East Midlands Ambulance Service NHS Trust

Clinical Management in End of Life Care Standard Operating Procedure

Links

The following documents are closely associated with this policy:

- End of Life Care Policy
- Resuscitation Decisions in End of Life Care Standard Operating Procedure
- Untoward Incident Reporting Policy

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1.0	20 November 2014	27 February 2015	Clinical Governance Group	New policy

Clinical Management in End of Life Care Standard Operating Procedure

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1. Introduction

1.1. East Midlands Ambulance Service NHS Trust is committed to providing high quality, safe and effective care to individuals approaching the end of their life.

1.2. The Trust recognizes that a patient approaching the end of life should be managed with dignity and with their wishes adhered to wherever possible.

2. Objectives

2.1. The objectives of this procedure are to:

- Ensure that all patients with identified end of life needs receive safe and effective care in the most appropriate place, including preferred place of death where appropriate.

- Ensure that all patients approaching the end of life receive care within a legal framework and that staff are empowered to achieve this with confidence.

3. Scope

3.1. This procedure document applies to all pre-hospital practitioners employed by EMAS attending a patient with end of life needs.

4. Definitions

4.1. **End of Life:** 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 coexisting 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.

4.2. **DNA-CPR: Do Not Attempt Cardiopulmonary Resuscitation:** a document that provides evidence that a patient should not receive CPR in the event of cardiac arrest (unless from an unrelated reversible cause for example choking).

4.3. **Advanced Care Planning:** A voluntary process of discussion and review to help an individual who has capacity to anticipate how their condition may affect them in the future and, if they wish, set on record choices about their care and

treatment and/or an advance decision to refuse treatment in specific circumstances.

4.4. **Lasting Power of Attorney:** A Lasting Power of Attorney (LPA) is a legal document which allows someone to nominate another person (or persons) to make decisions on their behalf after they lose mental capacity to make their own decisions.

4.5. **Advanced Decision to Refuse Treatment:** A legally binding decision to refuse specific treatment made in advanced by a person who has capacity to do so. This decision only applies at a time when that person lacks capacity to consent to, or refuse a treatment. If this involves refusal of life sustaining treatment it must be in writing, signed and witnessed and include the statement "even if life is at risk".

5. Responsibilities

5.1. The **Medical Director** is responsible for ensuring:

- This procedure is monitored and reviewed in line with current clinical guidance on an annual basis.
- That related Clinical Key Performance Indicators and subsequent action plans are regularly reviewed by the clinical team in collaboration with the Divisions.
- Advice is provided to the Director of Workforce on the requirements of training for all staff.
- Advice is provided to the General Managers on the requirements for equipment

5.2. **Consultant Paramedics** are responsible for ensuring:

- That the procedure is current best practice and is updated as required and in the event of changes to best practice or identified risk.
- That advice is provided to all relevant roles within the Trust and partner organisations.

5.3. **Locality Managers and Locality Quality Managers** are responsible for ensuring:

- The provision of suitable and sufficient equipment as per equipment stock recommendations.
- Staff within their area of responsibility attend training on end of life care in line with the approved Education Training plan.

- Adherence to this policy is monitored by clinical supervision, incident reporting and PALS/Formal Complaints and subsequent actions are taken in relation to identified needs and fed back to the Clinical Governance Group as appropriate.

- Action plans are implemented, actions are completed and reports on progress and outcome are produced for the relevant committee.

5.4. **Director of Workforce** is responsible for:

- The provision of suitable end of life education and training for all staff as per the Trust's training needs analysis.

- The production of regular reports on training to include both attendance and non attendance in relation to end of life care elements.

5.5. **Clinical Assessment Team Clinicians** are responsible for:

- Ensuring the provision of remote guidance in End of Life (EOL) care and use of anticipatory prescribing drugs using approved guidance.

5.6. **Operational Staff** are responsible for:

- Adherence to this procedure

- Raising concerns as per Trust reporting procedures (where applicable)

6. Clinical Significance

6.1. Although every individual may have a different idea about what would, for them, constitute a 'good death', for many this would involve:

- Being treated as an individual, with dignity and respect

- Being without pain and other symptoms

- Being in familiar surroundings

- Being in the company of close family and/or friends

6.2. A significant element within this is appropriate management of symptoms associated with underlying pathologies such as pain or distress.

6.3. Failure to manage such symptoms can lead to unnecessary suffering and distress to patients and their families.

7. Clinical Management

7.1. A majority of patients indicate that they wish to die at home meaning that a growing number of cases where staff will be required to support and facilitate these wishes through the timely management of symptoms present in EOLC.

7.2. Clinical management should be based upon the assessment and supportive management of patients using their personalized care plan wherever possible. However in the event of the absence of this planning or the need for further support, the overarching procedure for the **clinical management in end of life care procedure is shown in appendix 1.**

7.3. **Peri-arrest for patients in the last hours/days**: Is a complex and emotive situation for healthcare staff therefore management must be guided and appropriate.

- These patients will be unconscious, hypotensive and hypoxic.
- Management should follow **Clinical management in End of Life Care Procedure shown in appendix 1.**

7.4. **End of life Emergencies** are a separate clinical issue and require specialized assessment and management. **The key features of these are shown in appendix 5.**

8. Pharmacological Management of End of life Patients

8.1. Just in Case Packs / Anticipatory Prescribing

- Just in Case Packs or anticipatory prescribing allows for the needs of a patient to be foreseen and measures taken to allow for timely treatment to be given.
- These will include selected medications and Patient Specific Directions (a pre-written prescription for the administration of provided medicines).
- These medications can be legally administered by ANY healthcare professional as long as they are aware of the appropriate dosage, indications, potential side effects and the drug route required is within their scope of practice.
- In order to ensure clinical safety and staff support Clinical Advice MUST be sought from the Clinical Assessment team in EOC prior to administration of any Just in Case Pack medications. **Please see appendix 1.** Standardised guidance will be available from the Clinical Assessment Team (CAT) team as indicated in appendix 2.

8.2. **Use of EMAS Medications**

- In the event that a Just in Case Pack is not available then EMAS drugs should be considered for use with a consideration of interaction with previously administered medications.

- These medications should be used in line with EMAS and JRCALC/AACE Clinical Practice Guidelines

9. Consultation

9.1. These guidelines have been developed in conjunction with the East Midlands Clinical Advisory Group for End of life which includes representation from across the East Midlands.

10. References/Bibliography

- Leadership Alliance for the Care of Dying People (2014) One chance to get it right. HMSO, London.

- Department of Health (2008) End of Life Strategy

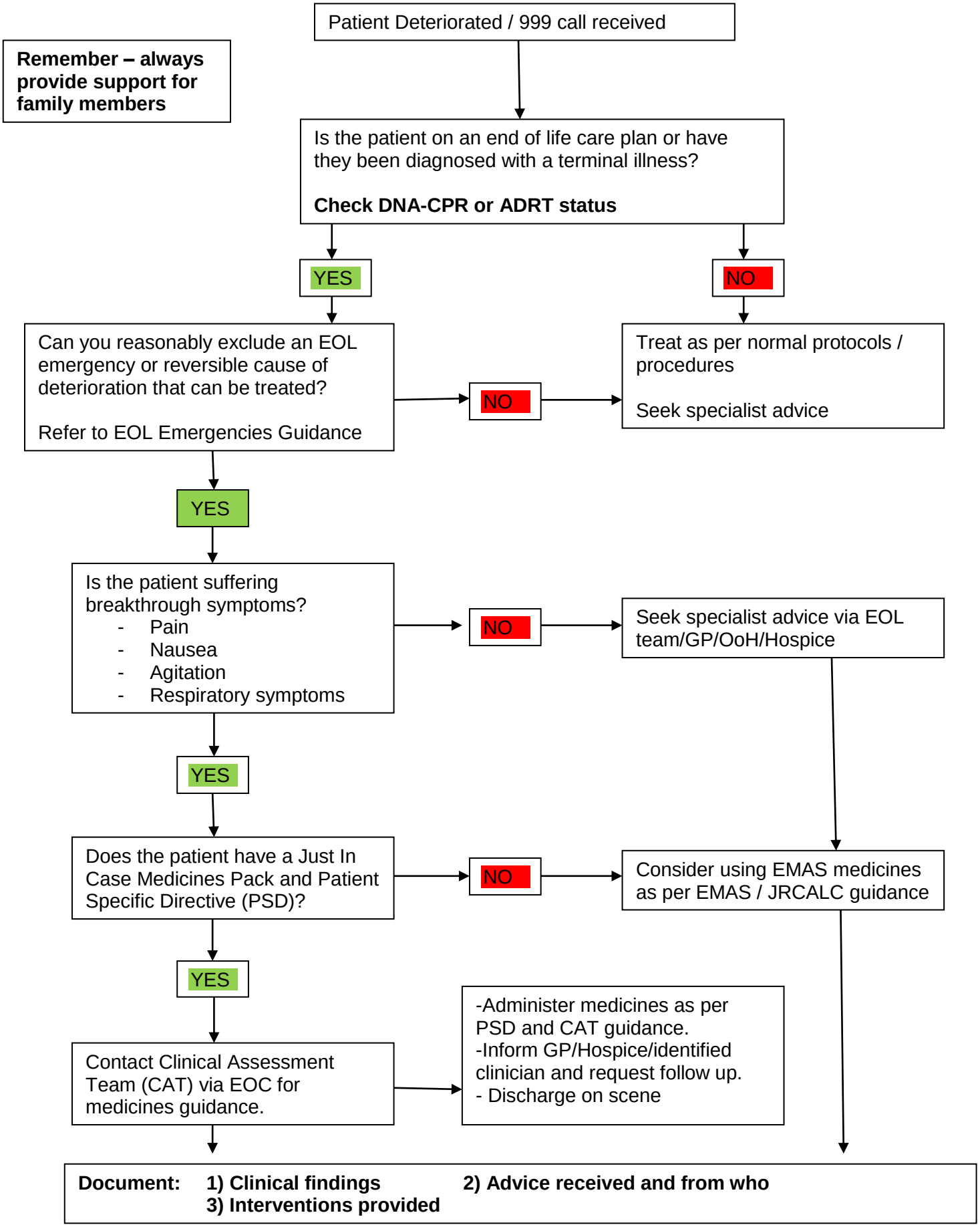
- Joint Royal Colleges Ambulance Liaison Committee (2013) UK Ambulance Service Clinical Practice Guidelines

- National End of Life Care Programme (2012) Capacity, care planning and advance care planning in life limiting illness. NHS EOLCP, London.

11. Monitoring Compliance and Effectiveness

11.1. The effectiveness of this procedure will be reviewed through the Clinical Effectiveness Group using local and regional reports of incidents and feedback and escalated to the Clinical Governance Group as required.

Appendix 1: End of Life Clinical Management Plan



Appendix 3 – Advanced Decision to Refuse Treatment

What is an ADRT?

An ADRT enables a person to refuse specified medical treatment in advance of a time where they may be unable to consent or refuse treatment following the loss of mental capacity. It is not possible to make an advance *request* for treatment; however such information can be used to inform consideration of the patient's best interests.

Who can make an ADRT?

A person may make an advance directive if they:
- Are over 18 years old and,
- Have capacity at the time of making the ADRT.

Do you have to have an End of Life Care (EoLC) diagnosis to make an ADRT?

ADRT's are not exclusive to End of Life Care, however are commonly seen in these scenarios. In EoLC situations ADRT's are often created to deal with resuscitation directives and it is essential to ensure that ADRT's which relate to life-sustaining treatment fulfil the legal requirement stipulated by the Mental Capacity Act 2005. It is reasonable to commence resuscitation whilst the facts of an Advance Directive are established.

Can an ADRT be made verbally?

Only where the treatment being refused does not constitute a life-sustaining treatment.

What if the ADRT is for Life-Sustaining Treatment?

The Mental Capacity Act 2005 stipulates that for an Advance Directive to be applicable for life-sustaining treatment it **must** meet the following criteria:

a) It must be in writing.

b) Where an ADRT is for life-sustaining treatment the law requires that it is made in writing, signed and dated, and witnessed and should include the term "even if life is at risk".

c) It must specify the treatment being refused; this can be written in layman's terms.

d) It must be signed by the patient or another in their presence if they are unable to sign it themselves.

e) It must be witnessed.

It has been established in case law that these criteria **must be met in full** for the Advance Directive/ADRT to be valid in law1.

1 See *An NHS v D [2012] EWHC 885 (COP)*

When is an ADRT *not* valid?

An ADRT is not valid if the patient:
a) Has withdrawn the directive at a time when s/ he has capacity to do so;

b) Has, under a Lasting Power of Attorney created **after** the ADRT was made, conferred the authority to a donee (or donees) to give or refuse consent to the treatment to which the ADRT relates, or

c) Has done anything else clearly inconsistent with the ADRT remaining his/ her fixed directive.

The patient has a DNA-CPR, but doesn't have an ADRT. Does that mean the patient has not been consulted?

Not necessarily. A DNA-CPR directive is a treatment directive taken in advance by a clinician. An ADRT is a refusal of treatment made in advance by the patient. The creation of an ADRT may be made for many personal reasons. ADRT's, where valid and applicable, like contemporaneous refusals of treatment should be respected regardless of whether the clinician understands or agrees with the patient's directive or their rationale.

What is the relationship between ADRT's and Lasting Power of Attorney?

If an ADRT is made, and subsequently the patient confers the authority to make the refusal specified in the ADRT to a donee under the Lasting Power of Attorney - Health and Welfare (LPA) the ADRT is no longer valid. Here, the LPA supersedes the Advance Directive. However, if the patient creates and registers a donee under Lasting Powers of Attorney, and subsequently makes an ADRT then the ADRT is valid. Essentially, the more contemporary of the two tools should be used. It is important to remember that ADRT are only applicable for the treatment specified.

When is an ADRT *not* applicable?

An ADRTis not applicable to the treatment in question if:
a) At the material time the patient has capacity to give or refuse consent to it;

b) The treatment is not the treatment specified

c) Any circumstances specified are absent, or

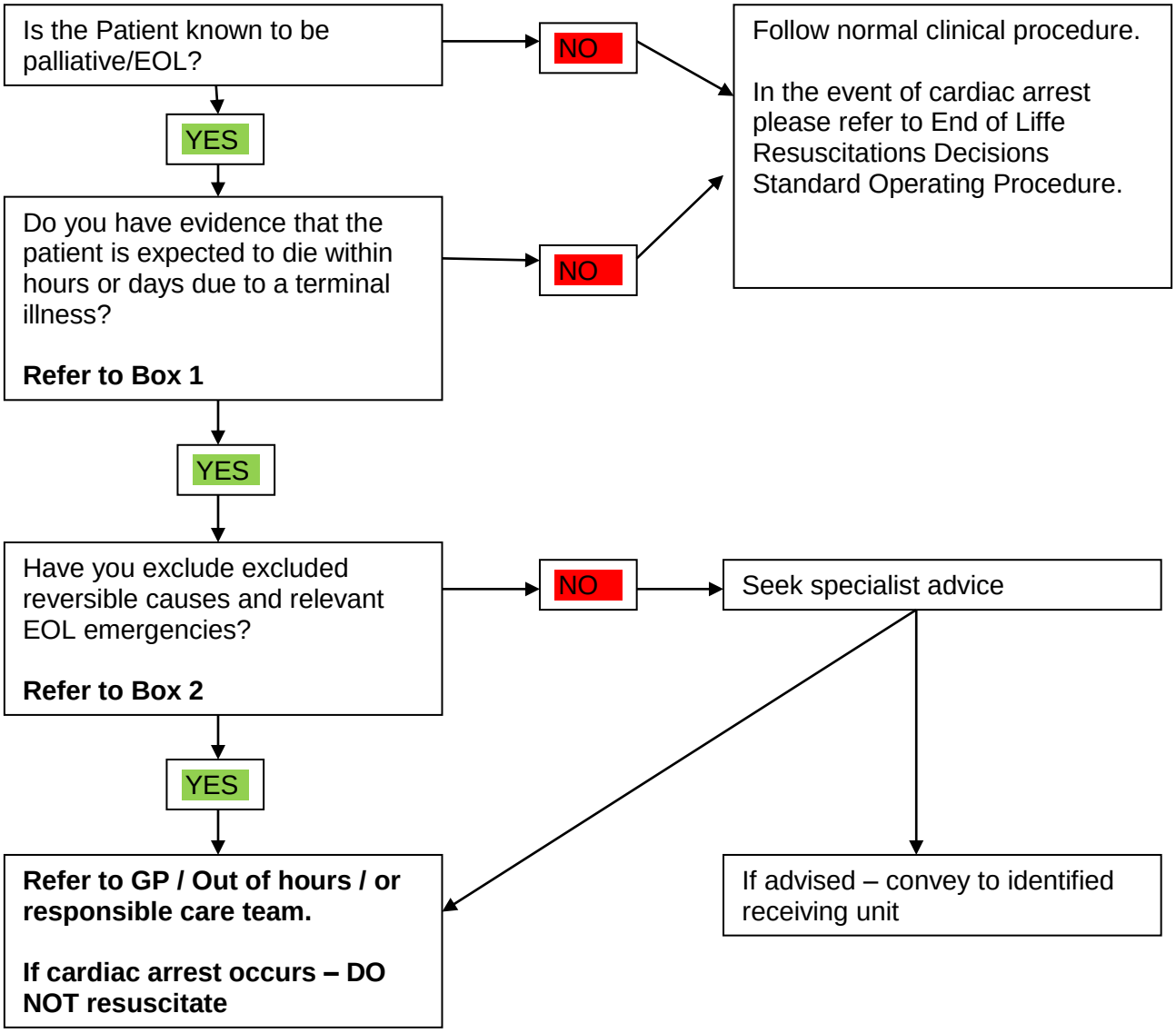
d) There are reasonable grounds for believing that circumstances exist which the patient did not anticipate at the time of the ADRT and which would have affected his directive had s/ he anticipated them.

If there is any uncertainty about the validity or applicability of an ADRT then clinical advice should be sought. In some cases, the Court of Protection will be required to intervene. Whilst advice is being sought, nothing in the ADRT should prevent the provision of life-sustaining treatment or treatment to prevent deterioration.
An invalid ADRT may still provide information which enables clinicians to assess a person's best interests if they have reasonable grounds to think it is a true expression of the person's wishes. In such circumstances, staff on scene should follow National Clinical Guidelines and seek clinical support.

Appendix 4: Peri-arrest events in End of Life Care Procedure

Recognising the Peri-arrest state

- **Hypoxic**
- **Bradycardic**
- **Hypotensive**



Box 1

Look for information to determine if the patient is at the end of life.

-District Nursing notes indicating terminal phase of disease.
-DNACPR / ADRT/ Care plan
-If possible contact responsible clinician to confirm.
-JRCALC/AACE 2013 guidance.

Box 2

Relevant End of life Emergencies

- Superior Vena Cava Obstruction
- Hypercalcaemia
- Opioid Toxicity
- Acute Intestinal Obstruction
- Choking

See guidance in appendix 5.

Appendix 5: Palliative Care Emergencies Guidance

In End of Life Care the priority of care is usually around palliative symptom control with an emphasis on treating patients in the community setting.

This guidance outlines a number of emergencies which are often seen in patients under palliative care which represent reversible emergencies which require prompt treatment to improve quality of life.

Many patients who present with palliative care emergencies have an established relationship with a palliative care team who may be able to assist if uncertainty exists and/ or may be able to assist with a direct referral/ conveyance to a specialist unit.

Acute infection/ Neutropenia

Neutrophils are white blood cells which have a crucial role in the body's response to infection. These cells are plentiful in normal circulation; however their numbers decrease enormously during chemotherapy leaving patients immunocompromised. This reduction in circulating neutrophils usually occurs between 2 to 7 days following chemotherapy, however patients up to three weeks post chemotherapy should be considered at risk.

Early sepsis can be subtle; however patients with neutropenic sepsis can deteriorate extraordinarily rapidly and must be treated as a time critical emergency.

Signs include:
- Fever (>38°C)
- Tachycardia
- Hypotension

Patients undergoing chemotherapy should have an alert card. This card will include details regarding their chemotherapy and emergency contact numbers. This can be used to seek advice and/ or to arrange a direct admission however this must be balanced with the urgency of the need to admit the patient.

Superior vena cava obstruction

The superior vena cava drains the head, neck, upper limbs and thorax and is a relative thin walled, low pressure vessel which can be easily compressed. Common causes are an intraluminal thrombus, external pressure or direct invasion of the vessel wall. It is usually associated with tumours of the mediastinum, most commonly primary bronchial carcinoma. Signs include (note signs may worsen when arms are raised above head):

- Congested veins of the arms, neck, anterior chest wall
- Facial flushing/ oedema (esp. peri-orbital)
- Oedema of the hands & arms
- Stridor (resulting from laryngeal oedema)
- Breathlessness/ sense of drowning/ tachypnoea
- Headache (worsens on stooping due to cerebral oedema)
- Dizziness/ visual changes/ syncope
- Cyanosis
- Reduced level of consciousness/ coma
- Dilated superficial veins of the upper chest (see image below)

SVC obstruction is a reversible condition. If suspected, patients should be conveyed to the ED for assessment and management. Aspects of care for the ambulance clinician focus on analgesia (if required) and oxygen therapy if hypoxaemic. Positioning the patient semi-recumbent (with head elevated may provide some relief).

Spinal Cord Compression

Spinal cord compression may occur in advanced cancers, and is most commonly caused by vertebral collapse. There is often a background of chronic pain preceding the compression associated with bony metastases and/ or developing compression of the cord. Always consider SCC in cancer patients with weak legs and/ or urinary or bowel symptoms.

Signs and symptoms
- Back pain
- Abnormal sensation/ sensory changes
- Changes to bowel/ urinary habits
- Lower limb weakness

Spinal cord compression should be treated as an emergency and patients should be conveyed to the ED; it may be useful however to contact the patient's palliative care team for advice and/ or to arrange an admission.

Hypercalcaemia

Occurring in 10% of cancer patients; hypercalcaemia is a very subtle presentation, with signs and symptoms which mimic many other conditions. The key here is to consider the patient presentation holistically and speak with a specialist if not conveying; these patients may present initially as appearing relatively well but will deteriorate rapidly without treatment.

Signs and symptoms:

Mild/ moderate
- Thirst and polyuria
- Anorexia
- Nausea, vomiting and constipation

Severe
- Weakness/ abnormal neurology
- Gross dehydration
- Confusion and drowsiness
- Cardiac arrhythmias

Haemorrhage

Haemorrhage in the end of life care patient can broadly be categorised into to two groups:

Acute (Catastrophic)

This complication of some cancers is extremely distressing, regardless of whether the patient and their family have been warned of its potential.
Where massive and irreversible haemorrhage in the EoLC patients presents as the terminal event, there is rarely sufficient time to move the patient to their preferred location of death (if this is not the place where they are presenting).

In such cases the priority of care will be to calmly provide supportive care. If the patient is in possession of a ‘crisis box’ containing emergency medication they may be given sedatives if prescribed (and the clinician is competent in the route of administration). Apply pressure to the bleeding and where possible use dark materials.

Non-acute

Non acute haemorrhages may require ED admission depending on the severity and may include:

- Evidence of anaemia
- PR bleeding, haemoptysis and/ or haematemesis (short of catastrophic)

In cases of non-acute haemorrhage consider the cause and the patient’s general presentation and consider conveyance to the ED. It may be helpful to contact the patient’s palliative care team for a clinician to clinician discussion prior to conveyance if appropriate.