

Consensus statement on the use of palliative sedation in the ACT



ACT Palliative Care Governance
Committee

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Canberra Health
Services



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Palliative Sedation Therapy (PST) is the monitored use of medications to lower a patient's awareness in order to provide relief of symptoms that are refractory to usual measures, are distressing and result in considerable suffering if unrelieved.

(Cherny et al 2009, Morita et al 2005)

Introduction statement

The points agreed to in this document will inform the basis of a guiding document for the ACT.

- The use of the word 'terminal' in this Consensus Statement is not limited to cancer, but appropriate for any end stage disease including dementia.
- This guideline should ensure that PST is carried out according to standards of best practice and is, as far as is possible, acceptable to the patient, family/carer, and health-care providers.
- This guideline should enable all medical clinicians, including General Practitioners (GPs), to understand that palliative sedation can be a therapeutic option for severe and otherwise irremediable symptoms in a patient who is close to death.
- The impact of symptoms is so far as this is possible, based on patient assessment.
- The topic of palliative sedation can give rise to a variety of moral questions and emotional reactions. This document does not seek to address these concerns, but rather to provide a clear explanation and guide to its appropriate use.

Palliative sedation therapy

- The purpose of PST is the relief of severe and otherwise refractory and distressing symptoms to provide patient comfort.
- PST is:
 - a mechanism to achieve patient comfort by reducing the awareness of symptoms through decreasing a patient's consciousness
 - an option that should be considered in the setting of care for the dying patient to manage severe and refractory symptoms
 - a symptom control strategy consistent with palliative care provision at the end of life
 - inclusive of a range of types of sedation (continuous/intermittent, and mild/deep)

- PST needs to be distinguished from the more common practice of managing symptoms such as anxiety, restlessness and/or insomnia through use of medicines with sedative properties. The intent of therapies in these contexts would not be sedation.
- Examples of use of PST.
- Occasionally patients in intensive care may be conscious prior to withdrawal of ventilatory support. Examples of such patients would include a ventilated patient with end-stage motor neuron disease or a ventilator-dependent patient with a high spinal lesion. Optimal care of these patients may involve prophylactic administration of anaesthetic or sedative drugs to unconsciousness, to avoid discomfort during the dying process (ANZIC 2014).
- Examples outside the ICU context would include people who were suffering significant refractory distress from advanced cancer, or end-stage organ illnesses who were being cared for in an inpatient setting and were thought to be close to dying.
- Terminal restlessness may occur as death approaches. A wide range of factors can contribute to terminal restlessness including refractory symptoms, biochemical abnormalities and unrelieved urinary retention. The recognition and management of these factors is crucial in the care of people experiencing terminal restlessness. Palliative sedation is sometimes required to maintain comfort, particularly with more severe and refractory cases of terminal restlessness¹
- Palliative sedation therapy is most commonly used for the treatment of physical symptoms. However, there may be situations in which the multidisciplinary team agrees that palliative sedation therapy is the appropriate treatment for psychological symptoms (such as anxiety). Palliative care specialists should follow a robust decision-making process and seek advice from relevant specialists before using palliative sedation therapy for the treatment of existential distress. If clinically appropriate, distressed patients may benefit from psychiatric review to exclude depression, delirium and anxiety².
- A decision to use PST is not dependent on or influenced by other end of life decisions such as whether to continue or withdraw nutrition and hydration. For further information refer to hospital guidance documentation.

Aim/intent

- The aim of PST is to relieve severe and refractory symptoms by lowering the patient's consciousness to the degree appropriate to maintain/achieve comfort.
- PST is different from euthanasia and assisted dying. In PST the aim is to relieve symptoms. In euthanasia and assisted dying the aim is deliberately to bring about the patient's death.

1 Statewide Guidance for Victoria 2020 p.4

2 Statewide Guidance for Victoria 2020 p.4

- PST may be used in combination with other palliative treatments.

Means

- The means used to achieve this goal of patient comfort is the monitored use of sedative medication in a degree appropriate to the relief of symptoms.

Terminality

- Palliative sedation shall be used only when patients are terminally ill; the precondition for its application, therefore, is in those patients who are expected to have a very limited survival.

Refractory

- The intervention should be considered when symptoms are refractory, that is, they cannot be satisfactorily relieved by any other, more direct, means.
- The patient's severe and otherwise irremediably suffering should have been appropriately diagnosed, and treatments for individual symptoms sought and tried, or at least carefully considered and determined to be ineffective. The ideal approach to determining that symptoms as refractory should include Assessment(s) by clinicians, including a psychologist where possible, and the treating team who have established a relationship with the patient and their family.

Proportionality

- The administration of the drug(s) is titrated according to the need to relieve symptoms.

Who should be involved in decision making?

- Unless there is urgent clinical need, the decision to use palliative sedation should be discussed among an interdisciplinary team, with input from a senior consultant who has experience in palliative care and symptom management, a specialist palliative care team member, allied health, nursing and patient's primary physician.
- PST may happen in an urgent clinical setting where time to discuss a decision is limited. Patients or their proxy decision makers must be included in decision making to the degree that that is possible. Family members should be informed and included within the process of decision making to the degree appropriate to the circumstances.
- Decision making should search for agreement (consensus) between all parties. Where no consensus is reached, a referral to Specialist Palliative Care Services or the clinical ethics committee should be considered.

- If there is an urgent clinical need, the decision to use palliative sedation may be made by the senior clinician (informing and involving the patient's proxy maker to the degree that is reasonably possible).

Patient assessment for possible palliative sedation

- Where PST is requested by patients and/or family members/carers as a therapy for the patient's suffering, symptoms, or distress, such requests should result in exploration and discussion of options between patient, family members/carers and clinical staff with clinical decisions resulting based on the principles in this document. Terminally ill patients suffering from severe distress should be evaluated urgently.
- The patient must be evaluated by a clinician with sufficient experience and expertise in palliative care. Ideally, one of the team members undertaking an assessment should ideally have an existing relationship with patient.
- The assessment/evaluation should include:
 - The patient's medical history;
 - All relevant investigations;
 - A physical examination of the patient;
 - Current goals of care and potential to achieve goals of care;
 - Any psycho-social and environmental factors, including sources of spiritual or existential distress, which may be adversely affecting the level of distress
 - Clear determination this person has entered a terminal phase. Indicators of this might include: the extent of disease, validated prognostic instruments (inpatient setting only), rate of decline in functional status, presence or absence of vital organ failure, and the presence or absence of adverse prognostic factors such as very poor performance status (inpatient setting only), dyspnoea, anorexia, degree of oral intake, delirium and oedema; and
 - Whether any available alternative options to relieve distress have been considered

Talking with patients and families

Prior to implementing palliative sedation

- In the situation of uncertainty among either family or health care providers, a referral to a clinician experienced in palliative care, or the Specialist Palliative Care team should be considered.

What should be discussed with the patient?

- The scope of these discussions should be predicated on the general goals and priorities of care.

- In non-critical situations in the management of patients with decisional capacity, the aims, benefits, and risks of the proposed sedation should be discussed including reference to the following:
 - The patient’s general condition including the cause of the intolerable distress, treatments that have been attempted, limitations of other options of care and, when relevant, limited anticipated survival.
 - Available treatment options, the likelihood that they may relieve distress, their inherent limitations, and the expected survival associated with each.
 - The rationale for the decision that sedation is the only method available for achieving symptom relief within an acceptable time frame.
 - The aim of PST, and the distinction between PST, euthanasia and assisted dying; in that PST does not aim to shorten life.
 - The method of sedation, including the depth of planned sedation, patient monitoring, possibility of planned and discontinuation of sedation
 - The anticipated effects of sedation including degree of reduction in consciousness, communication, and oral intake.
 - The possible side effects such as paradoxical agitation, delayed or inadequate relief, and the (foreseen but unintended) possibility of complications including hastened death.
 - Medical treatments and nursing care to be maintained during sedation: continued treatments and care to ensure patient comfort.
 - Available alternatives to palliative sedation, their benefits, burdens, and risks.
 - Commitment to the patient’s wellbeing and provision of best possible care irrespective of patient treatment choice of palliative sedation therapy.
- A patient may request a period of awakening, although it is important to warn them that there is no guarantee they will be lucid or comfortable. Similarly, carers may request a reduction in medication doses, but this is usually not recommended due to the risk of distress for the patient.³

Informing the family

- Type of information needed by relatives to inform decision making should include the above and:
 - Patient, family, and clinician goals of care
 - patient’s inability to communicate,
 - the patient’s symptom distress and treatment,
 - the dying process, and the impossibility of predicting when the patient will die

3 Statewide Guidance for Victoria 2020 p.10

During sedation

- The patient's family and loved ones should be offered the opportunity to be with the patient.
- Relatives may need to be provided with information once a decision has been made to proceed with PST. They may need:
 - Advice to prepare for the patient's death;
 - Advice about the possibility of the patient regaining consciousness;
 - Commitment that care will be continued to ensure that the patient dies in comfort.
 - Advice on typical features of the dying process, including the likelihood of noisy respiration, peripheral cyanosis, and decreased urinary output.
 - Reassurance that other methods have been sufficiently tried and/or carefully considered but were ineffective, and that sedation is unlikely to shorten the patient's life and that sedation can be discontinued or reduced if needed.
 - Regular information updates including: the patient's condition, degree of suffering, anticipated changes or, when appropriate, notification that death is approaching and what can be expected in the dying process.
 - Encouragement as to how they can be involved in the palliative sedation process, for example, by spending time with and observing the patient and providing physicians and nurses with information about the patient, talking to, and touching the patient, providing mouth care, and managing the atmosphere of the patient's care e.g. providing the patient's favourite music, scents, singing favourite songs, saying prayers or reading to the patient.
- The care team should support the members of the patient's family and/or friends. This includes listening to their concerns, attention to grief and physical or psychological burdens they may feel about their relative's impending death.

Consent

- The decision to act on palliative sedation relies on obtaining informed consent either from the patient or his or her substitute decision maker.
- When the patient (or substitute decision-maker) is not able to give consent, and the patient's need for symptom relief by palliative sedation is judged to be urgent, guidance about the appropriateness of a clinical decision to instigate palliative sedation may be found in the patient's Health Direction, or completed Statement of Choices.
- In circumstances in which a terminally ill patient who is actively dying has an urgent need for symptom relief by palliative sedation, and no guidance is available, a decision to instigate palliative sedation may be made by a senior clinician.

- When the patient is a child, parental consent is required; however, care options might be discussed in an age-appropriate manner for older children to facilitate their involvement and, if appropriate, assent.
- With the permission of the patient, it is generally preferable to conduct this discussion with the participation of significant family members. This approach improves communication and often facilitates important meaning-related discussions between patients and their families.
- In situations in which the family members are not part of the consent process, permission should be sought from the patient to communicate the decision with the patient's family.
- In some cultures, family assent may be deemed necessary or desirable. When this is the case and family members do not assent to the treatment plan, the care team should:
 - Provide sufficient information to help families better understand the patient's conditions and suffering;
 - Support the patient and their family by talking with each party and attempting to find a solution that is acceptable to both; and
 - Provide psychological support to families to relieve them of factors that contribute to conflicts, such as grief and guilt.
- Where consent is to be gained by a proxy, those involved should be informed of the information as per the 'What should be discussed with the patient' section. An inclusive discussion will likely enable the proxy to indicate what the patient would have wanted and the reasoning that leads them to their conclusion.

Documenting consent

- Where the patient is conscious and/or there is a delegated decision maker (EPOA), documentation of the informed consent and the provision of sedation in the clinical record should include the following statements:
 - The patient has been offered information about his/her condition and the treatment options.
 - The patient has been provided with the information that he/she wanted to receive about his/her condition, the treatment options, and the likelihood of benefit and risks involved.
 - The patient entrusts the informed decision-making to a nominated person who has been adequately informed of the likelihood for benefit, the potential risks and burden, and available therapeutic options. When informed treatment decision-making is delegated, it is prudent that the surrogate decision-maker affirms that there has been an informed decision-making process based on disclosure of the potential benefits, risks, and alternatives.

Sedative medication

- Medication choice should be based on degree of sedation required i.e. mild, intermittent.
- Benzodiazepines or sedating antipsychotics are used most often for palliative sedation and should be drug of first choice
- Doses should be titrated to effect and based on best evidence and individual clinical characteristics.
- Mild/intermittent palliative sedation choice can include less potent agents (such as the benzodiazepine, lorazepam) or lower doses of more sedating agents.
- Moderate palliative sedation may require more sedating agents (such as the benzodiazepine midazolam or sedating antipsychotics – such as olanzapine) and higher doses.
- In cases of severe distress (such as profound delirium) profoundly sedating antipsychotics (such as levomepromazine) may be required in conjunction with benzodiazepines.
- Use of a propofol or phenobarbitone infusion for PST may be appropriate in some situations.
- Opioids should not be used as the primary agent of sedation but will often still be required for comfort and to support the achievement of sedation in PST.
- A Palliative Care Specialist must be involved if a person (outside of ICU) requires palliative sedation and multiple agents, phenobarbitone or propofol is thought to be required.
- Different strategies to induce the appropriate degree of symptom control through sedation, and to maintain this control may be required. Both phases of care should be considered, and an appropriate care plan determined.

Monitoring and outcomes

- An experienced clinician along with the patient (if possible), family and staff should evaluate the below-mentioned parameters.

Patient monitoring

- Both indices of symptom control and depth of sedation should be monitored simultaneously. The required depth of sedation should be at the level which enables the patient to be able to tolerate the targeted refractory symptom while all other symptoms are controlled.
- The below parameters should be monitored:
 - Adverse effects of PST;
 - The severity/relief of suffering;
 - Patient's level of consciousness or level of sedation;

- The above-mentioned parameters can be assessed by:
 - Measuring relief of suffering by verbal comments of the patient, facial expressions, and body movements;
 - Assessing the level of consciousness by evaluation of the patient's response to non-painful stimuli;
 - Using the eyelash reflex to assess the level of consciousness.
- Scales to help assess distress in patients with lowered consciousness that may be considered for use are:
 - The depth of sedation and agitation: Richmond agitation sedation scale (RASS) (The Ramsay Sedation Scale can be used for Palliative Sedation in home settings);
 - Symptom control: Edmonton Symptom Assessment Scale. This may be completed by caregivers and family members;
 - Critical-Care Pain Observation Tool (CCPOT).
- Initially, the patient should be assessed at least once every 20 minutes to ensure relief of symptoms is achieved, and subsequently at least three times per day after adequate sedation has been achieved.
- The attending physician/nurse practitioner should be informed when the maximum dose range of midazolam has been reached.
- In all cases, the care team must maintain the same level of humane dignified treatment as before sedation. This level of care includes talking to patients and adjustment of the environment. Oral care, eye care, toileting, hygiene, and pressure wound care should be performed on the basis of the patient's wishes and the estimated risks/harms in terms of the goals of care.

Care of the family

- Family should be assessed for psychological and spiritual distress.
- Family should be offered support, encouraged to ask questions and to be able to grieve. They should be offered social work/pastoral care if available.

Care of staff

- Care of staff involved in palliative sedation therapy is needed due to the complex responses that it can engender.
- The care team should recognize the potential for staff distress.
- Distress can be mitigated by fostering a culture of sensitivity to the emotional burdens involved in care including participation in the deliberative processes leading up to a treatment decision and understanding of the rationale for sedation and goals of care, sharing information, and engaging in multidisciplinary discussions both before and after the event that offer the group or individual opportunities to discuss the professional and emotional issues related to such decisions.

- A staff member may responsibly use their right to not provide or participate directly in treatments to which they have a conscientious objection. In such circumstances, staff members must respectfully inform the person, their employer and other relevant colleagues of their objection and ensure the person has alternative care options (adapted from Nursing and Midwifery Board Australia, 20184).

Education

- Education should be provided on the implementation of the guidelines.
- PST should be an integral part of the professional skills of medical staff.

Documentation

- The prescriber or palliative care consultant should ensure that the discussion of the following issues is documented on the health record:
 - The medical rationale and criteria for recommending sedation;
 - The decision-making process;
 - The aims of sedation and the planned depth and duration of sedation;
 - The patient or his/her alternate decision maker's consent;
 - The agreed goals of care amongst the patient, family, and prescribers/health care providers.

Definitions

Term	Definition
Terminally ill	A condition which may cause death within days.
Clinician	In an acute inpatient setting this may refer to nursing, medical or allied health staff. In a community setting it may refer to the GP and Registered Nurse. In a Residential Aged Care Facility this may refer to a Registered Nurse, Nurse Practitioner or GP.
Existential distress	Existential distress is a variably defined term to describe the hopelessness a person experiences due to questioning their self-identity, the meaning of life, and worth as a person as they are facing death. If clinically appropriate, distressed patients may benefit from psychiatric review to exclude depression, delirium and anxiety ⁵ .

4 Nursing and Midwifery Board Australia (2018) *Code of Conduct for Nurses* Melbourne

5 Statewide Guidance for Victoria 2020 p.17

Polices/guidance documents

National Palliative Care Strategy 2018

ANZIPM Palliative Sedation Therapy Guidance Document.

ANZICS Statement on Care and Decision-Making at the End of Life for the Critically Ill Edition 1.0 2014

Nursing and Midwifery Board of Australia Code of Conduct for Nurses 2018

Australian Medical Association Position Statement on Conscientious Objection 2019

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ACT Health acknowledges the Traditional Custodians of the land, the Ngunnawal people. ACT Health respects their continuing culture and connections to the land and the unique contributions they make to the life of this area. ACT Health also acknowledges and welcomes Aboriginal and Torres Strait Islander peoples who are part of the community we serve.

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