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Readers are cautioned that therapies and clinical recommendations in the field of HIV are constantly evolving. This publication is provided for reference only. It does not replace the discretion and judgement of the individual caregiver in the care of people living with HIV.

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MODULE

7

# Rehabilitation Services

## *A Comprehensive Guide for the Care of Persons with HIV Disease*



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# Preface

*Module 7: Rehabilitation Services* was developed to respond to an emerging need: the rapidly growing role for rehabilitation professionals in HIV care. Although people living with HIV have always needed rehabilitation services, the proportion of rehabilitation providers with HIV patients has grown from a few per cent a decade ago to nearly 25% today.<sup>1</sup>

*Module 7* is the product of an extensive consultation among people living with HIV and a wide cross-section of rehabilitation and health care providers. This process has enabled the authors to bring together in one module conventional rehabilitation interventions and patient-centred care approaches.

*Module 7* is targeted primarily at rehabilitation professionals. Secondary target audiences include other HIV caregivers and people living with HIV and their communities.

## The Contents of This Module

*Module 7* is divided into two main sections.

### **Section I**

Section I describes the context within which people living with HIV access rehabilitation services. Chapter 1 provides a very basic introduction to HIV disease. Chapter 2 describes the social dimensions of HIV from the perspective of people living with HIV. This chapter was written by people living with HIV.

Chapter 3 briefly describes the role of complementary therapies in the care of people living with HIV. Issues specific to the dual diagnosis of HIV and chemical dependency are described in Chapter 4.

Chapter 5 provides a general description of rehabilitation. This chapter is directed primarily at the secondary target audiences for this module: HIV caregivers and people living with HIV.

### **Section II**

Section II describes the rehabilitation services themselves in detail. Chapter 6 provides a comprehensive listing of rehabilitation interventions for adults for each of seven major impairment areas. Rehabilitation interventions specific to children and infants are outlined in Chapter 7. Rehabilitation professionals providing services to children and infants living with HIV should consult both Chapters 6 and 7.

The rehabilitation interventions appropriate for adolescents and youth are similar to those outlined for adults in Chapter 6. However, some overlap with the interventions shown for children and infants in Chapter 7 may occur.

The areas of preventive and vocational rehabilitation receive special attention in this module; each has been accorded a separate chapter. Chapter 8 deals primarily with emerging issues around return-to-work decisions for people living with

HIV. Chapter 9 discusses the importance of preventive rehabilitation for people living with HIV and provides some basic information on two major components of preventive rehabilitation: exercise and nutrition.

Basic information on occupational exposure to HIV has been included in the appendix.

A list of resources has been provided at the back of the module. The list includes national professional and consumer organizations involved in HIV or rehabilitation, and some relevant printed materials.

References and suggested readings have been included at the end of each chapter.

## The Term “Rehabilitation”

The authors recognize that for many consumers of rehabilitation services, including many people living with HIV, the term “rehabilitation” is not popular. Because of the way in which the term is sometimes used, it can suggest interventions that are invasive and coercive in nature. This module is not about these types of interventions. On the contrary, it is about a wide range of services which people living with HIV can choose to access to rehabilitate themselves when they experience an impairment or disability caused by their illness. “Rehabilitation,” used in this context, is an ingrained term among providers of these services, the primary target audience for this module. Consequently, the authors decided that it would be not appropriate to try to substitute another term.

## The Clinical Resource Series: *A Comprehensive Guide for the Care of Persons with HIV Disease*

*Module 7* is part of a series of easy-to-use clinical resources funded by Health Canada under the National AIDS Strategy. These resources describe best practices, standards of care, and models of care.

This series, which has received international recognition, is being used for education in the United States, the United Kingdom, Western Europe, Mexico, South East Asia, and South Asia. Please see the accompanying table for a list of the modules in the series.

## Modules in the Series

### *A Comprehensive Guide for the Care of Persons with HIV Disease*

Module	Name	Host Organization	Primary Target Audience
Module 1, 2nd Edition	Adults — Men, Women, Adolescents	College of Family Physicians of Canada	primary care physicians, nurse practitioners, other primary care professionals
Module 2	Infants, Children & Youth	College of Family Physicians of Canada	primary care physicians, nurse practitioners, other primary care professionals
Module 3	Nursing Care	Canadian Association of Nurses in AIDS Care	the nursing profession
Module 4	Palliative Care	Mount Sinai Hospital and Casey House Hospice	interdisciplinary palliative care teams
Module 5	Managing Your Health	Community AIDS Treatment Information Exchange and Toronto People With AIDS Foundation	people living with HIV, members of HIV-affected families and communities
Module 6	Psychosocial Care	Canadian Association of Social Workers	professionals who provide psychosocial care
Module 7	Rehabilitation Services	The Wellesley Central Hospital	rehabilitation professionals
Supplement	HIV and Psychiatry: A Training and Resource Manual	Canadian Psychiatric Association	psychiatrists and other mental health workers

**To order copies** — Copies of Modules 1 through 7 and the supplement are available in English and French through the National AIDS Clearinghouse. In Canada, single copies are available at no charge. Orders can be sent to:

The National AIDS Clearinghouse  
 The Canadian Public Health Association  
 400-1565 Carling Avenue  
 Ottawa, ON  
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 Internet: <http://www.cpha.ca/CPHA/ch/ch.html>

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*The Context* **Section I**





# Introduction to HIV Disease

This chapter provides a basic introduction to the continuum of HIV disease. It covers the following topics:

- epidemiology
- pathogenesis
- treatment

## Introduction

Until recently, HIV was viewed as a disease which progressed from infection through AIDS to death. HIV disease is now considered chronic and cyclical, with periods of wellness and illness which provide multiple opportunities for disease prevention and rehabilitation interventions.

HIV transmission may occur through:

- unprotected anal or vaginal intercourse (and, rarely, oral sex)
- the sharing of HIV-contaminated needles and paraphernalia (e.g., during drug use)
- vertical transmission from mother to child *in utero*, during delivery and during breast feeding
- the transfusion of infected blood or blood products
- an occupational exposure (e.g., needlestick)

Transmission through an occupational exposure is rare. See the Appendix for some general information on the risk of exposure and for guidelines on preventing exposure.

Advances in knowledge and expertise, combined with the advent and use of potent antiretroviral drug combinations and better surrogate markers, have dramatically altered the course of HIV infection. Some people living with HIV have experienced marked clinical improvement and increased longevity. The focus on quality of life has become greater than ever. Unfortunately, we do not know how long this success will be maintained. We do know that new antiretroviral regimens fail early or within a relatively short period of time in some patients.

Rehabilitation professionals are already familiar with treating many of the common conditions seen in HIV disease (e.g., pain, fatigue, weight loss, weakness, breathing problems, cognitive problems, peripheral neuropathies, other central nervous system conditions). The approach of rehabilitation professionals to patient-centred care is compatible with the needs of people living with HIV.

## Epidemiology

The United Nations estimates that there were 29.2 million cumulative worldwide cases of HIV at the end of 1996 and that 8,500 people are being infected each day.<sup>1</sup> In Canada, about 50,000-54,000 cases have been reported for the same period.

On average, people live 10 years or more before developing one of the conditions that results in an AIDS diagnosis. Therefore, AIDS represents only the very end stages of the disease spectrum.

In 1996, in Canada, 50% of new infections were due to sexual activity, and 50% were due to injection drug use. Sexual activity between men accounted for 75% of sexually-transmitted infections. Important new trends in the shifting epidemiology reveal that women, injection drug users, and youth (especially gay youth) are at particular risk. As well, Aboriginal peoples and prison inmates are showing an increase in HIV infection.

### Transmission

*HIV is not transmitted casually. It cannot be transmitted through activities involving touching, as might occur in a health care or rehabilitation setting.*



**Viral load:** A surrogate marker which measures the amount of virus in plasma. It reflects the amount of replicating virus and is used to predict the rate of progression of HIV disease. It is also used to initiate, monitor, and change antiretroviral therapy. The goal of therapy is to reduce viral load as low as possible for as long as possible.

## Pathogenesis of HIV Infection

Once the virus has entered the bloodstream, it attaches to cells bearing a CD4 receptor, especially lymphocytes and monocytes, and replicates in them. Due to initially unchecked viral replication in the plasma, viral load rises to high levels. Then the virus disseminates into lymphoid tissue and other sites throughout the body. Between 50% and 90% of people experience an acute, short-lived viral-like illness resembling mononucleosis (with symptoms such as fever, fatigue, myalgia, headache, and rash) within two to four weeks of exposure to HIV. Many of these symptoms go unrecognized. Plasma viral load is often very high at this time. After this “seroconversion illness,” the viral load drops to a certain level or “set point” which differs for each individual.

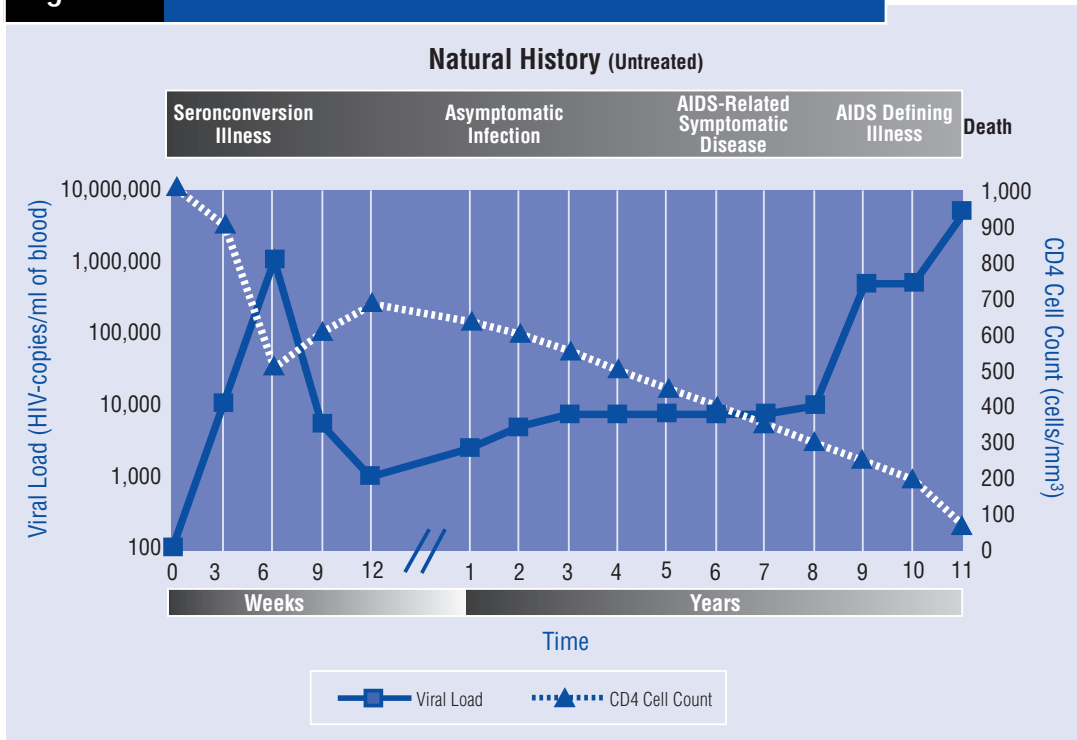
Initially, the immune system appears to contain the effects of the virus, but the relentless production of 10 billion new viral particles per day eventually overwhelms the body and clinical manifestations occur. The virus destroys CD4 cells and progressively weakens the immune system. The CD4 lymphocyte count reflects the extent of immune depletion. Certain clinical symptoms and conditions can be anticipated to occur at a low CD4 count.

An increase in CD4 count may occur after an individual starts effective antiretroviral therapy, but this does not always imply restoration of immune function.

### CD4 Count

Cells with CD4 receptors on their surface are the primary targets destroyed by HIV. CD4 receptor-bearing lymphocytes are measured and used to clinically stage the disease. The loss of CD4 lymphocytes and the rate of loss are associated with the development of characteristic opportunistic infections and malignancies resulting in the clinical manifestations of HIV. Most opportunistic infections occur at a CD4 lymphocyte count of less than 200/mm<sup>3</sup>.

**Figure 1** Clinical Course of HIV Infection and Disease



Adapted from: *AIDS Update 1997 — An Annual Overview of Acquired Immune Deficiency Syndrome*, Gerald J. Stine, PhD. Prentice Hall.

## Treatment

Effective HIV care and treatment should address the needs of the individual. In addition, care and treatment should also address the needs of the individual's family, friends, and community. Delivery of comprehensive HIV care necessitates that the individual be the focus of the care which may be provided by a wide range of professional and non-professional care providers.

There is no cure for HIV. Although dramatic clinical results have been obtained through the use of new potent antiretroviral drug combinations (popularly known as “cocktails”), these drugs are not effective in all persons. In addition, the durability of the favourable responses is not yet known. Much more needs to be known about development of resistance to individual drugs and cross-resistance among the antiretroviral agents to ensure their optimal use. The antiretroviral agents can be very toxic. Individuals may experience a wide range of drug interactions and therefore must be very closely monitored. They also require complex dosing schedules; adhering to these schedules can be challenging.

## Major Classes of Antiretroviral Drugs

To prevent further infection and immune depletion, several classes of antiretroviral drugs are used, each designed to perform different functions in HIV-infected cells. According to the best knowledge available at this time, the combination of three or more antiretroviral agents provides the most effective long-term results, including substantial viral suppression. Resistance develops rapidly in replicating viral particles and may limit the clinical success of the antiretroviral regimen. Because antiretrovirals can be toxic and cause harmful interactions, careful monitoring is essential. More research is required to understand both the resistance to individual drugs and the cross-resistance among antiretroviral agents.

There are three major classes of antiretroviral drugs:

- **Reverse Transcriptase Inhibitors (RTI)** — These drugs (also known as nucleoside analogues) inhibit replication of the virus at the level of the reverse transcriptase enzyme. Examples include: AZT, ddI, ddC, 3TC, and d4T.
- **Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTI)** — This class of drugs works on the reverse transcriptase enzyme to inhibit viral replication through a mechanism distinct from the RTI drugs. Examples include: nevirapine, delavirdine and efavirenz.
- **Protease Inhibitors (PI)** — These drugs interfere with the assembly of viral particles. Examples include: saquinavir, indinavir, ritonavir, and nelfinavir.

## Other Therapies

The prophylaxis and treatment of opportunistic complications is another major component in the medical care of people living with HIV. The improved morbidity and mortality statistics which were seen before the introduction of regimens containing protease inhibitors may be attributable to opportunistic infection prophylaxis and treatment efforts.

### Prophylaxis

Examples of prophylaxis in HIV disease include:

- medication to prevent *Pneumocystis carinii* pneumonia (PCP)
- medication to prevent *Mycobacterium avium* complex (MAC)
- appropriate nutrition
- exercise

## Summary

HIV disease and the care of those living with HIV have changed dramatically in the past 15 years. People living with HIV may present with multiple medical, social, and psychosocial problems concomitantly. The successes with prophylaxis and treatment and, recently, potent antiretrovirals have helped to highlight the need for multiple rehabilitation interventions during the fluctuating course of the disease. All individuals across the continuum of HIV are entitled to and must receive accessible, compassionate, and responsive health care. Services such as primary care, ambulatory care, in-patient care, and home care are best provided by an interdisciplinary team which recognizes that the patient is the central focus of the team and that the team also encompasses the patient's family, friends and community. The services should be planned, provided, and evaluated in partnership with consumers and advocates, community-based agencies, and other health care providers.

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# Interacting with Communities Affected by HIV



This chapter explores the social dimensions of HIV disease from the perspective of people living with HIV. It covers the following topics:

- resources available in the communities
- how communities have been affected
- the role of identity in HIV care
- how identity affects the patient-provider relationship
- characteristics of ethnicity and culture
- “hard-to-serve” or “hard-to-reach” populations



## Authorship

*This chapter was written by people living with HIV.*

## Introduction

Five years ago, HIV disease in Canada was widely considered to be a disease of gay men and people from countries where the virus was endemic. While thousands of people from these communities continue to live with HIV disease, the face of the epidemic is changing. Increasingly, new infections are occurring among people at society's margins, particularly injection drug users, the poor, and Aboriginals.

To those at the margins, becoming HIV positive is a disastrous complication in a difficult life. Many are already viewed by society at large with a mixture of trepidation, indifference, and disdain. Fear of disclosing their illness isolates them even from their own families and friends. As well, government support programs face service cuts; some of these programs specifically disqualify people whose disability arises from drug or alcohol use.

Recent advances in treatment have brought hope and respite to some people living with HIV. In practice, these treatments are not acceptable to everyone (because of their side-effects), not effective for everyone, and financially inaccessible to many. No one knows how long the benefits will last or whether damaged immune systems can be restored. Mounting evidence suggests that a cure for the disease remains a distant and elusive goal.

Despite set-backs, a climate of renewed hope has developed among those for whom the new drug treatments have been successful. Some people living with HIV are making long-term plans again, considering returning to work, and even viewing the uncertainty surrounding treatment with optimism. Today, care providers will encounter a broader spectrum of patient attitudes towards the disease and to the future than at any time in the past.

All evidence indicates that the bulk of the epidemic is ahead of us. In the affected communities, few people have escaped chronic emotional trauma and loss. Almost everyone has been touched by HIV through his or her own infection, the illness of friends or family members, or the death of partners in the prime of their lives. Some people living with HIV become remarkable survivors, coping with illness, and actively participating in their own care. They grow personally from the experience. Many make extraordinary contributions to their communities. Others do not, and are physically and psychologically devastated; of these, some can move forward with supportive intervention.

## Turning to Community Resources

In the midst of devastation and despair, remarkable responses have arisen from within some of the affected communities. A network of grassroots organizations has evolved to provide education, support and services defined specifically by the people using them. In many ways, AIDS service organizations are the model for successful HIV care. They have tackled the daunting and complex problems of changing sexual practice, managing profound grief, and enduring apparently unending trauma and loss. They have demanded and often obtained



**P**aul is a 32-year-old gay man who tested HIV-positive eight years ago. His CD4 count dropped to 50. Triple combination therapy greatly reduced his viral load but did not alter his CD4 count. Paul is devastated when he suddenly develops a systemic *Mycobacterium avium* complex (MAC) infection and is hospitalized for three weeks. He becomes deeply depressed by this unexpected failure of his recovery. He is referred by his HIV specialist to a nutrition team to help him regain some of the 35 pounds he lost as a result of the MAC infection.

fundamental changes in services to their communities, struggling to overcome sexism, racism and homophobia, as well as resistance to sex education, needle exchange, and prison services.

However, there are limits to what these organizations have been able to accomplish. Services remain scarce outside the major urban areas. As well, some groups at risk for HIV infection are less able to organize community-based responses to the epidemic.

Within all groups, knowledge and understanding of HIV disease varies widely. Some people possess an extraordinary medical knowledge, keeping up with the latest developments through the Internet and scientific journals. Some bring an innate understanding of the principles of holistic care to community programs, and some have drawn an array of complementary therapies into the fight against the disease. On the other hand, many affected people lack even elementary information about their infection and find explanations of HIV disease baffling. Developing a plan of care for such individuals requires a careful explanation of options, and recommendations about choices which otherwise would be overwhelming.

Rehabilitation professionals will recognize many “rehab-like” services delivered very successfully within existing community programs. While these services may differ in detail from more structured professional services, their success arises from their “fit” with the people served through self-help, self-care and peer-driven models. Many of these services reflect “people living with HIV helping people living with HIV”. The affected communities are often the first to recognize trends and changes in risk behaviour and needs among their members. **New interventions should add to, not seek to replace, existing programs.**

Although rehabilitation providers already possess many skills that can be used to treat people living with HIV, they will likely find the context of HIV disease unlike anything else in their experience. Knowledge and clinical approaches to HIV disease are changing constantly in a climate of intense uncertainty. Advice and interventions which seem prudent and accurate today may seem ill-advised or ineffective in a few months. Adaptability has been key to survival for people living with HIV, and will be key for providers.

## Affected Communities

HIV continues to spread within a wide range of communities and groups, including:

- gay men
- women
- bisexuals
- other men who have sex with men
- transgendered people
- people in the sex trade
- injection drug users
- sex partners of people at risk
- Aboriginal people
- people of colour
- street people
- blood product consumers
- prisoners
- young people
- people moving to Canada from countries with high HIV prevalence



**K**nown on the prostitution “stroll” as “Tess,” this transgendered youth struggles to raise enough money for surgical sex reassignment. Only recently diagnosed HIV-positive, Tess usually lives in a flop house, but meets the rehabilitation team through the recovery residence where she is now staying. Although she has previously worked as a hairdresser’s assistant, she can read and write only at a low level, which places most jobs out of reach. She over-uses female hormones, and snorts cocaine.

**DEFINITION** **Transgendered:** People who identify with a gender other than their biologic sex.

**DEFINITION** **Transvestite:** A person of any sexual orientation who dresses and effects the appearance of the opposite biologic sex.



## Chosen Family

*Many people develop close ties with people from their own communities who serve as a “chosen family.” In many cases, this choice represents a profound estrangement from the biological family, often because of rejection due to lifestyle or HIV status. Providers should attempt to determine which family plays a more central role in the patient’s life.*

Many of these communities and groups are already culturally or economically marginalized. Most importantly, their underlying health as a group tends to be worse, even before HIV infection, which adversely affects their prognosis. Many members of these communities and groups are reluctant to seek health care and do so only in emergencies. Others lack lasting relationships with providers and tend not to follow through with prescribed treatments. These factors combine to affect their:

- vulnerability to infection
- ability to cope with major illness
- ability to trust and to seek care
- ability to access, choose, and pursue effective HIV treatment
- prospects for survival, even with treatment

HIV disease is likely to worsen and solidify poverty, intensify discrimination and isolation, and make it harder to reach and use care services. Caregivers need to be careful not to make assumptions about prognosis, motivation and adherence to treatment based on a person’s economic or social status. Cultural and personal values will influence each person’s reaction to becoming HIV-positive. While some may fear rejection, others will be concerned about unauthorized disclosure of their serostatus or discussion of their sexual identity.

## The Role of Identity in HIV Care

We all seek to describe ourselves. We search for a bond with others, to assert an affinity with people with whom we feel a sameness — i.e., a commonality of origin, preference, or experience. In the process of developing identity, we manage isolation and build relationships. Individuals sharing identity become communities, and from each community, culture emerges as the sum of its shared values and practices.

From the outside looking in, others also seek to describe us, to classify us as a way of deciding how to interact, what “language” to speak, and what experiences to share and reveal. In this process, people ask, “In what ways are you like me?” This process of “labelling” is fraught with pitfalls, because the judgements and generalizations involved are imprecise; at their worst, they are the mechanism of bigotry.

The expression of identity is immensely complex, for each person is many things at once (e.g., someone who is Canadian, HIV-positive, woman, mother, wife, breadwinner and care provider). Throughout life, individual components of identity dominate at different times, depending on circumstances and events. Many people living with HIV report that HIV dominates their identity at times, superseding other dimensions, while at other times it recedes. At one time, a person may say he is “a person with AIDS,” while another time “a gay man,” each being true.

Furthermore, identity evolves. People change as life unfolds.



**M**artin is a 49-year-old car salesman with stable HIV disease and anal carcinoma. He works out and lifts weights at the gym five times a week. He eats well, drinks only bottled water, and complements his diet with multiple supplements. He gets a Vitamin B12 shot monthly and is taking androgenic steroid injections which he gets from a buddy at the gym.

HIV care and experience have taught us that even messages about behaviour may not be heard unless they are targeted to a specific community and take into account the particular characteristics of that community. For example, some communities have a long tradition of silence about anonymous sex between married men, reinforced by rigid institutionalized homophobia. Because many of these men adamantly deny being homosexual or bisexual, HIV prevention messages aimed at gay- or bisexual-identified men have been ineffective. This failure has had disastrous consequences, routinely placing the wives and partners of these men at risk, and making it hard for these men to even consider accessing care.



**J**ulie is a 31-year-old accountant and single mother who learned she was HIV-infected when Sarah, her 18-month-old daughter, developed *Pneumocystis carinii* pneumonia. Julie has stopped working to care for her child.

## Identity and the Patient-Provider Relationship

Patients and providers bring their own identities, cultures, and experiences to every interaction. This influences what options are proposed and what choices are made.

Even when recognizing that each person is unique in his or her blend of identities, there is a temptation to generalize (i.e., to stereotype). If people assume that they “know” what injection drug users or transgendered women are like or what they will need, they deny the high variability which occurs within identity groups. While a person may identify with a community, he or she will be distinct and different from every member of that group.

A successful provider-patient relationship is defined by certain principles:

- Identity matters. It is the lens through which we interact. Although we cannot enter another person’s identity, we can be aware of our own identity and be conscious of how that influences our interaction with others.
- People providing care will inevitably be different from those for whom they care. They will be closer at times, less related at other times.
- Both patient and provider have complex identities. For each, identity evolves and individual components of identity dominate at various times.
- All judgements and evaluations are made through the lens of identity, are influenced by community and culture, and are a potential source of error and miscommunication.
- Judgement is two-way — patients and providers are equally likely to misunderstand each other.

The skilled provider possesses personal insight, broad intercultural education, and experience gained through interaction with a range of communities. Central to these skills is a personal commitment to acceptance and respect of difference, traits which help define patient-centred care.

## Ethnicity and Culture

Ethnicity and culture often include components of visibility, language, religion, and spirituality, each of which encompasses values and beliefs on a wide range of issues.

These values and beliefs may address:

- work
- disability
- disease
- death and dying
- manner of accessing care
- medical tradition
- family
- reproduction
- parenting
- sexuality
- disclosure of illness
- substance use

When people experience cultural rejection or disapproval of an important component of identity, they will be less likely to reveal this aspect of themselves. This can be a powerful barrier to accessing care and developing frank and trusting relationships with care providers.

In addition, providers should consider the influence of life experiences, such as living on the street, substance use, and incarceration. These intense experiences may dominate some people's identities.

### "Hard to Serve" or "Hard to Reach" — For Whom?

Providers have labelled certain communities as "hard to reach" or "hard to serve," yet the affected communities often ask, "Why are we hard to reach and for whom?"

These communities represent a special challenge to highly structured medical programs, including rehabilitation clinics. For people who lack food or a safe place to live, or whose day is driven by the demands of drug addiction, arriving on time for a 15-minute appointment in a busy provider's clinic schedule can be a low priority. To be successful, these programs must be flexible, adaptable, and accessible.

In deciding that a population is "hard to reach," providers should consider whether this designation is not in fact primarily an expression of cultural difference. "Hard to reach" sometimes means **inaccessible in the form provided**.



**A** physiotherapist makes her first home visit to a man in the city's Little Portugal neighbourhood. She is met at the door by the man's wife, who says, "You're from the cancer clinic?" The woman ushers the therapist to their bedroom, and then leaves. The man, gaunt and sallow, sits in a chair wrapped in a blanket. The therapist says, "I'm Sally, from AIDS-Care." He stops her, saying, "You are never to say that word in this house again."

To enhance access, the following actions should be considered:

- take the initiative to reach the affected community
- involve communities in assessing their own needs
- do not make assumptions about the ability of the community to participate in or benefit from rehabilitation services
- provide services where the community lives
- hire members of the affected communities as providers
- integrate HIV services into primary care programs
- deliver rehabilitation services within the continuum of HIV care
- encourage the development of personal support systems
- explain clearly what services can and cannot be provided

Nevertheless, some people are in fact hard to serve because of underlying complications in their lives. Severe mental illness, particularly when coupled with homelessness or addiction, makes it difficult for patients to address HIV. This highlights the need for comprehensive care programs that treat people holistically, not disease by disease. For some patients, the relationship with a rehabilitation provider must be seen as a long-term process, one that might start with just accessibility and acceptance and without particular clinical goals. If possible, this relationship may evolve to a point where comprehensive care of multiple issues can begin.



**B**arry meets with the rehabilitation team while in hospital for *Pneumocystis carinii* pneumonia (PCP) and chronic hepatitis. His doctors have told him he has advanced HIV disease, which is complicated by his intravenous drug use of heroin and cocaine. He used to work as a prostitute and stole small items to support his drug use; he has no employable skills. He has been living in a flop hotel without cooking or laundry facilities. His only friends are those he meets at the smoking lounge of the local AIDS service organization.



## Complementary Therapies

This chapter addresses the use of complementary therapies by people living with HIV and briefly describes some of the more common therapies.

## Terminology

The terms “complementary therapies” and “alternative therapies” are both used to describe a group of therapies which are outside of conventional Western medicine.

“Complementary therapies” is sometimes employed to denote that these therapies are used to complement conventional Western therapies. “Alternative therapies” is sometimes employed to indicate that these therapies are used instead of conventional Western therapies.

This chapter uses the term “complementary therapies” in a generic fashion to encompass all therapies that are outside of conventional Western medicine, however they are used.

## Introduction

The use of complementary therapies by people living with HIV is commonplace. Unfortunately, some health care providers are unaware of the potential value of these therapies in a treatment repertoire, or they tend to diminish the value. Rehabilitation providers need to educate themselves on the wide range of complementary therapies; they also need to promote open and non-judgemental dialogue with individuals who choose to incorporate these therapies in their care.

Edward King, the editor of *HIV/AIDS Treatments Directory*, has described how complementary medicine differs from conventional medicine:

“The chief difference between conventional and alternative forms of medicine is the notion of ‘energy’ or ‘life-force’, a concept that is alien to Western Medicine because it is unmeasurable. Scientific methods cannot [find] the meridians of qi in Chinese medicine, the auras detectable by healers or the active agent in a highly diluted homeopathic remedy, but larger numbers of practitioners and patients are untroubled by this problem and continue to use these therapies successfully.

“All these forms of energy are taken for granted in alternative forms of medicine, and it has been argued that Western scientific methods are only just beginning to [come to grips] with these concepts as the fields of quantum physics, chaos and complexity theory begin to develop new ways of thinking about energy and matter.”<sup>1</sup>

Complementary therapies include nutritional supplements, herbal remedies, hands-on and body therapies, and mind-body interaction.

## Use of Complementary Therapies by People Living with HIV

Most people living with HIV who use complementary therapies do so to supplement their medical care and treatment. Some people living with HIV use complementary therapies as an alternative to antiviral and other medications. Although complementary therapies often have had a long history of use in various cultures — Chinese herbal medicines and Aboriginal sweat lodges, for example — people living with HIV have recently been at the forefront in promoting their use. The lack of a cure or vaccine for HIV infection is a contributing factor to the widespread use of complementary therapies by people living with HIV.

For some people, complementary therapies are part of a philosophy of living. For others, they are used to improve quality of life by:

- increasing energy or decreasing fatigue
- strengthening the spirit
- relieving chronic pain
- relieving specific symptoms such as nausea
- helping people recover from the complications of drug toxicity
- relieving stress and allowing people to cope with the difficulties of everyday living

Many AIDS service organizations offer financial assistance to purchase complementary therapies. Some of these organizations provide information on specific complementary therapies.

It is useful for physicians and other health care providers to know what complementary therapies their patients are taking.

## Specific Complementary Therapies

Examples of the more commonly used complementary therapies are shown below.

### Acupuncture

Acupuncture is an ancient Chinese treatment involving the insertion of very thin sterile needles into the body at specific points according to the meridian charts (pathways of energy). Many people use acupuncture to control painful conditions such as headaches, arthritis, low back pain, and allergies, as well as withdrawal symptoms experienced when stopping drugs or cigarettes. Although often practised on its own, acupuncture is more authentically used as part of an overall program of traditional Chinese medicine (see below).<sup>2</sup>

### 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. For example, certain odours can relax, stimulate, or help alleviate depression. They are generally applied as part of a massage therapy session, used in the bath, or taken by inhalation.<sup>2</sup>

### Chiropractic

Chiropractic is a method of care in which the spine, pelvis, and other articulating joints are manipulated to restore mobility, ease pain, and stimulate the body's own balancing of function. In addition to manipulation, practitioners may use massage, stretching techniques, and electrotherapy to facilitate the treatment.<sup>2</sup>

### Dietary and Other Supplements

Supplements are used for a variety of specific purposes. For example, acidophilus and bifidus are bacteria that are used to aid digestion. N-acetyl cysteine (NAC) is an amino acid that raises the level of glutathione in the cells of the body in an attempt to boost energy and strengthen the immune system. Liquid food supplements are used to supplement one's diet or to replace meals when it becomes difficult to eat.<sup>3</sup>



### A Word of Caution

*For the most part, complementary therapies currently are not evaluated using the same methodologies as conventional Western therapies. Before trying a new therapy, individuals should look for relevant articles, talk to their friends, and consult treatment information programs available through some AIDS service organizations.*

## Homeopathy

Homeopathy is an approach to health based on the principles developed by Dr. Samuel Hahnemann in Germany in the 1790s. These principles state that 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.<sup>2</sup>

## 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 powders. Massage can often 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, provide a relaxed sense of well-being.<sup>2</sup>

## Mind-Body Interaction

These are therapies that are designed to harness the power of the mind to promote and aid healing. Examples include: yoga, meditation, relaxation techniques, Tai Chi, affirmations and visualizations.<sup>4</sup>

## Native Traditional Medicine

This form of medicine addresses the spiritual origins of disease and health, and is based on the belief that healing arises out of the patient's relationship to society and the cosmos.<sup>5</sup> Sacred ceremonies, some of which rely on visions and symbolism, are important parts of Native healing.<sup>6</sup>

## Naturopathy

Naturopaths see disease as an attempt by one's body to get rid of toxins and to restore balance. They use products and procedures to boost the natural healing powers of the body. The patient is expected to play an active role in staying healthy. Naturopaths use an holistic approach to healing that can include herbal medicine, nutrition, dietary and nutritional supplements, homeopathy, traditional Chinese medicine, chiropractic, and other therapies.<sup>3</sup>

## Reflexology

Reflexology is based on the theory that there are places on the head, hands, and feet that are connected to each gland and organ in the body. Through both gentle and deep pressure massage of these points, reflexologists stimulate the organs and glands.<sup>3</sup>

## Shiatsu

Shiatsu is a Japanese word meaning "finger pressure," although thumbs, palms, and elbows are also used in treatments. The therapy is based on the Chinese theory of medicine that identifies meridian lines which relate to the internal organs.



According to the principles of Asian medicine, when energy becomes blocked or sluggish, systemic imbalances and various symptoms can occur. By applying sustained pressure along the meridians, the Shiatsu therapist attempts to stimulate the healing abilities of the body.<sup>2</sup>

### Therapeutic Touch

Therapeutic touch is based on the premise that each person has localized energy fields which extend beyond the body. Practitioners believe that in health, life energy flows freely throughout the body, while in disease, these energy fields get blocked or depleted. Through therapeutic touch techniques, the therapist attempts to “tune into” blocked areas by detecting a change in temperature which indicates a blocked energy field. The therapist attempts to direct life energy into the person to restore balance within the body.<sup>2</sup>

### Traditional Chinese Medicine

Traditional Chinese medicine incorporates an intricate theory and practice involving pulse diagnosis and the balancing of element and organ relationships.<sup>2</sup> Illness is seen as an imbalance of the body’s energy flow. Traditional Chinese medicine practitioners use acupuncture and often prescribe the use of herbs, usually in combination.<sup>3</sup>

### Vitamins and Minerals

Vitamins and minerals are used in higher doses than are normally recommended for healthy individuals. Examples of vitamins include: Beta-carotene, the B Vitamins, Vitamin C, Vitamin E, Folic acid. Examples of minerals include: zinc, iron, magnesium, selenium, copper.<sup>3</sup>

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4. Garmaise D. “An Overview of the Role of Complementary Therapies and HIV/AIDS: Care Treatment and Support Issues.” Paper prepared for the Care, Treatment and Support Program, Health Canada. Ottawa ON, 1997
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6. Dharmananda S. “Native American traditional medicine.” Article prepared for the Institute of Traditional Medicine. Portland OR, 1996

## Suggested Readings

Kaiser JD. *Immune Power: a comprehensive treatment program for HIV*. New York NY: St. Martin's Press, 1993

Ryan MK, Shattuck AD. *Treating AIDS with Chinese Medicine*. Berkeley CA: Pacific View Press, 1994

## Internet Sites

ARIC: An excellent Web site for information on complementary therapies. <http://www.critpath.org/aric/>

DAAIR (Direct AIDS Alternative Information Resources): One of the most comprehensive Web sites for alternative information. <http://daair.immunet.org/daair/>

Immunet: The home of AIDS *Treatment News* (the oldest AIDS treatment newsletter) is linked to several other important Web sites. A good starting point when looking for information.  
<http://www2.immunet.org/immunet/atn.nsf/homepage>



## HIV and Substance Use

This chapter presents some basic information on issues relating to HIV and substance use. It covers the following topics:

- harm reduction versus abstinence
- history-taking and assessment
- behaviour change
- coordination of care

## Introduction

Substance use has an impact on a person's health. It is important for a rehabilitation provider to be aware of an individual's substance use because that information will influence the treatment strategies that he or she recommends for the individual.

The history of care for persons with substance use issues is laden with judgement, discrimination, criminalization, and stereotyping. All professionals need to identify and examine their own values, attitudes, and beliefs about substance use. This may involve analyzing a part of the professionals' own personal backgrounds, including childhood experiences, which can affect their ability to be therapeutic and non-judgemental.

## Harm Reduction Versus Abstinence

There is an ongoing debate about whether harm reduction or abstinence is the best way to deal with substance use problems.

**The goal of harm reduction is to improve the safety and health of the person who is using substances. Abstinence is the total cessation of substance use.** Community organizations working in HIV/AIDS generally favour the harm reduction model. For more information on harm reduction versus abstinence approaches, see *Psychosocial Care: Module 6*.

## History-Taking and Assessment

Information about an individual's substance use is critical in providing optimal care. This underscores the importance of history-taking and assessment. All of the information is unlikely to be revealed in the first session. The details are more likely to emerge over time, as trust is built up in the patient-provider relationship.

In most health care settings, history and assessment information is gathered by a number of people, including physicians, nurses and rehabilitation professionals. A thorough patient history and assessment should include the following components:

- medical history
- cognitive assessment
- substance use history
- sexual history
- information about support networks

## Medical History

The medical history of a person living with HIV should provide the following information:

- confirmed HIV diagnosis
- length of time with HIV (if known)
- psychological effects of positive HIV test
- symptoms
- HIV-related conditions
- history of past and current HIV treatment, both conventional (i.e., pharmaceutical) and complementary

Some of this information may be relevant to the individual's use of substances. For example, testing HIV-positive may have resulted in increased drug or alcohol use, or in a relapse if the person was previously abstinent. Many symptoms of HIV resemble those from drug use (e.g., night sweats, weight loss).

## Cognitive Assessment

The cognitive assessment will help clarify the patient's ability to participate in ongoing planning of care. This assessment will also determine the needed levels of care and appropriate referrals.<sup>1</sup> Both HIV and substance use can cause cognitive impairment.

## Substance Use History

Without a substance use history, the rehabilitation professional may be unknowingly struggling with complications arising from a patient's undisclosed substance use. A thorough substance use history should cover:

- illicit drugs
- alcohol
- prescription and over-the-counter medications

Several tools are available for substance use history-taking. Minimally, the information gathered should include:

- substances used, including alcohol and prescription drugs (many users are polydrug users)
- frequency of use (i.e., binge use, sporadic use, or ongoing daily use)
- route of administration
- benefits of use (i.e., what does the patient gain from using?)
- consequences of use: physical, psychological, functional, interpersonal (support network), employment, financial, housing, spiritual<sup>2</sup>
- history of prior, ongoing, or current recovery and treatment programs
- history of recovery or abstinence attempts

Individuals presenting with current substance use may have a very chaotic lifestyle. This will affect whether the patient can participate fully in the planned care. A complete history will help to sort out the concerns presented. However, the rehabilitation professional should be aware that complex interactive processes are involved which may prevent clear knowledge about the causes of patient difficulties.<sup>1</sup>



### Tools

For more information on tools for substance use history taking, contact the Addiction Research Foundation in Ontario, Canada. See the Resources section for contact information.

## Sexual History

A sexual history will permit discussion of the individual's sexual identity, orientation, and risk(s). Assessing the potential for transmission of HIV and other sexually transmitted diseases requires knowledge of unsafe sexual practices. When taking a sexual history from a sex trade worker, caregivers need to be aware that the sexual practices these workers adopt with their clients may differ from those they use with their partners.

## Information About Support Networks

Caregivers may perceive chaos in the lives of patients who use substances. However, relationships in the substance-using community can be meaningful, can enhance quality of life, and can prolong survival. Many substance users who decide to stop using will be required to leave their existing relationships and begin building a new support system. This can be a very difficult process for people who often have been abandoned by family and friends outside the drug culture.

## Behaviour Change

Changing substance use behaviour is frequently a long and complex process which can be better understood by referring to the Stages of Change Theory, first outlined by Prochaska and DiClemente<sup>3</sup> and explained below.

## Stages of Change Theory

People attempting to modify drug-using behaviour, whether their ultimate goal is harm reduction or abstinence, move through a series of stages. The process is as follows:

### Stage I — Precontemplation

- this stage is characterized by no intention of changing behaviour
- people may be unaware of (or deny) their problems at this time
- substance use continues
- intervention should be focused on safer substance use

### Stage II — Contemplation

- people in this stage can admit that their substance use is causing problems but are not taking any action to modify their behaviours. This stage is characterized by an internal debate about the pros and cons of continued substance use, while use continues
- intervention should continue to focus on safer substance use

### Stage III — Preparation

- in this stage, people are preparing to take action to alter their behaviours in the near future
- substance use continues
- intervention should continue to focus on safer substance use

## Stage IV — Action

- at this point in time, people with substance use will take the necessary action to modify their behaviours
- as substance use is altered, people will have to make a commitment of time and energy, with relapse being an ever-present possibility

## Stage V — Maintenance

- people will now work to prevent relapse and to maintain their goals

Most people who attempt to modify their substance use behaviour will not be successful on the first try. It is important to note that change is not a linear process and that each person's path will be unique.<sup>3</sup> **Because relapse is always a possibility, it needs to be normalized and integrated in the work that rehabilitation professionals do with patients.**

The rehabilitation provider can assist patients by providing referrals to treatment specialists, programs, and self-help groups that are knowledgeable about the issues faced by a person living with HIV. Unfortunately, many substance use treatment programs are still largely unaware of these issues, although the situation is improving. Rehabilitation providers should check out which services are familiar with these issues and are non-judgemental about them, before recommending any of them to patients. If there are no such services, patients should be made aware of that fact before deciding whether to access the services.

Behaviour change goals are not limited to altering substance use behaviour. Behaviour change is the process used by people to stabilize their lives. As part of this process, people will endeavour to develop interpersonal relationships, secure housing, achieve financial security, and access a social support network.

## Detoxification

Controversy also surrounds the issue of whether to continue HIV treatments for someone undergoing detoxification. The process of detoxification is stressful and can therefore be immunosuppressive. A thorough discussion of all factors needs to occur among staff, the patient and his or her physician before a decision is made about whether to stop HIV treatment during detoxification.

A medical crisis or acute illness (particularly one requiring in-patient admission) is not the time to address detoxification or cessation of substance use. In fact, substance use may increase during this time as the individual tries to cope with a stressful situation. Providers can address this issue by prescribing other types of medications (e.g., methadone for heroin use) or by recognizing and accepting that the person will continue to use while in hospital. In addition, effective and adequate pain management is essential if the patient is to be expected to adhere to the prescribed medical treatment.

## Coordination of Care

With the knowledge acquired during the assessment and history-taking process, the rehabilitation provider will be able to assess the impact of substance use on the cognitive, motor, and emotional functioning of the patient.<sup>1</sup>

A coordinated approach to care is needed to address the chaos of the patient's life, which may include outstanding legal charges, psychosocial problems, medical diagnosis, and functional or vocational issues. Many different professionals will be involved in the patient's life. The goal of coordination is to ensure that everyone involved in the care, including the patient, receives and practises consistent and clear communication. To avoid overwhelming the patient, providers and the patient must coordinate their efforts when prioritizing care goals. Setting too many goals at one time will eventually overburden the patient and may result in a return to substance use or increased substance use.

The goals of care, as well as the role of each rehabilitation provider, need to be clearly communicated to patients and team members to avoid conveying mixed messages. This will go a long way to addressing the real needs of patients and will prevent the providers from getting caught up in patients' behaviour secondary to substance use.<sup>4</sup>

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# Introduction to Rehabilitation



This chapter provides a general description of rehabilitation and is directed primarily at the module's secondary target audiences: HIV caregivers and people living with HIV and their communities. The chapter covers the following topics:

- goals of rehabilitation
- the rehabilitation team
- rehabilitation in the context of HIV/AIDS
- the principles of HIV/AIDS rehabilitation
- the basic components of a rehabilitation program
- the settings where rehabilitation services are delivered
- issues around the costs of rehabilitation services

## Introduction

*“Rehabilitation is the development of a person to the fullest physical, psychological, social, vocational, avocational, and educational potential consistent with his or her physiological or anatomical impairment and environmental limitations.”*

DeLisa<sup>1</sup>

Rehabilitation is the process of enabling an individual to reach an optimum mental, physical, and social functional level. The process is goal-oriented and time-limited. Rehabilitation addresses the needs of the individual and the environment in which he or she functions, whether that environment be home, institution, work, school, or social.

A key premise of all rehabilitation is that people receiving services are central to the process and are active members of the rehabilitation team. They participate in assessing and identifying their rehabilitation needs and in deciding on the goals and treatment approaches.

## Goals of Rehabilitation

Rehabilitation services strive to:

- improve health
- improve quality of life
- assist individuals to realize or maintain their physical, social, functional, psychological, and vocational potential
- enhance independence
- restore self-esteem
- improve self-sufficiency

## The Rehabilitation Team

Rehabilitation services are provided by a variety of people trained in rehabilitation. Ideally, individuals receiving rehabilitation should be assisted by an interdisciplinary team that addresses their specific needs.

The rehabilitation team may be drawn from the following providers of rehabilitation services. The list is not exhaustive.

- **Physiatrists**  
Physicians who specialize in physical medicine and rehabilitation.
- **Physical Therapists**  
Professionals who plan and carry out individually designed programs of physical treatment to maintain, improve or restore physical function, alleviate pain, and prevent physical dysfunction.
- **Occupational Therapists**  
Professionals who assess function or adaptive behaviour, and assist an individual to maintain, rehabilitate or augment function or adaptive behaviour.
- **Speech Language Pathologists**  
Professionals who identify, evaluate, and treat a wide range of speech, language and swallowing disorders.

### ■ Rehabilitation Nurses

Professionals who assist and promote the participation of individuals in activities of daily living, with the primary goal being achievement of the individual's maximum functional potential.

### ■ Vocational and Rehabilitation Counsellors

Professionals who, through assessment, counselling, and training, assist people who have a medically documented disability that interferes with their ability to obtain and maintain employment, to develop and implement a realistic vocational plan.

### ■ Recreation Therapists

People who assist individuals to achieve an independent and rewarding leisure lifestyle.

## Rehabilitation and HIV/AIDS

The tradition in rehabilitation of making the individual a central part of the process fits in well with the practice that has evolved in the HIV/AIDS community where individuals take an active role in their care. Rehabilitation in HIV/AIDS is a collaborative partnership between the individual living with HIV, primary caregivers, rehabilitation providers, community HIV/AIDS organizations, payers, social agencies, and other interested parties.

### Other Team Members

*Other caregivers may be involved in the rehabilitation team (e.g., physicians, social workers, psychologists, substance use counsellors, community workers).*

## Principles of HIV/AIDS Rehabilitation

The following list of principles should guide the provision of rehabilitation services to people living with HIV. Providers should:

- place the individual at the centre of the rehabilitation team, involved in assessing, planning, selecting, implementing, and evaluating the services that he or she receives
- ensure that rehabilitation services are coordinated with HIV/AIDS community care providers
- recognize the importance of self-help and self-care, mutual assistance, and the natural support networks of people living with HIV
- ensure that rehabilitation services adopt a holistic approach addressing the physical, emotional, spiritual, and mental needs of the individual
- ensure that rehabilitation services address the determinants of health (see Chapter 8)
- accept and respect differences (see Chapter 2)
- assume a strong advocacy role on behalf of their patients
- recognize that people living with HIV may have multiple conditions at any one time
- use plain language, because language and terminology remain a potential barrier between professionals and HIV-affected communities
- learn about the common opportunistic infections seen in HIV disease so as to better understand the course of the disease, the prognosis for the individual patient, and the implications for formulating a treatment plan

## Interventions

Rehabilitation interventions are designed to address impairments, disabilities, and handicaps.

**DEFINITION** **Impairment:** loss or abnormality of psychologic, physiologic, or anatomic structure or function.

**DEFINITION** **Disability:** limitations to functional capacity caused by impairment.

**DEFINITION** **Handicap:** disadvantages encountered by the individual in society due to the individual's impairment or disability on the one hand, and environmental obstacles on the other.

In individual cases, overlap often occurs among these terms.

## Basic Components of a Rehabilitation Program

Individuals seeking rehabilitation services should receive the following program components:

- baseline assessment
- review of available information from other caregivers — primary care providers, specialists, or AIDS community care providers
- development of an individualized plan for rehabilitation services
- monitoring of progress toward established goals
- referral to other services and agencies as needs are identified
- provision of, or referral to, advocacy services
- discharge planning and coordination of services
- evaluation of services

## Where Rehabilitation Services are Provided

Where services are delivered depends on what services are available at a given location, the medical stability and acuity of illness of the individual, the outcomes desired by the individual, and the outcomes that are expected to be achieved. Some of the more common settings are:

- hospitals
- outpatient centres and clinics
- the private practices of health care professionals
- local AIDS service organizations
- the individual's place of residence
- hospices
- vocational work settings
- schools
- wellness centres
- community parks and recreation programs
- public health departments
- outreach programs

## Costs

Public or private insurance does not always cover the costs of rehabilitation services. In cases where coverage is provided, sometimes only a portion of the costs are covered. For persons without insurance, some rehabilitation providers may offer a sliding fee scale based on the individual's ability to pay. Individuals (or their advocates) should investigate cost coverage when selecting a provider. Local AIDS service organizations may provide some rehabilitation services free of charge.

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*Rehabilitation Services* **Section II**

# Adult Interventions



This chapter describes rehabilitation interventions for adults living with HIV.

The Introduction section covers the following topics:

- the features of rehabilitation that are unique to HIV/AIDS
- psychological impairments
- community resources that play a role in HIV rehabilitation
- how to use this chapter

Each of the remaining sections covers one of seven common impairment areas:

- pain
- weakness and coordination impairments
- fatigue
- weight loss
- cognitive impairments
- visual loss
- cardiac and respiratory impairments

## RED FLAG

**What are Red Flags?**

Red flags located throughout this chapter highlight particularly important clinical symptoms that indicate the need for immediate direct contact with a physician.

## Introduction

Providing rehabilitation services for people living with HIV is not a new concept. Since the beginning of the epidemic, health care professionals and patients have been actively involved in enhancing performance at home and work throughout the entire continuum of HIV disease.

Primary prevention, in the form of exercise, adequate nutrition, and maximizing mental health, is a mainstay of HIV care and also falls well within the scope of rehabilitation, though it may be less familiar to rehabilitation providers. Primary interventions tend to be based in the community rather than in medical facilities.

Secondary prevention has recently taken on added importance in HIV care. Preliminary successes with the newer drug regimens have focused even greater attention on the role of rehabilitation professionals in maximizing patient function. Although rehabilitation professionals are comfortable in this role when dealing with other chronic diseases such as diabetes mellitus, multiple sclerosis, and brain and spinal cord injuries, HIV disease represents new territory for many of them.

Fortunately, general rehabilitation philosophy and management principles can be readily applied to rehabilitation services for persons living with HIV. This chapter links basic medical and rehabilitation information, which allows rehabilitation professionals to provide appropriate care for persons living with HIV. This linkage is illustrated in Table 6.1, which furnishes examples of common medical conditions and potential rehabilitation management interventions within six basic categories.

**Primary prevention:**  
an activity or intervention designed to prevent the occurrence of a disease, condition, or injury.

**Secondary prevention:**  
an activity or intervention designed to prevent or postpone disease progression or death.

Please note that in the context of rehabilitation services, and in this module, the term “primary prevention” is not used to refer to the prevention of infection or re-infection with HIV.



**G**eorge is a 43-year-old executive with advanced HIV disease. He has severe bilateral peripheral neuropathy in his feet and lower legs. He feels a cold tingling and burning, with superimposed sudden, sharp searing pains. This discomfort makes falling asleep difficult. It takes him 10 minutes to put his pants on in the morning because he cannot feel where his feet are. He needs a cane for assistance with walking, but even with the cane he falls about once every two weeks.

**Table 6.1 Rehabilitation Intervention Categories**

General Intervention Category	Examples of HIV-Related Complications	Examples of Possible Rehabilitation Interventions
<b>Prevention of further complications</b>	<ul style="list-style-type: none"> <li>prolonged bed rest from medical illness</li> </ul>	<ul style="list-style-type: none"> <li>positioning and mobility assessment</li> <li>bedside exercise by caregiver, volunteer, therapist</li> </ul>
	<ul style="list-style-type: none"> <li>muscular contractures due to hemiparesis from cerebral toxoplasmosis</li> </ul>	<ul style="list-style-type: none"> <li>passive stretching and active assisted exercises</li> </ul>
	<ul style="list-style-type: none"> <li>dysphagia from brainstem tumour</li> </ul>	<ul style="list-style-type: none"> <li>swallowing evaluation and use of nutritionally complete, thickened liquid diet</li> </ul>
<b>Enhancement of affected systems</b>	<ul style="list-style-type: none"> <li>right-sided weakness from CNS lymphoma</li> </ul>	<ul style="list-style-type: none"> <li>neuro-facilitation techniques by therapists</li> </ul>
	<ul style="list-style-type: none"> <li>dysarthria from PML</li> </ul>	<ul style="list-style-type: none"> <li>alphabet picture board for communication</li> <li>oromotor exercises</li> </ul>
	<ul style="list-style-type: none"> <li>generalized weakness from HIV-associated weight loss</li> </ul>	<ul style="list-style-type: none"> <li>nutritional repletion and functional exercises</li> </ul>
<b>Enhancement of unaffected systems</b>	<ul style="list-style-type: none"> <li>paraplegia due to vacuolar myelopathy</li> </ul>	<ul style="list-style-type: none"> <li>strengthening of arms for transfers and wheelchair propulsion</li> </ul>
	<ul style="list-style-type: none"> <li>left-sided weakness following stroke in a left-hander</li> </ul>	<ul style="list-style-type: none"> <li>training for writing, buttoning, eating with right hand</li> </ul>
<b>Use of adaptive equipment</b>	<ul style="list-style-type: none"> <li>shoulder weakness due to AZT-induced myopathy</li> </ul>	<ul style="list-style-type: none"> <li>use of bilateral forearm orthosis for table-top activities</li> <li>long-handled reacher</li> </ul>
	<ul style="list-style-type: none"> <li>ankle weakness due to mononeuropathy simplex</li> </ul>	<ul style="list-style-type: none"> <li>ankle foot orthosis to facilitate ankle dorsiflexion during gait</li> </ul>
<b>Environmental modification</b>	<ul style="list-style-type: none"> <li>ataxia with poor safety awareness in bathroom</li> </ul>	<ul style="list-style-type: none"> <li>tub bench, grab bars, raised toilet seat</li> </ul>
	<ul style="list-style-type: none"> <li>inability to work due to stairs and visual deficits from CMV</li> </ul>	<ul style="list-style-type: none"> <li>ramp into work, telecommute, braille</li> </ul>
<b>Psychological techniques and adjustment to disability</b>	<ul style="list-style-type: none"> <li>memory deficits from early HIV Cognitive-Motor Complex</li> </ul>	<ul style="list-style-type: none"> <li>memory notebook to track appointments, work tasks, association of new tasks with old tasks</li> </ul>
	<ul style="list-style-type: none"> <li>depression from visual loss due to CMV retinitis</li> </ul>	<ul style="list-style-type: none"> <li>counselling for disability adjustment</li> <li>identification of compensatory strategies at work</li> </ul>
	<ul style="list-style-type: none"> <li>anxiety due to psychosocial stresses and uncertainty of prognosis</li> </ul>	<ul style="list-style-type: none"> <li>psychotherapy, hypnosis, visualization</li> <li>stress management, relaxation training</li> </ul>

**Legend:**

AZT: zidovudine

CMV: cytomegalovirus

CNS: central nervous system

PML: progressive multifocal leukoencephalopathy

Adapted from DeLisa<sup>1</sup>



## Unique Features of Rehabilitation in HIV Disease

People living with HIV are different from other rehabilitation populations in several respects:

- **Concomitant medical and neurological diagnoses.** Especially in late HIV infection, multiple medical and neurological impairments will be common. Examples include:
  - hemiparesis from cerebral toxoplasmosis together with generalized weakness from HIV-associated weight loss
  - shortness of breath from *Pneumocystis carinii* pneumonia together with pain from HIV peripheral neuropathy
- **Intermittent and ultimately progressive disease course.** As in multiple sclerosis, people living with HIV tend to have fluctuating disability. A person's functional deficits may be quite different over time depending on the underlying complication of HIV leading to the disability. Examples include:
  - fatigue due to severe prolonged episodes of diarrhea
  - chronic pain from progressive peripheral neuropathy
- **Parallel primary and secondary prevention efforts.** Rehabilitation professionals will generally be asked to minimize existing HIV disability; this constitutes secondary prevention. However, rehabilitation professionals should provide primary prevention concurrently with treatment of existing limitations by:
  - providing preventive nutritional information before wasting leads to additional fatigue (see Chapter 9)
  - promoting exercise for health maintenance from time of diagnosis (see Chapter 9)
  - encouraging individuals to do home exercises during and after rehabilitation to maintain cardiovascular and musculoskeletal health
  - identifying depression and anxiety
- **Uniqueness of persons served.** HIV disease has hit hardest among certain segments of the population — persons in mid-life or younger, gay and bisexual men, injection drug users, the poor, and urban minorities, for example. As in all rehabilitation care, eliciting and understanding the identity and psychosocial background of the person with HIV-related disability is essential in collaborating with them and their communities to plan, institute, and follow up on a rehabilitation program. The HIV population is also unique in that extensive community-based organizations have been developed over the past 15 years.

## Importance of Psychological Impairments

Psychological issues accompany all aspects of living with HIV and may well affect rehabilitative efforts.

Depression can occur pre- and post-HIV testing and anytime after diagnosis of HIV. Affecting about 30% of people living with HIV, depression can manifest as sadness, crying, changes in sleep and appetite, depressed mood, apathy, and lack of pleasure. Depression is sometimes confused with early HIV dementia because other conditions — such as impaired concentration and judgement, agitation, psychomotor retardation, diminished motivation, and lethargy — exhibit symptoms similar to

those associated with depression. The diagnosis of depression is even more complicated when the individual:

- is involved in substance use and abuse
- uses multiple medications
- has a central nervous system disease
- has a mental illness

Care management is multifaceted and may include complete psychosocial assessment, psychotherapy, and antidepressant medications. Even “reactive” depression can become a major depression and warrant pharmacological treatment.

Likewise, anxiety is very common and can be related to:

- vulnerability
- prejudice
- dependency
- loss of body image
- fear of physical and mental disability
- isolation
- unpredictability of HIV
- prospect of dying
- medical treatment
- loss of independence and control

Anxiety can manifest as:

- agitation
- insomnia
- restlessness
- sweating
- palpitations
- hyperventilation
- panic attacks
- shaking
- excessive worry
- change in appetite

Assessment and treatment should be appropriate to the emotional, cognitive and perceptual presentation and to the context of the person and the illness. Reassurance is critical. Rehabilitation professionals can teach individuals to relieve anxiety and provide them with therapies such as hypnosis, relaxation, and visualization. Referral for medication or other complementary therapies (e.g., acupuncture, aromatherapy, massage) may be indicated.

## Importance of Community Resources in HIV Rehabilitation

Community-based HIV/AIDS organizations provide a wide range of health promotion services and programs for people living with HIV and their caregivers. Although not usually described as “rehabilitation services,” many are designed to enable people living with HIV to regain or maintain optimal physical and psychosocial

functioning and are rehabilitative in nature. Linking individuals to local community organizations can reduce the isolation many people feel, and has a tremendously positive impact on overall rehabilitation outcomes. These organizations can include the many disability organizations that do not specifically target the HIV population but that do provide support to people living with a variety of disabilities. For example, many people living with HIV who have severe vision impairment due to cytomegalovirus retinitis access the Canadian National Institute for the Blind for needed practical training and emotional support, which helps them adapt to their new disability. (See “Community Resources” in the “Visual Loss” section of this chapter.)

In addition to providing health promotion programs and services, community organizations also maintain extensive referral lists for linking people living with HIV and their caregivers to relevant professional and community resources. Community-based AIDS organizations have been a vital resource and support system for HIV/AIDS-affected communities throughout the epidemic and can make significant contributions to the rehabilitation program of a person living with HIV. Rehabilitation professionals should be aware of local community resources, both HIV- and non-HIV-specific, that can provide an important complement to traditional rehabilitation services.

## How to Use this Chapter

Each of the following sections discusses an impairment area, starting with a general description of potential contributing disease processes. **These descriptions include red flags highlighting particularly important clinical symptoms that indicate the need for immediate direct contact with a physician.** A table providing information on the clinical aspects of that impairment area follows. The information in this table is important because functional changes may herald the onset or worsening of a medical complication; rehabilitation professionals may be in a position to identify new disease complications between medical evaluations. The table is followed by a detailed description of rehabilitation interventions and a list of resources available in the community. Some of the more straightforward rehabilitation interventions described in this chapter could be provided by non-professionals (such as family members or partners) after appropriate training. The listing of community resources is not exhaustive and not all resources shown may be available in any one community.

A reference list for further reading is provided at the end of the chapter.

### Note

*The tables and lists of interventions presented in this chapter are not intended to be exhaustive; they provide a starting point for linking medical and rehabilitation evaluations and treatment.*

## Pain

Pain is a common symptom in persons with HIV infection, particularly in persons with advanced disease. There are a variety of causes for pain (see Table 6.2). As well, multiple problems (e.g., pain from Achilles tendon tightness, foot pain from peripheral neuropathy) can occur at the same time. The presentation and character of the pain (locations, quality, intensity) can give clues to the etiology.

Musculoskeletal etiologies — which include myofascial pain secondary to inactivity, poor posture, deconditioning, and premorbid injury — tend not to be life-threatening. Likewise, the rheumatological etiologies can be quite debilitating, but rarely life-threatening. Pain associated with abnormalities in strength, sensation, and reflexes tends to occur with central or peripheral neurological disease as a pain source.

Management of pain in HIV infection generally requires both medications and multiple modalities for adequate control. Analgesic medications should be provided in a step-wise approach, using the least invasive route of administration. This is discussed more fully in *Palliative Care: Module 4* (pp. 19-27).



*New, changed, or poorly controlled pain should result in immediate medical referral.*



*New onset of headaches may be serious and should result in immediate medical referral.*

## Rehabilitation Interventions

### Peripheral Neuropathic Pain

#### **Physical modalities**

- electrotherapeutic agents such as transcutaneous electrical nerve stimulation (TENS) or interferential current (IFC) for symptomatic management

#### **Adaptive equipment**

- footwear: supportive, well-fitting, nonslip sole, and minimal seams to minimize irritation
- orthotics: ankle foot orthoses (AFO) for foot drop associated with pain
- foot orthosis: inserts for shoes to minimize pain by providing support and cushioning
- bed cradle or boxes to keep sheets off feet
- resting splints to hold ankles in dorsiflexion, especially helpful in relieving pain at night

#### **Desensitization techniques**

- alternate hot and cold contrast baths
- rub skin with various textured materials, soft to rough
- wear socks inside-out to avoid seams against feet

#### **Psychological counselling to facilitate coping and adjustment regarding symptoms, pain management**

- visualization
- meditation
- biofeedback

**Table 6.2 Clinical Aspects of Pain**

Category	Causes and Considerations
<b>Myofascial pain (including headache) syndromes</b>	<ul style="list-style-type: none"> <li>• inactivity, poor posture, deconditioning</li> <li>• exacerbation of pain by anxiety or depression</li> <li>• inadequate sleep</li> </ul>
<b>Joint pain</b>	<ul style="list-style-type: none"> <li>• joint destruction due to secondary processes, malignancy, drug effects, or repetitive strain due to over-use</li> <li>• psoriatic arthritis, recurrent hemarthrosis, bacterial and TB joint infections, malignancy</li> <li>• damage to “unaffected” joints (e.g., left knee pain due to compensating for painful right knee)</li> </ul>
<b>Myopathy</b>	<ul style="list-style-type: none"> <li>• inflammatory (e.g., polymyositis)</li> <li>• non-inflammatory</li> <li>• toxic (e.g., AZT)</li> </ul>
<b>Respiratory tract disease</b>	<ul style="list-style-type: none"> <li>• infection (e.g., PCP, TB)</li> <li>• tumour (e.g., KS)</li> <li>• pneumothorax</li> <li>• pulmonary embolus</li> <li>• pleural infarction</li> </ul>
<b>Pain associated with CNS lesions (including headache)</b>	<ul style="list-style-type: none"> <li>• possible CNS lesions: toxoplasmosis, fungal or bacterial abscess, CNS lymphoma</li> <li>• headache from abscess, cryptococcal meningitis, CNS lymphoma</li> <li>• meningismus (e.g., cryptococcal meningitis)</li> </ul>
<b>Distal symmetrical polyneuropathy</b>	<ul style="list-style-type: none"> <li>• HIV-mediated</li> <li>• drug-induced (e.g., ddC, d4T, ddl)</li> <li>• vitamin deficiency (e.g., B12)</li> </ul>
<b>Mononeuropathy simplex and multiplex</b>	<ul style="list-style-type: none"> <li>• primary effect of HIV</li> <li>• secondary immune complex</li> <li>• CMV (in late disease)</li> </ul>
<b>Progressive polyradiculo-myelopathy</b>	<ul style="list-style-type: none"> <li>• CMV infection of the cauda equina</li> </ul>
<b>Esophageal and abdominal pain</b>	<ul style="list-style-type: none"> <li>• infections (e.g., esophagitis)</li> <li>• malignancies</li> <li>• renal colic</li> <li>• hepatitis</li> <li>• drug-induced (e.g., narcotics, indinavir)</li> <li>• obstructions</li> <li>• biliary tract disease</li> <li>• pancreatitis</li> <li>• colitis</li> <li>• enteritis</li> <li>• malabsorption</li> </ul>
<b>Somatization, psychological pain disorder</b>	<ul style="list-style-type: none"> <li>• psychological factors have a major role in onset, exacerbation, severity, and maintenance of pain</li> </ul>
<b>Other sources of neuropathic pain</b>	<ul style="list-style-type: none"> <li>• acute herpes zoster, post-herpetic neuralgia</li> </ul>

**Legend:**

AZT: zidovudine

CMV: cytomegalovirus

CNS: central nervous system

ddc: zalcitabine

ddl: didanosine

d4T: stavudine

KS: Kaposi's sarcoma

PCP: *Pneumocystis carinii* pneumonia

TB: tuberculosis

**Environmental assessment**

- reduce tripping hazards (e.g., no loose scatter rugs)
- use a non-slip bath mat
- eliminate clutter

**Medication management**

- trial of analgesics, anti-inflammatories, antidepressants, antiseizures, antispasmodics and other co-analgesics, and adjuvant medications

**Miscellaneous**

- assess need for a mobility aid if balance and safety become a concern with severe pain
- monitor skin integrity of feet that are severely numb
- carefully check the temperature of bath water with unaffected limb
- use caution when trimming toenails

**Musculoskeletal and Joint Pain****Exercise**

- stretching of **tight** muscles (muscles commonly affected by prolonged inactivity include calf, thigh, and chest)
- strengthening of **weak** muscles, especially stomach, back, and thigh
- passive and active range of motion exercises to maintain mobility of joints if non-ambulatory due to pain

**Positioning**

- encouragement of proper posture and body mechanics in lying, sitting, and standing to maximize function and avoid secondary complications
- splints to prevent joint deformities and rest acutely inflamed joints
- education on joint protection strategies
- regular change of positioning to avoid pressure ulcers, if decreased or no activity due to pain
- gel pads to reduce risk of skin breakdown from shearing forces
- four-inch dense foam or air-inflated cell cushions, which may reduce risk of pressure ulcer development (especially at bony prominences)

**Physical modalities**

- hydrotherapy to maximize joint protection, improve flexibility, and improve exercise tolerance
- bath or shower in the morning to help alleviate pain and stiffness before dressing and self-care activities
- whirlpool to help relieve pain
- application of ice for acute pain management and either hot or cold for chronic pain (based on individual preference)
- TENS, IFC (see physical modalities for peripheral neuropathic pain)

**Medications management**

- trial of analgesics, anti-inflammatories, antidepressants, antiseizures, antispasmodics and other co-analgesics, and adjuvant medications

***Psychological counselling to address potential fear, distress, anger, excessive preoccupation, distortion of reality, anxiety, and phobia***

- visualization
- hypnotherapy
- meditation
- biofeedback

***Miscellaneous***

- acupuncture
- therapeutic touch
- Reiki
- massage therapy
- craniosacral therapy
- myofascial release
- Shiatsu



## Community Resources

Community organizations may provide the following resources:

- information on non-allopathic therapies as part of treatment information programs or libraries
- referrals to practising homeopaths and naturopaths
- culturally relevant strategies or therapies for dealing with pain and illness
- massage therapies, including Reiki and traditional deep muscle massage (often provided at no charge)
- stretching, yoga, Tai Chi, and fitness classes
- individual counselling, peer counselling, and support groups tailored to specific cultural groups

## Weakness and Coordination Impairments

Many of the common causes of weakness and coordination impairments are shown in Table 6.3. Neurological weakness from either peripheral or central lesions should be distinguished from weakness due to generalized deconditioning or fatigue because the evaluation, management, and prognosis are quite different. Weakness due to underlying peripheral or central neurological disease is often more localized, is associated with abnormalities on neurological examination, and tends to be more common in moderate to advanced HIV disease. Generalized weakness associated with deconditioning (as a result of a prolonged illness or immobility) is also common in advanced HIV disease.

Neurological etiologies will present with typical distributions of strength and reflex changes (e.g., proximal weakness with myopathies; hemiparesis, hyperreflexia, and hypertonia with cerebral or brain stem lesions; and distal weakness with peripheral neuropathy). Sometimes mild coordination problems are due to weakness, but cerebellar disease should also be considered. A variety of diagnostic testing and neuro-imaging may be necessary to initiate proper medical treatment before or during rehabilitation intervention.



*New neurological findings should result in immediate medical referral.*

**Table 6.3 Clinical Aspects of Weakness and Coordination Impairments**

Category	Causes and Considerations
<b>Focal lesions of brain</b>	<ul style="list-style-type: none"> <li>• cerebral toxoplasmosis, fungal or bacterial abscess, PML</li> <li>• HIV-related stroke in cerebrum or brainstem</li> <li>• CNS malignancy (primary lymphoma, metastatic)</li> <li>• long-term alcohol abuse</li> </ul>
<b>Spinal cord lesion</b>	<ul style="list-style-type: none"> <li>• HIV vacuolar myelopathy</li> <li>• tumour of the spinal cord (e.g., lymphoma)</li> <li>• abscess (bacterial, fungal, TB)</li> <li>• progressive polyradiculo myelopathy from CMV</li> </ul>
<b>Inflammatory demyelinating polyneuropathy (acute and chronic types)</b>	<ul style="list-style-type: none"> <li>• probably immune-mediated (acute inflammatory demyelinating polyneuropathy clinically resembles Guillain-Barré Syndrome)</li> </ul>
<b>Myopathy</b>	<ul style="list-style-type: none"> <li>• HIV-related</li> <li>• AZT-related</li> </ul>
<b>Generalized deconditioning and metabolic abnormalities</b>	<ul style="list-style-type: none"> <li>• prolonged bed rest or immobility</li> <li>• prolonged illness</li> <li>• anemia, electrolyte abnormalities</li> <li>• inadequate nutritional intake</li> </ul>

### Legend:

**AZT:** zidovudine

**CMV:** cytomegalovirus

**CNS:** central nervous system

**PML:** progressive multifocal leukoencephalopathy

**TB:** tuberculosis



## Rehabilitation Interventions

### General Guidelines

- exercises and functional activities relevant to each person's goals
- neuro-rehabilitation strategies for central nervous system impairments (e.g., proprioceptive neuromuscular facilitation [PNF] and Bobath techniques)
- oral exercises to improve dysphagia and decrease risk for aspiration pneumonia
- oromotor exercises to improve articulation and slurred speech

### For Enhancing Mobility

- practise ambulation on stairs, uneven surfaces, and outdoor surfaces which resemble community circumstances
- ensure correct prescription and sizing of mobility aids (including wheelchairs and scooters if appropriate)
- wear appropriate footwear and orthoses (see section on pain above)
- use general strengthening exercises that address large muscle groups (e.g., quadriceps, gluteal muscles)
- assess both standing and sitting balance
- use a mirror for visual feedback during gait retraining

### To Address Problems with Activities of Daily Living

#### ***General guidelines***

- ensure adequate trunk support and positioning to maximize upper extremity coordination and movement
- have patient dress the weak or uncoordinated side first

#### ***Adaptive equipment to enhance independence***

- grab bars on the tub or by the toilet
- bath seats and tub transfer benches with a backrest, if balance is poor
- raised toilet seats to ease transfers on and off toilet
- floor-to-ceiling pole at bedside to assist with transfers in and out of bed
- urinal or commode at bedside during the night
- more than one phone at home (cordless preferred)
- widened or weighted utensil handles to combat loss of coordination

### To Decrease the Risk of Falls

- conduct an environmental assessment of layout and potential safety concerns in the home
- assess patients for cognitive factors, including poor insight and impulsivity, and motor factors which may increase fall risk
- adequately widen paths for walking with assistive devices such as canes and walkers
- use safety call systems
- remove extension cords and clutter from home or room
- ensure adequate lighting
- avoid soft and low-height couches or chairs that make rising difficult with weak legs
- ensure belongings are within easy reach (e.g., reorganize kitchen and office for greatest accessibility to commonly used items)
- use reacher to pick things up off the floor



## Community Resources

Community organizations may provide the following resources:

- stretching, yoga, and other fitness classes
- individualized fitness or weight training programs by qualified instructors
- individual professional or peer counselling
- loan of mobility and adaptive equipment (e.g., canes, walkers, wheelchairs, bathseats)

## Fatigue

### Note

*Fatigue may sometimes result from overly aggressive rehabilitation interventions.*

Fatigue is one of the most common complaints in persons at all stages of HIV infection and is often multifactorial. There are a myriad of possible medical etiologies for fatigue, as outlined in Table 6.4. Sometimes a specific cause of fatigue is not identified. Important medical considerations include fatigue as a manifestation of systemic infection and as a side effect of medications. In many cases, fatigue will be the primary impairment leading to disability, even in individuals with focal neurological weakness.

The emotional stress of chronic disease and lack of social supports can result in fluctuating levels of anxiety and depression leading to complaints of fatigue, poor motivation, apathy, and anguish. Depression should be considered as both an etiology and a sequela of fatigue. When the related conditions of depression, fatigue, and physical disability are present, the root cause of each is difficult to determine.

Fatigue may exacerbate depression related to change of function, fear of losing control, or a perception of the “beginning of the end.” A combined pharmacological and psychotherapeutic approach may diminish actual or perceived physical limitation due to fatigue, as well as enhance ongoing rehabilitation interventions.

**Table 6.4 Clinical Aspects of Fatigue**

Category	Causes and Considerations
<b>Nutritional deficiencies</b>	<ul style="list-style-type: none"> <li>• deficiency of vitamins, trace elements, protein, lipids, calories (food energy)</li> </ul>
<b>Infections</b>	<ul style="list-style-type: none"> <li>• HIV</li> <li>• secondary infection (e.g., MAC, cryptosporidiosis, microsporidiosis)</li> <li>• virtually any chronic infection</li> </ul>
<b>Malabsorption</b>	<ul style="list-style-type: none"> <li>• HIV enteropathy</li> <li>• chronic diarrhea due to other etiologies (e.g., MAC, cryptosporidiosis, microsporidiosis)</li> </ul>
<b>Anemia</b>	<ul style="list-style-type: none"> <li>• HIV</li> <li>• chronic disease</li> <li>• opportunistic infections (e.g., parvovirus, MAC)</li> <li>• vitamin deficiency (e.g., B12, folate)</li> <li>• medication-induced (e.g., AZT, sulfa antibiotics)</li> </ul>
<b>Medication-induced fatigue</b>	<ul style="list-style-type: none"> <li>• indinavir</li> <li>• pain medication</li> <li>• anticonvulsant drugs</li> <li>• substance use</li> </ul>
<b>Psychological</b>	<ul style="list-style-type: none"> <li>• depression</li> <li>• anxiety</li> <li>• fatigue associated with chronic pain</li> </ul>
<b>Metabolic</b>	<ul style="list-style-type: none"> <li>• electrolyte imbalance</li> <li>• thyroid dysfunction</li> <li>• adrenal insufficiency</li> </ul>

### Legend:

**AZT:** zidovudine

**MAC:** *Mycobacterium avium* complex

## Rehabilitation Interventions

### Energy Management

- energy conservation — an approach to avoid fatigue through increased awareness of the easiest ways of carrying out necessary activities such as self-care, work, rest, and leisure. Examples include:
  - selection of priorities
  - time management
  - pacing
  - good posture and body mechanics
  - efficiency
  - organization
- timing of therapies and activities during “high energy” times of the day
- planning of outings and errands to reduce transportation time or physical demands
- setting of priorities by individuals (in the knowledge that energy limitations may preclude “doing everything today”)
- recruitment of assistance or delegation of energy-demanding activities of daily living (e.g., homemaking, errands, shared meal preparation)
- knowing one’s limits

### Environmental

- assessment of the home and workplace, including:
  - ergonomic assessment
  - need for and feasibility of worksite modifications
  - task analysis
  - need for job or equipment adaptations at work and home
- change in job structure or home schedule
- reduction in number of work hours
- organization of work and storage areas
- provision of assistive devices

### Exercise

- aerobic exercise (however, the energy demands of this type of exercise need to be weighed against the other competing life activity priorities requiring energy)

### Nutrition

- focus on easy, quick meals with high nutrient density
- use buddies to do grocery shopping, errands
- refer individuals to community food bank programs
- focus on efficient preparation techniques
- use meals-on-wheels programs, delivery services
- prepare extra portions for freezing for future meals

### Medication

- trials of medication to increase energy (e.g., Ritalin, B12, testosterone injections, anabolic steroids such as decadurabolin)
- antidepressants to try to elevate mood, increase activity and enhance energy level, if depression is present

## Psychosocial

- management of stress, depression, anxiety, and sleep disturbances through psychological, educational, and supportive counselling
- full consideration by the individual of the psychological, emotional, social, physical, and financial aspects of working or returning to work (see Chapter 8)



## Community Resources

Community organizations may provide the following resources:

- individual professional or peer counselling
- support groups
- nutritional assessments by registered nutritionists and dietitians (see also *Managing Your Health: Module 5* and *Healthy Eating Makes a Difference*)
- complementary health programs or funding to subsidize the purchase of vitamins, minerals, herbal remedies, and other complementary therapies
- health promotion and fitness programs
- home care
- loan of mobility and adaptive equipment (e.g., canes, walkers, wheelchairs)

## Weight Loss

Involuntary weight loss associated with HIV is a function of an imbalance between food energy intake and total energy expenditure (resting energy expenditure, diet-induced thermogenesis, and expenditure from physical activity). Multiple etiological factors exist (as outlined in Table 6.5) and a multitude of interventions are required. Both the magnitude and the rate of weight loss are important. The amount of fat lost is proportional to the amount of fat a person has to start with. However, when weight is gained following a significant loss, the composition of the weight gain may be more fat than lean mass. The introduction of antiretroviral therapy may alter the balance, but this remains to be established.

In early HIV disease, transient weight loss is commonly related to anxiety and depression. As HIV progresses, weight loss is associated with abnormalities of multiple organ systems. Infectious processes can affect both the gastrointestinal tract and endocrine system resulting in weight loss. Some medications used to treat specific conditions can result in weight loss secondary to anorexia or nausea (e.g., Septra/Bactrim, chemotherapy). Primary prevention in the area of weight loss and nutrition should be a component of treatment for existing physical limitations. See Chapter 9 for a more detailed discussion of nutrition.

People living with HIV are at nutritional risk and should receive nutritional intervention when changes in body weight or composition occur.



*Significant, unexplained weight loss should result in immediate medical referral.*

**Table 6.5 Clinical Aspects of Weight Loss**

Category	Causes and Considerations
<b>Anorexia</b>	<ul style="list-style-type: none"> <li>• esophagitis (e.g., CMV, HSV, candida)</li> <li>• psychological, emotional, or psychiatric problems</li> <li>• abnormal taste, pain, or dysphagia (e.g., oral and esophageal candidiasis, HPV, KS, OHL, CMV, HSV, aphthous ulcers, drug effect, idiopathic)</li> <li>• tumour necrosis factor, cytokine dysregulation</li> <li>• medication-related (e.g., AZT, ddl, ddC, ritonavir, indinavir, saquinavir)</li> <li>• chronic infection</li> </ul>
<b>Malabsorption with or without diarrhea</b>	<ul style="list-style-type: none"> <li>• HIV enteropathy</li> <li>• secondary infections (e.g., MAC, cryptosporidium, microsporidium)</li> <li>• medication-related (e.g., ddl, ritonavir, nelfinavir)</li> </ul>
<b>Obstruction</b>	<ul style="list-style-type: none"> <li>• tumour (e.g., KS, lymphoma)</li> </ul>
<b>Endocrine dysfunction</b>	<ul style="list-style-type: none"> <li>• adrenal insufficiency</li> <li>• hypogonadism</li> <li>• hypothyroidism</li> </ul>
<b>Hypermetabolic state or fever</b>	<ul style="list-style-type: none"> <li>• HIV</li> <li>• tumour</li> </ul>
<b>Psychological</b>	<ul style="list-style-type: none"> <li>• depression</li> </ul>

### Legend:

**AZT:** zidovudine  
**CMV:** cytomegalovirus  
**ddC:** zalcitabine  
**ddl:** didanosine  
**HPV:** human papillomavirus  
**HSV:** herpes simplex virus  
**KS:** Kaposi's sarcoma  
**MAC:** *Mycobacterium avium* complex  
**OHL:** oral hairy leukoplakia  
**PCP:** *Pneumocystis carinii* pneumonia

## Rehabilitation Interventions

### Nutritional

#### ***General***

- maintenance of a graphic log of both weight and body composition measurements (e.g., skin fold, mid-arm muscle area, bioelectrical impedance analysis) to provide an early warning of wasting and new medical complications

#### ***Anorexia and early satiety***

- small, frequent, nutrient-dense meals
- multivitamin or mineral supplements
- enteral or parenteral nutrition
- positive social environment during mealtimes

#### ***Alterations in taste (dysgeusia)***

- spices and seasonings to mask the offending flavours and foods
- mouth hygiene maintenance
- zinc supplements

#### ***Pain and inflammation in the mouth (mucositis) / Pain on swallowing (odynophagia)***

- consume foods at or below room temperatures
- determine individual tolerance to acidic, rough, or seasoned foods
- use artificial saliva or candies to help alleviate dry mouth
- “mask” oral medications in soft or mashed foods to improve swallowing

#### ***Difficulty swallowing (dysphagia)***

- swallowing studies to establish nutritionally adequate diet based on texture and consistency
- trial feeding, as directed by a speech pathologist

#### ***Dyspnea while eating***

- choose nutrient-dense meals and use supplemental oxygen as needed
- ensure that nasal cannula is available at mealtimes

#### ***Malabsorption and diarrhea***

- low-fat and low-lactose foods
  - altered insoluble and soluble fibre
  - replacement of vitamins, minerals, electrolytes, and fluid losses
- (Suggested dietary modifications are specific to cause and must be individualized.)

#### ***Nausea and vomiting***

- avoid known triggers to nausea and vomiting
- avoid sweet, fried, or fatty foods; choose bland or salty foods
- avoid strong-smelling foods
- avoid caffeine, alcohol, and gas-producing foods
- consume liquid and dry portion of the meal separately (allow a one-hour interval)
- wait until after a meal to take medications associated with nausea
- eat dry toast, cereals, and crackers
- take antiemetic medications (e.g., compazine)

**Abdominal cramping and bloating**

- assess lactase status
- consume nutrient-dense, low-fat, small, frequent meals
- avoid very hot or very cold foods and beverages

**Dehydration**

- replace losses (normal fluid replacement is 1,800-2,000 ml per day)
- encourage nutrient-dense fluids (e.g., Ensure, Boost)
- maintain electrolyte balance (e.g., sports drinks such as Gatorade)

**Constipation**

- gradually increase amount of soluble or insoluble dietary fibre
- increase fluids
- add bulking agents
- review drug side-effects

**Physical**

- strengthening exercises and weight-bearing activities to promote bone-density maintenance
- short-term, high-intensity progressive resistance training to help retain or increase muscle mass
- coordination of exercise with nutrition intervention to ensure appropriate energy balance
- consider stool softeners and motility agents

**Pharmacological**

- appetite stimulants (e.g., dronabinol, megestrol acetate)
- anabolic agents (e.g., oxandrolone, testosterone, growth hormone)
- cytokine modulators (e.g., pentoxifylline, thalidomide)
- antiemetic agents
- antimotility, luminal-acting, hormonal agents
- motility agents

**Miscellaneous**

- counselling on body image or eating disorders
- education on maintenance of skin integrity
- assistance in obtaining safe, nutritionally adequate food
- assistance in stabilizing economic and housing situation
- assistance in stabilizing substance use

**Community Resources**

Community organizations may provide the following resources:

- nutritional assessments (see also *Managing Your Health: Module 5* and *Healthy Eating Makes a Difference*)
- complementary health programs or funding to subsidize the purchase of vitamins, minerals, herbal remedies, and other complementary therapies
- food banks and high calorie dietary supplements (e.g., Boost, Ensure) which may be available to persons living with HIV who are on social assistance or who have limited incomes, at reduced prices or at no charge





## Cognitive Impairments



*Any changes in cognition should result in immediate medical referral.*

Cognitive decline is one of the most feared complications of HIV infection. Many of the common causes of cognitive impairments are shown in Table 6.6. **The most severe form — HIV Cognitive-Motor Complex, also known as HIV Dementia or AIDS Dementia Complex — presents with cognitive, behavioural, and motor dysfunction.**

Early cognitive symptoms include decreases in reaction time, attention, short-term memory, and general psychomotor slowing. Behavioural manifestations include apathy, social withdrawal, and impaired judgement. Motor problems include lower extremity weakness and spasticity, tremor, and balance dysfunction.

To guide rehabilitation intervention or vocational re-integration, trained personnel can use standardized psychometric tests with proven reliability and validity to establish the diagnosis and to assess relative cognitive strengths and weaknesses. Neuropsychological testing can help determine the relative contributions of organic and psychological etiologies to cognitive dysfunction.

**Competence — the ability to make sound decisions and manage one's affairs —** is another significant aspect of personal health assessment. All individuals with cognitive impairments should pursue a power of attorney for personal care and finances. In some places, a living will is a recognized legal document that outlines advanced directives for care. Because a change in one's medical status can affect competence, cognitive abilities should be tested following any such change.

Communication deficits in HIV infection have several etiologies. Infection or tumour of the language cortex in the dominant cerebral hemisphere leads to aphasia. Facial weakness or cranial nerve dysfunction can result in dysarthria. Severe infections of the mouth and esophagus can lead to difficulty in articulation and swallowing due to pain. Finally, cognitive-linguistic deficits can occur in the presence of HIV Cognitive-Motor Complex.

**Table 6.6 Clinical Aspects of Cognitive Impairments**

Category	Causes and Considerations
<b>HIV Cognitive-Motor Complex (HIV Dementia)</b>	<ul style="list-style-type: none"> <li>• HIV</li> </ul>
<b>Cognitive impairment due to other metabolic or neurological diagnoses</b>	<ul style="list-style-type: none"> <li>• hypoxia</li> <li>• cryptococcal meningitis, syphilis, neurovascular disease</li> <li>• focal cerebral disease</li> <li>• vitamin deficiency (e.g., B12, B6)</li> <li>• electrolyte abnormalities</li> </ul>
<b>Psychological disorders</b>	<ul style="list-style-type: none"> <li>• depression</li> <li>• anxiety</li> <li>• delirium</li> <li>• premorbid psychiatric disorders</li> <li>• post-traumatic stress disorder</li> </ul>
<b>Substance-related disorders</b>	<ul style="list-style-type: none"> <li>• prescription medications (narcotics)</li> <li>• over-the-counter medications</li> <li>• street drugs: premorbid or current</li> <li>• alcohol: premorbid or current</li> </ul>

## Rehabilitation Interventions

### For Managing Complex and Simultaneous Tasks

- segment tasks by breaking down complex tasks into several smaller, more manageable steps (may still require verbal or physical cueing by therapist or caregiver)
- reduce visual and auditory distractions in environment to enhance performance
- ensure clear transition period between activities to provide appropriate cueing to the commencement of a new task
- use calendars and agenda books to assist in planning appointments
- create structure in daily routines to prompt rote skills, especially with activities of daily living

### To Maximize Safety

- evaluate risks of wandering, and install appropriate environmental controls or supervision to ensure safety
- evaluate the environment
- address tripping hazards
- install railing to help with balance
- install good lighting
- wear good footwear
- unplug stove or remove knobs or fuses to prevent the individual from cooking when alone, if there are concerns about cooking
- lock up hazardous appliances, poisonous cleaners and medications

### For General Cognitive Deficits

#### ***Cognitive stimulation***

- provide familiar and meaningful activities within the person's abilities
- practise inductive and deductive reasoning skills (e.g., use of analogies, drawing conclusions, inferencing), using materials such as magazines, articles, videos, television and radio programs, and other relevant items
- present real-life situations: ask the person to identify the problems, solutions, and consequences of solutions; evaluate the pros and cons; and identify how the person feels in the situation
- use functional activities to develop practice in categorization, sequencing, prioritizing, and outlining (e.g., following a recipe)
- train caregivers and communication partners to speak simply and strategically
- ask the person to explain stories, jokes, and situations (using materials of interest)
- encourage and stimulate any form of oral expression
- establish a purposeful response to speech (e.g., “yes” and “no”) if cognition is severely limited
- use cues to enhance comprehension (e.g., short questions, simple directions)

#### ***Behavioural***

- be aware of triggers (antecedents) for behavioural outbursts
- minimize environmental overstimulation when a person begins to become agitated (e.g., dim light, turn off television and radio)
- develop behavioural contracts if cognitive status allows

**Motor**

- use mobility device such as a cane (supervision may be necessary to direct use of the device)
- use verbal and physical cues to initiate rote movements and activities
- provide assistance to the bathroom to decrease episodes of incontinence, if reaction time is slowed or person is unable to attend to bathroom needs
- for low-volumed voices, train to use breath support, phrasing strategies and amplification

**Memory**

- post signs to reduce purposeless wandering, loss of energy, and frustration with disorientation
- use dosettes labelled with time of day or meal, if person has difficulty with self-administration of medications
- provide a verbal cue or a watch with an alarm to help the person remember when medications are due
- use a variety of cues to build sustained, simultaneous, shifting, and selective attention
- maintain a routine to which the individual is accustomed and can function with the least amount of support and assistance from others (when orientation is impaired, times and dates are easily confused)
- use functional tasks (e.g., letters, lists, diaries) — this also improves connected narrative writing
- provide memory books with categories
- develop internal facilitatory strategies (e.g., cues, drawings, repetitions)
- use cueing hierarchy, delayed repetitions and naming strategies to improve word-finding
- use photos, written words, and gestures to compensate for anomia

**Physical environment**

- ensure that frequently used items are consistently put back in the same place (this will facilitate more independent functioning in addition to providing a cue in itself)

**Other**

- help individuals and their caregivers and support network to be more aware of the above strategies, thereby encouraging their use
- differentiate between hearing loss and receptive language problems, and refer to audiological services for hearing evaluation and devices as required

**Community Resources**

Community organizations may provide the following resources:

- buddy programs
- hospital and home visitation programs
- community day care programs
- equipment loan programs
- caregiver support groups
- respite and home care programs
- community mental health programs
- legal and advocacy services
- wandering patient registries (through local police departments)



## Visual Loss

Infection of the retina with cytomegalovirus (CMV) is by far the most common cause of visual loss in people living with HIV. CMV retinitis almost always occurs late in the disease course, once the CD4 count has dropped below 100. Signs and symptoms of CMV retinitis commonly include loss of visual field, floaters, and cloud-like white patches in the visual field. Photophobia or light sensitivity are less common.

When entire visual fields are lost (e.g., homonymous hemianopsia), lesions of the central nervous system are more likely to occur (see Table 6.7). Complaints of diplopia are most likely associated with problems with the cranial nerves controlling eye movements. It is important to remember that other, non-HIV-related disease processes (e.g., diabetes mellitus) can also result in visual loss.



**Any abrupt change in vision should result in immediate referral to an ophthalmologist with expertise in HIV.**

### Referrals

Referrals to the Canadian National Institute of the Blind should be made whenever any visual problem is diagnosed.

**Table 6.7 Clinical Aspects of Visual Loss**

Category	Causes and Considerations
Retinitis, choroiditis	<ul style="list-style-type: none"> <li>• CMV</li> <li>• toxoplasmosis, cryptococcus, <i>Pneumocystis carinii</i></li> <li>• acute retinal necrosis due to HSV, VZV</li> </ul>
Retinal detachment	<ul style="list-style-type: none"> <li>• primary</li> <li>• secondary (CMV)</li> </ul>
Primary retinal vascular disease	<ul style="list-style-type: none"> <li>• immune complex disease</li> <li>• microaneurysms</li> <li>• ischemic maculopathy</li> <li>• diabetic retinopathy</li> </ul>
Malignancy	<ul style="list-style-type: none"> <li>• Kaposi's sarcoma</li> <li>• Burkitt's lymphoma of the orbit</li> <li>• metastatic malignant melanoma</li> </ul>
Cranial nerve abnormalities	<ul style="list-style-type: none"> <li>• many potential causes including most causes listed above</li> <li>• central (e.g., PML)</li> <li>• peripheral (e.g., mononeuropathy)</li> </ul>
Cerebral lesions	<ul style="list-style-type: none"> <li>• occipital lobe disease</li> </ul>
Drug-induced	<ul style="list-style-type: none"> <li>• high-dose rifabutin</li> </ul>
Pre-existing disease	<ul style="list-style-type: none"> <li>• cataracts, glaucoma</li> <li>• refractive abnormalities</li> </ul>

### Legend:

**CMV:** cytomegalovirus

**HSV:** herpes simplex virus

**PML:** progressive multifocal leukoencephalopathy

**VZV:** varicella-zoster virus

## Rehabilitation Interventions

### Mobility

- ensure that the environment is free of obstacles
- ensure that lighting is good
- close cupboards and doors
- keep paths clear for safety during ambulation
- orient the person to the environment and inform the person of any changes to the environment, even if they appear insignificant to the sighted person
- use a support cane to assist with depth perception for stairs, curbs, detection of obstacles, and changes in level (if person is unsteady)
- use a sighted escort (proper techniques can be taught to caregivers, friends, family, and volunteers)

### Activities of Daily Living

#### ***Enhancing vision***

- refer for oculo-visual assessment
- use magnifiers
- compensate for peripheral vision
- wear an eyepatch, if double vision is a problem
- install proper lighting, including night lights
- use larger print size
- use black print on a light background to add contrast
- use large push-button telephones

#### ***Finances***

- order and fold money in wallet by denomination
- know exact amount of money being carried
- ask sales clerk to identify bills when giving change
- pay with bill closest to amount
- use direct debit and phone systems for regular expenses (reduces need for signature guides and templates for signatures)

#### ***Environment***

- keep personal items tidy, organized, and in a consistent location to reduce the need for assistance and labelling
- encourage caregivers to return things to the same place
- program names and phone numbers into phone systems
- make use of phone company service providing listings through operator assistance
- organize clothing by colour or texture
- use safety pins or tags to distinguish between similar items
- organize food in cupboards and refrigerator by type and date of expiration (“first in, first out”)
- use night lights

#### ***Meal preparation***

- organize work space and materials
- adequately label dials and controls on appliances
- conduct safety assessment

- use preparation tips (refer to occupational therapist and the Canadian National Institute for the Blind for assistance)
- use assistive devices (e.g., knife or slicer guide, liquid level)

### ***Shopping***

- organize lists according to store layout
- use magnifiers or penlights for reading labels
- ask store clerks for assistance
- use a volunteer to do shopping
- have items delivered

### ***Medications***

- organize by time of day
- identify containers by shape and size
- identify containers by using elastic bands, magnetic tape, coloured tape, or marked contrasts in labels
- contact the pharmacy to explore possibility of alternative packaging (e.g., bubble packs)

### ***Other***

- talking books (available through libraries)
- voice print (available through cable companies)
- technological aids (e.g., computer software) that enhance vision or permit the use of voice commands

## **Psychosocial**

- counselling and psychotherapy specifically to cope with feelings that may result from vision loss, such as: confusion, distress, anxiety, depression, rage, and “why me” thoughts (many people have a specific fear of going blind or dying blind)

## **Community Resources**

The following resources are available through the Canadian National Institute for the Blind:

- assessment and counselling
- keyboard skills
- orientation and mobility instruction
- visual aids
- adaptive and technical aids
- money management instruction
- library services



## Cardiac and Respiratory Impairments

RED FLAG

*Chest pain and new or acute shortness of breath are medical emergencies which require immediate medical evaluation.*

There are many etiologies for heart and, especially, lung problems in HIV infection, including bacterial, fungal, viral, and parasitic pneumonias (see Table 6.8). Pulmonary Kaposi's sarcoma can cause severe respiratory impairment. Lymphoma and other primary lung tumours can also cause significant decline in respiratory status. Pulmonary emboli are seen with surprising frequency in people living with HIV.

**Table 6.8 Clinical Aspects of Cardiac and Respiratory Impairments**

Category	Causes and Considerations
Endocarditis	<ul style="list-style-type: none"> <li>• bacteria</li> <li>• fungi</li> </ul>
Cardiomyopathy	<ul style="list-style-type: none"> <li>• viral pathogens</li> <li>• AZT-induced</li> </ul>
Pericarditis	<ul style="list-style-type: none"> <li>• infections (e.g., TB)</li> </ul>
Pre-existing lung disease	<ul style="list-style-type: none"> <li>• restrictive lung disease</li> <li>• post-pneumonia fibrosis</li> <li>• chronic obstructive lung disease (e.g., cigarette smoking, recurrent bronchitis or pneumonia)</li> <li>• bronchiectasis</li> <li>• reactive airways disease</li> </ul>
Acute lung disease	<ul style="list-style-type: none"> <li>• infections (e.g., PCP)</li> </ul>
Psychological	<ul style="list-style-type: none"> <li>• anxiety</li> <li>• panic disorder</li> </ul>
Tumours	<ul style="list-style-type: none"> <li>• Kaposi's sarcoma</li> </ul>

**Legend:**

**AZT:** zidovudine

**PCP:** *Pneumocystis carinii* pneumonia

**TB:** tuberculosis

## Rehabilitation Interventions

For cardiac conditions, traditional cardiac rehabilitation programs can be used. The interventions listed below are for pulmonary conditions.

### To Mobilize Secretions and Improve Lung Ventilation

#### *Traditional manual physiotherapy techniques*

- manual or mechanical percussion and vibration
- lateral costal facilitation
- intercostal muscle massage
- rib springing
- nasopharyngeal or oropharyngeal suctioning

#### *Strategies a client can perform independently*

- postural drainage
- autogenic drainage
- incentive spirometry
- positive expiratory pressure (PEP) mask
- deep breathing and coughing exercises
- aerobic exercise
- energy conservation techniques, including use of adaptive equipment (e.g., walker, reacher)

### For Aspiration

- consult a speech-language pathologist for a comprehensive swallowing assessment
- based on the assessment results, ensure client is prescribed the appropriate diet textures and is following the recommended feeding guidelines
- also consider specific exercises and manoeuvres, and postural and other compensatory strategies. A coordinated team approach involving rehabilitation providers, medical and nursing staff, and a nutritionist is essential for successful outcomes

(When intervening for aspiration prevention, it is especially important to consider quality of life and concomitant conditions which may impact on overall oral intake [e.g., oral lesions, GI conditions, effects of medications, depression].)

### For Shortness of Breath and Associated Anxiety

- use pursed lip breathing
- focus on exhale, prolong three times as long as inhale
- sit with upper extremities supported on table or knees
- relax or “drop” shoulders and arms
- massage the trapezius and sub-occipital muscles
- employ relaxation techniques (e.g., visualization and imagery, progressive muscle relaxation, use of tapes, music)

### Exercise

- develop activities of low intensity and long duration

(Exercise guidelines are directly related to the type and severity of the lung condition. Therefore, it is important to consult with the individual’s physician.)



## Oxygen Requirements

- consult a respiratory therapist
- check oxygen saturation at rest and on activity
- if home oxygen is required, ensure appropriate carrier is provided (e.g., liquid oxygen canister with shoulder strap)
- assess need for mobility aid with seat and basket for oxygen



## Community Resources

Community organizations may provide the following resources:

- exercise and nutrition programmes
- buddy programmes
- equipment loan programmes
- home care rehabilitation services

It may also be helpful to check out programs sponsored by the local heart and stroke organization and the local lung organization.

## Reference

1. DeLisa JA (Ed.). *Rehabilitation Medicine: Principles and Practice*. Second edition. Philadelphia PA: Lippincott, 1993

## Suggested Readings

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# Pediatric Interventions



This chapter describes rehabilitation interventions specific to children and infants living with HIV. The chapter covers impairments related to:

- feeding problems and poor growth
- movement and coordination
- behaviour, memory, and learning
- the respiratory system

The text for each impairment area starts with a general description of potential contributing disease processes. A table providing information on the clinical aspects of the impairment area follows. Finally, a detailed list of rehabilitation interventions is provided.

## RED FLAG

### What are Red Flags?

Red flags located throughout this chapter highlight particularly important clinical symptoms that indicate the need for immediate direct contact with a physician.

## Introduction

### Play

*Play is the child's work,  
learning, and therapy.*

The management of HIV infection in children and infants presents significant challenges for rehabilitation providers. An important consideration is the impact of HIV infection on the family. In many cases, diagnosis of HIV infection in the child or infant may be the first indication of HIV infection in the mother and other family members. The skills of each member of the rehabilitation team are required to address the complex psychosocial and physical needs of the child or infant and his or her family. Although many of the rehabilitation interventions described in Chapter 6 are relevant to children and infants living with HIV, there are some unique considerations for children and infants; these are described in this chapter.

For more information on dealing with complex psychological issues in caring for children living with HIV, please refer to *Infants, Children & Youth: Module 2*, and *Psychosocial Care: Module 6*. For more information on effective management of pain for children and infants, please consult *Palliative Care: Module 4*.



**S**arah, 4, has been infected with HIV from birth. At the time of her diagnosis, she appeared well and her developmental milestones were normal. However, by age 1, despite her ability to crawl, Sarah was not pulling herself to a standing position; when supported in an upright position, she was not able to place her feet flat on the floor. Although Sarah's CD4 and lymphocyte count was within normal range for her age, she was started on AZT because of her developmental delay. Sarah made some progress. However, she never reached her age-appropriate milestones. At age 2, Sarah was admitted to the hospital with cough, anorexia, and fever. A chest x-ray showed bilateral infiltrates and a bronchoscopy showed no evidence of PCP but grew cytomegalovirus (CMV). Sarah was also diagnosed with CMV in her right eye and was treated with ganciclovir.

Sarah has had several admissions with fever, severe anemia, and presumed CMV pneumonia. Her developmental delay has become more pronounced with regression. Her verbal language is limited and her skills in understanding are lagging. She is spastic, particularly in her lower limbs, cannot dorsiflex her ankles, and has trouble opening her hands and grasping objects.

## Feeding Problems and Poor Growth

Infants and children living with HIV are at high risk for malnutrition, which can have a negative effect on immunity and make it harder to fight infections. Malnutrition causes a lack of weight gain, poor growth, and even weight loss. Interventions are primarily focused on preventing malnutrition. This can be achieved if there is early detection of either weight loss or a falling off from age- and sex-corrected growth percentiles. The height and weight of children and infants living with HIV should be plotted on appropriate growth curves at regular intervals.

The many causes of malnutrition include poor appetite, nausea, vomiting, diarrhea, mouth sores, and depression (see Table 7.1). When an infant or child has a secondary infection, his or her caloric needs may be higher than normal. Gastroesophageal reflux and delayed gastric emptying are common problems in children with encephalopathy, and contribute to the risk of aspiration and increased incidence of vomiting, nausea, abdominal pain, and anorexia.

Other important factors that put an infant or child with HIV infection at risk for malnutrition include:

- feeding problems
- anorexia due to acute or chronic infection and illness
- health of parent(s) if infected with HIV
- financial resources of the family

The infant's rehabilitation providers need to address all of these issues.

### RED FLAG

*Any deviation from previously stable growth curves requires prompt medical assessment and intervention with supplemental nutritional strategies.*

### RED FLAG

*Any new gastrointestinal symptoms such as mouth sores, vomiting, or diarrhea require prompt referral for medical assessment.*

**Table 7.1 Clinical Aspects of Feeding Problems and Poor Growth**

Category	Causes and Considerations
<b>Inadequate feeding</b>	<ul style="list-style-type: none"> <li>• weak suck</li> <li>• poor coordination of breathing or swallowing</li> <li>• tires easily</li> </ul>
<b>Self-feeding problems</b>	<ul style="list-style-type: none"> <li>• unable to self-feed or tires easily</li> <li>• developmental delay or regression</li> </ul>
<b>Swallowing problems</b>	<ul style="list-style-type: none"> <li>• mouth sores</li> <li>• developmental regression</li> <li>• encephalopathy</li> </ul>
<b>Poor appetite</b>	<ul style="list-style-type: none"> <li>• anorexia, nausea, vomiting, fatigue, pain</li> <li>• decreased taste acuity</li> <li>• abnormal taste</li> <li>• side-effects of medication</li> <li>• psychosocial and emotional distress (e.g., separation, anxiety, depression)</li> </ul>
<b>Diarrhea</b>	<ul style="list-style-type: none"> <li>• malabsorption</li> <li>• medication side-effects</li> <li>• HIV enteropathy</li> <li>• altered gastric motility</li> <li>• infections (viral, bacterial, or parasitic)</li> </ul>
<b>Increased caloric demands</b>	<ul style="list-style-type: none"> <li>• hypermetabolic state (e.g., fever)</li> <li>• infections</li> <li>• HIV-related</li> </ul>



### Breast Feeding

*Because of the potential for maternal-to-infant transmission of HIV, breast feeding is not recommended for infants born to mothers with HIV/AIDS whenever safe alternatives exist. Instead, infants should be fed infant formula fortified with iron.*

## Rehabilitation Interventions

### Inadequate Feeding

- position (e.g., sidelying position) to maximize efficiency of bottle and spoon feeding
- use a nipple with larger hole when bottle feeding
- spoon liquid, if baby cannot suck
- use higher caloric infant formula as prescribed by a registered dietitian
- use infant cereal mixed with formula instead of water
- use oral stimulation techniques taught by a therapist to improve suck strength and the coordination of the suck, swallow, and breathe sequence

### Self-Feeding Problems

- use jaw control when bottle feeding or spoon feeding
- use adaptive cups that make it easier to drink
- use easy-to-hold finger foods
- use adaptive utensils and plates that make it easier to eat

### Difficulty Swallowing

- conduct a comprehensive feeding assessment regarding safety of different textures and consistencies and related aspiration risks
- maintain good dental hygiene
- avoid foods that are too salty, spicy, or acidic
- give soft, smooth, easy-to-chew foods
- use a straw for drinking, if mouth sores are present
- use food that is cold or at room temperature, if mouth sores are present
- provide thickened liquids, if thin liquids cause choking
- provide verbal or gestural cues to facilitate swallowing
- use a dry swallow after a normal swallow to clear any residue

### Poor Appetite

- use small, frequent meals
- use a higher caloric diet by choosing high-fat dairy products (if tolerated) and adding extra fat foods to table (e.g., butter, margarine, gravy, cream)
- give oral nutritional supplements
- give nutritional supplements via gastrostomy tube for anorexia

### Diarrhea

- treat infections, if present
- assess gastrointestinal motility and use appropriate medications as required
- use dietary interventions as recommended by a registered dietitian

### Increased Caloric Demands

- control fever with anti-pyretics
- identify and treat any contributing co-infections

## Movement and Coordination Impairments

A number of important and unique issues are involved when caring for children with impairments related to movement and coordination. The rehabilitation providers need to consider:

- the presence of encephalopathy and developmental delay
- spinal and corticospinal tract degeneration in children versus vacuolar myelopathy (affecting lateral and posterior columns) in adults
- the relatively rare occurrence of peripheral neuropathy in children

The common causes of movement and coordination impairments are shown in Table 7.2.



*Any acute loss of previously mastered skills or fluctuations in levels of consciousness require urgent medical assessment.*

**Table 7.2 Clinical Aspects of Movement and Coordination Impairments**

Category	Causes and Considerations
<b>Encephalopathy, developmental delay</b>	<ul style="list-style-type: none"> <li>• HIV infection of brain</li> <li>• malignancies (e.g., CNS lymphoma)</li> <li>• CNS infections (less common in children than adults) (e.g., CMV, Candida)</li> </ul>
<b>Cerebral vascular disease</b>	<ul style="list-style-type: none"> <li>• Vasculitis</li> </ul>
<b>Spinal cord lesion</b>	<ul style="list-style-type: none"> <li>• HIV-related spinal or corticospinal tract degeneration</li> <li>• Wallerian degeneration from white matter disease</li> <li>• spinal cord infections (e.g., CMV, HSV)</li> <li>• malignancies (e.g., lymphoma)</li> </ul>
<b>Myopathy (infrequent in children)</b>	<ul style="list-style-type: none"> <li>• AZT-related</li> </ul>
<b>Peripheral neuropathy (infrequent in children)</b>	<ul style="list-style-type: none"> <li>• infection-related</li> <li>• drug-induced (e.g., AZT, ddl)</li> </ul>

### Legend:

**AZT:** zidovudine

**CMV:** cytomegalovirus

**CNS:** central nervous system

**ddl:** didanosine

**HSV:** herpes simplex virus

## Rehabilitation Interventions

### Generalized Hypotonia and Delayed Achievement of Motor Milestones from Static Encephalopathy

- promote motor activity through play, positioning, and handling (e.g., neuro-developmental therapy)
- develop muscle strength and transitional movements
- use infant seats or chair inserts (to promote sitting)
- have infant in a variety of physical positions with only enough support to provide appropriate positioning (e.g., sitting, supine, lying prone, on side, supported standing)

### Hypertonicity from Progressive Encephalopathy

- use tone-inhibiting positioning and handling
- use splints or ankle foot orthoses
- promote motor activity through play, positioning, and handling (e.g., neuro-developmental therapy)
- develop muscle strength and transitional movements

### Problems of Limited Mobility from Encephalopathy or Neuropathy

- use a wheelchair (with seating insert if required)
- practise selective muscle strengthening, maintaining range of motion
- practise gait re-training
- practise balance re-education
- practise transfers and transitional movements
- assess for walking aids, splints, orthoses

### Loss of Independence in Self-Care

- install adaptations to home or school (e.g., bath seat, ramps)
- use diapers or special toilet seat

## Behaviour, Memory, and Learning Impairments

Encephalopathy can be the primary manifestation of HIV infection in children and can be characterized by developmental delays, delay or loss of motor skills and intellectual abilities, and behavioural anomalies. In infants and young children, language acquisition and use may also be significantly impaired. Although profound encephalopathy is seen in some children, the degree of disability is variable. The trend of decline may be static, slowly or rapidly progressive, or intermittently progressive.

Many of the common causes of behaviour, memory, and learning impairments are shown in Table 7.3.

Clinical studies have identified frequent patterns of neurological involvement in children infected perinatally. These patterns include:

- microcephaly
- cognitive deficits
- cerebral atrophy
- calcification of the basal ganglia
- delay or loss of developmental milestones
- abnormal reflexes
- electroencephalogram abnormalities

Confounding factors that may contribute to the observed developmental abnormalities include:

- secondary infections
- poor prenatal care
- repeated hospitalizations
- social isolation
- neglect
- nutritional deficiency
- disrupted social routines
- medication side effects
- effects of maternal substance use

In non-perinatally acquired HIV among older children and adolescents, cognitive symptoms are more similar to those manifested by adults. These include decreases in reaction time, attention, and memory, as well as general psychomotor slowing. It is often difficult to ascertain the extent to which these changes are caused by the HIV infection itself, as well as how much is secondary to general feelings of fatigue.

Early identification is a critical factor in maximizing the efficacy of treatment for developmental delays. It allows for timely assessment and for implementation of a suitable rehabilitation program.



*Any acute loss of already mastered skills requires prompt medical referral to rule out a co-infection or opportunistic infection.*



**Table 7.3 Clinical Aspects of Behaviour, Memory, and Learning Impairments**

Category	Causes and Considerations
<b>Developmental delays</b>	<ul style="list-style-type: none"> <li>• HIV encephalopathy</li> <li>• other congenital infections (e.g., cytomegalovirus)</li> </ul>
<b>Motor spasticity or hypotonia</b>	<ul style="list-style-type: none"> <li>• basal ganglia calcifications</li> </ul>
<b>Poor or absent expressive language</b>	<ul style="list-style-type: none"> <li>• HIV</li> <li>• diminished opportunities to use expressive language</li> <li>• hearing loss</li> </ul>
<b>Poor socio-adaptive skills</b>	<ul style="list-style-type: none"> <li>• developmental delays</li> </ul>
<b>Poor memory</b>	<ul style="list-style-type: none"> <li>• HIV</li> <li>• fatigue</li> </ul>
<b>Poor learning</b>	<ul style="list-style-type: none"> <li>• HIV</li> <li>• fatigue</li> <li>• pre-existing learning problems</li> </ul>
<b>Poor attention</b>	<ul style="list-style-type: none"> <li>• HIV</li> <li>• fatigue</li> <li>• attention deficit disorder</li> <li>• pain</li> </ul>
<b>General slowness</b>	<ul style="list-style-type: none"> <li>• HIV</li> <li>• fatigue</li> </ul>
<b>Irritability and frustration</b>	<ul style="list-style-type: none"> <li>• HIV</li> <li>• inability to make self understood</li> <li>• pain</li> </ul>

## Rehabilitation Interventions

### Infants

#### ***Slow acquisition of developmental milestones***

- consider developmental testing using standardized psychological measures
- use infant stimulation programs using bright, interesting toys (to stimulate infant to participate in play)
- provide play materials that stimulate a variety of senses (e.g., toys that have different textures; toys that roll, bounce, and make noises; water and sand play)
- provide a variety of play opportunities both within the home and in settings where the child is exposed to other people, environments, and situations (e.g., playgroup)
- consider early enrollment in group activities to provide opportunities for peer modelling, as well as respite for parents

#### ***Poor or absent expressive language***

- administer standardized language measures
- provide an abundance of speech examples by talking to the infant about everything in his or her environment
- pause in conversations with the infant to allow him or her to respond with some kind of verbal utterance
- provide labels for everything and encourage modelling or sound approximations
- do not anticipate the infant's every wish. Allow the infant to use what language he or she does have (e.g., if the infant gestures and grunts, do not immediately hand the infant the desired item; first attempt to encourage the infant to use a word or sound)
- expand on the infant's utterances (e.g., when the baby says "juice," the caregiver can say "You want some juice?")
- as the infant learns words, ask open-ended questions instead of those requiring only a yes or no response
- assess for hearing loss, a common cause of language delay in children
- initiate assessment by a speech language pathologist

### Children

#### ***Poor memory***

- conduct neuropsychological assessment
- repeat instructions and verbal reminders
- present materials in various forms (e.g., visual, verbal)
- support verbal information with written information
- use cues to help remember (e.g., use of a watch alarm to remind child when to take pills)
- use lists when more than one thing is required of the child
- use a daily agenda book containing all important information for the day (for older children)
- give the child simple, one-step instructions and ask the child to repeat the directions to be certain that he or she has understood the instructions accurately

***Attention and learning***

- administer standardized tests
- have remedial classes in areas of difficulty
- provide tutoring or give extra help in areas of difficulty
- set aside specific time (e.g., 30 minutes every night after dinner) to work on assignments in a quiet environment (if there is no homework, the child can use the time for a quiet activity such as reading)
- set short-term goals and use reward system when the child attains goals (e.g., stickers, stars)
- review learned material frequently
- have preferential seating to avoid distractions (e.g., away from windows, doors, and noisy classmates and at the front of the class near the teacher)
- allow for sufficient rest times during the day to ensure maximum alertness and ability to participate in the school day

## Respiratory Impairments

Respiratory tract problems are among the most frequent complications in children living with HIV. Common respiratory tract infections include:

- recurrent acute and chronic otitis media
- recurrent thrush
- sinusitis
- pneumonitis

Table 7.4 shows some of the common causes of these types of infection.

A common form of pneumonitis in children is lymphoid interstitial pneumonia, a chronic disease characterized by spontaneous exacerbations, intermittent wheezing, and chronic cough. The chest x-ray pattern varies often, showing migrating interstitial infiltrates. In some cases, the pattern is difficult to distinguish from tuberculosis. Although *Pneumocystis carinii* pneumonia occurs less frequently as a result of widespread prophylaxis, it remains one of the most common presenting infections in children not previously diagnosed with HIV infection, and in children unable to tolerate prophylactic treatment.

### RED FLAG

*Any acute changes in respiratory status (such as increased respiratory rate, difficulty breathing during minimal exertion, change in sputum colour, or fever) may indicate a significant infection requiring urgent medical assessment and treatment.*

**Table 7.4 Clinical Aspects of Respiratory Impairments**

Category	Causes and Considerations
Otitis media	<ul style="list-style-type: none"> <li>• bacterial</li> <li>• viral</li> <li>• serous exudate</li> </ul>
Thrush	<ul style="list-style-type: none"> <li>• yeast</li> </ul>
Sinusitis	<ul style="list-style-type: none"> <li>• viral</li> <li>• bacterial</li> </ul>
Pneumonitis	<ul style="list-style-type: none"> <li>• PCP</li> <li>• LIP</li> <li>• desquamative interstitial pneumonitis</li> <li>• bronchiolitis obliterans</li> <li>• nonspecific pneumonitis</li> <li>• viral or bacterial pneumonia</li> <li>• bronchiectasis</li> </ul>

### Legend:

**LIP:** lymphocytic interstitial pneumonitis

**PCP:** *Pneumocystis carinii* pneumonia

## Rehabilitation Interventions

### General

- positioning to maximize ventilation perfusion matching
- relaxation techniques
- breathing control exercises (where relevant)

### Deep Breathing Exercises

- diaphragmatic breathing
- bubble blowing (promotes an excellent breathing pattern and is also fun for the younger child to do)
- use of an incentive spirometer for children over five years of age

### Manual Techniques

- postural drainage
- percussion
- vibration
- neurofacilitation techniques

### Expiry Techniques

- forced expiry technique (FET)
- positive expiratory pressure (PEP)

(The PEP mask and FET techniques are appropriate for children over five years of age. PEP requires the patient be competent to use a mask or mouthpiece and perform 15 minutes of breathing exercises and coughing techniques.)

Manual physiotherapy techniques or the PEP mask should be used only if there is a clear indication that a superimposed acute or chronic lung disease process is present with evidence of lower airway secretions. Those patients with only upper airway secretions do not require manual physiotherapy techniques; they need suctioning only if they are unable to clear their own secretions with coughing.

**Special note for hemophiliacs:** Manual techniques such as percussion and vibrations are a relative contraindication in hemophiliacs due to their underlying bleeding disorder. Their bleeding problems are often compounded by low platelets. The PEP mask and FET techniques could be used instead for those children over five years of age. Positioning and suctioning (if necessary) are recommended for younger children. The risks and benefits of manual techniques need to be considered for each individual.

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# Vocational Rehabilitation

This chapter discusses emerging issues regarding vocational rehabilitation and return-to-work decisions for people living with HIV. The chapter covers the following topics:

- why it is important to use caution when approaching the subject of returning to work
- return-to-work principles
- factors that people living with HIV should consider before deciding to return to work
- issues around income security and health and disability insurance
- vocational rehabilitation programming
- the role of AIDS service organizations



## Basic Tenets

The approach to the topic of vocational rehabilitation in this chapter is based on three basic tenets:

- HIV is a cyclical disease with no known cure
- HIV vocational rehabilitation is unlike conventional vocational rehabilitation
- the individual's long-term goals are the primary consideration

## Introduction: A Cautionary Note

Recent advances in the clinical treatment of HIV have meant improved health and longevity for many people living with the disease. As a result, returning to or remaining in the work force despite HIV-related disabilities is a rapidly emerging issue. Individuals who have left work and are receiving benefits may be concerned about the risk of losing these benefits if they return to the work force. Little research has been done to assess the work force participation needs of this population or to evaluate the ability of existing public- and private-sector programs to respond to the needs of people living with HIV.

People living with HIV are advised to carefully assess the impact of returning to work and to consult widely before making a decision on whether to re-enter the work force. People living with HIV may want to consider daily activity options outside the paid work force, such as voluntary work or education and training. These productive daily activities may provide some of the same therapeutic benefits of the paid work force without endangering private or public disability benefits.

People living with HIV-related disabilities who want to work must be able to exercise that option and must be able to access appropriate vocational rehabilitation programs. When addressing vocational rehabilitation for people living with HIV, it is important to understand the clinical, psychosocial, economic, and infrastructural issues that affect the possibility of employment. Employment history, workplace accommodation, human resource policies (including sick leave), and other workplace environmental factors must also be considered, along with legal and human rights issues (e.g., the “reasonable accommodation” provisions in human rights and disability laws). As well, it is important to keep in mind that an increasing number of people living with HIV have little or no history of work force participation.

Rehabilitation professionals should not assume that vocational rehabilitation is an integral component of HIV rehabilitation, despite potential pressure from private or public insurers. It is critically important that the person living with HIV be the one to decide whether to pursue vocational rehabilitation as a therapeutic option. Because HIV-related disability is often cyclical, rehabilitation service providers should also be aware that traditional vocational rehabilitation programming needs to be adapted to fit the needs of this population.

Individuals currently considering returning to work represent a relatively small portion of the overall HIV population in Canada. Because the long-term efficacy of current treatments is unknown and no cure is in sight, it is important not to overemphasize the effectiveness of current treatments in returning people back to full working capacity. As well, clinical data is inconclusive on the effectiveness of immune reconstitution, even among people who respond well to combination therapy.<sup>1-3</sup> While the therapeutic value of returning to the work force is an important consideration, work also entails additional stressors which may have a detrimental impact on the health and quality of life of people living with HIV.



## Return-to-Work Principles

Consumers, clinicians, and representatives from community-based organizations in Canada and the United States have developed principles to help guide program development, advocacy, research, and education on this issue. These principles, listed below, are followed by a more detailed discussion of crucial issues and questions related to work force participation and vocational rehabilitation.

### Key Principles

- the issue of returning to work must be addressed within the broader context of health
- the person living with HIV must be at the centre of the decision-making process
- decisions about whether to return to work should be made by the person living with HIV, free from coercion
- returning to work should be an option available as part of the continuum of care
- return-to-work programs and services must be flexible and responsive to the individual's experience
- service providers should not make assumptions about the capacity of “hard-to-reach” populations, or the ability of any group to participate in, or benefit from, return-to-work services
- the person living with HIV must control medical confidentiality in correspondence with employers and private or public payers
- private and public payers cannot base return-to-work decisions solely on existing surrogate markers (such as CD4 count and viral load)

### Factors to Consider

Some people disabled by HIV may be able to return to work, or may want to engage in other kinds of productive daily activities. Although the process of returning to work may seem overwhelming and daunting, the many positive psychological, emotional, social, physical, and financial aspects of employment may be sufficient to overcome these barriers. A number of factors relating to physical or psychosocial health may have an impact on a decision whether to undertake vocational rehabilitation and seek employment or other productive daily activities.

The following is a partial list of physical and psychosocial health factors.

### Determinants of Health

*A number of factors, often referred to as determinants of health, contribute to overall health. These factors include:*

- *stable housing*
- *health care*
- *nutrition*
- *income security*
- *psychosocial support*
- *physical environment*
- *safety*
- *access to appropriate employment*

## Physical Health Factors

### Clinical

- how the individual's current health compares to his or her health at the time of the decision to leave work (some individuals experience improved health upon terminating employment)
- the extent to which work may be a stressor, with effects such as disruptions in sleeping and eating
- how access to medications and maintenance of therapeutic regimens (including medical appointments and follow-up) will be accommodated
- the extent to which constitutional symptoms (e.g., diarrhea, nausea, fevers) will be manageable
- whether the individual has sufficient stamina to tolerate the physical demands
- whether fatigue may compromise the regular daily activities (this factor can be more significant if the job involves considerable transportation time to get to and from work)
- whether the individual has experienced visual changes and changes in the ability to communicate which could affect his or her performance on the job
- whether the individual has experienced balance, coordination, or dexterity changes that could have an impact on job safety or his or her ability to do the job

### Cognitive and Behavioural

- the extent to which the individual retains skills such as concentration, memory, planning, problem-solving, dealing with pressure and change, and decision-making and organizational ability
- the extent to which the individual's mood stability, emotions, and reactions are appropriate to the situation
- whether the individual has appropriate coping skills, life skills, and social skills
- whether the workplace has supportive networks

### Environmental

- whether the workplace has hazards that may have an impact on health
- whether modifications to the physical workplace (such as changing the layout of equipment) are required and can be arranged
- whether task modifications (such as changes in job structure or work schedules) are required and can be arranged
- whether there is an opportunity to gradually take on the job demands (either by increasing the complexity of the task over time, or by moving from part- to full-time hours)
- whether self-employment or working from home is a viable option
- whether there is a risk of losing one's job after returning to work

## Psychosocial Health Factors

Psychosocial health factors are as important as physical health factors in determining the extent to which an individual is ready and able to return to work. Given the ambiguity of their health status, people living with HIV may be confused about what their goals are, and how they should plan for the future. Career goals can change dramatically, not only as a result of an HIV diagnosis, but also as a result of renewed health status. A wide variety of psychosocial factors should be considered, including:

- the fact that work requires substantial amounts of energy and time
- the extent to which stress associated with the workplace will have a negative impact on health and quality of life
- the risk of experiencing stigma once back in the workplace (e.g., resulting from having to explain one's absence from work, or from the failure to keep the individual's health status confidential)
- whether the individual would experience greater self-esteem as a result of going off public assistance and into the work force
- whether the individual is prepared to cope with relocation or a change in jobs (in situations where the individual's previous job is no longer available)
- whether caring for children or other dependent family members is a consideration
- whether the individual is experiencing fear or anxiety associated with returning to work
- whether the individual is concerned about the potential for failure in the workplace
- whether returning to the work force will provide the stability of income needed for maintaining access to medications

## People to Consult

Given the number of factors involved in making the decision, people living with HIV who are contemplating returning to work may want to talk it over with others. Some of the key people to consult are:

- health care providers, particularly those supplying supportive documentation for public or private payers
- people from AIDS service organizations who assist with disability issues
- staff at HIV/AIDS legal clinics who may help to decipher the fine print in documentation
- family members and friends
- vocational counsellors or workers from vocational rehabilitation programs
- workplace resources such as human resources staff, direct supervisors, occupational health and safety committee members or staff, and union representatives
- case managers or benefits counsellors from the relevant public or private payer

Various academic or educational institutions may provide additional resources. These resources provide retraining or skills development, which may eventually lead to greater employment opportunities.

## Income Security and Health and Disability Insurance

Because income status closely mirrors health status, people living with HIV should be able to pursue their education and employment goals without sacrificing financial security.<sup>4</sup>

**It is critically important that returning to work not jeopardize the income security or health insurance of people living with HIV.** However, the reality is that decisions to re-enter the work force can have a profound impact on long-term health insurance or disability benefits. It is important for people living with HIV, rehabilitation professionals, and other care-givers to be aware of this reality. What follows is a general description of income security and health and disability insurance issues. For individual cases, complete information on the implications of work force decisions should be obtained from the relevant government agency or private insurer.

Today, unfortunately, current income support programs in both the public and private sector present many barriers to effective, flexible work force participation, particularly for people with cyclical disabilities such as HIV. In Canada, the current patchwork quilt of federal and provincial or territorial income support programs — with differing rules and definitions governing health insurance, disability, and work force re-entry — make the issue of vocational rehabilitation a difficult one to navigate. Many individuals currently living with HIV are accessing public income assistance programs.

Provincial and territorial programs include health insurance that covers most or all of the cost of prescription drugs listed on provincial formularies, including many HIV/AIDS treatments. The drug coverage attached to social assistance benefits is critical to many people living with HIV who would otherwise be unable to afford the drugs. Many people have left work to go on social assistance precisely because they had no drug coverage at work. Drug coverage normally ends as soon as a person stops receiving public assistance, a factor which constitutes a potential barrier to returning to work. Accessibility to drug coverage and related health insurance must be carefully assessed before making work force decisions.

The programs described above are undergoing significant reforms in many jurisdictions. These changes may affect the benefit amount, eligibility requirements, and regulations governing continued receipt of benefits. As well, harmonization efforts between federal and provincial or territorial levels of government may have the effect of reducing the benefits that people living with HIV receive. People living with HIV and their care-givers need to know whether the regulations governing these programs allow an individual to participate in a vocational rehabilitation program and pursue employment without jeopardizing his or her benefits.

### Public Income Assistance Programs

These programs include:

- *Canada Pension Plan or Quebec Pension Plan disability benefits*
- *Employment Insurance sickness benefits*
- *provincial or territorial social assistance (welfare)*

A large number of people living with HIV are surviving on short- or long-term disability benefits from private insurers, many of whose policies do not include a vocational rehabilitation component. As well, private insurers often have stringent requirements concerning the amount of paid or unpaid work allowable under these policies. People living with HIV who are receiving benefits from private-sector income support programs, and who are contemplating a return to work, should get the answers to the following questions:

- Does the insurance program have a rehabilitation component?
- Does the program permit part-time or episodic work without threatening coverage?
- Are the insurance benefits portable (i.e., can the individual switch employers without jeopardizing benefits)?

## Vocational Rehabilitation Programming

Many existing vocational rehabilitation services were developed for different disability populations and may not be responsive to the needs of people with recurrent disabilities. To be effective, vocational rehabilitation programs must be sensitive to the range of psychosocial and clinical issues faced by people living with HIV, including the need for part-time or episodic employment. As well, programs need to address retraining or education for people who have been out of the work force for a significant amount of time or who have never been consistently employed.

Currently, few links exist among rehabilitation service providers, community AIDS organizations, disability organizations, and vocational rehabilitation providers. Those linkages will need to be established.

When assessing whether a particular vocational rehabilitation program is suitable for a person living with HIV who is contemplating returning to work, be sure to ask the following questions:

- Can the program be accessed by people living with HIV? (Many vocational rehabilitation programs are designed to take on the most severely disabled first and so may not be available to the HIV community.)
- Does the program have experience providing services to people living with HIV?
- Does the program provide for the possibility of gradual placement from part-time to full-time positions, or trial work periods?
- Does the program provide job counselling, matching, and placement for people who have a range of work experience and require a range of options in returning to work?
- Does the program provide counselling to address poor self-esteem and confidence, violence, fear, and confidentiality of serostatus?
- Is the program accessible to people dealing with substance use issues? (Employment can be an important component of a harm reduction model for such people.)

## Role of AIDS Service Organizations

Many community-based AIDS organizations advocate on behalf of individuals with provincial, territorial or federal income support programs. Some organizations address the employment needs of individuals living with HIV (through, for example, information seminars, benefits information, psychosocial counselling, financial and career planning, and vocational rehabilitation). In addition, some community AIDS housing projects offer vocational rehabilitation programs for individuals with no work history.

## Summary

Given what is at stake for people living with HIV, vocational rehabilitation must be addressed cautiously as a therapeutic option. To date, there is little research on the needs of the HIV population regarding work force participation. As well, current income support and disability programs in both the private and public sectors are not responsive to the needs of people with cyclical or episodic disabilities. Rehabilitation professionals and people living with HIV should obtain as much information as possible about the long-term consequences of re-entering the work force.

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# Preventive Rehabilitation



This chapter discusses the importance of preventive rehabilitation for people living with HIV, and covers the following topics:

- the role of exercise
- strategies for achieving optimal nutrition

## Resources

*Taking Care of Each Other, Vol. I<sup>1</sup> and II<sup>2</sup> are excellent resources on health promotion in the HIV movement.*

## Introduction

The goal of preventive rehabilitation is to prevent impairments, disabilities, and handicaps for which people are at risk as a result of being HIV-positive.

Preventive rehabilitation is a component of health promotion, which may be described as action by people to meet their own, self-determined positive health goals, pursued through personal, group, and community development in a context of supportive policies, resources, and environments.<sup>1</sup> The HIV community has a rich tradition of health promotion activities.

Most HIV/AIDS prevention and support programs in Canada have arisen from self-initiated community groups.<sup>2</sup> Thus, excellent opportunities exist for partnerships between rehabilitation professionals and community-based organizations to address issues of preventive rehabilitation.

Preventive rehabilitation encompasses a number of components which address the determinants of health. Two of them — exercise and nutrition — have been particularly well developed in the context of HIV disease.

## Exercise

Regular exercise is widely accepted as an integral component of optimal health. In HIV/AIDS, exercise has been shown to:

- relieve stress, and decrease anxiety and depression<sup>3-6</sup>
- increase muscle strength and cardiovascular fitness<sup>6-8</sup>
- improve immune function<sup>2,5,9</sup>
- improve self-image<sup>3</sup>
- improve bowel habits
- improve appetite
- improve sleeping patterns
- increase lean body mass
- provide social benefits and enjoyment

No precise exercise prescription guidelines for people living with HIV have yet been developed. However, recent research indicates that exercise training does not have a negative effect on CD4 cell count.<sup>6</sup> The best advice to give people living with HIV is:

- when starting an exercise program, inform your physician and rehabilitation providers
- start early and stay fit
- ensure an adequate warm-up and cool-down
- do what you can, and use common sense to decide how far you should go (if you have questions, consult your physician or exercise trainer)

A physical therapist can help design an exercise program.

In some communities, there are programs that combine exercising and group counselling.



## Nutrition

Optimal health for people living with HIV can only be achieved if nutrition is an integral part of preventive efforts. Preventive nutrition involves identifying those factors which lead to the state of being at nutritional risk and then reducing or eliminating them.

The goal of preventive nutrition is to provide the person living with HIV with the knowledge, resources, and capability to achieve and maintain an advantageous nutritional state. Achieving this state may be conceptualized as a function of dietary intake, nutrient absorption, and metabolism. Nutritional status is influenced by a broad range of interacting factors:

- human biology
- clinical condition
- lifestyle
- the social and physical environments in which people live

Disturbances in any of the components can lead to a state of malnutrition. While some controversy exists about what constitutes a healthy diet, particularly in relation to micronutrient supplementation, evidence to help define the concept of a healthy diet for persons living with HIV is accumulating rapidly.

Malnutrition and its complications can help to render a person susceptible to opportunistic infections, and reduce the effectiveness of and tolerance to medications and therapies. Furthermore, the accompanying fatigue, lean muscle mass wasting, and general malaise diminishes the quality of life and may result in decreased ability to perform daily living activities.

Practising preventive nutrition is better than playing catch-up. For example, prompt nutritional therapy, which monitors and detects loss of body weight (an indicator of protein-energy malnutrition and micronutrient deficiencies), is more effective than interventions initiated after severe wasting has occurred. With severe wasting, more intensive interventions are needed to stabilize and replenish lean muscle mass loss. As well, late-stage interventions are not always successful.

## Key Strategies for Optimal Nutrition

Five different strategies are described below. It is important to recognize that using one strategy on its own will have a limited effect. Maximum benefit is possible only by combining these strategies. As well, nutritional needs will vary with the stage of HIV disease.

### Achieve and Maintain Nutritional Adequacy

Recommended nutrient intakes<sup>10,11</sup> were established to identify the mean usual dietary intake of a population plus two standard deviations required to maintain health in an already healthy population. For people living with HIV, these recommended intakes and allowances are likely not sufficient to maintain

### Endurance

See Chapter 6 for information on acute illnesses or clinical events that can have an impact on endurance.



**Micronutrients include** vitamins and minerals.



**Macronutrients include** protein, fat, and carbohydrates.

health. However, at this time, no standardized and universally accepted nutritional recommendations have been developed for this population. Nevertheless, it is generally accepted that people living with HIV should prevent weight loss and lean muscle mass loss by maintaining energy and protein balance, and by taking at least a single daily multivitamin and mineral supplement.

### Monitor Nutritional Status

A comprehensive nutritional assessment should be done at baseline and again whenever the individual presents with significant new symptoms. A change in body weight is the most basic indicator of nutritional status that can be easily monitored by people living with HIV themselves. However, when used alone, this measurement can be deceptive because lean muscle mass loss and malnutrition can occur even in the absence of body weight loss. This can happen as a result of a relative increase in extracellular water and a decrease in intracellular fluid and protein.

Referrals to a clinical dietitian or nutritionist should be made in the following circumstances:

- the presence of dietary, anthropometric, clinical, or laboratory signs of macronutrient or micronutrient deficiencies or excesses
- the presence of symptoms with nutritional implications: fever, anorexia, weight loss or changes in body composition, loss of muscle strength, excessive fatigue, difficulty in swallowing, dementia, maldigestion/absorption, nausea, vomiting, diarrhea
- the presence of pediatric feeding difficulties, evidence of failure to thrive, or indications of poor growth
- when individuals have difficulty adjusting to complex drug regimens with dietary restrictions, or regimens with drug-nutrient interactions
- when people have questions about nutrition-based complementary therapies or adherence to cultural or religious dietary patterns
- when people have food allergies or intolerances, or are avoiding food groups without appropriate dietary compensation
- when people have concurrent conditions requiring nutritional intervention (e.g., pregnancy, diabetes, cardiovascular disease)
- when infant formula regimens are initiated

### Implement Safe Food, Water and Sanitation Practices

People living with HIV should ensure that they adequately cook animal foods; use only pasteurized dairy products and purified water; avoid cross-contamination of raw and cooked or uncooked foods; and are aware of risks associated with some fruits and vegetables. It is also important to follow kitchen sanitation and safe food storage practices. People living with HIV should be educated about hidden or unrecognized sources of contamination when eating out.

### Establish a Reliable Supply and Variety of Food

Nutritional status is closely linked to dietary intake. If dietary intake is impaired due to lack of available food, the most effective strategy is a combined intervention by social workers, AIDS service organization workers, and nutritionists.

## Explore Use of Nutrition-Based Complementary Therapies

A large proportion of people living with HIV use complementary therapies, many of which are based on dietary modifications and nutritional supplementation. Although peer-reviewed evidence to support or refute many of the claims for these therapies is lacking, most can be classified into three broad categories:

- beneficial
- unknown benefits and risks, but unlikely to cause harm
- harmful

People living with HIV should be encouraged to discuss the complementary therapies of interest to them. Therapies which incorporate healthy nutritional practices should be reinforced. However, caregivers and people living with HIV should be cautious about therapies:

- which suggest the exclusion of an entire food group or a large number of foods within a food group without replacement from other sources (e.g., some macrobiotic diets)
- which involve unsafe food and water practices (e.g., consumption of raw or undercooked meat)
- where the costs interfere with the ability to otherwise maintain an appropriate food budget (e.g., multiple nutritional supplements)

## References

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2. Trussler T, Marchand R. *More Reflections on Taking Care of Each Other: health promotion in community based AIDS work*, vol. II. Vancouver BC: AIDS Vancouver, 1994
3. Chesney MA, Folkman S. "Psychological impact of HIV disease and implications for intervention." *Psychiatric Clinics of North America* 1994; 17: 163-182
4. Lawless D, Jackson CG, Greenleaf JE. "Exercise and human immunodeficiency virus (HIV-1) infection." *Sports Medicine* 1995; 19: 235-239
5. LaPerriere A *et al.* "Exercise and psychoneuroimmunology." *Medicine and Science in Sports and Exercise* 1994; 26: 182-190
6. LaPerriere A *et al.* "Change in CD4+ cell enumeration following aerobic exercise training in HIV-1 disease: possible mechanisms and practical applications." *International Journal of Sports Medicine* 1997; 19 Suppl. 1: S56-61
7. Spence DW *et al.* "Progressive resistance exercise: effect on muscle function and anthropometry of a select AIDS population." *Archives of Physical Medicine and Rehabilitation* 1990; 71: 644-648
8. MacArthur RD, Levine SD, Birk TJ. "Supervised exercise training improves cardiopulmonary fitness in HIV-infected persons." *Medicine Science in Sports and Exercise* 1993; 25: 684-688
9. Nehlsen-Cannarella SL, Nieman DC, Balk-Lamberton AJ. "The effects of moderate exercise training on immune response." *Medicine and Science in Sports and Exercise* 1991; 23: 64-70
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11. Health and Welfare Canada. *Nutrient Recommendations: The Report of the Scientific Review Committee*. Ottawa, ON: Minister of Supply and Services Canada, 1990

## Suggested Readings

- American Dietetic Association. "Position of The American Dietetic Association: Food and water safety." *Journal of the American Dietetic Association* 1997; 97(2): 184-189
- American Dietetic Association and Canadian Dietetic Association. "ADA Reports — Position of the American Dietetic Association and the Canadian Dietetic Association: Nutrition intervention in the care of persons with human immunodeficiency virus infection." *Journal of the American Dietetic Association* 1994; 94(9): 1042-1045
- Calbrese LH, LaPerriere A. "Human immunodeficiency virus infection, exercise and athletes." *Sports Medicine* 1993; 15: 6-13
- Murphy S. *Healthy Eating Makes a Difference: A Food Resource Book for People Living with HIV*. Canadian Hemophilia Society. Montréal QC, 1996
- Pronsky ZM. *Food Medication Interactions*. Pottstown PA: Food-Medication Interactions, 1995
- Watson RR (Ed.). *Nutrition and AIDS*. Boca Raton FL: CRC Press Inc., 1994



## Occupational Exposure to HIV

### General Information

HIV is transmitted through unprotected sexual intercourse, exposure to blood, blood components or bloody body fluids, perinatally from mother to child, and through breast milk.

The risk of occupationally acquired HIV infection through exposure to intact skin or mucous membranes is too low for an accurate estimate. The greatest risk of occupationally acquired HIV infection is from exposure to blood or bloody body fluids through a hollow bore needle which has been in an artery or vein of a source patient who has a high viral load.

### Body Fluids Infectious for HIV

- blood
- cerebrospinal
- amniotic
- pericardial
- peritoneal
- pleural
- synovial
- seminal
- vaginal
- penile secretions
- breast milk
- inflammatory exudate
- human tissue

and any other body fluids which contain visible blood.

## Body Fluids Not Infectious for HIV

- stool
- urine
- tears
- saliva

Note: If these non-infectious body fluids contain blood, they may be infectious.

If someone is potentially exposed to HIV, the person should contact his or her occupational health department, or the emergency department within one or two hours to assess the need for antiretroviral prophylaxis.

## Guidelines for Preventing Occupational Exposure to Any Infection

The following steps are recommended:

- wash hands well
  - use warm running water
  - use moderate amount of soap
  - vigorously rub hands together, including between fingers, around nails and wrists
  - rinse well
  - dry hands with a paper towel
  - turn the tap off using the paper towel to grip faucet handle
- wear protective apparel when anticipating contact with blood or bodily fluids
- use needles and other sharps safely, and dispose of them safely in biological waste
- use appropriate respiratory precautions

## Suggested Reading

“CDC Update: Provisional Public Health Service recommendations for chemo prophylaxis after occupational exposure to HIV.” *MMWR* 1996; 45: 468-72.



This section contains a list of primarily national organizations involved in HIV care or rehabilitation, plus a list of printed materials specifically on rehabilitation and HIV disease.

## Canada

Canadian Association of Physical Medicine and Rehabilitation

Tel.: 613 730-6245

Fax: 613 730-1116

E-Mail: [capm&r@rcpsc.edu](mailto:capm&r@rcpsc.edu)

Internet: <http://www.capmr.medical.org>

Canadian Association of Nurses in AIDS Care  
c/o Casey House Hospice Inc.

Tel.: 416 962-7600

Fax: 416 962-5147

Internet:

<http://www.nursing.ucalgary.ca/CANAC.ACIS>

Canadian Association of Occupational Therapists

Tel.: 613 523-2268

Fax: 613 523-2552

E-Mail: [cvonzeck@caot.ca](mailto:cvonzeck@caot.ca)

Internet: <http://www.caot.ca>

Canadian Association of Social Workers

Tel.: 613 729-6668

Fax: 613 729-9608

E-Mail: [casw@casw-acts.ca](mailto:casw@casw-acts.ca)

Internet: <http://www.intranet.ca/~casw-acts/>

Canadian Home Care Association

Tel.: 613 569-1585

Fax: 613 569-1604

E-Mail: [chca@travel-net.com](mailto:chca@travel-net.com)

Internet: <http://www.travel-net.com/~chca>

Canadian National Institute for the Blind

Tel.: 416 486-2500

Fax: 416 480-7503

E-Mail: [nat-rehab@east.cnib.ca](mailto:nat-rehab@east.cnib.ca)

Internet: <http://www.cnib.ca>

Canadian Psychiatric Association

Tel.: 613 234-2815

Fax: 613 234-9857

E-Mail: [cpa@medical.org](mailto:cpa@medical.org)

Internet: <http://cpa.medical.org>

Canadian Psychological Association

Tel.: 613 237-2144

Fax: 613 237-1674

E-Mail: [jservice@cpa.ca](mailto:jservice@cpa.ca)

Internet: <http://www.cpa.ca>

Canadian Physiotherapy Association

Tel.: 613 742-5427

Fax: 613 742-5428

E-Mail: [physiotherapy.ott.ca@ibm.net](mailto:physiotherapy.ott.ca@ibm.net)

Internet: <http://www.physiotherapy.ca>

College of Family Physicians of Canada

Tel.: 905 629-0900

Fax: 905 629-0893

E-Mail: [info@cfpc.ca](mailto:info@cfpc.ca)

Internet: <http://www.cfpc.ca>

Dietitians of Canada

Tel.: 416 596-0857

Fax: 416 596-0603  
E-Mail: [centralinfo@dietitians.ca](mailto:centralinfo@dietitians.ca)  
Internet: <http://www.dietitians.ca>  
Canadian Pediatric Society  
Tel.: 613 526-9397  
Fax: 613 526-3332  
E-Mail: [webmaster@cps.ca](mailto:webmaster@cps.ca)  
Internet: <http://www.cps.ca>

### United States

American Academy of Physical Medicine and Rehabilitation  
Tel.: 312 464-9700  
Fax: 312 464-0227

E-Mail: [rweakland@aapmr.org](mailto:rweakland@aapmr.org)  
Internet: <http://www.aapmr.org>

American Congress of Rehabilitation Medicine  
Tel.: 847 375-4725  
Fax: 847 375-4777  
E-Mail: [acrm@amctec.com](mailto:acrm@amctec.com)  
Internet: <http://www.acrm.org>

American Dietetic Association  
Tel.: 312 899-0040  
Fax: 312 899-1979  
E-Mail: [cdr@eatright.org](mailto:cdr@eatright.org)  
Internet: <http://www.eatright.org>

The Rehabilitation Accreditation Commission (CARF)  
Tel.: 520 325-1044

Fax: 520 318-1129  
E-Mail: [cmacdonell@carf.org](mailto:cmacdonell@carf.org)

Internet: <http://www.carf.org>

Tel.: 613 567-1817  
Fax: 613 567-4562

### Canada

Canadian AIDS Society  
Tel.: 613 230-3580  
Fax: 613 563-4996  
E-Mail: [casinfo@cdnaids.ca](mailto:casinfo@cdnaids.ca)  
Internet: <http://www.cdnaids.ca>

Canadian Hemophilia Society  
Tel.: 514 848-0503  
Fax: 514 848-9661  
E-Mail: [chs@odyssee.net](mailto:chs@odyssee.net)

Canadian Aboriginal AIDS Network

Canadian HIV/AIDS Legal Network  
Tel.: 514 451-5457  
Fax: 514 451-5134  
E-Mail: [info@aidslaw.ca](mailto:info@aidslaw.ca)  
Internet: <http://www.aidslaw.ca>

Community AIDS Treatment Information Exchange  
Tel.: 416 944-1916 / 800 263-1638  
Fax: 416 928-2185  
E-Mail: [info@catie.ca](mailto:info@catie.ca)  
Internet: <http://www.catie.ca>

### United States

National Association of People With AIDS  
Tel.: 202 898-0414



Fax: 202 898-0435

## Canada

Addiction Research Foundation

Tel.: 416 595-6079

Fax: 416 595-6591

E-Mail: [acliffor@arf.org](mailto:acliffor@arf.org)

Internet: <http://www.arf.org>

Hospital for Sick Children

Tel.: 416 813-1500

Fax: 416 813-5032

Internet: <http://www.hscweb.sickkids.on.ca>

National AIDS Clearinghouse

Canadian Public Health Association

Tel.: 613 725-3434

Fax: 613 725-1205

E-Mail: [aidssida@cpha.ca](mailto:aidssida@cpha.ca)

Internet: <http://www.cpha.ca/CPHA/ch/ch.html>

Positively Fit Program

Victoria AIDS Respite Care Society

Tel.: 250 384-2366

Fax: 250 380-9411

Positive Living

Metro Central YMCA

Tel.: 416 975-9622 x5354

Fax: 416 324 4222

Internet: <http://www.ymcautoronto.org>

The Wellesley Central Hospital

Tel.: 416 926-7728

Fax: 416 926-5000

## United States

National AIDS Clearinghouse

Centers for Disease Control

Tel.: 301 519-0459

Fax: 301 519-6616

E-Mail: [cdcnaac@aspensys.com](mailto:cdcnaac@aspensys.com)

Internet: <http://www.cdcnac.org/>

## Printed Materials

Galantino ML (Ed.). *Clinical Assessment and Treatment of HIV: Rehabilitation of a Chronic Disease*. Thorofare NJ: Slack Press, 1991

Johnson JA, Pizzi M (Eds.). *Productive Living Strategies for People with AIDS*. New York NY: Haworth Press, 1990

Mukand J (Ed.). *Rehabilitation for Patients with HIV Disease*. New York NY: McGraw-Hill, 1991

O'Dell MW (Ed.). *HIV-Related Disability: Assessment and Management. State of the Art Reviews: Physical Medicine and Rehabilitation*. Volume 7 (Special Issue). Philadelphia PA: Hanley & Belfus, Inc., September 1993

**Note:** The modules in the series *A Comprehensive Guide for the Care of Persons with HIV Disease* are listed in the Preface.