

End of Life Care Provision and Care After Death Policy

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1 Introduction

Currently, the number of people living in England with a long term condition (LTC) is increasing year on year, with the number of people diagnosed with comorbid LTCs also rising. Many of these individuals will require palliative care due to the prognosis of their condition(s) and similarly, many will require end of life (EoL) care as they approach their last few weeks/days of life. It is therefore imperative that all healthcare professionals have an awareness and understanding of their responsibilities in terms of supporting the needs of these service users, and additionally, provide EoL care that is personalised, dignified and of an optimal standard.

The National Institute for Health and Care Excellence (NICE) [End of Life Care for Adults: Quality Standard 13](#) (2011, updated 2017 [online]) provides a range of comprehensive principles in relation to the provision of high quality EoL care. Tees, Esk and Wear Valleys (TEWV) NHS Foundation Trust embraces these standards and recommendations and is committed to improving the safety, effectiveness, and the personal experience of patients approaching the end of life.

Good EoL care supports those with progressive, advanced and incurable conditions in order to enhance quality of life, and to help individuals live as well as they can during the last phase of their life. EoL care includes the management of symptoms (i.e. pain, nausea, agitation) together with the provision of emotional, psychological, spiritual, social and physical care. As the provision of EoL care is not solely confined to Specialist EoL Care Services, Hospices and/or Acute Hospital Trusts, it is imperative that TEWV Trust staff who work within areas where patients may require EoL care, are able to (as part of their clinical role) provide treatment, intervention and support with the necessary understanding, awareness and competence.

TEWV NHS Foundation Trust provides care to a diverse range of service users across several specialties and localities, all of whom require varying degrees of need and support. As reiterated by the Care Quality Commission (2016 [online]) in their report [A Different Ending](#), EoL care provision is variable, with some groups of people continuing to experience inequalities at EoL. TEWV NHS Foundation Trust is therefore fully committed to ensuring that patients receive care that is individualised, holistic and evidence based, and that fair and equal treatment is offered to all. No one should have a poorer service or a lesser experience because of their differences, inclusive of care delivery at EoL. It is in keeping with this principle that this policy has been written.

2 Why we need this Policy

2.1 Purpose

Whilst the delivery of specialist EoL care is not the main clinical purpose of TEWV NHS Foundation Trust, it is acknowledged that TEWV Trust staff may be required to care for patients who have life threatening or life limiting conditions - whether this be a form of cancer or non-cancer related physical and/or mental health diagnoses (i.e. dementia, frailty, heart failure, chronic obstructive pulmonary disease (COPD) etc.). As people live longer, there are an increasing number of patients who have comorbid physical and/or mental conditions, some of which are advanced long-term conditions that may require complex, skilled interventions and require delivery of care within mental health in-patient settings such as the in-patient services provided by TEWV NHS Foundation Trust.

As an organisation, the Trust recognises the importance of EoL care as an integral part of the good health and social care that everyone should receive when they have a life limiting or life threatening diagnosis. In some circumstances, identifying the actual EoL phase may be difficult and therefore, it is integral that the delivery of effective and holistic EoL care is promoted through early identification by utilising a 'whole systems approach'. Trust staff are encouraged to work closely with other services, for example; Primary Care, Specialist Palliative Care Teams, District Nurses, Social Services and also, Acute Hospital Trusts to ensure that optimal EoL care is provided.

The purpose of this policy is therefore to:

- Ensure that patients receive EoL care that is individualised, holistic and evidence based, in accordance with their needs, preferences and wishes.
- Ensure that the delivery of EoL care is of an optimal standard.
- Ensure that the dying person and those identified as important to them are involved in discussions and decisions about treatment and care.
- Ensure that any decisions made as part of EoL care are reviewed and revised regularly.
- Ensure that an individual plan of care and/or any individualised intervention plans (that collectively form part of EoL care delivery) are implemented, revised and updated regularly.
- Ensure that EoL care is delivered to individuals with dignity, sensitivity and compassion.
- Ensure that robust bereavement support is provided (for family/carers, fellow patients, and for staff).

2.2 Objectives

The objectives of this policy are to:

- Provide a comprehensive framework by outlining best practice principles for providing appropriate and timely EoL care.
- Provide TEWV Trust staff with support, information and guidance which will assist to:
 - Enable the early identification of individuals nearing the end of their life
 - Deliver care to individuals at the end of their life
 - Deliver care to individuals after death
 - Support individuals, family/carers, fellow patients and staff
- Ensure that fair and equal treatment is offered to all patients across the Trust (who may require EoL care).
- Ensure that TEWV Trust staff are aware of the importance of EoL care including the significance of a holistic, person-centred approach to care delivery.
- Support the implementation of high quality EoL care Trust wide.

3 Scope

3.1 Who this Policy Applies to

This policy applies to all healthcare professionals working within TEWV NHS Foundation Trust. However key roles and responsibilities are outlined in **Section 3.2 Roles and Responsibilities**.

3.2 Roles and Responsibilities

Role	Responsibility
Medical Director	<ul style="list-style-type: none"> • Ensure that all Medical Staff are aware of this policy, and other policies, guidance and procedures which relate to this policy. • Ensure that adequate training is given to allow Medical Staff to implement this policy.
Executive Director of Nursing and Governance	<ul style="list-style-type: none"> • Ensure that all Registered Nursing Staff are aware of this policy, and other policies, guidance and procedures which relate to this policy. • Ensure that adequate training is given to allow Registered Nursing staff to implement this policy. • Responsible for the development, review and monitoring of this policy.
Medical and Registered Nursing Staff	<ul style="list-style-type: none"> • Ensure that they are aware and familiar with the contents of this policy, and other policies, guidance and procedures which relate to this policy. • In accordance to clinical role, ensure that their physical examination skills are maintained in accordance with the General Medical Council (GMC) or the Nursing and Midwifery Council (NMC) standards and requirements. • Complete all relevant documentation, care plans and/or intervention plans in relation to EoL care. • Deliver quality care and ensure that the needs of patients are identified in accordance with best practice guidance. • Inform Senior Management where the policy is not being implemented appropriately.
Team Leaders, Ward and Unit Managers	<ul style="list-style-type: none"> • Be fully aware of the contents of this policy and other policies, guidance and procedures which relate to this policy. • Ensure that staff read and have an awareness of the policy. • Ensure that staff undertake training appropriate to their role in order to achieve and maintain a level of competence in relation to EoL care.
Non Registered Clinical staff	<ul style="list-style-type: none"> • Ensure that they are aware and familiar with the contents of this policy, and other policies, guidance and procedures which relate to this policy. • Support Registered Nursing Staff and Medical Staff to deliver care to patients in accordance with all relevant care plans and/or intervention plans linked to EoL care. • Request training to develop skills and competence in accordance with this policy.
Allied Health Professionals	<ul style="list-style-type: none"> • Ensure that they are aware and familiar with the contents of this policy, and other policies, guidance and procedures which relate to this policy. • Support Registered Nursing Staff and Medical Staff to deliver care to patients in accordance with all relevant care plans

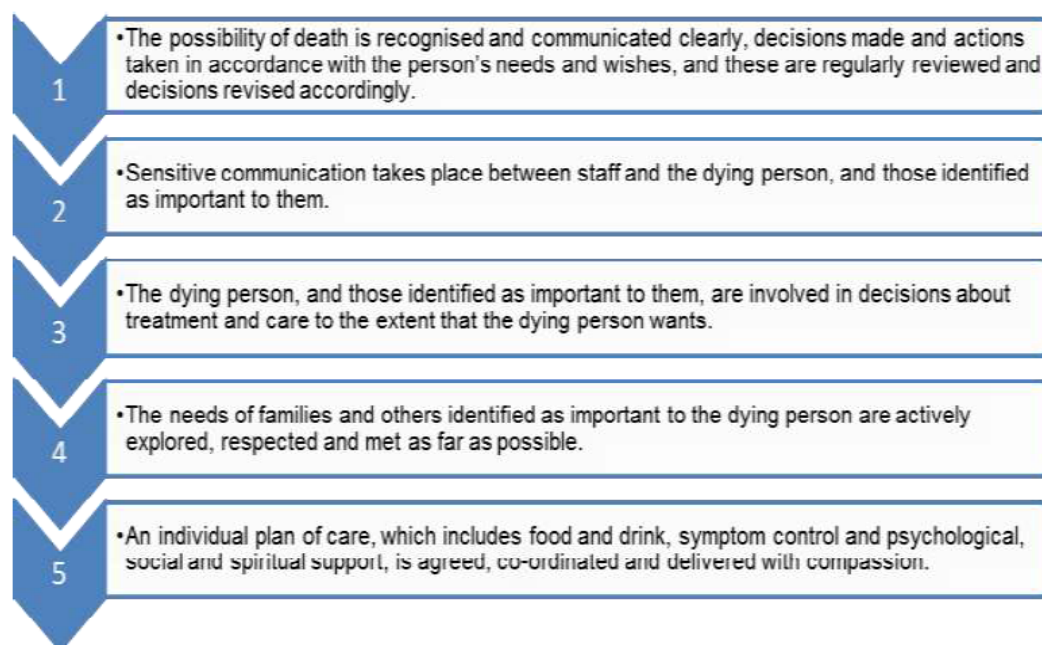
	and/or intervention plans linked to this policy.
Pharmacy	<ul style="list-style-type: none"> • Support the prescribing, dispensing and availability of necessary medication and equipment as required by this policy. • Support both Medical and/or Registered Nursing Staff in terms of providing guidance, information and advice regarding drugs/medications that may be prescribed and/or administered at EoL.
Chaplaincy	<ul style="list-style-type: none"> • Support service users, fellow patients, family/carers, and staff with spiritual and/or religious needs.

4 Background

Following the independent review of the Liverpool Care Pathway (LCP) and the subsequent publication of [More Care, Less Pathway: A Review of the LCP](#) (Neuberger et al, 2013 [online]), it was agreed to phase out the LCP to focus on much needed individualised care plans for EoL. Consequently, the Leadership Alliance for the Care of Dying People (LACDP) published [One Chance to get it Right](#) (2014 [online]). This approach outlines five key priorities for care at EoL and focuses much more on the needs and wishes of the dying person in the last few days/hours of life (including those closest to them, in both the planning and delivery of care, wherever that may be).

The Five Priorities of Care are as follows:

(LACDP, 2014 [online])



The Liverpool Care Pathway (LCP) must not be used anywhere in England. Instead, the care of dying people must be guided by the Five Priorities of Care set out in [One Chance to get it Right](#) (LACDP, 2014 [online]) and also: [Care of Dying Adults in the Last Days of Life: NICE Guideline 31](#) (NICE, 2015 [online]) and [Care of Dying Adults in the Last Days of Life: Quality Standard 114](#) (NICE, 2014 [online]).

4.1 Caring for the Dying Patient Documentation

In response to [One Chance to get it Right](#) (LACDP, 2014 [online]), and the aforementioned Five Priorities of Care, The Northern England Strategic Clinical Networks (NESCEN) have developed a comprehensive range of resources including: [Caring for the Dying Patient Documentation](#) for use across all hospital and community based services within the North East Region that provide EoL care. The Care for the Dying Patient Documentation was piloted in a variety of clinical settings and after an extensive consultation period, was rolled out across North East NHS Foundation Trusts.

Although it is well acknowledged that clear documentation by all clinical staff is a fundamental necessity, it is crucial to reflect the care being delivered during the last days and hours of life. The templates within the Caring for the Dying Patient Documentation provide an evidence-based framework that enables staff to deliver individualised care to the dying patient, and aims to improve the patient's quality of life from a holistic perspective during their last days and/or hours of life.

Whilst the electronic patient record – PARIS, is TEWV NHS Foundation Trust's primary patient care record and as such, must include a contemporaneous record of all patient care, interventions and clinical decision making, it has been agreed that the documentation templates (available as part of the Caring for the Dying Patient Documentation) should be printed and used for all relevant aspects of EoL care. This information must then be summarised within PARIS and the paper hard copy filed as appropriate within the patient's paper medical records.

All decisions relating to EoL care (from early discussions as EoL approaches in the identification phase to care provision after death) must be recorded in the Physical Health Case Note on PARIS.

A comprehensive list of the Caring for the Dying Patient Documentation is available by accessing the hyperlinks in Section 6.3.1 of this Policy. Alternatively, all documentation templates can be found by accessing the individual hyperlinks on the Northern Cancer Alliance website under the [Caring for the Dying Patient Documentation](#) page.

4.2 Care Provision at End of Life

EoL care is led by in-patient Medical and Registered Nursing Staff with full Multi-Disciplinary Team (MDT) support, and, an expectation that any additional support is accessed from other services, for example; Primary Care, Specialist Palliative Care Teams, District Nurses, Social Services and also, Acute Hospital Trusts to ensure that optimal EoL care is provided. Out of hours support can also be accessed by telephoning 111 to request specialist care advice.

Physical Health Nurse Practitioners are a key resource when a patient requires EoL care. The Physical Health Nurse must be informed at the earliest opportunity during the early identification stage that a patient is approaching EoL (if they have not already been involved in any initial discussions). Physical Health Nurse Practitioners can help support the ward team with the care of the patient and also support with documentation, plans of care, and/or EoL drug administration. They may also be able to provide advice, guidance, and signpost/contact other specialists/professionals that may assist the ward team to provide optimal care for the dying patient.

The decision to commence EoL care, including the use of the necessary documentation templates, must be endorsed by the most senior medical clinician responsible for the patient's care - usually a Consultant or General Practitioner (GP). Ideally this decision should be implemented following a MDT meeting and/or discussion whereby the physical, mental health, psychological, emotional, social and spiritual needs of the individual are discussed.

The patient, wherever possible (depending on their mental capacity and well-being), and their family/carers should also be informed that EoL care is being initiated and the necessary documentation is being commenced. It must be fully explained to the patient, and their family/carers that care provision will be individualised and tailored specifically to meet the needs of the patient (from a truly holistic perspective).

There is no 'blanket pathway approach' to providing personalised, compassionate and dignified EoL care.

5 Advance Care Planning

Advance Care Planning is a process whereby an individual deliberates, plans and ideally records their preferences and wishes in order for these to be taken into account by family/carers and those providing care and treatment should the individual lose the capacity to make such decisions in the future. Advance Care Planning is entirely a voluntary process and can be undertaken at any time (not necessarily at a time of ill health or as a result of an accident).

Advance Care Planning usually includes the person's priorities and preferences for their future (e.g. where an individual would like to be cared for at EoL, preferences regarding treatment and types of care, spiritual or religious beliefs that perhaps they would like reflected throughout their care). Any wishes that are expressed within an Advance Care Plan should be personal and relate specifically to the individual. **No-one is obliged to undertake Advance Care Planning.**

Although Advance Care Planning does not need to be in writing unless the advance decision is to refuse life-sustaining treatment, it is recommended that wherever possible, wishes and preferences are written, signed and dated.

As healthcare professionals, it is essential that we establish if a patient within our care has any Advance Care Planning arrangements in order for these to be followed (where possible) should the need arise. There are also numerous approaches in which an individual may have made decisions in advance as part of Advance Care Planning arrangements and therefore, staff should have an awareness of the various means in which Advance Care Planning may be undertaken (and which are outlined within this section of the Policy).

For patients detained under the Mental Health Act (MHA) and where Advance Care Planning is established, the Responsible Clinician (RC) will review the preferences and wishes of the individual within the framework of the MHA, including any treatment and/or interventions that may be required. As Advance Care Planning arrangements are only implemented at such times when an individual lacks the capacity to make decisions independently, capacity should therefore be assessed as part of an ongoing basis.

Patients who may be approaching EoL and who retain capacity around EoL care decisions should be encouraged and assisted, where appropriate, to make their wishes and preferences known.

Patients may choose to undertake this process via an Advance Statement (see section 5.1.1) or via alternative means (as outlined within the remainder of this section of the Policy).

5.1 Deciding Right

[Deciding Right](#) is a North East initiative which supports individuals to make care decisions in advance (Advance Care Planning). It enables a person to make their wishes known about future care and treatment should the individual lose their capacity to make such decisions at a later point in time. Any advance decisions made as part of *Deciding Right* remain inactive whilst the individual is able to make a decision independently. Advance Care Planning decisions only become active if an individual loses the capacity to make such decisions. *Deciding Right* therefore, enables an individual who lacks capacity to have decisions made in their 'best interests'.

Despite being a regional initiative, the authority of *Deciding Right* originates from the Mental Capacity Act (MCA) that empowers individuals, partners, relatives and healthcare professionals to ensure decisions are tailored to meet individual wishes, regardless of the care setting or environment. *Deciding Right* places the MCA at the centre of the shared decision making process and enables healthcare professionals and NHS organisations to comply with the MCA and fulfil the requirements of law.

Further information and guidance relating to *Deciding Right* (inclusive of the information outlined in this section of the Policy) can be obtained by accessing the following link: [Northern Cancer Alliance: Deciding Right](#).

Further *Deciding Right* educational resources for professionals, information leaflets and checklists can be obtained by accessing the following link: [Northern Cancer Alliance: Deciding Right Resources](#).

5.1.1 Advance Statement

An Advance Statement enables an individual to express their wishes, preferences, beliefs and values about future care and treatment (as established as part of Advance Care Planning). An Advance Statement can only be made by an individual who has mental capacity and the Advance Statement only becomes active should a time arise whereby the individual loses that capacity to make such decisions regarding their care.

Although an Advance Statement is not legally binding, healthcare professionals should still make every practical effort to follow a patient's wishes. Additionally, there is a legal requirement for healthcare professionals to take into account the wishes and preferences of an individual when making decisions in their 'best interests' by ensuring that legislation is followed as outlined within the MCA. Some examples of when a healthcare professional/team may decide not to follow an individual's wishes may include:

- When a treatment requested is not the best option for the individual
- When the treatment is illegal, such as an individual asking someone to help end their life
- When a healthcare professional acts in an emergency and there is not sufficient time to obtain an Advance Statement from an individual
- When the treatment requested is not available

- If it is deemed that the individual did not have the mental capacity to make the Advance Statement in the first instance

Being detained in hospital under the MHA should not affect the way that healthcare professionals use and consider an individual's Advance Statement.

An Advance Statement may be undertaken as part of a conversation or ideally, be recorded/documented on paper.

Further information, guidance and TEWV NHS Foundation Trust's standard Advance Statement Pro-forma can be obtained by accessing the Advance Decisions and Statements Procedure via the Trust intranet.

5.1.2 Advance Decision/Advance Decision to Refuse Treatment (ADRT)

An Advance Decision – also called an Advance Decision to Refuse Treatment is legally binding. It gives an individual the legal right to refuse a specific type of treatment or care in advance (should there be a time when the individual is unable to, or lacks the capacity to make a decision regarding the said treatment or care). An Advance Decision/ADRT only becomes active should the above circumstances occur and cannot be used for any other purpose (e.g. if the Advance Decision/ADRT contains information about what treatment the individual actually wants, healthcare professionals do not have to follow it, rather, this information may be considered but it is ultimately the decision of the healthcare professional/team to review what treatment is offered). Advance Decision/ADRTs are sometimes referred to as an 'Advance Directive', an 'Advance Direction' or a 'Living Will' but such terminology has no legal meaning.

There are specific requirements should an Advance Decision/ADRT relate to the refusal of treatment that is life sustaining (e.g. cardiopulmonary resuscitation (CPR) or artificial ventilation) in that it must be in writing, signed, dated, witnessed and a specific form of wording must be used. It is recommended that where a person is considering making an Advance Decision/ADRT, advice should be sought from an experienced healthcare professional that is fully aware of the individual's medical history.

Additionally, some Advance Decision's/ADRT's relate to the refusal of treatment only in some specific circumstances but not others, and therefore, the document must clearly specify all of the circumstances in which the refusal of a particular treatment should be adhered. **It must be established at the earliest opportunity if a person has an Advance Decision/ADRT in place as in most circumstances, healthcare professionals are legally bound to follow the decision but only if correctly written and applicable to the situation intended.**

For patients' detained under the MHA, healthcare professionals must follow the Advance Decision/ADRT if it is valid and applies to current circumstances **unless it is a refusal of medical treatment for a mental health disorder and the criteria for use of the MHA are met.** If a situation does occur whereby a detained patient is given treatment that they do not want, then a clear explanation and rationale must be provided. An exception to the non-adherence of an Advance Decision/ADRT pertains to the decision to refuse electroconvulsive therapy (ECT). Should the decision to refuse such therapy be clearly outlined within an individual's Advance Decision/ ADRT, then ECT cannot be delivered **unless it is to:**

- **Save life, or**

- **To prevent a serious deterioration in the patient's condition**

Advance Decisions/ADRTs regarding physical illnesses or conditions are not routinely affected by an individual being detained under the MHA.

Further information, guidance and TEWV NHS Foundation Trust's standard Advance Decision to Refuse Treatment (ADRT) Pro-forma can be obtained by accessing the Advance Decisions and Statements Procedure via the Trust intranet.



Should an ambulance transfer be required, the North East Ambulance Service (NEAS) will only accept the *Deciding Right* forms (including ADRT documentation). Always use the most recent version of the forms required. Forms can be printed from the links outlined throughout Section 5 within this Policy (in order to be completed manually).

5.1.3 Lasting Power of Attorney

A Lasting Power of Attorney (LPA) is a legal document that enables someone who has been appointed to make decisions on another's behalf should a time come when the individual is unable to make their own decisions. A LPA may be a partner, relative, friend or a solicitor but they can only be appointed by the individual at a time when they have capacity, and who has completed the appropriate legal documentation (usually obtained via the Office of the Public Guardian).

There are two types of LPAs:

- **Property and Financial Affairs:** authorising the LPA to make decisions relating to finances and property should the individual lose capacity regarding those decisions.
- **Personal Welfare (Health and Welfare):** authorising the LPA to make decisions about health and care should the individual lose capacity regarding those decisions.

It must be established at the earliest opportunity if a person has appointed a LPA to make health and welfare decisions on their behalf when they no longer have capacity (or if a court appointed deputy has been appointed to make such a decision). If there is an LPA/Deputy, they must be involved in all decision-making processes regarding EoL care.

If an individual has made an Advance Decision/ADRT in addition to appointing a LPA, the LPA will not be able to override the Advance Decision/ADRT if it is valid and applicable.

As mentioned, for patients' detained under the MHA, healthcare professionals do not legally have to adhere to an Advance Decision/ADRT, however, best practice suggests that the Advance Decision/ADRT is followed where possible. Similarly to the guidance provided under Section 5.1.2, should a LPA refuse ECT on behalf of an individual (because the individual no longer has capacity to make this decision) then ECT cannot be delivered **unless it is to:**

- **Save life, or**
- **To prevent a serious deterioration in the patient's condition**

Further information, guidance and resources relating to LPAs can be obtained by accessing the following link: [Office of the Public Guardian](#).

5.1.4 Emergency Health Care Plan (EHCP)

An EHCP is not a legal document; however, an EHCP can be valuable for those who may (because of their condition) need emergency treatment in the future. It enables the patient to decide in collaboration with their healthcare professional how they wish a potential future emergency to be managed (and therefore plan ahead for specific emergencies). An EHCP may contain information for family/carers (e.g. who to call, what first aid can be used), and also for healthcare professionals (e.g. what treatment would be appropriate, what drugs to use etc.). An EHCP can be written on behalf of a person who lacks capacity, but only if the decisions are made using the 'best interests' process of the MCA. In such circumstances the EHCP should contain the decisions that were made from the 'best interests' process which has helped to inform the care and treatment of an individual.

Further information, guidance and Regional EHCP documentation can be obtained by accessing the following link: [Northern Cancer Alliance: Deciding Right Regional Forms: EHCP Documentation.](#)



Should an ambulance transfer be required, the North East Ambulance Service (NEAS) will only accept the *Deciding Right* forms (including EHCP documentation). Always use the most recent version of the forms required. Forms can be printed from the links outlined throughout Section 5 within this Policy (in order to be completed manually).

5.2 Do-Not-Attempt Cardiopulmonary Resuscitation (DNACPR)

The cessation of the heartbeat and/or of breathing is an integral part of the natural process of dying (from any cause). As awareness and education regarding CPR has become much more widely available, attempts to provide CPR are now much more common in situations other than a sudden cardiac arrest. However, such situations may potentially include circumstances in which people are gravely ill, or nearing the end of their life in which attempts to resuscitate may not work, subject the individual to potential violent physical treatment (in an effort to re-start their heart), or, actually restore heart function, but may subject the individual to a further period of suffering from their underlying terminal illness (British Medical Association, Resuscitation Council and Royal College of Nursing, 2016 [online]).

It is therefore recognised that although there are circumstances in which CPR should most definitely be implemented in order to return an individual to hopefully, a worthwhile quality of life, there are clearly other situations whereby attempting CPR would be to prevent the natural and inevitable death of an individual.

It is absolutely essential that anticipatory decisions regarding CPR are made for patients who are gravely ill, and/or who are approaching the end of their life, so they are not subject to the trauma of attempted CPR with no realistic prospect of restoring life. Responsibility for making the DNACPR decision lies with the senior medical doctor (e.g. Consultant or GP) who has responsibility for the patient.

Ultimately, anticipatory decisions relating to CPR involve complex clinical and ethical considerations and a DNACPR order should only be implemented in accordance with the most up-to-date published guidance and recorded on the most recent version of the standardised form.

Always use the most recent version of the standardised form required. DNACPR forms can be printed from the following link: [Northern Cancer Alliance: Deciding Right Regional Forms: Do Not Attempt Cardiopulmonary Resuscitation](#) and within TEWV NHS Foundation Trust, these must be completed manually.

Standardised forms to record DNAR CPR provide a readily accessible means of documenting this information but as such, must be communicated effectively within healthcare teams in order to prevent staff from having to make an independent and/or instantaneous decision about whether or not to start CPR. **In accordance with TEWV NHS Foundation Trust's Resuscitation Policy, without exception, everyone in an emergency situation will be resuscitated unless a DNACPR order or a valid and applicable Advance Decision/ADRT has been confirmed.**

For patients who are gravely ill, palliative, or who are approaching the end of their life, consideration, discussion and a decision regarding CPR must be made at the earliest opportunity and **communicated clearly to all staff** involved in delivering care to the patient concerned. Ideally, such conversations and anticipatory decisions should be made as part of a wider, comprehensive discussion as part of Advance Care Planning, and therefore preventing a crisis situation which could necessitate a hurried decision.



Decisions relating to CPR are made on an individual patient assessment basis. **There is no 'blanket approach' for the implementation of a DNACPR.**

Where a patient or those close to the patient disagree with a DNACPR decision, a second opinion should be offered. Endorsement of a DNACPR decision by all members of a MDT may avoid the need to offer a further opinion.

(British Medical Association, Resuscitation Council and Royal College of Nursing, 2016 [online]).

Where there is a clear need for a DNACPR decision relating to a dying patient for whom CPR offers no realistic prospect of success, **that decision should be made and explained to the patient and those close to the patient at the earliest practicable and appropriate opportunity** (British Medical Association, Resuscitation Council and Royal College of Nursing, 2016 [online]).

Once a DNACPR decision has been made and documented (on the standardised form), the paper document must be kept and stored in the patient's paper notes. Photocopies are not valid. Local team/ward communication arrangements must be in place to ensure that staff are aware of both the DNACPR and its location.

Should a patient lack capacity, the MCA requires that a 'best interests' decision must include: seeking the views of anyone named by the patient as someone to be consulted, and anyone engaged in caring for the individual or interested in the individual's welfare. Under the MCA, healthcare professionals must act in the 'best interests' of a patient who lacks capacity.

Further comprehensive guidance and information relating to CPR decisions and specific information regarding patients' who lack capacity can be found by accessing the following link: [Decisions Relating to Cardiopulmonary Resuscitation](#).



Should an ambulance transfer be required, the North East Ambulance Service (NEAS) will only accept the *Deciding Right* forms (including the DNACPR form). Always use the most recent version of the forms required. Forms can be printed from the links outlined throughout Section 5 within this Policy (in order to be completed manually).



A DNACPR decision does not override clinical judgement in the event of a reversible cause if the respiratory or cardiac arrest does not match the circumstances to which the DNACPR decision was made and recorded (examples of reversible causes are: asphyxia due to a self-harm incident such as a ligature, choking, or a medical complication such as a blocked tracheostomy tube). In the event of such a reversible cause, CPR should be commenced.

Where there is no DNACPR decision documented, or where there is no explicit resuscitation decision documented in advance, CPR should be commenced. Medical and nursing colleagues should support anyone attempting resuscitation in such circumstances. If during resuscitation contrary information is ascertained such as a DNACPR order, or an ADRT then CPR should cease.

5.2.1 Cardiovascular Implanted Electronic Devices (CIEDs) at End of Life

Each year, thousands of people with diagnosed cardiac conditions undergo the procedure of having a CIED implanted, as a means of providing effective treatment by reducing and/or preventing symptoms. CIEDs include pacemakers, implantable cardioverter defibrillators (ICDs) and small recorders to monitor the heart's rhythm. Devices such as ICDs are routinely implanted for the treatment of life threatening ventricular arrhythmias and they have undoubtedly prolonged thousands of lives by preventing sudden cardiac death. However, for patients who are gravely ill such as those who are approaching the end of their life, the benefit from the device attempting to prolong life may be outweighed by the burden and distress of repeated shocks from the ICD.

All patients with a CIED should be provided with information about their device as part of the initial implantation procedure. Patients are usually advised to keep such information accessible should healthcare professionals require this information for future care and treatment. All patients with a CIED should have timely access to expert clinical support for their device and should be provided with clear information on how to obtain help whenever they need it. Standards for implantation and follow-up of cardiac rhythm management devices in adults have been defined by the British Heart Rhythm Society.

If a patient with an implantable CIED is believed to be approaching the end of their life, discussions about CPR should include device management with specific consideration given to the deactivation of the shock function. As stated previously, conversations relating to anticipatory decisions should be made as part of a wider, comprehensive discussion as part of Advance Care Planning, with the aim of preventing a potential crisis situation and/or hurried decision making. Discussions involving device management and potential deactivation must also include expert clinical input from the Cardiology Team at the Acute Hospital Trust. **Where planned deactivation of a device is agreed, suitable arrangements should be made in order for a member of the Cardiology Team to perform the procedure.**

Comprehensive guidance on the management of CIEDs (including the deactivation process when someone is approaching the end of their life) has been published by the Resuscitation Council

(UK), British Cardiovascular Society and National Council for Palliative Care (2016 [online]): [Cardiovascular Implanted Electronic Devices Towards the End of Life, During Cardiopulmonary Resuscitation and After Death.](#)

It must be established at the earliest opportunity if a person requiring or approaching EoL has an implantable CIED in place. Where this is established, the above comprehensive guidance should be read and all discussions, referrals and joint decision making clearly documented.

Additional information and guidance relating to CIED deactivation specifically at EoL can be accessed via the following link: [Cardiovascular Implanted Electronic Devices.](#)

6 Implementing End of Life Care

As previously mentioned, there is no 'blanket approach' to implementing or providing personalised, compassionate and dignified EoL care. Patients who are: gravely ill, palliative, or who have an irreversible life limiting/threatening condition should have a comprehensive assessment, review and discussion regarding whether death is anticipated (**Expected Death**) and as to whether EoL care needs to be implemented. If this is agreed, a DNACPR form must be completed and the decision recorded on PARIS.

As stated in **Section 4.2 Care Provision at End of Life**, the decision to commence EoL care (including the use of the necessary documentation templates) must be endorsed by the most senior medical clinician responsible for the patient's care (i.e. the Consultant Psychiatrist within TEWV Trust in-patient units) and wherever possible, the patient and their family/carers should be fully involved and informed that EoL care is being initiated. It must be fully explained to the patient, and their family/carers that care will be tailored specifically to meet the needs of the patient, incorporating the physical, mental health, psychological, emotional, social and spiritual needs of the individual.

For some individuals, an expected death may be anticipated several weeks beforehand and in such circumstances, it is useful to seek advice, guidance and input from additional services such as: Specialist Palliative Care Teams, Hospices, District Nurses and/or Social Services. It is also useful to involve specialist organisations for support and expertise such as Macmillan Cancer Care.

It is essential that the most appropriate and preferred place for the individual to receive EoL care is considered and agreed, and this may necessitate a transfer of the individual from their in-patient setting within TEWV Trust to an Acute Hospital Trust, a Specialist Palliative Care setting such as a Hospice, or home. Consideration should be given as to whether the [Fast-Track Pathway Tool for NHS Continuing Healthcare](#) needs completing; to ensure that immediate healthcare provision can be implemented on discharge.

Although the death of the individual may be inevitable, the provision of support, good communication and consideration of the patient's preferences and wishes (wherever possible) is paramount at this time, in order to minimise any emotional upset and distress as EoL approaches.

Good communication should also involve a practical discussion with the patient (where possible) and their family/carers regarding who to contact at the time of death (should family/carers not be

present), the preferred choice of Funeral Director and as to whether the family/carers would like to contact the Funeral Director independently when the need occurs, or whether they would like ward staff to make contact on their behalf. Please see **Section 7.5 Contacting a Funeral Director** for further information.

6.1 Early Recognition of End of Life

In some situations, it is difficult for healthcare professionals to recognise/identify when EoL care should be implemented. Although expected death may be anticipated, the provision of EoL care is not the main clinical purpose of TEWV NHS Foundation Trust, and as such, there will always be a degree of unfamiliarity compared to that of mental health care provision. This, together with the unpredictability of the dying process and the individual's signs and symptoms as they approach EoL, can make early recognition a complex process.

Below are some general indicators of an individual's decline/deterioration and increasing needs that may be useful when considering the implementation of EoL care:

- General Physical Health - unstable and deteriorating
- Advanced Disease - symptom progression
- Decreasing Response to Treatment
- Significant Comorbidities
- Increasing Dependence - needs additional support
- Decreasing Activity - in relation to activities of daily living
- Patient Choice - for no further active treatment
- Progressive Weight Loss
- Increasing Falls

Other indicators to consider:

- Doubly Incontinent (if not previously)
- Social Withdrawal
- Reduced Mobility
- Reduced Oral Intake - nutrition and hydration
- Change in Behaviour
- Change in Cognition
- Family Opinion,
- Recurrent Infections
- Physical Changes (in appearance or other): e.g. skin colour, cyanosis, coherence etc.
- Change in Breathing
- Change in Conscious Level

The above indicators are examples only and should not be used as sole reasons to implement EoL care.

Again, wherever possible, it is useful to seek advice, guidance and input from additional services such as: Specialist Palliative Care Teams, Hospices, District Nurses, specialist organisations such as Macmillan Cancer Care etc., but there are also a range of resources that may be accessed by clinicians as an aid to support:

[The Gold Standards Framework: Proactive Identification Guidance \(PIG\)](#) (Royal College of General Practitioners, 2016 [online]) provides a comprehensive outline of clinical indicators and

factors of deterioration that should be considered in order to recognise people who are approaching the end of their life.

[Treatment and Care Towards the End of Life: Good Practice in Decision Making](#) (General Medical Council, 2010 [online]).

6.2 Providing Individualised, Person-Centred Care

Holistic, individualised, person-centred care provision is integral to caring for an individual who is dying. Holistic, person-centred care includes the needs of the patient from an emotional, psychological, physical, social and spiritual perspective (and therefore, treating the person as a ‘whole’) but also looks to tailoring care specifically to suit the personal needs of the individual.

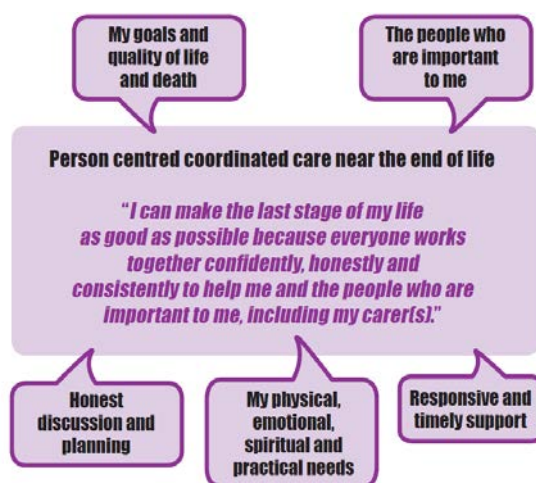
Person-centred, coordinated care is comprehensively outlined in [Every Moment Counts](#) (National Voices and the National Council for Palliative Care, 2015 [online]) which describes a number of: critical outcomes, success factors, and, support and treatment in EoL care, from the perspective of those who need that care, including their families/carers.

As the publication explains, all EoL experiences are unique: one size cannot fit all. The focus of this publication is to remind healthcare professionals to stop, think and respond in a way that is, and feels, personal to the person in front of them. It helps staff and organisations to review and consider the services they provide, through the eyes of the person who needs that care.

The document utilises evidence from a comprehensive literature review, research from the experience of bereaved carers, and incorporates the experience of those involved in EoL care provision (carers and professionals). Within the publication, five domains of person-centred care are identified:

6.2.1 Domains of Person-Centred Coordinated Care near the End of Life

[Every Moment Counts](#) (National Voices and the National Council for Palliative Care, 2015 [online])



6.2.2 Providing Information

If at any time, the patient asks for information regarding: their condition, prognosis, concerns, anxieties, treatment or plan of care, these should all be discussed by a suitable member of the MDT who knows the patient and can communicate effectively with them.

Family/carers should also be fully informed and kept up-to-date with the patient's condition (**unless of course the patient has previously expressed a wish for information not to be shared**).

The following link is a useful leaflet that TEWV Trust staff may print and give to the patient's family/carers as a means of further support and information: [When Someone is Dying: Information for Relatives, Friends and Carers](#) (NESCN, 2015 [online]).

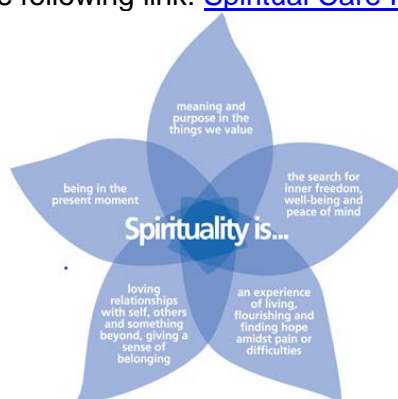
6.2.3 Religious and Spiritual Needs

It is important to acknowledge that as part of the implementation of EoL care, consideration must be given to an individual's personal religious and/or spiritual needs, and that these are addressed as part of their care planning arrangements. Staff must acknowledge equality and diversity inclusive of religion and spirituality. Patients from different faiths may have specific wishes or preferences and it is important that such needs are respected, valued and supported wherever possible.

Discussion regarding any specific beliefs and/or any religious/spiritual practices should be commenced with the patient and their family/carers (if appropriate) at the earliest opportunity in order for staff to facilitate the patient's wishes and/or make any appropriate plans prior to the individual's death.

Advice, further information or guidance in relation to addressing and supporting any specific religious and/or spiritual needs of the patient should be sought from: the patient themselves (where possible), their family/carers, and/or, from the Trust's Chaplaincy Service. The Chaplaincy Team should ideally be contacted as soon as a patient is identified as needing EoL care. Chaplains are available to support individuals of all faiths and none. Ward staff should liaise with the Chaplaincy Team in order to provide ongoing support in a timely manner. There is a Chaplain on call from 8am - 8pm every day of the year. Contact details for the Trust wide Chaplaincy Service are available via InTouch: [The Chaplaincy Service](#).

In addition, the Trust's '**Spirituality Flower**' can be used by staff as a resource to think about an individual's spiritual and religious needs. The petals of the flower represent five aspects of spirituality which may be of importance to the patient and/or their family/carers. Further information can be found by accessing the following link: [Spiritual Care Resources](#).



6.3 The Dying Patient

The following must be established:

- Medical team confirm that death is anticipated (expected death). DNACPR completed.
- Decision to commence EoL care has been agreed by the most senior medical clinician (i.e. the Consultant Psychiatrist within TEWV NHS Foundation Trust in-patient units).
- The patient and their next of kin, family/carers have been fully involved and informed that EoL care is being initiated (where at all possible).
- Any Advanced Care Planning arrangements have been considered and/or reviewed.
- It has been communicated to the patient, and their family/carers that care will be tailored specifically to meet the needs of the patient.
- The most appropriate and preferred place for the individual to receive EoL care has been considered and agreed.
- The patient's religious and spiritual needs have been identified and recorded.

It must be ensured that all conversations, discussions and decisions regarding EoL care planning arrangements are recorded within the Physical Health Case note on PARIS.

6.3.1 Commencing the Caring for the Dying Documentation

As previously mentioned in Section 4.1 of this Policy, the [Caring for the Dying Patient Documentation](#) (NESCEN, 2019 [online]) provides an evidence-based framework that enables staff to deliver individualised care to the dying patient, and aims to improve the patient's quality of life from a holistic perspective during their last days and/or hours of life.

All of the Caring for the Dying Patient Documentation can be accessed via the individual links below:

The Caring for the Dying Patient Documentation has 5 core components

1-4 must be completed and component 5 need only be completed if necessary:

1. [Title Page Contact Information](#) (Word document that may be adjusted for local use)
2. [Medical Assessment](#)
3. [Nursing Assessment](#)
4. [Daily Reassessment](#) (Word document that may be adjusted for local use)
5. [NESCEN Community Prescription Chart](#)
(May be necessary if there is a reluctance from healthcare professionals outside of TEWV NHS Foundation Trust to prescribe/administer medication utilising Trust medicine kardexes (i.e. Specialist Palliative Care Teams, District Nurses etc.).)

In addition, the following guidance has also been developed as a useful tool to assist staff to deliver an effective EoL care plan and is based on the Leadership Alliance for the Care of Dying People: Priorities for Care:

[Caring for the Dying Patient Guidance](#) (May be adjusted for local use)

There are also a number of additional core care plans that may be utilised depending on the patient's individual symptoms. These must not be used as a replacement for the 5 core components mentioned above (rather they are to be used as additional assessment tools):

- Agitation Core Care Plan
- Communication Core Care Plan
- Dyspnoea Core Care Plan
- End of Life Core Nursing Care Plan
- Nausea and Vomiting Core Care Plan
- Pain Core Care Plan
- Respiratory Tract Secretions Core Care Plan
- Spirituality Core Care Plan

6.4 Initial and Ongoing Assessment of the Dying Patient

Using the initial Core Components of the Care for the Dying Patient Documentation, a comprehensive, holistic, initial assessment must be undertaken and a robust individualised care plan formulated. In order to ensure that optimal care is provided, the initial assessment must include the following:

1. Document the information supporting the MDT's opinion that the patient is dying.
2. Make an individual plan of care, with patient involvement wherever possible, and involving the patient's family/carers if appropriate. The documented plan should incorporate:
 - The identification of any relevant decisions made in advance (DNACPR, Advanced Decision/ADRT etc.).
 - The decision(s) made about any further relevant monitoring and/or investigations and/or interventions.
 - Current symptoms, ongoing symptom monitoring and agreed options for symptom control.
 - The patient and their family/carers understanding and concerns of the situation.
 - The patient's wishes, preferences, beliefs, values, religious and spiritual needs.
 - Identify, discuss and agree (with the patient and their family/carers wherever possible) the options regarding hydration and feeding. Patients should be offered food and drink if they can swallow.
3. Incorporating the elements above, document the plan of care and the relevant conversations that have taken place.
4. Ensure that any equipment required and/or prescribed medication is available and that this has been discussed with the patient and their family/carers (wherever possible).
5. Medications must be prescribed subcutaneously (S/C) on an 'as required' (PRN) basis for symptoms that commonly occur at EoL (e.g. pain, agitation, respiratory secretions, nausea, vomiting and breathlessness).

6. Any prescribed regular medication should be administered via a syringe driver with the lowest dose(s) needed to manage an individual's symptoms. The purpose of the syringe driver and the medication administered should be fully explained (wherever possible), in addition to any common side-effects that may be envisaged (e.g. drowsiness).
7. Ensure anticipatory medications are prescribed and are available.

6.4.1 Medical and Nursing Responsibilities

1. Senior Medical Clinician:

- a) All dying patients must have an identified senior medical clinician (Consultant or GP) who will make key decisions. Within TEWV NHS Foundation Trust in-patient settings this would normally be a Consultant Psychiatrist, and can be delegated out of hours (see point C below).
- b) Clinical teams should review patients frequently, inclusive of care provision. Signs of further deterioration, escalation decisions and anticipating end of life situations should all be considered. Proactive planning must be considered.
- c) Recognition that the patient is dying should be endorsed by the Senior Clinician in collaboration with the patient, relative(s)/carer(s) and MDT. Out of hours, a Consultant or Registrar should be responsible for endorsing the recognition that a patient is dying (if this situation has not previously been anticipated).
- d) The Senior Clinician should make key decisions (unless it is an emergency). They should review the patient's condition regularly (i.e. whether the patient is still expected to die).

2. Nursing Staff:

- a) The patient must be assessed regularly in order to have their care needs re-evaluated and addressed accordingly. The assessment, outcome and necessary interventions should all be clearly documented.
- b) Any concerns regarding the patient's care needs, symptom control, and/or newly presenting symptoms should be reported at the earliest opportunity inclusive of out of hours.
- c) Clear and regular communication with the patient (where possible) and their family/carers should be maintained throughout the delivery of EoL care.

3. Medical and Nursing Responsibilities:

- a) At least a daily medical assessment (using the Medical Reassessment Document - contained within the Daily Reassessment template as per **Section 6.3.1 Commencing the Caring for the Dying Documentation**).
- b) At least 4 hourly nursing assessment (using the Ongoing Nursing Care Document - contained within the Daily Reassessment template as per **Section 6.3.1 Commencing the Caring for the Dying Documentation**).
- c) Regular ongoing assessment by the Senior Medical Clinician (again using the Medical Reassessment Document - contained within the Daily Reassessment template as per Section 6.3.1 Commencing the Caring for the Dying Documentation).
- d) Regular Completion of the Daily Ongoing Assessment Document (as per Section 6.3.1 Commencing the Caring for the Dying Documentation).

The information documented using the Caring for the Dying Documentation must be summarised within PARIS and the paper hard copy filed as appropriate within the patient's paper medical records. All aspects of EoL care delivery should be discussed and reviewed as part of the local in-patient area's duty handover, 'report out' and/or huddles.

6.5 Symptom Management

As the patient nears EoL, there may be a degree of variability in relation to physical symptoms. Often, if symptoms increase, medication doses may need to be titrated higher in order to provide adequate symptom control. Increasing and/or amending EoL medications should ideally be discussed with a palliative care professional first.

Pro-active EoL planning and care delivery includes the management of any potential associated symptoms. Therefore, anticipatory medications should be prescribed (with a clear instruction determining clinical use) on the patient's medication chart (even if such symptoms are not present at the time of prescribing). The MDT should anticipate potential symptom management problems and work collectively in collaboration. The [NECS Palliative and End of Life Care Guidelines: Symptom Control for Cancer and Non-Cancer Patients](#) should be referred to for prescribing guidance.

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

- Noisy and/or laboured and/or difficulty in breathing
- Pain
- Agitation
- Restlessness
- Nausea and vomiting
- Sweating
- Confusion
- Dry mouth
- Urinary incontinence or retention
- Oedema (swelling of the arms and legs caused by excess water collecting in the tissues)

It is important to note that some of the symptoms identified above may already be evident as part of the individual's ongoing illness. Others may present later as the patient nears the end of their life. All symptoms (both existing and new) should be managed with appropriate symptom control measures wherever possible.

6.5.1 Syringe Drivers

A syringe driver is a small, portable pump that enables medication to be continuously administered under the skin (sub-cutaneous) over a 24 hour period. Using a syringe driver avoids having to administer multiple injections in order to manage an individual's symptoms.

A syringe driver can be used to administer various medications and is normally indicated when symptom management requires medication that is best delivered via the sub-cutaneous route (S/C) or, when administering oral medication is not possible. This may include:

- A patient with swallowing difficulties
- A patient with nausea or vomiting
- A patient who is too weak or ill to take medication orally
- A patient with a reduced conscious level

Although a syringe driver should certainly be considered for those requiring EoL care, they are not always essential for every individual in relation to the management of symptoms. **If a syringe driver is required, TEWV staff are not permitted to use these (with the exception of the Physical Health Nurse Practitioners).** Where there is no Physical Health Nurse Practitioner, the syringe driver must be managed by Palliative Care Professionals/Teams or specially trained qualified nursing professionals such as Macmillan, Marie Curie and/or District Nursing Teams.

6.6 Ongoing Monitoring, Assessment and Care

As stated in **Section 6.4.1 Medical and Nursing Responsibilities**, the patient must be reviewed by nursing staff at least at 4hourly intervals and at least daily by medical staff. As part of this review, the qualified nurse and/or medic should ensure that ongoing monitoring and assessment includes:

Nutrition and Hydration

Patients should be supported to have food and/or fluids at EoL as long as it is their wish to do so. If eating and drinking is a cause for concern, or it appears that this is problematic for the patient (despite their wish to eat and/or drink), it may be necessary to involve the Speech and Language Team (SALT) so that a suitable action plan can be established. Often, when a person is approaching the end of their life, the desire to continue to eat and drink decreases quite significantly. In addition, their level of consciousness may decline to the point where they are no longer able to eat and/or drink.

Personal Hygiene and Care

Maintaining levels of good personal hygiene is essential for all patients, and most certainly during the delivery of EoL care when the patient is often more dependant on nursing staff for assistance. Personal hygiene includes bathing, toileting, general body hygiene and grooming. Although hygiene needs may be considered a highly personal matter (determined by a person's individual values and practices), nursing staff may be required to provide personal care that involves caring for a patient's skin, hair, nails, teeth, oral and nasal cavities, eyes, ears, perianal and genital areas (Royal Marsden, 2019 [online]).

Mouth Care

Mouth care is vitally important not only to promote comfort and dignity, but also, to prevent pain, soreness and dryness and cracking of the tongue and lips. Frequency of mouth care interventions should be assessed by nursing staff. Interventions may include: sips of fluid or mouth-care swabs (if water cannot be tolerated), lip balm and/or the use of soft tooth brush to clean the patient's teeth.

Contenance and Elimination

Contenance and elimination may be variable when an individual approaches EoL. If a patient loses their ability to inform staff when they need assistance with toileting needs (which may be common as a person approaches the last phase of their life), regular interval checking for continence is

absolutely essential. Should an individual be found to be in a soiled state, they should be washed and cleaned immediately. Staff should also consider the risk of urinary retention where there is little or no evidence that the patient is passing urine, or if there are concerns regarding how much urine an individual has passed. Bowel movements should also be closely monitored in order to prevent constipation.

Pressure Area Care

When a patient approaches the end of their life, it is usual that independent physical movement is often significantly reduced. An individual may spend very long periods in one particular position and whilst it is considerate not to disturb the person unnecessarily, positional changes are essential to ensure that pressure ulcers do not occur. Staff should use their clinical judgement to assess if positional changes and pressure relieving aids are appropriate but wherever possible, advice must be sought from the Trust's Tissue Viability Specialist Nurse.

Skin Integrity

In addition to pressure area care, staff should be familiar with the importance of keeping the individual's skin clean and dry. All individuals perspire – regardless of whether mobility is significantly reduced and/or the person is primarily nursed in bed (as is often the case when a person approaches EoL). It is vital that staff continue to check for any skin changes, breaks in the skin, excoriation (e.g. damage to the surface of the skin caused by incontinence), and/or moisture damage. Once skin is clean and dry, regular use of barrier creams and/or emollients may be appropriate. Again, staff should seek specialist advice from the Trust's Tissue Viability Specialist Nurse.

Medication Management

Any patient who requires critical medications for long term conditions such as Diabetes and/or Epilepsy should have their medications reviewed by a medic and a clear plan documented. On some occasions, an alternative route of medication administration may be required.

Pain

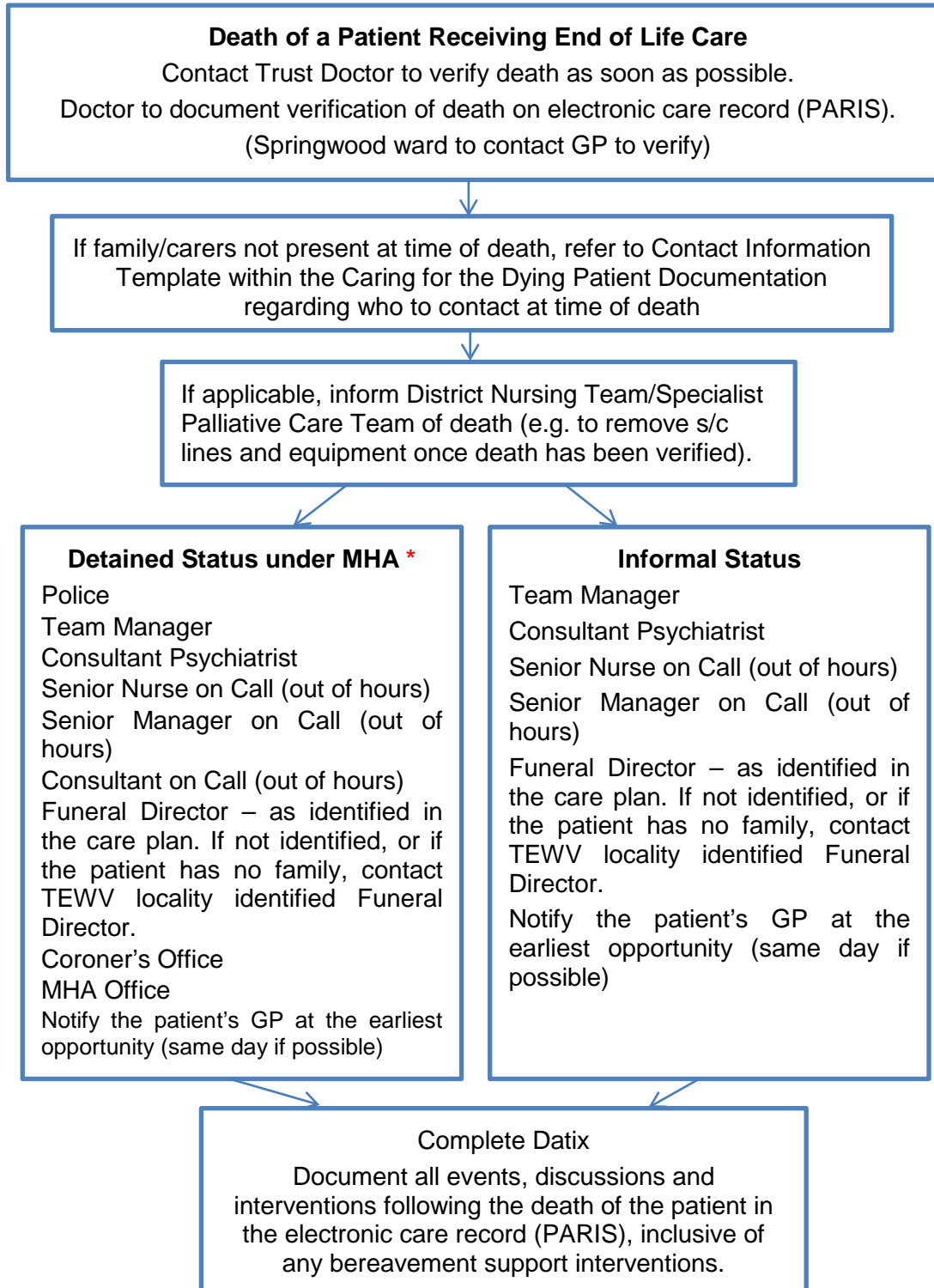
Ensure regular prescribed pain relief is being administered and reviewed. The use of PRN pain relief should be monitored and any concerns regarding pain should be escalated to a Medical Doctor, Physical Health Nurse Practitioner, or the Medical Doctor on Call (if out of hours). In some situations, the regular medication dosage may need to be increased if the PRN doses are required more often. It may also be necessary for staff to consider the use of available pain assessment scales (e.g. Abbey Pain Scale), and/or consider other means of alleviating pain such as non-pharmacological interventions including: holistic therapies, positional changes, addressing hygiene needs, providing pressure area care and/or adjusting the environmental area where possible (e.g. temperature, lighting etc.).

6.7 The Improving Patient

As stated in **Section 6.4.1 Medical and Nursing Responsibilities**, the patient must be reviewed by medical staff at least once daily. As part of this review, the clinician should not only assess for any further decline (in order to implement any appropriate action), but also, assess for any improvement. If there are signs that the patient is improving and/or it appears that the patient is no longer approaching the end of their life then EoL care can be withdrawn. In such circumstances, clear documentation is paramount. Where possible, the patient, family/carers and MDT members should be included in the consideration and decision making process.

7 Following the Death of a Patient

TEWV NHS Foundation Trust has a continued duty of care to patients who die whilst being cared for on Trust premises. Following the death of a patient receiving EoL care, the Nurse in Charge must follow the flow chart below:



* See also: Death of a Patient Subject to the Mental Health Act 1983 Procedure (Trust intranet)

7.1 Verification/Confirmation of Death

Verification or confirmation of death can be defined as deciding whether a patient is actually deceased. Those competent to verify/confirm death may differ from one organisation to another (and does not always require a medical practitioner to undertake this process). Those verifying death must have the training, skills and competence to do so. **Within TEWV Trust, only a Medical Doctor or an Ambulance Paramedic (attending the scene/ward) may verify/confirm death and therefore pronounce life extinct.**

7.2 Breaking the News to Family/Carers

If the patient's family/carers are not in attendance at the time of death, a qualified member of nursing staff on duty should be responsible for making contact via a telephone call. It is always good practice to have had prior discussions with relatives regarding times of the day/night they wish to be contacted in the event that death may occur – this information should be documented within the patient's electronic care record (PARIS) and also within the Contact Information Template in the Caring for the Dying Patient Documentation (see **Section 6.3.1 Commencing the Caring for the Dying Documentation**). When an individual dies, this information is essential and therefore, it should be clearly communicated within the staff team so all nursing staff on duty are aware of who and when to contact.

Breaking the news to family/carers can be an emotional and sensitive task. As mentioned, prior discussions should have already taken place in order to prepare the family/carer as much as possible. In some circumstances, a telephone call may not be appropriate, particularly if the family member/carer:

- Lives alone and/or has no support
- Is elderly, unwell or vulnerable
- Extremely emotionally distressed
- Has a learning disability
- Suffers from mental health problems that may be exacerbated
- English is not their first language and therefore, an interpreter is required

After receiving the news of the death, the family/carers may wish to visit the patient. If so, a member of staff should meet them on arrival and take them to a private, quiet room (if at all possible) where condolences should be offered. Staff are expected to discuss with the family/carers as to whether they would like some time alone with the patient or whether they would prefer ward staff support. Refreshments should be made available and adequate time and support given to the family/carers in a compassionate and sensitive manner. See Section 9 Bereavement Support regarding additional information.

7.3 Certification of Death

Death certification **does not** mean verification/confirmation of death. Certification of death is often referred to as 'certifying the death' and refers to the completion of a medical certificate of cause of death (MCCD). Only a Medical Practitioner can certify the cause of death of a patient and should be undertaken at the earliest opportunity. **Within TEWV Trust, only a Medical Doctor can complete a MCCD and therefore provide certification of death.**

In some circumstances, there may be a delay in completing the MCCD if for example; the death is reportable to the Coroner (see Section 7.4 Reportable Deaths). In such circumstances, advice should be sought from the Coroner's Office to confirm whether the MCCD can be completed prior to any potential inquest or further investigation.

Deaths are required by law to be registered within 5 days of their occurrence **unless** there is to be a Coroner's post mortem or an inquest. It is therefore vital that ward staff make clear arrangements with the patient's family/carers regarding when and where they may collect the MCCD (which is required in order for them to register the death at a registry office). In circumstances where the Coroner has requested that no MCCD is to be issued (until an investigation, inquest and/or post-mortem has been completed), this should be clearly communicated to family/carers and further arrangements made or alternative contacts provided.

7.4 Reportable Deaths

Deaths should be referred to the Coroner if there is reason to suspect:

- The patient died a violent or a unnatural death or
- The cause of death is unknown or
- The patient died while in custody or state detention. **This includes patients who were detained under the MHA and also, those subject to a Deprivation of Liberty (DoL).**

Whenever a patient detained under the MHA dies there will always be a coroner's enquiry and usually an inquest. Even if the death is expected and there are no suspicious circumstances.

In such circumstances, further information should be sought from the Death of a Patient Subject to the Mental Health Act 1983 Procedure available via the Trust intranet.

If staff are unsure as to whether or not to report a death, contact the Coroner's Officer for advice.

7.4.1 Coroner's Role

Senior Coroners are independent judicial officers in England and Wales who must carry out their duties in accordance with the Coroner's and Justice Act, 2009. Coroners are usually lawyers but may also be doctors. They are appointed by the local authority and each Coroner covers their own geographical area. Each Senior Coroner has one or more Assistant Coroners, one of which must be available at all times to deal with matters relating to inquests and post mortems. All Coroners' duties are overseen by the Chief Coroner (a senior Judge appointed by the Lord Chief Justice).

Following a referral of a death to the Coroner, preliminary enquiries may be undertaken to consider whether an investigation (which may include an inquest) is required. The Coroner will conduct an inquest where required to do so and to make a determination/conclusion based on their findings.

7.4.2 Coroner's Officer

Coroner's Officers work under the direction of Senior Coroners and are often Police Officers. The Coroner's Officer will liaise closely with ward staff, doctors, the patient's family, funeral directors and the police where necessary. The Coroner's Officer prepares individual cases to be taken to an

inquest. A Coroner's Officer cannot perform judicial functions, although the Coroner can delegate administrative functions to them.

7.5 Contacting a Funeral Director

Staff should be aware as to whether they are required to contact a preferred or an agreed Funeral Director. As stated in **Section 6: Implementing End of Life Care**, a practical discussion should have previously taken place with the patient's family/carers regarding after death arrangements and these should be clearly documented within the EoL care plan(s). The family/carers may prefer to contact their chosen Funeral Director directly or alternatively, they may require ward staff to support them with this task.

If there are no family, friends or carers, the NHS Trust or Local Authority has a duty to organise and pay for the patient's funeral. This situation occurs when no other suitable arrangements can be, or are being made. Initially, a NHS Trust may approach the Local Authority in order to establish if they are willing to arrange and pay for the individual's funeral (Fairbairn, 2019 [online], Department of Health, 2005 [online]). The Local Authority may then claim the costs of the funeral from the deceased's estate, if there are sufficient funds.

It is essential that each TEWV locality have local processes and/or agreements in place in order for staff to contact an identified Funeral Director should this be required. Anyone who makes arrangements with a Funeral Director may be considered to have a binding contract and may therefore be liable to pay the costs (Fairbairn, 2019 [online]).

For patients receiving EoL care, all attempts must be made to establish whether the patient has any next of kin. This may involve contacting Primary Care Services, Social Services and/or any other organisations that are familiar with the patient.

8 Care After Death

8.1 Managing Infection Risks

The Medical Practitioner who verified the death of the patient is responsible for ascertaining whether the individual had a known or suspected infection and whether this was notifiable. The Health and Safety Executive (HSE) has guidelines on the handling of deceased patients with infectious diseases, and all Doctors, Nurses and other Healthcare Professionals should be aware of TEWV NHS Foundation Trust's infection control policies and procedures.

If the deceased patient is known to have a suspected infectious disease/condition, the Infection, Prevention and Control (IPC) Team should have already been informed (whilst the patient was alive and being cared for by ward staff). When a patient with a known or suspected infectious disease/condition dies, there is a duty of care to ensure that those who subsequently handle the deceased's body are made fully aware of any potential risks so that appropriate infection, prevention and control measures can be implemented. Advice must be sought from the IPC Team if a plan is not already in place.

8.2 Personal Aftercare of the Deceased (Last Offices/Last Rites)

It should be noted that the delivery of personal aftercare of the deceased (last offices/rites) as outlined below is tailored specifically to those patients who have had an expected death – with EoL care having been delivered and a DNACPR in place. For patients' detained under the MHA, where the patient's death is reportable to the coroner, healthcare professionals must seek advice and confirmation from the Coroner's Officer before any personal aftercare can be performed.

Any patient found to have had an unexpected or a suspected sudden death (i.e. a death which was not anticipated and where there was not a DNACPR in place), would require staff to commence CPR in accordance with TEWV NHS Foundation Trust's Resuscitation Policy (and as previously referred to in Section 5.2 of this Policy). This may result in the patient being transferred by emergency ambulance to an Acute Hospital Trust or, the patient being verified deceased on scene by a Paramedic or Trust Doctor. Similarly, in such circumstances, the patient's death is reportable to the coroner and as such, healthcare professionals must seek advice and confirmation from the Coroner's Officer before any personal aftercare can be performed.

- Consider any specific IPC plan to manage risk (if necessary).
- Ensure that room is free from clutter and that the patient area looks presentable.
- Remove any mechanical devices such as syringe driver/infusion pump (contact District Nurse/Specialist Palliative Care Team to facilitate if no appropriately trained staff on duty).
- Ensure butterfly sharps are removed and disposed of appropriately.
- If in situ, remove or spigot the urinal catheter (if trained to do so).
- If in situ, remove nasogastric (NG) tube to prevent facial marking **unless the patient's death is reportable to the coroner.**
- Lay the deceased patient on his/her back.
- Straighten patient's limbs, palms flat and with close alignment to side of the body.
- Wash the patient **unless requested not to do so for religious/cultural reasons.**
- Cover any exuding wounds with a clean, absorbent dressing.
- If available, place in situ an incontinence pad (ideally with tape fasteners) to prevent any potential leakage from the anal orifice.
- Ensure patient's mouth is clean and free from debris. Clean dentures (if in situ) and place in mouth. If placement is not possible, these should be appropriately labelled, placed in a container and should go with the patient to the Funeral Director's.
- Brush/comb the patient's hair.
- If necessary, use a pillow/rolled towel to appropriately place underneath the patient's chin to assist in the closure of the mouth. This should be removed prior to any viewing at ward level (from family/carers, friends etc.).
- Remove all jewellery in the presence of another member of staff unless requested by family not to do so. Any jewellery removed should be clearly documented on PARIS and stored safely in accordance with local policy until this can be handed to family/carers etc. Again, the transfer of any jewellery (in addition to all patient property) must be recorded on PARIS. Similarly, any jewellery remaining on the patient should also be clearly documented.
- Dress the patient in clean, personal clothing (wherever possible) to ensure that dignity is maintained. Personal nightwear may be more practical unless a specific request has been made previously by patient, family/carers etc.
- Document all care interventions provided.

8.3 Patient's Property

Patient's property can hold sentimental value and meaning to family/carers etc. Therefore, it is imperative that property is handled appropriately and as per local policy.

- Patient's property must never be stored in orange clinical waste bags or black domestic waste bags.
- Soiled and/or damp clothing should be placed in a soiled linen bag and retained with the patient's property.
- Patient's property should be clearly labelled.
- All patient's property and/or valuables should be documented accordingly and handed over to the family/carers as per local policy.

9 Bereavement Support

It should be remembered that relatives/carers, fellow patients and MDT staff may need support following the death of a patient. It is essential that those affected by the death of an individual are communicated with in a sensitive, compassionate way and are offered immediate and ongoing bereavement, emotional and spiritual support, appropriate to their needs and preferences (NICE, 2011, updated 2017 [online]).

9.1 Support for Relatives/Carers

Ensure support is offered within an appropriate environment that facilitates sensitive communication and dignity. Support may include: provision of information about practical arrangements, local support services, supportive conversations, and in some cases sign-posting for counselling or more specialist support. Family/Carers should be encouraged to express their emotions in a calm, safe environment and staff should ensure that adequate support is provided and privacy respected. Wherever possible, staff should provide additional, supportive information in a printable format in order for relatives/carers to refer to at a convenient time. The following link provides information for staff to access in order to print and offer to relatives/carers as a further means of support: [Citizens Advice: What to do After a Death](#).

The Trust Chaplaincy Service is available to provide support to relatives/carers (in addition to service users and staff). Chaplains are available to support individuals of all faiths and none. Ward staff should liaise with those requiring support in order to provide contact details for the Chaplaincy Team. There is a Chaplain on call from 8am - 8pm every day of the year. Contact details for the Trust wide Chaplaincy Service are available via InTouch: [The Chaplaincy Service](#).

There are also a range of resources available for relatives/carers to access:

Cruse Bereavement Care - www.cruse.org.uk

Hospice UK – www.hospiceuk.org

The following leaflet is also available for staff to provide for grieving relatives/carers:

[Grieving: How Might It Feel?](#)

9.2 Support for Patients

Other in-patients are often aware that a death is expected or has occurred. It is therefore important to acknowledge and inform other patients when an individual dies, so they themselves can be offered support and reassurance.

In addition, many patients often develop friendships with their fellow residents through shared experiences or conversations. Regardless of the length of friendship, the death of a patient can be a significant loss for an individual and support should always be considered.

Again, ensure support is offered within an appropriate environment that facilitates sensitive communication and dignity. Support may include: supportive conversations regarding the acknowledgment of loss, the experience of grief and similarly, requesting advice/assistance from more specialist support such as the Chaplaincy Team or Psychological Services.

9.3 Support for Staff

In addition to the Chaplaincy Service, staff can access support from the Trust's Employee Support Officers and/or the Health and Wellbeing Team. Further information regarding the range of support available can be obtained via InTouch: [Employee Support Service](#).

Ward debrief sessions should be encouraged within local teams ensuring that they are arranged to include **all MDT members**. MDT peer support is invaluable during this time whereby staff are able to reflect on the care that they have provided and are able to openly discuss their personal feelings relating to the death of the patient. Consideration should also be given to the involvement of the Chaplaincy Team during debrief sessions as a further means of support.

Further guidance and advice on providing support for staff through debriefing for care at the end of life is available by accessing [Staff Debrief Toolkit](#).

10 Definitions

Definitions, terms and abbreviations used within this policy are as follows:

Term	Definition
ADRT	Advance Decision to Refuse Treatment
COPD	Chronic Obstructive Pulmonary Disease
CPR	Cardiopulmonary Resuscitation
DNACPR	Do-Not-Attempt Cardiopulmonary Resuscitation
DoH	Department of Health
ECT	Electroconvulsive Therapy
EHCP	Emergency Health Care Plan
End of Life (EoL) Care	“Care that helps all those with advanced, progressive, incurable illness to live as well as possible and to die with dignity.” End of Life Care is considered to be for people who are in the last days and/or hours of life.
EoL	End of Life
Expected Death	A death which is anticipated where active treatment has been discontinued and the patient is not for resuscitation.
GMC	General Medical Council
GP	General Practitioner
HSE	Health and Safety Executive
IPC	Infection, Prevention and Control
LACDP	Leadership Alliance for the Care of Dying People
LCP	Liverpool Care Pathway
LPA	Lasting Power of Attorney
LTC	Long Term Condition
MCA	Mental Capacity Act
MDT	Multi-Disciplinary Team
MHA	Mental Health Act
NEAS	North East Ambulance Service NHS Foundation Trust
NESCN	Northern England Strategic Clinical Networks
NICE	National Institute for Health and Care Excellence
NMC	Nursing and Midwifery Council

Palliative Care	Palliative care is for people living with a terminal illness/life limiting condition where a cure is no longer possible. It is also for people who have a complex/progressive illness who may need symptom management. The aim is to manage symptoms associated with their condition and to support from a physical, psychological, emotional, social and spiritual needs perspective.
RC	Responsible Clinician
Unexpected or Sudden Death	A death which is not anticipated and where the patient did not have a terminal diagnosis or life limiting condition and where there is not a DNACPR in place.
VoD	Verification of Expected Death

11 Related Documents

Access to Medicines and Pharmacy Services Outside Working Hours

Advance Decisions and Statements Procedure

Consent to Examination or Treatment Policy

Death of a Patient Subject to the Mental Health Act 1983

Mental Capacity Act 2005

Mental Health Act Policies, Procedure and Strategies

Physical Health and Wellbeing Policy (Inpatients and Community)

Physiological Assessment Procedure

NEWS and the Early Detection and Management of the Deteriorating Patient age 16 and above

Resuscitation Policy

12 How this Policy will be Implemented

<ul style="list-style-type: none"> • This Policy will be published on the Trust's intranet and external website.
<ul style="list-style-type: none"> • Line Managers will disseminate this Policy to all Trust employees through a line management briefing.
<ul style="list-style-type: none"> • The Policy will be discussed and disseminated at the Trust's Physical Health and Wellbeing Group.
<ul style="list-style-type: none"> • Line managers will disseminate this policy to all Trust employees through a line management briefing.

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14 Document Control

Date of approval:	09 October 2019	
Next review date:	09 April 2023	
This document replaces:	n/a	
Lead:	Name	Title
	Karen E Blakemore	Lead Nurse, Physical Health
Members of working party:	Name	Title
This document has been agreed and accepted by: (Director)	Name	Title
	Elizabeth Moody	Executive Director of Nursing and Governance
This document was approved by:	Name of committee/group	Date
	Physical Health and Wellbeing Group	23 September 2019
This document was ratified by:	Name of committee/group	Date
	EMT	09 Oct 2019
An equality analysis was completed on this document on:	09/08/2019	

Change record

Version	Date	Amendment details	Status
1	23 Sept 2019	New document	Published
1	22 Sept 2020	Review date extended by six months.	Published

Appendix 1 - Equality Analysis Screening Form

Please note; The Equality Analysis Policy and Equality Analysis Guidance can be found on InTouch on the policies page

Name of Service area, Directorate/Department i.e. substance misuse, corporate, finance etc.	Nursing and Governance/Physical Healthcare			
Name of responsible person and job title	Karen E Blakemore, Lead Nurse Physical Health			
Name of working party, to include any other individuals, agencies or groups involved in this analysis				
Policy (document/service) name	End of Life Care Provision and Care after Death Policy			
Is the area being assessed a...	Policy/Strategy	√	Service/Business plan	Project
	Procedure/Guidance			Code of practice
	Other – Please state			
Geographical area covered	Trust wide			
Aims and objectives	<ul style="list-style-type: none"> To standardise practice for all clinical staff regarding the provision of end of life care and care after death. To ensure that patients receive safe, effective and appropriate end of life care that is supported by current local and national guidance in accordance with best practice. To reduce the clinical risk(s) associated with inappropriately managed end of life care and care after death. 			
Start date of Equality Analysis Screening (This is the date you are asked to write or review the document/service etc.)	10/06/2019			

End date of Equality Analysis Screening (This is when you have completed the equality analysis and it is ready to go to EMT to be approved)	09/08/2019
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You must contact the EDHR team if you identify a negative impact. Please ring Sarah Jay or Julie Barfoot on 0191 3336267/3046

1. Who does the Policy, Service, Function, Strategy, Code of practice, Guidance, Project or Business plan benefit?

The Policy benefits service users by standardising the processes/interventions required by staff regarding the provision of end of life care. The information contained within the Policy is also aimed at reducing the clinical risk(s) associated with inappropriately managing end of life care and/or care of the individual after death. Similarly, the information within the Policy will help facilitate the provision and timely management of care, treatment and necessary interventions in order to ensure that patients receive safe, effective and appropriate end of life care and care after death that is supported by current local and national guidance in accordance with best practice.

2. Will the Policy, Service, Function, Strategy, Code of practice, Guidance, Project or Business plan impact negatively on any of the protected characteristic groups below?

Race (including Gypsy and Traveller)	No	Disability (includes physical, learning, mental health, sensory and medical disabilities)	No	Gender (Men, women and gender neutral etc.)	No
Gender reassignment (Transgender and gender identity)	No	Sexual Orientation (Lesbian, Gay, Bisexual and Heterosexual etc.)	No	Age (includes, young people, older people – people of all ages)	No
Religion or Belief (includes faith groups, atheism and philosophical belief's)	No	Pregnancy and Maternity (includes pregnancy, women who are breastfeeding and women on maternity leave)	No	Marriage and Civil Partnership (includes opposite and same sex couples who are married or civil partners)	No

No – The Policy will not impact negatively on any of the protected characteristic groups.

The positive impacts of the policy are: Patients receive safe, effective and appropriate end of life care and care after death that is supported by current local and national guidance in accordance with best practice.

<p>3. Have you considered other sources of information such as; legislation, codes of practice, best practice, nice guidelines, CQC reports or feedback etc.? If 'No', why not?</p>	<p>Yes</p>	<p>√</p>	<p>No</p>	
<p>Sources of Information may include:</p> <ul style="list-style-type: none"> • Feedback from equality bodies, Care Quality Commission, Equality and Human Rights Commission, etc. • Investigation findings • Trust Strategic Direction • Data collection/analysis • National Guidance/Reports 	<ul style="list-style-type: none"> • Staff grievances • Media • Community Consultation/Consultation Groups • Internal Consultation • Research • Other (Please state below) 			
<p>4. Have you engaged or consulted with service users, carers, staff and other stakeholders including people from the following protected groups?: Race, Disability, Gender, Gender reassignment (Trans), Sexual Orientation (LGB), Religion or Belief, Age, Pregnancy and Maternity or Marriage and Civil Partnership</p>				
<p>No – Given that this Trust Policy has been developed in accordance with a number of national key documents including: Clinical Guidelines and Quality Standards published by the National Institute for Health and Care Excellence (NICE), publications by the Department of Health and also, regionally approved documentation and guidelines, there has been no consultation with service users/stakeholders in terms of the actual writing of this document. The said Policy is therefore a standardised approach that enables clinical staff working within TEWV NHS Foundation Trust to adhere to national, and regional recommended best practice and guidance.</p> <p>09/08/19: Following submission of the Equality Analysis Screening Form, the following additions to the policy have been updated:</p> <ul style="list-style-type: none"> • Page 18 sentence added - The Chaplaincy Team should ideally be contacted as soon as a patient is identified as needing EOL care. • Page 19 in box under 6.3, sentence added - The patient's religious and spiritual needs have been identified and recorded. • Page 18 under 6.2.3, sentence added - Further information can be found by accessing the following link: Spiritual Care Resources. 				

5. As part of this equality analysis have any training needs/service needs been identified?					
Yes	Local training/education required to ensure that staff are familiar with the necessary processes/interventions that are required and which are specific to their locality/ward area. Additionally, some of the required interventions within the Policy may be cross-referenced as training needs specific to other guidelines, policies and procedures.				
A training need has been identified for;					
Trust staff	Yes	Service users	No	Contractors or other outside agencies	No
Make sure that you have checked the information and that you are comfortable that additional evidence can provided if you are required to do so					
The completed EA has been signed off by: You the Policy owner/manager: Type name: Karen E Blakemore					Date:29/06/19
Your reporting (line) manager: Type name: Karen Agar					Date:09/08/19
If you need further advice or information on equality analysis, the EDHR team host surgeries to support you in this process, to book on and find out more please call: 0191 3336267/3046					