

PALLIATIVE CARE TIPS

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MANAGING TERMINALLY ILL PATIENTS AT HOME

An increasing number of cancer patients are being cared for at home. Care at home holds numerous benefits, including privacy, care in familiar surroundings and may avoid anxiety related to hospitalization. It must be noted that patients' and families' needs change with time. These needs therefore need to be assessed on an ongoing basis.

To ensure adequate and effective home care, the following are all required:

- It is the expressed wish of the patient to be cared for and to die at home.
- Family/friend supports are available and committed. (A frail spouse who is the only support will not be able to provide long term care alone, even if he/she is committed. The brunt of care falls on family members and friends living in the same home as the patient.)
- Hands-on care by home care nurses/personnel appropriate to patient & family needs is essential.
- Regular assessments by Palliative Home Care personnel.
- An attending primary care physician who is available for home visits and who provides 24hr coverage.
- Ongoing communication between the patient, family, nurses and clinicians. This includes regular explanations of the disease process, information regarding medications and their administration, and discussions of management strategies available.
- Crises need to be prevented.
- Crises, if they occur, need to be managed promptly and effectively.

Preventing crises:

- Regular assessments (includes using scales of symptom intensity such as visual analogue or numerical scales on a frequent basis. If symptoms remain uncontrolled or worsen, an assessment by the attending physician is indicated.)
- As death approaches, more frequent home visits by the attending nurse and physician may be required.
- Discuss "code-status" early in the illness course. Ambulance authorities and Home Care need to be informed.
- Arrangements with a funeral home need to be made by the family.
- Ensure family know what to do in the event of a home death ie. to contact Home Care first.
- Prepare the families for various possibilities (eg. identifying delirium, the use of prn medications such as opioids for pain and haloperidol, loxapine for agitation, rectal diazepam if seizures are a problem, and dark towels/sc midazolam prn for patients at risk of catastrophic bleeds).

When a crisis occurs:

- A prompt and thorough examination and assessment of patient by the home-care nurse and attending physician is required. (Refer to previously published TIPS for information the management of various symptoms.)
- Communicate with the patient and family.
- Consider alternative routes of medication and fluid administration if the oral route is no longer available. Morphine can be given rectally. Meds that can be given SC include morphine, hydromorphone, codeine, clodronate (for hypercalcemia), haloperidol, metoclopramide, midazolam, methotrimeprazine, furosemide, dexamethasone, phenobarbitone, hypodermoclysis with normal saline or 2/3 1/3 (for hydration). The use of unconventional routes such as the cutaneous application of medications in gel form is not supported by research.
- The Regional Palliative Care Program offers a consult service to assist attending physicians and home-care nurses (tel: (780) 735-1300).

Barriers to Home Care/Death	Overcoming Barriers
Patients previously cared for in hospital may feel isolated.	Regular assessments & communication by nurse and physician
Caregiver physical & psychological burnout.	Main caregivers need some time to themselves for self care. Issues of guilt regarding being away need to be addressed. Advise the family/friends to establish roster for rotating care.
The financial costs of home care to family caregivers are often underestimated (ie. costs of drugs/dressings/pumps/tubing, loss of earnings through absence from work, payments for additional nursing and support services).	Simplify treatment/pharmacological regimes. (eg. Sophisticated pumps can be expensive and complicated for caregivers). If parenteral drugs are used, re-evaluate frequently and change to the oral route as soon as conditions allows.