

17. Hodgson RE, Burrows RX, Randal Curtis J. Management of death in the ICU room for improvement. *South African Journal of Critical Care* 2004; **20**: 54-58.
18. Bion JF. Severity and outcome of critical illness. In: Oh TE, ed. *Intensive Care Manual*. 4th ed. Oxford: Butterworth-Heinemann, 1997: 11-16.
19. Desbiens NA, Wu AW, Broste SK, SUPPORT principal investigators. Pain and satisfaction with pain control in seriously ill hospitalized adults: findings from the SUPPORT research investigations: Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. *Crit Care Med* 1996; **24**: 1953-1961.
20. Quill TE, Bayock IR, for the ACP-AISM End-of-Life Care Consensus Panel. Responding to intractable terminal suffering: the role of terminal sedation and voluntary refusal of food and fluids. *Ann Intern Med* 2000; **132**: 408-414.
21. Preston TA, Patterson JR, Hodges MO, et al. The Rule of Double Effect. *N Engl J Med* 1998; **338**: 1389-1391.
22. Bray K, Hill K, Robson W, et al. British Association of Critical Care Nurses position statement on the use of restraint in adult critical care units. *Nursing in Critical Care* 2004; **9**(5): 199-212.
23. Vincent J-L. Ethical principles in end-of-life decisions in different European countries. *Swiss Medical Weekly* 2004; **134**: 65-68.

24. Norton SA, Tilden VP, Tolle SW, et al. Life support withdrawal: communication and conflict. *Am J Crit Care* 2003; **12**: 548-555.
25. Corkery P. Ethics for health care. *The Furrow* 1995; **46**: 407-415.
26. Azoulay E, Chevret S, Leleu G, et al. Half the families of intensive care unit patients experience inadequate communication with physicians. *Crit Care Med* 2000; **28**: 3044-3049.
27. Schotsmans PT. When the dying person looks me in the face. *Ballieres Clinical Anaesthesiology* 1992; **6**(1): 177-191.

List of sources consulted

Bhagwangee S, Muckart DJJ, Jeena PM, Moodley P. Does HIV status influence the outcome of patients admitted to a surgical intensive care unit? A prospective double blind study. *BMJ* 1997; **314**: 1077-1081.
Clarke EB, Randall Curtis J, Luce JM, et al. 2003. Quality indicators for end-of-life care in the intensive care unit. *Crit Care Med* 2003; **31**: 2255-2262.
Levy MM. End-of life care in the intensive care unit: Can we do better? *Crit Care Med* 2001; **29**(2): suppl, N56-N61.

ARTICLE

The last hours of living in the ICU – priorities of care for critical care nurses



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Critical care is associated with a high mortality rate. While this varies, overall it is likely to be between 15% and 25%.¹ In some cases death occurs almost immediately after an emergency admission and there is little time to prepare either the patient or the family. In the majority of cases, however, death occurs after a period of time. It may be an expected outcome, or it may become evident that further intervention and continuation of treatment is futile and distressing for the patient, the family, and especially the nursing staff.

Once it has been decided that additional medical intervention will not assist the patient, the priorities change to those of care and comfort. It should be stressed to the family that this does not mean any reduction in the level of care that the patient will receive.² The last hours or days of living can include some of the most significant times in our patients' lives, allowing opportunities to finish business, create final memories, achieve spiritual peace, and of course say goodbye. While we are privileged and honoured to be with the patient and family at this time, we have only one chance to do it correctly. If it is done well it may result in significant personal and family growth; if it is done poorly, closure to life may be incomplete, all involved may suffer, and bereavement may be difficult and mourning prolonged.

Facilitators to providing a good death³

- Making environmental changes to promote dying with dignity
- Being present
- Managing the patient's pain and discomfort
- Knowing and following the patient's wishes for end-of-life care
- Promoting earlier cessation of treatment or not initiating aggressive treatment at all
- Communicating effectively as a health care team.

Although it may not be practical, the intensive care environment should be such as to allow the family and significant others privacy and access without disturbing the other patients. It is also recommended to advise the family that the time of death is unpredictable and to educate them about the usual course of a comfortable and peaceful death.

Signs and symptoms of impending death

- Increasing weakness and fatigue
- Difficulty in swallowing and pooling of oropharyngeal secretions with loss of gag reflex

- Decreasing level of consciousness. This is also dependent on analgesia and sedation
- Terminal delirium or agitation
- Respiratory changes, especially apnoeic spells despite being on ventilatory support
- In the very last hours, evident cardiovascular changes.

Stage 1. Preparation

This is the time of direct focus on the patient and the family. It is the critical care nurses' and intensivists' responsibility to educate the family on the death process to reduce fear and anxiety and increase their involvement at this time. This may have to be repeated a number of times, as it is likely that only minimal information will be taken in. At this time there should also be assistance in preventing family exhaustion.

Not all patients in the ICU are unconscious. Patients who are able to do so are encouraged to deal with spiritual feelings, last wishes and goodbyes. Aside, this is a good time to talk with the family or a designated family member/friend about the death certification process and what will happen with their loved one's body following death. Ideally an information sheet with such details should be available to give to the family. If not, make sure such information is written down, as the details are very likely to be forgotten.

Issues surrounding religious customs and rituals must be taken into consideration, treated sensitively and shared with the multidisciplinary team. Admittance of children and minors to the ICU environment is still under debate and may need to be discussed with all involved, especially as death approaches.

At this stage the patient and family should ideally not have to establish new relationships with members of the medical and nursing teams. This may not be feasible, given the shortage of permanent nursing staff and over-reliance on agency nursing resources. It is important to provide continuity of care from a few nurses who are known to the family and who may express an affinity to them. This will help support the family and relieve some of their stress. However, it is likely to increase the stress experienced by the nurses, and they may require extra support from those in charge, or their peers.²

Stage 2. Symptom management

Positioning

- Nurse the patient slightly on his or her side, supporting the trunk and shoulders with pillows.
- The head should be minimally elevated.
- The patient's position should be changed 3 - 4-hourly, except in the very last hours, when it can be changed

8-hourly. Use a draw sheet or other turning and lifting devices and techniques to avoid skin and tissue damage to the patient, as this may cause undue stress for the family. It must be remembered that patients are unable to assist in the change of their position, which may result in back strain and injuries in the nursing staff and others providing care.

Skin and mouth care

- If the patient's position is changed regularly and he or she is positioned well, decubitus ulcers and other skin pressure discolorations can be avoided or at least minimised.
- Gentle and frequent cleansing is recommended to maintain hygiene as well as to keep offensive odours from wounds, perspiration and general body dysfunction at bay. Odours can be distressing for the patient, the family and caregivers.
- Most patients are catheterised for urinary incontinence. The use of diapers and nappies for faecal incontinence is recommended. These should be changed as soon as it is necessary to avoid further skin breakdown and maintain the patient's comfort and dignity.
- It is often difficult and tedious to perform and maintain adequate oral hygiene. However, this is a perfect opportunity to allow the family and significant others to be part of the caring process. Avoid commercial mouthwash as it is too abrasive on the dry and often damaged oral cavity. There is also the possibility of aspiration due to an ineffective gag reflex and cough. Dissolve ½ teaspoon salt and 1 teaspoon baking soda in a litre of tap water and clean and moisten the mouth and dentures as required.

Pain

- Pain rarely increases in the last hours. Pain assessment may be difficult if the patient is very drowsy. Give morphine as required. Critical care nurses and intensivists often hesitate to be 'generous' with morphine. Our aim is make the patient comfortable and pain free and assist in a peaceful passing.
- Moaning may be related to delirium, agitation, being in an uncomfortable position, or an environmental change.

Nutrition and hydration

- Families are likely to be concerned that their loved one will suffer if they are unable to eat or drink. This requires good counselling and family education.
- It may be necessary to maintain hydration intravenously, as analgesia and sedation slows down peristalsis and enteral supplementation is impeded.
- Maintain hydration of the lips, nares and conjunctiva.
- Observe the patient for difficulties in swallowing.

Secretions

- Pooling of oropharyngeal secretions is common at the end of life. The inexperienced may misinterpret this as dyspnoea. Do not use the old term 'death rattle' as it is incorrect. Do not use death euphemisms.
- Turn the patient in the semi-prone position and perform gentle suctioning of the oropharyngeal cavity.
- Oxygen is rarely needed.
- It is not old fashioned to consider hyoscine/scopolamine or atropine to help 'dry up' the secretions to aid patient comfort.

Terminal delirium and agitation

- Unfortunately terminal delirium and agitation is very common, but it can be avoided.
- Avoid using opioids as sedatives, as these have the potential to increase agitation and delirium.
- Rather use benzodiazepines (midazolam, clonazepam) and other major tranquillisers such as haloperidol.

Terminal sedation

- Heavy sedation may be required at the end of life to control pain and suffering.
- Medication should be discussed between the family and the multidisciplinary team and decisions adhered to. It is inhumane to reduce dramatically or stop the analgesia and sedation once the patient is peaceful. We are often too concerned about the consequences should the patient pass away. After all, our goal is for the patient to die peacefully and comfortably.

Stage 3. At the time of death

Sensitive family members may have to be asked to not be at the bedside when death is imminent so as to prevent disruption of care for the other patients should they become anxious or afraid. This is the opportunity to say goodbye and advise the family to spend time with the deceased and to respect the sense of peace that accompanies most deaths. Should the patient's appearance need attention, i.e. removal of tubes and lines and a wash, now is the time to prepare the body for viewing as this facilitates grief and ultimate acceptance of the loss.

Conclusion

The quality of care the patient and the family receive in the critical care unit will have a major impact on their lives, not only at the time but also for many years afterwards. It is part of the caring aim of nursing to ensure that their experience is as compassionate as possible in the circumstances.²

1. Rowan KM, Kerr JH, Major E, *et al.* Intensive Care Society's APACHE II study in Britain and Ireland II: outcome comparisons of intensive care units after adjustment for casemix by the American APACHE II method. *BMJ* 1993; **307**: 977-981.
2. Adam SK, Osborne S. *Critical Care Nursing*. 2nd ed. Oxford: Oxford University Press, 2005.
3. Beckstrand RL, Callister LC, Kirchoff KT. Providing a 'good death': Critical care nurses' suggestions for improving end-of-life care. *Am J Crit Care* 2006; **15**: 38-45.

Additional reading

The last hours of living. <http://www.cme.utoronto.ca/endoflife> (accessed 20 October 2006).

Erratum

In the article entitled 'Support to critical care nursing personnel' by Odendaal and Nel, which appeared on pp. 95 - 100 of the November 2004 issue of the *South African Journal of Critical Care*, W E Nel should have appeared as first author. We apologise for this error.