Academic Department of Critical Care
Queen Alexandra Hospital Portsmouth

Portsmouth Hospitals NHS
NHS Trust

End of Life Care in Critical Care

Aim To provide guidance on end-of-life care in Critical Care

Scope All adult patients for whom ongoing active life sustaining measures may no longer be in their best interests

After consideration of the patient's clinical condition, the senior Critical Care clinical team determine that ongoing active life sustaining interventions are no longer likely to be in the patient's best interests[1]

Ensure multi-disciplinary agreement

Critical Care multi-disciplinary team and parent specialty team should be aware and in agreement. Document this in the notes.

Consider second opinion

This may be from other senior Critical Care team members or appropriate specialist(s)

Consider potential for organ and tissue donation

If felt to be a possibility, consider:

- Checking the organ donation register
- As best practice, involvement of SN-OD may be appropriate at this stage.[2]

Discuss with patient and/or next-of-kin

Discuss potential change of focus from active management to ensuring best interests at the end of life.

Further discussions with patient and/or next of kin

Second and potentially repeated conversations to confirm understanding and agree change of focus.

If potentially eligible, discuss donation

Organ and tissue donation is preferably discussed with SN-OD present.

Discuss end of life planning with patient and family

Confirm the agreed plan with the multi-disciplinary team:

- Pastoral / spiritual support offered and arranged[4]
- Environment considered
- If consented for organ/tissue donation, appropriate pathway and care bundle followed
- "End of Life" care medications considered and prescribed if necessary
- Palliative Care Team referral considered[6]

Therapies to consider for withdrawal with suggested order of withdrawal:[7]

- Antibiotics, DVT prophylaxis, gastric protection, pre-admission medication
- Renal replacement therapy
- Non-invasive ventilation
- Supplemental oxygen
- Vasoactive medications
- Ventilatory support (removal of endotracheal tube)
- Nutritional support / intravenous fluids
- Monitoring

Review care plan regularly

Complete a full review at least daily, but review should be continuous to ensure it remains in the patient's best interests.

Resuscitation Status

Ensure do-not-attempt cardiopulmonary resuscitation (DNACPR) status is documented in electronic notes.
For patients being transferred out of Critical Care, also complete a Trust DNACPR form.

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Key Points

1. The dignity and comfort of the patient is the priority of all staff involved in their care at the end of life.

2. All decisions must be made after appropriate thought and discussion with other medical professionals and allied health professionals, the patient and their family/next of kin and then clearly documented in the patient's medical record.

3. Involvement of other staff, such as Specialist Nurses in Organ Donation, the Palliative care team, and pastoral or other support staff should be considered in all cases, and contacted when felt appropriate. The timing of their involvement will vary for each patient, and in some cases may not be felt to be appropriate at all.

Supporting Notes

1. The decision that ongoing active management is not in the patient's best interests may be one that takes some time, depending on the clinical context. It is not a decision that can be made by one individual, and must be discussed at a senior level. Second opinions may be requested, either from within the Department of Critical Care, or from other specialities. All discussions must be documented in the patient's medical record. NICE guidelines (Quality Standard 13) state that people approaching the end of life should be "identified in a timely manner" and so while this decision should not be rushed, it should be discussed and considered once the issue of futility has been identified.

2. Organ donation may not be appropriate for all patients approaching the end of life on Intensive Care. However, it should always be considered and the organ donor register should be checked if the patient may be an appropriate donor. Specialist Nurses in Organ Donation (SN-OD) are on call and available to us at all times. The contact pager number for them is 07659 183499. If appropriate, best practice is to involve them before discussions with the patient's next of kin have occurred, as they are available to assist with and facilitate end of life discussions and care, even if organ donation is not possible, or is declined. Organ donation may take one of two forms; Donation after Brain Stem Death, and Donation after Cardiac Death (or non-heart beating donor). The sequence of withdrawal of cares varies depending on the method of organ donation and therefore the appropriate care bundle should be followed. Please refer to the PHT Guideline for Organ Donation for further details.

Tissue donation can also be offered. This can be facilitated by the SN-OD team if they are already involved. Alternatively, a referral can be made via the ALLIANCE scheme by sending a referral by email to: national.referral.centre@nhsbt.nhs.uk

This email is pre-set in the address book on the photocopier so once the form is complete, from the home screen select SCAN AND SEND, THEN ADDRESS BOOK, select the above email from the list and then press the green button.

3. Discussion with the patient and their next of kin is critically important, and may be very challenging for the intensive care team. The NICE guidance states that "People approaching the end of life should have the opportunity to make informed decisions about their care and treatment, in partnership with health and social care professionals and with their families and carers. Good communication between health and social care professionals and people approaching the end of life, and their families and carers is essential and should be sensitive to personal preferences." General Medical Council offers guidance for 'Adults who lack capacity to decide'. This guidance recommends that the caring physicians must (taken directly from GMC website):

    a) be clear what decisions about treatment and care have to be made.

    b) check the patient's medical record for any information suggesting that they have made a potentially legally binding advance decision or directive refusing treatment.

    c) make enquiries as to whether someone else holds legal authority to decide which option would provide overall benefit for the patient (an attorney or other 'legal proxy'). You should bear in mind that the powers held by a legal proxy may not cover all healthcare decisions, so you should check the scope of their decision-making authority.

    d) take responsibility for deciding which treatment will provide overall benefit to the patient, when no legal proxy exists, and you are the doctor with responsibility for the patient's care. You must consult those close to the patient and members of the healthcare team to help you make your decisions.

It is important that all discussions, including any disagreements between clinicians and the patient or their next of kin, are carefully documented in the medical records. Multiple discussions may need to occur to ensure all parties are well informed and comfortable with the change of focus from active management to ensuring best interests at the end of life.

4. Pastoral support can be arranged via the hospital switchboard and should be offered to all parties. The Chaplains offer access to a 24 hour service.

5. The medications prescribed at the end of life are to ensure comfort of the dying patient. Depending on the patient's needs and symptoms, they could include:

    a) Analgesics - commonly diamorphine/morphine via subcutaneous infusion, but can be given as a bolus

    b) Anxiolytics - Most often midazolam

    c) Anti-emetics - Ondansetron; Buccastem (can be given sub-lingually)

    d) Medications to control secretions - Hyoscine (s/c or via patch), Glycopyrrolate

All these medications should be prescribed, ideally via the subcutaneous route, so that they may be administered by the nursing staff should they feel they are necessary. If intravenous (IV) access is in place and is felt not be causing distress to the patient, then the IV route may be used. New intravenous access should not be established in patients at the end of life.

6. Consideration should be made to involve the specialist Palliative Care team, especially if death is not felt to be imminent. The Palliative care team (end-of-life section) is available via bleep 1384 (7 days a week, 0800-2000hrs). They would like a specialist palliative care team formal referral made by fax to extension 6132 in addition (form available via the intranet).

7. Withdrawal of all supportive cares should be considered. The decision to withdraw each care should be considered for each patient, and the order in which these are withdrawn should also be planned on an individualised basis; this may be altered if the patient is consented to be an organ donor. It may not be appropriate to withdraw all supportive cares for all patients. All comfort cares, such as mouth and eye care, should be continued unless there is a contraindication for these. The order in which supportive measures should be removed should be carefully considered by senior medical and nursing staff and communicated (verbally and written) clearly to other staff members caring for the patient. The plans should be explained to the patient (where relevant) and their relatives.

Therapies that should be considered for withdrawal, and a suggested order of withdrawal:

a) Antibiotics, thromboprophylaxis, gastric protection, patient's pre-admission medication
- Some may need to continue if patient is an organ donor

b) Renal replacement therapy
- Removal of the bulky machinery will also aid in creating a more pleasant environment for the patient and their family

c) Non-invasive ventilation
- Ensure patient will not be distressed once NIV is removed, may require anxiolysis

d) Ventilatory support, removal of endotracheal tube
- Not always withdrawn as may be distressing for family members, although must consider if the patient is distressed by presence of endotracheal tube

e) Oxygen

f) Vasoactive drugs
- Patient may die rapidly once these are ceased

g) Nutritional support / IV fluids
- Usually stopped, but may consider continuing for comfort/symptom control or if death is felt likely to be prolonged

h) Monitoring
- May consider removing earlier
- To remain in place if following organ donor pathway

8. Depending on the circumstances (e.g. prolonged dying, patient/relatives preferences), it may be appropriate to consider discussing the venue in which continuing palliative care is provided. This could be a hospital ward bed, a specialist palliative care bed, a hospice bed or indeed in their own home.

9. Sensitivity will be applied to relaxing the department's visiting arrangements with regard to the number by the patient's bedside.

10. If the patient dies on the Critical Care unit, please ensure the relevant documentation is completed:

    a) EOCL section on CIS to help document the decision making {double click the section to open up the drop down menus}

    b) Last offices checks

    b) Death confirmation section on CIS by medical team {double click the section to open up the drop down menus}

    c) Relevant Coroner's referral, discussion and if relevant death certification, EoLC coding form and cremation form

References and further reading

General reference

- Treatment and care towards the end of life: good practice in decision making. Published 20th May 2010. General Medical Council (website). Can be found at; www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp
- National Institute for Health and Care Excellence. Quality Standard 13; End of life care for adults: quality standard. Can be found at;http://guidance.nice.org.uk/QS13/LargePrint/pdf/English. Updated August 2012.

Adults who lack capacity

- End of life care: Adults who lack capacity to decide. General Medical Council (website). Can be found at; www.gmc-uk.org/guidance/ethical_guidance/end_of_life_adults_lacking_capacity_to_decide.asp
- Mental Capacity Act 2005. Can be found at; www.legislation.gov.uk/ukpga/2005/9/contents

Organ Donation

- End of life care; Organ Donation. General Medical Council (website). Can be found at; www.gmc-uk.org/guidance/ethical_guidance/end_of_life_organ_donation.asp
- Organ Donation – Clinical Guideline 135, Issued December 2011. Can be found at; http://guidance.nice.org.uk/CG135
- NHS Blood and Transplant. Approaching the families of potential organ donors, Best practice guidance. February 2013.
- Portsmouth Hospitals NHS Trust Organ & Tissue Donation Policy. http://www.porthosp.nhs.uk/Downloads/Policies-And-Guidelines/Clinical-Policies/Organ_Tissue_Donation_Policy.doc

Other Guidelines and research

- Truog R et al. Recommendations for end-of-life care in the intensive care unit; A consensus statement by the American College of Critical Care Medicine. *Critical Care Medicine*. Vol 36, No 3. 2008
- Sprung CL et al. End-of-Life Practices in European Intensive Care Units; The Ethicus Study. *JAMA*. Vol 290, No 6. August 2003

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South Central Organ Donation Services Team (SN-ODs)

24 HR ON-CALL PAGER
07659 183499

Please state:
YOUR LOCATION, CONTACT NUMBER & NAME

If you get no response after 20 mins please contact the NHSBT duty office on 0117 975 7580

Tissue donation referrals

These should be made on the referral form found in the bereavement pack.

Contact numbers can also be found there.