

End of Life Care Strategy 2015-2018

This strategy is designed to encourage a culture change across the organization; being open to, and not fearful of, discussion of death and dying. This will in turn encourage and enable patients and families to have these difficult conversations to improve the chance of delivering best possible care and, as far as possible, to fulfil patient and family choices in the process.

VERSION HISTORY

Version	Date Issued	Brief Summary of Change	Owner's Name
Initial draft for comment	03 November 2015	Requirement to have a strategy identified by the CQC during an inspection visit.	End of Life Care Lead
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For more information on the status of this document, contact:	End of Life Care Lead
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1. Executive Summary

The Northern Devon Healthcare Trust (NDHT) recognises the specific challenges in provision of end of life care to patients and families, and proposes this strategy to provide a framework within which such support is identified and provided. The overriding aim is to enable staff to provide the best possible quality of care to all patients and families at this time wherever they are cared for. This organisation is committed to provide education and training to support the skills required for delivery of this care, and support to clinical teams so that they are confident in their decision-making process, always acting in the best interests of the patient as a priority.

Part of the approach will be to encourage a culture change across the organization; being open to, and not fearful of, discussion of death and dying. This will in turn encourage and enable patients and families to have these difficult conversations to improve the chance of delivering best possible care and, as far as possible, to fulfil patient and family choices in the process.

To embed cultural change NDHT will concentrate on the acute hospital in year one and the community services including the community hospitals in years two and three.

End of Life Care (EOLC) in the context of this strategy is any care provided to a patient, family member or carer when that patient is felt to be likely to have less than a year to live.

This care may be provided by any member of staff employed by NDHT. It encompasses everything from provision of a clean environment, conversation, food and drink, appropriate transport, to all clinical and social care provided. This includes access to specialist care, whether by nurses, doctors or other health or social care professionals.

The principles under which such care is provided will include respect for every individual's views and beliefs, and recognition of the importance of providing privacy and dignity in care as far as realistically possible.

Patients and families will be encouraged to express any need for support regarding spiritual or religious beliefs at the end of life. If an inpatient this need will usually be met via members of the hospital Chaplaincy Team. Any wish to contact such a provider known to patient or family in the community will also be facilitated.

When very near the end of life (last few days), special efforts will be made to fulfil wishes of patient and family members as far as possible, even when this may mean "flexing" the rules. Individualised care, making a situation relevant and personal, and fulfilling expressed wishes to the best possible extent, is recognised as an essential part of providing meaning towards the end of a life.

End of Life Care delivered to family members and friends extends into the period after the patient has died via the immediate actions of staff, both in terms of communication with family, and care of the body. This care also involves Bereavement Office and Mortuary Staff in terms of provision of opportunities to view the body, and provision of documentation to support registration of a death, or information to family where such documentation is not possible to provide. Such care is detailed within the NDHT Performing Last Offices, Standard Operating Procedure 2013.

2. Links to Trust strategic objectives

2.1. This strategy supports the delivery of the following Trust Strategic Objectives

✓	Highest Quality	✓	Flexible and multi-skilled workforce
✓	Sustainable Services	✓	Efficient & Effective
	Integrated Health & Social Care		Provider of Choice

3. Background

The National End of Life Care Strategy (London, DH 2008, and Ref 1) was produced in recognition that there are specific challenges to providing quality care to patients and family members / carers when death approaches. This was acknowledged as a time when all involved are very vulnerable to distress, and need the best possible care and support. Staff also needs the appropriate support to be able to provide such care.

Following the review of the Liverpool Care Pathway for the Dying patient the Leadership Alliance for the Care of dying people published the One Chance to get it Right (June 2014). This set out five principles to be followed when a patient is in the last few days or hours of life.

Publication of the Mid Staffordshire Final Report (Robert Francis QC, Ref 2) in February 2013 highlighted the importance of addressing all aspects of care, from basic personal hygiene and comfort to specialist input when required. It also highlighted the need to empower staff at any level to challenge poor quality care wherever and whenever witnessed. EOLC within NDHT is provided within virtually every location, community, community hospitals, specialty, ward, out-patient clinic and clinical area, by staff from reception to Executive level. This strategy reflects the necessity of ownership of this care by all staff across all areas, and what will be required to provide that care.

Publication of the Independent Review into the Liverpool Care Pathway (LCP) for the Dying Patient (“More Care, Less Pathway” July 2013, London, Ref 3), scrutinising care in the last few days of life in acute hospitals, and associated press coverage and public reaction, has been very negative. It is clear that there is no one “tool” or “pathway” which ensures best care for all, and INDIVIDUALISED care planning is essential for best practice. This is therefore an ideal time to set out our End of Life Care Strategy including addressing care in the last few days of life.

The importance of delivery of quality EOLC in acute trusts has for the first time been given weight by its inclusion as one of 8 Key Areas of inspection for the Care Quality Commission (CQC). The August 2015 CQC inspection at NDHT included review of EOLC provision, their findings and report has given us an opportunity to evaluate our provision of EOLC and develop an action plan for implementation during the life of this strategy.

The structure of provision of care outlined by this strategy is based upon a national publication: One Chance to get it Right (Leadership Alliance for the Care of Dying People June 2014)

This strategy attempts for the first time to bring awareness of EOLC to Trust staff as a whole, and provide information as to how such care should be addressed, and the education, training and support which staff will require to deliver this care.

This is a new Strategy Document, currently in draft format and will be sent out for Consultation..

4. The scope of the strategy

This strategy has relevance to all members of NDHT staff, from those first encountered by patients and families when receiving care, to the Executive/Board Level. Clinical staff across the trust will be at the forefront of delivery of EOLC, though the likelihood and frequency with which they will be involved in delivery, and their experience of such, may vary extensively. All staff should be supported by their line managers, in order to receive the education and training necessary to fulfil their role in EOLC delivery.

Individual members of staff should be aware of the specific areas of EOLC which they are likely to be regularly involved with. At times, involvement with such care may be emotionally distressing to staff, and they should receive support from their immediate line managers and other appropriate staff if distress is experienced. Staff should also know whom to contact for specialist advice on care of the dying.

5. The overall Purpose of the strategy

5.1. Our Belief

End of Life Care is NOT ONLY everybody's business BUT ALSO everyone's responsibility

Successful implementation of this strategy relies on ownership of this responsibility at every level, from individual staff member, to ward or clinical area, to Specialty and Division, and to Senior Management and Trust Board level.

5.2. Our Promise

We will:

- Be **OPEN** and **HONEST** in all discussions with patient and family, including where outcome is uncertain.
- Be sensitive to the individual needs of patients and family members. This may include being aware of how we would like to be treated in similar circumstances.
- Be flexible, to fulfill the wishes of any patient or family member, with regard to end of life care delivered by our staff, wherever and whenever practically possible.

This will extend from the time when the approach of "end of life" is identified, whether that is hours, days, weeks or months away.

The only limitation on fulfillment of patient and family wishes will be where patient safety is at risk, or care cannot be supported in another preferred setting.

Whilst there are few paediatric deaths actually in the acute trust hospitals, it is recognised that there are paediatric patients receiving on going care and attending the hospital regularly who have been identified as having a very limited prognosis. The principles in this strategy should also be applied when dealing with paediatric patients and families. It is recognised that the staff members with appropriate experience may well be different, and that the balance between patient and family regarding expression of wishes, and legal responsibilities, may be affected by patient age and capability as well as capacity.

6. Definitions

End of Life Care (EOLC): in the context of this strategy is any care provided to a patient, family member or carer when that patient is felt to be likely to have less than a year to live.

PALS: The Patient Advice and Liaison Service

CQC: Care Quality Commission

CSSC: Clinical Support Services and Cancer Division

QAC: Quality Assurance Committee

HPCT: Hospital Palliative Care Team: the Specialist Palliative Care Team employed by, and presently working within NDHT

DQLG: Divisional Quality and Learning Group

MRC: Mortality Review Committee

ACP: Advance Care Planning (included in Ref 6) – any plans for the future relevant to end of life care before and after death. These may be in the form of written documents or verbally expressed wishes. Such documents may include:

- Do not attempt resuscitation
- Preferred Priorities of Care
- Advance Decision to Refuse Treatment (has legal standing) Lasting Power of Attorney (has legal standing)
- A Last Will and Testament, or Funeral Plan
- of “memory boxes” or other material for family members

7. Ownership & Responsibilities

End of Life Care delivery comes under the Executive ownership of the Director of Nursing. The board Chairman is the EOLC champion. There is an End of Life lead who is currently funded until December 2016 who will put forward a business case to develop EOLC requirements for the future.

Members of the NDHT, end of life steering group (EOLSG) and representatives from primary care including GPs and Community Hospital Managers, have also been involved in the development of processes to aid End of Life discharges and transfers from North Devon District Hospital (NDDH) to other settings of care. This includes provision of resource material to wards across the trust. Use of these resources is supported by specialist input and advice from the Hospital Palliative Care Team (HPCT) and those staff involved with assessments for funding / social care packages and equipment (Occupational Therapists and Discharge Liaison nurses). This material resource will be reviewed regularly by members of the group, and made available electronically in the future.

The NDHT EOLSG, in consultation with members of the HPCT, have been responsible for drafting and finalising this strategy document.

The strategy has been presented to the Quality Assurance Committee in draft and final format, and that Committee have approved the Strategy for use across NDHT

Prior to the submission of the final format of the strategy a “Listening into Action” event was held

The scope of the strategy will necessitate „ownership“ of delivery of EOLC at ward and clinical area level. This ownership will include identifying potential areas of care needing improvement, auditing delivery, and developing action plans to improve, then evidencing improvement by completing the audit cycle. The NDHT EOLSG will engage with Wards, Community teams Clinics and Specialties as appropriate to support such ownership, and provide information and advice to support development of appropriate audit and other forms of monitoring of delivery of care (such as patient or family feedback). However, the group cannot provide time or manpower to actually engage with the direct audit process. This resource will have to be provided from within the Specialty, Ward or clinical area being audited.

Any audits with an End of Life Care theme should be registered with the Quality and Safety department via the normal process, including a specific reference to an aim to improve delivery of EOLC in the stated setting or staff group. Hence performance of such audit will be possible to monitor. It is anticipated that an EOLC audit should form part of Specialty audit plans on an annual basis. Performance of such audits, or other care improvement initiatives should be facilitated and enabled via Link staff posts when ward-based.

The NDHT EOLSG monitor trust-wide quality of end of life care delivery, receiving quarterly reports regarding the numbers (and general areas of care delivery) of Complaints, Datix Incident reports, PALS contacts and Compliments which appear to have an end of life component. Ongoing work is being done to improve the quality and coverage of collection of such data.

Risk regarding delivery of EOLC is monitored via the NDHT EOLSG, and risk level is presented for review by the Chair of that group to the CSSC Divisional Governance Board (where the Chair’s employed post sits)

A quarterly report is submitted by the Chair of the NDHT EOLSG in draft form to the Divisional Governance Board meeting, and then finalised for submission to the Governance Committee, again on a quarterly basis. A report (and/or presentation) is also submitted to the Divisional Quality and Learning Group (DQLG) on request. The Chair of the NDHT EOLSG is also a member of the Mortality Review Committee (MRC), and this provides another route to identify potential areas of concern over deaths within the acute trust.

7.1. Role of the Managers

Line managers are responsible for:

- Ensuring that the staff whom they manage are aware of, have access to, and act upon, this strategy as relevant to their areas of work. This includes new and existing staff.
- Supporting development and delivery of audit or other service improvement projects relevant to this area of care.
- Assessing the education and training needs of their staff to support their provision of such care, and arranging appropriate access to such education and training

7.2. Role of the NDHT End of Life Care Steering Group

The NDHT End of Life Care Steering Group is responsible for:

- Receiving quarterly reports from the End of Life Lead
- Participating in the development and submission of any Business Case for substantive funding of that post in the future.
- receiving quarterly reports from the Complaints Department regarding Complaints, Datix Incident reports, PALS enquiries and Compliments relevant to EOLC delivery
- Reviewing and suggesting appropriate changes in the “Risk” level recorded for End of Life Care delivery across the trust, and reporting to the Clinical Services Executive Committee.
- Developing a Work plan, including a timetable for delivery of specific aims and objectives of the group (such as engagement with Specialties regarding Specialty level monitoring of quality of care delivered at the end of life).
- Contributing to a quarterly report delivered to the Governance Committee by the Chair of the group
- receiving specific reports from Specialty representatives at their request, or as invited by the group, in order to maintain an overview of introduction of guidelines and policies across NDHT which have relevance to EOLC delivery
- Supporting Wards, Specialties, clinical and community areas to engage in audit activity or other appropriate service improvement

projects to enhance the quality of care provided at end of life, providing specialist advice where and when useful.

8. Benefits

To Patients and Family Members / Carers - an improved experience of care at the end of life, especially through improved communication, and the „flexibility“ to meet specific needs or requests at this time.

To Staff – improving confidence in their ability to discuss areas of end of life care with patients and family members, and in their delivery of high quality end of life care wherever they work and whatever such care comprises, e.g. Via provision of education and training, and where necessary emotional support, to such staff.

To Staff – providing an ability to evidence and monitor changes in care given and their impact on quality care at the end of life

To the Trust – enhancing its reputation as an organisation that recognises, and is sensitive to, the needs of the most vulnerable of its patients and their families, and which is committed to supporting quality care at the end of life.

To the Trust – to enable work which in other trust settings has led to improved achievement of patients Preferred Place of Care at the end of life, reduced re-admissions and bed days in the last year of life. Hence there is the potential to reduce costs to the trust in the future.

9. Risks

If not implemented, risks could include

Significant distress to patients and family members / carers at a very vulnerable time

Distress to members of staff who do not feel supported, enabled or encouraged to deliver excellent care, whether because of lack of access to training, lack of support from their line management team, or lack of time due to staffing levels.

Complaints to the Trust re its provision of care (often by bereaved relatives or carers of a deceased patient)

Adverse publicity via local media regarding instances of less than satisfactory care

10. The Strategy

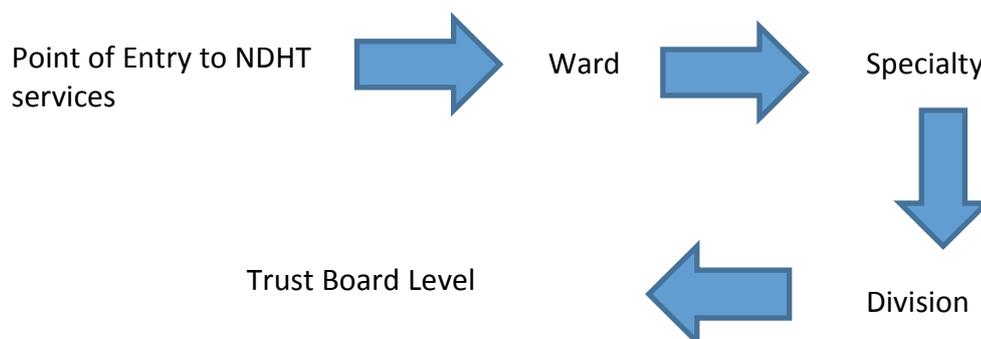
10.1. Principles

The principles outlined below are seen as priorities needing to be fully supported and embedded in practice. Real commitment is required, rather than any „lip service“, if this strategy is to be effectively implemented.

**‘End of Life Care is NOT ONLY everybody’s business
BUT ALSO everyone’s responsibility’**

- A culture change is necessary – no member of staff should feel unable to discuss an issue or raise a concern
- Values and attitudes should reflect commitment to compassionate care
- Any member of staff should feel comfortable if a patient, family member, or carer approaches them with any question or request related to provision of EOLC
- All staff should know at minimum whom to pass such a query or request on to, and should signpost the patient, family member or carer appropriately, or undertake to inform the appropriate member of staff re the question or request, to take forwards and respond to
- Ownership of improvement of care is an essential part of this strategy
- Including use of feedback from patients, families and staff, and ward-based audit

Support is vital from:



Support is also vital from entry of patient to the Trust, to discharge or transfer out of the Trust. This should include appropriate arrangements for transport, and communication of medical and nursing handovers re ongoing care needs (see Rapid Discharge pathway)

This will include appropriately resourced Ward audit and education programs, Specialty and Divisional reports, and, at minimum, an annual report to the Trust Board delivered in person by an EOLC Lead in a position to speak from experience and knowledge of what is happening on the ground

Appropriately resourced Education and Training Led by assessment of learning needs

- Tailored to individual disciplines, and to specialist needs of clinical areas
- empowering all staff to have input to meet patient/family or carer needs to the limit of their competence and experience
- Focusing on communications skills, from basic to advanced dependent upon level of input (e.g. including basic communications skills re end of life scenarios within customer care training, specific end of life care training at induction or other identified appropriate point)
- Identifying and addressing some areas of common ground e.g. spiritual/pastoral care needs assessment

10.2. We will achieve OUR PROMISE and PRINCIPLES by:

- Engaging in awareness raising activity using appropriate communication modalities, including key personnel / teams to contact with any questions re end of life care
- Adopting a focus of „compassionate, patient and family-centred care“, utilizing individual plans of care tailored to meet the specific needs of that patient.
- Accepting that death and dying are a part of life, and that care rather than cure becomes the appropriate focus.

- enabling whole team ownership of, and pride in, the delivery of quality care at the end of life
- breaking the “taboo” around discussion of death and dying and fostering a culture of acceptance, not fear, of discussion of death and dying to the limit of a patient’s wishes
- Identifying a key member of staff to co-ordinate the end of life care of each individual patient and family. Ensuring there is an identified member of staff on each shift whose responsibility it is to “be there” to fulfil needs of patient and family. Agreeing a process for each ward area to ensure handover of plan of care between shifts to maintain continuity of care, especially care specifically meeting individual patient requests. Patterns of working may need to be reviewed to enable this
- Encouraging continuity of care by use of a single point of documentation of care (e.g. as on wards where nursing, medical and allied health professional documentation is held within one folder). Duplication of record keeping, and unnecessary paperwork should be kept to a minimum. The emphasis should be on recording communication and discussion, especially discussions with patient and/or family, and multi-disciplinary team discussion and decision making. Records should evidence provision of quality care, or any failures in delivery of such care, including what the causes were and what has been done to address them for the future.
- Sharing information and involving patients and families in decision-making regarding treatment options to the limit of their wishes and not beyond.
- Ensuring family members are aware it is NOT their responsibility to make decisions about treatment, but rather to allow and encourage them to inform the clinical team what the patient’s wishes might have been, from their experience, if the patient lacks capacity or is too unwell to communicate. (NB, any person holding Lasting Power of Attorney for Health and Personal Welfare is legally entitled to be involved in the discussion of treatment options and other broader facets of care)
- Being open and honest in all such discussion INCLUDING being honest about uncertainty. Being flexible in the timing of such discussion to meet the needs of patient and family members.

- Recognizing and addressing issues of respect, privacy and dignity. This should include avoiding transfers between wards around the hospital, except an initial move
- From the “point of entry” to the trust, OR from the place the patient is in when end of life needs are recognized, to the place identified as most appropriate to meet that patient’s end of life care needs. Acknowledging that if an inpatient privacy for patient and family may be restricted by availability of side rooms, but achieving this principle as far as possible
- Adopting a positive attitude to achieving the best possible outcomes including:
 1. “Normalising” care as far as possible by enabling eating / drinking / communication / visiting / fast-track discharge planning when prognosis very short etc.
 2. Ensuring that the basic comfort care needs of patients at the end of life are met AS A PRIORITY, including pain and symptom control, and support to distressed patients and family members, and allowing for necessary staffing to support this, with appropriate specialist support as required wherever the patient is cared for.
 3. Fulfilling unusual requests, or “flexing” the rules where necessary
- Empowering staff, patients, and family members to challenge poor or inadequate care whenever and wherever witnessed
- Exploring options to make basic supplies (such as pillows, mouth care provision, clean laundry – pyjamas etc.) and specialist equipment (such as pressure area mattresses, suction equipment, syringe drivers, communication aids) available to patients at short notice and via one point of contact 24 hours a day, 7 days a week. This includes equipment required to support safe discharge to home or another setting of care as assessed by specialist therapists and discharge personnel
- Challenging fears and empowering and enabling staff to provide this care, via education and training, and support to staff in unfamiliar or distressing situations at whatever level required. Planning for the necessary time commitment and accessibility to fulfil education and training needs is key to this provision

- Engaging with other providers to co-ordinate provision of end of life education and training across all settings of care, using appropriate expertise and experience of any and all staff available and willing to participate in such provision. This should concentrate on advance care planning to facilitate fulfilment of patient choice, including re place of care, and reducing re-admissions to hospital when a patient has expressed a wish to avoid.
- Recognising that regardless of availability of education and training as an in reach from outside providers, there are significant areas where there will be a need for a specific facilitator post within NDHT Learning and Development, held by someone with an intimate knowledge of acute trust working. Experience of previous work within NDHT would be an advantage to any person holding such a post.
- Using established models of cascade of education, use of role models, or a “Buddy” system where appropriate and available e.g. via practice area-based Link staff
- Measuring our practice via patient, family and staff feedback, and/or regular audit to improve our standards of care wherever possible.
- Assessment documentation is provided on each ward via BOB, the electronic Intranet to prompt staff to have conversations around patient preferences and Wishes and ensure these are recorded.
- Exploring electronic options of use of documentation, and options to support communication across settings of care. This may include use of existing IT tools such as EPaCCS, development and use of future software to co-ordinate the care of the dying across settings of care in North Devon, or may be via provision of the advice and documents in existing Resource folder in an Electronic format, e.g. via BOB, or any combination of these and other options proposed.
- Ensuring access to specialist advice is available 24 hours a day 7 days a week, at minimum via telephone contact, with face-to-face visiting access as provided via acute trust and other provider service development. Ensuring staff in all areas aware of how to access this advice

10.3. Steps in Strategic Framework

(Examples only, for detail of each step see Appendix 1)

(Based on Steps within „The route to success in end of life care – achieving quality in acute hospitals“ National End of Life Care Programmed, July 2010,)

Step	Step 0	Step 1	Step 2	Step 3	Step 4	Step 5	Step 6
Description	Identification of patients approaching the end of life	Discussion as end of life approaches	Assessment, Care Planning and Review	Co-ordination of care	Delivery of high quality care in an acute hospital	Care in the last days of life	Care after death
Examples of Priorities	Identify early in admission, information gathering Communication on discharge	Key worker each shift for patient and family MDT decision-making	Individualised Care Plans Holistic assessment patient AND carer needs	Real-time communication across settings of care Identification of Preferred Place of Care	Fulfilment of specific wishes Access to specialist review when needed	Good Symptom control Information and discussion including Bereavement Office etc.	Respect for the patient's body and family needs Avoidance of delays where possible, in provision of documentation, or discussion with coroner

Common Themes:

- Senior clinical decision-making including views of team close to the patient, and an appropriately trained and supported workforce
- Regular discussion including all forms of 'Advance' Care Planning'
High quality end of life care making best use of resources
Resourced Education and Training
- Regular audit and/or feedback from patients, family and staff
- Strong governance including board oversight and senior management engagement

10.4. Time Scale

Work Plan will be agreed and monitored via NDHT End of Life Care Group – see table below for **examples** of approximate timelines

End of Life Lead post– funded for 12 months from December 2015

Projects / Future Plans	How will be achieved / Lead	Timescale	Outcomes sought	Challenges / Measurement
Assessment of End of Life Education and Training Staff have already accessed, and what they prioritise for the future			Insight into baseline level of training and what staff feel needs to be prioritised	Repeat survey minimum annually to track changes
General Education and Training Programme to fulfill needs Multidisciplinary delivery to any staff identifying a need	Examples: Early evening End of Life training sessions Training „on request“ flexible time and venue to clinical areas and teams Set up of cross-setting provider group for End of Life Education strategy		Improving knowledge of vital areas of end of life care Education tailored to fit specific staff or area needs Best use of expertise and time resource across care settings	Attendance records and feedback. These events were poorly attended Resource to deliver Will need to be responsive and tailored to changing need over time As above

Projects / Future Plans	How will be achieved / Lead	Timescale	Outcomes sought	Challenges / Measurement
A programme of Multi-disciplinary Communications Skills Training		<p>Hopefully a programme to be agreed</p> <p>May include delivery via induction, customer care, targeted training to specific staff groups etc.</p>	To enable any and all staff disciplines to acquire the necessary skills to support communication with patient and family around end of life issues at the appropriate level	<p>A very broad and on-going programme required to cover staff turnover.</p> <p>Measure success by rates of access, and feedback from staff AND from patients and families</p>
<p>Education and Training to support use of Prompts and Guidelines for End of Life Care in last few days</p> <p>Intensive Ward based Education</p>	Future wards will be targeted according to where greatest number of deaths occur		<p>Best Practice in End of Life Care in last few days. Staff confident in ability to deliver, and how to ensure happens</p> <p>Excellent communication with patient and family led by Senior Clinicians, Medical and Nursing.</p> <p>Excellent standards of documentation of discussions and clinical decisions</p>	Continuous and contemporaneous audit of appropriate proportion of deaths

10.5. Other Measurements of Improvement of Care:

How will we know if we are doing better?

The NDHT End of Life steering Group already has a mechanism in place to track numbers of Complaints, Datix incidents, PALS contacts, and Compliments with an End of Life component or theme. These will be analysed individually to see if themes of problems encountered, or of best practice, can be identified, and whether they change over time. Variation by ward will be included in this analysis, so that wards which have or have not had specifically targeted End of Life Education and Training can be differentiated.

We will have general feedback from Staff Survey and Friends and Family Test looking at wards where initiatives have been in place, and if there are any differences between these wards and those not yet targeted.

The NDHT End of Life Steering Group will produce a Work Plan which will include projects to specifically try to gain feedback regarding End of Life Care.

All such information will be sought in a sensitive and compassionate way, ensuring that any contributors are aware that our sole aim is to improve future provision of End of Life Care, and learn from the experience of patients, family members and carers, and staff.

10.6. Summary & Conclusion

This will be the first time that NDHT has adopted a comprehensive and meaningful strategy addressing the needs of patients, family and carers at a time when they are most vulnerable. It is responsive to the recent findings of the Francis Report and Liverpool Care Pathway Review, Only one chance to get it right and the NICE draft end of life publications, and prioritises compassionate care.

It acknowledges that ALL staff contribute to the care of the dying, and should all have access to education and training to support their role in delivery.

The potential to deliver excellent care is present in every care setting and in every member of staff. The first step in realising that potential is to promote open and honest communication with patients, family members and carers, between different clinical teams and different staff disciplines, and across settings of care to both health and social care professionals.

There are major challenges, starting with a culture change and addressing fears experienced by patients, family members or carers, and staff, regarding how to approach End of Life Care. The changes will not be rapid, and will need commitment over a prolonged period of time if best practice is to be consistently achieved across the trust. Success will depend upon commitment of individual members of staff at ward level, up to active support by the Executive Team and

Board. Ownership of delivery of end of life care at every level is essential to the success of this strategy.

11. Implementation and Action Plan

Acknowledging the fact that end of life care is part of CORE acute trust business, and the importance and universal relevance of this strategy across virtually all areas of the Trust, the launch of the strategy will be supported by significant publicity to be arranged in consultation with the NDHT Communications team. This may include:

- “Events” at each acute trust site
- Use of trust wide communication including Chief Executive Bulletins and a feature in the Pulse magazine
- Possible press release to support the launch visible coverage on the Intranet.

The Strategy will be available via the Intranet Document Library, and circulated via Policies and Guidelines bulletin.

Some specifics of timeline of certain actions to support this strategy are detailed on pages 14-17 above.

12. Monitoring compliance and effectiveness

Element to be monitored	
Lead	
Tool	
Reporting	

Reporting arrangements	<p>As above, to NDHT End of Life Steering Group, CSSC Governance Board and Governance Committee.</p> <p>Reports reviewed (and summary presented in person on request) at the above groups, and should be recorded in minutes of those meetings</p> <p>The responsibility for monitoring of data quality in terms of Complaints, Datix Incidents, PALS queries, and Compliments, and Risk Review lies in the first incidence with the NDHT End of Life Steering Group, and review is recorded in minutes of that group. Data quality is thoroughly reviewed and necessary actions to improve any deficiencies identified are recorded as actions in the minutes.</p>
Acting on recommendations and Lead(s)	As above
Change in practice and lessons to be shared	<p>This Strategy identifies the need for each clinical area, ward and Specialty to take ownership of delivery of end of life care, and develop their own means of reviewing quality delivery of such care in their particularly setting or specialty. This may be via audit or other projects. Audits will all be required to be registered in a way that records their relevance to end of life so that the registration, performance and actions from these will be possible to monitor via the Quality and Safety (audit) department. Each area will specify their own timeline for completion of such audits and projects, and monitor the dissemination of results and lessons learned, and the timeline for completion of resulting actions.</p> <p>The NDHT End of Life Steering Group will note the number and subject matter of such audits or projects, but does NOT take the responsibility for completion of stated action plans, which will devolve to the Ward, clinical area, or Specialty under which performed.</p>

13. Update and Review

This Strategy will be revised on a 12 monthly basis to reflect changes in time lines and end points of proposed actions, and any changes in names / roles of the author / Executive Lead or Divisional Manager

The strategy will be reviewed and formally updated in month year, as the strategy is only written to cover a three year period

14. Equality Impact Assessment

This document complies with the Northern Devon NHS Trust service Equality and Diversity statement which can be found in the 'Equality, Diversity & Human Rights Policy' or the Equality and Diversity website.

Equality Impact Assessment

Group	Positive Impact	Negative Impact	No Impact	Comment
Age	X			
Disability			X	
Gender			X	
Gender Reassignment			X	
Human Rights (rights to privacy, dignity, liberty and non-degrading treatment)	X			
Marriage and civil partnership			X	
Pregnancy			X	
Maternity and Breastfeeding			X	
Race (ethnic origin)			X	
Religion (or belief)			X	
Sexual Orientation			X	

15. References:

- 1 National End of Life Care Strategy 2008, London, Department of Health
- 2 The Mid Staffordshire NHS Foundation Trust Public Enquiry Chaired by Robert Francis QC. Final Report Feb 2013 HC 947 London
- 3 “More Care, Less Pathway”: Independent Review of the Liverpool Care Pathway, Chair: Rabbi Julia Neuberger, July 2013
- 4 Service Level Document End of Life Care Final Dec 2013, for CQC Inspection Jan 2014
- 5 The route to success in end of life care – achieving quality in acute hospitals. National End of Life Care Programme, July 2010
- 6 Summary of outcomes from “listening into Action” event held
- 7 Pilot Guidance and Prompts in the last few days, including Medical, Nursing and Symptom Observation charts
- 8 AMBER Care bundle Information and registration letter (to participate in a National Programme of implementation)

Appendix 1: Guidance for Doctors and Nurses Caring for People in the Last Days of Life

Decisions, Discussions and Documentation

Any decision that a person who is an inpatient at NDDH is likely to die in the next few days should be taken by the multidisciplinary team, led by Consultant, **NOT** by any one individual healthcare professional.

This decision should be reviewed regularly (daily if possible) to ensure no change in condition possibly indicating improvement, however unexpected, may be missed

Immediately such as decision is reached, discussion and communication with the patient, and/or family members should take place. Such conversations should where possible be with the involvement and leadership of senior medical and nursing staff, ideally Consultant and Sister / Charge Nurse.

If the patient has capacity, all discussion should be with patient (unless they do not wish to discuss), and with family members only with the patient's permission. If the patient lacks capacity, then discussion **MUST** take place with any person holding **Lasting Power of Attorney for Personal Health and Welfare** purposes. Discussion should take place with family members or carers whenever possible.

Discussion should include the following areas:

- **WHY** the clinical team feels the patient is now dying
- **Do not attempt resuscitation** decision and documentation (if not already completed)
- **Ceiling of treatment** / continuation or not of active treatment (e.g. antibiotics for sepsis)
- **Nutrition:** Explanation of needs / experience or not of hunger / impact on outcome if withheld (e.g. unlikely impact if short-term, over days) / risks of aspiration etc.
- **Hydration:** Explanation of needs / experience or not of thirst / dry mouth and measures to combat. Potential dangers of administration of parenteral fluids / impact on outcome and over what timescales (days to >1 week)
- Fluids and food should **never be withheld** from a patient who desires to eat or drink **UNLESS** administration would cause **GREATER** distress than withholding (e.g. extreme choking / respiratory obstruction risk)
- Any other relevant discussion specific to individual case, e.g. diabetes monitoring/Treatment

Outcomes of such discussions, including those present / involved, their roles, date and time, should be recorded in the patient's medical notes (and as appropriate in nursing notes as well). The entry should be signed and name and role of person recording printed, with bleep or extension number if relevant.

General Advice

Doctors and Nurses should also:

- Assess the patient regularly and frequently so that any end of life care plan can be made or adjusted, taking into account the patient's wishes (where known) and Family's views.
- Communicate with the patient (wherever possible) and family/carers regularly to address questions or concerns about any aspect of care. This opportunity must be presented regularly to follow up on any queries arising from the initial discussion as previous. In particular, families need to continue to be updated if the time remaining becomes clearer, so that they have time to begin preparing themselves, and communicate with family members further away who may wish to travel to visit.
- Ensure that a regular Senior review of the (dying) status of the patient, and their individual plan of care, takes place. These reviews should ideally be by the Consultant/GP and team who best know the patient. The patient (where possible) and family/carers should continue to be consulted and their agreement with the on-going plan confirmed. Any changes to the plan of care resulting from such discussions should be recorded in medical and nursing notes as appropriate, documenting who involved etc. as in the initial discussions. If there is dispute re the proposed plan of care, an Independent Mental Capacity Advisor could be consulted if the patient lacks capacity and dispute is with family members, and **should** be involved if dispute involves anyone holding Lasting Power of Attorney for Personal Health and Welfare involved. A second medical opinion may also be helpful in these situations.
- Continue to pay attention to, and address, symptom control and comfort measures (including offering oral fluids and good mouth care), and provision of psychological spiritual care.

Contacts Details for Advice

If you would like help or advice re end of life care in last few days, including symptom control advice, please contact:

In working hours: Hospital Palliative Care Team via 01271 311642 ext. 3642

Out of working hours (overnight and weekends): Specialist Palliative Care Advice Line North Devon Hospice 01271 347214 or Hospiscare 01392 688000

Continue normal baseline nursing care until you have the opportunity to contact team as above

Prompts for Nurses and Doctors which may promote quality

Care towards end of life, in last few days.

Nurses: Use Clinical Judgment, aide memoire below

Comfort Rounds for symptom control (suggested minimum hourly)

Nursing Observations – only if will contribute to quality care OR influence management:

Turning – interval between turns determined by pressure area risk and visualisation of

Pressure areas:

If patient visibly or audibly in discomfort, or non-specifically restless / agitated: MOST COMMON REASONS ARE RELATED TO BLADDER AND BOWELS: Check Bladder (catheter draining / evidence of urinary retention) and Bowels (if BNO>3 days PR assessment and suppositories if loaded rectally)

Document outcome

Check needs of patient / family for information including and support spiritual needs.

Document outcome

Inform Chaplaincy team if spiritual (not just religious) needs identified:

Or via NDDH switchboard for on-call Chaplain if out of hours

Doctors: Use Clinical Judgment, aide memoire below

A - Review regular medication:

Continue / start active treatment to agree limits previously

discussed. Set a review date.

B - Review other medications and stop ONLY if:

- There has been a decision to discontinue specific active medication e.g. antibiotics, anticoagulants
- Medications are not contributing to quality of life / symptom control (e.g. need to CONTINUE diuretics in L heart failure as may aid control of dyspnoea, need to CONTINUE anti-convulsants in some form – see advice re midazolam in accompanying prescribing information)
- Patient will not miss the medication (e.g. if patient has been steroid dependent for some time abrupt withdrawal may provoke unnecessary and distressing symptoms of fatigue, nausea and vomiting)
- Medication burdensome e.g. multiple oral medications when weak or difficulty swallowing, or very dry mouth

**If patient unable to take tablets, convert what necessary to a parenteral route
(Usually sub-cut, but could be IV if access available)**

C - Prescribe PRN medication

- As per accompanying prescribing guidelines
- Remember may need to use alternative medications in renal failure. Ideally discuss with specialist palliative care team:

Renal opioids:

Oxycodone (e.g. Oxynorm) IR Alfentanil or Fentanyl sub-cut

Renal Anti-Emetic: Haloperidol

Renal medication for Respiratory Tract Secretions: Glycopyrronium Bromide

Midazolam use remains the same in renal failure

Appendix 2: Prescribing Guidelines for Symptom Control

The End of Life Care Strategy - Prescribing Guidelines" has been published separately and can be accessed via

BOB specialist Palliative care Symptom Guidelines @

<http://ndht.ndevon.swest.nhs.uk/policies/?p=5306>

Appendix 3: Governance Information

Document Title	NDHT End of Life Care Strategy			
Date Issued/Approved:				
Date Valid From:				
Date for Review:				
Directorate / Department responsible (author/owner):				
Contact details:	01271 334472			
Brief summary of contents	A strategy to support the delivery of high quality end of life care. This includes care given to a patient and their family / carers when the patient's prognosis is likely to be less than 1 year.			
Suggested Keywords:	End of Life, Culture Change, Ownership, Audit, Education and Training, Staff support.			
Target Audience	NDHT			
	?			
Executive Director responsible for Policy:	Nursing Director			
Date revised:	New Document			
This document replaces (exact title of previous version):	New Document			
Approval route (names of committees)/consultation:				
Divisional Manager confirming approval processes				
Name and Post Title of additional signatories				
Signature of Executive Director giving approval				
Publication Location (refer to Policy on Policies – Approvals and Ratification):		?		
Document Library Folder/Sub Folder	Clinical / Palliative Care			

Links to key external standards	
Related Documents:	
Training Need Identified?	