

## **End of Life Care Guidance & Procedures**

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## 1 Principles

- 1.1. This document sits under the **End-of-Life Care Policy**
- 1.2. This document describes the requirements and processes which underpin care for patients at the end of their lives by South East Coast Ambulance (SECAmb) NHS Trust (the Trust).
- 1.3. To recognise that those approaching the end of life may have preferences for their treatment and care goals, which differ from the standard approach for acute treatment.
- 1.4. These procedures apply to all trust clinicians.
- 1.5. The trust encourages shared and joint decision making in complex cases. This can be via internal mechanisms of support or external GP services, specialist palliative care providers or any other appropriate clinician (subject to any restrictions in the <a href="Scope of Practice and Clinical Standards">Scope of Practice and Clinical Standards</a>
  <a href="Policy">Policy</a> appendix relevant to each clinical grade). As well as families and those closest to the patient.
- 1.6. As patients enter the end of life (EOL) phase, it is imperative that ambulance clinicians provide care following a patient's wishes, where practically possible.

## 2 Definitions

- 2.1. **Palliative Care** services for patients and their families with moderate to high complexity care needs, as part of a holistic, interdisciplinary approach to specialised medical and nursing care, where the aims are non-curative. Focus is on providing relief from the symptoms, pain, physical stress, and mental stress at any stage of their illness.
- 2.2. **End of Life Care** the provision of supportive and palliative care in response to the assessed needs of patients and family during the last year of life.
- 2.3. **Care of the dying adult (actively dying)** –refers to the management of patients during the last few hours and days of life.
- 2.4. **Expected death** where a death:
  - has occurred and was expected AND
  - A doctor or Health Care Professional (HCP) has had contact with the patient within the last 28 days of life.
- 2.5. **Unexpected Death, but no surprise** Deaths that may seem a surprise to those closest to the patient or were quicker than anticipated, but still clinically expected.

- 2.6. **Unexpected Death** if a death is not clinically expected or has occurred in suspicious, unnatural, violent, or unexpected circumstances.
- 2.7. **Preferred Place of Care (PPOC)** an individual's preference on where they would prefer to receive care.
- 2.8. **Preferred Place of Death (PPOD)** an individual's preference on where they would prefer to die.
- 2.9. Advance Care Plan (ACP) an umbrella term denoting a process for individuals to seek advice and support on how they would prefer care, treatment and medical management towards the end of their life.
- 2.10. Advance Decision to Refuse Treatment (ADRT) a legally binding document that sets out specific refusal of treatments, should an individual lose mental capacity.
- 2.11. **Lasting Power of Attorney (LPA)** for health and welfare, is a legal document that lets an appointed attorney make decisions on behalf of the individual when they lose mental capacity or have the inability to communicate effectively.

## 3 Recognising Advance Care Planning Documentation

- 3.1. <u>Definition</u>: Advance care planning (ACP) is a voluntary process of discussion about future care between an individual and their care providers.
- 3.2. <u>Clinicians Actions:</u> For individuals who have mental capacity at the time of a clinical decision being made, it is their current wishes which need to be considered.
- 3.3. These wishes may have changed from when an advance care plan had been written. If this is the case, an individual's current wishes should be followed.
- 3.4. Advance Care Plans are not legally binding however, they must be taken into consideration when making clinical decisions, particularly when making a best interest decision.
- 3.5. It is an individual's right to be able to decide Preferred Place of Care (PPOC) and Preferred Place of Death (PPOD), which SECAmb staff should always be respectful of.
- 3.6. Preferred places of care and death should be documented in an advance care plan.
- 3.7. Please see Appendix F for a summary and comparison of documentation.
- 3.8. Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)

- 3.8.1. <u>Definition:</u> ReSPECT is a process that creates personalised recommendations for a patient's clinical care in a future emergency in which they are unable to make or express choices. It provides health and care professionals responding to that emergency with a summary of recommendations to help them to make immediate decisions about that person's care and treatment in line with the patient's wishes. ReSPECT can be complementary to a wider process of advance/anticipatory care planning.
- 3.8.2. A ReSPECT form is created collaboratively through multiple conversations between a patient and their health and care professionals.
- 3.8.3. ReSPECT can be for anyone of any age but will have increasing relevance for people who have complex health needs, people who are nearing the end of their lives, and people who are at risk of sudden deterioration. Individuals may want to record their care and treatment preferences for other reasons.
- 3.8.4. <u>Clinicians Actions</u>: The ReSPECT form will contain a resuscitation decision that has been made with this patient, **including a decision** detailing whether resuscitation is appropriate or not.
- 3.8.5. This ReSPECT document will replace the existing DNACPR forms.
- 3.8.6. Similarly to a DNACPR form, the ReSPECT recommendations are not legally binding. However, clinicians should be prepared to justify valid reasons for overriding the recommendations on a ReSPECT form, remembering the information contained reflects the patient's wishes and preferences.
- 3.8.7. The ReSPECT tool will come in the format of a lilac two-page document. This may be in a paper format or an electronic copy/template.
- 3.8.8. The form can be printed in black and white although it is recommended that it is not photocopied. If you are presented with a black and white or photocopied form, please check and verify the information contained is up to date and still reflects the patient's wishes.
- 3.8.9. The document will not contain a specific review date, however, does contain space for amendments to be made by other health care professionals (outside of SECAmb).
- 3.8.10. If a resuscitation decision has been changed on the form, then the form must be re-written in its entirety.
- 3.8.11. The document is signed by the completing clinician, not the patient or family/carers. Electronic signatures or typed signatures are accepted, provided the clinicians registration number is also present.

## 3.9. Advance Decision to Refuse Treatment

#### **Definition:**

3.9.1. An Advance Decision to Refuse Treatment (ADRT) is a document in which a patient specifies refusal of treatments that they would not wish to receive.

## **Clinicians Actions:**

- 3.9.2. It is a legally binding document, provided it is valid and applicable to the current circumstances.
- 3.9.3. An ADRT decision may contain a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) instruction.
- 3.9.4. If an ADRT relates to life sustaining treatment (e.g., a wish not to be resuscitated/ventilated), it must be a written document.
- 3.9.5. The Mental Capacity Act 2005 confirms that an advance decision will be valid and legally binding if:
  - The patient was 18 years old or over.
  - Had capacity when the decision was made.
  - The decision is in writing, signed, dated by the patient and the patient's signature is witnessed.
  - Must contain the statement 'I refuse this treatment even if my life is at risk as a result'.
  - The circumstances that have arisen match those envisaged in the advance decision.
- 3.9.6. Healthcare professionals will be protected from liability if they:
  - Stop or withhold treatment because they reasonably believe that an advance decision exists, and that it is valid and applicable.
  - Treat a person because, having taken all practical and appropriate steps to find out if the person has made an Advance Decision to Refuse Treatment, they do not know or are not satisfied that a valid and applicable advance decision exists.
- 3.10. ADRT's in cases of suicide and self-harm
- 3.10.1. The role of ADRT in suicide is a complex issue which is not clearly defined in legislation or clinical practice guidance.
- 3.10.2. In the case of death by suicide an ADRT is invalidated and therefore resuscitation should be commenced.

- 3.10.3. ADRTs are written with the intention of ensuring a peaceful death, related to a progressive disease. HM Coroner has reviewed cases where an ADRT has been in place and suicide was given as the cause of death. Following these reviews HM Coroners have decided that ADRTs are not applicable in cases of suicide.
- 3.10.4. In complex situations such as these, it is strongly recommended that joint decision making is sought, via the Critical Care Desk or PP hub, with the option to escalate to Strategic Clinical Advisor within the trust.
- 3.11. Resuscitation Decision Tools (DNACPR Decisions)
- 3.11.1. <u>Definition:</u> A clinical decision, usually documented within an ACP, communicating to clinicians that the treatment of Cardio-Pulmonary Resuscitation (CPR) would not be appropriate for some patients.
- 3.11.2. <u>Clinicians Actions:</u> It is recognised that there are circumstances where attempting to prevent a natural and inevitable death could do harm.
- 3.11.3. A number of forms detailing resuscitation decisions exist across the Trust. This includes:
  - 'Do not attempt resuscitation' form (DNACPR)
  - 'Recommended Summary Plan for Emergency Care and Treatment' (ReSPECT)
- 3.11.4. If clinicians have genuine doubts, and are therefore not satisfied about the existence, validity, or applicability of the resuscitation decision or ADRT, resuscitation should be provided without delay.
- 3.11.5. Validity criteria.
  - Correct Patient name and date of birth.
  - Form signed by a Registered HCP.
  - If the signature is not in original ink, typed and electronic signatures are acceptable when paired with the HCPs registration number.
- 3.11.6. Citing learning disabilities as a clinical reason for a DNACPR form to be in place is not valid and any cases where this is found to be happening should be escalated via the Trust Datix system.
- 3.11.7. Where resuscitation has commenced and it becomes clear that it was inappropriate (presence or DNACPR or other clear indication of ACP or terminal illness), resuscitation should be ceased immediately. The Critical Care Desk can be called for joint decision making and support.
- 3.11.8. DNACPR's will increasingly be available in electronic form through shared care records.

- 3.12. Circumstances when a DNACPR decision may not be followed
- 3.12.1. DNACPR decisions are a clinical judgement, made in advance by the patients' healthcare team, as to the likelihood of a patient not responding to CPR in the event of cardiac arrest.
- 3.12.2. Where a patient suffers a cardiorespiratory arrest, arising from a readily reversable cause (i.e., Choking) BLS must be commenced and consideration should be given to addressing the reversable causes.

  DNACPRs are not applicable in these circumstances.
- 3.12.3. The patient's response to treatment should guide your ongoing management plan, including consideration of meeting the criteria for futility.
- 3.12.4. Decision support around resuscitation and DNACPRs can be sought via the Critical Care Desk.
- 3.13. **DNACPR decisions and suicide considerations**
- 3.13.1. Documented DNACPR decisions are not valid in cases of suicide.
- 3.14. Care plans for Children and Young People
- 3.14.1. Children and young people with complex illnesses are likely to have an advance care plan in place.
- 3.14.2. This is likely to be documented within the nationally recognised Child and Young Persons Advance Care Plan (CYPACP).
- 3.14.3. The CYPACP may or may not include a ReSPECT form.
- 3.14.4. Children and young people, who have reached an age where they have an understanding and competence, should be involved in decision making around their care. Parents should also be involved in this joint decision-making process.
- 3.14.5. When talking to children or young people and their parents or carers, be sensitive, honest and realistic about the care being offered. Give reassurance when appropriate and openly discuss any uncertainties about the condition and treatment.
- 3.14.6. A Trust Patient Specific Instruction (PSI) will document the treatment for a specific disease and/or expected deterioration, which may be outside of our usual protocols/JRCALC guidance. This guidance will have been reviewed by the PSI sign off panel and signed by a Consultant Paramedic or Medical Director.

## 4 Communication & Breaking Bad News

- 4.1. Communicating effectively with patients and those closest to them in a highly tense, crisis situation is arguably one of the most difficult, but essential skills for ambulance clinicians.
- 4.2. Breaking bad news can be difficult and complex, causing anxiety for clinicians. There are some key points that may help in this.
- 4.3. Avoiding euphemisms is key to providing clarity within your conversations. Don't be afraid to use the words Death & Dying, as this will give a clear message, at a time that is overwhelming for people and they will find it hard to take on board new information.
- 4.4. It is important to start conversations by building trust and with confidence. Therefore, the Trust advocates for the use of 'Hello my name is...' initiative. (https://www.hellomynameis.org.uk/)
- 4.5. Information & preparation ensure that you are ready to have the conversation. Have some phrases planned in your head. Are you the right person to be having the conversation? Do you have all the information needed?
- 4.6. Environment Information is best given in a quiet, calm environment. This may not always be possible within the ambulance sector; however, every effort should be made to make the person receiving the news as comfortable as possible. Perhaps taking the person into another room or just outside of the house if practical and appropriate.
- 4.7. Warning shots It is of vital importance to give the person receiving the bad news the information in an incremental way, preparing them for the headline news about to come. This might be something as simple as asking them to sit down or phrases such as 'I'm afraid the news is not what we hoped for' or 'What I am about to tell you is going to be difficult for you to hear...'
- 4.8. Power of silence Don't be afraid to use the power of silence in conversations. Although it may feel awkward to us as clinicians, the person receiving the news will have several things they are thinking about. Wait until they fill the silence or have something they would like to ask once you have given the headline messages.
- 4.9. Try to understand what information the person already knows. They may be aware of how serious the situation is and cover most of the difficult conversation for you.
- 4.10. Having these conversations in an open, honest, compassionate manner is key.

- 4.11. We are unlikely to know all the answers to people's questions. Being honest and saying we are not sure is absolutely fine. For example: 'I don't know the answer to this, but I can help you find someone who does....'
- 4.12. Empathy is not displayed by starting a conversation with 'I'. Try and change the conversation from 'I understand' (we rarely do fully understand) to 'This must be incredibly difficult for you...'.
- 4.13. Avoid the use of the term 'at least'. It is often not as reassuring as the intention of the phrase.
- 4.14. Try to avoid talking about your own experiences, even if there are parallels to your narratives, we very rarely experience exactly the same circumstances.
- 4.15. Changing the narrative from 'What is the matter with you?' to 'What matters most to you?', will enable you to have a holistic, patient centred conversation.
- 4.16. Always check back in at the end of the conversation, to ensure that your message has been heard and fully understood.
- 4.17. It is important to reflect on the conversation afterwards. What words and phrases went well? Is there anything you would say or do differently next time? No one is going to get this right 100% of the time.
- 4.18. There are some tools that are helpful to use, such as REDMAP. Please see Appendix D.
- 4.19. Further guidance and learning can be found on <u>Discover</u>, in the End of Life Care Modules.

## 5 Just in Case (JIC) medication administration

5.1. Ambulance clinicians may well be called to patients at the end of their lives, who require medications to relive complex symptoms. These medications are prescribed in advance and known as Anticipatory Prescribing or Just in Case (JIC) Medications.

## 5.2. Non-Registered Clinicians Actions

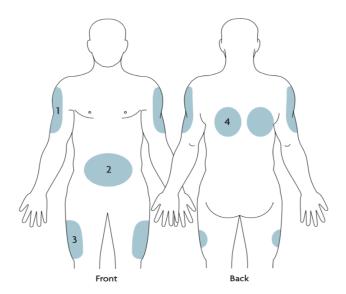
- 5.2.1. The successful treatment for symptoms experienced at end of life are not solely based around medications.
- 5.2.2. There are times when the most effective treatment is non-pharmacological.
- 5.2.3. Consider measures such as re-positioning the patient, environmental factors and psychological or spiritual causes for distress.

- 5.2.4. Non-registered clinicians are unable to administer injectable JIC medications, if you feel medications are required, please consider an early call to one of the below:
  - Hospice (if the patient is known to them)
  - District Nursing Teams
  - Paramedic backup
  - PP Hub
  - GP

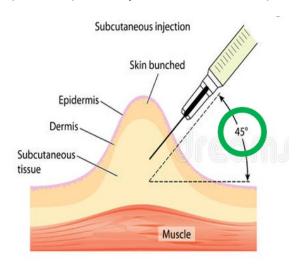
### 5.3. **Paramedic Actions**

- 5.3.1. Please see Appendix G for Paramedic administration of medications
- 5.3.2. Paramedics may administer a patient's own JIC medications under the following conditions:
  - That there is an accompanying Medicines Authorisation and Administration (MAAR) chart, signed by an authorised prescriber.
  - The administering clinician is confident and competent in administering the drug, via the route suggested.
  - The clinician is aware of each drugs' indication, appropriate dose, side effects, signs, and subsequent treatments if toxicity is to be suspected.
- 5.3.3. MAAR charts do not have a specific format but should include:
  - Name of patient and/or other individual patient identifiers (including age if a child).
  - Name, form, and strength of medicine
  - Route of administration, Dose, Frequency,
  - Signature of prescriber and date MAAR chart written
- 5.3.4. Please see Appendix I for an example of a MAAR chart used by community teams within the SECAmb area. Although there will be several different formats of these charts used across the trust geography.
- 5.3.5. Patients will often have two MAAR chart's present. One for the administration of medications as required (PRN), as well as for continuous subcutaneous Infusion (CSCI) administration, otherwise known as a syringe driver. Proceed with caution and ensure you are following the correct (PRN) chart.
- 5.3.6. There are no clinicians within the trust who are authorised under this procedure to set up a syringe driver for an end of life care patient.
- 5.3.7. For the majority of patients at the end of life, all medications should be administered through a sub-cutaneous route.

5.3.8. The appropriate sies for sub-cutaneous administration of medicines is shown below in order of preference:



5.3.9. The method for giving a sub-cutaneous (SC) injection is described in the image below. However, if you are not confident in giving a SC injection, please speak to your local leadership team to arrange practice sessions.



- 5.3.10. Prior to administering any medication, the most senior clinician on scene should conduct a double check with colleagues, or self-check if lone working. This is to confirm the appropriate dose and the full name of the medication, strength of drug, ampoule concentration/volume, as well as the drugs' expiry date. As per the Trust's <a href="Standard Operating Procedure for Administration of Medicines.">Standard Operating Procedure for Administration of Medicines.</a>
- 5.3.11. Clinicians are reminded of the importance of considering the psychological, social, and spiritual needs of the patient. The use of non-drug interventions in EOLC can be as impactful as medication in some circumstances and reliving psychological distress.

- 5.3.12. JIC medicines will usually be prescribed when a patient's clinical condition has been assessed to be deteriorating or unstable, however it may not mean that the patient is expected to die imminently.
- 5.3.13. JIC medicines may be kept either in a bag, box, or toolkit within the patient's own home.
- 5.3.14. Ambulance clinicians are encouraged to collaborate with the patients care team prior to the administration of medications. This is likely to be the Hospice team.
- 5.3.15. Hospice teams are likely to be able to provide advice around the medication & dosages given and what might have previously worked for the patient.
- 5.3.16. The administering clinician should complete and sign the MAAR chart. Documenting the drug name, dose, route, batch number and expiry date, as well as updating the Trust Patient Care Record (e-PCR).
- 5.3.17. Where possible, please photograph a copy of this into e-PCR.
- 5.3.18. If there is not a paper method of recording what medications we have given on scene, clear communication needs to take place with the patients care team, informing them of the treatments given and the e-PCR calling card must be left.
- 5.3.19. Future developments around shared care records across the local healthcare systems may mean that all records are kept and completed electronically.
- 5.3.20. When a patient has required an administration of JIC medications, clinicians must contact the relevant team coordinating the patient's care. It is likely these symptoms will return, and future management plans should be made.
- 5.3.21. There is no legally valid period for a MAAR chart allowing the administration of a medicine if an expiry date is not given. It is best practice for the prescriber to include a start and finish date as appropriate within the direction. This is to ensure it is acted on within a time frame following the assessment made by the prescribing clinician, to meet the needs of the patient.
- 5.3.22. If the MAAR chart specifies an expiry date and this date has passed, then the medications must not be administered.
- 5.3.23. Remote Prescribing/ Verbal Orders for the administration or supply of any Prescription Only Medicine (POM) drug is not supported by the Trust.
- 5.3.24. In many cases patients will wish to remain at home and it is reasonable to administer JIC medications and keep the patient at home in the majority of circumstances.

- 5.3.25. Further information and clinical advice can be sought from the <u>Adult</u> <u>Palliative Care Guidelines (PANG)</u>. Available at: https://book.pallcare.info/
- 5.3.26. All adverse effects experienced after the administration of JIC medication, must be reported via the Trust's Datix system.

# 5.4. Paramedic Practitioners (PP) & Critical Care Paramedics (CCP) Actions

- 5.4.1. PPs & CCPs may follow the above guidance for paramedics, with the addition of the following information.
- 5.4.2. Appendix H Supports PPs & CCP administration of your SECAmb issued JIC medication as per the PGD.
- 5.5. Management of Medications after death
- 5.5.1. Please see section 7.11 within the adult death procedure

## 6 Common Palliative Symptoms

- 6.1.1. The most common symptoms experienced with EOL patients (but not with all patients) include:
  - Pain
  - Nausea and Vomiting
  - Breathlessness
  - Respiratory secretions
  - Restlessness, anxiety and agitation.
- 6.1.2. A patient may also experience a palliative care emergency. Further learning around these conditions can be found in Discover.
- 6.2. **Pain**
- 6.2.1. Pain is a very common symptom experienced by patients at the end of life.
- 6.2.2. Clinicians should assess the cause of the pain prior to treatment. This includes a holistic assessment considering:
  - Physical effects or manifestations
  - Psycho-social factors
  - Spiritual aspects
- 6.2.3. The concept of 'total pain' as has been well accepted within the palliative care community and colleagues should consider this within their clinical assessments.

- 6.2.4. It is important to consider the source of the patient's pain, as causes may not relate to the patient's physical disease process may include poor positioning, urinary or bowel dysfunction, as well as spiritual or psychological distress.
- 6.2.5. Pain scores and assessment should be documented on e-PCR.
- 6.2.6. Assessing pain in people with dementia or cognitive impairment can be challenging. Use of the Abbey Pain Scale is recommended for these patients.
- 6.2.7. Careful consideration must be given to the choice of analgesia.
- 6.2.8. Wherever possible, administration of a patient's own JIC medicine should be sought.
- 6.2.9. Non-Opioids Non-opioids such as paracetamol have particular advantages in that they have very few side effects.
- 6.2.10. Weak Opioids These are used when non-opioids are ineffective. They include codeine phosphate and are often used in combination with paracetamol.
- 6.2.11. Strong Opioids Morphine remains the first-line strong opiate of choice and oral morphine is considered to be the gold standard as a first line therapy in palliative & EOLC. It is important to titrate any strong opiates to the patient's response.
- 6.2.12. Doses may well have been increased by a prescriber if the patient has already been on any opiate/opioid for some time.
- 6.2.13. If the patient is already taking a regular opioid, then the dose for breakthrough pain is generally 1/6th of the patient's 24-hour total dose. For example, if the patient has taken:
  - 15mg Modified Release (MR) Morphine at 7am + 15mg MR Morphine at 7pm
  - = 30mg total oral morphine taken in the last 24 hours.
  - Your 1/6 breakthrough dose will therefore be 5mg oral Morphine.
- 6.2.14. If you are required to give an injectable medication, you would divide the number in two. Therefore, your injectable dose for the calculation above would be 2.5mg Morphine.
- 6.2.15. Please refer to <u>Palliative Care Guidelines</u> for tools in assisting with this calculation.
- 6.2.16. Bear in mind that this may be a significant dose, more than a Paramedic would administer of their own Morphine supply. If you are unsure or you

- are not confident, please call for support from the specialist palliative care team or SECAmb PPs.
- 6.2.17. Effects should normally be seen in 15-20 minutes.
- 6.2.18. There may be rare circumstances when conversion dosages between different opioid medications are required. It is recommended that these calculations are not done in isolation and an opioid conversion chart is used. These can be accessed through specialist palliative care providers.
- 6.2.19. Parenteral medicines which are administered via the SC route should NOT be diluted.
- 6.2.20. If there are no prescribed JIC medications with the patient, please refer to the *JRCALC Plus* app, where there is dosage information and guidance under Morphine.

#### 6.3. **Breathlessness**

- 6.3.1. It is recognised that breathlessness can be very distressing for patients and occurs in about a third of all patients receiving palliative care.
- 6.3.2. A history and examination of the patient with breathlessness, will help determine the cause. The degree of intervention desired by the patient will vary and management decisions should be made with them and their families.
- 6.3.3. Some management options for breathlessness include:
  - Positioning
  - Use of fan
  - Breathing techniques (such as the calming hand breathing strategy)
  - low dose opiates (oral or SC)
  - an addition of a benzodiazepine (oral, buccal or SC)
- 6.3.4. Pharmacological treatment for breathlessness is commonly administration of a low dose opiate, in conjunction with treatments for anxiety and restlessness, such as Lorazepam or Midazolam. Administration of these medications must be guided by the patients MAAR chart.
- 6.3.5. If the patient is not prescribed JIC medications for Breathlessness, please seek further guidance within the JRCALC guidance, under Morphine.

#### 6.4. Nausea and Vomiting

- 6.4.1. An understanding of the likely causes of nausea & vomiting is required for accurate assessment and treatment, resulting in better symptom control.
- 6.4.2. Possible causes of nausea and vomiting include:
  - Irritation or stretching of the meninges by intracranial tumour
  - Pelvic or abdominal tumour

- Bowel obstruction, impaction
- Gastric stasis
- Chemically/metabolically induced e.g., hypercalcaemia
- Anxiety related
- Medication side effects
- 6.4.3. There are a number of anti-emetics that a patient may be prescribed to help with these symptoms, however patients will be prescribed a maximum of two on their MAAR chart.
- 6.4.4. If clinicians are unsure which anti-emetic to use, advised should be sought from specialist palliative care providers or the prescriber.
- 6.4.5. Clinicians should also consider non-pharmacological management of nausea, such as reassurance and environmental factors e.g., management of smells.
- 6.5. If there are no JIC medications on scene, administration of Ondansetron can be considered. Please see further guidance in JRCALC.
- 6.6. **Respiratory Secretions**
- 6.6.1. Respiratory Secretions are a terminal sign and should be an indicator that the patient is actively dying, prompting discussion with those closest to the patient and onward referral for management.
- 6.6.2. It is noted that respiratory secretions are very distressing, including for family, carer, or next of kin (NOK) and this should be considered in the management plan. Reassurance should be given that these symptoms are often more distressing to witness than experience.
- 6.6.3. The primary treatment is to reposition a patient to their side or sat more upright (dependant on patient comfort) and this should be done before any drug intervention.
- 6.6.4. Hyoscine or Glycopyrronium are often used to relief secretions and one of these are likely to be prescribed within the patients JIC medications.
- 6.6.5. Hyoscine and Glycopyrronium are best administered through CSCI (syringe driver) and therefore all patients must have an onward referral to facilitate setting up CSCI. This is likely to be district nursing or hospice teams.
- 6.6.6. If there are no JIC medications on scene, consider an early call to specialist palliative care teams for prescription of Hyoscine or Glycopyrronium.
- 6.6.7. If specialist palliative care teams are unable to facilitate this in a timely manner, discuss with PPs & CCPs for administration of their SECAmb carried JIC medications.

## 6.7. **Anxiety & Terminal Agitation**

- 6.8. Many patients will experience anxiety during their last year of life and this may or may not be linked to other symptoms, such as breathlessness and an increase in pain.
- 6.9. Terminal Agitation in the last days or hours of life may be caused by several factors and any reversable causes should be considered before pharmacological intervention. This may be, but not limited to, the following:
  - Poor positioning
  - Constipation
  - Urinary retention
  - Increased pain
- 6.10. Clinicians should be mindful to holistic approaches in treating anxiety, with non-pharmacological methods being sought in the first instance.
- 6.11. Sub-lingual Lorazepam is often prescribed for cases of anxiety, with or without breathlessness.
- 6.11.1. Midazolam is the usual drug of choice for terminal agitation and restlessness.
- 6.11.2. All medications should be titrated to response. If repeat doses are required, speak to specialist palliative care services for further advice and guidance.
- 6.11.3. If there are no JIC medications on scene, discuss with PPs & CCPs for the administration of their SECAmb carried JIC medications.
- 6.11.4. Discuss with specialist palliative care teams.

#### 6.12. Terminal Bleeds

- 6.12.1. Although rare, clinicians should be aware of the possibility of patients dying from a terminal catastrophic bleed.
- 6.12.2. This is likely to be patients with cancers, where fungating tumours develop over major blood vessels. These tumours commonly sit over the neck, groin or oesophagus and are at higher risk of catastrophic haemorrhage.
- 6.12.3. The patients care team are likely to be aware of the risk of a terminal bleed and prepare the patient and family appropriately.
- 6.12.4. This may be with an additional higher 'crisis' dose of midazolam and an analgesic prescribed on the patients MAAR chart. The purpose of this is to give a suitable dose of symptom control medications rapidly when we will not have time to give repeat doses and titrate medications to effect.

- 6.12.5. Where the patient is dying from a major vessel rupture it is likely that death will occur quickly. Medications prescribed and basic haemorrhage control should be administered in a timely manner, but where possible should not forgo comfort care of the patient and family to achieve this.
- 6.12.6. Dark towels/blankets may also be used to support haemorrhage control and help in keeping the scene calmer.
- 6.13. Common Medications used to treat symptoms at the End of Life
- 6.13.1. Most PRN drugs are written up as subcutaneous (SC) doses and generally **NOT** intravenously (IV).

Symptom	Drug
Pain	Morphine (SC)
	Oxycodone (SC)
Nausea and vomiting	Cyclizine (SC)
	Metoclopramide (SC)
	Haloperidol (SC)
	Levomepromazine (SC)
Anxiety, Panic	Midazolam (SC), Lorazepam (sub-
	lingual)
Agitation, Confusion, Terminal	Midazolam (SC)
Restlessness	
Terminal Bleeds	Midazolam (& Opiate) (as
	prescribed)
Respiratory Secretions	Hyoscine (SC)
	Glycopyrronium (SC)

## 6.14. Opioid Toxicity recognition and management

- 6.14.1. It is imperative clinicians ask about the doses of opiate/ opioid drugs that have been administered in the previous 24 hours and remain alert to the possibility of opioid toxicity.
- 6.14.2. In palliative care opiate/ opioid toxicity may present as subtle signs and should be considered when patients have been on opiate medication for some time or recently had a change in dose.
- 6.14.3. The use of Naloxone in palliative care is rare and other avenues to treating opioid toxicity should be sought, unless an emergency has occurred after a drug error.
- 6.14.4. Clinicians should speak with the specialist palliative care teams in cases of confirmed or suspected opioid toxicity.

## 6.15. Managing symptoms in the Absence of JIC medications

6.15.1. There may be occasions where a patient deteriorates rapidly and there has not been time for anticipatory prescribing to have taken place. There

- also may be times where either the medications or the MAAR chart is missing from a patient's home.
- 6.15.2. Clinicians should try to manage the patients' symptoms with comfort interventions and non-pharmacological measures where possible and contact the patient's care team urgently to initiate a prescription.
- 6.15.3. Within SECAmb, Paramedic Practitioners (PPs) and Critical Care Paramedics (CCPs) carry the following JIC medications, for a one-off dose in an end of life care emergency.
  - Midazolam (for terminal agitation & seizures)
  - Cyclizine (for Nausea & Vomiting)
  - Hyoscine Hydrobromide (Respiratory Secretions)

#### 7 Adult Death Procedure

- 7.1. This procedure relates to adult patients who have died. For any information regarding resuscitation, please see the <u>Resuscitation (inc. DNACPR) Policy, v2.0.</u>
- 7.2. An adult is defined as anyone who has reached their eighteenth birthday and older.
- 7.3. This procedure does not apply to Emergency Medical Advisors (EMAs) or Health Advisors (HAs), who work within the scope of NHS Pathways and relevant EOC/111 Call-Handling procedures.
- 7.4. Care following death is not only important for the deceased patient, but also extends to those who were close to or caring for the patient.
- 7.5. After a patient dies, physical care of the body should be considered in a caring, culturally sensitive, and dignified manner.
- 7.6. Once 'Recognition of Life Extinct' (ROLE) has been verified and completed, death should be assessed and categorised as an:
  - Expected death, or;
  - An unexpected, unnatural, unexplained, suspicious, or violent death.

## 7.7. **Expected Death**

- 7.7.1. For a death to be categorised as expected, there are two factors which must be established.
- 7.7.2. Firstly, clear evidence that the patient is known to be nearing the end of their life. This may be through end-of-life care plans, history suggestive of deterioration/ recognition of ordinary dying or through their past medical history.

- 7.7.3. Secondly, the patient must have seen their GP or Hospice team within the last 28 days. This enables a death certificate to be completed by a doctor.
- 7.7.4. A clinically expected death may not be anticipated by the patients' family/carers at the time it occurs and may come as a shock to the patient's relatives.
- 7.7.5. This may be termed 'Unexpected, but no surprise'. Meaning the death was unexpected to the family, but clinically it was no surprise.
- 7.7.6. Clinicians should ensure that if the above two points, as per 7.7.1, are met, then the death should still be treated as an expected death if it was clinically expected.
- 7.7.7. Expected deaths ordinarily do not require a Coroner review or referral to police.
- 7.7.8. Expected deaths should be referred a funeral director of the patient or family's choice.
- 7.7.9. Staff must not recommend specific funeral directors due to the significant financial implications this may have on the family.
- 7.7.10. Notifying a funeral director is not the duty of the SECAmb clinician. It is the responsibility of the family/NOK to choose and notify a funeral director. Families will have often made this choice prior to the death or choose one that is geographically close to home.
- 7.7.11. The majority of funeral directors have a 24hour contact telephone number and contingencies.
- 7.7.12. Prior to leaving scene, staff must ensure that the patient's next of kin (or equivalent) have been notified. Do not leave the deceased patient with a carer unless this has been previously agreed and the carer knows that they are now responsible to notify the NOK.
- 7.7.13. Staff should remind families that they must contact the patients GP surgery as soon as possible (the next morning if death occurs overnight or Monday morning if death occurs at the weekend) to discuss the MCCD (death certificate).
- 7.7.14. Families have a duty to register the death with a registrar within five working days.
- 7.7.15. In the rare circumstance that a patient has died alone at home and does not have anyone to organise a funeral on their behalf, the police should be contacted.
- 7.7.16. Advice should be given to families on where they can find further help and support. This is detailed within the SECAmb Bereavement information leaflet.

## 7.8. **Unexpected Death**

- 7.8.1. An unexpected death is one that is considered to be obviously unexpected, unnatural, suspicious, unexplained, or violent.
- 7.8.2. All unexpected deaths must be referred to the police (via EOC) to act on behalf of the coroner.
- 7.8.3. Once Recognition of Life Extinct (ROLE) verification processed have been completed and a referral to the police has been made, there is no obligation for crews to remain on scene until the police arrive, provided the patient can be left in the care of a responsible adult.
- 7.8.4. A responsible adult in this scenario is considered to be a person over their eighteenth birthday, who has capacity and who feels competent and able to wait with the patient for police arrival.
- 7.8.5. There may be reasons to remain on scene if one of the following apply.
  - To console a lone relative but please do consider where other support may be accessed, for example friends or family members to come and support the bereaved.
  - To safeguard the deceased's body in rare and unusual circumstances – consider contacting the police and request an upgraded response in these circumstances.
  - To ensure care is provided to pets when the patient has died alone and while provisions are being made. Please consider RSPCA other third parties/neighbours.
  - Where there are children / vulnerable third parties on scene.
- 7.8.6. The Police are responsible for the preservation of evidence. Where a death is potentially suspicious, the Police should attend to manage the scene.
- 7.8.7. SECAmb is not responsible for guarding or preserving the scene but should take reasonable steps to prevent the scene being contaminated or evidence being lost.
- 7.8.8. Prior to leaving scene the police CAD number must be obtained from EOC and entered into ePCR, confirming the referral has been made.
- 7.8.9. Under no circumstances should photographs of the deceased be taken.

#### 7.9. Additional Considerations

- 7.9.1. Individuals who are under a 'Deprivation of Liberty' order (DOLS), soon to be called 'Liberty Protection Safeguards' (LPS), and are expected to die, do not require police to be notified, as has previously been the guidance.
- 7.9.2. The presence of a DNACPR form does not necessarily mean the patient's death will be expected, or that HM Coroner would not wish to review the death.

- 7.9.3. Doctors use the terminology 'Confirmation of Death' (CoD), whereby nurses refer to the terminology 'Verification of Life Extinct' (VLE) 'or 'Verification of Expected Death' (VOED). All of these processes have parity with ROLE and are essentially the same clinical procedure of verifying the clinical fact of death.
- 7.9.4. If a paramedic has completed ROLE, then a nurse does not need to complete VOED and vice versa. Verification of death is the process of confirming the fact of death and is a separate process to the Medical Certification of Cause of Death (MCCD). MCCD must be completed face to face by doctors, usually a patient's own GP and SECAmb is not responsible for this process.

#### 7.10. After Death considerations

- 7.10.1. Staff should have an open, honest conversation with those closest to the patient, to ascertain if there are any specific cultural or religious needs for the patient once they have died.
- 7.10.2. If there is a need for a rapid burial or cremation (e.g., before the next sunset), this needs to be clearly communicated to either the police or the GP/funeral director. This cannot be guaranteed, based on a number of variables.
- 7.10.3. All actions and care plans should be clearly documented in e-PCR, with clear notes of the ongoing management plan that has been left with the LPA/ NOK/ responsible adult.
- 7.10.4. Following a face-to-face ambulance attendance, we must:
- 7.10.5. Leave additional information with those on-scene with the next steps to take, such as an ePCR advice sheet and SECAmb bereavement leaflet (both of which can be found in the PCR posset box). Copy of the paper ROLE form or e-PCR calling card if ROLE completed electronically.
- 7.10.6. Allowing time for those closest to the patient to start/continue grieving privately is often a family's preference.
- 7.10.7. Lie the patient flat before rigor mortice starts. This allows funeral directors to remove the patient in a dignified manner.
- 7.10.8. All deaths where a patient had a learning Disability need to be reported via Learning Disability Mortality Review (LeDeR).
- 7.11. Management of JIC medications and Syringe Drivers after Death
- 7.11.1. Refer to the overarching <u>Controlled Drugs (CD) policy</u> to see key principles around the management of waste medications.
- 7.11.2. It is highly likely syringe drivers will contain controlled medicines.

7.11.3. The McKinley T34 syringe driver/ pump (see picture below) is the 'industry standard' for the delivery of a continuous subcutaneous infusion (CSCI).



- 7.11.4. The main aims of using a syringe driver is to:
  - Promote a stable plasma concentration of medication used to maximise symptom control.
  - Eliminate the need for repeated injections, suppositories or oral medication.
- 7.11.5. A Syringe driver can be removed by a registered clinician, once the Recognition of Life Extinct (ROLE) process has been completed.
- 7.11.6. Note the amount of solution remaining in the syringe that can be seen by eye, the Volume To Be Infused (VTBI) number displayed on the screen and the medications present in the syringe. You may need to press the blue 'info' button for the information to be displayed.
- 7.11.7. This needs to be recorded in SECAmb documentation via e-PCR, but also on the MAAR chart and nursing notes in the patients records on scene.
- 7.11.8. Once your notes have been completed, follow these instructions:
  - Press and hold the 'info' button to unlock the driver.
  - Turn off the syringe driver (press and hold the red button).
  - Lift and turn the 'arm' holding the syringe in place.
  - Dispose of the syringe and contents into the sharps bin.
  - Remove and dispose the subcutaneous 'butterfly' needle & giving set in the sharps bin.
- 7.11.9. If there are any problems with following the above instructions, after completing documentation, simply remove the 9v battery from the back of the syringe driver by sliding the compartment cover and removing the battery (picture below).



7.11.10. If the syringe driver is in a lockable transparent box (see picture below); a key may be within the JIC pack on site, or alternatively support from the community team may be required.



- 7.11.11. The hospice or district nursing team will need to be notified of the patient's death and they will arrange collection of equipment from the patient's home, including the syringe driver.
- 7.11.12. Once the community team have collected any equipment and paperwork, the patient's family or next of kin will need to take all (not just the injectable) medications to the pharmacy for destruction.
- 7.11.13. Under no circumstances should a patient's own medication be returned to SECAmb property.
- 7.11.14. If you have concerns around the safety of the medications remaining on scene, please contact the police and the hospice/ district nursing team.
- 7.12. Conveyance of deceased patients/ Death enroute to hospital
- 7.12.1. SECAmb are not expected or commissioned to transport patients on behalf of a funeral director service.
- 7.12.2. For patients who die on-board an ambulance whilst being conveyed to a hospice (expected death), you should continue onto the hospice and speak with the hospice doctor on arrival. This provides the best support

- and after death care. All further actions, such as MCCD, can be completed by the hospice team.
- 7.12.3. Any patient who dies on board an ambulance whilst being conveyed to hospital, must be seen via the A&E department. This is to ensure that the patient has been seen by a doctor and a referral to the coroner can be made.
- 7.12.4. For clarity, under no circumstances should a patient who has died on board an ambulance, whilst enroute to hospital, be conveyed directly to the mortuary. They must be booked in and seen in A&E.
- 7.12.5. If we attend a patient who has died in a public place, the police must be called.
- 7.12.6. On the majority of occasions of death in a public place, the police service will call the coroners funeral directors to convey the patient to a mortuary. Therefore, SECAmb crews will not need to be involved in the case post-ROLE completion.
- 7.12.7. There may be rare occasions that a patient dies in a busy public place, when it is deemed most suitable for the ambulance service to convey rapidly to the mortuary for the patient's dignity.
- 7.12.8. If this request is made, the crew should contact EOCM or tactical on call via EOC dispatch for approval to make this journey. Balancing the needs of the situation vs wider demand in the area.
- 7.12.9. Clinicians must document the name and shoulder number of the police officer responsible for the patient on e-PCR.
- 7.12.10. The deceased must be conveyed with the police officer on board or following behind.
- 7.12.11. It is this police officer's responsibility to ensure that the patient is correctly booked into the mortuary system, a referral to the coroner has been made and two identification tags have been attached to the patient, clearly identifying them. This is not our responsibility but have courage to remind police officers to follow the appropriate tagging and identification processes before leaving the patient.
- 7.12.12. Coroners' office processes cannot begin until a patient has been appropriately tagged and identified.
- 7.12.13. Please refer to Appendix C: Conveyance of the Deceased Flowchart.

## 8 Child Death procedure

- 8.1. Patients covered under this procedure are:
- 8.1.1. All Neonatal Deaths.

- 8.1.2. Still born babies, over 24 weeks gestation, where birth was unwitnessed. If the birth was witnessed by a health care professional, this does not need to be reported. For clarification all SECAmb crews are understood to be a health care professional, however Doulas or Maternity Assistants do not sit within this category.
- 8.1.3. Cases where the deceased patient is known to be or suspected to be less than 18 years of age.
- 8.1.4. The child death process must be followed regardless of the cause of the death.
- 8.1.5. The above criteria are for both expected and unexpected deaths.

## 8.2. Unexpected Deaths

- 8.2.1. This procedure must be acted upon as soon as EOC staff (EOCM/Dispatch Team leader/Dispatcher) become aware of a child death, following an update from a crew on scene that CPR is being undertaken or if there is clear confirmed evidence on a call of a child death.
- 8.2.2. The police service must be notified, appropriate to the locality the child lives in (or where the call was made) rather than where the hospital receiving the patient is located.
- 8.2.3. The exceptions for not contacting the police are for patients who are expected to die or witnessed still births, as detailed below.
- 8.2.4. The duty safeguarding team must be notified of the incident immediately, via phone by EOC, usually completed by the Dispatch Team Leader.
- 8.2.5. The duty safeguarding team will be able to notify the relevant organisations and Local Child Death Panels.
- 8.2.6. On all occasions where CPR advice is given for a patient aged under 18 years, a call audit request must be raised by the EMATL to the EOC Practice Development Team (EOC Audit). This is with the aim of developing future practice and learning.
- 8.2.7. There may be some rare occasions where a child is discovered with unequivocal signs of death and resuscitation can be ruled out. Please refer to JRCALC guidance for further detail.
- 8.2.8. Any unexpected child deaths, regardless of cause, MUST be conveyed to hospital.
- 8.2.9. A call should be made to the receiving hospital (with paediatric facilities), notifying them of the case and our ETA. Ensuring that a named consultant paediatrician is aware of the patient.
- 8.2.10. EOC (Dispatcher/EOCM/Critical Care Desk) must update crews on scene with the information regarding the named paediatrician expecting the

- patient and where within the Emergency Department we should be expected.
- 8.2.11. All unexpected child deaths should be conveyed to A&E.
- 8.2.12. In the extremely rare occasion police on scene request that SECAmb do not convey the patient to hospital, please be aware that as part of the Child Death Process, it is still necessary for the police to discuss this with a Paediatric Consultant at the nearest hospital. Have confidence to remind Police Officers of this and ensure this has been done before leaving scene.
- 8.2.13. Crews cannot be stood down from the incident, until this discussion with a paediatric consultant is completed.
- 8.2.14. Police should not delay transport of the patient to hospital, particularly in the case of sudden unexpected death where there is no obviously identifiable reason for the child to have died.
- 8.2.15. Conveyance of children who have unexpectedly died is important for several reasons.
- 8.2.16. Firstly, is to enable the process for investigating the cause of death to start as soon as possible after the event. It has been shown that cell and tissue deterioration occur extremely quickly in children, and this can have a dramatic effect on whether a definitive cause of death can be found. This, of course, must be dealt with as sensitively as possible.
- 8.2.17. Secondly, is to enable the child death rapid response process to be initiated.
- 8.2.18. Any significant delay to conveyance must be escalated via e mail or phone to the Trust's duty safeguarding team.

## 8.3. **Expected Child deaths**

- 8.3.1. Children who have a DNACPR in place or clear palliative care pathway where the death is EXPECTED and planned may be exempt from investigative processes.
- 8.3.2. The police do not need to be called for expected deaths.
- 8.3.3. The palliative care team MUST be contacted under these circumstances to discuss the patient's post-death care. Please be mindful to search for and ask the family if the patient has a post- death care plan.
- 8.3.4. Palliative care teams may request that a child is conveyed to a Hospice.
- 8.3.5. On some occasions, hospices may be able to facilitate the child to remain at home. The palliative care team must be contacted and involved in this decision-making process. A child cannot be left at home without a clear and agreed plan.

8.3.6. Take account of the beliefs and values of children and young people and their parents or carers when thinking about funeral arrangements and the care of the child or young person's body after death.

#### 8.4. **Post Death Considerations**

- 8.4.1. Support should be made available to any staff attending an incident of this nature and EOC staff involved with the call. The option for staff to debrief as a team is key and should be facilitated, where possible.
- 8.4.2. It is of paramount importance that ALL details surrounding the child's death are documented. This may be details from the scene, as well as impressions or professional opinion.
- 8.4.3. Please be mindful when documenting the scene, that you differentiate between fact and opinion. This will be critical further into the investigation, which may be months or years after the death.
- 8.4.4. Crews MUST complete Child Death Report Form. This will allow rapid collection of information that can immediately be sent to child death coordination services for the purposes of the initial information gathering meetings.
- 8.4.5. Crews may be contacted by the safeguarding team or county child death co-ordinators for further information. In some cases, crew may be approached for further information gathering purposes by co-ordinators at the Accident & Emergency Department.
- 8.4.6. Should SECAmb staff have ANY concerns about other children or siblings within the family, a safeguarding referral form must also be completed. However, if you have any immediate concerns about safety, then the police should be contacted or duty social services team

#### 8.5. Child Death Reviews

- 8.5.1. Following the death of any child, there will be a multi-agency discussion with the priority of working out how best to support the bereaved family and identify the circumstances of the death.
- 8.5.2. An initial information gathering meeting is likely to be within 24-72 hours post death. Staff will be supported to attend these meetings where it is deemed appropriate by the safeguarding teams and individual staff members feel able to.
- 8.5.3. A further Child Death Review Meeting will take place after the post-mortem, likely to be within six months of the death.
- 8.5.4. Following on from this, a final Child Death Overview Panel (CDOP) will meet, however this is likely to be twelve months or longer after the death.

- 8.5.5. Any formal Child Death Process that we are involved with, will be coordinated internally via Safeguarding team and if anyone would like further advice regarding child deaths, please contact them.
- 8.5.6. The Trust's safeguarding team will complete the relevant child death notification forms (Part A & Part B).
- 8.5.7. All deaths where a patient had a learning Disability need to be reported via Learning Disability Mortality Review (LeDeR).
- 8.5.8. Within SECAmb, escalation will be via the Learning from Deaths process.
- 8.5.9. All deaths where a child was known to Mental Health services should be flagged to the Learning from Deaths group for review.
- 8.5.10. All deaths for people who are pregnant or who have recently given birth must be reviewed by the Learning from Deaths group. This includes maternal deaths for those under 18 years of age.
- 8.6. Child Death Internal Review Processes
- 8.6.1. All child deaths will be reviewed under the trusts Learning from Deaths processes.
- 8.6.2. Any learning for the trust from the post-death reviews will be shared through the learning from deaths processes.
- 8.6.3. Any feedback or trends noted though the EOC Audit processes will be fed back via the appropriate channels.
- 8.6.4. Where possible, any feedback will be given to the crew after the child death review process. Provided that this feedback is welcomed by the individual staff members, with staff welfare being the main focus of this feedback.
- 8.6.5. Any immediate concerns, trends or issues surrounding child deaths noticed by staff, should be escalated via Datix reporting to the safeguarding lead.

## 9 Responsibilities

- 9.1. The **Chief Executive Officer** has ultimate responsibility for ensuring the effective management of patients approaching the end of Life attended to by SECAmb.
- 9.2. The **Executive Medical Director** has executive responsibility for the care provided to those at the End of Life.
- 9.3. The **Executive Director of Operations**, through delegation by the CEO, has overall responsibility for the implementation, operation, and local assurance of this procedure. The Operations Director also has overall

- responsibility for holding their staff to account for any deviation from this procedure.
- 9.4. The Consultant Paramedic for Urgent and Emergency Care is responsible for overseeing the policy on a day-to-day basis.
- 9.5. The **End-of-Life Care (EOLC) Lead** has the responsibility for ensuring the policy is upheld by supporting leaders within their team, managers supporting staff and individual clinicians.
- 9.6. Managers must make documentation available to staff using the systems available (such as team briefing folders) and review staff understanding of key document through the PADR process.

## 10 Audit and Review (evaluating effectiveness)

- 10.1. This document will be reviewed in its entirety every three years or sooner if new legislation, codes of practice or national standards are introduced, or if feedback from employees indicates that the policy is not working effectively.
- 10.2. All changes made to this procedure will go through the governance route for development and approval as set out in the Policy on Policies.

## 11 References

- 11.1. <u>Ambitions for Palliative and End of Life Care: A national framework for local actions 2021-2026</u>
- 11.2. NICE Guideline: End of life care for adults: Service Delivery (NG142)
- 11.3. NICE Guideline: End of life care for infants, children and young people with life-limiting conditions: planning and management (NG61)
- 11.4. The Notification of Deaths Regulations 2019
- 11.5. NICE Guidelines: End of life care for adults (QS13)
- 11.6. Palliative Care Adult Network Guidelines

## 12 Financial Checkpoint

12.1. This document has been confirmed by Finance to have no unbudgeted financial implications.

## 13 Equality Analysis

- 13.1. The Trust believes in fairness and equality, and values diversity in its role as both a provider of services and as an employer. The Trust aims to provide accessible services that respect the needs of each individual and exclude no-one. It is committed to comply with the Human Rights Act and to meeting the Equality Act 2010, which identifies the following nine protected characteristics: Age, Disability, Race, Religion and Belief, Gender Reassignment, Sexual Orientation, Sex, Marriage and Civil Partnership and Pregnancy and Maternity.
- 13.2. Compliance with the Public Sector Equality Duty: If a contractor carries out functions of a public nature then for the duration of the contract, the contractor or supplier would itself be considered a public authority and have the duty to comply with the equalities duties when carrying out those functions.

## Appendix A - Adult Death, Initial Ambulance Service Actions

Patient confirmed to have died & ROLE completed.

- > Is the death clinically expected? Have they been assessed by HCP within the last 28 days of life?

  If YES to both, follow **Expected Death**
- > If unnatural, suspicious, or unexpected circumstances: follow **Unexpected Death**.

#### **Expected Death**

- Complete ROLE form on ePCR.
- > Consider any cultural or religious needs post-death.
- > Ensure family have notified Funeral Director.
- Notify GP if in hours. Out of hours, family to call as soon as open.
- If syringe driver (CSCI) in situ, inform/ seek advice from care provider, community team or hospice.
- Paramedics can stop & remove syringe driver.

### Unexpected, but no surprise?

- > Discuss with certifying doctor (likely to be GP or Hospice) and seek advice on management plan.
- > If the doctor feels they are able to certify death, manage through expected death pathway.
- If non-agreement reached for category of death or unable to speak with patients GP surgery:
  - follow unexpected death pathway/ refer to police or ask GP to contact police directly.

#### **Unexpected Death**

- > Request police attendance via EOC.
- Complete ROLE form on e-PCR.
- > There is no obligation to stay on scene for non-suspicious death.
- Liaise with EOC
   Tactical Commander if required/ delays in police attendance.

#### Consider

- > Support for Family, LPA, Carers, Care Establishment staff.
- > Signposting to further help e.g., SECAmb Bereavement leaflet, Charities etc
- > Patient & family preference for religious / cultural processes.

## Appendix B - Child Death - Initial

**Documentation** 

Document actions taken, ongoing management plan and details of medicines on ePCR. If the death is suspicious or unnatural, document details of scene with as much detail as possible.

REMINDER: DO NOT TAKE PHOTOS OF THE DECEASED FOR ANY REASON.

#### Note

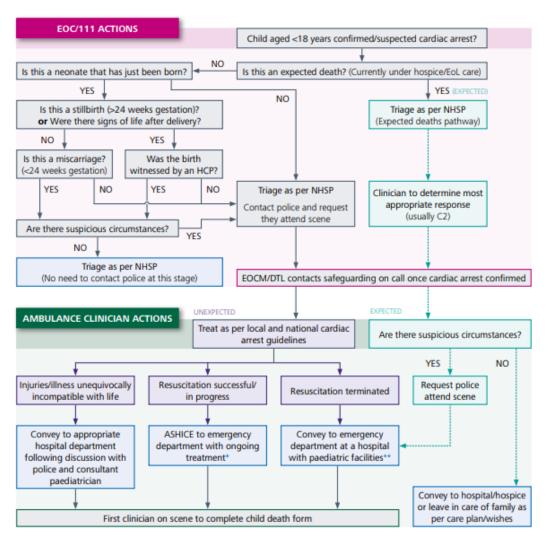
Whilst it is of paramount importance to ensure Family, LPA, carers are provided holistic support. If no clinical care is required and there is a clear management plan in place, we may leave scene. Priority should be given for private grief, allowing them time with the deceased.

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## Child Death Procedure



Initial Ambulance Service Actions



#### Notes

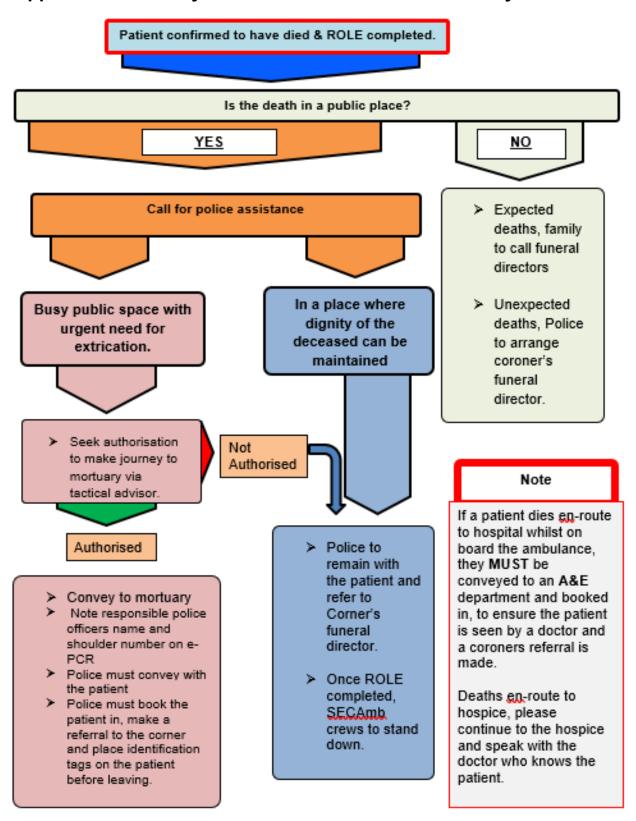
\*It is very rarely appropriate to go directly to maternity with a neonate in cardiac arrest. Liaise with the Critical Care Desk (CCD) if you are asked to go to any department other than ED. "It is important that the body is conveyed to ED so that toxicology and Kennedy samples can be taken. A body should not be left in the care of the police or taken to the mortuary without agreement from a consultant paediatrician at the regional hospital with responsibility for paediatric care.

Page 1 of 1

Child Death Procedure: Initial Ambulance Service Actions

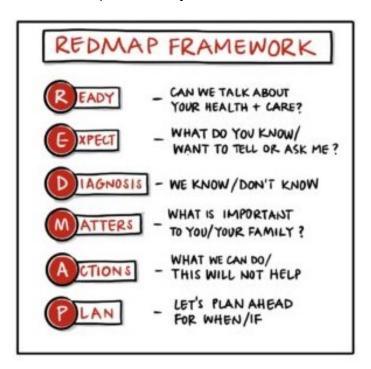
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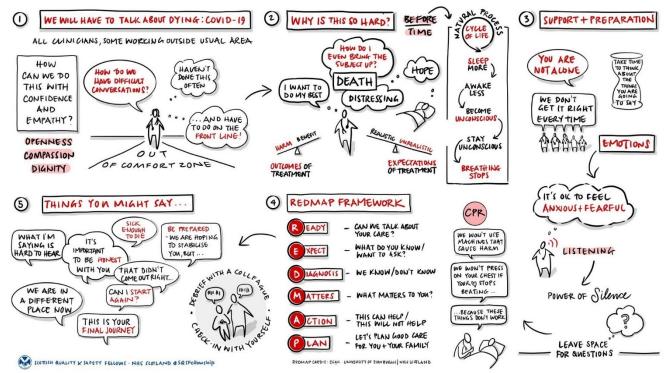
## Appendix C - Conveyance of the deceased to a mortuary



## Appendix D – REDMAP communication tool

Written and produced by NHS Scotland & University of Edinburgh.





## **Appendix F – EOLC Documentation Comparison Chart**

Document Type	ADRT (Advance Decision to Refuse Treatment)	ACP (Advance Care Plan)	DNACPR (Do Not Attempt Cardio-Pulmonary Resuscitation)	ReSPECT Recommended Summary Plan for Emergency Care and Treatment
Legality	Legally Binding for the specific conditions specified within the document.  Not applicable in cases of self-harm and suicide.	This document is not legally binding however it does have legal weight and should be considered in best interests' decision.	This document is not legally binding however it should be considered in best interests' decision. Any diversion from the patient's wishes must be documented and fully justified.  Not applicable in cases of self-harm and suicide.  Not applicable in cases of choking or other easily reversable cause e.g., Blocked tracheostomy.	This document is not legally binding however it should be considered in best interests' decision. Any diversion from the patient's wishes must be documented and fully justified.
Who signs it	Signed and dated by the patient and a witness who certifies the patients' capacity and verifies the patient's signature.	This is completed and signed by the patients' Healthcare Professional.	This is usually completed by a patients GP's, Nurse Specialists, Paramedic Practitioners working in the community or other speciality Doctors	This is usually completed by a patients GP's, Nurse Specialists, Paramedic Practitioners working in the community or other speciality Doctors
What decisions it contains	A patients' decision to refuse to a treatment or course of action (i.e., hospital admission). Patients do not have the right to demand treatments.	This document will contain the discussed wishes and preferences of patients and their carers/families.  Normally in place when a patient is suffering from a long-term condition.	This document contains a clinical decision that a patient is not for resuscitation, this decision is usually but not always made with the patient and/or their family.	It will contain a patient's wishes and preferences, as well as their clinical conditions and instructions. It will also contain a preference for or against resuscitation. (see DNACPR Decisions).

Who makes this decision?	A patient makes this decision, usually with legal advisement, however this is not a requirement.	The wishes and preferences in this document are the patients, usually in conjunction with their family/ carers.	These decisions are made by a patients care team or GP usually in discussion with the patient and/or their carers.	The wishes and preferences in this document are the patients, usually in conjunction with their family/ carers. Resuscitation decisions are made by clinicians.
Validity Requirem ents	<ul> <li>Patient name</li> <li>Patient signature and date</li> <li>Witness signature and date</li> <li>Clear and specific outcomes</li> <li>Clear understandin g of risk to life e.g. I do not want to receive blood for treatment even if my life is at risk.</li> </ul>	<ul> <li>Patient name</li> <li>Details of wishes and decisions made</li> <li>Usually, this document is updated regularly</li> <li>May contain signatures of clinicians collecting the information</li> </ul>	<ul> <li>Patient name and DOB</li> <li>Signature of completing clinician (sometimes countersigned)</li> <li>Dated at time of creation</li> <li>No review date or within review date limits if present</li> <li>If the document was produced electronically, it may have a typed name in signatory box or an electronic signature, this is acceptable when paired with the clinician's registration number.</li> </ul>	<ul> <li>Patient name and DOB</li> <li>Resuscitation decision</li> <li>Signature of clinician completing document in the three required places (two signatures in box 4 and one in box 7).</li> <li>If the document was produced electronically, it may have a typed name in signatory box or an electronic signature, this is acceptable when paired with the clinician's registration number.</li> </ul>

# Appendix G - Administration of Medications at End of Life for Paramedics

Patient known to be at the end of life and are symptomatic

- > Firstly, consider non-pharmacological management. Such as:
  - Repositioning
  - Relaxation techniques
  - Consider environmental changes, opening windows, music, having the right people in the room.
  - > Follow JRCALC EOLC Guidance

Do they have Just In Case (JIC) Medications dispensed at home AND a valid accompanying MAAR chart?

- Using a patient's own prescribed medication is preferable.
- A MAAR Chart must be in place.
- The prescribed medications must be in the patient's home.
- Administration is by registered Paramedics only.
- All JIC medications are to be given via Sub-Cutaneous (S/C) route.
- Ensure the administration chart is completed on scene with what doses you have given.
- Ensure medications are also documented on e-PCR.
- We cannot supply/ leave ANY SECAmb medication with the patient.

See section 5 of SECAmb EOLC Guidance Document

#### Consider the following

#### Pain

Administration of Morphine may be appropriate, follow JRCALC Morphine Guidance

#### Agitation

Continue with nonpharmacological treatment and consider early call for PP/ CCP input.

#### Breathlessness

Administration of Morphine may be appropriate, follow JRCALC Morphine Guidance

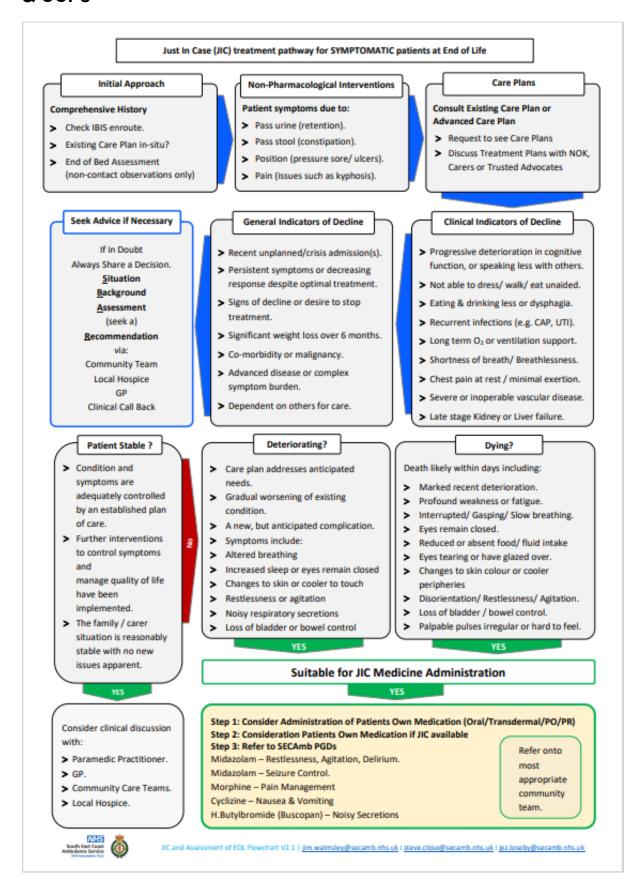
## Nausea & Vomiting

Administration of Ondansetron may be appropriate, follow JRCALC Guidance

Note

If you are unsure around the administration of medications in any way, please call for support and advice in your decision making. This may be via PP hubs, CCD or local Hospice/ palliative care teams who know the patient.

# Appendix H – Administration of JIC Medications for Specialist PPs & CCPs



## **Appendix I – Example of Community MAAR Chart**

PRN PRESCRIPTION CHA This chart is valid until indicated on the chart	RIPTION indicated on	CHART: Injectable Medicine as needed the chart or 3 months if no date is recorded in the review date box.	<b>able M</b> odate is re	edicine <u>a</u> corded in the re	sview date box.			
Last Name		First				DOB	NHS number	
GP & Practice name and contact details		Palliative and con	Palliative care team and contact details	E S		Weight (If needed)	Review date	
KNOWN ALLERGIES: (Including reaction)	. <del></del>							
Clinically assess - are s Ensure the PRN dose i	symptoms b is in line with	Clinically assess - are symptoms being effectively controlled? Check if transdermal patch in situ. Instruction if in place	Check if tr or more pr	ansdermal paton doses are ne	ch in situ. Instruc eded within a 24	tion if in place	Clinically assess - are symptoms being effectively controlled? Check if transdermal patch in situ. Instruction if in place	Illiative care team.
NIVO	Date	Name of Medicine	Route	Dose range	Frequency	Prescriber's name	Prescriber's signature or GMC/registration number	Comments e.g. maximum dose
NAUSEA	Date	Name of Medicine	Route	Dose range	Frequency	Prescriber's name	Prescriber's signature or GMC/registration number	Comments e.g. maximum dose
VOMITING								
ANXIETY	Date	Name of Medicine	Route	Dose range	Frequency	Prescriber's name	Prescriber's signature or GMC/registration number	Comments e.g. maximum dose
RESTLESSNESS								
RESPIRATORY	Date	Name of Medicine	Route	Dose range	Frequency	Prescriber's name	Prescriber's signature or GMC/registration number	Comments e.g. maximum dose
SECRETIONS								
OTHER (Please state)	Date	Name of Medicine	Route	Dose range	Frequency	Prescriber's name	Prescriber's signature or GMC/registration number	Comments e.g. maximum dose
FI	Date	Name of Diluent	Route	Volume	Frequency	Prescriber's name	Prescriber's signature or GMC/registration number	Comments e.g. maximum dose
DILUENI				As required	As required			Н
If this chart is emailed without a	mailed w		<mark>signatur</mark>	e it must be	sent from th	ne prescriber's per	prescriber's signature it must be sent from the prescriber's personal NHS email address to be valid	ess to be valid
Chart confirmed from prescriber's NHS em	prescriber	s NHS email and printed by: Name:	by: Name:		Signature:	Reg	Registration/PIN:	(Invalid if left blank)