## END OF LIFE CARE

<table>
<thead>
<tr>
<th>Policy Number:</th>
<th>SD47</th>
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</thead>
<tbody>
<tr>
<td>Scope of this Document:</td>
<td>All Staff Trust-wide</td>
</tr>
<tr>
<td>Recommending Committee:</td>
<td>Physical Health Strategy Group</td>
</tr>
<tr>
<td>Approving Committee:</td>
<td>Executive Committee</td>
</tr>
<tr>
<td>Date Ratified:</td>
<td>November 2017</td>
</tr>
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<td>November 2018</td>
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<td>Version Number:</td>
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<tr>
<td>Lead Executive Director:</td>
<td>Executive Director of Nursing</td>
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<tr>
<td>Lead Author(s):</td>
<td>Modern Matron (Physical Health)</td>
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**Striving for perfect care for the people we serve**
This document clarifies the responsibility of Mersey Care NHS Foundation Trust Community and Mental Services clinicians and establishes the standards in respect of end of life care for an expected death of a patient in inpatient and South Sefton Community Division services.

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Your Space Extranet: http://nww.portal.merseycare.nhs.uk
Trust’s Website www.merseycare.nhs.uk

To be read in conjunction with
SD29a Physical Health Policy
ICO1 Infection Prevention and Control Policy
SD07 Resuscitation Policy including the NHS, North of England, North West Unified DNACPR Adult Policy
SA19 Management and Decontamination of Medical Devices Policy
SD12 Handling of Medication Policy
SD06 Consent to Examination and Treatment Policy
SD 02 Death of a service User
SD 19 Advanced Statements and Advanced Decisions
SD 44 Nutrition Policy
SD 30 Management of Dysphagia

This document can be made available in a range of alternative formats including various languages, large print and braille etc

Version Control:

<table>
<thead>
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<th>Version</th>
<th>Circulated to:</th>
<th>Version History:</th>
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<tbody>
<tr>
<td>Version 1</td>
<td>Trust-wide Divisions, Associate Medical Director for Physical Health Strategy Group</td>
<td>September 2016</td>
</tr>
<tr>
<td>Version 3</td>
<td>Executive Committee - for Ratification</td>
<td>January 2017</td>
</tr>
</tbody>
</table>
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.
## Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Purpose and Rationale</td>
<td>5</td>
</tr>
<tr>
<td>2. Outcome Focused Aims and Objectives</td>
<td>5</td>
</tr>
<tr>
<td>3. Scope</td>
<td>5</td>
</tr>
<tr>
<td>4. Definitions</td>
<td>6</td>
</tr>
<tr>
<td>5. Duties</td>
<td>6</td>
</tr>
<tr>
<td>6. Process</td>
<td>7</td>
</tr>
<tr>
<td>7. Consultation</td>
<td>10</td>
</tr>
<tr>
<td>8. Training and Support</td>
<td>10</td>
</tr>
<tr>
<td>9. Monitoring</td>
<td>11</td>
</tr>
<tr>
<td>10. Equality and Human Rights Analysis</td>
<td>12</td>
</tr>
<tr>
<td>11. Supporting Documents</td>
<td>18</td>
</tr>
<tr>
<td>12. Appendices:</td>
<td></td>
</tr>
<tr>
<td>Appendix 1 – Pathway Referral Process</td>
<td>19</td>
</tr>
<tr>
<td>Appendix 2 – Personalised Care Plan for the Last Days of Life Guidance for Nurses</td>
<td>20</td>
</tr>
<tr>
<td>Appendix 3 – End of Life Symptom Guidance</td>
<td>22</td>
</tr>
</tbody>
</table>
1. PURPOSE AND RATIONALE

1.1 This policy establishes the trust wide minimum standards for the evidenced based guidelines for the holistic care of a patient who may be approaching the last few days of life in accordance to the ‘One Chance to get it Right’ document (LACDP2014).

1.2 The expected death of a patient in our care is an infrequent event for inpatient services and recurrent event for community services. Therefore staff may not be familiar with the standard of care required or the support services available in this situation. This policy aims to provide staff with the principles to ensure that consistent compassionate patient centred care is provided for patients who require end of life care in our services.

1.3 Dying is an uncertain process and it can be difficult to determine and predict when a person will die. Therefore, the care of a person who has been assessed to be at this stage of their life needs to receive consistent and responsive evidenced based patient centred care while they are in this transition period.

2. OUTCOME FOCUSED AIMS AND OBJECTIVES

2.1 When it is recognised that a person may be entering the last few months, weeks or days of their life the aims and objectives of this are as follows.

   a) to ensure that a patient receives ongoing assessments and regular reviews in order to identify any changes in their:

      • palliative care
      • physiological condition
      • treatment
      • physical health needs
      • risks
      • support
      • psychological needs
      • spiritual needs

      to determine if the patient is nearing death, stabilising or recovering.

   b) to ensure that the patient and/their family and/those who are important to them are involved in the patient’s care provision as appropriate;

   c) to ensure that the patient is consistently monitored throughout this stage of life and that a responsive care approach is tailored to the changing needs of the patient;

   d) for staff to ensure that the patient’s care provision is seamless across support services and that the patient is maintained in a state of comfort and dignity throughout this period.

3. SCOPE

3.1 This policy applies to all Trust-wide staff and South Sefton Community Division services.
4. DEFINITIONS (Glossary of Terms)

<table>
<thead>
<tr>
<th><strong>Glossary of Terms</strong></th>
<th><strong>Definition</strong></th>
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<tbody>
<tr>
<td>DNACPR</td>
<td>Do Not Attempt Cardiopulmonary Resuscitation</td>
</tr>
<tr>
<td>LACDP</td>
<td>Leadership Alliance for Care of Dying People</td>
</tr>
<tr>
<td>RC</td>
<td>Responsible Clinician</td>
</tr>
<tr>
<td>SLT</td>
<td>Speech And Language Therapist</td>
</tr>
</tbody>
</table>

5. DUTIES – BOARD OF DIRECTORS

5.1 Health care providers are under obligation to provide safe care to their patients and appropriate training to their staff. This duty encompasses ensuring the care of patients whilst under the care of the organisation and the Trust has an obligation to comply with its statutory and regulatory observations.

5.2 The Trust Board has overall responsibility for ensuring that all staff are appropriately trained and competent to effectively fulfil their role within the organisation and maintain the safety of patients.

5.3 **Lead Executive Director**

The Lead Executive Director for this policy (Executive Director of Nursing) has strategic responsibility for ensuring that the standards with this policy are monitored and reported to the board accordingly.

5.4 **Policy Lead**

The Policy Lead (Modern Matron – Physical Health) will oversee the implementation and promotion of the policy across the Trust. They will be responsible for monitoring and reviewing the policy as necessary.

5.5 **The Associate Medical Director for Physical Health and Medicines Safety**

Will support and oversee the implementation and promotion of this policy, especially to medical staff and supporting the monitoring and review of the policy.

5.6 **Divisional Senior Management Teams**

Accountable to the Director(s) with responsibility for Clinical Divisions for ensuring delivery of high standards of care and adherence to this policy within their clinical division.

5.7 **Service Care Leads, Modern Matrons and Ward Managers**

Service care leads, modern matrons and ward managers are responsible for ensuring that high standards of care are maintained within their areas of responsibility and to adhere to the standards set out in this policy. They also have responsibility to identify training needs of staff and to liaise with appropriate personnel to meet those needs.
5.8 **All Healthcare Practitioners**

All staff working with service users in inpatient services and community areas have a responsibility to work in accordance with the standards set out in this policy.

6. **PROCESS**

5 Priories of Care, One Chance to get it Right (LACDP 2014)

Priority 1
The possibility that a person may die within the coming days and hours is recognized and communicated clearly, decisions made about care are made in accordance with the person’s needs and wishes, and these are reviewed and revised regularly.

6.1 When it has been recognised that a person may be entering the last few days of life, their condition must be consistently monitored and assessed as to whether the condition is potentially reversible.

6.2 If it is decided that the person is entering their last days of life, the Consultant and Multi Disciplinary Team must communicate the prognosis in a clear and sensitive way to the patient, their family or people who are important to them. During this meeting the doctor may need to provide time for any queries that arise and sensitively establish where the patient would like to be during this part of their life.

6.3 If the patient, their family or people who are important to them decide that they would like to die in an inpatient setting then a holistic care plan will be devised. If not, then the team needs to make the necessary arrangements on behalf of the patient to assist transfer to the site where the patient has chosen to spend this part of their life.

6.4 If the patient is detained under the Mental Health Act or Deprivation of Liberty Safeguard (DoLS) the Doctor (Responsible Clinician) must consider whether it is appropriate to continue with the detention or decide if the order could be revoked.

6.5 When devising a plan of care the team must establish if the patient has:

a) The mental capacity to make an informed choice about her/his personalised care plan for last days of life.

b) If it is thought that the patient EITHER does not OR may not have the capacity to make such an informed choice, a Mental Capacity Act compliant capacity assessment must be completed:

c) Where it is established that a patient does NOT have the mental capacity to make such a decision a Best Interests checklist assessment must be completed. This will include checking for:

- an advance decision to refuse treatment (note: ordinarily such decisions may be verbal or written. However, if the decision is to refuse life-saving treatment it must be written, witnessed, signed by the patient and include a statement acknowledging that to refuse the treatment may result in her/his death),

- a Health and Welfare Lasting Power of Attorney (LPA) authorised to make treatment decisions on behalf of the patient,
• a Court Appointed Deputy decision authorised to make treatment decisions on behalf of the patient,
• any specific Court of Protection treatment decision.

6.6 In most case decisions taken by the above are legally binding. If in doubt contact the Trust’s Legal Team 0151 472 4535 or the On Call Service via Switchboard.

Priority 2
Sensitive communications take place between staff and the dying person and those identified as important to them.

6.7 The team must maintain regular, respectful, sensitive, open and honest communications with the dying person, their family or those identified as being important to them. Careful consideration must be given to the timing of sensitive communications and any quick decisions regarding the patient’s safety and comfort.

Priority 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.

6.8 Sensitive communications must be undertaken to establish if the dying person, their family or those who are important to them wish to be involved in the decisions regarding the treatment and the way it is delivered.

6.9 The multidisciplinary team must enable the patient, their family or those important to them, to be involved in the decisions and plans for the future treatment and care of the patient. The care plan must be made in accordance with the needs and wishes of the patient, their family or those who are important to them. This plan needs to be consistently reviewed and revised accordingly.

6.10 The dying person and those who are important to them must be informed of the Doctor and Named Nurse who has overall responsibility for the patient’s treatment and care.

6.11 Where the dying person lacks capacity, the staff must continue to attempt to involve the patient at all levels of care when Best Interests action is undertaken.

6.12 The resuscitation status of a dying person should be established and agreed in line with the Trust’s Resuscitation Policy incorporating Do Not Attempt Cardiopulmonary Resuscitation.

6.13 A holistic patient centred plan of care must include nutrition and hydration, symptom control, physiological, pharmacological, psychological, cultural, social and spiritual support to be agreed, coordinated and delivered with compassion.

6.14 The team must ensure that they work in partnership with external providers to deliver timely seamless holistic care for the patient and meet their physical, spiritual, emotional, social and psychological needs in order to maximize the patient’s comfort and symptom control during this period.

Priority 4
The needs of the families and others identified as important to the dying person are actively explored, respected and met as far as possible.

6.15 The team must be receptive and respectful to the needs of the family and others identified as important to the dying person.
6.16 It may not be possible to meet the needs of the family but staff can provide opportunities for open communications and respectful support.

6.17 Staff must recognise this is an emotive and challenging time for the family, offer appropriate support throughout this time of the patient's life.

6.18 Ensure where possible that the family and carers have privacy for reflection and any expressed emotion, in a quiet space or room.

6.19 Allow the family access to stay with the patient should they wish to and say their final goodbyes when the time comes.

Priority 5
An individual plan of care, which includes food and drink, symptoms and psychological, social and spiritual support, is agreed, coordinated and delivered with compassion.

6.20 The dying person’s preferences, expectations, needs and wishes must be assessed and used to formulate a holistic, compassionate patient centred plan of care. This must be done in collaboration with the patient, their family and those who are important to them together with the palliative care team the nurses, medics and any support teams that are involved. The team may include the: Palliative Care Team, District Nurses, Chaplaincy, Physiotherapists, Pharmacists, Dietitians, Legal Team and GP’s, etc. This will ensure that all the essential teams, supplies, key tools and measures are anticipated and in place for the delivery of optimal care at this time of the patient’s life.

6.21 In the last days of a patient’s life, the patient centred care plan must ensure that the patient’s comfort takes precedence over nursing/clinical procedures to ensure a dignified end to life. In addition to the person’s physical, emotional, psychological, cultural, social, spiritual, and religious needs the care plan must include:

- Symptom Control:
  There needs to be ongoing holistic assessment by the medical, pharmacological and nursing teams during the patient’s decline to ensure that the patient consistently receives an effective and responsive care approach that is tailored to the patient’s changing needs and the plan of care adjusted accordingly. The patient may need to be referred to specialist palliative care teams for effective pain management. The patient may need to be referred to the district nurses for any administration of medication that requires a syringe driver in conjunction with pharmacy. The patient may need to be referred to the Dietetics team. The clinical staff may need to arrange for the delivery of any anticipatory medication prescribed for keeping the patient comfortable in the last days of life.

  [www.nice.org.uk](http://www.nice.org.uk)  
  (Care of dying adults in the last days of life NG 16th December 2015)  
  (Care of dying adults in the last days of life Quality Standard 144 2nd March 2017)

- Nutrition and Hydration Intake
  The aim of nutrition care must be patient centred which includes to monitor, reassess and encourage the nutrition and hydration needs of the patient ensuring the patient’s comfort throughout the last days of life and maximise their quality of life.
The care plan should specify how the person will be supported to eat and drink for as long as it is safe to do so or for as long as the patient wishes to continue. The nurses must monitor the nutritional and fluid status of the patient using diet and fluid charts and report any issues throughout this period of the patient's life. The nurses can refer to the Dietetics or SLT Team for support as required. Refer to Oral feeding difficulties and dilemmas 'A guide to practical care, particularly towards the end of life' (The Royal College of Physicians 2010).

- **Mouth Care**
  There will come a time when food and drink is no longer needed. The team must ensure that the patient receives excellent mouth care to ensure the patient’s comfort through this transition time. Refer to Royal Marsden’s Manual of Clinical procedures Ninth Edition, for clinical procedure.

- **Comfort and Dignity**
  There must be an ongoing an assessment and review regarding the patient’s personal comfort throughout the person’s decline. Assessments must be made to establish if the patient would benefit from specialised equipment which if required must be sourced in advance.

- **Spiritual and Religious Care**
  The Religious and spiritual needs of the dying patient must be assessed and access to the Chaplaincy service enabled for the patient as required.

- **For additional guidance on End of Life Care, please see appendices for:**
  Personalised care plan for the last days of life:
  - End of life Guidance for community staff SSCD
  - Symptom Control Checklist.

6.22 Ensure that documentation and key information is kept up to date and clearly communicated in a timely manner.

6.23 Good end of life care does not end at death, please refer to Policy No. SD02 Death of a Service User for care after death has occurred.

7. **CONSULTATION**

7.1 The following staff were consulted in the development of this policy:

a) Medical staff;

b) Nursing staff;

c) Divisional Directors, Service Leads and Modern Matrons.

8. **TRAINING AND SUPPORT**

8.1 Training will be delivered to staff in line with this policy and through consultation with specialist clinicians within the divisions.
8.2 Training will be delivered according to the outcomes focused aim and objectives within this policy.

8.3 All training will be quality assured and evaluated to evidence continual improvement as part of the educational governance process within the Learning and Development Plan and policy.

9. MONITORING

9.1 The standards in this policy will be monitored at the Trust's Physical Health Strategy Group quarterly.

9.2 The application of this policy will also be subject to monitoring by the Trust's Mortality Review Group through consideration of themes arising from the analysis and mortality reviews of Datix reports generated on the death of a patient.
10. EQUALITY AND HUMAN RIGHTS ANALYSIS

Equality and Human Rights Analysis

Title: End of Life Care
Area covered: Inpatient Areas

What are the intended outcomes of this work?
This is a review of the policy that has been slightly amended to include an appendix (End of Life Guidance for Nurses).
In line with the ‘One Chance to get it Right’ document. This policy establishes the trust wide minimum standards for the evidenced based guidelines for the holistic care of a patient who may be approaching the last few days of life in accordance to the One Chance to get it Right document (2014).

Who will be affected?
Patients who require end of life care in our inpatient services.

Evidence
What evidence have you considered?
The policy.

Disability (including learning disability) No issues identified on discussion.
Sex No issues identified on discussion.
Race No issues identified on discussion.
Age No issues identified on discussion.
Gender reassignment (including transgender) No issues identified on discussion.
Sexual orientation No issues identified on discussion.
Religion or belief
Spiritual and Religious Care. The religious and spiritual needs of the dying patient must be assessed and access to the Chaplaincy service enabled for the patient as required.
Pregnancy and maternity No issues identified on discussion
Carers
To ensure that the patient and / their family and/ those who are important to them are involved in the patient’s care provision as appropriate.
Other identified groups No issues identified on discussion.
Cross Cutting
Where the dying person lacks capacity, the staff must continue to attempt to involve the patient at all levels of care when Best Interests action is undertaken.
<table>
<thead>
<tr>
<th>Human Rights</th>
<th>Is there an impact?</th>
<th>How this right could be protected?</th>
</tr>
</thead>
</table>
| **Right to life (Article 2)**                                             | Human Rights based approach supported.                                              | In line with the ‘One Chance to get it Right’ document. This policy establishes the trust wide minimum standards for the evidenced based guidelines for the holistic care of a patient who may be approaching the last few days of life in accordance to the ‘One Chance to get it Right’ document. The following added under End of life guidance for nurses.  
1. Following assessment and agreement the decision that patient is dying must be a MDT decision between a GP (for out of hours a GP working for the out of hours service) and the District Nurse (either by telephone or face to face).  
This ensures assurances about when a patient is dying there will need to multi team agreement.  
This will also ensure that those making the decision are part of a team and as such the responsibility is not focused upon one person. |
| **Right of freedom from inhuman and degrading treatment (Article 3)**      | Human Right based approach supported.                                              | Where it has been recognised that a person may be entering the last few days of life, their condition must be consistently monitored and assessed as to whether the condition is potentially reversible.  
If it is decided that the person is entering their last days of life, the Doctor must communicate the prognosis in a clear and sensitive way to the patient, their family or people who are important to them. During this meeting the doctor may need to provide time for any queries that arise and sensitively establish where the patient would like to be during this part of their life.  
Dignity  
The guidance ensures that a patient’s dignity is promoted at all stages in the end of life care. |
<p>| <strong>Right to liberty (Article 5)</strong>                                          | Human Rights Based Approach Supported                                              | If the patient is detained under the Mental Health Act or Deprivation Of Liberty Safeguard (DoLS). The doctor (RC) must consider whether it is appropriate to continue with the detention or decide if the order could be revoked - Seek advice from the legal team. |</p>
<table>
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<th>Right to a fair trial (Article 6)</th>
<th>Human Right Based Approach Supported</th>
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</thead>
<tbody>
<tr>
<td>When devising a plan of care the team must establish if the patient has:-</td>
<td></td>
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<tr>
<td>1. The mental capacity to make an informed choice about her/his end of life pathway.</td>
<td></td>
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<tr>
<td>2. If it is thought that the patient Either does not OR may not have the capacity to make such an informed choice, a Mental Capacity Act compliant capacity assessment must be completed.</td>
<td></td>
</tr>
<tr>
<td>Where it is established that the patient does NOT have the mental capacity to make such a decision, a Best Interests checklist assessment must be completed. This will include checking for: An advanced decision to refuse treatment (note: Ordinarily such decisions may be verbal or written. However, if the decision is to refuse life-saving treatment it must be written, witnessed, signed by the patient and include a statement acknowledging that to refuse the treatment may result in her/his death).</td>
<td></td>
</tr>
<tr>
<td>A Health and Welfare Lasting Power of Attorney (LPA) authorised to make treatment decisions on behalf of the patient – A Court Appointed Deputy decision authorised to make treatment decisions on behalf of the patient – Any specific Court of Protection treatment decision. In most cases decisions taken by the above are legally binding. If in doubt contact the Trust's Legal Team.</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Right to private and family life (Article 8)</th>
<th>Human Rights Based Approach Supported</th>
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<tbody>
<tr>
<td>If the patient, their family or the people who are important to them decide that they would like to die in an inpatient setting then a holistic care plan will be devised. If not, then the team needs to make the necessary arrangements on behalf of the patient to assist transfer to the site where the patient has chosen to spend this part of their life.</td>
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<tr>
<th>Right of freedom of religion or belief (Article 9)</th>
<th>Not Engaged</th>
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<tr>
<th>Right to freedom of expression</th>
<th>Note: this does not include insulting language such as racism (Article 10)</th>
<th>Not Engaged</th>
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</table>

| Right freedom from discrimination (Article 14) | Not Engaged |
Engagement and Involvement
detail any engagement and involvement that was completed inputting this together.

The following staff were consulted in the development of this policy:
Medical staff
Nursing staff
Divisional Directors, Service Leads and Modern Matrons.

Summary of Analysis

Eliminate discrimination, harassment and victimisation
This policy is about end of life care for inpatients. Processes in place to reduce the impact/ possibility of discrimination.

The process for the patients who require end of life care takes into account a wide range of issues:
• Dignity
• Capacity to make decisions
• Wishes of the family
• Principles of the Mental Health/Capacity Acts
• Human Rights
• Religious and spiritual needs.

Advance equality of opportunity
N/A

Promote good relations between groups
N/A

What is the overall impact?
Impact should be positive.

Addressing the impact on equalities
N/A

Action planning for improvement
N/A

For the record
Name of persons who carried out this assessment:
Joanna Morgan Physical Health Nurse
George Sullivan Equality and Human Rights Advisor
Reviewed by above

Date assessment completed:
19th August 2016.
Reviewed 11 August 2017
<table>
<thead>
<tr>
<th>Name of responsible Director: Executive Director of Nursing</th>
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<tbody>
<tr>
<td>Ray Walker</td>
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</tbody>
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<table>
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<tr>
<th>Date assessment was signed:</th>
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<tr>
<td>August 2016</td>
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# Action plan template

This part of the template is to help you develop your action plan. You might want to change the categories in the first column to reflect the actions needed for your policy.

<table>
<thead>
<tr>
<th>Category</th>
<th>Actions</th>
<th>Target date</th>
<th>Person responsible and their area of responsibility</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Monitoring</strong></td>
<td>The standards in this policy will be monitored at the Trust’s Physical Health Strategy Group.</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>The application of this policy will also be subject to monitoring by the Trust’s Mortality Review Group through consideration of themes arising from the analysis and mortality reviews of Datix reports generated on the death of a patient.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Engagement</strong></td>
<td>Policy to be placed on the Trust website along with this equality and human rights analysis.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Increasing accessibility</strong></td>
<td>This document can be made available in a range of alternative formats including various languages, large print and braille, etc.</td>
<td></td>
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</tr>
</tbody>
</table>
11. SUPPORTING DOCUMENTS

2. North West Boroughs Healthcare NHS Foundation Trust, End of Life Procedure
3. Human Right Act 1988
4. Leadership Alliance for the Care of Dying People (2014): One chance to get it right
6. Somerset Partnership NHS Foundation Trust End of Life Care
7. Mental Capacity Act (MCA) 2005 (amendments 2007)
8. The Mental Health Act (1983)
9. Oral Feeding difficulties and dilemmas ‘A guide to practical care, particularly towards the end of life’ (The Royal College of Physicians 2010)

The Trust would like to acknowledge and thank the following trusts for their contribution in compiling this policy:

- Somerset Partnership NHS Foundation Trust End of Life Care
- North West Borough Partnership NHS Foundation Trust, End of Life Procedure
- Liverpool Community Health NHS Trust with support from Liverpool Clinical Commissioning Group and South Sefton Clinical Commissioning Group
Appendix 1

End of Life Patient Referral Signposting Pathway

Patient referral signposting / pathway - End of Life

SERVICE USER IDENTIFIED WITH AN ISSUE/QUERY RELATED TO END OF LIFE/PALLIATIVE CARE REQUIRING SPECIALIST ADVICE

Practitioner to attend to patients needs if competent and trained in accordance with agreed patient individualised End of Life Care Protocol/Pathway

Still have concerns

Refer to patient to specialist teams, Palliative care, District Nursing Team

Ensure care from specialist teams is coordinated as advised

No longer have concerns

Continue with End of Life Pathway/support/care plan

Keep under review

Please remember to complete Patient Documentation.

If you are worried about a patient’s immediate safety you should call 999
Appendix 2

Personalised Care Plan for the Last Days of Life

Guidance for SSCD Nurses

1. Following assessment and agreement the decision that patient is dying must be a MDT decision between a GP (for out of hours a GP working for the out of hours service) and the District Nurse (either by telephone or face to face).

2. Ensure that the GP/CNS/DN have documented plan of care including:
   - Ensure anticipatory prescribing for EOL is available
   - Medicines to stopped or started and for what purpose
   - Interventions they wish to stop e.g. PEG feeding, ICD
   - What has been said to patient and carers and by whom.

3. Document all conversations you have with patient and carers about this plan of care. Offer Coping with Dying Leaflet to support patient and carer at this stage of care delivery.

4. For each service including Out of Hours ensure those caring for the patient understand the expectations of the patient where appropriate, and the carers about this plan.

5. If the patient is able to take oral fluids encourage carers to offer at each visit.

6. The family may wish to continue to give sips even when the patient is unable to swallow. This needs to be discussed sensitively, explaining why it is no longer safe to do so. If the patient is distressed by lack of fluids this will be discussed with the GP/ CNS. (See Sub Cut Fluids Policy).

7. Offer mouth care at each visit especially for patients who are unable to take oral fluids. If Carers wish to assist with this please show them what to do and encourage them. However, continue to monitor mouth care and document all attempts including when unable to provide mouth care and why.

8. Advise carers to offer food at acceptable regular intervals if able to tolerate. Please document all offers of food and what is taken or not.

9. Ensure patient has had personal care throughout day and night. Document what is offered and accepted. Complete Continuing Health Care funding application in a timely manner to achieve acceptable outcome for patient and carers.

10. Review symptom control at each visit:
   - Pain – If patient is taking oral analgesia ensure this is adequate and controlling the pain. If not ask a GP to review or refer to the Palliative Care Team. If the patient is unable to swallow but in pain give subcutaneous analgesia as prescribed and document in the care plan. If not adequate ask the GP and /or Palliative Care team to review.
   - Nausea – If not a problem review at each visit by asking patient/carer. If already a symptom review and give anti emetic as prescribed. If remains nauseous then ask GP to review and / or refer to the Palliative Care Team.
• Agitation – Look for possible causes, pain, urinary retention, constipation, requiring repositioning, mental distress. If remains distressed despite any interventional care then give appropriate medication as prescribed and document this in the care plan. If unsure or no medication prescribed ask the GP to review and /or refer to Palliative Care Team.

• Respiratory secretions – these may occur as death becomes more imminent. Hyoscine hydrobromide can be helpful to dry these secretions. Hyoscine hydrobromide can also cause sedation which may be helpful if the patient is restless or unsettled. An alternative is Glycopyrronium which is less sedative. If you are unsure ask the GP to review and /or refer to the Palliative Care team.

Please ensure that you explain to the patient/carers any and all interventions, including the giving of medication. Remember for patient and carers this may be their first and only experience of this situation. Sensitive and careful explanation of the care plan will assist in how we all cope with such a difficult and emotional time.

Appendix 3 End of Life Symptom Guidance

Patient Name: ____________________  NHS No: __________________  Date: ___________

Codes (Please enter in columns) Yes (Y) if outcome is achieved, No (N) if outcome is not achieved
If you chart “N” against any goal, please complete Outcome and action sheet.
If patient not symptom free, carry out appropriate intervention and reassure, annotating on the ‘Action
required’ sheet.

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<th>Patient problem/focus/outcome</th>
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Ongoing assessment

1) Pain

Patient is pain free:
- Verbalised by patient if conscious
- Pain free on movement
- Appears peaceful
- Consider need for positional change

2) Agitation

Patient is not agitated:
- Patient does not display signs of delirium, terminal anguish, restlessness (thrashing, plucking, twitching)
- Excludes retention of urine as cause
- Consider need for positional change

3) Respiratory tract secretions

Excessive secretions are not a problem:
- Medication to be given as soon as symptoms arise
- Consider need for positional change
- Symptom discussed with family/other

4) Nausea & Vomiting

Patient does not feel nauseous or vomits:
- Patient verbalises if conscious
- Consider CSCI if not conscious, or unable to swallow or vomiting

Free of other symptoms such as itching, oedema, seizures

5) Dyspnoea

Breathlessness is not distressing for patient:
- Patient verbalises if conscious
- Consider need for positional change

Treatment/Procedures

6) Mouth care

Mouth is moist and clean:
- See mouth care SOP
- Mouth care assessment at each visit
- Frequency of mouth care depends on individual need
- Family/other involved in care given
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7) **Micturition difficulties (bladder problems)**
   *Goal: Patient is comfortable:*
   - Last passed urine……..hours
   - Urinary catheter if in retention
   - Urinary catheter or pads if incontinent

8) **Patient does not have bowel problems**
   Bowels last opened…….hours
   Record on action sheet what interventions if any if no bowel movement for 3 days

9) **Patients skin integrity is maintained**
   Frequency of repositioning should be determined by individual patient assessment

10) **The patients hygiene needs are met**
    Relatives/carers and those important to the patient to be invited to be involved as appropriate

11) **Patients religious, spiritual, psychological needs are met:**
    - Consider cultural and religious needs

12) **The well-being of those important to the patient is maintained**
    - Annotate conversations, date time and with whom
    - Refer to support services if required

13) **Medication (if medication not required please record as N/A)**
    If McKinley pump in progress check at each visit according to monitoring sheet

Signature: