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 quality of life refractory symptoms
 Waterloo Wellington HPC Protocol

The Waterloo Wellington Palliative Sedation Therapy Protocol



Waterloo Wellington Interdisciplinary
 HPC Education Committee: PST Task Force

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Table of Contents

| | |
|--|-----------|
| Purpose | 1 |
| Introduction | 3 |
| Defining Palliative Sedation Therapy | 3 |
| When to Consider Palliative Sedation Therapy | 5 |
| Criteria for Initiating Palliative Sedation Therapy | 7 |
| Criteria | 7 |
| Palliative Sedation Therapy Process | 7 |
| Patient Assessment | 7 |
| Consent Process | 8 |
| Care Planning | 8 |
| Palliative Sedation Therapy Medications | 11 |
| Monitoring | 12 |
| Table 1. Common PST Medications | 15 |
| Family and Team Support | 19 |
| Supporting the Patient’s Family and Friends | 19 |
| Supporting the Team | 20 |
| Effective Team Process | 20 |
| Care of the Team Providing Palliative Sedation Therapy | 20 |
| References | 23 |
| Appendices | 27 |
| Appendix A. Glossary | 29 |
| Appendix B. Latimer Ethical Decision-Making Model | 31 |
| Appendix C. Quick Reference Guide for Palliative Sedation Therapy | 33 |
| Appendix D. The Hierarchy of Substitute Decision Makers [SDM(s)] | 35 |
| Appendix E. Richmond Agitation Sedation Scale – Palliative Version (RASS-PAL) | 37 |
| Appendix F. Patient Monitoring during Palliative Sedation Therapy | 39 |

Purpose

The Waterloo Wellington Palliative Sedation Therapy (PST) Protocol is an interprofessional peer-reviewed, evidence-informed clinical resource. Informed by a [palliative approach to care](#), this protocol aims to ensure effective, safe, timely and appropriate use of PST in the Waterloo Wellington Local Health Integration Network (LHIN).

Defining Palliative Sedation Therapy

Palliative Sedation Therapy (PST) is the intentional induction and continuous maintenance of a reduced level of consciousness to relieve a patient's [refractory symptom\(s\)](#) during their last days and weeks of life. The [interprofessional team](#) (herein referred to as team), guided by the use of evidence-based tools and techniques, is responsible for eliciting the patient's perception of their symptom experience and treatment choices. This may lead to the identification of [refractory symptoms](#)¹. [Palliative specialist support](#) may augment the team's understanding of a patient's eligibility for PST and approach to implementing PST.

PST is not an appropriate therapeutic option in response to a patient's request to avoid potential future symptoms associated with the dying process², nor is PST appropriate to enact based upon family perception of [refractory symptoms](#)³.

PST does not include unintended sedation as a side-effect of treatment or the temporary use of sedation where the causes of the symptom are reversible and attempts to treat the cause are being made, such as sedation secondary to the management of delirium with sedating medications⁴.

PST is not a form of, or substitute for, Medical Assistance in Death (MAID)⁵. MAID is the legal medical administration of lethal medications available to persons who meet certain eligibility criteria. The intent of MAID is to cause death to relieve suffering, whereas the intent of PST is to reduce awareness to relieve [refractory symptom\(s\)](#) and not hasten death. In fact, patients who receive PST have been shown to survive longer with fewer symptoms than those who did not receive PST⁶.

If a patient has requested MAID, assessment and procedure resources are available at [http://www.palliativecare.ca/62/Medical Assistance in Dying MAID/](http://www.palliativecare.ca/62/Medical_Assistance_in_Dying_MAID/)

¹ Koike, 2015; LeBoul, 2017; Nelson Bander, 2017; Swart, 2014; Tursunov, 2016; van Diejck, 2013; Voeuk, 2014.

² Collège des médecins du Québec, 2016; McCammon, 2015.

³ Cherny, 2014; Fraser Health, 2011.

⁴ Collège des médecins du Québec, 2016; Fraser Health, 2011.

⁵ Foley, 2015; van Diejck, 2015.

⁶ Beller, 2015.

When to Consider Palliative Sedation Therapy

While PST is initiated only in the last days to weeks of life, PST should be considered early on in the context of managing [refractory symptoms](#) to ensure timely initiation, if/ when a decision is finalized to proceed with PST.

Establishing a prognosis should be guided by validated functional assessments, such as the Palliative Performance Scale version 2⁷ and the Gold Standards Framework⁸. The prevalence and/or severity of symptoms is not an accurate measure of prognosis.

It is important not to label difficult symptoms as refractory because of a lack of skill or knowledge on the part of the health care provider(s), or because of an unwillingness to request a consultation. Consultation is necessary in cases of [refractory symptoms](#) to ensure that all possible options have been explored using [palliative specialist support](#).

Common indications for PST include refractory dyspnea, delirium, seizures, pain and nausea. Psychological, social, spiritual and [existential distress](#) are each considered controversial indications for the use of PST. Due to significant variance in presentation, complexity and definition of psychological, social and spiritual symptoms, team members should assess and manage patients experiencing distress in these domains, utilizing standardized assessments and therapies. It is recommended that refractory psychological, social, spiritual and [existential distress](#) should be confirmed after trials of standard therapies and consultation with relevant experts such as a palliative care specialist, spiritual care provider, ethicist and mental health professionals.

Ethical tension and concerns may arise for a variety of reasons at any point surrounding the use of PST. Ethical decision-making frameworks can be utilized by the team to guide their consideration and planning for PST⁹ [[See Appendix B](#) for an example]

⁷ Victoria Hospice Society, 2001.

⁸ The Gold Standards Framework Centre In End of Life Care CIC, Thomas, et al., 2011.

⁹ Latimer, 1991.

Criteria for Initiating Palliative Sedation Therapy

Criteria

- The patient has been diagnosed with a progressive, incurable illness
- The patient's prognosis is days to weeks
- The patient is supported by a team
- The patient is experiencing one or more [refractory symptom\(s\)](#) for which alternative effective treatment options are either not available or would not provide symptom relief, without unacceptable morbidity or within an acceptable time frame
- Informed consent for no Cardio Pulmonary Resuscitation (CPR) has been obtained
- Informed consent for PST has been obtained

Palliative Sedation Therapy Process

The way to promote safe and ethical implementation of PST is through comprehensive interprofessional assessment and collaborative decision-making. The essential steps in the decision making, planning and delivery process, for PST, includes a thorough patient assessment, establishment of informed consent, and development of the PST care plan. Detailed documentation to support all steps is essential. [[See Appendix C](#) for a quick reference guide for PST.]

Patient Assessment

A thorough patient assessment includes the following:

1. A review of the goals of care and the treatment plan.
2. Establishment of patient capacity.
3. Identification of the substitute decision maker(s) [SDM(s)]. Further information on determining the SDM can be found in [Appendix D](#).
4. Confirm informed consent is established for no CPR.
5. Symptom assessment and confirmation that criteria are met for PST ([palliative specialist](#) consultation is recommended to ensure optimal assessment and management approach).

6. Perform medication review to determine which medications:
 - a. are essential medications to continue
 - b. are unsafe medications to continue.
7. As the ability to swallow is impaired as part of the natural dying process, by sedation or both, it is essential to include into discussion details regarding artificial hydration and/or nutrition at end of life.

Consent Process

It is recommended that members of the team meet with the patient, SDM(s) and family regarding the topics below. It is important that the details supporting informed consent are clearly documented in the patient's record and shared with the team.

1. A review of the patient's goals of care.
2. Risks, benefits and alternative options to PST.
3. Management of nutrition, hydration, oral, eye and skin care.
4. Medication changes including the medication(s) chosen to provide sedation and how it will be administered.
5. Expected changes in level of consciousness and in respiratory patterns.
6. Timing of initiation of PST.
7. Ongoing monitoring.

Care Planning

Once the criteria have been met, and a decision has been made to initiate PST, the team should work collaboratively to develop a comprehensive care plan. Ongoing and deliberate communication amongst team members is critical. The involvement of front-line providers in the planning process is recommended for their expertise in anticipating procedural obstacles that may arise¹⁰. As the team works to prepare the patient and family for initiation of PST, it is important to gain an understanding of their wishes, i.e. space/time/privacy for rituals, spiritual or religious rites, saying goodbyes or expressing their feelings to others. Document any ongoing questions and concerns from the family/ team and how they were resolved.

¹⁰ Nelson-Bander, 2017.

The comprehensive care plan should include:

- Confirmation of Most Responsible Provider supporting 24/7 access to the PST plan
- Initiation date and time of PST
- Name and doses of medications to be administered for PST
- Titration plan
- Confirmation of team members to be present at initiation of therapy (two team members are recommended, i.e. physician and nurse; two nurses; nurse and personal support worker)¹¹
- Confirmation of the target goals of sedation using Richmond Agitation Sedation Scale (RASS-PAL)¹² (modified for patients receiving palliative care). [See Appendix E](#)
- Equipment & supply orders
- Hydration/ nutrition plan
- Bladder/ bowel management
- Skin care and positioning routine

¹¹ Leboul, 2017.

¹² Bush, Grassau, Yarm, Zhang, Zinkie, Pereira, 2014.

Palliative Sedation Therapy Medications

[[See Table 1](#) – Common PST Medications]

The patient's care location (home, residential hospice, hospital, retirement home, long-term care home etc.), and the availability of medication administration routes, such as intravenous, primarily guide the PST medication(s) used. The goal is to identify the lowest possible dose of medication and lightest level of sedation that achieves comfort. In some cases, comfort may be achieved with light to moderate sedation while others will require deeper levels of sedation. The doses required to achieve these various levels of sedation may vary considerably between individuals.

If a patient is already being treated with opioids and/or antipsychotics, these medications should be continued during sedation in accordance with the patient's needs. When an existing medication is being administered continuously, via the parenteral route, it is preferable to administer the sedative drugs via a separate site. This avoids an undesirable increase in the existing medication when the doses of sedatives are increased and avoids potential drug incompatibilities when mixed together.

There is no strong evidence to support a ranking of medications used for sedation. Choices depend on the experience of the physician, drug availability, institutional policy and location.

Benzodiazepines are the most commonly-used medication for PST, and of these Midazolam is most-frequently used. Midazolam parenterally administered can be used in all stages of sedation. Its short half-life allows it to be more easily titrated than other benzodiazepines. It also possesses anxiolytic, anticonvulsant and muscle relaxant properties. In some patients, benzodiazepines may have a [paradoxical excitatory effect](#). Where feasible, the use of a Midazolam by continuous subcutaneous infusion (CSCI) is preferred, to permit responsive titration¹³.

Sedating antipsychotics are less commonly used for PST, but of these Methotrimeprazine is preferred. It can be administered parenterally and has neuroleptic properties which may be helpful in cases where PST is used for a patient with refractory terminal delirium.

Barbiturates (e.g. phenobarbital) and drugs such as Propofol are also occasionally used for PST.

¹³ Fraser Health, 2011; Canadian Society of Palliative Care Physicians (CSPCP) Taskforce: Dean, Cellarius, Henry, Oneschuk, Librach, 2011.

Opioids are an inappropriate choice for PST because deep sedation will occur only when doses are used that cause [neurotoxicity](#) and respiratory depression leading to hastened death. However, it is essential to continue to provide opioid therapy for symptom management.

Monitoring

The frequency of patient monitoring and the parameters to be monitored are influenced by the setting, circumstances and the availability of clinical staff. Some parameters should be monitored routinely, while others are on a case-by-case basis. The parameters being assessed may also change over time.

Parameters that should be assessed using a valid tool include:

1. Level of sedation
 - Various clinical assessment instruments to assess the level of sedation are used in palliative care programs across the world. The use of such a clinical instrument standardizes the assessment method and provides physicians and nurses a standardized method of communicating about PST, assessing the effectiveness of treatments, and setting treatment goals.
 - The WW PST Committee recommends each organization modify their existing documentation to include the Richmond Agitation Sedation Scale (RASS-PAL)¹⁴ scoring. Each organization should modify existing documentation records to include RASS-PAL scoring on the medication administration record and/or flow sheet linked to medications administered to induce and maintain PST. ([See Appendix E](#))
2. Level of comfort or discomfort
 - Assess the degree to which the patient reports (if able to) comfort or discomfort. If the patient is unable to do so, the [clinician](#) must assess what they perceive the patient's level of comfort or discomfort to be.
3. Airway patency and air entry (if sedation is not being done for irreversible airway obstruction)
 - This is to avoid airway obstruction because of poor positioning of the patient or from vomiting. Reposition the patient and pull the jaw forward if there appears to be airway obstruction.

¹⁴ Bush, Grassau, Yarmo, Zhang, Zinkie, Pereira, 2014.

4. Parameters that may be monitored on a case-by-case basis include but are not restricted to: respiratory rate, oxygen saturation and bladder fullness (in patients who are not catheterized)
 - It is important to note that changes in respiratory rates and patterns, as well as reductions in oxygen saturation are normal end-of-life changes and will occur whether or not the patient is receiving PST. To titrate PST according to these parameters would therefore be inappropriate when death is imminent.

Any parameters that are assessed should be documented in the patient chart. [See Appendix F](#) for an example of a flow sheet to assist with patient monitoring.

The following table provides information on common medications used for PST.

Table 1. Common PST Medications

| Midazolam (Versed) | |
|--|---|
| Pharmacologic Category | Anticonvulsant, benzodiazepine |
| Advantages (When to Use) | <ul style="list-style-type: none"> • Potent, short half-life, easy titration up or down • Subcutaneous or Intravenous route administration • Continuous or intermittent dosing • Anxiolytic (anxiety) |
| Adverse Reactions (When to Avoid) | <ul style="list-style-type: none"> • Respiratory depression (additive to opioids) • Paradoxical reactions (aggression, hyperactivity) |
| Initiation | 2.5-5 mg subcut or IV STAT ¹⁵ |
| Titration | <p>Titrate dose Q1H as necessary until the goal of PST is achieved.</p> <p>Initial titration may need to be rapid until the patient is comfortable. Dose may require titration up as tolerance develops over many hours to days.</p> |
| Monitoring | |
| | Every 15 mins until the goal of PST is achieved. |
| | After four consecutive 15-min checks (1 hour) without additional titration or prn doses, continue with checks every 8 hours, at a minimum |
| | NOTE: Restart monitoring at Q 15mins any time a dose adjustment is made, or additional bolus/prn doses are given. |
| In-home, Long-Term Care Home or Retirement Home | Patient must have a capable caregiver (e.g. family member) present at all times and they must be educated about signs of impending death and instructed to call team members if patient becomes uncomfortable. |
| Maintenance | 0.5-1 mg/hour CSCI or CIVI ¹⁶ Range: 1-20 mg/hour ¹⁷ Bolus: 2.5-5 mg PRN dosing regimen (no CSCI/CIVI available): 2.5-5 mg q30-60min prn (temporary, 12-24 hours, half-life/duration of action short) |
| Adjuvant/Alternative | methotrimeprazine (add) phenobarbital (add) |

¹⁵ Edmonton Zone Palliative Care Program, 2015; Cherny, 2014; Fraser Health, 2009.

¹⁶ Cherny, 2014; Collège des médecins du Québec, 2016; Fraser Health, 2011.

¹⁷ Cherny, 2014; Collège des médecins du Québec, 2016; Fraser Health, 2009.

Methotrimeprazine (Nozinan)

| | |
|--|---|
| Pharmacologic Category | First generation (typical) antipsychotic |
| Advantages (When to Use) | <ul style="list-style-type: none"> • Subcutaneous (subcut) route administration • Intermittent dosing • Does not require the clinical expertise of a pain pump • Antipsychotic (delirium) • Analgesic (pain) |
| Initiation | 25 mg subcut (12.5 mg in very small, frail individual) |
| Titration | <p>Titrate dose Q1H as necessary until the goal of PST is achieved.</p> <p>If 25 mg Q6H is not sufficient, consider switching to Midazolam or adding Phenobarbital</p> |
| Monitoring | |
| | Every 15 mins until the goal of PST is achieved. |
| | After four consecutive 15-min checks (1 hour) without additional titration or prn doses, continue with checks every 8 hours, at a minimum |
| | <i>NOTE: Restart monitoring at Q 15mins any time a dose adjustment is made, or additional bolus/prn doses are given.</i> |
| In-home, Long-Term Care Home or Retirement Home | Patient must have a capable caregiver (e.g. family member) present at all times and they must be educated about signs of impending death and instructed to call team members if patient becomes uncomfortable. |
| Maintenance | 12.5-25 mg subcut q8h regular AND 12.5-25 mg q1h prn ¹⁸ Range: 25-300 mg/day ¹⁹ |
| Adjuvant/Alternative | midazolam (switch) phenobarbital (add) |

¹⁸ Cherny, 2014.

¹⁹ Fraser Health, 2009; Cherny, 2014; Collège des médecins du Québec, 2016.

| PHENobarbital (Phenobarb) | |
|--|---|
| Pharmacologic Category | Anticonvulsant, barbiturate |
| Advantages (When to Use) | <ul style="list-style-type: none"> • Subcutaneous or Intravenous route administration • Anticonvulsant (seizure) • Useful in patients that have developed tolerance or have contraindications to other options |
| Adverse Reactions (When to Avoid) | <ul style="list-style-type: none"> • Paradoxical reactions (excitation) |
| Initiation | 1-3mg/kg subcut or IV STAT ²⁰ |
| Titration | <p>Titrate dose Q1H as necessary until the goal of PST is achieved.</p> <p>Half-life is very long (52-118 hours) Several days required to meet steady state and optimal effect</p> |
| Monitoring | |
| | Every 15 mins until the goal of PST is achieved. |
| | After four consecutive 15-min checks (1 hour) without additional titration or prn doses, continue with checks every 8 hours, at a minimum |
| | NOTE: Restart monitoring at Q 15mins any time a dose adjustment is made, or additional bolus/prn doses are given. |
| In-home, Long-Term Care Home or Retirement Home | Patient must have a capable caregiver (e.g. family member) present at all times and they must be educated about signs of impending death and instructed to call team members if patient becomes uncomfortable. |
| Maintenance | <p>1-10 mg/kg q8-12h²¹</p> <p>Range: 200-2500 mg/day</p> |
| Adjuvant/Alternative | Midazolam (add) |

²⁰ Cherny, 2014.

²¹ Collège des médecins du Québec, 2016; Fraser Health, 2009.

Supporting the Patient's Family and Friends

Palliative sedation can be a welcomed method to assure patient comfort but can also be profoundly distressing to the patient's family members and/or friends. A few principles are useful when considering support for the patient's family and friends:

- Provide an opportunity for the patient, if possible, to express what they may want from their loved ones, or would find comforting, during the time they are sedated.
- Ascertain the level of involvement that the family wants in the process.
- Family and friends should be allowed and be encouraged to be with the patient. In many situations, an opportunity to say goodbye is of critical importance.
- Family and friends often need repeated 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.
- Family and friends should be kept informed about the patient's well-being and what to expect²².

The care team must provide supportive care to the members of the patient's family and/or friends. This includes listening to concerns or watching for signs of grief, physical/psychological burdens, feelings of guilt. In addition, they should be offered advice on ways to be of help to the patient (e.g. by being with, talking to, touching the patient, providing mouth care, and managing the atmosphere of the patient's care etc.).

The care team should provide regular information updates to the family including information about the patient's condition, comfort level, anticipated changes, or, when appropriate, notification that death is approaching and what can be expected in the dying process.

After the death of the patient, the family should be offered the opportunity to meet with care providers to give them the opportunity to express grief and to discuss any outstanding concerns that they may harbor about the care delivered in the last days of life²³.

²² Cherny, 2014.

²³ Cherny, 2014.

Supporting the Team

Effective Team Process

Open communication between nurses and physicians regarding their roles and responsibilities related to the provision of PST combined with increased team work will improve the experience of the team²⁴.

Effective communication towards family members is essential to prevent unrealistic expectations and to prevent putting pressure on the team to hasten the procedure. Sharing the burden of decision-making during the procedure with other health care professionals may diminish the perception of undue responsibility falling to one team member.

Team work helps reduce individual distress by clarifying the course of action, providing an opportunity for dialogue and organization and offering professional recognition and support²⁵.

Continuity of team work, good coordination and open communication between the various care providers are essential elements.²⁶

Care of the Team Providing Palliative Sedation Therapy

Situations in which a patient has undergone PST can also be profoundly distressing to team members. This is particularly true if there is lingering disagreement regarding the treatment plan among providers and in situations when the process is protracted.

The care team should recognize the potential for distress. All participating team members need to understand the rationale for PST and goals of care. Whenever possible this should be addressed at team meetings or case conferences, both before and after the event, to discuss the professional and emotional issues related to such decisions. Distress can be mitigated by fostering a culture of sensitivity to the emotional burdens involved in care, participating in the deliberative processes leading up to a treatment decision, sharing information, and engaging in interprofessional discussions that offer the group or individual opportunities to express their feelings²⁷.

²⁴ Aquinet, 2015.

²⁵ Leboul, 2017.

²⁶ Hoek, 2015.

²⁷ Cherny, 2014.

A more organized debriefing session for involved team members may be considered whenever:

- management of [refractory symptoms](#) was especially challenging.
- the decision to initiate PST was difficult.
- death was unusually traumatic.
- significant complications arose.
- at the request of a team member

The debriefing session(s) should be facilitated by an experienced [clinician](#), who may or may not have been involved in the care of the patient.

Most importantly, such offering of support can positively impact or offset moral distress experienced by health care providers. It also serves as an opportunity for increased team cohesion, overall team functioning, and learning opportunities for what was done well or what could have been done differently²⁸.

²⁸ Fraser Health, 2011.

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Appendix A. Glossary

A **Clinician** is “a health professional, such as a physician, psychologist, or nurse, who is directly involved in patient care, as distinguished from one who does only research or administrative work”²⁹.

Existential Distress describes a patient’s experience of suffering related to thoughts and/or fears of death or the unknown within the context of end of life care. It may include a sense of one or more of the following: meaninglessness of present life; hopelessness; burdening others; emotional irrelevance or isolation; dependence; grief; loss of dignity and life-purpose³⁰. The sources of existential distress are unrelated to a psychiatric disorder or social isolation, and the patient may or may not have physical symptoms³¹.

An **Interprofessional Team** is composed of different healthcare professionals collaborating around the patient and their family³² determined by patient location and resource availability. Team members may include but are not limited to: physician, pharmacist, nurses, social workers, allied health professionals, community care coordinators, spiritual care providers, ethicists, personal support workers, hospice volunteers and others.

Neurotoxicity describes the damage, destruction or impairment of the functioning of the central and/or peripheral nervous system caused by exposure to a natural or synthetic substance³³, including many medications. Neurotoxicity may develop in a dying person’s body due to disease advancement and organ-failure which impact normal metabolism and elimination. Symptoms of neurotoxicity may appear immediately after exposure or be delayed, and include sensory and behavioural changes, myoclonus, and delirium³⁴.

A **Palliative Approach to Care** aims to improve or maintain the quality of life for individuals who have a life-threatening illness. It is care that is holistic and best provided by a team. It seeks to neither hasten nor postpone natural death. It is an approach that emphasizes the importance of ongoing review of goals of care and adjusting care strategies as these goals change. Finally, it is care that encompasses ongoing psycho-social-spiritual support for both individuals and their families³⁵.

²⁹ Houghton Mifflin Harcourt Publishing Company, 2019.

³⁰ Rodrigues, 2018.

³¹ Canadian Society of Palliative Care Physicians Taskforce: Dean, M.M., Cellarius, V., Henry, B., Oneschuk, D. & Librach, 2012.

³² Hatrick Doane, 2012.

³³ Medscape, 2018.

³⁴ National Institute of Neurological Disorders and Stroke, 2018.

³⁵ Pallium Canada, 2016.

Palliative Specialist Support is provided by physicians and nurses with education and expertise in specialty palliative care. Early team discussion and consultation with a palliative care specialist physician and/or nurse can assist with identifying alternative management approaches, refractory symptoms, and prevent delayed initiation of appropriate PST³⁶. Specialist consultation must be timely and focused on what the patient's team needs (i.e. general/emotional support and mentorship vs clinical review). When time or distance is a limiting factor, telephone consultation is appropriate.

Paradoxical Excitatory Effect refers to an adverse reaction to a substance, almost always to a drug, characterized by the opposite of the intended effect. In the case of PST, the opposite reaction to sedating medications would be stimulation

Refractory Symptoms refers to symptoms experienced by a patient as intolerable, despite attempts to control them, without excessive and intolerable side effects and within an acceptable time-frame³⁷. Determining that a symptom is refractory is rare³⁸, and is determined through comprehensive assessment and interprofessional decision-making.

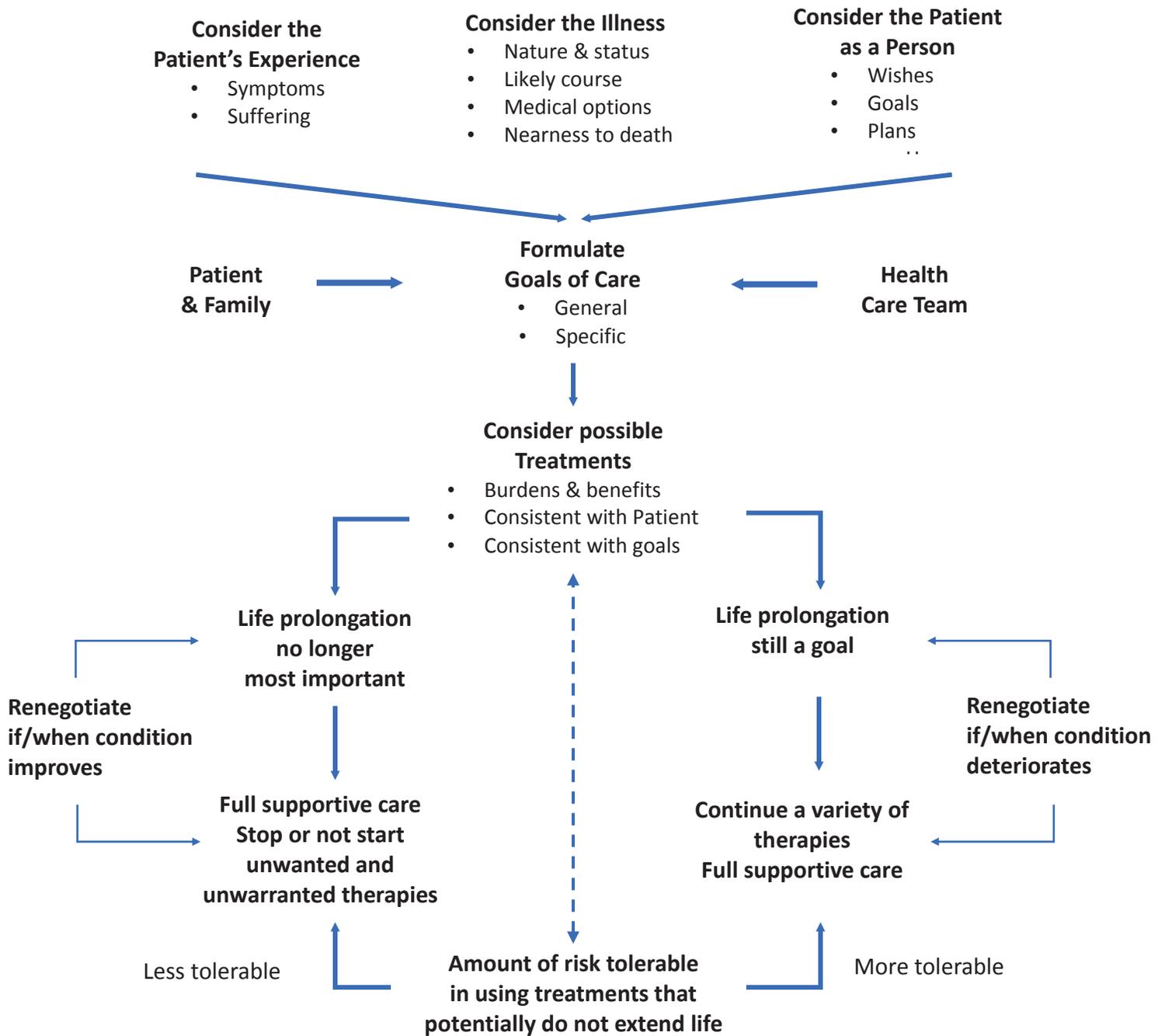
³⁶ Koper, 2014; Jimenez Rojas, 2015; Lux, 2017; Sercu, 2014; vanDeijck, 2015; Voeuk, 2014.

³⁷ Levy, 2005.

³⁸ Collège des médecins du Québec, 2016.

Appendix B. Latimer Ethical Decision-Making Model³⁹

As Part a Collaborative Team Process:



³⁹ Latimer, 1991; Latimer, 1998.

Appendix C. Quick Reference Guide for Palliative Sedation Therapy

Note: The process for PST assessment, planning and delivery may not be linear and will always require an individualized approach. Consideration of PST may occur as a result of a patient request or based on the assessment of member(s) of the Team. Ensure communication with the Team.

When to Consider PST

Action: Comprehensive assessment and management of symptom(s) to determine presence of [refractory symptom\(s\)](#).

Ensure communication with the Team.

Ensure consultation with [Palliative specialist](#).

Common indications for PST include refractory dyspnea, delirium, seizures, pain and nausea. Psychological, social, spiritual and [existential distress](#) are each considered controversial indications for the use of PST.

Document consultation recommendations that demonstrate consensus regarding [refractory symptom\(s\)](#).

Share with the team.

Criteria for Initiating PST

- The patient has been diagnosed with a progressive, incurable illness
- The patient's prognosis is days to weeks
- The patient is supported by a team
- The patient is experiencing one or more [refractory symptom\(s\)](#) for which alternative effective treatment options are either not available or would not provide symptom relief without unacceptable morbidity or within an acceptable time frame
- Informed consent for no Cardio Pulmonary Resuscitation (CPR) has been obtained
- Informed consent for PST has been obtained

Document criteria for initiation of PST are met, including detailed evidence of [refractory symptom\(s\)](#).

Confirm no CPR orders are in place.

Clear and detailed documentation of:

1. *Decision-making process*
2. *Informed consent for PST*

Share with the team.

PST Process

Action - Patient Assessment

- Review goals of care and PST treatment plan
- Including details regarding artificial hydration and/or nutrition at end of life
- Establishment of patient capacity
- Identify SDM(s)
- Confirm criteria for PST are met (see above)
- Perform medication review (refer to Medications section)

Document details of discussion; share with the team.

Action – Consent Process
Interprofessional care conference recommended regarding the topics below:

- Review goals of care
- Risks, benefits and alternative options to PST
- Management of nutrition, hydration, oral, eye and skin care
- Medication changes including the medication(s) chosen to provide sedation and how it will be administered
- Expected changes in level of consciousness and in respiratory patterns
- Timing of initiation of PST
- Ongoing monitoring

Document details of discussion; share with the team.

Action – Care planning
Ensure comprehensive care plan includes:

- Confirmation of Most Responsible Provider supporting 24/7 access to the PST plan
- Initiation date and time of PST
- Name and doses of medications to be administered for PST ([see Medications section](#))
- Titration plan
- Confirmation of team members to be present at initiation of therapy
- Confirmation of the target goals of sedation using RASS-PAL ([see Appendix F](#))
- Equipment & supply orders
- Hydration/nutrition plan
- Bladder/bowel management
- Skin care and positioning routine
- Monitoring plan ([see Monitoring section](#))

Document comprehensive care plan for PST; share plan and orders with the team.

Family and Team Support

Action - Supporting the patient’s family and friends
Useful principles:

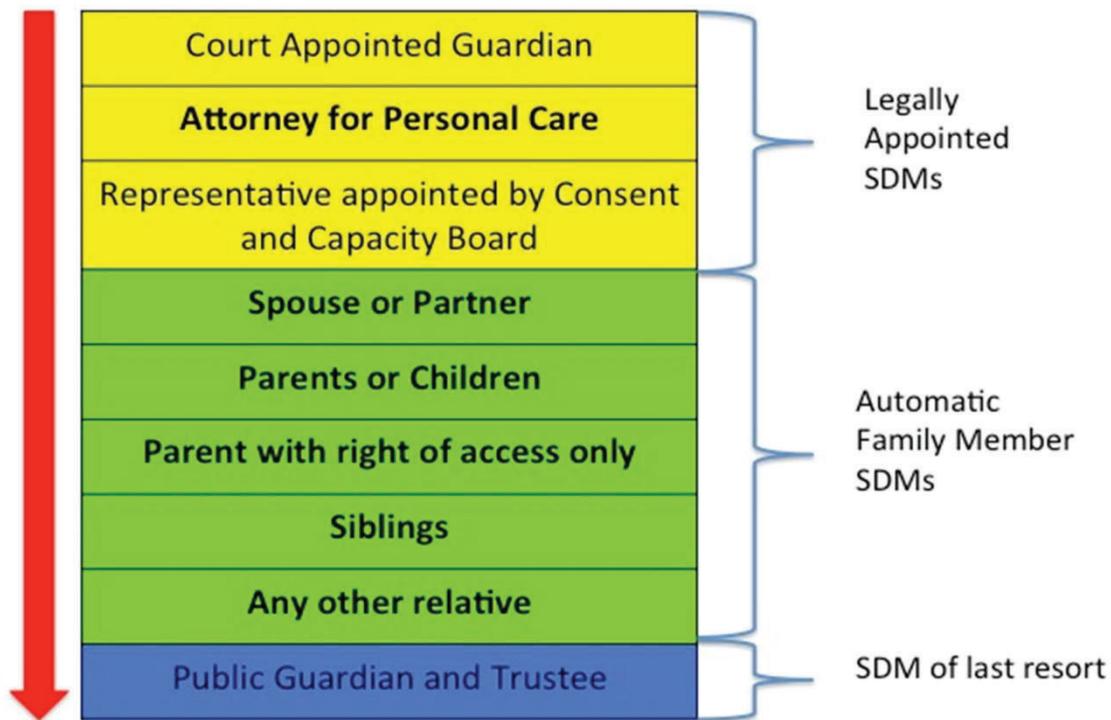
- Provide an opportunity for the patient to express what they may want during the time they are sedated
- Determine the level of involvement that the family wants in the process
- Provide an opportunity for family and friends to say goodbye
- Provide family and friends with regular information updates including information about patient’s condition, comfort level, and anticipated changes

Action – Supporting the team
Useful principles:

- Ensure open communication between providers about roles and responsibilities
- Continuity of team work, good coordination, and open communication between various care providers are essential elements
- Formal and informal debriefing opportunities can positively impact or offset moral distress

Document any ongoing questions and concerns expressed by the family and/or team and the approaches used to address the same.

Appendix D. The Hierarchy of Substitute Decision Makers [SDM(s)]



Ontario Health Care Consent Act, 1996

An SDM is required to be:

- Capable of giving consent with respect to the treatment proposed
- At least 16 years old
- Not prohibited by law i.e. there is no court order or separation agreement prohibiting access to the incapable person for giving or refusing consent
- Available when a decision is needed
- Willing to assume the responsibility of giving or refusing consent

For additional information please visit: www.acpww.ca.

Appendix E. Richmond Agitation Sedation Scale – Palliative Version (RASS-PAL)⁴⁰

Additional file 1: Figure S1- Richmond Agitation-Sedation Scale - Palliative version (RASS-PAL)

| Score | Term | Description | |
|-------|-------------------|---|-------------------------------|
| +4 | Combative | Overtly combative, violent, immediate danger to staff (e.g. throwing items); +/- attempting to get out of bed or chair | |
| +3 | Very agitated | Pulls or removes lines (e.g. IV/SQ/Oxygen tubing) or catheter(s); aggressive, +/- attempting to get out of bed or chair | |
| +2 | Agitated | Frequent non-purposeful movement, +/- attempting to get out of bed or chair | |
| +1 | Restless | Occasional non-purposeful movement, but movements not aggressive or vigorous | |
| 0 | Alert and calm | | |
| -1 | Drowsy | Not fully alert, but has sustained awakening (eye-opening/eye contact) to <i>voice (10 seconds or longer)</i> | } Verbal Stimulation |
| -2 | Light sedation | Briefly awakens with eye contact to <i>voice (less than 10 seconds)</i> | |
| -3 | Moderate sedation | Any movement (eye or body) or eye opening to <i>voice (but no eye contact)</i> | |
| -4 | Deep sedation | No response to voice, but any movement (eye or body) or eye opening to <i>stimulation by light touch</i> | } Gentle Physical Stimulation |
| -5 | Not rousable | No response to <i>voice or stimulation by light touch</i> | |

⁴⁰ Bush, 2014.

Additional file 2: TableS2- Procedure for RASS-PAL Assessment

1. Observe patient for **20 seconds**.

a. Patient is alert, restless, or agitated **for more than 10 seconds** Score 0 to +4

NOTE: If patient is alert, restless, or agitated for less than 10 seconds and is otherwise drowsy, then score patient according to your assessment for the majority of the observation period

2. If not alert, greet patient and call patient by name and say to open eyes and look at speaker.

b. Patient awakens with sustained eye opening and eye contact **(10 seconds or longer)**. Score -1

c. Patient awakens with eye opening and eye contact, but not sustained **(less than 10 seconds)**. Score -2

d. Patient has any eye or body movement in response to voice but no eye contact. Score -3

3. When no response to verbal stimulation, physically stimulate patient by light touch e.g. gently shake shoulder.

e. Patient has any eye or body movement to gentle physical stimulation. Score -4

f. Patient has no response to any stimulation. Score -5

PATIENT MONITORING DURING PALLIATIVE SEDATION

| Legend 1 – Richmond Agitation-Sedation Scale (RASS-PAL) (modified for palliative inpatients by Bush et al., 2014) | | |
|---|-------------------|---|
| Level | Description | Definition |
| +4 | Combative | Overtly combative, violent, immediate danger to staff (e.g. throwing items); +/- attempting to get out of bed or chair |
| +3 | Very agitated | Pulls or removes lines (e.g. IV/SQ/oxygen tubing) or catheter(s); aggressive, +/- attempting to get out of bed or chair |
| +2 | Agitated | Frequent non-purposeful movement, +/- attempting to get out of bed or chair |
| +1 | Restless | Occasional non-purposeful movement, but movements not aggressive or vigorous |
| 0 | Alert and calm | |
| -1 | Drowsy | Not fully alert, but has sustained awakening (eye-opening/eye contact) to voice (10 seconds or longer) |
| -2 | Light sedation | Briefly awakens with eye contact to voice (less than 10 seconds) |
| -3 | Moderate sedation | Any movement (eye or body) or eye opening to voice (but no eye contact) |
| -4 | Deep sedation | No response to voice, but any movement (eye or body) or eye opening to stimulation by light touch |
| -5 | Unarousable | No response to voice or stimulation by light touch |

| Legend 4 – Other possible observations | |
|--|----------------------------------|
| D | Respiratory distress (RR <8/min) |
| A | Respiratory pauses, apnea |
| S | Loud snoring |
| M | Myoclonus |
| P | Miotic pupils |

| Legend 2 – Pain Relief (Nociception Coma Scale adapted by Vinay, 2011) | |
|--|--|
| Face | |
| Relaxed = 1 | |
| Tense = 2 | |
| Strained = 3 | |
| Grimacing = 4 | |
| Tears | |
| Absent = 1 | |
| Present = 2 | |
| Moaning | |
| Absent = 1 | |
| Present = 2 | |
| Limbs | |
| Relaxed = 1 | |
| Stiff = 2 | |
| Rigid = 3 | |
| Movements | |
| Calm = 1 | |
| Fidgeting = 2 | |
| Agitated = 3 | |
| Very agitated = 4 | |
| Combative = 5 | |
| Respirations | |
| <19 = 1 | |
| ≥19 = 2 | |
| Pulse | |
| <110 = 1 | |
| ≥110 = 2 | |
| TOTAL | |

| Legend 3 – Respiratory Distress Observation Scale (RDOS) (Campbell, 2008, 2010) | | | |
|---|---------|-------------|-----------------|
| | 0 point | 1 point | 2 points |
| Heart rate (/min) | <90 | 90-109 | ≥110 |
| Respiratory rate (/min) | <19 | 19-29 | ≥30 |
| Restlessness: non-purposeful movements | No | Occasional | Frequent |
| Paradoxical breathing pattern: abdomen moves in on inspiration | No | | Yes |
| Accessory muscle use: rise in clavicle during inspiration | No | Slight Rise | Pronounced rise |
| Grunting at end-expiration: guttural sound | No | | Yes |
| Nasal flaring: involuntary movement of nares | No | | Yes |
| Look of fear: | | | |
| o Eyes wide open | | | |
| o Facial muscles tense | No | | Yes |
| o Brow furrowed | | | |
| o Mouth open | | | |
| o Teeth together | | | |