



St. John Ambulance

The Order of St. Lazarus
Grand Priory in Canada



HOME CAREGIVER SUPPORT PROGRAM - INTRODUCTION

The overall goal of the Home Caregiver Support Program (HCSP) 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.

The program is funded by The Military and Hospitaller Order of Saint Lazarus of Jerusalem. Content development and presentation is the responsibility of St. John Ambulance (SJA). There are two options for caregivers to take the course, either attend in person or take the online course with an optional follow-up session. The program is free for caregivers.

The HCSP in-person program is currently available in Ontario and consists of a series of presentations offered at an easily accessible location. Times of these presentations can vary (e.g., daytime, evening, etc.) with no single presentation exceeding 3 hours in length. The first two sections on Physical Needs (IA and IB) and Emotional Needs (IIA and IIB) have been divided into two parts, of 90 minutes duration each, if it is desired to give the presentation over two sessions. The last two sections on Social/Information (III) and Spiritual Needs (IV) can be presented in 90 minutes each or extended to 2-3 hours each to encourage discussion. They can also be combined into one 3-hour session. The complete program can be presented over 3-4 half-days. Participants can take one or more of these presentations, as their needs dictate. Since potential attendees may already be performing caregiver duties, respite care may be arranged by a local Branch of St. John Ambulance or local hospices, as part of the program. Interested parties should contact Ontario Council or the local Branch of St. John Ambulance.

The HCSP online course is designed for caregivers to do on their own time. Six modules address the same four primary needs faced by caregivers of terminally ill patients. Each module can be completed in about one hour. Caregivers can do any or all the modules as their needs dictate. An additional in-person practical session may be available in selected communities. After completing the online course, the practical session offers time for activities, discussion of local resources, peer-mentoring, and the opportunity to ask questions. Together, the online course with optional in-person practical session is identical to the full in-person Home Caregiver Support Program.

Most of the content for this program was used with permission from: *"A Caregiver's Guide - A Handbook About End-Of-Life Care"*, published by the Canadian Hospice Palliative Care Association and The Military and Hospitaller Order of Saint Lazarus of Jerusalem. Copyright of *"The Guide"* is the property of The Order of Saint Lazarus.

Concept of the program was by Capt. Anthony Lea, Executive Director K-W SJA, and Past Hospitaller, Western Ontario Commandery, Order of St. Lazarus.

Program development and additional content was written by Dr. Robert M. Boyko, Provincial Medical Advisor, Ontario Council, St. John Ambulance; and Hospitaller, Grand Priory in Canada, The Military and Hospitaller Order of St. Lazarus of Jerusalem. Dr. Boyko has experience as a Family Physician and Hospitalist, and is a Coroner for the Province of Ontario. He is also an Assistant Professor in the Department of Family and Community Medicine, Faculty of Medicine, University of Toronto.

Program content includes:

I. Physical Needs

Part A: Home Care

- Adapting the home (adaptive living mechanisms such as raised seating, hospital beds, bathroom rails)
- Living arrangements (physically moving someone to another floor in the house, moving in another family member to assist, arranging for hospital beds) and Infection control
- Patient movement (transfer, lifting)
- Physical care (mouth care, skin care, washing, toileting, etc.)

Part B: Symptom Management

- Dealing with physical problems and complications (bedsores, etc.)
- Pain management and assessing symptoms (caregivers need to be able to assess and advocate)
- Medication issues and side effects (what are prescribed medications doing, what to expect)
- Symptom control and complementary therapy (through non-pharmaceutical uses, awareness of changes in the body that take place during the last few days of life)

II. Emotional and Psychological Needs

Part A: Emotions

- What to expect and listening unconditionally
- Effective communication with the patient and others (therapeutic communication)
- Empathy (showing respect and compassion)
- Management of emotions, including depression (beyond normal grieving)

Part B: Stress Management

- Dealing with dying and death
- Bereavement support and grief – both volunteers and home caregivers will need to be aware of natural reactions following death, support mechanism for volunteers to express feelings, listing of professional agencies available to assist with bereavement
- Caregiver stress
- Prevention of burnout

III. Social and Information Needs

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

IV. Spiritual Needs

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

PARTICIPANT PREREQUISITES

None. Anyone who cares for someone at home who has a terminal or life limiting illness is encouraged to attend. There are no fees for attendance of the in-person sessions, as this is part of the community service arm of St. John Ambulance. A nominal registration fee may be required to offset on going costs and maintenance of the online version of the program, but it is currently being offered free to caregivers.

FACILITATOR PREREQUISITES

Each of the above areas should be presented by personnel who have knowledge in that particular topic. St. John Ambulance Branch or Provincial office staff will be responsible for coordination but may be used, with proper training, to also present. Local hospices and hospice volunteers can also become facilitators. It is preferable for facilitators to have presentation skills training or equivalent. As this program is part of the community service

arm of St. John Ambulance, facilitators should become volunteer community service members of St. John Ambulance to take advantage of the benefits of membership and be covered under their insurance. An example of appropriate facilitators for each section might be:

I. Physical Needs

- Hospice or personal support worker
- Visiting nurses' organization
- Palliative care physician

II. Social and Information Needs

- Hospice or Community Health Agency
- Social worker
- Lawyer/paralegal

III. Emotional and Psychological Needs

- Social worker
- Hospice worker
- Pastor or spiritual leader

IV. Spiritual Needs

- Social worker
- Hospice worker
- Pastor or Spiritual leader

COURSE EXAMINATION

None. This is a participation course. A certificate is issued after completion of any modules.

Online activities and questions to engage participants with Pre- and Post- surveys to determine effectiveness.

English version of online course: <http://stlazarus.sjatraining.ca>

French version of online course: <http://stlazarusfr.sjatraining.ca>

CONTACT INFORMATION

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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

PART B: SYMPTOM MANAGEMENT

- 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

PART B: STRESS MANAGEMENT

- 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.sjatrainng.ca>

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

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