23.12 END OF LIFE CARE

DESCRIPTION

When it has been assessed that continued therapy is unlikely to be beneficial, an active end-of-life (EOL) care process needs to be initiated. The following should be considered:

» In South Africa (SA), EOL care issues are regulated by *inter alia* The SA Constitution Act 108 of 1996, the Health Professional Act of 1974, the National Health Act 61 of 2003, HPCSA Ethical Guidelines (Booklets), Children's Act 38 of 2005 and Common Law.
» Health Care Workers (HCWs) are not obligated to provide treatments that they deem to be unnecessary, unethical, unreasonable, or non-beneficial, and as such may be withheld or withdrawn.
» The patient's wishes in the form of an advance directive (e.g. Living Will) must be taken into consideration with EOL decision-making
» Build consensus among the multidisciplinary HCW team, patients, and/or their surrogate decisions maker in a structured manner, by using clear communication skills.
» Timely and regular family conferences are essential to provide information (diagnosis, prognosis, therapy), address the family's concerns, gain insight into the patient's wishes, and understand family dynamics and coping mechanisms. (see Appendix 23.II for Family Meeting Form).
» In South Africa, the legal surrogate decision maker is determined in the following order: (i) spouse/partner; (ii) parent; (iii) grandparent; (iv) major child; and (v) sibling.

- » To resolve a disagreement, a second opinion from an independent practitioner, or a peer review team, or an ethics committee may be consulted. Legal recourse should be a last resort.
- » The agreed management plan for EOL care, and decisions about the use of life-sustaining treatment within that plan, should be clearly documented in the patient's medical records.
- » The method employed varies widely and is influenced by ICU protocols, physician beliefs, the clinical scenario as well as patient and family preferences. Additionally cultural factors, religious background (of the physician and the family) as well as the regional legal framework also influence the approach that is utilized.
- » The patient may experience pain, anxiety, delirium, respiratory distress, dyspnoea, vomiting, excessive broncho-pulmonary secretions and stridor. It is the physician's medical and ethical responsibility to ensure these issues are prevented and appropriately managed.
- » The HCW team may experience distress, anxiety and grief. A formal debriefing meeting should be held to alleviate HCW burnout by providing adequate emotional support in an atmosphere that is conducive of trust and mutual understanding.

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See Chapter 24: Medicines for palliative care for further details.

Definitions

- » *Advanced Directive:* A legally-binding, pre-existing, pre-written document wherein the patient reflects their EOL care wishes during times of incapacitation that clinicians are expected to respect.
- » *Withholding therapy*: Decision not to initiate or escalate a life-sustaining therapy or other therapies.
- » *Withdrawing therapy*: Decision to actively stop current life-sustaining therapy.
- » *Do Not Resuscitate (DNR) or No Cardiopulmonary Resuscitation (No CPR) orders*: Pre-emptive order to withhold cardiopulmonary resuscitation.

Determination of death

Brain death

Death is defined as the clinical endpoint characterized by the irreversible loss of consciousness and the inability to breathe. An accurate clinical examination is important to ensure the correct determination of death and should be performed in the absence of potential confounders (factors leading to an incorrect determination of death, e.g. poisoning, severe electrolyte derangements). If confounders are present, the clinical assessment should be

deferred until these have resolved, or confirmatory testing is available to make a diagnosis of death.

A diagnosis of death requires the presence of 3 conditions: persistent coma, absence of brainstem reflexes, and the lack of ability to breathe independently/apnoea.

Table 23.9 presents a summary of the clinical assessment process. Full details can be accessed here: South African guidelines on the determination of death, http://www.samj.org.za/index.php/samj/article/view/13264/9746.

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Table 23.9: Determination of brain death

Clinical domain	Test	Remarks
Coma	Apply pressure to the following areas: – condyles at the temporomandibular joint – supra-orbital notches – All four extremities	– Non-spinal reflex responses are incompatible with a brain death diagnosis. – Consultation with an experienced practitioner is recommended if the origin of a response is unclear. – Ancillary testing may be needed if responses are ambiguous.
Brain-stem reflexes	– Pupillary light reflex – Corneal reflex – Pain response in trigeminal distribution – Vestibulo-ocular reflex (Cold caloric test)	– All brain-stem reflexes must be absent to determine brain death. – Beware of drugs causing pupillary constriction or dilation, e.g. opioids or anticholinergic drugs. – Be mindful of spinal cord injuries – Assess brainstem mediated response rather than peripheral sensation/motor function.
Apnoea test	– Pre-oxygenate the patient with 100% oxygen for 10 minutes. – Perform a baseline arterial blood gas. measurement. – Disconnect the patient from the mechanical ventilator. – Supply continuous oxygen via a T-piece (preferred) or through a catheter inserted through the endotracheal tube and placed above the carina. – Observe continuously for any spontaneous breathing.	– Only proceed with the apnoea test if all above reflexes are absent. – Apnoea must persist in the presence of an adequate stimulus to spontaneous ventilation, i.e. an arterial PaCO2 >60 mmHg (8 kPa) and an arterial pH <7.30. – Take an arterial blood gas to document the rise in PaCO2 and change in pH. At the end of the test, reconnect the patient to the mechanical ventilator. – Monitor the patient's SpO_2 throughout the procedure. – Testing should be aborted if spontaneous respirations, hypotension, hypoxaemia (SpO_2 <85%), or arrhythmia is noted.

Adapted from Thomson D, Joubert I, De Vasconcellos K, Paruk F, Mokogong S, Mathivha R, McCulloch M, Morrow B, Baker D, Rossouw B, Mdladla N, Richards GA, Welkovics N, Levy B, Coetzee I, Spruyt M, Ahmed N, Gopalan D. South African guidelines on the determination of death. South Afr J Crit Care. 2021 Mar 1;37(1):10.7196/SAJCC.2021v37i1b.466. doi: 10.7196/SAJCC.2021v37i1b.466. PMID: 37214191; PMCID: PMC10193841.

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General remarks:

» The following features are incompatible with brain death: decerebrate or decorticate posturing, true extensor or flexor motor responses to painful stimuli or witnessed seizures.

Ancillary testing:
» When performed correctly, the clinical exam is the most accurate way of testing neurological function. Ancillary tests require the assumption of an intact neurological stimulus-integration-response arc.
» It is recommended that the clinical exam be completed to the fullest extent possible prior to conducting ancillary tests such as cerebral angiography, transcranial dopplers, radionuclide/scintigraphy studies, etc (see full details in the South African guidelines on the determination of death, http://www.samj.org.za/index.php/samj/article/view/13264/9746).

Circulatory death
Circulatory death is the preferred term when death is determined on circulatory grounds. This terminology is preferred to terms such as cardiac or cardiorespiratory death and is in alignment with the latest guidelines.

To make an assessment of death on circulatory grounds, one of the following criteria must be met:
» It is inappropriate to attempt cardiopulmonary resuscitation.
» Attempts at cardiopulmonary resuscitation have failed.
» Treatment aimed at sustaining life has been withdrawn. This may occur if further treatment is deemed unlikely to offer additional benefit to the patient, or to respect the patient's wishes via advanced directive, or as expressed by their legal surrogate decision maker.

The absence of mechanical cardiac function should be confirmed using a combination of the following:
» absence of a central pulse on palpation
» absence of heart sounds on auscultation.

In the hospital setting, circulatory cardiac function can also be assessed by looking for pulsatile flow with direct intra-arterial pressure monitoring, or by looking for contractile activity using echocardiography.

Once this has been determined, the patient should be observed by the person responsible for confirming circulatory death for at least five minutes for confirmation.

Note:
» Any spontaneous return of circulatory or respiratory activity during the five-minute observation period should prompt a reset and repeat of the observation period.
» Return of circulatory or respiratory activity is not an indication to begin resuscitation efforts where this has been determined to be inappropriate.