



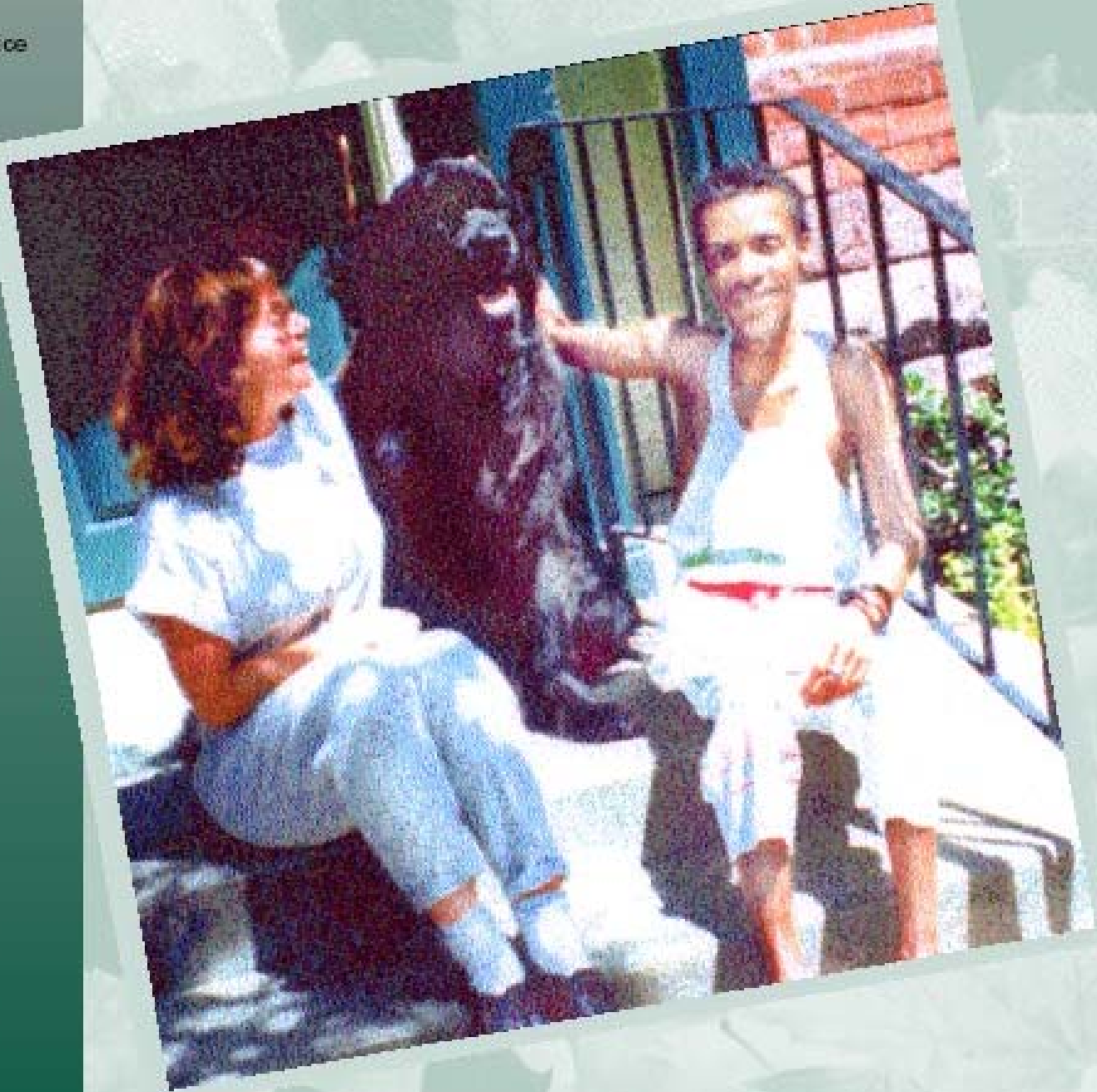
Mount Sinai Hospital



Casey House Hospice

A Comprehensive Guide for the Care of Persons with HIV Disease

Module 4: Palliative Care



Acknowledgments

CONTRIBUTORS

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.

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, MScN
 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, BScN
 Jack MacDonald, PhD
 Michael McCrimmon
 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 Lopezi
 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 Wahsuonaikkezhik

REVIEWERS

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, FRCPC
 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, MScN
 Robert St. Pierre, BA
 François Thérien
 Judith Thompson, RN, BScN
 Terry Trussler, EdD

We also wish to thank the many people who reviewed the Module as part of our focus groups in Montreal, Toronto, and Vancouver.

Table of Contents

Acknowledgments	i	8. Activities of Daily Living	91
Table of Contents	ii	9. Psycho-Social Support	98
1. Introduction	1	10. Caring for HIV & Substance Users	110
HIV /AIDS AND PALLIATIVE CARE		11. Legal Issues	114
2. One Voice	4	12. Advance Planning	118
3. What is HIV/AIDS	5	13. Spirituality	121
4. The Interrelationship of HIV/AIDS and Palliative Care	7	CARING FOR THE DYING AND THE BEREAVED	
CARING FOR THE LIVING		14. Last Hours of Living	126
5. Quality of Life	13	15. Funerals, Memorial Services and Rituals	132
6. Ethics	15	16. Grief, Loss and Bereavement	136
7. Symptom Management		CARE FOR THE CAREGIVER	
Introduction		17. Models of Palliative Care Delivery	143
General Principles	19	18. Care for the Caregiver	147
Issues Specific to Pain	22	19. Issues in Occupational Exposure for HIV/ AIDS Palliative Care	152
Children	27	20. Resources	156
Persons Living with Hemophilia and HIV/AIDS	28	Appendices	
HIV and Substance Users	29	A Diversity Checklist	158
Other Issues	31	B Medication Table	161
Symptoms		Index	179
General Problems	33		
Neurological Problems	44		
Neuro-Psychiatric Problems	49		
Cardio-Respiratory Problems	57		
Head and Neck Problems	62		
Gastro Intestinal Problems	66		
Genito-Urinary Problems	81		
Skin Problems	83		

Introduction

This Module is designed for caregiving professionals of all disciplines who seek to enhance their skill at providing Palliative Care for those living with HIV/AIDS.

Those living with HIV/AIDS, their family, volunteer caregivers and friends seeking information for their use, should refer to Living with Dying, Dying at Home (see Resources)

HOW TO USE THIS MODULE

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:

UNIFYING THEME	PURPOSE	CHAPTERS INCLUDED
HIV/AIDS and Palliative Care	This section enables readers to: <ul style="list-style-type: none"> hear the heartfelt message of persons living with HIV/AIDS establish a basic understanding of HIV/AIDS and obtain information on where to learn more review the principles and philosophy of Palliative Care and understand the significant impact HIV/AIDS has had on its practice 	One Voice What is HIV/AIDS The Interrelationship of HIV/AIDS and Palliative Care

<p>Caring for the living</p>	<p>These sections encompass the information caregivers need to provide care that optimizes quality of life for those living with HIV/AIDS.</p>	<p>Quality of Life Ethics Symptom Management Activities of Daily Living Psycho-Social Issues Caring for HIV+ Substance Users Legal Issues Advance Planning Spirituality</p>
<p>Caring for the dying and the bereaved</p>	<p>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.</p>	<p>Last Hours of Living Funerals, Memorial Services and Rituals Grief, Loss and Bereavement</p>
<p>Care delivery</p>	<p>These sections will be of personal interest to caregivers as well as those involved organizationally in planning and providing care.</p>	<p>Models of Palliative Care Delivery Care for the Caregiver Issues in Occupational Exposure for HIV/AIDS Palliative Care Resources</p>

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.¹ 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

1. Ferris FD, Cummings I, (eds). Palliative care: towards a consensus in standardized principles of practices (first phase Working document). Ottawa, ON: The Canadian Palliative Care Association, 1995 (in press)