases of life. One approach might be to designate it as a further cross cutting theme. Alternatively, thinking about the schematic of the potential action plan framework in the consultation document (P13), one might add "End Life Phase Specific Commitments" as a row. There are specific, achievable and relevant actions which could be taken under each of the proposed columns (Access, Data, Self Management and Patient Info, Clinician Info/Education, Prevention/Early Intervention).

As we argued earlier in this response the needs, experiences and outcomes of people with g term conditions approaching the end of life should be a major concern of the new framework. We gave 6 reasons:

1.   Universal Relevance – everyone reaches the end of life and most people will do so with palliative care needs and multiple health conditions.

2.   Improved Experiences – palliative care has been proven repeatedly to improve people's experiences of living with serious illness, dying and bereavement.

3.   Inevitability – SPPC welcomes efforts to slow the progress of LTCs and to support maintenance of health and independence. However, regardless of these efforts the final phases of life will always be reached eventually – end of life may be postponable but it is not preventable. A framework which fails to clearly encompass living with serious illness, dying and bereavement is necessarily inadequate.

4.   Prevention – whilst dying is inevitable it is not immutable. Good palliative care can: manage difficult symptoms; support shared decision making; promote dignity and

independence; provide family support; avoid burdensome/futile investigations and treatments; enable a focus on "what matters to you" in whatever time remains; and improve outcomes in bereavement (because the way in which someone dies impacts on those left behind).

5.   Efficiency in a Time of Scarcity – 1 in 3 acute hospital beds are occupied by people in their last year of their life (and most of these people have multiple long term conditions). A recent study has shown that Scotland spends £1.7billion on health and social care for people in the last year of life. The bulk of this expenditure is on unplanned acute admissions. A greater focus on the final phase of life can positively impact the reform and renewal challenges facing NHS Scotland. Acute capacity and flow, unscheduled care, delayed discharge and shifting the balance of care can all be valuably analysed, understood and addressed as final year of life issues. To date such analysis and framing has been conspicuously absent in policy making, investment and action.

6.   A Genuine Win Win! There is potential to improve outcomes for people and families whilst also making more efficient use of limited resources.