

Dignity in Care at the End of Life Policy

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Community Health Services	

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1. Introduction

1.1 East London NHS Foundation Trust (The Trust) recognises the need to support standards and a programme of education for all staff to deliver high quality, compassionate care to service users who have an advanced life limiting illness in the community or in hospital and provide support to their carers.

1.2 This guidance is underpinned by the national DoH (2009) End of Life Care Strategy: Quality Measures for End of Life Care, NICE (2011) End of Life Care for Adults Quality Standards, NICE (2017) Care of Adults in the Last Days of Life (Quality Standard) and NICE (2019) End of Life Care for Adults: Service Delivery.

It is also supported by Hospice UK (2015) Care after Death: Guidance for staff; NICE (2018) Dementia: assessment, management and support for people living with dementia and their carers; and NICE (2018) Care and support for people growing older with learning disabilities.

The target audience for the policy is all staff working with adults in East London NHS Foundation Trust. Staff caring for young people should refer to separate guidance.

1.3 The tools to support this policy include:

1.3.1 The Gold Standards Framework (GSF) which:

- Identifies patients in the last year of life
- Assesses their care needs and preferences
- Develops a proactive plan of care

Further information about the GSF can be found on the Gold Standards Framework website.

1.3.2 The five priorities of care for the dying person set out in: One Chance to Get it Right:

- Recognise
- Communicate
- Involve
- Support
- Plan & Do

1.3.3 Supportive & Palliative Care Indicators Tool (SPICT)

2.0 Purpose of the Guidance

2.1 To give staff the confidence to recognise that a patient or service user individual is entering the last year of life and to begin to plan their care accordingly.

2.2 To support staff to work with the wider integrated team to have conversations with patients who may be in the last year of life and to enable advance care planning.

2.3 To enable teams to work in partnership with specialist palliative care teams and other teams supporting patients at the end of life.

2.4 To support staff to develop person centred holistic care plans that ensure that symptoms are as controlled as possible and that consider the physical, psychological, spiritual, social and cultural end of life care needs of the patient.

2.5 To support patient choice at the end of life, including supporting patients to choose their preferred place to die as far as is reasonably possible.

2.6 To ensure that patients are treated with dignity and respect at the end of life.

- 2.7 To ensure that family, carers and others who are important to patients are supported, appropriately informed, enabled and empowered throughout the end of life of their relative or friend.
- 2.8 To improve staff confidence, communication and partnership working through the provision of standards of practice and education.

3 Consent

- 3.1 Patients have a fundamental legal and ethical right to determine what happens to them. The practice of seeking consent is further endorsed by the requirements of the Human Rights Act 1998.
- 3.2 The Trust's Consent to Treatment Policy sets out standards and procedures that define consent as a patient's agreement for a health professional to provide care.
- 3.3 Consent may be indicated non-verbally, orally or in writing for consent to be valid. It is essential that all healthcare professionals clearly document patient consent to interventions.

4 Capacity

- 4.1 The Trust has a duty to support people with impaired mental capacity so that they can make their own decisions about health and social care that they receive. People needing such support might include people with severe and enduring mental illness, people with dementia, people with learning disabilities and people at the end of a terminal condition.
- 4.2 Where an adult patient lacks the mental capacity (temporarily or permanently) to give or withhold consent for himself/ herself, no one else can give consent on their behalf unless there is an identified 'Lasting Power of Attorney' in relation to health matters as well as financial matters.
- 4.3 Treatment may be given if it is in the patients' best interests as long as it has not been refused in a valid and applicable Advance Decision to Refuse Treatment (ADRT), as stipulated in the Mental Capacity Act (2005) Code of Practice. In determining best interests, any Advance Statements the patient has made (verbal or written) should be taken into account during the decision making process. This must be clearly documented in the patient's notes.

5 Identifying people approaching the end of life and other people who are important to them

- 5.1 In line with NICE guidelines and to enable advance care planning, teams should aim to identify patients who might be at risk of dying within the next 12 months. Patients or service users may be identified as likely to be in the last year of their life by any health care professional involved in their care.
- 5.2 Tools available to identify people who may be approaching the end of their lives include the Supportive & Palliative Care Indicators Tool (SPICT) [Appendix 1] and the Gold Standards Framework (GSF) Prognostic Indicator Guidance [Appendix 2].
- 5.3 Teams should also aim to identify carers and other people who are important to patients or service users who may be approaching the end of their lives. This may include children, partners, friends and other family members.

6. Co-ordination of Care

- 6.1 In line with NICE guidelines palliative care registers should be used to support end of life planning in accordance with a person's wishes. Patients identified as likely to be approaching the end of their lives should be added to the local palliative care register, as per local procedure.
- 6.2 Patients approaching the end of life should be allocated a Care Co-ordinator who will take a lead role in liaising with the wider integrated care / multi-disciplinary team to promote effective communication and an integrated approach to care planning.
- 6.3 Within community settings, regular multi-disciplinary team meetings should be held between the Specialist Palliative Care Nurse and District Nurses to co-ordinate the care of patients with end of life care needs. The Care Co-ordinator (named nurse) and / or Palliative Care Nurse should also attend the monthly GP MDT meeting to provide an update and to share discussions around Advance Care Planning.

7 Advance Care Planning

- 7.1 Advance Care Planning is the process of discussing and planning ahead in anticipation of some deterioration in a patient's condition and is important for ensuring patient-focused care at the end of life. It might include how and where the patient would like to be looked after, spiritual and religious beliefs and practical matters. It may also include preferred place of care and place of death.
- 7.2 Where the person approaching the end of life agrees, carers and other people who are important to them should be offered the chance to be involved in discussions around advance care planning.
- 7.3 Wishes around advance care planning should be documented as per local protocol and shared with the wider integrated care team. In community settings discussions around advance care planning should be documented in Co-ordinate My Care (CMC) records where these exist and in emergency treatment plans such as ReSPECT or PACT.
- 7.4 For advice on advance care planning for people with dementia, the NICE guidelines (2018) Dementia: Assessment, Management and Support for people living with Dementia and their Carers should be referred to.
- 7.5 For advice on advance care planning for adults with learning disabilities, the NICE guidelines (2018) Care and Support of people growing older with Learning Disabilities should be consulted.
- 7.6 Advance care planning may also involve setting up Lasting Power of Attorney, whereby someone appoints another person to make decisions about their health and care in the event that they lose their mental capacity in future. Lasting Power of Attorney must be registered with the Court of Protection and there must be valid documentation to show this.
- 7.7 Advance Decision involves clarifying any specific treatments that people may *not* want to receive in future. For example someone may make an advance decision to refuse to be ventilated or to have other life sustaining treatment. In order to be valid an advance decision may only be made by someone who has mental capacity. Advance decisions are legally binding and must be followed by healthcare professionals. They are sometimes also known as "living wills".

8. Patients Making a Will

- 8.1 Patients wishing to make a will in community settings should be supported to do so, by referring on to local support services such as Age UK. If patients express a wish to make or alter a will whilst in in-patient settings, the team should seek advice from the Trust's Mental Health Department.
- 8.2 For inpatient settings, the Responsible Clinician (RC) in charge of the patient's medical care should sign and date in the patient's records that the patient is capable of making a will (has mental capacity) and comment about the patient's mental state and where there are any doubts about the patient's ability to write a valid will.
- 8.3 Health care staff including non-clinical staff involved with a patient cannot act as witnesses for the signing of the will. Staff should be aware of the vulnerability of patients to pressure from those who might have an interest in the will.

9 Resuscitation

- 9.1 Following a multidisciplinary team assessment that a patient has an advanced life limiting illness, a discussion with the patient and/or their carer should be offered regarding Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) status. This should be carried out with the utmost sensitivity and it should be noted that some patients may not wish to discuss this.
- 9.2 In community settings the GP should be involved in the discussion around DNACPR status and asked to complete a DNACPR form, an original copy of which should be kept in the patient's home. DNACPR status should be added to the patient's electronic care record and shared with other services as per local protocols. Where the patient has a CMC record, DNACPR status should be added to the record.
- 9.3 Unless a family has a lasting power of attorney, family members have no legal right to make the decision. The decision has to be made in the best interests of the patient; however, it is good practice to listen to family views.
- 9.4 Where no decision has been made or recorded in advance, the Trust will expect staff to attempt cardiopulmonary resuscitation. However in certain circumstances where there is no recorded decision (for example if a patient has features of irreversible death such as rigor mortis), a decision not to start CPR should be supported.
- 9.5 Decisions about resuscitation should be reviewed if there is a substantial change in the patient's clinical condition or prognosis; if there is a request from the patient or those close to them if they have lasting power of attorney; or if the patient is transferred to a different location. Where a patient has previously been informed of a decision and it subsequently changes, they should be informed of the change of decision and the reason for it.

10. Identifying that someone is in the Last Days of Life

- 10.1 In addition to identifying patients who may be approaching the end of life to enable advance care planning, teams should also aim to identify when someone may be entering the last days of their life and may die in the next few days or hours [Appendix 3 – Priorities of Care for the Dying Person]. This may not always be easy, however advice can be sought from the specialist palliative care team / palliative care nurses. Reversible causes such as opioid toxicity should be ruled out.
- 10.2 Signs & symptoms that could indicate that someone is in the last days of their life include:
- progressive weight loss, deterioration in consciousness, noisy respiratory secretions, mottled skin, agitation
 - increased fatigue, reduced desire for food & fluid, deterioration in swallow
 - deteriorating mobility & social withdrawal
- 10.3 Where it is felt that someone is in the last days of life, this should be discussed with the integrated team

11 Communication with Patients at the end of life and their Carers

- 11.1 Where it is felt that someone may be in the last days of life, a discussion should be held with the patient and their carer and / or those who are important to them explaining the potential for dying and the rationale for this. The team should decide who may be best placed to have this discussion.
- 11.2 A person-centred, holistic care plan should be discussed with both the patient and those who are important to them. Patients should be offered the chance to be involved in all aspects of their care including their preferred place of care and place of death.
- 11.3 In order to support patients to participate in the decision making at end of life, information should be provided taking into account their communication needs and preferences.
- 11.4 Communication should be sensitive and appropriate to individual circumstances and preferences. Information may be offered including what to expect, medications including anticipatory prescribing, practical support available and care options. The patient and those who are important to them should also be offered a chance to ask questions and share concerns.
- 11.5 The contact numbers of carers and others who are important to patients should be confirmed as well as who to contact if the patient's health should deteriorate. In in-patient settings times for family or next of kin to be contacted should also be agreed and documented in the patient's records.
- 11.6 If patients are in a hospital setting, carers should be offered the opportunity to support their relatives / friends at all times if appropriate to the patient's wishes. This should be supported by professional staff and over-night facilities provided in patient areas where possible.
- 11.6 Staff must also recognise that in some instances there may be a need for signposting family members and/or liaising with primary care services e.g. children's services and children's bereavement services, e.g. CHUMS and Child Bereavement UK.

12. Person Centred Care Planning

- 12.1 A holistic needs assessment should be carried out with the person approaching the end of life and those who are important to them, in order to enable the right support to be provided.
- 12.2 Where possible in order to support co-ordination of care and to reduce duplication, the holistic needs assessment should be completed with the patient and those who are important to them by the multi-disciplinary team. A person centred care plan should then be agreed with the patient approaching the end of life and shared with all those involved in the patient's care.
- 12.3 The individualised care plan should be completed according to local protocol and may include communication, symptom control, psychological support, social support and spiritual support. The care plan may include medications, essential care such as mouth care and bowel care; symptom review; and care after death.
- 12.4 The practical and emotional support needs of carers should also be assessed. Carers should be supported to access a carer's needs assessment in line with the Care Act 2014, where applicable. Staff should also recognize that young carers and children may need additional support.
- 12.5 A Fast Track (Continuing Health Care) assessment should be also completed where appropriate in order to access urgent care support . In community settings patients and their families at the end of life should be offered support from voluntary organisations including Marie Curie.
- 12.6 Contact numbers for support services should be provided for patients and those who are important to them, including for out of hours support.
- 12.7 The personalised care plan should also include the preferred place of care.

13. Anticipatory Prescribing

- 13.1 For patients at the end of life, it is important also to consider anticipatory prescribing as part of the care plan, explaining the rationale to the patient and family clearly. Medications should be prescribed in anticipation of symptoms to enable rapid relief if a patient develops distressing symptom. This should be documented in the patient's electronic care record.
- 13.2 Medications should be prescribed based on the individual needs of the person. These should be prescribed in advance and as early as possible to avoid delay in obtaining medicines that may be needed quickly. Advice may be sought on what to prescribe from the Specialist Palliative Care team.
- 13.3 Prescriptions and authorisation charts should specify the indications for use any anticipatory medication prescribed and the dosage, starting with the lowest effective dose.
- 13.4 If patients are not able to take or tolerate oral medication, subcutaneous injections should be given.
- 13.5 Where more than 2 or 3 doses of an as required medication are given in a 24 hour period, continuous medication via a syringe pump should be considered.

14. Eating and Drinking in the Last Days of Life

- 14.1 It is common to lose interest in food in the last days of life and everyone with a terminal illness eventually stops eating and drinking. This is not usually distressing for the person who is dying however it can be very difficult for family and friends.
- 14.2 Family and friends often ask about artificial hydration for example subcutaneous fluids. For some conditions this may be an option however for other conditions at end of life there is no evidence that artificial hydration will either extend life or improve the quality of life.
- 14.2 Staff should explain to family that eating and drinking less in the last days of life is normal. Where the dying person and / or their family ask about subcutaneous fluids, this should be discussed with the multi-disciplinary team and the risks and benefits explained.

15 Transfers to another Care Setting eg Hospice

There may be instances when a patient's needs are best met in another care setting, for example in a hospice, care home or acute hospital. Decisions such as these should be made at the earliest opportunity involving the patient and their carers and / or those who are important to them wherever possible. Trust staff will support continuity of care throughout the transfer process by providing a comprehensive handover of care and treatment to the receiving care team

16 Verification and Procedure for Expected Death

- 16.1 When the patient is known to have an advanced, incurable terminal illness and there is no active intervention to prolong life, this is regarded as an expected death. An expected death is recognised as a death that was anticipated as imminent by the patient, carer and by the multidisciplinary team.
- 16.2 Verification of death refers to confirmation that life has ceased, based on a physical assessment by someone who is competent to do so. Death can only be verified by a doctor or nurse who has been trained in verification of death [Appendix 4 – Verification of Expected Death Policy]

If a patient dies at home, their family or friends should be supported to contact the deceased patient's GP, the out of hours service or a nurse able to carry out verification of death. The time the death is verified is the official time of death.

- 16.3 A registered medical practitioner who has attended a deceased person within the last 14 days prior to death is required to issue the Medical Certificate of the Cause of Death, stating the cause of death "to the best of his/her knowledge and belief".

The certificate requires the doctor to state the date on which they saw the deceased person alive and whether or not they have seen the body after death. The doctor is not obliged to view the body, but good practice requires that if they have any doubt about the fact of death, the doctor should satisfy themselves in this way

Patients identified as nearing the end of life i.e. a prognosis of weeks, should receive regular reviews from their GP to ensure that the above arrangements are met and to avoid any unnecessary delays after death.

- 16.4 Where a patient has not been seen by their GP within 14 days before their death, the death may need to be referred to the Coroner. Other circumstances where a death should be

reported to the Coroner include: the cause of death is not known, the death was sudden or unexplained, the death was violent or unnatural, or the death may have been caused by an industrial disease.

- 16.5 All deaths of patients currently being seen by the Trust must be reported using the Trust incident reporting system (DATIX).

The deaths of any mental health patients discharged from the Trust's care within the last 12 months should also be reported via DATIX. Additionally the death of any community health service patient discharged from our care within the last 6 months should also be reported.

- 16.6 For guidance on caring for a deceased person following an expected death, please refer to the Royal London Marsden Manual of Clinical Procedures (2015): Care after Death. Please see Appendix 5: Personal Care After Death for guidance on caring for a deceased person in their own home.

17. Informing Relatives when a Patient dies

- 17.1 It is also important to consider if a patient's next of kin or carer wishes to be contacted if the patient is noted to be deteriorating and to document this in the record as soon as possible. This is important in both hospital settings and in community settings where the patient may live alone. It should also be noted whether the carer or next of kin wishes to be contacted at night
- 17.2 In practice it is the most senior nurse on duty who will contact relatives to inform them of any deterioration of the patient. Informing relatives of a patient's death, can be difficult and stressful for staff. Staff should receive training in the skills of breaking bad news and support as required after a patient dies.
- 17.3 In the event of the patient not having any known family or friends or that the family are unable to be with the dying patient, it is good practice for staff to contact someone able to provide spiritual support, such as the hospital chaplain or to make arrangements for a staff member to be with the patient. This would depend on the patients' preferences if known.
- 17.4 If the named next of kin or carer cannot be contacted after six hours staff should inform the police station local to the named relative. The police may be requested to call at the home and notify the next of kin/carers in person. Alternatively the police can leave a message asking the relatives to contact the hospital, home or community team.
- 17.5 If a third party is requested to contact the family, the nurse in charge must check with the third party (e.g. the police) to ensure that this communication has taken place.
- 17.6 It is noted that there will be occasions in both hospital and community settings where patients may die in sudden and unexpected ways. Staff may also be exposed to difficult and challenging deaths. In these instances it is important that staff are supported according to local protocols.

18 Patients Detained Under the Mental Health Act, Mental Capacity Act (DoLs) and Patients under the Care of the Forensic Directorate

- 18.1 If a patient is detained under the Mental Health Act (1983) at the time of death or subject to a Community Treatment Order, the Care Quality Commission (CQC) must be informed within 72 hours, as well as the relevant Trust Mental Health Act Administration Team. Details of how to report the death to the CQC are on page 10 of the Incident Policy. The Trust's local Mental Health Law office should also be notified.

- 18.2 The death of a patient at the time that they are deprived of their liberty under the Mental Capacity Act 2005, is also the subject of a coroner's investigation. This means that the person is considered to be 'in state detention' at the time of death if subject to a deprivation authorisation. In these circumstances, the coroner must be informed of the death as soon as possible.

Therefore all staff caring for the deceased need to ensure they are familiar with deaths that require such a referral as this will facilitate the correct personal care and enable staff to prepare the family both for the potential delay in receiving the Medical Cause of Death certificate and the possibility of a post-mortem examination. Forms are usually completed by the team responsible for the deceased's care. The Deprivation of Liberty Policy provides more detail as to the forms which are to be used.

19 Registration of Death

- 19.1 The relatives, where possible, should arrange for the death to be registered. In order to do so, the relatives will need the Medical Certificate of Cause of Death which should be issued the next working day in hospital settings and can be obtained from the patient's GP in community settings.
- 19.2 If the next of kin is unable to register the death or is unknown please refer to the local policy.

20 Bereavement Support

- 20.1 Families and carers should be supported to access bereavement support. It is recommended that bereaved people should be offered support at the time of the death. Support may also be required on a longer term basis and in some cases may begin before death.
- 20.2 Emotional and bereavement support may include:
- supportive conversations with health and social care professionals
 - practical support such as what to do with medications & equipment, help with contacting family members, advice on who to contact
 - signposting to local support services eg. City & East London Bereavement Service, Newham Bereavement Service, CRUSE and CHUMS.
 - referral for specialist support such as from local hospices.
- 20.3 In community settings a bereavement phone call and / or visit should be offered following the death of a patient.

21 Education, Development and Training

- 21.1 Staff should have access to appropriate training and education around caring for patients and service users at the end of their lives, including enabling patients to die in a place of their choice wherever possible. This should also include advanced communication skills training for core staff.
- 21.2 All staff have individual responsibility regarding their competency in the skills required to support patients with advanced life limiting illness and at end of life.
- 21.3 Team leads should ensure that this policy is disseminated to all staff and monitor its implementation.
- 21.4 Service leads must ensure that staff have access to appropriate training, and that team

leaders are aware of their responsibility for the implementation of this policy.

- 21.5 Service leads should have strategies in place to support and nurture staff so they are able to deliver compassionate care to patients at the end of their lives and those who are important to them.
- 21.6 Staff should be given time to debrief and reflect on end of life care, particularly when this has been emotionally challenging.

22 Related Documents

- Advanced Decision to Refuse Treatment Policy
- Health and Safety Policy
- Infection Control Manual
- Management of Dysphagia Policy
- Manual Handling Policy
- Mental Capacity Act (2005) Code of Practice
- Physical Healthcare Policy
- Pressure Ulcer Prevention And Management – Clinical Practice Guideline
- Safeguarding Vulnerable Adults at Risk – Policy Guidance for Trust Staff

23 References

- Department of Health (2009) End of Life Care Strategy: quality markers and measures for end of life care.
- Hospice UK (2016) Care after Death
- Leadership Alliance for the Care of Dying People (2014) How quality care for all, now and for future generations.
- NICE (2018) Care and support for people growing older with learning disabilities
- NICE (2018) Dementia: assessment, management and support for people living with dementia and their carers
- NICE (2011, updated 2017) End of Life Care for Adults: Quality Standards
- NICE (2019) End of Life Care for Adults: Service Delivery
- NICE (2004) Improving Supportive and Palliative Care for Adults with Cancer
- University of Edinburgh (2017) Supportive & Palliative Care Indicators Tool
- The Royal Marsden Manual of Clinical Procedures; Care after Death (2020) Wiley-Blackwell



Supportive and Palliative Care Indicators Tool (SPICT™)



The SPICT™ is used to help identify people whose health is deteriorating. Assess them for unmet supportive and palliative care needs. Plan care.

Look for any general indicators of poor or deteriorating health.

- Unplanned hospital admission(s).
- Performance status is poor or deteriorating, with limited reversibility. (eg. The person stays in bed or in a chair for more than half the day.)
- Depends on others for care due to increasing physical and/or mental health problems.
- The person's carer needs more help and support.
- Progressive weight loss; remains underweight; low muscle mass.
- Persistent symptoms despite optimal treatment of underlying condition(s).
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

Look for clinical indicators of one or multiple life-limiting conditions.

Cancer

Functional ability deteriorating due to progressive cancer.

Too frail for cancer treatment or treatment is for symptom control.

Dementia/ frailty

Unable to dress, walk or eat without help.

Eating and drinking less; difficulty with swallowing.

Urinary and faecal incontinence.

Not able to communicate by speaking; little social interaction.

Frequent falls; fractured femur.

Recurrent febrile episodes or infections; aspiration pneumonia.

Neurological disease

Progressive deterioration in physical and/or cognitive function despite optimal therapy.

Speech problems with increasing difficulty communicating and/or progressive difficulty with swallowing.

Recurrent aspiration pneumonia; breathless or respiratory failure.

Persistent paralysis after stroke with significant loss of function and ongoing disability.

Heart/ vascular disease

Heart failure or extensive, untreatable coronary artery disease; with breathlessness or chest pain at rest or on minimal effort.

Severe, inoperable peripheral vascular disease.

Respiratory disease

Severe, chronic lung disease; with breathlessness at rest or on minimal effort between exacerbations.

Persistent hypoxia needing long term oxygen therapy.

Has needed ventilation for respiratory failure or ventilation is contraindicated.

Other conditions

Deteriorating and at risk of dying with other conditions or complications that are not reversible; any treatment available will have a poor outcome.

Kidney disease

Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.

Kidney failure complicating other life limiting conditions or treatments.

Stopping or not starting dialysis.

Liver disease

Cirrhosis with one or more complications in the past year:

- diuretic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

Liver transplant is not possible.

Review current care and care planning.

- Review current treatment and medication to ensure the person receives optimal care; minimise polypharmacy.
- Consider referral for specialist assessment if symptoms or problems are complex and difficult to manage.
- Agree a current and future care plan with the person and their family. Support family carers.
- Plan ahead early if loss of decision-making capacity is likely.
- Record, communicate and coordinate the care plan.

Please register on the SPICT website (www.spict.org.uk) for information and updates.

SPICT™, April 2019

The GSF Prognostic Indicator Guidance

The National GSF Centre's guidance for clinicians to support earlier recognition of patients nearing the end of life

Why is it important to identify people nearing the end of life?

'Earlier identification of people nearing the end of their life and inclusion on the register leads to earlier planning and better co-ordinated care'

(GSF National Primary Care Snapshot Audit 2010)

About 1% of the population die each year. Although some deaths are unexpected, many more in fact can be predicted. This is inherently difficult, but if we were better able to predict people in the final year of life, whatever their diagnosis, and include them on a register, there is good evidence that they are more likely to receive well-co-ordinated, high quality care.

This updated fourth edition of the GSF Prognostic Indicator Guidance, supported by the RCGP, aims to help GPs, clinicians and other professionals in earlier identification of those adult patients nearing the end of their life who may need additional support. Once identified, they can be placed on a register such as the GP's QOF / GSF palliative care, hospital flagging system or locality register. This in turn can trigger specific support, such as clarifying their particular needs, offering advance care planning discussions, prevention of crises, admissions and pro-active support to ensure they 'live well until they die'.

Predicting needs rather than exact prognostication.

This is more about meeting needs than giving defined timescales. The focus is on anticipating patients' likely needs so that the right care can be provided at the right time. This is more important than working out the exact time remaining and leads to better proactive care in alignment with preferences.

Definition of End of Life Care General Medical Council, UK 2010

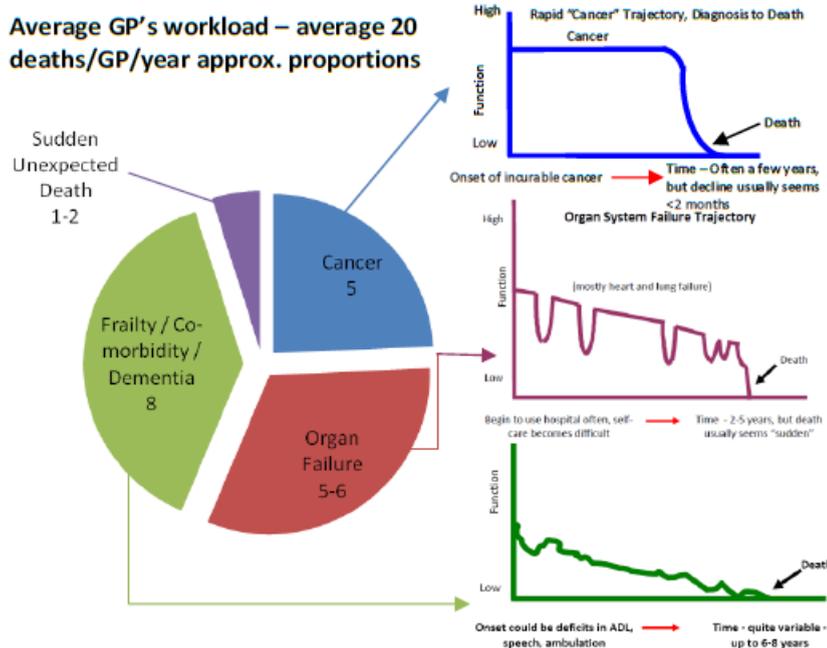
People are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

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

Three triggers that suggest that patients are nearing the end of life are:

1. The Surprise Question: 'Would you be surprised if this patient were to die in the next few months, weeks, days?'
2. General indicators of decline - deterioration, increasing need or choice for no further active care.
3. Specific clinical indicators related to certain conditions.

Average GP's workload – average 20 deaths/GP/year approx. proportions



Typical Case Histories



1) Mrs A - A 69 year old woman with cancer of the lung and known liver secondaries, with increasing breathlessness, fatigue and decreasing mobility. Concern about other metastases. Likely rapid decline

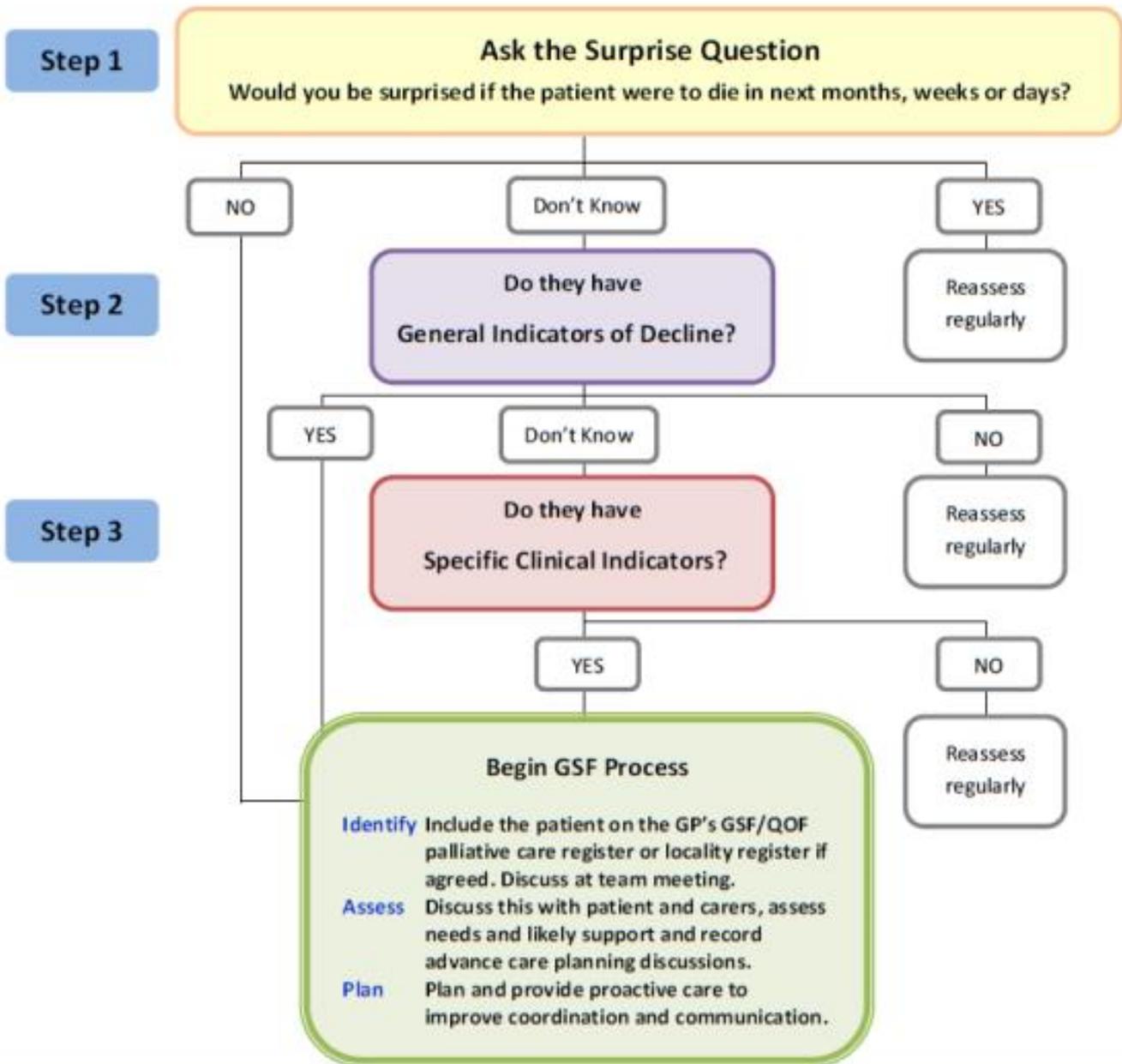


2) Mr B - An 84 year old man with heart failure and increasing breathlessness who finds activity increasingly difficult. He had 2 recent crisis hospital admissions and is worried about further admissions and coping alone in future. Decreasing recovery and likely erratic decline



3) Mrs C - A 91 year old lady with COPD, heart failure, osteoarthritis, and increasing signs of dementia, who lives in a care home. Following a fall, she grows less active, eats less, becomes easily confused and has repeated infections. She appears to be 'skating on thin ice'. Difficult to predict but likely slow decline

Summary of suggested three steps for earlier identification



How to use this guidance – what next?

GSF Needs Based Coding



This guidance aims to clarify the triggers that help to identify patients who might be eligible for inclusion on the register (supportive/palliative care/ GSF/ locality registers). Once identified and included on the register, such patients may be able to receive additional proactive support, leading to better co-ordinated care that also reflects people's preferences. This is in line with thinking on shared decision-making processes and the importance of integrating advance care planning discussions into delivery of care. It is based on consideration of people's needs rather than exact timescales, acknowledging that people need different things at different times. Earlier recognition of possible illness trajectories means their needs can be better anticipated and addressed. Specific tasks for each stage are part of the GSF Programmes in different settings, to enable better proactive coordinated care.



More details of Indicators – the Intuitive surprise question , general and specific clinical

Step 1 The Surprise Question

For patients with advanced disease of progressive life limiting conditions - Would you be surprised if the patient were to die in the next few months, weeks, days?

- The answer to this question should be an intuitive one, pulling together a range of clinical, co-morbidity, social and other factors that give a whole picture of deterioration. If you would not be surprised, then what measures might be taken to improve the patient's quality of life now and in preparation for possible further decline?

Step 2 General Indicators

Are there general indicators of decline and increasing needs?

- Decreasing activity – functional performance status declining (e.g. Barthel score) limited self-care, in bed or chair 50% of day) and increasing dependence in most activities of daily living
- Co-morbidity is regarded as the biggest predictive indicator of mortality and morbidity
- General physical decline and increasing need for support
- Advanced disease - unstable, deteriorating complex symptom burden
- Decreasing response to treatments, decreasing reversibility
- Choice of no further active treatment
- Progressive weight loss (>10%) in past six months
- Repeated unplanned/crisis admissions
- Sentinel Event e.g. serious fall, bereavement, transfer to nursing home
- Serum albumen <25g/l
- Considered eligible for DS1500 payment

Functional Assessments

Barthel Index describes basic Activities of Daily Living (ADL) as 'core' to the functional assessment. E.g. feeding, bathing, grooming, dressing, continence, toileting, transfers, mobility, coping with stairs etc .

PULSE 'screening' assessment - P (physical condition); U (upper limb function); L (lower limb function); S (sensory); E (environment).

Karnofsky Performance Status Score 0-100 ADL scale .

WHO/ECOG Performance Status 0-5 scale of activity.

Step 3 Specific Clinical Indicators - flexible criteria with some overlaps, especially with Those with frailty and other co-morbidities.

a) Cancer – rapid or predictable decline

Cancer

- Metastatic cancer
- More exact predictors for cancer patients are available e.g. PiPS (UK validated Prognosis in Palliative care Study). PPI, PPS etc. 'Prognosis tools can help but should not be applied blindly'
- 'The single most important predictive factor in cancer is performance status and functional ability' - if patients are spending more than 50% of their time in bed/lying down, prognosis is estimated to be about 3 months or less.

b) Organ Failure – erratic decline

Chronic Obstructive Pulmonary Disease (COPD)

At least two of the indicators below:

- Disease assessed to be severe (e.g. FEV1 <30% predicted)
- Recurrent hospital admissions (at least 3 in last 12 months due to COPD)
- Fulfils long term oxygen therapy criteria
- MRC grade 4/5 – shortness of breath after 100 metres on the level of confined to house
- Signs and symptoms of right heart failure
- Combination of other factors – i.e. anorexia, previous ITU/NIV resistant organisms
- More than 6 weeks of systemic steroids for COPD in preceding 6 months.

Heart Disease

At least two of the indicators below:

- CHF NYHA Stage 3 or 4 - shortness of breath at rest on minimal exertion
- Patient thought to be in the last year of life by the care team - The 'surprise question'
- Repeated hospital admissions with heart failure symptoms
- Difficult physical or psychological symptoms despite optimal tolerated therapy.

Renal Disease

Stage 4 or 5 Chronic Kidney Disease (CKD) whose condition is deteriorating with at least 2 of the indicators below:

- Patient for whom the surprise question is applicable
- Patients choosing the 'no dialysis' option, discontinuing dialysis or not opting for dialysis if their transplant has failed
- Patients with difficult physical symptoms or psychological symptoms despite optimal tolerated renal replacement therapy
- Symptomatic Renal Failure – nausea and vomiting, anorexia, pruritus, reduced functional status, intractable fluid overload.

General Neurological Diseases

- Progressive deterioration in physical and/ or cognitive function despite optimal therapy
- Symptoms which are complex and too difficult to control
- Swallowing problems (dysphagia) leading to recurrent aspiration pneumonia, sepsis, breathlessness or respiratory failure
- Speech problems: increasing difficulty in communications and progressive dysphasia. Plus the following:

Motor Neurone Disease

- Marked rapid decline in physical status
- First episode of aspirational pneumonia
- Increased cognitive difficulties
- Weight Loss
- Significant complex symptoms and medical complications
- Low vital capacity (below 70% of predicted using standard spirometry)
- Dyskinesia, mobility problems and falls
- Communication difficulties.

Parkinson's Disease

- Drug treatment less effective or increasingly complex regime of drug treatments
- Reduced independence, needs ADL help
- The condition is less well controlled with increasing "off" periods
- Dyskinesias, mobility problems and falls
- Psychiatric signs (depression, anxiety, hallucinations, psychosis)
- Similar pattern to frailty- see below.

Multiple Sclerosis

- Significant complex symptoms and medical complications
- Dysphagia + poor nutritional status
- Communication difficulties e.g. Dysarthria + fatigue
- Cognitive impairment notably the onset of dementia.

c) Frailty / Dementia – gradual decline

Frailty

Individuals who present with Multiple co morbidities with significant impairment in day to day living and:

- Deteriorating functional score e.g. performance status – Barthel/ECOG/Karnofsky
- Combination of at least three of the following symptoms:
 - weakness
 - slow walking speed
 - significant weight loss
 - exhaustion
 - low physical activity
 - depression.

Stroke

- Persistent vegetative or minimal conscious state or dense paralysis
- Medical complications
- Lack of improvement within 3 months of onset
- Cognitive impairment / Post-stroke dementia.

Dementia

There are many underlying conditions which may lead to degrees of dementia and these should be taken into account. Triggers to consider that indicate that someone is entering a later stage are:

- Unable to walk without assistance and
- Urinary and faecal incontinence, and
- No consistently meaningful conversation and
- Unable to do Activities of Daily Living (ADL)
- Barthel score <3.

Plus any of the following:

- Weight loss
- Urinary tract Infection
- Severe pressures sores – stage three or four
- Recurrent fever
- Reduced oral intake
- Aspiration pneumonia.

It is vital that discussions with individuals living with dementia are started at an early to ensure that whilst they have mental capacity they can discuss how they would like the later stages managed.

Use of needs based coding	Use of this guidance by different teams
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Prognostication or prediction of need.

Prognostication is inherently difficult and inaccurate, even when informed by objective clinical indicators. Most people tend to give undue weight to prognosis and too little to the importance of planning for possible need, especially for those with non-cancer illnesses, frailty and co-morbidities. In order to identify more accurately those patients who need additional pro-active supportive care, the focus should be on a pragmatic, even instinctive, prediction of the rate and course of decline. Some specific tools can help to predict accurately the time remaining for cancer patients but they should be used with caution (BMJ .2011; 343:d5171)

Rainy day thinking.



“Hope for the best but prepare for the worst.”

We suggest a move towards earlier consideration and more ‘rainy day thinking’ – bringing an umbrella just in case it rains. This instinctive, anticipatory and ‘insurance-type’ thinking relates more to meeting likely needs and planning ahead, rather than focusing on trying to predict likely timescales, and should ensure appropriate support and care can be mobilised.

If you can anticipate possible deterioration, then you can begin discussions about preferences and needs at an earlier stage. The aim of such advance care planning discussions is to establish patients’ sometimes unvoiced concerns, needs and preferences, enabling more people to live out the final stage of life as they choose (see ACP Guidance on GSF/ EOLC web-sites). This also means you can introduce practical measures to prevent crises and make referrals for extra help or advice.

Needs Based Coding - the right care at the right time

Patients have differing requirements at varying stages of their illness. The use of needs-based or colour coding can be very helpful in prioritising need. Some clinicians in care homes, GP practices and hospitals use this system to identify their patients’ stage of decline and so predict at an earlier stage their future needs. Although only a rough guide, this helps us focus on giving the right care at the right time, with regular reviews built in to trigger actions at each stage. As a result a needs/support care plan can be developed for each individual.

Needs Based Coding and Needs Support Matrices

Identifying the stage of illness and anticipating needs and support– to deliver the right care at the right time for the right patient

- **A – All – stable from diagnosis** years
- **B – Unstable, advanced disease** months
- **C – Deteriorating, exacerbations** weeks
- **D – Last days of life pathway** days

For further details of use of Needs / Support Coding and Matrices as part of the GSF Programmes contact the GSF Centre.

Long term conditions. There is a strong correlation between care for patients with long-term conditions and those with advanced disease nearing the end of life. This is especially true for patients with organ failure (heart failure, COPD). Close collaboration with case managers can reduce unplanned admissions and support good end of life care.

Primary care teams. Identifying patients, the first step of GSF, is key to developing a Palliative Care Register, which forms part of the QOF palliative care points in the GMS contract.

The National Primary Care Snapshot Audit (2010) in England demonstrated 3 key findings:

- Only about 25% of patients who died were included on the GP’s Palliative Care/ GSF register
- Only 25% of these had non-cancer conditions
- Most importantly, those patients identified early and included on the register received better quality coordinated care

Therefore this affirms the need for earlier recognition and identification of people nearing the end of life where possible, i.e. the 1% of the population who die each year, greater representation of patients with non-cancer, organ failure, and those with frailty and dementia is recommended, including those from care homes.

Two helpful questions for practice teams to ask:

1. **What is your register ratio?** The number of patients on your palliative care register over the number who died in your practice (using the 1% rule as an approximation e.g. 5000 population = about 50 deaths/ year).
2. **What is your non-cancer/cancer ratio on register?** What percentage of patients on the register has cancer or non-cancer conditions as their main cause of death?

For more details on the QOF points and guidance on Next Stage GSF in Primary care, see the GSF website.

Care homes. Use of the surprise question and this guidance has been found to help identify residents who are most in need in care homes. This can help focus care and trigger key pro-active support, thereby leading to reduced hospital deaths (e.g. halving of death rate in care homes using GSF in Care Homes Programme).

Acute hospital teams. About 25% of all hospital beds are occupied by someone who is dying. The National Audit Office estimates that at least 40% of those people have no medical need to be there. Improved early identification of people in the final year of life helps reduce hospitalisation and accessing supportive and palliative care services. It is extremely helpful if hospital teams notify GPs that a particular patient has advanced disease and might be included on their register.

Specialist teams. Specialist palliative care teams play a vital role especially with cancer patients, but there is a need for collaboration with other specialist teams for non-cancer patients to provide optimal care. These include those with dementia, care of the elderly, heart failure, etc. and this guidance may help clarify referrals.

Commissioners/managers. This guidance could be used as part of an end of life care strategic plan, with improved provision of services for all patients nearing the end of life and introduction of a locality register.

"It should be possible therefore to predict the majority of deaths, however, this is difficult and errors occur 30 per cent of the time... However, the considerable benefits of identifying these patients include providing the best health and social care to both patients and families and avoiding crises, by prioritising them and anticipating need. Identifying patients in need of palliative care, assessing their needs and preferences and proactively planning their care, are the key steps in the provision of high quality care at the end of life in general practice."
 (Quality and Outcomes Framework (QOF Guidance) 2011/12 Guidance)

'It is recommended that people approaching the end of life are identified in a timely way.'
 (Draft Recommendation NICE Guidance in End of Life Care 2001)

This is not attempting to answer the question that doctors often hear - 'how long have I got?' Rather, it responds to the underlying sometimes unspoken questions from people facing a new reality 'If I haven't got long, then what should I do and how can you help?'
 (Thomas K GSF Centre 2008)

"For many people suffering from a chronic illness, a point is reached where it is clear that the person will die from their condition. Despite this, for many conditions it may be difficult, if not impossible and potentially unhelpful, to estimate prognosis accurately. The Prognostic Indicator Guidance developed as part of the Gold Standards Framework (GSF) provides useful prompts or triggers to a healthcare professional that discussions about the end of life should be initiated, if this has not already happened". (DH End of Life care Strategy 2008 England)

Identification of people with a life-limiting illness when they are starting to need a change in their goals of care contributes to end of life care planning and can aid communication with patients and families. It depends on clinical judgement and weighing up a complex mix of pathology, clinical findings, therapeutic response, co-morbidities, psychosocial factors, and rate of decline. (Glare P J Palliat Med 2008)

"Using the GSF 'PIG' has helped us to identify these patients earlier than we previously did, especially those with non-cancer, thereby giving them earlier support as they face the end of their lives, leading to fewer crises and hospital admissions." (GP using Next Stage GSF Training Programme 'Going for Gold')

Development of this guidance paper. This guidance was originally commissioned from the GSF Centre in June 2006 to support GPs include appropriate patients on their QOF Palliative Care Registers i.e. those considered to be in the final 12 months of life. It is regularly revised following extensive consultation with clinical and disease specialist groups, palliative care specialists and GPs in the Royal College of General Practitioners. Particular thanks go to the NHS End of Life Care Programme and University of Edinburgh team for their help. Since publication, this Guidance has been widely used by clinicians in many sectors in the UK and internationally. A list of detailed references is available on request. This is one of several tools available to support improvements in End of Life Care, and further details on best use, IT support and further developments can be obtained from the GSF Centre.

Resources and Further Reading :

National Gold Standards Framework Centre for End of Life Care- Primary care, care homes and other areas www.goldstandardsframework.org.uk
 National Primary care Snapshot Audit (2009/2010) DH report + Next Stage GSF Primary Care Training www.goldstandardsframework.org.uk/GSFRnPrimary+Care
 NHS End of life care Programme www.endoflifecareforadults.nhs.uk
 NHS Department of Health. End of Life Care Strategy (2008) P51, 3.22 <http://www.endoflifecareforadults.nhs.uk/strategy/strategy>
 GMC End of Life Care www.gmc-uk.org/static/documents/content/End_of_life.pdf
 QOF Palliative Care - www.nhs.uk/employers/SiteCollectionDocuments/QOFguidanceGMScontract_2011_12_FL%2013042011.pdf
 NICE Draft Quality standards in End of Life Care (for consultation- due Nov 2011) www.nice.org.uk/guidance/qualitystandards/indevelopment/endoflifecare.jsp
 National Audit Office End of Life care Report Nov 08 www.nao.org.uk/publications/0708/end_of_life_care.aspx
 British Geriatrics Society. www.bgs.org.uk/index.php?option=com_content...id
 The 'Surprise question': Lynn J 2005 Altman Institute Center for Elder Care and Advanced Illness www.thehastingscenter.org/pdf/living-long-in-fragile-health.pdf
 Dying Matters- and the QIPP Find the 1% campaign - www.dyingmatters.org.uk or National Council for Palliative Care www.npc.org.uk
 Liverpool Care Pathway for the Dying Patient. <http://www.mcpcil.org.uk/liverpool-care-pathway/>
 QIPP Department of Health www.endoflifecareforadults.nhs.uk/strategy/policy/quality-innovation-productivity-prevention
 Frameworks for Implementation (2010) from the End of Life Care Programmes - www.endoflifecareforadults.nhs.uk/publications/end-of-life-care-for-heart-failure-a-framework, www.kidneycare.nhs.uk/Library/EndofLifeCareFINAL.pdf, www.endoflifecareforadults.nhs.uk/publications/care-towards-the-end-of-life-for-people-with-dementia, www.endoflifecareforadults.nhs.uk/publications/end-of-life-care-in-long-term-neurological-conditions-a-framework
 Renal advisory group of the NSF, British Renal Society, and British Transplant Society. www.britishtrenal.org
 Barthel Score: Barthel's index of activities of daily living (BAI), www.patient.co.uk/showdoc/40001654/
 Glare P (2011). Predicting and communicating prognosis in palliative care. *BMJ*;343:d5171
 Glare P, Sinclair CT (2008). Palliative medicine review: prognostication. *J Palliat Med*;11;84-103
 Gwilliam B, Keeley V, Todd C, Gittins M, Roberts C, Kelly L (2011) Development of prognosis in palliative care study (PiPS) predictor models to improve prognostication in advanced cancer: prospective cohort study. *BMJ*;343:d4920
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 Quinn TJ, McArthur K, Ellis G, Stott DJ (2011). Functional assessment in older people. *BMJ* ;343:d4681
 Quinn TJ, Langhorne P, Stott DJ (2011). Barthel index for stroke trials: development, properties and application. *Stroke*; 42:1146-51
 SPKCT Guidance University of Edinburgh (2010). Supportive and Palliative Care Indicators tool (SPCIT) www.palliativecareguidelines.scot.nhs.uk/careplanning/
 SPOTLIGHT: Palliative care beyond cancer: Recognising and managing key transitions in end of life care: Boyd K, Murray S *BMJ* 341
 Watson M, Lucas C, Hoy A, Back I (2005) Oxford Handbook of Palliative Care. Oxford University Press

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Priorities for Care of the Dying Person

Duties and Responsibilities of Health and Care Staff

Published June 2014 by the Leadership Alliance for the Care of Dying People

Local palliative care contact:

RECOGNISE

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.

Always consider reversible causes, e.g. infection, dehydration, hypercalcaemia, etc.

COMMUNICATE

Sensitive communication takes place between staff and the dying person, and those identified as important to them.

INVOLVE

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.

SUPPORT

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

PLAN & DO

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.

If unsure, or the dying person or those important to them raise concerns, a senior clinician must review the person and the goals and plan of care. The titles above are intended as memory prompts and attention should be paid to the whole description for each section. Expanded explanations are included overleaf.

Expanded explanations of the priorities

Recognise

- Consider potentially reversible cause if person unexpectedly deteriorates. A doctor must assess if change is potentially reversible or if person is likely to die within a few hours or days.
- If potentially reversible, take prompt action to attempt this, provided in accordance with person's wishes (or best interests, if lack mental capacity).
- If likely to die very soon, communicate this clearly and sensitively to the person (if conscious and have not indicated they would not wish to know) and family and those important to the person.
- Take into account the person's views and preferences, and develop and document plan of care.
- Regularly review person to make sure plan of care remains appropriate and respond to change in condition, needs and preferences.

Involve

- Involve the dying person to the extent they wish to be:
 - in day to day decisions about food, drink and personal care
 - in clinical and treatment decisions.
- Find out, and respect, the extent to which individuals wish their families and those important to them to be involved in decision-making.
- Tell the person, and those important to them, who is the senior doctor who has responsibility for their treatment and care, and who is the nurse leading their care.
- Where it is established that the dying person lacks capacity to make a particular decision, that decision or action taken on their behalf must be in their best interests. Involve them as far as possible.

Plan & Do

- Develop an individualised plan of care and treatment to meet the dying person's own needs and wishes, and document this so that consistent information is shared with those involved in the person's care and is available when needed.
- Pay attention to symptom control, including relief of pain and other discomforts.
- Pay attention to the person's physical, emotional, psychological, social, spiritual, cultural and religious needs.
- Support the person to eat and drink as long as they wish to do so.
- Refer to specialist palliative care if the person and/or situation require this, and ring for advice if unsure about anything.

Communicate

- Remember that open, honest and sensitive communication is critically important.
- Use clear, understandable and plain language – verbally and in all other forms of communication.
- If needed, provide additional support to help dying person understand information, communicate their wishes or make decisions.
- Remember that communication is two-way. Listen to views of person and those important to them, not simply provide information.
- Be sensitive, respectful in pace and tone of communication, and take account of what the dying person and those important to them want, and feel able, to discuss at any particular point in time.
- Check the other person's understanding of information that is being communicated, and document this.

Support

- Remember that families and those important to the dying person, including carers, have their own needs which can be overlooked at this time.
- Recognise that they may be physically and emotionally tired, anxious or fearful.
- Ask about their needs for support or information, and meet these as far as possible.
- Listen to, and acknowledge their needs and wishes, even when it is not possible to meet all of them.
- Where a dying person lacks capacity, explain the decision-making process to those people who are supporting the dying person and involve them as much as possible.

Each individual must have an individual care plan according to their needs. The plan should be discussed openly with the person and those identified as important to them. This plan must be reviewed on a daily basis.



Scan on a smartphone for quick access to website guidance

For further guidance www.nhs.uk/endoflifecare

PERATIONAL GUIDELINES

Verification of Expected Death in Community Services

OPERATIONAL SUMMARY

This policy outlines the process, and the competencies required, for Registered Nurses within East London NHS Foundation Trust Community Services (which includes Bedfordshire, Newham and Tower Hamlets Community Services) to undertake the Verification of Expected Death of patients living in their own home or residing in care homes, who are on the Palliative Care Support Register.

The Trust monitors the implementation of and compliance with this operational policy through one to one supervision and feedback from partner organisations (GP, Hospice, Acute Trust) through local the Bedfordshire (EOL) LIG.

CONTENTS	
Title	Section No
Introduction	1.0
Objectives	2.0
Scope	3.0
Process	4.0
Competency	Appendix 1
Verification Assessment Template	Appendix 2
GP Notifications	Appendix 3,4

VERIFICATION OF EXPECTED DEATH

1.0 INTRODUCTION

A key element of a 'good death' is the timely verification and certification of death. (End of Life Strategy 2008)

Delays in verification of death can lead to difficulties where patients require the disconnection of parenteral medication. Disconnection of such devices prior to verification has legal implications in the event of the coroner's department being involved in the case, whilst prolonged connection adds to relatives' distress.

Whilst some bereaved relatives are comfortable with keeping their family member at home after death, for others it is distressing and the transfer of the body to the undertakers is the next step that they wish to take.

Under English law, Registered Nurses (RNs) can undertake verification of death.

It is recognised that if a competent RN can verify expected patient death, increased quality of care can be offered both to the patient, relatives and carers, in addition to increased job satisfaction for staff who consider it to be performing the final act of care to the patient and the family/carers.

2.0 OBJECTIVES

The Nursing and Midwifery Council (NMC) states 'a registered nurse may confirm or verify that death has occurred providing there is an explicit local policy in place to allow such action'. The policy should, however only be used where death is expected and should include guidance on when other authorities e.g. the police or the coroner should be informed prior to removal of the body (NMC 2012).

This policy has been designed to provide a framework in which registered nurses undertake this responsibility, ensuring a safe and skilled verification of a patient's death.

Nurses verifying expected death must only do so once they have received appropriate training and have been assessed and deemed competent (NMC 2012).

3.0 DEFINITION

Verification of death is a series of physiological assessments confirming that a patient has died and that life is extinct; it is not to determine what caused the death.

Certification of death is the process of completing the "Medical Certificate of cause of death". This must be completed by a medical practitioner in accordance with The Births and Deaths Registration Act 1953 which underpins the legal position of recording a patient's death.

4.0 SCOPE

- **Registered Nurses**

This policy applies to all registered nurses in East London Community Services (including Bedfordshire, Tower Hamlets and Newham community services) who are appropriately trained to undertake the verification of expected death procedure for patients registered on the Palliative Care Support Register and residing in their own homes or residential care homes in the local areas.

Registered nurses working to this policy and deemed competent have the authority to verify death where end of life is expected and is clearly documented in the patient's record by the General Practitioner (GP); they can notify relatives, arrange for last offices and authorise the removal of the body to the care of the undertaker.

Registered nurses working to this policy will have training needs identified via supervision and appraisal. On completion of training registered nurses will be expected to complete the verification of expected death competency.

The competency (Appendix 1) will assess the individual's knowledge and ability to determine the physiological aspects of death and explore their accountability. Each member of the nursing staff undertaking this responsibility is accountable for their own actions, omissions and decisions.

- **Patient**

The patient must meet all three inclusion criteria below; otherwise they will be referred back to the GP:

1. **Expected Death**

An expected death is when the patient's death is anticipated to be in the near future and the GP would be able to issue a medical certificate as to the cause of death. The GP must have seen the patient within the last 14 days prior to death.

There must be no concerns regarding the care the patient has received and no requirement for the police to be called. A death that is expected will be documented as such in the patient's record by the GP responsible for the patient.

2. The patient will be registered on the palliative care support register.

3. A Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR) order will be present with the patient and will be in date and signed by a medical practitioner.

If an expected death may be due to an industrial disease or related to the deceased's employment, for example Asbestosis or Mesothelioma, or when the patient has had a surgical procedure or significant injury in the 12 months prior to death, the nurse may verify the death but the GP will need to refer the death to the coroner. The responsibility to identify the requirement for referral to the coroner rests with the GP on receipt of the notification of verification of death form.

- **Exclusion**

A patient meeting any of the criteria below must be referred back to the GP for verification of death

1. Unexpected death: for the purposes of this policy an unexpected death is a death that is not anticipated or is related to a period of illness that has not been identified as terminal.
2. In cases of expected death when death occurs in unexpected manner or unexpected circumstances.
3. Any unclear or remotely suspicious death.
4. Any death in the categories below (GP responsibility)

- **General/Medical Practitioner**

A Medical Practitioner must verify deaths in the following:

- All unexpected deaths
- The death of a child (0-18)
- Deaths of unidentified persons
- Deaths occurring within 24 hours of onset of illness, or where no firm clinical diagnosis has been made.
- Death as a result of an untoward incident, fall or drug error
- Death as a result of negligence or malpractice.
- Deaths following post-operative procedures or post-invasive procedures carried out in the preceding 48 hours.
- Deaths of people in police custody

- **Coroner Reportable Deaths**

The GP will be responsible for informing the coroner of reportable deaths, even when the death is expected.

For *expected* deaths with a DOLS order in place, there is no longer an indication for referral to the coroner and a death certificate can be issued (provided no other contraindications are in place)

RNs that are trained to undertake the verification of expected death procedures must be aware of issues requiring a referral to the Coroner before proceeding with the procedure and be prepared for situations that may only be identified during the verification process that require a referral to the coroner.

A death should be referred to the coroner if the:

- cause of death is unknown
- deceased was not seen by the certifying doctor either after death or within 14 days before death
- death was violent or unnatural or was suspicious
- death may be due to an accident (whenever it occurred)
- death may be due to self-neglect or neglect by others the death may be due to an industrial disease or related to the deceased's employment
- death may be due to an abortion

- death occurred during an operation or before recovery from the effects of anaesthetic
- death may be suicide
- death occurred during or shortly after detention in police or prison custody.

5.0 PROCESS

When an expected death occurs and the GP is notified by the family/carer/care home staff, the GP will arrange to attend the patient and verify death or contact the Integrated Adult Services through District Nurse Liaison and request that a registered nurse attend the patient and verify that an expected death has occurred. In Bedfordshire requests for verification are received via One call or PEPS, where the call will be triaged accordingly.

The registered nurse requested to attend the patient and verify death will confirm the inclusion criteria have been met prior to attending the patient's residence.

Where inclusion criteria have not been met, or exclusion criteria exist, the nurse will refer the verification process back to the GP or OOH Medical provider.

• Procedure for verification of death

Sensitivity and appropriate communication skills should be used to discuss the situation with relatives if they are present and confirm with them that the death was expected.

If the nurse is not present to record the exact time of death, the time of death should be established as closely as possible from any person in attendance when the patient died. The time of verification of death must also be recorded.

Equipment required:

- Penlight torch
- Stethoscope
- A watch with second hand to time observations accurately
- Verification of death documentation. (Appendix 2)

The individual should be observed by the nurse for a minimum of 5 minutes to establish that irreversible cardiorespiratory arrest has occurred.

After 5 minutes of continued cardiorespiratory arrest:

- Check for response to voice
- Check for absence of carotid pulse for one minute
- Check for absence of heart sounds using a stethoscope for one minute
- Check patient's pupil reactions to light using penlight torch – these should be fixed and show no reaction to light.
- Check for absence of breathing either use stethoscope to listen or place hand on chest and observe for chest movement for one minute.
- Check for response to pain by undertaking a sternal rub.

Any spontaneous return of cardiac or respiratory activity during this period of observation should prompt a further 5 minutes' observation from the next point of cardiorespiratory arrest and the verification tests repeated.

After this procedure has been followed and death formally verified, confirm to any relatives present that the person has died and check/confirm if there are any known religious or personal requests for care of the person's body after death.

Complete the VOED assessment template on S1 (Appendix 2)

Complete the notification of VOED on S1 (Appendix 3) and task the patient's GP practice (not individual clinicians) to advise of its completion and presence in the patient record. The surgery should also be contacted via their bypass phone number to confirm that this procedure has been completed.

Advise family to call undertaker.

If at the time of the verification of expected death procedure the nurse identifies a situation that requires a referral to the Coroner, that was not known at the time of the GP referral i.e. a fall, the nurse will immediately contact the requesting GP, highlight the identified concerns and inform the requesting GP that s/he is unable to verify death and authorise the removal of the deceased to the funeral director.

The nurse will explain the situation to the relative/carers (details may be limited depending on reason for referral i.e. suspicious circumstances) and complete a template for the requesting GP (Appendix 4).

If the requesting GP disagrees with the rationale offered by the nurse it is the requesting GP's responsibility to visit the patient and verify/certify that death has occurred.

If at any time the RN observes anything that raises a concern i.e. safeguarding adults, including medications discrepancies s/he must exercise their professional judgment and seek further advice from the requesting GP.

Patients with Syringe Drivers

- Whilst awaiting verification, the syringe driver and contents should be left in place, the battery can be removed being meticulous not to alter settings.
- In the event of an unexpected death or unexpected circumstance the G.P. should be contacted immediately and everything, including the syringe driver and contents, should be left in place untouched.
- Unused Controlled drugs should be disposed as per Trust Controlled Drug Standard Operating Procedure, or for nurses employed within a care home in accordance with their Home's policy.

Record Keeping and Actions

Staff are required to ensure adequate records are maintained at all times in line with The Code – professional standards for practice and behavior for nurses, midwives and nursing associates (2018).

The nurse who verifies that an expected death has occurred will document in the patient's electronic record journal e.g. SystemOne, EMIS or CERNERMILLENIUM that VOED has been undertaken and that the GP practice has been advised of the

completion of the VOED notification.

COMPETENCY STATEMENT – Verification of Expected Death for Adults

	The practitioner can:	Y/N
a)	Demonstrate attendance at ELFT training for Verification of Expected Death.	
b)	Explain how to locate the policy/protocol.	
c)	Explain when this procedure would be required and in what circumstances.	
d)	Explain the difference between verification and certification of death.	
e)	Explain what documentation is required in the patients notes both prior to, and following, the procedure being completed.	
f)	Explain what constitutes both expected and unexpected death	
g)	Describe who they would inform both before and after the procedure.	
h)	Explain in detail the five clinical checks that are required prior to verification and the time intervals required between checks.	
i)	Describe what they would do if the death was unexpected.	
j)	Describe the advice they would give to the carers or relatives.	
k)	Describe which situations would necessitate referral to the coroner and demonstrate a good understanding of who to contact in the event that they are unsure.	
l)	Practitioner demonstrates an understanding and awareness regarding faith/spirituality	

STATEMENT OF COMPETENCE

I certify that I am aware of my professional responsibility for continuous professional development and that I am accountable for my actions. With this in mind I make the following statement:

I am competent in the statements identified in the verification of expected death without further training.

Signature: Name:

My team leader/manager is aware of my competency and evidence of my competency is included with my CPD portfolio, part of my annual appraisal and an update will be recorded on the verification for expected death register my team leader/manager keeps a record of.

Team leader/Manager

Signature:..... Name:

I require further training or supervision.

My team leader/manager is aware of my competency deficits and my annual appraisal identifies learning needs to be addressed within the next 6 months through training and clinical supervision opportunities within my team.

Signature: Name:

Team leader/Manager

Signature: Name:

STATEMENT OF COMPETENCE

I certify that I am aware of my professional responsibility for continuous professional development and that I am accountable for my actions. With this in mind I make the following statement:

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Team leader/Manager

Signature:..... Name:

I require further training or supervision.

My team leader/manager is aware of my competency deficits and my annual appraisal identifies learning needs to be addressed within the next 6 months through training and clinical supervision opportunities within my team.

Signature:Name:

Team leader/Manager

Signature: Name:

Verification of Death Template for S1

<p>The overall duration of the assessment of cardiac and respiratory function must be at least 5 minutes. Any spontaneous return of cardiac or respiratory activity should prompt another 5 minutes of checks.</p> <p>Vital signs checked:</p>				
Carotid pulse absent on palpation	<table style="width: 100%; border: none;"> <tr> <td style="width: 20%; text-align: right;">Yes</td> <td style="width: 20%; text-align: right;">No</td> <td style="width: 60%; text-align: right;"><input type="checkbox"/></td> </tr> </table>	Yes	No	<input type="checkbox"/>
Yes	No	<input type="checkbox"/>		
Heart sounds absent on auscultation	<table style="width: 100%; border: none;"> <tr> <td style="width: 20%; text-align: right;">Yes</td> <td style="width: 20%; text-align: right;">No</td> <td style="width: 60%;"></td> </tr> </table>	Yes	No	
Yes	No			
Respirations absent for one minute	<table style="width: 100%; border: none;"> <tr> <td style="width: 20%; text-align: right;">Yes</td> <td style="width: 20%; text-align: right;">No</td> <td style="width: 60%;"></td> </tr> </table>	Yes	No	
Yes	No			
<p><u>AFTER 5 minutes</u> of continued cardiorespiratory arrest the following checks should be made:</p>				
Absence of pupillary response to light and corneal reflexes	<table style="width: 100%; border: none;"> <tr> <td style="width: 20%; text-align: right;">Yes</td> <td style="width: 20%; text-align: right;">No</td> <td style="width: 60%; text-align: right;"><input type="checkbox"/></td> </tr> </table>	Yes	No	<input type="checkbox"/>
Yes	No	<input type="checkbox"/>		
No motor response to painful stimuli (sternal rub)	<table style="width: 100%; border: none;"> <tr> <td style="width: 20%; text-align: right;">Yes</td> <td style="width: 20%; text-align: right;">No</td> <td style="width: 60%; text-align: right;"><input type="checkbox"/> <input type="checkbox"/></td> </tr> </table>	Yes	No	<input type="checkbox"/> <input type="checkbox"/>
Yes	No	<input type="checkbox"/> <input type="checkbox"/>		

**TEMPLATE OF LETTER TO GP
WHERE THERE IS NO CONTRAINDICATIONS**

**Notification Procedure Following Verification of an Expected Death for
Community Services**

Name of GP

Address

Address

Address

Tel number

Fax number

Date

Dear Dr,

Re - Name of Patient: Address: Date of Birth: NHS Number:

I saw this patient on ----- at ----- hours and verified that an expected death had occurred (certifiable). I have checked with the family/carers that they know of no reason why a death certificate cannot be issued.

I have therefore authorised the removal of the body by the undertaker and asked the family/carer to contact your surgery on ----- to discuss certification.

Yours sincerely

Name

Position

**Notification Procedure Following Request for Verification of Expected Death in
Community Services**

WHERE CONTRAINDICATIONS HAVE BEEN IDENTIFIED

Name of GP:

Address:

Tel Number:

Fax number:

Date

Dear

Re Name of Patient: Address: Date of Birth: NHS Number:

I saw this patient on ----- --at ----- hours.

I am referring this patient back to you as per The Verification of Expected Death Policy for the following reason/s:

- -----
- -----
- -----
- -----

I have therefore not verified death or authorised the removal of the body by the undertakers.

Yours sincerely

Name
Position

Appendix 5

Personal Care After Death – Community Services

A member of East London NHS Foundation Trust (ELFT) staff may attend the patient’s home if appropriate, for example to verify the death or to remove equipment.

During this visit the member of staff should offer to perform personal care if the patient’s family would like this.

Procedure	Rationale
Apply gloves and apron	Personal protective equipment (PPE) must be worn when performing Last Offices, and is used to protect yourself and all your patients from the risks of cross-infection (Fraise and Bradley 2009, E, HSAC 2003, C; Pratt <i>et al.</i> 2007, C, R2b; RCN 2005, C).
If the patient is on a pressure-relieving mattress or device, leave the mattress running.	If the mattress deflates too quickly, it may cause a manual handling challenge to the nurses undertaking personal care after death
Lay the patient on their back with the assistance of additional nurses if required and straighten any limbs as far as possible (adhering to your own organisation's manual handling policy).	To maintain the patient's privacy and dignity (NMC 2008, C) and for future nursing care of the body. Stiff, flexed limbs can be difficult to fit easily into a mortuary trolley, mortuary fridge or coffin and can cause additional distress to any carers who wish to view the body. However, if the patient's body cannot be straightened, force should not be used as this can be corrected by the funeral director (Green and Green 2006, E).
Remove any medical aids such as syringe drivers, heel pads and catheters once verification is complete. Apply gauze/tape to syringe driver sites and document disposal of medication (adhering to your own organisation’s disposal of medication policy.) Consider leaving prosthetics in situ as appropriate (e.g. limb, dental or breast prosthetics.)	To prepare the body for burial or cremation
Exuding wounds or unhealed surgical scars should be covered with a clean absorbent dressing and secured with an occlusive dressing (e.g. Tegaderm). Stitches and clips should be left intact. Consider leaving intact recent surgical	The dressing will absorb any leakage from the wound site (Naylor <i>et al.</i> 2001, R2b). Open wounds and stomas pose a health hazard to staff coming into contact with the body (RCN

dressings for wounds that could potentially leak, for example large amputation wounds. Reinforcement of the dressing should be sufficient.	2005, C). Disturbing recent large surgical dressings may encourage seepage and leakage (Travis 2002,E).
Stomas should be covered with a clean bag.	
Wash the patient, unless requested not to do so for religious/cultural reasons or carer's preference. Male patients should be shaved unless they chose to wear a beard in life. If shaving a man, apply water-based emollient cream to the face.	For hygienic and aesthetic reasons. As a mark of respect and point of closure in the relationship between nurse and patient (Cooke 2000, C).
It may be important to family and carers to assist with washing, thereby continuing to provide the care given in the period before death.	It is an expression of respect and affection, part of the process of adjusting to loss and expressing grief (Berry and Griffie 2001, E).
Mouth and teeth should be cleaned with foam sticks or a toothbrush. Insert clean dentures if the patient normally used them. Apply petroleum jelly to the lips and perioral area.	Teeth and mouth are cleaned for hygienic and aesthetic reasons (Cooke 2000, C) and to remove debris. Petroleum jelly can prevent skin excoriation or corrosion if stomach contents aspirate.
Dress the patient in personal clothing provided by the family.	For aesthetic or religious and cultural reasons, and to meet the needs of the family. (Green and Green, C, 2006)
Remove gloves and apron. Dispose of equipment according to local policy and wash hands.	To minimise risk of cross-infection and contamination. (Fraise and Bradley, E, 2009)
Discuss with the patient's family regarding contacting a chosen funeral director once verification has occurred.	To avoid decomposition which occurs rapidly, particularly in hot weather and in overheated rooms. Many pathogenic organisms survive for some time after death and so decomposition of the patient's body may pose a health and safety hazard for those handling it (Cooke 2000, E). Autolysis and growth of bacteria are delayed if the patient's body is cooled.
Remove all equipment from the patient's home, including any syringe drivers and consumables. Do not remove medication, advise the patient's family to return these to a pharmacy.	
Record all details and actions within the nursing documentation.	To record the time of death, names of those present, and names of those informed. (NMC, 2015)