

Last Hours of Living

OUR EXPERIENCE OF DEATH

Most of us have little experience with death. When confronted with it, we start to imagine many ways we could die. As fantasies and fears grow, fueled by our contact with death, a peaceful death often seems unattainable.

This does not need to be the case. If events surrounding death are well managed, those participating will more likely remember an acceptable, even peaceful, death. If death is punctuated by poorly controlled pain and delirium, those remaining will likely remember pain and suffering, further increasing fears of their own deaths.

PLANNING AHEAD

When a person's death is approaching, in any setting of care, several issues should be carefully considered by all involved:

- clarify personal agendas, fears, phobias
- review all treatment options and potential outcomes, considering the issues, stage and context of the person and his/her illness
- encourage a shift from "hope for life, hope to get better" to "hope for some time together, hope for a peaceful death." Whatever you do, don't shatter all hope
- an acceptable care setting ensures that:
 - if death is to occur at home, those remaining in the home afterwards must be able to live there without fear of ghosts
 - there are adequate facilities and caregivers
 - anticipated costs are acceptable
 - alternative settings of care are easily accessible, should the chosen setting become unacceptable or inappropriate
- ensure that advance directives and proxy(s) for substitute decision making are in place and clearly understood by all caregivers. Desire for or against cardio-pulmonary resuscitation (CPR) should be discussed. Consideration should be given as to whether CPR would be useful, futile or even damaging
- where possible, check that a will and business power of attorney have been prepared, clarifying choice of executor(s). If there is no will or power of attorney, determine the closest next of kin

While we may not understand the mystery of death, experience shows that the last hours of living can be a time of considerable growth, perhaps some of the most important hours in a person's life.

DEVELOPING A CARE PLAN

Develop a care plan acceptable to the person, his/her family and caregivers. While few are happy facing death, if everyone agrees on the care plan, an acceptable outcome will be more likely than if everyone has differing expectations. During the last hours of living, management should:

- minimize pain
- reduce shortness of breath
- control terminal delirium
- control and/or reduce risk of seizures
- minimize risk of aspiration
- keep mucous membranes moist
- minimize risk of skin breakdown
(see *Symptom Management*)

If symptoms and distress are not easily controlled, sedation may be appropriate if deemed acceptable by all those present (see *Symptom Management, Terminal Delirium*).

In developing the care plan, be sure to:

- discontinue as many unnecessary medications as possible. For those that must continue, choose the least invasive route of administration, i.e. po, pr or buccal mucosal, and avoid intermittent injections if at all possible. If injections must be used, consider a sc butterfly
- ensure all caregivers are knowledgeable about techniques of providing care outlined in the negotiated care plan
- encourage participants to give each other permission:
 - from the person to caregivers: to provide care (especially when they are family and friends)
 - within the family: to be family first, and caregivers only if comfortable in that role
 - from family to the person: to die when he/she is ready
 - from the person to family: to build a new life after the death
 - all: to express anticipatory grief, and change roles when necessary

COMMUNICATING WITH THE DYING PERSON

*“We need to participate in our health, including our death”
- one voice -*

Many who are dying, even those who seem unresponsive, may wait for someone to visit, or for a particular event like a birthday, then die soon afterwards. Even if the person isn't responding, assume they sense the environment around them and can hear everything, until they have died. Family and caregivers should:

- avoid walking on “egg shells”
- discuss good news at the bedside, and include the person in any conversations
- discuss bad or potentially distressing news as far away as possible from the bedside
- say things they need to say. Give permission as they believe it is needed, in a way that feels comfortable to them
- include any family, children, animals who want to be there
- touch, hold, lie beside the person
- play music the person usually likes, tune TV to a show they usually enjoy
- if at home, continue normal household activities
- reassure the person that he/she is safe and not alone, right up until death
- above all – listen, listen, listen

AS DEATH APPROACHES

- remind the family about:
 - the different loss that each person is about to experience
 - common things that they may experience as the time of death approaches including numbness, a sense of euphoria or transcendental spiritual experiences, i.e. seeing the loved one “filled with light”, trauma about the suffering experienced prior to death that is replayed over and over and leads to anger
 - difficulty anticipating how they will feel until death actually occurs
 - the possibility of death occurring when those closest are not

*“Family can be afraid to take responsibility or change a care plan. Health care workers can be more objective and help the family through the process of dying”
- one voice -*

SIGNS OF THE DYING PROCESS

- present
- verify previous decisions regarding resuscitation
- review events and signs of the dying process and death, i.e. possibility of gas, stool and urine movement even after death
- ensure family and caregivers know regulations regarding management, pronouncement, certification, and reporting of death to the coroner or medical examiner’s office. The local office can provide advice. Usually, an expected death does not need to be reported but an unexpected, unnatural or unexplained death must be reviewed by the coroner or medical examiner.
- make it clear that when death occurs:
 - focus of care shifts from the person who has just died to those who survive, i.e. family and caregivers
 - there is no need to rush as there are no specific rules and regulations about how quickly things should happen, only personal, cultural, religious customs and traditions
 - authority to make decisions moves from the person holding power of attorney (or proxy) to the executor of the estate under the will. If there is no will, then closest next of kin has this authority
- know which physician will attend to complete the death certificate and how he/she can be reached
- remind family not to call “911” or emergency rescue personnel if there is a “No CPR” or “DNR” order
- suggest that funeral and burial/cremation arrangements be considered, discussed or made (if this has not already been done)
- clarify whether or not an autopsy will be requested. These are readily arranged when death occurs in hospital, but when death occurs at home or in other institutions, there may be expenses for autopsy and associated transportation
- be prepared to discuss organ donation (only donation for research is appropriate with HIV/AIDS)

If death comes quickly, the person may go from consciousness to dead in a matter of seconds to minutes. However, if the dying process occurs over time, any or all of the following may occur:

- level of consciousness may decrease
- circulation may deteriorate, manifesting:
 - increased heart rate and decreased blood pressure
 - peripheral cooling
 - peripheral and/or central cyanosis
 - mottling of the skin
- urination may decrease and/or stop, manifesting:
 - decreased or no urine output
 - increased urine concentration/colour
- breathing may deteriorate, manifesting:
 - diminished tidal volume
 - gaps between breaths (apnea)
 - Cheyne-Stokes respiration
- gag reflex may diminish or disappear, manifesting:
 - difficulty swallowing

CHANGING THE SETTING OF CARE

- build-up of secretions in throat, often called death rattle
- signs usually indicating terminal delirium (must be differentiated from pain), i.e. restlessness, agitation, confusion, hallucinations, moaning and/or groaning

Late transfer of the dying person from home to another setting of care should be avoided, if possible. However, when problems like shortness of breath, bleeding and/or caregiver fatigue/burn-out cannot be managed at home, transfer may be unavoidable.

Plan for this possibility:

- always have at least one substitute setting of care available as back-up
- know whether ambulance services in your area will honour a “No CPR” or “DNR” order and how this information must be documented. Some jurisdictions do not allow ambulance personnel to honour a “No CPR” order unless the physician accompanies the person
- if calling for a transfer ambulance, ensure other emergency services are not inappropriately alerted

WHEN DEATH OCCURS

When death occurs, caregivers should support, comfort and educate family and friends who have suffered a loss.

WITHIN HOURS OF THE DEATH

Caregivers should (not necessarily in sequence):

- comfort those who need comforting without getting in their way
- encourage family and caregivers to take time to see and feel the change that has occurred so they can start to say good-bye. Encourage them to use signs of affection they are used to, like touching, holding, kissing, while maintaining body substance precautions. Some must see and touch in order to realize death has occurred. For many, the longer they stay with the body, the sooner their hearts begin to realize a very significant change has taken place
- provide acute grief support. Caregivers should be careful that their own sense of loss doesn't get in the way
- respect all personal, cultural and religious values, beliefs and practices
- verify whether the death is reportable to the coroner or medical examiner, and call attending physician if necessary
- notify or arrange to contact those close who need to know about the death. Where possible, avoid breaking unexpected bad news by telephone. Person-to-person communication provides better opportunity for support. Remind those who will notify others that the fact of death is public information, but the cause of death remains confidential, unless the executor and/or next of kin wishes to release that information

*“Funeral people also need to treat the person with love and care as they remove the body. To be rough with the body would seem to me like violating the person”
- one voice -*

- encourage those present to position, bathe and dress the body if they so desire. Remove any catheters and lines, once those present are over their acute grief reactions. If the coroner or medical examiner will attend, the body should not be altered, moved or lines removed until such permission has been obtained
- if the physician is not in attendance, call him/her when those present are ready. This may be soon after death if they require or request support, or it may be several hours later if they want time alone. The physician usually attends to certify the death within a reasonable time and at that time will:
 - verify desire for autopsy or not
 - complete appropriate forms, if not yet done
 - complete and explain the death certificate, reminding those present that the information, particularly cause of death, must be reported by law but remains confidential
 - explain local and provincial registration processes
- if requested, help the family select and notify a funeral service and:
 - answer any questions about the funeral process, including embalming. Assure the family that, if they wish, they can keep the body at home until burial or cremation but, if so, the funeral service provider should prepare the body beforehand (see *Funerals, Memorial Services and Rituals*)
 - assist in calling the funeral service providers when appropriate. Funeral service providers will usually remove the body day or night, and will clarify their availability when called

WHEN APPROPRIATE

Caregivers should:

- notify health care agencies who have been providing care about the person's death, so that services can be terminated appropriately
- secure valuables in the custody of executor. Verbal wishes of the deceased may only be honoured when the executor of the will has the authority to do so in the will, or has the agreement of all beneficiaries
- clean and remove other equipment, maintaining universal precautions and using appropriate sterilization techniques. Some items and supplies may be returned to the provider or used by others
- dispose of medications. Narcotics should be flushed away or destroyed by a family member and witnessed by a caregiver. Other prescribed medications become the property of the estate, but cannot be used or kept, and should be destroyed or returned to a pharmacy by the executor
- discuss biological waste disposal

- counsel family concerning:
 - practical matters surrounding the death
 - how to obtain documents to execute the will, complete business, redeem insurance
 - notification of various official and private agencies, i.e. pension authorities, Ministry of Health to cancel health insurance card, banks, insurance companies
 - legal and financial obligations and benefits, such as probate of the will, income tax filing, Canada Pension Plan death benefits. A legal counsellor may be helpful at this point
- offer to arrange follow-up visitation and bereavement support