



Strategic Commissioning of Palliative and End of Life Care by Integration Authorities

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



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Introduction and Purpose of this Advice Note

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.

All Integration Authorities¹ (hereafter referred to as 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 plans](#)² and the [localities guidance](#)³, and is focused on palliative and end of life care (PEOLC).

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.

- Getting health and social care right for people is a vital aspect of Partnerships' role in planning, commissioning and delivery, and this is especially important towards and 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 personalised care and support .
- There is also emerging evidence that people provided with **early palliative care and support** in all settings had better outcomes, with a better quality of life, fewer depressive symptoms, and on average live longer, even when opting less for curative (and often futile) treatment⁴. Effective support at end of

¹ An **Integration Authority** can be a local authority, a health board or an integration joint board, according to the model of integration adopted. It covers both models of integration whether body corporate (IJB) or lead agency. An **Integration Joint Board** is the decision making and governance body for all delegated functions, services and budgets, identified in individual integration schemes. It is a statutory body, constituting a separate legal entity to local authorities and health boards. A **Health and Social Care Partnership** is led by a Chief Officer and is the operational and delivery aspect of integration, bringing together staff from the relevant health board and local authority.

² <http://www.gov.scot/Publications/2015/12/7436>

³ <http://www.gov.scot/Publications/2015/07/5055>

⁴ <http://www.nejm.org/doi/pdf/10.1056/NEJMoa1000678>

life and investment in supporting people in all settings, but especially at home, can have a beneficial impact on balance of care indicators, the quality of care, achieving place of death, as well as preventing unwarranted hospital admission⁵.

- In an era of Realistic Medicine⁶ and realistic care, this area of work should 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 the agenda the person sets.⁷

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:

- Understanding the mortality rates and patterns for populations within your Partnership and beyond, and the profile of advanced or long-term conditions that underpin that.
- Understanding consumption patterns and variation locally, drawing on the person-linked data through [Source](#)⁸, which makes use of routinely-gathered information to systematically identify opportunities to support and improve people's pathways of care - so that, that no matter which setting a person is in when they are dying, they have the benefit of effective and high quality PEOLC. This requires a whole system approach, where anyone who wishes to die at home, as far as possible, is supported to do so – and where those who do not wish to die at home benefit from care that has as many elements of home as is practical, person centred and meets their needs.
- Each Partnership will want to be clear about their accountability for the commissioning and delivery of PEOLC to those who need it and to ensure the full breadth and depth of those needs can be met. This may be aided by the identification of a lead person for both PEOLC and for bereavement care, for the Partnership, where such arrangements are not already in place.
- 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. Such conversations, to support shared decision making, are featured in the Chief Medical Officers' annual report '[Realistic Medicine](#)'. Currently the only available infrastructure capable of supporting such sharing is the Key Information Summary (KIS) and we now know that having a key information summary is associated with reduced bed-days for people at the end of life⁹.

⁵ <http://spcare.bmj.com/content/early/2016/04/13/bmjspcare-2015-001014>

⁶ <http://www.gov.scot/Resource/0049/00492520.pdf>

⁷ <https://www.nuffieldtrust.org.uk/research/exploring-the-cost-of-care-at-the-end-of-life>

⁸ <http://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Health-and-Social-Care-Integration/Analytical-Outputs/>

⁹ <http://spcare.bmj.com/content/early/2016/04/13/bmjspcare-2015-001014>

Working Definitions of Palliative and End of Life Care and Bereavement.

Definitions for palliative and end of life care are the subject of on-going debate. However, for the purposes of this advice note, the World Health Organisation definition of [palliative care](#)¹⁰ is used.

Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.

Again, for the purposes of this note some further explanation may be helpful.

Non-specialist care and support are the types of care which most people will receive as their health and well being declines. Such care is provided to people living in the community, care homes and in hospitals, by professionals across health and social care, and may be an integral part of the fabric of the 'compassionate communities' in which people live. Such care, which although frequently not identified as palliative care, can and should be delivered alongside active treatment, where this is appropriate. Such care can be delivered with varying degrees of specialist palliative support throughout the health and social care system.

Specialist Palliative Care can help people with more complex palliative care needs. It is provided by specially trained multi-professional 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, without which other forms of care and support would not be sustainable.

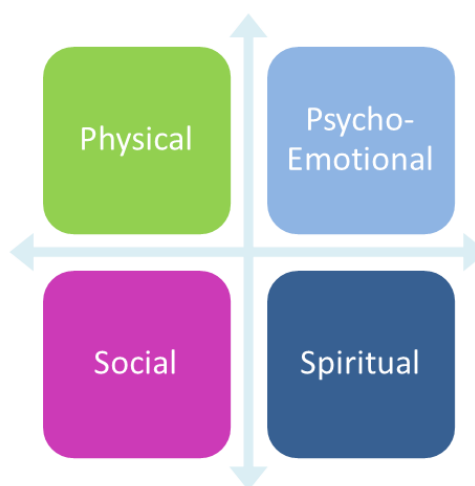
End of Life Care – or care of the person living through the dying phase of life - is that part of palliative care which should follow from the recognition that a person is entering the process of dying, and there is a high likelihood of them dying over the next few hours, days or weeks, whether or not he or she is already in receipt of palliative care. This phase could vary between weeks, days or hours, and with less predictability particularly in the context of COPD or other organ failure scenarios in such cases – illness can be unpredictable, and changes can occur suddenly and unexpectedly. It is helpful to address populations' needs around end of life care, and not assume it is covered by dealing with palliative care.

¹⁰ <http://www.who.int/mediacentre/factsheets/fs402/en/>

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’¹¹, 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.

Four Dimensions of Palliative Care

In assessing needs, and planning how the full breadth of those needs will best be met sustainably, the four dimensions of palliative care should always be considered. Attending to the spiritual, social and psycho-emotional in addition to the physical 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 (i.e. from diagnosis to bereavement) and all settings. There are many elements of continuity with the services and supports required by people as they become frail or seek to live well with their long term conditions.

¹¹ Parkes, C. and R. Weiss, *Recovery from bereavement*. 1983. New York: Basic Books.

National Policy Context

Health and social care integration puts people 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 resources to target preventative activity, and to ensure people get the right care and support for their individual needs. As at other stages of life, services and supports should be seamless and responsive to the people who use them. These will often call for effective and purposeful periods of admission to acute settings, to deal with emergent needs, and collaborative approaches across settings – but wherever possible and desired enabling people to stay at home or in a homely setting within their communities. This collaborative approach, with good integrated working to deliver high quality care, is particularly important when commissioning palliative and end of life care services and supports, as discontinuity of care across settings is a frequent cause of distress.

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 for PEOLC and emphasises the importance of reducing health inequalities and treating people closer to home. For the integration aspects of the delivery plan, the Ministerial Strategic Group (MSG), which provides joint political oversight for integration through Ministers and COSLA, has sought Partnerships to share key data and local objectives in order to gain an overview of progress with integration across the Partnerships. This work includes local objectives for improving PEOLC.

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.

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 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 PEOLC.

In 2016/17 there were about 57,000 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.

Much of this need will be met by families, informal carers, primary care, community nursing, care at home and in care homes; this palliative care may not be identified as palliative, and good supportive care will be required irrespective of the setting of that care or whether people are on a curative or a palliative treatment pathway.

However, while a death in hospital may be entirely appropriate, a significant majority of people express a preference to die at home. Where possible, appropriate and in line with the person's preferences, treatments should be provided through community-based care, rather than in hospital.

In 2016/17 only 45% died in their usual place of residence (26% at home and 19% in care homes). Around 48% of deaths currently occur in hospital, and 6% in a hospice or palliative care unit.

The spend on people close to death can have a major effect on Partnership budgets:

- On average 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;
- 29% of all acute bed days are used by people in their last year of life.

We expect to see a continuing shift in the numbers of people enabled to die at home or in a homely setting, which should contribute to improved outcomes and reduction in acute hospital costs.

In late 2016 Scottish Care sought to capture the experience of workers providing palliative and end of life care. The resulting report 'Tree's that bend in the wind' set out the findings of this enquiry. 'Care workers play a crucial role in someone's palliative and end of life care journey. They are often the people that know the needs and wishes of individuals best, and who can recognise and communicate changes to the rest of the person's professional and personal support network. They can make the difference between someone having a "good" death or a "bad" death through the solace they offer, whether for a few hours or a few years'¹².

There is some evidence that many people receive non-beneficial treatments, without having been informed of other possible care options, including being cared for at home. These other options may also have been more in keeping with their wishes at the end of life, had they been explored and made available.

Each death will have a significant impact on around four other people, who may in turn have bereavement support needs. How the people close to the person who has died experience their death, and the days leading up to it, will also impact on their bereavement

Partnerships' Responsibilities for Adult and Children's PEOLC

The Public Bodies (Joint Working) (Scotland) Act 2014 requires as a minimum that adult social care, community health care and a proportion of hospital based 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 (CHAS) has been managed through NHS Lothian, and arrangements for future years are being established.

Due to medical advances babies born with life shortening conditions frequently live for far longer than their peers from earlier generations. There is therefore an increasing need for a focus on good palliative and end of life care for babies, children and young people.

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 with each Partnership is ongoing.

¹² <http://www.scottishcare.org/scottish-care-news/scottish-care-launches-new-report-on-palliative-and-end-of-life-care/>

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 PEOLC – but all of the outcomes and indicators are considered as important as each other, therefore the suite of indicators need to be considered as a package, with many of them contributing to good outcomes for people at the end of life¹³. So improvement in outcome indicator 7 ('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 contribute to improvement on indicators 15 and 23 – '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 – which also represent precious days spent at home, if that is what the person wants - 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.

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+).

¹³ <http://www.gov.scot/Resource/0047/00473516.pdf>

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, LGBTI people and those with poor health outcomes arising from poverty and deprivation.

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 Staff Development

A unique feature for all staff across all settings providing elements of PEOLC 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 quality of the provision of PEOLC is sustained through support for staff by capacity building, education and training - and a commitment to person-centred care. Such provisions should meet both general and specialist PEOLC needs.

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.

Using the Learning and Development Framework for Palliative Care

A test of change started August 2017 involving the Prince and Princess of Wales Hospice and Thistle Health Southview Care Home. The aim for this approach was to invest in a culture of **collaboration** across the sectors in Glasgow that are delivering PEOLC, and to identifying gaps and improve practice.

The educational leads for the two organisations **used the** domains from the Learning and Development Framework to **undertake a scoping exercise**, mapping the existing and future educational palliative care resources **each has to meet the challenges of supporting and providing appropriate 'workforce' learning and development needs across** front line nursing assistant staff and care home front line staff **respectively**.

Results from this mapping will help them to compare skills and experience across these staff groups. Early results show clear similarities in the skills and experience enabling them to support palliative and end of life care. The care home staff report more autonomous decision making and more provision of non-medical care of the dying.

Care Planning, Palliative Care, and Other Linked Policies

Care planning acts as a common thread along the whole pathway of care and is vital to the planning and delivery process. Good conversations about what matters, between people (and with those that matter to them) and the team that supports them, recorded in a sharable format, should enable the team to remain loyal to that plan. This of course applies to palliative and end of life care, but also applies to Self Management Support, Dementia Care, Self Directed Support, Shared Decision Making and so on.

Data generated from care planning is a significant and developing source of information for supporting commissioning decisions. The strategic commissioning of palliative and end of life care should take account of these other related areas of policy and delivery. A focus on care planning will help in safeguarding people's ability to make informed choices and have control over their care and support. This in turn will help in enabling them to live and die well, on their own terms, where possible at home or in a homely setting, and make the best use of their communities and their assets.

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 (LIST) 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 National Implementation Advisory Group (NIAG data sub-group and LIST analysts, will support Partnerships in their commissioning 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.

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.

In 2016 the Scottish Public Health Network, Dr David Gray of the Accord Hospice, (ScotPHN) and a group of front line staff within Renfrewshire Health and Social Care Partnership (HSCP), used the Source data and existing local services and supports to map and develop a protocol for using routinely available data to examine, at individual level, the health and social services and support use in the last year of life of adults in their HSCP area. Detailed supporting papers are available¹⁴.

¹⁴ <https://www.scotphn.net/projects/palliative-and-end-of-life-care-pelc/palliative-and-end-of-life-care-pelc-2/>

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, those partners may come from all the settings set out below, though care homes and particularly care at home services together with community nursing and other community based services, are recognised as playing a very significant role in enabling people to stay in their homes and communities, and this community focus is only set to increase.

Extension of Community Health Outcomes and Highland Hospice

ECHO is a tool and approach for mentoring (or 'tele-mentoring') as well as building a mutually supportive community which has been used by Highland Hospice. They have found it vital for supporting community palliative care in which there are many lone workers faced with often extremely challenging situations.

The methodology developed by the ECHO project, over the 12 years since its inception in New Mexico, is being applied across the world in a wide variety of health care specialties. ECHO has been pioneered in the UK by Prof. Max Watson and the Northern Ireland Hospice¹⁵. The Hospice now administers and facilitates 29 different ECHO groups of which palliative care makes up only a small proportion.

Highland Hospice currently run three ECHO groups for Macmillan Cancer and Palliative Care Nurse Specialists, Care Homes and Out of Hours Emergency and Unscheduled Care Practitioners with a fourth for Community Pharmacists about to start. They have plans for groups for GPs with responsibility for care homes or community hospitals and Community Nurses.

¹⁵ <https://www.kingsfund.org.uk/sites/default/files/media/Max%20Watson%20slides.pdf>

Palliative Care Services

Palliative care is provided through a mix of inter-dependant specialist and non-specialist services.

Specialist Palliative Care

Specialist Palliative Care Services provide care directly, support others in provision of PEOLC clinically through advisory roles, and provide out of hours support across all settings in health and social care. Such services are often well integrated into their local communities and provide leadership related to PEOLC. The majority of specialist palliative care services also provide a broad range of education and training to support local populations and professionals in provision of palliative care. Such services provide an accessible resource that can be drawn upon when care needs require more than standard approaches.

Specialist palliative care services often include an in-patient unit which in many settings will be the local hospice, but will have a wide range of services including – out patient reviews, day care, community support services and hospital care services.

It is important that specialist palliative care services are involved in the strategic commissioning process for PEOLC, in order to influence and inform commissioning decisions.

Hospices and Specialist In-Patient Units

Many Partnership areas will have specialist services and these will often be hospices. Such specialist services have been used as hubs from which other services can be supported. Some specialist services do not have this model, and they provide in-patient care from within designated areas of a hospital, whilst others operate with a day care or community model.

Hospices have historically led the development and provision of palliative care. Their specialist expertise has often supported non-specialist services at the end of life, .

They may have also provided

- Direct care in all settings
- Support for care through advice, discussion and advisory reviews in all settings
- Out of Hours support
- Education and training across all settings and professional groups
- Leadership

Hospices also typically are able to attract high numbers of volunteers, and generate significant levels of charitable income from their communities.

As stated above, involving palliative care specialists in the strategic commissioning process for PEOLC will be important. 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 wider contribution hospices can make, from Strathcarron Hospice

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 showed Tom how to provide personal care for Susan, and helped with some practical care for him after her death.

Hospitals

Hospitals typically serve the communities they are set in. PEOLC is one of the key components of hospital care. It is known that on given day in Scotland:

- Around 30% of people admitted to hospital are likely to be in the last year of life,
- 90% of these emergency admissions lead to return to community setting,
- 10% will die in the hospital setting; and
- Overall the majority of deaths occur in the hospital setting in Scotland.

For many of those admitted the hospital admission may be the time when they are diagnosed with the illness that will lead to their death, or when the progression of existing conditions is identified and discussed.

Arrangements for transitions of care between hospital, home, hospice, community hospital and care home should be established so that they are robust, clear and purposeful.

Hospital and Community Based Collaboration and Coordination of Care.

A young woman with long term disabilities and lung disease admitted to hospital with pneumonia. Her breathing was so poor support in a medical high dependency unit was required. She had recovered from such episodes before. On this occasion, it became clear that recovery seemed unlikely, and the medical team spoke with her and her parents about end of life care. She had expressed clearly that she wished to be at home and not in hospital should she be dying. She needed a level of oxygen support that meant that moving out of a high dependency environment would not be possible without sudden decline. In conjunction with the hospital palliative care service, and in discussion with the young woman and her family, medications were used to ease the sense of discomfort from breathlessness. Over a day this allowed for a tapering off of the ventilator support. In parallel the team and her family spoke with her community team, and plans were made for her transfer home, understanding that during the journey itself there was a high risk of death occurring. She and her family knew and trusted her community team. Appropriate medications were provided and prescriptions completed in advance of discharge on the 24th of December. Her community nurse stayed with her and the family at home - and she was able to be at home for a short time prior to her death.

Non-specialist Care

Most palliative care is provided by non-specialists, in non specialist settings, and will usually not be identified as 'palliative'. The focus on community provision – in which social care and care provided by families and carers are the major contributors - will be ever more significant. The coordination of care across settings and services is central to the strategic framework for action on palliative and end of life care. Partnerships will be aware of the variety of local support which work together to provide the required care. The relevant community services and supports will include:

- Care homes
- Care at home
- Community nursing services
- GPs.

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. *Good Life Good Death Good Grief* has been funded by the Scottish Government to provide a hub supporting the development of practice in this area.^{16 17} 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.

¹⁶ www.goodlifedeathgrief.org.uk

¹⁷ <https://www.scotphn.net/projects/palliative-and-end-of-life-care-pelc/palliative-and-end-of-life-care-pelc-2/>

One example of this overarching population approach is provided by 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:

- Inverclyde 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 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.

Support for Developing Commissioning Plans for Palliative and End of Life Care

The [Scottish Partnership for Palliative Care \(SPPC\)](https://www.palliativecarescotland.org.uk/)^[1] plays a particular role running network functions which connect health and social care professionals from hospitals, social care services, primary care, hospices and other charities, to find and share ways of improving people's experiences of declining health, death, dying and bereavement. SPPC is significantly funded by the Scottish Government and its membership to fulfil this role, and its activities aim to offer to support PEOLC in all settings, across statutory, voluntary and independent sectors.

Partnerships should also consider other national resources which provide guidance regarding high quality, safe and effective PEOLC.

These resources include:

- [Health and Social Care Standards](http://www.newcarestandards.scot/)¹⁸
- [Scottish Palliative Care Guidelines](http://www.palliativecareguidelines.scot.nhs.uk/)¹⁹
- SIGN Guidelines, which include guidance on palliative care for specific conditions such as [heart failure](http://www.sign.ac.uk/assets/sign147.pdf)²⁰
- NICE [Guidance on end of life care](https://www.nice.org.uk/guidance/qs13)²¹ and [End of life care for infants, children and young people](https://www.nice.org.uk/guidance/qs160)²² amongst others
- [A Road Less Lonely - Moving forward with public health approaches to death, dying and bereavement in Scotland \(2018\)](https://www.palliativecarescotland.org.uk/content/publications/A-Road-Less-Lonely-WEB.pdf)²³
- [The NES and SSSC - Education and Development framework and an introductory learning resource](https://learn.nes.nhs.scot/2450/palliative-and-end-of-life-care-enriching-and-improving-experience)²⁴
- Resources developed as part of the [Learning Disabilities and Palliative Care Project](https://www.ldpcproject.co.uk/)²⁵

Healthcare Improvement Scotland, and in particular the iHUB and the ['Living Well in Communities'](http://ihub.scot/a-z-programmes/living-well-in-communities/)²⁶ 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.

[1] <https://www.palliativecarescotland.org.uk/>

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

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

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

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

22 <https://www.nice.org.uk/guidance/qs160>

23 <https://www.palliativecarescotland.org.uk/content/publications/A-Road-Less-Lonely-WEB.pdf>

24 <https://learn.nes.nhs.scot/2450/palliative-and-end-of-life-care-enriching-and-improving-experience>

25 <https://www.ldpcproject.co.uk/>

26 <http://ihub.scot/a-z-programmes/living-well-in-communities/>



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This publication is available at www.gov.scot

Any enquiries regarding this publication should be sent to us at
The Scottish Government
St Andrew's House
Edinburgh
EH1 3DG

ISBN: 978-1-78851-861-1 (web only)

Published by The Scottish Government, May 2018

Produced for The Scottish Government by APS Group Scotland, 21 Tennant Street, Edinburgh EH6 5NA
PPDAS43518 (05/18)