



Mike Harlos MD, CCFP, FCFP
Professor, Faculty of Medicine, University of Manitoba
Medical Director, WRHA Palliative Care Sub Program
Medical Director, St. Boniface General Hospital Palliative Care
Room A8024, St. Boniface General Hospital, 409 Taché Ave.,
Winnipeg, Manitoba, Canada R2H 2A6
Ph: 204-235-3929 Fax: 204-237-9162 Pager: 204-932-6231 E-mail:mike@harlos.net

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Anticipating And Preparing For Predictable Clinical Challenges In The Medical Care Of The Terminally Ill Person Wishing To Die At Home.

Patients with progressive terminal illness can be expected to undergo a steady decline in functional status, often with a cognitive decline in the final phase. In endeavoring to support the patient and his/her family in planning for an expected death at home, specific challenges can be anticipated and prepared for, often avoiding the need for hospitalization.

A critical component of supporting a patient and family in such circumstances is open discussion about what to expect, and what options exist to address challenges as they develop. Such discussion is usually best undertaken proactively, rather than reacting to a crisis that has developed.

Examples of approaching such discussion with patients/families are given below.

For the clinical scenarios discussed below, it is generally assumed that the patient is imminently dying (within hours to a few days) from a terminal illness, and wishes to remain in the home. A different approach may be indicated in:

- circumstances with a potentially longer prognosis
- a facility with more options for investigation and intervention than the home
- situations in which the expectations of the patient/family are for ongoing efforts to investigate and reverse disease.

Table 1: Common Clinical Challenges in the Care of the Dying in the Home

Clinical Problem	Observation	Considerations and Options	Notes
Inability to transfer to a toilet, commode, chair, bed.	A decline in mobility is an expected consequence of a terminal illness	<ul style="list-style-type: none"> • Grab bars, hospital bed, bedside commode, walker • Indwelling Foley catheter for urinary incontinence • For fecal incontinence: Occasionally- Planned constipation with “orchestrated” bowel movements. The patient is kept mildly constipated, and every 2nd or 3rd night is given 4-6 Senokot tablets with a Dulcolax & Glycerin suppository the following day. If the suppositories are ineffective, a fleet enema is given later in the day. 	Work with Home Care, through the Palliative Care Coordinator if registered on a palliative care program
Decreased food intake	<ul style="list-style-type: none"> • Often upsets families more than patients: feel “helpless” • Caloric intake does not correlate with weight, energy, well-being, or longevity in dying individuals • Patient usually not hungry; encouraging food may aggravate nausea, bloating 	<p>The patient and (particularly) the family need to be informed about the body’s inability to process calories under such circumstances, and encouraged to eat only small amounts of favourite foods, if and when the patient is hungry.</p> <p>High-calorie commercial food products are ineffective and unnecessary in the terminally ill approaching death.</p> <p>Family should be supported in finding other ways to be involved in care, even if it is simply being present.</p>	Proactive communication around the issue of diminished intake is critical in supporting the dying person at home. Generally, terminally ill individuals
Decreased fluid intake	<ul style="list-style-type: none"> • A natural consequence of the progressive weakness & obtundation in the dying process • Comfort can usually be achieved with vigilant mouth care • Prognosis generally a matter of days (rarely, up to 2 weeks) in the absence of fluid intake • Hypoalbuminemia and progressive renal insufficiency are often present, compromising the handling of fluid. Edema potentially aggravated by increasing fluid intake. 	<p>Specific circumstances exist for which hydration in the dying patient may improve comfort:</p> <ul style="list-style-type: none"> - Opioid neurotoxicity - Hypercalcemia <p>The issue of thirst vs. dehydration in the dying remains controversial; each situation must be approached individually.</p>	hoping to die at home would not want interventions to prolong the dying phase of their illness; usually the overriding goal is comfort. This can almost always be achieved without hydration or caloric supplementation.
Inability to swallow medications	This is virtually a certainty in persons nearing death from progressive terminal illness. It should consequently be anticipated and planned for. The sublingual route is the least complex and burdensome, and many medications can be given in this manner (see Table 2)	Table 2 lists various medications that can be given by a non-oral route for symptom control.	It is likely that many of the medications given sublingually are actually swallowed reflexively and then absorbed. As long as they are empirically effective, this is not relevant.

<p>End-stage delirium</p>	<ul style="list-style-type: none"> • 80 – 90% in studies¹ • very distressing for everyone involved • very difficult to handle in the home setting... need to take an active, aggressive approach to management (ie. almost “zero tolerance” for agitated delirium) • unlikely to be reversible in the final hours or days, particularly if wants to stay home (limited investigations) • consider starting with low dose sedatives/neuroleptics, however effective sedation for an agitated terminal delirium in the final hours/days often requires achieving a state of minimal response to stimuli 	<ul style="list-style-type: none"> • If possible and appropriate, change potentially reversible factors (eg/ infection, meds with anticholinergic effects, consider rotating opioids, need to void, fecal impaction) • Treat with medications such as neuroleptics (haloperidol, methotrimeprazine) and/or benzodiazepines • Benzodiazepines alone may disinhibit and result in a paradoxical worsening of agitation • Neuroleptics alone may not be sufficiently sedating • Lower potency neuroleptics (methotrimeprazine, chlorpromazine) can lower seizure threshold. In vulnerable patients consider benzodiazepines alone for sedation, and adding haloperidol if needed. 	<p>It is important to inform families of the likelihood of impaired cognition, and of possible restlessness. Managing delirium at home in the final hours/days of terminal illness usually involves sedation, with little likelihood of further response from the patient prior to death. If the family does not fully realize this, there may be expectations of further communication, as it is understandable to desire “one more good-bye”. Families should be encouraged to talk to even comatose patients on the assumption that there is awareness on some level. It can be very therapeutic to have the opportunity to speak to a dying loved one, even if there is no obvious response; encourage individuals to have time alone, if needed, for private words.</p>
<p>Dyspnea in the final hours/days</p>	<ul style="list-style-type: none"> • Approx. 70% of advanced cancer patients², and higher for advanced lung CA specifically³ • Very frightening for patient and family/caregivers • Focus should be on aggressive pursuit of comfort; unlikely to find and address reversible causes in the home setting, particularly in the imminently dying 	<ul style="list-style-type: none"> • Opioids are the most widely used centrally acting medication in the palliation of dyspnea in the terminally ill⁴ • Titrate as one would for pain⁵; symptoms change quickly in final hours/days – vigilance is critical • Generally use short-acting opioids (morphine or hydromorphone immediate release) to facilitate titration • Example starting doses in an opioid-naïve patient: <ul style="list-style-type: none"> - Morphine 2.5 – 5 mg po q4h plus q2h as needed - Hydromorphone 0.5 – 1 mg po q4h plus q2h as needed <p>If anxiety is a significant factor, consider chlorpromazine starting at 10 mg po q6h or methotrimeprazine 6.25 – 12.5 mg po q6h; these have been shown to help in dyspnea and do not significantly add to the respiratory depressant effects of opioids, in contrast to benzodiazepines.</p>	<ul style="list-style-type: none"> • Dyspnea is a <i>subjective</i> experience; tachypnea in the absence of distress is not dyspnea • It would be unusual to have dyspnea with a normal or low respiratory rate. If that is the case, consider using chlorpromazine or methotrimeprazine as previously noted. • Oxygen generally helps in dyspnea (at least in hypoxic individuals), however it may be challenging to access quickly in the home. Consider having home O₂ in place early if dyspnea is a significant symptom. You may have to arrange this through private agencies if the provincial program cannot be accessed given the circumstances.
<p>Terminal Secretions (“Death Rattle”)</p>	<p>Due to pooling and ineffective clearing of pulmonary secretions, often with pneumonia as a final event.</p>	<p>Scopolamine is the most commonly used medication for drying secretions in the terminal hours. In highest-to-lowest order of effectiveness:</p> <ol style="list-style-type: none"> 1. Scopolamine injectable 0.3 – 0.6 mg SQ q1h prn 2. Scopolamine Gel 0.25mg/0.1ml: Apply 0.5 mg to skin q4h 3. Scopolamine patch (Transderm-V®) 2-3 patches at once. 	<p>Scopolamine is very sedating, however by the time that it is used for terminal secretions the patient is usually unresponsive. If used in high doses in an alert individual, it will usually result in a delirium.</p>

Table 2: Non-Oral, Non-Intravenous Routes for Common Palliative Medications

MEDICATION	USES	PREPARATION	ROUTES Other than Oral/IV/IM	NOTES
Morphine Hydromorphone	<ul style="list-style-type: none"> • Pain • Dyspnea 	<ul style="list-style-type: none"> • Elixir 	<ul style="list-style-type: none"> • Sublingual 	<ul style="list-style-type: none"> • Morphine 50 mg/ml allows for small volumes • Hydromorphone is 1 mg/ml
		<ul style="list-style-type: none"> • Injectable 	<ul style="list-style-type: none"> • Sublingual • Subcutaneous 	
		<ul style="list-style-type: none"> • Suppository 	<ul style="list-style-type: none"> • Rectal 	<ul style="list-style-type: none"> • Burdensome
Fentanyl	<ul style="list-style-type: none"> • Pain • Dyspnea 	<ul style="list-style-type: none"> • Transdermal patch (Duragesic®) 	<ul style="list-style-type: none"> • Transdermal 	<ul style="list-style-type: none"> • Slower to titrate than shorter acting meds, but useful if variable or poor oral intake • Minimal burden on care providers
		<ul style="list-style-type: none"> • Injectable 50 micrograms/ml 	<ul style="list-style-type: none"> • Sublingual 	<ul style="list-style-type: none"> • 25 - 50 micrograms sublingually 15 minutes prior to painful activity (dressing change, catheterization)
Haloperidol	<ul style="list-style-type: none"> • Agitation • Nausea 	<ul style="list-style-type: none"> • Injectable 	<ul style="list-style-type: none"> • Sublingual, • Subcutaneous 	<ul style="list-style-type: none"> • Potent antiemetic as well as its use for restlessness, delirium
Methotrimeprazine (Nozinan®)	<ul style="list-style-type: none"> • Agitation • Nausea 	<ul style="list-style-type: none"> • Injectable 25 mg/ml 	<ul style="list-style-type: none"> • Sublingual, • Subcutaneous 	<ul style="list-style-type: none"> • Antiemetic, analgesic, sedative May use with benzodiazepines if need aggressive sedation
Scopolamine Patch (Transderm-V ®)	<ul style="list-style-type: none"> • Secretions, Nausea 	<ul style="list-style-type: none"> • Transdermal patch 	<ul style="list-style-type: none"> • Transdermal 	<ul style="list-style-type: none"> • Potential to cause delirium!! • May need 2-3 patches for secretions

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