Lincolnshire Community Health Services
St Barnabas Lincolnshire Hospice
United Lincolnshire Hospitals
Marie Curie Lincolnshire

The Five Priorities for Care of the Dying Person (Adult)

Lincolnshire Guidelines

Reference No:	(Assigned by Corporate Admin Team)
Version	
Ratified by:	(Completed by Corporate Admin Team)
Date ratified:	LCHS Trust Board
Name of originator / author:	Kay Howard, Cheryl Kern, Lyn Wilkinson, Gwen Eldred, Becky Portess (LCHS) Dr Kat Collett, Emma Warner, Di Rigby (St Barnabas Lincolnshire Hospice) Anna Pringle (United Lincolnshire Hospitals NHS Trust) Jayne Unwin (Marie Curie) Yve White-Smith (ULH)
Name of responsible committee / Individual	Five Priorities for Care cross organisational working party (LCHS, St Barnabas, ULH, Marie Curie)
Date issued:	(Completed by Corporate Admin Team)
Review date:	
Target audience:	
Distributed via	Website

Appendix F – Page 2

Five priorities for care of the dying person – Lincolnshire Guidelines

Version Control Sheet

Version	Section / Para / Appendix	Version / Description of Amendments	Date	Author / Amended by
1		New	14.09.15	Kay Howard
2				
3				
4				
5				
6				
7				
8				
9				
10				
11				
12				
13				
14				
15				
16				
17				
18				
19				
20				

Five priorities for care of the dying person – Lincolnshire Guidelines

Contents

Five priorities for care of the dying person – Lincolnshire guidelines

Procedural Document Statement

Background Following the withdrawal of the Liverpool Care Pathway (LCP) a national coalition of organisations called the Leadership Alliance for the Care of Dying People (LACDP, 2014) published national guidance in the 'One Chance to get it Right' document. This document set out the approach that all organisations caring for dying patients should follow and recommended the implementation of five priorities for care of the dying person.

Statement In Lincolnshire a cross organisational approach has been taken to developing the implementation of the 'Five Priorities for Care of the Dying Person' (LACDP,2014). Lincolnshire Community Health Services (LCHS), United Lincolnshire Hospitals (ULH), St Barnabas Lincolnshire Hospice and Marie Curie Lincolnshire have worked collaboratively and consulted with General Practioner representatives and Commissioners in the production of these Lincolnshire guidelines.

Responsibilities These guidelines apply to all health care organisations providing end of life care in Lincolnshire in the last days of life

Training The 'Five Priorities for care if the dying person guidelines' are already in use within ULHT. A plan for roll out to community settings will be devised by the cross organisational working group.

Dissemination A copy of this procedure will be available for all staff on trust intranet sites. Ward, department and service leads will be responsible for ensuring relevant information is cascaded to all clinical staff in their area.

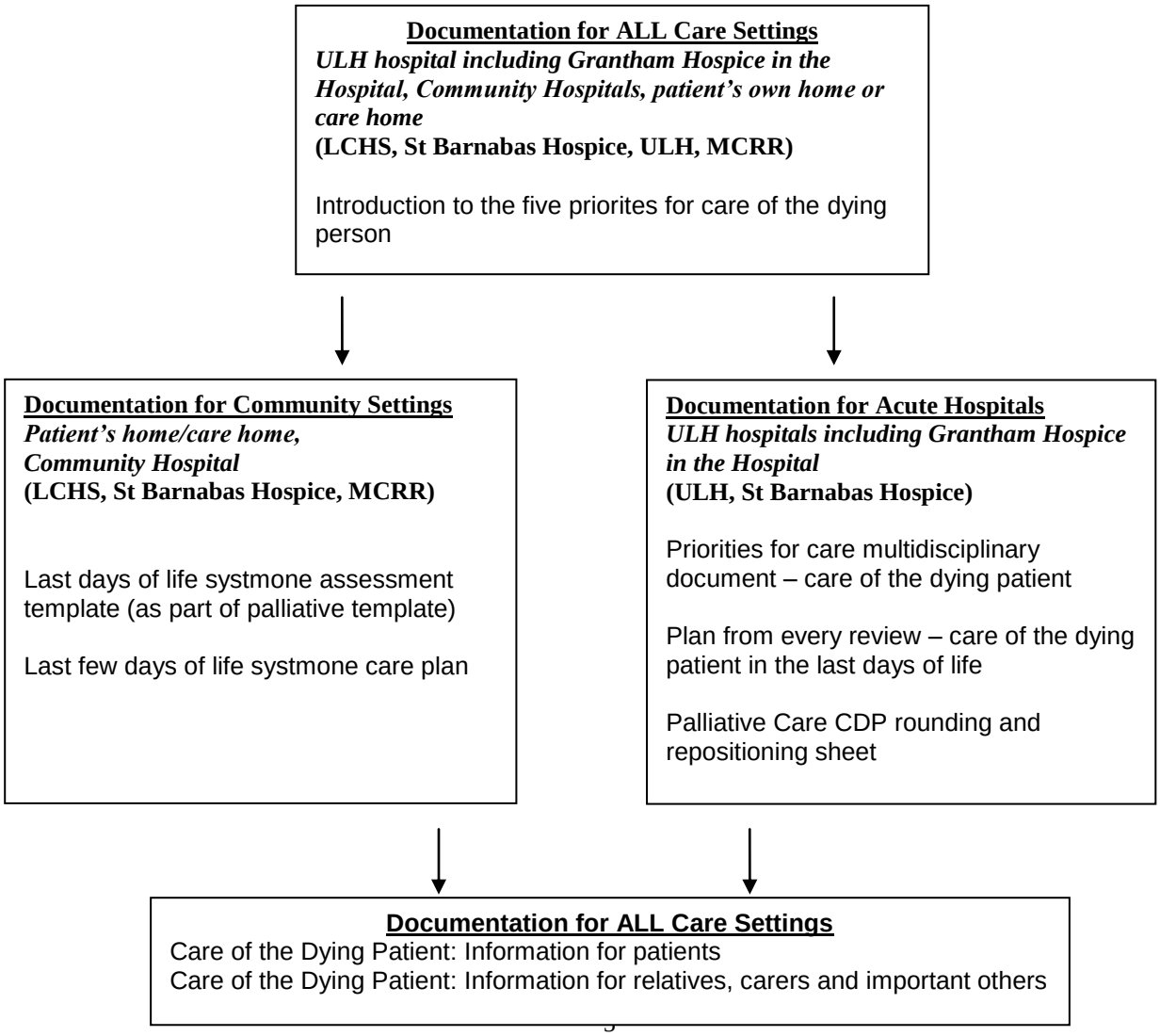
Resource Implication Dying people receive appropriate individualised care according to their wishes and needs. Their concerns and those of their loved ones are discussed and considered

Consultation Lincolnshire Community Health Services (LCHS), United Lincolnshire Hospitals (ULH), St Barnabas Lincolnshire Hospice and Marie Curie Lincolnshire have worked collaboratively and consulted with General Practioner representatives and Commissioners in the production of these Lincolnshire guidelines.

1.Background

Following the withdrawal of the Liverpool Care Pathway (LCP) a national coalition of organisations called the Leadership Alliance for the Care of Dying People (LACDP) published national guidance in the 'One Chance to get it Right' document. This document set out the approach that all organisations caring for dying patients should follow and recommended the implementation of five priorities for care of the dying person.

In Lincolnshire a cross organisational approach has been taken to developing the implementation of the 'Five Priorities for Care of the Dying Person' (LACDP,2014). Lincolnshire Community Health Services (LCHS), United Lincolnshire Hospitals (ULH), St Barnabas Lincolnshire Hospice and Marie Curie Lincolnshire have worked collaboratively in this process. Different patient settings and different approaches to documentation across organisations involved in delivering end of life care within Lincolnshire has meant that there are variances in the actual paperwork / electronic documentation used but the overiding principles and approach are applicable to all patient settings and to employees of all the above named organisations.



These Lincolnshire guidelines set out the implementation, within Lincolnshire, of the five priorities for care of the dying person. It will also identify the procedure for documentation of assessed needs, care planning, care delivery and review. An early review date of the guidelines will be set to ensure they reflect the future publication of NICE Guidance.

Symptom Guidelines for last few days of life are being reviewed by the cross organisational group and until these are ratified and published reference should be made to the 'Palliative Adult Network Guidelines' (Watson et al, 2011).

Reference

Watson M, Lucas C, Hoy A, Back I, Armstrong P (2011) 'Palliative Adult Network Guidelines' third edition

1. Introduction to the five priorities For care of the dying Person

'How people die remains in the memory of those who live on'
Dame Cicely Saunders, Founder of the modern hospice movement

'Every person in the last days of their life regardless of who they are, where they are or who cares for them has the right to receive high quality care given with compassion and skill.

Every person in the last days of their life regardless of who they are, where they are or who cares for them should expect that their loved ones receive high quality support given with compassion and skill. '
Kat Collett, Consultant in Palliative Medicine, Lincolnshire.

This introduction describes the five priorities for providing high quality care for people in their last days of life and will be linked to individualised palliative and end of life care plans and other documents that can be used to support care. It is based on the five priorities for care outlined in 'One Chance to Get it Right' guidance from Leadership Alliance for the Care of Dying People (LACDP,2014).

Recovery and cure are not always possible and for every person there will come a time when either death can no longer be prevented or the burden of treatments outweighs the benefits for that individual. Acknowledging this and providing high quality nursing and medical care focused on comfort and support allows a dying person to avoid unnecessary physical, psychological and spiritual distress and allows them to spend quality time with their loved ones in a place of their choosing. End of life decision making needs to be led by senior clinicians and the whole team needs to be engaged with these priorities. Clear communication within the team is paramount.

It is recognised that while staff have a responsibility for providing high quality care to all patients including those at the end of their life some professionals will be much more involved in caring for these patients than others. It is expected that each organisation will support staff to use the new documentation alongside input from specialist palliative care teams for both individualised patient support and education in order to develop high quality end of life care.

If it is a possibility that a person may die within the next few days or hours the following needs to happen:

PRIORITY ONE – '*RECOGNISE'*
The possibility that a person may die within the next few days or hours is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, these are reviewed regularly and decisions revised accordingly.

PRIORITY TWO – '*COMMUNICATE*'
Clear and sensitive communication needs to take place between staff and the person who is dying and those identified as important to them. This includes identifying the extent of the person's need for information and allowing them to decline discussions regarding the possibility that they may be dying.

PRIORITY THREE – '*INVOLVE'*
The dying person and those identified as important to them are involved in decisions about treatment and care to the extent that the dying person wishes.

PRIORITY FOUR – *'SUPPORT'*
The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.

PRIORITY FIVE – '*DO'*
An individual plan of care is agreed, coordinated and delivered with compassion.
(Including: food and drink, symptom control, psychological, social and spiritual support).

- Ensure unnecessary interventions are minimised.
- Daily review of the person's condition and agreed decisions/wishes.
- Evaluate and update those decisions as needed to ensure appropriateness and effectiveness

Unless decisions need to be made urgently, this decision making process should be done in normal working hours.

References

End of Life Care Strategy, Department of Health 2008.
End of Life Care Quality Standards, NICE QS13, August 2011.
The Route to success in end of life care – achieving quality in acute hospitals. National end of life care programme 2012.
More Care, Less Pathway report. A review of the Liverpool care pathway. July 2013.
Leadership Alliance Care of Dying People, 2nd interim statement. March 2014.
One Chance to get it right. Leadership Alliance Care of Dying People. June 2014

2. Documentation for COMMUNITY setting

3.1 Systmone template on palliative care template

LAST DAYS OF LIFE ASSESSMENT - The Five Priorities for Care of the Dying Person

Priority 1 (“*Recognise”)*
The possibility that a person may die within the next few days or hours is recognised and communicated clearly, decisions made and actions taken in accordance with the person’s needs and wishes, and these are regularly reviewed and decisions revised accordingly.
Has a decision been made that end of life is likely to be within a few days? **YES /NO**

Priority 2 (“*Communicate”)*
Sensitive communication takes place between staff and the person who is dying, and those identified as important to them.
How has this decision been made and who was involved? Insert free text box

Priority 3 (“*Involve”)*
The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
Describe what actions are being taken to meet the needs of the patient. Insert free text box
Give a brief description of conversations that have taken place and who was included in the conversation Insert free text box

Priority 4 *(“Support”)*
The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
Give a brief description of any concerns raised by patient and significant others Insert free text box

Priority 5 *(“Do”)*
An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, coordinated and delivered with compassion.
Has an individual care plan been completed? **YES / NO**
Is this accessible to all professionals involved in the patient’s care? **YES / NO**
(It is recommended that the individual plan of care is printed and left within patient’s notes along with a communication sheet)

Reference
Leadership Alliance for the Care of Dying People (2014) ‘One Chance to Get it Right’

Documentation for COMMUNITY setting

2.2 Systmone Care Plan template to be individualised as appropriate to assessment

Care Plan for _____

End of Life Care

NHS Number:
Date of Birth:
Contact Details:
Date Printed:
Implementation Date:
Review Required:
Care Needed: Care of the dying patient.
Goal: To give holistic and high quality care to patients in the last few days of life.

Instruction	Responsibility	Date Performed	Performed By	Signature
Priority 1 "Recognise"				
Identify with the MDT that the patient is approaching last few days of life	Nurse			
Ensure effective communication with patient, family and carers to inform them that the patient is entering last few days of life.	Nurse			
Priority 2 "Communicate"				
Ensure Patient and Carer has the opportunity to discuss and review their wishes around Advance Care Planning, Preferred Place of Death.	Nurse			
Give the Carers/Family End of Life care booklet, if appropriate	Nurse			
If effective symptom, management is not achieved, liaise with the GP, refer to the Specialist Palliative Care Macmillan CNS, or Specialist Out of Hour's service.	Nurse			
Allow carers and family to discuss feelings and address any concerns and issues shared.	Nurse			
Ensure patients and carers/family are aware who to contact out of hours or in an emergency.	Nurse			
Ensure the carers/family are aware who to contact following patient's death	Nurse			
Priority 3 "Involve"				

Allow opportunity for family to be involved in care where wished and appropriate and document wishes on palliative template.	Nurse			
Priority 4 "Support"				
Offer support to the carers/family in preparation for the patient's death	Nurse			
Give Bereavement support booklet and offer bereavement support visit.	Nurse			
Assess need for additional and on-going bereavement support and refer to appropriate support agency as needed.	Nurse			
Priority 5 " Do"				
Ensure DNACPR is up to date and completed appropriately.	Nurse			
Assess the need for clinical observations , oxygen therapy, blood tests and Subcutaneous fluids	Nurse			
Assess pain and respond accordingly	Nurse			
Assess agitation, restlessness and anxiety and respond accordingly	Nurse			
Assess secretions and respond accordingly	Nurse			
Assess ability to swallow and respond accordingly. Promote nutrition and hydration as patient wishes, considering and discussing risks.	Nurse			
Assess nausea and vomiting symptoms and respond accordingly	Nurse			
Assess breathing and monitor for signs of distress and respond accordingly	Nurse			
Assess for other symptoms and respond accordingly				
Follow symptom guidelines for care of the dying patient and / or PANG guidelines for advice.	Nurse			
Ensure elimination needs are met	Nurse			
Assess need for mouth care and respond accordingly	Nurse			
Assess skin integrity, if appropriate and respond accordingly (in reference to the countywide Tissue Viability End of Life Pathway)	Nurse			
Review appropriateness of medication and discuss with the MDT as required	Nurse			
Assess patient's psychological/spiritual needs and respond accordingly	Nurse			
Review plan of care and agreed decisions at least daily	Nurse			

Ensure completed and accurate documentation of the End of Life Assessments are on Systmone or the communication sheet in the patients notes after each contact.	Nurse			
After death; Complete care after death as per Organisational Policies	Nurse			

3. Documentation for ACUTE (Hospital) setting

4.1 Priorities of Care

Multidisciplinary Document
Care of the Dying Patient Last Days of Life

Decisions to be made in discussion with patient and those identified as important to them.
This document is to be completed jointly by Medical and nursing staff. When complete place in the patient's current ULHT documentation on date of discussion.
Senior Clinician to review and Daily Plan from Every Review (PFER) to be completed.

Senior Clinician **……..** **Name of person identified by patient to be involved with decisions / discussions** **……..** **Contact Number……** **(Discontinued……..… Refer to daily PFER)**	**Affix Patient Sticker**

Date Active	**Role/Initial Dr & Nurse**	**Name of Doctor completing this form**…… **Name of Nurse completing this form**……
Priority 1. (Recognise) Recognising the possibility that a person may die within the next few days or hours. This should be communicated clearly and sensitively with decisions made and actions taken in accordance with the person's needs and wishes.		
		A decision has been made that the end of life is likely to be within a few days Yes /No
		How was this decision made and who by
		If there are limits to what the person wishes to know about their situation then this should be respected. Patient's wishes:
		Is there an Advance Care Plan Yes / No Advance decision to refuse treatment Yes / No DNACPR in place Yes / No

Priority 2. (Communication) Sensitive communication takes place between staff and the person who is dying, and those identified as important to them		
		Brief description of conversation and who was involved • Does the patient have capacity to make decisions about their care and treatment at this present time? Yes / No (if no refer to mental capacity act policy) • Identification of patients preferred place of care and/or death …….. • Lasting Power of Attorney: Health……... • If Preferred place of Care/dying identified by patient and family as other than acute hospital refer to Discharge Community Link Nurse for Palliative and End of Life Care.
Date Active	**Role/Initial Dr & Nurse**	
Priority 3. (Involve) The dying person, and those identified as important to them, are involved in decisions about treatment and care.		
		Minimise unnecessary interventions. To be considered with the patient, or those identified as important to them, if the patient is unable to participate
		• Observations: continued ☐ discontinued ☐
		• Oxygen: continued ☐ discontinued ☐ N/A ☐
		• Bloods: continued ☐ discontinued ☐
		• IVT: continued ☐ discontinued ☐ N/A ☐
Priority 4. (Support) The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.		
		• Ensure family have time to express feelings and are encouraged and supported to communicate any wishes / concerns
		• Do they wish to be contacted at any time of day / night ……
		• Ensure spiritual care offered to family as well as patient. Refer to chaplains if wished
Priority 5. (Do) An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support is agreed, coordinated and delivered with compassion. Consider what the patient finds distressing.		

		Have anticipatory medications been prescribed Yes / No Refer to symptom control guidelines for care of the dying patient. (ULHTCDP & PANG) Refer to ULHT Specialist Palliative Care Team (ie Macmillan Palliative Care CNS) for symptom management if not yet achieved
		• Pain (5)
		• Nausea / vomiting
		• Breathlessness
		• Respiratory tract problems
		• Psychological needs: Agitation/distress
		• Plans for food and drink(3)
		• Mouth care(3)
		• Continence(4)
		• Skin care (repositioning/comfort)(6)
		• Social concerns
		• Spirituality
		• Does the patient have any wishes for care after death?

4.2 Documentation for ACUTE (Hospital) setting

Identified frequency of scheduled rounding/repositioning in care plan as discussed with patient / important others(PLEASE TICK APPROPRIATE BOX BELOW)

☐ **Hourly** ☐ **2 hourly** ☐ **3 hourly** ☐ **4 hourly** ☐ **6 hourly**

Time	**Number* / Tick boxes to confirm that you have asked and assessed the patient:** **(leave blank if symptoms not present)** **P = Pain control, N = Nutrition/fluids, NV=Nausea/Vomiting, B=Breathless /respiratory problems, A=Agitation/ Distress, M=Mouth care, R = Repositioning (enter number from key) E = Elimination, S=Spirituality, O = Other**										**Comments:** **Identified concerns and action to be documented in patient evaluation.** **Describe reasons if patients not asked (e.g. asleep / patient or important others have asked not to be interrupted)**	**Name of Nurse / HCSW / Student nurse**
	P	**N**	**NV**	**B**	**A**	**M**	**R**	**E**	**S**	**O**		
01:00 (AM)												
02:00												
03:00												
04:00												
05:00												
06:00												
07:00												

Identified frequency of scheduled rounding/repositioning in care plan as discussed with patient / important others(PLEASE TICK APPROPRIATE BOX BELOW)

☐ **Hourly** ☐ **2 hourly** ☐ **3 hourly** ☐ **4 hourly** ☐ **6 hourly**

Time	**Number* / Tick boxes to confirm that you have asked and assessed the patient:** **(leave blank if symptoms not present)** **P = Pain control, N = Nutrition/fluids, NV=Nausea/Vomiting, B=Breathless /respiratory problems, A=Agitation/ Distress, M=Mouth care, R = Repositioning (enter number from key)** **E = Elimination, S=Spirituality, O = Other**										**Comments:** **Identified concerns and action to be documented in patient evaluation.** **Describe reasons if patients not asked (e.g. asleep / patient or important others have asked not to be interrupted)**	**Name of Nurse / HCSW / Student nurse**
	P	**N**	**NV**	**B**	**A**	**M**	**R**	**E**	**S**	**O**		
08:00												
09:00												
10:00												
11:00												
12:00 (PM)												
13:00												
14:00												
15:00												

Identified frequency of scheduled rounding/repositioning in care plan as discussed with patient / important others(PLEASE TICK APPROPRIATE BOX BELOW)

☐ **Hourly** ☐ **2 hourly** ☐ **3 hourly** ☐ **4 hourly** ☐ **6 hourly**

Time	**Number* / Tick boxes to confirm that you have asked and assessed the patient:** **(leave blank if symptoms not present)** **P = Pain control, N = Nutrition/fluids, NV=Nausea/Vomiting, B=Breathless /respiratory problems, A=Agitation/ Distress, M=Mouth care, R = Repositioning (enter number from key)** **E = Elimination, S=Spirituality, O = Other**										**Comments:** **Identified concerns and action to be documented in patient evaluation.** **Describe reasons if patients not asked (e.g. asleep / patient or important others have asked not to be interrupted)**	**Name of Nurse / HCSW / Student nurse**
	P	**N**	**NV**	**B**	**A**	**M**	**R**	**E**	**S**	**O**		
16:00												
17:00												
18:00												
19:00												
20:00												
21:00												
22:00												
23:00												

Identified frequency of scheduled rounding/repositioning in care plan as discussed with patient / important others(PLEASE TICK APPROPRIATE BOX BELOW)

☐ **Hourly** ☐ **2 hourly** ☐ **3 hourly** ☐ **4 hourly** ☐ **6 hourly**

Time	**Number* / Tick boxes to confirm that you have asked and assessed the patient:** **(leave blank if symptoms not present)** **P = Pain control, N = Nutrition/fluids, NV=Nausea/Vomiting, B=Breathless /respiratory problems, A=Agitation/ Distress, M=Mouth care, R = Repositioning (enter number from key)** **E = Elimination, S=Spirituality, O = Other**										**Comments:** **Identified concerns and action to be documented in patient evaluation.** **Describe reasons if patients not asked (e.g. asleep / patient or important others have asked not to be interrupted)**	**Name of Nurse / HCSW / Student nurse**
	P	**N**	**N V**	**B**	**A**	**M**	**R**	**E**	**S**	**O**		
00:00												

Please select leaflet appropriate to patient setting – customised with contact details

Care of the Dying Patient
Information for Patients

Lincolnshire Community Health Services Specialist Palliative Care Team
www.lincolnshirecommunityhealthservices.nhs.uk

This information is written for you, but you may find it helpful to read it together with those important to you.

Information/Communication

Those caring for you will discuss your care with you and will help you understand any changes in your condition including indications that your condition is deteriorating.

Recognising that someone may be dying is always complex and unique to each individual, but a plan of care can be commenced to ensure you receive the best quality of care at the end of life.

An individualised plan of care can be made, which considers your wishes, needs and where you would wish to be cared for, if at all possible. This can be reviewed daily, and you may wish to be involved with these discussions and decisions.

Your nursing and medical team will be happy to respond to any questions about your condition. Some people find it easier to talk to someone outside their family. If you think this would be helpful, you can talk to your doctor or specialist nurse, nurse or chaplaincy for further support. As you near the end of life, you may find that you need more support at different times.

Please do not hesitate to ask to speak with the doctors or nurses about any concerns you have. Your healthcare team are here to help you to work through your worries and concerns and to offer you care and support at this difficult time.

What you may notice

Sleeping: Generally, people eventually become more sleepy. They may not be able to be woken at all but may still be able to hear and be aware of those around them. Some people have phases where they are awake and can talk, and then slip back into unconsciousness.

Reduced Need for Food and Drink: Food and drink may not be wanted or needed and fluids in a drip may not be appropriate. Your decisions or needs for hydration and nutrition can be discussed with the clinical team caring for you. You may just wish to have sips or a little of what you enjoy rather than meals. You may not feel thirsty or hungry at this time but your mouth may be dry and you may wish to be assisted with mouth care to keep it moistened.

1.1.1 *Skin and Sensation Changes*: Your hands, feet and skin may at times feel very cold. Sometimes the skin changes colour and becomes slightly more blue, grey or white. Your skin may also be very sensitive to touch. Several layers of light, warm clothing and bedding can help to keep you at a comfortable temperature.

1.1.2 *Symptoms:* Some people may develop signs of being uncomfortable for example: pain, nausea, vomiting, breathlessness, restlessness. If this should happen, the use or dose of medications may need to be reviewed. The doctors and nursing team will also check for other causes of these changes.

1.1.3 *Breathing*: You may notice changes in your breathing. Talk with the clinical team looking after you if you experience any changes that are worrying you.

1.1.4 Medication/Treatment: If you find your symptoms change, your medicines may also need to change. Some medicines may no longer be needed and may be stopped. If new symptoms develop, new medicines can be started.

If there are problems with swallowing, it is possible to give medicines either by injection, by patches or by using a small battery operated pump called a syringe driver which delivers very small amounts of medication almost continuously, subcutaneously.

You may hear the doctor, nurse or palliative care nurse talk about 'just in case' medicines. If you do develop symptoms that are worrying to you, "just-in-case"

Medicines can be prescribed by your doctor to enable a nurse to administer appropriate medication to relieve these symptoms without delay

Observations

It may also be appropriate for blood tests, monitoring of blood pressure or temperature to be stopped. This can be discussed with you and those important to you.

Spiritual/Pastoral and Religious Needs

Many people wish to explore their human spirituality such as their personal values, beliefs, wishes or desires as the end of a life approaches. We encourage people to voice what is important to them. Not everyone has a formal religious tradition or faith based belief, but where they have we will do our best to contact your local religious minister or faith group if wished. We will work with you to support your needs.

For further information/advice please contact

Community Nurses

(Monday to Friday 9am-5pm)

Telephone **.....**

Community Macmillan Clinical Nurse Specialist

(Monday to Friday 9am-5pm)

Telephone **.....**

Marie Curie Rapid Response

(Monday to Friday 3pm-7am

Weekends and Bank Holidays 24 hours a day)

Telephone 0845 055 0709

www.macmillan.org.uk//Endoflife/Thelastfewdays
www.mariecurie.org.uk

This leaflet has been developed by the ULH Specialist Palliative Care Team
With information from Macmillan and Marie Curie
Authors Anna Pringle & Yve White Smith

www.mariecurie.org.uk
www.england.nhs.uk/ourwork/qual-clin-lead/lacdp

Information for relatives, carers and those important to the patient

Lincolnshire Community Health Services Specialist Palliative Care Team
www.lincolnshirecommunityhealthservices.nhs.uk

This information is written for relatives and friends, but you may find it helpful to read it together with your loved one.

Information/Communication

Those caring for your relative/friend consider that there has been a change in their condition which indicates that their condition is deteriorating and they may be dying.

Recognising that someone may be dying is always complex and unique to each individual, but a plan of care can be commenced to ensure your loved one receives the best quality of care at the end of their life.

An individualised plan of care can be made, which considers the patient's wishes, needs and where they would wish to be cared for, if at all possible. This can be reviewed daily, the patient may wish for you to be involved with these discussions and decisions.

Your nursing and medical team will be happy to respond to any questions about your loved one's condition. Some people find it easier to talk to someone outside their family. If you think this would be helpful, you can talk to your doctor or specialist nurse, nurse or chaplaincy for further support. As your relative or friend nears the end of their life, you may find that you need more support.

Please do not hesitate to ask to speak with the doctors or nurses about any concerns you have. Your loved ones healthcare team are here to help you to work through your worries and concerns and to offer you care and support at this difficult time.

What You May Notice

Sleeping: Generally, people eventually become more sleepy. They may not be able to be woken at all but may still be able to hear and be aware of those around them. Some people have phases where they are awake and can talk, and then slip back into unconsciousness.

Reduced Need for Food and Drink: Food and drink may not be wanted or needed and fluids in a drip may not be appropriate. Your loved one's decisions or needs for hydration and nutrition can be discussed with the clinical team caring for them. They may just wish to have sips or a little of what they enjoy rather than meals. Your relative or friend won't usually feel thirsty or hungry at this time but their mouth may be dry and need to be moistened.

1.1.1 *Skin and Sensation Changes*: Your relative's or friend's hands, feet and skin may at times feel very cold. Sometimes the skin changes colour and becomes slightly more blue, grey or white. Their skin may also be very sensitive to touch. Several layers of light, warm clothing and bedding can help to keep them at a comfortable temperature.

1.1.2 *Symptoms:* Your relative or friend *may* develop signs of being uncomfortable for example: pain, nausea, vomiting, breathlessness, restlessness. If this should happen, the use or dose of medications may need to be reviewed. The doctors and nursing team will also check for other causes of these changes.

1.1.3 *Breathing*: You may notice that their breathing pattern changes. Breathing may become irregular, with longer gaps between breaths. It may also become noisy. This may be distressing for you but it isn't usually distressing for the person who is dying.

Medication/Treatment

If your loved one's symptoms change, their medicines may also need to change. Some medicines may no longer be needed and may be stopped. If new symptoms develop, new medicines can be started.

If there are problems with swallowing, it is possible to give medicines either by injection, by patches or by using a small battery operated pump called a syringe driver which delivers very small amounts of medication almost continuously, subcutaneously.

You may hear the doctor, nurse or palliative care nurse talk about 'just in case' medicines. If your loved one develops symptoms, "just-in-case" medicines are prescribed by their doctor to enable a nurse to administer appropriate medication to relieve symptoms without delay

Observations

It may also be appropriate for blood tests, monitoring of blood pressure or temperature to be stopped.

Spiritual/Pastoral and Religious Needs

Many people wish to explore their human spirituality such as their personal values, beliefs, wishes or desires as the end of a life approaches. We encourage people to voice what is important to them. Not everyone has a formal religious tradition or faith based belief, but where they have we will do our best to contact your local religious minister or faith group if wished. We will work with you to support your needs.

For further information/advice please contact

Community Nurses

(Monday to Friday 9am-5pm)

Telephone **……**

Community Macmillan Clinical Nurse Specialist

(Monday to Friday 9am-5pm)

Telephone **……**

Marie Curie Rapid Response

(Monday to Friday 3pm-7am

Weekends and Bank Holidays 24 hours a day)

Telephone 0845 055 0709

This leaflet has been developed by the ULH Specialist Palliative Care Team
With information from Macmillan and Marie Curie
Authors Anna Pringle & Yve White Smith

www.macmillan.org.uk//Endoflife/Thelastfewdays
www.mariecurie.org.uk
www.england.nhs.uk/ourwork/qual-clin-lead/lacdp

Lincolnshire Community Health Services NHS Trust

St Barnabas Lincolnshire Hospice caring for life

United Lincolnshire Hospitals NHS Trust

Lincolnshire Community Health Services NHS
NHS Trust

Equality Analysis

Introduction

The general equality duty that is set out in the Equality Act 2010 requires public authorities, in the exercise of their functions, to have due regard to the need to:

- Eliminate unlawful discrimination, harassment and victimisation and other conduct prohibited by the Act.
- Advance equality of opportunity between people who share a protected characteristic and those who do not.
- Foster good relations between people who share a protected characteristic and those who do not.

The general equality duty does not specify how public authorities should analyse the effect of their existing and new policies and practices on equality, but doing so is an important part of complying with the general equality duty. It is up to each organisation to choose the most effective approach for them. This standard template is designed to help LCHS staff members to comply with the general duty.

Please complete the template by following the instructions in each box. Should you have any queries or suggestions on this template, please contact Qurban Hussain Equality and Human Rights Lead.

Name of Policy/Procedure/Function*
Five priorities for care of the dying person – Lincolnshire guidelines

Equality Analysis Carried out by: Kay Howard
Date: 21.05.15
Equality & Human rights Lead:
Date:
Director\General Manager:
Date:

***In this template the term policy\service is used as shorthand for what needs to be analysed. Policy\Service needs to be understood broadly to embrace the full range of policies, practices, activities and decisions: essentially everything we do, whether it is formally written down or whether it is informal custom and practice. This includes existing policies and any new policies under development.**

Section 1 – to be completed for all policies

A.	Briefly give an outline of the key objectives of the policy; what it's intended outcome is and who the intended beneficiaries are expected to be	To promote the five priorities for care of the dying person as recommended by the National Alliance for the care of dying person. Promote best practice for the care of patients in the last days of life		
B.	Does the policy have an impact on patients, carers or staff, or the wider community that we have links with? **Please give details**	Dying people in the last days/hours of life and those important to them		
C.	Is there is any evidence that the policy\service relates to an area with known inequalities? **Please give details**	Aims to promote high quality care for dying people in all care settings in Lincolnshire		
D.	Will/Does the implementation of the policy\service result in different impacts for protected characteristics?			
		Yes	No	
	Disability		x	
	Sexual Orientation		x	
	Sex		x	
	Gender Reassignment		x	
	Race		x	
	Marriage/Civil Partnership		x	
	Maternity/Pregnancy		x	
	Age		x	
	Religion or Belief		x	
	Carers		x	
	If you have answered 'Yes' to any of the questions then you are required to carry out a full Equality Analysis which should be approved by the Equality and Human Rights Lead – please go to section 2			
The above named policy has been considered and does not require a full equality analysis				
Equality Analysis Carried out by:		Kay Howard		
Date:		15.05.15		

Section 2

Equality analysis

Title:
Relevant line in:

What are the intended outcomes of this work? *Include outline of objectives and function aims*
Who will be affected? *e.g. staff, patients, service users etc*

Evidence *The Government's commitment to transparency requires public bodies to be open about the information on which they base their decisions and the results. You must understand your responsibilities under the transparency agenda before completing this section of the assessment.*
What evidence have you considered? *List the main sources of data, research and other sources of evidence (including full references) reviewed to determine impact on each equality group (protected characteristic). This can include national research, surveys, reports, research interviews, focus groups, pilot activity evaluations etc. If there are gaps in evidence, state what you will do to close them in the Action Plan on the last page of this template.*
Disability *Consider and detail (including the source of any evidence) on attitudinal, physical and social barriers.*
Sex *Consider and detail (including the source of any evidence) on men and women (potential to link to carers below).*
Race *Consider and detail (including the source of any evidence) on difference ethnic groups, nationalities, Roma gypsies, Irish travellers, language barriers.*
Age *Consider and detail (including the source of any evidence) across age ranges on old and younger people. This can include safeguarding, consent and child welfare.*
Gender reassignment (including transgender) *Consider and detail (including the source of any evidence) on transgender and transsexual people. This can include issues such as privacy of data and harassment.*
Sexual orientation *Consider and detail (including the source of any evidence) on heterosexual people as well as lesbian, gay and bi-sexual people.*
Religion or belief *Consider and detail (including the source of any evidence) on people with different religions, beliefs or no belief.*
Pregnancy and maternity *Consider and detail (including the source of any evidence) on working arrangements, part-time working, infant caring responsibilities.*

Carers *Consider and detail (including the source of any evidence) on part-time working, shift-patterns, general caring responsibilities.*

Other identified groups *Consider and detail and include the source of any evidence on different socio-economic groups, area inequality, income, resident status (migrants) and other groups experiencing disadvantage and barriers to access.*

• Engagement and involvement

Was this work subject to the requirements of the Equality Act and the NHS Act 2006 (Duty to involve)? (Y/N)

How have you engaged stakeholders in gathering evidence or testing the evidence available?

How have you engaged stakeholders in testing the policy or programme proposals?

For each engagement activity, please state who was involved, how and when they were engaged, and the key outputs:

Summary of Analysis

Considering the evidence and engagement activity you listed above please summarise the impact of your work. Consider whether the evidence shows potential for differential impact, if so state whether adverse or positive and for which groups. How you will mitigate any negative impacts. How you will include certain protected groups in services or expand their participation in public life.

Now consider and detail below how the proposals impact on elimination of discrimination, harassment and victimisation, advance the equality of opportunity and promote good relations between groups.

Eliminate discrimination, harassment and victimisation

Where there is evidence, address each protected characteristic (age, disability, gender, gender reassignment, pregnancy and maternity, race, religion or belief, sexual orientation).

Advance equality of opportunity

Where there is evidence, address each protected characteristic (age, disability, gender, gender reassignment, pregnancy and maternity, race, religion or belief, sexual orientation).

Promote good relations between groups

Where there is evidence, address each protected characteristic (age, disability, gender, gender reassignment, pregnancy and maternity, race, religion or belief, sexual orientation).

What is the overall impact?

Consider whether there are different levels of access experienced, needs or experiences, whether there are barriers to engagement, are there regional variations and what is the combined impact?

Addressing the impact on equalities *Please give an outline of what broad action you or any other bodies are taking to address any inequalities identified through the evidence.*

Action planning for improvement *Please give an outline of the key actions based on any gaps, challenges and opportunities you have identified. Actions to improve the policy/programmes need to be summarised (An action plan template is appended for specific action planning). Include here any general action to address specific equality issues and data gaps that need to be addressed through consultation or further research.*

Please give an outline of your next steps based on the challenges and opportunities you have identified. Include here any or all of the following, based on your assessment

- **For the record**

Name of person who carried out this assessment:

Date assessment completed:

Name of responsible Director/ General Manager:

Date assessment was signed:

NHSLA Monitoring Template

This template should be used to demonstrate compliance with NHSLA requirements for the procedural document where applicable and/or how compliance with the document will be monitored.

Minimum requirement to be monitored	Process for monitoring e.g. audit	Responsible individuals/group /committee	Frequency of monitoring /audit	Responsible individuals / group / committee (multidisciplinary) for review of results	Responsible individuals / group / committee for development of action plan	Responsible individuals / group / committee for monitoring of action plan
Implementation of the guidelines and completion of the documentation	Audit	Cross organizational palliative care working group	Annual			