

## ***Seniors' Caregiver Handbook***

### **Section 15**

#### **Hospice/Palliative Care**

Hospice palliative care is for anyone facing a life-threatening or terminal illness. Hospice palliative care provides physical, emotional, and spiritual care, and support for individuals and their loved ones. Through a care-giving team of family, friends, healthcare professions and volunteers, a person's needs and choices are sensitively met. Palliative Care can be provided in any setting - at home, in hospitals, in nursing homes or in specialized hospice facilities. Most of all, hospice palliative care is about living fully to the very end of life with dignity and comfort, and providing ongoing bereavement support after the death of a loved one.

Palliative Care – source – The Canadian Palliative Care Association

Palliative Care is the combination of active and compassionate therapies intended to comfort and support individuals and families who are living with a life-threatening illness. Palliative care applies to any patient in terminal stages of an illness that may need intensive management of their physical symptoms, along with assistance dealing with emotional, social or spiritual concerns. It can involve a treatment team that can include a range of professionals, from specialists, physicians and other health practitioners to spiritual counsellors and social workers. As well, family and friends and volunteers may choose to share in the care of the patient and become integral members of the team. Continuity of care, aimed both at clinical outcomes and quality of life issues, must be a goal of any palliative program. Home palliative care requires a carefully coordinated approach to complement the care provided by the hospital or hospice and family physician and other care and service providers. Integral to effective palliative care is the provision of opportunity and support for the caregivers and service providers to work through their own emotions and grief, related to the care they are providing. Basic principles apply in the provision and delivery of end-of-life care no matter what the setting – home, hospital or long-term care facility.

Palliative care means comprehensive examinations, regular assessments and continual re-evaluations of patient care. It means the caregiver needs

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to know as much about the condition of the care-receiver and the progression of the illness.

Most clinical conditions that become palliative tend to be associated with significant pain. Palliative pain usually can be controlled. The first step is to assess the pain. This involves evaluating the causes of the pain, its location, its type and its severity. Uncontrolled pain can disrupt the patient's ability to rest comfortably, sleep, eat, and can limit their mobility. It can restrict their interaction with family members and friends and generally lower their overall quality of life.

## Palliative Care

- a) tending to care by reducing the intensity of pain.
- b) tending to providing care for patients in the final states of a terminal illness

**(a) Who Provides It**

Some physicians may follow their patients through the palliative stage or may refer to a palliative care unit at an appropriate hospital.

Salvation Army Toronto Grace Health Unit 416-925-2251 Ext.261

Palliative Care Information Centre 416-480-4844

The Hospice Palliative Care Network Team (HPCNET) is a joint venture between Community Care Access Centres, The Temmy Latner Centre and Toronto hospices. They are able to offer families and Caregivers access to an experienced interdisciplinary team of Caregivers, palliative care physicians, nurses, home care co-ordinators, psycho social-spiritual consultants and volunteers. For more information call the following:

Contact the Toronto Community Care Access Centre 416-217-3822  
or

The Temmy Latner Centre 416-586-8594

Evening and week-end consultation calls are for urgent matters only.

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### Home Palliative Care Program

A physician is available to provide in-home medical care. In addition to pain and symptom management, the palliative care physician, whose visits are covered by OHIP, helps to co-ordinate other needed services and provide support to the family.

### Hospice Palliative Care Network Project (HPCNet)

This project is a partnership involving the Temmy Latner Centre for Palliative Care and other agencies and services in developing a model for the delivery of home palliative care. Physicians from the Centre work with teams of nurses and care coordinators to provide a more coordinated approach to palliative care in the home.

### Inpatient Palliative Care Program

This program offers palliative care in specialized palliative care units at the bedside for patients in hospitals and long-term care facilities. This Care Program is offered at the Sunnybrook and Women's College Health Sciences Centre, and Mount Sinai Hospital.

Hospice palliative care is about living fully to the very end of life with dignity and comfort and providing ongoing bereavement support after the death of a loved one. An interdisciplinary team provides expert medical care to help with pain and other symptoms, but also focuses on choice and quality of life while providing a home-like setting.

The four areas of concern in hospice care are the physical, emotional, spiritual needs of the patient, as well as those needs of the family.

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### **A Patient's Rights**

1. A right to ongoing assessment
2. The right to be dealt with honestly and to have a choice in the treatment plan
3. The right to have the goals of palliative care defined

### **A Patient's Responsibilities**

1. To communicate symptoms to any member of the palliative care team
2. To keep track of their medications

Ontario's hospices are community-based, volunteer driven organizations. Programs complement the nursing and other professional care provided in the client's home by the Community Care Access Centre and by the family physician. Some examples of hospice services include:

- skilled hospice volunteers to visit with clients, and give emotional and practical support
- hospice chaplains who can respond to spiritual needs, help to plan celebrations of life and memorial celebrations
- information about other services (financial, legal, funeral homes etc.)
- bereavement support - group support, individual counselling, self-care, drop-in, telephone "comfort lines"

Hospitals and long term care facilities provide hospice care in specialized palliative care units. An interdisciplinary team provides not only expert medical care to help with pain and other symptoms, but also focuses on choice and quality of life while providing a home-like setting.

Information about hospices and palliative care units is available through the

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|--|----------------|
| • Hospice Association of Ontario       | 1-800-349-3111 |
| • Palliative Care Information Centre   | 416-480-4844   |
| • Bayview Community Hospice            | 416-385-8885   |
|  |                |
| • Toronto Community Care Access Centre | 416-506-9888   |
| • Trinity Home Hospice                 | 416-364-1666   |

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### **Grief – the Healing Process**

During the grieving process you may experience a wide range of emotions, and at times they might be intense and overwhelming. All of these reactions are normal and a necessary part of the grieving process.

Some common responses to grief are:

- feeling numb and empty
- a constant need to review the death
- lack of energy
- change in appetite and sleep patterns
- withdrawal from others

As you confront the pain of your loss, you may:

- feel anxiety, anger, sadness, guilt, and loneliness
- need company, but be unwilling to ask for it
- experience lack of meaning in your life
- feel confused

What often helps:

- talking to supportive people
- taking good care of yourself, physically and emotionally
- visiting your family physician
- telling friends how they might help you
- attending a self help support group

The length of time for mourning differs with everyone. Each person's grief is unique and will reflect the relationship you had with the deceased.

Funeral homes have information on bereavement support groups and for other grief related concerns.

Getting through the holidays after the death seems impossible. Your loss requires an adjustment to your life. Anticipate one thing at a time. When making decisions about the holidays, involve family and friends in the discussion but remember you have the final say. Grieving will probably leave you feeling exhausted and slowed down. Listen to what your body and mind are saying. Pace yourself and lower your expectations about

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being at your best during the holiday season. Let your tears flow when you feel like it – crying can release your sadness.

### Frequent Concerns

- being alone
- being asked to go somewhere when I don't want to go
- hurting the feelings of relatives and friends
- feeling like a "fifth wheel"
- being too emotional and spoiling the day for others
- ignoring the absence of the deceased
- having to pretend you are fine

### Helping a man who is grieving:

- men feel the need to be strong
  - men feel the need to be active
  - men feel the need to be protectors
  - generally, avoid word clichés
  - make contact and remain available
  - be aware of holidays and other significant days
  - watch for warning signs of long-term problems
  - chronic depression
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- withdrawal and low self-esteem
  - deterioration in relationships with friends and family
  - physical complaints
  - chronic anxiety, agitation, and restlessness
  - chemical abuse or dependence
  - understand the importance of the loss

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### **Bereavement**

Issues to consider:

- Pastoral care is offered by churches and all religious groups
- Funeral homes have bereavement counsellors on staff
- Funeral plans should be discussed openly

Coping with grief:

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1. Share your grief
2. Life one day at a time. Be kind to yourself
3. Identify your support system
4. Accept your feelings
5. Eat at least one good meal per day
6. Look out for your needs
7. Keep a journal
8. Give yourself permission to change your routine
9. Identify the bad times for you

Find supportive family and friends who accept your feelings and will listen when you need to talk. Grieving uses a lot of energy. There will be mood swings, trouble sleeping, and eating. You will feel extremely tired, fragile, and vulnerable. Allow a year or longer to work through physical and mental turmoil of grief and mourning. Respect that mourning is a healthy natural process. Read books or see films that deal with grief to normalize the experience. Sometimes religious rituals are comforting.

### Community resources for support

- Local Hospitals
- Funeral Homes
- Survivor Programs

Bereaved Families of Ontario (Toronto) 416-440-0290

Baycrest Centre 416-785-2379

Create a support team of family or friends to allow control and flexibility when home care is needed for long periods of time. These supporters work with the professions to help the Caregiver keep as much control over their life as possible by providing practical help and emotional support. The Care-Receiver should become an active participant in the making of decisions. One of the members of the support team should be the co-ordinator of the family and friends. The support team should be able to provide companionship, and lessen the fear and isolation of the person who is ill.

A logbook is a helpful communication tool when more than a few people are involved in providing support at home. The logbook could contain



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information about what to do in an emergency. Health Care number, medication, likes and dislikes of the Care-Receiver, key names and phone numbers connected with the Care-Receiver. Much of the information that is personal from the person who is ill, and their family members, should be treated as confidential and must not be repeated to anyone without permission.

Many disease or condition-specific organizations provide different kinds of supports (eg. Cancer Society, Red Cross, Meals on Wheels, friendly visiting services, community agencies, and home care agencies.)

The four areas of concern in hospice care are the physical, emotional, spiritual and information needs of the patient, and secondly of the family.

Hospice care can be provided in someone's home or in institutional settings.

Emotional care includes providing opportunities for expression in creative ways.

Emotional and spiritual care offered to a Care-Receiver is important when there are no family or friends nearby. The hospice Caregiver is able to offer support, understanding and compassion. Spiritual care is available through a chaplain or spiritual leader. The Care-Receiver and family should decide if they wish formal religious guidance and assistance. The chaplain or clergy often act as an interfaith spiritual leader and may continue to support during time of grief.

### **Types of Hospice Care**

- Informal hospice care - support circle of friends, family, volunteers
- Home Care - Community Care Access Centres
- Community Hospice - volunteer and staff-run organizations who work closely with the Care-Receiver's family physician, health care providers and home care programs
- Hospital-Based Palliative Care Unit
- Hospital-Based Hospice Team
- Extended Care Services - found in nursing homes, long-term care facilities

Volunteers are very important to an effective hospice care program. They generally receive specialized training and do home care visits.

**Peace of Mind:**

Caregiver and Care-Receiver should make plans to prepare for own death. Care-Receiver should set down clear instructions as to financial and legal matters. Appropriate counsellors should be engaged.

Private medical insurance should be fully paid up and the Caregiver should know exactly what it covers. Life Insurance should be reviewed to make sure it is appropriate. When a life insurance policy names a beneficiary, those funds will go immediately to that beneficiary without being subject to probate, taxation and possible claims by creditors.

It is important to know what income pensions, annuities and Registered Retirement Income Funds are providing in the way of income and what will happen to payments upon death.

Both Caregiver and Care-Receiver should have wills, which should be reviewed every three years or so. Fairly minor changes in bequests can simply be listed in a letter to the Executor.

A Living Will is a statement attesting that the person signing it, does not want medical personnel to take heroic measures or use artificial means to prolong life. It can be handwritten, without the participation of a lawyer. Two witnesses, who will later be able to testify that the person who drew up the will was of sound mind at the time, must co-sign it. If you are caring for someone who often talks about dying and no longer enjoys life, you might suggest that this is the time to make a Living Will.

Funeral arrangements - when drawing up a will, the Care-Receiver should state what funeral arrangements are preferred and whether the body is to be buried, cremated or donated to medical research. It is important that the Caregiver and Care-Receiver think through and set down in writing somewhere what should be done in the event of death.

When someone dies at home, you dial 911 for emergency assistance. An ambulance, the fire dept. and the police will arrive. If the ambulance attendants determine there are no vital signs, they will call a doctor or a coroner to pronounce that this person is no longer alive.

If the death is expected and the senior chooses to die at home, arrangements should be made in advance with the family, the attending

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physician and a funeral home. When the death occurs, contact the attending physician. If the physician is not available contact the funeral home for guidance.

In either situation contact all of the deceased's relatives, friends and the clergy, if the deceased was an active member of a religious community.

After the funeral you should notify:

- the lawyers for the Care-Receiver
- the bank
- life insurance company
- insurance agents – car, property
- Ministry of Transportation and Communications
- Care-Receiver's employer – retirement and pension plans and survivor benefits
- OHIP – Ontario Hospital Insurance Program
- Supplementary Medical Insurance
- OAS – Old Age Security
- CPP – Canada Pension Plan
- GIS – Guaranteed Income Supplement
- DVA – Department of Veteran Affairs
- A war veteran's allowance recipient
- A disability pensioner
  - documentation required
  - veteran's discharge papers
- GAINS – Guaranteed Annual Income Supplement
- Welfare
- WSIB – Workers' Safety Insurance Board
- Public Trustee if there is no will or next-of-kin
- Unions, clubs, organizations
- Real Estate – consult a lawyer for assistance in administering real estate
- Safe Deposit Boxes
- Savings Bonds
- RRSPs
- Stocks and Bonds – transfer agent
- Credit cards

If there is to be a funeral, a family member or the physician calls the chosen funeral home. From here on, the funeral director takes over, if that is what you wish.

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Funerals can be paid for in advance. The money you pay goes into a trust fund and the interest that it earns compensates the funeral director if costs rise. It is important to know if Care-Receiver has chosen to do this.

Mourning - Mourning lasts for variable time frames.

1. Accept the reality of the loss – there is a need to talk about the loss – funeral plans and rites are important.
2. Experience the pain of grief – caregivers can encourage the bereaved person to identify feelings and express them.
3. Adjust to an environment that has changed – caregivers can give support around the changes in life in day-to-day terms. Discourage major life-changing decisions until later.
4. Reinvest energy in other relationships and activities. Caregivers can give encouragement to explore.

### **Your Notes - Section 15**

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