

Response ID ANON-Q39F-ERK1-P

Submitted to Health and Social Care Strategy for Older People
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Integrated Planned Care

1 Tell us about any social care or other outside help with everyday living that you (or a family member) have received in your own home?

Please provide your response in the box below:

2 What was your experience of these services?

Please provide your response in the box below:

3 As an older person, what are your experiences of health and social care services working together?

Please provide your response in the box below:

4 What could be done to improve joint working between health and social care services?

Please provide your response in the box below:

5 Do you live with a long term physical or mental health condition or illness?

Not Answered

6 If yes, how do you feel about the way your health is monitored and reviewed? If no, how do you feel about your ability to access regular health checks?

Please provide your response in the box below:

7 Where would you prefer that regular health checks are provided and who by?

Please provide your response in the box below:

8 What support would you need to assist you in self managing your general health or any long term health conditions that you have?

Please provide your response in the box below:

9 Tell us about your experience of any health care appointments you have had in the last 2 years

Please provide your response in the box below:

10 What additional support would you need to make online or telephone medical appointments easier?

Please provide your response in the box below:

11 What would make it easier for you to know who to contact when in need of advice, support or assistance for a health issue?

Please provide your response in the box below:

12 What is currently working well to support planned health care and treatment?

Please provide your response in the box below:

13 What needs to be improved?

Please provide your response in the box below:

14 Is there anything else you would like to add?

Please add any additional comments you have on this section:

15 When you, or a family member approach end of life, what care and support would you want?

Please provide your response in the box below:

Scottish Partnership for Palliative Care welcomes the inclusion of palliative care as a theme within the strategy.

We recently published a comprehensive analysis of palliative care in Scotland - progress, remaining challenges, recommendations for future action. It was based on extensive engagement with stakeholders involved in providing and improving care, and drew too on what is know about the beliefs, attitudes, preferences and views of the public. Our answers to this consultation are based on this report, which can be accessed at <https://www.palliativecarescotland.org.uk/content/everystorysending/>

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

Support, Empathy, Information

What a person needs depends on their personal circumstances and what is important to them. 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.

Autonomy, Opportunity, Honesty

Compassion, practical support, human connections and thoughtful intervention can go a long way to giving people quality and meaning in their lives.

Three inter-dependent factors are key:

Autonomy

People generally value a sense of being in control, yet ill-health often throws people into situations no-one would choose. The options available to an individual may be limited for various reasons, but it is important that people are supported to retain the autonomy to choose from the options that are available for as long as possible.

Opportunities to explore personal preferences

Planning ahead for deteriorating health increases the likelihood that a person will receive the kind of care they would like. Therefore, efforts to encourage this kind of planning and to promote more cultural openness about death are welcome. Not everyone will want to plan ahead or talk about death, but everyone should have opportunities to do so, accompanied by the recognition that people's needs and wishes can change over time. It is important that every individual has the opportunity to tell their own story, and that others listen to find out what matters to them and what support they might need.

Honesty and openness

While remaining sensitive to an individual's situation and sensitivities, healthcare and social care professionals need to be honest with the person about their expectations for that person's health. This includes what uncertainties are involved, what support will be reliably available, and any limits there might be to the support provided. The desire to shield people from unwelcome information is understandable. Learning that someone will not get better, or that the ideal support services are not available, or that the end of life is close, will likely always be difficult. Yet, without honest information, individuals and families are ill-equipped to make decisions or plan ahead. Thinking about serious illness and death can be difficult for both professionals and for the public but recognising shared mortality and common humanity is where good palliative and end of life care builds from.

Privacy, Individuality, Relationships - Unpacking "I will want to die at home"

People often express a wish to be cared for and to die at home.

For many people their home is somewhere familiar, where loved ones can be to hand, and where important words and moments can be shared in privacy. Home can be a personal, intimate and individual space steeped in meaning.

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 by. Sometimes there may be trade-offs to consider and choices to be made between the place someone would ideally want to be and other things that are important to them.

Care homes, hospitals, hospices and individual homes are all places where people can live and receive good care when they are seriously ill or dying. For some people at the end of life "home" may be a prison or a homeless hostel and good care should be available there too, despite evident challenges. Each setting has an important role to play as complementary parts of a single system.

It is therefore important that, wherever someone is living, efforts are made to enable them to experience as much of the 'essence of home' as possible. For many of us, that is about having privacy, individuality and space for intimacy and important relationships.

16 When thinking about palliative and end of life care in Scotland, what is working well?

Please provide your response in the box below:

The vast majority of palliative care in Scotland is provided to people above retirement age.

Most care is informal care provided to people approaching the end of life comes from family, friends and other community members.

In terms of formal services it is important to be clear about who provides palliative care in Scotland.

In Scotland most of the care that people receive when their health is deteriorating could be termed generalist palliative care, being provided by health and social care professionals to people living in the community, in care homes and in hospitals. It is palliative care regardless of whether someone has cancer, organ failure (including neurological conditions) or 'old age', or whether they are living at home, in a hospice, in a care home, in prison or in a medical ward, in ICU or a homeless shelter, or in a neonatal ward.

Specialist palliative care by multi-professional specialist teams

Specialist palliative care can help people with more complex palliative care needs and is provided by specially trained multi-professional specialist palliative care teams who are generally based in a hospice, an NHS specialist palliative care unit or an acute hospital, but whose expertise should be accessible from any care setting and at any time. Services labelled 'palliative' are usually specialist palliative care. Key contributions of specialist palliative care include:

- # assessment and management of complex physical, psychological and spiritual symptoms
- # supporting complex clinical decision-making, seeking to apply relevant ethical and legal frameworks alongside clinical assessment and respect for personal autonomy and values
- # direct provision and management of symptom management interventions
- # providing care and support to those important to the person receiving care, including facilitating bereavement care
- # providing specialist advice and support to the wider care team which is providing direct care to the person
- # liaison with and between different settings
- # providing formal and informal education and training for the wider health and social care system
- # attending and providing input to multidisciplinary team meetings, including key decision-making contributions
- # providing strategic expertise and leadership to support the health and care system to recognise and meet the needs of people approaching the end of their lives.

End of life care

Palliative care includes, but is not exclusively about, end of life care.

End of life care is a core part of palliative care which should follow from the diagnosis of someone entering the process of dying, whether or not they are already in receipt of palliative care. This phase could vary between months, weeks, days or hours in the context of different disease trajectories. There can be uncertainty involved in identifying when someone might be expected to die – illness can be unpredictable, and changes can occur suddenly and unexpectedly.

Provision of palliative care

Palliative care is provided by the NHS, the Third Sector, the Independent Sector and local authorities.

Organisations involved in delivering palliative care include primary care; care homes; care at home services; hospices; NHS 24; Scottish Ambulance Service; NHS specialist palliative care units; acute hospitals; community hospitals.

Legal responsibility for the strategic commissioning of adult palliative care lies with Integration Authorities (IAs). Children's palliative care is delivered by partnership working between Health Boards, Local Authorities, and CHAS (as the single national provider of children's hospice care), with Scottish Government funding for CHAS managed through NHS Lothian.

Anecdotally there is a lot of good palliative and end of life care provided in Scotland, but there is no systematic approach to understanding the experiences of care and outcomes of people approaching the end of life and who are bereaved. The health and care experience survey explicitly excludes this perspective. This makes it hard to give a robust answer to "what is working well".

17 What could be improved?

Please provide your response in the box below:

We believe there are 8 priority areas to improve palliative care for older people:

1. Establishing Leadership, Commitment, Collaboration and Accountability

Palliative and end of life care is provided in the context of multiple delivery agencies, parallel planning processes and complex lines of accountability. There is therefore a need for a strategic approach, with strong national and local leadership and clear accountabilities. There is also a need for commitment and collaboration from a wide range of organisations, alongside an infrastructure to support learning, innovation, collaboration and investment. Some important aspects of improvement and sustainability require investment.

At system level there is a need to identify what improved outcomes towards the end of life should look like, and then plan to achieve these explicitly identified outcomes. Achieving good population outcomes means tailoring support to individual needs. Processes should support partnership and collaboration between different sectors and should involve and reflect local communities and their needs. Palliative care is highly valued by people and their families and is relatively low-cost care.

2. Measuring and Valuing What Matters

Currently no-one can adequately evidence the quality of care and outcomes delivered for people living with serious illness, dying and bereavement in Scotland. Local and national measures of quality of care and experience towards the end of life should be developed. Such measures should inform commissioning decisions, inform the focus of improvement work and provide public assurance at local and national level.

3. Planning and Commissioning for Success

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collaboration between different sectors and should involve and reflect local communities and their needs. Palliative care is highly valued by people and their families and is relatively low-cost care.

4. Empowering Communities

Most care and support is provided informally by family and other community members. This should be recognised and supported with a 'public health approach' that nurtures community-led action and builds everyday knowledge and skills relating to death, dying, loss and care.

5. Promoting and Enabling Planning Ahead for Serious Illness and Death

Thinking ahead and making plans for declining health and dying can improve people's experiences and outcomes. There is therefore the need for a co-ordinated national approach to anticipatory care planning (ACP) which encompasses public awareness/information, staff education, clear triggers, and with clarity on roles and responsibilities. This must be underpinned by a digital Anticipatory Care Plan (ACP) which supports citizen access and allows updating and sharing across health and social care settings, including independent and Third Sectors.

6. Ensuring Responsive Support from Community Health and Social Care Services

Many of the needs people have towards the end of life can be met at home through the efforts of family carers with the support of skilled and confident primary and social care staff. However, this kind of professional support is not consistently and reliably available across Scotland, putting additional pressure on unpaid carers. "Out of hours" can be a particularly worrying and challenging time for families who are providing the first line of care for a relative approaching the end of life. Rapidly responsive support should be available 24/7, making a big difference for people and also avoiding unnecessary and undesired admissions to hospital.

7. Improving Bereavement Support

Palliative care includes bereavement support. During the pandemic many more people have experienced bereavement, often in difficult and traumatic circumstances. A public health approach to bereavement should be developed which identifies the experiences and levels of need of the population, maps current capacity, identifies unmet need and which brings together providers and commissioners to collaborate on clear pathways, adequate resourcing of services and building informal community capacity.

8. Building and Sustaining the Workforce

Improving care towards the end of life requires the success of national workforce planning measures addressing well-documented challenges such as the recruitment and retention of social care staff, the imminent retirement of a high proportion of GPs, district nurses and nurse specialists, and trauma/burnout from the COVID-19 pandemic. In addition there must be adequate palliative and end of life care education for generalists. National and local workforce planning must also ensure adequate specialist palliative care capacity to provide direct care, support to generalist colleagues, education and leadership.

18 Is there anything else you would like to add?

Please any additional comments you have on palliative and end of life care:

DEMOGRAPHIC CHANGE:-

MOPPRE PEOPLE DYING, AND AT AN OLDER AGE

The next 20 years will see a steady increase in the number of people dying in Scotland each year. By 2040 it is projected that 65,757 people in Scotland will die each year, a 16% increase on 2016. To put this rise in context, by 2040 as many people will die every year as have died during the first 12 months of the COVID-19 pandemic. It is expected that on average people will die at an older age - including a 59% increase in deaths of people aged 85+, who will account for 45% of all deaths (up from 33% in 2016).

MORE PEOPLE WILL NEED PALLIATIVE CARE

Alongside the growth in the numbers of people dying there will be an increase in the numbers of people needing palliative care. By 2040 it is estimated that between 74% and 95% of those who die would benefit from a palliative approach. It is projected that 14-20% more people may need palliative care by 2040.

Cancer and dementia will increase as the main underlying causes of death, but even more significant will be an increase in multi-morbidity. The care of people with multi-morbidity can be complex and require greater integration of services. The proportion of people dying from multiple chronic progressive diseases spanning different disease groups will rise by 60%. Such deaths will account for 46% of palliative care deaths by 2040.

MORE PEOPLE WILL LIVE LONGER WITH MULTI-MORBIDITY AND UNCERTAIN PROGNOSIS

Since on average people have an extended period of ill health towards the end of life those living with serious illness and multi-morbidity significantly outnumber the number of people who die each year. There will be uncertainty about how and when their health may deteriorate, and uncertainty as to whether any particular episode of deterioration will lead to death or be followed by an extent of recovery. The numbers of people with multi-morbidity who are in caring roles will also increase.

Making and guiding decisions about clinical care for people with multi-morbidity is difficult because of the uncertainties involved. Medical advances widen the range of possible interventions but without necessarily providing any greater certainty as to outcome. The balancing of possible risks and possible benefits becomes more complicated.

Understanding what matters most to the person should guide decision-making but may be difficult if the person has reduced agency including reduced mental capacity. By 2040 it is estimated that over 115,000 people in Scotland will have dementia - a 74% increase on 2019.

These changes are already having real effects on how people living with advanced multi-morbidity live their lives.

19 What would assist you in having discussions with family or medical professionals about how you would like to be cared for, as you approached the end of life?

Please provide your response in the box below:

Public basic education about end of life issues

Accessible information which gives open and honest information which doesn't omit difficult issues

Proactive approach from GP or other practitioner, upstream, early on, not a response to deterioration and crisis

Normalisation of this process - hearing public figures, including senior government leaders talk about these things.

20 Who would you prefer to have these conversations with?

Please provide your response in the box below:

Ideally someone with a pre-existing relationship. Someone with good communication skills.

21 Is there anything else you would like to add about integrated planned care for older people?

Please add any additional comments you have on this section:

Good care towards the end of life will involve a mixture of planned, proactive care but also unplanned reactive care responding to changing and unpredictable circumstance.

Integrated Unscheduled Care

1 What is currently working well to support older people who require urgent or emergency care?

Please provide your response in the box below:

2 What could be improved?

Please provide your response in the box below:

3 Is there anything else you would like to add?

Please provide your response in the box below:

A recent study has shown that nearly 95% of people in their last year of life have unscheduled care contacts with NHS 24, Primary Care Out of Hours, Scottish Ambulance Service, A&E and or emergency admission. The median number of contacts is 5, with 5% of people having 20 or more contacts. Over 34% of contacts are in the last month of life. Macmillan are currently supporting a project to develop the palliative and end of life care provided by paramedics.

Patterns of access to unscheduled care vary significantly according to the main underlying condition and also in relation to the level of deprivation. Even with further development and improvement of anticipatory care planning, reactive care, as evidenced by this data, will remain a critical and major component of good care towards the end of life.

"Out of hours" (night, weekends and bank holidays) represents 63% of the week. In some areas of Scotland there are palliative care teams working out of hours and dedicated palliative care phone lines. However, access to care in the community can be particularly patchy outwith normal working hours. There is often very limited access to specialist nursing, a skeleton district nursing service and an out of hours GP service that can be very stretched and which struggles to respond quickly. Staff working out of hours in the community face major challenges in providing high quality palliative and end of life care :

- Staff may have limited access to information about the patient.
- The prognosis may be uncertain, making it hard to decide whether the patient's condition is potentially reversible with treatments available in hospital or whether this is not the case and it would be better for the patient to remain at home with a focus on managing symptoms.
- A lack of confidence in providing palliative and end of life care.

Out of hours can be a scary time for families who are providing the first line of care for a relative approaching the end of life. A lack of responsive, adequate support outwith normal hours is often reflected in unnecessary and undesired admissions to hospital.

4 What support do older people need after surgery?

Please provide your response in the box below:

5 Do you have any experience of Hospital at Home? What are your thoughts on the service?

Please provide your response in the box below:

6 If you have no experience of Hospital at Home, do you think this is a service you would use if needed and benefit from?

Please provide your response in the box below:

7 Is there anything else you would like to add about integrated planned care for older people?

Please add below any additional comments you have on this section:

8 Please use this space to highlight or raise any other areas you feel should be included in the new health and social care strategy for older people.

Please add any additional comments you have in the box below:

About you

1 What is your name?

Name:

Mark Hazelwood

2 What is your email address?

Email:

mark@palliativecarescotland.org.uk

3 Are you responding as an individual or an organisation?

Organisation

4 What is your organisation?

Organisation:

Scottish Partnership for Palliative Care

5 Where in Scotland do you live?

Please select your answer from the dropdown list:

Edinburgh

6 What age are you?

Please select your answer from the dropdown list:

50-59

7 The Scottish Government would like your permission to publish your consultation response. Please indicate your publishing preference:

Publish response only (without name)

8 We will share your response internally with other Scottish Government policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for Scottish Government to contact you again in relation to this consultation exercise?

Yes

9 I confirm that I have read the privacy policy and consent to the data I provide being used as set out in the policy.

I consent

Evaluation

1 Please help us improve our consultations by answering the questions below. (Responses to the evaluation will not be published.)

Matrix 1 - How satisfied were you with this consultation?:

Very satisfied

Please enter comments here.:

Matrix 1 - How would you rate your satisfaction with using this platform (Citizen Space) to respond to this consultation?:

Neither satisfied nor dissatisfied

Please enter comments here.:

Platform could be improved by:

Allowing basic formatting

A spellchecker

Allowing download of drafts (as editable word) before submission - would help me to engage interactively with other stakeholders more easily.

Thanks