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| Palliative sedation therapy  Evidence-based guidance supplement |

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# 1. What we delivered

## Topic selection

### Why did we develop this guidance?

This guidance aimed to adapt The Australian & New Zealand Society of Palliative Medicine (ANZSPM) for the Victorian context.

Safer Care Victoria’s (SCV) Palliative Care Clinical Network was commissioned by the Department of Health and Human Services (DHHS) to undertake this work.

People at the end of life sometimes experience symptoms that are more difficult to manage than normal. These are symptoms like pain, nausea and breathlessness that are expressed in an extreme way. When this happens, these symptoms are distressing for the person and their family/carers. These symptoms can cause suffering.

Palliative sedation therapy is used after all the other types of medicines or therapies have been tried. Palliative sedation therapy is managed by specially trained palliative care staff. It only happens after a detailed assessment and a conversation with the patient and their family/carers. Patients can also request to have palliative sedation therapy as part of identifying their wishes for end of life care.

This guidance project is in response to the Victorian Parliament Legal and Social Issues Committee’s Inquiry into end of life choices (2016) recommendations around palliative sedation and will aim to support Victorian palliative care services to use palliative sedation therapy in a consistent way.

### Scope of the guidance

This guidance is aimed at specialist palliative care clinicians to support consistent delivery of palliative sedation therapy. The guidance also plays a role in supporting these specialists to train other palliative care professionals.

This guidance is not intended for use by generalist clinicians.

## Expert working group

An expert working group was convened by the SCV Palliative Care Clinical Network to develop this clinical guidance.

* A member of the Palliative Care Clinical Network Governance Committee was appointed as chair.
* An expression of interest was promoted through SCV and network communications. Applicants were asked to submit relevant information about their interest and expertise in being part of the working group.
* All expressions of interest were reviewed by SCV staff, and final membership of the group was endorsed by Palliative Care Clinical Network clinical lead.
* A consumer member was involved in the expert working group process. They were reimbursed for their time and travel expenses.
* The membership of the expert working group included experts from medical, nursing and pharmacy disciplines. Recruitment was purposeful to ensure representation from metropolitan and regional areas.

Table 1: Palliative sedation therapy expert working group membership

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| Member | Role | Organisation |
| Juli Moran (chair) | Palliative Care Physician | Austin Health |
| Valerie Armenante | Nurse Consultant (Palliative Care) | Djerriwarrh Health Services |
| Melanie Benson | Palliative Care Physician | Latrobe Regional Hospital/ Peninsula Health |
| Marie Coffey | Nurse Practitioner | Wimmera Health Care Group |
| Rowan Hearn | Consultant in Palliative Medicine | Calvary Health Care Bethlehem |
| Lisha Kuruvilla | Palliative Care Pharmacist | Barwon Health |
| Adriana Mulla-Limllari | Consumer | Consumer |
| Siva Subramaniam | Palliative Care Physician | Goulburn Valley Health |
| Anita Wild | Nurse Practitioner | Bendigo Health |

### Conflict of interest

No relevant conflicts were identified.

## Methodology to develop the guidance

### Development timeline

This guidance was developed from November 2018 to January 2020.

### Search method to review the evidence

* Expert clinicians completed a search and review of the literature.
* Key literature was summarised and shared with the group to ensure consensus and saturation of evidence.

### Sources of evidence

The strengths and limitations of the body of evidence reviewed are described in the guideline text and areas of uncertainty are acknowledged.

### Referencing

Modified Vancouver style with superscript.

## Reaching consensus

Consensus was reached through a variety of techniques including aphinity diagrams that grouped themes and review of guidance versions until saturation of feedback was reached.

Feedback collected throughout the development and consultation was shared with the time limited working group members and/or the commissioning and endorsing partners.

## Consultation

After the expert working group developed a draft document, we extended an invitation to directors and senior leaders of palliative care services in Victoria to comment on the guidance. As the commissioning body, DHHS also provided comment at this point.

An event was held on 16 October 2019 to allow for group discussion and consensus using the following key questions:

* Is the document easy to understand?
* Does this guidance reflect what the evidence says about treatment and care?
* Do you know about any important evidence this guidance has not taken into account?
* Does this guidance take into account patient and clinician needs for information and support specific to the topic?
* Is the wording respectful to patients and clinicians?
* Does the wording reflect the importance of partnerships between healthcare professionals and patients?

A final copy was then produced, and attendees were given an additional two weeks to review.

### Response to feedback

Table 2: Feedback from consultation with experts

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| Feedback theme | Decision |
| Use of an ethical framework to guide framework development | This guidance is adapted from the ANZSPM guideline and its specific ethical framing for palliative sedation therapy was supported by the experts consulted. An ethicist was a member of the working group and provided expertise in this area. |
| Resourcing for palliative sedation therapy | Resourcing for palliative sedation therapy is out of scope for this guidance. |
| Monitoring rates of sedation | As reported in the *Parliamentary Inquiry into end of life choices,* measuring rates of palliative sedation is not supported. |
| Palliative sedation therapy is a specialist skill | The ANZSPM guideline supports palliative sedation therapy being a specialist skill. Consultation with a wide range of experts including members of the multidisciplinary team and sector leaders supported the statements used in this guidance around specialisation.  Refer to ‘Scope of practice’ in the guidance document. |
| Distinguishing voluntary assisted dying and palliative sedation therapy | Consultation with a wide range of experts including members of the multidisciplinary team, sector leaders and the DHHS Voluntary Assisted Dying unit supported the statements used in this guidance. |
| Distinguishing terminal restlessness and palliative sedation therapy | Consultation with a wide range of experts including members of the multidisciplinary team and sector leaders supported the statements used in the guidance. |
| Medication dosage and titration | Consultation with a wide range of experts including members of the multidisciplinary team (including pharmacy) and sector leaders supported the statements used in the guidance. |
| Discussion of artificial nutrition and hydration | Discussion of artificial nutrition and hydration is a core element of care in the last days of life as per the Care Plan for the Dying Person – Victoria. |

### Endorsement

The guidance was endorsed by DHHS and the Palliative Care Clinical Network Governance Committee in January 2020.

## Consumer information

A consumer was involved in the expert working group phase of this project and provided consumer insights as the guidance document was drafted.

While the guidance document is for a clinical audience, the use of plain language and accessible formatting supports consumers to access the guidance as required.

## Review

At the time of development, the expert working group determined that the guidance will be reviewed by the Palliative Care Clinical Network Governance Committee every five years, or more frequently if required, to reflect any changes in evidence and best practice.

# 2. Supporting health services to implement the guidance

## Implementation

As part of the development and implementation of this guidance, the following activities were undertaken by the SCV Palliative Care Clinical Network:

* Launch of the draft guidance with a group of senior and/or medical directors of palliative care from across Victoria.
* Awareness raising via SCV communication channels.
* Awareness raising and promotion of the guidance to clinical networks.

Suggested activities to support implementation of the guidance at your health service include:

* Endorse the guidance for use in the health service and communicate this to staff.
* Promote the introduction of the guidance to relevant health service staff.
* Support education and ongoing training opportunities.
* Align clinical care with guidance recommendations.

## Dissemination

* The final guidance will be uploaded to the SCV website.
* Promotion of the new guidance will occur via SCV social media and newsletter platforms.
* Health services are encouraged to link to the guidance page on the SCV website in their local policies and education packages.

## Measuring the impact of our guidance

### Evaluation strategy

The guidance will be available to health services on the SCV website to use and adopt into their local policies.

A ‘pulse check’ survey will be conducted six months after the guidance is published to determine use and reach.

### Auditable measures

The Victorian Government did not accept the recommendation from the Legal and Social Issues Committee Inquiry into end of life choices (2016) that rates of palliative sedation be measured (Rec 27).

Locally collected measures may help services to govern and monitor quality and safety in palliative care.

Table 3: Auditable measures

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| Use of the guidance in Victorian health services | Number of services who report using the guidance |
| Specialist palliative care services will educate and support their staff about the guideline | Percentage of specialist palliative care clinicians aware of the Palliative Sedation Therapy Guideline  Number of staff educated  Feedback around staff support/debrief opportunities |
| Patients and families will be supported when they require palliative sedation therapy | Number of patients and families provided with written information about palliative sedation |
| Guidance is available to health services | Number of downloads from SCV website |

## Future research opportunities

There are currently no identified future research opportunities.

# 3. Governance

## Approval

This guidance was approved by the Palliative Care Clinical Network Governance Committee and Clinicians as Partners Director.

## Funding

Funding was received from the DHHS Palliative Care unit to enable the development of this clinical guidance.

