



Palliative and End-of-Life Care Resource Booklet



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Defining Palliative Care Approach

What is palliative care?

Palliative care is defined as a special kind of health care for individuals who are living with a progressive life-threatening illness or condition. Palliative care becomes the main focus of care once curative treatments are no longer effective. Palliative care neither hastens nor prolongs death; rather, it aims to keep the individual as comfortable as possible as the natural dying process takes its course.¹

Goals of Palliative Care Approach

- *Maintaining comfort and dignity as well as quality of life for the person and his or her loved ones;*
 - *Providing relief from pain, suffering, and other distressing symptoms;*
 - *Addressing the physical, psychological, social, emotional, and spiritual needs of the person and his or her loved ones.*
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Conversations surrounding the individual's goals and wishes for end-of-life are a key part of the palliative care approach. We believe that these conversations should take place upon admission and should be ongoing as a person's needs and preferences may change over time.

¹ Ross M.M. *Palliative Care and the Elderly Persons: Issues and Challenges*. Report prepared for Health Canada, 1988.

Palliative and End-of-Life Care at SJCCC

Vision and Mission

Compassionate care focused on the body, mind and soul of all those whose lives we touch.

The goal of SJCCC is that all individuals shall live in comfort and with dignity until the very end of life. Accomplished through compassionate, multidisciplinary care focused on alleviating the physical, psychosocial and spiritual distress of individuals and their families. SJCCC strives to provide the dying individual with lots of time with loved ones, time to reflect and reminisce, and finally time to say good-bye – with as little pain and discomfort as possible.

When is a palliative care approach appropriate?

Palliative care may be proposed by the multidisciplinary team when curative treatments are no longer effective and/or the person is experiencing a significant decline in health.

When these indications are present, the team will discuss an appropriate plan of care with the individual and his or her family. An individual may be identified as “slow palliative” where there is a predictably slow decline in health or as “active palliative” (EOL) where there is a predictably rapid decline in health. At other times, diseases and circumstances can leave us with a very unpredictable situation and an individual’s health that is unstable; it is then possible that a person may move in and out of active palliative care.

End-of-Life (EOL) Care

End-of-life care, also referred to as active palliative care, is the final stage of the palliative care approach. It becomes the focus of care when death is expected within the very near future (weeks, days). During this final stage, family may expect to see changes in their loved one such as a decrease in food and fluid intake, social withdrawal and with daily activities, and alternating levels of consciousness.

Multidisciplinary Team Approach

Our multidisciplinary team of trained professionals all work together to provide the best palliative and end-of-life care possible, making sure to communicate with one another and to provide care to both person and family during this final journey.

The multidisciplinary team at SJCCC consists of:

- Physician and Nurse Practitioner
- Nurses and Health Care Aids
- Resident/Patient and Family Advisors
- Spiritual Health Specialist and Resident Priest
- Therapy Staff (Recreation, OT, PT)
- Housekeeping/Environmental Services
- Dietary Staff
- Volunteers
- Pharmacist

Services Offered

- Individualized plan of care / comfort measures
- 24 hours stay available to immediate family
- Complimentary refreshment basket
- Complimentary comfort cart including lotions, towels, etc.
- Information and resources for residents and families
- Volunteer Support
- Café meals (see page 14)

The Final Stages: Signs and Symptoms at End-of-Life

Physical Signs and Symptoms

Circulation

- As circulation slows, the person's hands, arms, feet, and legs may become increasingly colder to the touch
- Blotchy, purple discoloration may be noted to the hands, arms, knees, or feet (also referred to as *mottling*)
- Fingers, earlobes, lips, and nails may appear blue or light gray in color
- Blood pressure will gradually decrease as the heart rate increases but weakens

Metabolic Changes

As time goes on, there will be a decrease in the person's food and fluid intake. This is a normal part of the dying process. As swallowing becomes more difficult and fluid intake decreases, urination will also become less frequent.

FAQ: How will staff ensure that my loved one is eating and staying hydrated? Forcing food or fluids when a person does not want them or is no longer physically able to accept or digest them properly can be unsafe and may cause discomfort, nausea, vomiting, choking, or other problems. It is important to let the person lead and trust that he or she is following cues from his or her own body as the dying process takes its course.

FAQ: Should an intravenous be started? *In our experience, intravenous adds to the discomfort of the individual. IV increases fluid intake in the body which puts added strain on the heart and causes a backup in the lungs. As a result, the person may experience a drowning sensation, which can be very distressing and uncomfortable.*

Congestion and Secretions

As fluid intake decreases and the person is no longer able to effectively cough up normal secretions, these secretions will thicken and build up in the lungs and/or the back of the throat. As this occurs, it may produce a loud rattling sound coming from the chest or produce a moist, congested sounding breathing. It is important to note that this is a normal change and does not indicate that the person is experiencing any pain or discomfort. Individuals are generally unaware of these changes.

FAQ: Should a suction machine be used to remove secretions from the mouth? *Using a suction machine can not only increase the amount of secretions but also cause more discomfort for the person. The loud sounds coming from the machine may also frighten the person and contribute to an increase in anxiety and agitation. Non-intrusive mouth care is preferred and provided regularly by staff.*

Breathing

As time goes on, the person's regular breathing pattern will become increasingly irregular. Breath may alternate between periods of slow, rapid, shallow breathing and periods of no breathing for 5-60 seconds (also referred to as *apnea*). These changes are normal and do not indicate shortness of breath. Individuals are generally unaware of these changes in breathing.

Pain and Pain Management

FAQ: How will I know if my loved one is in pain? How can staff prevent my loved one from suffering? *Pain is one of the most common*

symptoms experienced at end-of-life. Therefore, pain and symptom management are an essential part of the palliative care approach.

Signs that a person might be in pain:

- Grimacing
- Agitation*
- Moaning or crying out (especially upon movement)

Pain management as a comfort measure

- Regular pain assessments
- Personalized plan of care for pain management
- Subcutaneous medication administration (“butterfly” site): easier, safer, and does not restrict the person’s movement

Medications during end-of-life care

All persons receiving palliative or end-of-life care are assessed by the registered staff on the unit for use of medication. Family who sit at the bed side will be asked for their opinion of how their loved one is progressing. Medications take time to work; injection is one of the fastest action methods. Some medications have a longer time span, allowing for the effect of the medication to work longer. The main goal is to keep your loved one pain free and comfortable. Subcutaneous butterflies, or catheters left under the skin, are applied – typically one per medication. This will allow for the administration of medication without picking your loved one.

Medications most frequently used during end-of-life care:

Nozinan: used as an analgesic to assist with pain control, and an antiemetic for nausea or vomiting, or for a sedating calming effect when agitated. Given every 4-6 hours.

*Please note that agitation could also be a side effect of the pain medication. If this is the case, a sedative can also be given alongside the pain medication.

Scopolamine: helps reduce respiratory secretions, also useful for nausea. Given every 4-6 hours.

Midazolam: used as a sedative resulting in a calming effect when agitated. Given every 4-6 hours.

Lorazepam: used as a sedative resulting in a calming effect when agitated. Given every 4-6 hours.

Hydromorphone: an analgesic, synthetic morphine, used for pain control. Given every 2-3 hours or more frequently depending on the order received by the physician.

FAQ: How long will the end-of-life stage go on? Some diseases and circumstances may indicate a predictably slow decline versus a rapid decline, while others may be completely unpredictable. The team will do their best to provide an educated timeline but it is important to note that death is as unique as the individual who experiences it. There is no sure way of knowing how long the person will live.

How can staff provide physical comfort?

- A visit from the Occupational Therapist to assess individual comfort needs
- Gentle repositioning (as needed)
- Bed baths (as needed)
- Incontinence care (as needed)
- Frequent mouth care (as needed)
- Pain and symptom management
- Skin assessments (as needed)

How can family and friends provide physical comfort?

- Providing a gentle hand, arm, or forehead massage can be soothing and also comforting to the person
- Providing mouth care by using a moist cloth or moisture spray
- Notifying staff of any signs of pain
- Utilizing items from the comfort cart such as towels, moisture spray, lotions, etc.
- Bringing in the person's favorite creams, lotions, etc.

Cognitive and Emotional Signs and Symptoms

Restlessness

As oxygen to the brain decreases, the individual may show signs of increased agitation and restlessness, including agitated and repetitive motions such as pulling at bed linen or clothing. This could be a sign that the individual is experiencing pain or side effects from the pain medication. This may also indicate that the resident is trying to work through unresolved spiritual or emotional issues that may be preventing them from letting go.

Disorientation

As time goes on, the individual may become increasingly disoriented to time, place and person, including close family and friends. The person may also speak to people or about places and events that are unknown or not visible to family or staff. This does not generally indicate that the individual is hallucinating or experiencing a reaction to a medication. Rather, it is often a sign that the person is beginning to detach and is preparing to transition from this life.

Withdrawal

An individual who is nearing the end of life may experience alternating levels of consciousness. As time goes on, the individual may spend more time sleeping and become increasingly unresponsive, uncommunicative, and difficult to rouse. It is important to note that this is a normal part of the dying process and indicates that the person is preparing to let go.

FAQ: Is my loved one aware of what is happening? Can he or she hear me?** Always assume that the person can hear you and that on some level your presence is known. **Hearing is the last of the senses to be lost.

How can staff provide emotional comfort?

- Providing a calm and comfortable environment for the person (noise, temperature, etc.)
- Administering medication that can help reduce anxiety and agitation
- Letting the person know what care is being provided and by whom

How can family and friends provide emotional comfort?

- Letting the person know that you are there and that they are not alone by talking to them, holding their hand, etc.
- Identifying yourself by name when you are speaking and keeping the person informed of what is happening around them
- Not interfering with or restraining agitated motions
- Creating a comfortable environment by playing soft music
- Recalling your loved one's favorite place or reading something comforting to them
- Reminding your loved one of all that they have contributed to their relationships, their accomplishments, and the life lessons and legacies they are leaving behind
- Reminiscing as a family of treasured moments, fond memories, and important life events
- **Giving your loved one permission to let go when they are ready**
- Making sure to say everything you need in order to say good-bye to your loved one. This may include telling the person that you love them, making amends or apologizing for actions or things left unsaid, offering/asking for forgiveness, etc.

Spiritual Signs and Symptoms

What is spirituality at the end of life?

Spirituality is unique to each individual. Spirituality refers to the deepest part of you; the part that lets you make meaning of your world.

The spiritual needs of a dying person may be obvious at times and not so obvious at other times. A common spiritual need no matter what a person's belief system, is to know that they are important and that their life has had meaning and purpose.

Earlier in the dying process, the individual may face spiritual issues such as:

- The meaning of life
- Accepting death
- Accepting and grieving losses
- Forgiving and being forgiven in search of inner peace and peace with others
- Loss of interest in spiritual activities that were once important to the person such as prayer, Scripture reading or attending spiritual services
- Feelings of anguish or uncertainty in an attempt to understand why this suffering is permitted
- The person may start to look back on life and look ahead to the unknown. There may be questions of being remembered or being missed.

How can staff provide spiritual comfort?

The Spiritual Health Specialist and Resident Priest offer the following services:

- Prayer/meditation
- Scripture readings or poems
- Spiritual counselling
- Sacrament of the Sick
- Journaling/self-reflection
- Guided autobiography/life review
- **Dove of Peace – a “Cloth Dove” is hung on your loved one's door to let staff, other residents, and visitors know that the person is receiving palliative or end-of-life care and to allow them respect, dignity, and time with family.**

How can family and friends provide spiritual comfort?

- Listening to the person as they share their fears and concerns; you do not need to feel obligated to have the answers; simply reassure your loved one that feelings of uncertainty are normal at this time
- Offering comfort by reminding the person of their relationships, their accomplishments, or their good works
- Offering to pray with the person if prayer is important to them
- Accepting the person's need to say good-bye to loved ones
- If the person has an important spiritual advisor (for example, parish priest, rabbi, etc.), inviting them to be spiritual companions. The Spiritual Health Specialist and the Resident Priest at SJCCC are also available to provide spiritual support as requested
- Playing soft music that the person enjoys; talking/reading to the person; providing gentle touch or holding the person. Sounds and touch can also be soothing to your loved one, it helps them to know that they are not alone.

Caring For Yourself -The Caregiver-

Maintaining Basic Needs

Nutrition

- Preparing nutritious meals and eating regularly
- Preparing double portions and freeze leftovers
- Stocking up on healthy snacks
- Staying hydrated

Note: At SJCCC, the first four family members can eat at no cost in the resident's dining room area after resident mealtimes. All additional family members can purchase meals at a 50% reduction in the café. Dietary services will also offer complimentary refreshments in room. The SJCCC Café serves daily meals from 11:00-12:30 and 4:00-5:30pm.

Exercise

- Taking frequent walks around the building
- Getting outside frequently for fresh air
- Maintaining preferred daily exercise

Sleep

- Maintaining regular sleep patterns
- 24 hour stay is available for immediate family members. A cot is available upon request

Respite Care

Respite, meaning “rest”, is important for caregivers. As a caregiver, it is essential to take breaks from your responsibilities in order to help you feel refreshed and better

able to cope. There is no prescribed length; whatever you are comfortable with.

- Ask a friend or family member to stay with your loved one while you rest
- SJCCC offers daily mass (Sunday to Friday) which family are welcome to attend
- Other spiritual resources are available to families – please refer to our Spiritual Health Specialist
- Friendly visits from SJCCC staff and volunteers can be arranged in order to allow you to take brief physical breaks (walk, lunch, etc.) and/or brief mental breaks (reading, talking to a friend, engaging in a spiritual activity that comforts you, etc.)

FAQ: I want to stay by my loved one's side but am feeling tired in need of a break. Is it OK to leave the room? While we understand that family want to spend as much time as they can with their loved one, it can be draining for both family and the individual. As end-of-life approaches, individuals often struggle to stay awake and can find it tiresome to entertain loved ones. Many individuals will wait until family leave the room to pass on. It is important to be mindful of your loved one's wishes to be alone at times.

What Happens After Death

After-Life Care

Once the person is deceased, family are welcome to take time to say goodbye and spend final moments with their loved one. When family are ready, the RN will contact the preferred funeral home to come in (unless family wish to make the arrangements themselves). Once the funeral home has been contacted, nursing staff will remove any medical items from the person's body. The body may also be washed, however this is typically done by the funeral home. The nursing staff will also gather any personal items such as dentures to send with the funeral home.

Please note: SJCCC does not provide individual funeral services or lease space for individual funeral services.

Quilt of Peace

The “Quilt of Peace” – also known as a pall – is draped over the body when the funeral home arrives to transport your loved one within the building.

Resident/Patient’s Belongings

It is important for family to collect their loved one’s belongings within an appropriate time frame. It is recommended that family do not wait until after their loved one has died as there is generally very little time to collect and remove belongings amidst funeral arrangements and services.

There may be items from the individual that you wish to donate. If you choose to do so, please note that SJCCC staff may discard inappropriate items at their own discretion. In order to donate items you must complete a Gift Form and submit it to staff.

Room Blessing

A Room Blessing is held for each resident/patient that passes away. The Room Blessing is a brief service in memory of the deceased and gives the opportunity for staff, fellow residents/patients, and family to engage in prayers and sharing of memories. The Room Blessing aims to be a source of comfort and healing for all those close to and involved with the care of the deceased. The Room Blessing also prepares the hearts and minds of caregivers in welcoming a new person to SJCCC.

Bereavement Support

Grief is a normal response to the loss of a loved one and is a personal journey that requires time to heal. While individuals will experience grief in their own way and in their own time, having the support of others plays an important role in the healing process.

Personal supports

While it can be difficult for some, asking for and accepting help from friends and family during the grieving process can make a big difference. Talking about one's loss with close supports can also lessen the burden and provide a great source of comfort.

Community supports

Community supports are also available to help individuals and families cope with the loss of a loved one.

- **Bereaved Families of Ontario (Cornwall & area)**
Offer one-on-one support, telephone support, and support groups to bereaved individuals and families.

For more information:

216 Montreal Road
Cornwall, ON K6H 1B4
T: 613-936-1455

Memorial Service

A memorial service is held twice a year to remember those who have died throughout the year. Invitations are sent to families and friends are also welcome to attend. At the service, memories are shared and families are presented with a small token to commemorate their loved one. All are invited to stay for refreshments following the service.

References and additional resources

Comfort Care at the End of Life: A guide for Caregivers. Health and Social Services Centre — University Institute of Geriatrics of Sherbrooke, 2005.

Beyond Our Sight: A Guide to Understanding Death and Dying. Brockville and District Hopsice – Palliative Care Service, 2006.

Hospice Patient and Family Information. Franciscan Hospice and Palliative Care, n.d.

Macmillan, Karen, et al. *A Caregiver's Guide: A Handbook About End-of-Life Care.* Canadian Hospice Palliative Care Association, 2010.

Ross, M.M. *Palliative Care and the Elderly Persons: Issues and Challenges.* Report prepared for Health Canada, 1998.



CENTRE DE SOINS PROLONGÉS
ST. JOSEPH'S
CONTINUING CARE CENTRE