

PALLIATIVE CARE TIPS

Issue # 12 FAQ's #1 (Frequently Asked Questions) of the Terminally Ill or Their Families: Useful Information

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RELATING TO “PALLIATIVE CARE” (PC)

If he's referred to PC doesn't that mean he'll think he's going to die soon and will give up hope?

Many patients and often their family members benefit from referral long before they are actively dying, for symptom control/psychosocial and spiritual support. It is crucial that patients suffer as little as possible at all stages of their disease, for both compassionate reasons and minimization of fears of uncontrollable suffering in later stages.

Isn't it very depressing to be on a PC unit?

While it is true that patients and their family members are going through major losses during their course of illness, PC provides active relief of their symptoms in the context of the clear sense of goals of care and priority of their limited lives which is shared by patients, their family members and professional team. This sense of team approach may provide positive hope and sense of strong support to patients and their family members.

Will PC services keep me alive against my wishes?

PC services do not provide any intent to prolong life in futility. Treatments would not be offered when the expected outcome is only prolonging life without improving the quality of life. Conversely, nor does PC services offer measures to deliberately shorten life (i.e. euthanasia/ physician-assisted suicide). Patients are encouraged to appoint a proxy or write a personal directive in order to be respected in their decision related to healthcare when they are no longer able to express their wishes.

RELATING TO CARE AT HOME

I want to die at home. What do we need to do?

Referral to Palliative Home Care (HC) (through CCA: Community Care Access #: 496-1300), which provides 24h service. You will need; a family physician who provides home visits **proactively** (active monitoring, with object to **abort crises**) and 24h call coverage (self or designate). You also need; **more than one healthy** family/friend caregiver able to provide bedside nursing care. HC resources provide registered nurse monitoring, occupational and physiotherapy, respiratory care, social work intervention, and limited personal care attendant/licensed practical nursing, but the majority of care must be provided by family/friends.

What do we do if there's a crisis?

The family should call HC. There are nursing staff available 24/7 who will assess by phone/home visit if necessary, then call the family physician on call if appropriate. Strongly recommend DNR code status be established as soon as appropriate. A copy of DNR order should be in home. During community pharmacy “off hours” the family physician may access the Quick Response Kit (minimum supply of drug, and equipment in order to relieve symptoms and maintain the care in the home; Please refer PC Tip #11 or Clinical Practice Guideline at www.palliative.org) through Regional Palliative Care Program on call, by calling CCA 24 hour # 496-1300 . Family physician can also access the Regional Palliative Care Program physician on call for advice, through CCA.

What do we do when (s)he dies?

At the time of death of a patient at home families/caregivers are advised to call Home Care at 496-1300, not to call 911. The police or medical examiner is not required to be involved for a planned home death. Following the death the funeral home is notified and a time is arranged for the removal of the body from the home. The primary physician may advise the home care staff where the signed Medical certificate of Death will be located. The funeral director will collect the certificate at the specified location following the removal of the body from the home. The primary care physician will be notified of the client's death by the home care staff. There is no requirement for the physician to “pronounce” the death as long as the home death was anticipated as a direct result of the final illness.

What do we do if we can't manage at home anymore?

The home care case manager will review options with you. If continuing the care at home is unrealistic, options are: a referral to the RPCP Community team for possible: admission to hospice at Edmonton General Site, Capital Care Norwood or St Joseph's if patient is in stable condition. Emergency and “off-hour” admissions to the hospice setting are avoided if at all possible due to limitations of hospice staffing. Admission to an acute care setting usually is warranted if there are acute care issues/needs. For patients who are not able to be stabilized in any setting, the tertiary palliative care, Grey Nuns Community Hospital is available through referral to the Regional Palliative Care Program (496-1300). For admission to hospice or the tertiary unit, patients/family must accept DNR status: resuscitation is medically futile in the advanced palliative patient population.

REMEMBER: For referrals, questions, or telephone consultations call 496-1300 weekdays and weekends.

Palliative Care Tips are now available on our Website: www.palliative.org