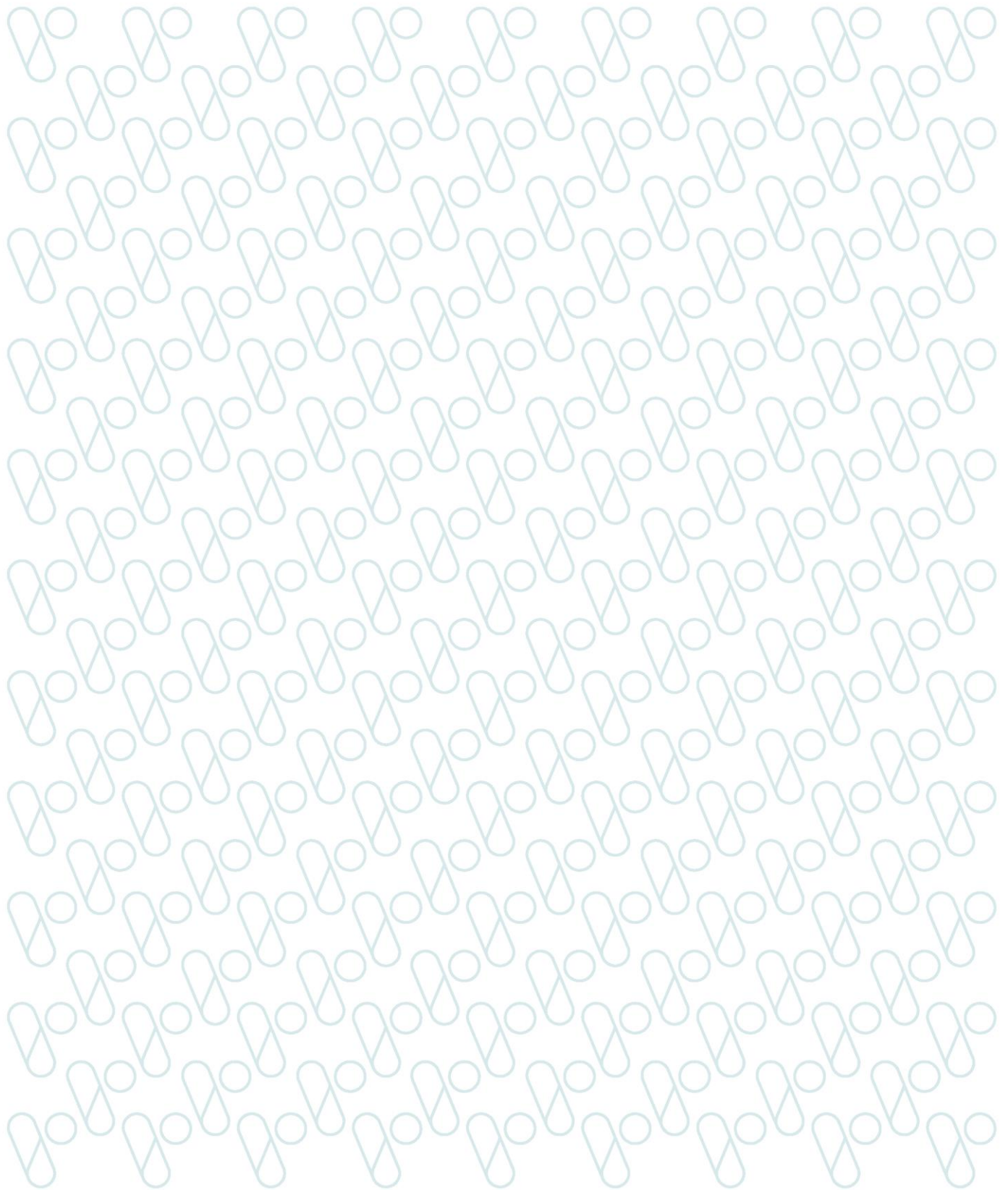

Palliative sedation therapy

Statewide guidance for Victoria





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Authorised and published by the Victorian Government, 1 Treasury Place, Melbourne.

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ISBN 978-1-76069-382-4 (pdf/online/MS word)

Available at www.safercare.vic.gov.au



About this document

This document outlines the Victorian best practice approach for using palliative sedation therapy in a specialist palliative care setting. It will help palliative care specialists (and those who work with them) support the patient, their family and carer to make decisions about care in the last days of life.

What is palliative sedation therapy?

For the purpose of this guidance, palliative sedation therapy is the intentional use of proportionate sedation to relieve a patient's suffering from inadequately controlled symptoms.

Palliative sedation therapy has three key elements:

1. It uses pharmacological agent/s to reduce consciousness.
2. It is reserved for treatment of intolerable and refractory symptoms.
3. It is only considered in patients with advanced progressive illness who are rapidly approaching death.



For more definitions, see the glossary at the back of this document.

WHAT DOES THIS GUIDANCE COVER?

This document details **sedation in the management of refractory symptoms** at the end of life^{1,2}. Use of sedative drugs for management of specific symptomatology, for example seizures, are not included in this guidance.

It **does not** include:

- respite sedation
- sedation as a side effect of symptom control measures
- transient sedation for noxious procedures
- sedation as part of burns care
- sedation used in end of life weaning from life sustaining treatment (e.g. ventilator support)
- catastrophic orders/emergency sedation.

This guideline is intended for adults. For paediatric patients, please consult with the Victorian Paediatric Palliative Care Program (phone: 03 9345 5374).

BACKGROUND

This document was developed with an expert working group. While it was adapted from the Australia and New Zealand Society of Palliative Medicine (ANZSPM) guidance 'Palliative Sedation Therapy', the working group agreed this additional resource was needed to specifically support Victorian palliative care specialists.



This document aligns with Safer Care Victoria's 'Evidence based guidance: A new approach to sharing best practice core principles'.

SCOPE OF PRACTICE

This document is intended for use by specialist palliative care clinicians in the care of people in the last days of life. Palliative sedation therapy is a specialist skill and undertaken by a palliative medicine specialist¹.

The document also serves as an educational and clinical support resource for specialist clinicians when they are training palliative medicine specialists, nurse practitioners or all other medical practitioners including general practitioners, who may be part of the extended multidisciplinary care team.

HOW TO USE THIS DOCUMENT

Icons are used throughout this document to direct you to important information.



Glossary: find more information in the glossary



Conversation point with patient and those important to them



Clinical team conversation point



Documentation point



Within document link



Link to additional resources

IMPLEMENTING THIS GUIDANCE

The implementation of this guidance should consider local context. We recommend you use a standardised quality improvement methodology to understand local processes, barriers and solutions for the use of palliative sedation therapy.

CONTACT US

Has your service used this guidance or developed resources to support it?

Please share with us by emailing us at palliativecare.clinicalnetwork@safercare.vic.gov.au.

Understanding palliative sedation therapy

Although palliative sedation therapy is considered controversial by some^{3,4,5} it is an accepted therapy available as part of specialist palliative care in Australia.

Specialist palliative care services can be found in inpatient settings, community-based teams, or consultancy services. Most rural services will have links with a specialist palliative care service.

Palliative sedation therapy is usually provided in inpatient settings. However, with the support of a specialist palliative care team it can be provided in the patient's preferred place of care.

Palliative sedation therapy is different to voluntary assisted dying

Palliative sedation therapy is not voluntary assisted dying – it is distinct by virtue of the intent and the action¹. Describing it as 'slow euthanasia' is also incorrect.

While there are some reports that palliative sedation therapy can hasten the death of a patient⁶, there is more evidence to support that it doesn't^{7,8,9}.



[Voluntary assisted dying – resources for health professionals](#)

Terminal restlessness and palliative sedation therapy

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 retention¹⁰. The recognition and management of these factors is crucial in the care of people experiencing terminal restlessness. Palliative sedation is sometimes required, particularly with more severe and refractory cases.



Please see the glossary for more information about terminal restlessness.

Palliative sedation therapy to treat existential distress

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.

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 anxiety¹³.



Please see the glossary for more information about existential distress.

WHEN TO USE PALLIATIVE SEDATION THERAPY

In most cases, palliative sedation therapy is reserved for imminently dying patients in the last days of life. The median survival of sedated patients is one to four days¹⁶.

As with any medical procedure, palliative sedation therapy must have a specific clinical indication, a target outcome and a benefit/risk ratio that both you and the patient or medical treatment decision maker (MTDM) accept and consent to^{16,17,18}.

Table 1: Criteria for using palliative sedation therapy

Criteria	Appropriate	Not appropriate
The patient has advanced or terminal disease and death is imminent	Prognosis is clear	Prognosis is unclear
A multidisciplinary team agrees that the patient is likely in their last two weeks of life	Team agrees	Team does not agree
The patient is suffering from refractory physical and/or non-physical symptoms	Symptoms are irreversible and causing intolerable suffering	Symptoms are reversible
A multidisciplinary team (minimum doctor and nurse) has discussed and clarified remaining therapeutic options and goals of care	All options for alternative treatments have been explored	All options for alternative treatments have not yet been explored
The patient has been assessed by a palliative medicine specialist	Patient has been assessed by, or discussed with, a palliative medicine specialist	Patient has not been assessed by, or discussed with, a palliative medicine specialist
The patient or MTDM agrees to the therapy (as per competent patient, advance care directive or prior discussion with patient)	Patient or MTDM agrees	Patient does not agree

In rare situations, the MTDM may disagree with the multidisciplinary team about the use of palliative sedation therapy.

This can occur for a variety of reasons, and may occur if the MTDM feels that the patient would not agree to palliative sedation therapy if they had decision making capacity.



This can be challenging for palliative medicines specialists to manage. To facilitate agreement between the MTDM and the multidisciplinary team, clinicians should provide information and support.



Supporting patients, families and carers – page 7

Even if the MTDM is being guided by the clearly documented wishes and preferences of the patient, including by way of a valid and relevant values directive, it should be noted that Section 12 of the *Medical Treatment Planning and Decisions Act 2016*¹⁷ provides that a person cannot refuse palliative care in an Instructional Directive.

Sections 54 and 57 provide that a MTDM cannot refuse palliative care either, although the clinicians must ensure that the palliative care is consistent with the patient's values and preferences and consult with the MTDM.

Supporting patients, families and carers

Patients and carers can have mixed emotions about palliative sedation therapy. Providing patients, their medical treatment decision maker (MTDM), families and friends/carers with educational information about palliative sedation therapy is important. It leads to improved satisfaction among carers, and helps them in their bereavement. Please encourage questions and the opportunity to say goodbye.

Having made the decision to pursue sedation, carers may struggle if deep sedation and relief of distress is not achieved within one to two hours^{13,19}.

At a minimum, clarify goals of care with the patient or MTDM and family/friend/carer and provide them with the following information:

- The person's general condition including severity of illness and likely prognosis.
- Limitations of other available treatment options with reassurance that this is the best approach and does not shorten life¹⁵.
- Explanation and support around the concept that comfort cannot be provided without providing sedation.
- An explanation of the aims and methods of palliative sedation therapy, ideally before day of treatment¹⁵ to support planning.
- The effects of sedation and any key risks.
- Reassurance that medical and nursing care will continue after sedation.
- The support available from the multidisciplinary team and opportunities for referral.
- Give regular updates on progress¹⁵.

Document all discussions in the patient notes and ensure clinical handover to all involved staff and carers. See more details in **Appendix 1**.

Managing palliative sedation therapy

The below figure outlines the steps involved in palliative sedation therapy. For more information please see the following pages.

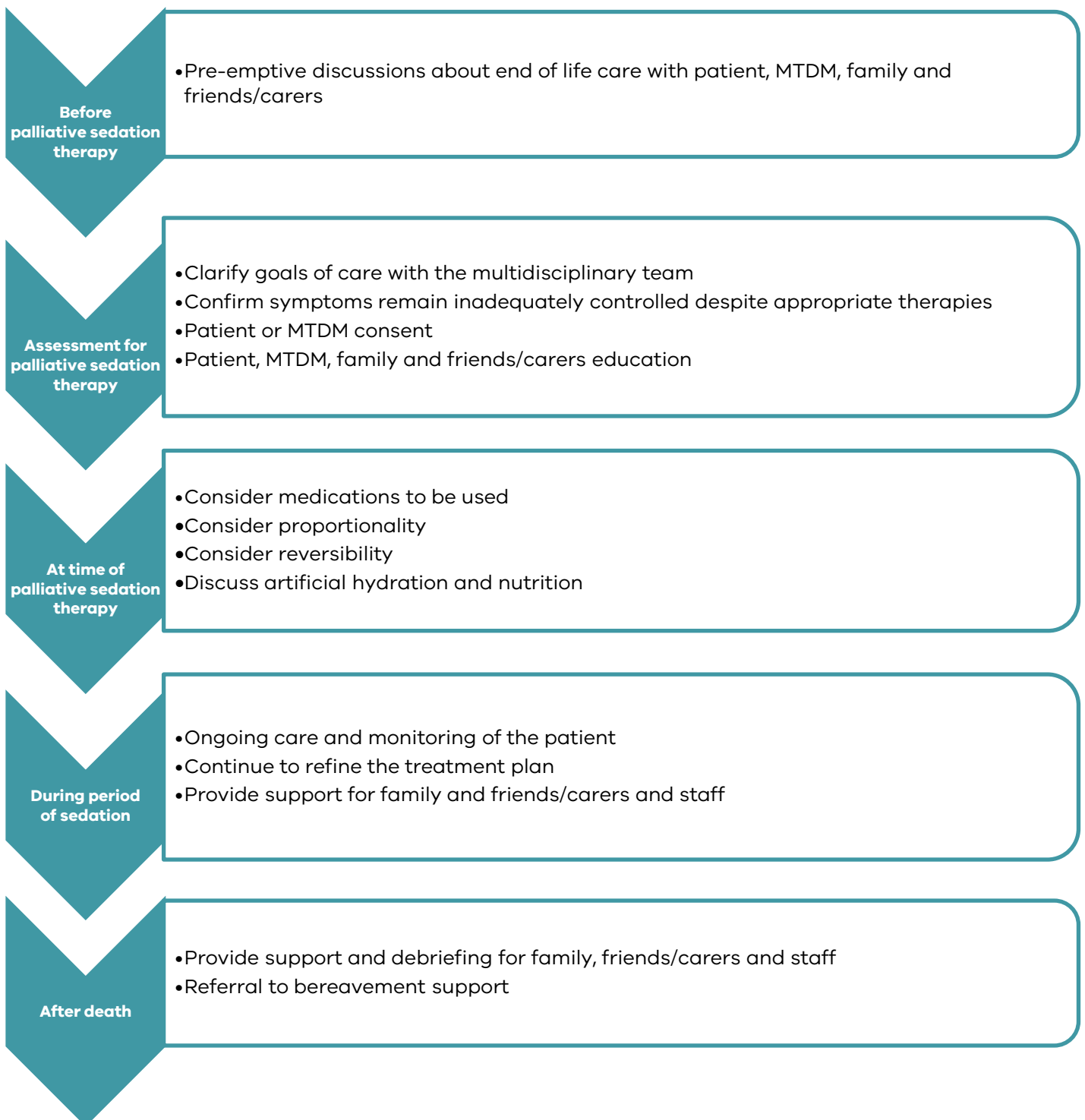


Table 2: Additional information to support management of palliative sedation therapy

Step	Key considerations	Action
Before palliative sedation therapy		
Pre-emptive discussions about end of life care with patient, MTDM, family and friends/carers	<p>Discuss preferences around end of life care with any patient at risk of dying, including:</p> <ul style="list-style-type: none"> • patient values and wishes • advance care planning • use of treatments such as antibiotics • nutrition and hydration options. <p>If there is the potential for distressing symptoms, discuss palliative sedation therapy^{2,14}.</p> <p>If the patient doesn't want to have the discussion, ask them to identify their MTDM so you can have these discussions with them when the patient loses capacity¹⁴.</p>	<p>Document discussion clearly in notes.</p> <p>Complete goals of care and medical decisions paperwork.</p> <p>Review decision regularly²⁰.</p> <p>Identify the MTDM and ensure they are part of the conversation with the patient's consent or if the patient is not competent.</p>
Assessment for palliative sedation therapy		
Clarify goals of care with the multidisciplinary team	<p>Meet with multidisciplinary team (nurses and doctors as a minimum) and ensure goals of care and outcomes are clear²¹.</p> <p>Complete local limitations of medical treatment paperwork²².</p>	<p>Discuss with the multidisciplinary team.</p> <p>Seek support from experienced clinician if required.</p> <p>Document decisions including limitations of treatment.</p>
Confirm symptoms remain inadequately controlled despite appropriate therapies	<p>Exclude acute deterioration/reversible causes of symptoms².</p> <p>For agitation – including bladder, bowel, drugs – refer to your local policy on management of delirium.</p> <p>Consider psycho-social factors².</p> <p>Reach consensus that the patient has refractory symptoms and intolerable suffering²⁰.</p>	<p>Discuss with the multidisciplinary team.</p> <p>Seek support from experienced clinician if required.</p> <p>Document decisions including limitations of treatment.</p> <p>Document patient has met criteria.</p>
Patient or MTDM consent	<p>Establish patient's capacity to make medical decisions².</p> <p>Consult with competent patients, ideally with their carers involved.</p> <p>For patients without capacity, seek guidance from their MTDM and any advance care directives.</p>	<p>Consult patients and/or carers.</p> <p>Determine capacity and document result of this assessment.</p>
Patient, MTDM, family and friends/carers education	<p>Provide the patient, MTDM, family and friends/carers with information about palliative sedation therapy.</p>	<p>Document education provided to patient, MTDM, family and friends/carers.</p>

Step	Key considerations	Action
At time of palliative sedation therapy		
Consider medications to be used	There is currently no clear evidence regarding medications to be used ¹⁸ .	Refer to Appendix 2 for guidance on medications. Document decisions in medical records and drug charts.
Consider proportionality	Prescribe the minimum dose of sedatives needed to achieve acceptable relief of suffering ^{12, 23} . This minimises the risk of adverse events while maximising the patient's ability to interact. This needs to be balanced according to patient and carer values ¹² .	Document decisions in medical records and drug charts.
Consider reversibility	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 ^{14, 15} .	Document decisions.
Discuss artificial hydration and nutrition (ANH)	This is a common concern for carers but should be a separate discussion to palliative sedation therapy itself ^{7, 14, 23} . Carers should be reassured that: <ul style="list-style-type: none"> • food is not required at this stage as patient usually not hungry^{7, 13} • fluids are not routinely offered as no evidence that this improves outcomes^{13, 15, 23} • in cases where there are religious or cultural reservations about ceasing ANH then it can be continued, while monitoring for evidence of direct patient harm^{13, 15}. 	Document decisions and ongoing plans (e.g mouth care using mouth swabs, hydration via fluid sips).

Step	Key considerations	Action
During period of sedation		
Ongoing care and monitoring of the patient	Continue to assess patient and monitor effectiveness of sedation therapy.	Seek feedback from family. Assessment tools such as the Richmond Agitation-Sedation Scale might be considered to support review and monitoring ⁵ .
Continue to refine the treatment plan as condition changes or if initial treatment plan not effective	Review current sedating medications. Consider using sedation related prn medication. Consider discussing with other specialists, for example anesthetists.	Titrate medications. Introduce additional medications. Discuss with palliative medicine colleagues or other specialists.
Provide support for family and friends/carers and staff	Family should be monitored for psychological and spiritual distress. Provide ongoing explanation of symptoms and course of illness. Families are usually relieved that palliative sedation has reduced symptom distress ¹⁹ . Monitor staff for psychological and spiritual distress. Distress can be reduced by involving all disciplines in the assessment of the symptoms, goals of care and decision making around palliative sedation therapy. There should be opportunities for staff to discuss the situation before, during, and after ¹⁴ . Provide pre death bereavement support.	Provide opportunities for debriefing and/or case review. Provide support through regular supervision. Provide local supports (for example Employee Assistance Program) Refer to bereavement and spiritual care support services. Offer written material to family/carers.
After death		
Provide support and debriefing for family, friends, carers and staff	Ensure ongoing support and communication with patient and MTDM, family/carers.	Provide opportunities for debriefing and/or case review. Provide support through regular supervision.
Referral to bereavement support	Ensure ongoing support and communication with multidisciplinary team.	Provide local supports (for example Employee Assistance Program). Refer to bereavement and spiritual care support services.

Appendix 1: Documentation

Documentation is important to ensure all members of the care team, including the patient, MTDM, family and friends/carers are equally informed. It also supports multidisciplinary team communication.

The headings below outline the minimum inclusions for documenting the use of palliative sedation therapy. This resource should be used with local documentation policies.

Background

1. Presentation of distress^{22,23}
2. Symptoms requiring sedation²³
3. Contributing and causative factors
4. Previous treatments tried²³
5. Prognosis
6. Resuscitation status²⁶
7. Discussion with care team (interdisciplinary consensus that symptoms are refractory)
8. Discussion with family, patient/MTDM (ensure that they understand and provide informed consent)^{22,23}
9. Discussion about artificial nutrition and hydration²⁶

Assessment

1. Baseline sedation score
2. Titration of sedation²³ (including monitoring of symptom distress and sedation)

Recommendations/plan

1. Ongoing support of family and staff²²
2. Complications and their possible management²²
3. Plan for care (consider Care Plan for the Dying Person – Victoria)



[Care plan for the dying person – Victoria](#)

Evaluation

1. Effectiveness of sedation for relief of suffering, time from institution of sedation to death, whether it was reversed, family satisfaction with process

Appendix 2: Medicines used for palliative sedation therapy

The below medication formulary is provided as a guide only. Please refer to local guidelines and hospital restrictions for use before prescribing.

Some medications may not be available under PBS. Clinicians need to consider the cost and accessibility of medications before prescribing.



Contact pharmacist for additional information.

Principles of medication management in palliative sedation therapy

- Palliative sedation indicates an intended reduction in consciousness and excludes sedation secondary to medicines used for symptom control (e.g. opioids for analgesia or shortness of breath).
- There are a wide range of doses recommended for medications used in palliative sedation therapy. Most guidelines recommend that the goal of titration should be adequate control of suffering and the level of consciousness that is necessary to achieve this.
- Opioids are not recommended to be used solely for the purpose of sedation but if they are used for other indications, their use should be continued. Subcutaneous route of administration is recommended as it is less invasive.
- Not all medications are compatible with each other within the same syringe driver.

Major classes of medication used in palliative sedation therapy

- a) Benzodiazepines
- b) Antipsychotics
- c) Barbiturates

There are case reports of other drugs such as propofol or dexmedetomidine being used in rare circumstances. Their use is beyond the scope of this document.



[Syringe driver compatibility guidelines](#)

[Opioid conversion guidelines](#)

Medication	Pharmacology	Availability PBS quantity/repeats (if NON-PBS pack size and cost)	Recommended dosage and route of administration	Additional information
First line medications used for palliative sedation therapy				
<i>Clonazepam</i>	Benzodiazepine	inj, 1 mg/mL, 1 mL, 5 mL PBS general schedule authority clinical criteria: for use in epilepsy	Subcutaneous administration Starting dose: 0.5 mg SC, 2 hourly prn Maintenance dose with CSCI 2–8 mg/24 hours	There is a significant loss when infused through PVC tubing which can be addressed by using non-PVC tubing or titrating the dose to desired effect Indication(s) including non-sedating effects: Epilepsy, myoclonus, neuropathic pain, restless leg syndrome, terminal restlessness
<i>Midazolam</i>	Benzodiazepine	inj, 1 mg/mL, 5 mL, 10 mL inj, 1 mg/mL, 5 mL, 5 mL, 10mL inj, 5 mg/mL, 1 mL, 10 mL inj, 5 mg/mL, 1 mL (plastic), 10 mL inj, 5 mg/mL, 3 mL, 5 mL inj, 5 mg/mL, 3 mL, 10 mL, 5 mL	Subcutaneous administration Starting dose: 5–10 mg SC, stat and 1 hourly prn Maintenance dose with CSCI 10–60 mg/24 hours If higher doses are required, would usually introduce an antipsychotic agent in addition Water soluble	Short acting Most commonly used agent in hospitals Short duration of action hence continuous infusion is generally required to maintain a sustained effect Water soluble, can be mixed with other medications Adverse effects: Paradoxical agitation, respiratory depression, withdrawal if the dose is rapidly reduced after continual infusion and tolerance Indication(s) including non-sedating effects: Seizures, anxiety, sedation for terminal restlessness, have synergistic sedative effects with opioids and antipsychotics

Medication	Pharmacology	Availability PBS quantity/repeats (if NON-PBS pack size and cost)	Recommended dosage and route of administration	Additional information
<i>Haloperidol</i>	Antipsychotic	inj, 5 mg/mL, 1 mL, 10 mL, 25 mL inj, 5 mg/mL x 10 amps available PBS general schedule	Subcutaneous administration Starting dose: 1.5- 5 mg SC, stat and 1 hourly prn Maintenance dose with CSCI : 2.5 mg–10 mg/24 hours	Not used as a sole agent as it is a weak sedative. May be used in combination with benzodiazepines for patients with delirium Adverse effects: Extrapyrasidal side effects, tachycardia, orthostatic hypotension, akathisia Indication(s) including non-sedating effects: Agitation, nausea, delirium

Other medications that may be used for palliative sedation if inadequate response with first line agents (local restrictions for access and use may apply)

<i>Levomepromazine</i> (<i>Methotrimeprazine</i>)	Phenothiazine antipsychotic	25 mg/mL x 10 amps Non-PBS, available under the Special Access Scheme https://www.tga.gov.au/form/special-access-scheme	Subcutaneous administration Starting dose : 12.5–25 mg SC 1 hourly prn Maintenance dose with CSCI: 50–300 mg SC/24 hours Usual maximum of 300 mg 24 hourly via CSCI	Subcutaneous: Check guidelines or contact pharmacist as it has some incompatibilities. It is compatible with morphine and midazolam Often given in conjunction with a benzodiazepine Limited community availability when needed urgently Adverse effects: Orthostatic hypotension, paradoxical agitation, extrapyramidal symptoms, anticholinergic effects Indication(s) including non-sedating effects: Nausea/vomiting, sedation for terminal restlessness. Advantageous if delirium is present , some analgesic effect, rapid onset
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Medication	Pharmacology	Availability PBS quantity/repeats (if NON-PBS pack size and cost)	Recommended dosage and route of administration	Additional information
<i>Phenobarbital</i> (<i>phenobarbitone</i>)	Barbiturate	inj, 219 mg/mL x 5 amps PBS general schedule	Subcutaneous administration Starting dose: 50–200 mg SC, 1 hourly prn (urgent care may be given IV) Maintenance dose with CSCI: 600 mg–1200 mg/24 hours Usual maximum dose: 2400 mg/24 hours, anecdotal evidence of up to 3000 mg/24 hours.	No analgesic effect hence opioids may be necessary to manage pain Use a separate syringe driver Long half-life, reversal of sedation may be difficult Reliably and rapidly causes unconsciousness. May be useful in patients who have developed extreme tolerance to opioids and benzodiazepines Anticonvulsant Adverse effects: Paradoxical excitation in high doses or in the elderly, injection site irritation, hepatotoxicity, hypotension, nausea, vomiting

Glossary

Anticipatory prescribing

Prescribing medications before symptoms start, enabling prompt relief when they do. Many end of life symptoms can be predicted and managed proactively.



Anticipatory medicines: Statewide guidance for Victoria

Carer

A carer (usually a family member or friend) is someone who is unpaid and provides care to a person (usually at home). The carer may or may not live with the person, and the carer may be aged or have their own health issues.

End of life care

Care delivered to people with progressive, incurable illness to help them to live as well as possible until they die. It supports the needs of both the patient and their family for approximately the last 12 months of life²⁷.

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.

Intolerable suffering

Suffering that the person perceives to be unbearable.

Medical treatment decision maker (MTDM)¹⁷

A person authorised under the Medical Treatment Planning and Decisions Act to make a medical treatment decision on behalf of another person who does not have capacity to make that decision. The MTDM for a person is the first person, 18 years of age or older, in the list below. They must be reasonably available and willing and able to make the decision. Where there are two or more relatives who are first on this list, the eldest is the MTDM.

1. The person's appointed medical treatment decision maker
2. A guardian appointed by the Victorian Civil and Administrative Tribunal to make decisions about medical treatment for the person
3. The first of the following people who is in a close and continuing relationship with the person:
 - a) the person's spouse or domestic partner
 - b) the person's primary carer (see definition of carer)

-
- c) an adult child of the person
 - d) a parent of the person
 - e) an adult sibling of the person.

Note: Appointments made before the Medical Treatment Planning and Decisions Act commenced on 12 March 2018 are valid. See 'medical treatment decision maker' above.

Palliative care

Care that improves the quality of life of patients and their families facing the problems associated with lifethreatening or life limiting illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems – physical, psychosocial and spiritual²⁷.

Prescriber

A health professional authorised to write prescriptions and medication orders, and give directions (verbal or written) about administration and supply of prescription-only medicines.

Refractory symptoms

Inadequately controlled symptoms which cause the patient to suffer despite maximal efforts from clinical experts to identify a tolerable therapy.

Respite sedation

Sedation induced for a predetermined period of time (for example overnight) to give the patient respite from intractable refractory symptoms causing suffering.

Specialist palliative care

Palliative care provided by medical, nursing or allied health professionals, as individuals or part of a specialist team. They have specialist palliative care qualifications and accreditation²⁵.

Terminal illness

Illness that is expected to cause death within days.

Terminal restlessness

A cluster of symptoms that commonly presents with increased physical restlessness or agitation, anxiety and altered mental state.

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