

Comfort Care at End-of-Life

Resource Booklet



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Defining the 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.*

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.

What is 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 (week(s) to days). During this final stage, the family may expect to see changes in their loved one such as a decrease in food and fluid intake, social withdrawal with daily activities, and alternating levels of consciousness.

The Palliative Care Approach at SJCCC

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

The belief of SJCCC is all that individuals shall live in comfort and with dignity until the very end of life. Accomplished through compassionate, multidisciplinary care, focused on alleviating the physical, psycho-social and spiritual distress of individuals and their families.

Multidisciplinary Team Approach

Our multidisciplinary team of trained professionals works together to provide the best end-of-life care possible by communicating with one another and providing care to both the individual and their family during this final stage.

The multidisciplinary team at SJCCC consists of:

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

Services Offered

- An individualized plan of care/comfort measures
- 24-hour stay available to 1 designated person per night
- Complimentary comfort cart including basic care supplies and refreshments
- Information and resources for residents, patients and families
- Coordination for the Sacrament of the Sick or any other spiritual/religious accommodations

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 on the hands, arms, knees, or feet (also referred to as mottling)
- Fingers, earlobes, lips, and nails may appear blue or light gray in colour
- 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.

FAQs:

How will staff ensure that my loved one is eating and staying hydrated?

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. Forcing food or fluids can be unsafe and may cause discomfort, nausea, vomiting, choking, or other problems.

Should an intravenous (IV) be started?

In our experience, IV 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.

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 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?

Non-intrusive mouth care is preferred and provided regularly by staff. A suction machine can increase the number of secretions and 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.

Breathing

As time goes on, the person's regular breathing pattern will become increasingly irregular. Breaths 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

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
- A personalized plan of care for pain management
- Subcutaneous medication administration ("butterfly" site): easier, safer, and does not restrict the person's movement

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.

Medications during end-of-life care

Every person receiving end-of-life care is assessed by registered staff for use of medication. The family who sits at the bedside will be asked for their opinion on how they feel their loved one is doing and if they appear to be comfortable.

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 up 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.

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 last?

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 moisture spray, lotions, etc.
- Bringing in the person's favourite 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?

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 favourite 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
- Say everything you need in order to say goodbye 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 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.

The Wellness and Spiritual Health Coordinator and Resident Priest offer the following services:

- Prayer/meditation
- Scripture readings or poems
- 1:1 support/active listening
- Sacrament of the Sick
- Journaling/self-reflection
- Upon request, coordination of community-based religious/spiritual services

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 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 goodbye to loved ones
- If the person has an important spiritual advisor (for example, parish priest, rabbi, etc.), invite them to be spiritual companions. The Spiritual Health Specialist and the Resident Priest at SJCCC are also available to provide and/or coordinate 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.



Questions or concerns? We're here for you.

Long Term Care

Resident & Family Relations Advisor
ext. 22106

Hotel Dieu Hospital

Patient & Family Relations Advisor
ext. 22370

SJCCC

Wellness & Spiritual Health Coordinator
ext. 21213

Caring For Yourself: The Caregiver

Maintaining Basic Needs

Nutrition

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

Exercise

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

Sleep

- Maintaining regular sleep patterns
- 24-hour stay is available. A cot is available upon request (1 designated person per night)

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 families are welcome to attend. Mass is streamed on channel 46.
- Other spiritual resources are available to families – please refer to our Wellness and Spiritual Health Coordinator
- 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 and in need of a break. Is it OK to leave the room?

While we understand that families want to spend as much time as they can with their loved ones, 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 their family leaves 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 the family is ready, the RN will contact the preferred funeral home to come in (unless the family wishes to make the arrangements themselves). Once the funeral home has been contacted, the 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: SJCC does not provide individualized 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.

Honour Guard

As a sign of respect, volunteers, residents and staff are invited to form a silent honour guard at the front entrance as your loved one leaves the home for the final time.

Blessing Ceremony

The Blessing ceremony is an opportunity for staff and residents/patients to engage in prayer while reflecting on and remembering the deceased. The Blessing ceremony aims to be a source of comfort and healing for all those close to and involved with the care of the deceased. The Blessing ceremony also prepares the hearts and minds of caregivers for welcoming a new person to SJCCC.

Resident/Patient's Belongings

It is important for families to collect their loved one's belongings within an appropriate time frame. It is recommended that families 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 the staff.

*SJCCC may only accept adaptive clothing and therapeutic equipment.

Donations and Acknowledgements

Many families and loved ones choose to make a donation to a charity in memory of their loved ones. SJCCC is a non-profit organization, and donations in memory of past residents are both welcomed and appreciated. Memorial donations may be made through our website at www.sjccc.ca.

Memorial Service

A memorial service is held twice a year to remember those who have died throughout the year.

Bereavement Support

Grief is a normal response to the loss of a loved one and 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 difficult for some, asking for and accepting help from friends and family during the grieving process can make a great difference. Talking about one's loss with close support can also lessen the burden.

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 1:1 support, telephone support, and support groups to bereaved individuals and families.

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

Canadian Mental Health Association (Cornwall main office)

329 Pitt Street
Cornwall, Ontario K6J 3R1
T:(613) 933-5845

Online Supports

Virtual Hospice

www.virtualhospice.ca

Canadian Mental Health Association

www.cmha-east.on.ca

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 Hospice – 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.

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