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European Recommendations for End-of-Life Care for Adults in Departments of Emergency Medicine

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European Recommendations for End-of-Life Care in Departments of Emergency Medicine*

Summary of Recommendations

1. ED staff should receive guidance in all role relevant aspects of end-of-life care.
2. Patients and their families should be involved, whenever possible, in end-of-life care decisions. All discussions should be documented, with details of those who took part in the discussions.
3. ED doctors should endeavour to determine whether end-of-life care plans have already been made by asking the patient and their family.
4. Discussions regarding patient treatment preferences should be communicated to family doctors, care homes and inpatient teams to enable continuity of care and end-of-life care planning.
5. If the end of life is imminent, it may be appropriate to consider interdisciplinary discussions, leading eventually to a "Do not Attempt Resuscitation" (DNAR) order.
6. It is recommended that all European countries accept the concept of DNAR orders. It is advisable that such orders should be interdisciplinary and not based solely on the opinion of one doctor.
7. Establishing a DNAR order does not exclude other care. A checklist or other end-of-life care documentation may be useful so that all necessary aspects of care are considered.
8. All DNAR decisions should be discussed with the patient, if he/she is competent and/or with the family if appropriate.
9. Organ and tissue donation should be considered as part of end-of-life care in the Emergency Department.
10. All Emergency Departments should have adequate facilities for caring for bereaved relatives.

* Adopted and adapted from the relevant document of the Royal College of Emergency Medicine [1].

Contents

Introduction

End-of-life medical care and the questions it raises in terms of dignity of the patient, despite variations in cultural and societal approaches among European countries, is one of the current concerns of the Council of Europe. Recently, the Council issued guidelines on the principles that can be applied to the decision-making process regarding medical treatment in specific end-of-life situations [2].

Staff in Emergency Departments (EDs) manage patients who are near death or who have died. This may prove challenging.

- Emergency physicians (EPs) may have to make difficult ethical decisions regarding resuscitation, the appropriateness or otherwise of escalation of treatment, and the initiation of palliative care.
- After a patient's death, the care given to the patient's family has a major influence on their grieving.
- Achieving a dignified death for all patients who die in the ED should be a principal aim for ED personnel and a rewarding experience for all involved in caring for the patient and family. Although there has been a moderate increase in recent years in the number of people who die at home, it is still significantly less than the number who express a preference to die at home.
- EPs and nurses should receive guidance in all role relevant aspects of end-of-life care, communication, ethics, symptom care and caring for relatives.
- ED personnel would benefit from fostering links with local palliative care services to help with training and to improve services.

Scope

These recommendations aim to improve the quality of clinical practice in European EDs regarding the end-of-life care of adult patients. This involves the delivery of care in a patient-centred way, as well as the care of relatives. These recommendations are not intended for children and adolescents at the end of their life.

Definition

End-of-life care in the Emergency Department is defined as the care provided in situations in which a severe deterioration in health, due to the

evolution of a disease or another cause, poses an imminent threat to the life of a patient or has resulted in his/her death.

SECTION 1: Emergency Department Patients at the End of Life

1.1 Principles of Making End-of-Life Decisions in the ED

- Prolonging life and not hastening death is the duty of ED personnel. However, there are situations in which the alleviation of suffering is a more appropriate goal.
- In an emergency, the best treatment option should give the most overall benefit and should be least restrictive of the patient's future choices.
- Patients and their families should be involved in making decisions about their care whenever possible and appropriate.
- Staff should pay particular attention to how they communicate with patients, especially those who are vulnerable, have learning difficulties or cognitive impairment. They should try to understand non-verbal clues if the patient is unable to talk, as they may otherwise receive a lesser standard of end-of-life care.
- Emergency physicians should be familiar with assessing patient capacity.

1.2 Advance Care Planning

Emergency physicians should be able to identify patients nearing the end of life (from whatever cause) and to make care plans for them in the ED, although they may not be in a position to make plans for the future.

- Patients may confide in ED personnel what care they do or do not want, and in particular where they want to be cared for.
- Patients should be asked, when possible, whether they have made any advanced care plans with their family doctor or hospital specialist and whether these plans apply to the situation they are currently in.
- Documentation of end-of-life care plans and access to them varies around Europe. Whenever possible it is recommended that EDs work with inpatient specialties to be able to access general and palliative care records.
- Any discussions with patients or their relatives, if the patient is not in a position to enter into such discussions regarding future care, which could assist with end-of-life care planning, should be clearly

documented and communicated to the patient's family doctor, 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, when equipment, care and prescriptions can be accessed quickly and when the patient´s condition enables transport home.
- The patient's regular medications should be reviewed before discharge and modifications may be proposed for consideration by the patient's family doctor.
- Copies of a discharge letter should be given to the family, care homes (if relevant) and the patient's general or family doctor.
- The Emergency Department ideally should be involved in the planning and organisation of services to enable patients to be discharged for care at home when this is possible.

1.4 End-of-Life Care Discussions in the ED

- A senior named EP should be involved with and responsible for every end-of-life care patient.
- When a patient is clearly dying, ED personnel should try to gauge the extent to which the patient and relatives want to be involved in treatment decisions. If so they should involve the patient and their family, as much as possible, in discussions about their care.
- When breaking bad news the principles outlined in the section 2.1 should be used.
- Depending on relevant national legislation, the family may have no legal right to make decisions on behalf of their relative unless they have an enduring power of attorney (for health care decisions). However, family members should be involved in discussions, acknowledging their role and concerns when appropriate. Family members are often able to say what the patient's wishes were, when he/she did not lack capacity, or what their values are, so helping to make a decision in the best interests of the patient.
- If patients who are dying lack capacity or means of expressing their opinions and have no family or friends to represent them, then an independent advocate should be sought. In a more acute situation, the responsible Emergency Physician is the most appropriate person to be able to take decisions in the best interests of the patient.
- All discussions with patients and their family should be clearly documented in the patient's notes.

- Patients, as well as family, should be offered spiritual support from the hospital Chaplaincy or their own religious leader.
- ED personnel should discuss issues of hydration and nutrition with the patient and their family. Intravenous hydration is not usually required but may occasionally make a patient more comfortable.

1.5 Do not Attempt Resuscitation Decisions (DNAR) within the ED

- Prospective decisions to withhold cardio-pulmonary resuscitation (CPR) are allowed in some European countries, whilst in other countries or religions the withholding of CPR is not allowed or is illegal [3].
- The lack of consistency in terminology about withholding CPR, such as "Do Not Attempt Resuscitation" (DNAR), "Do Not Attempt Cardiopulmonary Resuscitation" (DNACPR) or "Allow Natural Death" (AND), may be confusing and may generate misunderstandings in national legislation and jurisdiction [3,4]. "Allow Natural Death" (AND) emphasises that the order is to allow natural consequences of a disease or injury and ongoing end-of-life care. The DNAR order explicitly describes the resuscitation interventions to be performed in the event of a life-threatening emergency [5].
- A DNAR decision should be instituted if the patient wishes or if a senior EP, after appropriate consideration and discussion, feels that the initiation of attempted cardiopulmonary resuscitation following a cardiac arrest would be futile or would lead to unacceptable outcomes because of the patient's presenting condition or pre-existing co-morbidities.
- A DNAR decision should always be discussed with the patient if he/she has capacity, unless it is felt that the discussion may cause physical or psychological harm, or unless the patient indicates that he/she does not want to be involved in treatment decisions. In such cases a senior EP should exercise careful judgement on behalf of the patient.
- DNAR decisions should be discussed with a patient's family when appropriate.
- Discussions with patient and family relating to DNAR should be clearly documented and if a decision is taken not to discuss a decision for DNAR with a patient, the reasons should also be clearly documented [3].
- A decision of DNAR should be made by a senior doctor and in difficult circumstances should be shared with other senior colleagues. Legal advice 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 doctor. A patient cannot demand CPR

if the treating clinician thinks the treatment is futile. However it is recommended in such circumstances that the patient is offered a second opinion.

- Resuscitation decisions made in the ED for patients nearing the end of life should be a trigger to consider other aspects of care and to avoid further escalation of treatment, if appropriate.
- There is evidence that a DNAR order may be considered as limiting the care to be given to a patient [6,7]. Therefore it is important that a statement about what active care the patient is to receive is also included in the notes.
- Rarely, some patients with a DNAR order may develop potentially reversible events such as a blocked tracheostomy tube, anaphylaxis or choking, when resuscitation techniques would be appropriate while the reversible cause is being treated.
- In some European countries a DNAR decision is only valid for the specific admission and should always be reconfirmed with every contact, otherwise is not valid any longer.

1.6 Advance Decisions to Refuse Treatment

- Advance decisions are decisions about treatment made prospectively by an individual in case they are unable to participate directly in medical decision-making at some point in the future [8].
- If a patient has an advance decision an assessment should be made, by a clinician, of its applicability to the patient's current situation.
- Advance decisions are now legally supported in the majority (20 out of 31) of European countries [9]. The need for harmonisation in legislation, jurisdiction, terminology and practice is evident [3].
- An advance decision 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,
  - it is clearly not in the interest of the patient –from a medical and legal perspective– to follow the advance decision, e.g. in a suicidal attempt from self-poisoning or any other reversible condition.

1.7 Commencing Palliative Care

- Palliative care in hospitals [10] has been identified as being variable in quality and lags behind hospice care and care at home [11]. EDs should do their utmost to give good care.

- Patients at the end of life should be made as comfortable as possible:
    - 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 the management of distressing symptoms,
    - each intervention and likely side effects should be explained to the patient and family where possible,
    - the minimum dose of medication needed to make the patient comfortable should be used.
- Palliative care support should be requested whenever necessary as palliative teams can provide valuable expertise and support.
- Decisions on hydration and nutrition should be documented, where appropriate, such as:
    - offering regular drinks,
    - providing mouth care if the patient is unable to swallow,
    - participation by the patient's family in caring for their dying relative, if they both so wish.
- An end-of-life care checklist of all necessary aspects of patient care can be helpful in the ED.
- All interventions and conversations should be documented either in the ED notes or in specific end-of-life care documentation.

SECTION 2: Care of Bereaved Relatives in the ED

The care of bereaved relatives after a sudden or even an expected death in the ED is as important as the care given to the dying patient.

2.1 Breaking Bad News in the ED

Breaking bad news in the ED [12] should be carried out by the most experienced clinician available who knows the patient.

- The doctor should be sensitive to religious, cultural or other needs of the family.
- A good starting point is to find out what the family already knows 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.

- When the doctor is breaking bad news, he/she should ideally be accompanied by a nurse to help in supporting the family.

2.2 Procedures Near and After Death in the ED

ED personnel should refer patients who are expected to die and are intubated and ventilated, to their local Organ Donation Team or National Referral Centre, according to local regulations. This will allow an early assessment of suitability for organ or tissue donation. If the patient is a potential organ donor then these organisations can provide guidance on the appropriate medical management and support for the family. Even if the patient is not a potential organ donor support may be provided to the staff and the family.

- If organ or tissue donation is a possibility, the patient's next of kin will be approached for consent, if appropriate.
- If referral to the coroner or other appropriate official is required, this should follow national legislation.

After a patient's death, EDs should have an agreed process for informing the patient's family doctor and other professionals who have been involved in the patient's care. EDs could use an after death checklist to ensure that all tasks are completed [1].

2.3 The Ideal Environment for the Patient and Family in the ED

The Emergency Department can be a difficult place to care for the bereaved family and every effort should be made to provide the highest standard of care.

- All departments should have a private relative's room to accommodate family members close to the resuscitation room, with drinks available, if possible.
- 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 will be valuable.

2.4 Care of Bereaved Relatives in the ED

A nurse should be assigned to care for the patient and be attentive to the needs of the family both whilst the patient is being looked after in their last hours and after death.

- Family should be offered spiritual support by the hospital chaplain or other religious officers as appropriate.
- Written information should be available to the family to guide them through obtaining a death certificate, legal processes and undertaker's arrangements.
- It is good practice to provide follow-up for the relatives of a deceased patient, such as a letter of condolence to the family after the event.

2.5 ED Staff Support

- After every death or incident ED staff should be encouraged to talk together about the event. In some cases a formal debrief can be valuable although there is now some evidence that formal debriefing sessions may increase the risk of post-traumatic stress in staff who have been involved [13,14].
- Further support should be available to staff through their supervisor or from occupational health.

Acknowledgemets

The European Society for Emergency Medicine acknowledges the kind agreement of the Royal College of Emergency Medicine to adopt and adapt its original document to the present form.

Disclaimers

EuSEM recognises that end-of-life patients, their individual circumstances, the facilities of Emergency Departments and the availability of staff all vary considerably across Europe and this guidance 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.

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