

CARE OF THE DYING PERSON AND THE HANDLING AND CARE OF THE DECEASED	Policy Register No. 06059 Status: Public
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Appendix 1: Guidance for Care in the Last Days of Life

1.0 Purpose

- 1.1 This document outlines the expected standards of care of the adult dying person (i.e. those who are in the last few days and hours of life) and those important to them, whilst in the care of Mid Essex Hospital Services NHS Trust (the Trust).
- 1.2 The objective of this document is to provide easily accessible and practical guidance for all healthcare professionals employed by the Trust who are involved in the care of the dying person.
- 1.3 This document does not seek to cover the specialist areas of perinatal, neonatal and paediatric deaths and bereavement.
- 1.4 This policy excludes:
 - Procedures following a neonatal or child death
 - Procedures in the mortuary or during a post-mortem examination which are addressed in mortuary standard operating procedures
 - Disposal of retained tissue or body parts

2.0 Policy Statement

- 2.1 Mid Essex Hospital Services NHS Trust is committed to ensuring that all care given to people in the last few days and hours of life:
 - Is compassionate
 - Is based on and tailored to the needs, wishes and preferences of the dying person and, as appropriate, their family and those identified as important to them
 - Includes regular and effective communication between the dying person and their family and staff and between staff themselves
 - Involves assessment of the person's condition whenever that condition changes and timely and appropriate responses to those changes
 - Is led by a senior responsible doctor and a lead responsible nurse, who can access support from specialist palliative care services when needed
 - Is delivered by doctors, nurses, carers and others who have high professional standards and the skills, knowledge and experience needed to care for dying people and their families properly.
- 2.2 The document will be based on care of the dying adult in the last days of life (NICE 31 and Quality Standard 144). The guideline covers the clinical care of adult who are dying in the last 2-3 days of life.
- 2.3 The Trust will continue to review the care delivered for dying people against the

five priority areas, including considering how they will demonstrate delivery of each of them for individual dying people and those important to them.

- 2.4 The Trust will ensure that staff understand the relevant statutory and legal frameworks and all best practice guidance and will create and support the systems and learning and development opportunities that enable this to happen.
- 2.5 The Trust will also implement and support mechanisms for feedback which facilitate service improvement

3.0 Roles and Responsibilities

- 3.1 **Managing Director:** To ensure the Trust has an effective policy in place for care of the dying person which is regularly reviewed and updated to reflect best practice.
- 3.2 **Director of Nursing and Chief Medical Officer:** To ensure the Trust has systems and processes in place to enable delivery of this policy by nursing and medical staff.
- 3.3 **End of Life Steering Group:** To facilitate the delivery of this policy and ongoing development, implementation and evaluation of initiatives in the care of dying persons, ensuring that related services link effectively with relevant local and regional stakeholder organisations.
- 3.4 **Associate Directors of Nursing and Clinical Directors:** Take responsibility to ensure their staff have knowledge and competencies aligned to their roles and responsibilities.
- 3.5 **All medical and nursing staff:** have a responsibility to ensure they understand this policy and act on its contents in accordance with the professional codes of conduct.
- 3.6 **Hospital Specialist Palliative Care Team:** Support staff in the implementation of this policy by assessment of those with complex needs and through contribution to education and training.
- 3.7 **Pharmacists:** To support ward teams by reviewing medications prescribed for the dying person to ensure these are appropriate.
- 3.8 **Integrated Discharge Team:** Prioritise people who are dying so that they are transferred to their place of care / death in a timely manner and with adequate support for those important to them.

4.0 Priorities for Care of the Dying Person

- 4.1 Caring for people who are close to death demands compassion, kindness and a skilled application of knowledge. Care needs to be based on the following five Priorities when it is thought that a person may die within the next few days or hours:
 - The possibility (that a person may die within the next few days or hours) is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly. **RECOGNISE**

- Sensitive communication takes place between staff and the dying person, and those identified as important to them. **COMMUNICATE**
- The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants. **INVOLVE**
- The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible. **SUPPORT**
- An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion **PLAN** and **DO**

4.2 The priorities for care reinforce that the focus for care in the last few days and hours of life must be the person who is dying. They are all equally important to achieving good care.

5.0 “RECOGNISE”

- 5.1 When a person’s condition deteriorates unexpectedly, they must be assessed by a doctor who is competent to judge whether the person’s change in condition is potentially reversible or they are likely to die in the next few hours or few days.
- 5.2 Consider treatment of reversible causes if appropriate, provided this is in accordance with the person’s wishes or in their best interests if it is established that they lack capacity to make the decision about treatment at that time.
- 5.3 If the doctor judges that the person is likely to die soon, s/he must clearly and sensitively communicate this to the dying person (if conscious). This includes explaining when and how death might be expected to occur and the basis for that judgement, acknowledging and accepting any uncertainty about the prognosis, and giving the dying person the opportunity to ask questions. The same communication must take place with those important to the dying person and others involved in that person’s care
- 5.4 The decision must be reviewed at the next available opportunity by a senior clinician within the person’s care team who is competent to assess whether the person has reached the stage where they are dying, also taking into consideration the views of the wider multi-professional team.
- 5.5 The goals of treatment and care must be discussed and agreed with the dying person, involving those identified as important to them and the multidisciplinary team caring for the person.
- 5.6 These discussions must be clearly documented and accessible to all those involved in the person’s care, taking into account the person’s wishes about sharing their confidential information.
- 5.7 The dying person must be reviewed by a senior clinician within the person’s care team at least daily thereafter or sooner if there is an unanticipated change in the person’s condition to assess whether they are still likely to be dying and if the plan of care remains appropriate. Consider need for specialist input.

6.0 “Communicate”

- 6.1 Communication must be regular and proactive. Staff must make time to talk with dying people, their families and those identified as important to them, including carers. They must listen, respond sensitively to their issues and concerns, provide information in a way that meets their communication needs and check that explanations and information are understood.
- 6.2 Open and honest communication between staff and the person who is dying, and those identified as important to them, including carers, is critically important to good care. Clear, understandable and plain language must be used.
- 6.3 If the dying person needs additional support to understand information, communicate their wishes or make decisions, these needs must be met. This should also take into account the needs of those whose preferred language is other than English, and tailored to the needs of those with disabilities and communication difficulties. If a translator is required “Big Word” should be contacted, in accordance with the Trust’s Interpreting and Translation policy. Consider the need to contact the Trust Specialist Nurse: Learning Disabilities and Autism for such patients who can communicate in Makaton if required.
- 6.4 The content and outcome of all discussions must be documented and accessible to all those involved in the person’s care. This includes conversations about prognosis, goals of treatment and care plans at each point in time, and particular concerns that the person, their family and those identified as important to them have expressed.”
- 6.5 Consent should also be sought to allow sharing of information where appropriate. If/when sharing consent has been obtained from the person, those important to them should be kept informed of clinical progress and be given clear explanations, as necessary, about the care that is being provided.

7.0 “Involve”

- 7.1 Clinical teams must give the dying person, their families and those important to them the name of the senior doctor in the team who has overall responsibility for providing appropriate treatment and care for the dying person, the name of the nurse leading the care and explain how that responsibility is handed over in times of absence or change in care arrangements or settings.
- 7.2 All decisions must involve consideration of the potential benefits, burdens and risks of treatment (or non-treatment) for the individual person. Individuals must be supported to make informed decisions as much as possible and to the extent they wish.
- 7.3 Individuals vary in the extent to which they wish to be involved in decisions about their own treatment. Involve the dying person to the extent they wish to be:
 - In day to day decisions about food, drink and personal care
 - In choosing their preferred place of care and death
 - In clinical and treatment decisions including Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)

- 7.4 The dying person's wishes about the extent to which families and those important to them are involved in discussing their treatment and care must be respected and supported.
- 7.5 Staff must understand the difference between explaining what is going on (including any decisions made); seeking the person's consent for specific interventions or actions; and consulting the person's family and those important to them about making a best interests decision.
- 7.6 If there is a continuing difference of opinion about the treatment or care of a dying person, or if additional reassurance about a decision would be helpful, staff must consider obtaining a second opinion and getting support to facilitate communication to reach a consensus,
- 7.7 **Capacity and advance decisions:** Where it is established that the dying person lacks capacity to make a particular decision, the decision made or action taken on their behalf must be in their best interests, and they should still be involved as far as possible in that decision.
It is important for staff to address these issues at the earliest to ensure they respect advance decisions that are valid and applicable to the circumstances.
- 7.8 An Advance Care Plan (ACP) is an indication about the kind of treatment that the patient would wish to receive if they lose mental capacity to make decisions about that particular aspect of their clinical care. These are not legally-binding documents, but are useful when the clinical team may need to make a "best interests" decision for the patient.
- 7.9 An Advance Decision to Refuse Treatment (ADRT) is a legally binding document, that allows an adult patient to refuse treatment in specific circumstances when they lack capacity to make that decision.
- 7.10 Professionals must ensure that they comply with legal requirements in relation to representation or advocacy for people who lack capacity to consent. Some patients may have appointed an individual to act on their behalf for their health and welfare at a time when they lack capacity to make specific decisions. This is a Lasting Power of Attorney (LPA) and should be registered with the Office of the Public Guardian.
- 7.11 If a dying patient wishes to make a will, staff should be aware of the vulnerability of such patients to pressure from those who might have an interest in such a will and should ensure those patient's rights are protected. Under no circumstances should staff be a witness to a will.
- 7.12 Early discussions regarding arrangements for transfer across settings to the dying person's Preferred Place of Care will be important to ensure that the necessary support services are in place at an appropriate time.

8.0 “SUPPORT”

- 8.1 Staff must regularly assess and address (if possible) the needs of families and those important to the dying person, and offer information about getting access to other sources of help and support. Although it is not always possible to meet the needs or wishes of all family members, listening and acknowledging these can help.
- 8.2 Check the need for an interpreter, BSL (British Sign Language) Signer or advocate at the earliest opportunity, to allow for possible delays in obtaining help.
- 8.3 If a person who is dying lacks capacity to make a decision, the decision-making process should be explained to those people who are supporting the person and they should be involved as much as possible.
- 8.4 Staff must ensure families are welcome and enabled to spend time with the dying person to the extent that they and the dying person wish.
- 8.5 Family members who wish to participate in caring for the dying person must be supported by staff to do so, e.g. by showing them simple practical techniques. Where the person’s family or those identified as important to them are involved in the care of the dying person, their observations and judgements must be taken into account as part of the ongoing discussion and planning of care.
- 8.6 Staff must offer information and explanations to the dying person’s family and those important to them, including carers, to prepare them for what happens when a person is close to death.
- 8.7 When a person is imminently dying, the responsible nurse or other healthcare professional must check with the dying person’s family and those important to them about how they would best wish to be supported.
- 8.8 Pastoral support is available from the Hospital Chaplaincy Team who will also contact other faith leaders as required. Staff should be proactive in asking whether a Chaplain is needed either in a supportive role or for specific religious observances and refer appropriately.
- 8.9 When a person has died, the wellbeing of the bereaved family and carers must be considered, and staff must ensure adequate support is available for their immediate needs. If appropriate, they could be referred to the Mid Essex Adult Bereavement Service (MABS) for support in the future.

9.0 “PLAN and DO”

- 9.1 A plan for care and treatment must be developed to meet the dying person’s own needs and wishes in relation to how their care should be managed and any treatment preferences they may want to express. The extent to which the dying person wishes to be involved in developing a plan of care must be respected; and their wishes about who else to involve in these discussions .
- 9.2 This plan of care must be documented the Individual Plan of Care in the Last days of Life document so that consistent information about the person’s needs and wishes is shared with those involved in the person’s care and available at the time this information is needed. It must be regularly reviewed.

- 9.3 It should include assessment for common end of life symptoms as well as an on-going review of the dying person's physical (including but not limited to nutrition and hydration), emotional, psychological, social, spiritual, cultural and religious needs.
- 9.4 All assessments must be conducted with respect for personal privacy and dignity. The frequency of review and how the person's comfort is monitored, including the use of assessment tools, must be individualised and agreed with the person .
- 9.5 The person must be supported to eat and drink as long as they wish to do so and their comfort and dignity prioritised.
- 9.6 If the dying person is unable to swallow, decisions about clinically assisted hydration and nutrition must be in line with the General Medical Council 2010 guidance. Treatment and care towards the end of life: good practice in decision-making and relevant clinical guidelines.
- 9.7 All medications, including anticipatory medicines, must be targeted at specific symptoms, have a clinical rationale for the starting dose, be regularly reviewed, and adjusted as needed for effect. The reason for any intervention, including the use of a syringe driver, must be explained to the dying person and to those important to the dying person (this should be done before it is used unless there are exceptional circumstances) Likely side effects of specific interventions (particularly sedation) should be discussed.
- 9.8 There must be prompt referral to, and input from, specialist palliative care for any patient and situation that requires this.
- 9.9 Psychological support can be provided within the multi-disciplinary team, additional support can be provided by qualified counsellors / psychotherapists to people who are dying and those important to them if required.
- 9.10 It is important at all times to respond to the spiritual, cultural and religious needs of the dying person and those important to them. All staff involved must find out from the dying person, their family and those important to them, the details of any cultural or religious-specific requirements, including what constitutes respectful treatment of the body after death.
- 9.11 Patients should be informed that the chaplaincy team are available and that representatives of most faiths can attend if required. The chaplaincy team can also offer non-religious based support.

10.0 Organ and Tissue Donation

- 10.1 When it is certain that a person will die staff may wish to consider, where appropriate, issues relating to the donation of organs or tissue for use in transplantation, therapy, education or research. Access to a range of information will be needed by the dying person and families/those important to them before making a decision .Close liaison across a number of disciplines may be necessary, e.g. with organ transplant coordinators.
- 10.2 It may be appropriate to discuss the possibility of organ donation with the dying person, their family. When appropriate it is important to involve the Transplant Co-

ordinator (24 hour telephone number 07659 117499) or Tissue Services Co-ordinator (0800 432 0559) at the earliest possible stage. This is especially significant when there is evidence that the dying person wishes this e.g. by carrying a donor card. Staff should document all wishes carefully and ensure that requests are followed as long as they are appropriate and within the law.

- 10.3 A member of the medical team or the senior nurse on duty must initiate any request for tissue or organs at the time with the transplant or tissue services co-ordinator. Any discussion should take place in complete privacy.
- 10.4 Formal, informed consent is needed for the donation of organs or tissue. Where donation is for transplantation, formal consent could come either from the potential donor (e.g. from a living will or through being on the Organ Donor Register) or from a person in a 'qualifying relationship' as stated in Section 27 of the Human Tissue Act 2004. Please see the Trust Organ Donation guidelines.
- 10.5 Good communication will be essential and special training for staff may be required in order to manage these situations well.

11.0 Care of the Dying Person in Unexpected Circumstances (e.g. after an accident)

- 11.1 Families/those important to the dying person should be instructed via the telephone where to go and who to ask for on arrival at the hospital.
- 11.2 They should preferably not be informed prior to their arrival at the hospital if the person has died. This is to ensure that they receive appropriate care when the news is broken to them. However, if they have a great distance to travel that information should be given. This situation should be managed as follows:
 - If at all possible they should be met on arrival and taken to an appropriate environment to ensure privacy and comfort
 - Families/those important to the dying person should be kept up to date with their loved one's condition as regularly as possible particularly if there are any changes
 - They should be accompanied by a senior nurse who will explain procedures to them
 - It may be necessary to discuss issues around regarding resuscitation
 - Discussion regarding Tissue and Organ donation if appropriate
 - Great sensitivity should be used when informing the family of their loved one's death
 - Avoid ambiguous language
 - The families/ those important to the dying person should be informed of the Chaplaincy service and that the Chaplains can contact an appropriate faith representative
 - Give them the opportunity to spend as long as they want to with the deceased person with as much privacy as possible
- 11.3 Any non-essential equipment should be removed from the body to allow the deceased to be as visibly normal as possible, but if the Coroner's Officer is likely to be involved, only the endotracheal tube should be removed. All other lines should remain in situ, until such time as the death has been deemed not to be a Coroner's case, or until it has been confirmed by the Coroner that a Post Mortem is not being

performed. If in doubt, staff are advised to contact the Coroner's Officer for advice. When family have finished spending time with the deceased arrange for transportation of the deceased to the mortuary.

- 11.4 If the family is not present, consider the need to involve the Police to inform relatives and ask them to attend the relevant clinical area.
- 11.5 Complete relevant paperwork in accordance with Trust policy, including informing the coroner of the death.
- 11.6 In the event of sudden and traumatic death, care should be taken that medical / nursing staff are available to provide support and answer questions for the deceased's relatives. This can happen alongside other ongoing support.
- 11.7 Ensure the deceased's property and valuables are given to family or stored safely in accordance with Trust policy.
- 11.8 Provide family with all the relevant information e.g. Bereavement Booklet, explaining information to them verbally including discussing possible need for autopsy, role of the police / coroner / coroner's officer in all sudden death, death certification etc.
- 11.9 Appropriate documentation must be completed with regard to who has been informed and what has been said. This is especially important if there is no next of kin or best contact recorded and for example; the key to the patient's home is held by a neighbour.
- 11.10 Staff should have the opportunity to de-brief before going off duty.

12.0 Handling and Care of the Deceased

- 12.1 The Trust recognises that 'Good end of life care does not stop at the point of death'. When a person dies, all staff need to be familiar with good practice for the care and viewing of the body and be responsive to carer and family wishes and cultural or religious and spiritual needs'.
- 12.2 To ensure that the deceased are cared for safely, staff must comply with 11040 Infection Prevention: Care of the Deceased Policy.
- 12.3 Everyone involved in the care of / contact with a body, at whatever stage and in whatever way, should respect the dignity and confidentiality of the person who has died and ensure that the body is secure at all times.
- 12.4 For advice and guidance regarding minority faiths contact the On-Call Hospital Chaplain via Switchboard or access the information pack from GICU.

13.0 Medical Records and Death Certification

- 13.1 When a person dies, a doctor is required to examine the body to certify the death.
- 13.2 The notes of the deceased person are delivered by the porter to the bereavement office en route to the mortuary with the body. The bereavement officer will then contact a doctor who has been involved in the care of the deceased to come and complete the medical certificate of cause of death. The deceased person's notes are independently scrutinised by the Medical Examiner (a doctor who is not involved in

the person's care). The Medical Examiner and doctor issuing the certificate must both agree on the cause of death. Once the death certificate is issued the next of kin can then register the death formally and begin to organise the funeral.

13.3 Before a body can be cremated, however, the Cremation Acts of 1902 and 1952 require that two doctors complete a certificate to establish beyond any doubt the deceased's identity and that the cause of death is not suspicious in any way. It is important to establish the identity and confirm that there were no suspicious circumstances surrounding the death.

13.4 The doctors are also required to confirm the absence of any hazardous implantable device such as a cardiac pacemaker or implantable defibrillator in the body since these devices can explode causing damage to the cremator.

14.0 Preparation of the Body

14.1 Firstly, refer to Infection Prevention: Care of the Deceased Policy.

14.2 Care after death (last offices) must be carried out with the utmost care and dignity. The eyes and the mouth of the deceased should, where possible, be closed during last offices.

14.3 Whilst it is normally the responsibility of nursing staff to carry out care after death, it is recognised that in some instances relatives may wish to assist in some appropriate manner. Such involvement may be significant in the journey through bereavement. Every care must be taken to ensure that religious and cultural practices appropriate to the patient or relatives are observed.

14.4 It must be noted if rings or other pieces of jewellery should remain on the deceased person at the express wish of their next of kin. Rings in particular may be difficult to remove later. This information must be noted in the medical records. All removed jewellery and property must be managed in accordance with the 07003 Patients Valuables Policy.

14.5 It is usual practice to replace the deceased's dentures if possible during care after death.

14.6 No unauthorised person should have access to the body

15.0 Information for Families/those Important to the Dying Person

15.1 All wards and departments should have the Trust bereavement booklet. Ward staff need to provide emotional support for the bereaved as well as practical information giving simple instructions of what they need to do next e.g. death certificates, property and advice about funeral arrangements.

15.2 If the death has been sudden or suspicious the Coroner will need to be informed. (In some circumstances it may be necessary to leave equipment e.g. drips and tubes in place until permission is given to remove them). If in doubt, staff are advised to contact the Coroner's Officer for advice.

15.3 After the immediate care and support of bereaved relatives, ward staff will need to provide the contact details of the Bereavement Office to the relatives and advise they must call to make an appointment.

- 15.4 If the family live some distance from the hospital they should be given any travel details necessary to reach the hospital, to visit the ward where their loved one was a patient and how to reach the Bereavement Office.
- 15.5 Families must be made aware that the mortuary is a clinical area, not a chapel of rest and unless there is a good reason for viewing the deceased in the Mortuary, they should be advised to wait until the body has been removed to the funeral director.

16.0 Removal from the Ward

- 16.1 Firstly, refer to 'Infection prevention: care of the deceased policy'; register number 11040.
- 16.2 The senior nurse on duty will request the porters to remove the body to the mortuary. after the relatives have left, and last offices completed
- 16.3 The bodies of people who are either known or suspected of having an infectious disease or condition at the time of death must be managed in accordance with 'Infection prevention: care of the deceased policy'; register number 11040. The procedure for people who have died from Creutzfeldt Jacob Disease is set out in the 'Jacob Disease or Variant Creutzfeldt Jacob Disease'; register number 04078.
- 16.4 The bodies of the deceased that continue to discharge any bodily fluids should be placed in a body bag. When this is the case the funeral director should be informed as to the reason why a body bag is required.
- 16.5 The body shall be removed to the mortuary by the porters using concealment trolley with the body wrapped in a dignified way and covered in such a way that the body is completely concealed, using a pre-planned direct and discreet route whereas few members of the public as possible see the transfer.
- 16.6 All hospital inpatients must have two identification wrist bands in place or the ankle may be used if the wrist is not practical or ankle bands in place if wrist not practical. Each band must include full name, date of birth, NHS or hospital number
- 16.7 The patient can remain on the ward for a maximum of 4 hours after death before having to be moved to the mortuary.

17.0 Role of the Porters

- 17.1 The portering services in Mid-Essex play a crucial role in the bereavement service given by the Trust. In view of the nature of their work they must undergo formal training for their role provided by the Senior Anatomical Pathology Technician (APT).
- 17.2 On being contacted by the ward the porters will:
- Collect the body of the deceased from the wards using a concealment trolley and take it to the mortuary via a pre-planned direct and discreet route.
 - On arrival at the mortuary, carefully transfer the body from the concealment trolley onto a tray in the refrigerator, before completing the porters' booking in form, which enables an APT to register the deceased into the mortuary. Portering staff do not access or complete the mortuary register themselves.

17.3 Porters will not make arrangements for viewings or the release of bodies to undertakers, which are tasks for APTs alone.

18.0 The Mortuary

- 18.1 Bodies must be kept in the best possible condition and protected from interference, accidental damage or avoidable deterioration.
- 18.2 All bodies, organs and other human tissue must be tracked from arrival in the mortuary to release using the mortuary register and electronic database.
- 18.3 The Trust's mortuary services documentation procedures are described in the Cellular Pathology standard operating procedures and pathology quality manual, contained within the Q-Pulse document management system.
- 18.4 In order to maintain the high standards of practice a regular review and audit of the service should take place to identify areas of improvement and to make any necessary changes. Records of audit activity and outcomes are recorded in the Cellular Pathology Q-Pulse system.
- 18.5 The mortuary should have a safe, clean and tidy environment where both staff and users feel at ease. Signage should be clear, and if necessary include any non-English languages commonly used in the area the Trust serves. Step-free access is available for visitors.
- 18.6 When additional storage is required on site it should be secure, kept close to the mortuary and out of sight of the public when possible.
- 18.7 The mortuary should have in place a system to ensure that any personal possessions on the body are kept securely or released to an appropriate person.

Viewing the Body in the Mortuary

- 18.8 Relatives of the deceased may wish to view or have some final contact with the body. Such viewing and possible superficial contact, such as touching or kissing, is best facilitated either in the ward environment or after transfer to the undertaker .
- 18.9 Viewing in the mortuary can be undertaken in the dedicated viewing room but relatives must be reminded that the mortuary is a clinical area, not a Chapel of Rest and that the viewing may be best left until after the transfer to the undertaker.
- 18.10 If a death has been referred to the Coroner the body is under his/her jurisdiction, and viewing may be restricted. Viewing may also be restricted if the death is the subject of a police investigation.
- 18.11 Viewings are generally discouraged after a post mortem examination has been carried out as bodies can deteriorate quicker and represent an infection risk after these procedures. If relatives do wish to view, body bags may be rolled down temporarily to allow superficial contact. There is no need to deny the relatives this opportunity if a post-mortem has been performed, however it may be appropriate for the APT on duty to prepare the family if the body is in a poor condition and if necessary advise against viewing
- 18.12 Viewings may be arranged by contacting the on call APT via the hospital switchboard

The Release of the Body

18.13 The body can only be released by a qualified APT. Before this happens, the mortuary staff must ensure that all necessary documentation has been completed, and that identity has been confirmed both by mortuary staff and the person to whom the body has been released i.e. a member of the family or their representative, most often the funeral director.

19.0 Property of the Deceased

19.1 Staff must refer to the 07003 Patients Valuables Policy

19.2 The official inventory form recording the deceased's personal possessions must be kept with their medical record. Possessions should be removed to the Bereavement Officer's office by the ward clerk or their deputy at the earliest opportunity

19.3 All wards and departments must use the mortuary property form which will be brought to the ward by the porters collecting the deceased. This is to be witnessed by two nurses involved with the family, if any property belonging to the deceased is taken away in an appropriate container or one provided by the family. This may be removed from the ward by the family or from the Bereavement Officer's office the next working day.

19.4 Specials bags should always be used for the return of property, ensuring that anything damp should not be in the same bag as anything dry. Black dustbin liners must not be used.

19.5 Soiled clothing should be disposed of by the Trust rather than returning it to the next of kin.

19.6 If any clothing is left with the Trust it should be stored for a period of time e.g. 1 month, in case the relatives decide to reclaim it. After which the Trust may make use of the clothing or dispose of it as appropriate

19.7 Any spectacles belonging to the deceased will be kept with any other valuables. If the family do not claim spectacles owned by the deceased, these will, in due course, be forwarded to a charity.

19.8 Toiletries and partially eaten food e.g. fruit or confectionary, that has not be removed from the ward by relatives will be disposed of by the Trust.

20.0 Dealing with the Bereaved – Role of the Bereavement Officer

20.1 It is the role of the Bereavement officers to deal with the practical aspects of dying.

20.2 There is a quiet room where the Bereavement Officer may talk privately and confidentially about the next steps.

20.3 The officer will:

- Ensure the medical certificate is completed
- Explain the forms and process that releases bodies for cremation
- Contact the mortuary to arrange for body viewing
- Give information about local undertakers

- Advise about registering the death
- Organise the proper return of deceased patients' property in accordance with the Trust's Standing Financial Instructions
- Give all families Social Security Booklet D49 'What to do after a death in England and Wales'
- Inform the GP about the death if this has not already been done
- Liaise with Coroner's Officers both locally and in other areas in cases of sudden or suspicious death. (In these cases The Coroners take over most of the above duties)
- Seek to make the Cremation Certificate available to the funeral director the next working day with the exception of weekends and Bank Holidays.
- Use accessible formats where appropriate

20.4 There is a process that the Bereavement Officer follows in cases where a patient dies and there are no Best Contact or Next of Kin details recorded on IT Lorenzo.

21.0 Staff Training and Support

21.1 All staff who have contact with dying people must have the skills to do this effectively and compassionately. This includes clinical and support staff (e.g. porters, reception staff and ward clerks). The Trust will require and enable staff to acquire and maintain the necessary competences for delivering the Priorities for Care of the dying person, commensurate with the individual's role and responsibility in line with the Trust's Mandatory Training Policy and Training Needs Analysis.

21.2 Many of the competencies that are needed to deliver effective care for people in the last few days and hours of life are generic. However there needs to be specific attention to the topics of nutrition and hydration, symptom management and communication skills..

21.3 The Trust will ensure that staff have access to locally agreed advice for palliative and end of life care based on current best available evidence. This would include the availability of trust-wide clinical provisions and protocols promoting patient comfort, dignity and privacy, up to and including the death of the patient

21.4 The Trust will also ensure access to an adequately resourced specialist palliative care workforce to provide leadership, education and training, including for pre-qualifying education and support to non-specialist front-line health and care workers.

21.5 The Trust will provide mentorship, support and direct involvement from senior clinical staff in recognising when dying is likely in the next few days or hours. This would be in the form of assessing reversibility, communicating uncertainty and making appropriate decisions in line with the dying person's needs and preferences.

21.6 It will also be essential to ensure that staff know:

- When to offer the services of an interpreter for dying people and their families who may not have English as their first language, (or other forms of communication support, such as signing) and ensure that such services are readily accessible.
- How to find out about the specific needs of dying people, and those important to them, who have disability or impairments, and ensure that they can obtain any necessary aids, equipment or expert help as quickly as possible.

- About the role of advocates as an independent voice (formal and informal), including when this is required under the Mental capacity act.

21.7 All medical and nursing staff need to ensure that their knowledge, competencies and skills are up to date and in line with their roles and responsibilities. On-going discussion as necessary will take place at all relevant operational and directorate meetings.

21.8 It is important to recognise that conversations about dying and death are difficult and staff need support, and time and opportunity for reflection, if they are to continue to have resilience to do this in an effective and compassionate manner.

21.9 All staff, and the Trust have a responsibility to contribute to and learn from, audit and evaluation that is necessary to continually improve the quality of the dying.

21.10 In certain circumstances they may need the opportunity to have:

- A debriefing session
- Receive counselling or to speak with someone not associated with the ward (e.g. member of the Hospital Specialist Palliative Care Team) .
Staff should be aware that booked counselling sessions are available to staff from the Occupational Health Service

22.0 Audit and Monitoring

22.1 Where failure to follow this guidance compromises patient care, incidents of clinical risk will be reported via the central risk events database (Datix system). Patient/family concerns or complaints are reported through PALS. Both components will be reviewed at Directorate and operational team level and quarterly by the End of Life Steering Group to ensure thematic analysis and Trust wide learning.

22.2 Any identified problems which cannot be solved by the End of Life Steering Group will be escalated to the Trust's Clinical Governance Group.

22.3 The Mortality Review Group, which provides oversight and co-ordination of mortality review activity across the Trust, will ensure that an assessment of appropriate standards of care forms part of the standardised review process for in hospital deaths.

22.4 The Trust should undertake a local audit of care of the dying, including the assessment of the views of bereaved relatives, at least annually. These audits will be led by the End of Life Steering Group with support from the Clinical Audit department and reported to the Patient Safety and Quality Committee via the Clinical Governance Group.

22.5 The Trust will have a formal process for discussing and reporting on care of the dying at least annually.

23.0 Communication and Implementation

23.1 Corporate services will ensure that the guideline is uploaded to the intranet and the website and notified to staff via Focus.

- 23.2 All link nurses will be informed of updated guidelines at regular meetings for them to disseminate to their areas/wards.
- 23.3 Medical staff will be informed of revised guidelines via senior medical staff within the Hospital Specialist Palliative Care team at departmental meetings and the regular teaching sessions for all trainee doctors.

24.0 References

Leadership Alliance for the Care of Dying People .One Chance to get it Right, Improving people's experience of care in the last few days and hours of life.: June 2014

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'Care and Respect in Death – Good Practice Guidance for NHS Mortuary Staff' (DoH August 2006

Human Tissue Authority (2005) When A Patient Dies DoH October

Social Security Booklet D49 'What to do after a death in England and Wales'
'The care and support provided immediately after death are crucial to the success of the bereavement process and should be sensitive, practical and evidence-based.'
Hannah Kent BN(Hons), Joan McDowell RN, RNT, SCM, DN, MN, Dip N , Sudden bereavement in acute care settings, Nursing Standard 19,6,38-42)

Appendix 1

GUIDANCE FOR CARE IN THE LAST DAYS OF LIFE

The approach to care must be based on the Priorities for Care of the Dying person defined by the Leadership Alliance for the Care Of Dying People. The Priorities for Care are that, when it is thought that a person may die within the next few days or hours:

1. This possibility is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.
 2. Sensitive communication takes place between staff and the dying person, and those identified as important to them.
 3. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
 4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
 5. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.
- There should be a focus on recognition of patients who are clinically unstable and may not recover despite medical treatment, on changes in the condition of someone who is likely to be dying, rather than focusing on a 'diagnosis of dying'. It is important to acknowledge, accept and communicate uncertainty that exists about the prognosis.
 - **Recognition of dying** is based on:
 1. **Knowledge of patient**
 - In depth knowledge of disease & stage of illness
 - Treatment history and response
 - Further options / ceiling of care
 2. **Background of general deterioration:**
 - Gaunt physical appearance, progressive weakness, essentially bed bound
 - Disinterest in food / fluids, poor oral intake, difficulty in swallowing
 - Increasing drowsiness, reduced level of consciousness, disorientation, agitation
 - Increasingly laboured or noisy breathing
 - The decision to initiate an individual plan of care should be taken by the multidisciplinary team led by the senior clinician and must be discussed and agreed with the dying person if possible and those identified as important to them.
 - The person must be regularly reviewed, the frequency and how the person's comfort is monitored, must be individualised.
 - A senior clinical review of the care plan should take place at least daily to check that the plan of care remains appropriate and to respond to changes in the person's condition, needs and preferences.
 - Anticipatory medication guidance is available on the intranet to ensure that medication is prescribed and available on an as required (PRN) basis for symptoms that commonly arise in the last days of life.