



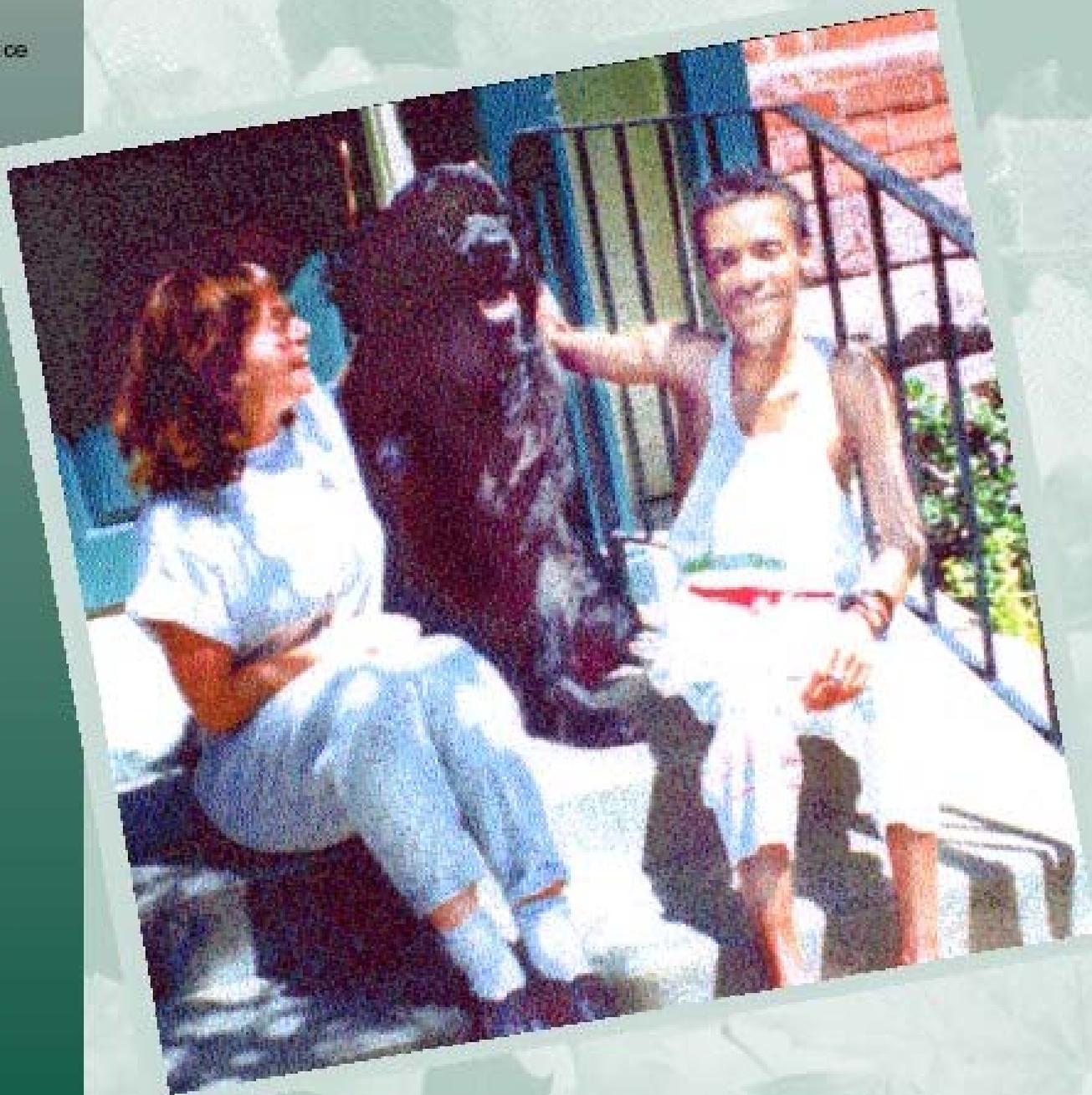
Mount Sinai Hospital



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.

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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.

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One Voice

“Three weeks, two dead — two more lost from the magic circle. To put it another way, two more rocks flung at the vast glass house of the world’s complacency — falling short as usual. But the numbers of the disappeared are relative, at best, and buried in the thicket of lies called statistics. As Randall Jarrell said succinctly, counting bodies of another war:

‘We died on the wrong page of the almanac... When we died they said, Our casualties were low.

As for my own losses, the pile of bodies is hardly countable anymore — except in the heart — because the dead outnumber the living now.’”

— Paul Monette¹

“...the measure of our response to AIDS is the measure of the humanity of our society...”

- Dr. David Roy²

“The great tragedy of the AIDS epidemic lies in our unwillingness — individually or collectively — to face death. Instead, we have chosen to look for someone or something to blame, thereby diminishing the meaning of our deaths.

The lives and stories in all our communities bear witness to what we are living through, and can bring meaning to our deaths. Caregivers must tell the stories of those they have known, those who worked hard at living...and dying.

Stories often answer the questions, “What brings you here?”, “How are you feeling?”. The caregiver must initially recognize and understand the true function of these narrative efforts. They explain our life events, sustain and/or project certain images of us, justify our behaviour, illustrate how we handle the crises and transitions created by our illness.

Through our stories, you can help us find answers in our search for meaning. Help us work together to alleviate our suffering, without excessive drugs making us unaware of our environment. Stories will help us deal with multiple losses in our lives, which incite fear that we will be the one left behind, with no one to care when those close to us have all died or walked away. In our isolation and fear, we need to be assured that services will be available to care for us when our time comes.

Our stories must be stated loudly — on behalf of those who died slowly, bit by bit, consciously accepting their inevitable dependence — assuring those who loved and wanted to care for them that such dying is not undignified. Recognize and support us through our deliberations around ending our lives at the moment of our choice, rather than facing the possibility of unbearable pain and suffering.

Through our stories, hear our concerns for our families, partners and friends. Help our parents — caught in their own web of aging, community and generation — to understand our grief and their own. Bridging disparate realities eases our isolation, enabling those around us to help us live safely in whatever place we choose to call home.

Listen closely to our stories and you will understand our desire for empowerment, for control over who we are and how we live our lives. In turn, you will help us be proud of who and what we are.

Help us share our stories so that others may know of a caring, compassionate and courageous way of living and dying.”

Anonymous

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What is HIV/AIDS?

INTRODUCTION TO HIV DISEASE

Without fear, HIV would be just another disease.

Author Unknown

HIV disease is caused by a retrovirus which infects lymphocytes and other cells with CD4 receptors. The primary effects of HIV infection are two fold. One is a progressive deterioration of immune system function, which leads to increased susceptibility to infections caused by viruses, bacteria, fungi, and protozoa, and also to certain malignancies. The other is progressive deterioration of the nervous system, mental deterioration, seizures, and sensory and motor changes.¹

CD4 cell count is the term used to define the marker on specific lymphocyte subpopulations. These CD4 lymphocytes are responsible for the coordination of the immune system response. Declining CD4 cell counts are indicators of the degree of immune system compromise.¹

The course of the disease is highly variable for any particular individual. Table 1, (next page) illustrates illness progression over time, and associated clinical management. Shaded areas identify clinical issues where consultation with more experienced colleagues could be considered.

Historically, HIV disease has largely affected gay or bisexual men or recipients of HIV infected blood and blood products. Today, more women are living with HIV infection than previously, as they increasingly become infected through heterosexual transmission or other risk behaviours. Women and children present with different symptoms than men and their experiences of HIV/AIDS are diverse. At the same time, the number of adults and children infected through HIV infected blood and blood products is decreasing. Diagnosis of an HIV+ child remains an indirect test of the HIV serostatus of the biologic family and the potential for multiple infected family members.

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SUGGESTED READING

Tobin MA, Chow FJ, Bowmer MI, Bally GA (Eds). A comprehensive guide for the care of persons with HIV disease: module 2: infants, children, youth. Mississauga, ON: The College of Family Physicians of Canada. (in press)

TABLE 1: Clinical management by CD4 lymphocyte cell count

| DEGREE OF IMMUNODEFICIENCY BY CD4 CELL COUNTS (PER MM ³) | ASSOCIATED SYMPTOMS AND ILLNESSES | CLINICAL FOLLOW-UP | FREQUENCY OF CD4 TESTING (MONTHS) | MANAGEMENT | | |
|--|---|-----------------------|-----------------------------------|--|-----|----------------------------|
| | | | | ANTIRETROVIRALS | PCP | PROPHYLAXIS TOXO MAC |
| Over 1,000 virtually normal | | q 6–12 | q 6–12 | | | |
| 500 mild | <i>Herpes simplex</i> , Generalized lymphadenopathy, Shingles, recurrent bacterial pneumonia, Candida vaginitis. | q 3–6 | q 3 | Consider antiretrovirals and recommend if symptomatic. | | |
| 300 moderate | ITP, Thrush Tuberculosis | q3 | q3 | Recommend antiretrovirals | | |
| 200 moderate – severe | PCP, Toxoplasmosis, Esophageal candidiasis | q1 | q3 | | YES | YES |
| 100 severe 0 | Wasting, Lymphoma, Cryptococcosis, M. avium complex, CMV. | q1 or more frequently | As required | | | YES |

* Table reprinted with the permission of the Society of Obstetricians and Gynecologists of Canada

The Interrelationship of Palliative Care & HIV/AIDS

WHAT IS PALLIATIVE CARE?

We now accept that dying of AIDS is qualitatively different from dying of other illnesses. Not only is there an excess burden on young people, but dying of AIDS remains a highly stigmatizing and socially isolating experience for the individual and his/her caregivers

HIV/AIDS has challenged Palliative Care. The complex dynamics of the disease process, the treatments, the social circumstances, including stigmatization, have all brought new dimensions to the provision of Palliative Care. Historically, most Canadian Palliative Care and hospice programs/services did not respond quickly to meet the needs of persons living and dying with HIV/AIDS. Over time, a few specialized programs have developed, particularly in centres with large numbers of persons living with HIV/AIDS. Today there remain large gaps in the Palliative Care resources available to persons living with HIV/AIDS across Canada.

Illness often starts silently and most people only become aware that they have a problem either when symptoms start or when they receive information (laboratory or x-ray results) that suggests or confirms a diagnosis. Figures 1 and 2 illustrate the continuum of Palliative Care and how various Palliative Care programs fit into the trajectories experienced by the person living with any life-threatening illness, his or her family and those who care for them. All who participate are affected by illness and death, and become the focus of the attention of Palliative Care.

While symptom control and support may be needed prior to knowing the diagnosis, disease-specific therapies are likely to play an important role soon afterwards. As the degree of disease, distress, discomfort and dysfunction waxes and wanes over time, there is a varying need for:

- disease-specific therapy (anti-retrovirals, anti-microbials, chemotherapy and surgery), and
- therapy focused on providing comfort, including symptom control, and support

During the last days of a person's life, therapies that provide comfort and support are usually more important, though disease-specific therapies may continue until death, i.e. anti-retrovirals, anti-microbials for CMV.

DEFINITION OF PALLIATIVE CARE¹

Palliative Care as a philosophy of care, is the combination of active and compassionate therapies intended to comfort and support individuals and families who are living with life-threatening illness. During periods of illness and bereavement, Palliative Care strives to meet physical, psychological, social and spiritual expectations and needs, while remaining sensitive to personal, cultural and religious values, beliefs and practices. Palliative Care may be combined with therapies aimed at reducing or curing the illness, or it may be the total focus of care.

Palliative Care is planned and delivered through the collaborative efforts of an interdisciplinary team including the individual, family and caregivers. It should be available to the individual and his/her family at any time during the illness trajectory and bereavement.

While many caregivers may be able to deliver some of the therapies that provide comfort and support, the services of a specialized Palliative Care Program may be required as the degree of distress, discomfort and dysfunction increases.

Integral to effective Palliative Care is the provision of opportunity and support for caregivers to work through their own emotions and grief related to the care they are providing.

FIGURE 1¹

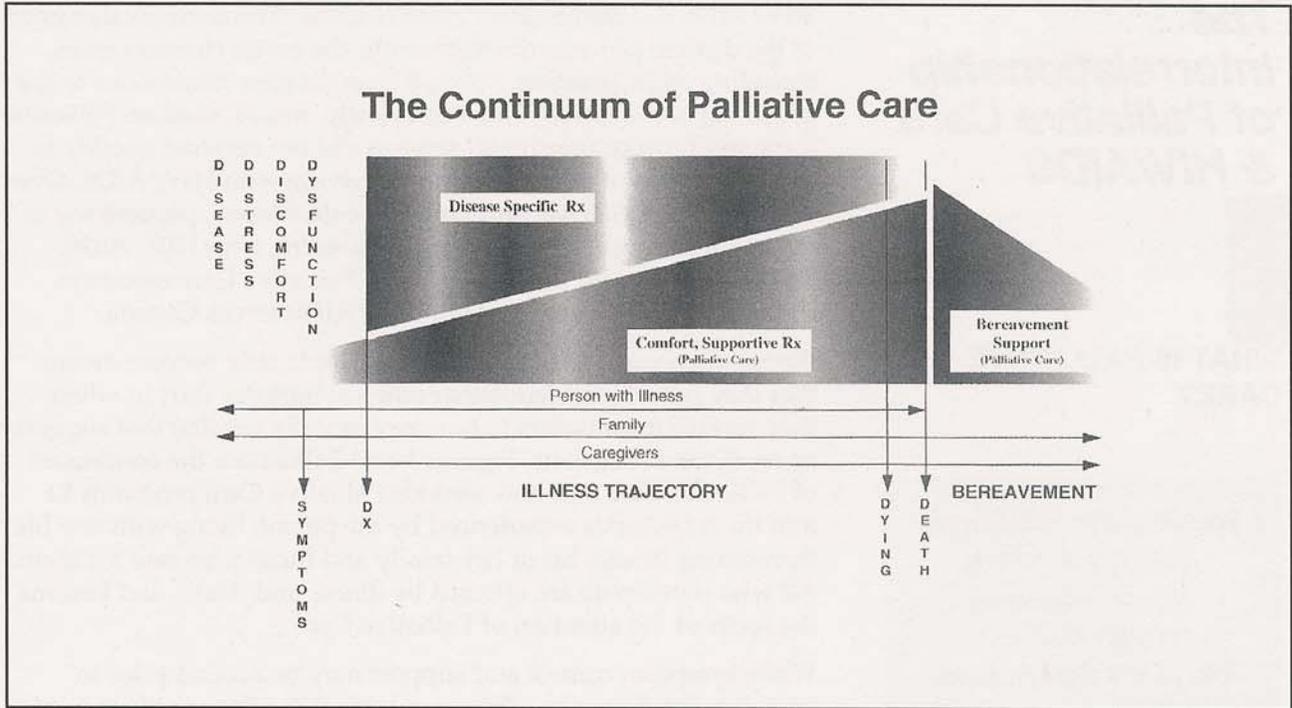
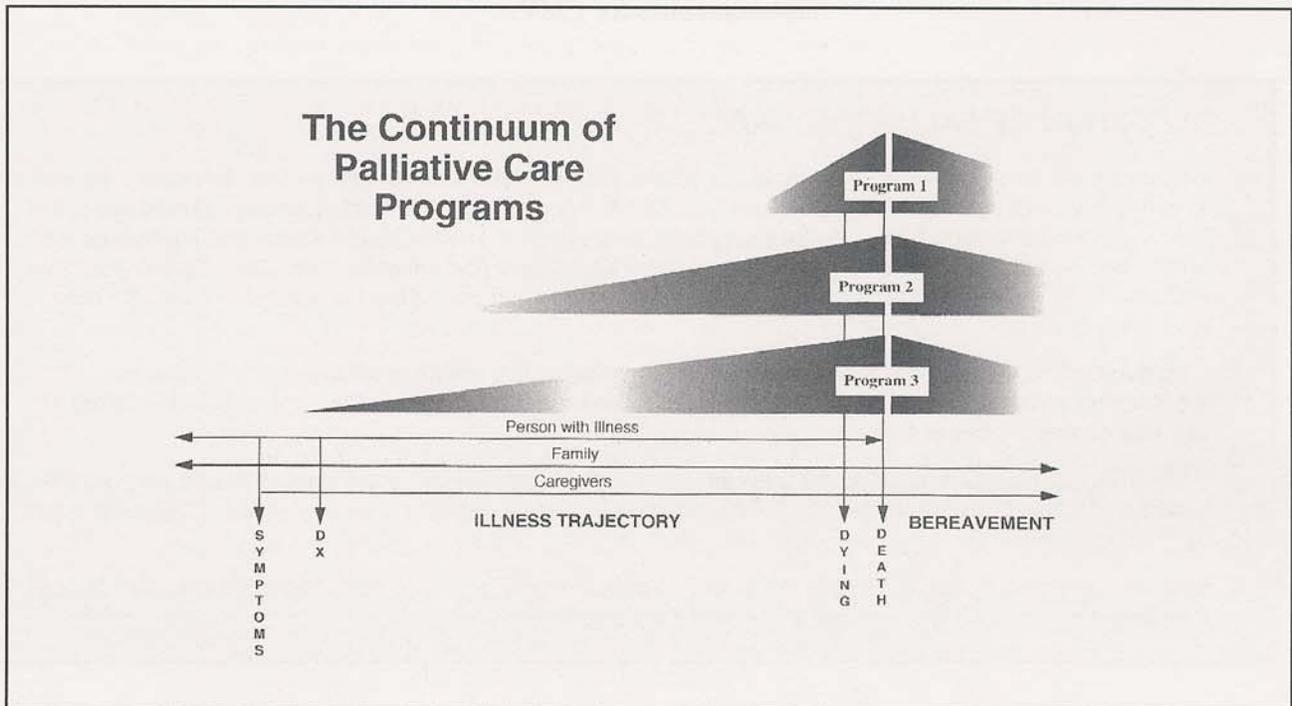


Figure 2 illustrates 3 different Palliative Care program models. Program 1 might be an inpatient Palliative Care unit where stay is only a few days. Program 2 might be a community based program or an inpatient consultation service which gets involved much earlier and remains involved. Program 3 might be an HIV clinic or a community nursing service that gets involved very early, and plays a varying role over time.

FIGURE 2¹



PHILOSOPHY OF PALLIATIVE CARE¹

Palliative Care is based on the belief that:

- when living with a life-threatening illness, and especially when dying, every individual has the right to participate in informed discussion about health care resource options, and to choose the best possible option to maximize the quality of his/her life
- Palliative Care strives to meet physical, psychological, social, and spiritual needs of individuals and families, with sensitivity to personal, cultural and religious values, beliefs and practices. This includes supportive interventions at the direction of the individual, whether or not the individual is receiving anti-disease therapy
- care should be delivered in a person focused, family centered environment
- it is the individual's right to access information and services from an interdisciplinary team of appropriately trained professionals and volunteers, who receive continuing Palliative Care education and evaluation

PRINCIPLES OF PALLIATIVE CARE¹

The principles of Palliative Care include:

1. **Holistic Care:** meets physical, psychological, social, and spiritual expectations and needs of the person and his/her family with sensitivity to personal, cultural and religious values, beliefs and practices
2. **Unit of Care:** the individual and his/her family
3. **Information is a Right:** it is the individual's right to be informed about his/her disease, potential treatments and outcomes, appropriate resources and options. It is the family and caregiver's right to be informed about the disease, potential treatments and outcomes, appropriate resources and options, respecting the individual's right to confidentiality
4. **Choice is a Right:** decisions are made by the individual and family in collaboration with caregivers, respecting the level of participation desired by the individual and family. The individual's and family's choices for care, settings of care and information sharing are respected within the limits of available resources
5. **Access to Care and Information:** individuals and families have timely access to information and services provided by Palliative Care when they need and are prepared to accept them. Information and care is provided in a language they can understand. Essential Palliative Care services are available 24 hours/day, 7 days/week
6. **Equal Availability of Services without Discrimination:** services are equally available to all regardless of age, gender, national and ethnic origin, geographical location, race, colour, language, creed, religion, sexual orientation, diagnosis, disability, availability of a primary caregiver, ability to pay, criminal conviction, or family status
7. **Ethics and Confidentiality:** care is provided in accordance with principles of ethics, including confidentiality
8. **Interdisciplinary Team:** care is provided by an interdisciplinary team of caregivers working collaboratively with the individual and family
9. **Continuity of Care:** a coordinated, continuous plan of care incorporating minimal duplication is maintained across all settings of care, from admission of the individual to bereavement support for the family

All who provide therapies that comfort and support through the illness trajectory and into the bereavement period should strive to achieve the standard of practice implied by the philosophy and principles of Palliative Care shown above.

THE CHALLENGE FOR PALLIATIVE CARE

The challenges facing Palliative Care as a result of HIV/AIDS include:

EVOLVING THE CONCEPTUALIZATION OF PALLIATIVE CARE

Palliative Care evolved from the management of persons living with cancer. It developed from the ideology that cancer could be beaten: that treatment usually starts with a period of active and aggressive therapy, followed by a cure or period of remission, and ultimately by a transition to Palliative Care. In many ways, the original perception of Palliative Care, and when to access services,

“We have been fighting forever. We don’t like to admit we are going to die, and some of us have difficulty accepting palliative care as it is delivered today”
– one voice –

is an impediment to care and the development of care delivery models for HIV/AIDS.

The current trend is to involve the broad range of Palliative Care services when the individual is first diagnosed with a life-threatening illness. These interventions can range from simply providing information about Palliative Care services to working with those with HIV/AIDS and their families on advance planning or anticipatory grief issues.

This shift in conceptualization of Palliative Care has now been adopted nationally and internationally.^{2,3} It is one of the important insights that HIV/AIDS has given to the delivery of health care. However, the conceptualization of Palliative Care continues to evolve due to the tensions inherent in balancing investigation, diagnosis and treatment versus measures directed solely at palliative comfort.

MULTIPLE PROBLEMS/COMPLEXITY OF CARE

The second challenge to Palliative Care is the dynamic nature of HIV/AIDS treatment.

- persons living with HIV/AIDS are surviving longer and are experiencing more problems as a result of treatment advances:
 - under optimal circumstances, survival with a diagnosis of AIDS has increased to 23-30 months, of which up to 50% of these days may be associated with the need for Palliative Care⁴
 - multiple simultaneous opportunistic infections and/or cancers, as well as multiple complex symptom control and psycho-social issues⁵
 - complex inter-relationships of the problems and their therapies
- new treatment options have shifted care from inpatient settings to either outpatient clinics or the person’s home:
 - approximately 10% of persons living with HIV/AIDS avoid hospitalization or require only a brief admission immediately prior to death
 - the average cumulative hospitalization has remained at 30-40 days (range 0-200 days), in spite of the significant increase in length of survival⁴

SOCIO-ECONOMIC IMPACTS OF THE DISEASE

Further adding to this complexity are the variety and diversity of the psycho-social issues faced by those with HIV/AIDS, their families and friends.

Judgments are often made about a person’s lifestyle that result in physical and social isolation. Financial losses may accrue as a result of job loss and, as the disease progresses, Palliative Care issues can be compounded by lack of housing, poor nutrition and inability to afford treatment.⁶ Multiple experimental and newly approved medications, many of which may need to continue up to, or close to, death are often expensive and unique to HIV/AIDS, and may not be covered by provincial health plans.

“I’m afraid that my family, my friends and society will abandon me”
– one voice –

Stigmatization and social isolation occur at unprecedented levels in HIV/AIDS Palliative Care and challenge caregivers to seek out or define new service options and partnerships.

In AIDS care there may be no clear transition between active treatment and Palliative Care. Active aggressive treatment often continues right up to death.⁷

ROLLER COASTER OF HIV/AIDS

With all of these changes in the disease and its treatment, many persons, their families and caregivers are experiencing the roller coaster of HIV/AIDS:

- unpredictability of HIV/AIDS progression: declining health alternating with periods of stability
- swings in physical and emotional well-being due to the unpredictability of the disease
- chronic uncertainty about the meaning and potential outcome of each event and intervention

SERVICE AVAILABILITY

The rate and nature of the progression of the disease, social circumstances and the poverty which may come with HIV/AIDS all interact to challenge our ability to deliver comprehensive compassionate care to individuals.

The experience of Palliative Care in HIV/AIDS in Canada is by no means homogeneous. The specifics of Palliative Care for any particular individual in any community will vary according to programs available, and the density and complexity of the local caseload.

To meet the challenge, new Palliative Care initiatives will have to be developed that are sensitive to the evolving needs of those living with HIV/AIDS.

CONCLUSION

The services that are available, and the way they are provided, will affect the quality and quantity of life for these living with HIV/AIDS, and the utilization of health care services. Adequate funding to ensure cost effective delivery of Palliative Care will avoid the use of high cost institutional alternatives. Palliative Care must respond to the continuing challenges of HIV/AIDS.

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Quality of Life:

Mr. Maurice Nouvelle went to the heart of all quality of life concerns when he said, "I am afraid everything will be over and I won't have had anything. Does a dinosaur, I mean a dinosaur's daughter, understand that?"¹ This anxious quest for understanding comes from a man who thinks he is a dinosaur, and who sees his psychiatrist, Dr. Susan Baur, as a dinosaur's daughter.

Mr. Nouvelle is quite mad, his thoughts all mixed up, his memories a mish-mash of delusion. He is as helpless as a child. Yet, as Dr. Baur explains, his feelings and suffering are utterly sane. He seeks love and esteem. He seeks to be understood and treasured. He seeks, as do we all, someone who would "catch the sound of our soul singing as it did before it lost its courage and its love."² In that search, all those threatened with biological and personal disintegration – the insane, the broken people, the dying – join the common human condition. A mark of this condition is that quality of life for anyone depends on the presence of others.

The expression "quality of life" refers both to experiences that make life meaningful and conditions that allow people to have such experiences.

Multiple interventions of curative medicine and Palliative Care centre on quality of life in the second sense: they deal with conditions enabling people to have experiences that make life enduring and worthwhile.

Survival is obviously one of these conditions, the sine qua non for all experience. It explains massive past and current efforts to develop and expand technology of drugs and surgical operations for the one purpose of saving lives. Individuals and their families have learned all too painfully that being biologically alive is necessary, but not sufficient for meaningful, worthwhile living. Other requisite conditions must be satisfied, if sick and dying people are to be ready and receptive for achievements and experiences that give meaning and interest to their remaining life.

Emancipating sick people from pain and unendurable symptoms is one of the conditions that sick, dying people most need in order to live their remaining time as fully as possible, true to themselves and family. Unrelenting pain, persistent symptom distress, and crushing fatigue bind consciousness to the loss of one's own time. A person's time cannot then be used for anything else. It cannot bring joy, peace, promise or hope which might momentarily counter, weaken or even dispel haunting threat of disintegration. Great efforts of Palliative Care to control pain and manage symptoms serve deeper existential purpose in freeing a sick, dying person's time. Freeing a dying person's time? For what? For any meaningful act or personal experience powerful enough to demonstrate "that for a short moment there is no death and time does not unreel like a skein of yarn thrown into an abyss."³

These lines from Czeslaw Milosz's poem *Earth Again* symbolize the kinds of events and experiences that bring the unconditioned into people's lives. The unconditioned here refers to experiences of grace, gift, or presence that can redeem tragedies of the past, fill a present threatened by absence and emptiness, and illuminate a future seemingly short and dark. This is a first meaning of quality of life and measurement has nothing directly to do with it. Such experiences cannot be guaranteed or measured, and medical, nursing, and other health care professionals cannot provide them.

But this is only part of the quality of life story. One tragedy of the human condition is that people can live and die without ever experiencing even a short moment "where there is no death" and where time holds together with transcendent peace and joy. Others fall into such deep misery that they cannot remember experiences when they have, indeed, occurred nor return to them for strength, light, and hope. Experiencing the unconditioned in the sense of the Milosz poem, or rediscovering such experience, depends primarily on freedom from abject misery of body and mind.

Quality of life in a second sense consists of such freedom. Multiple interventions of health-care professionals have much to do with provision of that freedom. Quality of life measurements control the degree to which that provision is occurring. During delivery of care, quality of life studies and measurements prevent devastating separation of a person's body from a patient's biography. Such separation, as A. Feinstein insisted, blocks scientific attention to a person's pain, discomfort, distress, insomnia, fatigue, anxiety, joys, sorrows, and other component conditions of a genuinely human life.⁴

The purpose of scientific, measured attention to data, deriving from both a person's body and biography, is to humanize medical and health care technology. Humanization requires two kinds of excellence from those who care for the sick and the dying: that expressed in effective relief of pain and symptoms, and that expressed in ability to read and respond to messages and quests between unwritten lines of each person's biography. This is where unique, personal suffering is so often found. This is where we can catch the sound of someone's soul singing as it did before it lost its courage and love.

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Ethics

“Clinical ethics concern decision making and the resolution of certain doubts, dilemmas or value conflicts which arise at the patient’s bedside. There are also on occasion conflicting perceptions, presuppositions, and beliefs. Clinical ethics should lead to a practical judgement of what is best done now to help one particular patient survive or die, in a way which respects the patient’s dignity as a man or woman.”¹

TREATMENT OPTIONS AND RESUSCITATION

Persons living with HIV/AIDS generally value autonomy and self-determination, asserting their right to be included in decision making

To care effectively for those living with HIV/AIDS, approaches to ethical issues such as decision making, assisted suicide and euthanasia on demand must be understood.

Solutions to these ethical dilemmas can only emerge from a global view of the person living with HIV/AIDS, considering the person’s clinical condition, personal values, aspirations, perceptions, beliefs, relationship with family and caregivers.

Global understanding of a person and his/her experience begins when the caregiver enters a therapeutic relationship. Opposing points of view emerge, challenging the art and science of clinical ethics and medicine to find an acceptable consensus. This is the ideal, but some caregivers have difficulty with therapeutic limits and failures, viewing death as a barrier.

Controversies surrounding major existential questions – the meaning of life, reasons for suffering and death – force society to question utopian ideals of a society free of suffering, pain, misery, evil, and death. We search for the meaning of life, the significance of suffering and death, yet answers elude us.

Treatment options and resuscitation pose some of the most difficult questions encountered by professional caregivers. The caregiver must demonstrate moral strength and sensitivity when discussing ethical issues with the person living with HIV/AIDS. It is difficult for young individuals and caregivers to accept that nothing more curative may be done. Confronting personal limits overwhelms some caregivers with paralysing helplessness, preventing them from finding other uses for their skills.

Some clinicians react to an individual’s refusal of treatment as if it were a personal rejection, repudiation, or accusation of incompetence. But if refusal of treatment follows frank, open dialogue, and if the individual is made to feel that the caregivers respect his/her decision and will carry it out, mutual respect and trust ensue.

These issues should generally be discussed in advance with the person living with HIV/AIDS. Increasingly, individuals are making a living will and/or giving power of attorney with instructions for the time of their death. However, lack of a living will or power of attorney does not mean that the person desires excessive therapeutic treatment at the end of his/her life. In fact, resuscitation efforts at the end of life may not only be futile but damaging. This highlights the importance of having frank discussions about these issues in advance.

Canadian jurisprudence has established the principle of self-determination and freedom of choice. It has freed the physician and other health professionals from risk of criminal lawsuits by removing legal and judicial ambiguities governing refusal of treatment and cessation of treatment on demand.

TABLE 1

Guidelines for Arriving at a Clinical Decision Concerning Resuscitation, Unjustified or Excessive Treatment, Refusal of Treatment, or Cessation of Treatment²

- evaluate the clinical condition of the person living with HIV/AIDS
- evaluate his/her decision making competence (see *Legal Issues*)
- if he/she is competent, explain the facts necessary to make an informed decision (see *Legal Issues*). If he/she is not competent, speak to family
- evaluate how the individual currently perceives the quality of his/her life, and how it may be affected by decisions being made
- evaluate the ultimate objective of the specific treatment in question: maintaining life and/or maintaining a quality of life
- obtain the opinion of the care team
- keep a clear record in the individual's chart of all conversations and decisions concerning treatment
- respect any change in the wishes of the person living with HIV/AIDS
- periodically re-evaluate all decisions
- frankly discuss any unreasonable demands made by the person living with HIV/AIDS or his/her family
- provide Palliative Care to improve the individual's physical and psychological comfort, and to provide support for family

ASSISTED SUICIDE AND EUTHANASIA

A person living with HIV/AIDS and severe diabetes develops a bronchopneumonia for which he refuses treatment.

He progresses to a semi-comatose state and you question yourself on the appropriateness of continuing insulin.

This question has never been discussed with the person. Is insulin now fulfilling the objective for which the person had been taking this medication all his life?

Debate continues concerning assisted suicide and euthanasia, particularly within the HIV/AIDS community. While individuals have the accepted right to refuse specific treatment, even by advanced directive, the right to aid or abet a suicide is not legally recognized (see *Legal Issues*). The third party (physician or other) who assists with suicide or provides euthanasia is not insulated from criminal and civil culpability.

Persons living with HIV/AIDS often involve caregivers in questions about euthanasia and assisted suicide. It is difficult to answer such questions frankly without dodging the issue. Most requests for euthanasia and assisted suicide are generated by one or more of the following reasons:

- fear of suffering
- loss of mental faculties
- physical pain
- disfigurement
- affirmation of the personal right to self-determination over the act of dying and moment of death
- loss of control
- loss of dignity
- dementia
- rejection of dependence

Again, the caregiver must be honest with the person living with HIV/AIDS. Whether or not assisted suicide and euthanasia are decriminalized or are morally acceptable, the caregiver must understand, respect and support the person living with HIV/AIDS through the decision process. The caregiver's attitudes and availability of Palliative Care may often reduce the perceived need for assisted suicide and euthanasia.

TABLE 2

Basic Guidelines for Handling Requests for Assisted Suicide or Euthanasia

- do not evade controversial questions. Listen actively
- ask open, non-judgemental questions about motives behind the request. Allow the person to express him/herself freely
- ensure that an informed decision is made voluntarily. The person should be free of external social pressures and family constraints, and internal factors like depression
- attempt to decode the request for death. It may mask other silent requests for things he/she might want more than death, like assurance that he/she will not be abandoned
- do not assume that all requests for death can be decoded as a request for something else. Some requests for death are genuine and mean exactly what they say
- ensure that the person has your professional and personal support by providing the best possible Palliative Care
- reassure the person of your respect for his/her choice
- when an explicit, repeated request conflicts directly with the caregiver's moral conscience, or is illegal:
 - do not abandon the person but maintain the dialogue
 - express your perception of the situation, including one's own right to freedom of conscience and any legal constraints
 - seek advice from a trustworthy colleague

Caregivers have the moral obligation to relieve suffering in all its forms, respecting the individual's right to self-determination as much as possible, while facing their own social, personal and professional responsibilities. Compromises are inevitable. Caregivers cannot ignore or elude extreme cases where life can no longer be good in itself, where to live becomes a relative, subjective, or objective burden. In therapeutic decision making, caregivers can no longer avoid weighing the changes in the present and future quality of the person's life occasioned by their decisions.

However, it would be disquieting to see assisted suicide and euthanasia become expedients which allowed society, the individual's loved ones, and the health care team to shirk their duty and fail to provide excellent Palliative Care.

CONCLUSION

"How can we help the individual live and die in such a way that we respect his/her dignity as well as our own?"

Dr. David Roy³

How are we to solve the ethical dilemmas which we must increasingly confront? Who will make the decisions? Using which criteria and principles? Resources are scarce and our pragmatic society, with its pressures for efficiency at any price, is inclined to place increasingly relative value on human life.

Dignity comes from the person, as a caregiver once put it. But it also comes from the view others have of that person. The subjective nature of individual perceptions of dignity and quality of life is influenced by the perceptions that others have of one's own dignity and quality of life. Bearing these concerns in mind will help us resolve many value conflicts which we will encounter. Our personal and social consciences will be tested, no matter what legislative and judicial framework happens to be in place.

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Symptom Management

GENERAL PRINCIPLES

Symptom = any functional evidence of disease or of a person's condition

Pain = an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage.¹

INTRODUCTION

Most individuals living with HIV/AIDS suffer significantly from multiple symptoms, including pain, that are the result of inter-related physiological, psychic changes, and the:

- variable and unpredictable nature of HIV/AIDS
- many concurrent, on-going opportunistic infections
- affects on numerous body systems
- major psycho-social stressors (remember the concept of "total pain/suffering")²
- multiple medications, drug interactions and side-effects

Symptoms, including pain, can:

- occur simultaneously
- affect one or more body function(s)/system(s) at a time
- produce excitation or depression
- lead to other symptoms

PREVALENCE

Data collected from two different study populations suggest the prevalence of symptoms in persons living with HIV/AIDS:

Casey House Hospice, Toronto³
(100 persons)

| Symptom | Prevalence |
|------------------------------|------------|
| Anorexia/weight loss | 91% |
| Fatigue/weakness | 77% |
| Pain | 63% |
| Incontinence (urine/stool) | 55% |
| Shortness of breath | 48% |
| Confusion | 43% |
| Nausea/GI upset | 35% |
| Cough | 34% |
| Anxiety/depression | 32% |
| Visual loss | 25% |
| Skin Breakdown | 24% |
| Constipation | 24% |
| Edema | 23% |
| Psych. issues | 18% |
| Skin problems | 17% |
| Seizures | 16% |
| Fever | 13% |
| Potential for skin breakdown | 6% |
| Dysphagia | 4% |
| Agitation | 1% |

Multi-centre French National Study⁴
(314 persons)

| Symptom | Prevalence |
|---------------------|------------|
| Pain | 52% |
| Tiredness | 50% |
| Anxiety | 40% |
| Sleep Disturbance | 37% |
| Mouth sore | 33% |
| Sadness | 32% |
| Weight loss | 31% |
| Nausea | 28% |
| Fever | 27% |
| Cough | 27% |
| Depression | 24% |
| Diarrhea | 24% |
| Skin problem | 24% |
| Pruritis | 23% |
| Respiratory Problem | 22% |
| Vomiting | 20% |

ASSESSMENT

Symptoms, including pain, are often missed or under-estimated, especially in substance users.

Assessment should include:

- an accurate and thorough history and physical examination:
 - sit comfortably at the same eye level as the person you are talking to
 - use open ended questions
 - listen carefully
 - trust the person's assessment of their symptoms
 - observe facial expressions, body posture and ability to function and interact
 - individualize the use of appropriate measurement tools
- a comprehensive differential diagnosis
- investigations
- frequent reassessment

At all times assessment and investigations should be appropriate for the presentation, stage and context of the person and their illness.

Questions to assess symptoms, including pain, might include:

| | |
|----------------------------|--|
| site | <ul style="list-style-type: none"> • where is the symptom/pain? |
| radiation | <ul style="list-style-type: none"> • does it spread anywhere? |
| timing | <ul style="list-style-type: none"> • how long have you had it? • does it come and go? • when it comes, how long does it last? • is it always there? • is there a particular time of the day that is better or worse? |
| quality | <ul style="list-style-type: none"> • describe the symptom in your own words |
| severity | <ul style="list-style-type: none"> • how severe is it? • on a scale of 0-5 or 0-10, how would you score its intensity/severity (use visual analogue scale, if possible)? |
| aggravating factors | <ul style="list-style-type: none"> • what brings on the symptom/pain? • what makes it worse, i.e. movement, pressure, food? • do several symptoms impact on each other, i.e. pain, nausea, diarrhea, constipation, dyspnea, anxiety? |
| relieving factors | <ul style="list-style-type: none"> • is there anything you can do to decrease it? |
| impact on ADL | <ul style="list-style-type: none"> • does the symptom/pain disturb your sleep (especially pain)? • does it cause you to be depressed or discouraged? • how has it affected your activities, i.e. your job, recreation, sexual function, meal preparation, dressing, social life, hobbies, etc.? |
| previous therapy | <ul style="list-style-type: none"> • which medications or treatments, including complementary therapies, have you tried (ask for the dose, duration, frequency, route of administration)? • which were effective, which ineffective? • did you stop the medication or treatment? If so, why? |
| adverse effects | <ul style="list-style-type: none"> • did you experience any adverse or side-effects? If so, what? |

LOCATING THE PAIN⁵ ▼

Ask patient to point to area of pain

| | | | |
|-----------|--------------------------------|----------------------------|-------------------|
| 你感到那處痛楚 ? | DOVE AVVERTE IL DOLORE? | आप को कहां दर्द होता है ? | ONDE É A SUA DOR? |
| | | | |
| | WHERE DOES IT HURT? | LIEU DE LA DOULEUR? | |

PAIN RATING SCALES⁵ ▼

Show chart to patient and ask

| | | | |
|-------------|--|--|-------------|
| 你痛楚的程度有多大 ? | QUANTO È INTENSO IL DOLORE CHE PROVA? | आप का दर्द कितना गम्भीर है ? | QUANTO DÓI? |
| | <p>NO PAIN AUCUNE DOULEUR 無痛</p> <p>0 1 2 3 4 5 6 7 8 9 10</p> <p>NESSUN DOLORE NÃO HÁ DOR कोई दर्द नहीं</p> | <p>WORST PAIN DOULEUR EXTRÊME 最痛</p> <p>10</p> <p>NESSUN DOLORE NÃO HÁ DOR सब से अधिक दर्द</p> | |
| | HOW BAD DOES IT HURT? | INTENSITÉ DE LA DOULEUR? | |

PAIN RATING FOR CHILDREN 5 YEARS AND OVER⁶ ▼

| | | | | |
|--|--|--|--|--|
| | | | | |
| | | | | |

Children are asked to select the face which most closely resembles the distress felt by them during a specific painful procedure. This measurement is not used generally for chronic pain but for acute pain or discrete painful procedures such as injections, lumbar punctures, etc.

Combined with the visual analogue scale for correlation has been successful in children over one year of age for charting pain. Use the corresponding number below to chart the face.

| | | | | |
|---|---|---|---|---|
| | 4 | 3 | 2 | 1 |
| 5 | | | | |
| | 6 | 7 | 8 | 9 |

MANAGEMENT

Symptoms, including pain, may be:⁷

- reversible if the cause can be treated, i.e. an infection
- non-reversible, if:
 - optimal treatment has already been tried and did not help
 - no direct treatment is available (this is the most relevant in HIV/AIDS)
 - not all treatment options have been accessed, i.e. complementary therapies

At all times, symptom management should strive to:

- be appropriate for the presentation, stage and context of the person and their illness
- enhance perceived “quality of life”
- control all existing symptoms
- offer comprehensive symptom management appropriate to the presentation, stage and context of the person and their illness
- treat the underlying cause(s), where appropriate (refer to *Modules 1–4*)
- anticipate and minimize other potential symptoms and treatment side-effects

As with all therapies, treatment strategies should be individualized and negotiated with each person and his/her family in advance, particularly as some will choose to live with their symptoms rather than risk side-effects from further treatment.

While many symptoms can be successfully managed by competent community care practitioners, as the complexity of the symptoms, medication schedules and potential for drug interactions increases, a skilled interdisciplinary team knowledgeable in various therapies is often required to either consult or take over care in order to achieve optimal results.

Co-ordination of prescribing is essential and can be achieved through collaboration of those prescribing, and the person living with HIV/AIDS, the family and the other caregivers.

ISSUES SPECIFIC TO PAIN^{8,9}

PRESENTATION

Pain is:

- always subjective, i.e. what the person says it is and not what others think it ought to be
- an experience that results from the integration of nerve interconnections leading to (afferent) and from (efferent) the areas of the brain responsible for the perception of pain (thalamus and higher cortical centres).¹⁰ The exact components of the nerve pathways, and the neurologic events that produce the experience of pain, are not totally known⁹

CAUSES

The pain that the person experiences:

- is most often initiated by normal stimulation of chemical, pressure, stretch and temperature receptors (nociceptors) found in varying proportions throughout the skin, blood vessels, muscles, connective tissues, periosteum (bone covering), joints, body organs, etc. (**nociceptive** or **visceral pain**)

| Pain in HIV/AIDS French National Study (n=163) ⁴ | |
|---|------------|
| Mechanism | Prevalence |
| Neuropathic | 21% |
| Digestive | 17% |
| Muscular | 15% |
| Infectious | 14% |
| Bone and joint | 10% |
| Iatrogenic | 4% |
| Psychogenic | 3% |
| Tumour | 1% |
| Unknown | 5% |

- is less frequently the result of abnormal (increased or decreased) nerve function or death. A reduced blood supply (ischemia), irritation, trauma, invasion by tumour or over stimulation may all lead to changes in the electro-chemical function of a nerve, loss of its insulating covering (myelin sheath) or nerve cell death (**neuropathic pain**)
- may be a mixture of nociceptive, visceral and/or neuropathic pains combined (**mixed pain**)
- is influenced by the person’s emotions, sense of well-being and/or psychic distress, activity level, cultural and family expectations and experiences (**total pain**)
- may be made worse by movement, including sitting, standing, ambulating, bending, masticating, swallowing, breathing, urinating, and defecation (**movement pain**)
- may be associated with muscle spasm and/or a variety of other symptoms (associated symptoms)

CHARACTERISTICS

- pain may be constant or intermittent
- each person’s description of their pain will vary based on past experience, culture, language, etc. The words used below exemplify those frequently chosen:

| | Description | Motor, sensory changes | Location |
|--|--|--|--|
| Nociceptive | aching, gnawing, throbbing | normal cutaneous sensation and motor function | well localized |
| Visceral | aching, sharp, penetrating | normal cutaneous sensation and motor function | referred to the cutaneous sites that are characteristic of problems with the particular viscera |
| Neuropathic (nerve compression, irritation which may evolve into nerve damage) | sharp, stabbing, “shooting electrical feeling” | usually normal cutaneous sensation, may be decreased motor function | local or distal to area of nerve irritation (dermatomal), more common/usually occurs in long nerve axons first |
| Neuropathic (nerve damage, infiltration) | burning, tingling, pins and needles | altered cutaneous sensation with hyperalgesia (allodynia) or hypoalgesia (numbness), may be decreased motor function | local and distal to area of nerve damage (dermatomal), more common/usually occurs in long nerve axons first |

Allodynia = an area of altered sensation (decreased or enhanced) in an area of cutaneous sensory deficit during an activity or movement that is not normally painful, i.e. light touch of skin, bed sheets moving across legs

MANAGEMENT

The principles of pain management may be applied to the management of any symptom.

ESTABLISH TYPE OF PAIN

- establish whether nociceptive, visceral, neuropathic or mixed
- distinguish between rest and movement pain

USE MULTIPLE APPROACHES

- modify the disease, i.e. antivirals, antibiotics, chemotherapy, radiation therapy, surgery
- modify the perception of the pain, i.e. medications, education, massage therapy, psychological support, relaxation therapy, therapeutic touch
- modify or interrupt pain transmission pathways, i.e. transcutaneous electrical nerve stimulation (TENS), acupuncture, chiropractic, nerve blocks, neurosurgery
- modify lifestyle, i.e. occupational therapy assessment, physiotherapy, homemaking services

PROVIDE STEPWISE ANALGESIA

1. use analgesics in incremental steps. Keep it simple - become familiar with 1 or 2 medications in each step and know them well

| Step | Analgesic |
|------------------|--|
| 1. mild pain | <ul style="list-style-type: none"> • non-opioids, i.e. ASA, acetaminophen, NSAID's |
| 2. moderate pain | <ul style="list-style-type: none"> • add a weak opioid, i.e. codeine to the non-opioids |
| 3. severe pain | <ul style="list-style-type: none"> • replace the weak opioid with a strong opioid, i.e. morphine, hydromorphone, oxycodone, fentanyl, methadone |

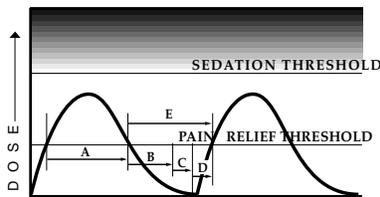
- don't mix agonists, use one at a time (except when using morphine or hydromorphone to manage breakthrough pain when Fentanyl patches are being used)
- avoid medications with potentially toxic metabolites that have a longer half-life than the parent compound, i.e. meperidine, anileridine
- avoid agonist-antagonists and medications with a high incidence of associated side-effects, i.e. pentazocine
- be aware of ceiling effects with weak opioids such as codeine (upper limit of effectiveness is 200-300 mg/24 hours) and the lack of ceiling effect with strong opioids
- convert from one analgesic to the next and from one route of administration to another using appropriate analgesic equivalents (taking into account the differences in first pass effects and active metabolites, see the *Medication Table, Appendix B*)
- minimize the number of different medications and the number of doses to be taken

ROUTE OF ADMINISTRATION

- use the least invasive route of administration i.e. oral tablets or liquids, sublingual, buccal mucosal, suppositories and avoid injections whenever possible
- in the last hours of life, the buccal mucosa is an effective route for administering concentrated liquid opioids. Rarely, parenteral injections or infusion may be preferable if the dose is too high to administer against the buccal mucosa

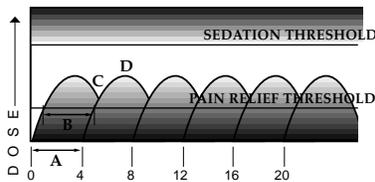
DOSING FOR OPTIMAL PAIN CONTROL⁶

▶ NEVER PRN DOSING



- A. Pain free interval
- B. Pain recurs - patient waits until "needs" to take again
- C. Patient waits, after asking, until meds received
- D. Patient waits for meds to be absorbed
- E. Total time patient is in pain

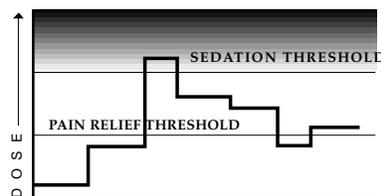
▶ ALWAYS REGULAR DOSING



- A. Drug half life and frequency
- B. Interval of pain relief
- C. As one dose fails, the next is rising
- D. Peak effect stays below sedation threshold

▶ Incremental Titration

Titration is upward over time until there is full pain relief. Once the pain is relieved, careful decreases may be tried if there are side effects.



DOSING

- provide "around the clock dosing" for constant pain at rest, following the basic rules of pharmacology. Never provide prn dosing alone for constant pain
 - initially provide routine doses of immediate release preparations once every half-life, i.e. q4h po or q3h sc for morphine, hydromorphone
 - wait 5 half-lives (until steady state) before increasing the routine dose
- provide breakthrough (prn) dosing for intermittent pain, i.e. extra pain, movement pain
 - initially offer one-half of the routine 4 hourly oral dose every 1 hour (or one-half of the routine 3 hourly sc dose every 30 minutes). Subsequently, increase or decrease the dose based on need
- titrate the dose of medications individually:
 - start at the lower end of the dosing range and work upwards
 - add recurring breakthrough doses into the routine dose once every 5 half-lives, i.e. once per day for most opioids
 - avoid combination medications that limit flexibility
 - never use sustained release products for titration or breakthrough doses
- once the 24 hour dose is stable, minimize the number of doses/day, by using:
 - sustained release preparations, unless there is severe constipation, bowel obstruction or a very rapid transit time, i.e. short bowel syndrome (never cut or crush sustained release tablets), or
 - long acting transdermal medication patches, i.e. Fentanyl (Duragesic[®])
- modify the dosing interval for renal failure, particularly in the last hours of life

CONTINUOUS INFUSIONS

- consider a continuous parenteral infusion, preferably sc, only when the person:
 - is unable to swallow
 - is experiencing intractable nausea
 - has a very rapid transit time, i.e. severe diarrhea and may not be absorbing the medication well
 - has too much medication to swallow, i.e., >800-1,400 mg sustained release morphine q8h

- is experiencing a bolus effect, i.e. toxicity after each dose (usually drowsiness) and pain before the next dose
- has poor pain control and requires rapid titration
- would otherwise use intermittent im or sc injections (iv infusions should be avoided due to increased tachyphylaxis)
- when changing the route of administration convert the dose appropriately, i.e. for either morphine or hydromorphone: po : parenteral (sc, iv, im) \approx 2 : 1
- provide breakthrough (prn) dosing for intermittent pain, i.e. extra pain, movement pain
 - initially offer one-half of the routine 1 hour sc or iv dose every 30 minutes. Subsequently, increase or decrease the dose based on need
- sc infusions are safe even with extreme thrombocytopenia. Any bleeding usually occurs when the needle is removed. Apply pressure appropriately

POTENTIAL SIDE-EFFECTS

- anticipate and educate about potential side-effects, i.e. constipation, nausea/vomiting, dry mouth, drowsiness/sedation, confusion/delirium, urinary retention, twitches/jerks/myoclonus, respiratory depression (rare)
- be prepared to lower the opioid dose significantly if delirium presents along with fever/sepsis (delirium due to a relative opioid excess may be the first sign of sepsis, preceding even the fever)
- know how to manage opioid overdose:
 - if breathing rate is acceptable, hold further opioid, push fluids and wait for the metabolites to clear
 - if breathing rate is too low, administer naloxone appropriately (see *Appendix B, Medication Table*)

ADJUVANT MEDICATIONS

- consider NSAID's for inflammation or visceral pain i.e. arthritis, pleurisy, peritonitis, organomegaly with capsule stretch (ensure adequate cytoprotection, hydration, renal and platelet function)
- steroids may also have a role, but must be considered carefully in light of their potential to further suppress immune function in those who are already compromised
- nitrous oxide or ketamine (Ketalar®) may be useful for painful manoeuvres, movement or painful dressing changes
- see specific pain sections for other adjuvant therapies

COMPLEMENTARY THERAPIES

The holistic approach that is so much a part of Palliative Care has been integral to the “complementary therapies” for centuries. “Complementary therapies” include a variety of natural-based remedies and techniques (see page 32) and are often referred to as “alternative therapies” to indicate their distinction from standard medical practices. However, the term “complementary therapy”

emphasizes the fact that these remedies and techniques can be used in conjunction with allopathic, pharmaceutical treatments to lower medication dosages, reduce symptoms or side-effects or even substitute for other medications altogether. As favourable results have been suggested with a wide range of complementary therapies, you are encouraged to seek further information.¹¹

EDUCATE

- provide ongoing teaching and support about:
 - choice of medications
 - dosing schedules
 - use of breakthroughs for routine vs. extra/movement pain
 - potential side-effects and strategies for their control
 - issues of addiction, dependence, and tolerance

CHILDREN

There are a number of issues in the management of symptoms, including pain, in infants and children which are different from adults, and require special consideration and consultation, when appropriate:

ASSESSMENT

- children do not complain in the same way as adults do
- the stage of cognitive development affects the expression and presence of symptoms and signs (and the understanding of treatment)
 - caregivers need to be educated about the interpretation of symptoms and signs
- observation may have to replace self-reporting in very young children who are unable to communicate effectively:
 - observational rating scales need to be age appropriate
 - a consistent caregiver should do the observations wherever possible
- children may have intense fears of separation and of procedures. This may affect assessment

MEDICATION ADMINISTRATION

- children may not be able to swallow pills or tolerate intramuscular injections
- many drugs are not commercially available in appropriate pediatric doses or dosage forms:
 - your pharmacy may be able to make special liquid preparations appropriate for your situation
- compliance may be a significant problem:
 - getting children to take oral medication may be difficult
 - developmental factors may lead to poor compliance
- myths about pharmacotherapy in children need to be dispelled to avoid under-treatment

DOSING

- the doses of most drugs need to be adjusted according to body weight
- immature metabolism in infants may necessitate lower dosages
- faster elimination may result in the need for relatively higher doses than in adults
- with some medications, idiosyncratic toxicity may occur in young children, i.e. valproic acid
- fixed-dose combinations may be best avoided if they do not allow for optimal dosing of each component medication
- experience with medications in children is often quite limited and the optimal dosing and range of toxicity may not be known

OTHER THERAPIES

- medication should be combined with other interventions including:
 - play, stories, games to refocus attention/distract
 - breathing/relaxation exercises
 - imagination/self-hypnosis to reduce pain

PERSONS LIVING WITH HEMOPHILIA AND HIV/AIDS^{12, 13}

Hemophilia is a sex chromosome (X) linked genetic disorder resulting in reduced quantities or absence of specific blood clotting proteins:

- Hemophilia A = Factor VIII deficiency
- Hemophilia B = Factor IX deficiency

As a result, bleeding, generally into joints and muscles, occurs when there is minimal to severe trauma, or when surgery or an invasive procedure is performed. To stop the bleeding, missing clotting factors must be replaced by intravenous infusion of factor concentrates.

Between 1979 and 1985, 850 Canadians living with Hemophilia became infected with HIV through the use of concentrates manufactured from HIV infected blood. While blood donor screening and viral inactivation procedures virtually eliminated HIV from factor concentrates prepared in Canada by 1985, tragically in 1987, another 10 Canadian hemophiliacs were infected through imported factor concentrates that were contaminated. Since mid-1987, even though human plasma remains the source for concentrates of Factor IX and some of the Factor VIII (recombinant sources for Factor VIII are replacing the human sources), there have been no further reports of contamination or infection.

As Hemophilia is genetically transmitted through the X chromosome from mother (unaffected carrier) to son (affected), one or more male members of the family are likely to be affected. Given the penetration of the genetic defect, some families are living with, or have lost, several members of their family who have been infected with HIV/AIDS.

COMPLICATIONS

| | |
|--|---|
| pain | <ul style="list-style-type: none"> multiple bleeds into joints may lead to joint damage, arthritis and pain ensure that pain is well controlled, encourage analgesics prior to activity (see Arthralgia/Myalgia-hemophilia and Bleeding-hemophilia) |
| bleeding | <ul style="list-style-type: none"> when bleeding occurs, replacement factor must be given promptly and in adequate doses (see Bleeding-hemophilia) |
| impaired mobility | <ul style="list-style-type: none"> impaired mobility can be due to: <ul style="list-style-type: none"> bleeding into joints and muscles joint deformity arthritis joint replacements decreased muscle strength, weakness and fatigue to improve mobility: <ul style="list-style-type: none"> encourage the person to voice his/her own physical limitation related to activity allow for adequate rest periods organize a safe environment to promote independence and to prevent injury provide appropriate assistive devices ensure that available orthotic devices or special shoes are used when ambulating |
| other blood transmitted viruses | <ul style="list-style-type: none"> the presence of Hepatitis B and C has seriously compromised the health of those living with hemophilia/HIV. A high frequency of liver impairment may be further complicated by cirrhosis or hepatoma and may have implications for the use of anti-retrovirals and other medications the risk of bleeding may be increased further as the liver fails to produce other clotting factors and as the bone marrow fails to produce adequate platelets. Bleeding may occur spontaneously into mucous membranes, soft tissues and the brain. |

To ensure optimal care of the patient with hemophilia and HIV/AIDS, close collaboration with the hemophilia comprehensive care centre must be maintained.

HIV+ SUBSTANCE USERS

When we discuss the client-centered care model, it is important to consider both harm reduction and options (see *HIV+ Substance Users in Palliative Care*). Harm reduction within this model takes into consideration medication which will probably reduce the harm caused by other substances being used. The following examples may be taken into consideration:

| | ISSUES FOR SUBSTANCE USERS | OPTIONS |
|---|---|--|
| opioids (codeine, morphine, heroin, hydromorphone, methadone, pentazocine) | <ul style="list-style-type: none"> higher tolerance to morphine derivatives hepatic failure | <ul style="list-style-type: none"> increase dose shorten interval between doses (following principles of pharmacology) choose a morphine derivative that acts selectively with other receptors, i.e. replace morphine with methadone (see below) monitor dosages carefully to avoid overdosing and consequent side-effects |
| | <ul style="list-style-type: none"> withdrawal | <ul style="list-style-type: none"> treatment of symptoms (clonidine, benzodiazepines, anti-spasmodics, anti-inflammatories) increase methadone by 10mg q 1-2 days until withdrawal symptoms disappear |
| | <ul style="list-style-type: none"> drug interactions - phenytoin, rifampin and rifabuton (Mycobutin®) increase elimination of methadone | <ul style="list-style-type: none"> increase methadone doses to compensate |
| | <ul style="list-style-type: none"> drug interactions - simultaneous use of agonist and antagonist or agonist/antagonist, i.e. pentazocine, can rapidly provoke withdrawal symptoms | <ul style="list-style-type: none"> avoid mixing medications |
| Benzodiazepines (Valium®, Librium®, Ativan®, Halcion®, etc.) | <ul style="list-style-type: none"> higher tolerance to benzodiazepines | <ul style="list-style-type: none"> increase dose shorten interval between doses (following principles of pharmacology) use longer-acting benzodiazepines |
| Alcohol | <ul style="list-style-type: none"> cross-tolerance to benzodiazepines | <ul style="list-style-type: none"> increase dose of benzodiazepines shorten interval between doses of benzodiazepines (following principles of pharmacology) use longer-acting benzodiazepines |
| | <ul style="list-style-type: none"> hepatic failure | <ul style="list-style-type: none"> the pharmacokinetics of certain medications can be altered. Adjust dosages and dosing intervals appropriately |
| Cocaine | <ul style="list-style-type: none"> withdrawal | <ul style="list-style-type: none"> use longer-acting benzodiazepines |

| | | |
|----------------------------------|---|---|
| | <ul style="list-style-type: none"> • hepatic failure | <ul style="list-style-type: none"> • the pharmacokinetics of certain medications can be altered. Adjust dosages and dosing intervals appropriately |
| | <ul style="list-style-type: none"> • withdrawal | <ul style="list-style-type: none"> • use benzodiazepines for acute withdrawal • bromocriptine or amantadine to reduce the craving |
| Methadone | <ul style="list-style-type: none"> • Methadone is a potent opioid analgesic that demonstrates incomplete cross tolerance with other Mu-opioid receptor agonist analgesics. Although there has been no research into the palliative use of methadone in the opioid tolerant person with pain and HIV/AIDS, conversion of the opioid tolerant person with cancer-related pain to methadone has suggested that methadone may represent an important therapeutic option for the management of this difficult problem.¹⁴ It is strongly recommended that more research be conducted into the use of methadone in Palliative Care in an effort to provide an optimum quality of life by minimizing potentially harmful medications. | |
| Medicinal THC, (cannabis) | <ul style="list-style-type: none"> • although the use of cannabis sativa is illegal, some who have used it previously, refuse to stop using it as they feel it reduces their nausea and stimulates their appetite, especially when these symptoms are problems in HIV/AIDS. Synthetic cannabinoids may provide effective alternatives (see <i>Symptom Management – Anorexia/cachexia, Asthenia, and Nausea/vomiting/retching and Appendix B, Medication Table</i>) | |

As can be seen by the above examples, choices and harm reduction strategies are available, though further research is necessary in order to effectively judge their merits.

OTHER SYMPTOM MANAGEMENT ISSUES

Symptoms other than pain share management issues similar to those for pain. Use the symptom management and medication tables as a reference guide to refresh your current knowledge and stimulate the acquisition of new treatment strategies, not as a cook book.

In the sections that follow:

- emphasis is placed on the management of adults. However, except as noted earlier in this section and in the text that follows, the overall strategies are similar for infants and children. You are also encouraged to refer to *Module 2: Infants, Children, Youth*
- when reviewing the lists of potential presentations and causes for each symptom, remember that many may be occurring/ present simultaneously
- multiple medications have been included with brief prescribing information. More detailed dosing information for adults, appropriate dosing for infants and children, potential side-effects and drug interactions may be found in the *Appendix B, Medication Table* and in the references
- For the most part suggestions for consultations have not been included. Become familiar with the resources in your area and consult them when needed.

COMPLEMENTARY THERAPIES

ACUPUNCTURE

Acupuncture is an ancient Chinese treatment involving the insertion of very fine sterile needles into the body at specific points according to meridian charts (pathways of energy). It is used by many people to control painful conditions such as headaches, arthritis and low back pain, as well as non-painful problems such as allergies and withdrawal symptoms when stopping drugs or cigarettes. Although often used on its own, it is more authentically used when it is part of an overall program of traditional Chinese medicine which incorporates an intricate theory and practice involving pulse diagnosis, balancing of element/organ relationships, and the use of herbs.

AROMATHERAPY

Aromatherapy is the therapeutic use of natural oils extracted from flowers, seeds, roots and fruits. Aromatherapists are trained to choose an oil appropriate to the need, i.e. certain odours can relax, stimulate or help to alleviate depression. They are generally applied as part of a massage therapy session, used in the bath, or taken by inhalation.

CHIROPRACTIC

Chiropractic is a method of care which employs manipulation of the spine, pelvis and other articulating joints to restore mobility, ease pain and stimulate the body's own balancing of function. In addition to manipulation, practitioners may employ massage, stretching techniques, electrotherapy to facilitate the treatment.

HOMEOPATHY

Homeopathy is an approach to health based on the principles developed by Dr. Samuel Hahnemann in Germany in the 1790's. By administering very diluted doses of one of 2,000 natural substances which in their raw form would either cause, or in some way reflect the person's complaint, a re-balancing of energy is achieved which markedly alleviates the symptoms. Remedies can be prescribed for rapid, drug-free action on acute symptoms, or for more chronic or constitutional complaints. In both cases this approach recognizes the interaction of physical, emotional and spiritual components in health.

MASSAGE THERAPY

Massage therapy is a healing art comprised of specific techniques designed to promote circulation, enhance lymphatic flow and ease musculoskeletal pain. Treatments are either full-body or area-specific and generally involve the use of oils, creams or powder. Massage can help to maintain skin durability (particularly at pressure points over bony prominences), aid in respiration, allay symptoms of abdominal cramping and nausea, and above all, afford a relaxed sense of well-being.

SHIATSU

Shiatsu is a Japanese word meaning "finger pressure", although in actual treatments thumbs, palms and elbows are also used. It is based on the Chinese theory of medicine which identifies meridian lines which relate to the internal organs. According to the principles of Oriental medicine, when energy becomes blocked or sluggish, systemic imbalances and various symptoms can occur. By applying sustained pressure along the meridians, the Shiatsu therapist stimulates the body's healing abilities.

THERAPEUTIC TOUCH

Each person has localized energy fields which extend beyond the body. In health, life energy flows freely throughout the body. In disease, these energy fields get blocked or depleted. Through therapeutic touch techniques, the therapist "tunes into" blocked areas by detecting a change in temperature which indicates a blocked energy field. The therapist directs life energy into the person to restore balance within the body.

Symptom Management

GENERAL PROBLEMS

ANOREXIA/CACHEXIA, ASTHENIA

Anorexia = lack or loss of appetite

Asthenia = lack or loss of strength and energy, including fatigue, lassitude, generalized weakness

Cachexia (wasting) = a state of malnutrition characterized by a significant loss of body weight, adipose tissue and muscle mass

Generalized weakness = the anticipatory subjective sensation of difficulty initiating activity

PRESENTATIONS

May include:

- anorexia
- cachexia, particularly of fat and muscles
- fatigue, lethargy
- nausea (chronic)
- peripheral edema (associated with hypoalbuminemia)
- asthenia
- muscle pain, spasm, weakness
- drowsiness
- pallor
- areas of skin erythema or breakdown

CAUSES

Infectious:

- HIV wasting syndrome
- opportunistic infections (all causes)

Malignant:

- Kaposi's sarcoma
- lymphoma
- squamous cell carcinoma

Other:

- anemia
- economic or social debilitation making self care difficult
- malabsorption including lactose intolerance
- medication side effects (including chemotherapy)
- psychological
- reduced dietary intake

APPROACHES AND INTERVENTIONS

Examination, investigation and treatment of underlying causes should be appropriate to the presentation, stage and context of the person and illness.

- reduce medications where possible
- space out activities over time
- practice energy conservation (occupational therapy)
- encourage active and passive exercises (physiotherapy)
- if bed-dependent, turn q2h
- provide support for loss of body image, self esteem (see *Activities of Daily Living*)

| PROBLEMS | INTERVENTIONS |
|--|---|
| altered taste | <ul style="list-style-type: none"> • choose foods that address preference for salt or sweet • may wish to increase seasoning, marinate foods • drink more fluids |
| anemia | <ul style="list-style-type: none"> • transfuse to correct anemia, if symptomatic, particularly if hemoglobin <75. May improve exertional fatigue for mobile individuals. Transfuse HIV + individuals with CMV negative blood |
| anorexia | <p>To stimulate appetite:</p> <ul style="list-style-type: none"> • try small quantities of alcohol before meals (not in children) • megestrol acetate 40 mg od-160 mg tid (doses up to 800 mg/24 hrs may be useful, particularly in early HIV/AIDS. May be very expensive. • steroids: (in decreasing order of choice) <ul style="list-style-type: none"> – prednisone 10-40 mg po od or dexamethasone 1-4 mg po od-q6h – nandrolone 25-50 mg im q1wk – nandrolone decanoate 50-100 mg im q3-4wks – depo-testosterone 200-400 mg im q3-4wks • consider homeopathy: alfalfa tincture 8-10 drops in 70 mls water ac tid |
| autonomic dysfunction, postural hypotension | <ul style="list-style-type: none"> • ensure adequate hydration • mobilize slowly • fludrocortisone 100 µg po od-bid • steroids as above |
| difficulty taking and/or keeping oral fluids and foods¹⁵ | <ul style="list-style-type: none"> • may be due to dysphagia, odynophagia, nausea/vomiting/retching, reflux, regurgitation, head/neck pain and/or problems • to improve esophageal peristalsis and gastro-esophageal sphincter tone: <ul style="list-style-type: none"> – metoclopramide 5-10 mg po, im, iv tid-qid, 1/2 hr ac + hs, or – domperidone 5-20 mg po, tid-qid, 1/2 hr ac + hs, or – cisapride 5-10 mg po tid-qid, 1/4 hr ac + hs or 20 mg po bid • consider naso-gastric, gastric or jejunal tube feeding, especially if dysphagia is reversible • total parenteral nutrition may improve nutrition and serum albumin in early illness and selected cases (not useful in end-stage HIV/AIDS) - see Dehydration |
| reduced nutritional intake or increased metabolic need (i.e. tumour)¹⁶ | <ul style="list-style-type: none"> • assess dietary needs and preferences, nutrition consult may be helpful • choose high caloric and/or high protein fluids and foods • vitamin supplementation • commercial caloric and/or protein supplements (can be diluted with water or ice chips, especially if difficult to swallow or producing diarrhea) • pay attention to food presentation and feeding: <ul style="list-style-type: none"> – prepare small frequent meals – choose food of a consistency which is palatable, easy to chew and swallow |

| | |
|----------------------|--|
| | <ul style="list-style-type: none"> – use appropriate feeding technique, i.e. feed on the same level, let the person take the food, do not rush – provide appropriate environment, socialization to stimulate eating, accompany the person while eating |
| malabsorption | <ul style="list-style-type: none"> • maintain lactose free diet or use lactase enzyme tablets • elemental enteral feeding supplements (isotonic, 30% fat, medium chain triglycerides) |

COMPLEMENTARY THERAPIES

- acupuncture may boost energy
- aromatherapy:
 - for energy, mixtures of bath oils can be made by aromatherapist
- Swedish massage
- therapeutic touch
- traditional Chinese medicine

ARTHRALGIA, MYALGIA

Arthralgia = pain in joint(s)
Myalgia = pain in muscle(s)

PRESENTATIONS

May be a constant achiness in one or more joints or muscles. May get worse with activity.

CAUSES

ARTHRALGIA

Infectious:

- infective arthropathies

Other:

- joint stiffness from lack of movement
- other arthropathies:
 - osteoarthritis
 - psoriatic arthritis
 - rheumatoid arthritis

MYALGIA

Infectious:

- HIV myositis
- drug induced
 - AZT
 - cotrimoxazole

Other:

- denervation:
 - muscle spasm
- flexion contractures
- medication side-effects
- night-time leg cramps
- non-specific manifestation of a systemic viral infection

APPROACHES AND INTERVENTIONS

Examination, investigation and treatment of underlying causes should be appropriate to the presentation, stage and context of the person and illness.

- reduce the risk of joint stiffness, muscle spasm, contraction flexures, and position fatigue, by keeping joints and muscles warm and moving, through intermittent active or passive exercise

| PROBLEMS | INTERVENTIONS |
|--|--|
| pain, joint stiffness | <ul style="list-style-type: none"> NSAID's may reduce pain, joint stiffness due to inflammation <ul style="list-style-type: none"> - see Pain - stepwise analgesia chiropractic for musculoskeletal pain homeopathy: <ul style="list-style-type: none"> - for aching muscles, arnica cream topically - for stiff joints, Rhus toxicodendron 30 ch bid qam and qhs |
| bleeding in hemophilia^{12, 13} | <ul style="list-style-type: none"> where there is an increase in, or a new site of pain, bleeding must be considered to manage pain due to bleeding into joints or muscles: <ul style="list-style-type: none"> - manage associated bleeding (see Bleeding - hemophilia) - ice may be used to relieve the initial pain and reduce swelling - provide stepwise analgesia (see Pain) do not use ASA as this binds irreversibly with platelets NSAID's may be needed, however, they should be used with caution as they interfere with platelet function (reversibly) and are potentially dangerous in hemophilia where parenteral medications are required, use only the iv or sc routes of administration. Do not give im injections as they may induce bleeding |
| muscle spasm | <ul style="list-style-type: none"> for neurologically related spasm: <ul style="list-style-type: none"> - diazepam 5–10 mg po q6–8h prn - dantrolene (Dantrium®), start with 25 mg po od, increase by 25 mg per day up to 25–50 mg po bid-qid - baclofen, start with 5 mg po tid, increase q3 days up to 20 mg po tid if required for musculo-skeletal related spasm: <ul style="list-style-type: none"> - diazepam 5-10 mg po q6–8h prn - cyclobenzaprine (Flexeril®) 10 mg po bid-qid - orphenadrine (Norflex®) 100 mg po bid or 60 mg im, iv bid (for acute skeletal muscle spasm) - methocarbamol (Robaxin®) 6–8 g po od for 2–3 days, then reduce to 500-1000 mg po tid-qid aromatherapy: for muscle tension, rosemary and lavender used in massage |
| night-time leg cramps | <ul style="list-style-type: none"> quinine sulphate 200–300 mg po qhs prn |

COMPLEMENTARY THERAPIES

- acupuncture
- Swedish Massage

BLEEDING

Hematuria = blood in the urine

Petechia = small, round, non-raised purplish red spots caused by intradermal or submucosal hemorrhages

Ecchymosis = extravasation of blood under the skin

Hemoptysis = coughing up blood or blood stained sputum

Purpura = area(s) of confluent petechiae or ecchymosis

PRESENTATIONS

May include:

- bleeding problems specific to hemophilia
- bruising
- hematuria
- petechia
- upper and lower GI bleeds, including oral cavity
- bleeding tumour(s)
- ecchymosis
- hemoptysis
- purpura

Bleeding problems specific to persons with hemophilia:^{12, 13}

Minor Bleeding Episodes

- early bleeding into joints or muscles
- prolonged nose bleeds or severe gum bleeding
- urinary bleeding lasting more than several days (check with the attending physician first)

Major Bleeding Episodes

- advanced joint or muscle bleeding
- neck, tongue or throat hematoma
- following head injury, with or without symptoms
- following severe physical trauma
- severe abdominal pain
- gastrointestinal bleeding (vomiting blood, bleeding through rectum, or black, tarry stools)
- any bleeding that suggests nerve entrapment
- psoas muscle bleed

CAUSES

Infectious:

- pneumonia
- TB
- UTI
- sepsis

Malignant:

- Kaposi's sarcoma
- squamous cell carcinoma
- lymphoma

Other:

- hemophilia
- hepatic dysfunction (all causes)
- thrombocytopenia
 - HIV related ITP
 - ITP
 - other
- trauma

APPROACHES AND INTERVENTIONS

Examination, investigation and treatment of underlying causes should be appropriate to the presentation, stage and context of the person and illness.

- consider misoprostol prophylaxis 100–200 µg po q12h–q6h in persons who will use NSAID's, steroids and have a history of bleeding, gastritis or severe anorexia/cachexia
- use standard principles for the management of bleeding:
 - maintain good hydration
 - transfuse to maintain appropriate hemoglobin, hematocrit, coagulation, platelet count. Use CMV negative blood/plasma in those who are HIV +
 - consider vitamin K₁ injections 10 mg iv or fresh frozen plasma

| PROBLEMS | INTERVENTIONS |
|---|---|
| hematuria, urinary tract infection (UTI) | <ul style="list-style-type: none"> • maintain good urinary output • minimize local trauma, i.e. catheter • irrigate bladder to remove clots |
| thrombocytopenia | <ul style="list-style-type: none"> • AZT (refer to <i>Module 1</i>) • prednisone 40-60 mg po od for 1-2 weeks then taper to maintenance dose • transfuse platelets only if required (rare) • consider splenectomy, as a last resort if it will enhance symptom control and the prognosis warrants it |
| medication related bleeding | <ul style="list-style-type: none"> • discontinue responsible medication(s) • if NSAID related <ul style="list-style-type: none"> – initiate misoprostol 200µg po q6h – consider covering gastric ulcers with sucralfate 1 gm po q6h 1 hr ac+hs • if associated gastritis, consider antacids (see Odynophagia-hyperacidity) • if duodenal bleeding, consider H₂ receptor inhibitors <ul style="list-style-type: none"> – Ranitidine® 150 mg po bid or 50 mg iv tid – Omeprazole® 20-40 mg po od |
| skin and tumour bleeding | <ul style="list-style-type: none"> • manage small bleeding sites with silver nitrate sticks • more extensive bleeding may require the application of: <ul style="list-style-type: none"> – topical thrombin 1,000–5,000 units sprayed on bleeding site (Thrombostat®) – Kaltostat™ dressing – epinephrine 1:1000 dabbed or sprayed on bleeding site – absorbent pressure dressings • if risk of large bleeds, warn family and caregivers of potential risks and develop a clear management plan which may include: <ul style="list-style-type: none"> – removal of family from the room – use of red or coloured towels • provide adequate analgesia, sedation |
| problems specific to hemophilia^{12, 13} | <ul style="list-style-type: none"> • take special precautions to minimize the risk of falling, especially in those who are weak and fatigued • where there is an increase in, or a new site of pain, bleeding must be considered • to manage bleeding: <ul style="list-style-type: none"> – ensure that a supply of the appropriate factor is kept in your local blood bank and the person's home (obtainable from the local Red Cross) – when bleeding occurs, infuse the clotting factor over 5 minutes through a 22 gauge medicut or 25 gauge butterfly needle, then flush the line with 25 mls of N/S and discontinue the iv access. As each unit of Factor VIII / kg body weight increases the factor concentration by 2%, and each unit of Factor IX / kg body weight increases the factor concentration by 1%: (see next page) |

1. for **Hemophilia A** and:

- **minor bleeds**, infuse 15 units of Factor VIII / kg of body weight to increase the factor concentration by 30%
- **major bleeds**, infuse 25 units of Factor VIII / kg of body weight to increase the factor concentration by 50%
- **head injuries**, infuse 50 units of Factor VIII / kg of body weight to increase the factor concentration by 100%

2. for **Hemophilia B** and:

- **minor bleeds**, infuse 20 units of Factor IX / kg of body weight to increase Factor IX concentration by 20%
- **major bleeds**, infuse 40 units of Factor IX / kg of body weight to increase Factor IX concentration by 40%
- **head injuries**, infuse 70 units of Factor IX / kg of body weight to increase Factor IX concentration by 70%

– as Factor VIII has a half-life of 8-12 hrs and Factor IX has a half-life of 12-24 hrs, a second infusion may be necessary within 12-24 hrs if bleeding continues

- to reduce the risk of bleeding, especially where there is a risk of seizures (that could lead to injury), consider infusing the missing factor 2-3 times per week prophylactically
- manage associated pain (see Arthralgia, Myalgia/hemophilia)
- where parenteral medications are required, use only the iv or sc routes of administration. **It is advisable not to give im injections** as they may induce bleeding. Depending on the severity of hemophilia, im injections in severe hemophilia may require Factor VIII/IX before and several days after the injection

DEHYDRATION

Anuria = no urine output

Oliguria = reduced urine output, usually dark in colour

Poor skin turgor = reduced fullness of skin, increased wrinkling, often dry, flaking

Xerostomia = dryness of mouth from lack of normal secretions

PRESENTATIONS

May include, even in the presence of ascites, peripheral or pulmonary edema:

- anuria
- asthenia
- fatigue
- light-headedness, dizziness, orthostatic hypotension
- poor skin turgor
- thirst
- xerostomia

CAUSES

Other:

- reduced fluid intake
- fluid loss due to sweating, fever, diarrhea, nausea and vomiting, etc.
- hypoalbuminemia

APPROACHES AND INTERVENTIONS

Examination, investigation and treatment of underlying causes should be appropriate to the presentation, stage and context of the person and illness.

- always check for postural hypotension
- carefully monitor fluid intake and output
- address issues that are limiting fluid intake or causing excess fluid losses
- reduce elevated body temperature (see Fever)
- **do not overhydrate**, especially in the cachectic person with hypoalbuminemia (monitor skin turgor and minimize ascites, peripheral and pulmonary edema)
- the syndrome of inappropriate anti-diuretic hormone secretion (SIADH) and other electrolyte imbalances may occur in HIV/AIDS

| PROBLEMS | INTERVENTIONS |
|--|--|
| dehydration with normal albumin (normal oncotic pressure) | To rehydrate <ul style="list-style-type: none"> • initially, replace intravascular volume with salt and fluids, then • replace free water and continue to correct electrolyte imbalances • do not over-hydrate |
| dehydration with hypoalbuminemia (reduced oncotic pressure) | To rehydrate <ul style="list-style-type: none"> • initially, carefully replace intravascular volume with salt and fluids. With a lower albumin, you will need less salt and fluid replacement, then • carefully replace free water • do not over-hydrate (watch closely for peripheral and pulmonary edema) • it may not be possible to correct electrolyte imbalances |
| hypoalbuminemia | <ul style="list-style-type: none"> • increase protein intake (if possible) • albumin infusions are not appropriate. The infused albumin is rapidly catabolized and does not correct hypoalbuminemia |

HYDRATION TECHNIQUES

Rehydration may be accomplished by several routes of administration:

| ROUTE OF ADMINISTRATION | SALT SOURCES | FLUIDS WITH MINIMAL SALT |
|-------------------------|--|---|
| oral | <ul style="list-style-type: none"> • club soda, soups, "red" vegetable juices, i.e. tomato, V8, commercial salt and fluid replacement solutions (sport and medical) • extra salt on foods • popcorn, potato chips, nuts • do not push salt intake to the point that it is nauseating | <ul style="list-style-type: none"> • soft drinks, juices (other than "red" vegetable juices), water, mineral waters • tea, coffee and alcohol are diuretics |
| intravenous | <ul style="list-style-type: none"> • normal or half-normal saline (N/S) • Ringer's lactate • others | <ul style="list-style-type: none"> • dextrose and water • half-N/S • 1/3 saline, 2/3 dextrose and water • others |

| ROUTE OF ADMINISTRATION | SALT SOURCES | FLUIDS WITH MINIMAL SALT |
|---|--|---|
| <p>subcutaneous (hypodermoclysis)</p> <ul style="list-style-type: none"> – inject 150 units of hyaluronidase at the needle site before starting infusion (optional) – then infuse 1,000–1,500 mls per 24 hours, rate as tolerated | <ul style="list-style-type: none"> • N/S | <ul style="list-style-type: none"> • not used for sc rehydration |
| <p>rectal</p> <ul style="list-style-type: none"> – route of last choice – not indicated with diarrhea, anal or rectal problems – insert small pediatric feeding tube pr – then instill 250 mls q1h up to 500 mls and wait several hours before repeating | <ul style="list-style-type: none"> • warm N/S | <ul style="list-style-type: none"> • not used for rectal rehydration |

| LAST HOURS | INTERVENTION |
|--|---|
| <p>dehydration¹⁷</p> | <ul style="list-style-type: none"> • iv/sc hydration is only useful if condition is reversible and should not be started during the last hours of living unless there is a clear indication for it • isotonic dehydration may be protective as increased ketones may induce some anesthesia • the individual will suffer from dehydration: <ul style="list-style-type: none"> – if free water consumption leads to hyponatremia (may produce nausea) – if mucous membranes dry out and become painful – if feeling thirsty • rehydration may settle terminal delirium if dehydration is a factor • see Dysphagia |
| <p>dry mucous membranes</p> | <p>Eyes</p> <ul style="list-style-type: none"> • keep conjunctiva moist with: <ul style="list-style-type: none"> – artificial tears or N/S 2 drops each eye q1h prn, especially when eye is open, or – ocular lubricant, i.e. Lacri-lube™ • the eye lid may not be able to close properly when the eyeball sinks back into its socket, (as the fat behind the orbit disappears in extreme anorexia/cachexia) <p>Lips and Nares</p> <ul style="list-style-type: none"> • reduce evaporation from exposed mucous membranes by applying a thin layer of petroleum jelly or other moisturizer, i.e. Secaris™ q1h prn (caution: avoid petroleum products with plastic tubing, i.e. nasal prongs) |

dry mucous membranes

Mouth and Teeth

- keep moist and clean using baking soda mouthwash q30-60 min prn (1 tsp baking soda, 1 tsp salt, 1 quart tepid water)
- avoid commercial mouthwashes
- do not insert fingers beyond the teeth (avoid bites)
- apply mouthwash and any medications with sponge swabs
- avoid lemon-glycerine swabs (while these are stimulating in the individual who can produce saliva, the glycerol is desiccating and the lemon irritating in the individual with xerostomia)
- cover oral ulcers with topical anesthetics
- dab candida with mycostatin suspension
- a humidifier may reduce drying (be careful not to increase risk of respiratory infections)

EDEMA, LYMPHOEDEMA, ASCITES

Edema = accumulation of excessive fluid in extracellular spaces

Lymphoedema = accumulation of excessive lymph fluid in extracellular spaces

Ascites = accumulation of excessive serous fluid in the abdominal cavity

PRESENTATIONS

May appear in:

- | | |
|---------------|------------------|
| • abdomen | • back |
| • conjunctiva | • feet and legs |
| • genitals | • hands and arms |
| • head/neck | • lungs |

Edema of subcutaneous tissues may be **pitting** (due to serous fluid leakage from blood vessels) or **non-pitting** (due to chronic lymphatic fluid leakage from blocked lymphatic drainage channels).

CAUSES

PITTING PERIPHERAL EDEMA

Malignant:

- Kaposi’s sarcoma
- lymph node obstruction

Other:

- congestive heart failure (CHF)
- dependent (postural) edema
- hypoalbuminemia
- over-hydration
- thrombosis
- venous insufficiency
- venous obstruction

NON-PITTING PERIPHERAL EDEMA

Malignant:

- Kaposi’s sarcoma
- lymphoma

ASCITES

Malignant:

- Kaposi’s sarcoma
- lymphoma

Other:

- CHF
- hypoalbuminemia
- liver congestion
- over-hydration

PULMONARY EDEMA

Other:

- CHF
- over-hydration
- uremia

- manage salt and fluid balance carefully, do not over-hydrate
- elevate and/or carefully support edematous and dependent part(s) of the body to move fluids and reduce risk of skin breakdown (see Skin care/problems)

APPROACHES AND INTERVENTIONS

Examination, investigation and treatment of underlying causes should be appropriate to the presentation, stage and context of the person and illness.

| PROBLEMS | INTERVENTIONS |
|--------------------------|--|
| ascites | <ul style="list-style-type: none"> • diuretics may be helpful if albumin is not too low. Start gently and increase dose as appropriate: <ul style="list-style-type: none"> – spironolactone 50–250 mg po od-bid and/or – furosemide 20–120 mg po od (caution: excessive diuresis may produce postural hypotension, especially in presence of hypoalbuminemia) • consider paracentesis if symptomatic (abdominal discomfort or pain, dyspnea, orthopnea) and appropriate for the stage of the illness |
| non-pitting edema | <ul style="list-style-type: none"> • elevate and support edematous and dependent limbs • protect skin, especially at points of contact (see Skin Care/problems) • manage concurrent pitting edema • steroids may reduce obstruction causing edema: <ul style="list-style-type: none"> – dexamethasone 1–8 mg po, iv, im sc q6h • consider prophylactic measures to reduce risks of deep vein thrombosis and pulmonary embolism, i.e. heparin 5,000 units sc bid-tid |
| pitting edema | <ul style="list-style-type: none"> • elevate and support edematous, dependent limbs • protect skin, especially at points of contact • diuretics may be helpful if albumin is not too low. Start gently and increase dose as appropriate: <ul style="list-style-type: none"> – spironolactone 50–250 mg po od-bid – furosemide 20–40 mg po, iv od • use Tedd™ stockings to compress edematous legs • if there is no skin breakdown consider using a sequential lymphoedema pump, i.e. Lymphopress™ to move fluids • consider prophylactic measures to reduce risks of deep vein thrombosis and pulmonary embolism, i.e. heparin 5,000 units sc bid-tid |
| pulmonary edema | <ul style="list-style-type: none"> • manage cough, shortness of breath (see Cough, Dyspnea) • use appropriate cardiac medications to manage arrhythmias, CHF, ischemia • diuretics: <ul style="list-style-type: none"> – furosemide 20–240 mg po, iv prn, or – ethacrynic acid 50–200 mg po, iv • oral nitrates or nitro paste may enhance peripheral venous dilatation • administer oxygen, as appropriate • avoid over-hydration |

COMPLEMENTARY THERAPIES

- massage therapy may help move fluids around (use caution on thin, fragile or leaking skin)

FEVER

Fever = increased body temperature greater than 37.5°C (99.5°F) oral or groin, 38.0°C (100.5 °F) rectal or 37.0°C (98.5 °F) axilla. May result from bacteria and their endotoxins, viruses, yeasts, antigen-antibody reactions, drugs, tumour products or other exogenous pyrogens affecting the thermoregulatory control centres in the hypothalamus.

PRESENTATIONS

May include:

- asthenia
- dehydration
- light-headedness, dizziness
- chills, rigors
- delirium
- sweating, night sweats

CAUSES

Many different causes (refer to Fever and/or night sweats, *Module 1*).

APPROACHES AND INTERVENTIONS

Examination, investigation and treatment of underlying causes should be appropriate to the presentation, stage and context of the person and illness.

- maintain hydration (see Dehydration)
- manage sweating (see Skin Care)
- manage confusion (see Delirium)
- if delirium present, consider reducing opioid dosage

| APPROACHES | INTERVENTIONS |
|-------------------------|---|
| reduce body temperature | <ul style="list-style-type: none"> • acetaminophen or ASA 325–650 mg po, pr q6-8h prn • NSAID’s may be used with caution, especially with neoplastic fever, i.e. ibuprofen 200–400 mg po q4h prn |
| reduce skin temperature | <ul style="list-style-type: none"> • remove excessive bed coverings and/or clothing • avoid plastic bed coverings • cool room and move air over the person (open windows, fan) • bathe skin (cool water, ice water, or alcohol in extremes) |

COMPLEMENTARY THERAPIES

- homeopathy: belladonna 6 ch qid ac + hs, increase to 30 ch bid, if needed

NEUROLOGICAL PROBLEMS

NEUROPATHIC PAIN

PRESENTATIONS

- see Symptom Management, Pain Characteristics

CAUSES

One of the most common causes of pain in advanced HIV/AIDS.

Infectious:

- direct involvement of the nerve with HIV or CMV
- post herpetic neuralgia

Other:

- certain chemotherapeutic agents
- superimposed medical or metabolic processes, including alcoholism

Malignant:

- Kaposi’s sarcoma
- lymphoma
- squamous cell carcinoma

APPROACHES AND INTERVENTIONS

Examination, investigation and treatment of underlying causes should be appropriate to the presentation, stage and context of the person and illness.

- educate about the difference between pain on movement and pain at rest
- if contact with skin produces increased pain, look to methods for minimizing such contact, i.e. positioning, bed cradles to keep bedding off legs/feet

| PROBLEMS | INTERVENTIONS |
|--|--|
| pain due to nerve damage, infiltration | <ul style="list-style-type: none"> • provide stepwise analgesia (see Pain) • tricyclic anti-depressants (TCA’s), i.e. amitriptyline, desipramine, imipramine may be effective and enhance the effect of opioids: <ul style="list-style-type: none"> – start with 10-25 mg at bedtime for 3-5 days – if no adverse effects, increase in 10-25 mg increments every 3-5 days up to 75-150 mg/24 hours – maximal response may take 2-4 weeks • local anaesthetics, membrane stabilizing antiarrhythmics (do not combine with TCA’s) <ul style="list-style-type: none"> – mexiletine: <ul style="list-style-type: none"> • start with 100 mg q8h, increase 100 mg q8h every 3 or more days as needed – flecainide: <ul style="list-style-type: none"> • start with 50 mg po q12h, increase 50 mg q12h every 4 or more days as needed • capsaicin 0.025-0.075% cream, apply to affected areas tid-qid |
| pain due to nerve compression, irritation | <ul style="list-style-type: none"> • provide stepwise analgesia (see Pain) <ul style="list-style-type: none"> – carbamazepine: <ul style="list-style-type: none"> • start with 100-200 mg po q12h, increase to 100-400 mg po tid-qid, monitor therapeutic plasma levels – valproic acid: <ul style="list-style-type: none"> • start with 125 mg po q8h, increase to 250-1,000 mg po q8h as needed – phenytoin <ul style="list-style-type: none"> • start with 100 mg po q8h, monitor therapeutic plasma levels to modify dose as needed – clonazepam: <ul style="list-style-type: none"> • start with 0.5 mg po q12h, increase to 0.5-3.0 mg po q8h as needed |

COMPLEMENTARY THERAPIES

- acupuncture
- chiropractic: lumbar manipulation
- homeopathy: hypericum 6 ch qid + hs, increase to 12 ch tid ac, then 30 ch bid if effectiveness diminishes
- massage therapy
- TENS may provide additional relief, however it is unpredictable
- therapeutic touch

SEIZURES, MYOCLONIC JERKS

Myoclonic jerks = random shock-like contractions or twitches of a portion of a muscle, an entire muscle or a group of muscles in one or more parts of the body

PRESENTATIONS

May include:

- focal motor seizures
- grand mal seizures
- myoclonic jerks

CAUSES

Infectious:

- encephalitis (all causes)
- meningitis (all causes)
- toxoplasmosis

Malignant:

- lymphoma, cerebral

Other:

- medication excess or withdrawal:
 - neuroleptics
 - benzodiazepines
 - opioids
 - medication side-effects:
 - foscarnet
 - metabolic:
 - hypoglycemia
 - hypoxia
 - Na, K, Ca, Mg imbalance
 - uremia
 - substance use
- reduce potential for harm to the person:
 - maintain the airway
 - position on side to minimize the risk of aspiration
 - provide oxygen if available
 - protect from physical injury (but not necessarily restrain)
 - reduce external stimuli
 - rehydrate, especially if myoclonic jerks are secondary to opioid build-up (see Dehydration)
 - reduce or discontinue all medications that are producing CNS excitation or lowering the seizure threshold

APPROACHES AND INTERVENTIONS

Examination, investigation and treatment of underlying causes should be appropriate to the presentation, stage and context of the person and illness.

| PROBLEMS | INTERVENTIONS |
|---------------------|--|
| seizures | <ul style="list-style-type: none"> • to control acute seizures <ul style="list-style-type: none"> – diazepam 10 mg iv, pr q5–10 min prn – lorazepam 3-4 mg iv, sc q 5–10 min prn – midazolam 1-5 mg iv, im, sc q1h prn – phenobarbital 60–120 mg iv, im, pr q10–20 min prn |
| seizure prophylaxis | <ul style="list-style-type: none"> • use phenytoin, carbamazepine or other anti-epileptic medications in loading and maintenance doses appropriate for the person (require therapeutic blood level monitoring) (see <i>Medication Table, Appendix B</i>) • if there is hypoalbuminemia, phenytoin doses may need to be reduced |

| LAST HOURS | INTERVENTIONS |
|-----------------|--|
| seizures | <ul style="list-style-type: none"> • as swallowing deteriorates, oral medications for seizure prophylaxis may become more difficult, or impossible, to administer • lorazepam placed against the buccal mucosa with a few drops of water will provide ongoing prophylaxis, (midazolam sc could also be used) • phenytoin (standard doses of parenteral solution) may also be administered pr • phenobarbital 60-120 mg iv, im, pr q10-20 min prn |

VISUAL LOSS

PRESENTATIONS

May present as loss of central or peripheral vision (dark shadows encroaching from the edges) or blurring of vision.

CAUSES

Infectious:

- CMV retinitis
- herpes simplex or zoster
- PML
- pneumocystis
- toxoplasmosis

Other:

- dehydration
- ischemia
- hemorrhage
- vestibular problems

Malignant:

- lymphoma, cerebral

APPROACHES AND INTERVENTIONS

Examination, investigation and treatment of underlying causes should be appropriate to the presentation, stage and context of the person and illness.

Examination and investigation must be undertaken quickly. Many conditions may lead to permanent blindness, and require an urgent ophthalmologic consultation, particularly as the associated lesions are often difficult for the untrained examiner to see:

- to prevent blindness, continue therapy (particularly for CMV retinitis) until irreversible loss of consciousness has occurred, i.e. ganciclovir, foscarnet (refer to *Module 1*)
- provide early intervention by Canadian National Institute for the Blind (CNIB) or similar agency to help allay fears, and familiarize person with orientation, mobility and rehabilitation teaching possibilities
- provide counselling and psycho-social support as this is a devastating condition
- provide a familiar environment, remove hazards, i.e. floormats and obstacles
- provide assistive devices, i.e. "talking" clocks, special watches with time one can touch

HEARING LOSS

Tinnitus = a noise in the ears including ringing, buzzing, roaring, clicking

PRESENTATIONS

May present with a hearing deficit, loud speech, difficulty understanding conversations, tinnitus

CAUSES

Infectious:

- encephalitis
- oral candida
- otitis externa and media
- PML
- sinusitis

Other:

- chemotherapeutic agents, i.e. vincristine
- eustachian tube dysfunction
- coincidental
- external ear blockage i.e. wax

Malignant:

- Kaposi's sarcoma, external ear

APPROACHES AND INTERVENTIONS

Examination, investigation and treatment of underlying causes should be appropriate to the presentation, stage and context of the person and illness.

- consider anti-histamines or decongestants, if appropriate
- provide hearing aids
- utilize sign language as appropriate (interpreter)

LOSS OF MOTOR/SENSORY FUNCTION

PRESENTATIONS

May include:

- altered reflexes
- areas of muscle weakness, loss of muscle function/wasting
- areas of sensory abnormality or loss

CAUSES

Infectious:

- CMV myelopathy
- encephalitis (all causes)
- HIV encephalopathy or myelopathy

- meningitis
- toxoplasmosis
- PML

Malignant:

- Kaposi's sarcoma (peripheral effects)
- lymphoma (central or peripheral effects)

Other:

- medications:
 - AZT, ddI, ddC
 - chemotherapy
- diabetes
- alcohol

APPROACHES AND INTERVENTIONS

Examination, investigation and treatment of underlying causes should be appropriate to the presentation, stage and context of the person and illness.

- consider physical aids to enhance activities of daily living (see *Activities of Daily Living*)
- consider active and passive exercise
- maintain good skin care (see *Skin care/problems*)

NEURO-PSYCHIATRIC PROBLEMS

DEMENTIA

The term *dementia* is used interchangeably with *HIV encephalopathy*. It is also known as AIDS dementia complex (ADC).

Dementia may be related to HIV (direct cause) or it may be the result of another infection, a space occupying lesion or a metabolic imbalance (indirect cause).

PRESENTATIONS

| Early dementia | Late dementia | Very late dementia |
|--|--|---|
| <ul style="list-style-type: none"> • blunted affect • decreased concentration • forgetfulness • mental slowing • short term memory loss | <ul style="list-style-type: none"> • apathy • disorientation • fatigue • generalized weakness • hypomania • loss of balance • night time delusions • psychomotor retardation • sundown syndrome • tremors • vacant stare • wandering • withdrawal | <ul style="list-style-type: none"> • confusion • dysarthria • incontinence • mutism • seizures |

CAUSES

Infectious:

- HIV
- other opportunistic infections

Other:

- PML
- delirium
- prolonged depression

APPROACHES AND INTERVENTIONS

Examination, investigation and treatment of underlying causes should be appropriate to the presentation, stage and context of the person and illness.

- continue only essential medications
- a trial of methylphenidate 5-20 mg po qam has cleared mild dementia
- manage associated agitation (see Delirium)
- provide a protective, safe, structured environment
- keep familiar objects in visible proximity
- establish daily routines including regular activity and sleep times
- reduce external stimuli, i.e. noise, conversations not specifically directed to the person
- consider competency (see *Legal Issues*)
- provide as much control as possible
- make instructions clear, simple
- minimize number of caregivers
- monitor finances, spending habits
- occupational therapy

| PROBLEMS | INTERVENTIONS |
|--|--|
| orientation | <ul style="list-style-type: none"> • calendar • clock • night lights • explanations • have caregivers and visitors identify themselves regularly • label cupboards, drawers and containers |
| safety | <ul style="list-style-type: none"> • use a sensory pad • attach a call bell • observe frequently • raise side rails (caution: may increase agitation. May lead to an accident if person attempts to climb over them) • use a room monitor, i.e. baby monitor • see <i>Activities of Daily Living</i> |
| psychomotor retardation/ somnia | <ul style="list-style-type: none"> • methylphenidate 5-20 mg po q4h. Avoid late afternoon and evening doses as these can interfere with sleep at night time. Occasionally, doses late in the day can keep the person alert for visitors or pleasurable activities (Do not use if person is delirious or agitated) |
| HIV encephalopathy | <ul style="list-style-type: none"> • anti-retrovirals (AZT, ddl, ddC) may protect against or reverse HIV-related dementia |

COMPLEMENTARY THERAPIES

- aromatherapy
- art therapy
- massage therapy
- music therapy
- therapeutic touch

DELIRIUM, DECREASED LEVEL OF CONSCIOUSNESS, TERMINAL DELIRIUM

PRESENTATIONS

May include:

- agitation
- bad dreams, nightmares
- decreased level of consciousness, somnolence (often fluctuating)
- disorientation
- hallucinations or other perceptual disturbances
- hypervigilance
- moaning, groaning
- reduced concentration
- restlessness
- short term memory difficulties
- sleep/wake cycle reversal

Moaning and groaning may be the result of partial closure of the vocal cords due to stress during the dying process. They are rarely the result of pain, unless they have been present prior to the onset of delirium.

May be related to psycho-social or spiritual distress. Pain, even in the unconscious person, is usually associated with furrowing of the brows and/or signs of tension across the forehead

CAUSES

Depression:

(some are associated with agitation, delusions, hallucinations, memory impairment)

Hypomania/mania:

- manifestation of a pre-existing bipolar disorder

Psychosis:

- brief reactive
- schizophrenia
- other etiology

Other:

- HIV encephalopathy
- opportunistic infections, sepsis
- increased intracranial pressure
- medications: side effects and/or withdrawal, including
 - benzodiazepines
 - opioids
 - anti-cholinergics
- metabolic abnormalities including hepatic or renal failure
- hypoxia
- environmental changes, i.e. hospitalization, ICU
- fecal impaction
- urinary retention

APPROACHES AND INTERVENTIONS

Examination, investigation and treatment of underlying causes should be appropriate to the presentation, stage and context of the person and illness.

- continue only essential medications. Discontinue any that could cause delirium
- provide familiar environment, orient frequently, enhance safety (see Dementia)

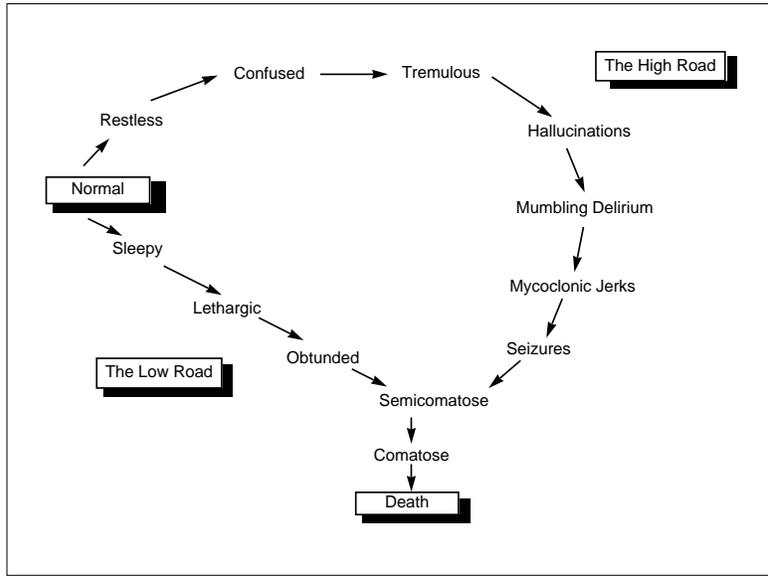
| PROBLEMS | INTERVENTIONS |
|--|--|
| <p>agitation, restlessness, psychosis</p> | <ul style="list-style-type: none"> • neuroleptics may help to re-organize thought patterns as well as provide sedation • choice of drug depends largely on familiarity • start with smallest possible doses: <ul style="list-style-type: none"> – haloperidol 0.5 mg po, im, sc; thioridazine 10 mg po; loxapine 2.5 mg po, im; chlorpromazine 10 mg po, pr, im – adjust upward as necessary. Frequent dosing may be necessary until control is achieved – once under control, reduce total daily acute dose by 25-33% and divide daily maintenance dose into 2-3 doses/24 hrs – be aware of potential side-effects: <ul style="list-style-type: none"> • higher potency, i.e. haloperidol, perphenazine, are associated with extrapyramidal side-effects • lower potency, i.e. thioridazine, chlorpromazine, are associated with more sedation and anti-cholinergic side-effects • mid potency, i.e. loxapine, trifluoperazine, provide a balance • in severe agitation, iv haldol can provide rapid relief with few side-effects: <ul style="list-style-type: none"> – haloperidol 0.5-2 mg iv, infuse at 1 mg/min, repeat q30min until person is calm – if agitation is particularly severe, may add lorazepam 1-2 mg iv • use anti-cholinergics as necessary for side-effects i.e. Benztropine |

COMPLEMENTARY THERAPIES

- homeopathy: arsenicum 30 ch bid to decrease anxiety and enhance “letting go”
- massage therapy
- music therapy
- therapeutic touch

THE TWO ROADS TO COMA¹⁸

In the dying, coma and death may ensue along 2 different trajectories.



The low road is a hypo-active state where the person slips quietly into a coma and dies peacefully. The high road is a hyper-active state consistent with terminal delirium.

| LAST HOURS | INTERVENTIONS |
|-------------------|---|
| terminal delirium | <ul style="list-style-type: none"> • irreversible, cannot treat the underlying causes, so focus on settling the person • goals in managing terminal delirium include: <ul style="list-style-type: none"> – muscle relaxation, including reduction of moaning/groaning – reduction of anxiety – reduction of risk of seizures – inhibition of the perception of the last hours of living • benzodiazepines may settle terminal delirium and/or induce sedation: <ul style="list-style-type: none"> – lorazepam 1-4 mg against buccal mucosa q1h prn (pre-dissolved in 0.5-1.0 mls of water) even in the person who is unconscious and/or unable to swallow. Doses of 20-50 mg per 24 hours may be required in individuals who are very restless – midazolam 1-5 mg sc, im, iv q3h prn or by continuous infusion • haloperidol, chlorpromazine and methotrimeprazine may also be useful, but im injections may be too painful in the cachectic person (haloperidol, methotrimeprazine could be administered sc) |

- where terminal delirium is extreme or sedation is difficult to achieve with benzodiazepines, phenobarbital or sodium thiopental (Pentothal®), may be required to settle the person. This should be discussed in detail with the family prior to initiating therapy:
 - phenobarbital 100-130 mg iv, im q6h or by continuous infusion 1-5 mg/hr (starting with lowest dose and titrating upwards until sedation is achieved)
 - sodium thiopental, consult with an anesthetist
- educate the family about the causes and significance of terminal delirium, particularly the distressing features, i.e. moaning/groaning
- maintain good mucous membrane and skin care (see Dehydration, Skin care/problems)
- do not measure blood pressure, heart or respiratory rate unnecessarily
- discontinue blood work, x-rays
- measure oxygen saturation only if necessary, no blood gases

COMPLEMENTARY THERAPIES

- music
- gentle massage
- therapeutic touch

DEPRESSION

PRESENTATIONS

May include:

- agitation
- crying
- lack of pleasure
- suicidal ideation
- apathy
- guilty ruminations
- sadness
- withdrawal

May also include neuro-vegetative symptoms (less helpful in the severely medically ill):

- decreased appetite
- insomnia (or hypersomnia)
- decreased energy
- weight loss

CAUSES

Other:

- dementia
- medication
- medical illness:
 - acute infection
 - system failure

Note:

- attempt to distinguish dysphoria associated with losses from a more severe clinical depression. Even a “reactive” depression can become a major depression and warrant pharmacological treatment:
 - index of suspicion will be high if guilty ruminations, apathy, withdrawal are present
- diagnosis is difficult due to diagnostic criteria (refer to *DSM-IV*) which rely on neuro-vegetative symptoms that are invariably disrupted in severe medical illness
- diagnosis is important as appropriate intervention may improve quality of life considerably

APPROACHES AND INTERVENTIONS

Examination, investigation and treatment of underlying causes should be appropriate to the presentation, stage and context of the person and illness.

- reduce doses of medication if possible
- eliminate unnecessary medications
- provide a familiar, safe, protective environment (see Dementia)
- consider supportive and/or insight oriented psychotherapy

| PROBLEMS | INTERVENTIONS |
|------------------------------------|--|
| clinical depression | <ul style="list-style-type: none"> • choice of medication depends on presentation and side-effect profiles: <ul style="list-style-type: none"> – early tricyclic anti-depressants, i.e. doxepine, imipramine, are sedating and have risk of anticholinergic side effects including constipation, xerostomia – newer tricyclic anti-depressants, i.e. nortriptyline, desipramine, have fewer side effects than other older antidepressants, and offer advantage of monitoring blood levels – newer anti-depressants, i.e. sertraline, fluvoxamine, can be stimulating and have risk of agitation/restlessness, GI upset or sleep disturbance – trazadone can be sedating with less risk of other side effects – avoid fluoxetine due to long half life • start with half usual adult starting dose, increase slowly, expect response only after two or more weeks on a therapeutic dose: <ol style="list-style-type: none"> 1. tricyclic anti-depressants including desipramine, doxepine, imipramine, nortriptyline: <ul style="list-style-type: none"> – start with 10–25 mg po od-tid and increase in 25 mg increments, if no side-effects, up to a max of 100–200 mg in 1–3 doses/24 hrs (max 100 mg/24 hrs for nortriptyline only) 2. serotonin re-uptake inhibitors including sertraline and fluvoxamine: <ul style="list-style-type: none"> – start with 50 mg po od and increase if no side-effects up to 150–200 mg/24 hrs (wait at least 7 days between increments) 3. trazodone: <ul style="list-style-type: none"> – start with 50 mg po od and increase if no side-effects up to 150–200 mg/24 hrs (wait at least 7 days between increments) |
| psychomotor retardation/somnolence | <ul style="list-style-type: none"> • methylphenidate 5–20 mg po q4h, avoid late afternoon and evening doses as these can interfere with sleep: <ul style="list-style-type: none"> – helpful in the medically ill. Rapid but likely a limited response |

COMPLEMENTARY THERAPIES

- homeopathy:
 - nat mur 30 ch bid for deep sadness, with blocked emotions, anger
 - iamara (ignatia amara) 30 ch bid for emotions

ANXIETY

PRESENTATIONS

May include:

- agitation
- insomnia
- restlessness
- sweating
- tachycardia
- hyperventilation
- panic
- shaking
- sympathetic discharge
- worry

CAUSES

Other:

- delirium
- medication effects
- hallucinations

APPROACHES AND INTERVENTIONS

Examination, investigation and treatment of underlying causes should be appropriate to the presentation, stage and context of the person and illness.

- provide a familiar, safe, environment (see Dementia)

| PROBLEMS/APPROACHES | INTERVENTIONS |
|-------------------------|--|
| anxiety | <ul style="list-style-type: none"> • medication choice depends on desired half-life: <ul style="list-style-type: none"> – longer half-life: more sustained effect, but may accumulate – shorter half-life: risk of withdrawal and rebound anxiety • lorazepam and oxazepam are not metabolized in the liver and are a better choice in presence of hepatic failure • consider possibilities of withdrawal if stopped abruptly, i.e. agitation, rebound anxiety, delirium: <ul style="list-style-type: none"> – long half-life: <ul style="list-style-type: none"> • clonazepam 0.25–2 mg po q12h • diazepam 2–10 mg po q8h – moderate half-life: <ul style="list-style-type: none"> • lorazepam 0.5–2 mg po, sl q6-8h – short half-life: <ul style="list-style-type: none"> • alprazolam 0.25–0.5 mg po bid-tid, max 3 mg/24 hrs (particularly for panic attacks and nightmares) • oxazepam 15–30 mg po q4-6h • chloral hydrate 500–1,000 mg po qhs • diphenhydramine 25–50 mg po, iv tid-qid • zopiclone (Imovane®) 7.5 mg po qhs • homeopathy: <ul style="list-style-type: none"> – anxiety attacks, aconitum 6 ch tid, if recurrent or acute 30 ch prn – generalized anxiety, arsenicum 30 ch bid – high anxiety, argentum nitricum 30 ch bid |
| anti-depressants | <ul style="list-style-type: none"> • anti-depressants may be very helpful, i.e. trazodone |

COMPLEMENTARY THERAPIES

- acupuncture: raises endorphin levels, sedates
- aromatherapy: general calming effect, see practitioner for appropriate aromatherapy oils (melissa, bergamot, lavender, neroli)
 - warm baths and oils
- biofeedback
- chiropractic: specific cervical and thoracic manipulation to enhance parasympathetic outflow
- hypnosis
- imagery
- massage therapy
- relaxation therapy
- therapeutic touch: general calming effect

INSOMNIA

PRESENTATIONS

May include:

- difficulty falling asleep
- frequent awakenings
- nightmares
- early morning awakening
- night-time restlessness
- fear

CAUSES

APPROACHES AND INTERVENTIONS

Examination, investigation and treatment of underlying causes should be appropriate to the presentation, stage and context of the person and illness.

Other:

- anxiety disorder
- depression
- pain
- delirium
- medication side effects
- give corticosteroids in the morning to reduce interference with sleep
- look for reversible symptoms which cause discomfort at night time

| APPROACHES | INTERVENTIONS |
|----------------------------------|--|
| enhance environment | <ul style="list-style-type: none"> • reduce noise • control light • improve comfort of bed • adjust ambient temperature and humidity • provide comforting objects i.e. teddy bears |
| establish sleep routines | <ul style="list-style-type: none"> • reduce daytime napping • go to bed at the same time each night • reduce stimulation 2 hours before sleeping • wake at same time every morning |
| remove dietary stimulants | <ul style="list-style-type: none"> • avoid caffeinated medications and beverages, i.e. coffee, tea, soft drinks • avoid alcohol at bedtime |
| anxiolytics | <ul style="list-style-type: none"> • choice depends on half-life: <ul style="list-style-type: none"> – short: may lead to withdrawal, arousal – long: may result in daytime sleepiness, hangover or impaired cognition. However, may provide anxiolytic effect during the day • do not use nightly: <ul style="list-style-type: none"> – avoids attenuation effect – reduces potential for dependency • abrupt stoppage may lead to rebound insomnia • effective doses may be very small in the elderly • dosing: <ul style="list-style-type: none"> – lorazepam 0.5–2 mg po, sl qhs prn – oxazepam 15–30 mg po qhs prn – diazepam 2–5 mg po qhs prn – alprazolam 0.25–0.5 mg po qhs prn |
| anti-depressants | <ul style="list-style-type: none"> • low doses of sedating anti-depressants may be very helpful over long term: <ul style="list-style-type: none"> – amitriptyline, desipramine, doxepin 10–25 mg po qhs – trazodone 25–50 mg po qhs |
| other sedatives | <ul style="list-style-type: none"> • diphenhydramine 25–50 mg po qhs prn • dimenhydrinate 25–50 mg po qhs prn • chloral hydrate 500-1,000 mg po qhs prn • zopiclone (Imovane®) 7.5 mg po qhs prn |

COMPLEMENTARY THERAPIES

- aromatherapy: see practitioner for specific oils
- guided meditations, imaging
- herbal treatments, soothing teas

- homeopathy: coffea 12 ch bid in evening spaced 3 hrs apart before bedtime, allow 4 days to assess, increase to 30 ch, if needed
- massages
- relaxation therapies:
 - progressive muscle relaxation
 - self hypnosis
 - focused muscle relaxation
- therapeutic touch
- warm milk, Ovaltine™

CARDIO-RESPIRATORY PROBLEMS

CHEST PAIN

PRESENTATIONS

May occur at rest, on movement, on exertion, on inspiration. May be generalized or localized and may be specific to one or more dermatomes.

CAUSES

Infectious:

- (including pericarditis, pleurisy, pneumonia)
- atypical mycobacterium (MAC)
 - CMV
 - fungi
 - herpes zoster
 - pneumocystis carinii
 - pyogenic bacteria
 - TB

Other:

- costochondritis
- ischemia
- musculoskeletal
- pneumothorax
- pulmonary embolism
- trauma

Malignant:

- Kaposi's sarcoma
- lymphoma

APPROACHES AND INTERVENTIONS

Examination, investigation and treatment of underlying causes should be appropriate to the presentation, stage and context of the person and illness.

- distinguish between non-esophageal and esophageal pain (see Odynophagia)
- pain on inspiration, exertion may indicate rib subluxation

| PROBLEMS | INTERVENTIONS |
|---|---|
| chest wall inflammation, trauma, pericarditis, pleurisy | <ul style="list-style-type: none"> • provide stepwise analgesia, especially NSAID's (see Pain) • if costochondritis, consider local steroid/xylocaine injections • for extreme, chest wall pain consider nerve block |
| herpes zoster | <ul style="list-style-type: none"> • acute - provide stepwise analgesia (see Pain) • chronic - see Neuropathic Pain |
| ischemia | <ul style="list-style-type: none"> • use appropriate cardiac medications - nitroglycerin, nitrates, calcium channel blockers, beta blockers • provide stepwise analgesia (see Pain) |
| pneumothorax | <ul style="list-style-type: none"> • manage acutely with chest tube and suction, if appropriate • provide stepwise analgesia (see Pain) |

COMPLEMENTARY THERAPIES

- chiropractic assessment and treatment
- TENS
- physiotherapy
- therapeutic touch
- acupuncture for musculo-skeletal pain

COUGH

PRESENTATIONS

May include:

- areas of pulmonary dullness
- crackles
- stridor
- gagging, retching
- hemoptysis
- bronchospasm (wheezing)
- intercostal indrawing
- tachypnea
- cough induced nausea, vomiting

CAUSES

Pulmonary:

- bronchospasm
- embolism
- effusions
- Kaposi’s sarcoma
- obstruction
- opportunistic infections
- pneumothorax

Other:

- allergy
- chemical and mechanical irritants
- psychological, i.e. anxiety

Cardiac:

- CHF with pulmonary edema
- ischemia

APPROACHES AND INTERVENTIONS

Examination, investigation and treatment of underlying causes should be appropriate to the presentation, stage and context of the person and illness.

- distinguish between productive and non-productive cough
- reduce allergens, irritants, i.e. smoking
- elevate to semi-sitting position
- provide abdominal splints for persistent coughing episodes
- manage associated bronchospasm (see Dyspnea)

| PROBLEMS | INTERVENTIONS |
|------------------------|---|
| cough | <ul style="list-style-type: none"> • suppress with: <ul style="list-style-type: none"> – dextromethorphan hydrobromide 15–45 mg po q4h prn – opioids: <ul style="list-style-type: none"> • codeine 15–60 mg po q4h prn (even when taking another opioid for pain management) • hydrocodone 5-10 mg po q4-6h prn • hydrocodone and phenyltoloxamine complex (Tussionex®) 5 mls or 1 tablet q8–12h prn • morphine 5–20 mg po q4h prn (may be increased further) • normethadone and hydroxephedrine compound (Cophylac®) 15 drops po bid prn – Nabilone 1-2 mg po bid-tid-qid (max 6 mg/24 hrs) prn |
| hyperactive gag reflex | <ul style="list-style-type: none"> • nebulized lidocaine 5 mls of 2% solution (100 mg) q3-4h prn • reduce associated anxiety (see Anxiety) |

increased quantity or difficulty clearing airway secretions

- maintain adequate hydration
- keep mucous membranes moist
- increase humidity in the room (be careful not to increase risk of respiratory infections)
- try nebulized saline to loosen thick secretions
- postural drainage
- massage/respiratory physiotherapy
- oropharyngeal or nasopharyngeal suction only if absolutely necessary (very stimulating)
 - scopolamine 0.3–0.6 mg sc q4–8h prn or scopolamine (Transderm-V®), patch 1-2 behind alternating ears q72h
 - glycopyrrolate (Robinul®), 0.1-0.4 mg im, iv q4-6h prn (non-sedating)

COMPLEMENTARY THERAPIES

- acupuncture
- aromatherapy - eucalyptus, pine, benzoin oils to chest
- massage, gentle clapping on back to move sputum

DYSPNEA, RESPIRATORY DISTRESS

PRESENTATIONS

Person may feel short of breath before there are objective signs which may include:

- areas of pulmonary dullness
- crackles
- inability to clear secretions
- stridor
- bronchospasm (wheezing)
- cyanosis, central or peripheral
- intercostal indrawing
- tachypnea

CAUSES

Pulmonary

- asthma
- effusions
- embolism
- hypertension
- infections:
 - opportunistic
 - other
- Kaposi’s sarcoma
- obstruction
- pneumothorax

Other

- anemia
- ascites
- fatigue
- neuromuscular:
 - myelopathy
- psychological:
 - anxiety
 - depression

Cardiac:

- CHF with pulmonary edema
- ischemia

APPROACHES AND INTERVENTIONS

Examination, investigation and treatment of underlying causes should be appropriate to the presentation, stage and context of the person and illness.

- respond quickly
- elevate head of bed
- keep air moving using fans, open windows (avoid excessive cooling)
- reduce environmental irritants, i.e. smoking
- minimize number of people in the room
- teach and support family
- manage associated anxiety (see Anxiety)

| PROBLEMS | INTERVENTIONS |
|-----------------------------|--|
| bronchospasm | <ul style="list-style-type: none"> • salbutamol 2–3 puffs q4-8h (with aerochamber) or 2.5–5.0 mg diluted to 4.0 mls with saline up to q4h via nebulizer • ipratropium bromide (Atrovent®) 2-3 puffs q 4-8 h prn • steroids: <ul style="list-style-type: none"> – prednisone 10–60 mg po od – dexamethasone 1–8 mg po, iv, im, sc q6h • racemic epinephrine 2–3 puffs q4–6h |
| hypoxia | <ul style="list-style-type: none"> • use oxygen judiciously. It is not essential to reduce the sense of being short of breath, and may not be effective by itself • compressed air may be as effective as oxygen • oxygen only indicated if % saturation <90% • if oxygen is used, exercise clinical judgment. Measure % oxygen saturation, not arterial blood gases, unless absolutely necessary • monitor % oxygen saturation to establish ongoing need for oxygen therapy |
| obstruction | <ul style="list-style-type: none"> • steroids: <ul style="list-style-type: none"> – prednisone 10–60 mg po od – dexamethasone 1–8 mg po, iv, im, sc q6h • racemic epinephrine 2–3 puffs q4–6h |
| pleural effusion | <ul style="list-style-type: none"> • thoracentesis • for recurrent effusions: <ul style="list-style-type: none"> – talc or tetracycline poudrage/pleuradesis – insert Tenckhoff™ catheter for repeat drainage |
| pulmonary edema | <ul style="list-style-type: none"> • careful salt and fluid management • appropriate cardiac medications • diuretics: <ul style="list-style-type: none"> – furosemide 20–240 mg po, iv prn – ethacrynic acid 50–100 mg po, iv od-bid • nitrates or nitro paste to enhance peripheral venous dilation |
| respiratory distress | <ul style="list-style-type: none"> • for opioid naive: <ul style="list-style-type: none"> – morphine 5–15 mg po, pr, sl, sc, im, iv q1–4h prn or – hydromorphone 1–3 mg po, pr, sl, sc, im, iv q1–4h prn • for persons already taking opioids: <ul style="list-style-type: none"> – increase dose of same opioid by 25–100% q4h. • nebulized opioids may be helpful: <ul style="list-style-type: none"> – preservative free parenteral solutions of morphine 10–40 mg or hydromorphone 2–20 mg diluted to 3-4 mls with saline q4h may be very effective (type of nebulizer may improve delivery) • for associated anxiety: <ul style="list-style-type: none"> – benzodiazepines (always adjust based on response to previous doses): <ul style="list-style-type: none"> • lorazepam 0.5–2.0 po, sl, buccal mucosal q1h prn • diazepam 5–10 mg po qid prn • clonazepam 0.25-2.0 mg po q12h prn • midazolam 1–5 mg sc q3h prn or 0.5-2.0 mg q1h sc infusion – nabilone 1–2 mg po bid-tid prn • for extreme distress: <ul style="list-style-type: none"> – use doses as above, but deliver parenterally only, or – a combination of morphine (doses as above), scopolamine 0.3–0.6 mg in the same syringe sc as a stat dose may also be very effective. May repeat in 5–10 minutes – midazolam 5-10 mg sc, repeat q10 min until settled |

| | |
|--|---|
| secretions, increased quantity or difficulty clearing | <ul style="list-style-type: none"> • to reduce quantity of secretions: <ul style="list-style-type: none"> – scopolamine 0.3–0.6 mg sc q4–8h prn or scopolamine (Transderm-V®) patch 1-2 behind alternating ears q72h – glycopyrrolate (Robinul®) 0.1–0.4 mg im, iv q4–6h prn (non-sedating) • maintain adequate hydration • keep mucous membranes moist • increase humidity in the room (be careful not to increase risk of respiratory infections) • try nebulized saline to loosen thick secretions • postural drainage • massage, respiratory physiotherapy • oropharyngeal or nasopharyngeal suction only if absolutely necessary (very stimulating) |
|--|---|

| LAST HOURS OF LIVING | INTERVENTIONS |
|----------------------------|---|
| respiratory failure | <ul style="list-style-type: none"> • a significant change in the person’s breathing pattern, i.e. Cheyne-Stokes breathing, or short, shallow respirations, is one of the cardinal signs that death is occurring • focus on treating the sense of shortness of breath, clearing or reducing secretions while continuing to treat underlying causes, if possible • oxygen may prolong death rather than improve quality of life, and may not be appropriate. Use it judiciously • provide ongoing teaching or support for those at the bedside, particularly if the dyspnea is perceived as being distressing |

COMPLEMENTARY THERAPIES

- acupuncture
- aromatherapy - eucalyptus, pine, benzoin oils to chest
- therapeutic touch

HICCUPS

PRESENTATIONS

May be very distressing, especially if ongoing or out of control.

CAUSES

- cerebral tumour
- gastric distension
- renal insufficiency
- diaphragmatic irritation/irritability
- phrenic nerve irritation

APPROACHES AND INTERVENTIONS

Examination, investigation and treatment of underlying causes should be appropriate to the presentation, stage and context of the person and illness.

- reduce or discontinue medications that may be causing CNS excitation, i.e. opioids

| PROBLEMS/APPROACHES | INTERVENTIONS |
|----------------------------|--|
| central suppression | <ul style="list-style-type: none"> • chlorpromazine 25-50 mg po, pr, im, iv q4-6h prn • for cerebral tumours may also try: <ul style="list-style-type: none"> – phenytoin 200-300 mg po, iv od – carbamazepine 100-200 mg po bid-tid – valproic acid 250 mg po bid-qid |

| | |
|---------------------------------|---|
| increase pCO₂ | <ul style="list-style-type: none"> • 5% CO₂ by face mask at bedside • breath holding • re-breathing, i.e. supervised use of paper bag |
| pharyngeal stimulation | <ul style="list-style-type: none"> • granulated sugar with lemon juice • nasal catheter • stimulation of pharynx with finger and cotton ball |
| gastric distention | <ul style="list-style-type: none"> • anti-flatulants • antacids, standard doses q2h prn • naso-gastric tube suction • peristaltic stimulation to facilitate gastric emptying, including: <ul style="list-style-type: none"> – metoclopramide 10 mg iv stat, then 10 mg po q6h prn – mint water, peppermint tea |
| other medications | <ul style="list-style-type: none"> • nifedipine 10–20 mg po, sl q8h or 30–60 mg po od (sustained release) (observe for hypo-tension) • baclofen 5–20 mg po bid-tid • steroids: <ul style="list-style-type: none"> – prednisone 10-40 mg po od – dexamethasone 2-8 mg po, iv, im, sc q6h |

COMPLEMENTARY THERAPIES

- acupuncture
- chiropractic
 - manipulation of C 3, 4, 5
 - manual diaphragm release
- therapeutic touch

HEAD AND NECK PROBLEMS

HEADACHE

Meningismus = stiff neck due to meningeal irritation/pain.

PRESENTATIONS

Pain occurs in one or more locations across the head, including the sinuses. May radiate into ear(s), eye(s), mouth, neck. May change with movement and be associated with meningismus.

CAUSES

Infectious:

- encephalitis:
 - cryptococcal
 - HIV
 - herpetic
- herpes zoster
- meningitis (all causes)
- sinusitis
- toxoplasmosis

Malignant:

- lymphoma

Other:

- torticollis/muscle spasm
- cervical spondylosis
- diagnostic test, i.e. lumbar puncture
- intoxication or substance withdrawal, i.e. alcohol, caffeine
- medications
- migraine
- tension
- therapeutic interventions

APPROACHES AND INTERVENTIONS

Examination, investigation and treatment of underlying causes should be appropriate to the presentation, stage and context of the person and illness.

- treat migraines using conventional medical therapy
- provide stepwise analgesia (see Pain)
- NSAID's may reduce meningismus
- corticosteroids may reduce edema around space occupying lesions and may control severe meningismus:
 - prednisone 10-80 mg po od
 - dexamethasone 1-8 mg po, iv, im, sc q6h

COMPLEMENTARY THERAPIES

- acupuncture
- chiropractic manipulation may relieve headache of cervical and suboccipital musculoskeletal origin
- aromatherapy
- homeopathy: numerous symptom specific interventions
- massage therapy
- relaxation therapy
- TENS
- therapeutic touch

HEAD AND NECK PAIN

PRESENTATIONS

Includes pain occurring in the ear, nose, oral cavity (mouth), pharynx (throat) and larynx.

May change with movement including chewing or swallowing. May be associated with meningismus.

CAUSES

Infectious:

- candida
- chelitis
- dental abscess, decay
- gingivitis
- herpes simplex
- herpes zoster
- pharyngitis
- parotitis
- tonsillitis
- ulcers:
 - aphthous
 - others

Malignant:

- Kaposi's sarcoma
- squamous cell carcinoma

Other:

- malnutrition
- medications:
 - chemotherapy
- radiation therapy
- stones
- trauma
- temporomandibular joint syndrome

APPROACHES AND INTERVENTIONS

Examination, investigation and treatment of underlying causes should be appropriate to the presentation, stage and context of the person and illness.

| PROBLEMS | INTERVENTIONS |
|---------------------------------|---|
| pain | <ul style="list-style-type: none"> analgesics: <ul style="list-style-type: none"> provide stepwise analgesia (see Pain) NSAID's may be particularly helpful |
| painful oral/pharyngeal lesions | <ul style="list-style-type: none"> anesthesia: <ul style="list-style-type: none"> lidocaine 2% viscous, 5-15 mls rinse mouth, gargle, then spit out or swallow. May mix 1:1 with Magnolax® to make more palatable (max. 15 mls q3h, 120 mls q24h) benzylamine oral rinse (Tantum®) 15-30 mls tid-qid rinse mouth, gargle, 15 secs then spit (may also spray into mouth) oxethazaine, aluminum and magnesium hydroxide mouthwash (Mucaine®) 15-30 mls tid-qid, rinse mouth, gargle, 15 secs then swallow caution: risk of aspiration within 1 hr of use steroids: <ul style="list-style-type: none"> prednisone 5–60 mg po od dexamethasone 1–2 mg po q6h triamcinolone apply to oral lesions tid-qid after meals |

COMPLEMENTARY THERAPIES

- acupuncture
- relaxation therapy
- therapeutic touch

HEAD AND NECK PROBLEMS

Halitosis = bad breath

Mucositis = mucous membrane inflammation

Rhinorrhea = free discharge of thin nasal mucous, runny nose

Sialorrhea = excessive salivation

Includes problems occurring in the ear, nose, oral cavity (mouth), pharynx (throat) and larynx.

PRESENTATIONS

May include:

- altered taste
- halitosis
- mucositis
- receding gums
- sialorrhea
- tooth decay
- bleeding
- masses
- oral lesions, ulcerations (including gum)
- rhinorrhea
- xerostomia

CAUSES

Infectious:

- candida
- chelitis
- dental abscess, decay
- gingivitis
- herpes simplex

Other:

- malnutrition
- medications:
 - chemotherapy
- radiation therapy
- stones
- trauma

Infectious (cont.)

- herpes zoster
- pharyngitis
- parotitis
- tonsillitis
- ulcers:
 - aphthous
 - others

Malignant:

- Kaposi's sarcoma
- squamous cell carcinoma

APPROACHES AND INTERVENTIONS

Examination, investigation and treatment of underlying causes should be appropriate to the presentation, stage and context of the person and illness.

| PROBLEMS | INTERVENTIONS |
|----------------------|--|
| altered taste | <ul style="list-style-type: none"> • explore food preferences, choose foods that address desire for salt or sweet • increase seasoning, marinated foods • drink more fluids |
| gingivitis | <ul style="list-style-type: none"> • 0.2% chlorhexidine oral rinse or brushing tid |
| halitosis | <ul style="list-style-type: none"> • oral and dental hygiene as below • maintain adequate hydration • hydrogen peroxide 1% gargles |
| hygiene | <ul style="list-style-type: none"> • brush teeth regularly • use mouthwashes q2-3h prn: <ul style="list-style-type: none"> – baking soda – 1 tsp baking soda + 1 tsp salt in 1 quart of water – chlorophyll in isotonic solution, 1 dropper to 8 oz. water – 1/3 N/S, 1/3 hydrogen peroxide, 1/3 Cepacol®, mouthwash – do not use over-the-counter mouthwashes that contain alcohol, as they may be irritating • Moistir® spray • lemon glycerin swabs may be useful if the person is able to produce saliva. However, in the presence of xerostomia, these swabs may further dry the mouth (as glycerol is desiccating), and the lemon may irritate any open sores |
| rhinorrhea | <ul style="list-style-type: none"> • nasal decongestants • antihistamines, preferably non-sedating, use standard doses |
| sialorrhea | <ul style="list-style-type: none"> • tricyclic antidepressants, i.e. Amitriptyline 25 mg po od-tid • oral scopolamine 0.02mg/kg rinse, swallow od-bid |
| xerostomia | <ul style="list-style-type: none"> • hard sour candies, chewing gum, licorice • frequent sips of ice water • suck on ice chips • baking soda mouthwash (see above) • artificial saliva • lip gloss • provide adequate humidity in the environment (be careful not to increase risk of respiratory infections) |

| LAST HOURS OF LIVING: | INTERVENTIONS |
|-----------------------|--|
| mouth care | <ul style="list-style-type: none"> keep mucous membranes and teeth moist and clean using baking soda mouthwash q30–60 min prn apply mouthwash and any medications with sponge swabs do not insert fingers beyond the teeth (avoid bites) avoid lemon-glycerine swabs cover oral ulcers with topical anesthetics dab candida with Nystatin suspension a humidifier may reduce drying (be careful not to increase risk of respiratory infections) |

COMPLEMENTARY THERAPIES

- relaxation therapy
- therapeutic touch

GASTRO-INTESTINAL PROBLEMS

ODYNOPHAGIA

Odynophagia = pain on swallowing.

PRESENTATION

Most often described as retrosternal pain associated with a sense of spasm or fullness. Usually made worse by swallowing fluids/food.

CAUSES

Infectious:

- candida (may occur without an oral infection)
- CMV
- herpes simplex/zoster

Other:

- esophageal ulcerations
- excess alcohol
- hiatus hernia
- hyperacidity, reflux
- radiation therapy
- spicy food
- stress

Malignancy:

- Kaposi's sarcoma
- lymphoma
- lift head of bed, lie in upright position

APPROACHES AND INTERVENTIONS

Examination, investigation and treatment of underlying causes should be appropriate to the presentation, stage and context of the person and illness.

| PROBLEMS | INTERVENTIONS |
|--|--|
| pain | <ul style="list-style-type: none"> analgesics: <ul style="list-style-type: none"> provide stepwise approach (see Pain) NSAID's may be particularly helpful anesthesia: <ul style="list-style-type: none"> oxethazaine, aluminum and magnesium hydroxide mouthwash (Mucaine®) 15–30 mls tid-qid, rinse mouth, gargle, then swallow |
| gastroesophageal reflux heartburn, hyperacidity | <ul style="list-style-type: none"> to neutralize excess acid: <ul style="list-style-type: none"> Al or mg antacids, 15-30 mls po q2h prn (many available) alginate acid (Gaviscon®) 10–20 mls or 2-4 tabs po qid pc + hs |

- to reduce acid production:
 - ranitidine 150 mg po q12h
 - famotidine 20-40 mg po od, 10-20 mg iv q12h
 - omeprazole 20-40 mg po od
- to cover open esophageal/gastric ulcers; sucralfate 1 gm po qid ac+hs

COMPLEMENTARY THERAPIES

- chiropractic – diaphragm release for hiatus hernia
- relaxation therapy
- therapeutic touch

DYSPHAGIA

Dysphagia = difficulty swallowing.

PRESENTATIONS

May eat and drink less. Foods or thickened fluids may be easier to swallow than thin fluids. May not be swallowing, even saliva.

CAUSES

Infectious:

- candidiasis
- CMV
- herpes simplex
- herpes zoster
- neuromuscular:
 - HIV encephalopathy
 - PML

Other:

- acid reflux
- asthenia
- irritants:
 - alcohol
 - spicy foods
- poor mastication
- ulcers

Malignant:

- Kaposi's sarcoma
- lymphoma

APPROACHES AND INTERVENTIONS

Examination, investigation and treatment of underlying causes should be appropriate to the presentation, stage and context of the person and illness.

- always ensure that the person can protect his/her airway before giving oral fluids, food or medications
- reduce or discontinue irritating medications/substances
- minimize oral medications
- change to an alternate route of drug/fluid administration if necessary
- consult nutritionist for alternate fluids/foods, thickeners, etc.
- consider swallowing assessment (consult speech pathologist)
- manage associated heartburn, hyperacidity gastroesophageal reflux (see Odynophagia)

| PROBLEMS | INTERVENTIONS |
|---|--|
| slow to swallow, fluids/food “sticking”, poor gastro-esophageal sphincter tone | <ul style="list-style-type: none"> to increase peristalsis: <ul style="list-style-type: none"> metoclopramide 5–10 mg po, im, iv tid-qid, 1/2 hr ac + hs, or domperidone 5–20 mg po tid-qid, 1/2 hr ac + hs cisapride 5–10 mg po tid-qid, 1/4 hr ac + hs or 20 mg po bid |
| poor food intake | <ul style="list-style-type: none"> establish whether fluids, thickened fluids or soft foods are easier to swallow (consult speech pathologist) if ability to swallow and/or aspiration are of concern, test ability to swallow with a small quantity of water before each feeding cool, soft foods may be easiest to swallow small, frequent meals feed slowly, in upright position. If assistance is required, the feeder should practice good feeding techniques do not force feed catheters may be used to introduce nutrition past the epiglottis when the person is aspirating frequently naso-gastric feeding tubes may be needed if long term support is required (not to be used if aspiration is a problem) consult nutritionist |
| dysphagia in children | <ul style="list-style-type: none"> acute dysphagia may require a limited course of total parenteral nutrition (TPN) to avoid or reduce weight loss during an acute episode |

| LAST HOURS OF LIVING | INTERVENTIONS |
|--|---|
| loss of gag, loss of ability to swallow | <ul style="list-style-type: none"> loss of the gag reflex and the ability to swallow is one of cardinal signs that death is occurring families and caregivers must be instructed when to stop oral intake. Avoid aspiration and the possible guilt that someone may have caused the death fluids may build-up in the back of the throat and present as gurgling and crackling as air moves through the thick mixture (known as the “death rattle”). This is often perceived as choking. Provide education and support to settle those who find the sound distressing management should include: <ul style="list-style-type: none"> no further administration of fluids and food keep mucous membranes moist, not wet (see Dehydration) scopolamine (hyoscine) may decrease saliva production and reduce the amount of fluid collecting in the back of the throat: <ul style="list-style-type: none"> start with scopolamine 0.3-0.6 mg sc q4-8h prn for first 12-16 hrs and apply 1–2 Transderm-V® patch(es) behind alternating ears q72h (takes 12 hours to work). Atropine is not indicated as it may lead to cardiac, respiratory and/or CNS stimulation use postural drainage or repositioning to clear or move fluids (to get over the “coffee percolator-like” effect) in extreme or re-occurring situations, i.e. PML, oropharyngeal or nasopharyngeal suctioning may be needed (may be very stimulating/irritating) |

COMPLEMENTARY THERAPIES

- massage with relaxing oil in lateral lying position, i.e. neroli oil
- relaxation therapy

ABDOMINAL PAIN**PRESENTATIONS**

May be constant, intermittent (colic, cramps), burning, associated with food or not, radiate into back, chest, shoulder or gonads.

CAUSES**APPENDICITIS (RARE)**

- **Infectious**
- **Malignant:**
 - Kaposi's sarcoma, lymphoma
- **Other:**
 - fecolith

CHRONIC PELVIC INFLAMMATORY DISEASE

- **Infectious:**
 - salpingitis

BOWEL OBSTRUCTION

- **Infectious:**
 - MAC
- **Malignant:**
 - Kaposi's sarcoma
 - lymphoma
- **Other:**
 - stool

ENTERITIS

- **Infectious:**
 - campylobacter
 - cryptosporidiosis
 - MAC
 - salmonella
 - shigella

CHOLECYSTITIS

- **Biliary tract obstruction:**
 - Kaposi's sarcoma
 - stones
 - lymphoma
- **Infectious:**
 - campylobacter fetus
 - candida
 - CMV
 - cryptosporidiosis
 - MAC

SPLENIC

- **Infectious:**
 - MAC
- **Malignant:**
 - lymphoma

PANCREATITIS

- **Infectious:**
 - CMV
 - cryptococcosis
 - MAC
- **Drug Induced:**
 - alcohol
 - corticosteroids
 - ddI
 - pentamidine

PERITONITIS

- **Infectious:**
 - gram negative pathogens
 - histoplasmosis
 - MAC
 - pneumocystis
 - TB
- **Malignant:**
 - Kaposi's sarcoma
 - lymphoma
- **Other:**
 - bowel perforation

RETROPERITONEAL ADENOPATHY

- **Infectious:**
 - MAC
 - TB
- **Malignant:**
 - Kaposi's sarcoma
 - lymphoma

HEPATITIS

- **Infectious:**
 - hepatitis A, B, C, D
 - MAC
- **Malignant:**
 - lymphoma

ILEUS

- **Infectious:**
 - HIV
 - other
- **Drug Induced:**
 - anesthesia
 - opioid

COLITIS

(may lead to bowel perforation)

- **Infectious:**
 - clostridium difficile
 - CMV
 - histoplasmosis

OTHER

- ascites
- gastritis
- organomegaly
- ulcers:
 - duodenal
 - gastric

MESENTERIC LYMPH NODE ENLARGEMENT

- **Infectious:**
 - MAC
- **Malignant:**
 - Kaposi's sarcoma
 - lymphoma

APPROACHES AND INTERVENTIONS

Examination, investigation and treatment of underlying causes should be appropriate to the presentation, stage and context of the person and illness.

- in many, the exact etiology may not be determined
- lab results may be misleading, i.e. low or normal WBC count in presence of infection
- do not assume that a perforated viscus is irreversible; laparotomy may be appropriate
- persons with HIV / AIDS are not at increased risk for abdominal wound complications

| PROBLEMS | INTERVENTIONS |
|---|--|
| pain | <ul style="list-style-type: none"> • provide stepwise analgesia (see Pain) |
| bloating, distention, flatulence | <ul style="list-style-type: none"> • may need NG or rectal tube (with or without suction) • may need to alter or restrict diet, remove lactose • antacids containing simethicone • homeopathic: lycopodium, start with 6 ch. qid ac + hs, increase to 30 ch tid ac, if needed |
| colic, cramps | <ul style="list-style-type: none"> • for obstruction that you believe to be reversible: <ul style="list-style-type: none"> – codeine 30–60 mg po, pr, sc q4h prn – for opioid naive: morphine 5–10 mg po, pr, sc q4h prn (or hydromorphone equivalent) – for those on opioids: increase morphine (or hydromorphone) by 25–50% or add codeine – may also add: <ul style="list-style-type: none"> – diphenoxylate (Lomotil®) 2.5–5.0 mg po q4–6h prn, max 20mg/24hrs – loperamide (Imodium®) 2–4 mg po q4–6h prn, max 16 mg/24hrs |

| | |
|------------------------------------|--|
| | <ul style="list-style-type: none"> – hyoscine butylbromide (Buscopan®) 10–20 mg po, sc, im, iv 1-5 times/24 hrs – dicyclomine (Bentylol®) 10-20 mg po tid-qid or 20 mg im q4-6h prn • for obstruction that you believe to be irreversible: <ul style="list-style-type: none"> – use diphenoxylate and/or loperamide as above, routinely, not prn – may also add opioids as above • for irritable bowel symptoms: <ul style="list-style-type: none"> – trimebutine (Modulan®) 100-200 mg po tid ac – homeopathic: staphysagria, start with 6 ch. qid ac + hs, increase to 30 ch tid ac, if needed • for intense cramping: <ul style="list-style-type: none"> – avoid foods that may cause gas or cramps, i.e. beans, cabbage, broccoli, cauliflower, highly spiced foods or too many sweet or carbonated drinks – homeopathic: colocynth, same dosage as staphysagria above |
| peritoneal pain (rebound) | <ul style="list-style-type: none"> • provide stepwise analgesia (see Pain) • NSAID's may be very helpful |
| visceral pain, organomegaly | <ul style="list-style-type: none"> • provide stepwise analgesia (see Pain) • steroids may be very helpful: <ul style="list-style-type: none"> – prednisone 10-80 mg po od – dexamethasone 1-8 mg po, iv, im, sc q6h • NSAID's may also be helpful |

COMPLEMENTARY THERAPIES

- relaxation therapy
- therapeutic touch
- abdominal massage to reduce tension in abdominal wall
- aromatherapy-fennel or camomile (to reduce abdominal tension)

NAUSEA, VOMITING, RETCHING

PRESENTATION

Nausea may be much more distressing than vomiting. Vomiting without associated nausea is likely to be due to a motility problem or mechanical obstruction. Retching may occur without nausea or vomiting.

CAUSES

Often multi-factorial and subjective (**10 M's of emesis**):

| PROBLEMS | CAUSES |
|--|--|
| cerebral Masses, increased intracranial pressure, nerve dysfunction | <ul style="list-style-type: none"> • lymphoma of brain • toxoplasmosis |
| Meningeal irritation, stimulation, increased intracranial pressure | <ul style="list-style-type: none"> • infectious • space occupying lesions |
| Mental anxiety | <ul style="list-style-type: none"> • heightened by: <ul style="list-style-type: none"> – dislikes, i.e. foods, activities – fear and fantasy – smells |

| | |
|--|---|
| vestibular stimulation, Movement | <ul style="list-style-type: none"> • medications, especially opioids, i.e. morphine • motion sickness |
| Medications acting on chemoreceptor trigger zone | <ul style="list-style-type: none"> • chemotherapy • opioids |
| Mechanical obstruction, intra and/or extra luminal | <ul style="list-style-type: none"> • upper GI tract: <ul style="list-style-type: none"> – malignancies, i.e. Kaposi's sarcoma, lymphoma producing gastric outlet obstruction, i.e. squashed stomach syndrome • lower GI tract: <ul style="list-style-type: none"> – faeces, bowel obstruction – hemorrhoids – malignancies, i.e. Kaposi's sarcoma, lymphoma, squamous cell carcinoma |
| altered GI Motility, slow swallowing, gastric emptying, ileus | <ul style="list-style-type: none"> • decreased peristalsis: <ul style="list-style-type: none"> – medications, especially: <ul style="list-style-type: none"> • anti-cholinergics • opioids – PML – post anaesthetic • increased peristalsis: <ul style="list-style-type: none"> – infection/inflammation, especially with fever – obstruction • hyper active gag reflex: <ul style="list-style-type: none"> – cough – hiccups |
| Mucosal irritation, esophageal or gastric | <ul style="list-style-type: none"> • infections: <ul style="list-style-type: none"> – candidiasis – CMV • medications: <ul style="list-style-type: none"> – ASA, NSAID's – steroids • hyperacidity, reflux, hiatus hernia • blood in stomach |
| Metabolic | <ul style="list-style-type: none"> • dehydration • electrolyte imbalance • liver failure, obstruction • uremia |
| Myocardial | <ul style="list-style-type: none"> • CHF • ischemia • myopathy • pericarditis |

APPROACHES AND INTERVENTIONS

Examination, investigation and treatment of underlying causes should be appropriate to the presentation, stage and context of the person and illness.

- restrict and/or hold fluid and food intake, if appropriate
- fluid replacement should be the primary focus of attention as dehydration (salt and water loss) is a frequent complication:
 - encourage electrolyte balanced fluids, i.e. Gatorade®, soups
- avoid fried, greasy foods, alcohol or medications that may cause nausea or vomiting
- position person upright (sit or elevate head to a semi-sitting position)
- provide anti-emetics 1/2 hr before meals

| PROBLEMS | INTERVENTIONS |
|---|---|
| cerebral Masses | <ul style="list-style-type: none"> decrease intra-cranial pressure: <ul style="list-style-type: none"> dexamethasone 1–8 mg po, iv, im, sc q6h to reduce pressure acutely, mannitol 100 mls of 10 or 20% solution may be given as a rapid iv infusion once or twice decrease stimuli |
| Meningeal irritation | <ul style="list-style-type: none"> manage increased intra-cranial pressure as above in metastases manage headache to influence central chemoreceptor zone <ul style="list-style-type: none"> prochlorperazine 5–20 mg po, pr, im, iv q4h prn haloperidol 0.5–5.0 mg po, sc, im q4–6h prn chlorpromazine 10–25 mg po, pr, im q6–12h prn nabilone 1–2 mg po q6-12h prn |
| Mental anxiety and fear | <ul style="list-style-type: none"> benzodiazepines may be very useful: <ul style="list-style-type: none"> lorazepam 0.5–2 mg po, sl q6–8h prn diazepam 2–10 mg po q6-8h clonazepam 0.25–2 mg po q12h manage hyperactive gag reflex (see Cough) relaxation therapy |
| vestibular stimulation (Movement) | <ul style="list-style-type: none"> use prophylaxis before activity dimenhydrinate 50–100 mg po, pr, im, iv q4–6h scopolamine 1.5 mg transdermal patch behind alternating ears q72h (takes 12 hours for initial effect) scopolamine 0.3–0.6 mg sc q4–8h prn meclizine (Bonamine®) 25-100mg po od-qid cyclizine (Marzine®) 50mg im q8h |
| Medications | <ul style="list-style-type: none"> to influence central chemoreceptor zone (see Meningeal irritation above) |
| Mechanical obstruction, upper GI tract | <ul style="list-style-type: none"> restrict or hold oral fluid intake, hold solid food intake NG tube and/or suction may be appropriate for partial obstruction with altered mobility consider peristaltic stimulants (see altered GI Motility below) to control heartburn, hyperactivity (see Odynophagia) may also add a centrally acting anti-emetic (see Meningeal irritation above) |
| Mechanical obstruction, lower GI tract | <ul style="list-style-type: none"> restrict or hold oral fluid intake, hold solid food intake NG tube and/or suction may be very appropriate for high intestinal obstructions, reduce hepatic/pancreatic secretions using scopolamine 0.3–0.6 mg sc q4–8h prn or a continuous infusion 0.1–0.2 mg sc q1h treat reflux and/or hyperacidity as above for upper GI tract obstruction treat colic (see Abdominal Pain) treat reversible causes of obstruction (see Constipation/Bowel obstruction) may also add one of: <ul style="list-style-type: none"> a centrally acting anti-emetic (see Meningeal irritation above) |

| | |
|---|---|
| <p>altered GI Motility (Gastric stasis, ileus)</p> | <ul style="list-style-type: none"> to stimulate peristalsis, tighten the lower esophageal sphincter, relax the pyloric sphincter: <ul style="list-style-type: none"> metoclopramide 5–10 mg po, im, iv tid-qid, 1/2 hr ac + hs domperidone 5–20 mg po tid-qid, 1/2 hr ac + hs cisapride 5–10 mg po tid-qid, 1/2 hr ac + hs or 20mg po bid (may be dangerous in complete obstruction) if caused by opioids, consider alternate opioid, i.e. hydromorphone |
| <p>Mucosal irritation</p> | <ul style="list-style-type: none"> treat underlying infections low spice, low acid food encourage to remain sitting 30 minutes after eating to control reflux: and reduce excess acid production (see Odynophagia) for NSAID induced mucosal irritation: <ul style="list-style-type: none"> ensure adequate hydration misoprostol 100–200 µg q6h consider holding or discontinuing NSAID H₂ receptor antagonists are not indicated unless excess acid is also a problem if not controlled, may also add one of: <ul style="list-style-type: none"> prochlorperazine 5–10 mg po, pr, im, iv q4h prn, or haloperidol 0.5–4.0 mg po, sc, im q4–6h prn, or chlorpromazine 10–20 mg po, pr, im q4–6h prn |
| <p>Metabolic</p> | <ul style="list-style-type: none"> correct electrolyte imbalance and dehydration (see Dehydration) correct hypercalcemia: <ul style="list-style-type: none"> rehydrate with N/S, using furosemide as needed to ensure adequate output steroids may be added: dexamethasone 1–8 mg po, iv, im sc q6h if not controlled, add one of prochlorperazine, haloperidol, chlorpromazine (see Mucosal irritation above) |
| <p>Myocardial</p> | <ul style="list-style-type: none"> treat underlying cardiac causes treat cardiac pain (see Chest/cardiac pain) if not controlled, add one of prochlorperazine, haloperidol, chlorpromazine (see Mucosal irritation above) |

COMPLEMENTARY THERAPIES

- acupuncture
- aromatherapy: extract of wild strawberry
- homeopathy: ipecac 6 ch qid ac + hs, increase to 12 ch qid to 30 ch tid if needed
- relaxation therapy
- therapeutic touch

CONSTIPATION, BOWEL OBSTRUCTION

Tenesmus = ineffectual and painful straining at stool or in urinating.

PRESENTATION

Reduced numbers of bowel movements with increased stool consistency. Overflow diarrhea mixed with hard stool.

May lead to difficulty defecating. In extreme, may lead to little or no stool movement, fecal impaction, bowel obstruction, overflow incontinence and/or tenesmus

CAUSES

Infectious:

- HIV autonomic neuropathy

Malignancy:

- Kaposi’s sarcoma
- lymphoma

Other:

- ileus:
 - post operative
 - narcotic bowel syndrome
- lack of mobility (inability to get to bathroom or other equipment)
- lack of privacy
- medications:
 - opioids
 - anti-cholinergics
- metabolic:
 - hypercalcemia
 - hypokalemia
- spinal cord compression
- dehydration
- peri-anal problems

APPROACHES AND INTERVENTIONS

Examination, investigation and treatment of underlying causes should be appropriate to the presentation, stage and context of the person and illness.

- establish the person’s normal bowel habit, current number of bowel movements/week, consistency, colour and volume of stool
- mobilize as tolerated
- maintain adequate hydration (see Dehydration)
- maintain regular bowel routine, especially if the underlying causes are neurological
- toilet regularly, strongest peristalsis is in early morning (7-9am)
- sit upright if possible
- maintain good peri-anal care (see Peri-anal problems)
- for laxatives, use po routes first. If not adequate after 2-3 days, use rectal suppositories. If still no results, use enemas

| APPROACHES | INTERVENTIONS |
|---|--|
| increase bulk (except if opioid related) | <ul style="list-style-type: none"> • psyllium • fiber, bran, pectin • increase fluid intake (see Dehydration) |
| soften stool | <ul style="list-style-type: none"> • sodium or calcium docusate 100–200 mg po od-tid • osmotic cathartics: <ul style="list-style-type: none"> – magnesium salts, i.e. Phillips’ Milk of Magnesia® 15-30 mls po od-qid – lactulose 15–30 mls po od q8h |
| reduce bloating, distention, gas | <ul style="list-style-type: none"> • reduce air swallowing by educating, behaviour modification • may need to alter or restrict diet, remove lactose • may need NG or rectal tube (with or without suction) • homeopathic: lycopodium, start with 6 ch qid ac + hs, increase to 30 ch tid ac, if needed • antacids with simethicone |
| stimulate peristalsis (ileus, narcotic bowel syndrome) | <ul style="list-style-type: none"> • bowel irritants: <ul style="list-style-type: none"> – prune juice 120-240 mls od-bid – senna tablets or tea 1–2 po od-bid – bisacodyl 10 mg pr od-tid – cascara 5-10 ml + magnesium hydroxide + mineral oil (Magnolax®) 25 mls prn |

| | |
|--|--|
| | <ul style="list-style-type: none"> propulsive medications: <ul style="list-style-type: none"> metoclopramide 5–10 mg po, im, iv tid-qid, 1/2 hr ac + hs domperidone 5–20 mg po tid-qid, 1/2 hr ac + hs cisapride 5–10 mg po tid-qid, 1/4 hr ac + hs or 20 mg po bid <p>Caution: may be dangerous if mechanical obstruction present</p> |
| relax and/or anaesthetize anal sphincter | <ul style="list-style-type: none"> sitz bath digital sphincter stimulation glycerin suppositories 1 pr od-tid lidocaine spray or jelly (2% unidose syringes) dibucaine 1% (Nupercainal®), apply as directed post bowel movement, apply silicone ointment to rectal area |
| disimpaction | <ul style="list-style-type: none"> digital extraction after topical anaesthesia enemas: <ul style="list-style-type: none"> sodium phosphate (Fleet®) tap water or saline mineral or peanut oil (ask about peanut allergy first) 2 bottles of sodium phosphate + 50 mls hydrogen peroxide (added at the last minute) |

COMPLEMENTARY THERAPIES

- therapeutic touch
- homeopathy:
 - moderate, with cramping: staphysagria 6 ch tid ac
 - extreme, no movement: alumina 30 ch bid
 - other pattern: consult practitioner

DIARRHEA

Diarrhea = Stools that are looser than normal in consistency.

PRESENTATIONS

May occur with increased frequency:

- flatulence
- multiple bowel movements/day
- hemorrhoids
- fissures
- rectal bleeding
- watery bowel movements
- cramps/colic

CAUSES

Infectious:

- lospora
- cryptosporidium
- microsporidium
 - MAC
 - salmonella
 - other enteric pathogens

Other:

- GI bleeding
- malabsorption:
 - high osmotic feeds
 - HIV enteropathy
 - lactose intolerance
- medications
- obstruction with overflow incontinence
- rectal incontinence
- stress

APPROACHES AND INTERVENTIONS

Examination, investigation and treatment of underlying causes should be appropriate to the presentation, stage and context of the person and illness.

- establish the person’s normal bowel habit, current number of bowel movements/day, consistency, colour and volume of stool and fluid
- maintain adequate hydration (see Dehydration)
- ready access to a bathroom or commode
- use incontinent devices to prevent soiling
- deodorize
- maintain dignity, privacy, especially while toileting
- maintain good peri-anal care (see Peri-anal problems)

| APPROACHES | INTERVENTIONS |
|-------------------------------------|--|
| diet, lactose intolerance | <ul style="list-style-type: none"> • small, frequent, low fat, low lactose meals: <ul style="list-style-type: none"> – for lactose intolerance, use lactase enzyme 1–4 tablets 15–30 minutes before meals • if cramping is a problem, avoid foods that may cause gas or cramps, i.e. beans, cabbage, broccoli, cauliflower, highly spiced foods or too many sweet or carbonated drinks |
| increase bulk | <ul style="list-style-type: none"> • psyllium • fiber, bran, pectin |
| manage transient diarrhea | <ul style="list-style-type: none"> • attapulgate (Kaopectate®) 30 mls or 2 tabs prn • aluminum antacids (Amphogel®) 15-30 mls po q4h prn • bismuth salts (Pepto Bismol®) 15-30 mls po bid-qid |
| reduce intestinal secretions | <ul style="list-style-type: none"> • octreotide (Sandostatin®) 100-500 µg sc q8h |
| reduce peristalsis | <ul style="list-style-type: none"> • opioids: <ul style="list-style-type: none"> – diphenoxylate 2.5-5.0 mg po q4–6h prn, max 20 mg/24 hrs – loperamide 4 mg po first dose then 2-4 mg after each unformed stool, max 16 mg/24 hrs Note: under careful supervision, might increase maximum doses of diphenoxylate and loperamide) – codeine 30-60 mg po, im q4h prn – strong opioids: <ul style="list-style-type: none"> – for opioid naive: morphine 5-10 mg po, pr, sc q4h prn (or hydromorphone equivalent) – for those on opioids: increase morphine (or hydromorphone) by 25–50% or add codeine |

COMPLEMENTARY THERAPIES

- relaxation therapy
- therapeutic touch
- homeopathy:
 - periodic diarrhea, with colic: DIA complex prn
 - gripping pain: cuprum arsenicum 6 ch tid
 - other patterns: many effective, symptom specific remedies, consult practitioner

BOWEL INCONTINENCE

PRESENTATION

Loss of sphincter competence that leads to consistent loss of stools.

CAUSES

Infectious:

- autonomic neuropathy:
 - CMV
 - HIV

Malignancy:

- cord compression:
 - Kaposi's sarcoma
 - lymphoma
 - squamous cell carcinoma

Other:

- fecal impaction (overflow incontinence)
- peri-anal problems
- post traumatic loss of sphincter competence
- delirium
- dementia

APPROACHES AND INTERVENTIONS

Examination, investigation and treatment of underlying causes should be appropriate to the presentation, stage and context of the person and illness.

- increase bulk in the diet
- toilet regularly with appropriate privacy
- use diapers and protective bed coverings as preferred by the individual
- anticipate pain (see Peri-anal pain)
- if incontinence appears early in HIV disease and will be an ongoing, unmanageable problem, consider a bypass colostomy

PERI-ANAL PAIN

PRESENTATION

May be increased with bowel movements, rectal manipulation/penetration, sitting or urination.

Bowel movements or urination may lead to tenesmus.

CAUSES

Infectious:

- abscess
- candida
- CMV
- herpes simplex or zoster
- warts
- other sexually transmitted diseases

Other:

- fissures
- fistulae
- hemorrhoids
- inflammatory strictures

Malignant:

- Kaposi's sarcoma
- lymphoma
- squamous cell carcinoma

APPROACHES AND INTERVENTIONS

Examination, investigation and treatment of underlying causes should be appropriate to the presentation, stage and context of the person and illness.

- sitz baths may improve hygiene and peri-anal pain
- cover open fissures, ulcers with mineral oil or zinc oxide ointment (to reduce contact with oxygen, which produces the pain)
- sit on soft cushions, or foam cushions with cut-outs (or donuts) to reduce discomfort
- maintain hydration (see Dehydration)

| APPROACHES | INTERVENTIONS |
|----------------------------|---|
| manage pain | <ul style="list-style-type: none"> • to anaesthetize locally: <ul style="list-style-type: none"> – lidocaine 10% endotracheal spray, tid-qid, before or after bowel movements – lidocaine 2% jelly or 5% ointment, tid-qid, before or after bowel movement – dibucaine (Nupercainal®) cream, ointment or suppositories, tid-qid, before or after bowel movements • selective nerve blocks (see Nerve blocks) • provide stepwise analgesia (see Pain and Neuropathic Pain) • may need to bypass painful area <ul style="list-style-type: none"> – rectal tube – colostomy if prognosis warrants the procedure |
| reduce inflammation | <ul style="list-style-type: none"> • Burrow's compresses • consider steroids: <ul style="list-style-type: none"> – prednisone 10-60 mg po od – dexamethasone 1-4 mg po, iv, im, sc q6h |
| soften stool | <ul style="list-style-type: none"> • diet, increased fiber, bran, pectin • sodium or calcium docusate 100-200 mg po bid-tid |

COMPLEMENTARY THERAPIES

- homeopathy:
 - internal hemorrhoids: collubrina 6 ch qid ac + hs (stimulates portal circulation)
 - external hemorrhoids: aescylus hippocastrum 6 ch qid ac + hs
- hydrotherapy
 - alternate hot and cold water over region using personal shower attachment
 - otherwise, alternate warm compresses and ice packs

PERI-ANAL PROBLEMS

PRESENTATION

May include:

- bleeding
- fissures
- hemorrhoids
- superficial ulcerations, lesions
- discharges
- fistulae
- pruritis

CAUSES

Infectious:

- herpes simplex or zoster
- CMV
- warts
- candidiasis
- other sexually transmitted diseases
- abscess

Other:

- stress
- loss of anal sphincter competence
- inflammatory strictures

Malignant:

- Kaposi's sarcoma
- lymphoma
- squamous cell carcinoma

APPROACHES AND INTERVENTIONS

Examination, investigation and treatment of underlying causes should be appropriate to the presentation, stage and context of the person and illness.

- use sitz baths to improve peri-anal hygiene and decrease discomfort
- sit on soft or foam cushions with cut-outs (or donuts) to remove pressure from the peri-anal area
- prevent constipation (see Constipation)
- incontinence device if required
- provide absorbant pad if discharge present
- moistened rectal wipes for hygiene and comfort (avoid wipes with alcohol)

| PROBLEMS | INTERVENTIONS |
|-----------------------|--|
| bleeding | <ul style="list-style-type: none"> • compression • silver nitrate sticks for small, accessible bleeding spots • (see Bleeding) |
| fissures, hemorrhoids | <ul style="list-style-type: none"> • relieve pressure • stool softeners (see Constipation/Bowel obstruction) • astringents, i.e. zinc sulphate with/without pramoxine • topical hydrocortisone |
| pruritis | <ul style="list-style-type: none"> • topical corticosteroids (do not apply to herpetic lesions) • topical anesthetics (see Peri-anal pain) |
| ulceration | <ul style="list-style-type: none"> • acyclovir 200-800 mg po 5 times/day. • Burrow's compresses • protect with silicone cream, zinc oxide ointment, etc. |

COMPLEMENTARY THERAPIES

- laser therapy (infra-red/helium) to ulcerations
- relaxation therapy, therapeutic touch

GENITO-URINARY PROBLEMS

GENITO-URINARY PAIN

Dysuria = Pain on urination

PRESENTATIONS

Pain may be constant ache or burning. May be intermittent and/or increased with bowel movements, erection, ejaculation, vaginal intercourse or urination.

CAUSES

Infectious:

- candida
- pelvic inflammatory disease
- UTI
- other sexually transmitted diseases

Other:

- catheter
- HIV neuropathy
- sexual intercourse
- trauma
- medications: foscarnet

Malignant:

- Kaposi's sarcoma
- lymphoma

APPROACHES AND INTERVENTIONS

Examination, investigation and treatment of underlying causes should be appropriate to the presentation, stage and context of the person and illness.

- maintain good genito-urinary hygiene
- maintain adequate hydration (see Dehydration)

| PROBLEMS | INTERVENTIONS |
|---------------|---|
| bladder spasm | <ul style="list-style-type: none"> • relieve obstruction with intermittent or indwelling catheter • analgesia: <ul style="list-style-type: none"> – provide stepwise analgesia (see Pain) – phenazopyridine (Pyridium®) 200 mg po tid • reduce spasm: <ul style="list-style-type: none"> – NSAID's may be very helpful • smooth muscle relaxants: <ul style="list-style-type: none"> – hyoscine butylbromide (Buscopan®) 10-20 mg po od-5 times/day – flavoxate (Urispas®) 100-200 mg po tid-qid – oxybutynin (Ditropan®) 5 mg po bid-tid – amitriptyline 25-50 mg po qhs |
| dysuria | <ul style="list-style-type: none"> • phenazopyridine (Pyridium®) 200 mg po tid |
| pain | <ul style="list-style-type: none"> • provide stepwise analgesia (see Pain and Neuropathic Pain) |
| renal colic | <ul style="list-style-type: none"> • provide stepwise analgesia (see Pain) • NSAID's may be very helpful |

COMPLEMENTARY THERAPIES

- acupuncture
- homeopathy: numerous, symptom specific interventions, consult with a practitioner

URINARY CONTROL PROBLEMS

PRESENTATION

May include:

- frequency
- incontinence
- urgency
- hesitancy
- retention

CAUSES

Infectious:

- autonomic neuropathy:
 - HIV
- cystitis(all causes)
- myelitis:
 - CMV
 - HIV
- prostatitis (all causes)
- urethritis (all causes)

Other:

- medications:
 - opioids
 - anti-cholinergics
- delirium
- dementia

Malignant:

(cord compression or local destruction/obstruction)

- Kaposi’s sarcoma
- lymphoma
- re-evaluate medications

APPROACHES AND INTERVENTIONS

Examination, investigation and treatment of underlying causes should be appropriate to the presentation, stage and context of the person and illness.

| PROBLEMS | INTERVENTIONS |
|---|--|
| incontinence, urgency, frequency | <ul style="list-style-type: none"> • maintain close proximity to toilet facilities • toilet regularly • use condom catheter, if tolerated • use diapers and protective bed coverings as preferred by the individual • oxybutynin (Ditropan®) 5 mg po bid-tid |
| retention, hesitancy | <ul style="list-style-type: none"> • apply pressure in the suprapubic area of the abdomen to try to initiate urination • non-obstructive: <ul style="list-style-type: none"> – bethanechol chloride 10-50 mg po tid-qid or 2.5-10 mg sc tid-qid may improve function, otherwise treat as obstructive • obstructive: <ul style="list-style-type: none"> – indwelling urinary catheter, silastic if long term – intermittent urinary catheterization |

COMPLEMENTARY THERAPIES

- homeopathy: many remedies available, initially try equisetum tincture qid, consult practitioner for more symptom specific remedy if needed

GYNECOLOGICAL PROBLEMS

Dyspareunia = pain on vaginal penetration

PRESENTATION

May include:

- bleeding
- dyspareunia
- ulcers
- discharge
- pruritis

CAUSES

Refer to: *Practice Guidelines for Obstetrical and Gynecological Care of Women Living with HIV.*

APPROACHES AND INTERVENTIONS

Examination, investigation and treatment of underlying causes should be appropriate to the presentation, stage and context of the person and illness.

- maintain good genito-urinary hygiene
- provide stepwise analgesia (see Pain)

COMPLEMENTARY THERAPIES

- homeopathy: many highly effective remedies, consult practitioner

SKIN PROBLEMS**SKIN PAIN****PRESENTATION**

May become worse with movement or on contact with clothing, sheets.

Infectious:

- abscesses
- cellulitis
- herpes simplex or zoster

Malignant:

- Kaposi's sarcoma (malignant ulcers)

Other:

- decubitus ulcers
- medication:
 - chemotherapy
- neuropathy:
 - HIV related
 - post-herpetic

APPROACHES AND INTERVENTIONS

Examination, investigation and treatment of underlying causes should be appropriate to the presentation, stage and context of the person and illness.

See below

| PROBLEMS | INTERVENTIONS |
|----------|--|
| pain | <ul style="list-style-type: none"> • provide stepwise analgesia (see Pain and Neuropathic Pain) • to reduce contact, irritation: <ul style="list-style-type: none"> – light, non-irritating clothing or bed coverings – over-bed cradle to keep sheets off hyper-sensitive skin – ensure even weight distribution on bed (see Skin Care/problems particularly support) |

COMPLEMENTARY THERAPIES

- massage therapy

SKIN CARE^{19,20}

GENERAL PRINCIPLES OF SKIN CARE

Skin care requires considerable attention, particularly as a person spends more time in one position on the bed, including:

| APPROACHES | INTERVENTIONS |
|------------|--|
| bathing | <ul style="list-style-type: none"> • bathe with non-abrasive soap and tepid water • air or towel dry • bathing stimulates circulation, reduces odours and the risk of infection • maintain body fluid precautions while bathing |
| bleeding | <ul style="list-style-type: none"> • manage small bleeding sites with silver nitrate sticks • more extensive bleeding may require the application of: <ul style="list-style-type: none"> – topical thrombin 1,000-5,000 units sprayed on the area of bleeding (Thrombostat®) – Kaltostat™ dressing (layer of Jelonet™ on top of Kaltostat™ will reduce sticking, and risk of bleeding) – absorbent pressure dressings • if there are risks of large bleeds, warn family and caregivers of potential risks and develop a clear management plan which may include: <ul style="list-style-type: none"> – the removal of family from the room – the use of red or dark coloured towels – analgesic and/or sedative medication – (see Bleeding) |
| dry skin | <ul style="list-style-type: none"> • maintain adequate hydration (see Dehydration) • use hydrating creams, ointments, oils, i.e. Uremol™ HC • humidify room |

| | |
|--------------------------|--|
| infections | <ul style="list-style-type: none"> • fungal infections: <ul style="list-style-type: none"> – topical or systemic anti-fungals as indicated • staphylococcal or streptococcal infections, i.e. cellulitis: <ul style="list-style-type: none"> – staphylococcal-cloxacillin 250-500 mg po, iv q6h for 10 days – streptococcal-clindamycin 450 mg po q6h or – amoxicillin 250-500 mg po q8h – topical antibiotics with or without occlusion • anaerobic infections, i.e. malignant ulcers: <ul style="list-style-type: none"> – metronidazole 10% cream bid-tid or – silver sulfadiazine (Flamazine®) cream bid-tid – if extensive: <ul style="list-style-type: none"> • systemic metronidazole 250-500 mg po, iv tid or • metronidazole vaginal ovules diluted with 50 mls N/S or iv solution mixed with N/S and sprayed onto lesions will prevent buildup associated with creams |
| massage | <ul style="list-style-type: none"> • can enhance capillary blood flow, reduce the risk of local ischemia of skin, and relax muscles and stiff joints • may shift peripheral edema • should be avoided on erythematous or open leaking areas |
| movement, turning | <ul style="list-style-type: none"> • intermittent moving and turning reduces the risk of skin breakdown and reduces position fatigue/discomfort • combine with massage prior to turning • a draw sheet may assist turning and will reduce shearing forces • pillows behind the back and between legs/ankles will provide support and prevent skin-to-skin contact pressure ulcers • if turning is painful, it may need to be stopped. An air mattress or air bed may be the only way to prevent skin breakdown |
| odour control | <ul style="list-style-type: none"> • air fresheners, filters • place charcoal dressing on top of non-stick dressings • apply yogurt and honey directly to the lesion • place Cepacol® soaked gauze on top of other dressings (do not get Cepacol® onto wound site) • place kitty litter or activated charcoal in the room (under the bed) • vinegar or vanilla also reduce odour in room |
| protection | <ul style="list-style-type: none"> • cover reddened pressure points clear plastic dressings to reduce shearing, tearing and pain • cover pressure ulcers with hydrocolloid dressing to provide cushioning as well as reduce shearing, tearing and pain (see Skin Breakdown/ Pressure ulcers) |
| pruritis | <ul style="list-style-type: none"> • consider medication, environmental or food allergies • bathe with/without oatmeal or oils • maintain adequate hydration (see Dehydration) • apply astringents such as calamine (if indicated) • apply protective creams, oils • consider topical steroids (except when herpetic lesions are present) • consider oral antihistamines, especially hydroxyzine, cyproheptadine • apply camphor, menthol, praxnoxine (Sarna-P®) prn • for severe, refractory pruritis, consider oral steroids: <ul style="list-style-type: none"> – prednisone 10-60 mg po od • if jaundice present, consider ammonium ion exchange resins, i.e. cholestyramine |

| | |
|------------------------------------|---|
| support | <ul style="list-style-type: none"> • for intact skin, use a thick (>4 inch) egg-crate, air or bubble mattress • for extensive edema, skin breakdown or pain on turning, an air mattress or air bed may be more effective • under all circumstances, try to avoid contact with plastic or abrasive materials |
| sweating, night sweats | <ul style="list-style-type: none"> • reduce body and skin temperature (see fever) • bathe as above, dry thoroughly • remove plastic and use absorbant bed coverings, i.e. terry cloth, flannelette • re-evaluate medications: <ul style="list-style-type: none"> – alcohol, morphine, tricyclic anti-depressants • maintain hydration (see Dehydration) • indomethacin 25-75mg po, pr q8-12h for night sweats • if extreme, try hyoscyamine (Levsin®) 0.125-0.25 mg po, sl q4h routinely or prn • NSAID's may be useful if due to morphine • if limited to palms, soles and/or axillae, use 20% aluminum chloride hexahydrate (deodorant) • manage associated anxiety (see Anxiety) |
| temperature | <ul style="list-style-type: none"> • keep warm, but not too hot: <ul style="list-style-type: none"> – coverings (warm, but light weight) – appropriate room temperature • manage fever (see Fever) |
| wet, leaking skin, exudates | <ul style="list-style-type: none"> • clean regularly to remove exudates and debris • Burrow's compresses 1/20 bid-tid • cover with non-stick dressings, including non-stick meshes, i.e. Jelonet™ with dry gauze wrapping |

| LAST HOURS OF LIVING | INTERVENTIONS |
|-----------------------------|--|
| skin care | <p>As the dying person loses his/her ability to move, skin care may become increasingly problematic if the process becomes prolonged.</p> <p>In addition to general skin care:</p> <ul style="list-style-type: none"> • turning may need to be reduced or discontinued, particularly if it is painful • bathing should be continued right up until death |

COMPLEMENTARY THERAPIES

- homeopathy: for periodic sweats: sulphur 30 ch bid-tid, if ongoing, may need to drop to 6 ch, prn
- aromatherapy: geranium and lavender oils are soothing
- infrared-helium neon laser therapy may improve decubitus ulcers
- massage: sweet almond oil nourishes dry skin

SKIN BREAKDOWN/PRESSURE ULCERS^{19,20}

Ulcer = a loss of substance on a cutaneous or mucous surface, causing gradual disintegration and necrosis of the tissues.

Pressure/decubitus ulcer = an ulceration caused by prolonged pressure on an area of skin in a person confined to bed for a prolonged period of time.

Skin breakdown/ulceration is the result of ischemia in the affected area and occurs in persons who are:

- poorly nourished/cachectic
- immobile and lie in the same position constantly
- dehydrated/have dry skin
- edematous/have wet skin
- dependant on others for personal hygiene

PRESENTATIONS

- Stage 1 nonblanchable erythema of intact skin (the heralding lesion of skin ulceration, not to be confused with reactive hyperemia)
- Stage 2 partial thickness skin loss involving epidermis and/or dermis
- Stage 3 full thickness skin loss involving damage or necrosis of subcutaneous tissue that may extend down to, but not through, underlying fascia
- Stage 4 full thickness skin loss with extensive destruction, tissue necrosis or damage to muscle, bone, or supporting structures.

Note:

- identification of stage 1 pressure ulcers may be difficult in those whose skin is darkly pigmented
- when eschar is present, accurate staging is not possible until the eschar has sloughed or the wound has been debrided

CAUSES

Malignant:

- malignant ulcers

Other:

- reactive hyperemia

APPROACHES AND INTERVENTIONS

Examination, investigation and treatment of underlying causes should be appropriate to the presentation, stage and context of the person and illness.

- assess risk of skin breakdown using Norton²¹ or Braden²² assessment scales
- consider consulting a wound care specialist, i.e., enterostomal therapist, dermatologist or plastic surgeon
- remove necrotic tissue by cross-hatching with a scalpel, then apply a debriding agent, i.e. elase, elase with chloromycetin, hypertonic gel, (i.e. Hypergel[®], Intrasite Gel[®])
- treat clinical infection
- obliterate dead spaces with packing or gel
- remove exudates
- keep wound clean, moist (enhances growth of new tissue):
 - clean with normal saline or diluted hygeol in head and neck area
 - avoid iodine containing solutions when there is any skin breakdown/ulceration as this inhibits re-epithelialization
- insulate, protect wound surface
- maintain adequate circulation
- laser therapy may be useful

| PROBLEMS | INTERVENTIONS |
|------------------------------|--|
| stage 1 pressure ulcer | <ul style="list-style-type: none"> • clean with normal saline • apply a transparent adhesive dressing, i.e. Tegaderm[®], OpSite[®], to protect against shearing forces • do not massage |
| stage 2 pressure ulcer | <ul style="list-style-type: none"> • apply a protective hydrocolloid dressing, i.e. Comfeel Ulcus[®], Duoderm[®] |
| stage 3 and 4 pressure ulcer | <ul style="list-style-type: none"> • use saline gel, i.e. Normagel[®] and absorptive dressing, i.e. gauze, or Mesalt[®] to absorb thick exudates • non-stick dressings may be applied first, e.g. Telfa[®], Jelonet[®] with petroleum jelly, Mepital[®] to reduce tearing with dressing changes |

COMPLEMENTARY THERAPIES

- laser therapy: infrared-helium neon laser therapy may improve pressure ulcers

AIDS SPECIFIC SKIN PROBLEMS

Standard therapies for these problems follow.
For hard to manage situations, consider consulting a dermatologist.

| PROBLEMS | INTERVENTIONS |
|---|---|
| bacillary angiomatosis | <ul style="list-style-type: none"> Refer to <i>Module 1</i> also itraconazole 100-200 mg po od |
| folliculitis | <ul style="list-style-type: none"> topical skin cleansers, i.e. povidone-iodine, erythromycin in alcohol, triclosan (Tersaseptic®), hexachlorophene (PhisoHex®) topical anti-fungals i.e., itraconazole 100-200 mg po od systemic antibiotics and anti-fungals |
| herpes simplex, herpes zoster | <ul style="list-style-type: none"> for primary management refer to <i>Module 1</i> continue prophylactic treatment as long as possible in order to avoid symptomatic recurrences for associated pain, see Neuropathic Pain |
| impetigo | <ul style="list-style-type: none"> warm soaks topical and systemic antibiotics |
| malignant ulcers (KS, skin carcinomas and melanomas) | <ul style="list-style-type: none"> for the primary management of Kaposi's sarcoma, refer to <i>Module 1</i> malignant ulcers may require more extensive cleansing with: <ul style="list-style-type: none"> Burrow's compresses 10% Proiodine® N/S 3% boric acid solution manage exudates, superimposed infections and odours as in general principles of skin care (see Skin breakdown/Pressure ulcers) |
| psoriasis | <ul style="list-style-type: none"> apply topical corticosteroids in combination with anti-fungal, i.e. ketoconazole, terbinafine if very scaly, add salicylic acid calcipotriol (Dovonex®) ointment, apply bid consider oral vitamin A therapy |
| scabies | <ul style="list-style-type: none"> clean laundry topical lindane 1% lotions |
| seborrheic dermatitis | <ul style="list-style-type: none"> terbinafine 125 mg po bid or 250 mg po od apply hydrocortisone 1% and anti-fungal cream combinations, i.e. ketoconazole, terbinafine, clotrimazole use ointment forms if very dry |
| warts, molluscum contagiosum | <ul style="list-style-type: none"> cryofreeze with liquid nitrogen apply topical cantharidin (Cantharone®) once q1-2 weeks for diffuse areas, apply 5% fluorouracil cream q3-7 days (use with caution, very irritating) |

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SUGGESTED READINGS

Activities of Daily Living

*"We may wish to struggle along at home."
– one voice –*

Much of what brings meaning to life is expressed through, and experienced in, activities of daily living (ADL). To assist caregivers in addressing issues related to ADL, a comprehensive assessment tool has been adapted for use with persons living with HIV/AIDS. It is based on the SAFER Tool¹ developed by Community Occupational Therapists and Associates.

In using this tool, three important points must be stressed:

1. understand the context of the living environment of the person, as care and access to resources will vary depending on the person's living situation. Care in a well-equipped apartment can be extremely different from that provided in a hot-plate hotel, boarding house or rooming house
2. whenever possible, consultation with rehabilitation professionals such as physiotherapists and occupational therapists is strongly recommended. Palliative Care includes rehabilitation, especially if it will enhance quality of life
3. include the person in all discussions related to changes in their environment which may be needed to provide safe and effective care

LIVING SITUATION

Access/entrance/security

Many persons living with HIV/AIDS prefer to die at home. To provide optimal quality of life and to enable the person to die at home if he/she chooses:

- develop a plan for caregiver access to the home
- assess the home environment to determine necessary resources and adaptations to maintain a safe, supportive living environment
- make environmental modifications where required to adapt the home setting for providing access and safe care

Support network – family/friends

Home support workers and volunteer caregivers may be instrumental in assisting with daily household chores. Assess the person's support network (family, friends, neighbours) and the level of care and support they are able and willing to provide:

- what level of care and support does the individual wish?
- is it realistic given available resources?
- what are the caregiving training needs of family/friends?
- who will provide this training?

Stairs

- check that surfaces are non-slip
- ensure adequate lighting on stairways
- encourage the use of handrails when using stairs
- in multi-level housing:
 - consider reorganizing care on one level
 - install a safety gate to prevent falls down the stairs

Elevator

- if there is an elevator in the person's building, consider placing a convenient chair so that they can rest while waiting for the elevator
- if necessary, advocate for improved elevator design, i.e. handrails, legible and accessible controls, visual and sound controls

- Environment cluttered**
- negotiate removal of hazardous, unnecessary clutter
 - ensure clear walkways
 - stabilize unsteady furniture

-
- Scatter rugs/flooring**
- remove scatter rugs
 - no-wax floors are recommended

MOBILITY

Positioning Teach correct positioning techniques and back care to caregivers. Assess need to alter height of bed or chairs for persons living with HIV/AIDS and caregivers:

- lying:
 - reposition with supports every 2-3 hours
 - use special mattresses, i.e. foam, egg crate, air, to protect skin
- seating:
 - use special seating cushions, chairs with arms to promote safety
- bed care:
 - if required, consider using a hospital bed with working brakes, monkey bar, floor-to-ceiling pole or rope ladder, lifting sheet, bed cradle, mechanical lifting device

Transfers Teach correct transfer techniques. To facilitate transfer, consider the following equipment:

- bed blocks, chair with arms, cushion, transfer board, vertical pole, lifting sheet or transfer belt, mechanical lift

Walking/devices The gradual loss of strength and mobility can be demoralizing, and it is important for persons living with HIV/AIDS to maintain activity and strength without overexertion. Focus on ability rather than disability:

- simple, regular exercises can enable the person to maintain strength more effectively than just continuing normal activities
- to assist with walking, recommend well-fitting footwear with enclosed heels and toes
- ensure walking aids are appropriate, height adjusted, correctly fitted and in good working order
- check rubber tips on cane or walker to ensure they are secure
- provide an ice pick for cane in winter
- when leg weakness due to neuropathy, or generalized weakness, impairs ability to walk, a walking aid such as a cane or wheeled walker should be considered

Wheelchair/scooter

- a scooter or electric wheelchair will enable the person to maintain independence when weakness progresses and prohibits walking more than a short distance
- while a scooter may be preferred, as weakness progresses, climbing onto such may become difficult or unsafe
- at that point, electric wheelchairs are recommended, so that the person will not lose a valuable tool for independence

Venturing outside Maintaining regular activity is crucial to a sense of well-being:

- encourage and/or offer to structure regular outings
- ensure that appropriate clothing is worn when venturing outdoors

Transportation

Investigate transportation supports in your community, i.e. public transport authority, local AIDS Service Organizations or other volunteer agencies.

- if appropriate, obtain a disabled parking permit and/or arrange for transportation for the disabled
- assist with arranging for transportation to/from appointments

KITCHEN**Appliances**

Encourage independence where possible:

- place frequently used items at an accessible level
- provide a long reacher for dials at back of stove
- teach fire safety

If confusion is present:

- unplug appliances when not in use
- remove appliances no longer in use
- remove matches and other potential hazards

Food supply

Arrange for regular shopping:

- keep the person's personal tastes and needs in mind
- arrange items for easy access
- ensure person can reach items in cupboards and fridge

FIRE HAZARDS**Smoking**

If the person smokes, recommend:

- a safety ashtray
- supervised smoking, especially in bed
- safety matches
- a fire retardant apron
- adjusting flame height on lighter

If oxygen is in use:

- ensure all are instructed regarding oxygen safety measures, i.e. no smoking while in use

Smoke detector

- smoke detectors should be placed appropriately throughout the home
- ensure all are in good working order

Electric blanket/pad/heater

If the person uses an electric blanket/pad:

- ensure it is in good working order
- consider pre-warming bed and turn it off when the person is in bed
- do not use if the person is incontinent (wool blankets or duvets are good alternatives)

Fire exit

Know location of fire exit:

- ensure accessibility
- review safety route and procedures with all caregivers

FOOD**Nutrition**

Although people with HIV/AIDS often choose to eat and drink less, the role of adequate nutrition cannot be underestimated. Persistent infections, wasting, or gastrointestinal disorders can contribute to rapid deterioration, weakness and emotional distress.

Consumption of adequate nutritional requirements is important and, when necessary, should be assessed through consultation with a nutritionist.

- dysphagia and problems with malabsorption are common and may require use of special nutritional supplements or alternative feeding techniques
- when eating, consider that correct positioning, a pleasant atmosphere and assistive devices will help maintain appetite and encourage consumption
- appetite, the senses of smell and taste, and food allergies should be taken into consideration when preparing and serving meals
- pay careful attention to food safety when preparing meals
- frequent small snacks/meals throughout the day are generally better than three large meals
- promote independence in eating by using appropriate dishes and cutlery, drinking straw, and a non-slip mat or damp cloth under the place setting
- reduce distractions such as noise
- do not put too much on the plate
- if using cutlery is difficult, suggest finger foods

HOUSEHOLD

Financial

- consult with the person or his/her power of attorney to ensure sufficient financial resources are available to meet the person's needs
-

Bed making

- ensure position of bed gives easy access for caregivers
 - check bed height to ensure proper back care of caregivers
 - assess linen supplies and need for special mattresses and/or other caregiving aids, i.e. extra pillows, foot cradle
-

Cleaning/laundry

- provide appropriate support where necessary
 - maintain body substance precautions with any soiled clothing/linens
-

Child care

Child care is of great concern to those persons living with HIV/AIDS who have children. It is crucial to address the support needs of the entire family:

- provide opportunities for the person living with HIV/AIDS to maintain his/her role as a parent
- assist him/her to delegate tasks where appropriate
- when suitable, and with parental consent, include children in the care team's activities

DRESSING

Dressing/undressing

The person's sense of well-being may be enhanced by maintaining a routine of grooming and dressing:

- choose suitable garments including loose fitting, velcro fastenings, front openings, elastic waistbands, slip-on shoes with non-slip soles, front opening bra or cotton vest
 - dress in sitting position
 - provide devices to assist with dressing, i.e. reacher, long-handled shoe horn
 - lower clothes rod in closet to promote accessibility
 - lay out clothes for the day
-

GROOMING

Hair care, nail care, shaving, teeth/oral hygiene

Maintaining personal hygiene is often difficult for the dying person due to weakness, depression or social withdrawal. Adequate personal hygiene is important to prevent new infections or exacerbation of previous conditions. Hygiene and grooming may also play an important role in preserving or enhancing the person's self-esteem:

- arrange for haircuts and manicures
- apply make-up to visible KS lesions. This may help reduce isolation by restoring confidence in the person's self-concept and body image
- pay diligent attention to skin and mouth care, especially when physical symptoms are present, i.e. diarrhea, incontinence, dry mouth, mucosal infections, vomiting
- for those who are bed dependent, use hair washing tray with drain
- refer to chiropodist where required

BATHROOM AND TOILET

Sponge bath/shower/bath

Select suitable assistive devices and safety equipment and provide assistance as required.

- bath bench, shower extension, grab bar, rubber-backed bath mat

Continence (bladder and bowel)

If incontinent:

- consider using a plastic mattress cover, night light, commode, urinal/bedpan, Attends™/Depends™, condom or foley catheter
- reduce fluid intake before sleeping
- establish a regular toilet routine
- provide frequent reminders

Toilet

Select appropriate equipment:

- ensure privacy if possible
- a raised toilet seat, Versaframe™/grab bar
- ensure toilet roll is within reach
- leave bathroom light on at night
- a sign on the bathroom door may be helpful if the person is confused

MEDICATION

Persons living with HIV/AIDS may be taking a broad range of medications. It is important to assess the person's:

- knowledge of the medications he/she takes
- ability to read labels
- understanding and follow-through on prescribing instructions
- ability to open containers
- use of non-prescription medications and natural preparations

To assist with medication management, consider:

- a medication dispenser
- instructing family or friends to supervise medications
- medication alarms
- accessing nursing or pharmacy services to pre-pour medications

In some situations, a professional caregiver is required to teach and/or administer medication (i.e. iv therapy, narcotic titration)

Ordering and storage

As access to a pharmacy and particular drugs like narcotics may be restricted, it is important to anticipate and plan for the person's medication needs:

- store medications safely away from children
- check expiry dates regularly
- if person is self-medicating, ensure easy access
- if confusion is present, a pre-poured or supervised system is recommended
- lock away the remaining medication supply

COMMUNICATION

Use of telephone

- assess locations of telephones and ability to dial
 - consider using a cordless phone, speaker phone, phone with automatic dial
 - place a chair by phone
 - clearly post emergency contacts and phone numbers, and rehearse their use
-

Speech

With advanced HIV disease, speech impairment is not uncommon:

- consider the person's preferred language
 - use a calm, gentle approach and allow time to respond
 - use short sentences, eye contact and touch
 - consider a word/letter board, picture cards
 - consider referral to speech pathologist, if appropriate
-

Vision (reading and writing)

Impaired vision may be experienced by persons with advanced HIV disease. It is frightening and, if it occurs, it substantially increases dependence on caregivers:

- referral to the CNIB can provide invaluable assistance to the person dealing with visual impairment
 - reading: provide good lighting, a tilt table to hold book, large print books, talking books and clocks, volunteer readers
 - writing: use a tape recorder for correspondence
-

Hearing

- consider use of interpreter
 - access to appropriate equipment and communication devices
 - access "peer counselling" where available
-

SOCIAL/LEISURE

Social interaction/hobbies/leisure

- encourage social interaction compatible with the person's level of function, interests and wishes. Balance this with the need for social interaction and the opportunity for privacy and social withdrawal
- some persons living with HIV/AIDS may choose to be more dependent, in order to gain/maintain physical and/or emotional contact with others. In such cases, encourage social interaction with partners, family members, friends and volunteers
- it is also important to consider the meaning of special family or community events, and holidays
- the role of pets cannot be underestimated. Attention must be given to supporting the person and his/her family with pet care
- social interaction may include stress reducing techniques such as massage, relaxation, art and music therapy
- while social interaction may enable the person to participate in life as fully as possible, careful attention must be paid to the conservation of energy for activities of choice

- investigate past leisure interests. Hobbies and other interests may need to be modified in order to be pursued and enjoyed. Opportunities for play and interaction with peers is particularly important for young children and adolescents

Sexuality/intimacy

- the requirement for affection and a sense of belonging form a basic, common human need. However, the degree and manner of affection and physical contact vary from one person to the next. Many of these feelings are grounded in past experience, culture and personal beliefs. Coming to understand these aspects of a person living with HIV/AIDS will guide the caregiver in how they might extend their affection and human touch. When outright affection or touch is not what is wanted by the person living with HIV/AIDS, there may be underlying reasons which he/she may or may not wish to explore. In all cases, the wishes of the person living with HIV/AIDS should be respected
 - the assumption that people who are dying have no interest in sex is unfounded, and is more probably related to discomfort with discussing issues around sexuality. Although persons living with HIV/AIDS may lose their function and interest in sex, per se, their need for affection, physical contact and sensuality may be greater than ever before.
 - when sex is part of the life of the person living with HIV/AIDS, every effort should be made to provide privacy for the person and his/her partner
 - instruction on safer sex is very important, and consultation with a health professional experienced in sexuality issues may be helpful, should problems arise
-

SUMMARY

This section has discussed many, but certainly not all, of the issues related to ADL and HIV/AIDS Palliative Care. Readers are cautioned to use an individualized approach when assessing the ADL needs of persons living with HIV/AIDS. Experience has taught us that we must always be prepared for new and challenging situations. In doing so, we will support the person living with HIV/AIDS and his/her caregivers, and help them realize a quality of life that promotes autonomy, dignity, comfort, and love.

REFERENCES

1. Community Occupational Therapists and Associates. The SAFER tool. Toronto, ON: COTA, 1991

Psycho-Social Support

“...the most fundamental task for the dying person and his/her family is to establish those connections that give the final separation meaning”¹

*“Caregivers should provide care, not judgement.”
– one voice –*

DEALING WITH DIVERSITY

SUPPORTING HIV+ ADULTS

Addressing the psycho-social needs of persons living with HIV/AIDS requires that caregivers adhere to principles of Palliative Care described in *The Interrelationship Between HIV/AIDS and Palliative Care* section. These include:

- providing open communication
- respecting the individual
- nurturing unconditional positive regard
- involving significant others
- developing the support network

This chapter is organized into four sections, each focusing on a specific group. Each section provides insights into pertinent HIV specific issues, and suggests strategies to assist with interventions. The sections are:

- supporting HIV+ adults
- supporting HIV+ children and teens
- supporting family and friends
- considerations for caregivers

In order to provide excellent Palliative Care, the caregiver must have underlying respect and understanding for the individual living with HIV/AIDS.

Needs and interventions should never be taken in isolation, but in the context of family members and friends with whom the person is involved.

It is also important that caregivers are prepared to encounter people from different ethno/cultural, aboriginal and socio-economic backgrounds. In doing so, caregivers must be careful not to make judgments on an individual's reactions to death, dying and grief without understanding their culture.

To meet the challenges of diversity, *Appendix A* contains a checklist designed to foster awareness, to help set aside preconceptions and encourage caregivers to consider more fully the unique needs of each person. If this checklist is used, along with the information in this chapter, the diversity of each individual and their needs can be more fully understood and respected in the delivery of care.

In supporting anyone living with HIV/AIDS, the role of the psycho-social caregiver is to assist the person to use healthy coping mechanisms, maximize positive aspects of self-concept, and enhance soothing, supportive interpersonal relationships. It is important to understand issues facing persons living with HIV/AIDS, and intervention techniques that may help achieve these goals.

HIV is a powerful motivator for overcoming old patterns of behaviour which, having served the individual well in earlier years against hurt and anxiety, may now contribute to a sense of isolation. However:

- many individuals have experienced severe stigmatization,

social isolation, or early life traumas. Others have developed powerful defenses for self preservation. One may encounter difficulties when attempting to work with such individuals in the final stages of life

- those who have learned to survive on the street or in a particular sub-culture (homeless, street youth, sex trade workers, substance users) have developed unique coping skills unfamiliar to some caregivers. A calm, open approach and clear boundary setting generally work best during interactions. These skills can be passed on to the person's network to help them deal with their loved one
- competency is an issue if there is any suspicion of confusion or cloudy judgment due to dementia or multiple treatments. This is best determined by a medical doctor (see *Legal Issues*)
- many people living with HIV disease do not have social or financial supports that ease delivery of care, requiring care providers to be creative, proactive and practical in their service. For the homeless, it may be necessary to set up an alternate care setting such as a hostel, where those living with HIV/AIDS can come when they are sick and leave when they want. Lack of good financial and social supports can often lead to a transient lifestyle with frequent changes in housing

PSYCHO-SOCIAL CONSIDERATIONS FOR HIV+ ADULTS

Age

- HIV/AIDS affects people of all ages, but many are under the age of 30:
 - not well equipped to deal with crisis due to limited life experience and maturity
 - unable to get established in a career, perhaps still in school
 - regret being unable to realize certain goals
 - may have young children, and face leaving them without a parent

Stigmatization

- great stigma associated with HIV/AIDS can be very debilitating:
 - moral judgments are often made on person's lifestyle, once it is revealed that he/she has AIDS
 - people living with HIV/AIDS often reluctant to seek help until very sick
 - frequently prevents development of close nurturing relationships

Disclosure

- persons living with HIV/AIDS have made various choices regarding disclosure:
 - many have not wanted to be associated with the stigma, and some heterosexuals fear being associated with gay lifestyle
 - fears may include: loss of job or business, isolation for a child at school, social loneliness
 - for those who have disclosed publicly, personal tensions and reactions to dying process are impacted by repercussions from public exposure
 - for those who are homosexual or bisexual, disclosure of HIV status may evoke memories of any bad experience they may have had with disclosing their sexual orientation

Sexuality

- if person is gay, lesbian or bisexual, there may be many issues of acceptance by society and family of origin:
 - may feel shame or guilt
 - likely dealing with stigmatization and discrimination
- women are often stigmatized for being sexual. Being HIV+ compounds this

- women with HIV/AIDS are presumed to be sex trade workers, or promiscuous
- HIV+ women who become pregnant face judgement

Intimacy

- contact, sexual or otherwise, is still needed throughout life, especially when ill or dying:
 - physical contact, i.e. touching and hugging, is important and life-sustaining for many
 - individual may fear passing on virus to someone they love

Roles

- the role a person plays in his/her family or network changes when that person becomes ill and increasingly dependent on others for care:
 - the adult child, once self-sufficient, may require care from family

Socioeconomics

- HIV/AIDS is financially very draining:
 - many with HIV/AIDS have little or no economic security and live below poverty line
 - many need help accessing social assistance, drug cards, supportive housing
 - if young, may not qualify for CPP disability insurance
 - many are unemployed or working in jobs with no insurance
 - traditionally, persons with hemophilia have been unable to access life insurance plans except through work benefits

Mental/cognitive functioning

- many psychological manifestations may be encountered, both HIV related and otherwise:
 - impairment is common in latter stages of HIV disease
 - includes dementia, delirium, and secondary mood states (depressive syndromes and hypomania/mania)

Aloneness

- perhaps one of the most profound issues faced by the dying person:
 - complicated by stigma and isolation associated with being HIV+, gay, having abused substances, having been a sex trade worker, having engaged in any sexual activity

Meaning

- stigmatization, isolation and marginalization often result in lack of meaning in life:
 - internalizing society's negative attitudes contributes to loss of meaning
 - women who have traditionally viewed themselves as caregivers, and derived meaning from this role, may lose this significance because of the disease
 - many find meaning in past and present relationships

Denial

- may be a part of their coping strategy

Losses

- in addition to prospect of losing their own life, there are massive losses: control, body functions, body image, ability to work, mental functioning, other friends, family connections, role:
 - may feel resentment over perceived/real control in past, i.e. gay men may feel threatened by homophobic society, sex trade workers may deal with control imposed by clients, pimps or society
 - for persons with hemophilia, introduction of home care permitted much more freedom and spontaneity. HIV/AIDS threatens loss of newly formed autonomy and portends a return to dependency on hospital system

Withdrawal

- a process of letting go:
 - time to do some internal emotional work
 - time for final preparation

- may want to be left alone
- may panic and run away
- may limit contact with loved ones
- not everyone experiences this

Dying

- for those who have focused on living with hope for a cure, dealing with grief and final stages of illness is complicated by approaching reality of death:
 - may have witnessed deaths of many friends from AIDS
 - will it be the same for me?
 - may be frightened of death or afraid of the unknown. What should I prepare for/expect?
 - fears of pain, disfigurement, dementia, loss of control, dependency, abandonment
 - may fear punishment after death for lifestyle or sexual orientation
 - what will be a “good death” for me? Am I ready?
 - what business must I still take care of?
- may be facing death isolated from sources of support, i.e. traditional religion
- may face prohibitions against practising non-traditional rituals
- to enhance cultural sensitivity, it is recommended that caregivers use the *Diversity Checklist, Appendix A*.

INTERVENTIONS

Persons living with HIV/AIDS may be helped by a therapeutic relationship which addresses interpersonal dynamics.

The following insight-oriented psycho-therapeutic technique has been found helpful in improving interpersonal connections and developing more compassionate self-concept:

- define what the individual wants in relation to others. This may realistically include interactions which are non-judgemental, respectful and loving
- explore negative reactions the person expects from others
- identify what the person does in response to this expectation, i.e. isolates self, withholds wishes or feelings. Responses and individual fears are frequently based on past negative experiences, but therapeutic guidance can help distinguish between past experiences and realities. The individual can be helped to see how he/she creates isolation from positive aspects of present relationships. This frequently results in a series of more open encounters with others, and internalization of more soothing opinions of others
- engage significant people in the individual’s life to strengthen supportive aspects of these relationships and help counter isolation and aloneness

“This is not about making decisions for people. It’s about helping people make their own decisions.”
– one voice –

Other interventions include:

- to help ease feelings of aloneness, caregivers can bridge the gap between despair and support by being present and empathic to deeper levels of the person within. Remain calm in the face of anxiety and despondency, employ non-judgmental listening and offer practical assistance
- to assess self-concept, it is important to define the metaphors that the person attaches to HIV/AIDS, i.e. punishment for sin or lifestyle, proof that he/she is unlovable

- Sort out reality from projections due to internal self-concept
- a life review may help deal with issues of meaning.
- Encourage the person to become involved in planning the future for those they love, and/or in decision-making processes at home
- to support the individual's sense of control and autonomy, caregivers need to give persons living with HIV/AIDS as much control as feasible over what is happening to them
- it is important to address all issues in the context of the person's belief system (see *Spirituality*)

SUPPORTING HIV+ CHILDREN AND TEENS

When considering emotional/psycho-social needs of children facing illness and death, it is essential to acknowledge the family's role. A dying child is intensely affected by how everyone in the family is coping with the situation. Therefore, helping the family provide the best care is often the best way to support a child.

Psycho-social needs of the child are individual and quite dependent on the child's:

- age
- developmental concept of death
- overall course of illness
- parental coping skills
- general family views of death

Within this broader context of individuality, several issues should be considered when supporting children.

PSYCHO-SOCIAL CONSIDERATIONS FOR HIV+ CHILDREN/TEENS

Facing death

- usually aware, at some level, that condition is serious but may not be able to verbalize it
- ability to discuss condition directly relates to parent's ability to face reality
- will try to protect parents so that parents don't withdraw from them
- may feel responsible for illness or that they have done something wrong
- need to acknowledge bad feelings, sadness and have misinformation corrected

Facing living

- need routine and normalcy
- need play for expression and communication
- can act out in attempt to regain security and sense of boundaries
- adolescents may have trouble verbalizing feelings. Much of their behaviour may be motivated by body image, self-esteem and strong need to belong

Around HIV/AIDS

- may not be told their diagnosis to protect them from emotional pain and societal stigma
- may never know diagnosis but must have chance to address issues around dying

INTERVENTIONS

The same guidelines for interventions shown above apply to all interventions directed towards supporting a child with HIV/AIDS and his/her family, including realization that all children facing illness and death have a right to autonomy, self-esteem, mastery, dignity.

Play, which is the “work” of children, is an important part of expressing the child’s self-concept. It is a tool to communicate stress and anxiety created when routine is changed, as with illness or hospitalization. Cues to anxiety can often be found when spontaneous play is observed. Experienced professionals may initiate play, art or music therapy to promote expression of non-verbalized feelings and release of tension. Going to school is also a vital part of a child’s life and socialization, and should be encouraged when possible. Special arrangements can be made for home schooling, and interactions with peers should be encouraged and facilitated when possible.

With adolescents, it can be challenging to deal with a teen who reaches for attention on one hand and withdraws on the other. Expressive therapies can help decrease anger and stress.

Other strategies for supporting children:

- provide them with clear information and correct misconceptions
- encourage questions, discuss concerns and fears
- maintain consistent disciplines and routines

Sibling rivalries and needs can be significant when dealing with a young child or teen with HIV/AIDS. Strategies for assisting sibling(s) of a young child:

- provide special time and attention for the sibling
- inform sibling’s school there is a serious illness in the family
- involve sibling in visits to the clinic or hospital, and in caring for the sick child

For more information on HIV/AIDS and children, refer to *Module 2 of The Comprehensive Guide for the Care of Persons with HIV Disease*.

SUPPORTING FAMILY AND FRIENDS

Often the most meaningful form of support for a person living with HIV/AIDS is achieved by assisting their network, i.e. spouse/partner, family, friends. This network is a powerful resource and much more encompassing than any form of individual caregiver support. Effort should be made to assess consequences of denial, multiple loss, renewed feelings of anger, sorrow and guilt, and the impact on partners and parents who have coped with HIV for several years. Caregiver relief, child care and psychological support are essential for the comfort of the person and his/her family.

PSYCHO-SOCIAL CONSIDERATIONS FOR FAMILY AND FRIENDS

Age

- parents are dealing with a child dying ahead of them which is not the “natural order” of life
- friends are experiencing having someone their own age die

Facing living

- parents, family members and friends may themselves be infected
- HIV+ parents and partners may feel guilt at infecting another person, which impacts their own stress and wellness levels
- for people who knowingly enter a relationship with a person living with HIV/AIDS, the realities of the illness are usually far more devastating

than imagined. The caregiver role is heavier than anticipated, fears of being left alone and worries about disclosure are strong

- when both parents are HIV+, serious concerns and issues about ongoing care for children include guardianship, custody, financial planning
- deep feelings of grief for an unborn child may be part of spousal mourning
- may not want to provide structure or discipline out of anticipatory grief for young child or teen, though these are critical to child's sense of security
- need to treat person as normally as possible, to demonstrate concern and support, especially when helping a child deal with the situation at hand
- language barriers may impede access to care and support
- family of choice may conflict with family of origin
- may face prohibitions against practising non-traditional rituals
- may feel guilt/shame from relief that they don't have the illness
- may envy/resent sick sibling or partner getting more attention
- may exhibit such traits as withdrawal, irritability, school problems or acting out behaviour

Disclosure

- may share information that is not complete but accurate in part
- partner may live secretly with diagnosis or be faced with possible impact on his/her job or lifestyle
- may be reluctant to tell child of family member's diagnosis for fear they may disclose to others. This can have negative repercussions if they accidentally discover they themselves or a family member are infected

Stigmatization

- friends may be unfamiliar with HIV and/or irrationally frightened about risk of contagion
- may prevent partner or family from receiving necessary support

Sexuality

- may not be accepting or understanding of person's sexuality
- may not be accepting of gay or lesbian partner
- may be first time they were aware of person's sexuality, so they are dealing with that in addition to the person dying
- if friends/family are gay or bisexual, they may be dealing with similar issues
- may open up whole new aspect in the relationship

Intimacy

- friends and family may have an irrational fear of contagion
- partner and family may need to be encouraged to cuddle and be affectionate
- space, time and privacy must be provided to support intimacy
- partner of person may have been exposed to HIV/AIDS, or person with HIV/AIDS may already have lost a partner. Issues of sero-positivity re-emerge and death becomes an uncomfortable reminder of what lies ahead. Re-negotiation of issues within relationship can be problematic

Socioeconomics

- financial burden on partner and family can be significant
- may need help to access additional supports at home
- spouse or family member may need to leave work to care for person with HIV/AIDS. Some families can afford attendant services because of extended health care benefits, but others cannot

Roles

- someone may have to take over more of other person's roles within the family, creating additional stress caused by the person's deterioration
 - may be thrust into role of informal or primary caregiver and therefore carry a major portion of stress
-

| | |
|--|--|
| | <ul style="list-style-type: none"> • caring for person with HIV/AIDS can put stress on friends and family members' other roles, i.e. work • unaffected children may assume role of caring for another family member at a very young age |
| Aloneness | <ul style="list-style-type: none"> • parent or partner may feel geographically isolated in his/her caring role • may anticipate future aloneness • may be isolated from normal sources of support, (i.e. church, etc.) |
| Denial | <ul style="list-style-type: none"> • may fear discussion will create unmanageable anxiety and destroy defences • may engage in "mutual pretence" wherein everyone knows the person is dying but pretends he/she will live • some denial originates from emphasis on "hope" and "fighting spirit" as important for longevity • denial may centre around how the person became infected • too vigorous confrontation of denial can lead to alienation |
| Losses | <ul style="list-style-type: none"> • facing loss of partner • family and friends may experience multiple losses • refer to section on <i>Grief, Loss and Bereavement</i> |
| Mental/cognitive functioning | <ul style="list-style-type: none"> • may need help dealing with person's depression and/or dementia |
| Withdrawal | <ul style="list-style-type: none"> • may feel unloved or rejected • may feel hurt, sad, angry • may need to withdraw as a way of separating or because they are not comfortable around someone who is dying |
| Issues specific to persons living with hemophilia | <ul style="list-style-type: none"> • many persons with hemophilia wrestle with the irony that treatment which enabled more freedom brought life threatening disease, leading to disillusionment, anger and mistrust of health care system • in a single family with multiple individuals with hemophilia, not all may have been exposed to HIV/AIDS. Each one may deal differently with HIV disease in psycho-social adjustment and behaviour • maternal guilt over passing genetic disorder is compounded for mothers who gave the blood product to their son. Fathers may feel guilt over amount of time spent with son, or having given blood product to son • long term chronic condition in son(s) may have exacerbated marital issues leading to separation/emotional distance or divorce. Prominence of HIV/AIDS magnifies these problems. Children feel guilty if their condition affects parental marriage • because hemophilia is a genetic disorder, many members of a nuclear or extended family may be exposed to or already have died of HIV/AIDS • many persons with hemophilia rely on their families during end stage illness, rather than utilize AIDS resources like hospice care. Results in physical, emotional and financial demands on the family • urban and rural families have different access to hemophilia comprehensive care. Treatment for bleeds is a major worry during palliative phase |
| Issues specific to the blood-transfused | <ul style="list-style-type: none"> • for parents of children infected via transfusion, there may be guilt over consenting to treatment as well as anger at government and medical system. These emotions make trust and decision-making more difficult |
| Palliation | <ul style="list-style-type: none"> • the need to maintain hope may impede move to palliation • may feel palliation is "giving up" and carry enormous responsibility for the decision |

- grief may impact coping strategies
- in the case of a child, conflicts may arise if parents are separated, divorced or one parent has custody
- extended family may add pressure to decision making around palliation and may decide they need to intervene

Dying

- if HIV+, then may be witnessing their own future
- survivor guilt: Why not me?
- may respond by not talking about death
- parents may be caring for their child (whether adult or child) while grieving potential loss of that child
- caring for a dying person is a new experience for many
- parents/siblings may be alienated from person who is dying
- young siblings and children may have misconceptions about what is happening, may fear the same thing will happen to them, may feel they “caused” this to happen
- professionals may dislocate family from primary care role

Saying good-bye and letting go

- relative youth of dying person may make this more difficult
- may be residual, unresolved issues related to anger
- see sections on *Last Hours of Living* and *Grief, Loss and Bereavement*

INTERVENTIONS

Given the typically young age of the dying person with HIV/AIDS, the situation is apt to have profoundly disruptive influence on the family. This may be aggravated by other issues, i.e. disclosure of sexuality or acquisition of the virus outside what appeared to be a monogamous relationship. Grief plays a prominent role in this work (see *Grief, Loss and Bereavement*).

Timely interventions are essential for maximizing the family’s healthier coping strategies and preserving integrity of the family system. This means establishing connections that give the death meaning for all involved. For a fuller discussion on interventions, see Gillian Walker’s *In the Midst of Winter* (see Suggested Reading). However, typical interventions include:

DEALING WITH DENIAL

Not everyone will be able to give up their denial. However, if individuals do not deal with denial they will be unable to help one another. While they may be aware of what is happening, they will not be able to talk about it with each other and therefore be emotionally unavailable to each other. The professional caregiver should:

- listen for subtle openings to discussion of feelings
- work with various levels of denial within the family system, helping individuals find balance
- maintain equilibrium between collusion and helping a family confront its denial of impending death, recognizing that a degree of collusion may be necessary to stay within the “trusted circle”
- realize impact of his/her own denial

HEALING RIFTS WITHIN THE FAMILY

- anger may lie just below the surface and must be acknowledged. Likewise, guilt and shame are feelings that can keep family members apart

*“There is denial of death and dying, even within communities that have dealt extensively with HIV/AIDS”
– one voice –*

- dealing with old areas of conflict may be unproductive and may result in parties becoming defensive
- families may be helped by exploring areas where more constructive connections can be made, to develop nurturing aspects of the relationship

SAYING GOOD-BYE AND LETTING GO

Caregivers can:

- encourage expression of feelings (see *The Last Hours of Living* and *Grief, Loss and Bereavement*)
- provide survivors with transitional relationship which can help sustain them in the face of their loss

*“If people weren’t afraid to talk about death, that might make me feel very different about death”
– one voice –*

Other interventions include:

- encourage the family to be open to expressions of intimacy
- have supportive interactions and detailed discussions with caregivers concerning outcomes and options
- avoid rushing family/partner into making decisions and ensure they know decisions can be re-evaluated at any time
- assist family/partner/friends to understand that one goes through a unique process when dying, which may be quite different from what is expected or wished for by others
- help those affected to understand that social withdrawal does not mean the individual does not love them
- give family and friends the opportunity to express their feelings, if they are not comfortable with the lifestyle of the person living with HIV/AIDS
- recognize parents of a young child may feel guilt if they haven’t told the child the diagnosis, and be careful not to reinforce this guilt

CONSIDERATIONS FOR THE CAREGIVER

The caregiver must address his/her own attitudes, values and feelings in relation to care of the dying individual, particularly as they relate to sexuality, homosexuality and drug usage. Some issues that must be considered are summarized in the table below.

PSYCHO-SOCIAL CONSIDERATIONS FOR CAREGIVERS

Sexuality

- caregivers need to examine their own attitudes around sexuality
 - do not assume that someone’s lifestyle caused his/her HIV diagnosis
 - it is not necessary to know how someone became infected. It may become relevant throughout the course of your therapeutic relationship should the person choose to share this information with you
 - recognize that the person may have been dealing with discrimination due to lifestyle, and may now be dealing with discrimination due to diagnosis

Age

- there is a risk of over-identification with the dying person
 - caregivers may have feelings about the death of a young person

Withdrawal

- if caregiver has had time to develop a relationship, he/she may feel rejected, hurt or unappreciated as the person withdraws

Facing death

- encourage families and friends to discuss progression of the illness with the person, at the level they feel comfortable
 - offer support to parents in talking with a child or, with parent’s permission, speak to the child about dying
 - encourage individual, friends and family to confront fears and receive effective support

- identify family or culture-specific meanings and practices around care and death, and find ways within those boundaries to deliver the best care

Boundaries

- the boundaries between the caregiver and the one caring may become blurred for a number of reasons. Recognize the difference between your agenda and that of the individual

Disclosure issues

- explore sensitive disclosure issues and do not assume disclosure has occurred

Issues specific to persons living with hemophilia

- be sensitive with family secrets, such as hemophilia and HIV/AIDS
- education, advocacy and referral are required, possibly more so during palliative phase
 - issues about the value of one's life when a financial settlement is involved, lowered self esteem, and anger at the blood system may have led to feelings of disillusionment in dealing with social/health care agencies
 - because hemophilia is a life-long disorder, there should be no assumption that the individual and family are equipped to deal with social services/health care system

Issues specific to the blood transfused

- in making recommendations around eligibility for financial benefits and home health care, those who contracted HIV/AIDS through blood transfusion may still accept Federal and Provincial settlements without precluding eligibility for other Federal or Provincial programs, i.e. CPP disability

A REMINDER TO CAREGIVERS

- the caregiver may find him/herself anxious about sitting at the bedside of the dying person. It may help to realize that it is all right to ask the dying person what they want from the caregiver. Usually, it is enough simply to sit quietly with the person
- remember it is very difficult, if not rare, to find just the right thing to say to a dying person to neutralize his/her pain
- denial serves an important protective function. However, at times, it interferes with the process of working through interpersonal conflict and self-concept, depression and anxiety. Too vigorous a confrontation of denial or other defences can heighten anxiety and strengthen the individual's defences, making them less accessible. In this instance, the person may consider the caregiver to be dangerous and hostile, and the relationship is seen to repeat earlier stigmatizing, isolating relationships
- the caregiver must be realistic about what can be accomplished with any particular individual. In some cases, there is little hope that interventions will change the nature of how the person relates to others or him/herself
- angry dying people may challenge the caregiver or reject his/her attempts to connect. The caregiver must avoid taking such reactions personally, but place them in the context of the person's anger and fear

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Caring for HIV+ Substance Users

The number of HIV+ persons infected as a result of substance use, and now seeking Palliative Care, is increasing rapidly across Canada

*“If I screw up royally, I don’t want to be rejected or abandoned. Accept me for who and what I am.”
– one voice –*

Emergence of the HIV+, chemically dependent population presents support and service challenges to caregivers.

Those working in the Palliative Care setting must be aware that, to date, there has not been significant work published to provide guidelines toward development of appropriate interventions. However, this section presents the most current expertise on this subject (for medical intervention, see *Symptom Management*).

To work effectively with this population, caregivers need to:

- be able to assess competently the chemical dependency issues (see below)
- recognize that reasons for drug use vary, from fear, coping with a serious illness, anger, and pain, to such issues as dual-diagnosis (psychiatric complications and substance abuse issues) and low self-esteem
- understand that substance use may elicit different responses from each individual, even though they may be using the same drug
- continuously seek new information to expand their current knowledge base related to the care of the HIV+ chemically dependent person
- be aware of issues of safety and security

CHARACTERISTICS OF THE SUBSTANCE USER

- substance users may present with strong feelings of anxiety, insecurity and emotional instability
- among their behavioural problems may be manipulation, seduction and an unwillingness to tolerate frustration
- the relationship with the substance will be different depending on the type of drug used
- the substance user may have had severe problems as a result of substance use. Low self-esteem and self-destructive attitudes may be part of the individual’s makeup
- the substance user may be tempted to self-medicate to anesthetize feelings associated with HIV/AIDS. Results may include:
 - in the community: missed appointments, frequent changes of address, coming to appointments intoxicated and a failure to follow treatment
 - in hospital: may not follow rules, may not tolerate pain well, may use pain to increase access to substance, and may, in face of any pain, demand rapid effective relief

CAREGIVERS’ REACTIONS

Attitudes and behaviors associated with substance use can provoke a rift with caregivers who may feel invaded, overwhelmed and discouraged by the situation. Likewise, caregivers’ fears, beliefs and attitudes can come into play, including the fear of encouraging dependency or of being manipulated by the user.

ASSESSMENT PROCEDURE

A thorough assessment, including a complete medical history, will provide a much clearer picture of the person’s current health status, particularly as it relates to substance use, and will present a more focused view of the person’s needs. Ideally, this assessment would be taken as part of a standard intake procedure prior to the

person becoming symptomatic. The importance of this assessment cannot be underestimated within the realm of HIV disease, as many medications prescribed have addictive potential or interact with non-prescription drugs and alcohol.

Elements of the assessment include:

| SUBSTANCE USAGE | PSYCHIATRIC HISTORY | PERSON'S NEEDS/PERCEPTIONS REGARDING PAIN MANAGEMENT |
|---|--|--|
| <ul style="list-style-type: none"> • history of drug and alcohol use • date and time of last use • amount used • method of use • frequency of use • prescription medications (frequency and dosage) • cigarette smoking • history of drug and alcohol treatment and outcomes • reasons for using drugs and alcohol | <ul style="list-style-type: none"> • confirmation of diagnosis (if applicable) • treatments <ul style="list-style-type: none"> – therapies – past medications – current medications • hospitalizations • evaluation of the current situation | <ul style="list-style-type: none"> • evaluation of the person's perceptions and needs regarding pain relief (to establish clear treatment guidelines and a climate of trust) • evaluation of person's knowledge of analgesic medications (in terms of treatment of pain) |

INTERVENTIONS

It is recommended that those working in the Palliative Care setting incorporate the assessment information in their intake package and, thus, begin the process of better understanding the drug using person with HIV disease

The purpose of interventions is not to “save” the person at all costs, but rather to support harm reduction.

HARM REDUCTION MODEL

Any Palliative Care setting should support a client-centred, harm-reduction model which assumes the client is the best person to make decisions about him/herself.

The philosophy of harm reduction is to reduce the amount of risk in drug-using behaviors and increase the health of the person living with HIV/AIDS, their caregivers and society as a whole. The hierarchy of harm reduction with the injection drug user begins with a focus on safer drug use techniques (i.e. safer injection techniques, safer location choice), cessation of injection, then cessation of drug use. Incorporated within this is attention to health problems and the prevention of health problems before they occur. The harm reduction model is not specific to injection drug use and can also be applied to all other drugs.

INTERVENTION SCENARIOS

| CLIENT | ISSUES IN CARE | STRATEGIES FOR INTERVENTION |
|---|--|---|
| <p>Person with current addiction</p> | <ul style="list-style-type: none"> • steps toward abstinence may not improve quality of life • pain and health risks from detoxification, stress and emotional upheaval may cause damage • drug use (especially CNS stimulants) may lead to disruptive behaviour, which can put stress on housing and health care | <p>For all HIV+ persons with a current addiction</p> <p>To implement an appropriate care plan, negotiation with the person around drug use and associated behaviour, with clear consequences defined, would be important. This person may be able to take part in a medically supervised detoxification program, conceivably providing health benefits and better quality of life.</p> <ul style="list-style-type: none"> • tailor approach to the individual (i.e. novice or “veteran” user) and his/her current reality (i.e. hospital, street, at home) • create a climate of trust through consistent approach |

| CLIENT | ISSUES IN CARE | STRATEGIES FOR INTERVENTION |
|---|--|---|
| <p>Person with current addiction (cont.)</p> | | <ul style="list-style-type: none"> • help him/her improve quality of life (better nutrition, community cooking, resources that offer meals) • provide support to help through the HIV/AIDS crisis • encourage him/her to seek support in the community • caregivers in the interdisciplinary team must work together to avoid manipulation, “splitting” and other behaviors characteristic of substance users <p>For HIV+ persons who stop using drugs</p> <ul style="list-style-type: none"> • provide psychological support • initiate external follow-up during detoxification • reinforce person’s decision to stop • strengthen ties to his/her network • discuss potential relapse situations <p>For HIV+ persons who cut down on drug use</p> <ul style="list-style-type: none"> • reinforce person’s choice to cut down drug use • foster self-awareness through repeated check-ups <p>For those who maintain or increase substance use</p> <ul style="list-style-type: none"> • provide psychological support if person so desires • foster self-awareness through repeated check-ups • encourage joining support groups • try a social approach, i.e. recreational activities, to create a sense of belonging to a group • use requests for physical care to strengthen bond of trust • propose short-term shelter (or permanent shelter in the final stages of life) to help break out of social isolation |
| <p>Person with past addiction</p> | <ul style="list-style-type: none"> • use of an analgesic medication (especially opioids) may be perceived as backsliding by some individuals. At the same time, a return to past drug use, particularly for the opiate addicted person, is a real possibility • many persons with a past history of drug addiction, having completed an abstinence oriented treatment program, are reticent to embrace what may have been their drug of choice for a second time. It is necessary that a knowledgeable physician offer appropriate options to the person, taking into consideration their fears of relapse | <ul style="list-style-type: none"> • informed decisions must be made around this issue with a strong understanding of the balance between appropriate medications, their health effects and non-medical use of medication • when a lifetime is often measured in months, addiction should not be an issue when considering the use of a medication. The focus should be on pain relief and the person’s general sense of well-being |
| <p>Abstinent person and pain medication</p> | <ul style="list-style-type: none"> • many persons who have had experience with addiction may be resistant to pain medication, especially if these medications have addictive properties • use of these medications may be viewed as a failure or a relapse | <ul style="list-style-type: none"> • pain medication should be introduced to these individuals in the same context as insulin for a diabetic • pain medication should be presented to the person in a supervised manner and changes managed collaboratively. This latter action supports the person’s confidence in him/herself |

CONSIDERATIONS FOR CAREGIVERS

Caregivers are wise to consider that the crisis generated by HIV/AIDS diagnosis may well result in anger, denial and, possibly, violence. The following are some suggestions for caregivers to deal with some of the issues that may arise: (see also *Care for the Caregivers*)

| SITUATION | CONSIDERATIONS |
|--|--|
| Fear of death and death anxiety | <ul style="list-style-type: none"> ensure that all members of the staff can be psychologically supportive |
| Anxiety | <ul style="list-style-type: none"> do not hesitate to discuss death. Defusing fears can ease pain use of narcotics and anxiolytics can arouse concerns for both the person and the staff. When used judiciously and wisely, both can offer additional support that is indispensable to the person's sense of well-being |
| Psychiatric problems | <ul style="list-style-type: none"> existing or new psychiatric problems can have a profound effect on the functioning of both the person and the Palliative Care team. Access to qualified, well-trained staff and appropriate medications are a necessary part of managing the HIV+ substance user |
| Violence | <ul style="list-style-type: none"> accept anger as an outlet but do not accept violence in any form set clear limits be truthful establish a firm contract to which both parties are committed do not feel guilty if it is necessary to terminate an interview or course of action in order to impose limits perform interventions with two people present if possible |

Caregivers need to:

- access improved educational protocols to enhance their competence in dealing with the chemically dependent/HIV+ person
- insist upon an appropriate drug and alcohol assessment of the drug using person with HIV disease, thus enabling appropriate planning
- be aware of issues of safety and security (see *Issues in Occupational Exposure for HIV/AIDS Palliative Care*). Inappropriate medications, lack of sufficient follow-up, or inappropriate referrals to substance abuse treatment may result in a rapid decline of a person who under other circumstances might have retained quality of life for a longer period of time.

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Legal Issues

Ideally, a lawyer should be an active participating member of the inter-disciplinary Palliative Care team. He/she should understand HIV legal issues and the circumstances of the individual with AIDS.

For referral to a lawyer, or for legal information and advice, consult:

- legal licensing bodies
- legal professional associations, i.e. provincial branches of the Canadian Bar Association or others
- legal clinics
- legal aid programs
- national and local AIDS organizations

In Palliative Care, several issues must be considered:

CONFIDENTIALITY

Confidentiality is a basic ethic and understanding for health professionals, and is an expectation of those receiving care. It is required by professional codes of practice, licensing bodies, institutions and statutes. It is recognized under the Charter of Rights and Freedoms' guarantee of a person's right to security. Confidentiality may be breached only with consent of the competent person, by rule of law in provinces governed by common law or by special dispositions of the law in Quebec.

For a non-competent person, information is released to next of kin, as defined by relevant statute or common law and practice. An individual may, by power of attorney, define persons who are to receive information should the individual become incompetent. This is an important aspect of advance planning.

Confidentiality is important in Palliative Care, especially HIV/AIDS care, as unauthorized or inadvertent release of information may go against the person's wishes and result in unexpected stigmatization, isolation, financial consequences, or job loss.

Numerous specific statutes speak to disclosure or breaching of confidentiality. Each refers to a particular circumstance and specifies the information to be disclosed and to whom. For example, provincial public health legislation may require physicians to report an AIDS or TB diagnosis to a local Medical Officer of Health.

Common-law doctrine has also developed that if substantial danger to an identified person or persons exists, required confidentiality may be breached to protect public interest. However, under Quebec Civil Law, it is illegal to divulge confidential information to a third party, even if this party is the partner, unless every effort has been made to have the person communicate this information themselves. In providing care, confidentiality about an individual's HIV status can be maintained, if everyone is taught and practises the universal application of body substance precautions.

Laws in Canada vary from province to province. This section is intended to provide guidance on issues about which caregivers should be aware. For specific problems or situations, persons living with HIV/AIDS, families and caregivers are actively encouraged to seek advice from a lawyer knowledgeable about relevant local laws

Persons living with HIV/AIDS should be encouraged to consider whether disclosure will have negative or positive consequences for them. For some, lack of disclosure leads to isolation where support would have been possible, if others were informed.

For information regarding disclosure and confidentiality guidelines in your area, contact your local Department of Public Health.

MENTAL COMPETENCY

Competency is a state in which the person is capable of taking legal acts, consenting or refusing treatment, writing a will or power of attorney.

Elements Required for Fully Informed Consent

A person must know:

- *action to be taken and reasonable alternatives if they exist*
- *reasons for undertaking this act, expected outcomes, and effects of not undertaking the act*
- *complications which frequently occur, even if minor and transient in nature*
- *serious complications which may endanger life and organ system, even if rare*
- *specific circumstances relevant to their own individual situation*
- *full answers to all questions asked*

Competency is fundamental to the ability to consent and the exercise of personal autonomy. It involves doing or deciding a specific thing, at a specific time. Thus, it can vary from time to time and according to the act or decision undertaken. Other than with children, there is a basic presumption that a person is competent. This assumption may be refuted by facts.

To facilitate the exercise of autonomy and to forestall inappropriate challenges (which may be lengthy, expensive and exhausting), caregivers should be familiar with various standards for competency. When significant decisions are being made, i.e. making a will, power of attorney, or disposing of property, caregivers should make specific written note of their observations and questioning of the decision-maker. Legal authorities may request a medical certificate attesting to the person's capacity. Therefore the medical chart or files must contain all pertinent information. When competency is questioned, the decision is always made retrospectively, so documentary evidence from the time of the action is important.

The legal test for competency to create a valid will requires that the person making the will must understand:

- the nature and effect of a will
- the extent of property involved
- that claims and expectations may arise from those close to the testator
- that there must be no disorder of the mind which prevents exercise of natural decision making faculties

These specific tests of competency may be generalized and applied to other decision making assessments:

- does the decision maker know the nature and effect of the decision to be made?
- does the decision-maker appreciate the consequences on his/her own circumstances?

Competency is a complex matter. Some intellectual functions are readily quantifiable, i.e. with Mini-Mental Status examination. But, the emotional and lifestyle effects of HIV disease are profound, and the impact of illness, drug use, discomfort, depression, weakness and process of dying may be hard to measure.

As a rule of thumb, a competent decision is one consistent with an individual's lifestyle, history, previous actions and best interests.

SUBSTITUTE DECISION MAKER/LIVING WILLS

*"I'm most happy as a human being when I have autonomy, choices and information."
– one voice –*

If a person is not competent, a substitute decision-maker may be identified for certain purposes by statute or by court application. When individuals anticipate loss of competency, decisions about finances, care and treatment will need to be made. Individuals should address the following issues while still able (see *Advance Planning*):

- advance directives
- power of attorney for financial matters
- power of attorney for care and treatment

These formal statements of preferences in care and financial management, along with information from informal conversation, will help ascertain the individual's wishes should he/she lose competency.

For specific information on competency and substitute decision making guidelines in your province, contact your provincial branch of the Canadian Bar Association.

INFORMED CONSENT

To ensure informed consent, the treating health professional must communicate:

- on a level which the person can appreciate
- in a culturally appropriate manner
- repeatedly
- with tests of understanding

Several interviews may be necessary. Written recording of the process is advised

The informed consent to treatment of a competent person is another basic legal and social expectation in the exercise of autonomy. Individuals have the right to accept or reject treatment in almost all circumstances. The right to refuse treatment, even life sustaining treatment, is recognized in common law and enforceable by seeking damages.

In general, Canada has evolved consent law based on an individual's own wishes and circumstances. Thus, information given while informing for consent must be individualized. Standard informational tracts may help but are not sufficient. The Supreme Court of Canada set forth elements required for fully informed consent.

One cannot consent to a vague, imprecise course of treatment, nor to treatment when there is the possibility that circumstances may change. Consent may be evidenced by a simple act of compliance, for example, offering an arm for a blood test, or by a signed consent form. Although forms are required in some circumstances, such as consent to surgery in hospital, it is the individual's consenting state of mind which is crucial, not the fact of a signed form.

Consent to research requires a higher standard of information. While consent to research was formerly completely separate from consent to therapy, advanced therapy may be sought within an AIDS research project.

ASSISTED SUICIDE / EUTHANASIA

“If palliative care were more available, there would be fewer people considering euthanasia”
– one voice –

After the Supreme Court of Canada decision regarding Rodriguez, debate on the issue of assisted suicide continues. Individuals have the legal right to refuse specific treatment. However, assisted suicide/euthanasia involving a physician or other party, is an illegal act (see *Ethics*).

Through the use of appropriate advance directives and substitute decision-makers, the perceived need by some for assisted suicide may be reduced.

DISCRIMINATION

“Many don’t want to work with those who they know are infected.”
– one voice –

Discrimination can limit access to service, immigration, employment, housing, domestic relations, inheritance and tax treatment, among others.

Because HIV/AIDS was linked very early to homosexual orientation, discrimination against those with HIV/AIDS has been based on issues of sexual orientation, relationship status and disability. Provincial human rights codes currently proscribe discrimination on the basis of sexual orientation in seven provinces and the Yukon Territories (not included are Alberta, Newfoundland, Prince Edward Island, and the Northwest Territories). While the Canadian Human Rights Act does not explicitly include this prohibition, the Act has been interpreted by courts to include it.

Discrimination on the basis of disability is more settled and better understood by analogy to other disabilities. Enforcement, however, may be difficult. Provincial or federal human rights commissions may provide advice, assistance, and a formal adjudication process. Practically, time delays should be expected.

UNSAFE ACTIVITIES

Unsafe activities can be reduced through education, implementation of body substance precautions, and safe sexual practices. Criminal and civil law may be used to compensate for, control or deter unsafe activities. Where appropriate, caregivers should warn an individual who is at risk of serious harm, and involve local public health officials.

CROSSING INTERNATIONAL BORDERS

Regulations for individual countries regarding visitation, work entry and immigration should be considered in advance of international travel. Some countries require HIV testing for immigration or prolonged visits. Practical approaches and advanced consideration may prevent delays or refusal. Check legal and regulatory process of the country involved.

PROVINCIAL HEALTH CARE ELIGIBILITY

Before moving to another province check for relevant eligibility criteria.

There are no restrictions on Canadians moving between provinces. Access to basic health care is provided to all Canadian residents regardless of the province they are in. However, guidelines may restrict coverage for certain types of care until specified eligibility criteria have been met. There are significant differences between provinces regarding access to, and eligibility criteria for, drugs, home-care services, etc.

Advance Planning

*“I want to know about the options available to me before I need to exercise them.”
– one voice –*

Planning is an important yet often difficult part of caring for someone living with HIV/AIDS. If planning is not done in a timely and appropriate way, both the person and those they love can suffer needlessly.

HIV/AIDS can impact a person’s ability to plan and make reasoned decisions. It is important to be informed about planning and be available to offer assistance if required:

- what planning is vital?
- what supportive resources exist?
- who should be involved?

At the same time, caregivers should be aware that in some cultures, discussions related to future planning would be considered inappropriate, and should be approached with great sensitivity.

Planning can involve just the person living with HIV/AIDS, or encompass those who have various roles and relationships with that person. It can be done on a single occasion, or may take place as the person is ready, over a longer period of time. Planning may be done readily and with a sense of relief, or it may be accompanied by much emotion and a sense of loss. To help persons living with HIV/AIDS, their partners and families undertake necessary planning, caregivers must be aware of relevant legal formalities. For some items, it is advisable to contact a lawyer (see *Legal Issues*) and for others, advocacy may be required to secure entitlements from various programs.

Whatever the process, caregivers should encourage planning to be done:

- at relevant times and stages during the person’s illness
- in a manner that is respectful of the person’s wishes and strengths
- permitting sense of control over their own life

Owing to the roller coaster nature of HIV/AIDS, caregivers are encouraged to raise planning issues sooner rather than later. Certainly, it is advisable to document all steps and decisions as the process proceeds.

The following is a guide to assist caregivers in working with persons living with HIV/AIDS and their families to complete the necessary planning with a minimum of confusion and uncertainty.

CHECKLIST FOR ADVANCE PLANNING



FULLY UNDERSTAND THE BENEFITS AVAILABLE FROM

- Health care and social support programs, i.e. home care, medicare, nursing care, drug benefits, government health care
- Unemployment Insurance
- Workers’ Compensation

- Canada Pension Plan – disability benefits
- Welfare and family benefits
- Private insurance – health and disability policies
- Private insurance policy – explore possibilities for early redemption of benefits
- Union, employment or association benefits
- Support from private individuals or agencies, charities and AIDS organizations
- Compensation for victims of crime, i.e. HIV transmission during sexual assault
- Old Age Pension

KNOW WHERE INFORMATION AND DOCUMENTS ARE LOCATED

- Is a list of relevant items conveniently located in a safe location known to someone other than the individual him/herself? This includes: statistics, health and financial cards, insurance and legal documents, certificates, bank books, insurance policies, other papers
- Are these papers accessible by those who may need them?

ENSURE FINANCIAL MATTERS ARE IN ORDER

- Is there joint tenancy of real estate and other investments? This may facilitate management and transfer at time of death
- Is there joint tenancy on bank accounts? This is useful because the survivor becomes the owner and it can facilitate transfer at the time of death
- Is there a power of attorney on all bank accounts? This ends at time of death, or when revoked
- Is there a power of attorney in place for financial purposes?
- What credit and credit card arrangements exist?
- Is it appropriate to create a living trust that deals with property management and inheritance?
- Are arrangements in place for RRSP/RRIF management and withdrawal?
- Is there property to be distributed during life, such as gifts and charitable donations?
- Are there any outstanding legal claims, such as tort claims, that must be resolved?
- Who is responsible for income tax preparation and filing?

PLAN FOR CARE AND TREATMENT

- Is there power of attorney for care and treatment purposes? These identify an individual to serve as substitute decision maker in specified circumstances and for specified purposes. They may also identify individuals who may obtain release of confidential information
- Are there advanced directives in place? Advanced directives deal with the person's wishes regarding resuscitation, as well as nutrition, drugs, procedures and moves. (Refer to forms available from Dying with Dignity, those shown in *Let Me Decide* by Dr. W. Mulloy, or the University of Toronto Centre for Bio-Ethics Advanced Directives)

- Is everything in place for a court application to declare incompetence (if needed), and for the management of estates and/or persons? This can involve time and expense to put in place
- Is the chosen setting of care acceptable to the person, family and caregivers?
- If the home is the chosen setting of care:
 - if death is to occur at home, will those remaining be able to live in the home without fear of ghosts?
 - are there adequate facilities and caregivers?
 - are anticipated costs acceptable?
 - are substitute settings of care easily accessible, should the chosen setting become unacceptable or inappropriate?
 - if planning to be cared for at home, have arrangements been made for transfer to back-up setting(s), if required?
 - if a late change in care setting is anticipated (see *Last Hours of Living*), what are the rules for ambulance services in your area regarding “DNR” and “No CPR” orders?
- In the event of hospitalization, who has access and visitation privileges?

PLAN AHEAD FOR WHAT IS NEEDED AT OR AFTER DEATH

- What are the person’s wishes regarding their death? Who does he/she want at the bedside? Who would they prefer not be present?
- What rituals are important just before or upon their death? What rituals should not happen? Who should perform these rituals?
- Which physician will attend to complete the death certificate and how can he/she be reached?
- Is there a will including identified executor(s)? The format, number of witnesses and separation between witnesses and beneficiaries are issues governed by provincial law. In some provinces, signed holograph wills (fully hand written) are acceptable. Simple will forms are available. Professional caregivers should never agree to be executors of the will of someone for whom they are caring
- Who has the right to post-mortem consent for disposition of the body? The executor has the highest authority. Otherwise the next of kin decides, unless, during life, the person signs an authorization form which then takes precedence
- Are organs to be donated for research or anatomic study? Donation for transplantation is not appropriate in HIV/AIDS
- What arrangements have been made for burial or cremation? The executor has this responsibility, unless prior arrangements have been made
- What arrangements have been made for funeral and memorial services, including donations in remembrance? Done in advance, these preparations can constitute part of leave-taking
- Who will notify Canada Pension Plan to ensure access to appropriate death benefits, spousal benefits and benefits to dependent children?
- Who will notify Old Age Pension?
- Have estate income tax and estate tax considerations been addressed?
- Are there designated beneficiaries for any RRSP/RRIF? Designating beneficiaries may avoid estate evaluation
- Do all insurance policies have designated beneficiaries?
- Do all brokerage accounts have designated beneficiaries?
- Has guardianship been established for any dependent children?

Spirituality

SPIRITUALITY AND HIV/AIDS PALLIATIVE CARE

There is profound suffering associated with HIV/AIDS. Suffering is the most significant chronic psycho/social/spiritual dynamic, both for the person with HIV/AIDS and his/her family.

Many faith traditions have a wealth of experience and tradition in understanding the dynamics of suffering, and how it can be turned into a positive experience.

Reflection, prayer, and spiritual expression can enhance the dying process for everyone.

Caregivers are encouraged to seek appropriate community resources to support them in better understanding the dynamics of human suffering.

This will help caregivers support and nurture people living with HIV/AIDS and their families.

SPIRITUALITY VS. RELIGION

Diagnosis of life threatening illness raises questions of mortality, life after death, suffering, spirituality, and religion. In Palliative Care these issues take on greater importance because of the stigmatization and judgement which still accompany HIV/AIDS.

The over-riding dynamic of spirituality is the ability it gives an individual to discern one's "otherness" within him/herself. It allows us to be conscious of something other than what we immediately see or touch. Our spiritual side challenges us to explore and answer those questions which give purpose, meaning and substance to our lives. Questions such as:

- who am I?
- what am I?
- do I have meaning?
- what is my role and purpose in this world?

Spiritual care can promote healing of past or painful relationships. It facilitates the personal psychic integration of the person living with HIV/AIDS and its accompanying chaos and destruction. For many, spirituality plays a vital daily role and provides a strong source of support. Spiritual care is an important part of caring for the whole person, and can be facilitated by a pastoral or spiritual counsellor.

- *pastoral counselling* is a systematic approach undertaken by a minister or chaplain. He/she combines psychological and clinical skills with spiritual and religious insights when working with a person on life problems and destiny
- *spiritual counselling* refers to the practice of a caregiver (including ministers or chaplains) supporting a person through interpersonal and listening skills, enabling them to discuss their spiritual dimension

Depending on the person's needs, either a pastoral or a spiritual counsellor can facilitate healing and integration.

- *spirituality* is that which pertains to the soul, spirit or incorporeal being as distinguished from the physical being or body. Spirituality can be expressed within religion but is no way limited by what we may call traditional North American religious observance
- *faith* is the belief in that for which there is no empirical or objective evidence or proof. Faith is belief in a god, system of gods, or no god (Buddhism for example favours the search for enlightenment and has no sense of god or soul) which are defined through statements of creed or dogma
- *religion* is a cultural institution. It is the public expression of a personal faith. It exists in a particular form and changes over time. Religion binds people into communities through shared symbols of ritual, myth, and ethical norms

A person's "religion" is the expression of their spirituality. Within HIV/AIDS Palliative Care, it is important that caregivers respond to unique, personal expressions of spirituality.

It is important to recognize the differences between spirituality, faith and religion. Many people living with HIV/AIDS are profoundly spiritual but not religious, nor do they observe any specific faith

Many organized religions have difficulty responding to the spiritual needs of people living with HIV/AIDS because the disease raises issues of sexuality and lifestyle which they have historically condemned. Some faiths denounce homosexuality altogether as sinful or inherently evil. Most accept homosexuality as an inherent part of the person, but believe homosexuals must never “act out” or “live” their orientation in relationships. Many persons with HIV/AIDS view this as hypocritical and do not want people nearby who cannot accept them for who and what they are. As a result, when people most need the spiritual counsel of clergy or ministers, they fear being condemned and judged by church officials.

Many faith groups condemn injection drug use and believe the user must change his/her self-destructive behaviour and seek forgiveness for the past.

RELIGIOUS ISSUES WHICH MAY CAUSE CONFLICT BETWEEN INDIVIDUALS, FAMILIES, AND CLERGY

- suicide, assisted suicide or euthanasia
- definitions of sin and its consequences
- definition of family - who is permitted to visit and make decisions regarding medical care
- who qualifies as a “believer”, and is therefore entitled to the services of the church, temple or synagogue, i.e. funerals, clergy visits
- what is meant by suffering. Why do people suffer. Suffering can be seen as a means of spiritual growth, purification, punishment, i.e. the greater the sin, the more the person must suffer

THE DYNAMICS OF SPIRITUALITY

*“Each person’s approach to spirituality is unique and needs to be respected by caregivers.”
– one voice –*

Expressing and exploring our spiritual side during times of illness or crisis help us access our interior life and acquire a sense of internal healing or wholeness. This travels far deeper than simple physical or emotional healing.

Spiritual exploration provides a new sense of hopefulness, peace and understanding. This hopefulness is not for physical healing, but for honest expression of love given and received. The transition can be a time of real transformation from social preoccupation with materialism to a deeper realization of the value of relationships and accepting people simply for who they are. It provides an opportunity to experience the transcendence of humanity.

This search for internal healing can be reflected through questions such as:

- do I take an active role in my healing?
- what is my attitude towards life? Is it positive, negative, apathetic?
- what does healing mean to me at this point in my life?
- what is my attitude towards my death?

For some persons living with HIV/AIDS, there is a spiritual “return to childhood” that takes place, often in parallel with a return to their hometown to be cared for by friends and family. In returning, the person may re-encounter childhood spiritual/religious influences. This can either be rewarding and comforting, or a source of intense pain and disagreement with family members —especially if the person’s beliefs have diverged from those of their family or community of origin. The latter case may require the counsellor to serve as facilitator, supporting the individual in meeting their needs, while assisting the family to reach a workable position that does not deprive them of the support and comfort provided by their beliefs

METHODS OF EXPRESSING/ FACILITATING SPIRITUAL CARE

- will I be forgiven? Do I forgive the people in my life? Can I forgive myself?
- do I enjoy inner peace and strength?
- do I accept and love myself? (very important in HIV/AIDS)
- am I loved? Do I experience love unconditionally from the deepest power of the universe?

Questions such as these touch on intensely private thoughts and feelings. They impact on the very core of our self-perception. They are questions which help us articulate an understanding of our soul, spirit, or sense of being.

When facilitating any reflective process, the spiritual counsellor must deeply respect the person. Answers must be received as a gift and nurtured to conclusions which promote personal integrity and self-worth. To force someone into a “socially acceptable” box or norm can be highly destructive. Each person’s spiritual expression is unique and must be seen as such.

In the last days of life, the person may experience friends and family who have died previously or even persons of spiritual significance “coming to them”. It is important to offer support in exploring these connections (see *Last Hours of Living*).

We are all spiritual counsellors. Paid or volunteer caregiver, nurse or chaplain, we all have the ability to speak honestly about our own sense of spirituality. Effective spiritual or pastoral counselling facilitates the individual’s personal expression, while guarding against forced social norms of religious expression.

BASIC REMINDERS FOR SPIRITUAL EXPRESSION

- we all have a spiritual dimension. Whether or not we recognize and nourish it is our choice, not the choice of the caregivers or family
- spirituality affects all aspects of our life: psychological, emotional, physical, social
- spirituality involves understanding how we live and choose to die
- our environment can affect our spirituality deeply. For some, a noisy cluttered room may hinder spiritual reflection, while a quiet restful room may assist a person’s spiritual exploration and expression

FAMILIAR FORMS OF SPIRITUAL EXPRESSION

| | |
|------------------------------|--|
| Meditation and prayer | There is an extensive history of prayer and meditation within established faith traditions. The individual and/or family who already live their faith and exercise their tradition will benefit from structured prayer and facilitated times of meditation. However, some religious families may feel uncertain or unsure of how to express their faith within secular health care facilities. They would benefit from gentle encouragement by staff to express their faith, and may need added privacy. Alternatively, they may take greater comfort from prayer groups, so occasionally meeting rooms or lounges may need to be offered for family/group services. |
| Ritual and sacrament | At important moments in life, ritual and sacrament can soften the blow of approaching death and/or create an environment of spiritual healing. Laying on of hands, anointing, or intercessory prayer can help. |
| Clergy | Most faith traditions recognize or licence certain people to act on behalf of that community, exercising authority and conducting appropriate rituals. Whether called clergy, minister, shaman, rabbi, or elder, they work to promote spiritual healing. It is important to know the wishes of the individual regarding the presence of such a person. Family may desire the "clergy to come" but the individual may resist due to past experiences of alienation and condemnation. |

SOME NON-TRADITIONAL FORMS OF SPIRITUAL EXPRESSION

| | |
|---------------------|--|
| Dream Work | We process and integrate many life experiences through our dream world. Accessing and reflecting upon dreams in a disciplined way enhances self knowledge and clarifies spiritual issues. (Be aware of dream-suppressing side effects from drugs.) |
| Ritual | Personalised ritual can be one of the most powerful and effective forms of facilitating spiritual/pastoral care. Encourage the person to design and create their own ritual using important symbols and meaningful objects from their life. There is tremendous creativity and expression of ritual within the HIV/AIDS community. The chaos of this disease, the youthful age of its casualties, and the minority status of its population have given birth to unique rituals and personal symbols which speak of life, love, and life after death. Ritual speaks of the truth that the human spirit cannot be vanquished by disease, alienation or stigma. To be truly effective, spiritual/pastoral counselling must respect, encourage, and support expression of individual spirituality. |
| Peer Support | Sharing your experience and life story with another is generally understood to be an initial step towards inner healing. Peer support groups create safe environments for expressing pain, fear, love, and spiritual anguish due to HIV/AIDS. They can play a vital role in promoting health and assisting people infected and affected by HIV/AIDS to cope with the disease. Spiritual/pastoral counsellors may facilitate such groups using creative listening skills taught to them through prayer and meditation. |

QUALIFICATIONS FOR HIV/AIDS PASTORAL CARE

It is important that the individual's wishes are always followed, even if he/she is too ill to communicate. Therefore, ask the person as early as possible:

- *what are his/her wishes?*
- *what does he/she want to happen at the bedside before death and at the time of death?*
- *which rituals are important and which rituals should not happen?*

Good pastoral/spiritual care involves the nurture, promotion and growth of the person's sense of spiritual identity, not the imposition of what the chaplain, pastoral counsellor or family may think is "right"

Not everyone is suited to HIV/AIDS pastoral care or spiritual counselling. Many professional caregivers are uncomfortable with discussing issues of faith and spirituality, owing to their own experience or lack of belief. No one should be forced into the role of pastoral or spiritual counsellor. However, persons living with HIV/AIDS will often "pick" someone with whom they wish to discuss spiritual concerns. Many times this will not be the chaplain. Often staff or volunteers are picked first because they appear less threatening or because the person living with HIV/AIDS knows them better than the chaplain.

At institutions run by religious organizations, or where religious symbols are widely evident, it may be presumed by the individual that all caregivers share these religious beliefs. It can impede counselling if the person does not share these beliefs. In this setting, the counsellor may need to establish his/her "neutrality" to foster trust and openness.

Some health care facilities will not have chaplains on staff or available. Then it is necessary to access community resources. Identify persons familiar with Palliative Care and HIV/AIDS, who can respond quickly to pastoral or spiritual care issues as they arise.

Whoever the spiritual/pastoral resource person may be, these are skills necessary to HIV/AIDS Palliative Care:

- familiarity with issues of sexuality, sexual orientation, drug use
- flexibility
- no imposition of spiritual beliefs
- non-judgemental acceptance
- openness to non-traditional forms of spiritual expression
- "gay positive" attitude
- ability to access non-Christian and Christian community faith resources
- ability to facilitate and lead non-traditional services in various settings

Many educational programs offered across the country deal with issues of drug use, homophobia, and HIV/AIDS specific issues. Such training should be considered essential for those who are entering the HIV/AIDS Palliative Care field. Some hospital chaplaincy training centres offer field placement opportunities in HIV/AIDS clinics or Palliative Care facilities.

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Last Hours of Living

OUR EXPERIENCE OF DEATH

Most of us have little experience with death. When confronted with it, we start to imagine many ways we could die. As fantasies and fears grow, fueled by our contact with death, a peaceful death often seems unattainable.

This does not need to be the case. If events surrounding death are well managed, those participating will more likely remember an acceptable, even peaceful, death. If death is punctuated by poorly controlled pain and delirium, those remaining will likely remember pain and suffering, further increasing fears of their own deaths.

PLANNING AHEAD

When a person's death is approaching, in any setting of care, several issues should be carefully considered by all involved:

- clarify personal agendas, fears, phobias
- review all treatment options and potential outcomes, considering the issues, stage and context of the person and his/her illness
- encourage a shift from "hope for life, hope to get better" to "hope for some time together, hope for a peaceful death." Whatever you do, don't shatter all hope
- an acceptable care setting ensures that:
 - if death is to occur at home, those remaining in the home afterwards must be able to live there without fear of ghosts
 - there are adequate facilities and caregivers
 - anticipated costs are acceptable
 - alternative settings of care are easily accessible, should the chosen setting become unacceptable or inappropriate
- ensure that advance directives and proxy(s) for substitute decision making are in place and clearly understood by all caregivers. Desire for or against cardio-pulmonary resuscitation (CPR) should be discussed. Consideration should be given as to whether CPR would be useful, futile or even damaging
- where possible, check that a will and business power of attorney have been prepared, clarifying choice of executor(s). If there is no will or power of attorney, determine the closest next of kin

While we may not understand the mystery of death, experience shows that the last hours of living can be a time of considerable growth, perhaps some of the most important hours in a person's life.

DEVELOPING A CARE PLAN

Develop a care plan acceptable to the person, his/her family and caregivers. While few are happy facing death, if everyone agrees on the care plan, an acceptable outcome will be more likely than if everyone has differing expectations. During the last hours of living, management should:

- minimize pain
- reduce shortness of breath
- control terminal delirium
- control and/or reduce risk of seizures
- minimize risk of aspiration
- keep mucous membranes moist
- minimize risk of skin breakdown
(see *Symptom Management*)

If symptoms and distress are not easily controlled, sedation may be appropriate if deemed acceptable by all those present (see *Symptom Management, Terminal Delirium*).

In developing the care plan, be sure to:

- discontinue as many unnecessary medications as possible. For those that must continue, choose the least invasive route of administration, i.e. po, pr or buccal mucosal, and avoid intermittent injections if at all possible. If injections must be used, consider a sc butterfly
- ensure all caregivers are knowledgeable about techniques of providing care outlined in the negotiated care plan
- encourage participants to give each other permission:
 - from the person to caregivers: to provide care (especially when they are family and friends)
 - within the family: to be family first, and caregivers only if comfortable in that role
 - from family to the person: to die when he/she is ready
 - from the person to family: to build a new life after the death
 - all: to express anticipatory grief, and change roles when necessary

COMMUNICATING WITH THE DYING PERSON

*“We need to participate in our health, including our death”
- one voice -*

Many who are dying, even those who seem unresponsive, may wait for someone to visit, or for a particular event like a birthday, then die soon afterwards. Even if the person isn't responding, assume they sense the environment around them and can hear everything, until they have died. Family and caregivers should:

- avoid walking on “egg shells”
- discuss good news at the bedside, and include the person in any conversations
- discuss bad or potentially distressing news as far away as possible from the bedside
- say things they need to say. Give permission as they believe it is needed, in a way that feels comfortable to them
- include any family, children, animals who want to be there
- touch, hold, lie beside the person
- play music the person usually likes, tune TV to a show they usually enjoy
- if at home, continue normal household activities
- reassure the person that he/she is safe and not alone, right up until death
- above all – listen, listen, listen

AS DEATH APPROACHES

- remind the family about:
 - the different loss that each person is about to experience
 - common things that they may experience as the time of death approaches including numbness, a sense of euphoria or transcendental spiritual experiences, i.e. seeing the loved one “filled with light”, trauma about the suffering experienced prior to death that is replayed over and over and leads to anger
 - difficulty anticipating how they will feel until death actually occurs
 - the possibility of death occurring when those closest are not

*“Family can be afraid to take responsibility or change a care plan. Health care workers can be more objective and help the family through the process of dying”
- one voice -*

SIGNS OF THE DYING PROCESS

- present
- verify previous decisions regarding resuscitation
- review events and signs of the dying process and death, i.e. possibility of gas, stool and urine movement even after death
- ensure family and caregivers know regulations regarding management, pronouncement, certification, and reporting of death to the coroner or medical examiner’s office. The local office can provide advice. Usually, an expected death does not need to be reported but an unexpected, unnatural or unexplained death must be reviewed by the coroner or medical examiner.
- make it clear that when death occurs:
 - focus of care shifts from the person who has just died to those who survive, i.e. family and caregivers
 - there is no need to rush as there are no specific rules and regulations about how quickly things should happen, only personal, cultural, religious customs and traditions
 - authority to make decisions moves from the person holding power of attorney (or proxy) to the executor of the estate under the will. If there is no will, then closest next of kin has this authority
- know which physician will attend to complete the death certificate and how he/she can be reached
- remind family not to call “911” or emergency rescue personnel if there is a “No CPR” or “DNR” order
- suggest that funeral and burial/cremation arrangements be considered, discussed or made (if this has not already been done)
- clarify whether or not an autopsy will be requested. These are readily arranged when death occurs in hospital, but when death occurs at home or in other institutions, there may be expenses for autopsy and associated transportation
- be prepared to discuss organ donation (only donation for research is appropriate with HIV/AIDS)

If death comes quickly, the person may go from consciousness to dead in a matter of seconds to minutes. However, if the dying process occurs over time, any or all of the following may occur:

- level of consciousness may decrease
- circulation may deteriorate, manifesting:
 - increased heart rate and decreased blood pressure
 - peripheral cooling
 - peripheral and/or central cyanosis
 - mottling of the skin
- urination may decrease and/or stop, manifesting:
 - decreased or no urine output
 - increased urine concentration/colour
- breathing may deteriorate, manifesting:
 - diminished tidal volume
 - gaps between breaths (apnea)
 - Cheyne-Stokes respiration
- gag reflex may diminish or disappear, manifesting:
 - difficulty swallowing

CHANGING THE SETTING OF CARE

- build-up of secretions in throat, often called death rattle
- signs usually indicating terminal delirium (must be differentiated from pain), i.e. restlessness, agitation, confusion, hallucinations, moaning and/or groaning

Late transfer of the dying person from home to another setting of care should be avoided, if possible. However, when problems like shortness of breath, bleeding and/or caregiver fatigue/burn-out cannot be managed at home, transfer may be unavoidable.

Plan for this possibility:

- always have at least one substitute setting of care available as back-up
- know whether ambulance services in your area will honour a “No CPR” or “DNR” order and how this information must be documented. Some jurisdictions do not allow ambulance personnel to honour a “No CPR” order unless the physician accompanies the person
- if calling for a transfer ambulance, ensure other emergency services are not inappropriately alerted

WHEN DEATH OCCURS

When death occurs, caregivers should support, comfort and educate family and friends who have suffered a loss.

WITHIN HOURS OF THE DEATH

Caregivers should (not necessarily in sequence):

- comfort those who need comforting without getting in their way
- encourage family and caregivers to take time to see and feel the change that has occurred so they can start to say good-bye. Encourage them to use signs of affection they are used to, like touching, holding, kissing, while maintaining body substance precautions. Some must see and touch in order to realize death has occurred. For many, the longer they stay with the body, the sooner their hearts begin to realize a very significant change has taken place
- provide acute grief support. Caregivers should be careful that their own sense of loss doesn't get in the way
- respect all personal, cultural and religious values, beliefs and practices
- verify whether the death is reportable to the coroner or medical examiner, and call attending physician if necessary
- notify or arrange to contact those close who need to know about the death. Where possible, avoid breaking unexpected bad news by telephone. Person-to-person communication provides better opportunity for support. Remind those who will notify others that the fact of death is public information, but the cause of death remains confidential, unless the executor and/or next of kin wishes to release that information

*“Funeral people also need to treat the person with love and care as they remove the body. To be rough with the body would seem to me like violating the person”
- one voice -*

- encourage those present to position, bathe and dress the body if they so desire. Remove any catheters and lines, once those present are over their acute grief reactions. If the coroner or medical examiner will attend, the body should not be altered, moved or lines removed until such permission has been obtained
- if the physician is not in attendance, call him/her when those present are ready. This may be soon after death if they require or request support, or it may be several hours later if they want time alone. The physician usually attends to certify the death within a reasonable time and at that time will:
 - verify desire for autopsy or not
 - complete appropriate forms, if not yet done
 - complete and explain the death certificate, reminding those present that the information, particularly cause of death, must be reported by law but remains confidential
 - explain local and provincial registration processes
- if requested, help the family select and notify a funeral service and:
 - answer any questions about the funeral process, including embalming. Assure the family that, if they wish, they can keep the body at home until burial or cremation but, if so, the funeral service provider should prepare the body beforehand (see *Funerals, Memorial Services and Rituals*)
 - assist in calling the funeral service providers when appropriate. Funeral service providers will usually remove the body day or night, and will clarify their availability when called

WHEN APPROPRIATE

Caregivers should:

- notify health care agencies who have been providing care about the person's death, so that services can be terminated appropriately
- secure valuables in the custody of executor. Verbal wishes of the deceased may only be honoured when the executor of the will has the authority to do so in the will, or has the agreement of all beneficiaries
- clean and remove other equipment, maintaining universal precautions and using appropriate sterilization techniques. Some items and supplies may be returned to the provider or used by others
- dispose of medications. Narcotics should be flushed away or destroyed by a family member and witnessed by a caregiver. Other prescribed medications become the property of the estate, but cannot be used or kept, and should be destroyed or returned to a pharmacy by the executor
- discuss biological waste disposal

- counsel family concerning:
 - practical matters surrounding the death
 - how to obtain documents to execute the will, complete business, redeem insurance
 - notification of various official and private agencies, i.e. pension authorities, Ministry of Health to cancel health insurance card, banks, insurance companies
 - legal and financial obligations and benefits, such as probate of the will, income tax filing, Canada Pension Plan death benefits. A legal counsellor may be helpful at this point
- offer to arrange follow-up visitation and bereavement support

Funerals, Memorial Services, and Rituals

Rituals, funerals, and memorial services can capture in a powerfully symbolic way our understanding of life and death. They speak through action and symbol, poetry and music, prayer and philosophy, of who we are, what we believe, and how we want to be remembered

Rituals, funerals, and memorial services should not be “done to or for” people

FUNERALS

The term “funeral” is used to describe several events that take place immediately following a person’s death

WHY HAVE A FUNERAL?

AIDS has challenged many young people to think about how they wish to be remembered.

Often the person living with HIV/AIDS will want to design his/her own funeral service, or create rituals for the time of death. This “advance planning” can have powerful healing effects for the individual, partner, and family. It can facilitate anticipatory grieving and ensure the deceased’s wishes are respected and followed. In many ways, planning for death in this way can be seen as the final gift to beloved family and friends.

Most find traditional funerals and church services do not speak of their experience. In designing their own ritual(s), funeral, or memorial service(s), persons living with HIV/AIDS may want the service to reflect honestly who they are. They may want to bear witness to relationships which cause the family discomfort. While painful for some, it is important at the time of death to be honest. When secrets grow, healthy grieving is hampered as families and friends are caught in the web of secrecy and deception.

The service should be the loving creation of friends and family, and those who facilitate or conduct the service must be flexible. If the service is a true creation of the deceased and those who loved him/her, then death’s pain can be eased. Because few terminally ill people have given much thought to funeral arrangements, caregivers must be prepared to offer advice if requested.

These events will often include:

- the wake, when friends and family gather in the presence of the body to offer support to one another
- a funeral service or memorial service (formal or informal) that occurs in a place of worship or elsewhere. Usually, the body is present at a funeral service but not at a memorial service
- burial or cremation (whether attended by relatives and friends, or not)
- often a less solemn reception or gathering will follow these events

A funeral can:

- serve as the conscious beginning of the grieving process. For those in a state of denial, it may be the time when reality of the loss begins to sink in
- provide an opportunity for friends to mourn the loss of a friend and to offer support to the family
- provide time when tribute is paid to the person, his/her uniqueness, and accomplishments
- be a rite of passage providing a formal setting for family and friends to say “good-bye” to the deceased

It is an opportunity for survivors to think about the meaning of life and death, to give thanks for the one who has died. Often this is done within the context of worship.

HOW TO CHOOSE A FUNERAL SERVICE PROVIDER

The funeral business is currently undergoing change. Depending on where you live, there may be choices between funeral homes, memorial societies or transfer services. Before contacting a funeral home, consideration should be given to what services are to be provided and approximately how much money can be spent. While the majority of funeral directors will help make those decisions, it is good to think ahead before calling.

CHECKLIST OF THINGS TO REMEMBER WHEN PLANNING A FUNERAL SERVICE:

-
- friends and family to be notified
- is the body to be embalmed, and will it be buried or cremated?
- how is the body to be prepared, i.e. clothes, hair style?
- is the casket to be open or closed?
- will there be a time for visiting?
- will there be a service? Will the body be present?
- where will the service be held?
- who will conduct the service? Who else will speak?
- what music will be used?
- will there be a notice in the newspapers? What information will it contain?
- does the family wish to order flowers?
- would remembrances of flowers or memorial donations be preferred, or both?
- will there be a reception following the funeral? If so, where?

CONSIDER THESE POINTS WHEN MAKING A DECISION ABOUT FUNERAL SERVICE PROVIDERS:

-
- what is the reputation of the funeral service provider?
Do you believe they respect confidentiality?
- are they convenient to the home or community?
- will they provide the service desired? Do they ask what is desired or do they decide what must be done?
- will they embalm the body of a person who has died of an AIDS-related illness? If so, will there be an additional charge?
(There should not be an additional charge.)
- what are their fees? Some provinces legally require funeral homes to provide a price list. Don't be afraid to ask pointed questions about fees
- is the staff fair and respectful?

COMMON QUESTIONS ABOUT FUNERALS

What are the legal minimum requirements that must take place after death has been certified?

A body must be either buried or cremated (or in some cases, may be given to medical science for research).

Must you have clergy to conduct a funeral?

No, you do not. Anyone may do it. If the funeral or memorial service occurs in a place of worship, it is normally conducted by clergy. If so, you may be obligated to conform to the order of service of that particular religion, but friends and family may possibly take part in planning. If other than clergy officiates, there may be more flexibility. You may want to consider music, readings, special symbolic acts and tributes to the deceased.

Does a body have to be embalmed?

No, not always. A body should be embalmed for aesthetic reasons if there will be public viewing in a funeral home, or if the funeral must be delayed. By law, some provinces in Canada require embalming if the body must be shipped out of province. In Alberta (at the time of printing) embalming is not permitted for persons whose death certificates list HIV or AIDS as cause of death. Such practice is inconsistent with what we know of HIV transmission and the HIV community is advocating for changes to this practice.

Is cremation the least expensive way to dispose of a human body?

It may be, but not in every situation. A simple immediate cremation with no additional services may be the least expensive method. Final costs will be determined by other services you require from your funeral caregiver.

Do all funeral homes charge the same price?

No, not all funeral homes or funeral service providers are alike. Prices vary from place to place, so check with more than one. You can request a price list from a funeral home, although items may require clarification by the funeral director. Don't be afraid to ask questions about cost.

What if the person who dies has no money?

The family must apply to Social Services before making arrangements in their community for assistance with the burial. Some religious and aboriginal communities provide funds for burial of their members.

Is pre-arranging a funeral a good idea?

Pre-arranging a funeral can help people accept the reality of impending death. However, there are some cultures where pre-arranging the funeral is looked upon with suspicion, so this must be approached sensitively. If finances are a concern, check with Social Services for any guidelines that must be followed before making arrangements.

Is it legal to scatter cremated remains?

Cremated remains, or ashes, can be scattered anywhere, i.e. in a public cemetery, lake, river, farm or at a family cottage.

Is there a board that regulates funeral service providers?

Yes, each province has its own board. In addition, the Funeral Service Association of Canada has an office in Ajax, Ontario. If you encounter difficulties when dealing with a funeral home or memorial service provider, do not hesitate to contact the provincial or national association. (see *Resources*)

PLANNING THE FUNERAL SERVICE

Many people would like to avoid attending funerals, but these are important events that deserve careful planning. It helps, of course, to discuss funeral plans with the person before death occurs. Whether or not this is possible, consider these points when planning the service:

- what religion or philosophy of life did the person embrace while alive?
- the service should be faithful to the values, beliefs and activities of the one who died
- in addition, the service should comfort survivors

Many people think that because a person wasn't religious, a service can't be held. This is not true. Often a service can be planned to include some religious components, although they may not strictly conform to the rites of one particular religion. Here are some components of a funeral service:

| | |
|----------------------|---|
| Music | include favourite music of the one who has died. You may also want to enlist the services of musicians for the event |
| Readings | involve scripture, poetry, or a letter from the deceased |
| Tributes | have a number of family and friends speak about the deceased. Occasionally, the service is opened up to anyone who wishes to speak |
| Symbolic acts | candles, helium filled balloons, rainbow ribbons, flags, incense, music, flowers, or pictures may all be used effectively to convey ideas about life, death, and letting go |
| Prayers | prayers may be chosen from more than one religious tradition, and/or include humanistic prayers |

FOR MORE INFORMATION

See the Funeral Services sub-section in *Resources*.

SUGGESTED READING

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 Stuart E. Daring to speak love's name: a gay and lesbian prayer book. London, UK: Hamish Hamilton, 1992.

Grief, Loss and Bereavement

The challenge of AIDS grief is to understand what is “normal” in such an “abnormal” situation

AIDS GRIEF

“We expect our grief to be something special. In fact, our grief is as old as our self-image, so familiar in fact that we often do not recognize it when it affects us.”²

Stephen Levine

The death of a person living with HIV/AIDS represents the end of a life which profoundly affected many circles of people: family members, loved ones, neighbours, acquaintances, and volunteer and paid caregivers who accompanied them through their fight with AIDS.

Just as AIDS has challenged us to rethink much about providing Palliative Care, so too has the disease impacted our understanding of grief. This section reviews issues pertinent to AIDS grief, along with interventions for working with multiple loss and supporting community initiatives related to grief.

While there seems to be a natural constellation of responses to death, additional factors associated with AIDS increase the complexity of grieving (see Table 1). There is tremendous impact from social isolation, stigma, disenfranchisement, lack of spiritual support, fear of contagion, multiple loss, homophobia, illness related complications and survivor guilt.

Other grief experiences accompanying the loss of a person with HIV/AIDS include:

- inner chaos, i.e. future is a “void”
- outer chaos, i.e. accident-prone, absent-minded
- intense intellectual efforts to regain control, and to make sense of the experience
- sensed presence of the loved one
- desire to help others living with AIDS

In any general study of bereavement, these symptoms might signal “pathology”. However, this type of reaction can also be seen as *normal response to catastrophic events* rather than maladaptive reaction to a normal stressor.¹ *AIDS grief must be perceived as “normal grief” in an “abnormal time”.*

Several approaches can help bereaved individuals:

- support groups
- listening one-on-one
- buddy systems
- professional therapeutic support

Ultimately, bereavement support should take the mourner beyond reactions to the loss. Many caregivers assist the bereaved with beginning stages of grief, encouraging people to express reactions to the death. Caregivers do not always continue with the important latter processes involving reorientation to the deceased, self and external world.³

Modest goals of bereavement care include:

- supporting the griever through initial pain of loss
- working gently to mobilize coping strategies so they feel they can carry on
- providing useful information on grief, rather than rigid frameworks
- reviewing the lost relationship to help integrate past and present

WORKING WITH AIDS BEREAVED INDIVIDUALS

Symptoms of grief associated with AIDS include a greater than usual amount of rage, fear, shame, unresolved grief, guilt, helplessness, loss of intimacy, physical symptoms, self-destructiveness, insecurity, numbness, and pessimism

*The goal is to grieve well,
not to grieve right*

- reinforcing outcomes of increased self-awareness, self-esteem, stronger coping mechanisms
- renewed awareness of strengths
- growing sense of identity, deeper engagement in social network of friends and intimates

INTERVENTIONS

There are general guidelines for supporting individuals who have lost loved ones to AIDS. These apply in more condensed form to people suffering from anticipatory grief, including people infected with HIV and their friends/families who are dealing with a series of losses preceding death. For a comprehensive guide to bereavement counselling, an excellent resource is *Treatment of Complicated Mourning*⁵ by T. Rando, from which the following interventions are summarized:

*“In times of grief,
you are often running on
your reserve tank of oil,
and you don’t know
that your main tank has run
out until your reserve
tank is empty too.”
- one voice -*

- **establish a relationship** through your presence and active listening, as you assess and plan appropriate interventions
- **reach out** to the bereaved, offering to help them in some concrete manner, especially during the early aftermath of death when they are dazed and in shock. Say “Let me accompany you to the casket” rather than “Call me if you need anything”
- it is a critical time to give people permission to grieve. They may begin to cry and check for your tolerance and support
- maintain a “**family systems**” perspective in dealing with the griever
- ensure the griever receives **appropriate medical evaluation** and treatment if physical symptoms warrant

Rando’s *Treatment of Complicated Mourning*⁵ has a detailed, structured interview schedule and inventory for assessing grief and mourning.

WHEN GRIEF GOES WRONG

There may be times when additional resources can help with problematic grief reactions. The following may indicate complications with mourning and require expert consultation:

- chronic or exaggerated grief responses with extreme reactions over prolonged period of time
- self-destructive impulses and behaviour
- delayed grief reaction and absent mourning with “flight” cure, i.e. radical changes in lifestyle, avoidance of activities, places and people associated with the deceased
- long-term clinical depression or false euphoria

USE OF MEDICATION

Grieving people often consult family physicians about medication to help abolish suffering. There has been much discussion about use of medication to manage acute, normal grief. Medication ought to be used sparingly to provide relief from anxiety or insomnia, rather than relief from depressive symptoms (see *Symptom Management-Anxiety, Insomnia and Depression*). Worden⁶ advised against giving antidepressant medication to people undergoing acute grief reactions, noting that antidepressants take time to work. They rarely relieve normal grief symptoms, and by not facilitating verbal expression of grief, a delayed or abnormal grief response may occur.

TABLE 1: GRIEF ISSUES IN AIDS BEREAVEMENT

| | <i>Partner/spouse</i> | <i>Family of origin</i> |
|--|---|---|
| DISENFRANCHISED GRIEF⁴ | <ul style="list-style-type: none"> relationship not recognized: ex-spouse/common-law/affair loss not supported: partner was IDU so “is to blame” inadequate bereavement leave lack of meaningful funeral practical problems: will, belongings lack of spiritual support | <ul style="list-style-type: none"> relationship to person with AIDS not acknowledged, thus delaying grief shame or anger about family member’s “lifestyle” grief needs of children complexity of sibling relationships not acknowledged |
| HOMOPHOBIA AND HETEROSEXISM | <ul style="list-style-type: none"> lack of institutional sanctions for relationship problem with will, belongings, home, financial future lack of meaningful funeral and religious/spiritual support internalized homophobia: doubts about self-worth | <ul style="list-style-type: none"> may blame partner for disease may be dealing with shock of having gay child may be in conflict with partner and friends shame about life-choices of gay family member |
| STIGMA OF AIDS, SECRECY AND ISOLATION | <ul style="list-style-type: none"> may be isolated from own family/friends reluctance to disclose details of death, prolonging grief insufficient/no bereavement leave discrimination in workplace and home/neighbourhood | <ul style="list-style-type: none"> issues of disclosure and confidentiality may be geographically distant traditional sources of support unavailable lack of meaningful funeral/memorial |
| SURVIVOR GUILT | <ul style="list-style-type: none"> “why not me?” difficulty feeling joy in being alive guilt if suspected source of transmission | <ul style="list-style-type: none"> “children don’t die before their parents” guilt if source of transmission (mother/child) other family may wonder “why not me?” |
| ILLNESS RELATED COMPLICATIONS | <ul style="list-style-type: none"> fear of contagion anger about quality of care if poor exhaustion due to roller coaster of illness and caregiving spectrum of losses along the way: sight, physical appearance, ability, dementia | <ul style="list-style-type: none"> fear of contagion low level of physical and emotional reserve if caregiving young deaths: forces confrontation with own mortality may be dealing with Hemophilia there may be several in same family with HIV |
| MULTIPLE LOSS | <ul style="list-style-type: none"> many friends may also have died, depleting sources of support uncertainty about future: AIDS is not over loss of community may be called on to care for others | <ul style="list-style-type: none"> may be coping with additional illness of several family members mourning the death of a family in bits and pieces |

| <i>Friends</i> | <i>HIV +</i> | <i>Caregivers</i> |
|--|---|--|
| <ul style="list-style-type: none"> • lack of recognition of relationship • lack of closure; funeral | <ul style="list-style-type: none"> • own needs put aside | <ul style="list-style-type: none"> • trained not to “attach” as professional resulting in denial of grief • lack of closure; rituals/funerals |
| <ul style="list-style-type: none"> • invalidated and unrecognized in role of “chosen family” | <ul style="list-style-type: none"> • dealing with societal blame | <ul style="list-style-type: none"> • may negatively affect caregiving role, resulting in guilt, anger • may be pulled into conflict between family/partner |
| <ul style="list-style-type: none"> • may be isolated from family/friends • reluctance to disclose details of death, prolonging grief • no bereavement leave • lack of meaningful funeral/memorial | <ul style="list-style-type: none"> • issues of disclosure about own status | <ul style="list-style-type: none"> • may face harassment about caring for people with HIV/AIDS |
| <ul style="list-style-type: none"> • “why not me?” • difficulty feeling joy in being alive | <ul style="list-style-type: none"> • “why not me?” • difficulty feeling joy in being alive | <ul style="list-style-type: none"> • may lead to overwork/burn-out to compensate for internal distress about own health |
| <ul style="list-style-type: none"> • fear of contagion • anger about quality of care if poor • exhaustion due to roller coaster of illness and caregiving role • spectrum of losses along the way: sight, physical ability | <ul style="list-style-type: none"> • sexual repression • fear about progression of own infection | <ul style="list-style-type: none"> • fear of contagion • low level of physical and emotional reserve from complex care • young deaths force confrontation with own mortality • may be working with hemophilia or other complicated illnesses as well |
| <ul style="list-style-type: none"> • many friends may have died, depleting sources of support • “grief on the run” • uncertainty about future • may be called on to care for others | <ul style="list-style-type: none"> • stress of multiple loss can impact immune system • may worry about who will be there for him/her | <ul style="list-style-type: none"> • lack of structured support for integrating ongoing losses, delaying grief • may be affected by inadequately addressed losses prior to AIDS death • helplessness/lack of joy in work |

SPECIAL CONSIDERATIONS

“At this point in the AIDS crisis, communities of HIV affected people are suffering from bereavement overload. We are in a constant state of mourning, even though we may not be in a state of acute grief.”⁸

L. McKusick

CHILDREN:

- children’s understanding of death depends on their stage of development:
 - generally, pre-school children (3-5) view death as a temporary departure
 - in early school years (5-9), death is an entity which surprises or takes people away. Children begin to understand death as a permanent separation
 - by 10, children usually understand that they themselves must die at some point⁷
- children feel the pain of death but are often unable to verbalize their feelings. Parents may need support in being gentle but truthful when telling children about an impending death
- some children lose both parents to AIDS. This group often benefits from professional help to work through grief, and a safe place to talk about what happened
- part of bereavement support involves disclosing issues about the nature of AIDS death, i.e. stigma, shame, anger, fear of contagion, peer rejection. If facilitators are AIDS-sensitive, bereavement groups for children are an excellent referral

HIV STATUS:

- when mourners themselves are HIV+:
 - intense grief work for lost friends is often “put on hold” as they struggle with their own health status. Watching a friend die of AIDS can intensify fears about their own impending death
 - physical symptoms associated with grieving often mimic HIV related illnesses, i.e. shortness of breath, headaches, fatigue
 - educational material about grief provides a cognitive framework allowing individuals to normalize grief responses
 - encourage people to develop a comprehensive health maintenance plan which integrates ongoing grief work
- when mourners are HIV negative:
 - there can be a sense of joyous relief about their sero-status which may be unacceptable to express within their social circles
 - grief may be complicated by survivor guilt and a sense of exclusion
 - fears of an uncertain future must be explored, i.e. “what will my world be like when AIDS is over?”
 - encourage people to develop a comprehensive health maintenance plan which integrates ongoing grief work

LOSS OF A CHILD:

- whether a child is six or twenty-six, his/her death is very difficult for everyone involved. Most affected are the parents whose grief reactions are often more intense and longer lasting
- disclosure issues may prevent a parent from receiving appropriate support from friends and community. Caregivers involved with the child become important links following his/her death

- when an adult child dies in a large city, and the family lives in a small community and choose not to disclose his/her sero-status, local resources will not be able to support the parents appropriately
- for more information on dealing with the needs of parents and siblings facing the loss of child, see *Psycho-Social Support*

FAMILY MEMBERS:

Grief can rip families apart. This may be compounded by multiple HIV infections and anticipatory grief within the family, or caregiving responsibilities following the death of one family member. Individuals grieve in their own way and time. Family members may find themselves in their own grief spiral, unable to provide adequate attention and support to one another. Recognizing this as normal can help families:

- facilitate open dialogue about changes occurring in the family as a result of the death
- the stigma of AIDS can remove traditional sources of family support, increasing the caregiver's responsibility to maintain consistent external support. Family network systems can help parents, siblings and extended family members communicate openly with peers
- contact the Bereaved Families Association or grief support services in your area for information about groups

INTERVENTIONS IN MULTIPLE LOSS

*"It's going to be really strange when they announce a cure. On the one hand it will be great, but on the other, people will finally be able to stop and will have to come to terms with the incredible amount of death that has occurred. I think that will be very scary."*⁹

People experience bereavement overload when they have no time to express fully one loss before other losses occur, or further losses are anticipated. Multiple loss requires additional help in developing enhanced coping skills.

Working with multiple loss:

- the first step is for individuals to admit all losses so they can begin to move through the process of grief
- focus on one central loss and work it through so the bereaved can have the experience of completing one grief process.⁵ Develop the mourners' trust, deal with their feelings of not knowing where to begin, and help them focus on one loss
- people may be dealing with a diminished capacity to feel because they have psychically insulated themselves from the world. Rando⁵ suggests additional techniques for helping the mourner confront denial and numbing reaction, and experience emotional expression/catharsis
- expect to hear stories repeatedly, about the way things were and who the loved ones were
- secondary losses must be thoroughly explored because they often go unrecognized in multiple loss, i.e. social support, sexual freedom, ability to have children, hope for the future
- the concept of the assumptive world is powerful in HIV/AIDS, as people are continually forced to reassess assumptions of the way the world "should have been". Purposes in living and reasons for suffering must continually be re-examined as losses mount

PLANNING AND PROVIDING BEREAVEMENT FOLLOW-UP

Good bereavement care includes consistent, on-going outreach through the first year of bereavement. It provides information and support to the bereaved and permits monitoring to identify people needing helpful intervention. A plan for bereavement care must consider three primary components:

- **community:** demographic information, awareness and attitudes, existing services, current needs
- **program:** mandate, staffing, financial resources
- **client:** assessment, referral procedures, available support, information requirements, grief related considerations

For more information, refer to *Bereavement care: a plan for grief support*, Victoria Hospice Society, 1993.¹⁰

RESPONDING TO COMMUNITY NEEDS

“Heal the community by healing the individuals and in this way, resurrect the sense of community fundamental to the mental health of the individual.”¹¹

Herman Kaal

Along with individuals and families suffering from AIDS loss, entire communities are moving through stages of communal grief. The role of communities in supporting bereaved individuals is essential. The goal of attending to the health of communities and their members is equally worthwhile. We must expand our intervention to the community level, using goals similar to those for bereaved individuals:

- acknowledge what has been lost: death notices in community papers, public AIDS memorials
- mourn what has been lost: candlelight vigils, regular AIDS memorial services offered in churches and synagogues
- popularize the topic of grief through educational forums
- promote awareness that volatile reactions of some community members or agencies is potentially rooted in unrecognized grief
- mobilize coping strategies so people feel they can carry on in the midst of the crisis. Provide community leaders and key members with information, train peers to provide informal individual and group support. Encourage public acceptance of active mourning, not simply tolerance
- actively endorse and participate in the creation of rituals and memorials to remember, celebrate and learn from those who have died, so their gifts, stories, and contributions will never be lost

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Models of Palliative Care Delivery

*“The services available are not sufficient, both in terms of access to palliative care beds and availability of services to support care in the home”
– one voice –*

Palliative Care in Canada is often associated with institutional care and traditionally Palliative Care programs have been developed within acute care hospital settings. Within the past decade, new models have evolved to meet the changing needs and expectations of those living with HIV/AIDS. Across the country there are numerous creative responses to the care needs of persons living with HIV/AIDS.

Common models of care delivery include, but are not limited to:

Palliative Care Units/Beds
Free-Standing Hospice
Palliative Care Consultation Services
Community Palliative Care Programs/Services
Volunteer Hospice/Palliative Care Programs

ISSUES ARISING IN THE PROVISION OF PALLIATIVE CARE SERVICES:

Regardless of the care setting, there are a number of important issues to be considered in the development and provision of Palliative Care services. This section outlines some challenges and potential strategies.

| CHALLENGES | POTENTIAL STRATEGIES |
|--|---|
| INDIVIDUAL CHOICES | |
| <ol style="list-style-type: none"> Individuals may choose care options which are impractical or contrary to the wishes of family or other caregivers | <ol style="list-style-type: none"> Care options must be clearly discussed with individuals early in their illness to ensure that choices are informed. To their best ability, caregivers must respect the individual's decisions |
| CONTINUUM OF CARE | |
| <ol style="list-style-type: none"> Movement across the care continuum is often fragmented There is often a lengthy waiting list to access services | <ol style="list-style-type: none"> Care providers must talk early with individuals living with HIV/AIDS about their care options and preferences Facilities with waiting lists must have an outreach component. Regional service registries could facilitate access to care |
| CARE IN RURAL VS URBAN CENTRES | |
| <i>The challenges identified for rural areas may also apply in some suburban areas.</i> | |
| <ol style="list-style-type: none"> Low prevalence of HIV/AIDS in rural communities may preclude development of HIV-specific Palliative Care programs | <ol style="list-style-type: none"> Services must be integrated into existing Palliative Care and hospice programs, i.e. reviewing current programs (including admission criteria), training of all staff and volunteers in HIV and related issues, reviewing fiscal and other resources to ensure appropriate allocation to meet complex care requirements |

CHALLENGES**POTENTIAL STRATEGIES**

- | | |
|--|--|
| <p>2. There are often fewer resources available in rural communities</p> <p>3. Persons living with HIV/AIDS may live outside the local community, resulting in long-distance travel for designated caregivers. Other factors include time, inclement weather safety of the caregiver</p> <p>4. Caregivers may have had limited exposure to HIV/AIDS, resulting in lack of HIV knowledge, discrimination and fear</p> | <p>2. Hospital and community based programs must develop services collaboratively. Prevent waste of unused supplies by establishing system to recycle supplies</p> <p>3. In some communities, it may be appropriate to develop regional teams (both professional and volunteer care teams) to most effectively service outlying areas. To ensure the individual receives required care as scheduled, and to ensure safety for staff and volunteers, appropriate backup systems and supports must be built into community programs. These may include: use of cellular phones in caregivers' cars, backup caregiver for each scheduled shift, 24-hour on-call system, etc.</p> <p>4. Additional to Palliative Care education, designation of an HIV/AIDS Palliative Care consultant is a useful support to caregivers</p> |
|--|--|

COMMUNITY CARE CHALLENGE

- | | |
|---|---|
| <p>1. Many individuals living with HIV/AIDS receive care from several caregivers and agencies in the community. This can result in fragmented and/or uncoordinated care, lack of communication, "splitting", "turf wars", and less-than-optimal service to the individual</p> <p>2. Many community-based Palliative Care programs do not operate 24 hours/day. This precludes many people living with HIV/AIDS from staying at home</p> | <p>1. Designate a coordinator to work collaboratively with the individual. This simplifies lines of communication for all involved, particularly the person living with HIV/AIDS. The designated coordinator must be agreeable to the person living with HIV/AIDS and their role validated by all members of the team. Some programs have developed enhanced communication tools which are left in the individual's home for use by the individual and caregiver. It is particularly important to coordinate assessment activities through "shared" documentation to eliminate duplication and unnecessary individual assessments. When scheduling caregivers, strive for consistency of caregivers wherever possible. Regular team or teleconferencing meetings of the "care team" are essential if interdisciplinary collaboration is to be achieved</p> <p>2. To permit the option of dying at home, community-based Palliative Care programs must provide service 24 hours/day. Access to respite care is essential to any community program. Palliative quick response teams which respond to urgent needs may prevent unnecessary hospital admissions</p> |
|---|---|

INSTITUTIONAL CARE CHALLENGES

- | | |
|---|--|
| <p>1. Many Palliative Care units strive to create a home-like environment with greater emphasis on individual autonomy</p> <p>2. Providing care in acute care hospitals is costly. An American study found the average per diem cost in acute care hospitals is \$1,105.00 to \$1,235.00 Canadian dollars¹</p> | <p>1. Institutions which provide Palliative Care must strive to develop an atmosphere promoting individual autonomy, dignity and choice</p> <p>2. Models of care which demonstrate quality care and cost effectiveness should receive funding priority</p> |
|---|--|

CHALLENGES

POTENTIAL STRATEGIES

RESOURCE ALLOCATION CHALLENGES

- | | |
|---|---|
| <ol style="list-style-type: none"> 1. Health care reform across Canada is shifting to community care 2. In allocating funds, it is generally held that provision of care in the community is less costly than institutional care. Although this may be true, this view is largely subjective and unsubstantiated 3. Programs must manage their limited resources and justify the economics of their activities | <ol style="list-style-type: none"> 1. Community programs and institutions must foster and develop strategic partnerships to ensure efficient use of scarce resources, while avoiding duplication of services 2. Initiate research comparing costs associated with care provision in various settings 3. Most papers that address economic issues of Palliative Care simply compare total program costs with average hospitalization costs, and do not perform an appropriate economic analysis. If Palliative Care is to find a place in Canadian health care, more complex analyses examining economic effectiveness, benefit and even program utility must be done |
|---|---|

QUALITY OF CARE CHALLENGES

- | | |
|--|--|
| <ol style="list-style-type: none"> 1. Palliative and Hospice Care programs need to be credible in Canadian health care 2. Programs need to continuously improve the quality of the care they provide | <ol style="list-style-type: none"> 1. To be credible, Canadian Palliative Care programs must develop a consensus regarding practice and standards of Palliative Care. This process is ongoing through the Canadian Palliative Care Association and the Canadian Council on Health Services Accreditation 2. Through development of program standards of practice, and application of continuous quality improvement, programs can measure activity outcomes and continuously improve quality of care |
|--|--|

DEVELOPING YOUR COMMUNITY'S CARE DELIVERY MODEL

Persons living with HIV/AIDS have complex Palliative Care needs which require various approaches to care delivery. Several different models have evolved across the country in response to consumer needs.

Whichever model of Palliative Care delivery you choose, it is important that it be driven by the:

1. needs of the persons living with HIV/AIDS in your community
2. response by your community to these identified needs
3. available resources and potential partnerships

Considering these factors, Palliative Care can be delivered in a setting which will best meet the identified needs of each individual and, thus, enhance quality of life.

*“There is a need for coordination of care which is collaborative rather than controlling”
– one voice –*

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Care for the Caregivers

AIDS PALLIATIVE CARE WORK-ENVIRONMENT STRESSES

*“There is a need for greater teamwork and communication between caregivers.”
– one voice –*

Care for the caregiver is an essential element of any Palliative Care initiative. While care of the person with HIV/AIDS can be extremely rewarding, at times professional and volunteer caregivers may also find the work to be quite stressful. This section identifies sources of distress, manifestations of stress and burn out in HIV/AIDS caregivers and discusses helpful coping strategies. The message underlying all strategies and information contained herein is the recognition that approaches to caring for the caregiver must be flexible and responsive to the needs of specific individual caregivers.

Research indicates there are stressors that are unique to AIDS care.^{1,2} These work-environment stressors have often been found to be more stressful than hands-on work.

HIV/AIDS REALITIES:

Caregivers providing support can be stressed by the realities of HIV/AIDS, including:

- multiple deaths
- youthful age of the people for whom they are caring
- sexual orientation
- complex care needs
- dementia
- multiple losses
- conflict over what constitutes Palliative Care (tension between active treatment and comfort care)
- roller-coaster nature of the disease

WORK ENVIRONMENT STRESSORS

- scarce resources
- communication problems with administration/board
- unrealistic expectations of/for organization
- team communication problems
- difficulty with resource allocation

INDIVIDUAL/FAMILY VARIABLES

- difficulty with person’s lifestyle
- caregivers with HIV/AIDS
- risk-taking behaviour of person/family
- personality/coping problems of person/family
- communication problems between person/family

ROLE STRESSORS

- role conflict
- role strain
- inadequate preparation for role
- lack of control in work environment
- active vs. Palliative Care role

ILLNESS-RELATED VARIABLES

- fear of contagion
- manifestations of disease: body image, dementia
- mode of contracting disease
- financial costs of disease
- impact of disease on particular communities
- multiple family members
- issues with confidentiality
- difficulty with symptom management

PERSONAL VARIABLES

*"We lost much of our youth to fighting this epidemic. We woke up one day and found we were middle-aged and had never been young"*³

(Saynor, 1994).

MANIFESTATIONS OF STRESS

- *avoidance of clients/families*
- *grief overload*
- *anxiety and fear*
- *job/home interaction*
- *punitive behaviour*
- *feelings of hopelessness/impotence*
- *feelings of guilt with iatrogenic illness*
- *staff conflict*
- *health problems*

SYMPTOMS OF BURN OUT⁵

- *emotional exhaustion*
- *depersonalization*
- *reduced personal accomplishment*

AGE ISSUES

In the early days of the HIV/AIDS movement, it was noted that HIV/AIDS was receiving different attention within the health care system because both persons living with HIV/AIDS and their caregivers were young. While the population of HIV/AIDS caregivers may be aging, their work has forced them to deal with issues of death and dying at an early age. Long-term implications of this have yet to be fully understood.

SEXUAL ORIENTATION

- one's own sexual preference may affect response to a person living with HIV/AIDS:
 - heterosexual caregivers may be homophobic and want to avoid persons who are gay
 - gay and lesbian caregivers may feel they are constantly exposed to HIV/AIDS in both their personal and professional lives, and suffer from "grief overload"
- caregivers who have "come out" may have difficulty if gay persons living with HIV/AIDS choose not to do the same. Such caregivers may need to reflect on how much of what is identified as the person's "unfinished business" is actually the caregiver's "unfinished business"⁴

HIV STATUS

- caregivers who are HIV+ may foresee their own future, and worry that there will be no one left to care for them

PERSONALITY AND COPING STYLE

- working with the dying has been found to shape one's attitude towards death and dying. Those who cope adequately with death tend to live in the present, rather than the past or future. They score higher on inner-directedness, self-actualizing value, existentiality, spontaneity, self-regard, self-acceptance, acceptance of aggression and capacity for intimate contact⁶
- the *hardy personality* is a personality characteristic proven effective in combating work stress in oncology settings, and could be of help in HIV/AIDS settings. This personality type is characterized by:
 - sense of commitment (as opposed to alienation) reflecting the hardy person's curiosity about, and sense of, meaningfulness of life
 - control (as opposed to powerlessness) reflecting belief that one has power to influence the course of events
 - challenge (as opposed to threat) epitomizing expectation that it is normal for life to change and for development to be stimulated⁷

SOCIAL SUPPORT

- "participating in a network of caring and reciprocal relationships with others, and creating a sense of belonging and a reason for living that transcends one's individual self"⁸ or social support, has been found to be one of the most important coping mechanisms. High levels of mental ill health in hospice nurses were found to be predicted by lack of social support

COPING WITH CAREGIVER STRESS

Stress derives from interaction between one's personal life and one's occupational life, and may be manifest in physical, psychological or behavioural symptoms. Coping mechanisms need to involve both work environment and individual action

STRESSFUL LIFE

- events may serve as a source of strength as well as being a stressor. Previous stressful life events can give one strength to bring to the workplace. However, unresolved previous losses or present stressors, such as illness or impending death of someone close, can leave one vulnerable and lacking emotional energy necessary to cope in the workplace

Given that stress evolves from both personal and professional spheres, coping mechanisms must involve both aspects of one's life. Mechanisms for coping with professional stress have been identified by many authors and include the following:

ORGANIZATIONAL COPING

- assume roles across continuum of care
- avoid work overload
- regular discussion groups to deal with staff stress issues
- clear awareness of role of person in decision-making about active vs. palliative treatment
- ongoing education about disease, treatment, caregiver risk
- provision of safe environment for the person and his/her caregivers
- involvement of team in decisions about changes in work environment due to economic realities of society
- provision of appropriate time away from direct caregiving role

DEALING WITH MULTIPLE LOSS

- recognize that one can learn as much about self by focusing on joys as by examining sorrows. Search for and explore past memories of joy and connection
- meaning in life is derived three ways:
 - creating a work or doing a deed
 - experiencing something or encountering someone
 - when we can no longer act, being aware of the attitude we take toward unavoidable suffering, through the courage and grace we assume when all else is lost⁹
- multiple losses from AIDS means that if one were to allow oneself to feel the pain of each grief, one would never get beyond acute grief
- psychological flooding of emotion may incapacitate rather than heal. To defend against this flooding, some people may become emotionally numb, leading to symptoms similar to Post Traumatic Stress Disorder
- encourage those in denial-numbing phase to re-experience their feelings by retelling traumatic events
- those in intrusive-repetitive phase (often characterized by overwhelming emotion) need leadership and external structure. Encourage stress reduction and suppression of painful emotions⁹

PERSONAL COPING

- avoid excessive involvement which may preclude objective counselling, advice and medical care

Caregivers need to have permission to say no and to limit their activities in order to sustain their own health and well-being

- recognize anger directed at caregiver should not be taken personally, but may be part of the person's own coping strategy or the effect of the disease (see *Psycho-Social Issues*)
- do not allow AIDS care to dominate one's life
- personal insight into need for overwork/overinvolvement
- awareness that immersion in caregiving, both in personal and professional roles, may lead to emotional exhaustion and burn out
- maintaining a positive attitude in the face of random suffering promotes coping by enhancing self-esteem and sense of power
- caregivers have self-selected, so that many "stressors" aren't stressful

LIFE STYLE MANAGEMENT

- participate in outside activities
- engage in physical activities and diversions
- organize non job-related social interaction, i.e. take time off
- attend to personal nutrition and adequate sleep
- use meditation and relaxation techniques
- be aware of what helps you sustain your own well-being

INDIVIDUAL SUPPORT

- using the above information, individuals involved in Palliative Care need to develop flexible, responsive strategies for meeting their personal needs
- caregivers should look to their own work and personal environments to find those to whom they can relate, creating a personal support network

ORGANIZATIONAL SUPPORT

- planned, professional interventions for caregiver support (see Organizational Coping above) should be a regular, arranged part of the activities of any Palliative Care setting
- often these interventions are pushed aside due to lack of time or other resources, but they are fundamental to the maintenance of a healthy, caring environment

CARE OF THE INFORMAL CAREGIVER

*"It was very distressing to be in the situation of having to make decisions, rather than simply being a mother."
– one voice –*

Those closest to the person living with HIV/AIDS often play a large part in providing care. As a result, they are at risk physically and emotionally. There is a strong tendency to be self sacrificing, to do anything possible to help the person living with HIV/AIDS.

Informal caregivers should be:

- taught proper techniques to prevent injuries to themselves and others
- encouraged to seek emotional support through talking to a friend or counsellor
- supported in seeking respite care to allow for physical and emotional rest away from the person living with HIV/AIDS.

This will allow the caregiver to regain energy and enhance the relationship with the person living with HIV/AIDS

- informed of (and encouraged to consider) their need for bereavement care following the death of their loved one

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Issues in Occupational Exposure for HIV/AIDS Palliative Care

TRANSMISSION OF HIV

*“I experienced discrimination in the hospital because I had AIDS. I was placed in isolation and no one would come in to see me”
– one voice –*

Fear of contagion has led some caregivers to use excessive or inappropriate HIV precautions. Others, especially in HIV/AIDS Palliative Care, feel that infection control techniques create artificial barriers to communication with the person living with HIV/AIDS. These providers take unnecessary, unacceptable risks when delivering care. The challenge in AIDS Palliative Care is to maximize quality of care while minimizing risk to staff.

- HIV is transmitted through unprotected sexual intercourse, exposure to blood, blood components or bloody body fluids, perinatally from mother to child, and rarely through breast milk
- risk of occupationally acquired HIV infection through exposure to intact skin or mucous membranes is too low for an accurate estimate
- for health care providers, the greatest risk of occupationally acquired HIV infection is from exposure to blood or bloody body fluids through a hollow-bore needle stick injury.
- persons with endstage HIV/AIDS disease have high viral loads, so vigilance is essential when using or disposing of needles and other sharps. Before choosing an invasive route, use all non-invasive techniques in the delivery of drugs, or essential diagnostics and treatment
- skin infections, like molluscum contagiosum, and herpes simplex are common in HIV+ persons.
- there is a world-wide resurgence of tuberculosis (TB). HIV and TB have a synergistic action, posing an additional threat for those living with HIV/AIDS and their caregivers.

In 1987, Health and Welfare Canada recommended implementation of Universal Precautions (UP) in all health-care facilities in Canada in consideration of all persons potentially infected with HIV or other bloodborne pathogens¹. Lynch proposed Body Substance Precautions (BSP) as an alternative approach². Either UP or BSP should be established in all institutional or home health care settings. Note that there is a move in the U.S. and in Canada to standardize Universal and Body Substance Precautions which will be known as Standard Precautions. Whichever approach is implemented in your setting, the following guidelines should be adhered to:

GUIDELINES FOR PREVENTING OCCUPATIONAL EXPOSURE TO ANY INFECTION

- HANDWASHING:
 - use warm running water
 - moderate amount of soap
 - vigorously rub hands together, including between fingers, around nails and wrists
 - rinse well
 - dry hands with a paper towel
 - turn tap off using the paper towel to grip faucet handle.
- PROTECTIVE APPAREL when anticipating contact with blood and/or body fluids
- SAFE USE and DISPOSAL OF NEEDLES AND OTHER SHARPS in biological waste
- Appropriate use of RESPIRATORY PRECAUTIONS

MANAGEMENT OF ACCIDENTAL EXPOSURES TO BLOOD/BODY FLUIDS

The following summary addresses the management of an occupational exposure to hazardous body fluids (HBF).

DEFINITION OF EXPOSURE

Hazardous body fluids (HBF) include blood, bloody fluids, and other body fluids known or assumed to be associated with transmission of blood-borne pathogens

| | |
|-------------------------------------|--|
| Massive exposure | <ul style="list-style-type: none"> transfusion of blood injection of a large volume of blood or HBF (>1 ml) parenteral exposure to laboratory or research specimens containing high titre of virus |
| Definite parenteral exposure | <ul style="list-style-type: none"> injection of blood or HBF (<1 ml) deep im (>3mm) injury produced by blood or HBF contaminated needle or instrument laceration or wound causing spontaneous bleeding in caregiver visible laceration or similar fresh wound inoculated with blood or HBF fluid |
| Probable parenteral exposure | <ul style="list-style-type: none"> subcutaneous/superficial injury with blood or HBF contaminated needle or instrument laceration or similar wound produced by blood or HBF contaminated instrument which does not cause spontaneous bleeding in care provider prior wound or skin lesion visibly contaminated with blood or HBF fluid mucous membrane inoculation with blood or HBF |
| Doubtful parenteral exposure | <ul style="list-style-type: none"> subcutaneous/superficial injury with non-HBF needle or contaminated needle or instrument laceration or similar wound produced by non-HBF contaminated instrument prior wound or skin lesion contaminated with non-HBF mucous membrane inoculation with non-HBF |
| Non-parenteral exposure | <ul style="list-style-type: none"> intact skin visibly contaminated with any body fluid |

TREATMENT

| | |
|-----------------------------|--|
| Wound care/first aid | <ul style="list-style-type: none"> seek assistance from fellow staff members immediately cleanse injury <ul style="list-style-type: none"> carefully flush mucous membranes or eye with large quantities of water or saline thoroughly clean wound/needle stick injury with soap and water or antiseptic soap promote passive bleeding of needle stick wound report to institutional First Aid/Occupational Health services (WCB designated attendant), doctor's office or emergency room complete WCB reporting and appropriate institutional incident report |
|-----------------------------|--|

Early treatment

- evaluate need for tetanus, HBV prophylaxis, suturing and implement appropriately
- evaluate seriousness of injury based on Definition of Exposure (above)
- baseline HIV testing
- evaluate appropriateness of antiretroviral therapy for HIV:
 - may be recommended for massive and definite exposure in known HIV/AIDS
 - should be discussed but not routinely prescribed for other exposures
 - is not prescribed for non-parenteral exposure (there is no evidence proving the efficacy of antiretroviral therapy in an occupational exposure)
- if starting antiretroviral therapy, consider either:
 - zidovudine 200mg 5 times daily for 28 days, or
 - if the source individual has received one or more antiretroviral agents, and may be presumed to have a drug resistant virus, combination therapy may be considered using AZT (Retrovir®) 200mg 5 times daily, for 28 days and ddI (Videx™) 200mg bid < 75 kg, for 28 days
 - in all cases where antiretroviral therapy is administered, every effort must be made to initiate therapy within 2 hours of exposure. The injured person should receive follow-up management by his/her physician or appropriate specialist and the institution's occupational health service
- pre and post-test counselling, especially if person declines antiretroviral therapy
- repeat HIV testing at 6 weeks, 3 months, 6 months

Provide counselling for prevention of transmission of HIV (Health and Welfare Canada, 1990) in workplace and in personal life (i.e. use of condoms), and for critical incident stress associated with occupational exposure³

Follow-up

- report exposure to Laboratory Centre for Disease Control, Ottawa
 - monitor response/side effects of antiretroviral therapy
 - maintain schedule of repeat HIV testing
 - provide emotional support
-

HIV AND TUBERCULOSIS

Critical synergistic interaction exists between HIV and TB. In HIV infected persons the source of the TB may be:

- previous exposure and reactivation
- new exposure and infection
- new exposure and active disease

Individuals exposed to TB but not infected with HIV have a 10% lifetime risk of developing TB. Those infected with both HIV and TB have a 10% per annum risk of developing TB. Until proven otherwise, TB should be suspected in all HIV infected persons exhibiting a productive cough. Avoid caring for such persons in communal areas like open emergency rooms and multi-bed ward rooms⁴. Known HIV+ persons must not be exposed to persons with productive coughs.

Usually TB is an "early infection" (500 helper cells). However, Palliative Care programs must be alert when investigating and diagnosing productive coughs, because reactivation or new TB infection/disease could occur at any point on the trajectory of HIV disease⁵. Skin testing with five TU of PPD, and prophylaxis with isoniazid as required, should be completed at diagnosis of HIV⁶.

As HIV takes hold in Canada, higher incidences of TB in groups like aboriginals, immigrants or drug users, will increasingly challenge management of palliative AIDS care. The U.S. reports multiple drug resistant tuberculosis (MDRTB) in persons living with HIV/AIDS and health care providers⁵. This is not yet a major problem in Canada, but only vigilance and aggressive therapeutic management will prevent an ever increasing occurrence of TB or the introduction of MDRTB.

CAREGIVERS AND AIDS PALLIATIVE CARE

TESTING FOR TB:

Caregivers, whether HIV+ or not, should regularly consult their family practitioner and/or occupational health program, to monitor their health, PPD status, and risk of occupational exposure to tuberculosis. PPD screening should be done every six months, and if there is a positive test (induration >10mm) a chest x-ray should be done. Where there is evidence suggesting TB inoculation, prophylactic therapy may be necessary, with a referral to provincial TB services, or a specialist in infectious disease or pulmonary medicine may be necessary. Even if previously exposed to BCG, positive tests should be investigated further and prophylaxis considered. BCG is not currently recommended for persons living with HIV/AIDS or health care providers. Consult local public health agencies or provincial tuberculosis agencies when developing guidelines for your organization.

TESTING FOR HIV:

Widely publicized transmissions of HIV from an American dentist to several individuals⁷ raised concern about mandatory testing of health care personnel, continued employment of HIV+ persons in health care, and performance of exposure prone procedures by HIV+ health care providers. No scientific evidence exists for mandatory testing of health care providers. Ethics and morality demand diligent use of body substance and respiratory precautions. If a health care worker's blood is exposed, reciprocal responsibilities require testing and appropriate therapy as described in guidelines for managing occupational exposure.

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Resources in Canada

SOURCES OF INFORMATION ON AIDS

Modules of "The Comprehensive Guide for the Care of Persons with HIV Disease"

Throughout this document, references have been made to other modules of "A Comprehensive Guide for the Care of Persons with HIV Disease". These modules are available from The National AIDS Clearinghouse of the Canadian Public Health Association (see address below). The available modules include:

- Module 1: Adults - Men Women and Adolescents
- Module 2: Infants, Children, Youth
- Module 3: Nursing
- Module 4: Palliative Care
- Living with Dying, Dying At Home
- Practice Guidelines for Obstetrical & Gynecological Care of Women Living with HIV
- "Safeguarding" Mental Health and HIV Infection: Ending the Isolation

NATIONAL NON-GOVERNMENTAL ORGANIZATIONS

The Canadian AIDS Society (CAS):

100 Sparks Street
Suite 400
Ottawa, Ontario K1P 5B7
(613) 230-3580 (Office/Bureau)
(613) 563-4998 (Fax/Télécopieur)

The Canadian Association of Social Workers

383 Parkdale Avenue
Suite 402
Ottawa, Ontario K1Y 4R4
(613) 729-6668 (Office/Bureau)
(613) 729-9608 (Fax/Télécopieur)

The Canadian Ethnocultural Council

AIDS Committee
251 Laurier Avenue West
Suite 1100
Ottawa, Ontario K1P 5J6
(613) 230-3867 (Office/Bureau)
(613) 230-8501 (Fax/Télécopieur)

Canadian Foundation for AIDS Research (CANFAR)

165 University Avenue
Suite 800
Toronto, Ontario M5H 3B8
(416) 361-6281 (Office/Bureau)
(416) 361-5736 (Fax/Télécopieur)

Canadian Hemophilia Society

National Office
1450 City Councillors Street
8th Floor
Montréal, Québec H3A 2E6
(514) 848-0503 (Office/Bureau)
(514) 848-9661 (Fax/Télécopieur)

Canadian Labour Congress

Workplace Health and Safety
Department of Field Services
2841 Riverside Drive
Ottawa, Ontario K1V 8X7
(613) 521-3400 (Office/Bureau)
(613) 521-4655 (Fax/Télécopieur)

Canadian Medical Association

Department of Public Health and Promotion
1867 Alta Vista Drive
Ottawa, Ontario K1G 3Y6
(613) 731-9331 (Office/Bureau)
(613) 731-9013 (Fax/Télécopieur)

Canadian National Institute for the Blind

1929 Bayview Avenue
Toronto, Ontario M4G 3E8
(416) 486-2500 (Office/Bureau)
(416) 480-7677 (Fax/Télécopieur)

CANAC - Canadian Association of Nurses in AIDS Care

P.O. Box 688, Station B
Ottawa, Ontario K1P 5P8

Canadian Public Health Association

AIDS Education and Awareness Program
National AIDS Clearinghouse
1565 Carling Avenue
Suite 400
Ottawa, Ontario K1Z 8R1
(613) 725-3769 (Office/Bureau)
(613) 725-9826 (Fax/Télécopieur)

College of Family Physicians of Canada

2630 Skymark Avenue
Mississauga, Ontario L4W 5A4
(905) 629-0900 (Office/Bureau)
(905) 629-0893 (Fax/Télécopieur)

Confédération des Syndicats Nationaux

Service de formation
1601, Avenue de Lorimier
Montréal, (Québec) H2K 4M5
(514) 598-2228 (Office/Bureau)
(514) 598-2089 (Fax/Télécopieur)

AIDS HOTLINES

| | |
|---|-----------------------|
| Alberta | 1-800-772-AIDS (2437) |
| British Columbia | 1-800-972-2437 |
| Manitoba | 1-800-782-2437 |
| New Brunswick | 1-800-561-4009 |
| Newfoundland | 1-800-563-1575 |
| Northwest Territories | 1-800-661-0795 |
| Nova Scotia | 1-800-425-2437 |
| Ontario | 1-800-668-2437 |
| (bilingual) | 1-800-267-7432 |
| Québec | 1-800-463-5656 |
| (Québec – for health professionals working in HIV/AIDS) | 1-800-363-4814 |
| Saskatchewan | 1-800-667-6876 |
| Yukon Territory | 1-800-661-0507 |

EMERGENCY DRUG RELEASE PROGRAM

(613) 993-3105

FUNERAL SERVICES

Funeral Service Association of Canada

Suite 201
206 Harwood Avenue South
Ajax, Ontario L1S 2H6
(905) 619-0983 (Office/Bureau)

PALLIATIVE CARE RESOURCES

The Canadian Palliative Care Association

5 Blackburn Avenue
Ottawa, Ontario K1N 8A2
1-800-668-2785 or (613) 230-3343 (Office/Bureau)
(613) 230-4376 (Fax/Télécopieur)

British Columbia Hospice/Palliative Care Association

1060 West 8th Avenue
Vancouver, B.C.
V6H 1C4
(604) 734-1661 (Office/Bureau)

Palliative Care Association of Alberta

Suite # 214 - 9768 - 170 Street
Edmonton, Alberta
T5T 5L4
(403) 352-3337 (Office/Bureau)
(403) 887-2241 (Office/Bureau)
(403) 352-2691 (Fax/Télécopieur)

Saskatchewan Palliative Care Association

332 - 845 Broad Street
Regina, Saskatchewan
S4R 8G9
(306) 359-7484 (Office/Bureau)
(306) 757-8161 (Fax/Télécopieur)

Provincial Association For Manitoba

Manitoba Hospice Foundation
2109 Portage Avenue
Winnipeg, Manitoba
R3J 0L3
(204) 889-8525 (Office/Bureau)
(204) 888-5574 (Fax/Télécopieur)

Ontario Palliative Care Association

57 Simcoe Street South
Suite 2M
Oshawa, Ontario
L1H 7N1
(905) 436-0145 (Office/Bureau)
(905) 436-2969 (Fax/Télécopieur)

The Community Hospice Association of Ontario

40 Wynford Drive
Suite 313
Don Mills, Ontario
M3C 1J5
(416) 510-3880 (Office/Bureau)
(416) 510-3882 (Fax/Télécopieur)

Association Québécoise de soins palliatifs

(Québec Palliative Care Association)
2075, rue de Champlain
Montréal, Québec
H2L 2T1
(514) 527-2194 (Office/Bureau)
(514) 527-1943 (Fax/Télécopieur)

New Brunswick Palliative Care Association

Dr. Everett Chalmers Hospital
Social Work Department
P.O. Box 9000
Fredericton, New Brunswick
E3B 5N5
(506) 452-5321 (Office/Bureau)
(506) 452-5947 (Fax/Télécopieur)

Nova Scotia Hospice/Palliative Care Association

Cape Breton Regional Palliative Care Service
Sydney Community Health Centre
409 King's Road
Sydney, Nova Scotia
B1S 1B4
(902) 562-2322, Ext. 129 (Office/Bureau)
(902) 562-8593 (Fax/Télécopieur)

Prince Edward Island – Island Hospice Association

5 Brighton Road
Charlottetown, Prince Edward Island
C1A 8T6
(902) 368-4498/5632 (Office/Bureau)

Newfoundland and Labrador Palliative Care Association Inc.

P.O. Box 5411, Station "C"
St. John's, Newfoundland
A1C 5W2
(709) 368-0380 (Office/Bureau)
(709) 368-4139 (Fax/Télécopieur)

Appendix A Diversity Checklist

Delivering Palliative Care in the second decade of HIV means caregivers will be challenged by a greater diversity of people with HIV/AIDS - a diversity that has its root in the diversity of each person, relationship, family, socioeconomic class, gender, ethno-cultural and aboriginal community.

The goal of this section is to provide a tool which caregivers can use to ensure that differing characteristics, values and beliefs are understood and respected in the delivery of care. The assessment list that follows is designed to support caregivers in assessing the possible impacts of cultural differences and to help them to identify their own personal values and the values of the person with whom they are working. The assessment list was prepared based on data compiled from key informant interviews with representatives of HIV affected communities in Canada.

For a comprehensive understanding of the issues that may be impacting specific individuals, the assessment list should be used in conjunction with the information discussed in *Psycho-Social Issues*.

| COMMUNICATION (Verbal, Non-Verbal and Written) | | ✓ |
|--|--|---|
| Is language a barrier to the person accessing and receiving appropriate care? | | |
| Is literacy a barrier to the person understanding his/her care options? | | |
| Is the communication style used (e.g. question-and-answer) appropriate to this person ? | | |
| Is the person able to articulate his/her needs? If not, do they have a committed advocate? | | |
| What are the non-verbal cues - either positive or negative (e.g. crossed arms, greater physical distance) - that are being used by the person, family, friends or caregivers? | | |
| DIVERSITY OF FAMILY | | |
| Have you identified the family of origin, family of acquisition and family of choice, and their unique relationships? | | |
| Are these relationships and their dynamics being acknowledged and valued by caregivers? | | |
| Are you clear who the person wants to have authority for decision making around his/her care? Is this choice respected by family and friends? | | |
| Is there a "conspiracy of silence" (e.g. around diagnosis, disclosure) among the family and friends? | | |
| Some communities do not support non-traditional family structures. Is this an issue? | | |
| ISOLATION, REJECTION, STIGMATIZATION, BIAS, PREJUDICE | | |
| Has the person chosen to disclose his/her sero-status? To whom? | | |
| As a result of disclosure of sero-status, is the person experiencing rejection or isolation due to others' beliefs/values about life choices (e.g. drug use, street-involved, sex trade) whether those choices are real or imagined? | | |
| Is disclosure of sexual identity/sexual orientation resulting in isolation or stigmatization? | | |
| A person's hierarchy of needs can be impacted by drug use. This may not be acceptable to family and caregivers. Is this a consideration in this situation? | | |

| | |
|--|--|
| Is progressive disability as a result of HIV/AIDS resulting in other stigmatizing losses, such as inability to contribute at home or in community, etc.? | |
| Society values health and ability. Is the person experiencing isolation, stigmatization or loss as a result of declining health? | |
| Is HIV/AIDS impacting the person's body image? Is this affecting his/her self-esteem? | |
| Is the person being stigmatized or isolated by the health care system? | |
| Is the person experiencing stigmatization as a result of a lack of confidentiality? | |
| Is the person comfortable accessing available health care services? | |
| Is the person comfortable accessing services through existing ASOs? | |
| CULTURALLY APPROPRIATE CARE | |
| Does the person's sero-status result in isolation from the rest of his/her cultural community? | |
| Are the person's cultural and spiritual traditions being respected and supported by those providing care? | |
| Are the unique care and medical cultures of the person's community recognized by those providing care? | |
| INDEPENDENCE AND AUTONOMY VS. DEPENDENCE | |
| In the face of increasing dependence, is autonomy being supported as fully as possible? | |
| Is a diminished ability to control home life resulting in diminished safety or self-esteem, anger, frustration or a sense of loss? | |
| Are work and the ability to contribute closely tied to the person's self-esteem/self-worth? | |
| DEATH AND DYING, RELIGION AND SPIRITUAL ISSUES | |
| Is the person's religious tradition supportive of those living with HIV/AIDS and the person's chosen lifestyle? | |
| Does his/her religious tradition see suffering as related to blame, penance or retribution? Is this impacting the person's self-image? | |
| If the setting of care has a religious affiliation, is this supportive of the person's chosen lifestyle and non-judgemental of his/her sero-status? | |
| As death approaches are family and friends being supported in taking whatever care role feels comfortable to them? | |
| Are the family or friends being affected by multiple losses or chronic grief? | |
| After death, will the family and friends be able to be open about their loss, and supported in dealing with their grief? | |
| WOMEN'S ISSUES | |
| Are caregivers sensitive to the unique needs of women living with HIV/AIDS? | |
| Is the situation being impacted by the limitations a woman's culture places on her? | |
| Is the woman's financial situation or role in her family compromising her access to services? | |
| Is the woman experiencing others' prejudices about HIV+ women and promiscuity? | |
| If the woman is a lesbian, is she being judged based on assumptions about her having had sex with men or being a substance user? | |

| | |
|--|--|
| If an HIV+ woman is pregnant, is she facing judgment, blame or stigmatization? | |
| Women often perceive their partner, children, family and friends as extensions of themselves. Are these individuals accommodated and encouraged to be present in the care setting? | |
| PARENTING, REPRODUCTIVE ISSUES AND GUARDIANSHIP | |
| Is the person being affected by losses relating to reproductive choice and parenting ? | |
| Is the person concerned about loss of custody or contact with his/her children? | |
| Have care arrangements for children been adequately addressed? | |
| For those who are homosexual or bisexual, are their requests regarding guardianship of their children going to be respected after their death? | |
| Do cultural values prevent or impede disclosure of HIV status to infected children or adolescents? | |
| ISSUES FOR THE SOCIO-ECONOMICALLY DISADVANTAGED | |
| If the basic necessities of life are not met, it is almost impossible to introduce HIV prevention, health promotion, and early HIV treatment and care. | |
| Are financial or community resources such that comprehensive care and optimal symptom control is possible? | |
| Is socio-economic status impacting access to care, the quality of care received or the person's relationship with caregivers? | |
| Does the person have access to adequate housing that meets his/her needs? | |
| Does the person have access to adequate nutrition? | |
| Does the person have access to necessary medications? | |
| Does the person have access to appropriate treatment? | |
| Does the person have a support system that is willing and able to assist them when they are no longer able to care for themselves? | |
| Are there other problems compounding care and living issues such as mental illness? | |
| ISSUES FOR PEOPLE WITH DISABILITIES | |
| All of the issues identified above apply equally to those with disabilities. However, the following additional issues should be considered: | |
| Does a pre-existing disability limit access to services? | |
| Has the person been sexually exploited as a result of his/her disability? Is this still occurring? | |
| ISSUES FOR INMATES AND THOSE PREVIOUSLY INCARCERATED | |
| This is a significant and rapidly growing section of the population living with HIV/AIDS. Many of the issues above apply to this population. In addition, consider the following: | |
| Are there adequate care, treatment and support resources for the inmate or previously incarcerated person? | |
| If the disease was contracted in prison, is the person facing further isolation and judgement from family, partner or friends during visitation or after release/parole? | |
| Can compassionate release be arranged if the person has advanced HIV disease? | |