A Comprehensive Guide for the Care of Persons with HIV Disease

Module 4: Palliative Care
When we began the writing of this Module, we had intended to acknowledge contributions at the beginning of each section. As the document has progressed, this has become impossible because there has been a wonderful sharing and exchanging of information and ideas. Therefore, we wish to acknowledge all of our contributors. Their expertise, comments and insights have enhanced the entire document.

CONTRIBUTORS

LEAD EXPERT AUTHORS
Cheryl Arneson, RN
Gerry Bally, MD
Brenda Barr, BPT
William E. Berinati, MA, DC
Louise Binder, BA, LLB
Claudia Brabazon, BSc, MSc
Jack DaSilva, BSc Pharm
Peter DeRoche, MD, CCFP, FRCP(C)
Frank D. Ferris, MD
John Flannery, RN, MSc
Gail Flintoft, MSW
Frank Foley, MD, CCFP, CAFC
Irene Goldstone, RN, MSc
Rev. Douglas Graydon
Richard Isaac, MD, LIB, FCLM
David Kuhl, MD
S. Lawrence Librach, MD, CCFP, FCFP
Andrew Johnson, RN, BSc
Jack MacDonald, PhD
Michael McRimmon
Helen McNeal, BBA
Wayne Moore
Michel Morissette, MD
Yvette Perreault
Linda Prentice, MSW, CSW
David J. Roy, STL, PhL, DTheol
Rev. John K. Saynor
Mary A. Schouten, OT
Mary Vachon, RN, PhD

RESOURCE PERSONS
Ann Beaufoy, RN, CIC
Michel Bouchard, MD
Tony Caines
Don Cook, RN
Pierre Côté, MD
Claire Desrosiers, B Admin
Jim Donovan, RN, BA
Janet Dunbrack, BA, MSc
Linda Durkee, RN, BScN, MEd
Thérèse Eustache, t.s.
Judy Filman, RN, BA
Johanne Fillion, t.s.
David Fitzgerald, BSW
Jacqueline Fraser, MD, MB, BCh
Michel Giroux, LIB
Carol Grossman
Ann Harrington, RN
Penelope Holeton
Prashant Joshi, MD, FRCPC
Normand Lapointe, MD
Christine Leonard
Daphne Lobb, MD
Len Lopez
Malcolm MacFarlane
Sheri Margolese
Katrin Marley, BSc Pharm
Diane McGuire, RMT
Alastair McLeod, MD
Shirley Morrison
Kshama Patel
Marc Pelchat, PhT
Deborah Randall-Wood, RN
Dawn Ross, MD
Ken Runciman, MD
Connie Shaw
Margaret Shaw
Jo-Ann Stacey
Jill Sullivan, RN
Darien Taylor
Jerome Teitel, MD, FRCP(C)
David Thompson
Rae Westcott, MSW
Sheila Wahsquinaikkezhik

REVIEWS
Olga Anderson
Bonnie Boyd
Ina Cummings, MD
Odette Desilets, MD
Ron DeBurger, BA, CPH, CPHI(C)
Shari Douglas, RN
Claire Duchesneau, MSW
Drew Ferrari, BES
Russell Gessner
Helen Hays, CM, MD, CCFP, FCFP
Don Kilby, MD
Antoinette Lambert, inf
Claude Lamontagne, MD
Arlette Lefebvre, MD, FRCP
Marilyn Lundy, RN
Guy Milner, MSW
Michael O’Shaughnessy, MD
Claude Olivier, MSW
Alan Peterkin, MD, FRCP(C)
Carlyle Phillips, MD, CCFP
René Raymond
Donna Roe, RN, MSc
Robert St. Pierre, BA
François Thérien
Judith Thompson, RN, BSc
Terry Trussler, EdD

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**Introduction**

Palliative Care for persons living with HIV/AIDS is the unification of science, compassion and spirituality. This Module endeavors to reflect this vital union. Contrary to what many believe, there is no specific time for Palliative Care. Throughout its trajectory, advanced HIV disease presents continuing challenges for all, but experience proves that those knowledgeable in Palliative Care can relieve the intense, broad suffering of persons living with the disease. The result can be a unique experience respectful of each individual and healing to those he/she loves. This Module endeavors to strengthen the skills that make this experience possible.

Its development brought together experts from across Canada, from every discipline and type of care setting, reaching out, listening, and including the voice of their experience. Its pages are intended to reflect the finest in concepts underlying care and practical applications in Palliative Care for those living with HIV/AIDS.

As the Module is dedicated to enhancing the care available to those living with HIV/AIDS, it was important to capture their perspectives, as well as those of their families, friends and partners. To do this, various informal forums were organized through AIDS and Hemophilia organizations in Edmonton, Montreal, Toronto, Vancouver and Victoria. Additional sessions were held in conjunction with provincial and regional meetings in Atlantic Canada, Ontario and Quebec, and at the 1994 Rural Conference in Jasper. Their voices and experience strongly influenced the writing of the Module and specific quotations appear throughout the document.

As Palliative Care does not refer to a single discipline or one place for caring, this Module includes information for professionals in all disciplines and encompasses care in all settings.

Palliative Care professionals will find the Module helpful in increasing their awareness of HIV-specific issues; those experienced in HIV care will gain practical techniques for use in delivering Palliative Care.

To assist with access, chapters were arranged in the document as follows:

<table>
<thead>
<tr>
<th>UNIFYING THEME</th>
<th>PURPOSE</th>
<th>CHAPTERS INCLUDED</th>
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<tr>
<td>HIV/AIDS and Palliative Care</td>
<td>This section enables readers to:</td>
<td>One Voice</td>
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<td></td>
<td>• hear the heartfelt message of persons living with HIV/AIDS</td>
<td>What is HIV/AIDS</td>
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<td>• establish a basic understanding of HIV/AIDS and obtain information</td>
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<td>on where to learn more</td>
<td>HIV/AIDS and Palliative Care</td>
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<td>• review the principles and philosophy of Palliative Care and</td>
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<td>understand the significant impact HIV/AIDS has had on its practice</td>
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| Caring for the living | These sections encompass the information caregivers need to provide care that optimizes quality of life for those living with HIV/AIDS. | Quality of Life
Ethics
Symptom Management
Activities of Daily Living
Psycho-Social Issues
Caring for HIV+ Substance Users
Legal Issues
Advance Planning
Spirituality |
| Caring for the dying and the bereaved | These sections include information around care during the last days and hours of life, and the care for the bereaved both before and after the death of their loved one. | Last Hours of Living
Funerals, Memorial Services and Rituals
Grief, Loss and Bereavement |
| Care delivery | These sections will be of personal interest to caregivers as well as those involved organizationally in planning and providing care. | Models of Palliative Care Delivery
Care for the Caregiver
Issues in Occupational Exposure for HIV/AIDS Palliative Care
Resources |

**COPYING AND USING INFORMATION**

Readers of this Module are encouraged to use the information contained herein not only in their own work but also to assist in educating others. See Resources for information on how to obtain additional copies. In addition, we actively encourage photocopying of any sections of specific interest for quick reference.

**IMPORTANT TERMINOLOGY**

In this text, the term *caregiver* refers to any person providing care to meet the physical, psychological, social, spiritual expectations and needs of the person and family. In the following pages, caregiver is used primarily to refer to paid providers of services. Whenever it is relevant to refer to unpaid or volunteer providers of care, the terms volunteer caregiver, volunteer or unpaid caregiver will be used.

The word *partner* is used to refer to a person of either sex who is involved in an intimate relationship with another person. Individuals could be married, living common-law or dating, in a gay, lesbian or heterosexual relationship.

*Family* is used throughout this document, and refers to those closest in knowledge, care and affection to the person living with HIV/AIDS. It is specifically inclusive of:

- family of origin – birth parents, siblings
- family of acquisition – relations by marriage or contract
- family of choice – anyone the person chooses to have close to them

An *interdisciplinary team* is a team of caregivers from different backgrounds and professional disciplines, and sometimes via linkages or contracted arrangements from different programs or services, who work together to deliver Palliative Care services to the individual and/or family.
These definitions are based on those developed by the Canadian Palliative Care Association, as part of their standards development process. They were chosen for use in this document for their inclusivity of all those involved in caring.

Every effort has been made to be gender neutral. In the event that the terms he, she, him or her have been inadvertently used alone – except where a sex is relevant to the reference, as with “A mother caring for her child” – consider such references to refer equally to persons of either gender.

Throughout the text, generic names for the medications have been used. At times, trade names have been included for unfamiliar generics. For additional trade names, see the Medication Table, Appendix B.

HIV/AIDS has challenged Palliative Care in Canada to grow and fulfill the broadest aspects of its mandate. This Module is inspired by that challenge, reflects the response of experienced caregivers, and presents a challenge of its own: fulfill Palliative Care’s mission to care by bringing together science, practical compassion and gifts of the spirit in all you do. See the world as it occurs for others, without bias or fear, and your caring will bring healing to those living and dying with HIV/AIDS and those they leave behind.

REFERENCES