

Caring for people in the last days and hours of life

National Statement

Caring for people¹ in the last days and hours of life National Statement

In December 2013 the Scottish Government accepted the recommendation that the Liverpool Care Pathway (LCP) should be phased out in Scotland by December 2014. This statement confirms the current position.

Health and Care providers across Scotland are committed to the provision of consistently high quality end of life care for all that reflects the 4 principles set out in the guidance '*Caring for people in the last days and hours of life*' published at the end of 2013 -

Principle 1: Informative, timely and sensitive communication is an essential component of each individual person's care

Principle 2: Significant decisions about a person's care, including diagnosing dying, are made on the basis of multi-disciplinary discussion

Principle 3: Each individual person's physical, psychological, social and spiritual needs are recognised and addressed as far as is possible

Principle 4: Consideration is given to the wellbeing of relatives or carers attending the person.

That Guidance and associated principles are now confirmed as the framework for further planning and development at a local level across Scotland.

Purpose

The purpose of this statement is to:

- support NHS Boards and all health and care providers develop, test and implement identification, assessment and care planning materials, policies and guidance to deliver consistently high quality care for all in the last days and hours of life.
- suggest that NHS Boards and all health and care providers use the driver diagram as set out at **Annex A** to begin to assist with thinking about change and improvement actions to support this work.
- provide an update on the work being taken forward by NHS Education Scotland (NES) to establish a portal within the NES Clinical Knowledge

¹ All those in the last days and hours of life including adults, young adults and children

Publisher to access this Guidance. Further portal development work will enable local resources and examples to be posted and shared.

- describe some of the actions being taken centrally and locally to support further improvements in the quality of end of life care.

This statement can be used by stakeholders as the framework within which to further plan and develop local identification, assessment and care planning materials, policies and guidance for the provision of care in the last days and hours of life ahead of completing the phasing out locally of the use of the Liverpool Care Pathway at the end of 2014.

A copy of the full Guidance document can be accessed at <http://www.scotland.gov.uk/Publications/Recent>

Scope

The target audience for this statement is health and social care staff involved in providing care for people in the last days and hours of life and their families. Adhering to the principles will support staff in the provision of good care for people in the last days and hours of life. The principles highlight essential areas of care for teams to address when caring for dying people and those close to them.

This statement is also available to members of the public.

Taking Action

In December 2013, the Scottish Government accepted the recommendation from the *Living and Dying Well* National Advisory Group that the Liverpool Care Pathway (LCP) should be phased out in Scotland by December 2014. The collective aim of all health and care providers across Scotland is the provision of consistently high quality end of life care for all that reflects the principles. The drivers to achieve this aim are to build on and further develop education and training materials for the public and health and care professionals, improvement activities and scrutiny in this area working with patients/carers and the public, NHS Education for Scotland, Healthcare Improvement Scotland, NHSScotland, Care Inspectorate, Local Authorities, independent and third sector providers of health and care services.

This statement can be used by health and care providers to form part of their narrative supporting change, improvement and governance. The guidance is focused around an aim of providing care in the last hours and days of life, where all care needs are identified and effectively addressed through responsive and holistic care planning, reflecting the agreed principles of high quality care. The primary drivers of consistently achieving this aim are:

People will receive the information that they need and feel sufficiently informed and supported to make decisions.

People approaching the end of life and their families and carers are offered information, in an accessible and sensitive way in response to their needs and preferences and feel sufficiently informed about what they wish to know and supported to make decisions about their care.

Care is co-ordinated effectively across all settings, clinical and care disciplines and includes a focus on carers and relatives wellbeing.

This will mean that care is coordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the person's current medical condition, care plan and preferences.

Assessment and care planning focus is holistic, anticipates and supports personalised action that meets all needs.

This recognises that people approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment.

People closely affected should receive support that is appropriate to their needs and preferences.

Delivering consistently high quality care is only possible when people are communicated with in a sensitive way, are offered immediate and ongoing emotional and spiritual support appropriate to their needs and preferences including bereavement support.

The links between aim and proposed primary drivers is outlined at Annex A. This driver diagram also proposes some secondary drivers that contribute to implementation of high quality care in the last days and hours of life. This is reproduced to illustrate the way in which NHS Boards and providers of care might wish to develop their local change packages and improvement actions in a way that is informed by nationally agreed principles and the aim of care provision at the end of life.

Actions

Whilst a lot of progress has been, made more can be done. Some of the actions and next steps being taken by organisations centrally and locally to help further improve the quality of end of life care is set out in the table below.

Table

Role	Actions
Patients/Carers/ Public	Stronger Voice The Cabinet Secretary for Health and Wellbeing, Alex Neil MSP, announced at the NHS event in June that: “we must do more to listen to, and promote, the voices of those we care for. We need the voices of our patients, those receiving care and their families, to be heard in a much clearer and stronger way”.

	<p>The Scottish Government’s ambition is to ensure that our services are co-produced with the communities they serve, build on people's assets and support the health and wellbeing of the whole person and their family. We believe this can only be achieved by creating a much stronger voice for people and communities using services.</p> <p>This voice will be focused on improving outcomes, and it will have a key role in driving the future shape of health and social care services, both nationally and locally. Proposals for the Stronger Voice are being developed in a partnership involving the Scottish Government, Healthcare Improvement Scotland, the Scottish Health Council, COSLA and the ALLIANCE, and will be brought forward by the end of the year.</p> <p>More information on the Stronger Voice is available on the Scottish Health Council website.</p> <p>Patient/Carer Experience</p> <p>There are various systems and methods in place across NHSScotland that capture ‘real time’ information relating to people’s experiences of local systems. Healthcare Improvement Scotland has developed a measurement framework for use by local teams involved in the Person-Centred Health and Care Collaborative, which includes measures that support teams to drive improvement in real time and develop a deeper understanding of what is working well and what needs to be improved.</p> <p>The key <i>surveys</i> about quality of health care services are the National Patient Experience Surveys.</p> <p>Public Engagement</p> <p>The Scottish Partnership for Palliative Care and Scottish Government are currently mapping out how best to support the public engagement work required, to help further inform and contribute to the development of future work in this area. This will likely include utilising already existing NHS Board Public Involvement mechanisms and consideration of any targeted approach.</p>
<p>Health and Care Providers</p>	<p>NHS Boards/Independent Hospices</p> <p>NHS Boards and other health and care providers have been developing local assessment and care planning materials, policies and guidance. Some NHS Boards and Hospices have shared centrally the work they have been doing and this has been collated. NHS Education Scotland has established a portal within the NES Clinical Knowledge Publisher to access this Guidance. Further portal development work will enable local resources and examples to be posted and shared. This can be accessed at http://www.ckp.scot.nhs.uk/ScottishGovernmentGuidanceEndofLifeCare/?id=1045</p>

<p>Leadership</p>	<p>Palliative and End of Life Care National Advisory Group A new Palliative and End of Life Care National Advisory Group (NAG) met for the first time in November 2014.</p> <p>The core NAG will be supported by a wider Stakeholder Group. This group will be facilitated by the Scottish Partnership for Palliative Care.</p> <p>The Scottish Government will work with the new NAG in supporting key stakeholders to set out how they can apply the ‘Three Step Improvement Framework for Scotland’s Public Services’ to the changes that they identify in support of the strategic framework².</p> <p>NHS Board Palliative and End of Life Executive leads A national meeting of NHS Board Palliative and End of Life Care Executive Leads was held at the end of September 2014 to help establish new arrangements to support engagement and leadership in this area.</p>
<p>Quality Improvement/Best Practice</p>	<p>Clinical Guidelines – Healthcare Improvement Scotland Palliative care clinical guidelines in Scotland have been developed and are available via the Healthcare Improvement Scotland (HIS) website. These provide practical, evidence based or best practice advice on the management of pain, symptom control, palliative emergencies and end of life care in a readily usable format.</p> <p>They help to provide the evidence base for improvements in palliative care services across all health and care settings. It is recognised that publication of these guidelines is not an end in itself. Work needs to continue to explore how best to design and develop measurement and quality improvement capacity nationally and locally linked to the content of the guidelines.</p> <p>HIS is developing a light touch process to ensure the currency of these guidelines in the future</p> <p>Anticipatory Care Planning/Conversation Ready Three Scottish NHS Boards have been working throughout 2014 as test sites with the Institute for Healthcare Improvement (IHI). The context for this work is framed by caring for people in the last days and hours of life guidance and the 4 principles. They have developed local improvement projects working within 5 core IHI project principles to:</p> <ul style="list-style-type: none"> • engage with people and families to understand what

² The 3-step Improvement Framework for Scotland’s public services accessible at <http://www.scotland.gov.uk/Resource/0042/00426552.pdf>

	<p>matters to them at the end of life;</p> <ul style="list-style-type: none"> • steward this information in a reliable way; • respect peoples wishes for care at the end of life by developing shared goals of care; • exemplify this work in our own lives to understand the benefits and challenges; and • connect in a manner that is respectful of each person and their family <p>This work is due to report towards the end of 2014/early 2015 and, together with other improvement work ongoing across Scotland, will be shared widely.</p> <p>Measurement The importance of data in order to measure improvements and change practice is well recognised. Work is underway, led by Healthcare Improvement Scotland to identify a Palliative and End of Life measurement framework that links to existing national improvement programmes of work e.g. deteriorating patient; cardiac arrest and person-centred programmes.</p>
<p>Education and Training</p>	<p>Work with colleagues from NHS Education for Scotland and education providers across Scotland to build on and develop education and training for palliative and end of life care.</p> <p>Caring for People in the Last Days and Hours of Life Guidance is easily accessible to staff via the NES Clinical Knowledge Publisher website (available at http://www.ckp.scot.nhs.uk/ScottishGovernmentGuidanceEndofLifeCare/?id=1045) along with associated links to education and learning materials. This will help embed this work in the improvement agendas being pursued locally.</p>
<p>Scottish Government</p>	<p>The Scottish Government has agreed to support the development of a <i>Strategic Framework for Action</i> providing a renewed focus to further support high quality palliative and end of life care.</p> <p>The development of the <i>Strategic Framework for Action</i>, will be linked with the 2020 Vision for Health and Social Care, ensuring that the Scottish Government’s commitment to high quality palliative and end of life care for all is clear to everyone.</p>

Caring for People in the Last Days and Hours of Life

All care needs are identified and effectively addressed through responsive and holistic care planning

People receive the information they need and feel sufficiently informed and supported to make decisions

Information is provided to support what matters most to people and to support decision-making.

Clarification on what matters most, expectations and wishes for end of life care inform communication.

Communication and the focus of the team is informed by needs for information and support for decisions.

Care is co-ordinated effectively across all settings clinical and care disciplines (and includes a focus on carer and relative wellbeing)

There are effective mechanisms to identify and recognise last days and hours of life.

Ensure that care is provided in a manner that is consistent with care plan, wishes and desired setting.

Ensure that dialogue, decisions and communication is recorded and shared across teams.

Assessment and care planning focus is holistic, anticipates and supports personalised action to meets all needs

Identify, assess and review care needs across all domains.

Actions to ensure comprehensive assessment and care across all domains are identified and implemented.

Essential elements of care delivery for nutrition, hydration, managing uncertainty are implemented.

Carers and families are involved with care planning through listening, involvement, support, advice and information about end of life care and after death.

CARING FOR PEOPLE IN LAST DAYS & HOURS OF LIFE – Driver Diagram

- NHSScotland is committed to provision of consistently high quality end of life care for all that reflects **key principles** and ensures careful consideration of the **approach to be taken** to address key issues of nutrition, hydration, recognition of imminent death and communication.
- The name of the lead clinician should be clear to everyone at all times

All actions within the national guidance are focused on delivery of an overall aim where all people's care needs are identified and effectively addressed through responsive and holistic care planning. The statement of this aim will allow local teams to review care and determine the extent to which this is being delivered. Teams will want to set 'how much by when' aims statements and outline the local measures that are in place to identify if changes locally are resulting in the improvements desired. The proposed primary drivers can be used to identify tests of change and improvement actions that will contribute to learning about how best to consistently deliver the aim for everyone during the last days and hours of their lives.

Staff may find it helpful to refer to the summary below, which outlines the way in which the principles underpinning the guidance are supported by some key actions, which if taken consistently, will contribute to high quality care.

PRINCIPLES

Principle 1: Informative, timely and sensitive communication is an essential component of each individual person's care

- Information provision
- Elicit and clarify expectations
- Discuss wishes & care goals/plan
- Support team communication

Principle 2: Significant decisions about a person's care, including diagnosing dying, are made on the basis of multi-disciplinary discussion

- Team recognition of last days or hours of life
- Ensure appropriate interventions consistent with care goals/plan
- Ensure care provided in desired setting
- Record decisions and communicate these

Principle 3: Each individual person's physical, psychological, social and spiritual needs are recognised and addressed as far as is possible

- Recognise, anticipate and meet care needs in all domains
- Assess, review and plan care in all domains – daily review
- Include assessment of key symptoms
- Consider need for specialist palliative care advice
- Ensure decisions are documented
- Explain decisions to family

Principle 4: Consideration is given to the wellbeing of relatives or carers attending the person.

- Explanation, preparation and support for death – listening to worries and fears
- Ongoing support, practical advice and information essential after a death
- Explain content of death certificate and provide chance to ask questions
- Provide information about support to cope with bereavement

APPROACH TO BE TAKEN

Nutrition and Hydration

- Support people to eat and/or drink
- Ensure good mouth care at all times
- Decisions must always be communicated and explained to family and carers

Recognising Uncertainty

- Ensure open discussion of uncertainty
- Consider risks and make sure on-going monitoring and team discussion takes place

Communication

- Remember to focus on condition, expectations of change, wishes and agreed care goals
- Discussion about signs of imminent death and enabling preferences re presence at time of death
- Regular communication within and between teams supports continuity and ensures information is accurate for people and their family



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The Scottish Government
St Andrew's House
Edinburgh
EH1 3DG

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