14. HIV and rehabilitation

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The impact of living with HIV disease can make certain everyday tasks and activities difficult. This chapter discusses rehabilitation services for people living with HIV and offers some suggestions about how to lessen the physical, mental, emotional and social challenges of living with this disease.

Living with the challenges of HIV

Do you or people you know have health-related problems due to living with HIV or side effects of HIV treatment? Perhaps you have tingling or numbness in your feet, pain in your legs or arms, or feel weak and tired when you try to stand, climb stairs or walk for any length of time. Maybe you can’t feel the temperature of the water in the bathtub or shower.

Are you finding it harder to concentrate or focus on your activities the way you used to, forget things more easily, and/or find it more difficult to work or visit with friends?

Many of these problems were described in Chapter 11, Side effects and symptoms. Maybe they don’t happen all the time, but perhaps they are happening more often than before. Some people may say, “Oh, I’m just getting older,” (which is true for all of us), but it also may be that the impacts of living with HIV are making it more difficult to do the things you want to do.

It doesn’t have to be this way; there are people and supports that can help you. This chapter about rehabilitation will suggest ways to reduce many of the health- and life-related challenges of living with HIV.

Perhaps there are activities you can no longer participate in or which you can no longer do.

You know better than anyone that living with HIV presents many challenges. These may include challenges to your physical, mental, emotional or social health, and may be due to HIV infection itself or its associated treatments. Perhaps there are activities you can no longer participate in or which you can no longer do.

A disability is a health-related challenge that interferes with meaningful, active living.

You may not think of these as disabilities. Most people think of a disability as a permanent physical condition, such as a spinal cord injury that results in paralysis. But, in the world of rehabilitation, disability is a much broader concept. A disability is a health-related challenge that interferes with meaningful, active living.

Disabilities fall into three main categories:

- Physical or mental challenges: for example, symptoms that include pain, fatigue, diarrhea, numbness or
tingling, reduced sex drive (libido), decreased memory, changes in body fat distribution and speech or language difficulties.

- Difficulties with day-to-day activities: for example, walking, climbing stairs, carrying groceries, standing for a long period of time or taking a bath.
- Social participation restrictions: for example, difficulty working, participating in social activities or relationships.

Most disabilities related to HIV are episodic—they come and go.

While some people living with HIV have chronic (long-term) disabilities, most disabilities related to HIV are episodic—they come and go. You may have experienced this—periods of wellness and then periods of illness. These episodes may occur daily (you have good days and bad days), or include more major health changes (such as an infection that results in hospitalization). Often, you may have no way of knowing how you will feel from one day or week to the next, what kinds of health challenges you’ll experience, or how long they will last. The uncertainty of not knowing when an episode might arise and how severe that episode might be are challenges commonly faced by people living with HIV.

In addition, since anti-HIV drugs are helping people to live longer, you may begin to experience common diseases of aging such as heart disease, diabetes, cognitive changes and arthritis. No matter whether these other conditions are caused by HIV, your anti-HIV drugs or the aging process, they can still compound the physical and mental challenges of living with HIV.

Questions for your healthcare team

This list covers some of the health challenges that rehabilitation services can help with. If you are experiencing any of the health challenges below and are not sure how to answer any of the following questions, speak with your healthcare team to learn more:

- What can I do to deal with fatigue, pain and other physical symptoms?
- Where can I get support to help me with:
  - personal care and household chores?
  - the impact of HIV on my financial situation?
  - my feelings about having HIV?
  - the way my family and friends respond to HIV?
  - the way my partner and I deal with my HIV?
- What kinds of exercises will help me?
- Are there any assistive devices or types of equipment that could help me?
- Where can I get more information about HIV and how to manage it?
- Do I understand the impact of HIV on my employment, income support and extended healthcare benefits?
- Should I talk with my employer and colleagues at work about HIV—and how?

What is rehabilitation?

Rehabilitation is about helping people to manage their health problems. It also means providing support so that people can be included in their communities while continuing to live as independently as possible.

Rehabilitation is any service or activity that can address or prevent the health-related challenges (or disabilities) that people living with HIV might face. Rehabilitation is an important component of the best care for many common diseases such as arthritis, heart disease and diabetes. In these diseases, rehabilitation is not only used as a treatment, but also to prevent new conditions from developing, or current ones from worsening. Research has shown that rehabilitation interventions like stress management, maintaining a healthy weight and regular exercise can prevent or reduce the severity of many diseases. So it makes sense that rehabilitation can be helpful for people living with HIV at any stage, in periods of both wellness and illness.

But rehabilitation is about much more than diet, weight management and exercise. Rehabilitation is about helping
people to manage their health problems. It also means providing support so that people can be included in their communities while continuing to live as independently as possible. Rehabilitation services can include physiotherapy, occupational therapy or speech–language therapy, as well as complementary or alternative therapies such as acupuncture, massage therapy and counselling.

How can rehabilitation services help me?

To address the different types of health-related challenges you may face, there are several different types of rehabilitation and rehabilitation providers.

Physical rehabilitation

Some of the challenges you face may be caused by physical changes in your body.

A physical therapist (physiotherapist) can work with you to develop strategies that can help you with:

- managing or reducing pain, numbness or tingling sensations;
- feeling less tired;
- strengthening your muscles;
- improving movement in your joints;
- maintaining or improving your flexibility, balance and co-ordination;
- building your activity tolerance;
- learning to use a walker if you need one.

An occupational therapist can help you learn to manage your daily activities and make adjustments in your home or workplace to allow for any physical changes you are experiencing. This could include:

- suggesting changes in your living or working space to accommodate any physical limitations you have;
- organizing your activities to assist with focus and memory;
- suggesting ways of organizing your days to conserve your energy;
- showing you how to use helpful aids or equipment;
- strategizing around complex medication schedules;
- determining how your family or other services in the community can support you.

A speech–language pathologist (speech therapist) can:

- help you with issues affecting communication and swallowing;
- help you to maximize oral and written communication skills for staying at or returning to work (for example, reading, writing and public speaking).

A physiatrist is a doctor who specializes in physical medicine and rehabilitation. A physiatrist can help you with:

- regaining movement or physical functioning you have lost;
- chronic pain;
- accessing any special tests or procedures.

Psychosocial rehabilitation and support

People living with HIV can experience stress, anxiety, depression, changes in sleep and appetite and reduced sex drive (libido). Self-esteem and relationships also can be affected.

Psychiatrists, psychologists, psychotherapists, occupational therapists and mental health counsellors can help by:

- providing therapy or counselling to help you cope with the emotional impact of HIV;
- suggesting strategies and techniques to relieve anxiety and stress;
helping you reduce feelings of stress and isolation;
connecting you with peer-support groups;
improving your self-esteem, maintaining personal relationships and support networks;
prescribing medication, if necessary (only doctors and psychiatrists can do this).

Social supports, such as friends, family, cultural and other community organizations, can also provide both emotional and practical support.

Some people with HIV also find that complementary or alternative therapies are helpful to address the many physical, mental or emotional challenges they face. These include:

- acupuncture;
- massage therapy;
- homeopathy;
- naturopathy;
- aromatherapy;
- chiropractic treatments;
- yoga, mediation, Tai Chi.

Some of these supports and therapies are discussed in more detail in Chapter 3, Your healthcare team, Chapter 5, Complementary and alternative therapies, and Chapter 6, Your emotional health.

Work-related issues

Staying in the workforce, or returning to the workforce after a period of illness, is often complicated if you have HIV.

- You may be concerned about how you will be treated if people find out you are HIV-positive.
- You may not know if or when to tell your employer about your HIV status.
- You may not want to leave your anti-HIV drugs where they might be found at work.
- You may not have the stamina to work full time, and your workplace might not be able to accommodate part-time hours.

If you have been on long-term disability benefits and return to work, you may be concerned about income or health benefits if you get sick again. Occupational therapists, vocational rehabilitation programs and some AIDS service organizations provide:

- counselling about income support, health and disability benefits;
- information about your legal rights;
- advocacy on your behalf;
- job search and interview support;
- training and employment counselling.

Rehabilitation professionals may work alone, but are commonly part of a larger team, including physicians, nurses, social workers, dieticians, pharmacists, substance use counsellors and community workers.

Rehabilitation professionals may work alone, but are commonly part of a larger team, including physicians, nurses, social workers, dietitians, pharmacists, substance use counsellors and community workers. It is important to talk to your doctor about all of the challenges you experience in your day-to-day life—physical, mental, emotional, financial or work-related. Many of these challenges can be addressed by various types of rehabilitation or support.

The basic components of a rehabilitation program

In rehabilitation, the person living with HIV is a central part of the process. Therefore, you will be encouraged to play an active role in your care. Rehabilitation is most effective when it includes a team approach that includes you, your
primary caregivers, rehabilitation providers, those who pay for your rehabilitation services (for example, your insurance program or company) and other agencies you may be involved with.

When you are referred to a rehabilitation service, you can expect the following:

- a baseline assessment of your areas of concern;
- a review of available information (for example, medical notes) from other caregivers—primary care or HIV community care providers;
- establishment of short- and long-term rehabilitation goals;
- an individualized rehabilitation plan to achieve those goals;
- monitoring of your progress towards your goals;
- referral to other services and agencies as needed or identified;
- discharge planning and co-ordination of services.

You may also be asked to evaluate the rehabilitation services you received.

Where are rehabilitation services provided?

The place where services are provided will depend on the services available, the medical stability of your illness and your desired and expected outcomes. Some of the more common settings are:

- hospitals;
- outpatient centres and clinics;
- the private practices of healthcare professionals;
- local AIDS service organizations;
- your own home;
- hospices;
- work settings;
- schools;
- wellness centres;
- community parks and recreation programs (for example, YMCAs);
- public health departments.

You will need an assessment and referral by a doctor to access many rehabilitation services.

How can I access rehabilitation services?

You will need an assessment and referral by a doctor to access many rehabilitation services. This is especially important if they are being paid for by your province's health plan or private insurance. If the service is provided by your local AIDS service organization, you probably won't need a referral, and it may be free.

Who pays for rehabilitation services?

The types of rehabilitation services paid for by public (government) health plans in Canada vary from province to province. Private (employer or individual) health insurance plans often cover some rehabilitation services, but there is usually a yearly maximum or a maximum per treatment, which may mean that you have to pay some of the costs with the insurance provider.

You will need to talk to your doctor, rehabilitation provider, human resource department, insurance company and/or local AIDS service organization to find out what is covered for you.

Some of the possibilities include:
Provincial health plan: If you receive rehabilitation services while you are in hospital, they are covered by your provincial health plan. If you continue to receive rehabilitation from the hospital in an ambulatory or outpatient clinic after you leave, it may also be covered.

Private insurers: Some rehabilitation services may be covered by your employer’s group health insurance plan (if you are still working or on disability benefits) or by private health insurance you purchased on your own. However, even if you have a plan through your employer, there are usually yearly maximums and sometimes only a portion of the cost is covered. Check your plan.

Sliding fee scales: Some rehabilitation providers have a sliding fee scale for people without insurance. Sliding scale means that the fee is based on the individual’s ability to pay.

HIV organizations: Local HIV organizations may provide some rehabilitation services for free.

Despite the importance of rehabilitation for people living with HIV and the increasing number of persons who may require rehabilitation, access to rehabilitation services continues to be a challenge across Canada. For example, some provinces have removed certain rehabilitation services from public coverage. This can create a significant burden for those individuals who can only access rehabilitation services through publicly funded channels.

Emerging issues in HIV and rehabilitation

Among the many emerging issues relating to HIV and rehabilitation, a few have been identified as particularly important to the overall health of people with HIV:

- income support and work;
- rehabilitation strategies you can start yourself;
- living with HIV and other conditions;
- managing your anti-HIV drugs and their side effects.

Income support and work

Many people living with HIV find it difficult to work or to work full time. If your health status is changing monthly or daily, work may not be possible for you or it may be difficult to accommodate. Income security (having a reliable and predictable source of income) is a major source of stress for many people living with HIV. It can have a major impact on your health. Many people must rely on health and disability benefits such as:

- Employment Insurance sickness benefits;
- long-term disability and extended health benefits (vision, dental, prescription drugs, physiotherapy, etc.) provided by employee group insurance plans;
- Canadian Pension Plan Disability Program;
- provincial disability and social assistance programs.

These benefits programs are described in detail in Chapter 20 (Money matters).

Rules and definitions vary between programs. Your local AIDS service organizations, occupational therapist or doctor may be able to provide you with information, explain what benefits you are entitled to and help you fill out any necessary forms. It is important to ask for this information and assistance. You have a right to this information; however, research has shown that many people do not receive this information unless they ask about it.

In addition to working with rehabilitation professionals, there are many important components of rehabilitation you can start yourself.

Rehabilitation strategies you can start yourself
In addition to working with rehabilitation professionals, there are many important components of rehabilitation you can start yourself. These include regular exercise, approaches for managing fatigue, such as energy conservation (see the Five Ps of energy conservation), and strategies to help with changes in your thinking and mental health.

**Five Ps of energy conservation**

If you have HIV, you may get tired easily. You can conserve or increase your energy level by following the Five Ps of energy conservation.

1. **Pacing**: Break large tasks into several smaller ones. Do some jobs today and some another day.
2. **Positioning**: Use correct posture and body positions while sitting, standing, taking part in recreational or other activities—even sleeping. Make sure beds, chairs, desks, tables and computer keyboards are at a comfortable height.
3. **Planning**: Make a list of things you have to do during the day. Plan to do the most difficult tasks when you’re feeling your best. Keep the work you need to do close by and organized.
4. **Priority setting**: Do only what you decide is most important. Eliminate less important things or ask someone to help you with them.
5. **Problem solving**: Increase your energy by asking yourself:
   • Is there an easier and better way of doing this? (Pushing instead of pulling; using two hands instead of one?)
   • Is there some device, such as an electrical appliance or piece of equipment that can make this job easier?
   • Do I really need to do this?

Some people experience changes to their brain, which can affect their thinking and their emotional state. You may find that your judgment, attention, focus, motivation and ability to deal with emotional situations have changed. You may also experience some form of depression, anxiety or difficulty coping with the life changes resulting from your illness.

Rehabilitation strategies that can help you with these changes include:

- using verbal or written cues or memory aids such as making lists, using a journal or calendar to help remember activities;
- developing a routine and structure to your time. For example, try to meet with someone for support on a regular basis;
- developing healthy coping strategies to assist with life situations.

Research studies have shown that aerobic and resistive exercise training is safe and may be beneficial for people living with HIV who are medically stable. While research has shown that exercise won’t boost your CD4+ cell counts or lower viral loads, it will not harm the immune system or worsen virological status for people living with HIV who are medically stable. Before you start to exercise, it is important to gear any exercise program to your physical capabilities and personal goals. Be sure to talk with your doctor, physical therapist or other healthcare provider to find out which program might be right for you. See Chapter 4, Healthy living, for more information on exercise.

Research has shown that regular aerobic or resistance exercise can:

- improve your strength;
- improve your cardiovascular fitness;
- improve and maintain your mood;
- help you to maintain a healthy weight.

Recommended exercises and activities include activities that use large muscles, such as those in your arms and legs. Rehabilitation professionals often recommend:

- exercising in water or swimming;
- walking;
- cycling;
- dancing.

Work up to exercising for a total of at least 30 minutes, three to five times a week. Regular exercise is the key to
success, but you don’t have to do it all at one time. Three 10-minute periods of exercise a day work just as well as one 30-minute session.

Walking can help you to build strong bones and prevent osteoporosis.

Exercising with hand and ankle weights or weight machines can increase your strength and reduce pain.

Some people find it easier to exercise in warm water. Many community recreation centres have warm water exercise programs. Pool programs geared towards arthritis or osteoporosis may be especially beneficial for persons living with HIV.

Living with HIV and other conditions

Many people with HIV will live a long time, thanks to new drug treatments. However, this may put you at risk for developing other conditions associated with aging, or other longer-term side effects of HIV treatments.

Additional conditions you may be faced with could include:

- musculoskeletal conditions, including joint problems (arthritis), muscle problems and thinning of the bones (osteoporosis);
- metabolic and endocrine conditions, including diabetes and increased cholesterol and triglycerides;
- cardiopulmonary system (heart and lungs) conditions. These conditions, for example, heart attacks and stroke, are the greatest cause of mortality for people living with HIV;
- neurological conditions including neuropathy (nerve pain resulting in loss of sensation or tingling) and cognitive difficulties (memory loss, difficulty concentrating).

Rehabilitation can play an important role in the management of all these conditions. You may also be able to access rehabilitation services targeted specifically to these conditions (for example, you may be able to access arthritis rehabilitation therapy services if you have a diagnosis of arthritis in addition to HIV).

Managing your anti-HIV drugs and their side effects

Several types of rehabilitation professionals can help you with the many aspects of managing your anti-HIV drugs:

- speech-language pathologists can help you with problems in swallowing your medications;
- occupational therapists or pharmacists can help you to develop strategies to deal with complex drug regimens (for example, using pill boxes and timers) and help you deal with the challenges of injectible HIV drugs;
- physical therapists can help you to deal with physical side effects of your drugs, such as peripheral neuropathy (numbness and tingling) and fatigue.

See Chapter 11, Side effects and symptoms, for more information on how to manage side effects that can be caused by anti-HIV drugs.

Your role on the rehabilitation healthcare team

You are an important part of the rehabilitation team and you may have to ask for these supports if your healthcare provider does not offer to connect you to them. It is important to maintain an up-to-date personal health record and to give this to your healthcare provider. Your personal health record should include a list of:

- medical conditions and surgeries from childhood to the present;
- all drugs, vitamins and herbal supplements you are now taking or have taken in the past and their dosage;
- all treatments you have had, and whether they were helpful or not.
When seeing a healthcare or rehabilitation provider, keep these things in mind:

- make notes with dates of any changes in your condition as well as any side effects from drugs;
- list any other treatments you have had since your last appointment;
- bring your health notes to your appointment;
- bring a family member or friend with you if you need help to remember the information discussed during your appointment;
- be on time for your appointment. If you need to reschedule, phone the office as far in advance as possible;
- tell your healthcare provider in advance if you may need a longer appointment than usual to discuss questions about HIV or your treatment.

Resources

Realize (formerly the Canadian Working Group on HIV and Rehabilitation) provides references for this chapter and links to a variety of resources and organizations related to HIV and rehabilitation.

Many other relevant resources can be accessed through the CATIE Ordering Centre or by calling CATIE at 1-800-263-1638.

About the author

Realize (formerly the Canadian Working Group on HIV and Rehabilitation) is a national, charitable organization that responds to the rehabilitation needs of people living with HIV/AIDS. The working group bridges the traditionally separate worlds of HIV, disability and rehabilitation. Through research, education and cross-sector partnerships, the group is working to improve the lives of people with HIV.
Disclaimer

Decisions about particular medical treatments should always be made in consultation with a qualified medical practitioner knowledgeable about HIV- and hepatitis C-related illness and the treatments in question.

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Production of this content has been made possible through a financial contribution from the Public Health Agency of Canada.

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