

The Royal College of Emergency Medicine

Best Practice Guideline

**End of Life Care for
Adults in the
Emergency
Department**



March 2015

Summary of recommendations

1. All ED staff should receive regular training in all aspects of end of life care.
2. Patients and their families should be involved, wherever possible, in end of life care decisions. All discussions should be documented, with details of who took part in the discussions.
3. ED doctors should endeavour to determine what end of life care plans have already been made by having access to electronic end of life care registers and by asking the patient and their family.
4. Discussions regarding patient treatment preferences should be communicated to GPs, care homes and inpatient teams to enable continuity of care and end of life care planning.
5. If a patient is at the end of life, it may be appropriate to set a ceiling of treatment in the Emergency Department
6. Establishing a 'do not attempt cardiopulmonary resuscitation' order (DNACPR) should not always limit other care given. A statement of planned active care should also be documented where appropriate including what care should and should not be provided.
7. Patients nearing the end of life should have a resuscitation decision made before leaving the Emergency Department and this should be appropriately documented.
8. All DNACPR decisions should be discussed with the patient's family and the patient unless the patient is unable to understand the decision or unless it is thought the discussion will cause physical or psychological harm to the patient, family or carers.
9. Clinicians should be trained and able to commence medicines for symptom control. A checklist or other end of life care documentation may be useful so that all necessary aspects of care are considered.
10. Opportunities for organ and tissue donation should be considered as a usual part of end of life care in the Emergency Department.
11. All Emergency Departments should have procedures for dealing with sudden death including clinical governance review.
12. All Emergency Departments should have adequate facilities for dealing with bereaved relatives.

Scope

This guideline defines best practice in all areas of end of life care for adults. It covers both patient and relative care in the Emergency Department. It has been revised in the light of the withdrawal of the Liverpool care pathway in 2014 and recent National recommendations^{1, 2}.

Reason for development

To improve the quality of clinical practice in end of life care in UK Emergency Departments.

Introduction

Dealing with patients who are near death or who have died is challenging.

- There may be difficult ethical decisions to make regarding resuscitation and inappropriate escalation of treatment and institution of palliative care.
- Many deaths in the Emergency Department are in tragic circumstances.
- After a death, the care given to the patient's family has a major influence on how they grieve.³

Achieving a dignified death for all patients who die in the ED should be a principal aim for ED clinicians, and can be a rewarding experience for all involved in caring for the patient and family.

The National End of Life Care Strategy launched in 2008⁴ aims to improve recognition of patients nearing death and to provide better palliative care in an appropriate setting. The number of people now dying at home has risen to 42.4%⁴, however between 56-78% of people wish to die at home⁵.

- All ED doctors and nurses should receive regular training in all aspects of end of life care, communication, ethics, symptom control and caring for relatives.
- ED teams would benefit from fostering links with local palliative care services to help with training and improve services.

SECTION 1: PATIENTS WHO ARE JUDGED TO BE DYING

1.1 Making end of life decisions with patients – principles⁶

- We should start from a presumption of prolonging life and not hastening death. However, we should recognise that alleviating suffering is sometimes a more appropriate goal.
- In an emergency, the best treatment option gives most overall benefit and is least restrictive of the patient's future choices.
- Patients and their families should be involved with making decisions about their care wherever possible and appropriate.
- Patients who are vulnerable, have learning difficulties or cognitive impairment sometimes receive a poorer standard of end of life care. Staff should pay particular attention to how they communicate with these patients, and try to understand non verbal cues if the patient is unable to talk.

Emergency physicians should be familiar with assessing capacity and applying the principles of the Mental Capacity Act.⁶

1.2 Advance Care planning

The National End of Life Care Strategy⁴ encourages clinicians to make care plans for patients identified to be at the end of life (from whatever cause). Emergency Department staff may not be in a position to make those future plans, but can often identify patients coming to the end of their life. Patients may confide in us what care they do or do not want, and in particular where they want to be cared for.

- Patients should where possible be asked whether they have made any advanced care plans with their GP or specialist and whether these plans apply to the situation they are currently in.
- Access to documented end of life care plans varies around the country. Some departments have access to the patient's summary care record or electronic palliative care co-ordination systems (EPaCCS). It is recommended that EDs work with inpatient specialties and commissioners to be able to access these records.
- Any discussions we have with patients regarding future care, which could assist with end of life care planning, should be clearly documented and communicated to the patient's GP, care home and/or admitting team.

1.3 Discharging end of life care patients home from the ED

- Discharging dying patients from the ED may be appropriate and is best practice if an appropriate care plan can be initiated and continued at home. A rapid discharge pathway is ideal where equipment, care and prescriptions can be accessed quickly. For example, if arranging patient transport is proving problematic, use of a private ambulance to facilitate transfer home may be appropriate.⁷
- This may require access to medication to palliate symptoms, e.g. diamorphine, midazolam etc and in some cases syringe drivers which community nurses can use. In order for community nurses to administer the medication a community prescription form may be needed.
- The patient's regular medications should be reviewed before discharge in order to stop unnecessary medication taking.
- Copies of a discharge letter should be given to the family, care homes and the GP.
- The Emergency Department should be involved in the planning and organisation of services to enable patients to be discharged for care at home.

1.4 End of Life Care discussions in ED

- A senior named ED clinician should be involved with and responsible for every end of life care patient. This will usually be the ED Consultant but may be an ST4 or above out of hours, who should discuss such patients with their Consultant by phone as a minimum.
- When a patient is clearly dying, try to gauge the extent to which the patient and relatives want to be involved in treatment decisions. Involve the patient and their family as much as possible, in discussions about their care.
- Use the principles of breaking bad news outlined in section 2.1.
- Remember that family have no legal right to make decisions on behalf of their relative unless they have an enduring right of attorney (for health decisions) and are registered with the office of the public guardian. However, where appropriate

we should aim to involve family members in discussions, acknowledging their role and concerns. Family members are often able to tell us what their relative's wishes were in situations when the patient lacks capacity, helping a decision to be made in the patients 'best interests'.

- If a patient who is dying has no capacity or means of expressing their opinions and has no family or friends to represent them, then an independent advocate should be sought. This may be a formal Independent Mental Capacity Advocate (IMCA) under the capacity act in England and Wales or more likely a chaplain or volunteer not directly involved in their care¹. In an emergency, the Emergency Department doctor is the most appropriate person to be able to take decisions in the patient's best interests.
- Document all discussions with patients and their family clearly in the patient's notes.
- Patients, as well as family, should be offered spiritual support from the hospital Chaplaincy or their own religious leader.
- Discuss the need for hydration and nutrition with the patient and their family. Usually intravenous (IV) hydration is not required but may occasionally make a patient more comfortable.

1.5 Do not attempt cardio-pulmonary resuscitation decisions (DNACPR) within the ED⁸

- A DNACPR decision should be instituted if the patient wishes or a senior clinician, after appropriate consideration and discussion, feels that chest compression following a cardiac arrest would be futile or lead to unacceptable outcomes as a result of the patient's presenting condition or pre-existing co-morbidities.
- A DNACPR decision should always be discussed with the patient if they have capacity, unless it is felt that the discussion may cause physical or psychological harm, or unless the patient indicates that they do not want to be involved in treatment decisions. A concern that the discussion may cause distress alone is not sufficient grounds for not discussing the decision^{9, 10}. However, in some cases a discussion such as this will cause psychological harm particularly if the patient is very unwell, so a senior ED doctor should exercise careful judgement.¹¹
- DNACPR decisions should be discussed with a patient's family wherever possible.
- Discussions with patient and family should be clearly documented and if a decision is taken not to discuss a decision for DNACPR with a patient, the reasons should be clearly documented.
- A decision of DNACPR should be made by a senior doctor and in difficult circumstances should be shared with other senior colleagues. Advice from the trust legal team or medical defence organisation may be sought in very difficult circumstances.
- The final decision on whether a patient should receive CPR in the event of an arrest rests with the senior clinician. A patient cannot demand CPR if the treating clinician thinks the treatment is futile, however it is recommended that the patient is offered a second opinion.
- Some patients now come to hospital with a community DNACPR order. It is recommended that this is briefly reviewed to check that circumstances have not changed before converting this to a hospital DNACPR document. Some regions have multi-signatory, community-wide DNACPR orders which are valid for the emergency department.
- Patients nearing end of life should have a resuscitation decision made before leaving the Emergency Department.

- Resuscitation decisions made in the Emergency Department should be a trigger for the ED team to consider other aspects of care. Avoiding further escalation of treatment may be appropriate
- There is evidence that a DNACPR order can limit the care given to a patient^{12, 13}. Therefore it is important that a statement about what active care the patient is to have is also included, where appropriate. The Universal Form of Treatment Options (UFTO) is recommended as a tool to improve decision making and documentation^{14, 15}.
- Uncommonly some patients with a DNACPR order may develop potentially reversible events such as a blocked tracheostomy tube, anaphylaxis or choking where resuscitation techniques would be appropriate while the reversible cause is treated.

1.6 Advanced Decisions refusing treatment^{6, 13}

- If a patient has an advance directive an assessment should be made, by a clinician, of its applicability to the patient's current situation.
- An advance directive is legally binding under the Mental Capacity Act (2005) in England and Wales if:
 - the patient was over 18 and had capacity when it was made.
 - it is in writing, is signed and is witnessed.
 - it includes a statement 'even if life is at risk'.
- An advance directive is not valid if:
 - the patient was under undue influence at the time it was made.
 - the patient has since acted in a way that is inconsistent with its terms.
 - the patient has appointed a lasting power of attorney since the directive was made.
- An advanced directive in Scotland and Northern Ireland is not covered by statute but is likely to be binding under common law if the above criteria are met. In Scotland the patient can be 16 years or older.

1.7 Commencing palliative Care

- Palliative care in hospitals has been identified as being variable in quality and lags behind hospice care and care at home¹⁶. We should do our utmost to give good care¹⁷.
- End of life patients should be made as comfortable as possible by requesting an air mattress or similar bed and turning the patient regularly if they are unable to do so themselves.
- End of life care should be tailored to the patient and their condition. The patient's current symptoms should be reviewed and adequate and appropriate medications prescribed for management of distressing symptom. Each intervention and likely side effects should be explained to the patient and family where possible. Use the minimum dose of medication to make the patient comfortable (see appendix two for common medications used for symptom control).
- Access palliative care support whenever necessary as these teams can provide valuable expertise and support.
- Decide on and document what hydration and nutrition is appropriate. Continue to offer regular drinks; or mouth care if the patient is unable to swallow.

- The patient's family may wish to participate in caring for their dying relative, if so they should be helped by staff to do so.¹⁸
- An end of life care checklist can be helpful in the ED as there are many facets to patient care. However it should not be regarded as a prescription for care (see appendix two).
- All interventions and conversations should be documented. This may be in the ED notes or may be in specific end of life care documentation.

SECTION 2: AFTER SUDDEN OR EXPECTED DEATH IN ED

The care of the bereaved relative is as important as the care given to the dying patient¹⁹.

2.1 Breaking bad news²⁰

- Breaking bad news should be carried out by the most experienced clinician available who knows the patient.
- The doctor should be sensitive of religious, cultural or other needs of the family.
- A good starting point is to find out what the family already know about the patient's current condition.
- Bad news should be communicated in a timely and sensitive way, avoiding euphemisms and jargon.
- Listening is as important as talking when breaking bad news.
- A nurse should accompany the doctor when breaking bad news in order to support the family.

2.2 Procedures near and after death

- ED staff should refer all patients who are expected to die, and who are intubated and ventilated, to their local Specialist Nurse in Organ Donation (SNOD)²¹. Referral to the SNOD should be as early as possible as they can offer valuable support and guidance for the team and family. The SNOD will assess patient suitability for organ donation and approach the patient's next of kin for consent, if appropriate. Kidney donation from non-heart beating donors (now classified as 'donor after cardiac death')²² has been shown to have good outcomes even when the donor is elderly^{23, 24}. Donors after brain death require brain stem death testing which is not usually carried out in the ED.
- Tissue (e.g. corneas and heart valves) can be retrieved up to 24 hrs after death²⁵. For tissue donation, referrals should be made via the National Referral Centre on: 0800 4320559. This service co-ordinates consent from family and tissue retrieval.
- The process of referral to the coroner varies between regions in the UK. Local policy should be followed.
- Hospitals should have guidelines on laying out the body. It is good practice to offer relatives the opportunity to take part in this taking into account religious and/or cultural practices¹⁹.
- After a patient's death, departments should have an agreed process for informing the patient's GP and other professionals involved in the patient's care. This should occur within one working day.¹⁹
- Departments could use an after death checklist to ensure all tasks are completed (Appendix two).

- It is good practice to make arrangements for a doctor who can complete the death certificate and/or cremation form to be contactable the next working day by, for example, writing in the notes who can be contacted and how. This reduces delays for distressed families.

2.3 The Ideal Environment for the patient and family

- The Emergency Department can be a difficult place to care for the bereaved family²⁶, however every effort should be made to provide excellent care.
- All departments should have a relative's room to accommodate several family members that is close to the resuscitation room²⁷.
- The room should be private and ideally sound-proof^{28, 29}. It should contain comfortable chairs and sofas, tissues and a telephone with direct dial access. Hot and cold drinks should be available.
- Access to outside space^{29, 30} is valuable for patients and their families.
- A patient receiving palliative care should be cared for in a quiet room with space to accommodate family.
- Every patient and family should have access to a space that allows their cultural and spiritual needs to be met.
- A separate viewing room for family to see the body is valuable. Alternatively the mortuary chapel of rest may be used.

2.4 Care of Bereaved relatives

- A nurse should be assigned to care for and support the family both whilst the patient is being looked after in their last hours and after death³¹.
- Clinicians may choose to book relatives as patients in order to extend the care they can give to them.
- Family should be offered spiritual support in the form of the hospital chaplain or other religious officers.
- Written information should be given to the family to guide them through obtaining a death certificate, coroner's processes and undertaker's arrangements.
- It is good practice to provide follow up for the relatives of a deceased patient. A letter of condolence to the family after the event is appreciated. Departments should consider giving the name and telephone number of a Consultant that relatives can contact at a later date. Providing the family with an appointment a few weeks after the death to discuss the events has been shown to help families with their grieving process³².

2.5 Staff Support

- After every death or incident staff should be encouraged to talk together about the event. In many cases a formal debrief can be valuable.
- Further support should be available to staff through their supervisor or from occupational health.

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None.

Review

January 2018 or sooner if important information becomes available.

Conflicts of Interest

None.

Disclaimers

The College recognises that patients, their situations, Emergency Departments and staff all vary. This guideline cannot cover all possible scenarios. The ultimate responsibility for the interpretation and application of this guideline, the use of current information and a patient's overall care and wellbeing resides with the treating clinician.

Research Recommendations

None identified.

Audit standards

There should be a documentation and audit system in place within a system of clinical governance.

Key words for search

Bereavement, end of life care

Appendix 1

Methodology

Where possible, appropriate evidence has been sought and appraised using standard appraisal methods. High quality evidence is not always available to inform recommendations. Best Practice Guidelines rely heavily on the consensus of senior emergency physicians and invited experts.

Evidence Levels

1. Evidence from at least one systematic review of multiple well designed randomised control trials
2. Evidence from at least one published properly designed randomised control trials of appropriate size and setting
3. Evidence from well designed trials without randomisation, single group pre/post, cohort, time series or matched case control studies
4. Evidence from well designed non experimental studies from more than one centre or research group
5. Opinions, respected authority, clinical evidence, descriptive studies or consensus reports.

Appendix 2: Example of checklist

Emergency Department

Sudden Adult Death Sample Checklist:

(Use separate form for Sudden Unexpected Death In Childhood)

Patient name:	Date:
DOB:	Time of arrival:
ED number:	
Address:	Date & time of death:
	Time of departure/moved to mortuary:
Named nurse:	
Doctor confirming death:	

Checklist	Yes	No	N/A
2 x Name bands applied	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ET tube removed & documented in notes (please leave cannulae in situ) If coroner involvement (use local policy)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Shroud	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Property listed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Property book serial number	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Valuables listed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Valuables book serial number	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
NOK / Relatives informed (include name of relative spoken with)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Relatives attending ED?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Property given to relatives?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Property in safe keeping?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Property given to police?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Chaplain offered/ religious belief arrangement	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ED Departmental /PALS leaflet given	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
DOH leaflet given	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mortality Screening instituted	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Death Book completed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Appropriate agencies/contacts notified (see over page)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Transplant co coordinator informed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Contact list:

	Contact Number	Time Informed	Comments
Police, via Force Control room (Coroner's Representative)	Direct number available from Shift Co-ordinator		Incident No:
Primary Care: In hours (09:00 – 17:00) GP			
For out of hours if GP is out of area pass to Shift Co-ordinator to contact on next working day			
Mortuary – if patient confirmed dead in ambulance and conveyed direct to mortuary.	Mortuary number		

Print name & sign:	
Documentation passed to clerical team	<input type="checkbox"/>

Reception Clerical Officer Checklist

	Yes	No	N/A
Tracking steps completed (function TP):	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patient Treatments completed (function APT):	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
GP Letter printed, signed & posted:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Reception Clerical Officer (Name & signature):
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Copy of checklist taken to Bereavement Office <u>by porter same day</u>	<input type="checkbox"/>
Copy of ED card taken to mortuary <u>by the porter same day</u>	<input type="checkbox"/>

Receptionists to leave original ED card, mortality screening and checklist in Medical Secretary's tray.

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