Submission by the Scottish Partnership for Palliative Care to the Health & Sport Committee’s Inquiry into Palliative and End of Life Care

1. About the Scottish Partnership for Palliative Care (SPPC)

SPPC is the umbrella body representing the major organisations involved in palliative care in Scotland. SPPC has 52 member organisations, comprising all territorial NHS Boards, all the voluntary hospices, 15 national charities, support organisations and a range of professional associations. Our membership is detailed at www.palliativecarescotland.org.uk. The Partnership contributes at national level to the development and strategic direction of palliative care in Scotland and to service improvement at local level. An important part of our role is the development, identification and dissemination of good practice, through our eBulletin, website and events. The Partnership’s aim is to promote equitable access throughout Scotland to high quality palliative care for all patients and families.

2. How this Submission is Structured

This submission begins by considering briefly what it is as a society that we are trying to achieve in this field. Next it attempts to establish some terminological and conceptual clarity about palliative and end of life care – this section also addresses differences between specialist and generalist palliative care, and explores the role of conversations. The submission then assesses current access to palliative and end of life care in Scotland. Barriers to access are then identified and finally a series of actions for improving palliative and end of life care are proposed.

Palliative care in Scotland suffers from a lack of good data for many purposes; for local improvement, for performance management, for quality assurance, to assess current and future needs, to characterise patterns of service use (including inequalities), and patterns of resource use. At national level data currently relates to processes and activities and not to outcomes which are meaningful to patients and families. For this submission SPPC has used its networks to inform reasonable judgements and estimates about the current state of palliative and end of life care in Scotland.

3. What Are We Trying to Achieve?

SPPC’s vision is that Scotland should be a place where:-

- People’s wellbeing is supported even as their health declines.
- People die well.
- People are supported throughout bereavement.

More specifically:

- People receive health and social care which supports their wellbeing, irrespective of their diagnosis, age, socio-economic background, care setting or proximity to death. Each individual's care may look very different.
- People have the opportunity to discuss and plan for future possible decline in health, preferably before a crisis occurs, and be supported to retain autonomy for as long as is possible.
- People know how to help and support each other at times of increased health need and in bereavement, and the importance of families and communities working alongside formal services is recognised.
- Cultures, resources, systems and processes within health and social care empower staff to exercise their skills in providing good care for people and families, and to care *about* the people and families they work with.

4. Towards Terminological and Conceptual Clarity

What Is Palliative and End of Life Care?

Three formal and widely referenced definitions of Palliative Care, Children's Palliative Care and End of Life Care are shown in Appendix 1. Despite the existence of these definitions public and professionals remain unclear about the meaning of the terms.

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 holistic 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 and dying – 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.

Palliative care includes, but is *not exclusively about,* end of life care. End of life care is that part of palliative care which should follow from the diagnosis of a patient entering the process of dying, whether or not he or she is already in receipt of palliative care. There can be uncertainty involved in identifying when someone is dying – illness can be unpredictable, and change can occur suddenly and unexpectedly. The term 'end of life care' is used by different people to mean different things, since this phase could vary between months, weeks, days or hours in the context of different disease trajectories. The English End of Life Care Strategy used the term to mean care in the last year of life (though what turns out to be someone's last year of life is something which can only be identified in retrospect).

Who Provides Palliative Care?

Much of the care that people receive when their health is deteriorating could be termed **general palliative care**, being provided by health and social care professionals to people living in the community, in care homes and in hospitals. This may be part of the work of a range of health and social care practitioners including GPs, district nurses, home care workers, care home staff and hospital staff. It is palliative care regardless of whether someone has cancer, organ failure or “old age”, or whether they are living at home, in a hospice, in a care home, a neonatal ward or in an ITU. Palliative care can and should be delivered alongside curative care where that is appropriate.

Specialist palliative care can help people with more complex palliative care needs (e.g. complex pain management or psychological support), and is provided by specially trained multi-professional specialist palliative care teams who are generally based in a hospice or NHS specialist palliative care unit, but whose expertise should be accessible from any care setting.

Though the care and expertise provided by formal services is essential, it is important to remember that most care is provided by carers, family, friends and community.

Who Needs Palliative Care?

Over 40,000 people in Scotland each year could benefit from palliative care. Most people with palliative and end of life care needs are aged 65+ and a rapidly increasing proportion of deaths occur in people aged 85+. However some babies, children and young people also have palliative and end of life care needs. These different life stages bring distinct contexts, challenges and needs.

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 for as long as possible the autonomy to choose from the options that are available.

Opportunities to explore personal preferences

Planning ahead for declining health increases the likelihood that a person will receive the kind of care they would want. Therefore, recent 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 the *opportunity* to do so. 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

Without honest information, individuals and families are ill-equipped to make decisions. Health care and social care professionals need to be honest about their expectations for a person’s health, what uncertainties are involved, what support will be reliably available, and any limits there might be to the support provided.

Conversations About Palliative and End of Life Care

The timing and content of discussions which include recognition of mortality need to be responsive to the needs, circumstances and preferences of each and every individual. It is important to understand and respect the different ways people cope with serious illness. Some people want detailed information and to plan ahead. Others find this too distressing and want to focus on managing from day-to-day. Skilled communication allows such people to hope whilst planning 'just in case'. Such conversations should not be one off events and incremental exploration and update of changing circumstances and priorities is important.

A range of different events (e.g. frequent hospital admission, admission to a care home, a deterioration in health) should prompt health and care professionals to consider the need for such a conversation. The SPICT www.spict.org.uk is a tool designed to help patients, professionals and carers to recognise signs of poorer health and help prompt discussions.

Ideally such conversations should occur where there is time and privacy, and take place with a professional familiar with the individual and their family. Thus primary care and general practice have an important role. However, since admission to hospital following deterioration is very common staff in the acute sector also have a key role, and hospital specialists may be well placed to inform discussion about prognosis. All staff involved in the person's care have a responsibility to know what conversations have taken place and not to assume that it is the role of others.

Anticipatory care plans exist to record the outputs of discussions and (where shared) to inform further discussion with other professionals and to inform the care provided.

5. Current Access to Palliative and End of Life Care

Current access is very variable and there is huge scope for improvement. The type of condition someone has significantly influences where they are cared for, their referral pathways, who funds their support and accommodation, and therefore overall, the support they can access. People with cancer are much more likely to get the palliative care support they need than people with non-malignant conditions (including frail older people with multi-morbidities and dementia), and this applies both to specialist palliative care and generalist palliative care support. Marginalised groups in society also tend to have worse access (e.g. people experiencing homelessness, prisoners, people with learning disabilities).

It is estimated that 40,000 people with palliative care needs die in Scotland each year. At March 2013 around 11,800 people were on palliative care registers in General Practice. Most people on these registers were added a relatively short time before they died and most of them had cancer. Late identification (and referral) is a major issue. In November 2013 there were 8,979 Key Information Summary (KIS) records that were marked as palliative. 47 per cent of residents of care homes for older people had an anticipatory care plan at the point at which they died (2013).

Data is not readily available to evidence the development of services or the improvement of actual outcomes. *Living and Dying Well: Reflecting on Progress* (SG 2012) noted some of the achievements associated with the implementation of *Living and Dying Well*. Awareness of palliative care as an approach relevant regardless of diagnosis has probably increased. The numbers of patients on palliative care registers has increased. Anticipatory prescribing has been rolled out in many NHS Boards. The quality of end of life care in hospitals was supported and generally improved through work on the LCP or equivalent pathways. The development of the ePalliative Care Summary and subsequent KIS has provided a nascent ICT infrastructure to support sharing of information across settings.

6. Barriers to Palliative Care and End of Life Care

The key barriers to consistent access to palliative and end of life care are:-

- A cultural reluctance to think and talk about death, dying and bereavement. This leads to low levels of knowledge and awareness about end of life issues and underpins failure to discuss and plan for supporting wellbeing during declining health and for end of life care. People often don't understand why it could be beneficial to think and talk about these issues and opportunities for discussion are limited.
- Professional and public beliefs that palliative care is terminal care only of relevance and benefit shortly before death, and primarily of relevance to people with cancer (or other diseases with relatively predictable trajectories).
- Inadequate provision of general palliative care in general settings due to i) a failure to identify that a person has palliative care needs ii) a lack of staff understanding of palliative care and their role in providing it iii) a lack of confidence/skills and a very human fear of causing distress iv) insufficient linkage with specialist support and advice.
- Inadequate co-ordination between different parts of the health and social care system, and patient and family difficulties in navigating the system. This includes current challenges in accessing and updating the KIS record in different settings across different IT platforms. It is also important to highlight the challenges of communicating nuanced conversations and complex circumstances through a (brief) written record.

7. Improving Palliative Care and End of Life Care Including Equitable Access

The following actions are recommended to improve palliative and end of life care in Scotland:-

- Invest in professional and public awareness/education programmes which increase knowledge of the ways to cope with the practical, legal, financial, social, emotional and medical issues associated with death, dying and bereavement. This should include but not be limited to increasing public and professional understanding of palliative care. The programmes should promote and model greater openness about all these issues. Politicians and other leaders should model openness. Good Life, Good Death, Good Grief www.goodlifedeathgrief.org.uk is leading work in this area which should be scaled up.

- Build the skills and confidence of generalist staff to provide palliative care by taking a structured and comprehensive approach to training and education which ensures that all health and social care staff involved in the care of people who may have palliative care needs are equipped with competencies appropriate to their role. In terms of scale and scope the dementia *Promoting Excellence Framework* is one model of how this might be approached. Death, dying and bereavement should also be embedded in the undergraduate education of health and social care staff. There are lots of good educational resources (and examples of excellent educational partnerships between hospices and other providers), but staff find it difficult to get time to access them.

- Further develop anticipatory care planning, with a rigorous emphasis on the quality of discussion. Improve the ICT infrastructure supporting KIS so that the outcomes of discussions can be shared across settings and rapidly updated.

- Develop more rapidly responsive models of support in the community to avoid unnecessary/undesired hospital admission and to facilitate discharge.

- Identify or develop sources of the data required to underpin improvement of palliative care in Scotland; for local improvement, for performance management, for quality assurance, to assess current and future needs, to characterise patterns of service use (including inequalities), and patterns of resource use. Most importantly develop measures of outcomes which are meaningful to patients, families and the wider public.

- Increase the availability of age-appropriate services for children and young adults together with effective processes for transition.

- Increase the capacity of specialist palliative care to better support generalist services through:-

    - 24/7 advice

    - Better access to specialist assessment

    - Education and training in all settings

    - Development of models of joint working with other specialties (in non-malignant disease)

- Most palliative care is provided within generalist settings of the health and social care system and so wider systemic issues impact on the quality of palliative care which people experience. Key requirements include:-

    - Terms and conditions of employment which support better recruitment, retention and skills/knowledge development in the social care sector. Care homes for older people, for example, support residents with typically high levels of need and 22% of people die in a care home.

    - Adequate capacity in general practice/primary care to support sensitive conversations, continuity and co-ordination of care.

    - Adequate capacity (and environment) to provide palliative and end of life care in very busy acute hospital wards. Often dying at home will not be possible (or ultimately desired) by the patient/family, so there is a need to consistently enable ways of dying in hospital which reflect elements of a “homelike” experience (privacy, peace, contact with loved ones, connections to meaningful memories).

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Appendix 1 - Three Formal and Widely Referenced Definitions for Palliative Care, Children's Palliative Care and End of Life Care

The World Health Organisation (WHO) defines **palliative care** thus:

"Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- *provides relief from pain and other distressing symptoms;*
- *affirms life and regards dying as a normal process;*
- *intends neither to hasten or postpone death;*
- *integrates the psychological and spiritual aspects of patient care;*
- *offers a support system to help patients live as actively as possible until death;*
- *offers a support system to help the family cope during the patient's illness and in their own bereavement;*
- *uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;*
- *will enhance quality of life, and may also positively influence the course of illness;*
- *is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications."*[1]

WHO has a separate definition of **palliative care for children**

"Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998a):

- *Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.*

- *It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.*

- *Health providers must evaluate and alleviate a child's physical, psychological, and social distress.*

- *Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.*

- *It can be provided in tertiary care facilities, in community health centres and even in children's homes."*[2]

The General Medical Council defines **end of life care** as the care provided to patients who are approaching the end of life stating that:-

"patients are 'approaching the end of life' when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with:

a. advanced, progressive, incurable conditions
b. general frailty and co-existing conditions that mean they are expected to die within 12 months
c. existing conditions if they are at risk of dying from a sudden acute crisis in their condition
d. life-threatening acute conditions caused by sudden catastrophic events."[3]

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[1] http://w http://www.who.int/cancer/palliative/definition/en/

[2] http://www.who.int/cancer/palliative/definition/en/

[3] http://www.gmc-uk.org/guidance/ethical_guidance/end_of_life_guidance.asp