# Community Services Division Clinical Policy Document

## End of Life

<table>
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<tr>
<th>Policy Number:</th>
<th>104</th>
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<tr>
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<td>End of Life Group</td>
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<td>Lead Author(s):</td>
<td>Specialist Palliative Care Team Leaders</td>
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**Striving for perfect care and a just culture**
# COMMUNITY SERVICES DIVISION CLINICAL POLICY DOCUMENT

## END OF LIFE

**Further information about this document:**

<table>
<thead>
<tr>
<th>Document name</th>
<th>End of Life (104)</th>
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<tbody>
<tr>
<td>Document summary</td>
<td>To enable all staff to provide appropriate and dignified care for all patients and those important to them at end of life</td>
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<tr>
<td>Author(s)</td>
<td>Specialist Palliative Care Team Leaders</td>
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<td>Copies of this document are available from the Author(s) and via the trust’s website</td>
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<td>To be read in conjunction with</td>
<td>This document can be made available in a range of alternative formats including various languages, large print and braille etc</td>
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## Version Control:

<table>
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<tr>
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SUPPORTING STATEMENTS
this document should be read in conjunction with the following statements:

SAFEGUARDING IS EVERYBODY’S BUSINESS
All Mersey Care NHS Foundation Trust employees have a statutory duty to safeguard and promote the welfare of children and adults, including:

- being alert to the possibility of child / adult abuse and neglect through their observation of abuse, or by professional judgement made as a result of information gathered about the child / adult;
- knowing how to deal with a disclosure or allegation of child /adult abuse;
- undertaking training as appropriate for their role and keeping themselves updated;
- being aware of and following the local policies and procedures they need to follow if they have a child / adult concern;
- ensuring appropriate advice and support is accessed either from managers, Safeguarding Ambassadors or the trust’s safeguarding team;
- participating in multi-agency working to safeguard the child or adult (if appropriate to your role);
- ensuring contemporaneous records are kept at all times and record keeping is in strict adherence to Mersey Care NHS Foundation Trust policy and procedures and professional guidelines. Roles, responsibilities and accountabilities, will differ depending on the post you hold within the organisation;
- ensuring that all staff and their managers discuss and record any safeguarding issues that arise at each supervision session.

EQUALITY AND HUMAN RIGHTS
Mersey Care NHS Foundation Trust recognises that some sections of society experience prejudice and discrimination. The Equality Act 2010 specifically recognises the protected characteristics of age, disability, gender, race, religion or belief, sexual orientation and transgender. The Equality Act also requires regard to socio-economic factors including pregnancy /maternity and marriage/civil partnership.

The trust is committed to equality of opportunity and anti-discriminatory practice both in the provision of services and in our role as a major employer. The trust believes that all people have the right to be treated with dignity and respect and is committed to the elimination of unfair and unlawful discriminatory practices.

Mersey Care NHS Foundation Trust also is aware of its legal duties under the Human Rights Act 1998. Section 6 of the Human Rights Act requires all public authorities to uphold and promote Human Rights in everything they do. It is unlawful for a public authority to perform any act which contravenes the Human Rights Act.

Mersey Care NHS Foundation Trust is committed to carrying out its functions and service delivery in line with a Human Rights based approach and the FREDA principles of Fairness, Respect, Equality Dignity, and Autonomy.
1. Introduction

There were 529,655 deaths registered in England and Wales in 2015, an increase of 5.6% compared with 2014 and current mortality trends suggests that 25% more people will die each year by 2040. In 2015, mortality rates for respiratory diseases (including flu) increased notably for both males and females. Cancer was the most common broad cause of death (28% of all deaths registered) followed by circulatory diseases, such as heart disease and strokes (26%). Care at the end of someone’s life is a key role not for just community nurses but all healthcare professionals in the community. Although death and dying are not primary health and social care events; they affect every aspect of people’s lives and experience (NHSE).

End of Life Definition- General Medical Council’s definition of end of life, as cited in Guide for Commissioners on end of life care for adults (NICE 2011), is

People are approaching End of Life when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

- Advanced, progressive, incurable conditions
- General frailty and coexisting conditions that mean they are expected to die within the next 12 months
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- Life threatening acute conditions caused by sudden catastrophic events

This policy focuses on the care of those in the last year of life

1.1 This policy is based on the Department of Health ‘End of Life Care Strategy’ (2008), current Trust practice and SOPs. This policy also recognises and includes principles identified in the Leadership Alliance for the Care of Dying People (LACDP) document ‘One Chance to get it right’ and the Ambitions for Palliative and End of Life Care Framework (2015).

1.2 Mersey Care NHS Foundation Trust recognises the need to support standards to deliver high quality care to patients that have an advanced life-limiting illness in the place they identify as home and to provide support to their carers

1.3 The Department of Health’s overriding aim is to ensure high quality care for all people approaching the end of life, irrespective of age, gender, ethnicity, religious belief, disability, sexual orientation, diagnosis or socioeconomic status. It should enhance choice, quality, equality and value for money. These objectives can be achieved through:

- Increasing public awareness and discussion of death and dying
- Ensuring the focus of care for the dying person is the highest priority
- Ensuring that all people are treated with dignity and respect at the end of their lives
• Ensuring that pain and suffering amongst people approaching the end of life are kept to an absolute minimum
• Ensuring that all those approaching the end of life have access to physical, psychological, social and spiritual care
• Ensuring that individual needs, priorities and preferences for end of life care are identified, documented, reviewed, respected and acted upon wherever possible
• Ensuring that services are well coordinated
• Ensuring that high quality care is provided at all times
• Ensuring that carers are appropriately supported during a patient’s life and into bereavement
• Ensuring that health and social care professionals at all levels are provided with the necessary education and training to enable them to provide high quality care
• Ensuring that services provide good value for money

1.4 Following the publication of ‘One Chance to Get it Right’ by the Leadership Alliance for the Care of Dying People, Mersey Care NHS Foundation Trust commits to uphold the five priorities for the care of the dying person:

• The possibility of end of life is recognised and communicated clearly, decisions made and actions taken in accordance with the persons needs and wishes, and these are regularly reviewed and decisions revised accordingly
• Sensitive communication takes place between staff and the dying person, and those identified as important to them
• The dying person and those identified as important to them, are involved in decisions about treatment and care to the extent of the dying persons wants
• The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible
• An individual plan of care which includes food and drink symptom control and psychological, social and spiritual support is agreed coordinated and delivered with compassion, dignity and respect

1.5 The personalised care plan for the last days of life, Gold Standard Framework and North West Palliative Care Framework are key tools and principles for all clinical staff to ensure the delivery of optimal care at end of life. Relevant staff should familiarise themselves with the contents of each document and ensure that care is assessed, coordinated and delivered in accordance with these documents and detailed within the policy. An overview of the North West End of Life Care Model can be viewed in Appendix A
1.6 This policy builds upon the care delivering choice to our patients and those important to them across the Mersey Care NHS Foundation Trust in order to deliver patient centered care at the end of life.

2. Purpose and Scope

2.1 To enable the multi-disciplinary teams (MDT) in conjunction with Primary Care to develop a person-centred plan of care, ensuring symptoms are as controlled as possible to meet the needs of patients at the end of their life.

2.2 To ensure that the privacy, dignity and respect of all patients in the end stages of their life is maintained in all aspects of their care. This is also applicable in the event of unexpected, or unpredictable, death.

2.3 To ensure that the optimum level of care is given to maximise the quality life and enabling patients to die in their preferred place of death whenever possible.

2.4 To ensure that carers are supported, appropriately informed, enabled and empowered throughout the end of life stages of their loved ones illness.
3. Definitions / Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
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<tr>
<td>EOL</td>
<td>End Of Life</td>
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<tr>
<td>PPC</td>
<td>Preferred Place of Care</td>
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<td>PPD</td>
<td>Preferred Place of Death</td>
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<td>SPCT</td>
<td>Specialist Palliative Care Team</td>
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<td>ADRT</td>
<td>Advance Decision to Refuse Treatment</td>
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<td>uDNA CPR</td>
<td>Unified Do Not Attempt Cardio Pulmonary Resuscitation</td>
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<td>OOH</td>
<td>Out Of Hours</td>
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<tr>
<td>D/N</td>
<td>District Nurse</td>
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<td>MDT</td>
<td>Multi- disciplinary Team</td>
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<td>General Practitioner</td>
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<td>CHC</td>
<td>Community Health Care Funding</td>
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<td>Gold Standards Framework</td>
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<td>UC24</td>
<td>Urgent care medical services</td>
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<td>ACP</td>
<td>Advance Care Plan</td>
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4. Duties and Responsibilities

4.1 The **Board of Directors**’ has overall responsibility for procedural documents and delegate’s responsibility as appropriate.

4.2 **Medical Director** will oversee implementation of the End of Life Care Policy.

4.3 **End of Life Group** will provide assurance that the End of Life Policy is fully implemented.

4.4 **All Service Leads are** responsible for ensuring that staff are aware of the policy and that any staff training needs are identified and addressed, this includes bed based services.

4.5 The multi-disciplinary team members, including bed based services, have a responsibility to remain updated with the policy and to identify patients nearing the end of their life and to work in collaboration with other community staff.
members as appropriate e.g. district nursing teams, specialist palliative care team. See Appendix B for End of Life Care Good Practice Guide.

5. Mersey Care End of Life Working Party Purpose

5.1 The purpose of Mersey Care NHS Foundation Trust End of Life Group is to:

• This group has been formed to ensure high quality services are provided to patients and their families in all matters pertaining to end of life care

• The group is authorised by the Clinical Effectiveness Sub-Committee to investigate any activity within its terms of reference. It is authorised to seek the information it requires from any employee, and all employees are directed to co-operate with any request made by the group

• The group is authorised by the Clinical Effectiveness Sub-Committee to obtain independent professional advice and to secure the attendance of people/organisations from outside the Trust

5.2 The overarching aims of the End of Life Group are to:

• Ensure delivery of high quality palliative care for patients and families, and measure its impact, keeping the five Priorities of Care for the Dying Person uppermost

• Continue to develop and implement comprehensive seamless and equitable palliative care services across the footprint of the Trust

• Build and strengthen leadership

• Ensure we have the right staff, with the right skills in the right place

• Support a positive patient, family and staff experience in End of Life situations

5.3 The End of Life Group shall:

• Draw upon the highest levels of expertise in its decision making

• Enable a multidisciplinary, cross-organisational style of working to ensure seamless provision and governance
• Support the development of pertinent, clinically significant performance indicators or outcome measures to monitor service delivery across the organisation

• Review delivery of current practice and performance through monitoring and service audit against best practice and current research

• Ensure that the care delivered is benchmarked against national best practice standards e.g. NICE guidance

• Ensure that the processes and systems are in place to disseminate and share best practice in palliative care across the organization

• Recommend actions to improve palliative care for future patients

• Discuss all End of Life/Palliative Care related significant events, complaints and Datix, ensuring input into a lessons learned process and enable the development of a learning culture, with dissemination across the Trust as appropriate

• Develop and support peer review requirements, in relation to specialist palliative care

• Ensure the appropriate level of engagement with patients, primary care and other key stakeholders, including providers and commissioners

• Be the responsible body to manage, implement and consider the Trust’s response to national and local audits of standards, and actions required from these

• Be able to give necessary assurances regarding standards of palliative care provided, and escalate risks where appropriate

6. Community Nursing Service

• District Nurses are the key worker for patients with a life limiting illness at home or in a residential setting.

• Patients may also be active within the Community Matron caseload although referral to DNs would be expected when declining condition is identified. This referral should be made in a timely manner, but can come at any point along the disease trajectory dependent on needs. It is important that this referral is prior to terminal deterioration in condition to ensure relationships are built between the patient and their key workers.
• Community Matrons and Specialist Nursing Services must also ensure that their patients identified as in the last year of life are registered on the Gold Standard Framework at the appropriate GP surgery for discussion. They may also attend these meetings as needed.

• The Community Nurse will liaise with the GP to ensure that the patient is registered on the Gold Standard Framework and that these patients are discussed at regular GSF meetings as arranged in collaboration with the GP practice. The DN caseload holder will ensure that regular liaison takes place with GP, other primary care team members; secondary, tertiary and third sector care to ensure comprehensive patient centered holistic care is planned and delivered.

• The DN, as key worker, will work in partnership with other healthcare professionals to ensure that the patient and carers have access to all the necessary health and social care services in order to meet the agreed care plan. This should include ordering of any equipment that may be required and any anticipatory medication. The DN caseload holder is also responsible for ensuring that all team members are aware of key information relating to the plan of care.

7. Personalised and Advance Care Planning

7.1 Advance care planning is defined by the NHS End of Life Care programme as a voluntary process of discussion about future care between an individual and their care providers, irrespective of discipline. Advanced care planning can also include ADRT, preferred priorities of care, preferred place of death and decision relating to cardio-pulmonary resuscitation. Care at end of life varies according to the individual person. Care needs should be regularly reassessed and should be marked by a comprehensive initial holistic assessment of care needs, undertaken jointly with the patient and those important to them. Patients should have the opportunity to discuss these at key points along their journey, such as diagnosis, change in condition, hospital admission. Although it is important to recognise that the patient’s wishes may change at any point.

7.2 All patients should be offered the opportunity to undertake this process as part of the ongoing support from the community teams. The use of a tool to document this allows people to communicate their wishes when they are well about how they would like to be treated should they become unwell and unable to communicate their wishes. These decisions should be communicated with their care team which may include family and friends. An advanced statement of wishes and preferences can also form part of a personalised plan of care and should be reviewed as and when required.

7.3 There is a significant difference between an advanced statement and advanced decision to refuse treatment. The terms are not interchangeable.

7.4 Advance Statements: people who understand the implications of their choices can state in advance how they wish to be treated if they suffer loss of mental capacity. An advance statement is not legally binding, but can be used to inform health care professionals of a patient’s wishes about how they would like to be cared for should they be unable to make the decisions themselves.
7.5 **Advance Decision to Refuse Treatment (ADRT):** The MCA provides the framework for people aged 18 or over to make an ADRT and confirms the requirements that must be met to ensure that it is valid and applicable. An ADRT is a decision by an individual to refuse a particular treatment in the future should they lose capacity to make the decision at that time. A valid and applicable ADRT is legally binding. The criteria for an ADRT relating to refusal of life-sustaining treatment, such as CPR, to be valid are as follows:

- The person was 18 years old or over and had capacity when the decision was made
- The decision is in writing, signed and witnessed
- It includes a statement that the advance decision is to apply even if the person’s life is at risk
- The advance decision has not been withdrawn
- The person has not, since the advance decision was made, appointed a welfare attorney to make decisions about CPR on their behalf
- The person has not done anything clearly inconsistent with its terms
- The circumstances that have arisen match those envisaged in the advance decision

If an ADRT does not meet these criteria but appears to set out a clear indication of the person’s wishes, it will not be legally binding but should be taken into consideration in determining the person’s best interest.
8. Resuscitation

8.1 Following clinical assessment and/or recognition that the patient has an advanced life-limiting illness, staff should offer a discussion with the patient and those important to them regarding future treatments that may or may not be of benefit to the patient. This will be carried out with the utmost sensitivity and include all aspects of care, treatment and resuscitation.

8.2 The legal responsibility in making a decision relating to cardio-pulmonary resuscitation rests with the senior health care professional responsible for care, in the community this is the GP and documented as per Trust Policy. This will be both electronic and hard copy.

8.3 Patients may be discharged from hospital with a uDNACPR in place. This should be part of the discharge summary and should be handed over to all front facing staff. The original form (lilac copy) will be sent with the patient and should be placed in the front of the District Nursing patient held notes.

8.4 Where possible these decisions must be explained to the patients, clear rationale not to have this discussion must be documented in the patient’s records, and the distressing nature alone is not sufficient justification. Following the Tracey Judgment the decision not to attempt cardio-pulmonary must also be discussed with next of kin/significant others unless the patient specifically requests that the family/significant others are not to be informed. This should be documented on the form and in the patient’s notes/EMIS.


8.5 The Trust will expect staff to attempt resuscitation for all patients, unless discussions regarding the above have taken place and a decision is made that the patient is ‘not for resuscitation’. Healthcare professionals have a duty of care to consider withdrawal of non-contributory therapies and the distress caused by resuscitation measures in those near the end of life with a progressive and irreversible decline in their condition. General Medical Council (2010). Where no explicit decision about CPR has been considered and recorded in advance there should be an initial presumption in favour of CPR. However, in some circumstances where there is no recorded explicit decision (for example for a person in the advanced stages of a terminal illness where death is imminent and unavoidable and CPR would not be successful) a carefully considered decision not to start inappropriate CPR should be supported.”

8.6 Decisions about resuscitation must be reviewed regularly when there is any change in the patient’s condition. Some decisions will be deemed indefinite, however, this should not prevent further discussion or review by the MDT/patient/relatives
8.7 When a DNACPR has been made a patient’s right to die is peaceful and with dignity must be respected.

8.8 If an uDNACPR decision has been agreed the appropriate documentation must be completed as per uDNACPR policy. The GP should be encouraged to code this as an active problem on the EMIS record and as such it can be accessed by the community team on the shared record. This information should be shared with the DN team and discussed at the District Nursing safety huddle and GSF meetings.

9. Involvement with patients and carers

9.1 Discussion with and involvement of a patient’s family and those important to them is an integral part of care, communication between key providers and family members is essential to maintain continuity of care.

9.2 The patient’s next of kin and/or carers who are to be involved in the care should be identified as soon as possible and documented within the personalised care plan. Accurate contact details should be recorded within the patient’s record and regularly checked and updated as required.

9.3 It is essential that the patients are fully involved in all aspects of their care and should be given the choice to be involved in decisions regarding their preferred place of care/ preferred place of death, and any other wishes discussed e.g. organ donation.

9.4 The patient and next of kin and/or carer must be given the opportunity to revisit the advance care plan and personalised care plan as they wish. If there is no plan in place, the carer and/or family will be given the opportunity to discuss their needs with a view to immediate support and that which may also be required in the future.

9.5 Carers will be given the opportunity to be involved at all stages of the process as appropriate, where the patient has given consent for them to be involved. Carers will be offered the opportunity to support their relatives/friends at all times if appropriate to patient’s wishes. Consent to discuss care with families or those important to the patient must be sought and documented within the patient’s notes/EMIS.

9.7 It should be recognised that family and those important to the patient may include children and young adults. Staff must recognise that in some instances there may be need for sign posting and/or liaising with children’s services, bereavement services to help the children through this incredibly distressing time. Children’s anxieties can be higher prior to bereavement because of the fear of the unknown. These children’s needs must also be assessed and identified in order to input the most appropriate support prior to the death of a relative.
10. Capacity

10.1 A person must be assumed to have mental capacity unless it is proved otherwise and until all practicable steps have been taken to help someone make a decision without success they cannot be treated as lacking capacity. A perceived unwise decision does not in itself indicate a lack of capacity (MCFT mental capacity policy 2015).

10.2 In the event that a patient is assessed as lacking capacity to make a decision about the issues listed below and there is no one to support or represent them in making a decision then a referral to the Independent Mental Capacity Advocate (IMCA) Service should take place. The care team have a responsibility to ensure that the IMCA is instructed prior to:

- Moving into or between care settings (e.g. long term care home)
- Serious medical treatment e.g. potentially life prolonging treatment
- Adult protection procedures
- Care reviews

10.3 If a patient is detained under the Mental Health Act (1983) at the time of death detailed guidance can be found within the document 'Statutory notification, Regulation 17, Care Quality Commission (Registration) Regulations 2009: Death of a person who is detained or liable to be detained under the Mental Health Act 1983'. This document is available via the following hyperlink:

http://www.cqc.org.uk/content/mental-health-notifications

10.4 There is also need to document the process if a patient dies under a Deprivation of Liberty Standard or Urgent Authorisation DoLS. It is the responsibility of the unit manager in which the patient has been cared for to inform the local authority if the patient is subject to a DoLS authorisation when they die.

10.5 From 3rd April 2017 the Coroners and Justice Act 2009 was amended that people subject to authorisations under the Deprivation of Liberty Safeguards (DoLS) were no longer considered to be 'otherwise in state detention' for the purposes of section 1 of the Coroners and Justice Act 2009. This means that where the deceased was subject to DoLS authorisation the coroner will no longer have a duty to conduct an inquest in all cases. The death will only be reported where the cause is unknown or if any concerns that the cause of death is unnatural or violent, including where there is any concerns about the care given having contributed to the persons death.

10.6 It is the Doctors responsibility to report to the coroner all patients who die and have a DoLS order in place even if the death is expected.
11 Care of patients in last year of life

11.1 A person’s needs at the end of life are individual as are their views on how they would want their care to be provided and also what they may also wish to refuse now or in the future. It is the role of the health and social care professional to assess these needs in a holistic manner. End of life care requires an active compassionate approach that treats, comforts, and supports individuals who are living with or dying from progressive or chronic life threatening conditions. Such care is sensitive to personal, cultural and spiritual values, beliefs and practices and encompasses support for families and friends up to and including the period of bereavement. (Ross, et al, 2009).

11.2 Prognostic Indicator Guidance (PIG) found on the GSF website, http://www.goldstandardsframework.org.uk, or within the specialist palliative care referral criteria is available to support clinicians. It could be marked by diagnosis of a condition that has a poor prognosis, or by exacerbation of a long-term condition that has resulted in a sudden and marked deterioration in the person’s physical health and independence. For others death is an unforeseen event, and in this situation coroner involvement can be necessary.

11.3 Care needs should be regularly reassessed and should be marked by a comprehensive initial holistic assessment of supportive and palliative care needs, undertaken jointly with the patient, relatives and carers. Needs should be holistically reassessed to ensure timely referral to specialist services, allied health professionals and other appropriate support services.

11.4 Following initial assessment patient visits should be scheduled based on patients and carers needs. The frequency may alter dependent on the patient’s clinical condition but the schedule should be agreed following collaboration with the patient and carer. Patients on District Nursing case load with a palliative diagnosis MUST have a schedule of visit plans in order to provide ongoing support, unless the patient has declined ongoing assessment/review.

11.5 Following recognition of a palliative diagnosis the following should take place:

- Immediate support will be offered to the patient to enable them to comprehend and reflect upon the information they have received
- The patient’s care coordinator/relevant lead professional will be informed
- The patient will be given the opportunity to identify those important to them and contact will be made with that person should the patient so wish
- The patient will be offered the opportunity to discuss preferences for future care and treatment. “Planning your future care” is an information leaflet used locally to help facilitate these discussions.
• If the patient is unable to understand their condition and plan of care, then the key worker will discuss the patient’s care with the patient’s identified main carer. The patient may also not wish to have these discussions; they may be had with a nominated party if the patient consents.

• The opportunity must be given to the patient and/or carer to discuss and identify their physical, psychological, spiritual and social needs as part of the holistic assessment process.

• With the patient’s consent a plan of care must be discussed with the patient and/or main carer/legal representative and recorded in the care plan. This will include the patient’s preferred contacts, any advance decisions and Lasting Power or Attorney (LPA) for health and welfare.

• Information about preferences for future care, including preferred place of care and death, should be recorded on the End of Life template on EMIS and within the patient’s care plan. The GP practice will record this on the Electronic Palliative Care Co-ordination System (EPaCCs).

11.6 Following assessment of care needs as part of the holistic assessment process, where a care package has been deemed appropriate, a funding decision is made following completion of either an application for continuing health care or a financial decision by adult social care. A decision regarding the funding stream of a patient’s care should not delay the commencement of care. The decisions relating to funding streams should be in accordance with prognosis of the patient: the north-west end of life care model and prognostic indicator guidance can be utilised to aid decision making.
12 Gold Standards Framework

12.1 The Gold Standards Framework developed within primary care focuses on improving communication, continuity of care, advance care planning and patient care and support. The three processes for this are:
- Identifying if the patient is likely to die within the next 12 months
- Assessing their care needs and preferences
- Developing a multi-disciplinary individualised plan of care

12.2 All patients identified as in the last year of life should be on the GSF register and this should be documented in the patient’s records on EMIS. This will enable more effective communication of patients’ preferences, including preferred place of death. This data will be pulled through to the End of Life Co-ordination tab on EMIS. The information should include:
- Diagnosis
- GSF status
- Advance care planning status
- DS1500 issued/benefits entitlement
- Consent to share information
- Anticipatory medication
- Resuscitation status
- Date of discharge/death
- Commencement of the personalised care plan for the last days of life

12.3 Key clinical information discussed at the GSF meeting should be documented on EMIS and within the GSF District Nursing folder. Any changes to the plan of care of key information should be discussed and documented within team safety huddles.

12.4 People living with dementia are often very frail with a steady progressive decline in health for months or years before death. The Dementia Strategy “Helping people live the lives they want” (2012-2014) clearly recommends that all dementia patients who are identified as nearing the end of their life should be included on the Gold Standard Framework register.
13 Transfer to another Facility

13.1 There may be instances when a patient’s needs are best met in another facility, for example in an acute hospital or hospice. Decisions such as these should be made by the MDT at the earliest opportunity involving the patient and carers wherever possible.

13.2 When transferring a patient to another facility community staff will provide support throughout the process in order to maintain continuity of care throughout this process by providing:

- A comprehensive handover of care and treatment to the receiving care team (verbal and written). This will include the uDNACPR form if this decision has been made (please refer to uDNACPR Policy), and any ACP documentation

- Regular and appropriate contact with patients, carers and staff should be maintained. This will be coordinated by an identified health care professional who will also ensure the care is seamless and proactive
14 Care of Patients in the Last Days of Their Life

14.1 Recognition of the dying phase is an important part of effective and compassionate end of life care. For some this may seem to happen suddenly and without warning but for many others it can be a gradual process.

14.2 When an individual is recognised as dying community staff must take the appropriate action, to ensure a dignified death is achieved. As such a multi-disciplinary discussion should take place and when there is agreement that the person is recognised to be dying a personalised care plan for the last days of life should be commenced.

14.3 In relation to care of the patient all nurses must:

• Recognise the value and importance of the care and compassion shown to the person who is dying.

• Develop, update the personalised care for the last days of life and regularly review this in order to meet the dying person’s needs and wishes in relation to how their care should be managed and any treatment preferences they may want to express. This plan includes attention to symptom control and the person’s physical emotional, psychological, social, spiritual, cultural and religious needs.

• Be able to communicate with the patient and those important to the patient in a way that facilitates a regular and proactive approach to actively seek to communicate, listening to views of the person that are important to them and responding in a way that is respectful in pace and tone.

• Ensure clear communication is offered sensitively to the patient that they have entered into the final stages of life (if conscious) giving the dying person the opportunity to ask questions. The same communication will take place with those important to the dying person and others involved in that person’s care. Discussions around prognosis and dying should be confirmed as understood and documented in the patients personalised care plan. They should also be reinforced with the appropriate patient information leaflets: “Coping with dying” and “What to do when someone dies.”

• Check if the patient has an advance care plan in place to inform decision making. Be aware and respect prior wishes of the patient such as choice of visitors, requirement to see faith leader, method of delivery of care, plans for organ / tissue donation and donation of bodily parts for research purposes. This should be clearly documented in the patient’s care plan and the relatives and care team should be made aware of these wishes.
• Be respectful of any preference regarding place of death and ensure that this is honoured where possible. Consider facilitating transfer to preferred place of death if this can be achieved safely and with dignity. Consider moving the patient to a side room if the patient is being cared for within bed based services.

• During planning of preferred place of death, the patient’s condition must be regularly reviewed to ensure the original plan is still safe and dignified, e.g. discharge home from inpatients unit, or transfer to hospice.

• Comply with the assessment and procedures of the NHS fast track Continuing Health Care (CHC) tool and implement it as appropriate to facilitate discharge.

• Ensure any changes are communicated to the GP, District Nurses and Palliative Care and wider healthcare team.

• Ensure that injectable medication is available in the patient’s home in anticipation of patient's need to ensure timely access to symptom control when required. Ensure that injectable medications are prescribed for the five main symptoms experienced: pain, agitation, nausea/vomiting/respiratory tract secretions and dyspnoea. These should be also prescribed in the drug authorisation sheet with both stat injection and syringe driver prescribed as required. Community staff members are to ensure that robust, clear, pain and symptom management plans are in place and are regularly reviewed.

• Ensure that the patient’s comfort is assessed. This may take precedence over nursing and clinical procedures, for example if the patient is asleep and comfortable it may be inappropriate to disturb them. If it causes discomfort to move the patient then limited repositioning should be considered. It may also be appropriate to administer a stat dose of analgesia prior to procedures if the action of moving causes discomfort. Frequency of repositioning should be determined by individual patient assessment. Ensure that the patient is offered food and fluids as and when appropriate in accordance to the patient's wishes and safety.

• Ensure that key information is documented and kept up to date such as next of kin contact details.

• Ensure that any changes to the patient’s clinical condition are shared with all OOH services (DN and GP) and that the patients are discussed daily at patient safety huddle.

• Ensure that the individual's spiritual and religious needs are addressed and appropriate referrals made, such as to their faith leader. Document any wishes the patient has for the time of their death or afterwards within the personalised care plan. Families may require signposting to local services.
Due to the irregularity in which interventions such as syringe drivers are required in the mental health in-patient setting; appropriate specialist advice should be sought from the wider multi-disciplinary team, such as the GP, District Nursing Team or Specialist Palliative Care Team. Nursing services will support such areas with the ongoing management of the medication use via the syringe driver.

15 Relationship Responsibilities

15.1 In relation to care of family and carers all nurses should:

- Offer appropriate support to families and carers, ensuring that they are guided step by step through the dying process and what to expect. This will include allowing time for explanations, questions and communication, offering physical presence as needed for support and providing written information as appropriate
- Ensure that decisions made regarding changes to treatment plan, withdrawal of treatment and deactivation of implanted cardiac devices, is given careful consideration with regard to the timing of such communication to the family and relatives
- Forward planning and anticipation of needs is important in maintaining dignity and to avoid ‘on the spot’ decisions regarding patient’s safety and comfort where it could be anticipated to decide with the team responsible for care.
- Be clear about the individual’s prognosis, and make all attempts to allow the family to have the opportunity to say their final goodbyes
- Ensure that the family and carers have privacy and a quiet space or room for reflection and express emotions in a private environment
- Recognise this is an emotive and challenging time for the family and the importance of the nurse ‘being there’ for them as well as the patient
- Ensure family and carers have access to food and drink and are also able to stay with the patient should they wish. Again they should also be provided with the appropriate patient information leaflets.

15.2 In relation to other professionals / team members all nurses should:

- Be aware of their own and other colleagues’ emotional needs and ask for support when needed.
- Support others in the team, especially those who are newly qualified or new to the team.
- Participate in regular Clinical Supervision and reflect on experiences as per Mersey Care NHS Foundation Trust’s Clinical Supervision Ethos
- Staff members are encouraged to access staff support as required and that debriefing occurs following challenging clinical situations. The specialist palliative care team can support the debrief if required.
15.3 In relation to other patients on the bed based services all nurses should: (ward 35)

- Consider if any other patients within the ward may be unsure of what is happening (seeing or hearing different activity) and have concerns and questions that they feel unable to communicate. Opportunities should be offered to enable them to express these concerns and whilst respecting confidentiality, an explanation given to them.
- Be aware they may have developed or already have a friendship with the individual and may wish to spend time with them and this should be facilitated if it is the individual’s or family’s wish.

16 Care after Death

Good end of life care does not stop at the point of death. After death all staff must follow good practice for the care and viewing of the body as well as being responsive to family wishes in order to promote dignity. The support and care provided to relatives and carers will help them cope with their loss. The death of a patient is likely to be a very emotional time for carers, other patients and staff. It is essential that care and sensitivity is upheld throughout the procedures that need to take place after death has been verified. The needs of all those involved must be considered and met as far as possible.

16.1 Care after an expected death

- Families are advised to contact the District Nursing team on duty at the time of death to report the death. It is best practice in order to support the family at this difficult time for the District Nurse to then contact the GP or GPOOH if no nurse is available to verify the death. This is to ensure that the GP or GPOOH are aware that the death is expected and to ensure there are no unnecessary call outs from the police or ambulance service.

- A nurse trained in Verification of Expected Death (VOED) can verify the expected death of a patient in order to ensure timely access to verification, in line with NICE guidance (see Mersey Care NHS Foundation Trust Verification of Expected Death Policy). The person verifying the death is responsible for confirming the identity and ensuring that the appropriate documentation for GP records and the Funeral Directors is completed and contained within the personalised care plan for the last days of life.

- Ensure the family is aware to make arrangement to remove the body to the funeral directors and support with this as appropriate, following verification and last offices. If the patient is going from the ward either with the funeral director chosen by the family, or where a hospital mortuary is appropriate arrange with the appropriate hospital staff.
• If the patient is on bed based services collect together the patient’s property, listing it in the patient property book, pack it neatly into bags and place in an agreed safe place to await collection. Any valuables or cash in excess of £20 should be managed as per Aintree University Hospital Trust’s Patient Property Policy ensuring that all belongings are returned to relatives in a sensitive, appropriate and respectful manner and that the property book is completed accurately.

• If the patient is in bed based services when releasing the deceased to the funeral director pass on any relevant information including infection risk, implantable devices or the presence of jewellery.

• Stock check all injectable medication and document within the patient’s notes and advise the family to return unused medication to the community pharmacy as per the Denaturing of Controlled Drugs (CD) in the Community by registered Community Nurses SOP.

• Medication should be denatured in the patient’s home only if the risk of diversion has been identified within the patient’s risk assessment.

• Injectable medication is to remain in the residential/nursing home for 7 days after death in case of coroner involvement. It is then the responsibility of the home to arrange for this to be denatured, as per Denaturing of Controlled Drugs (CD) in the Community by registered Community Nurses SOP.

• Ensure that the patient’s preferred place of death and actual place of death is documented within the end of life template on EMIS.

In relation to the family and carers the nurse’s role may include:

• Informing them of the person’s death (if they are not present) by the method previously agreed and documented.

• Providing clear information and guidance as to the next steps that they need to take whilst recognising that this can be a confusing and overwhelming time. This will include information on collection of the Medical Certificate or Cause of Death (MCCD), advice on collection of property, the location and contact details of the local registry office. This should be supported with the relevant information leaflets.

• The MCCD can be written by the Medical Practitioner attending the patient as long as they have seen the deceased within the last 14 days, alternatively the certificate may have to wait until a Medical Practitioner who has seen the deceased in the last 14 days returns to duty. The duty Medical Practitioner can contact the Coroner to discuss the case and may then be able to write the MCCD.
• Ensuring that the family have sufficient privacy and that if they wish they are able to spend time with their loved one after death to say their goodbyes in the way that they want to, taking care to provide a sensitive and dignified environment.

• Facilitating access to any religious / spiritual support required.

• Ensuring that the family and carers know how to access assistance in the future following their bereavement and offer a follow up bereavement contact from the team.

In relation to other staff the nurse’s role may include:

• Informing other multi-disciplinary team members that the person has died.

• Informing the individual’s own GP and multi-disciplinary team that they have died if required.

• Completing Datix form if no uDNACPR form in place at time of death or other issued identified.

16.2 Care after an unexpected death

In relation to the patient the nurse must:

• In the first instance if death is unexpected and no uDNACPR form is in place it is expected that NWAS are contacted and CPR attempted. If it is clear that life is extinct then contact GP and police if necessary .

• Maintain an environment that promotes dignity and respect at all times.

• Call the Ward Doctor/GP and request they attend to verify death; it is not the role of the Nurse to verify death in unexpected circumstances. During the out of hours period contact the Out of Hours Doctor on NHS 111, and request he/she attends to verify death. The patient’s usual doctor will decide if they are able to issue a Medical Certificate of Cause of Death (MCCD) or if the death needs to be referred to the coroner.

• Preserve the patient and the patient’s environment as it is until it has been decided by the Coroner in liaison with the Doctor, whether there is any complaint about the care of the patient or the circumstances surrounding the death giving rise to suspicion which may require forensic investigation. The Coroner’s office can be contacted on 0151 233 5770 (Liverpool) and 0151 934 3047 (South Sefton) between the hours 0930 - 1400hrs. Outside of these hours the Police should be contacted and will act as Coroner’s officers.
• If a MCCD is able to be issued, care should continue as per care after death SOP.

• If the Doctor is unable to issue a MCCD he/she must contact the Coroner who will advise on the next steps. When contacted the Coroner will require the following details: the professional’s telephone number; the deceased person’s name, address, date of birth and GP details; family members’ names, contact details and relationship to the deceased person; date and time of death; details of the person who pronounced life extinct and details of what happened leading up to the death.

• When the Coroner wishes to investigate suspicious circumstances as above, he will arrange for the police to attend to examine the scene and no further input from District Nurse is immediately required.

• Leave all intravenous and subcutaneous cannulas and lines in situ and lines clamped but intact. Leave any catheter in situ with the bag and contents. Do not wash the body or begin mouth care to preserve evidence. Leave all equipment in situ. Continue using universal infection control measures to protect people and the scene from contamination.

• Receive information from the Coroner / Coroner’s Officer (Police representative) regarding which funeral director they have arranged. The deceased must only be released to the funeral director named by the Coroner / Coroner’s Officer once their examination of the scene is complete.

• Ensure the body has the correct identity labels in place on wrist or ankle and that the patient’s records are collected together ready to go with the body for the post mortem examination.

• If injectable medication is present within the house then stock check and document within the patients notes. Do not remove or denature this mediation, this must remain in the house as this may be required by the coroner or police, medication should be left for a minimum of seven days.

• Staff should not remove any equipment from the patient or from their property for seven days following an unexpected death.

• Staff should then Datix the death as per the Responding to Death Policy.
17 Last Offices

To carry out this procedure the healthcare worker will be required to wear personal protective equipment as provided by the Trust. The standard hygienic preparation of bodies usually involves the washing of the deceased hands and face, closing the eyes and mouth, tidying the hair and possibly shaving the face. In the case of cultural and religious ritual and significant others may want to prepare the body before burial. If there is a risk of infection the hazards must be assessed and advice given in these situations (HPA 2004). If family members wish to prepare the body staff must ensure that the family members are aware of the risks and that appropriate infection control precautions are undertaken as outlined in this policy:

- Prior to verification of death the body may be washed and presented for the family but no equipment is to be removed. Once death has been verified remove all intravenous or subcutaneous lines, catheters, central lines, nasogastric tubes and syringe drivers.
- Use of gloves and plastic aprons
- Any open wound on the body to be dressed with a suitable waterproof dressing
- If body fluids are leaking, the body should be clothed in a water-repellent disposable gown, (seek advice from the Aintree University Hospital NHS Trust Infection Prevention and Control Team for bed-based services)
- When used, body bags must be carefully secured. Identity labels and Notification of Death labels should be discreetly attached to outside of the bag. No labels should state the diagnosis of infection
- The Undertaker staff needs to be alerted to the danger of infection. The exact specification of the pathogen involved must not be divulged as this breaches patient confidentiality.

Staff should refer to the Standard Operating Procedure for Care after Death for further reference.
18 Infection Prevention and Control

Mersey Care NHS Foundation Trust is fully committed to the prevention of Health Care Associated Infections (HCAI’s) and to ensuring compliance with the Hygiene Code of Practice (DH, 2006, revised January 2008) and Health and Social Care Act (DH 2012) across all services. Most bodies pose minimal risk of infection to staff if standard precautions are followed. Some bacteria and viruses do hold a risk if staff become exposed to fluid/material containing those organisms. Infection Prevention and Control precautions following the death of a patient should follow local guidelines as contained within the Mersey Care NHS Foundation Trust infection prevention and control policies. Relatives who have had any physical contact with a body must be encouraged to wash their hands, unless significant risk has been identified and as such should be discouraged.

Within Mersey Care NHS Foundation Trust bed based services it is an expectation that staff follow Aintree University Hospital Trusts guidelines and policies.

18.1 Pandemic Influenza

- When performing last offices for deceased patients during a pandemic Influenza outbreak, healthcare workers must follow standard infection control principles; appropriate masks should be considered if there is a risk of splashes of blood and body fluids, secretions (including respiratory secretions or excretions onto the nose and mouth).

- The body should be fully wrapped in a sheet. Transfer to the mortuary should occur as soon as possible after death. If the family wishes to view the body, they may be allowed to do so and instructed to wear Personal Protective Equipment (PPE) in accordance with standard infection control principles.

On bed based services, the mortuary staff should be informed that the deceased had influenza. Standard infection control principles should be followed; there is no further risk of droplet spread. Funeral directors should be informed on the level of infection risk (that is, a low infection risk).
19 Viewing

Families should be encouraged to spend as much time with their loved one after the have died as they feel they need. As such ensuring that last offices are undertaken in a timely manner is important to facilitate this.

In relation to Ward 35

In relation to other patients on the ward all nurses should:

- Consider if any other patients within the ward may be unsure of what is happening (seeing or hearing different activity) and have concerns and questions that they feel unable to communicate. Opportunities should be offered to enable them to express these concerns and whilst respecting confidentiality, an explanation given to them.

- Be aware they may have developed a friendship with the individual and may wish to spend time with them and this should be facilitated if it is the individual’s or family’s wish.

In relation to other patients in the bay / ward the nurse’s role may include:

- Informing other patients in the same Bay / Room that the person has died, without giving any detail or breaching confidentiality.

- Being aware of the needs of other patients and offering support as appropriate, this may include supporting those that are facing their own mortality.

- Maintaining a dignified environment when the deceased person is being removed from the ward by the funeral directors, this may include informing other patients that you are pulling their bed curtains around to maintain respect and privacy at this time.
20 Legal Requirements

Consent - patients have a fundamental legal and ethical right to determine what happens to them. The practice of seeking consent is further endorsed by the requirements of the Human Rights Act (1998). The main purpose of seeking consent is to protect and respect the patient’s autonomy and individual rights, whilst ensuring medical accountability, involving the patients and carer in all stages of their care is essential and allows the wishes of the patient to be respected and implemented wherever possible.

Mersey Care NHS Foundation Trust consent and capacity to consent to treatment policy sets out standards and procedures that define “consent” between patients and health professionals providing treatment.

Consent may be indicated non-verbally, orally or in writing. For consent to be valid the patient must:

• Have capacity to make a decision
• Have received sufficient information to enable him/her to make an informed choice
• To be free from duress when making decisions

Trust staff must ensure patients and their carers have access to professional interpreting services if English is not their first language, or if they have sensory impairment. This will help to ensure that they are giving informed consent and are fully involved with decisions about their care.
21 Training Requirements

The Trust will work towards all staff being appropriately trained. No specific mandatory training relates to this policy. All documents referred to in this policy are accessible to staff on the Trust Intranet. All registered Nurses will be required to comply with the NMC Code: Standards of Conduct, performance and ethics (2014).

All staff caring for patients should develop and maintain basic professional competence in caring for patients nearing the end of their life and those at the end of life. They should have a good understanding of the physiological processes and the practical and emotional challenge in the final stages of a patients care. Appropriate Mersey Care NHS Foundation Trust staff should attend a programme of training relating to end of life care, which includes advance care planning, verification of expected death and syringe driver training, in agreement with their line manager.

For training to support the implementation of this policy, please refer to the training programme held within the Learning and Development Bureau.

22 Equality & Diversity

All relevant persons are required to comply with this document and must demonstrate sensitivity and competence in relation to the nine protected characteristics as defined by the Equality Act 2010. In addition, the Trust has identified Learning Disabilities as an additional tenth protected characteristic. If you, or any other groups, believe you are disadvantaged by anything contained in this document please contact the Document Lead (Author) who will then actively respond to the enquiry.
23 Monitoring Compliance and Effectiveness

a. Monitoring arrangements for compliance and effectiveness

- Overall monitoring will be by the End of Life Group, by review of incidents
- The Trust’s End of Life Group will monitor procedural document compliance and effectiveness
- Ongoing audit of the personalised care plan for end of life

b. Methodology to be used for monitoring

- Concerns/Complaints monitoring
- Incident reporting via DATIX
- Include in the 3 year Trust audit plan

c. Frequency of monitoring:

- Annual reporting

d. Process for reviewing results and ensuring improvement in performance occur

Audit results will be presented to the Trust’s End of Life Group for consideration, identifying good practice, any shortfalls, action points and lessons learnt. This Group will be responsible for ensuring that improvements, where necessary, are implemented.

Lessons learnt will be included in the quarterly report submitted to the Clinical Effectiveness meeting. The report will be accessible to all staff in the trust.

24 Counter Fraud

The Trust is committed to the NHS Protect Counter Fraud Policy – to reduce fraud in the NHS to a minimum, keep it at that level and put funds stolen by fraud back into patient care. Therefore, consideration has been given to the inclusion of guidance with regard to the potential for fraud and corruption to occur and what action should be taken in such circumstances during the development of this procedural document.
25 Relevant Care Quality Commission (CQC) Registration Standards

a. Health and Social Care Standards
Under the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014 (Part 3), the fundamental standards which inform this procedural document, are set out in the following regulations:

Regulation 9: Person-centred care
Regulation 10: Dignity and respect
Regulation 11: Need for consent
Regulation 12: Safe care and treatment
Regulation 13: Safeguarding service users from abuse and improper treatment
Regulation 15: Premises and equipment
Regulation 16: Receiving and acting on complaints
Regulation 17: Good governance
Regulation 18: Staffing
Regulation 19: Fit and proper persons employed
Regulation 20: Duty of Candour
Regulation 20A: Requirement as to display of performance assessments.

b. Care Quality Commission (CQC) Regulations
Under the CQC (Registration) Regulations 2009 (Part 4) the requirements which inform this procedural document are set out in the following regulations:

Regulation 16: Notification of death of service user
Regulation 17: Notification of death or unauthorised absence of a service user who is detained or liable to be detained under the Mental Health Act 1983
Regulation 18: Notification of other incidents

c. CQC Guidance
Detailed guidance on meeting the requirements can be found at: http://www.cqc.org.uk/sites/default/files/20150311%20Guidance%20for%20providers%20on%20meeting%20the%20regulations%20FINAL%20FOR%20PUBLISHING.pdf

d. Relevant National Requirements
- Department of Health (2010) Equity and Excellence: Liberating the NHS

e. Guidance for staff responsible for care after death (last Offices)
www.nhsiq.nhs.uk/media/care_after_death__guidance.pdf
26 References, Acknowledgements and Associated Documents

25.1 References

- NICE Quality Standards (QS144) March 2017
- NICE Guideline (NG31) December 2015
- Leadership Alliance for the Care of Dying People (2014): One chance to get it right: Improving peoples experiences of care in the last few days and hours of life: [www.gov.uk/government/publications/one-chance-to-get-it-right](http://www.gov.uk/government/publications/one-chance-to-get-it-right)
- Department of Health (2003): Building on the Best, Choice, Responsiveness and Equity
- Department of Health (2006): End of Life Care Programme, Progress Report
- Department of Health (2006): Our Health, Our Care, Our Say, A new direction for community services
- Health and Social Care Act ( DH 2012)
- Treatment and care towards the end of life: good practice in decision making. London 2010) General Medical Council
- Ross, Fisher et al (2000): In Introductory Guide to End of Life Care in Care Homes, Department of health 2006
- Health Protection Agency (2004): The Infection Hazards of Human Cadavers. Guidelines on Precautions taken with Cadavers of those who have died with a known or suspected infection
- Infection Control Nurses Association 2004, Module 17 Infection Control and Dignity in Death
• NHS National End of Life Care Programme. Route to success: nursing to end of life care
• NHS National End of Life Care Programme, Guidance for staff responsible for care after death (last offices)
• NMC Code: Standards of Conduct, Performance and Ethics
  www.nmc-uk.org/documents/standards/the-code
• ‘Statutory notification, Regulation 17, Care Quality Commission (Registration) Regulations 2009: Death of a person using the service who is detained or liable to be detained under the Mental Health Act 1983’

Trust Guidance is accessible to staff via the Trust Intranet

INCLUSION: Patients who are over 18 identified as having an incurable illness that are entering the dying phase

EXCLUSION: Any person under 18. Any person with curable disease that is not entering the dying phase
Appendix A

The North West End of Life Care Model

Supporting the people of the North West to live well before dying with peace and dignity in the place of their choice

End of life care

- Is about the individual and those important to them
- Is about meeting the supportive and palliative care needs for all those with an advanced progressive incurable illness or frailty, 'to live as well as possible until they die'.
- Support may be needed in the last years, months or days of life.

It should include:

- A person centered approach to care – involving the person, and those closest to them in all aspects of their care including the decision making process around treatment and care
- Open, honest and sensitive communication with the patient and those important to them
- Care which is coordinated and delivered with kindness and compassion
- The needs of those identified as important to the person to be actively explored, respected and met as far as possible
- All discussions to follow guidance set within the Mental Capacity Act (MCA 2005)

Key recommended training for health and care staff:
- Communication skills
- Holistic assessment to include: physical, psychological, spiritual and social care
- Symptom control
- Advance care planning
- Caring for carers
- Priorities for care of the dying person
- Bereavement support
- Mental Capacity Act

The model supports the assessment and planning process for patients from the diagnosis of a life limiting illness or those who may be frail. The model comprises 5 phases and the Good Practice Guide (overleaf) identifies key elements of practice within each phase to prompt the assessment process as relevant to each setting.
# Appendix B

## End of Life Care Good Practice Guide

<table>
<thead>
<tr>
<th>LAST YEAR OF LIFE</th>
<th>INCREASING DECLINE</th>
<th>LAST DAYS OF LIFE</th>
<th>CARE AFTER DEATH</th>
<th>1 year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient identified as deteriorating despite effective management of underlying medical condition(s)</td>
<td>Medical review</td>
<td>All reversible causes of deterioration explored</td>
<td>Nurse verification of death where indicated</td>
<td></td>
</tr>
<tr>
<td>Clear, sensitive communication with patient and those identified as important to them</td>
<td>Clear, sensitive communication with patient and those identified as important to them</td>
<td>All reversible causes of deterioration explored</td>
<td>Certification of death</td>
<td></td>
</tr>
<tr>
<td>Person and agreed others are involved in decisions about treatment and care as they want</td>
<td>Person and agreed others are involved in decisions about treatment and care as they want</td>
<td>Multidisciplinary Team agree patient is in the last days of life</td>
<td>Clear sensitive communication</td>
<td></td>
</tr>
<tr>
<td>Needs of those identified as important are explored, respected and met as far as possible</td>
<td>Needs of those identified as important are explored, respected and met as far as possible</td>
<td>Clear, sensitive communication with patient and those identified as important to them</td>
<td>Relatives supported</td>
<td></td>
</tr>
<tr>
<td>Patient included on Supportive Care Record/GP Gold Standards Framework register and their care reviewed regularly</td>
<td>Priority assigned at Gold Standards Framework meeting</td>
<td>Dying person and agreed others are involved in decisions about treatment and care as they want</td>
<td>Department for Work &amp; Pensions General Practice</td>
<td></td>
</tr>
<tr>
<td>Requested consent to share information and onsets</td>
<td>On-going District Nurse support</td>
<td>Agree on-going monitoring and support to avoid crisis</td>
<td>OOH North West Ambulance Service</td>
<td></td>
</tr>
<tr>
<td>Holistic needs assessment</td>
<td>Holistic needs assessment</td>
<td>Ongoing communication with Keyworker</td>
<td>OOH North West Ambulance Service</td>
<td></td>
</tr>
<tr>
<td>Keyworker identified</td>
<td>Keyworker identified</td>
<td>Review or alter advance care plan, share information with patients consent</td>
<td>OOH North West Ambulance Service</td>
<td></td>
</tr>
<tr>
<td>Identify where there is an opportunity to offer an Advance Care Planning discussion and/or formal ADRT/POA/GP/DNACPR making a will</td>
<td>Consider Continuing Health Care funding OOH15000</td>
<td>Equipment assessment</td>
<td>OOH North West Ambulance Service</td>
<td></td>
</tr>
<tr>
<td>Benefits review of patient and care including Grants/prescriber exemption</td>
<td>DNACPR considered, outcome documented, information shared appropriately including ambulance services</td>
<td>Anticipatory medication prescribed and available</td>
<td>OOH North West Ambulance Service</td>
<td></td>
</tr>
<tr>
<td>Provide information on Blue Badge (disabled parking) scheme</td>
<td>Out of Hours/NWAS updated including DNACPR status and Advanced Care Plan</td>
<td>DNACPR considered, outcome documented, information shared appropriately including ambulance services</td>
<td>OOH North West Ambulance Service</td>
<td></td>
</tr>
<tr>
<td>Agree on-going monitoring and support to avoid crisis</td>
<td>Referral to other services e.g. Specialist Palliative Care</td>
<td>Out of Hours/NWAS updated including DNACPR status and Advanced Care Plan</td>
<td>OOH North West Ambulance Service</td>
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<tr>
<td>Referral to other services e.g. Specialist Palliative Care</td>
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<td>OOH/NWAS updated including Advance Care Plan/DNACPR</td>
<td>OOH/NWAS updated</td>
<td>Update EPaCCS Record as and when necessary</td>
<td>OOH North West Ambulance Service</td>
<td></td>
</tr>
<tr>
<td>ICD discussion if applicable</td>
<td>ICD discussion and deactivation</td>
<td>Referral to other services e.g. Specialist palliative care</td>
<td>OOH North West Ambulance Service</td>
<td></td>
</tr>
</tbody>
</table>

ADRT – Advance Decision to Refuse Treatment  
DNACPR – Do Not Attempt Cardiopulmonary Resuscitation  
EPaCCS – Electronic Palliative Care Coordinating System  
GP – General Practitioner  
ICD – Implantable Cardiac Defibrillator  
NWAAS – North West Ambulance Service  
OOH – OutOfHours  
PPC – Preferred Priorities of Care  

Jan 2016