Scottish Partnership for Palliative Care

Health and Sport Committee Inquiry into Preventative Agenda

About the Scottish Partnership for Palliative Care (SPPC)

The SPPC is a collaboration of over 50 organisations involved in providing care towards the end of life. SPPC’s membership includes all the territorial NHS Boards, all the hospices, a range of professional associations, many national charities, local authorities, social care providers and universities.

The Scottish Partnership for Palliative Care (SPPC) brings together health and social care professionals from hospitals, social care services, primary care, hospices and other charities, to find ways of improving people’s experiences of declining health, death, dying and bereavement. We also work to enable communities and individuals to support each other through the hard times which can come with death, dying and bereavement. This response was developed in consultation with SPPC Council members (listed in Appendix A).

Which areas of preventative spending/ the preventative agenda would it be most useful for the Health and Sport Committee to investigate?

Much of the literature on preventative spend rightly focuses on tackling determinants of ill health upstream so as to reduce treatment costs at a later date.

However, as we continue to strive to increase healthy life expectancy, it is important to recognise that even the most healthy, active and independent individuals eventually face ill health or frailty as they approach the end of their lives. Death remains inevitable.

This is an important reality to consider when exploring financial matters, as a high proportion of the health and care budget is used in the final year of life. Evidence shows that use of health and care resources rises steeply in the last year of life and that resource use is more closely correlated to proximity to death than to age.

Therefore the Committee should examine how the health and care system supports people in their last year of life, and consider what interventions and approaches might reduce expenditure whilst also improving the quality of care people experience.

We suggest that the Committee should explore the following areas as a focus for ‘preventative spend’:

- Advance Care Planning.
- Increased Care Home and Care at Home provision.
- Enhance specialist palliative care resources.

More detail is provided below.

(Within this submission we have summarised three areas that we feel are of particular relevance to the Committee’s inquiry into the Preventative Agenda. A fuller exploration of related issues is
Advance Care Planning

What is it?
Advance care planning is the process of planning ahead for illness and death, and can include aspects such as:

- Granting a Power of Attorney/Welfare Attorney
- Making a Will
- Completing an Advance Directive (sometimes called a “living will”)
- Making an Anticipatory Care Plan (ACP)

An ACP is likely to include information about key people involved in care, emergency contacts, important specific information about an individual’s health, and information about previous hospital admissions. Anticipatory care planning may include the development of a personal emergency care plan which records what treatments will be of benefit and in line with the person’s preferences in the event of a sudden deterioration in health.

How can advance and anticipatory care planning help to improve the experiences of individuals and their families?

People’s preferences for care often shift. In good health and middle age many say they would like to die at home. In their eighties, with an exhausted spouse and uncertain of community support, hospital may offer some things which home no longer can. Alternatively, someone who is frail or drawing to the end of life may feel that there comes a time when they do not want to be burdened by further tests or treatments that are intrusive, sap their energy, and are unlikely to improve their condition – they may not wish to go to hospital. Alternatively they might wish to go to hospital, but opt out of certain treatments.

By sharing their personal preferences, an individual makes it more likely that they will get the care they would choose, and in the place they would choose.

How might encouraging advance and anticipatory care planning represent ‘preventative spend’?

By reducing emergency hospital admissions:
There is evidence to suggest that using primary and secondary care data to identify patients at risk of hospital admission, and agreeing and implementing an Anticipatory Care Plan in this population can help to reduce hospital admission rates.¹ (Emergency hospital admissions are expensive.)

By reducing delayed discharges:
We estimate that at any one time 150 NHS beds being used by people who do not need hospital treatment but who cannot be released as they are unable to give their consent to be moved to a more appropriate care setting (ie they do not have a Power of Attorney so they have to wait in hospital while their families apply for a Legal Guardianship order).

By reducing unwanted medical interventions towards the end of life
As highlighted by Dr Catherine Calderwood, Chief Medical Officer for Scotland, in her report *Realistic Medicine*, there is a prevalent culture which encourages medical staff to attempt to prolong an individual’s life with whatever means is available, even though treatments are often invasive and unpleasant. When given an honest prognosis and a choice, many individuals would decline such interventions in favour of a focus on maintaining their comfort.

Where are we now?
National Scottish work on ACP is underway, led by HIS, as part of their Living Well in Communities portfolio. This is welcome, and there is a need to ensure that momentum and support for this work is maintained in the long term, to ensure the project has maximum impact across Scotland.

The Key Information Summary (KIS) has been established as a functional vehicle to communicate such information across healthcare settings. However, further work is required to ensure that the key components of an ACP care captured in the KIS, including its redesign to allow the KIS to be written not solely by primary care, but by others involved in someone’s care, and directly by the person themselves. The numbers of KIS in Scotland are rising but there needs to be a focus on the quality of recorded information relating to ACP and shared decisions.

There are also lessons to be learnt from other Scottish work relating to advance care planning more widely. This includes the work of Good Life, Good Death, Good Grief and its members to promote more open and supportive attitudes and behaviours around death, dying and bereavement. Cultural change of this sort is necessary if the open and honest discussions which underpin ACP and shared decision making are to take place.

**Increase Care Home and Care at Home provision**

With the right resourcing and support, there are many settings in which people can be cared for well as their health deteriorates and they approach the end of life, including at home, in hospital, in a care home and in a hospice. Which setting is right for an individual depends on their circumstances and preferences.

However, it is a reality that people’s care pathways towards the end of life are influenced by the options available at the time. For example, an individual may wish to stay at home despite a medical emergency, their GP may feel home is the best place for a person to be, but without the availability of appropriate social care support, admitting someone to hospital may be the only way of quickly ensuring the individual’s safety.

Investment is required to ensure it is as easy to arrange a social care package as it is to call for an ambulance. More specifically, this means:

a) increasing the provision of care at home and care home places,

b) additional investment to ensure that social care services are empowered to provide a high standard of care.

To achieve this, commissioners need to resource social care providers to be able to provide:

- Terms and conditions of employment which support better recruitment, retention and skills/knowledge development in the social care sector.
- Appropriate training in palliative and end of life care for staff
- Realistic timescales for staff to carry out personal support to clients.
How will this help to improve the experiences of individuals and their families?

Ensuring adequate availability of social care support will enable more individuals to access support that matches their needs and preferences.

How might this represent ‘preventative spend’?

By providing an alternative to emergency hospital admission, and reducing delayed discharges:

Most recent ISD data indicates that in December 2016 around 10816 days were spent in hospital by people awaiting completion of arrangements for social care support (e.g. carer) in order to live in their own home, and a further 10816 days were spent in hospital by people awaiting place availability in a care home.

In 2015 Scottish Care published Home Delivery, A profile of the Care at Home Sector in Scotland 2015. The report explores the concept of the “care pound”, and attempts to gauge the level of expenditure consumed by emergency admissions and consider alternative forms of care that could be purchased with the same expenditure. Within that report, it is estimated that, the cost of one average emergency admission (estimated at £4,846.62) could alternatively be used to purchase an average week of care at home provision for 27.7 older persons or 9.28 weeks in a residential care home.

Enhance specialist palliative care resources

In Scotland, much of the care that people receive when their health is deteriorating can 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. Health and social care staff with various roles provide generalist palliative care, to people with cancer, organ failure (including neurological conditions) or ‘old age’, whether at home, in a hospice, in a care home or in a medical ward, ICU or neonatal ward.

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. As well as supporting people at later stages of their illness, specialist palliative care can intervene soon after a diagnosis to improve a person’s quality of life.

To achieve optimum outcomes for individuals, specialists and generalists work together – it is appropriate that most people are cared for outside a specialist palliative care unit. However, generalists need to be able to call on specialist palliative care colleagues for specialist assessment, education, advice and other support when necessary.

How can enhancing specialist palliative care resources help to improve the experiences of individuals and their families?

The Scottish Government’s Health and Social Care Action Plan committed to “doubling palliative and end of life provision in communities”. This can only be achieved by increasing the capacity of specialist palliative care to provide support to generalists working in communities.
There is clear evidence that early intervention in cancer from specialists in palliative care help achieve improved quality of life, reduction in chemotherapy use, increased symptom control and increased likelihood of dying in preferred place (predominately home). Early intervention models have been trialled in community and acute settings and function to reduce length of stay and improve quality outcomes.iii

How might this represent ‘preventative spend’?

Having the right specialist palliative care support available in communities should support the reduction of emergency hospital admissions.

Investment in early specialist palliative care intervention has been evidenced to bring economic benefits.iv For example, the recent TCAT sponsored study in Fife has shown that providing proactive supportive care at the outset for patients newly diagnosed with lung cancer can help to prevent acute hospital bed days, reduce overall spend and most importantly improve quality of care.v

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Appendix 1: SPPC Council Members

This response was developed in consultation with SPPC Council members:

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3 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3799294/
5 https://www.ncbi.nlm.nih.gov/pubmed/9924595
7 http://ascopubs.org/doi/abs/10.1200/JCO.2014.60.2334
8 A Model of Proactive Best Supportive Care for Patients with Lung Cancer, A Service Development led by Fife Specialist Palliative Care, Published by NHS Fife, Fife Health and Social Care Partnership, Transforming your Cancer Care, Macmillan. November 2016.