

## Final days at home

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Most dying people wish to be cared for and die at home. A home death has often been shown to have a positive effect on patients and their families.<sup>1-5</sup> Ensuring that all involved experience a home death as a “good death,” and that the family and care team feel supported 24 hours a day, 7 days a week, requires considerable planning. In the final days at home, care goals are focused on comfort, and the health care team, all family, and paid and unpaid caregivers need to be aware of the patient’s anticipated course. Family physicians should have knowledge of local practices regarding an expected death at home, available family supports, and useful medications including their routes of administration, purpose, and off-label indications.<sup>6</sup>

*One of your family practice patients, 40-year-old A.B., has locally advanced ovarian cancer, with a recurrent bowel obstruction. She lives with her husband and their 6-year-old son. In the past few months they have moved into her parents’ home nearby to have help with child care as well as with A.B.’s care. You have been involved in her care with support from the local palliative team.*

*Her symptoms include abdominal pain, which has been well managed with subcutaneous hydromorphone; and nausea and vomiting, which have been comfortably managed in the past with subcutaneous octreotide, dexamethasone, and as-needed haloperidol. She has struggled unsuccessfully to talk to her family about her evolving goals or about dying. However, she has reiterated her wish to not be hospitalized again, in spite of the fact that her present obstruction has not resolved.*

*She is becoming more weak and tired, and is sleeping much of the time, but she remains alert and oriented. Over the past 36 hours she has had minimal intake, but she is neither hungry nor thirsty. She has been taking sips of water to moisten her lips and mouth, and has minimal or no nausea. She has localized abdominal pain, which she rates at about 3 out of 10 in severity. She has generalized pain (8 out of 10) associated with moving for her daily shower and toileting, and she can no longer get downstairs to join in any family activity. She needs extensive help with all activities of daily living (ADLs), which her husband provides.*

*During your visit you find her abdomen distended and silent, with firm, tender, irregular masses, but A.B. appears not to be in distress. Based on her deterioration*

*(increased somnolence and weakness, decreased intake), it is clear that her time is limited to perhaps “days to weeks at best.” In response to your prodding she is cautiously willing to talk with you and her husband about the “what ifs,” but does not want to discuss dying or prognosis. Although she continues to hope the obstruction will once again resolve, she acknowledges that if things do not improve she has some things she would like to do; she wants to see other family members and complete a few small tasks, “just in case.”*

*Talking with her family separately (with A.B.’s permission), it is clear they support her choice to remain at home. As they wish to continue to provide personal care, including transfers and bathing, they are reminded how to do so safely. Equipment needs are reviewed, and they are given information about what to expect in the coming days. Her decreasing intake is reviewed at length to allay any fears they might have. The link to the Canadian Virtual Hospice’s “When Death Is Near” article<sup>7</sup> and other online information sources are provided. The family declines more help from other support workers. They identify a funeral home, and you ensure that a letter of anticipated death (LAD), or its equivalent, is in place. Nursing visits are now scheduled daily, and will be provided more often if needed. You are available to answer nursing inquiries, to adjust medications, to answer questions, and to offer support.*

The final days of life tend to culminate in a common cluster of symptoms regardless of the underlying disease or site of care. There can also be specific complications more particular to each disease.

To avoid any need for emergency personnel or police there must be a copy of the LAD at the funeral home and medical examiner’s office. The LAD usually provides the patient’s demographic information and names the professional who will complete the registration of death. Clarify the preferences and rules specific to your region with the local medical examiner.

The family needs to be prepared and advised to call the care team, and not 911, if they need help before or following the death.

### Common symptoms in the last days

The cluster of potential signs and symptoms to be anticipated in the last days are pain, dyspnea, delirium, dysphagia, weakening of voice, loss of appetite, incontinence (whether due to decreased ability to move despite support, or loss of consciousness), dry mouth, and noisy upper airway secretions. As loss of the ability

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to take medication orally is almost universal, care must be taken with prescribing in the final days. All unnecessary medications should be discontinued.

**Pain.** Although subcutaneous administration is commonly used, not all families will be able to manage it. In these cases, sublingual dosing of higher-concentration opioids (eg, 10 mg/mL of intravenous [IV] hydromorphone, 50 mg/mL of methadone) eases the situation. In some cases the drug might be absorbed sublingually<sup>8</sup> and in others the volume might be so small that it is tolerated orally. Caution is suggested with the fentanyl patch, as it will not be amenable to frequent dosing changes, and its effect might be compromised in very cachectic patients, those with circulatory issues, or those with massive edema.

**Dyspnea.** In addition to the use of a fan for airflow, the same medications (with the same considerations and limitations) used to manage pain are effective for the management of dyspnea. As with incident pain, dyspnea associated with ADLs, turns, etc, can be managed with sublingual fentanyl (potency 100 times that of IV morphine) or sufentanil (potency 1000 times that of IV morphine), or a similar dose can be given intranasally, which offers very quick onset of action and bioavailability.<sup>9</sup>

**Delirium.** Delirium is reported in up to 88% of patients at the end of life.<sup>10</sup> An agitated, irreversible delirium can certainly lead to challenges in providing care at home. This symptom can cause distress, as patients' safety and dignity can be threatened and families might not be able to manage. Typical or atypical antipsychotic medications should be available (and are useful antiemetics as well). Disintegrating tablets or wafers of olanzapine, subcutaneous haloperidol, or subcutaneous or sublingual methotrimeprazine (25 mg/mL) are commonly used. If required in addition, an appropriately dosed benzodiazepine is also indicated but is not the first choice. Subcutaneous phenobarbital is occasionally required if agitation persists despite all of the above.

**Nausea and vomiting.** Although treatment depends on the presumed cause of nausea and vomiting, metoclopramide, which acts on multiple receptors, is often the first-line option. Metoclopramide is available for subcutaneous, oral, or rectal administration (it can be compounded with other antiemetic drugs in suppository form, if you have access to a pharmacy that offers compounding). Second-line agents include other dopamine agonists acting on the chemoreceptor trigger zone, such as haloperidol, methotrimeprazine, and drugs in the 5-HT<sub>3</sub> class (eg, ondansetron). Some of these drugs can be augmented with dexamethasone.<sup>11</sup> All of these medications are available for subcutaneous administration.

### Online resources for professionals

Bailey FA, Harman SM. Palliative care: the last hours and days of life. Waltham, MA: UpToDate; 2014. Available from: [www.uptodate.com](http://www.uptodate.com). Accessed 2014 Feb 9.

Canadian Virtual Hospice. WRHA PCH Program end of life symptom management pathways and guides. Winnipeg, MB: Canadian Virtual Hospice; 2011. Available from: [www.virtualhospice.ca](http://www.virtualhospice.ca). Accessed 2014 Feb 9.

**Noisy upper airway secretions.** The *death rattle* (although this term is less commonly used now) is often perceived as distressing, but frequently patients' facial expressions suggest it is not uncomfortable for them.<sup>12</sup> Nonetheless, if desired, reduction of noisy breathing can be best achieved with repositioning or with anticholinergic medications (eg, glycopyrrolate, scopolamine, or atropine). Glycopyrrolate does not cross the blood-brain barrier so should not cause delirium in an alert patient. Note that these medications might not eliminate secretions once secretions are present, but they will help reduce further accumulation.<sup>13</sup>

**Dry mouth.** There are multiple reasons for a dry mouth, and good mouth care is important. Moistening the mouth and lips and cleaning the teeth, palate, and gums with toothettes or baby toothbrushes can provide comfort. Over-the-counter products designed to relieve dry mouth can also provide comfort, as can simple fine sprays of club soda or water.

**Weakness and fatigue.** Mobility will decrease and family members should be educated about transfers, turning, changing, feeding, and other personal care issues in order to ensure safety for all. A commode at bedside or Foley catheter might be required.

### Care plan and course for A.B.

*Although A.B.'s intake is minimal, the digestive tract is probably still secreting, so continuing her octreotide is appropriate to reduce the risk of her nausea and vomiting returning. The oral and subcutaneous haloperidol and subcutaneous ondansetron remain as-needed options.*

*Pain continues to be managed with subcutaneous hydromorphone around the clock and as needed (with teaching that if dyspnea were to develop it would be helpful for that too). Intranasal fentanyl is added to facilitate ADLs and turns.*

*For potential delirium, hallucinations, or agitation, subcutaneous haloperidol or 25 mg/mL of subcutaneous or sublingual methotrimeprazine are used as needed. Although methotrimeprazine is more sedating than haloperidol, given her decreasing levels of wakefulness*

already, it might be the better option and it avoids leaving too many choices that can lead to confusion for the family in deciding which to administer. Sublingual lorazepam in low doses for anxiety or restlessness is made available in case it is needed.

For potential secretions, a transdermal scopolamine gel is compounded by the local pharmacy, to be used if required.

A few days later on your return visit, she is sleeping, as she has been much of the day. She appears uncomfortable, and you adjust her hydromorphone dose, explaining that the goal is to manage pain, and that the increase will not hasten death<sup>14</sup> (a common misconception). Her colour is good, her breathing seems easy, and her radial pulse is strong. She has developed more difficulty talking and her voice is very quiet. On inquiry, the family reports that at times she appears to ramble in her thinking and that her hands occasionally pick at the air in front of her when she is sleeping. They also report that when she wakes and is given sips of water, she coughs, which aggravates her pain. The family has not noted any jerking of her arms or legs. She has voided once in the past 24 hours.

You advise the family to anticipate further changes in mentation and recommend using the methotrimeprazine if an uncomfortable restlessness develops. You also advise that she requires mouth care but not fluids to avoid aspiration. You review the signs that death might be within hours, such as peripheral cyanosis (mottling) around the knees and feet, and changes in breathing with gaps (Cheyne-Stokes respiration), often with the mouth open. They are reminded of the plans for once she has died.

The next day A.B. has a period of alertness, and briefly recognizes those around her, before becoming unresponsive and developing occasional episodes of opioid-related myoclonus, managed with sublingual lorazepam dissolved in a few drops of water.

Following her death the family does not rush to call anyone, as her husband, son, and parents sit with her. A couple of hours later they call the funeral home and let the nurse know.

After A.B.'s death the nurse visits. Further bereavement care by the team will follow in future if required. As is your practice, you call and speak with the family members, and then send a card to acknowledge their loss and express what a privilege it was to know A.B. 🌿

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#### Competing interests

None declared

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## BOTTOM LINE

- Most dying people wish to be cared for and die at home. Ensuring that all involved experience a home death as a "good death" requires considerable planning. In the final days at home, care goals are focused on comfort, and the health care team, all family, and paid and unpaid caregivers need to be aware of the patient's anticipated course and of what to do if they need help before or following the death.
- The final days of life tend to culminate in a common cluster of symptoms, regardless of the underlying disease or site of care. Symptoms include pain, dyspnea, delirium, dysphagia, weakening of voice, loss of appetite, incontinence, dry mouth, and noisy upper airway secretions.
- As loss of the ability to take medication orally is almost universal, care must be taken with prescribing in the final days. All unnecessary medications should be discontinued. To avoid any need for emergency personnel or police after the death, there must be a copy of the letter of anticipated death at the funeral home and medical examiner's office. Family members need to be prepared and advised to call the care team, and not 911, if they need help.

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