

CHCA Project ECHO Home-Based Palliative Care

All Teach, All Learn

Bridging the Knowledge Gap in Home-Based Palliative Care



Case Study: Recognizing End-of-Life in Home-Based Palliative Care

Case Study: B.T.

- Age: 43
- Gender: Non-binary (they/them)
- Diagnosis: Metastatic pancreatic cancer with liver and peritoneal metastases
- Setting: Rural home in central Manitoba; nearest hospital emergency department is in Thompson, MB
- Living situation: Resides with spouse, supported by a large extended family; B.T. does not have children of their own
- Care plan: B.T. wishes to remain and die at home; advanced care plan documented in electronic health record
- Care team:
 - Local home care nurse and personal support worker (PSWs) through the regional health service
 - Primary care provider (family physician)
 - Virtual specialist palliative care team for consultation and symptom management (through WRHA)

Presenting Situation:

B.T.'s condition has been declining steadily over the past two weeks. B.T. is resting for longer periods, but is also experiencing episodes of agitation that appear to be causing B.T. distress and this is extremely upsetting for the family to watch and witness. When not resting or asleep, B.T.'s family notes him to be distracted, withdrawn or "lost in his thoughts". B.T.'s appetite is generally poor. B.T.'s pain is satisfactorily controlled and is comfortable for much of the time; B.T. and the family do not have concerns about uncontrolled or unmanaged pain.

However, over the past 48 hours, the family as well as the home care team have noticed a significant change in B.T.'s presentation. B.T. is now resting or sleeping nearly continuously and his times of alertness are becoming less and less. Occasionally, while alert, B.T. mumbles words and phrases that are incomprehensible or do not make sense. Feeling unable to understand or comfort B.T. causes the family additional anxiety and stress. B.T. continues to have periods of extreme agitation. B.T. is no longer interested in any food or fluids and this is upsetting to the family as they are aware of the importance of nutrition and hydration, and meal times have been an cherished family tradition. As family caregivers they have read some materials to prepare them for end of life, but feel overwhelmed by the lived experience.

Situational Challenge

The home care nurse has been working in home care for just over 5 years. Home-based palliative care is not something that is encountered frequently, although the nurse has supported a few other individuals in palliative care, although no one as young as B.T. and no one with significant agitation as B.T.

The home care nurse recognizes the emotional distress the family is currently experiencing and this contributes to the nurse's own anxieties and their desire to support the family and B.T. The nurse is aware that B.T.'s condition has changed but is unsure whether these changes indicate the final hours to days of life. They lack confidence in interpreting the subtle differences between late-stage decline and the actively dying phase, and feel hesitant about:

- Initiating anticipatory guidance with the spouse and extended family
- Deciding when to escalate to the virtual palliative team for medication adjustments
- Shifting the focus entirely to comfort and end of life care.



Since 2021, the CHCA Project ECHO Home-Based Palliative Care has been delivering evidence-informed content and case studies to tackle the competency challenges faced by providers across the country. Through Virtual ECHO Sessions and our online resource HUB, we are breaking down major barriers to high-quality care at home. By engaging home and community care providers and palliative care specialists, we are building the skills, knowledge, and attitudes needed to meet the needs of patients, their families, and caregivers.

The Canadian Home Care Association (CHCA) is a national non-profit association focused on strengthening integrated home-based care. Representing public and private organizations across the country the CHCA partners with members to address pan-Canadian priorities through advocacy, awareness, innovation, and knowledge exchange.

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