Government of **Western Australia**
Department of **Health**

Statewide guidance for the safe, effective and ethical use of palliative sedation

Disclaimer:

This *Statewide guidance for the safe, effective and ethical use of palliative sedation* has been developed to assist public and private, adult and paediatric Palliative Medicine Specialists, and the Specialist Palliative Care teams, multidisciplinary teams and health professionals who work with them, to:

- support patients and their family/carers to make decisions about care in the last days of life
- acquaint themselves with the practice of palliative sedation
- provide guidance regarding assessment, documentation, consent and communication.

This guidance document does not replace the need for application of clinical judgement to each individual presentation, nor variations based on care provided in metropolitan, rural and remote locations in Western Australia. In addition, it does not replace the need for application of clinical judgement based on variations of care provided across different settings of care (e.g. in-patient and community).

Service providers should implement this guidance in line with specific health service governance structures and related policies.

Acknowledgement:

The Department of Health Western Australia acknowledges the support of Sage Publications Ltd in providing permission to use the *European Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care (10-point summary)*, which has been modified to the Western Australian context.

Reference:

Cherny N., Radbruch L. and the Board of the European Association for Palliative Care (2009). European Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care. Palliative Medicine. 23(7) 581-593.

The Department of Health Western Australia also wishes to acknowledge that some of the content of this document has been adapted from the Australia and New Zealand Society of Palliative Medicine (ANZSPM) *Guidance Document: Palliative Sedation Therapy* (2017) and wishes to thank ANZSPM for providing permission for adaptation.

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1. Intended audience

This document outlines the best practice approach for using **palliative sedation*** in a **specialist palliative care*** setting, for adult and paediatric patients. It will assist **Palliative Medicine Specialists***, and the Specialist Palliative Care and multidisciplinary teams who work with them, to support patients and their family/**carers*/guardians*** to make decisions about care in the last days of life.

Health practitioners* who are seeking advice regarding palliative sedation should contact the Palliative Medicine Specialist working within their health service and/or regional area in accordance with existing governance structures.

2. What is palliative sedation?

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

Palliative sedation 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 adults and children with advanced progressive illness and an expected prognosis of hours or days at the most.

Palliative sedation is an extraordinary measure[1] utilised by **Palliative Care Practitioners***, overseen or supervised by a Palliative Medicine Specialist, with the input of a multidisciplinary team.

It is important to note that when palliative sedation is used as a therapeutic intervention the patient dies of natural causes – from the disease itself and not the effect of the pharmacological agent used.

Palliative sedation is also referred to as **continuous deep sedation***, **continuous palliative sedation*, palliative pharmacological sedation*, palliative sedation therapy*, terminal sedation* and therapeutic sedation***.

3. What does this guidance cover?

This guidance details sedation in the management of intolerable and refractory symptoms at the end-of-life.[1, 2]

It aims to set best practice standards and to promote optimal care. It conveys the important message to Palliative Medicine Specialists, and the Specialist Palliative Care and multidisciplinary teams who work with them, that palliative sedation is an accepted, ethical practice[2], used in a small number of selected adult and paediatric patients with life-limiting illness who are experiencing intolerable and refractory symptoms. These symptoms include, but are not limited to:

- Progressive and refractory **dyspnoea***
- Intolerable and untreatable pain

* Defined term – see Glossary of terms

- Refractory nausea and vomiting
- Refractory psychological or existential distress that severely compromises comfort.

4. What does this guidance not cover?

Palliative sedation needs to be distinguished from other types of sedation used in **palliative care***.[1] Use of sedative medications to aid tolerance of poorly controlled symptoms and/or primary management of symptoms experienced during routine end-of-life care is not covered in this document.

This document does not include:

- **Respite sedation***
- Sedation as a side effect of symptom control measures, including the management of **terminal delirium***
- **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
- Seizure management.

Many patients are unresponsive in the terminal phase of illness, with or without the use of medication. This unresponsiveness is a function of the natural dying process.

It should be noted that palliative sedation is not **voluntary assisted dying*** – it is distinct by virtue of the intent and the action (refer to 6.8).

5. Alignment with national and international guidance

This guidance aligns with the:

- ANZSPM Guidance Document: Palliative Sedation Therapy[1]
- Palliative sedation therapy: Statewide guidance for Victoria[3]
- 10-point summary of the European Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care outlined at section 9.[2]

* Defined term – see Glossary of terms

6. Guiding principles

The following guiding principles are provided in relation to palliative sedation:

6.1 Any symptoms that are considered refractory should necessitate immediate referral to specialist palliative care for assessment or discussion. Good palliative care greatly reduces the need for palliative sedation.[4]

6.2 Palliative sedation is usually utilised in an inpatient setting, but it can be facilitated in a patient's home.

6.3 The involvement of a multidisciplinary team is a key feature of the decision to undertake palliative sedation.

6.4 Palliative sedation should only be utilised after a comprehensive assessment of the patient's symptoms and their psychosocial and spiritual needs, and should be supported by skilled and experienced Palliative Medicine Specialists.

6.5 Discussions concerning palliative sedation should commence in a timely manner and continue, as necessary, during the illness trajectory to plan care in accordance with the patient's wishes, informed by health practitioners' opinions and supported by family. Discussions must be clearly documented on each occasion.

6.6 Following a decision to proceed with palliative sedation, thorough clinical care planning is essential. This planning should consider the clinical setting of care (e.g. inpatient or community) and occur in accordance with specific health service governance including staff requirements to ensure safe and high-quality care.

6.7 If **consent*** is obtained and palliative sedation is administered, the treatment must be specifically noted in the patient's medical record as *palliative sedation*. This requirement aligns with Recommendation 18 of the *My Life, My Choice* Report of the Parliamentary Joint Select Committee on End of Life Choices, 2018.[4]

6.8 Palliative sedation is not voluntary assisted dying – it is distinct by virtue of the intent and the action. Describing it as euthanasia is also incorrect. For further information regarding voluntary assisted dying in Western Australia, refer to: https://ww2.health.wa.gov.au/voluntaryassisteddying.

6.9 Palliative sedation is an appropriate approach for a small number of paediatric patients and this guidance is applicable to paediatric practice. Discussions should involve the **child*** at an age appropriate level, if possible, and their **parents***. This should be led by the Paediatric Palliative Care Service in consultation with the treating team.

Refer to section 8.3 and section 8.4 for further details regarding assessment and decision-making including consent for **mature minors*** and children.

6.10 Service providers should implement this guidance in line with specific health service governance structures and related policies.

* Defined term – see Glossary of terms

7. Additional guidance for rural and remote health practitioners

In addition to the points outlined below, please note that all guiding principles outlined at section 6 above apply for rural and remote health practitioners.

In addition:

7.1. Clinical discussions in relation to palliative sedation for adults and mature minors (subject to 7.7 below) should always be led by the Palliative Medicine Specialist and Regional Specialist Palliative Care team for each region in Western Australia, working in partnership with the patient's treating team and senior doctor responsible for the patient's care.

7.2. Palliative care after-hours and/or on-call support should be accessed in accordance with health service arrangements.

7.3. The Palliative Medicine Specialist and Regional Specialist Palliative Care team are well placed to support any discussions regarding palliative sedation.

7.4. In most cases, and especially if the patient has refractory symptoms, the patient will be known to the Palliative Medicine Specialist and Regional Specialist Palliative Care team.

7.5. Specialist Palliative Care teams should liaise with the Palliative Medicine Specialist working within, or contracted to work in, their respective regional areas.

7.6. Clinical discussions in relation to palliative sedation for children (excluding mature minors, as explained at 7.7 below) should always be made collaboratively with parents, the Specialist Paediatric Palliative Care Service, the treating team and the Regional Specialist Palliative Care team.

7.7. In the case of mature minors, clinical discussions in relation to palliative sedation should be made with the Specialist Paediatric Palliative Care Service, the treating team and the Regional Specialist Palliative Care team. As guided by the mature minor, a parent should also be included in discussions, but note that the mature minor may consent in their own right.

Refer to section 8.3 and section 8.4 for further details regarding consent requirements for children including mature minors.

8. Consent requirements

8.1 Policy and legislation requirements

This guidance should be read in conjunction with relevant policy and state legislation, including but not limited to:

1. current statewide Consent to Treatment Policy which outlines the minimum mandatory requirements for health practitioners when seeking a patient's consent to treatment.

To be valid, consent must be:

- **Voluntary** – the decision to either give or withhold consent to the proposed treatment must not be unduly influenced by the health practitioner, friends or family.

- **Informed** – the patient (or person authorised to make a decision on their behalf) must receive meaningful information about the proposed treatment (as relevant to the patient's case, including any material risks) to enable them to make an informed decision.
- Given by a person **who has capacity** to understand the information presented to them and to make a decision about the proposed treatment.
- **Covers the treatment to be performed** – treatment provided must fall within the scope of consent that has been given by the patient.
- **Current** – consent must be reviewed if, after consent was obtained, the patient's circumstances (including treatment options and risks) have changed.

For further information regarding consent, refer to section 9.4.

2. the *Guardianship and Administration Act 1990*[5] which applies to treatment decisions when a patient 18 years or over is not able to make reasonable judgements regarding proposed treatment.

   Note: If the adult patient is unable to make reasonable judgements about their treatment and if they do not have an **Advance Health Directive*** which refers to consent matters about palliative sedation, the treatment decision will be made on the patient's behalf according to the WA Hierarchy of Treatment Decision-Makers* (also known as the 'Treatment Hierarchy'), which is based on sections 110ZD and 110ZJ of the *Guardianship and Administration Act 1990*.

Generally, parents may authorise treatments on behalf of their children, where the treatment is in the child's best interests. However, as their maturity increases, the child may be assessed as a mature minor (refer to section 8.3). Responsibility for treatment decisions may not remain with parents if children are in the care of the CEO of the Department of Communities. Parental responsibilities may also be varied under Family Court orders. If a health practitioner believes that the child's best interests are not served by the treatment decision of a parent, legal assistance should be sought.

8.2 Consent documentation

Regardless of whether the patient consents to or declines the proposed treatment, it is imperative that the details relevant to consent discussion(s) are documented in the patient's medical records, according to local HSP policy. This documentation (be it a consent form or other document) will form part of the record which shows that consent was sought, obtained or declined and that obligations as outlined in section 8.1 have been met by the health practitioner.

8.3 Assessment and decision-making including consent for mature minors

An assessment of a child as a mature minor must be made in the context of the treatment in question; that is, maturity in relation to one treatment decision does not necessarily equate to maturity for all treatment decisions. There is no specific age at which a child becomes a mature minor.

A mature minor, in the context of palliative sedation, is a child who has been assessed by the Paediatric Palliative Care Service in collaboration with the treating team (the **Combined Clinical Team***) as fully understanding the nature and consequences of palliative sedation and who is capable of making a consent decision (and who wishes to make that decision).

* Defined term – see Glossary of terms

This assessment by the Combined Clinical Team may benefit from the inclusion of a psychologist or psychiatrist.

Discussion regarding the concept of palliative sedation and seeking a mature minor's consent to palliative sedation requires the involvement of the Combined Clinical Team. Involvement of parents is encouraged and should be undertaken if the mature minor agrees, however it is not a legal requirement that parents be involved in discussions or decision-making as mature minors have a right to make decisions in their own right. For complex clinical cases consultation with other teams, for example child and adolescent psychiatry, legal advice etc., should be considered.

8.4 Decision-making including consent for children

The Combined Clinical Team will assess and conduct age/developmentally appropriate discussions with the child and their parents regarding the use of palliative sedation. This process *may* benefit from the inclusion of a psychologist or psychiatrist.

Decision-making, including consent, in relation to palliative sedation for children (excluding mature minors as noted above at 8.3) should be made with the child's parents together with the child up to their level of understanding. This should be led by the Combined Clinical Team, ideally through the medium of a multidisciplinary meeting.

9. The European Association for Palliative Care recommended framework for the use of sedation in palliative care: 10-point summary

This guidance aligns with the **European Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care 10-point summary**[2], outlined below. The EAPC framework is widely endorsed and is based on pre-existing guidelines, published experience and extensive peer review.

The EAPC 10-point summary intends to ensure that Palliative Medicine Specialists assess patients with refractory symptoms and apply palliative sedation in the setting of multidisciplinary specialist palliative care and within good clinical and ethical practice. The 10-point summary focusses on the key clinical issues of assessment, documentation, consent and communication, as follows:

9.1 Pre-emptive discussion of the potential role of palliative sedation in end-of-life care and contingency planning

Health practitioners are strongly encouraged to address end-of-life care preferences with all patients at risk of dying, particularly those with progressive **terminal illness*** or illness characterised by intermittent life-threatening exacerbations. The scope of these discussions should be predicated on the general goals and priorities of care.

In some situations, the discussion may need to address specific issues such as cardiopulmonary resuscitation, ventilator support, vasopressor support, comfort care, antibiotics and artificial hydration and nutrition. When there are concerns about the possibility of severe distress at the end-of-life, these should be addressed. When it is clinically appropriate, the relief of extreme distress should should be predicated on the general goals and priorities of care.

* Defined term – see Glossary of terms

In some situations, the discussion may need to address specific issues such as cardiopulmonary resuscitation, ventilator support, vasopressor support, comfort care, antibiotics and artificial hydration and nutrition. When there are concerns about the possibility of severe distress at the end-of-life, these should be addressed. When it is clinically appropriate, the relief of extreme distress should be discussed. This should include discussion regarding the use of sedation as an appropriate and effective response to relieve distress when simpler measures are inadequate for the task or in emergency situations at the end-of-life. This is particularly relevant for patients who do not want resuscitation or ventilatory support and to those for whom these interventions would be inappropriate.

When the potential for catastrophic events such as bleeding or extreme distress is foreseen, contingency plans for the management of these events should also be discussed.

Outcomes of these discussions should be documented and the documentation stored in a prominent place on the patient's record. Patient and family/carer goals and concerns should be revisited periodically, with attention paid to ongoing documentation of these discussions, even if there is no change in the plan of care.

9.2 Indications in which palliative sedation may or should be considered

Palliative sedation is potentially indicated for patients with intolerable distress due to physical symptoms, when there is a lack of other methods for palliation within an acceptable timeframe and without unacceptable adverse effects (e.g. refractoriness).

The specific intolerable symptoms should be identified. The most common symptoms include agitated delirium, dyspnoea, pain and convulsions. Emergency situations may include massive haemorrhage, asphyxiation, severe terminal dyspnoea or overwhelming pain crisis.

Palliative sedation should only be considered if the patient is in the terminal stages of their illness with an expected prognosis of hours or days at the most. Transient or respite sedation may be indicated earlier in the patient's trajectory to provide temporary relief whilst waiting for treatment benefit from other therapeutic approaches.

Occasionally, when patients approach the end-of-life, palliative sedation may be considered for severe non-physical symptoms, such as refractory depression, anxiety, demoralisation or **existential distress***. There is no consensus on the appropriateness of sedation for these indications. Special precautions for these clinical circumstances are outlined at Appendix 1.

9.3 Assessment and consultation procedures

Extreme distress is a medical emergency and patient assessment must be performed with due urgency.

Palliative sedation should only be utilised after a comprehensive assessment of the patient's symptoms and their psychosocial and spiritual needs, supported by skilled and experienced Palliative Medicine Specialists. Comprehensive assessment should include:

1. The patient's medical history
2. All relevant investigations
3. A physical examination of the patient.

* Defined term – see Glossary of terms

In particular, assessment should exclude acute deterioration caused by a potentially treatable complication of life-limiting illness such as sepsis, a reversible metabolic event, medication toxicity and common events such as pleural effusion, pericardial tamponade, ureteric obstruction, upper airway gastrointestinal obstruction, gastrointestinal obstruction, active bleeding, urinary retention or elevated intracranial pressure.

The assessment should evaluate any psychosocial and environmental factors, including sources of spiritual or existential distress, which may be adversely affecting the level of distress. Input should be sought from psychosocial health practitioners involved in the patient's care, as well as nursing staff and family/carer(s). If clinically appropriate, distressed patients may benefit from psychiatric review to exclude depression, anxiety and delirium. All efforts should be made to involve the patient's primary care team in the assessment process and in any recommendations.

The assessment should include estimates as to whether death is anticipated within minutes to hours, hours to days, days to weeks, or longer. This prognostic assessment should be based on the extent of the disease, validated prognostic instruments, 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, dyspnoea, anorexia, degree of oral intake, delirium and oedema.

The assessment must evaluate the patient's capacity to make decisions about ongoing care. This should be based on standard criteria such as:

1. The patient, including mature minors, can express their own will
2. The patient can understand the relevant information
3. The patient can understand and acknowledge the implications of their choice.

For further information relating to assessment and decision-making for mature minors and children refer to section 8.3 and section 8.4.

If decisional capacity is in doubt, then expert evaluation by a relevant expert may be required.

If there is uncertainty in the patient evaluation, especially with regards to whether all options to relieve distress have been considered, consultation with experts (e.g. psychiatrists, anaesthetists, pain specialists, oncologists, radiotherapists and specialist nurses) should be sought.

Whenever possible, the medical rationale for palliative sedation as well as the decision-making process should be based on input from the multidisciplinary palliative care team. Case discussion and team conferences may be suitable platforms to facilitate this process.

The medical rationale for recommending palliative sedation, the decision-making process, the aims of sedation and the planned depth and duration of sedation should be recorded, in an easily retrieved document (e.g. the patient's medical record).

9.4 Consent requirements

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:

1. 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.
2. The rationale for the decision that palliative sedation is the only method available for achieving symptom relief within an acceptable timeframe.
3. The aims of palliative sedation.
4. The method of palliative sedation, including the depth of planned palliative sedation, patient monitoring, possibility of planned weaning (in some circumstances), with an option to discontinue sedation (in some circumstances).
5. The anticipated effects of palliative sedation including degree of reduction in consciousness levels, estimated effects on mental activities, communication and oral intake.
6. The potential uncommon risks such as paradoxical agitation, delayed or inadequate relief, and the possibility of complications including hastened death.
7. Medical treatments and nursing care that are to be maintained during palliative sedation, the continuation of treatments and care to maximise patient comfort and respect for the patient and their family/carers' wishes.
8. The expected outcomes if palliative sedation is not performed, including other treatment options, degree of suffering likely to persist with each option and expected survival with each option.
9. Commitment to the patient's wellbeing and provision of best possible care irrespective of patient treatment choices.

With the permission of the patient, it is generally preferable to conduct this discussion with the participation of family/carers. This approach maximises communication and often facilitates important meaning-related discussions between patients and their families/carers while the opportunity still exists.

The content and conclusions from the discussion should be documented in the patient's medical record.

If the patient is unable to make reasonable judgements about their treatment and if they do not have an Advance Health Directive which refers to consent matters about palliative sedation, the treatment decision will be made on the patient's behalf according to the WA Hierarchy of Treatment Decision-Makers (also known as the 'Treatment Hierarchy'). The treating team must seek a decision for non-urgent treatment, from the first person on the hierarchy who is 18 years of age or older, has full legal capacity and is willing and reasonably available to make the decision.

It is the responsibility of the multidisciplinary team to discuss medical treatment options (including, if necessary, the use of palliative sedation). The treating team should emphasise to the decision-maker, that they should indicate what the patient would have wanted and the reasoning that leads them to their conclusion.

9.5 Discussion regarding the decision-making process with the patient's family/carer

In situations in which the family/carers were not part of the consent process, permission should be sought to communicate the decision with the patient's family/carers. Informing the family/carers should be presented to the patient as usual practice and permission sought in the form of consent.

With the patient's consent, discussion should be held with the family/carers to inform them of the patient's condition, treatment options, potential outcomes of those treatment options and the consequences of a patient's expressed preferences. Wherever possible this discussion should be held with the patient and family/carers, to address concerns and enable them to achieve a common understanding of the patient's preferences for palliative sedation.

In the uncommon event of the patient not permitting discussion with their family/carers, the reasons should be explored and the patient should be strongly encouraged to reconsider their decision (but duress or undue influence should be avoided, as it is likely to negate the validity of consent). In some cases this may include the need to counsel them about the potential distress that withholding of information may cause to family/carers.

In the event that the family/carers do not support the treatment plan, or the consent decision made by the patient, the multidisciplinary team should:

1. discuss with the family/carers the patient's legal right to make a decision on their own behalf
2. provide sufficient information to help families/carers better understand the patient's conditions and suffering
3. support the patient and their family/carers by talking with each party and attempting to find a solution that is acceptable to both; and
4. provide psychological support to families/carers to help them to understand the factors that contribute to conflicts, such as grief and guilt.

Health practitioners should remember that in some cultures, consent provided by family/carers may be considered necessary or desirable. This differs from West Australian law which upholds the right of a patient with capacity to make a decision on their own behalf. Wherever possible, the multidisciplinary team should discuss, consider and respect the patient's, family and carers' cultural diversity but note that if undue pressure or coercion is applied to the patient, their consent will not be valid.

9.6 Selection of the sedation method

In general, the level of sedation should be the lowest necessary to provide adequate relief of suffering. Other than in emergency situations at the end-of-life, intermittent or mild sedation should generally be attempted first. For some patients a state of 'conscious sedation' in which the ability to respond to verbal stimuli is retained and may provide adequate relief without total loss of interactive function.

Doses can be titrated down to re-establish lucidity after an agreed interval to re-evaluate the patient's condition and preferences regarding sedation or for pre-planned family/carers' interactions (this is a potentially unstable situation, and the possibility that lucidity may not be restored promptly, that the refractory symptoms may reappear or that death may ensue should be explained to both the patient and family/carers).

Deeper sedation should be adopted when mild sedation has been ineffective.

Continuous deep sedation could be selected first if:

1. the suffering is intense
2. the suffering is definitely refractory
3. death is anticipated within hours or a few days
4. the patient's wish is explicit; and
5. in the setting of an end-of-life catastrophic event such as massive haemorrhage or asphyxia.

9.7 Medications, dose titration, patient monitoring and care

Medications usually used for palliative sedation in Western Australia are as follows:

a) Benzodiazepines (e.g. Midazolam, Clonazepam).

b) Antipsychotics (e.g. Haloperidol (usually in combination); Levomepromazine – only via the Special Access Scheme).

c) Barbiturates (e.g. Phenobarbitol).

Note: the medications listed above have been modified from the EAPC framework, to align with the Australian context and availability.

Palliative sedation should be undertaken or supervised by a Palliative Medicine Specialist. The patient should be assessed frequently until adequate sedation is achieved and subsequently at least twice daily after sedation has been achieved.

The severity of suffering, level of consciousness and adverse effects related to palliative sedation (such as delirium, agitation or aspiration) should be evaluated regularly. The doses of the medications should be increased or reduced gradually to a level at which suffering is palliated with a minimum suppression of the consciousness levels and undesirable effects, with documentation of the reason for changes and the subsequent responses. Consciousness is assessed by the patient's response to stimuli, agitation or motor activity, and facial expression.

When the goal of care is to ensure comfort until death for an imminently dying patient, the only critical parameters for ongoing observation are those pertaining to comfort. Observations of heart rate, blood pressure and temperature do not contribute to the goals of care at this stage and should be discontinued. Respiratory rate is monitored primarily to ensure the absence of respiratory distress and tachypnoea. Since downward titration of drug doses places the patient at risk for recurrent distress, in most instances it is not recommended even as the patient approaches death. In dying patients, gradual deterioration of respiration is expected, and this alone should not constitute a reason to decrease sedation.

In all cases, the multidisciplinary team must maintain the same level of humane dignified treatment as before sedation; this level of care includes talking to patients and adjusting the environment. Oral care, eye care, toilet, hygiene and pressure area prevention should be performed on the basis of the patient's wishes and the estimated risks/harms in terms of the goals of care.

9.8 Guidance for decisions regarding hydration and nutrition and other medications taken by the patient

The decision about artificial hydration/nutrition therapy is independent of the decision about palliative sedation itself. Whether artificial hydration/nutrition therapy is performed should be individually decided through comprehensive evaluation of the patient's wishes and the estimated benefits/harms in view of the treatment aim, which is the prevention and palliation of suffering.

Opinions and practices vary. This variability reflects the heterogeneity of attitudes of involved health practitioners, ethicists, patients, families/carers and local norms of good clinical and ethical practice.

Individual patients, family members/carers and health practitioners may regard the continuation of hydration as a non-burdensome humane supportive intervention that represents one means of reducing suffering. Alternatively, hydration may be viewed as a superfluous impediment to inevitable death that can be appropriately withdrawn because it does not contribute to patient comfort or the prevailing goals of care.

Often, the patient will request relief of suffering and give no direction regarding hydration and nutrition. Under these circumstances, the multidisciplinary team and the family/carers must work to reach a consensus on what constitutes a morally acceptable plan based on the patient's best interests.

If adverse effects of artificial hydration and/or nutrition therapy exacerbate patient suffering, then reduction or withdrawal of artificial hydration/nutrition should be considered.

Medications for symptom palliation used before sedation should be continued, unless they are ineffective or have distressing side effects. Medications that are either inconsistent with or, irrelevant to, the goal of patient comfort may be withdrawn. In most cases opioids should be continued, possibly with dose modification, unless adverse effects or signs of overdose (e.g. myoclonus) are observed. If symptoms are well palliated and overdose signs are observed, opioid doses should be reduced, but should not be withdrawn rapidly, owing to the risk of precipitating withdrawal.

9.9 Informational needs and care for the patient's family/carers

Situations in which a patient is sedated are often profoundly distressing to family members/carers. Families/carers should be allowed and encouraged to be with the patient and, in many situations, an opportunity to say goodbye may be of critical importance. If the patient is hospitalised, every effort should be made to provide privacy for emotional and physical intimacy. Visitation restrictions should be minimised, especially for children. To promote the family/carers' sense of well-being and peacefulness, consideration should be given to the aesthetics of the care environment, including the availability of basic supports for the family/carers such as tissues, chairs, water, access to a telephone, and opportunity to sleep in the room or nearby, if possible.

The multidisciplinary team must provide supportive care to the members of the patient's family/carers. This includes listening to the family/carers' concerns, attention to grief and physical/psychological burdens and guilt. The multidisciplinary team should counsel the family/carers in the ways that they can continue to be of help to the patient, for instance by being with, 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 (if appropriate) or reading to the patient).

Families/carers of sedated patients need to be kept informed about the patient's well-being and what to expect. The multidisciplinary team should provide regular and pre-emptive information updates to the family/carers including the patient's condition, the treatment of symptoms, anticipated changes or, when appropriate, notification that death is approaching and what can be expected in the dying process.

Having made the decision to pursue palliative sedation, the multidisciplinary team should be aware that families/carers may struggle if deep sedation and relief of distress is not achieved within the desired timeframe.

Families/carers often need repeated reassurance that other methods have been sufficiently trialled and/or carefully considered but were ineffective, that palliative sedation is unlikely to shorten the patient's life, and that it can be discontinued or reduced if needed.

After the death of the patient, the family/carers should be offered bereavement support and counselling as determined by their assessed needs.

9.10 Care for the health care team and managing staff distress

Situations in which a patient is sedated can often be profoundly distressing to staff members. This is particularly true if there is discord regarding the appropriateness of the intervention and in situations when the process is protracted.

The multidisciplinary team should recognise the potential for staff distress. All participating staff members need to understand the rationale for palliative sedation and goals of care. Whenever possible this should be addressed at team meetings or case conferences, before, during and after the event, to discuss the professional and emotional issues related to such decisions and to improve local procedures when necessary. It may also be necessary to arrange a formal team debrief to discuss the psychological, social and emotional impact of certain cases involving palliative sedation to foster a culture of sensitivity and self-care.

Distress can be mitigated by fostering a culture that is sensitive to the emotional burdens involved in care, participating in the deliberative processes leading up to a treatment decision, sharing information and engaging in multidisciplinary discussions that offer the group or individual opportunities to express their feelings.

Care should be taken pre-emptively for staff welfare before embarking upon palliative sedation for a patient with troublesome refractory symptoms.

Clear communication about the purpose of palliative sedation, any expected adverse features and methods of mitigating further symptoms, must occur. Members of the multidisciplinary team must be given an opportunity to clarify any major issues they may have before starting this intervention.

It is imperative to arrange a formal staff debrief following a case of palliative sedation to discuss the psychological, spiritual and emotional impact of this measure. This helps to promote a culture of intentional self-care that is essential to the practice of **Palliative Medicine***.

* Defined term – see Glossary of terms

Glossary of terms

Advance Health Directive	A document recognised under the *Guardianship and Administration Act 1990* (WA) which records a competent adult's decisions about possible future treatment. Treatment decisions recorded in a valid AHD must be followed in circumstances where the maker of the AHD can no longer make or communicate the decision themselves.[6]
Carer(s)	A person who provides ongoing unpaid care or assistance to another person who has a disability, a chronic illness, including a mental illness or a person who because of frailty requires assistance with carrying out everyday tasks.
Child/Children	Individuals aged under 18 years.
Combined Clinical Team	In the paediatric setting, this refers to the Paediatric Palliative Care Service, in collaboration with the treating team.
Consent (to medical treatment)	A patient's agreement that a health practitioner can proceed to perform a specific proposed treatment.
Continuous deep sedation/ Continuous palliative sedation/Palliative pharmacological sedation /Palliative sedation/ Palliative sedation therapy /Terminal sedation/ Therapeutic sedation	The continuous use of sedatives to relieve intolerable and refractory symptoms resulting in the total loss of a patient's consciousness until death. Palliative sedation is **not** the use of sedative medications to aid tolerance of poorly controlled symptoms and/or primary management of symptoms experienced during routine end-of-life care.
Dyspnoea (shortness of breath)	A subjective experience of difficult, laboured and uncomfortable breathing.[7]
Existential distress	Distress experienced at end-of-life, including feelings of hopelessness, burden to others, loss of sense of dignity, desire for death or loss of will to live[8] and threats to self-identity.[9,10] If clinically appropriate, distressed patients may benefit from psychiatric review to exclude depression, anxiety and delirium.
Guardian(s)	In relation to an adult, means the person formally appointed by the State Administrative Tribunal as a guardian of that adult under the *Guardianship and Administration Act 1990* (WA).

Health practitioner(s)	In the Health Practitioner Regulation National Law (WA) Act 2010 (the National Law) at section 5, a "health practitioner" is an individual who practices a health profession. The following are "health professions" under the National Law: (a) Aboriginal and Torres Strait Islander health practice; (b) Chinese medicine; (c) chiropractic; (d) dental; (e) medical; (f) medical radiation practice; (g) midwifery; (ga) nursing; (h) occupational therapy; (i) optometry; (j) osteopathy; (ja) paramedicine; (k) pharmacy; (l) physiotherapy; (m) podiatry; and (n) psychology. For the purposes of this document, individuals who practice in the health professions of social work and speech pathology are also considered "health practitioners", despite not being recognised as such under the National Law. These health practitioners are currently regulated outside of the National Law.
Intolerable distress/symptoms	Suffering that the patient perceives to be unbearable.
Mature minor(s)	In the context of palliative sedation, is a person under the age of 18 who has sufficient emotional and intellectual capacity to fully comprehend the nature, consequences and risks of a proposed action (e.g. a treatment decision or a decision to release health information), irrespective of whether a parent (or legal guardian) consents to it. A child who is assessed to be a mature minor may consent to or decline the proposed treatment.
Palliative care	An approach that improves the quality of life of people (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial and spiritual.[11]
Palliative Care Practitioner	For the purposes of this document, Palliative Care Practitioner covers a wide range of professions, including specialists, doctors, nurses, allied health and members of the multi-disciplinary team. Some specialise in palliative care as a full-time role and others will have palliative care as a part of their daily work.

Palliative Medicine	Palliative Medicine is the specialist care of people with terminal illnesses and chronic health conditions in community, hospital and hospice settings. Palliative Medicine Physicians/Specialists work collaboratively with a multidisciplinary team of health practitioners to provide end-of-life care, provide relief from pain and symptoms of illness, and optimise the quality of life for a patient. Palliative medicine treats the physical aspects of illness, and integrates psychological and spiritual facets of patient care.
Palliative Medicine Specialist/Physician	A Palliative Medicine Specialist (or Physician) is a medical specialist who is a Fellow of the Royal Australasian College of Physicians and has completed the College's training programme in palliative medicine, a Fellow of the Australasian Chapter of Palliative Medicine, or both.
Palliative sedation	The continuous use of sedatives to relieve intolerable and refractory symptoms resulting in the total loss of a patient's consciousness until death. Palliative sedation is **not** the use of sedative medications to aid tolerance of poorly controlled symptoms and/or primary management of symptoms experienced during routine end-of-life care.
Parent(s)	In relation to a child, means the person having parental responsibility for that child. Such person will usually be a parent of the child unless parental responsibility has been varied, such as by an order made by the court (e.g. a parenting order made by the Family Court or certain types of protection orders made under the *Children and Community Service Act 2004* (WA)).
Refractory/ refractory symptoms/ refractoriness	Inadequately controlled symptoms which cause the patient to suffer despite maximal efforts from clinical experts to identify a tolerable therapy.[3]
Respite sedation/transient sedation/transient palliative sedation	Sedation induced for a predetermined period of time (for example overnight) to give the patient respite from intractable refractory symptoms causing suffering.[3] The preferred term in Western Australia is transient palliative sedation.

Specialist palliative care	Care undertaken by a professional palliative care team or service with recognised qualifications or accredited training in palliative care. They provide direct care to people, and their family/carer with complex palliative care needs and/or provide consultation services to support, advise and educate specialist and non-specialist teams providing end-of-life care and palliative care and/or to provide direct care to people with complex palliative care needs.[12]
Terminal delirium	A condition of disturbed consciousness, with reduced ability to focus, sustain or shift attention occurring in the last days or hours of life.[13]
Terminal illness	Illness that is expected to cause death within days.
Voluntary assisted dying	The administration of a voluntary assisted dying substance, including the steps reasonably related to that administration (section 5, *Voluntary Assisted Dying Act 2019* (WA)).
WA Hierarchy of Treatment Decision- Makers or Treatment Hierarchy	Refers to the priority order in which certain persons may be identified to make decisions on behalf of persons who are not themselves able to make reasonable judgements about proposed treatment (i.e. patients who lack "capacity"). The Treatment Hierarchy identifies the criteria for each person responsible and the order in which they should be consulted about a treatment decision.

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Appendix 1 - Special considerations for the use of palliative sedation in situations of refractory existential or psychological distress

Rationale for special considerations

Palliative sedation in the management of refractory psychological symptoms and existential distress is different from other situations for four major reasons:

1. by virtue of the nature of the symptoms being addressed, it is much more difficult to establish that they are truly refractory;
2. the severity of distress of some of these symptoms may be very dynamic and idiosyncratic, and psychological adaptation and coping is common;
3. the standard treatment approaches have low intrinsic morbidity; and
4. the presence of these symptoms does not necessarily indicate a far advanced state of psychological deterioration.

Special guidelines

1. This approach should be reserved for patients in advanced stages of a terminal illness.
2. The designation of such symptoms as refractory should only be done following a period of repeated assessment by health practitioners skilled in psychological care who have established a relationship with the patient and their family/carers along with trials of routine approaches for anxiety, depression and existential distress.
3. The evaluation should be made in the context of a multidisciplinary case conference, including representatives from services such as psychiatry, chaplaincy and spiritual care, together with ethics, as well as those providing care at the bedside.
4. In the rare situations that this strategy is indeed appropriate and proportionate to the situation, it should be initiated on a respite basis for 6-24 hours with planned downward titration after a pre-agreed interval.
5. Palliative sedation should only be considered after repeated trials of respite sedation with intensive intermittent therapy have been performed.

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