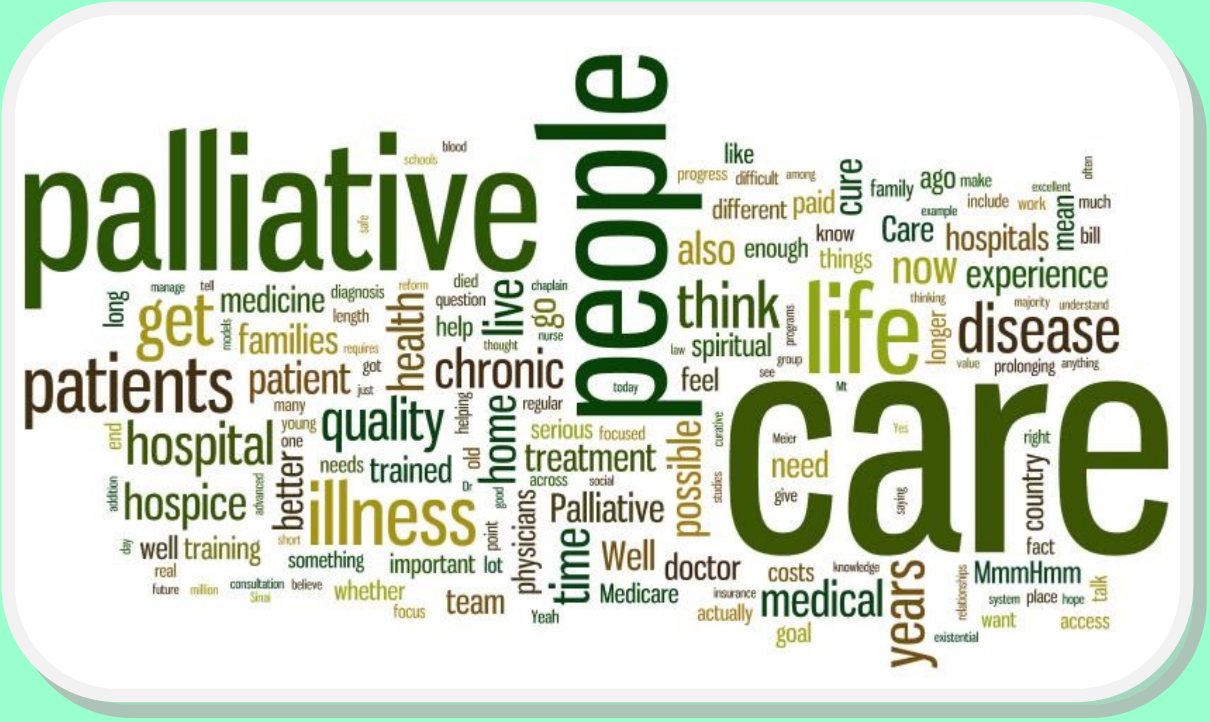
MANITOUWADGE PALLIATIVE CARE TOOLKIT



Santé Manitouwadge Health

MANITOUWADGE PALLIATIVE CARE TOOLKIT

CREATED BY THE MANITOUWAGE PALLIATIVE CARE TEAM

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People might forget what you said, people will forget what you did, but people will never forget how you made them feel. Maya Angelou

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CLIENT AND CAREGIVER RESOUCES

CLIENT AND CAREGIVER INFORMATION PAGES

Advance Care Planning

Helping you know and exercise your rights in preparing for a time when you may be unable to make decisions about your care.

Practical matters

- End of life decision making is a process, not a one time event
- You may wish the care team to participate in meetings to learn relevant information, available treatments, and to offer emotional and psychological support.
- Discuss questions or concerns about physical care with your doctor, nurse, social worker and Community Care Access Case Manager.
- Contact your spiritual advisor if there are spiritual matters to be explored or if you need help with the memorial service or funeral
- You may discuss emotional and family matters with a social worker.
- Talk with your Community Care Access Center Case Manager to arrange a Palliative Care volunteer who can visit you in the home, if available.
- Talk with a lawyer to assist with your estate matters, the making of a will and designating a power of attorney for personal care and property. A will and organized financial matters will be easier for the family.
- The care team is available to help look at all options.

Planning Ahead

- Ensures that wishes are known and respected
- Reduces the number of decisions that will need to be made at time of death and right after death.
- Gives an opportunity to talk about concerns and feelings
- Allows for affairs to be in order for those left behind
- Reduces family stress during the early time of grief
- “Speak Up” brochure provides information to help you know and exercise your right in preparing for a time when you may be unable to make decisions about your care.

Substitute Decision Maker

A Substitute Decision Maker is someone who makes decisions on your behalf if you become incapable of making them yourself. You appoint them through a document called a Power of Attorney for Personal Care. The person(s) you appoint is called your Attorney for Personal Care. Talking with the appointed person, family members and the family physician will ensure that your personal care decisions are honored. You may wish to discuss the use of specific treatment at the end of life including life-sustaining treatments, Do Not Attempt Resuscitation orders, antibiotics, artificial nutrition and hydration, the withholding and withdrawal of therapies at the end of life.

Continuing Power of Attorney of Property

It is important to appoint a person who will act as Attorney for Property in the event that you are no longer able to make decisions regarding finances, home, possessions and property matters. Talking with the appointed person will ensure that your wishes are carried out.

Mouth Care

As a person becomes weaker he/she is unable to drink their usual amounts of fluids. This may happen with nausea, vomiting and or lack of appetite. When body fluids are reduced, saliva may dry up. If the person breathes through their mouth or is using oxygen it can be worsened.

You May Notice:

- The person complains of a sore mouth or of a bad taste in the mouth
- The person complains of the mouth feeling dry and uncomfortable
- The tongue may be red and coated
- The lips may be dry and cracked

What may help:

- Maintaining a clean mouth with good oral hygiene.
- After cleaning the mouth lubricate the lips. Vaseline is a good unless the person has oxygen treatment. An alternative to Vaseline would be a water soluble lubricant.
- Remove and brush dentures once daily. Swab the mouth with a swab stick or gauze moistened in a mouth rinse (water, baking soda) after the dentures are removed. If the person is very drowsy, the dentures should be removed.
- Mouth care should be done hourly if the person is taking very little orally.
- Add a small amount of lemon juice to water and crushed ice to stimulate saliva.
- Check commercial mouth washes as some have alcohol and my make a dry mouth worse.
- Rinsing the mouth by using a small amount of one of the following mouth rinse solutions:
    - 4 cups water, 1 teaspoon salt, 1 teaspoon baking soda
    - 1 oz Ginger Ale and 2 teaspoons baking soda
    - Mixture containing 1/3 water, 1/3 hydrogen peroxide, 1/3 mouth wash
    - Natural methods ie: cedar boughs boiled in water.

Skin Care

Skin breakdown is a potential problem for the dying person. It can cause discomfort and increase isolation from people. The odor that an occur with skin breakdown (ulcers) and infection can be offensive to people, who then avoid interaction with the dying person.

You May Notice the Person:

- Develops red skin at pressure areas such as the tailbone, elbows and heels.
- Has broken areas in the skin, itchy areas or rashes.

What may help:

- Prevention is the best cure.
- Keep skin clean and dry. Skin is irritated by sweat, urine, feces, wound drainage.
- Urinary catheters may help keep skin clean and reduce the amount of help needed to care for a dying person.
- Use incontinence pads on the bed for bed ridden people, if stool incontinence is occasional or small mount, rather than using diapers.
- Change the person's position every 2-4 hours. Some health care providers recommend changing a person's position every 8-12 hours as long as appropriate and sufficient skin care prevention measures are used.
- Learn how to move the person safely and protect yourself as well. Avoid shearing the skin by using bed pads, or folded flannel sheets, to move and turn the dying person.
- As the person becomes weaker, the best position in bed is slightly on the side propped up by pillows along the whole body, particularly supporting the shoulders and trunk areas.
- Use small pillows or rolled up towels between knees.
- Keep skin folds and creases clean by daily sponge baths. Dry thoroughly. Daily baths my not be necessary as it may be very drying to the skin.
- Use bath oils and lotions on dry or itchy skin. If cream is applied, rub it in gently to avoid irritation.
- Put extra padding on the bed to cushion the person: egg crate foam, sheepskin pads, and special mattresses.
- Tell the health care provider about any reddened or open areas in the skin. There are protective dressings that can be applied to sensitive skin or open areas that will reduce irritation and provide comfort.
- Control of odors may be achieved by: opening the window for fresh air, opening kitty litter or activated charcoal in a pan under the bed, having a open cup of vinegar in the room.
- Observe for signs of pain when person receiving care. They may need more medication, or decline skin care until pain medication takes effect.
- Know that in the last few hours of life the person may not want to be disturbed.

Medication and Pain Management

To be successful in managing pain, attention must be given to all the causes or components of pain: physical, psychological, family, social. Each person's particular circumstance is unique and variable from day to day. Such things as the person's interaction with family and caregivers, their knowledge about their illness, and their involvement in their care plan all influence pain management.

- Pain can be a one of, or a mixture of, the following types of pain:
    - Superficial-usually localized and non-radiating
    - Deep-usually localized and non-radiating
    - Visceral-more spread out over the involved internal organs
    - Neuropathic pain-radiation of pain along nerves, may be burning and/or deep aching, or lightening like jabs of brief sharp pain.
- It will help the health care provider to know the location, duration, radiation of pain, and activities or medications that relieve or worsen the pain.
- Does the pain affect sleep, socializing, or activities of daily living?
- Keeping track of when and how often the medications are taken is easier to do if a medication record is used. Preparing the medications ahead of time helps. A Dosette can work for separating pills throughout the day.
- Pain may be due to the disease but may also be due to other causes such as arthritis and muscle stiffness.
- Pain can change moods and can be influenced by thoughts or emotions.
- Report any change in pain to the health care provider.
- Encourage and allow the person to talk about their feelings regarding pain.
- Relieve pain by using medicine, natural healing methods, humor, music, relaxation, deep breathing, guided imagery, television, reading, therapeutic touch, massage, cold packs, warm blanket, position changes.
- Pain is usually treated with medication on a regular basis. A smaller dose of the medication (break through or rescue dose), can be given to help relieve the pain that comes between doses of schedule pain medication.
- If having difficulty swallowing pills, have them try drinking water first and place the pill at the back of the tongue and then swallow more water. Some pills can be mixed with applesauce or pudding. It is important to talk to the health care provider before crushing pills. Some cannot be crushed ie. MS-Contin.
- Medications come in many forms: liquids, suppositories, injectable, or patch.
- A constant source of discomfort requires a constant source of relief.
- Opioid analgesics (narcotic pain relieving medications) are potent and safe for relieving moderate to severe pain.
- Observe for side effects of opioids: common-constipation, nausea, drowsiness, sedation, dry mouth; less frequent-hallucinations, vertigo (dizziness), pruritus (itchy skin), confusion, urinary retention; rarely-respiratory depression (slow breathing). Side effects can often be managed.

- Opioids do not cause the psychological dependence involved in addictions.
- Physical dependence is not the same as addiction. Its presence does not mean that opioids cannot be discontinued. If pain decreases or disappears, opioids can be reduced or discontinued under the health care provider's guidance.
- As death nears, stop all unnecessary medication.

Nausea and Vomiting

Nausea and vomiting are common problems in progressive disease. The person may feel sick, have loss of appetite, may vomit occasionally or often, have trouble keeping down oral medication, and may feel comfortable at rest but feel sick with movement.

Interventions:

- Relaxation and cognitive therapy such as mental imagery can be used to control some causes of nausea.
- Transcutaneous electrical nerve stimulation and acupuncture may help.
- Encourage change in diet to tolerable food, ie. Small amounts of clear fluids.
- Encourage taking of any prescribed anti-nausea medication regularly.
- Some medications may be given by suppository or bandage type of patch.
- Provide sufficient mouth care.
- Remove any vomit soiled clothing or containers as soon as possible
- Fresh air may help.

Constipation

This common problem is associated with a reduced frequency of bowel movements and an increase of stool consistency (hardness) that leads to difficulty passing stool. It can be caused by the natural progression of the disease, mechanical obstruction from a tumor, bowel adhesions or hernia, decrease in fluid intake, changes in diet, some medications, and decreased activity.

Interventions:

- Schedule toileting for same time each day, after a meal or warm drink is sometimes more effective.
- Try to get to a toilet or onto a commode, or at least a sitting position.
- Avoid bulk agents like bran since it is not a good laxative, and it requires you to drink a lot of water, it may also taste bad and in debilitated people it may lead to a bowel obstruction.
- Take appropriate laxatives, suppositories, or enemas as recommended by physician eg. Prune juice 120-240ml once to twice per day, Senna, Bisacodyl, lactulose, milk of magnesia, magnesium citrate, glycerin suppositories, etc.
- If there is no bowel movement in three days, it is important to tell your health care provider so they can adjust the medication, suggest a suppository or enema.

Diarrhea

Diarrhea is passage of frequent, loose stool, usually more than 3 unformed stools per 24 hour period. The most common cause at the end of life is overuse of laxatives followed by infection. Investigations will depend on stage of illness.

Interventions:
- Encourage drinking clear fluids
- Avoid milk and gas forming foods
- Hold laxatives
- Consider bulk agents such as bran but beware of causing constipation or bowel obstruction
- The physician may consider use of medications to stop the diarrhea

Appetite

Decreased appetite and dehydration is a normal part of dying. The dying person may not feel the thirst and hunger that would be expected from not eating or drinking. Natural endorphins prevent the dying person from feeling hunger. The person may also feel less hungry and thirsty because they are not as active and their bodies become unable to process food as they normally would. Loss of appetite and loss of weight are frequently accompanied by fatigue. Even if it was possible to increase appetite and nutrition, loss of weight does not improve. Nutrition will not stop the progression of disease. Dying people and their loved ones must understand that loss of weight is a common part of the dying process.

You May notice the person:
- Eats very little, is not interested in food or may feel unable to eat
- Refuses solids and will only drink liquids
- Loses weight

You can help by:
- Serving small portions of favorite foods, as tolerated and desired.
- Offering nutritional supplements, as desired
- Avoiding disagreeable or nauseating smells
- Making meal time a social occasion
- Freshening and cleaning the person's mouth before and after eating
- Having loose dentures relined or try Poly grip
- Telling the health care provider if nausea is a problem, as anti-nausea medications can be helpful
- Offering small amounts of fluids taken as often as tolerated
- Offering ice chips or popsicles for the person to suck on
- Understanding that the provision of artificial nutrition and hydration is a medical treatment. Withholding or withdrawing artificial nutrition and hydration is not done to hasten death, but is done because the burdens may outweigh any benefits

Fatigue

Fatigue and/or decreasing strength can happen over a number of weeks and months, or can occur fairly quickly over a few days. Fatigue is a very distressing symptom and frequent occurrence of dying people. It prevents them from achieving their goals and enjoying even simple activities. As the ill person gets weaker, patterns of daily life in the home will need to change and adjust.

A person may:

- Experience fatigue and easy tiring, generalized weakness, exhaustion, or mental tiredness
- Tire more easily and need to nap often
- Become tired or exhausted after activities that once were easy
- Become short of breath easily, such as when changing position or talking
- Need help to walk, bath, or dress
- Feel anxious or frustrated with changes in energy and strength
- Become extremely weak and may need to be cared for in bed

You can help by:

- Adapt activities of daily living to coincide with times of maximum energy
- Help the dying person to perform and enjoy as many of the activities as are most important to them
- Giving reassurance as loss of independence can be upsetting for anyone
- Finding a way the person can call for help if needed, ie. Blow a whistle, bang on plastic cup, jingle a bell
- Discussing methods to rest before activities, to ensure the person can do the things they want to do
- An Occupational Therapist or Physiotherapist may be able to offer suggestions for assistive devices and training in energy conservation
- Learning how to help the person move more easily. Members of the care team may have suggestions to help
- Providing equipment such as a walker or wheelchair to increase safety and make care in the home easier

Anxiety

Life threatening illness creates an uncertain future which causes anxiety. The anxiety may increase as the illness progresses. This makes it more difficult to cope with the situation. Anxiety is common for the person with advanced disease and in partners and relatives. If it persists or is severe consult with your health care team.

You may notice:

- Fear about the situation or people/events around them
- Increase irritability, poor concentration
- Difficulty getting to and staying asleep

What might help:

- Encourage expression of the feelings
- Give the information they need to ease the anxiety (you may have to consult members of the health care team)
- Allow them to feel in control whenever possible
- Music or aroma therapy or other complementary therapies

Shortness of Breath

Shortness of breath is one of the most feared symptoms, and perhaps the most distressing to a dying person. Regardless of the cause, the person can be made more comfortable by doing a few simple things. The shortness of breath can be caused by some things that can be remedied by your health care team (ie. Chest infections with antibiotics) so it is important to report shortness of breathe to them.

What might help:

- Providing a cool draft from an open window or a fan blowing across, not at, his/her face
- Maintain a calm presence
- Positioning may help. Try to position him/her at the side of the bed leaning on a table with a pillow with shoulders raised or pillows under the arms if lying in bed
- Try to prevent accumulation of blankets and keep things away from the head area
- Avoid strong scents such as perfumes, cleaning agents, food and any other odors
- Acupuncture or pressure, distraction, relaxation exercises and imagery may help
- Breathing techniques which your health team can show you (ie. Pursed lip breathing) may help

What is Palliative Care?

Hospice palliative care is aimed at relief of suffering, and improving quality of life for persons who are living with or dying from advanced illness or is bereaved.

Palliative care is a special kind of health care for individuals and families who are living with a life threatening illness that is usually at an advanced stage. The goal of palliative care is comfort and dignity for the person living with the illness as well as the best quality of life for both the person and his/her family. A "family" is whoever the person says his/her family is. It may include relative, partners and friends.

An important objective of palliative care is relief of pain and other symptoms. Palliative care is planned to meet not only physical needs but also the psychological, social, cultural, emotional and spiritual needs of each person and family. Palliative care may be the main focus of care when a cure for the illness is no longer possible.

Palliative care servicers are helpful not only when person is approaching death but also at earlier stages of illness. Palliative care may be combined with treatments aimed at reducing or curing the illness, such as chemotherapy. Families also benefit from support when their loved one is dying and after his/her death.

Adapted CHCPA, 2002

Palliative Care:

- Affirms life and regards dying as a normal process;
- Intends neither to hasten or postpone death;
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Adapted WHO, 2007

End of Life Decision Making

When diagnosed with a life threatening illness, our reaction, the decisions we make, and what influences our decisions are not based solely on medical facts, risks and benefits. The way we interpret them, the importance we place on different risks and benefits are deeply personal. We must confront some very difficult decisions. The entire health care team is available to provide information and support with making these difficult decisions.

- When nearing the end of life, discussions about possible care should be in the context of whether the care will prolong life and whether the possible benefits outweigh the burdens and discomfort. In the last stages of illness nearing the end of life, life sustaining interventions are not usually undertaken since they would only serve to prolong the dying process.
- *"Life support" with a ventilator involves*: Being a patient in the hospital Intensive Care Unit (ICU), drugs to make the person drowsy, a tube through the mouth into the windpipe is hooked up to a machine that helps the person to breathe. One cannot eat or talk with the tube in place. A second smaller tube is put through the mouth or nose into the stomach to provide nutrition. Monitoring equipment for oxygen levels and blood pressure, and intravenous fluid lines are also required.
- *"Life support" with medication involves*: Being a patient in ICU, drugs to support the blood pressure and heart. These cannot fix the problem. Because the drugs can damage the small veins in the arm, a central line is needed. This special intravenous is placed in the larger veins in the neck, collarbone or leg areas. Another intravenous is needed in an artery to monitor oxygen levels and blood pressure.
- *Cardiopulmonary resuscitation (CPR)* in the event of cardiac or respiratory arrest must be discussed. In situations in which chances of successful resuscitation are non-existent physicians are not obliged to offer CPR.
- *CPR involves*: Attempting to resuscitate by pushing on the chest over the heart area, giving intravenous medications, and using electric shock to attempt to restart the heart. A tube is put through the mouth into the windpipe to get oxygen into the lungs by artificial respiration. Some of the ribs may break and internal organs can be bruised because of CPR. If the heart cannot be restarted quickly, brain damage will occur. This brain damage can be significant-ranging from loss of memory to total dependence on others for day to day activities. If successful at restarting the heart, life support will be needed afterwards. Only 1-4% of patients with chronic illnesses survive to leave the hospital and almost no one with cancer survives. Many people who do survive are sicker and they may have brain damage that could be severe.
- *A Do Not Resuscitate* order does not mean the person and health care providers have given up. It simply means that the person recognizes the severity of illness and the gravity of the situation in which CPR would be needed and understands chances of successful resuscitation are uncertain or low and does not wish to undergo CPR.

Adapted from Ian Anderson Program in End of Life Care.

Needs of the Family

In Palliative Care we strive to support both the patient and family/care providers to enable their choices. Family caregivers play an important role in providing both physical and emotional support to a loved one at the end of their life. Having the support of family and friends is very important in helping them cope with the disease in end of life care. Family caregivers also need support to adjust to the reality that a loved one is dying. You will undergo a grieving process-a normal human emotional response to loss. The loss occurs not only at the time of death, but often much earlier such as at the time of diagnosis, and as the ill person and family experiences the many losses associated with the End-of-Life journey. This is known as anticipatory grief, which is an unconscious preparation for changes in status.

Most people have not witness an actual death and therefore need factual information and the opportunity to get answers to their concerns and questions. Understanding the individual needs of the dying person will not only help you as a caregiver to accept what is happening, but will also help your loved one obtain the best quality of life through this journey.

- Ask for information about the illness, treatment options, the dying process and available resources.
- Remember-there are no silly questions. Don’t be afraid to bring up topics surrounding death, to ask questions or express concerns with other members of the care team.
- For additional information, refer to “A Guide for Caregivers”
- Do not hesitate to reach out to others for support, such as the visiting nurse, social worker, chaplain, visiting volunteer.
- Set realistic expectations-don’t demand too much of yourself.
- Accept that you may need the help of others (personal support worker, volunteer, friends, and other family members) for household tasks and childcare if required.

Remember it is very important to attend to the needs of the family caregiver as well as the dying person. See additional resources supplied or speak with your health care provider.

Needs of the Children

It is normal for parents to protect their children from harm and pain, particularly painful information about death and dying. However, most children cope better if given honest information-information appropriate to their age and development stage. Even very young children can sense when others around them are upset.

- Talk to your health care provider about specific resources and professional supports available for children.

The Last Days and Hours

The dying person will go through a number of physical changes as the body “slows down” and prepares for the final stag of life. As a caregiver, it is beneficial if you are aware of these physical changes, and know these to be normal. Each situation is different. Not all of these signs and symptoms will occur in all dying persons. Persons are often aware of their impending death.

When a person is dying, they may………

1. Be less responsive, sleep longer periods and sometimes have difficulty waking.
    - Weakness and fatigue usually increase as the person gets closer to death
    - May clench teeth, grasp hands, moan with position change or movement
    - Keep visiting time brief or encourage visitors to sit quietly at the bedside
2. Have a decrease in intake of food and fluids.
    - Usually causes dry mouth and nose, less urine production
3. Have difficulty swallowing, “forget” to swallow, loose their gag reflex.
    - “Forcing” to eat or drink can cause vomiting and choking
    - The mouth may often be open
4. Become confused, restless, or agitated, unable to recognize familiar people or surroundings.
    - Speak calmly and naturally, avoiding argument
    - The physician may recommend medications to calm the person
5. Become restless, pull at bed linen, or may have visions of person or things not present.
    - Give reassurance, the experience is real to the person, and is normal
    - Calm soothing music or gentle massage may ease a restless person
    - Discuss with the Case Manager, if caregiver relief may be available
6. Have irregular pulse or heartbeat, low blood pressure.
    - Normal signs of the slowing down process
7. Have moaning, irregular, shallow, rapid, or shallow pant-like breathing, or increased use of accessory respiratory muscles.
    - It is quite common to have long pauses of 10-30 second periods between breaths
    - Giving oxygen is rarely necessary, may only prolong the dying process
8. Develop “wet or rattily” sounding breathing.
    - This is caused by saliva collecting at the back of the throat, and because of weak muscles, the person cannot swallow. This does not mean that the person is uncomfortable.
    - You can wipe the mouth with a moist cloth or sponge-tipped swab]
    - Try turning, and supporting, the person on their side with the use of pillows.
    - Raise the head of the bed, or raise the upper body with pillows
    - It is often more distressing to caregivers than to the person
9. Be responsive to voice or touch.
    - Speak calmly-everything you say may be heard-whether eyes are open or closed

10. Lose control of bladder or bowels.
    - Protective padding can be used on the bed. A urinary catheter may be helpful.
    - The amount of urine will decrease, and may be darker color, as death approaches

11. Have cool legs and arms with the skin showing a mottled blue/purple appearance.
    - The underside of the body may become a darker color
    - Use just enough coverings to keep the person comfortable
    - Avoid using an electric blanket

At the Time of Death

- There will be no response
- There will be no breathing
- There will be no heartbeat or pulse
- Eyes will be fixed in one direction-they may be open or closed
- There may be loss of control of urine/bladder or bowels

If You Think Death Has Occurred

1. Remain calm
2. Do not call 911, Police, Fire, or Ambulance. This is not necessary when the death is expected. If these personnel come to the home they may attempt resuscitation and transfer to the hospital's Emergency Department.
3. Notify the Home Care Nurse/Doctor, as discussed and arranged with the Home Care Nurse/Doctor and/or CCAC Care Coordinator/Case Manager.
4. Call family, a spiritual advisor, and friends that would like to be present.
5. Take time to say goodbye before calling the funeral home, or alternative.
6. Call the funeral home, or alternative.
7. Please call the CCAC Care Coordinator/Case Manager and leave a message.
8. There is no hurry to do any of this. Spend as much time with your loved one as you wish. If you feel you want help with the things that need to be done ask for help.
9. Funeral plans can be made by appointment during business hours as convenient.
10. Your physical and emotional wellbeing as a caregiver is just as important as the dying person's. Talk to the CCAC Care Coordinator/Case Manager if you have any concerns or fears about the death or expected death.

CLIENT, CAREGIVER AND HEALTH CARE PROVIDER RESOUCES

Your Home Chart

- This chart is for you, your family, and your other caregivers to use to improve communications and help you to participate in planning your care. We encourage you to use your chart to participate in planning and making decision for your care.

- This chart will help you to share your needs, concerns and wishes with all members of your care team. It will also provide you with a schedule of when people come to your home along with appropriate names and phone numbers.

- The chart binder should be kept in a visible place in your home. You may bring this chart with you when you visit your doctor. Please make sure you bring the chart back home with you.

The Members of your health Team may include:

- You
- Family and Friends
- Doctors
- Nurses
- Therapists
- Social workers
- Care Coordinators/Case Manager
- Palliative Hospice Volunteers
- Homemakers/PSW's
- Spiritual Advisor

Signature Sheet

Print Name	Designation	Agency	Signature

Signature Sheet

Print Name	Designation	Agency	Signature

Client Information

Name:_______________________________________ Date of Birth:____________________

Telephone: Home: ( )________________________Other: ( )____________________

Address:

____

____

Language Spoken: ____

Other Family or Friends Involved in Client's Care:

Family member with the most responsibility for the Client:_____________________________

Telephone: Home: ( )________________________Other: ( )_____________________

Is there a Legal Power of Attorney for Personal Care? Yes No

Name:

____

Name of Family/Friend	Relationship	Phone#	Comment

Professional Care Providers:

Physician with the Most Responsibility for the Client:________________________________

Telephone: ( )________________________ Other: ( )_________________________

Family Physician:____

Telephone: ( )________________________ Other: ( )_________________________

Specialists:________________________________ Telephone: (   )_____________________

_________________________________Telephone: (   )_____________________

_________________________________Telephone: (   )_____________________

CCAC Coordinator/Case Manager: ____

Telephone: (   )_________________________ Other: (   )__________________________

Nursing Agency/Primary Nurse:____

____

Telephone: (   )_________________________ Other: (   )__________________________

Telephone: (   )_________________________ Other: (   )__________________________

Homemaking Agency/Name: ____

____

Telephone: (   )_________________________ Other: (   )__________________________

Telephone: (   )_________________________ Other: (   )__________________________

Pharmacy:____

Telephone: (   )_________________________ Other: (   )_________________________

Hospice/Palliative Care Volunteer:____

____

Telephone: (   )_________________________ Other: (   )__________________________

Social Worker/Counselor:____

____

Telephone: (   )_________________________ Other: (   )__________________________

Spiritual Advisor: ____

Telephone: (   )_________________________ Other: (   )__________________________

CLIENT MEDICATION LOG

NAME:

ALLERGIES:

Medication (name, time, amount, route)	**Date (month, day, year)**						
Medication: Amount: Route: Time: What is it for:							
Medication: Amount: Route: Time: What is it for:							
Medication: Amount: Route: Time: What is it for:							
Medication: Amount: Route: Time: What is it for:							
Medication: Amount: Route: Time: What is it for:							

CLIENT MEDICATION LOG

NAME: **ALLERGIES:**

Medication (name, time, amount, route)	Date (month, day, year)						
Medication: Amount: Route: Time: What is it for:							
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Medication: Amount: Route: Time: What is it for:							

CLIENT MEDICATION LOG

NAME: **ALLERGIES:**

Medication (name, time, amount, route)	**Date (month, day, year)**						
Medication: Amount: Route: Time: What is it for:							
Medication: Amount: Route: Time: What is it for:							
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CLIENT MEDICATION LOG

NAME: **ALLERGIES:**

Medication (name, time, amount, route)	**Date (month, day, year)**						
Medication: Amount: Route: Time: What is it for:							
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Medication: Amount: Route: Time: What is it for:							

Month: ______________________ Name:_____________________________________

HOW ARE YOU FEELING TODAY?

Pertinent issues to share with our Health Team

You may use this to track specific info your care team frequently asks you (bowel movements, weight, appetite, etc.)

DATE	INFORMATION ABOUT YOUR HEALTH

Month: ______________________ Name:____________________________________

HOW ARE YOU FEELING TODAY?

Pertinent issues to share with our Health Team

You may use this to track specific info your care team frequently asks you (bowel movements, weight, appetite, etc.)

DATE	INFORMATION ABOUT YOUR HEALTH

Month: ______________________ Name: ____________________________________

HOW ARE YOU FEELING TODAY?

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HOW ARE YOU FEELING TODAY?

Pertinent issues to share with our Health Team

You may use this to track specific info your care team frequently asks you (bowel movements, weight, appetite, etc.)

DATE	INFORMATION ABOUT YOUR HEALTH

Client Name:___________________

Interdisciplinary Notes

(ie. Physician, Case Manager, Complementary Therapy, Homemaker, Occupational Therapy, Physiotherapy, Social Worker, Volunteer, Dietician)

Date and Time	Interdisciplinary Notes

Client Name:___________________

Interdisciplinary Notes

(ie. Physician, Case Manager, Complementary Therapy, Homemaker, Occupational Therapy, Physiotherapy, Social Worker, Volunteer, Dietician)

Date and Time	Interdisciplinary Notes

Client Name:___________________

Interdisciplinary Notes

(ie. Physician, Case Manager, Complementary Therapy, Homemaker, Occupational Therapy, Physiotherapy, Social Worker, Volunteer, Dietician)

Date and Time	Interdisciplinary Notes

Client Name:___________________

Interdisciplinary Notes

(ie. Physician, Case Manager, Complementary Therapy, Homemaker, Occupational Therapy, Physiotherapy, Social Worker, Volunteer, Dietician)

Date and Time	Interdisciplinary Notes

Expected Death Check List

Name:_____________________________________ Date of Birth:_________________________

Telephone: (   )____________________________ Other: (   )________________________

Funeral Home: ________________________________ Telephone: _______________________

In the event of death: DO NOT CALL 911

- Do not attempt resuscitation order
- DNRC Form
- Notify main contact
- If main contact unavailable, notify alternate contact or support person as identified in the Plan of Care
- Notify Doctor/Registered Nurse/Nurse Practitioner to pronounce death, Doctor/ Nurse Practitioner to complete medical certificate of death
- If Doctor unavailable, notify prearranged alternate
- Call spiritual advisor, if arranged/desired
- Notify funeral home, or funeral alternative, for pick up of deceased body
- Notify CCAC Case Manager/Community Coordinator, who will notify CCAC service providers.

Additional Information:____

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REFERENCES

Cancer Care Ontario. (2020). How to manage your anxiety. Retrieved from https:/www.cancercareontario.ca/en/symptom-management/3981

Cancer Care Ontario. (2020). Loss of appetite. Retrieved from https://www.cancercareontario.ca/en/symptom-management/3141

Cancer Care Ontario. (2020). How to manage bowel problems. Retrieved from https://www.cancercareontario.ca/en/symptom-management/35041

Cancer Care Ontario. (2020). How to mange your shortness of breath. Retrieved from https://www.cancercareontario.ca/en/symptom-management/3126

Cancer Care Ontario. (2020). How to manage your constipation. Retrieved from https://www.cancercareontario.ca/en/symptom-management/3146

Cancer Care Ontario. (2020). How to mange your depression. Retrieved from https://www.cancercareontario.ca/en/symptom-management/3986

Cancer Care Ontario. (2020). How to manage your diarrhea. Retrieved from https://www.cancercareontario.ca/en/symptom-management/3151

Cancer Care Ontario. (2020). How to mange your fatigue. Retrieved from https://www.cancercareontario.ca/en/symptom-management/3991

Cancer Care Ontario. (2020). How to tell if you have a fever. Retrieved from https://www.cancercareontario.ca/en/symptom-management/4001

Cancer Care Ontario. (2020). How to manage hormonal symptoms. Retrieved from https://www.cancercareontario.ca/en/symptom-management/35046

Cancer Care Ontario. (2020). Mouth care during cancer treatment. Retrieved from https://www.cancercareontario.ca/en/symptom-management/3156

Cancer Care Ontario. (2020). How to mange your mouth problems. Retrieved from https://www.cancercareontario.ca/en/symptom-management/3156

Cancer Care Onatrio. (2020). How to manage your nausea and vomiting. Retrieved from https://www.cancercareontario.ca/en/symptom-management/3131

Cancer Care Ontario. (2020). Neutropenia. Retrieved from https://www.cancercareontario.ca/en/symptom-management/35081

REFERENCES

Agency for Integrated Care: A Caregiver's Guide to Avoid Burnout. Retrieved from https://www.aic.sg/sites/silverpagesassets/SilverPages%20Assets/Publications%20(Caregiving)/Burnout%20Guide.pdf

Agency for Integrated Care: Body Mechanics: Positioning, Moving and Transfers. Retrieved from https://www.aic.sg/sites/silverpagesassets/SilverPages%20Assets/Publications%20(Caregiving)/Body%20Mechanics.pdf

Cancer Care Ontario: Constipation Symptoms in Adults with Cancer Algorithm: https://www.cancercareontario.ca/en/system/files_force/symptoms/CCODiarrheaAlgorithm.pdf?download=1

Cancer Care Ontario: Delirium in Adults with Cancer: Screening and Assessment Algorithm. Retrieved from file:///C:/Users/warford.a/Downloads/CCODeliriumAlgorithm%20(1).pdf

Cancer Care Ontario: Diarrhea Symptoms in Adults with Cancer. Retrieved from https://www.cancercareontario.ca/en/symptom-management/3151

Cancer Care Ontario: Dyspnea in Adults with Cancer: Screening and Assessment. Retrieved from https://www.cancercareontario.ca/en/symptom-management/3126

Cancer Care Ontario: Edmonton Symptom Assessment System (ESAS). Retrieved from https://www.cancercareontario.ca/sites/ccocancercare/files/assets/CCOESAS-English.pdf

Cancer Care Ontario. Loss of Appetite in Adults with Cancer: Screening and Assessment. Retrieved from https://www.cancercareontario.ca/en/symptom-management/3141

Cancer Care Ontario. Nausea and Vomiting in Adults with Cancer: Screening and Assessment. Retrieved from https://www.cancercareontario.ca/en/symptom-management/3131

Cancer Care Ontario. Oral Care (Mouth Care). Retrieved from https://www.cancercareontario.ca/en/symptom-management/3156

Cancer Care Ontario. Pain in Adults with Cancer: Screening and Assessment. Retrieved from https://www.cancercareontario.ca/en/symptom-management/3121

Government of Ontario, Service Ontario. Request for Death Certificate. Retrieved from http://www.forms.ssb.gov.on.ca/mbs/ssb/forms/ssbforms.nsf/FormDetail?OpenForm&ACT=RDR&TAB=PROFILE&SRCH=1&ENV=WWE&TIT=death+certificate&NO=007-11075E

Government of Ontario, Service Ontario. Request for Marriage Certificate. Retrieved from http://www.forms.ssb.gov.on.ca/mbs/ssb/forms/ssbforms.nsf/FormDetail?OpenForm&ACT=RDR&TAB=PROFILE&SRCH=1&ENV=WWE&TIT=marriage+certificate&NO=007-11078E

Health Link East Toronto Healthlink. Cardiopulmonary Resuscitation (CPR). Retrieved from https://setfht.on.ca/files/CPR%20ETHeL%20Feb%202016.pdf

Hospice Northwest Services: Grief and Bereavement Support Services. Retrieved from https://www.aic.sg/sites/silverpagesassets/SilverPages%20Assets/Publications%20(Caregiving)/Body%20Mechanics.pdf

Hospice Northwest Services: Hearts and Hope. Retrieved from https://www.hospicenorthwest.ca/wp-content/uploads/2019/12/hearts-and-hope-brochure-2018.pdf

Hospice Northwest Services. Making Moments Matter. Retrieved from https://www.hospicenorthwest.ca/wp-content/uploads/2019/12/Main-Brochure.pdf

Hospice Northwest Services. Making Moments Matter. Regional Palliative Care Program. Retrieved from https://www.hospicenorthwest.ca/wp-content/uploads/2019/12/Hospice-Template_Regional.pdf

Ministry of Health and Long Term Care of Ontario: Medical Assistance in Dying Information for Patients. Retrieved from http://www.health.gov.on.ca/en/pro/programs/maid/docs/maid.pdf

North East Health Line. Til Death Do Us Part. Retrieved from https://www.capo.ca/resources/Documents/Guidelines/7.%20A%20Pan-Canadian%20Practice%20Guideline-%20Prevention,%20Screening,%20Assessment%20and%20Treatment%20of%20Sleep%20Distur bances%20in%20Adults%20with%20Cancer.pdf

Pan-Canadian Practice Guideline: Screening, Assessment and Management of Psychosocial Distress, Depression and Anxiety in Adults with Cancer. Retrieved from: https://www.capo.ca/resources/Documents/Guidelines/3APAN-~1.PDF

Pan-Canadian Practice Guideline: Screening and Assessment-Cancer Related Fatigue in Adults with Cancer. Retrieved from https://www.capo.ca/resources/Documents/Guidelines/6.%20Algorithms%20for%20Cancer%20related%20Fatigue.pdf

Pan-Canadian Practice Guideline: Prevention, Screening, Assessment and Treatment of Sleep Disturbances in Adults with Cancer. Retrieved from https://www.capo.ca/resources/Documents/Guidelines/7.%20A%20Pan-Canadian%20Practice%20Guideline-%20Prevention,%20Screening,%20Assessment%20and%20Treatment%20of%20Sleep%20Disturbances%20in%20Adults%20with%20Cancer.pdf

Quality Hospice Palliative Care Coalition of Ontario. Caregiver and Patient Declaration of Rights for Hospice Palliative and End of Life Care. Retrieved from http://hpco.ca/qhpcco/declaration.php

Royal College of General Practitioners. The Gold Standard Framework Prognostic Indicator Guidance. Retrieved from https://www.goldstandardsframework.org.uk/cd-content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf

Speak Up: Cardio-Pulmonary Resuscitation (CPR). Retrieved from: https://www.advancecareplanning.ca/wp-content/uploads/2015/10/ACP-CPR-Tool_FINAL-web.pdf

Speak Up: Start the Conversation About End-of-Life-Care. Retrieved from: https://www.advancecareplanning.ca/wp-content/uploads/2016/08/ACP-national-workbook-Eng-july2016-web.pdf

Speak Up Ontario: Advance Care Planning Workbook Ontario Edition. Retrieved from: https://www.speakupontario.ca/wp-content/uploads/2018/07/ACP_Ont_workbook_2018_Eng.pdf

The Office of the Public Guardian and Trustee. Powers of Attorney. Retrieved from https://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/poa.pdf

The Office of the Public Guardian and Trustee. Power of Attorney and “Living Wills”. Retrieved from https://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/livingwillqa.pdf

The Ontario Caregiver Organization: Caregiver Wellness Quiz. Retrieved from https://ontariocaregiver.ca/wp-content/uploads/2020/02/Caregiver-Wellness-Quiz_Feb-2020.pdf

The Ontario Caregiver Organization: Welcome to the Ontario Caregiver Organization. Retrieved from https://ontariocaregiver.ca/wp-content/uploads/2019/12/OCO-brochure-Dec-2019_English_office-print.pdf

The Palliative Pain and Symptom Management Program. Food for Thought. Retrieved from http://www.palliativealliance.ca/assets/files/Alliance_Reources/Physical_Care/English.pdf

Thunder Bay Regional Health Sciences Centre. My Code Status Level. Retrieved from https://tbrhsc.net/home/caring-for-patients-families/code-status-level/
Victoria Hospice Society. Palliative Performance Scale (PPS). Retrieved from https://www.ontariopalliativecarenetwork.ca/sites/opcn/files/VictoriaHospice-PPSScaleTool.pdf

Virtual Hospice. The Palliative Approach for Advanced Frailty in Long Term Care. Retrieved from http://www.virtualhospice.ca/Assets/Frailty_Jan21_2016_FINAL_20170720124531.PDF

Virtual Hospice. The Palliative Approach for Advanced Heart Failure in Long Term Care. Retrieved from http://www.virtualhospice.ca/Assets/Heart_Jan21_2016_FINAL_20170720125009.PDF

Virtual Hospice. The Palliative Approach for Advanced Dementia in Long Term Care. Retrieved from http://www.virtualhospice.ca/Assets/Dementia_Jan21_2016_FINAL_20170720122956.PDF

Virtual Hospice. The Palliative Approach for Advanced Kidney Disease in Long Term Care. Retrieved from http://www.virtualhospice.ca/Assets/Kidney_Jan21_2016_FINAL_20170720125746.PDF

Virtual Hospice. The Palliative Approach for Advanced Lung Disease in Long Term Care. Retrieved from http://www.virtualhospice.ca/Assets/Lung_Jan21_2016_FINAL_20170720130218.PDF

Northwest CCAC (2020). Care in your home. Retrieved from http://healthcareathome.ca/northwest/en/news/Documents/Brochures/JENNY'S%20PAMPHLETS/G2_Care%20in%20Your%20Home_EnglishSept%202014.pdf#search=caregiver%20burnout

REFERENCES

Hospice Northwest Thunder Bay: http://www.hospicenorthwest.ca/

End of Life Care Network: http://www.nwoendoflifecare.ca/index.php

Northwest CCAC: http://healthcareathome.ca/northwest/en

Alzheimer's Society: http://www.alzheimer.ca/en

Canadian Hospice Palliative Care Association: http://www.chpca.net/

College of Nurses of Ontario: http://www.cno.org/

Health Care Consent Act: http://www.canlii.org/en/on/laws/stat/so-1996-c-2-sch-a/latest/so-1996-c-2-sch-a.html

Ontario's Senior Secretariat: http://www.seniors.gov.on.ca/en/

World Health Organization: http://www.who.int/en/

St. Joseph's Care Group: http://www.sjcg.net/

Thunder Bay Regional Health Sciences Centre: http://www.tbrhsc.net/

Manitouwadge General Hospital: www.mh.on.ca

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