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Guidance
Caring for people in the last days and hours of life

The Scottish Government
Riaghaltas na h-Alba

Guidance

Caring for people in the last days and hours of life

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Any Comments/Enquiries should be addressed to david.leslie@scotland.gsi.gov.uk

Foreword

In December 2013 the Scottish Government accepted a recommendation that the Liverpool Care Pathway (LCP) should be phased out in Scotland by December 2014. This Guidance and 4 principles are now confirmed as the framework to support the continuous planning, development and improvement underway at a local level across health and care settings in Scotland.

NHS Education Scotland has placed this guidance along with the 4 principles on the Clinical Knowledge Publisher portal for ease of access. This is available at http://www.ckp.scot.nhs.uk/ScottishGovernmentGuidanceEndofLifeCare/?id=1045. This new development also provides an opportunity for sharing examples that capture local learning and resources. I would encourage all NHS Boards to upload local material and make connections with colleagues across Scotland. Further information about how to upload local material is available at Sections 3 and 5 of this Guidance

During the past year palliative and end of life care policy development has been rapidly developing. The importance of leadership, measurement and support for implementation and improvement has been recognised.

Earlier in the year the Scottish Government committed to the development of a Strategic Framework for Action for Palliative and End of Life Care. This new Framework will be published in Spring 2015 and will be informed and shaped through contributions from everyone with an interest in continuously improving the quality of palliative and end of life care in Scotland. This work will be significantly influenced by the improvement-focused model as outlined in our '3-Step Improvement Framework for Scotland's Public Services'.

New clinical guidelines designed to improve the care of people with life limiting illnesses – NHSScotland Palliative Care Guidelines - were published in November 2014. These updated guidelines reflect expert opinion about good practice in the management of adults at the end of life (including but not restricted to last days and hours of life) and provide practical, evidence-based or best-practice guidance on a range of common clinical issues including pain management, symptom control, palliative care emergencies, end of life care and use of medicines. These clinical guidelines can be used by health and care staff in conjunction with the guidance and 4 principles set out in this document and are available to access at:
http://www.healthcareimprovementscotland.org/news_and_events/news/news_palliative_care.aspx

I had the pleasure of Chairing the first meeting of the newly established National Advisory Group for Palliative and End of Life Care in November – an important first step in establishing the conditions for future work. The Scottish Partnership for Palliative Care will be developing and refining their approach to deliver enhanced arrangements for engagement with a wider professional/patient/public stakeholder group. This will be an essential element to inform and influence the focus and future work of the National Advisory Group.

Colleagues and I at Scottish Government look forward to working with people whose lives are affected by the issues covered in this guidance, with the new National Advisory Group and a wide range of organisations, clinical and care staff to support this work.

Although I, of course, welcome the opportunity to commend this guidance document to you, I recognise that issuing guidance does not mean that the required actions outlined within it will automatically take place every time this should happen.

This will require support for leadership, measurement and tailored local arrangements to support change and improvement. It will also act as a source of information for colleagues across Government and public services, outlining the principles to inform care delivery and providing the basis for educational and improvement support resources to be targeted as required.

Mechanisms to support learning and to test/refine our understanding of how to reliably implement this guidance is therefore vital. I would therefore encourage you to share learning, feedback and any proposed information that will be helpful to support implementation – you can do this by emailing david.leslie@scotland.gsi.gov.uk

This guidance can then be updated, amended and linked with resources to reflect new insights into how to make this happen for everyone in the last days and hours of their lives.

Professor Craig White
Chair, National Advisory Group for Palliative and End of Life Care
Divisional Clinical Lead
The Quality Unit
Scottish Government Health and Social Care Directorates

Purpose of this document

In December 2013 the Scottish Government accepted the recommendation that the Liverpool Care Pathway (LCP) should be phased out in Scotland by December 2014. The national statement published today confirms the current position as set out below.

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 this guidance '*Caring for people in the last days and hours of life*[1]'

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.

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

Scope of this document

The principles set out within this document are applicable in all care settings.

There can be uncertainty involved in identifying when someone is dying – illness can be unpredictable, and change can occur suddenly and unexpectedly. This is an important consideration highlighted within the principles in *section 1*. This document is designed to provide guidance relating to the end of life, where 'end of life' is defined as '*when the team caring for the person agree that death is expected within hours to days and a natural death*[i] *is occurring with all possible reversible causes having been considered*'.

How to use this document

This document does not provide detailed instructions or a list of steps to be taken. Each individual person is different. The principles in this document should inform the thinking which is necessary to provide person centred care which meets the needs of each individual person.

Staff can be confident that they are providing good care for people who are in the last days and hours of life by:

- adhering to the principles set out within *section 1* of this document; *and*
- ensuring their care takes into account the uncertainty involved in identifying if someone is dying,
- understanding the importance of sensitive and clear communication with people and their families,
- understanding the role of hydration and nutrition at the end of life, as explained within *section 2; and*

- following locally recognised good practice guidance on end of life care (*section 5)*, and/or the good practice guidance referenced within *section 3* of this document; *and*
- directing people and families to relevant information, as referenced within *section 4* of this document.

Section 1: Principles

Adhering to the principles below 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.

For each of the four principles, this document provides a rationale explaining why it is important, and gives examples (but not a definitive list) of some steps that can be taken to facilitate good care in the last days and hours of life.

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

Sensitive communication must take place with the person (where possible), family, any welfare attorney and those close to the person. This communication should include the person's condition, expectations relating to how their condition is likely to change, the wishes of the person and their family including preferred place of death, and agreed goals[ii] for the care that will be provided. This communication must acknowledge any uncertainties that may be involved in predicting what is likely to happen and should reassure families that regular review will form a core part of the care provided. Significant changes in the person's condition should be communicated as quickly as possible. Communication between staff about the person's changing condition and management plan at any transition or handover of care between teams is essential.

Rationale:

When someone is unwell, those close to that person will want to know what is happening - so they can provide appropriate help and support to that person and to others affected by the person's illness, and so they can prepare for what is likely to happen next. Professionals caring for the person will want to find out about the person's wishes and preferences from those close to the person if the person is no longer able to communicate about these. Good communication between health and social care professionals is key to ensuring that any changes to a person's condition are recognised and responded to by the staff with current responsibility for the person's care.

Examples of steps that should be taken and documented to support principle 1:

- Sensitive conversations should be undertaken with the person (where possible) and family that include psychological support, and capturing the person's and family wishes, including preferred place of death. These must include a sensitive and informative explanation about the individual person's needs relating to artificial nutrition/fluids (by drip or feeding tube) as they approach the end of their life, and how these will be addressed. This is distinct from food and drinks which the person will be supported to take as able and wanted. (See also section 2.1).
- The person (where possible) and family should know who is the lead clinician responsible for the person's care. This should be a named person at senior level.
- The family should be made aware of arrangements for contacting the team providing care.
- A clear and structured approach should be used in any communication between teams if the person is transferred from one place of care to another. The Situation Background Assessment Recommendation (SBAR) communication tool[iii] is one example of such an approach.

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

Agreement that a person’s death is expected within hours to days must be based on a multi-disciplinary discussion about the person’s condition which recognises that diagnosing dying involves an element of uncertainty. Responsibility for decisions reached is carried by the senior clinician responsible for the care of the person.

Rationale:

Diagnosing dying can be highly complex, and the perspectives of the different professionals involved in the person’s care are essential to ensure that a person is accurately identified as being in the last days to hours of their life. Making this diagnosis will result in not continuing any medical interventions that are inappropriate. The circumstances, care needs and wishes of each individual person need to be considered in deciding which interventions are inappropriate. This consideration should include the balance of burden and benefit to the person of each intervention and the contribution of each intervention to the overall goals of care. The focus of care will shift towards interventions that keep the person comfortable. Identifying that a person may be in the last days to hours of life also allows the team to focus on any preferred place of death identified by the person and begin rapid plans to achieve this aim if appropriate and possible. Team discussion enables all members of the team to understand the reasons for the change in focus of care, and to sensitively and informatively communicate this to the family. It is also essential that all members of the team recognise that diagnosing dying involves an element of uncertainty, so regular ongoing monitoring of a person’s changing condition and needs should continue.

Examples of steps that should be taken and documented to support principle 2:

- A plan for managing the person’s condition should be made. This should include a record of decisions made by the multi-disciplinary team, including explanation of reasons for a diagnosis of dying, and any decisions to stop or not begin medical interventions which are considered to be of no benefit to the person.

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

People who are dying must be cared for with respect and dignity with their needs anticipated and managed by competent staff. Symptom management is a priority for staff when caring for a dying person and there should be ongoing assessment, review and care planning relating to a person’s needs in the four domains - physical, psychological, social and spiritual.

Rationale:

The needs of the person must always be the prime consideration when planning and providing care, and this applies equally to the last days and hours of life as to other times:

'You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.' *Dame Cicely Saunders, Founder of the Modern Hospice Movement.*

People have more needs than their physical needs.

Examples of steps that should be taken and documented to support principle 3:

- Agreed individualised goals of care should be documented and reviewed at least daily.
- The person’s preferred place of care should be identified and achieved if possible.
- The outcome of any ward round or multi-disciplinary discussion should be clearly documented in the case record.
- Key symptoms such as: pain; agitation; breathlessness; nausea & vomiting; and respiratory tract secretions, should be assessed and any intervention documented in the case record.
- When symptoms are not controlled and are resistant to interventions then help should be sought from specialist palliative care.
- Individual assessment regarding nutrition/fluids should be clearly documented (see also section 2.1 of this document).
- The outcome of any intervention, and of any subsequent action should the intervention fail to meet a person’s needs, should be clearly documented in the case record.
- The resuscitation status of the person should be reviewed, so that it is clear what should happen when death / cardiac arrest occurs (see national Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) policy). For a person who is recognised to be imminently dying in days or hours, an explicit discussion about the fact that cardiopulmonary resuscitation will not be attempted when their heart stops may risk causing unnecessary distress to them and/or their family and can seem inappropriate and irrelevant to them. Communication should focus on ensuring that the family are aware that death is expected in days or hours and that even when a person is in their last days, death can sometimes happen more suddenly than expected. Families should be reassured that whether the death happens gradually and predictably or with a very sudden deterioration the person’s comfort and dignity will be the priorities. They should know that staff will communicate to ensure that the right care happens and that unhelpful or potentially harmful treatment is avoided whenever the person dies.
- Flexible visiting should be made available to the person’s family and friends.
- Any outstanding psychological and social issues causing distress for the person and their family should be identified and addressed where possible.
- The person’s religious and/or spiritual needs must be identified and contact made with relevant individuals who may be in a position to support the person and family if they wish.
- The person should be treated with respect and dignity whilst last offices are undertaken (where relevant).

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

It is important to recognise that the last days and hours of a loved one’s life will be a distressing time for family members and others who are close to the person. Staff should recognise and respect this, both before and after a person has died, and support families accordingly.

Rationale:

Bereavement care is an integral part of good care, and is relevant both before and following the death of a person. Lasting memories of what happened around the time of death can stay with those who have been bereaved for many years and can support or hinder them in their adjustment to the death. Preparing people to face the approaching death of a loved one will help them to cope after the death has occurred. When a person dies, the care does not end and that continuing duty of care should be recognised. Practical advice and support is also important in this process. [iv]

Examples of steps that should be taken and documented to support principle 4:

- Staff should listen and respond to worries and fears.
- Supportive conversations with relatives and/or carers before and after the death of the person should take place, and information provided explaining the next steps.
- What is written on the death certificate should be explained when it is given to the family, answering any questions and checking for understanding.
- Bereavement information packs should be provided.

Section 2: Three Specific Areas of Importance

The report *More Care, Less Pathway* highlighted concerns about cases of inadequate care in the last days and hours of life for some people and families in England. Most of these cases were chiefly related to three issues. In providing good care in the last days and hours of life it is very important therefore to give these specific issues careful consideration:

1. Nutrition and hydration in the last days and hours of life
2. Recognising the uncertainty of a diagnosis of dying
3. Communication with people and families and between staff

These issues have already been mentioned in the previous section. Further brief information is provided below which is designed to reinforce key messages relating to these three areas.

2.1 Hydration and/or Nutrition

Those who are able to eat and/or drink (including thickened fluids) should be supported to do so, unless they choose not to. They should be monitored for signs of aspiration/choking or distress.

Good mouth care remains important during the last days and hours of life.

Decisions about the use and/or discontinuation of artificial hydration (i.e. drips and subcutaneous injections) must be based on consideration of the needs and circumstances of the particular individual person. Different people may have different needs (and these needs may change over time) and so there is no simple default which can be adopted. The best interests of the person should always be paramount.

The reasons for decisions and/or changes should be promptly communicated and carefully explained to family and carers. For example, where a drip is not started or is withdrawn because fluid is building up in the lungs of the person, it is important to explain carefully to the family that, as the process of dying continues, the body does not need the same amount of fluid and usually cannot cope with extra fluids from a drip. The family should be supported to understand that fluid from a drip can start to build up in the body including the lungs and make breathlessness worse, which is distressing for the person. Decisions to start or continue artificial hydration in the last days and hours of life must always be communicated with an acknowledgement that it will be reviewed and discontinued if it causes problems for the person.

2.2 Recognising the uncertainty of a diagnosis of dying

Diagnosing dying can involve an element of uncertainty. Whether or not a person is dying, and also how long it may be before they die, can be difficult to predict accurately, reliably and consistently. This uncertainty should be recognised by staff and should inform how care is provided.

Sometimes it may be uncertain whether an intervention aimed at reversing a deterioration in a person’s condition may work. Depending on the wishes and preferences of the individual person, it may be appropriate to continue with some treatment interventions, recognising that the person may die if there is no response to treatment, whilst at the same time addressing any symptoms (e.g. pain, breathlessness) as well as psychological, spiritual and social needs.

It is important that communication with the person and their family includes open discussion of this uncertainty and clear acknowledgement by all of the risks associated with initiating or continuing with interventions aimed at reversing deterioration. Risks such as pain, side-effects or missing the opportunity to die in the preferred place of care must be explained in the context of this uncertainty.

Ongoing monitoring of a person's condition should take place. The care provided for the person should reflect their changing needs, based on regular assessment and team discussion.

2.3 Communication with people and families and between staff

Sensitive communication should take place with the person (where possible), family and those close to the person. This communication should include the person's condition, expectations relating to how their condition is likely to change (including the likelihood of their dying), the wishes of the person and their family (including preferred place of death), and the agreed goals of care that will be provided.

It may be helpful to make the family aware of certain physical signs that may occur as the person deteriorates and signs that can indicate death is very imminent. Family members who wish to be present at the time of death must be identified and enabled to attend if possible. However, it is important to emphasise to the family that sometimes death can happen without any further warning.

Communication between staff about the person's changing condition and management plan at any transition or handover of care between teams is essential. In addition to ensuring continuity of care, such communication also allows staff to provide up to date information to the person (where possible) and family.

Section 3: Guidance

Across Scotland, local resources exist to support the provision of good care to people in the last days and hours of life. This is being placed on the NHS Education Scotland newly established Clinical Knowledge Publisher portal that focusses on palliative and end of life care and can be accessed at http://www.ckp.scot.nhs.uk/ScottishGovernmentGuidanceEndofLifeCare/?id=1045.

Staff should familiarise themselves with local guidance and / or refer to the following:

- NHSScotland clinical guidelines published in November 2014 http://www.healthcareimprovementscotland.org/news_and_events/news/news_palliative_care.aspx

- National DNACPR Policy (currently undergoing a light-touch review – revisions due to be published by March 2015). http://www.scotland.gov.uk/Topics/Health/Quality-Improvement-Performance/Living-Dying-Well/DNACPR
- Adults with Incapacity Act Code of Practice http://www.scotland.gov.uk/Publications/2010/10/20153801/0
- Local guidance and resources can be uploaded to the online version of the *Caring for People in the last few days and hours of life* Guidance at http://www.ckp.scot.nhs.uk/ScottishGovernmentGuidanceEndofLifeCare/?id=1045. If local NHS Boards wish to do this please contact knowledge@nes.scot.nhs.uk

Section 4: Information for People and Families

As highlighted in the principles (see Section 1) it is important that families are kept informed, understand about the dying process and are able to prepare for bereavement. Useful information for people and families is available from:

- The palliative care zone on the NHS Inform website or call NHS Inform 0800 22 44 88 http://www.nhsinform.co.uk/PalliativeCare
- Preparing for Death and Bereavement http://www.nhsinform.co.uk/PalliativeCare/deathandbereavement
- The bereavement zone on NHS Inform website http://www.nhsinform.co.uk/bereavement

- When Someone Dies http://www.hris.org.uk/patient-information/information-about-health-services/bereavement/

- What to do after a death in Scotland http://www.scotland.gov.uk/Publications/2012/05/4929

Section 5: Local Guidance and Resources

Local guidance and resources can be uploaded to the online version of the *Caring for People in the last few days and hours of life* Guidance at http://www.ckp.scot.nhs.uk/ScottishGovernmentGuidanceEndofLifeCare/?id=1045. If local NHS Boards wish to do this please contact knowledge@nes.scot.nhs.uk

Section 6: National Statement

http://www.scotland.gov.uk/Publications/Recent

Appendix 1: Further Useful Resources

Palliative Care in Practice website
The Palliative Care in Practice portal aims to support health and care workers to develop their knowledge and understanding of two key areas of practice: principles of palliative and end of life care and advance care planning.
www.palliativecareinpractice.nes.scot.nhs.uk

GMC Good Medical Practice Guidance: Treatment and care towards the end of life: good practice in decision making (2010)
A framework to support doctors to support patients who are approaching the end of their life to live as well as possible until they die.
http://www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp

Shaping Bereavement Care – a framework for action (2011)
Shaping Bereavement Care presents a framework for action to develop quality bereavement care within the NHS in Scotland
http://www.sehd.scot.nhs.uk/mels/CEL2011_09.pdf

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[i] Definition of a 'natural death': a death that is primarily attributed to an illness or an internal malfunction of the body not directly influenced by external forces.

[ii] The "goals of care" are the things which those providing care are trying to achieve for the patient. These goals are based on discussion with patient (if possible) and the family of available treatment options and what matters most to them.

[iii] More information about SBAR is available here: http://www.qihub.scot.nhs.uk/knowledge-centre/quality-improvement-tools/situation-background-assessment-recommendation-(sbar).aspx

[iv] Shaping Bereavement Care – a framework for action **(2011)**

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

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