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# Regional Palliative Care Services

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## Preparing for a Death at Home — Clinician Considerations

By Jennifer Ferguson, Palliative Care Nurse Consultant

We know that a significant number of people who are living with an advanced life-limiting illness would prefer to die in their own homes, where they feel safe and comfortable in familiar surroundings. Despite these wishes, we know that a large number of our patients are still dying in acute care and the reasons for this are plentiful.

This article will help the primary care clinicians who are involved in the care of the dying patient plan for an expected death in the home, in the hopes that patients can stay in their own homes for as long as possible. A planning meeting or family conference may be helpful to the patient and family as well as the clinical team to determine what the patient's needs will be at home as their illness pro-

gresses and to develop the best plan for meeting these needs.

With good community support and attention to symptom management, many people can remain in their own homes to die if that is what their wishes are. It can be challenging for one person to provide the 24 hour/day care that a dying person requires so coming up with a plan for who can assist the family with this care, both formally and informally, is a top priority.

When the patient is registered on the Northern Health Palliative Care Program as well as the BC Palliative Care Benefits Program by their physician or Nurse Practitioner, many of the costs of providing care for someone at home are covered.

### Planning Ahead:

Ensure that the patient's wishes and beliefs in regards to their care are known and goals-of-care discussions occur while the patient is still able to do so. Having these discussions and making some care decisions

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early on can reduce stress on the caregivers who may be asked to make decisions at a later time. Ask whether or not there is an [Advance Care Plan](#) or an Advanced Directive in place that may guide the care they receive.

**Paperwork** – ensure that the patient has been registered on the [Northern Health Palliative Care Program](#) as well as the [BC Palliative Care Benefits Program](#) so that medications, supplies, equipment and services are covered. Ensure that a No CPR or MOST form has been completed and keep this in a visible place, usually taped to the refrigerator. Complete the [Expected Death in the Home](#) form if a clinician will not be going to the home to pronounce death and the funeral home will pick up the patient's body directly from the house.

**Equipment** – have an assessment completed to determine any equipment needs for the patient's current functional abilities as well as needs that will likely arise as the patient's condition deteriorates and they become less mobile/ambulatory. Having equipment that supports completing ADLs more easily in the home may allow for the patient to maintain more independence as well as to reduce some of the strain on the caregivers earlier on in the disease trajectory. Help the family to set up a "comfort room" in the home as the patient's activities become more restricted to the bedroom.

**Medications** – planning for medications that will be required at home is crucial. Are there any medications that are redundant or not essential that could be discontinued? Thinking about what medications the patient will likely need as their

condition deteriorates allows for clinicians to get the required orders from the physician/nurse practitioner as well as to ensure that the medications are in the home for when they are required to prevent a delay in treatment. This is particularly important if the patient is living in a remote area that may require several days for medications to arrive from another location. If your community has a [Symptom Management Kit \(SMK\)](#), have it ordered and dispensed from the pharmacy before problems arise so that symptoms can be quickly treated in the home. Ensure that the family knows how/when to administer medications, including rescue/PRN medications for pain or other symptoms. Keeping a medication log often helps families adhere to the medication administration schedule. As well, it is important to have a plan of action for when the patient is unable to swallow their medications. If your community does not have an SMK, you can create your own SMK based on what symptoms your patient will likely experience at end of life. If you are unsure of what symptoms to expect or which medications to have, connect with your Palliative Care Nurse Consultant or Pharmacist Lead for help with this planning.

**Oxygen** – if the patient has previously required oxygen for treatment of dyspnea, have a [Home Oxygen Program](#) assessment completed to see if they qualify for oxygen therapy in the home.

**People Resources** – are there other team members/community resources who can be involved in the care of the patient at home to help alleviate some of the stress placed on the family caregivers? Community Health Workers, hospice volunteers, grief counsellors, Social Workers, clergy,







and death-doulas may also be of great help in the palliation of someone at home. Informal supports such as friends, neighbours, community groups and/or church members can also help to provide some support relief to the caregivers. Encourage caregivers to access as much help as they can as caring for a family member who is dying at home can be very tiring and stressful.

**Plan B** – having a discussion with the patient and family ahead of time to determine a backup plan if the patient is unable to stay at home for the duration of their illness. Could an admission or an addition to a waitlist for a [designated palliative care bed](#) in a long term care facility or Hospice House be the backup plan, instead of acute care? Respite/symptom management admissions can also occur for short periods of time to provide a break for caregivers and also to stabilize more difficult symptoms and then the patient can return home. If you need information about these beds or how to access them, please consult with the Nurse Consultant in your area.

**Personal Affairs** – encourage the patient to ensure that their personal affairs and Advance Care Plan are in order. Has anyone been identified as a representative for health care decisions and has a Power Of Attorney been named for financial decisions? Are there any specific wishes for funeral/memorial services, an obituary or other considerations/wishes?

**Prepare the family for the death** – research tells us that if families know what to expect as their loved ones become closer to death and are aware of the physical changes

that will occur, the family experiences less stress and anxiety. Prepare the family with resources such as the “Palliative At Home Binder” and “[My Loved One is Dying](#)” to assist with this. Ensure the family is aware of how to provide physical care to the patient such as turning, mouth care and incontinence care.

**Who to Call?** – ensure that the family knows who to call if an unexpected or new symptom arises as well as who to call if they have questions or concerns about their loved one. Also knowing who to call when the patient passes away to prevent an unnecessary call to emergency services. Provide the number for the [After Hours Palliative Nursing Service \(AHPNS\)](#) so that families can access help during the overnight hours when community nursing is not available. The after-hours resource nurses will provide advice to patients/families to help manage safely through the night.

It is not always possible to predict what will happen as a patient becomes closer to death and what challenges will arise. If clinicians are able to prepare as best they can by considering the areas mentioned in this article, patients may be able to avoid unnecessary emergency room visits and admissions to the hospital and instead be supported to die in the location of their choice.

#### References:

Canadian Virtual Hospice. (2019) *Considerations for a Home Death*. Retrieved from [http://www.virtualhospice.ca/en\\_US/Article/Decisions/Considerations+for+a+Home+Death.aspx](http://www.virtualhospice.ca/en_US/Article/Decisions/Considerations+for+a+Home+Death.aspx)

## Northern Lights in Palliative Care



Bryce Kaiser, UHNBC Medical SW

*Death is a journey. Sometimes the process is fast and unexpected, other times the circumstances are slow and capable of preparations. When I get involved in this journey with my patients, I strive to uphold their values and represent their stories to the rest of the medical team. I like to take the time to provide supportive care to their family members, who may be in a different place of acceptance. I think it is important to provide quick lessons about grief and normalize the natural feelings that come with saying goodbye. Working with death in acute care is something that has become very special to me and I love being alongside the patients and their families in a time of the unknown and in a time of saying goodbye. ~ Bryce*

## Upcoming Palliative Education Opportunities

### Education Sessions by Skype

A team of experts in palliative care will be presenting a series of interdisciplinary webinars on palliative care. Health professionals from all care settings are invited to attend. A specific subject will be taught each month and repeated throughout the month to allow more people to participate. Webinars are recorded and provided on OurNH and the external website.

Month	Topic	Presenter
July	Symptom Management Kit Review	Suzy Stever
August	Changes in Bowel Function—Kath Murray	Jennifer Ferguson
September	TBA	Dr. Inban Reddy / Seth Gysbers

***If you are interested in having your name added to our distribution list, please contact [Palliative.Care.Consult.Team@northernhealth.ca](mailto:Palliative.Care.Consult.Team@northernhealth.ca)***

### Symptom Management Kit (SMK) Training Now On The LearningHub

It is required that any physicians, community nursing and community pharmacy involved with the Symptom Management Kits (SMK) complete an orientation on using the SMK and how to properly document using provided forms before accessing a SMK. By accessing the Learning Hub module, individuals can complete the education when it is most convenient for them.

The Symptom Management Kit is a program run by the Northern Health Palliative Consultation Team which is dispensed in an anticipatory fashion to allow timely and adequate treatment of symptoms as they arise. It provides treatment for the most common palliative symptoms that may be used until clients are able to fill ongoing prescriptions to manage the symptom. The goal is to allow clients to remain in their place of residence at end-of-life.

[NHA-CL-Palliative Care- Symptom Management Kit \(SMK\)](#)