East London NHS Foundation Trust

End of Life Care Policy

Version number :	4.0
Consultation Groups	Clinical Policies Alignment committee Mental Health Senior Nurses Group
Approved by (Sponsor Group)	Nursing Development Steering Group
Ratified by:	Quality Committee
Date ratified:	21st June 2023
Name of originator/author:	Lead Nurse for Palliative Care, Bedfordshire Lead for End of Life Care, Tower Hamlets Interim Lead Nurse for Palliative Care, Bedfordshire
Executive Director lead :	Director of Nursing
Implementation Date :	June 2023
Last Review Date	June 2023
Next Review date:	June 2026

Services	**Applicable**
Trust wide	All services working with Adults.
Mental Health & LD	
Community Health Services	

Version Control Summary

Version	Date	Author	Status	Comment
1.0	05/03/14		Final	
2.0	07/12/15		Final	
3.0	31/01/2020		Final Approved – Chief Medical Officer	
4.0	12/04/2023			

.

Members of ELFT Community Services Clinical Polices Alignment Group are:

- Caroline Ogunsola – Professional Development Nurse for Community Services - *Convener*
- Kikelomo Pinheiro Community Services Pharmacist – Bedfordshire
- Nike Bademosi – Lead Nurse – Tower Hamlets
- Fiona Davies – Clinical Lead – Tower Hamlets
- Chantal Riviera – Clinical Lead Newham
- Caroline White – Clinical Lead - Bedfordshire
- Juliette Fiore-Fuller – Deputy Lead Nurse, Newham
- Georgina Amparado – Molina – Clinical Lead Tower Hamlets
- Fatima Hafesji – Lead Pharacist – Tower Hamlets
- Davinder Kaur – Clinical Lead - Tower Hamlets
- Sharon Eplett – Head of Quality & Performance, Bedfordshire
- Rashida Goswami – In-Reach Team Lead, Tower Hamlets

Contents

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 NICE Quality Standards (2011, updated 2021) End of Life Care for Adults, NICE Quality Standards (2017) Care of Adults in the Last Days of Life and NICE (2019) End of Life Care for Adults: Service Delivery.

It is also supported by NHS England (2021) Ambitions for Palliative and End of Life Care: A national framework for local action 2021 – 2026 and Hospice UK (2022) Care after Death: Guidance for staff.

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 The 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 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 Care for people nearing the end of life should be well co-ordinated both within and across different services and organisations, and there should be an integrated approach to care planning.

6.2 Patients approaching the end of life should be added to the local palliative care register and be allocated a named nurse to lead on the co-ordination of the patient's care.

6.3 Regular multi-disciplinary discussions should be held, including with specialist palliative care teams. There should be regular reviews of advance care plans and of care and support needs.

6.4 With the consent of the person or if they lack capacity in their best interests, wishes around advance care planning should be recorded and shared with all those involved in their care.

6.5 In community settings discussions around advance care planning should be documented in the shared Universal Care Plan (UCP) or System one records where these exist or in emergency treatment plans such as ReSPECT or PACT.

7 Advance Care Planning

7.1 Patients approaching the end of life should be offered the opportunity to have an honest, informed and sensitive conversation about death and dying and to create a personalised advance care plan. Opportunities to talk about advance care planning and to review existing plans, should be offered regularly.

7.2 Advance care plans should allow people to express their preferences for their future care and what matters to them most, including their preferred place of care and place of death. They might also include setting personal goals for the time that they have left.

7.3 Where the person approaching the end of life agrees, carers and other people who are important to them should also be offered the chance to be involved in the discussions around advance care planning.

7.4 Additional support should be sought where needed to support advance care planning for example for people with learning disabilities or dementia

7.5 Advance care planning may also involve setting up Lasting Power of Attorney, whereby someone appoints another person to make decisions on their behalf 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.

7.6 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.

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 patients 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 Considering whether or not to attempt CPR is an important part of good quality end of life care and advance care planning.

9.2 The DNACPR decision should be made on the basis of a careful assessment of the person's individual situation. Where a patient is nearing the end of life and it is appropriate to consider a DNACPR decision, this should be done at the earliest possible opportunity.

9.3 The DNAPR decision should be made by the most senior clinician in charge of the patient's care and discussed with the wider health care team. In community settings (such a district nursing) this will usually be the GP.

9.4 DNACPR decisions should be discussed with and explained to the patient and those close to them, and the opportunity to challenge the decision provided. Discussions about DNACPR may be sensitive and complex and should only be carried out by experienced clinical staff.

9.5 Where there is uncertainty about whether CPR is appropriate, resuscitation should be started straight away.

Please see Trust Decisions Relating to Cardiopulmonary Resuscitation Policy for further information.

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 or 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 should be offered including what to expect, medications including anticipatory prescribing, practical support available and care options.

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.

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.

12. Person Centered 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 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 and cae after death.

12.4 The care plan should manage physical pain and symptoms, but should acknowledge that distress may be caused by or exacerbated by emotional or psychological anguish, social or spiritual distress.

12.5 The practical and emotional support needs of those who are important to the dying person / carers should also be assessed. Carers should be supported to access a carer's needs assessment where applicable.

12.6 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 may be offered support from voluntary organisations such as Marie Curie.

12.7 Contact numbers for support services should be provided for patients and those who are important to them, including for out of hours support.

.

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 of any anticipatory medication prescribed and the dosage, starting with the lowest effective dose.

13.4 If patients are not able to swallow 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. If already on established dose of oral medications, predicted dose should be converted in collaboration with specialist palliative care.

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. (See Adminstration of Subcutaneous Fluids Policy for further guidance)

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.

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 expected death where relevant. 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 28 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 28 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.

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. 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 If relatives or other key contacts are not present when the person dies, sensitive and honest communication should take place with them. Informing relatives of a patient's death, can be very 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 patient's 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/carer 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. 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 Care after Death

19.1 Personal care after death in hospital settings (sometimes known as "last offices") should be carried out by a Registered Nurse. Personal care after death in community settings may be undertaken by family or carers of the person who has died. However community nurses should offer support with this if appropriate, especially if they are present when the person has died. Please see Appendix 4 on the Procedure for Personal care after Death.

19.2 Personal care after death may include washing and dressing the person who has died and removing medical aids such as syringe drivers and catheters. It is important always to ensure the privacy, dignity and respect of the person who has died.

19.3 Care after death also includes supporting the spiritual, religious and cultural wishes of the person as well as their family and carers.

19.4 Other aspects of care after death may include arranging the removal of equipment and supporting with the disposal of controlled drugs. (Please see Safe Management of Controlled Drugs in a Domiciliary Setting Policy for further guidance)

20. Registration of Death / Funerals

20.1 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.

20.2 Relatives should be advised to register the death within 5 days and that funerals can only take place after the death is registered.

20.3 Where a person dies and they have no next of kin, or where their next of kin, family or friends are unable or unwilling to arrange a funeral, they are entitled to a public health funeral arranged by the local authority.

21 Supporting and caring for those who are important to the dying person, including bereavement support

21.1 Good palliative care also includes giving care and support to the families, friends, carers and all those who are important to the dying person. This includes good bereavement care.

21.2 Bereaved people should be offered support at the time of death, but may also need support on a longer term basis, as well as before the death.

21.3 Support for people dealing with bereavement may include:
- Preparing them for what to expect when the person dies
- Acknowledging that everybody grieves in a different way and there is no right or wrong.
- Answering any questions they may have about what happens next.

- Supporting with self care for example getting enough sleep, taking a walk, getting outside

21.4 While many people find that talking to friends and family is the main support they need, when grieving, other people may find they need more support. (Please see appendix 5 for national and local organisations providing bereavement support).

22 Education, Development and Training

22.1 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.

22.2 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.

22.3 Team leads should ensure that this policy is disseminated to all staff and monitor its implementation.

22.4 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.

22.5 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.

22.6 Staff should be given time to debrief and reflect on end of life care, particularly when this has been emotionally challenging.

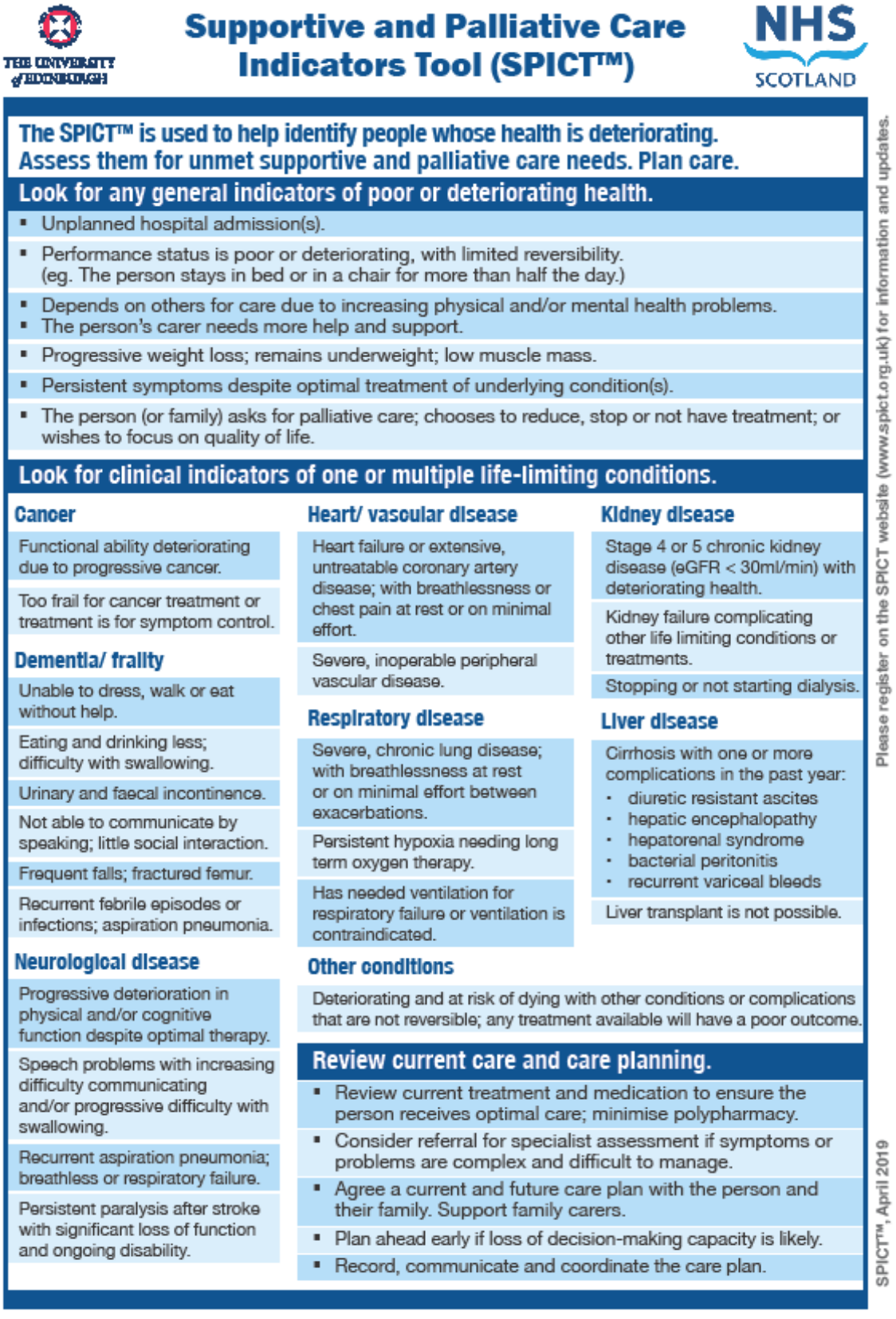
23 Related Operational Documents

- Advanced Decision to Refuse Treatment Policy
- Decisions Related to Cardiopulmonary Resuscitation Policy
- Health and Safety Policy
- Infection Control Manual
- 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
- Verification of Death local guidelines

24 References

- Department of Health (2009) End of Life Care Strategy: quality markers and measures for end of life care.
- Hospice UK (2022) Care after Death, Fourth Edition
- Leadership Alliance for the Care of Dying People (2014) How quality care for all, now and for future generations.
- NHS England (2021) Ambitions for Palliative and End of Life Care: a national framework for local action 2021 - 26
- 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 2021) 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

Appendix 1



THE UNIVERSITY of EDINBURGH

Supportive and Palliative Care Indicators Tool (SPICT™)

NHS SCOTLAND

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.

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.

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.

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

East London NHS
NHS Foundation Trust

Appendix 2

the gold standards framework

4th Edition
October 2011

The GSF Prognostic Indicator Guidance

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

RCGP Royal College of General Practitioners

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 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

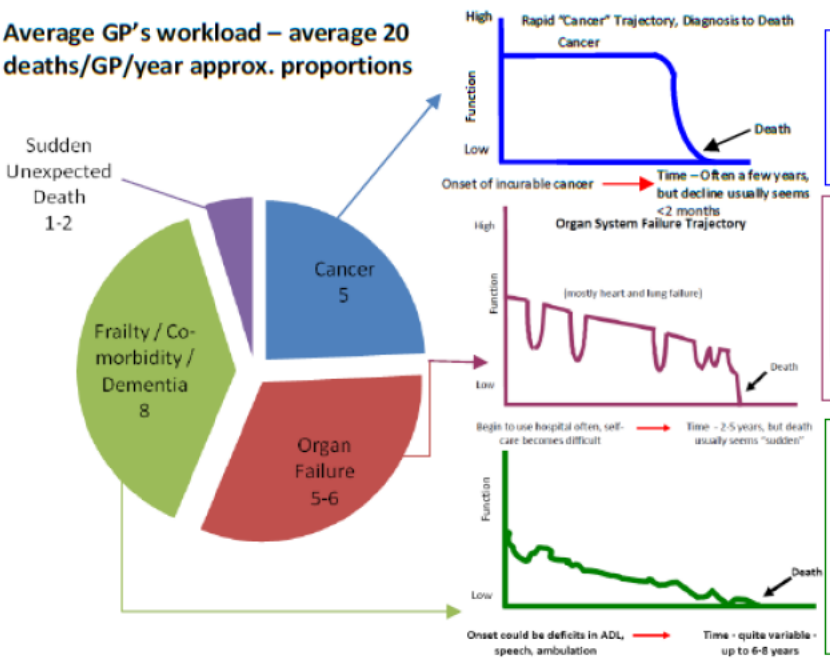
People are 'approaching the end of life' when they are **likely to die within the next 12 months**. This includes people whose death is imminent (expected within a few hours or days) and those with:

- 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

East London NHS
NHS Foundation Trust

Summary of suggested three steps for earlier identification

Step 1

Ask the Surprise Question

Would you be surprised if the patient were to die in next months, weeks or days?

NO | Don't Know | YES

Step 2

Do they have General Indicators of Decline?

YES | Don't Know | NO

Reassess regularly

Step 3

Do they have Specific Clinical Indicators?

YES | NO

Reassess regularly

Begin GSF Process

Identify Include the patient on the GP's GSF/QOF palliative care register or locality register if agreed. Discuss at team meeting.

Assess Discuss this with patient and carers, assess needs and likely support and record advance care planning discussions.

Plan Plan and provide proactive care to improve coordination and communication.

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.

GSF 3 Steps Process

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).

Karnofksy 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 o confined to house
- Signs and symptoms of right heart failure
- Combination of other factors – i.e. anorexia, previous ITU/NIV resistan 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 o breath at rest on minimal exertion
- Patient thought to be in the last year o life by the care team - The 'surprise question'
- Repeated hospital admissions with heart failure symptoms
- Difficult physical or psychologica 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/Karnofksy
- 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.

East London NHS
NHS Foundation Trust

Use of needs based coding

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.

Use of this guidance by different teams

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 od 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/GSFInPrimary+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.pdf3
QOF Palliative Care - www.nhsemployers.org/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 Altarum 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.ncpc.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.britishrenal.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
McDaid P (2011) Quick Guide to Identifying Patients , Islington PCT, (personal communication)
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
SPICT 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*

The Gold Standards Framework Centre CIC
info@gsfcentre.co.uk www.goldstandardsframework.org.uk +44 (0) 1743 291 891 / 367 066

East London NHS
NHS Foundation Trust

Appendix 3

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

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.

Local palliative care contact:

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.nhsiq.nhs.uk/endoflifecare

Appendix 4

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 *et al.* 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.	The dressing will absorb any leakage from the wound site (Naylor *et al.* 2001, R2b). Open wounds and stomas pose a health hazard to staff coming into

Consider leaving intact recent surgical dressings for wounds that could potentially leak, for example large amputation wounds. Reinforcement of the dressing should be sufficient.	contact with the body (RCN 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)

Appendix 5

National bereavement support services

Age UK
Bereavement support for older people including carers. www.ageuk.org.uk

At a Loss
Support & signposting for all those who are bereaved:
www.ataloss.org

Child Bereavement UK
Support for children, young people, parents and families. 0800 02 888 40 or visit www.childbereavementuk.org

Cruse Bereavement Care
Support for all those who are bereaved - call for free on 0808 808 1677 or visit www.cruse.org.uk

The Good Grief Trust
Run by people who have experienced a bereavement themselves:
www.thegoodgrieftrust.org

Marie Curie
Support for all who are bereaved, including pre-bereavement – 0800 090 2309 or visit https://www.mariecurie.org.uk/help/support/bereavement

Macmillan
Advice and information if the person who died also had cancer. Visit www.macmillan.org.uk/cancer-information-and-support/supporting-someone/coping-with-bereavement.

Sudden
Support for those affected by a sudden death. 0800 2600 400 or visit www.sudden.org

Support after suicide
Support after suicide: supportaftersuicide.org.uk

Survivors of bereavement by suicide.
https://uksobs.org/

Winston's Wish
Support for children and young people. www.winstonswish.org

East London NHS
NHS Foundation Trust

Local bereavement support services

Adult Services

Cruse Bereavement Care – Bedford area
Tel 0300 200 4108 or email bedfordshire@cruse.org.uk

City and East London Bereavement Service (CELBS)
specialist bereavement service for residents of Tower Hamlets & the City.
Visit www.celebs.or.uk

Newham Bereavement Service
delivered by Mind for adults living in Newham. Visit www.mithn.org.uk
To make a referral call 0207 510 1081 or 0207 510 4268 or by emailing referral@mithn.org.uk.

NHS Talking Therapies (IAPT)
Offering psychological interventions for common mental health problems, such as anxiety, low mood. Self-referrals are welcomed and encouraged.
Newham: www.newhamtalkingtherapies.nhs.uk
or call: 020 8475 8080
Tower Hamlets: towerhamletstalkingtherapies.nhs.uk
or call: 020 8475 8080

Hospice Bereavement Services

Keech Hospice Care
Bereavement support for people in Bedfordshire
https://www.keech.org.uk/

St Joseph's Hospice
Specialist bereavement support available where the person who died was under the care of the hospice. (East London) www.stjh.org.uk

Sue Ryder St John's Hospice
Bereavement support for people in Bedfordshire
https://www.sueryder.org/how-we-can-help/sue-ryder-st-johns-hospice

Children's Services

Child Bereavement UK East London
specialist bereavement service for children, young people & their families in East London. Visit londonsupport@childbereavementuk.org

CHUMS Bereavement Service
specialist bereavement service for children, young people & their families cross Luton & Bedfordshire. Visit chums.uk.com/bereavement-service

East London
NHS Foundation Trust

Procedure for Managing Sudden Unexpected or Near Death of a Patient

Version number :	2.0
Consultation Groups	Lead nurse and Duty Senior Nurses
Approved by (Sponsor Group)	Quality committee
Ratified by:	Quality committee
Date ratified:	10th March 2021
Name of originator/author:	Claire Mckenna
Executive Director lead :	Lorraine Sunduza
Implementation Date :	March 2021
Last Review Date	March 2021
Next Review date:	March 2024

Services	Applicable
Trustwide	X
Mental Health and LD	
Community Health Services	

Version Control Summary

Version	Date	Author	Status	Comment
01	1/03/21	Claire Mckenna		

Contents

Managing Death or near Death on Wards

1. Introduction

1.1 The sudden unexpected death of a hospitalised patient is distressing to the family and the healthcare team.

1.2 While sudden deaths have very different causes, what unites them all is that they are unexpected and consequently unanticipated.

2. Definition of sudden or unexpected death

2.1 A sudden death is any kind of death that happens unexpectedly. This includes:

- Suicide
- Overdose
- Road crash or other transport disaster
- Drowning, falls and fractures, fire or other tragedy
- Murder
- War or terrorism
- Undiagnosed advanced terminal illness, such as advanced cancer
- Sudden natural causes, such as heart attack, brain haemorrhage, or cot death
- Sudden death from a serious illness that was known about, but where death wasn't expected, for example epilepsy, diabetes, respiratory conditions.

3. Scope

3.1 The purpose of this procedure is to provide teams with guidance to make the required process easier and seamless, ensuring mandatory, corporate and legal responsibilities are met.

3.2 There is an end of life policy that looks at expected deaths.

4. Inpatient Unexpected death Roles and Responsibilities

4.1 Upon discovery of a collapsed service user the ambulance or crash team should be contacted immediately.

4.2 Attempts to resuscitate should commence and continue until emergency services arrive.

4.3 Dependent upon the success of CPR attempts, the ambulance or crash team will decide whether the service user should be transferred to the local general hospital for further treatment, or will remain in the ward for the funeral directors to transport to the mortuary when the police indicate it is appropriate to do so.

4.4 A log of events should be completed by the DSN or nominated other (Appendix 1).

4.5 It is important that all relevant managers are notified (via completion of a Datix report) of a death when it occurs to allow any remedial or immediate action to be initiated. Guidance for staff on the reporting and management of incidents is set out in the Trust's Incident Policy.

5. Escort

5.1. If taken to the general hospital, an escorting nurse should be identified. This should preferably be a qualified nurse who knows the service user and their recent treatment input.
5.2. Where this is not possible, the escort should have the contact details of a Senior Clinician who can give further information if required.
5.3. The role of the escorting nurse is to give medical staff information, to support the service user if they are conscious, and relay medical progress to the Duty Senior Nurse (DSN).
5.4. Where a service user is unconscious, and is unlikely to gain consciousness for some time, the modern matron (DSN out of hours) should liaise with general hospital medical colleague to review progress and decide whether to discontinue the requirement of an escort.

6. Preserving the Scene and Police Input

6.1. Given the unexpected nature of the event, the Death should be treated as a potential crime scene until the police indicate otherwise.
6.2. The role of the police officer in an unexpected death is to ensure that a 3rd party has not been involved in the death or that a criminal act has not taken place.
6.3. The police should be contacted as soon as the immediate life support efforts have either stabilised the service user or been confirmed as being unsuccessful.
6.4. The ambulance crews are likely to inform the police of the event.
6.5. In addition, the DSN should also contact the police on 999 and report the incident. The police will then attend the unit.
6.6. While waiting for police attendance, the area where the event took place should be locked or blocked to ensure the scene is maintained. All equipment used must be left as it is in the room.
6.7. There should be no attempt to disturb the area in any way until authorised by the police.
6.8. The staff that were at the scene should remain in the locality, as the police will decide who they wish to see to take a police statement. This allows the police to quickly assess the situation.

7. Managing the Scene

7.1. Once the police have agreed, the environment must be made clean and safe ensuring that areas are de-contaminated.
7.2. Personal property should be searched, packed and stored in readiness for collection.
7.3. After the room is decontaminated and clean, arrange for a deep clean with Domestic Services. Please note Domestic Services are not responsible for cleaning bodily fluids.
7.4. Release of service user's personal belongings to the identified next of kin will be arranged with a property list given a copy retained in the Service Users notes.

8. Management of the Deceased

8.1. When the Police have agreed for the body to be released, the DSN will allocate 2 experienced ward staff to prepare the body for collection by funeral services.
8.2. Staff should be mindful of cultural and religious beliefs of the service user and expectations in relation to the preparation of the deceased while on the unit,. This might include allocating same sex staff in the preparation process.
8.3. If the Service User is soiled, they can be cleaned and covered with a sheet.
8.4. The service user should be labelled with their Name, NHS No and DOB.

9. Funeral Services

9.1. Where attempts to preserve life have been unsuccessful, ambulance and crash teams are likely to recommend collection by funeral services to transport to the mortuary.
9.2. As it is an unexpected death, the police would need to give authorisation for the service user to be moved.
9.3. Each locality would have an identified funeral director who should be contacted, post police authorisation.
9.4. Consideration should be given to supporting access to the ward, and the discreet movement through the building as this could cause other service users considerable distress.

10. Statements

10.1. All involved staff members should complete a contemporaneous account of the incident; staff may require support to do so. This needs to occur as soon as it is safe to do so and before leaving shift. This will provide service leads with a full picture of the incident, and it is also recognised that over time the detail of events are harder to remember.

11. Information Giving

11.1. A Senior Clinical should contact the family or next of kin to inform them of the incident, giving details of the service user's current condition, and where the service user will be moved to.
11.2. If the service user is deceased in most cases the police will inform the family as they are able to attend the address to ensure the family are safe and supported.

Modern Matron /DSN (Nominated other)

Contact	**When to Contact**
Ambulance on (9) 999. Hackney 2222 for Crash Team	As soon as individual is found.
Police on (9) 999 (ring 9 to get outside line, followed by 999)	Immediately, post incident
<u>In Working Hours</u>	

• Borough Director • Clinical Director • Borough Lead Nurse <u>Out of Hours</u> • On Call Manager • On Call Consultant	Immediately, post incident
Family/Next of Kin	Immediately, post incident
If Deceased – Funeral Directors	Following Police Confirmation

Borough Director/On Call Manager (nominated other)

Contact	**When to Contact**
<u>In Working Hours</u> • Chief Operating Office • Chief Nurse • Chief Medical Officer <u>Out of Hours</u> • Director on call	When fully informed of incident
Where appropriate inform Safeguarding Team	Within 48 working hours
Family/Next of Kin Meeting	Within 24 working hours
Mental Health Act Team	Within 24 working hours
If Service User is on a restrictive order inform Ministry of Justice (0300 303 2079)	Within 24 working hours
Inform CCG (in cases of a death)	Within 48 working hours

Chief Nurse

Contact	**When to Contact**
Inform CQC (in case of death)	As soon as possible

12.Service User Support

12.1As soon as is practical, the matron (DSN out of hours) should arrange a meeting with Service Users in the clinical area. In this meeting minimal information can be given. The purpose of this meeting is to acknowledge that a significant event has occurred, and to listen and discuss the support that will be offered.

12.1Directly post the Incident, the Consultant/On-call Consultant and Senior Members of Nursing staff should undertake a review of all service users to consider enhanced care and support where required.

12.1The review should occur daily for the next 72 hours.

12.1On the next working day the Matron and/or Ward Manager supported by the DMT should conduct a de-brief.

12.1Planning with Consultant and Borough Lead Nurse will be required to decide what level of disclosure is appropriate.

12.1The de-brief should provide an opportunity for service users to discuss their thoughts, feelings and fears.

12.1Individual meetings with Service Users should occur where individuals are significantly affected.

12.1The Locality Borough Director, Clinical Director and Borough Lead Nurse will agree who will contact the family to offer face to face meeting to discuss the events, give family carers an opportunity to ask questions and provide support. Where telephone contact is unsuccessful a written offer letter should be sent.

12.1The spiritual care team can provide individual or group support if service users would find this useful.

13. Staff Support

13.1.All staff members involved should receive an initial de-brief before leaving the unit. This could be conducted by the DSN or Manager-On-Call.

13.2.The Borough Lead Nurse should arrange an official staff de-brief within 10 days of the incident. This would be facilitated by a confident, competent facilitator independent of the immediate team affected. The full team and any other staff affect by the incident should be invited.

13.3.Individual staffs within teams are likely to be affected in different ways. Post the incident, the Ward Manager, Matron and Discipline leads should offer a meeting to all staff members involved, and discuss the incident in supervision with the full team.

13.4.Where required, increased levels of support should be offered which might include increased levels of meetings, directing to the Staff assistance programme via occupation health.

13.5. Staff can contact the spiritual care team to provide individual or team support.

14. Learning and Scrutiny

14.1.Within 48 hours a local review of the incident and initial learning points will be established.

14.2.Due to the nature of the event, a Serious Incident Review and a comprehensive within 60 days.

14.3.All inpatient death will result in a coroner review. Staff involved in the incident may be asked to appear.

14.4.If this occurs, support in relation to writing statements and understand process will be given by Trust Legal team.

15. Community death

15.1 If an unexpected death occurs in a service users home the emergency services (ambulance) should be called. Where approapriate and instructed by emergency services CPR should be commence .Wait for the emergency services to arrive and co-operate with their instructions.
15.2 Death will be confirmed by the ambulance crew who will inform the police.
15.3 Do not remove anything from the scene and the environment should be disturbed as little as possible.
15.4 Inform your line manager, complete an incident form, consider need for safeguard alert, and make a full RIO entry before finishing shift.
15.5 The team manager should inform the GP within 8 hours of the event occurring.

Appendix 1 - Managing Sudden Death or Near Death Log
To be completed by the DSN or Nominated other.

Directorate	
Ward/Area	

Service User Details	
Name	
Date of Birth	
Address	
GP Details	
Next of Kin Details	
Outline Admission Details (brief)	
Outline any Medical Conditions	

Time Log

Details	Completed by	Time	Initials
Service User found			
By Whom			
CPR commencement			
Ambulance or Crash Team called			
Ambulance or Crash Team attended			
If pronounced time of death			
Transfer to Hospital or Mortuary			

Details	Completed by	Time	Initials
Handover Clinical Information to emergency services			
Inform Family/Next of Kin			
Contact Police to inform of incident			
Brief Police on attendance			
In working hours, contact Borough Director, Clinical Director and Borough Lead Nurse			
Out of Hours contact On-Call Manager for Locality and On-Call Consultant			
Borough Director to contact Chief Operating Officer, Chief Medical Officer to inform of incident Out of Hours On-call Manager to inform Director On-Call			
Modern Matron/DSN to Log Incident on RIO			
Complete Incident Report			
Complete Safeguarding alert where required			

Managing the Scene

Details	Completed by	Time	Initials
Area secured and locked off (where possible)			
Notes, including Drug Charts, Fluid, News and Observation Charts locked securely			

Staff/Other Service users

Details	Completed by	Time	Initials
Deploy staff from other areas to ensure ward safety is maintained.			
Book additional staff for the ward for next 24 hours			
Staff involved to write Statement before leaving duties (staff may need support) DSN to ensure all statement secured and scanned to Borough Lead Nurse and Borough Director			
Service Users informed of Incident (minimal detail at this point)			
Initial Staff de-brief			
Service Users Management review with Nurse in Charge and Medical Team			

Staff Members Involved

Name:	
Contact Details:	
Role:	
Name:	
Contact Details:	
Role:	
Name:	
Contact Details:	
Role:	
Name:	
Contact Details:	
Role:	
Name:	
Contact Details:	
Role:	
Name:	
Contact Details:	
Role:	

Form to be completed and sent to trust legal team with service users notes and charts.

Appendix 2 – Employee Assistance Programme (EAP)

When you are anxious or stressed about something personal or work-related it can be difficult to be your best at work or at home. That's why we offer the Confidential Care service to anyone working for the Trust.

Confidential Care gives you, your partner and dependent family members a place to turn for support any time of day or night, 365 days a year. Support is available for whatever issues you might be facing, including work stress, depression, marriage and relationship issues, legal concerns, coping with change, parenting issues, financial problems and much more.

How does it work?

You simply call the freephone number whenever it's convenient for you. No appointment is necessary and the service is as close as your phone.

Experienced, professional counsellors are available to listen to your concerns, determine appropriate resources, and then help you take the next steps.

By calling in you can access professional support services offering emotional, psychological and practical help, ranging from referrals for face to face counselling to information and advice teams who will support you through a wide range of personal and work-related issues.

Sometimes you may have more than one issue that's bothering you, rest assured that Confidential Care can provide you with support that will help.

Is this really free?

Absolutely, there is no cost to you and everything is completely confidential, on top of this the people at Confidential Care have many years of specific experience in supporting the unique issues faced by those who work with or for the NHS, If you have access to the internet you can also access the Confidential Care wellbeing website by visiting www.well-online.co.uk, just log in using the username: 'ELFTlogin' and the password: 'wellbeing' (all lower case). By visiting Well Online you can research for yourself the range of support available to you, watch videos and access a wide selection of help sheets and articles written on topics that relate to you and your own wellbeing, we update our help sheets and articles at least once a month so be sure to check back for more if you've already visited.

Are there any limits to the service?

Although the service includes access to structured counselling support for some, this will only be offered following an assessment with one of CiC's Adviceline staff. Our Advice line, staff are themselves counsellors and are professionally qualified to determine the most appropriate course of structured support for you given your own unique set of circumstances.

Face to face counselling is not the only form of structured support that may be offered to you, CiC also make use of structured telephone appointments and a number of other forms of support as well, including our recently introduced 'Introduction to Mindfulness'.