

# Home Caregiver Support Program



The Order of St. Lazarus  
Grand Priory in Canada





# Outline of this Presentation

- Trajectory of end-of-life illnesses
- Caregiver issues
- On line caregivers support Program
- A Vision for municipal councils



# Trajectory of end-of-life illnesses

- Early phase of illness
  - 100% function: Needs emotional support
- Mid phase of illness
  - 75% function: Can do most activities with effort and frequent rests
- Late phase of illness
  - 50% function: Needs help with usual activities
- End-of-life
  - <40% function: Needs help getting out of bed
  - <20% function: Bed bound and needs help eating and drinking















# Trajectory of end-of-life illnesses

- Early Phase of illness
  - Few symptoms of disease
- Mid phase of illness
  - Pain, Shortness of breath, nausea, fatigue, anxiety, appetite decreases
- Late phase of illness
  - Symptoms worsen, constant medications, weakness, low energy,
- End-of-life
  - Extreme weakness, low food intake, no energy, very sick



# Care of Vulnerable Canadians,

- “Family care givers provide 70% - 80% of care given in Canadian homes and communities.
- Family and friends have been described as the unseen backbone of the Canadian healthcare system.
- Nearly a quarter of family caregivers miss one or more months of work.
- 77% of caregivers are women





# Care of Vulnerable Canadians

- Caregivers need information about end-of-life issues to carry out their care giving role.



# Family Caregivers

- Caregiving will become the most important issue of social policy in the years ahead.



# Not to be Forgotten: Support for Caregivers

- Family caregivers need support dealing with the stresses that often come with the care giving role.
- Following the death of a loved one, the caregiver is left very vulnerable in terms of physical and mental health.





# Online HCSP



## HOME CAREGIVER SUPPORT PROGRAM

The overall goal of the Home Caregiver Support Program is to provide information and assistance to non-professional caregivers who are providing care for family members or friends suffering from chronic or terminal illnesses within the confines of their own home.

Caregivers can include other family members, partners, parents, children, and close friends.

Topics include:

### PHYSICAL NEEDS

#### PART A: HOME CARE

- Adapting the home
- Living arrangements
- Patient movement

#### Physical care

- Physical problems and complications
- Pain management/symptoms
- Medication issues/side effects
- Symptom control/Complementary therapy

### EMOTIONAL/PSYCHOLOGICAL NEEDS

#### PART A: EMOTIONS

- What to expect
- Effective communication
- Empathy

#### Management of emotions

- Dealing with dying and death
- Bereavement support/Grief
- Caregiver stress
- Prevention of Burnout

### SOCIAL/INFORMATION NEEDS

- Advice and assistance/Planning for a death at home
- Development of caregiver support networks
- Publicly funded care
- Private home care agencies
- Hospices
- Advance care planning
- Estate planning
- Government programs and benefits

### SPIRITUAL NEEDS

- Spirituality
- Concerns about life-after-death
- Encouraging inner spiritual strength
- Spiritual caregivers
- Different religious practices
- Funeral arrangements
- Funeral homes
- Mourning

Visit the website of your choice for this free online program for caregivers:

English Site - <http://stlazarus.sjatraining.ca>

French Site - <http://stlazarusfr.sjatraining.ca>

Brought to you by:



The Order of St. Lazarus  
Grand Priory in Canada



## SOUTIEN AUX PROCHES AIDANTS

Ce programme de soutien aux proches aidants offre de l'information axée sur les besoins des aidants naturels qui prennent soin d'un membre de leur famille ou d'un ami souffrant d'une maladie chronique ou en phase terminale dans leur propre résidence. Un module préliminaire explique le cours et définit clairement ce que sont les soins palliatifs. Il est suivi de modules optionnels qui explorent plus en détail les besoins courants des gens en situation de soins palliatifs à domicile.

### BESOINS PHYSIQUES

#### PARTIE A: prendre soin d'une personne à domicile

- Adaptation de la maison
- Adaptation du mode de vie
- Déplacements du patient

#### Soins physiques

- Traitement des problèmes physiques et des complications
- Soulagement de la douleur et évaluation des symptômes
- Médicaments et effets secondaires
- Thérapies complémentaires

### BESOINS AFFECTIFS ET PSYCHOLOGIQUES

#### PARTIE A: les émotions

- Réactions à prévoir et écoute inconditionnelle
- Communication efficace
- Empathie

#### Gestion des émotions

- Approche à l'approche de la mort et au deuil
- Soutien au deuil et au chagrin
- Stress chez le proche aidant
- Prévention de l'épuisement

### BESOINS SOCIAUX ET INFORMATIONNELS

- Conseils et soutien — planifier un décès à domicile
- Établissement d'un réseau de soutien pour le proche aidant
- Services de santé publics
- Organismes privés de soins à domicile
- Résidences de soins palliatifs
- Planification préalable des soins
- Planification de la succession
- Programmes gouvernementaux et prestations

### BESOINS SPIRITUELS

- Spiritualité
- Préoccupations concernant la vie après la mort
- Préoccupations concernant la vie après la mort
- Guides spirituels
- Pratiques religieuses variées
- Dispositions funéraires
- Salons funéraires
- Deuil

Visitez:

English - <http://stlazarus.sjatraining.ca>

Français - <http://stlazarusfr.sjatraining.ca>

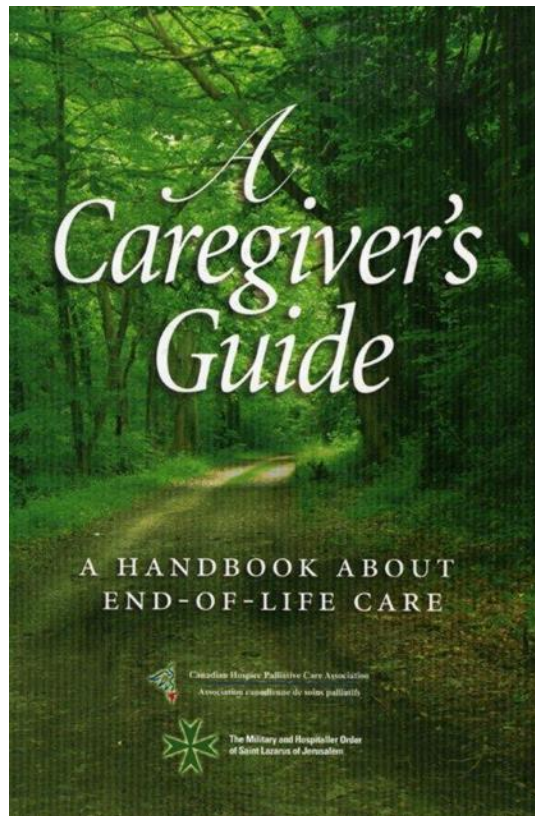


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## Based on: *A Caregiver's Guide – A Handbook About End-of-Life Care*



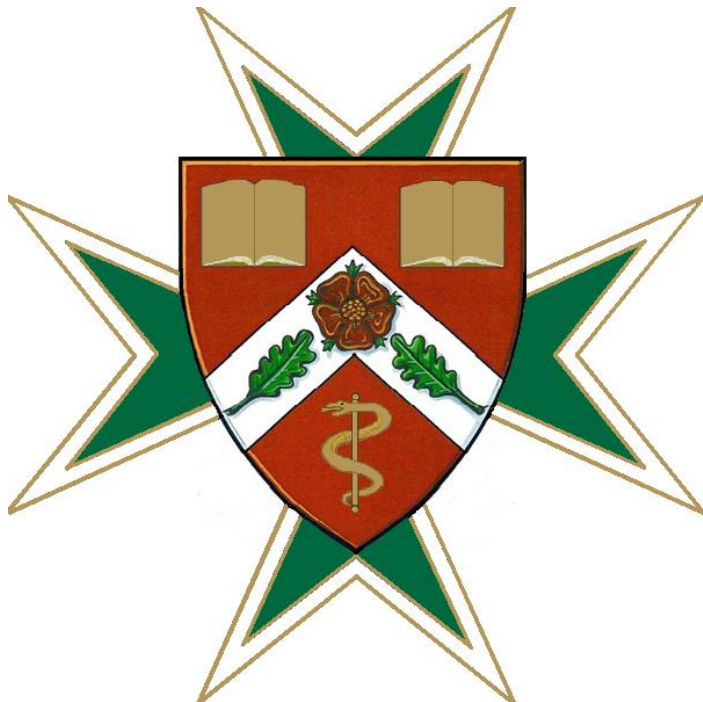
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# Home Caregiver Support Program

- The overall goal of the Home Caregiver Support Program: Train, Educate, Support
- Caregivers can include partners, parents, children, and close friends.
- Volunteers can take the program



# Facets of Palliative Care

- I. PHYSICAL NEEDS
  - A. Home Care
  - B. Symptom Management
- II. EMOTIONAL/PSYCHOLOGICAL NEEDS
  - A. Emotions
  - B. Stress Management
- III. SOCIAL/INFORMATION NEEDS
- IV. SPIRITUAL NEEDS



# I. Physical Needs

## A. Home Care

- Adapting the home
- Living arrangements
- Patient movement
- Physical care





# I. Physical Needs

## B. Symptom Management

- Physical problems and complications
- Pain management
- Medication issues/Side effects
- Symptom control/Complementary therapy



## II. Emotional/Pyschological Needs

### A. Emotions

- What to expect
- Effective communication
- Empathy
- Management of emotions



## II. Emotional/Psychological Needs

### B. Stress Management

- Dealing with dying and death
- Bereavement support/Grief
- Caregiver stress
- Prevention of burnout



## III. Social/Information Needs

- Advice and assistance/Planning for a death at home
- Development of caregiver support networks
- Private home care agencies
- Hospices
- Advance care planning
- Estate planning
- Government programs and benefits
  - End of Life program via community care nurses





## IV. Spiritual Needs

- Spirituality
- Concerns about life-after-death
- Encouraging inner spiritual strength
- Spiritual caregivers
- Different religious practices
- Funeral arrangements
- Funeral homes
- Mourning



# Online HCSP

- Online set of six modules covering the didactic portion of the program
- Each module will take about 1 hour to complete
- Pre- and post-surveys with interactive exercises
- After completing the online component, an optional practical session offers time for questions
- Contact [HomeHospiceNI@outlook.com](mailto:HomeHospiceNI@outlook.com) to book the virtual follow up sessions



# A Vision

- Information about home hospice available at municipal council offices
- Caregivers can avail of the on-line caregiver support program with virtual follow up session
- Volunteers can avail of this program
- Municipal councils sponsor a volunteer support network



# Contact us

- <http://stlazarus.sjatraining.ca>
- <http://stlazarusfr.sjatraining.ca>
- [HomeHospiceNL@outlook.com](mailto:HomeHospiceNL@outlook.com)
- This on-line course and follow up session are free and supported by the Order of Saint Lazarus NL





## Questions?

