

End of Life Clinical Guideline

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CLINICAL GUIDELINE SUMMARY
This document applies to all patients cared for by EPUT. The guideline outlines the standards for the care of patients who are end of life. It will ensure that practice is evidence based and that there is a systematic and multi-disciplinary approach to the assessment, delivery and management of end of life care across the Trust.
The Trust monitors the implementation of and compliance with this clinical guideline in the following ways;
End of Life Care Dashboard Clinical Supervision End of Life Care audit Mortality review meeting Record keeping Datix reporting Patient and Carer Feedback

Services	Applicable	Comments
Trustwide	✓	
Essex MH&LD		
CHS		

The Director responsible for monitoring and reviewing this Clinical Guideline is the Executive Nurse

ESSEX PARTNERSHIP UNIVERSITY NHS FOUNDATION TRUST

End of Life Care Clinical Guideline

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ESSEX PARTNERSHIP UNIVERSITY NHS FOUNDATION TRUST**End of Life Care Guideline****1.0 INTRODUCTION**

- 1.1 Essex Partnership University NHS Foundation Trust – EPUT is committed to complying with statutory and regulatory requirements to promote a culture that assures the safety of our patients, their families, carers, staff and visitors. How we care for our dying is an indicator of how we care for all sick and vulnerable people. It is a litmus test for health and social care services and therefore the actions we take in planning and preparing for death for those that are dying, as well as the people around them, needs to be strengthened and we must improve our ability to provide care whatever the circumstances of dying patients are.

High quality end of life care is a fundamental component of EPUT's overarching End of Life Care Framework (2018). Our vision for end of life care is:

'All people, irrespective of diagnosis, who are recognised as approaching the last year of their life, should have an integrated approach to their end of life care, aligned to external organisations and services. Every person identified at end of life should be offered the opportunity to discuss, plan and record their preferences for care, inclusive of where they would like to die. We believe that every person identified at end of life must be treated with dignity, respect and compassion as an individual. Our aim is to ensure symptoms are managed and that suffering is kept to a minimum with access to skillful symptom management for optimum quality of life.'

The Trust approach to End of Life care seeks to enhance quality of life in the face of death by addressing the physical, psychological, social and spiritual needs of patients with advanced disease and their families (Addington-Hall 2002). Good end of life care encompasses recognition of the dying phase, high quality coordinated care, carer support and advice delivered in a personalised, dignified and respectful manner. Every person identified at end of life should be offered the opportunity to discuss, plan and record their preferences for care, inclusive of where they would like to die.

The majority of people in their last year of life wish to spend as much of their time as possible at home in their own community. A person's own home is the preferred place of care and death for most people.

The Trust End of Life Care Framework aims to ensure:

- i. The number of patients identified to be in the last year of life increases.
- ii. All patients at the end of their life receive high quality, holistic personalised care.
- iii. Patients and carers are supported in identifying and living the life they wish at the end of their life and planning for a good death.
- iv. All end of life and palliative care services are coordinated effectively.

These guidelines provide the operational requirements that underpin the Trusts End of Life Care Framework and is focused towards children and adults thought to be in the last year of life. It is directed at general healthcare staff and does not include all aspects of specialist palliative care.

These guidelines should be read in conjunction with the following EPUT frameworks, policies, guidelines and documents. These are available via EPUT intranet:

- EPUT End of Life Care Framework
- EPUT Care of Deceased Patient Guideline – CG84
- EPUT policy on mental capacity – MCP2
- Assessment of Capacity Form – MCP2, Appendix 1
- Best Interests Decision Form – CG16, Appendix B
- DNA CPR – CLPG14B
- Medicines Management Policy – CLP13
- Non-Medical Prescribing policy – CLPG13-CHS Appendix 19, CLPG13-MHJS Appendix 19
- SystmOne End of Life Care and Pain template
- Syringe Pump policy – EPUT McKinley T34 Standard Operating Procedure, SEOP6A
- Verification of expected death policy – SEOP2 (SEECHS) & WEOP1 (WECHS)

- 1.2 **For children** these guidelines are to be used in conjunction with “A Guide to End of Life Care, care of children and young people before death, at the time of death and after death” (Together for Short Lives 2012).

2.0 PURPOSE

- 2.1 The aim of the guidelines are to ensure that children and adults identified as being at the end of life have the right to the same level of high quality, holistic person centered healthcare and confidentiality of the general population. This reflects the national ambitions and the vision of the EPUT End of Life Care Framework.

The purpose of the guidelines are to set out the key operational requirements and standards for EPUT staff to achieve high quality consistent end of life care based on the needs of individual patients, families and carers.

- 2.2 The guidelines reflects the aim of the EPUT End of Life Care Framework (2018) which is underpinned by the National Ambitions for Palliative and End of Life published in 2015 by a partnership of national bodies including Royal Colleges, charities and patient groups. Each ambition is described from the perspective of a person nearing the end of life:
1. **Each person is seen as an individual** - *I, and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon. I am asked what matters most to me. Those who care for me know that and work with me to do what's possible.*
 2. **Each person gets fair access to care** - *I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life.*
 3. **Maximising comfort and wellbeing** - *My care is regularly reviewed and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible.*
 4. **Care is coordinated** - *I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time of the day or night.*
 5. **All staff are prepared to care** - *Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care.*
 6. **Each community is prepared to help** - *I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways.*

3.0 DUTIES

The Trust Board has overall responsibility for ensuring:

- The principles of this guideline and other associated procedures are implemented across the organization.
- The availability for any necessary financial resources to ensure staff are trained appropriately.

The Executive Nurse has lead responsibility to ensure:

- Clinical and Executive Leadership for End of Life Care for EPUT.
- To provide leadership and steer at organisational level
- Clinical Guidelines are embedded into clinical practice and in ensuring these are updated regularly.
- That any clinical risk issues identified are addressed with relevant line managers.
- The implementation of national guidance in relation to the end of life care.

Directors and Senior Management are responsible for:

- Disseminating, implementing and monitoring this guideline within their services via clinical audit and supervision.
- Ensuring that EPUT policies and procedures are followed.

Managers and other Persons in Charge will ensure that:

- The procedures and principles detailed within this guideline are followed, to ensure best practice and that national guidelines are met.
- Staff receive appropriate and correct training.
- The monitoring the implementation of this guideline via clinical audit and supervision.
- End of life care is included in the monthly locality Quality and Safety across all clinical services to ensure this guideline is implemented, meets the standards and that the standards and the guidelines are monitored and reviewed.

Keyworker/coordinators will, with the patient's consent and agreement, play a key role in coordinating the patient's care, promoting continuity and ensuring the patient knows who to access for information and advice in relation to their illness. The key worker's name, designation and contact details will be recorded in the patient medical records and included in all correspondence.

All staff will ensure:

- Any difficulties relating to carrying out the care of patients at end of life are reported to their line manager.
- That they adhere to all EPUT policies and guidelines.
- That they are familiar with these guidelines and associated documents and know where to locate them i.e. on the Trust intranet (Input).

4.0 DEFINITIONS

- **ACP** – Advance Care Plan written when someone has capacity.
- **ADRT** – Advance Decision to refuse Treatment a decision made by someone with capacity to refuse treatment even if it limits their life.
- **Adult** – defined in law as a person who is aged 18 years or over.
- **Carer** – for the purposes of this guidance, a carer may be defined as a person who provides emotional or practical support to a family member or a friend or partner who is ill and approaching the end of their life.
- **A child’s carer** is usually their parents and, depending on age and capacity, the parent will act on behalf of the child in some decision making
- **Child** – a person under 18 years of age.
- **Community care** – care provided in the patient’s own home, nursing home, care home or community hospital.
- **End of Life** – ‘approaching the end of life’ and expected to die within the next 12 months. In a child end of life is considered when a child is likely to die within the next 12 months and there is no further curative treatment available
- **End of Life Care (EOLC)** – “care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die”. In EOLC, patients are ‘approaching the end of life’ when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with (a) advanced, progressive, incurable conditions (b) general frailty and co-existing conditions that mean they are expected to die within 12 months (c) existing conditions if they are at risk of dying from a sudden acute crisis in their condition (d) life-threatening acute conditions caused by sudden catastrophic events (General Medical Council, 2010)
- **GSF** – Gold Standards Framework.
- **Holistic** – treating the whole person rather than just symptoms.
- **Holistic Needs Assessment (HNA)** - undertaken when patient referred and at key times during their care e.g. when their needs change. It includes physical, psychological, social, spiritual needs
- **Hospice** - An establishment providing care for people with palliative and end of life care needs.
- **The Outcome Assessment and Complexity Collaborative (OACC)**
A suite of measures that reflect the key domains of palliative care and holistic assessment. These include the phase of illness, the patient’s functioning, symptoms and other important concerns, and the impact palliative care services are having on the patient’s and family’s quality of life. These are used by palliative care services
- **Palliative care** - an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (World Health Organisation 2017).

- **Specialist Palliative care** - is the active, total care of patients with progressive, advanced disease and (of) their families. Care is provided by a multi-professional team who has undergone specialist palliative care training. Palliative and End of Life care that is not delivered by specialists is termed 'Generalist Palliative Care'
- **Spiritual care** - care which recognises and responds to the needs of the human spirit when faced with trauma, ill health or sadness and can include the need for meaning, for self-worth, to express oneself, for faith support, perhaps for rites or prayer or sacrament, or simply for a sensitive listener. It begins with encouraging human contact in a compassionate relationship, and moves in whatever direction need requires (National Council for Palliative Care 2010).

5.0 IDENTIFICATION OF LAST YEAR OF LIFE

- 5.1 Recognising that someone may be entering their last year can be of benefit to patients and carers, allowing time to focus on priorities and to plan accordingly for appropriate end of life care. People are "approaching end of life" when they are likely to die within the next 12 months.
- 5.2 Recognising last year of life can be undertaken by all staff and partners (e.g. GPs, hospital clinicians, Social Workers, Care Home Staff). It is very important to identify as this will allow the patient to access timely and appropriate care.
- 5.3 All staff must be confident to use the three triggers that suggest that a person is nearing the end of life, which are:
- The Surprise Question: 'Would you be surprised if this patient were to die at any time within the next year?
 - Prognostic indicator tools e.g. GSF Prognostic indicator tool
 - General indicators of decline deterioration, increasing need or choice for no further active care.

If the answer to the Surprise Question within the prognostic indicator tool is "No", or the other indicators suggest the person is in the last year of life a Holistic Needs Assessment and Advance Care Planning should be initiated.

- 5.4 General indicators of decline include the presence of any of the following, which should trigger concern when associated with advanced age and/ or disease:
- Limited self-care and interest in life: in bed or a chair more than 50% of their time
 - Breathless at rest or on minimal exertion
 - Progressive weight loss (>10% over last six months)
 - History of recurring or persistent infections and/or pressure ulcers

- 5.5 Advance care planning in dementia needs to be offered earlier in the illness when they still have capacity to be part of the discussions. Leaving it until the last year of life may be too late for the patient to express their preferences and wishes for care.
- 5.6 For Children the general indicators of decline are very similar as stated above but can be more subtle as children may eat and drink right to the end of their life. Regular reviews of the child or young person will support with the recognition of end of life. The parents/carers are a very good judge of when a child/ young person has deteriorated and this is always very helpful to the practitioner. Parents/carers know their child/ young person the best and they may pick up on subtle signs to indicate that their child is dying.

6.0 HOLISTIC NEEDS ASSESSMENT

- 6.1 People approaching the end of their life frequently have complex, wide-ranging and changing needs. Meeting these needs requires effective care co- ordination, strong communication and a sound understanding of the individual's needs, preferences and priorities for their care. Effective, holistic needs assessment is key to meeting these needs. The place of assessment will be determined by the person's care setting and preferences and should ensure comfort and privacy.

All patients identified as approaching end of life by any clinician should be offered a holistic needs assessment at any the point along the patient pathway as follows:

- At the first point of identifying the individual as likely to be within their last year of life.
- At the point of referral to generalist and specialist palliative care team.
- Entering the last few days of life
- At any other time that the individual may request
- At any other time that a professional carer may judge necessary

- 6.2 The holistic needs Trust assessment tool should include the following domains:

- Background information and assessment preferences
- Physical needs
- Social and occupational needs
- Psychological wellbeing
- Spiritual wellbeing
- Information needs
- Carer current needs

7.0 GOLD STANDARDS FRAMEWORK FOR EOLC

- 7.1 This guideline adopts the following key national standards an approach which are therefore not repeated in the body of this document. The GSF is a format used to improve palliative care from within primary care to provide gold standard care to patients at the end of their lives. It is used to help identify patients at risk of dying in the next year, few months or weeks, no matter what the underlying illness is, **NEW Updated Proactive Identification Guidance - 6th edition 2016** supports the identification of patients using evidence based guidance they can be accessed through the link: www.goldstandardsframework.org.uk/PIG those identified can then be placed onto the GSF Supportive Register either held by their GP or can be added by any professional to local system wide End of Life Palliative Care Registers, (where these are locally available). Information held on locality registers can also be used by professionals from a range of provider organisations (such as out of hours and emergency services) who might be or may need to become involved in care delivery for that person.
- 7.2 The GSF prognostic indicators use a rag rated colour code system to identify patients in their last year of life. The colour code identifies patients so they can be discussed at GSF meetings and monitored regarding their care according to deteriorating diagnosis. The amber and red patients who are at higher risk of dying within weeks and are discussed more frequently. The patients in blue and green are lightly to only be discussed if they have specific priorities or needs at that time. EPUT community staff in SEECHS and WECHS form part of the multidisciplinary team who join primary care GP's to discuss palliative care patients at GSF meetings. This assists with early identification and effective coordination of patients whom are recognised as End of Life Care.

8.0 ADVANCE CARE PLANNING

- 8.1 These guidelines adopt the principles of Advance Care Planning recommended by the DH End of Life Care Strategy 2008, General Medical Council guidance and Gold Standards Framework as a means of recording patients' priorities', wishes and preferences for end of life care.
- 8.2 All people identified as being in the last year of life should be offered an Advance Care Planning discussion, with their family and/or carer, about their wishes and thoughts for the future. Care. This should be recorded in the patients' clinical record and may include:
- Where they would like to receive their care in the last year of life.
 - Their preferred place of death.
 - Who the individual wishes to have involved in decisions about their care – this may include discussion about Lasting Power of Attorney – LPA

- Their views on future care and treatments e.g. antibiotics, blood transfusions, intravenous fluid resuscitation, respiratory ventilation
 - The treatment escalation plan or anticipatory care plan, (information guidance given to patient/carer)
 - Interventions which may be considered or undertaken in an emergency, such as cardiopulmonary resuscitation
 - Recording of Advance Decisions to Refuse Treatment
 - The patient's needs for religious, spiritual or other personal support
 - Organ and tissue donation
 - Anything that the person wishes to record as important to them in their care at the end of life
- 8.3 Provision of “just in case” medications for symptom control. These need to be tailored to the individual patient refer to the local Clinical Commissioning guidelines. For detailed information regarding Palliative Care Adult network refer to <http://book.pallcare.info> Palliative Care Drugs - www.palliativedrugs.com or NHS Scotland Palliative Care Guidelines www.palliativecareguidelines.scot.nhs.uk
- 8.4 Advance care planning discussions should be reviewed in partnership with the patient and those important to them whenever their circumstances or needs change. Timescales will therefore vary and should be dictated by the patient themselves if they have capacity.
- 8.5 If a person lacks capacity for decision making, a formal capacity assessment and best interest's decision must be carried out and documented. The Trust Policy on Mental Capacity, which includes Children and Young People from the age of 16 years, provides guidance. A formal capacity assessment should be documented using an Assessment of Capacity Form and a Best Interests Decision Form. Capacity must be assessed on a decision by decision basis. The EPUT Resuscitation/ CPR/DNACPR Policy provide guidance on DNACPR decisions and recording those decisions.
- 8.6 Advance care planning discussions should be reviewed in partnership with the patient and those important to them whenever their circumstances or needs change. Timescales will therefore vary and should be dictated by the patient themselves if they have capacity.
- 8.7 If a person lacks capacity for decision making, a formal capacity assessment and best interest's decision must be carried out and documented. The Trust Policy on Mental Capacity, which includes Children and Young People from the age of 16 years, provides guidance.

A formal capacity assessment should be documented using an Assessment of Capacity Form and a Best Interests Decision Form. Capacity must be assessed on a decision by decision basis. The EPUT Resuscitation/ CPR/DNACPR Policy (CLP14, CLPG14A & B) provide guidance on DNACPR decisions and recording those decisions. Timescales will therefore vary and should be dictated by the person themselves if they retain capacity to continue to be involved in decision making.

When capacity is lost, ongoing decisions can be made in partnership with any person who is legally responsible for best interest health and welfare decisions for the patient (such as a legal power of attorney or the senior medical /responsible clinician for that person).

9.0 LASTING POWER OF ATTORNEY

- 9.1 As part of the advance care planning, clinicians should ask whether the patient has a Lasting Power of Attorney (LPA). A LPA allows the person to nominate an Attorney(s) to manage their finances and health and welfare affairs should they lose capacity in this respect. Additionally, attorneys for a personal welfare LPA are able to make all specific health and welfare decisions on behalf of the person lacking capacity (although for life sustaining treatment there should be specific reference made to this in the LPA). Any decisions made by the attorney must be taken in the best interests of the person. Staff should advise people in their care who are considering setting up an LPA to seek further advice e.g. legal advice. Additional information regarding LPA can be found in the Trust policy on mental capacity.
- 9.2 Within Children's Services we always keep the child and young person at the heart of all our discussions and involve them where appropriate. Many young children below 16 years have an opinion on what they would like to happen and what treatment they want. A parent would make the ultimate decision but the child/young person's voice would be heard.

10.0 INDIVIDUALISED CARE PLAN FOR THE DYING PERSON

- 10.1 Every person identified as being within the last days of life should have an individualised care plan for the dying person which provides a single coordinated approach to the care to be provided to them. The senior responsible clinician (usually the GP, Consultant or nominated Deputy) must review the patient and confirm the patient is dying, and there are no reversible conditions. This needs to be clearly documented and monitored for further changes to determine if there is an improvement and if it is stabilising and be involved in communicating this to the patient and those important to them. All decisions must involve the person, those identified as important to them and/or their LPA if appropriate.

10.2 This assessment and subsequent plan of care should be based on the five priorities for care of the dying person set by the Leadership Alliance for the Care of Dying People in “One chance to get it right” – Improving peoples experience of care in the last few days and hours of life (LACDP, 2014): as follows:

- **Recognise**- the possibility 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.
- **Communicate** sensitively between staff and the dying person and those important to them.
- **Involve** the dying patient and those identified as important to them are involved in decisions about treatment and care to the extent that the dying patient wants. Their involvement is also important in reviewing the ICPDP.
- **Support** -The needs of the families and other identified as important to them are actively explored, respected and met as far as possible.
- **Plan And Do** - An individual plan of care, which includes food and drink, symptom management and psychological, social and spiritual support is agreed, coordinated and delivered with compassion

10.3 As a minimum, the assessment and subsequent Individualised Care Plan should include the following aspects of care:

- Risk assessment
- Mental Capacity assessment
- Consent to share information
- Advance Directive to Refuse Treatment if requested
- Preferred place of death if appropriate
- DNACPR
- On-going medication reviews including “just in case”
- Medication Nutritional status and MUST score
- Pressure areas and Waterlow score
- Continence
- Psychological needs
- Plan for food and drink
- Physical discomfort
- Spiritual needs

11.0 ADVANCE DECISION TO REFUSE TREATMENT

11.1 People at the end of life may want to record an Advance Decision to Refuse Treatment - (ADRT). This is separate from statements of values, preferences, and wishes about end of life care which are reflected in the individuals care plan.

11.2 An advance decision to refuse treatment may be made by an individual in anticipation of future mental incapacity. An ADRT only comes into force if/when the individual making it loses mental capacity

- 11.3 The ADRT can be written or verbal (but must be written, signed and witnessed if refusing life sustaining treatment and include the statement 'even if life is at risk').
- 11.4 A properly valid and applicable ADRT is legally binding upon healthcare professionals in the same way that a contemporaneous refusal to consent is.
- 11.5 These guidelines adopt the national proforma "My Advance Decision to Refuse Treatment" as the mechanism for recording ADRT's. This is also found as a red section in the Advance Care Planning Booklet but is set out in the same way.
- 11.6 Staff must follow the national proforma and ensure that decisions are recorded in the patient's notes and the clinical record including where they keep the document.
- 11.7 Additional information regarding ADRT can be found on the Trust Intranet end of life care page.

12.0 PAIN ASSESSMENT

- 12.1 The presence of pain adversely affects quality of life and is a common symptom of both cancer and chronic non-malignant diseases.
- 12.2 Pain is a subjective personal experience and can also be affected by psychological, social or spiritual issues. Patient self-reporting of pain is the best method of scoring pain, with consideration for patients requiring assistance such as partially sighted or blind and/or patients with a learning or physical disability.
- 12.3 A pain assessment should be an integral part of the EPUT assessment process for all patients cared for by all services. The Pain Template in paper form on wards or on electronic records should be completed to provide a full assessment of pain and pain scores using the EPUT pain scoring system(s).
- 12.4 The pain assessment should be reviewed regularly using a pain chart and changes in pain severity, type, place and response to treatment should be documented. To allow comparison and audit, the agreed questions in the template must be used. Audit of pain relief is included in the end of life audit plan.

Triggers for additional pain review include:

- When a patient reports unexpected or increased pain.
- When the patient is undergoing a procedure or treatment which has the potential to cause pain, and following a change to pain medication (to assess response).

- 12.5 For patients with learning disabilities the Entonox pain tool (Appendix 1) and for patients with cognitive impairment the Abbey Pain Assessment Tool will be used. Appendix 2).
- 12.6 Pain assessment tools for Children's will use the Wong Baker pain tool (Appendix 3) available at <http://wongbakerfaces.org/>
- 12.7 In Children, the pain assessment may include play therapy, led by the Nursery Nurse within the Children's Community Nursing Team.

13.0 MEDICINE MANAGEMENT AND NON-MEDICAL PRESCRIBING

- 13.1 For detailed information refer to the current policy and procedure located on the intranet.
- 13.2 All medicines related activities (including prescribing, supplying and administering) undertaken by EPUT staff should be performed in a safe, effective and secure manner compliant with current legislation and local policies/procedures
- 13.3 EPUT staff must adhere to the EPUT Safe and Secure Handling of Medicines Policy (CLP13) plus any relevant appendices. Staff must attend the mandatory training plus the relevant training for their clinical area. This includes just in case medications and handling and administration of controlled drugs.
- 13.4 Non-medical prescribing is the prescribing of medication by nurses, pharmacists, podiatrists, therapeutic radiographers and optometrists within their clinical competence. There are restrictions for prescribing controlled drugs and this information can be found in Appendix 19 'Non-medical prescribing' of CLPG13 on the intranet
- 13.5 Many of the medications used in adults are also used in children. The lead professional for the child/young person is responsible for writing a Symptom Management plan with the correct drug dosages and the correct ranges. This is usually the Palliative Care outreach team from Great Ormond street hospital and local hospices.
- 13.6 This plan is written and discussed at length with the child's GP who provides the prescribed drugs. Regular contact with all professionals involved is essential to ensure that all parties are up to date with any changes in condition.

14.0 SUBCUTANEOUS FLUID ADMINISTRATION FOR ADULT PALLIATIVE CARE PATIENTS

- 14.1 Subcutaneous fluid administration may be suitable for patients with mild dehydration as part of patient preference, cultural or psychological issues, admission to hospital or hospice, following assessment by a doctor. Discussion will take place by Multi-disciplinary team regarding risks and benefits of hydration. This will be assessed daily whilst on the ICPDP involving the patient and those important to the patient.

15.0 SYRINGE DRIVER PUMPS FOR PALLIATIVE CARE PATIENTS

- 15.1 Continuous subcutaneous infusion administration may be suitable to deliver symptom control medications to adult and child palliative care patients in specific clinical situations
- 15.2 Continuous subcutaneous infusion administration must adhere to the EPUT Standard Operation Procedure for McKinley T34 24 hour syringe driver. This can be found on the intranet.

16.0 IMPLANTABLE CARDIOVERTER DEFIBRILLATOR DEACTIVATION

- 16.1 An implantable cardioverter defibrillator (ICD) is a small device placed in the chest or abdomen that links to the heart. The device uses electrical pulses or shocks to help control life-threatening arrhythmias.
- 16.2 Patients with an ICD often suffer from progressive conditions in which a stage may be reached when it is no longer medically appropriate for the device to be used. At this time, and following discussion with the patient, their family, carers and medical team, a decision can be made to turn off or 'deactivate' the device.
- 16.3 Deactivation of the shock mode of an ICD does not deactivate the pacemaker function and in itself does not end a patient's life, but will allow for a natural death without the risk of unpleasant and unnecessary shocks.
- 16.4 Discussion about de-activating the ICD should take place as early as appropriate in the patient's management to enable proactive care management and avoid unnecessary distress. Placement of patients on the Gold Standards Framework should prompt discussion about deactivation of ICD between the GP or cardiologist, the specialist nurse or other health care worker and the patient, their carers and relatives.
- 16.5 If the patient is not under the active care of specialist palliative or cardiac services, it is the responsibility of the patient's GP to alert such services on initiation of the GSF to inform the multidisciplinary teams and assist in appropriate care planning.
- 16.6 Ideally, criteria for deactivating a defibrillator should be discussed with the patient and / or their next of kin / LPA when resuscitation issues are explored or when a patient's condition is worsening. It is best to think and decide about ICD deactivation in advance, rather than in a crisis.

16.7 Important points to explain to people about ICD deactivation include:

- Deactivating your ICD will not cause death.
- Once your ICD has been deactivated, if you have a heart rhythm change that could cause death, your ICD will not deliver treatment for it.
- Deactivating the shock function of your ICD does not deactivate its pacemaker function.
- Deactivating your ICD will be painless.
- Near the end of your life your ICD may deliver shocks that are painful and distressing and are of no benefit.
- If your condition improves unexpectedly or you change your mind the ICD can be reactivated.

16.8 Patients will be assessed and identified as suitable for deactivation, or not reactivating an ICD, if they fulfill one or more of the following criteria:

- Following discussion between the medical team, patient and carers, a decision has been made that continued use of an ICD is inconsistent with patient goals of care
- The patient is considered to be imminently dying.
- The patient has end stage terminal disease or palliative care requirements and has requested that their device be deactivated
- An active DNACPR order is in force.

16.9 Reactivation of the ICD may be considered if the patient recovers sufficiently from a worsening of their condition.

16.10 Following deactivation a copy of the de-activation form should be sent to the GP and other members of the healthcare team such as the heart failure nurses, district nurses and palliative care team, informing them that deactivation has occurred and the rationale for this decision.

16.11 Any plans/decisions should be clearly relayed to the cardiac physiologists and clearly documented in the patient's electronic record.

16.12 For Implantable Cardioverter Defibrillator Deactivation process and for guidelines on the emergency use of a magnet to temporarily deactivate the ICD in a primary care setting refer to Appendix 4.

17.0 CULTURAL AND SPIRITUAL CARE

- 17.1 It is essential that religious and cultural beliefs held by the patient are identified on first contact or prior to death, so that staff can adhere to the wishes of the patient and relatives.
- 17.2 For people in their own homes, staff should enquire whether they are in touch with anybody from their own faith community, e.g. Vicar, Minister, Priest, Rabbi, Imam, and whether they would like that person to be involved in their spiritual care. If the patient would like you to make a referral to the local faith leader, ascertain whether there are any specific matters for which help is sought.
- 17.3 For people admitted to inpatient services please contact the multi-faith services where a local faith leader or volunteer can support patients and their relatives irrespective of religion. The chaplaincy service will support spiritual and cultural needs via a group of volunteers.
- 17.4 Parents/ Carers may want to carry out rituals related to their religious and cultural belief and this should be considered and supported where necessary. Some religions may have specific requirements to facilitate burial or cremation at the earliest opportunity (e.g. within 24 hours) which means respecting such timescales by professionals might be required.
- 17.5 Individual requirements may vary, even amongst members of the same faith, as there are differences of emphasis within all the world's religions. The identified religion may indicate an association with particular cultural and national roots, rather than indicate a significant degree of adherence to a particular faith.
- 17.6 The holistic needs assessment should also include other potential areas of spiritual pain such as a "why me", leaving behind loved ones, faith crises etc.
- 17.7 The way in which care is provided should address their spiritual/cultural care needs including, for example, what brings meaning and purpose to their life e.g. music, having key family members around them.
- 17.8 There will be occasions when legal requirements supersede religious and cultural ones and in these circumstances this will need to be explained sensitively to relatives.

Appendix 5 depicts the detail of faith requirements for the major world religions.

18.0 CARER'S ASSESSMENT

- 18.1 Carers provide valuable emotional and practical support for people at the end of life and may in turn have needs to enable them to fulfil this role. All carers should have access to an assessment of their needs and signposting to appropriate support services and resources. Staff should carry out a Carer's assessments and should encourage carers to access this assessment. (Information available on the EPUT intranet).

- 18.2 When a child is dying the family usually has significant support from health and social care services prior to the episode around death. However, this should not be assumed to negate the potential benefits of a carer's assessment especially if the child is at the end of life for many months. Involvement of various other support agencies that can support the whole family e.g. charities and local hospice support services should be taken into consideration. Involvement of the parent's GP in supporting them through this difficult time should be ensured at all the time.

19.0 PSYCHOLOGICAL NEEDS OF PATIENTS AND CARERS

- 19.1 The psychological need of patients and their carers to manage their emotional health and wellbeing is assessed through a holistic needs assessment on approved Trust templates.
- 19.2 Additionally, the NICE Guidance on Supportive and Palliative Care for adults with cancer psychological support services (2004) provides a framework for the assessment and management of the psychological wellbeing of adults with cancer which can also be used in End of Life Care for patients with other diseases.
- 19.3 The Children's Community Nursing team signpost parents/carers to support agencies available to them from their own GP and local children's hospice's support services.

20.0 BEREAVEMENT SERVICE

- 20.1 Bereavement support should be offered to all families following the loss of a loved one.
- 20.2 Bereavement contact is made by phone or face to face following the death of a patient in their usual place of residence by the keyworker/case manager.
- 20.3 The bereaved relatives will be provided with a Trust leaflet giving details of their local bereavement services and a questionnaire asking for feedback on the end of life services they received, this can be found on the end of life care intranet page.

21.0 ORGAN AND TISSUE DONATION

- 21.1 The underlying principle of deceased donation is that organs and tissue can only be removed with consent.
- 21.2 The UK has an "opting in" system of consent which means that individuals or their representatives actively choose to donate organs/tissues (Human Tissue Act 1961). Consent for organ or tissue donation can be given by family members after death based on their perception of the patient's wishes. The stated wish of a patient (via

organ donor register) can be over-ridden by family although they are encouraged to respect the wishes of the patient.

- 21.3 It is important that patients are encouraged to ensure their family members are fully aware of their wishes or, if necessary, nominate a representative to speak for them and to register their wishes on the organ donor register prior to their death. (For further guidance refer to Appendix 6)
- 21.5 Within Children's Services it is important to have discussions around tissue/organ donation. Many of our young people have had these discussions at school and are already organ donors. Important to acknowledge this fact and have discussions when donation is not suitable due to disease/illness.

22.0 IMPLEMENTATION AND TRAINING

- 22.1 EPUT values the importance of education and training both to develop its own workforce to support the delivery of high quality care on a sustainable basis, and to play a part in the wider training of the future NHS workforce.
- 22.2 Education and training also supports the creation of a learning culture so that the organisation keeps itself up to date with academic and research developments informing innovation and improvement in care and delivery to benefit patients and staff.
- 22.3 Clinical teams associated healthcare professionals and clinical team leaders and managers must ensure that their staff are aware of and follow these guidelines. The guideline will form part of the induction checklist of new starters to a relevant unit or service.
- 22.4 To support EPUT in ensuring its continuing role in education and training, an education and training framework has been developed which will formalize training around End of Life issues, for example recognition of any person who may be entering the last year of life, how to initiate advance care planning discussions to explore future preferences for a person's care, recognizing the dying phase, carrying out a holistic needs assessment, initiating DNACPR discussions, essentials of symptom management and "just in case" subcutaneous medications.
- 22.5 Line Managers and Locality Managers are responsible for ensuring implementation of the guidelines including ensuring all relevant staff receives appropriate training both at induction and thereafter, annual competence assessment monitored through appraisal process and regular update training.
- 22.6 Staff must ensure that they are confident and competent and have the appropriate knowledge and skills to support effective end of life care including communication skills and that both they and their manager are satisfied that they are competent to undertake this care according to the agreed competencies.

- 22.7 Staff must ensure they are familiar with all policies, frameworks and guidelines strategically and professional documents related to end of life care. Staff are responsible and accountable for maintaining and improving their own professional knowledge, competence and standards of practice and any widening of the scope of practice of their professional activity. Where there are gaps in knowledge and skill, staff should be supported to address these.
- 22.8 All clinical staff that sees patients in their last year of life within their scope of practice will be trained to be confident and competent in delivery end of life care.

23.0 MONITORING COMPLIANCE AND EFFECTIVENESS OF GUIDELINE

- 23.1 The compliance and effectiveness of this guideline will be tested primarily through audit of Key Performance Indicators as shown below related to services and care delivery. The monthly dashboard developed within the End of Life care Trust Wide Group will also be used to ensure Key Performance Indicators are shown in accordance to services. Performance measures will include:
- Numbers of end of life care patients using services
 - Patient and carer experience
 - Expressed preferred place of care and place of death
 - Actual place of care and place of death
 - Datix related to end of life
 - Safeguarding and serious incidents
 - Complaints
 - Compliments
 - Staff training
- 23.2 End of life care will be a standing agenda item at the locality Quality and Safety Meetings represented by all team managers for every service. This will formulate the governance for local involvement and provide assurance to the board

24.0 REFERENCES

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- “A Guide to End of Life Care. Care of Children and young people before death, at the time of death and after death”, Together for Short Lives, 2012
- Treatment and care towards the end of life: good practice in decision making, General Medical Council, 2010
- WHO definition of Palliative Care. <http://www.who.int/cancer/palliative/definition/en/>
- The Missing Piece: Meeting People’s Spiritual Need in End of Life Care, National Council for Palliative Care 2010
- Advance Decisions to Refuse Treatment, <http://www.adrt.nhs.uk>
- End of Life Care Strategy, Department of Health 2008
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- “One Chance to Get It Right”, Leadership Alliance for the Care of Dying People 2014
- NICE Guidelines, Improving Supportive and Palliative Care for Adults with Cancer 2004
- Policy MPD901/5. NHS Blood and Transplant Authority, 2016
- <http://wongbakerfaces.org/>
- <http://www.bochealthcare.co.uk/en/products-and-services/products-and-services-by-category/medical-gases/entonox/entonox.html>

25.0 FURTHER READING

An introduction to advance care planning in practice, Mullick et al, *BMJ* 2013
 Quality Standard for End of Life Care, NICE 2013

Deactivation of implantable cardioverter-defibrillators towards the end of life,

Resuscitation Council (UK), the British Cardiovascular Society and the National Council for Palliative Care March 2015

Quality Standard for End of Life Care, NICE March 2017

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