NHS
Northumberland,
Tyne and Wear
NHS Foundation Trust

Document Title	End of Life Care Policy
Reference Number	NTW(C)49
Lead Officer	Anne Moore - Group Nurse Director, Safer Care
Author(s) (name and designation)	Dennis Davison Associate Director Dorothy Matthews MacMillan Nurse
Ratified by	Business Delivery Group
Date ratified	May 2016
Implementation Date	May 2016
Date of full implementation	May 2017
Review Date	May 2019
Version number	V02.1

	Version	**Type of change**	**Date**	**Description of change**
Review and Amendment Log	V02	Review	May 16	Reviewed documentation
	V02.1	Update	Sep 17	Update due to clinical supervision

This policy supersedes the following policy which must now be destroyed:

Document Number	**Title**
NTW(C)49 – V02	End of Life Care Policy

Care of the Dying Policy

Policy appendices listed separately

Title	Content	Issue	Issue Date	Review Date
Appendix 1	Preferred Place of Care Document (PPC)	1	May 16	May 19
Appendix 2a	End of Life Documentation Pack –Caring for the Dying Patient **- NTW Inpatient Services**	2	Jun 16	May 19
	• Index – Core Care Plans • Caring for the Dying Patient – Relative/Carer Information			
	Medical Assessments			
	• Medical Assessment - Recognition Patient is Dying • Medical Assessment - Developing a Plan of Care • Medical Assessment – Nutrition and Hydration • Medical Assessment – Plan of Care and Communication			
	Initial Holistic Nursing Assessment (physical problems, social/environmental concerns, emotion wellbeing and spiritual/religious needs)			
	• Initial Nursing Assessment Summary • End of Life Core Nursing Care Plan • Nursing Communication with Patient and/or Relative/Carer			
	Daily Ongoing Assessment			
	• Caring for the Dying Patient - Daily Ongoing Assessment • Caring for the Dying Patient – Ongoing Nursing Care • Caring for the Dying Patient – Medical Reassessment • Caring for the Dying Patient – Multi-Disciplinary Notes			
	Care After Death			
	• MDT Notes			
	Pain at End of Life			
	• Supplementary information • Opioid Dose Conversation Chart to be used at the End of Life • Nausea and/or vomiting at the End of Life • Restlessness and /or Agitation at the End of Life • Respiratory Tract Secretions at the End of Life • Breathlessness at the End of Life • Guidelines for the management of person with TYPE 1 DIABETES towards the End of Life • Guidelines for the management of person with TYPE 2 DIABETES towards the End of Life • Supply of Specialist Drugs in the North of Tyne Area • List of Drug Preparations • Specialist Drugs • Pharmacies which stock specialist drugs • Community 24 Hour Advice for Health Care Professional			

Appendix 2b	End of Life Documentation Pack –Caring for the Dying Patient **- NTW Patients in Community Services**	2	Jun 16	May 19
	• Index – Core Care Plans • Caring for the Dying Patient – Relative/Carer Information			
	Medical Assessments			
	• Medical Assessment - Recognition Patient is Dying • Medical Assessment - Developing a Plan of Care • Medical Assessment – Nutrition and Hydration • Medical Assessment – Plan of Care and Communication			
	Initial Holistic Nursing Assessment (physical problems, social/environmental concerns, emotion wellbeing and spiritual/religious needs)			
	• Initial Nursing Assessment Summary • End of Life Core Nursing Care Plan • Nursing Communication with Patient and/or Relative/Carer			
	Daily Ongoing Assessment			
	• Index – Core Care Plans • Caring for the Dying Patient – Relative/Carer Information			
	*** FOR COMMUNITY PATIENTS ONLY:** **Community Prescription Chart**			
	• *As required (PRN) Medication • *Regular Medication – 24 hour continuous subcutaneous infusion • *Compatibility Chart			
	*** Drug Administration Record**			
	* **Controlled Drugs Stock Balance**			
	Care After Death			
	• MDT Notes			
	***Verification of Death (Community Patient Only)**			
	Pain at End of Life			
	• Supplementary information • Opioid Dose Conversation Chart to be used at the End of Life • Nausea and/or vomiting at the End of Life • Restlessness and /or Agitation at the End of Life • Respiratory Tract Secretions at the End of Life • Breathlessness at the End of Life • Guidelines for the management of person with TYPE 1 DIABETES towards the End of Life • Guidelines for the management of person with TYPE 2 DIABETES towards the End of Life • Supply of Specialist Drugs in the North of Tyne Area • List of Drug Preparations • Specialist Drugs • Pharmacies which stock specialist drugs • Community 24 Hour Advice for Health Care Professional			

Policy appendices listed separately				
Title	**Content**	**Issue**	**Issue Date**	**Review Date**
Appendix 3a	**BOOKLET –** When Someone is Dying – Easy Read	2	Jun 16	May 19
Appendix 3b	**BOOKLET –** When Someone is Dying	2	Jun 16	May 19
Appendix 4a	**BOOKLET –** End of Life - Grieving	2	Jun 16	May 19
Appendix 4b	**BOOKLET –** Grieving – Easy Read	2	Jun 16	May 19
Appendix 5	NICE – Adults in the last days of life	2	Jun 16	May 19
Appendix 6	Presence of advance Decisions and End of Life Flag Referral	2	Jun 16	May 19
Appendix 7	Deciding Right - Discussing future care with patients v19 - algorithm	2	Jun 16	May 19
Appendix 8	Contact telephone numbers and email addresses for NTW clergy	1	May 16	May 19
Appendix 9	Care Plan Accountability for Dying Patient	2	Jun 16	May 19
Appendix 10	Core Care Plan – Agitation Core	2	Jun 16	May 19
Appendix 11	Core Care Plan – Community Nursing	2	Jun 16	May 19
Appendix 12	Core Care Plan – Communications	2	Jun 16	May 19
Appendix 13	Core Care Plan - Dyspnoea	2	Jun 16	May 19
Appendix 14	Core Care Plan - Nursing	2	Jun 16	May 19
Appendix 15	Core Care Plan – Nausea and Vomiting	2	Jun 16	May 19
Appendix 16	Core Care Plan - Pain	2	Jun 16	May 19
Appendix 17	Core Care Plan – Respiratory Tract Secretions	2	Jun 16	May 19
Appendix 18	Core Care Plan – Spirituality Core	2	Jun 16	May 19

1. Introduction

1.1 Northumberland Tyne and Wear NHS Foundation Trust (the Trust/NTW) is committed to ensuring that patients receive high quality care, that is holistic, evidence based, safe and enhances the patients experience, this includes end of life care; where we have “only one chance to get it right”

1.2 Currently there are 15 million people in England with a long term condition (LTC) and by 2025 the number of individuals with at least one LTC will rise to 18 million. The number with two or more LTC is projected to increase from 5 million to 6.5 million. Most of these people will require palliative /end of life care as they approach their last years, months and days of life. It is therefore imperative that NTW staff have an awareness of their responsibility in supporting the needs of these patients.

1.3 The purpose of this guidance is to assist clinicians in enabling the identification of individuals nearing the end of their life, outlining best practice principles and a comprehensive framework for providing appropriate support to patients, carers and family.

1.4 Whilst the delivery of specialist end of life (EoL) is not the main clinical role of NTW Trust staff it is acknowledged that teams may care for patients who have life threatening / life limiting conditions i.e. cancer or none cancer including frailty, dementia, heart failure and also individuals with co-morbidities such as chronic obstructive pulmonary disease (COPD) where identifying the end of life phase can be difficult. As people live longer there will be an increase, in the numbers of our patients who have long-term, advanced conditions and who will require more complex skilled support towards the end stages of their lives.

1.4.1 Trust service areas that are deemed appropriate to deliver palliative / end of life care will be identified by the Group Nurse Director and Associate Director, staff will be supported to develop the appropriate skills and attend training as required.

1.5 The preferences and wishes of Patients and families must be adhered to wherever possible. The philosophy of holistic care should also continue after death and into bereavement with support being available for family/friends/carers as appropriate.

1.6 Delivery of effective and holistic EoL care requires early detection (including by Trust staff utilising results from the physical health assessments undertaken by staff) and then a holistic and whole systems approach with Trust staff care planning and working with other services, for example primary care, specialist palliative care nurses, hospices, out of hour’s medical support, social services etc.

1.7 The National Institute for Health and Care Excellence (NICE) Quality Standard for End of Life Care for adults (2011) provides a comprehensive picture of what high quality end of life care should look like, NTW covenants the guidance and is committed to improving the effectiveness , safety and experience of patients approaching the end of their life.

1.8 Good end of life care supports those with advanced, progressive, incurable illness to have a quality of life that is personalised, dignified and as pain free as possible, to help them to live as well as they can throughout the last phase of their life and into bereavement. This care includes the management of pain and other symptoms and the provision of psychological, social, spiritual and practical support. The provision of EOLC is not solely confined to specialist end of life care services, end of life care can be provided by identified groups of NTW staff who work within service areas which as part of their clinical practice can provide care for individuals approaching the end of their lives.

1.9 The Trust provides care to a wide range of service users with varying needs, CQC highlight within their report *A different Ending* (2016) that the end of life care of some groups of people is not always considered and understood under the Equality Act (2010) It is essential therefore that staff have an awareness of the inequalities service users in minority groups may face in accessing appropriate end of life care and that staff strive to ensure that end of life care for individuals within NTW services is delivered to a high standard.

2 Purpose

2.1 As an organisation NTW recognises the importance of end of life care as an integral part of the good health and social care that everyone should receive when they have a life limiting or life threatening diagnosis. Following the review and subsequent withdrawal from practice of the Liverpool Care Pathway in 2014, NTW have worked collaboratively with colleagues across the region to develop alternative documentation and education to ensure the continued provision of high quality palliative and end of life care for individuals who may access NTW services.

2.2 The purpose of this policy is to provide clinicians with guidance which will assist in enabling the identification of individuals nearing the end of their life, thus providing a comprehensive framework for providing appropriate timely end of life care extending into bereavement support for relatives and carers.

3 Duties and Responsibilities

3.1 The Chief Executive on behalf of the Trust retains ultimate accountability for the health, safety and welfare of all service users, carer’s staff and visitors however; key tasks and responsibilities will be delegated to individuals in accordance with the content of this policy

3.2 **The Medical Director and Executive Director of Nursing Operations are required to:**

- Ensure that all Medical and Registered Nursing staff are aware of this policy and other policies and guidance which relate to this policy
- Ensure that adequate training is given to allow medical and registered nursing staff implement this policy safely

- To inform Senior Management if the policy is not being implemented appropriately

3.3 **Medical and Registered Nursing Staff are required to:**

- Ensure that they are aware of the contents of this and supporting policies
- Ensure that their physical examination skills are maintained in accordance with General Medical Council (GMC) or the Nursing and Midwifery Council (NMC) requirements
- To identify via relevant pathways appropriate training /development requirements
- Deliver quality care and ensure that the needs of patients are identified in accordance with best practice guidance.
- To inform via senior management the medical Director and Executive Director of Nursing Operations if the policy is not being implemented appropriately.

3.4 **Unqualified nursing staff are required to:**

- Be aware of the contents of this policy and supporting policies and guidance
- Support registered nurses and medical staff to deliver care to patients in line with care plans linked to this policy
- Request training to develop skills in line with this policy and Trust appraisal

4 Definition of Terms and Abbreviations

4.1 Definitions and terms used within this policy are listed below; further defining can be obtained within the National End of Life Strategy 2008. Abbreviations used within the policy are shown below:

- **Expected Death** – A death which is anticipated in a patient where active treatment has been withdrawn and the patient is usually not for resuscitation
- **Unexpected or Sudden Death** – A death which was **not anticipated** and where the patient did not have a terminal diagnosis or life limiting condition and did not have a DNACPR in place
- **Palliative Care** is for people living with a terminal illness / life limiting condition where a cure is no longer possible. It is also for people who have a complex / progressive illness and need their symptoms controlled. The aim is to manage pain and other physical symptoms associated with the condition, psychological, emotional, social and spiritual needs

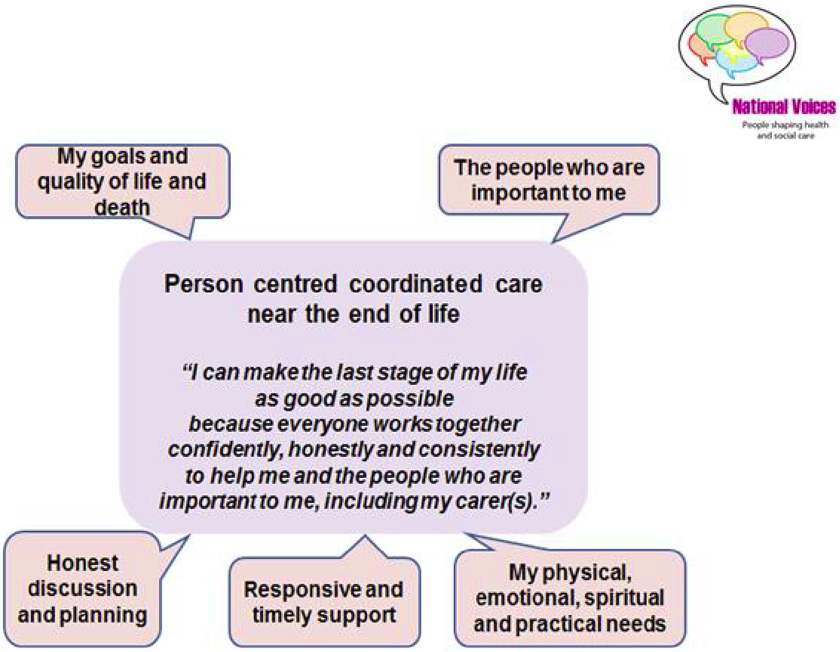
- **End of Life (EoL) care – "**Care that helps all those with advanced, progressive, incurable illness to live as well as possible and to die with dignity". End of Life Care is considered to be for people who are in the last months of life leading up to the last days and hours of life

- **EOL**- End of Life
- **DOH** – Department of Health
- **PPC** – Preferred Priorities of Care
- **CPR** – Cardio Pulmonary resuscitation
- **DNACPR** – Do Not Attempt Cardio Pulmonary Resuscitation
- **VOD** – Verification of Expected Death
- **GPC** – General Practitioners Committee
- **BMA** – British Medical Association
- **GP** – General Practitioner

5 Care of the Patient / Service user

5.1 The focus on holistic care is paramount. This includes the individual's emotional, spiritual and physical welfare. The comfort of the patient is the ultimate goal of treatment at the end of life. Regnard C. Dean M. (2004) **A guide to symptom relief in Palliative Care, 5th edition**

5.2 "Every Moment Counts" outlines what person centred coordinated care means in the context of end of life care and sets out clinical outcomes, support and treatment from the perspective of the people who need care their carer's , families and those close to them. (Developed for NHS England by National Voices 2014)



Person centred coordinated care near the end of life

"I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s)."

5.3 It is important that staff are aware of the patients/carers views and of their personal Religious needs and that these needs are addressed via appropriate care planning. More information on different cultural needs can be found in Hollins (2006) **'Religions, Culture and Healthcare'**.

5.4 Patient's diagnosed with a life limiting/threatening condition, may be receiving input from a Specialist Palliative care nurse i.e. Macmillan or Marie Curie Nurse as part of their care - this input can be provided at any point in a person's illness from diagnosis through to the end of life.

- Please Note: In Northumberland there is also access to a Macmillan Nurse for people who have learning disabilities

5.5 In addressing appropriate care for people who are dying, **The National End of Life Care Strategy** (2008) was implemented by the Department of Health, the key objective being: "To offer all patients nearing the end of their life, regardless of their diagnosis, the choice and access to high quality end of life care which includes helping patients to die in a place of their choice".

5.6 In addition Guidance to assist patients and professionals in decision making as the end of life approaches has also been published, **Capacity, care planning and advance care planning in advance illness** National End of Life Care (EOLC) programme (2011) available at:

http://www.endoflifecareforadults.nhs.uk/publications/pubacpguide

6. Deciding Right

6.1 **'**Deciding Right' is an NHS North East initiative launched in (2012) the document provides guidance and sets out principles towards facilitating an integrated approach to Making care decisions in Advance with children, young people and adults.

6.2 Deciding Right focuses on Care planning Advance Care Planning, The Mental Capacity Act, Advance Decisions to Refuse Treatment (ADRT), CPR decisions (DNACPR) and Emergency Health Care Plans (EHCP).

6.3 Resources for documenting the patient's wishes and decision making are included within the document along with algorithms for discussing future care with patients, differences in general care planning and decisions made in advance, the process for making best interest decisions in care crises and planning future care in adults.

6.4 Deciding Right - Benefits to NTW:

- Minimising confusion, documentation and boundary barriers, improving communication and ultimately the patient's journey

- Improved proactive care that reduces reactive decision making resulting in less serious untoward incidents

- Compliance with national legislation as well as reinforcing the embedding of DOH guidance such as the MCA into clinical practice

- Providing a framework which applies to individuals from all areas that NTW provide a service for including Planned Care, Urgent Care and Specialist Services

- Ensuring concordance with, and complement the principles promoted by, NTW e.g. following the individual along pathways of care

- Provide a well-developed framework which improves dialogue between the patient, healthcare professionals and partner organisations resulting in consistency and shared decision making

6.5 A copy of Deciding Right, Regional forms and resources are available from

http://www.nescn.nhs.uk/common-themes/deciding-right/regional-forms/
(accessed 18.6.2018)

7. Tools for use in the provision of End of Life Care:

7.1 The Preferred Priorities of Care' document (PPC) – See Appendix 1 (Including an accessible version). This document determines and records the wishes of the patient in relation to choices regarding their care and ultimately their place of death. The PPC document can be used as the basis for advance care planning by patients who have capacity, however although the PPC is not a legally binding document the preferences and wishes within the document must be taken into consideration in any decision making, should the patient loose capacity.

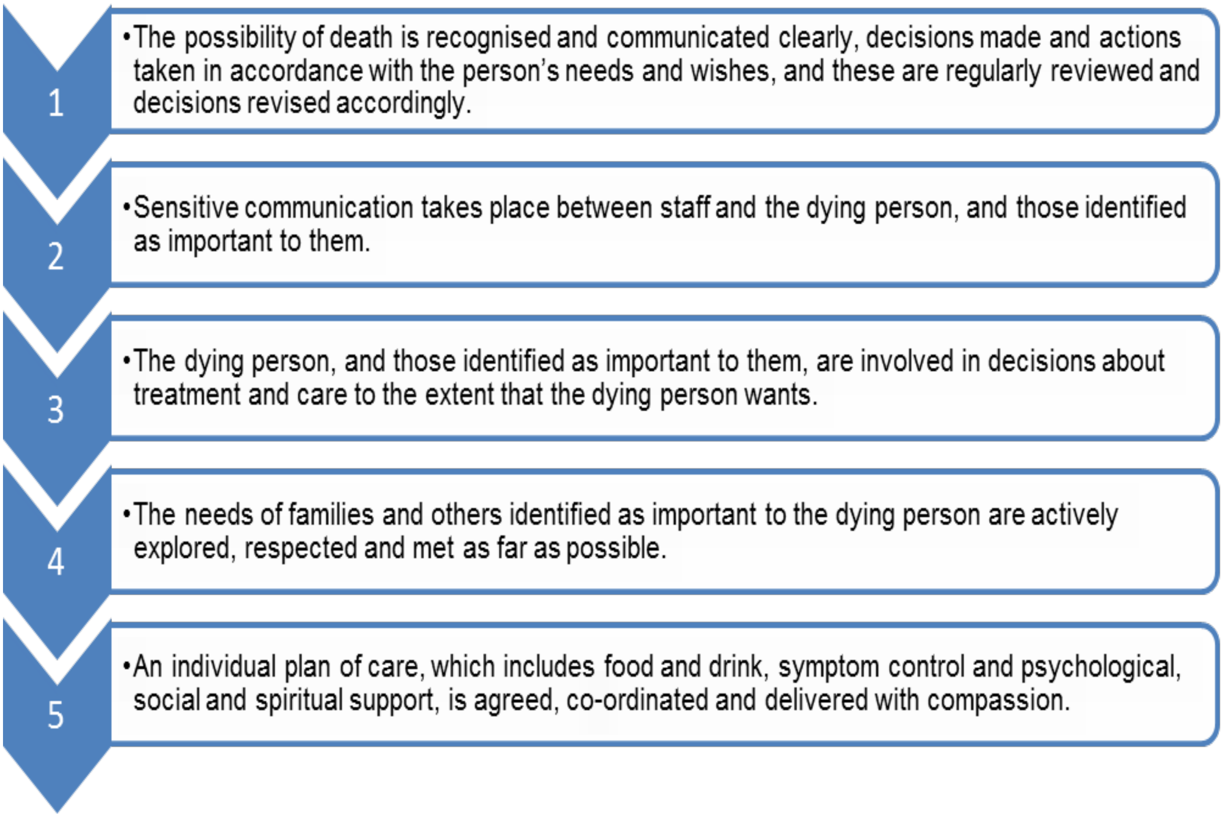
7.2 The PPC is a patient held document that can be completed by the patient alone, or with help from their family/carers or professional involved in their care.

7.3 Further Information on the Preferred Priorities of Care document (PPC) can be obtained via the EOLC site at:

http://www.endoflifecareforadults.nhs.uk/eolc/CS310.htm

8 The Leadership Alliance for the Care of the Dying Patient Group

8.1 This group was formed in 2013 the report published by the alliance – **One Chance to Get it Right** (June 2014) highlights five key priorities for providing care at the end of life, this is also referenced in the Care Quality Commission (CQC) good practice case studies document “A Different Ending” May 2016



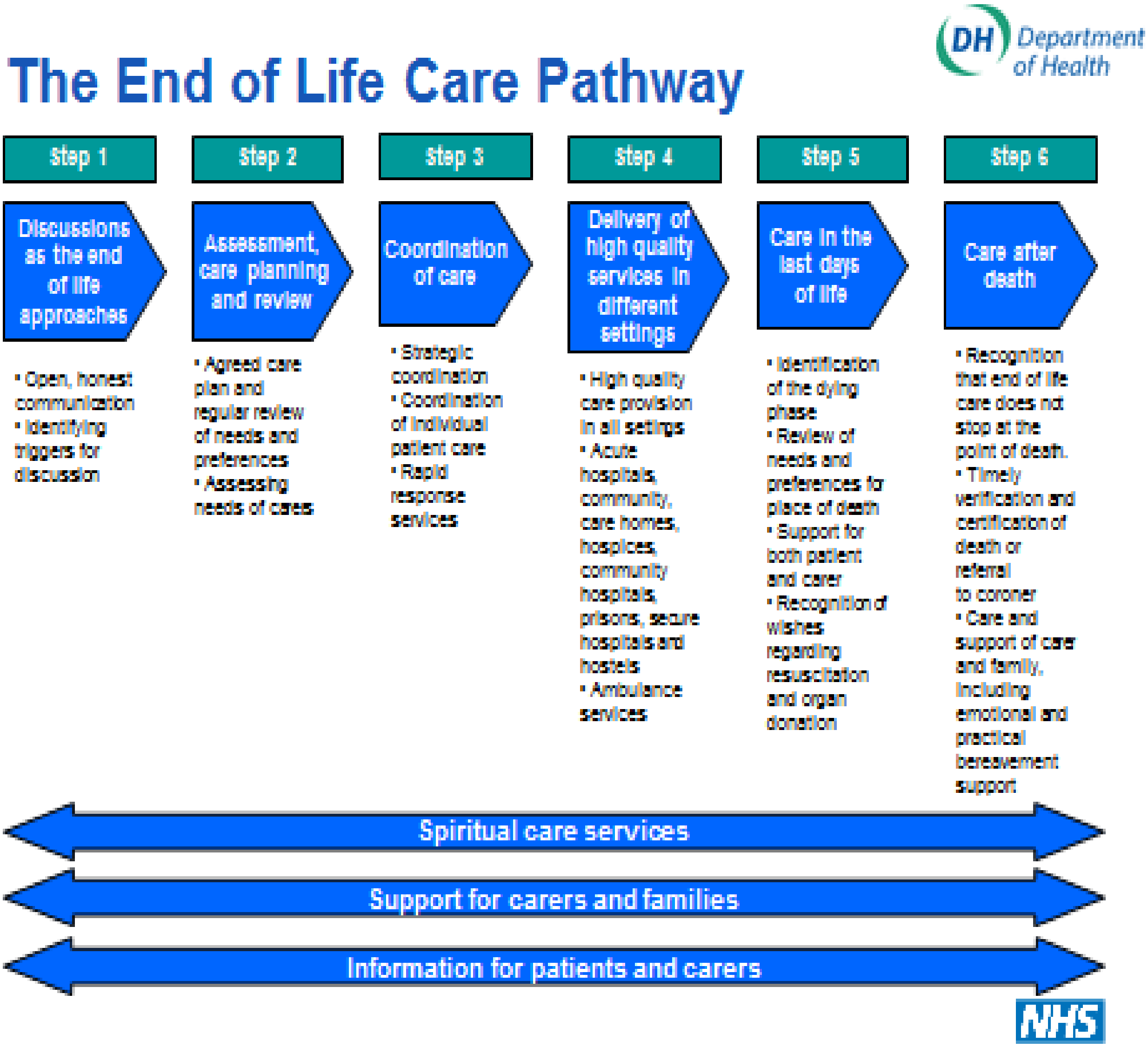
1. The possibility of death is recognised and communicated clearly, decisions made and actions taken in accordance with the person’s needs and wishes, and these are regularly reviewed and decisions revised accordingly.
2. Sensitive communication takes place between staff and the dying person, and those identified as important to them.
3. 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.
4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
5. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

8.2 In response to the Leadership Alliance for the Care of The dying priorities an End of life documentation pack has been developed in the North East for use across all hospital and community based services providing care from discussions as end of end of life approaches to care after death. **See Appendix 2a and 2b.**

8.3 Clear documentation by all clinical staff is crucial in order to reflect the care being provided in the last days and hours of life. Set Principles should be followed in both the community and in hospitals by nurses and doctors.

8.4 The Care of the Dying Patient Pack provides an evidence-based framework and aims to improve the quality of care in the last hours and days of life and provides guidance in the delivery of individualised care for the dying patient, their family and those who matter to them.

8.5 End of Life Care Pathway (EOLP) is developed and maintained by a multiagency team approach to ensure that the care delivered is inclusive, person centred, effective and driven by best practice from discussions to the end of life. This is outlined in line with the National End of Life Strategy (2008) in the 6 stages below:



8.6 The decision to commence the end of life documentation pack for any individual due to a poor prognosis must be endorsed by the most senior clinician responsible for the patients care (i.e. Consultant / GP) adhering to the above pathway

8.7 The patient (where possible: capacity and well-being dependent) and their family and those who matter to them will also be informed via discussion that the End of life documentation pack is being commenced.

8.8 The pack includes:

8.8.1 Initial medical and nursing assessments

- **Mandatory Care plans:**
    - End of life care
    - Communication
    - Spirituality

- **Additional Care plans:**
    - Pain
    - Nausea and vomiting
    - Agitation and restlessness
    - Dyspnoea
    - Respiratory secretions

- **Multidisciplinary evaluation and reassessments**
    - Verification of expected death
    - Care after death/continuation notes sheet
    - Palliative Care guidelines for symptom management

- Refer to Appendix 2b for Care Plan Guidance

8.9 The End of life documentation pack which records and evaluates care, treatments and any interventions including recording of any known alert or allergies will then be commenced; this documentation adheres to the five priorities of care at the end of life as advocated by the Leadership Alliance for the Care of the Dying, the pack will be held in the patients Purple Rio support file. Supporting information from the Deciding Right guidance will also be provided and held in the purple RiO support file for information / guidance

8.10 If relevant completion of the face risk / Narrative risk profiles will continue - this will be decided by the Multi-Disciplinary Team (MDT).

8.11 The Responsible Clinician will also review the frameworks of the Mental Health Act at this time and capacity will be continually assessed, consideration will also be given to Deprivation of Liberty Safeguards guidance as outlined in Trust policy. (Refer to section 26).

8.12 Further information about the Care of the dying patient documentation can be obtained form the **Macmillan Nurse, for People with Learning Disabilities NTW Telephone: 01670 394 808** or from Palliative care teams, Primary and secondary care services within individual geographical areas.

8.13 The multi-disciplinary team need to anticipate potential symptom management problems and work in collaboration with each other

9 Common Physical symptoms in the last forty-eight hours may include:

- Noisy breathing, laboured or difficult breathing
- Urinary incontinence/retention
- Pain
- Agitation
- Nausea and vomiting
- Sweating
- Jerking
- Confusion
- Dry mouth

9.1 Some of the symptoms identified above, may already be evident earlier in the patients illness and managed with appropriate pain symptom control measures, others may present later as the patient nears the end of their life

10. Providing Information

10.1 If the Patient asks for information the facts should be discussed by a suitably experienced member of the multi disciplinary team who knows the patient and can communicate effectively with them. **See guidance in Appendix 7 - Deciding right algorithm - Discussing future care with patient.**

10.2 Relatives and or carer's should also be sensitively informed and kept up to date with the patient's condition (unless the patient has previously expressed a wish for information not to be shared).

10.3 Discussion should also take place with the patient and their relatives /carers (where appropriate) about the patient's beliefs and religious practices, this will enable the staff to facilitate the patient's wishes and/or make any appropriate plans prior to the person's death.

10.4 Members of the multi disciplinary team should also be encouraged to reflect upon and prepare themselves for the death. Supporting each other at this time is important.

10.5 Although death may be inevitable the provision of support and holistic care to the patient, including appropriate communication and support for relatives / carers is paramount, this will minimise the emotional upset and distress as the end of life approaches and will assist in facilitating the grieving process and into bereavement.

11 END OF LIFE CARE

11.1 Expected Death

11.1.1 Patients with an irreversible life limiting / threatening disease, along with their carers, relatives and advocates (where appropriate), should be involved in the development and planning of their End of Life Care (EOLC) as outlined in **Section 5** of this policy **'Care of the Patient / Service User'**.

11.1.2 For some patients who have an irreversible life limiting, life threatening disease it may be appropriate for medical staff along with the nursing team to make the decision that an individual patient would not benefit from cardio pulmonary resuscitation (CPR). Wherever possible the decision should be discussed with patients and relatives (it is equally important to ensure that relatives do not feel burdened with any responsibility for the decision being made).Capacity and ability to process this should be considered before discussing with patients / carers.

11.1.3 Once the decision has been made a Do not attempt resuscitation (DNACPR) decision document should be completed in line with **Trust's NTW(C)01 – Resuscitation Policy**. The algorithm within the policy "making a CPR decision" gives guidance for the decision making process.

11.1.4 The DNACPR decision form and algorithm utilised by NTW are the Regional forms within the Deciding Right guidance – this is the only DNACPR decision form that will be accepted by the North East Ambulance Service (NEAS) – the document must be held in the purple Rio support file the original form must be available if requested by Medical practitioners or NEAS, a photocopy will not be accepted. The DNACPR decision form is available in **Appendix 6.**

Important note:

- Decisions about CPR can only be made following a documented medical assessment of an individual's condition. in addition, should the patient lack capacity then documented evidence of best interest's discussions and meetings relating to a DNACPR must also be available in line with the MCA (2005). The original DNACPR decision document (not a photocopy) must remain with the patient in their place of care, however in the absence of a current, valid and original DNACPR decision document the patient must receive CPR to preserve life as outlined in Professional Governing Bodies Guidance.

It is not the sole decision of the responder either not to commence CPR or to end CPR they must commence and continue CPR until guidance / support is received from emergency services.

11.1.5 Some deaths may be anticipated some days or weeks beforehand, in this instance if may be necessary to seek advice / input from a specialist palliative care professional (if the person is not already receiving palliative care input into their care). It is essential that the most appropriate and preferred place to receive care is agreed and this may be in the patients usual place of care within a palliative care ward in an acute hospital or a hospice.

11.1.6 Once it is agreed with medical staff that death is anticipated, the staff team should then have discussions with the Next of Kin or carers regarding the person's anticipated death. If the person is not able to return home to die as a preferred place of death then this may be the appropriate time to discuss where the patient will receive care in the last days and hours of life. It may not be appropriate to continue to provide care within an NTW environment due to patient need / treatment. Negotiations for transfer to palliative care service within an acute setting or hospice should commence.

11.1.7 This may also be an appropriate time to give family, carer's information leaflets (in either generic or accessible format) "When someone is dying" and "Grieving" (See **Appendix 3)**

11.1.8 Reassurance should be given regarding arrangements for extended visiting times so that the relatives can spend more time with the person if they wish, in line with National guidance EOLC strategy (2008) Promoting high quality care for all adults at the end of life. A comfortable chair and where necessary a blanket or duvet should be provided for the relative, friend or carer along with regular refreshments and psychological support as appropriate.

11.1.9 Care Plans should clearly outline interventions; treatment should always be within the scope of practice for the relevant professional. The ability to provide interventions should be in line with Trust policy NTW C 29. Specialist interventions should be performed / supported by relevant personnel for example District Nurse. If treatments are not within the Trusts scope of care delivery then a decision should be made to transferring care to acute services, palliative care ward or hospice. This will be a collaborative decision.

11.1.10 Staff will clearly document and have an awareness of clinical interventions, symptom management, physical observations and impact of the patient's condition upon these for example COPD and the actions required when a patient is deteriorating in line with the National Early Warning Scale (NEWS) and when to gain assistance. This will be clearly documented in care plans

11.1.11 NTW staff maybe required to continue to support patients transferred to acute services, for example those detained under the Mental Health Act. The role of the NTW staff should be established at point of transfer; however they should continue to provide support and compassion reducing anxiety and elevating distress at the end of life.

11.1.12 If the relative, friend or carer can not be contacted or does not wish to be with their relative at the EOL, a member of the multi disciplinary team should be identified to spend time with the patient, to provide support, reassurance and to monitor symptoms and minimise any agitation and / or anxiety as the individual comes to the end of their life.

11.1.13 The patient, friend or carer may wish to have support from the hospitals clergy or their own clergy. Staff should make the appropriate arrangements to facilitate the expressed wishes of the patient, relative, friend or carer. **Contact details for NTW Clergy are available in Appendix 8.**

12 Breaking the News

12.1 Where the patient's relatives, carer or friend are not at the hospital at the time of death a qualified member of staff on duty should be responsible for contacting them via telephone. It is good practice to have had prior discussions with relatives regarding times of the day/night they wish to be contacted in the event that death occurs – this information should be documented within the patients "Getting to Know You" RiO document and communicated within the staff team.

12.2 In some circumstances a personal visit may be necessary to inform the relatives / carers of the death.

12.3 Breaking the news by telephone may not be appropriate if the carer, relative or friend:

- Lives alone with no support
- Is elderly or infirm
- May be extremely emotionally distressed
- Suffers from Mental health problems or has a learning disability
- English is not their first language therefore an interpreter is required

12.4 Upon receiving news of the death should the relative, carer or friend wish to visit the patient, a member of staff should meet them on their arrival and take them to a quiet private room, staff should then offer some refreshments and discuss with the relative, carer or friend if they would like to spend time with the individual on their own or if they would prefer staff to support them with this. In this situation NTW staff need to take their lead in terms of the level of support that is needed from the relative, friend or carer as this is a sensitive area of practice and the needs of grieving relatives, friends or carers maybe very different.

12.5 Should the patient have been taken to the agreed funeral home then the relative, carer should be advised of the location if they are not already aware.

12.6 Staff must acknowledge that patients from different faiths may have wishes / religious needs. Advice on this should be sought from family and / or religious advisers, staff should ensure the individuals wishes are met in a timely manner. The Trust's Chaplains are always willing to provide support and advice to staff, relatives and carers and can be contacted via the Trust's switchboard Telephone 0844 811 5522 Ext 28820, or via direct telephone contact for relevant areas. **Appendix 8**

12.7 Relatives, carers and friends must feel that they can express their emotions in a calm and safe environment and staff should ensure that they are supported and that their privacy is respected.

12.8 Other patients living in the same environment as the deceased person are often aware that a death is expected or has occurred. It is important therefore to inform them when someone dies, so that as individuals they are offered support, reassurance and any questions which they may have are answered sensitively so as to allay any fears or anxieties.

12.9 Patient/service users will be supported by the most appropriate individual or professional at this time.

13 Unexpected or sudden Death

13.1 In the event of an unexpected or sudden death the Nurse in Charge should contact the following people:

- Associate Director / Clinical Nurse Manager / Point of Contact/Senior Manager on Call
- Advice/guidance will be given regarding management of the situation
- The Incidents and Claims department will give guidance and support when staff are managing a sudden or expected death

14 Support after Death

14.1 Members of the multi disciplinary team should be encouraged to provide peer support and reflect on the care provided and their personal feelings relating to the death of the patient/resident. An After Action Review will take place and staff will be able to attend where possible to reflect upon the event.

14.2 A member of the clergy is always happy to provide any support to members of the multi disciplinary team and can be contacted on; **Telephone No: 0844 811 5522 Ext 28820 or see Appendix 8 for NTW Clergy contact details.**

14.3 Members of the multi disciplinary team should also be reminded of the availability of Independent Counselling Services, who may also be able to offer support, Care First **0800 174319** or www.care-first.co.uk for the confidential chat room service. Open 24 hrs, 365 days. Staff can self refer to the service or request referral via Team Prevent Occupational Health Service. Staff can access Team Prevent and Care First Services via NTW switchboard.

14.4 Many patients/residents develop friendships with their fellow patients/residents through their shared experiences. Regardless of the length of friendship the death of one patient/resident can be a significant loss for fellow patients/residents therefore support should be considered.

14.5 Every person will experience loss or bereavement at some point in their lives, but many people shy away from discussions involving death and dying, and as a consequence these issues have become stigmatised by society.

14.6 This reluctance to share the loss results in fellow patients and staff suppressing their grief and having feelings of uncertainty, tension and fear. These problems may occur because patients and staff failed to view the death holistically from physical, psychological, social and spiritual points of view.

14.7 The following are some helpful and unhelpful things to do, in terms of starting to share the loss with patients:

a. **Honesty:** Honesty is the place to start. Every person is an individual in their own right and their specific needs will vary, but more harm will come from hiding fellow patients/residents from the truth

b. **Others suffer too*:*** Fellow patients/residents are as likely to suffer from the loss of a friend as anyone else. Taking time to sit and talk with a patient/relative can be very beneficial and this includes people with alternative communication

c. **Don't "jolly":** It should be remembered that it is quite normal to feel sad and hurt during a time of loss, it is not helpful and potentially damaging to try to "jolly" the person along

d. **Reflecting back.** For many people life story work is a useful way to communicate significant life events, and can be seen as a vital element in helping the person bring back memories both good and bad that would otherwise be forgotten. The concept of life storybooks is also acknowledged in bereavement counselling

e. **Look for changes in behaviour, which might indicate difficulty in expressing an emotion***:* Don't assume behaviour changes as a result of grief (they may be related to something else). Remember that for some people, grief reactions may take time to manifest themselves

f. **If memory is poor: reinforce** the loss to assess the individual's **understanding/fears related to their friend's death**

g. **Adjustment to the change***:* **Ensure** individuals are given help/ support whilst they are adjusting to living in an environment where their friend is missing. Regnard C. (2004) **Current Learning in Palliative Care, Helping the patient with Advanced Disease: Radcliffe Medical Press Oxford**

15 Identification of Stakeholders

15.1 This policy has been reviewed and updated in accordance with new legislation and standards.

- North Locality Care Group
- Central Locality Care Group
- South Locality Care Group
- Corporate Decision Team
- Business Delivery Group
- Safer Care Group
- Communications, Finance, IM&T
- Commissioning and Quality Assurance

- Workforce and Organisational Development
- NTW Solutions
- Local Negotiating Committee
- Medical Directorate
- Staff Side
- Internal Audit

16 Training

16.1 The Trusts expectation is that healthcare staff will keep their skills up to date in accordance with their respective codes of practice. A range of training opportunities will be available to staff including clinical skills training:

- Providing holistic care to the dying patient and their relatives

- Best Practice guidance : Deciding Right , EoL tools such as PPC and the end of life documentation pack

- The role of primary care services and other external agencies e.g. local palliative care teams

16.2 Staff who have had additional skills training would be expected to champion and promote those skills within their clinical area and teams.

17 Equality and Diversity assessment

17.1 In conjunction with the Trust's Equality and Diversity Officer this policy has undergone an Equality and Diversity Impact Assessment which has taken into account all human rights in relation to disability, ethnicity, age and gender. The Trust undertakes to improve the working experience of staff and to ensure everyone is treated in a fair and consistent manner.

18 Implementation

18.1 Taking into consideration all the implications associated with this policy, it is considered that a target date of **12 months from date of issue** is achievable for the contents to be embedded within relevant service areas identified by Associate Directors from across the organisation.

19 Monitoring compliance

19.1 There are a number of ways in which the compliance to this policy and practice guidance notes will be monitored via audit if applicable to the service area. See Appendix C)

19.2 Multi-disciplinary reviews of the policy will enable appropriate feedback, examine activity and discuss any areas of problems or difficulty, relating to both clinical issues and provision of appropriate services for those who are dying, and will also highlight where the policy has made a positive impact on individuals nearing the end of life.

20 Standards/Key Performance indicators

- This policy will be operated in compliance with:
  - The End of Life Care Strategy, Department of Health (2008) – Promoting high quality care for all adults at the end of life. London
  - The End of Life Care Initiative, Department of Health (2003) London
  - General Practitioners Committee. Confirmation and Certification of Death: Guidance for GPs in England and Wales London BMA, 1999

21 Fair Blame

21.1 The Trust is committed to developing an open learning culture. It has endorsed the view that, wherever possible, disciplinary action will not be taken against members of staff who report near misses and adverse incidents, although there may be clearly defined occasions where disciplinary action will be taken.

22 Fraud, Bribery and Corruption

22.1 In accordance with the Trust's policy NTW(O)23 – Fraud, Bribery and Corruption Policy, all suspected cases of fraud and corruption should be reported immediately to the Trust's Local Counter Fraud Specialist or to the Executive Director of Finance.

23 Associated Documentation

- NTW(C)01 – Resuscitation Policy
- NTW(C)17 - Medicine Management Policy

- NTW(C)18 - Tissue Viability Policy
- NTW(C)20 - Care Coordination Policy
- NTW(C)26 - Management of Dysphagia Policy
- NTW(C)29 - Physical Assessment Policy
- NTW(C)34 – Mental Capacity Act Policy
    - MCA-PGN-02 – Advance Decision to refuse Treatment and Advance Statement practice guidance note (PGN)
- NTW(C)36 - Deprivation of Liberty Safeguards Policy
- NTW(C)40 - Dignity in Care Policy
- NTW(C)55 – Mental Health Act Policy
- NTW(O)05 – Incident Policy (including serious untoward incidents)
    - IP-PGN-01 – Incident Reporting PGN

24 References/Resources:

- Care Quality Commission (CQC): **A Different Ending Addressing: inequalities in end of life care** (2016) www.cqc.org.uk/differentendings

- Coroner and Inquests: **When Sudden Death Occurs** (2002) Home Office, London.

- Deciding Right (2012): **An integrated approach to making care decisions in advance with children, young people and adults** NHS North East

- Department of Health (2008) **The End of Life Care Strategy – Promoting high quality care for all adults at the end of life**. London

- Department of Health (2003): **The End of Life Care Programme** London.

- Department of Health (1997), **Guidelines for Patients who Die in Hospital** HM (72)41 NHS Executive Circular http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Healthserviceguidelines/DH_4018378

- End of Life Care Strategy (2008): Promoting high quality care for all adults at end of life: www.dh.gov.uk/pub

- National End of Life Care (EOLC) programme (2011) **Capacity, care planning and advance care planning in advance illness** available at: http://www.endoflifecareforadults.nhs.uk/publications/pubacpguide

- GPC (General Practitioners Committee) (1999). **Confirmation and Certification of Death:** Guidance for GPs in England and Wales London, BMA,

- Hollins S. (2006) **Religions, Culture and Healthcare**, Radcliffe Publishing Oxford.

- National End of Life Care Programme (2010) **Route to Success: achieving quality in care homes**

- National End of Life Care Programme (2011), **Guidance for Staff responsible for care after death (last offices).**

- Preferred Priorities of Care: http://www.endoflifecareforadults.nhs.uk/eolc/CS310.htm

- Regnard C. Hockley J. (2004) **A Guide to Symptom Relief in Advanced Disease 5th Ed**. Radcliffe Medical Press Oxford

- Regnard C (2004) Current Learning in Palliative Care, **Helping the Patient with Advanced Disease, A work book**, Radcliffe Medical Press Oxford

- The Leadership Alliance for the Care of the Dying Patient: (June 2014) **"One Chance to Get it Right"** Gateway Reference 01509

- The End of Life Care Strategy: New Ambitions November 2013: www.dyingmatters.org

- The National Council for Palliative care (NCPC): www.ncpc.org.uk

- NICE End of Life Care for Adults http://guidance.nice.org.uk/QS13

- National Bereavement Survey (VOICES) 2012 www.ons.gov.uk/ons

- Matters of Life and Death: Helping people to live well until they die www.rcgp.org.uk

- NHS End of Life Care Website (England) www.endoflifecareforadults.nhs.uk

- National Gold Standards Framework Centre www.goldstandardsframework.org.uk/

- Every Moment Counts: http://www.ncpc.org.uk/news/every-moment-counts-new-vision-coordinated- care-people-near-end-life-calls-brave-conversations

Appendix A

Equality Analysis Screening Toolkit

Names of Individuals involved in Review	**Date of Initial Screening**	**Review Date**	**Service Area / Locality**
Chris Rowlands	Sept 15		

Policy to be analysed	**Is this policy new or existing?**
NTW(C)49 – End of Life Care Policy	Existing

What are the intended outcomes of this work? Include outline of objectives and function aims

Northumberland, Tyne and Wear NHS Foundation Trust (the Trust) are committed to ensuring that those patients/service users who die within the Trust are treated with respect and dignity. Patients/Residents and family wishes must be honoured wherever possible. The philosophy of holistic care should also continue after death with family, friends and carers being continued to be supported by the former patient/service user's multi disciplinary team.

The death of a patient/resident in hospital is not an uncommon occurrence and this policy gives staff advice on handling the death of a patient/resident sensitively and appropriately together with practical information on the procedure to be followed following the death.

Who will be affected? e.g. staff, service users, carers, wider public etc

Service Users Carers

Protected Characteristics under the Equality Act 2010. The following characteristics have protection under the Act and therefore require further analysis of the potential impact that the policy may have upon them

Disability	Positive as the policy has clear regard for the access requirements and dignity and respect of all service users
Sex	Positive as the policy has clear regard for the access requirements and dignity and respect of all service users
Race	Positive as the policy has clear regard for the access requirements and dignity and respect of all service users
Age	Positive as the policy has clear regard for the access requirements and dignity and respect of all service users
Gender reassignment (including transgender)	Positive as the policy has clear regard for the access requirements and dignity and respect of all service users
Sexual orientation.	Positive as the policy has clear regard for the access requirements and dignity and respect of all service users
Religion or belief	Positive as the policy has clear regard for the access requirements and dignity and respect of all service users
Marriage and Civil Partnership	Positive as the policy has clear regard for the access requirements and dignity and respect of all service users

Pregnancy and maternity	Positive as the policy has clear regard for the access requirements and dignity and respect of all service users
Carers	Positive as the policy has clear regard for the access requirements and dignity and respect of all service users
Other identified groups	Positive as the policy has clear regard for the access requirements and dignity and respect of all service users

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

Through policy making process

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

Through policy review

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

Key stakeholders

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.

Positive Impact

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. Where there is evidence, address each protected characteristic

Eliminate discrimination, harassment and victimisation	Positive impact
Advance equality of opportunity	Positive Impact
Promote good relations between groups	Positive impact
What is the overall impact?	**Positive**
Addressing the impact on equalities	**Positive**

From the outcome of this Screening, have negative impacts been identified for any protected characteristics as defined by the Equality Act 2010? No

If yes, has a Full Impact Assessment been recommended? If not, why not?

Manager’s signature: Chris Rowlands **Date: Sept 2015**

Appendix B

Communication and Training check list

Key Questions for the accountable committees designing, reviewing or agreeing a new Trust policy

Is this a new policy with new training requirements or a change to an existing policy?	Existing Policy
If it is a change to an existing policy are there changes to the existing model of training delivery? If yes specify below.	Understanding the application of the policy and the implications for clinical practice to enable a seamless approach across the Trust to caring for dying patients
Are the awareness/training needs required to deliver the changes by law, national or local standards or best practice? Please give specific evidence that identifies the training need, e.g. National Guidance, CQC, NHS Resolutions etc. Please identify the risks if training does not occur.	Replaces previous care of the dying patient policies. Complies with: End of life strategy DOH (2008) chapters 1-6 End of Life Care Programme DOH (2003) Preferred Priorities of Care DOH (2007) Deciding Right (2012) Capacity, care planning and advance care planning in advance illness DOH (2011)
Please specify which staff groups need to undertake this awareness/training. Please be specific. It may well be the case that certain groups will require different levels e.g. staff group A requires awareness and staff group B requires training.	Policy applies to all nursing staff working within clinical settings where it may be necessary to provide end of life care.
Is there a staff group that should be prioritised for this training / awareness?	Managers, Registered Nurses, clinicians to understand responsibilities in order to manage end of life care in a professional manner, hence meeting the needs of the dying person their family / carers Staff awareness
Please outline how the training will be delivered. Include who will deliver it and by what method. The following may be useful to consider: Team brief/e bulletin of summary Management cascade Newsletter/leaflets/payslip attachment Focus groups for those concerned Local Induction Training Awareness sessions for those affected by the new policy Local demonstrations of techniques / equip with ref documentation Staff Handbook Summary for easy reference Taught Session, E Learning	Via the trust Intranet/Internet NTW Physical Health and Well-Being Group – cascade Safer Care Group Hard Copies in policy files within clinical areas
Please identify a link person who will liaise with the training department to arrange details for the Trust Training Prospectus, Administration needs etc.	Dennis Davison / Dorothy Matthews

Appendix B – continued

Training Needs Analysis

Staff/Professional Group	Type of training	Duration of Training	Frequency of Training
Qualified Nursing Unqualified Nursing Medical staff	Training re policy awareness and implications for practice. Understanding of national tools used in end of life care		On commencement of service and as required due to changes in practice / policy
Qualified Nursing Unqualified Nursing Medical Staff	Training re policy awareness and implications for practice. Understanding of national tools used in end of life care		On commencement of service and as required due to changes in practice / policy
Qualified Nursing Unqualified Nursing Medical Staff	Training re policy awareness and implications for practice. Understanding of national tools used in end of life care		On commencement of service and as required due to changes in practice / policy
Qualified Nursing Unqualified Nursing Medical Staff	Training re policy awareness and implications for practice. Understanding of national tools used in end of life care		On commencement of service and as required due to changes in practice / policy

Copy of completed form to be sent to:

Training and Development Department,
St. Nicholas Hospital

Should any advice be required, please contact:- 0191 245 6777 (internal 56777-Option 1)

Appendix C

Statement

The Trust is working towards effective clinical governance and governance systems. To demonstrate effective care delivery and compliance, policy authors are required to include how monitoring of this policy is linked to auditable standards/key performance indicators will be undertaken using this framework.

NTW(C)49 – End of Life Care Policy - Monitoring Framework			
Auditable Standard/Key Performance Indicators		**Frequency/Method/Person Responsible**	**Where results and any associated action plan will be reported to, implemented and monitored;**(this will usually be via the relevant governance group).
1	Staff who have been identified as requiring education / training relating to end of life care have accessed education / training provided by NTW	Clinical Nurse Managers and Ward managers As/when required Identify staff group and ensure they have undergone relevant education / training	Individual training records

The Author(s) of each policy is required to complete this monitoring template and ensure that these results are taken to the appropriate Quality and Performance Governance Group in line with the frequency set out.