

**National Implementation Advisory Group for the Strategic
Framework for Action on Palliative and End of Life Care
Wednesday 13 December 2017**

**Near final draft advice note on commissioning of palliative and end
of life care – for discussion**

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For information _____

For discussion **X** _____

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STRATEGIC COMMISSIONING OF PALLIATIVE AND END OF LIFE CARE

ADVICE NOTE

This advice note has been prepared to support the Statutory Guidance for Strategic Commissioning Plans and should be read along-side the statutory guidance.

December 2017

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Introduction and purpose of this Advice Note

All Integration Authorities (Partnerships) completed their Strategic Commissioning Plans by 1st April 2016. These had variable focus on palliative and end of life care, which are delegated functions to each Partnership. This advice note should inform future iterations of strategic commissioning plans, and any specific plans developed by Partnerships in respect of palliative and end of life care.

This advice note has been prepared to support the existing statutory guidance on strategic commissioning plans¹ and the localities guidance² and is focused on palliative and end of life care.

In December 2015, the Scottish Government published the Strategic Framework for Action on Palliative and End of Life Care (SFA), which set out the aim that by 2021 everyone in Scotland who needs palliative care will have access to it. The Strategic Framework for Action includes outcomes and ten commitments to support improvements in the delivery of palliative and end of life care across Scotland. The second of these reads 'We will provide guidance to support Health and Social Care Partnerships with the development of the content of their Strategic Commissioning plans in relation to palliative and end of life care services'. This advice note meets this commitment.

Why Palliative and End of Life Care matters

There are many reasons for having a focus on palliative and end of life care services and supports.

- There is a compelling and growing body of evidence that effective support at end of life, and investment in supporting people at home can have a major beneficial impact on balance of care indicators, the quality of care, and prevent unwarranted hospital admission.
- In an era of Realistic Medicine³ and realistic care, this area of work ought to be at the forefront of a new approach to person-centred decision making, based on the core question 'What matters to you?' - and then staying loyal to agenda the person sets.⁴

¹ <http://www.gov.scot/Publications/2015/12/7436>

² <http://www.gov.scot/Publications/2015/07/5055>

³ <http://www.gov.scot/Resource/0049/00492520.pdf>

⁴ <https://www.nuffieldtrust.org.uk/research/exploring-the-cost-of-care-at-the-end-of-life>

- We are united by our common mortality and humanity, and only get one chance to get it right for someone at the end of life. When we do get it right it is typically by working with everyone involved to provide holistic, multi-disciplinary and person centred care and support.

Important considerations for strategic commissioning

There are a number of key considerations when planning, designing and commissioning palliative and end of life care, including the following:

- Improving the early identification of those with palliative care needs, as a gateway to establishing support in line with what matters to the person.
- Having conversations about '[What Matters to Me](#)' with those affected, leading to a shareable plan – most often an Anticipatory Care plan. Currently the only universally available infrastructure to support this sharing is the Key Information Summary (KIS). We now know that having a key information summary is associated with reduced bed-days for people at the end of life⁵.
- Gaining an understanding about consumption patterns and variation locally, drawing on the ever developing person-linked data arrangements (which make use of routinely-gathered information) to systematically identify opportunities to support people's pathways of care, so that where they wish to be enabled to live and die well at home or in a homely setting, they can be.
- National and local reports are regularly produced which offer specific and often helpful additional analysis on the basis of surveys etc, which may also be useful.

⁵http://spcare.bmj.com/content/early/2016/04/13/bmjspcare-2015-001014?utm_source=TrendMD&utm_medium=cpc&utm_campaign=SPC_TrendMD-1

Four dimensions of palliative care

In assessing needs, and planning how those needs will best be met sustainably, the four dimensions of palliative care should always be considered. Attending to the spiritual, social and psychological are not optional extras, and doing so may impact positively on the physical supports a person needs.



Palliative care involves all these dimensions. Meeting the vision set out in the Strategic Framework for Palliative and End of Life Care, that all who need it should have access to it by 2021 – is not a simple task. Partnerships should also regard palliative and end of life care as encompassing all illnesses, all times, all settings and all dimensions.

National Policy Context

Health and social care integration puts people and not services at the centre of commissioning decisions, and is a core aspect of public service reform in Scotland. Planning, designing and commissioning services in an integrated way, from a single budget, allows Partnerships to take a joined-up approach, making it easier to shift shifting resources to target preventative activity and to ensure people get the right care and support for their individual needs. Services and supports should be seamless and responsive to the people who use them - where possible enabling them to stay at home or in a homely setting within their communities. This is particularly important when commissioning palliative and end of life care services and supports.

Health & Social Care Integration: Our Vision

“Let me be clear about the objectives of this programme of reform. We want to ensure that adult health and social care services are firmly integrated around the needs of individuals, their carers and other family members; that the providers of those services are held to account jointly and effectively for improved delivery; that services are underpinned by flexible, sustainable financial mechanisms that give priority to the needs of the people they serve rather than the needs of the organisations through which they are delivered; and that those arrangements are characterised by strong and consistent clinical and professional leadership.”

Nicola Sturgeon, MSP, Deputy First Minister and Cabinet Secretary for Health and Wellbeing, December 2011

The Scale and Growth of Need for Palliative and End of Life Care

Partnerships are increasingly routinely using data to inform their strategic commissioning activity, and have developed a good awareness and understanding of their local data from which to plan how best to meet the needs of people requiring palliative and end of life care.

In 2016/17 there were about 54,000 deaths in Scotland, a figure set to rise slightly to just over 60,000 by 2037. Around 75% of these people will have needs arising from living with deteriorating health for the years, months or weeks before they die.

Despite the majority of people expressing a preference to die at home, in 2016/17 only 45% of died in their usual place of residence (26% at home and 19% in care homes). Although hospital is the least preferred place of death, 48% of deaths occurred in hospital, and just 6% in a hospice or palliative care unit.

Proximity to death has a major effect on partnership budgets:

- Each year, about 15% of partnership budgets are spent on people dying in that year;
- By far the largest contributor to this is unplanned hospitalisation, with 25% of unplanned bed days every year being used by those who go on to die;
- 15% of residential care budgets are spent on people at the end of life.
- 29% of all acute bed days are used by people in their last year of life

There is evidence that many people at the end of life receive non-beneficial treatments through hospitalisation which could have been appropriately provided through community-based care, providing improved outcomes, and at lower cost. Enabling people to live and die well on their own terms, at home or in a homely setting will likely be the locus for innovation, as new approaches to the design and provision of sustainable new models of care are developed.

It is also estimated that each death will have a significant impact on around four other people, who may in turn have bereavement support needs.

As set out in 'Realistic Medicine' an increased focus on conversations about what matters to people, and the associated shared decision making should reduce overtreatment at the end of life, and along with better coordinated care, increase the proportion of people enabled to spend more time in their last six months at home.

In addition to the aging population requiring support, medical advances have also led to an increasing need for palliative and end of life care for babies, children and young people, who are now able to live far beyond the historical life expectancy of those born with life limiting conditions.

Health and Social Care Delivery Plan

The Scottish Government Health and Social Care Delivery Plan which was published in December 2016 sets out a blueprint for achieving this vision and emphasises the importance of reducing health inequalities and treating people closer to home.

Partnerships will make the key contribution to achieving the overarching aim of the Strategic Framework for Action on Palliative and End of Life Care and the more specific action set out in the Health and Social Care Delivery Plan:

By 2021, we aim to: Ensure that everyone who needs palliative care will get hospice, palliative or end of life care. All who would benefit from a 'Key Information Summary' will receive one – these summaries bring together important information to support those with complex care needs or long-term conditions, such as future care plans and end of life preferences. More people will have the opportunity to develop their own personalised care and support plan. The availability of care options will be improved by doubling the palliative and end of life provision in the community, which will result in fewer people dying in a hospital setting.

Responsibilities of Partnerships for Adult and Children's PEOLC

Public Bodies (Joint Working) (Scotland) Act 2014 requires as a minimum that adult health and social care is delegated. Partnerships are best placed to understand any consequences arising from the specific arrangements which apply in their area, especially regarding any functions delegated beyond the minimum requirements.

The palliative care of children and young people is supported with funding from the Scottish Government for the next five years. In 2017/18 the commissioning of Children's Hospices Across Scotland has been managed through NHS Lothian, and arrangements for future years are being established.

Children's Hospices Across Scotland (CHAS) works closely with the relevant networks for children and young people's services and aims to ensure palliative care services, including children's hospice services, are

integrated and working closely together. These networks include the National Managed Service Network for Children and Young People with Cancer and the National Managed Clinical Network for Children with Exceptional Health Care Needs. Work on refining commissioning arrangements in each integration Authority area is on-going.

How PEOLC contributes to the Health & Wellbeing Outcomes

Integration legislation established 9 National Health and Wellbeing Outcomes and 23 indicators were subsequently developed, which form the basis of the reporting requirement for Partnerships to their local communities..

There are two indicators (15 and 23) which have explicit links with palliative and end of life care – but all of the outcomes and indicators are considered as important as each other, and so the suite needs to be considered as a package, not a set of individual unrelated indicators, with many of them contributing to good outcomes for people at the end of life⁶. Improvement in other outcome indicators will contribute to improvement on indicators 15 and 23 – for example ‘the percentage of adults supported at home who agree that their services and support had an impact in improving or maintaining their quality of life’ (indicator 7) will impact on the proportion of the last six months spent at home or in a community setting.

One example which brings these threads together comes from Glasgow.

Fast Track Palliative Care Service Glasgow HSCP

This service has been rolled out city wide in the last year. The aims are to meet patients’ needs identified during Anticipatory Care Planning (ACP) conversations; increase the proportion of care provided to palliative patients in a homely setting; and support improvements in palliative care for patients in acute hospitals as set out in *‘The strategic Framework for Action on Palliative and End of Life Care.*

The service is delivered by Marie Curie and it has worked with acute hospitals, hospices and the HSCP to create a referral pathway, which involves supporting discharge at the end of life by providing comprehensive practical and emotional support for patients & carers; and preventing palliative care patients being unnecessarily admitted to hospitals or hospices when they want to remain at home. The numbers of patients supported by the service and the estimated impact in terms of avoiding unplanned acute bed days is shown below.

Indicator	Actual
Number of Patients	556
Number unplanned acute bed days avoided by preventing admissions	4440
Number unplanned acute bed days avoided by facilitating discharge	14,961

Notes: Estimate based upon dates of death and dates of admission/discharge from the service.

⁶ <http://www.gov.scot/Resource/0047/00473516.pdf>

While not being the only factor, the service will have contributed to the reduction in the proportion of deaths which take place within acute hospital settings, which relates to the national aim of supporting more people in the community in the last 6 months of their lives. The percentage of deaths occurring in acute hospitals has been consistently falling over the last few years and this has continued during 2016/17. Rates fell from 46.4% in 2013/14 to 39.8% in 2016/17 (aged 65+) and from 46.5% to 39.7% (aged 75+).

Data

The Strategic Framework for Action on End of Life and Palliative Care includes a commitment on improving data capture and usage. This is linked with the support provided by the Local Information Support Team and the use of 'Source', which brings together information on health and social care, to assist Partnerships with planning and commissioning locally.

The collaborative work to develop datasets, undertaken by the NIAG data group and LIST analysts, will support partnerships in their commission cycle, which in turn will facilitate the provision of effective palliative and end of life care.

Work to include KIS data amongst the linked data sets is on-going, and routine data drawn from KIS and whatever replaces it is likely to be of increasing significance for establishing both quality and quantity in the provision palliative and end of life care, in line with the aim of all being able to access it by 2021.

Issues of Equality

The needs of groups of people who experience variation in outcome should be specifically identified. These groups include:- homeless people, prisoners, people with mental health problems, people with learning disabilities, people living alone, prisoners, and LGBTI people.

The approach to engaging with people who use services and supports should include both those listed above and those currently at the end of life.

Palliative and End of Life Care Staffing

A unique feature for all staff across all settings providing elements of palliative and end of life care is how the degree of comfort they have in regard to their own mortality will shape the care they are able to offer people as they approach death.

The Learning and Development Framework for Palliative and End of Life Care was published in the spring of 2017, and should be viewed in the context of the wider workforce strategy.

Other Linked Policies

This advice note relates specifically to strategic commissioning of Palliative and End of Life Care, but this has a number of interactions with other policy areas, which are also supportive of people along a pathway of care, ranging from anticipatory care planning and dementia, to frailty and funeral poverty.

The strategic commissioning process should take account of these policies and support people's ability to make informed choices and have control over their care and support, enabled with flexible responses, supportive of them having a decent quality of life and enabling them to live and die well, on their own terms, where possible at home or in a homely setting, making the best use of communities and their assets.

Public Health approaches to Palliative Care

An overarching population health and wellbeing approach that encompasses more than health and social care services is helpful, and it should harness the capacities and capabilities of families, friends and local communities.⁷⁸ Informal and unpaid carers provide the greatest share of support to people at the end of life, and support for these carers will be affected by forthcoming regulations under the Carers Act and these will set timescales for the preparation of a young carer statement or adult carer support plan where a person being cared-for is considered to be terminally ill. Volunteers also play a significant role and support for them should also be taken into account.

One example of this overarching population approach is Compassionate Inverclyde.

Compassionate Inverclyde Inverclyde HSCP

Compassionate Inverclyde is an innovative, multi-agency, community-wide initiative which aims to build a compassionate community in Inverclyde by encouraging an ethos that end-of-life is the responsibility of the whole community and not just one part of it (such as the NHS).

A number of agencies are signed up to Compassionate Inverclyde, including:

- the HSCP
- Inverclyde Council
- carers
- third sector organisations
- Police Scotland
- the independent care sector
- community representatives
- faith organisations and others.

The programme is led by Ardgowan Hospice. There are many strands to the

⁷ www.goodlifedeathgrief.org.uk

⁸ <https://www.scotphn.net/projects/palliative-and-end-of-life-care-pelc/palliative-and-end-of-life-care-pelc-2/>

initiative, including No One Dies Alone (NODA which is in the process of development and will focus heavily on deploying and training volunteers to develop community led responses to palliative care. It is envisaged that Compassionate Inverclyde will contribute to the Acute Service Review. A successful launch of the initiative was held at the Beacon Arts Centre in March 2017 which was opened by the Scottish Governments' Communities Minister, Aileen Campbell.

To date the initiative has been unfunded and has developed through the voluntary efforts and in-kind contributions of the partner agencies, but represents another example of working together for better outcomes.

Working definitions of Palliative and End of Life Care and bereavement.

For the purposes of this advice note, **palliative care** is understood as being the provision of 'good care' to people whose health is in irreversible decline or whose lives are coming to an inevitable close. Such 'good care' is different because a person's mortality has started to influence clinical and/or personal decision-making. Such care attends to the physical, spiritual, psychological and social wellbeing of people in those circumstances.

Specialist Palliative Care can help people with more complex palliative care needs where the focus of care is on quality of life, and who have unresolved complex needs that cannot be met by the capability of their current care team. It 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. Specialist palliative care has a particular role in providing support, advice and education to the rest of the health and care system.

Generalist palliative care is non-specialist palliative care, provided in any setting including acute. In the community it often involves primary care – supporting people and their carers either at home or in care or nursing homes. The care people receive towards the end of life in community settings will often not be fully recognised as 'palliative care'.

End of Life Care is that part of palliative care which should follow from the diagnosis of a person entering the process of dying, whether or not he or she is already in receipt of palliative care. This phase could vary between 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.

Bereavement is understood as 'the entire experience of family members and friends in the anticipation, death, and subsequent adjustment to living following the death of a loved one'⁹, and **bereavement care** may be defined as any care provided formally or informally, through statutory or voluntary services or by members of the community to those affected. The needs for support will apply to those affected by both expected and unexpected loss and death.

Bereavement Support

Pre and post death bereavement support should be taken account of in the needs assessment and commissioning planning.

Delivery and Planning Partners

The statutory guidance states that 'those involved in the strategic commissioning process need to develop their skills in working with a range of partners including the independent and third sector, along with service users and their carers to build and implement commissioning priorities'. In the context of palliative care, in addition to the support of hospices, this will likely include care home and care at home providers.

Hospices

Hospices have historically led the development and provision of palliative care. Their specialist expertise is also often crucial to a Partnership's capacity to provide generic palliative and end of life care, either directly or through training. They also typically are able to attract high numbers of volunteers, and generate significant levels of charitable income from their communities.

It is important that hospices are involved in the strategic commissioning process for palliative and end of life care, in order to influence and inform commissioning decisions. This relationship is reciprocal, as the same process will inform what is required from hospices, including in-patient hospice and community based care, which hospices have been moving increasingly to support and provide.

One example of the contribution hospices can make, from Strathcarron Hospice

⁹ Parkes, C. and R. Weiss, *Recovery from bereavement*. 1983. New York: Basic Books.

Strathcarron Hospice@Home

Susan was already known to the Strathcarron Community Clinical Nurse Specialist, so her symptom control was being assessed regularly. She was referred to Hospice@Home for carer support and personal care. She had refused personal carers, and her husband was not coping. The Hospice@Home nurse had significant conversations with Susan and discussed her personal wishes regarding resuscitation, and her concern that her husband Tom wasn't coping. We helped with her last wishes and also helped her plan her funeral - it was reassuring to her husband that, although the funeral was very simple, it was exactly as she wished.

We helped her husband understand what to expect at the end, and why Susan no longer wanted to eat or drink. We provided pre-bereavement counselling for Tom and complementary therapies for both of them, which they found helpful. We taught Tom how to provide personal care for Susan, and helped with some practical care for him after her death.

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Support for Developing Commissioning Plans

The [Scottish Partnership for Palliative Care \(SPPC\)](https://www.palliativecarescotland.org.uk/)¹⁰ plays a particular role as a focal point, bringing 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. It is significantly funded by the Scottish Government and its membership to fulfil this role with other funding coming from its member organisations, which span all settings and statutory, voluntary and independent sectors.

Partnerships should also consider other national resources which provide guidance regarding high quality, safe and effective palliative and end of life care.

These resources include:

- [National Care standards](#)¹¹
- [Scottish Palliative Care Guidelines](http://www.palliativecareguidelines.scot.nhs.uk/)¹²
- SIGN Guidelines, which include guidance on palliative care for specific conditions such as [as heart failure](http://www.sign.ac.uk/assets/sign147.pdf)¹³
- NICE [Guidance on end of life care](https://www.nice.org.uk/guidance/qs13)¹⁴ and [End of life care for infants, children and young people](#)¹⁵ amongst others
- [Clinical Standards for Specialist Palliative Care \(2002\)](#)¹⁶
- [NHS England Specialist Level Palliative Care: Information for commissioners April 2016](https://www.england.nhs.uk/wp-content/uploads/2016/04/specilst-palliatv-care-comms-guid.pdf)¹⁷
- The [NES palliative care community of practice website](#)¹⁸

Healthcare Improvement Scotland and in particular the ihub and the ['Living Well in Communities'](#)¹⁹ work stream focuses on key areas of health and social care that can prevent unnecessary admission to hospital and enable people to remain at home or in a homely setting, with support from their family and the community. The current work streams include palliative and end of life care alongside anticipatory care planning, frailty and falls in the community, intermediate care and reablement, and neighborhood care. Their forward work-plan is likely to be increasingly shaped by the needs and demands of Integration Authorities.

¹⁰ <https://www.palliativecarescotland.org.uk/>

¹¹ <http://www.newcarestandards.scot/>

¹² <http://www.palliativecareguidelines.scot.nhs.uk/>

¹³ <http://www.sign.ac.uk/assets/sign147.pdf>

¹⁴ <https://www.nice.org.uk/guidance/qs13>

¹⁵ [End of life care for infants, children and young people](#)

¹⁶ http://www.healthcareimprovementscotland.org/previous_resources/standards/specialist_palliative_care.aspx

¹⁷ <https://www.england.nhs.uk/wp-content/uploads/2016/04/specilst-palliatv-care-comms-guid.pdf>

¹⁸ <http://www.knowledge.scot.nhs.uk/pceducation.aspx>

¹⁹ ['Living Well in Communities'](#)