Palliative Care In The Final Days

Considerations for Clinical Care and Psychosocial Support

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About Palliative.info

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Palliative.info offers an organized, up-to-date collection of links to palliative care resources on the internet, as well as locally developed palliative care material.

... more info ...

What is Palliative Care? (a personal definition)

Palliative Care is an approach to care which focuses on comfort and quality of life for those affected by life-limiting/life-threatening illness. Its goal is much more than comfort in dying: palliative care is about living, through meticulous attention to control of pain and other symptoms, supporting emotional, spiritual, and cultural needs, and maximizing functional status.

The spectrum of investigations and interventions consistent with a palliative approach is guided by goals of patient and family and by accepted standards of health care, rather than being boundaried by preconceptions of what is or is not “palliative”.

See also the World Health Organization’s definition

Links Grouped by Topic:

- Aboriginal / Indigenous Peoples
- Advance Directives (Health Care Directives)
- Advocacy, Govt Policy
- Assessment/Evaluation Tools
- Programs
- Psychosocial Professional
- Quality of Life
- Research Sites Related to Palliative Care
- Specific Diseases/Populations
- Spiritual / Faith-Based
- Standards and Norms

Teaching Material

- Manitoba Resources - Lectures/Presentations/Handouts
- Ian Anderson Modules
- StopPain.org: Topics in Pain Management - A Slide Compendium

Local (Winnipeg) Documents
Note: Some of the slides or other material will be difficult to interpret without the explanation of the author (particularly the photographs or cartoons); they may be very dependent on the context of the lecture and surrounding discussion at the time. You can either leave those out of your own presentation, or contact the original author for explanation.

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Disclosure Statement

The presenters have no conflicts of interest to disclose
Objectives

• To review common clinical challenges in the final days/hours of life
• To develop an approach to preemptive planning and symptom management for supporting patients and families at end-of-life
• To review common communication issues around patient and family concerns as death nears
Clinical Considerations In The Final Hours

1. Are there preexisting medical conditions needing attention in the final hours?
   - not typically necessary to continue ongoing medical management of underlying illnesses, with the possible exception of seizure disorder

2. What new symptoms might arise (typically dyspnea, congestion, agitated delirium), and related medication needs?
   - Uncommon for pain to arise as a new symptom in final hours
   - What are the available routes of medications administration?

3. Anticipated concerns of family
Some Problems Are Easily Predictable
You don’t need one of these to know that as death nears...

- functional decline occurs
- food/fluid intake decr.
- oral medication route lost
- symptoms develop: dyspnea, congestion, delirium
- family will need support & information
The Perception of the “Sudden Change”

When reserves are depleted, the change seems sudden and unforeseen.

However, the changes *had* been happening.

*Melting ice = diminishing reserves*

Day 1  Day 2  Day 3  Final

That was fast!
Final Common Pathway

**Progressive Illness**
- cancer,
- neurodegenerative illness
- organ failure (heart, kidney, lung, liver)

**Sudden Health Conditions**
- non-survivable brain injury (CVA, anoxia, trauma)
- sepsis
- inoperable surgical conditions (ischemic gut or limbs)

- bedridden
- weak, swallowing impaired, poor airway protection, can’t clear secretions;
  *pneumonia* – dyspnea, congestion
- *delirium* – agitation
Symptom Prevalence In Final Days

• Dyspnea: 80% +
• Congestion: reported as high as 92%
• Delirium: 80% +
• Families who would be grateful for support and information: must be near 100%

When these issues arise at end-of-life, things haven’t “gone wrong”… they have gone as they are inclined to.
Symptom Prevalence in the Last Week of Life

Conill et al; JPSM 1997 14(6); 328-331

- **Delirium**: Avg. 6.5 wks before death
- **Dyspnea**: Approx 48 hrs before death
- **Dysphagia**: Approx 48 hrs before death
- **Pain**: Approx 48 hrs before death
- **Nausea**: Approx 48 hrs before death
- **Vomiting**: Approx 48 hrs before death
Role of the Health Care Provider

• **Anticipate** changes

• **Prepare** a care plan for predictable issues, including:
  - plan for addressing loss of mobility, self-care, food/fluids
  - medications by appropriate routes for potential symptoms
  - Health Care Directive and/or Advance Care Plan, and Letter of Anticipated Home Death for patients at home

• **Preempt** concerns/questions:
  - what can we expect?
  - how long can this go on? what will things look like?
  - not eating/drinking; sleeping too much
  - are medications causing the decline?
  - how do we know they are comfortable?
  - can they hear us?
  - don’t want to miss being there at time of death
# Management of Symptoms

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Drug</th>
<th>Non-Oral Route(s)</th>
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<tbody>
<tr>
<td><strong>Dyspnea</strong></td>
<td>opioid</td>
<td>• sublingual (SL) – small volumes of high concentration; same dose as oral</td>
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<td></td>
<td></td>
<td>• subcutaneous – supportable in most settings; same dose as IV = ½ po dose</td>
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<td></td>
<td></td>
<td>• IV – limited to hospital settings</td>
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<td></td>
<td></td>
<td>• intranasal – fentanyl – lipid soluble opioid; use same dose as IV to start</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Note: Transdermal not quickly titratable</td>
</tr>
<tr>
<td><strong>Pain</strong></td>
<td>opioid</td>
<td>see above</td>
</tr>
<tr>
<td><strong>Secretions</strong></td>
<td>scopolamine</td>
<td>• subcutaneous</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• transdermal (patches; compounded gel)</td>
</tr>
<tr>
<td></td>
<td>glycopyrrolate</td>
<td>• subcutaneous</td>
</tr>
<tr>
<td><strong>Agitated Delirium</strong></td>
<td>neuroleptic (methotrimeprazine; haloperidol)</td>
<td>• SL – use same dose for all routes</td>
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<tr>
<td></td>
<td>lorazepam</td>
<td>• SL – generally use with neuroleptic</td>
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**Medications Needed**

1. **Opioid**: pain, dyspnea
2. **Antisecretory**: congestion
3. **Sedative** (neuroleptic +/- benzodiazepine): agitated delirium

*Plus*

whatever condition-specific medications are needed (e.g. anticonvulsants)
Opioid Use in Final Days/Hours

• specific doses will depend on the degree of distress and existing opioid tolerance

• usually need to use short-acting opioid in order to respond quickly to changing symptoms (dyspnea)

• if patient is on long-acting morphine or hydromorphone, switch to equivalent daily dose of short-acting divided q4h (½ the oral dose if switching to subcutaneous or IV)

• if patient is on transdermal fentanyl, consider leaving this as is, and adding a q4h dose of morphine or hydromorphone, starting low and titrating up as needed

• the interval between prn (as-needed) doses should not exceed one hour, regardless of route. The effect of a prn dose will be evident by 1h; a longer interval will cause needless suffering
Dyspnea

- An uncomfortable awareness of breathing... an experience of breathlessness
- Not the same as tachypnea, which is a fast rate of breathing
- “...the most common severe symptom in the last days of life” (Davis C.L. The therapeutics of dyspnoea Cancer Surveys 1994 Vol.21 p 85 – 98)
- Increasing incidence as death nears (approx. 80 %)... likely related to the prevalence of pneumonia at the end of life
Opioids in Dyspnea

- Uncertain mechanism
- Comfort achieved before resp compromise; rate often unchanged
- Often patient already on opioids for analgesia; if dyspnea develops it will usually be the symptom that drives the need for titration
- Dosage should be titrated empirically
- May need rapid dose escalation in order to keep up with rapidly progressing distress
Common Concerns About Aggressive Use of Opioids at End-Of-Life

• How do you know that the aggressive use of opioids for dyspnea doesn't actually bring about or speed up the patient's death?

• “I gave the last dose of morphine and he died a few minutes later… did the medication cause the death?”
1. **Literature:** the literature supports that opioids administered in doses proportionate to the degree of distress do not hasten death and may in fact delay death.

2. **Clinical context:** breathing patterns usually seen in progression towards dying (clusters with apnea, irreg. pattern) vs. opioid effects (progressive slowing, regular breathing; pinpoint pupils).

3. **Medication history:** usually “the last dose” is the same as those given throughout recent hours/days, and was well tolerated.
Typically, with excessive opioid dosing one would see:

- pinpoint pupils
- gradual slowing of the respiratory rate
- breathing is deep (though may be shallow) and regular
COMMON BREATHING PATTERNS IN THE FINAL HOURS

Cheyne-Stokes

Rapid, shallow

“Agonal” / Ataxic
Congestion in the Final Hours ("Death Rattle")

- Positioning

- **ANTISECRETORY:**
  - scopolamine 0.3-0.6 mg subcut q2h prn
  - glycopyrrolate 0.2-0.4 mg subcut q2h prn (less sedating than scopolamine)

- Consider suctioning if secretions are:
  - distressing, proximal, accessible
  - not responding to antisecretory agents
The Management Of Irreversible Delirium In The Imminently Dying
What Makes A Delirium Irreversible At End Of Life?

1. **Clinical factors:**
   - Refractory to available interventions, e.g. recurrent hypercalcemia after multiple bisphosphonate treatments
   - No therapeutic options available – e.g. end-stage liver failure

2. **Directive from patient/proxy** that no further investigations be done and that interventions focus strictly on comfort

3. **Limitations of care setting** chosen by patient/family – e.g. a steadfast commitment to remain at home to die
Considerations Regarding Aggressive Sedation

- Meds titrated to effect… the correct dose is “the one that works”
- Tend to use a neuroleptic +/- benzodiazepine; subcutaneous route is most common, but can use SL
- Methotrimeprazine (Nozinan®) commonly used, as haloperidol is less sedating… however be aware that its anticholinergic effects may potentially aggravate the delirium
- Can add a benzodiazepine such as sublingual lorazepam
- Commonly need regular intermittently scheduled doses (eg. q4h or q6h) plus a prn dose of q1h prn
- prn medication orders must allow “stacking” doses… i.e. repeating a dose once its empirical effect should have occurred, yet before it has begun to lose effect
Examples of Sedation Orders in Final Hours

**Note:**
- these are conservative starting doses… may need higher
- some patients may just need prn dosing

- **Neuroleptics**
  - methotrimeprazine (Nozinan®) 2.5 – 5 mg subcut/SL q4-8h regularly plus q1h prn
  - haloperidol 0.5 -1 mg subcut/SL q6-8h regularly plus q1h prn

- **Benzodiazepines** (not recommended for use without neuroleptic; may exacerbate agitated delirium)
  - lorazepam 0.5 – 1 mg SL 46h plus q1h prn
Life-And-Death Decisions?

- In situations where death will be an inescapable outcome, family may nonetheless feel that their choices about care are life-and-death decisions (treating infections, hydrating, tube feeding, etc.)

- It may be helpful to say something such as:

  “I know that you’re being asked to make some very difficult choices about care, and it must feel that you’re having to make life-and-death decisions. You must remember that this is not a survivable condition, and none of the choices that you make can change that outcome.

  We are asking for guidance about how we can ensure that we provide the kind of care that he would have wanted at this time.”
Helping Family And Other Substitute Decision Makers

• Rather than asking family what they would want done for their loved one, ask what their loved one would want for themselves if they were able to say

• This off-loads family of a very difficult responsibility, by placing the ownership of the decision where it should be… with the patient.

• The family is the messenger of the patient’s wishes, through their intimate knowledge of him/her. They are merely conveying what they feel the patient would say rather than deciding about their care
Can They Hear Us?

The question of “can they still hear us?” frequently arises regarding unconscious patients nearing death … of course it’s not possible to know this, however:

- Hearing is a resilient sense, as evidenced by its potential to endure into the early phase of general anesthesia
- Hearing vs. an awareness of presence of family… restless, minimally alert patients often settle when family are present
- In our behaviour at the bedside we should assume that some nature of hearing/awareness/connection is maintained… may influence nature of bedside conversations
Supporting Families

- Effective sedation can change the bedside dynamics from one in which people are afraid to visit and there is no meaningful interaction to one in which people can talk, read, sing, play favorite music, pray, tell stories, touch.

- Health care team has a role in facilitating meaningful visits... family/friends may not know “the right things to do”

- Individuals may want time alone but be reluctant to ask others (friends/family) to leave the room. The health care team can suggest that this might be something that the family can explore with each other
Helping Families At The Bedside: Physical Changes

- physical changes of dying can be upsetting to those at the bedside:
  - skin colour – cyanosis, mottling
  - breathing patterns and rate
  - muscles used in breathing

- reflect inescapable physiological changes occurring in the dying process.

- may be comforting for families to distinguish between who their loved one is - the person to whom they are so connected in thought and spirit - versus the physical changes that are happening to their loved one's body.
Helping Families At The Bedside: Missed The Death

- some family members will miss being present at the time of death

- consider discussing the meaningfulness of their connection in thought & spirit vs. physical proximity

- whether they were at the bedside, or had stepped out of the room for a much needed break, or were in fact in a different country, their connection in spirit/heart/soul was not diminished by physical distance.
Family Themes

• Doing to being
• Expectations
• Fears
• Fatigue
• Relief
• Variety of responses
• Promises
• Anticipatory grief
• Caregiver “presence”
• …what else??
Reflective Activity

• Am I taking care of myself well enough to do this kind of work?

• Do I offer myself the same kind of compassion that I offer those in need?

• When do I sit down to just sit with the reality of my vulnerability?

Chris Marchand (2008)
Exploring Obstacles to Self Care

• Self care is selfish and that if you act selfishly you should feel guilty
• Everyone else’s needs should be met first and then if you have time or energy left over you can look after yourself
• Self care is a luxury for the rich and famous that requires huge amounts of time and money

Katherine Murray (2009)
Ask Yourself

Write down your favourite belief/reason for not taking care of yourself and then ask:

• Is this belief true?
• Does this make sense?
• Is this how I want things to be?
• Does this belief serve me well?

Kath Murray (2009)
Self Care Begins with Self Awareness

“When we do not feel valued it is hard for us to value others.

When we feel invisible, it is hard for us to see and acknowledge others.

When our own spirits are dying of starvation, with no sign of nourishment in sight, it is impossible for us to feed and nurture the bodies and spirits of those in our care who are ill or dying.

We have nothing to give if we are literally running on empty.”

Elizabeth Causton
In Closing.....

- From the events of our lives come the songs of our hearts;
- From the struggle to survive comes the melody of hope;
- From the broken places of spirit come our anthem of praise;
- From the deep silence of our soul comes the solace of peace;
- From the offerings of love come new shapes of the divine;
- From the community we share comes the promise of tomorrow.