



Rehabilitation Can Help You Do That

**A guide to how rehabilitation services can help you deal
with your HIV-related challenges and live the life you
want**

E-guide Development Team

Patricia Solomon, PT, PhD

Professor and Associate Dean
School of Rehabilitation Science
McMaster University

Nicole Gervais

Research Coordinator
School of Rehabilitation Science
McMaster University

Nancy M. Salbach, PT, PhD

Associate Professor
Department of Physical Therapy
University of Toronto

Lynne Sinclair, PT, MA (Ad Ed)

Assistant Professor
Department of Physical Therapy
University of Toronto

Kelly O'Brien, PT, PhD

Assistant Professor
Department of Physical Therapy
University of Toronto

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Catherine Worthington, PhD

Associate Professor
School of Public Health & Social Policy
University of Victoria

Stephanie Nixon, PT, PhD

Associate Professor
Department of Physical Therapy
University of Toronto

Canadian Working Group on HIV and Rehabilitation

<http://hivandrehab.ca/EN/index.php>

Larry Baxter

HIV+ community volunteer
Volunteer with the Canadian Working Group on HIV and Rehabilitation

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Acronyms and Short Forms

ASOs – AIDS service organizations/HIV service organization

CATIE – Canada’s source for HIV and hepatitis C information

CBT – Cognitive Behavioural Therapy

COPD – chronic obstructive pulmonary disease

CWGHR – Canadian Working Group on HIV and Rehabilitation

HIV – Human immunodeficiency virus

OT – Occupational therapy or occupational therapist

OTC – Over the counter (medications that do not require a prescription)

PT – Physiotherapy, physiotherapist, physical therapy

RMT - Registered massage therapy or therapist

SLP – Speech-language pathology or pathologist

TENS - Transcutaneous electrical nerve stimulation

Glossary

Canadian Working Group on HIV and Rehabilitation (CWGHR): A Canadian organization started in 2007 to help address the rehabilitation needs of people living with HIV.

Disability: A word used by rehabilitation professionals to refer to the health-related challenges faced by the person they are helping.

Electrotherapy: The use of electrical stimulation on the body to reduce pain and/or increase function.

Episodic condition: A condition that causes you to have periods when you are feeling well mixed with periods when you are feeling unwell.

Lipodystrophy: changes to the way your body looks due to fat loss or fat gain in parts of the body.

Rehabilitation/Rehab: Any healthcare service that helps you prevent or deal with any health-related challenges you might face in your life.

Rehabilitation professional: A person that provides rehabilitation services. We focus on three main professions in this e-guide: occupational therapy, physiotherapy, and speech-language pathology.

Self-management: A set of actions a person living with a health condition may take to better cope with the effect of the condition on their health.

About this e-guide

Why was the e-guide developed?

To help HIV+ people understand what rehabilitation is.

The word rehabilitation can be confusing to some people. They may have heard the term in relation to recovering from drug abuse, and not be aware of the separate field of rehabilitation to overcome health-related challenges. Even those familiar with health rehabilitation may not know all about the services provided by rehabilitation professionals. This e-guide will give more information about this area of healthcare.

To help HIV+ people understand the role of rehabilitation in managing their health-related challenges.

There is often confusion about how rehabilitation can help people who are living with chronic or episodic conditions such as HIV. This e-guide will help you get a better sense of what rehabilitation professionals can do to help you manage your health-related challenges.

To help HIV+ people get access to rehabilitation services.

Not all family doctors or HIV specialists know how rehabilitation can help HIV+ people improve their health and their lives. This e-guide will help you, as a person living with HIV, learn about what rehabilitation can do, so that you can help your doctor or other specialists understand what you need.

To help HIV+ people better manage their health and adopt a healthy lifestyle.

Research shows that self-management leads to better health and well-being¹. This e-guide will share some self-management techniques that will allow you to be pro-active with your own health, and keep doing the things you want to do.

How was this e-guide developed?

This e-guide was inspired by an e-module developed for rehabilitation professionals. That module focuses on teaching rehabilitation professionals about HIV, and how their services can be helpful to HIV+ people. You can find it here:

http://hivandrehab.ca/EN/information/care_providers/documents/CWGHR_E-moduleEvidence-InformedHIVRehabilitationfinal.pdf

Feedback on this module was gathered during a research study. In this study, we asked a number of HIV+ people to review the information to see if they would find the information useful. HIV+ people said the information was useful, so we asked how we could make it easy for them and others living with HIV to find, understand, and use the information. We used the feedback to create this e-guide.

Using this e-guide

You can use this e-guide in several ways. If you have never worked with a rehabilitation professional before, and are not sure how rehabilitation can help, we recommend reading this e-guide through from beginning to end. If you are experiencing a particular symptom, or have interest in a particular rehabilitation professional, we recommend that you find that section first.

If you understand HIV and rehabilitation, this e-guide is a great place to turn to when you find yourself struggling with a new symptom or health-related challenge.

If you have trouble understanding any of the words we used in this e-guide, please use the glossary or acronym definition page. At the end of this e-guide, there is a list of rehabilitation resources. This is a good place to start if you want to learn more about HIV and rehabilitation.

Much of the information in this e-guide has been drawn from the earlier e-module. Some new information has been drawn from outside sources, and you will find references to this outside information in the e-guide.

We have worked hard to make this information available in different formats. You can review this e-guide or its separate chapters online at {web address}. You can also save it to your computer as a .pdf file. And finally, you can print it if you prefer a paper copy.

Note

When we link to any outside information (e.g., the CATIE website) the information will pop up in a new window, so you do not have to worry about losing your place if you click on these links.

Chapter 1 Getting Involved

Why should I be involved in my own care?

You are your own best champion when it comes to your health. You know your condition(s), your background, and your needs better than anyone else. Decisions about your care affect you more than anyone else. It is only natural to want to take an active part in your own care to ensure you receive the best possible services. The more involved you can be in your care, the better. If you find it difficult to get involved on your own, you can ask a family member, partner, or friend to help you. In some regions, there are also peers, health advocates, or health navigators to help you get more involved in your care (ask your local AIDS service organization or your doctor about these services).

How do I get involved in my own care?

Get active in your own care by learning and speaking up.

Learn!

- Learn about your conditions – HIV, and any other health conditions you might be facing.
- You can learn about your conditions by:
 - o Talking with healthcare professionals.
 - o Talking with staff at AIDS service organizations.
 - o Talking with staff at condition-specific organizations (e.g. If you are facing depression, you can contact people at the Canadian Mental Health Association).
 - o Attending talks and workshops at health organizations (e.g. “lunch and learns” at places like municipal public health departments) and AIDS service organizations.
 - o Reading pamphlets and handouts from clinics and AIDS service organizations.
 - o Looking online at reputable websites, such as CATIE (www.catie.ca) and CWGHR (www.hivandrehab.ca).
 - o Talking with HIV+ people that you trust.
- Stay up to date with health information. Health information is always changing as new research happens and practice evolves. Make sure you are paying attention to these changes. Revisit your information sources often to find out what is new.

Speak up!

- If you do not understand something a healthcare professional is telling you, ask them to explain it again, or in a different way. Ask them for references or websites you can check out for yourself.
- If you have questions about what a healthcare professional is doing, ask them.
- If you have questions about your condition or treatment, ask your healthcare provider.
- The Internet is a great place for suggestions on how to speak up for yourself. For example, Riverside Health Care² provides a list of good questions to ask healthcare professionals:
 - o Could you please explain that to me?

- Can I come back with my family, partner, or friend to talk about this again?
- How sure are you that I have this condition?

Chapter 2 What is rehabilitation?

- In this e-guide, we define rehabilitation as:
 - Any service that can address or prevent a range of health-related challenges (sometimes called disabilities) that people face.
 - An important part of good care for people with common chronic conditions such as arthritis, heart disease, and diabetes.
 - Care, treatment, and support, but also as prevention of certain conditions or worsening of current health problems.
 - Read more in the CWGHR's Rehabilitation Fact Sheet:
<http://hivandrehab.ca/EN/resources/documents/FactSheet-Patient-EN.pdf>

Who is part of the rehabilitation healthcare team?

There are many different rehabilitation professionals, each with their own specialities. In this e-guide, we are focusing on three rehabilitation professions: occupational therapy, physiotherapy, and speech-language pathology. These were chosen because there is little information available on their practice with HIV+ people at the moment.

Rehabilitation professionals can work alone, or as part of a team with other health or rehabilitation professionals. We will also describe some other professionals, such as physiatrists, dietitians, social workers, and vocational/employment counsellors, that can play a rehabilitation role in the lives of HIV+ people.

Nurses, nurse practitioners, pharmacists, family doctors, and psychiatrists/psychologists are some of the other people who might be part of a rehabilitation team, in roles that you are likely to be familiar with (e.g., prescribing medications, running tests, etc.).

Finally, the work of rehabilitation professionals can be used in conjunction with complementary therapies. Complementary therapies can be defined as “medical practices that fall outside conventional Western medicine.”³ These can include Eastern-based treatments, treatments that harness the mind-body connection, and touch-based therapies. Some of the common complementary therapies will be outlined.

Occupational Therapists

Occupational therapists work with you to build strengths and lessen barriers so you can engage more fully in all of the many roles you want to play in life. These roles may be related to your work, whether paid or unpaid (e.g., plumber or volunteer dog walker), your family and friends (e.g., partner, parent, friend, caregiver), your hobbies (e.g. knitter, golfer) or your day-to-day tasks (e.g., grocery shopper,

housekeeper, bather). For example, one person may have occupations as a cook, a friend, a dancer, and a traveller⁴.

List of services offered (please note that this list is not exhaustive)

- Assessment of;
 - possible safety problems in the home, such as tripping hazards
 - challenges with things you do every day (dressing, eating, getting in and out of the bathtub, etc.)
 - ability to carry out your activities in the workplace
 - cognitive health such as your memory, concentration, and ability to focus your attention
 - the home, to discover any barriers to effective living
- Treatments include:
 - Working with you to develop a reasonable set of short- and long-term goals.
 - Helping you to remove or work around barriers in the home.
 - Recommending orthotics (insoles to help foot and leg problems), braces, and other helpful tools.
 - Helping you get necessary tools (e.g., canes, walkers, orthotics, braces).
 - Giving you information about items that can help compensate for a decrease in ability (e.g. an inexpensive electric can opener if grip strength has decreased).
 - Helping you develop a schedule to conserve energy.
 - Helping you develop a plan to keep track of medications, doctors' appointments and other health-related needs.
 - Helping you develop plans to overcome challenges in your life (e.g., paying bills or remembering appointments).
 - Addressing health challenges related to memory and cognition (e.g., trouble remembering, thinking clearly, or concentrating).
 - Helping you develop new and easier ways of completing regular tasks (e.g. getting in and out of wheelchairs).
 - Helping you connect with organizations and resources that can help you live a richer life.
 - Helping to support you in being able to return to or stay at work (or volunteer job).
 - Working with you to improve or maintain your driving skills.

Please refer to the section of the Canadian Association of Occupational Therapists' website called, "What is Occupational Therapy?" (<https://www.caot.ca/index.asp>) for more information.

Physical Therapists (also called Physiotherapists)

Physical therapists work with clients to improve overall function and mobility. They may focus on different parts of the body, such as the lungs, muscles, nerves, and joints, so you can move more easily. Physical therapy treatments aim to decrease pain and swelling, and improve movement and fitness. This will help you to walk, do stairs, and engage in work, and other activities that are important to you.

List of services offered (please note that this list is not exhaustive)

- Assessment of;
 - muscle and joint injury
 - muscle weakness and tightness
 - problems breathing and coughing up fluids
 - decreased fitness or fatigue
 - problems with balance and muscle control
 - wounds and sores
 - chronic pain
 - problems with mobility (e.g., walking, standing up/sitting down, climbing stairs, etc.)
 - need for helping tools, such as walking aids (e.g., canes, walkers), orthotics or braces
 - the home, to discover any barriers to moving about safely
- Treatments include:
 - Working with you to develop a reasonable set of short- and long-term goals
 - Creating personalized exercise plans to restore or maintain normal functioning after injury or illness
 - Educating you to prevent health-related challenges from getting worse.
 - Helping you make plans to help you improve your mobility (e.g., walking, climbing stairs, and getting out to doctors' appointments, grocery store).
 - Providing soft tissue therapy techniques, such as massage.
 - Providing joint therapy techniques, such as spinal and joint mobilization and manipulation.
 - Providing acupuncture and electrotherapeutic therapy techniques, such as TENS or ultrasound.
 - Providing education on how to prevent injury and promote health.
 - Helping you get necessary tools (e.g., canes, walkers, orthotics, braces).
 - Helping you to remove or work around barriers in the home.
 - Helping you connect with organizations and resources that can help you live a richer life.

Please refer to the “Description of Physiotherapy” section of the Canadian Physiotherapy Association (www.physiotherapy.ca) website for further information.

Speech-Language Pathologists

Speech-language pathologists work with clients to improve the ability to swallow, and to communicate through speaking and writing. These are important skills that people need every day to eat, drink, work, and socialize.

List of services offered (please note that this list is not exhaustive)

- Assessment of;
 - new challenges in speech or language

- speech-fluency problems, such as stammering or stuttering
- tone or loudness of your voice
- challenges related to eating and swallowing
- problems communicating with others
- literacy skills
- Treatments include:
 - Working with you to develop a reasonable set of short- and long-term goals.
 - Providing education and practical exercises to overcome speech and language challenges.

Please refer to the “Speech Language and Swallowing” section of the Ontario Speech-language Association (<https://www.osla.on.ca/>) for more information.

Other people involved in rehabilitation

Physiatrists

Physiatrists are medical doctors that specialize in rehabilitation. They work to identify and treat people who have a disability.

List of services offered (please note this list is not exhaustive)

- Assessment of:
 - health-related challenges you may be living with
 - problems with the skeletal structure, such as arthritis and herniated disks
 - problems with nerves and muscles
 - soft tissue injuries
 - chronic pain
- Treatments include:
 - Working with you to develop a reasonable set of short- and long-term goals.
 - Requesting medical tests to help make a proper diagnosis.
 - Prescribing the necessary medications to ease pain and increase joint movement.
 - Prescribing orthotics, braces, and other helpful tools.
 - Providing an exercise plan that rebuilds strength and flexibility in an injured or weakened body part.
 - Providing a tailored activity plan that meets your fitness goals without causing further pain or injury.
 - Referring you to other rehabilitation professionals if needed.

Please refer to the “What is a Physiatrist?” section of the Canadian Association of Physical Medicine & Rehabilitation (<http://capmr.ca/>) website for more information.

Dietitians

Dietitians are responsible for developing and running a wide variety of food- and nutrition-based programs. The most important job of a dietitian for you is to create a healthy eating plan. Healthy eating helps the body function in the best way possible and can help to prevent disease.

For more information on dietitians, please visit the Dietitians of Canada website:

<http://www.dietitians.ca/>

Social Workers

Social workers address challenges in the lives of individuals (i.e. emotional, social or work life), families (i.e. changing relationships, grief/loss), or communities (i.e. teaching coping strategies). Social workers help clients to identify the root cause(s) of these challenges and to develop the skills and confidence to overcome them⁵. They also help you find the information you need and suggest where to find help from the community. Social workers can be especially important during times of transition (e.g., moving from hospital to home, or from homelessness to supportive housing), as they can help coordinate the services you need and work with you to manage your feelings about change. Social workers may also provide counselling and psychotherapy if you are experiencing challenges with mental health.

For further information on social work, please visit the Canadian Association of Social Workers website:

<http://www.casw-acts.ca/en>.

Vocational or Employment Counsellors

A vocational, or employment, counsellor helps clients with their working life. They can help if you want to go back to work, or if are working, but are worried about your future work life.

The vocational or employment counsellor works with you to overcome barriers to working, and recommends tools and routine changes that allow you to work to your full potential. These changes may include: updating your resume, building skills to prepare you for a new type of job, counselling you about requesting additional support from a current employer (i.e. flexible hours to attend medical appointments, the ability to work from home), or talking about whether or not you should disclose your HIV status in the workplace.

For further information on vocational counselling, please visit the Vocational Rehabilitation Association of Canada's website: <http://www.vracanada.com/>

Complementary Therapies

Important

Some complementary treatments may interact in unexpected ways with the medications you are taking, or the therapies you are undergoing. It would be a good idea to check with your HIV specialist or family doctor before exploring complementary therapies.

Acupuncture

Acupuncture providers usually have a background in a health-related field such as physical therapy or chiropractic, and special training in acupuncture. Acupuncture may decrease pain, increase energy, and improve mood and bodily function.

For more information on acupuncture, please visit the Canadian Contemporary Acupuncture Association's website: <http://www.contemporaryacupuncture.ca/index.php>

Chiropractic

Chiropractors work to assess, diagnose, and treat conditions in the muscular and skeletal systems without the need for surgery. They do this by performing various spinal manipulations, sometimes applying other treatments such as massage or acupuncture.

The noted benefits of chiropractic care include: relief from head, neck, or back pain; better posture, increased flexibility, prevention of muscle and joint injury, and an improved sense of well-being.

For more information, please visit the Canadian Chiropractic Association website: <http://www.chiropractic.ca/>

Massage therapy

Massage therapy eases muscles, ligaments, and joints of the body through the use of the massage therapist's hands or specialized tools. Massage therapy can be done alone or as part of a larger therapy plan. Registered massage therapists, physical therapists, and chiropractors can all provide massage therapy.

The goals of massage therapy are to reduce pain, improve joint movement, reduce muscle tension, and improve circulation.

Please see the Registered Massage Therapists of Ontario website for more information: <http://www.rmtao.com/home>

Naturopathy

Naturopathic medicine aims to blend modern medical science with traditional healing methods. It looks at the body as a whole, and treats issues by improving the flow of the whole. Naturopathic medicine

uses natural therapies including plants, food, and water to treat disease. Treatment is geared to each person, and may include diet and lifestyle changes, supplements, and traditional Chinese medicine.

For more information, please visit the Canadian Association of Naturopathic Doctors website:

<http://www.cand.ca/>

Chapter 3 How can rehabilitation help me?

Jump to:		
Breathing Challenges	Feeling Anxious	Memory Challenges
Digestive Issues	Feeling Low, Down or Depressed	Pain
Discomfort with Body Changes	Focus/Concentration Challenges	Sensory Loss
Fatigue	Insomnia	Weakness
Self Care	Home Care	Getting Around
Running Errands	Work or School Issues	Social Life Challenges

HIV+ people can face many challenges in their daily lives, either because of HIV or side effects of treatment, or for reasons unrelated to their status. The goal of rehabilitation for people with HIV is to help you improve your life and engage in active living by helping to:

- prevent health problems, or recover from or deal with health problems
- become or remain independent and self-sufficient
- improve or preserve ability to work, volunteer, and socialize
- improve physical and mental health and emotional well-being

One key thing about HIV is that rehabilitation and other healthcare professionals consider it an episodic condition. This means that many HIV+ people have times when they are feeling well, and other times when they are feeling unwell. These periods can happen within a day (e.g., having energy in the morning but feeling tired in the afternoon) or may happen over a longer period of time. Commonly reported challenges in a period of feeling unwell are fatigue, pain, and nausea, but any challenge might be faced. Sometimes these periods have a known cause, such as starting a new medication, but sometimes there is no obvious reason for it.

These periods of feeling unwell can cause uncertainty in some people. They have trouble making plans because they do not know if they will be feeling up to it. Or they may have a more general anxiety about the future because of it.

If you feel your challenges are episodic, please let your rehabilitation professional(s) know. In addition to the treatments for each challenge listed, rehabilitation professionals can help provide tips and suggestions for preventing or working through the periods of feeling unwell. They might also be able to give suggestions to help you deal with any uncertainty you face.

Important

In the following section, we outline possible issues that a HIV+ person may face. Please do not let it overwhelm you, as most people only face a few of these issues over their lifetime.

You should only start rehabilitation treatments after speaking with your primary care doctor, to rule out any new illnesses, such as diabetes or infections, which need medical treatment.

Note

The treatments listed on the next pages are examples only. Each rehabilitation professional will do an assessment and determine the best course of action based on each person's unique needs.

Physical Health

1. Pain

Pain is a common symptom reported by HIV+ people. Pain can be located in areas which may include (but are not limited to) the joints, muscles, stomach, or head. Treatment of pain must start with a careful assessment of cause. Here are some common treatments for general pain and pain from peripheral neuropathy:

a. General pain

- A psychiatrist may prescribe pain-killers, anti-inflammatories, or other medications.
- A physiotherapist can
 - use ultrasound or ice to decrease swelling which might be causing pain.
 - provide electrotherapy, which uses electrical stimulation on the body, to reduce pain and improve function.
- A physiotherapist or psychiatrist can provide exercises that can strengthen weak muscles and stretch tight muscles, which can relieve pain.
- A psychiatrist, physiotherapist, or occupational therapist can teach you about proper posture and other methods of movement to prevent further strain on the painful area of the body.
- Hydrotherapy can help ease tight muscles and stiff joints, and reduce pain. Physiotherapists or psychiatrists can determine if hydrotherapy is necessary.

Other Rehabilitation Therapies

- A social worker can help you work through any emotional issues that might arise from the pain, or may be contributing to the pain.
- A social worker or occupational therapist can teach you some techniques such as meditation or visualization to help you control your pain levels.

Complementary Therapies

- A naturopath can suggest supplements that might ease pain.
- Acupuncture can decrease pain for some people.
- Massage therapy can decrease pain by easing tight muscles.

- b. Pain resulting from peripheral neuropathy.* Peripheral neuropathy can cause pain and/or numbness in the hands and feet, which can lead people to trip and fall, and drop items. Treatments include those listed for pain above, plus;

- A physiotherapist can provide electrotherapy, which uses electrical stimulation on the body, to reduce pain and improve function.
- If the sense of touch is affected, an occupational therapist or physiotherapist can teach safety techniques to prevent burning the skin on hot items (e.g. drawing a bath or shower, handling hot beverages like coffee or tea).
- A physiotherapist or occupational therapist can create a plan that helps decrease sensitivity to pain.
- A physiatrist may recommend orthotics or other equipment to strengthen and support the affected body part.
- A physiatrist, occupational therapist, or physiotherapist can give suggestions around footwear that will reduce pain and irritation.
- An occupational therapist can provide home adjustment suggestions to prevent trips and falls.
- A physiotherapist can prescribe a cane or walker if balance has become an issue.
- An occupational therapist can help you get access to tools such as a cane or walker if balance becomes a concern.
- An occupational therapist can provide suggestions of gadgets that may help you to overcome difficulties with day to day tasks (e.g. electric can openers).

Other Rehabilitation Therapies

- A social worker or occupational therapist can
 - help you work through any emotional issues that might arise from the pain, or may be contributing to the pain.
 - teach you some techniques such as meditation or visualization to help you control your pain levels.

2. Fatigue and decreased physical fitness.

Fatigue can have many causes. Different causes need different treatments, so figuring out the cause will be the first step in any treatment plan.

- A physiotherapist can provide you with exercises that might raise energy levels.
- An occupational therapist can
 - work with you to create a plan for energy conservation and management. This involves setting priorities, scheduling your day building in rest breaks, and teaching you to recognize your limits.
 - do a home or workplace review, and suggest changes that will make tasks more efficient and less draining.
 - help you find outside assistance, such as meals-on-wheels programs.
- A physiatrist may prescribe medications such as testosterone or vitamin B12 to boost energy levels.

Other Rehabilitation Therapies

- A dietitian can work with you to build a healthy meal plan that can provide energy.
- A social worker can
 - help you work through any issues that may be contributing to fatigue.
 - help you find outside assistance, such as meals-on-wheels programs.

3. Weakness.

Several HIV-related illnesses can cause weakness. A long period of rest to recover from an illness or an inactive lifestyle can also cause weakness. Treatment focuses both on regaining strength, and avoiding further injury resulting from a weakened state.

- A physiotherapist can
 - provide an exercise routine to increase strength
- A physiotherapist or occupational therapist can
 - work with you to practice walking and climbing stairs to reduce worries about falls
 - help you figure out the best ways to stand, sit, and move to make the best use of your strength
 - help you get a cane, walker, or scooter if balance has become an issue
- An occupational therapist can
 - help you get access to the tools that you need to get around, such as a wheelchair or cane
 - do a home review to find potential hazards in the home. They can recommend tools and equipment to help, such as grab bars by the tub or shower
 - help you rearrange you home to minimize the energy needed to do day-to-day tasks, such as reorganizing a kitchen to make cooking easier
- A speech-language pathologist can
 - help with exercises to improve eating and drinking if the swallowing muscles have been affected
 - help with exercises if weakness has affected your speech

Other Rehabilitation Therapies

- A social worker can help you deal with the emotional impact of weakness or other life changes.

4. Nausea, diarrhea and other digestive issues

Many of the medications used in the treatment of HIV can cause problems with your digestion.

- A physiatrist can
 - prescribe medications (e.g. anti-nausea agents, appetite stimulants) to combat digestive issues
 - work with you to determine if there are any food allergies that can be causing issues

Other Rehabilitation Therapies

- A dietitian can
 - work with you to figure out why you feel unwell
 - recommend diet changes to remove triggers
 - help you replace lost electrolytes and vitamins
 - help you put together a meal plan to be sure you are getting the vitamins and minerals you need
 - recommend vitamins and/or supplements if needed

Complementary Therapies

- A naturopath can recommend supplements to improve digestion

5. Respiratory problems

Some HIV+ people will face some respiratory challenges, often due to smoking. Chronic obstructive pulmonary disease (COPD) among HIV + smokers is of particular concern.

- A physiotherapist or occupational therapist can teach you improved breathing techniques.
- An occupational therapist can teach you relaxation techniques to ease breathing.
- A physiotherapist, occupational therapist, or physiatrist can help you develop a physical activity plan that works with your lung strength.
- If oxygen is required, an occupational therapist can help you adjust to having to carry it with you.
- A speech-language pathologist can help if swallowing is also affected.

Complementary Therapies

- Massage therapy can ease muscles and help breathing.

6. Sensory Loss

Some HIV+ people, especially older adults, report some loss of their sense of sight, hearing, or touch.

- Sight
 - An occupational therapist can
 - do a home review to assess and overcome safety hazards

- help you get access to tools such as a magnifier, large button phones, and computer software that use voice commands
- work with your friends, family members, or caretakers to teach them how to help you get around better
- help you organize things in your environment (e.g. clothes, food, or money) to make it easier to find what you need
- recommend changes to your daily tasks to make your life easier, such as getting groceries delivered, or setting up auto-payment for regular bills
- All rehabilitation professionals can suggest community groups that can provide support, such as the Canadian National Institute for the Blind.

Other Rehabilitation Therapies

- A social worker can
 - help you work through the emotional impact of sight loss
 - recommend changes to your daily tasks to make your life easier, such as getting groceries delivered, or setting up auto-payment for regular bills

➤ Hearing

- A speech-language pathologist can
 - help you find ways to improve your communication with others, such as reducing background noises, learning how to read non-verbal cues, and learning how to lead the conversation⁶
 - help you make sure that your speaking voice is not too loud or too quiet⁶
- An occupational therapist can
 - recommend changes in lighting in the home so you can better see the other person's non-verbal cues⁶
 - recommend changes to reduce other distracting noises in the home, such as adding carpets or unplugging appliances⁶
- All rehabilitation professionals can suggest community groups that can provide support, such as the Canadian Hearing Society.

➤ Touch

- An occupational therapist or physiotherapist can teach safety techniques to prevent burning the skin on hot items (e.g. drawing a bath or shower, handling hot beverages like coffee or tea).
- An occupational therapist can teach you how to monitor yourself for injuries or irritations that you might not be able to feel.

Mental and Cognitive Health

7. Feeling anxious

A HIV+ person may experience feelings of anxiety from time to time, either due to their condition and treatment, or due to other parts of their life. No matter the cause, rehabilitation can help, and no formal diagnosis of anxiety is required, though the rehabilitation professional or complementary therapist might recommend seeing someone who can make a diagnosis if they feel it is necessary.

- A physiotherapist or occupational therapist can recommend an exercise plan to reduce stress and anxiety⁷.
- A physiotherapist can teach you relaxation techniques and breathing exercises to promote relaxation⁸.
- An occupational therapist can
 - teach you relaxation techniques and breathing exercises⁹
 - teach you techniques to change negative thoughts

Other Rehabilitation Therapies

- A social worker can teach you techniques to change negative thoughts.

Complementary Therapies

- Massage therapy can reduce tension, which can positively affect anxiety.

8. Feeling down or depressed

A HIV+ person might feel down or depressed for a number of reasons, which may or not be related to their condition. No matter the cause, rehabilitation can help. No formal diagnosis of depression is required, though the rehabilitation professional or complementary therapist might recommend seeing someone who can make a diagnosis if they feel it is necessary.

- Exercise can be helpful in improving depression symptoms; a physiotherapist or physiatrist can work with you to develop an exercise plan that meets your needs.
- An occupational therapist or social worker can help you challenge negative thoughts that may be contributing to depression.
- An occupational therapist can teach you relaxation and mindfulness techniques as coping strategies.
- If depression is affecting your ability to perform daily tasks, an occupational therapist can use techniques such as scheduling to rebuild your activity level.
- Depression can cause other issues, such as weight loss/gain, insomnia, anxiety, and difficulties with memory. Rehabilitation services can help in these instances, as outlined elsewhere in this chapter.

Other Rehabilitation Therapies

- Poor eating habits can affect mood¹⁰. A dietitian can help you to improve eating habits.

Complementary Therapies

- Some people find that reflexology and acupuncture improves their mood.
- Massage therapy can help reduce tension, which can improve mood in some people.

9. Discomfort with body changes (wasting, weight gain, lipodystrophy)

Wasting, lipodystrophy, or weight gain can occur with some anti-retrovirals, though newer medications are less likely to have this side effect. Weight loss and weight gain can also be due to other conditions, or can occur without a clear cause.

- An occupational therapist can suggest tools (e.g., cushions) or body positioning to compensate for physical discomfort.

Men often report wasting (extreme weight loss) until they are on effective medication. Women often report weight gain after diagnosis, regardless of medication used or viral load.
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- A physiotherapist can recommend an exercise plan to help with weight loss.

Other Rehabilitation Therapies

- A dietitian or nutritionist can work with you to develop a meal plan that meets your goals.
- A social worker can
 - help you work through emotional issues that may be causing the body changes.
 - help you with the emotional impact of the bodily changes.

10. Focus or concentration

Many HIV+ people report that they sometimes have trouble keeping their minds focused on what they are doing. Whether it is due to HIV, its treatment, or something unrelated, rehabilitation professionals have therapies that can help.

- An occupational therapist can
 - help you review your space and lessen distractions that might affect focus or concentration.
 - help you break down complex tasks into a series of smaller tasks that are easier to focus on.
- Fatigue can often negatively affect concentration. The treatments listed in the section on fatigue might be helpful.
- An inability to focus can be due in part to sleep difficulties. Rehabilitation techniques can help in this area, as noted elsewhere in this chapter.

Other Rehabilitation Therapies

- Problems in focus or concentration can be due to nutrients lacking from your diet. A dietitian can work with you to develop a balanced meal plan.

Complementary therapies

- A naturopath can recommend supplements that may benefit concentration and focus.

11. Memory

Some HIV+ people report problems with memory. This can make it hard to stay on top of their treatment and everyday life. Treatment involves steps to improve memory, and the use of tools to help work around the memory challenge.

- An occupational therapist can help develop memory aids, such as:
 - A note-keeping system to track doctors' visits and medication
 - Alarms and packaging to help you take the right medication at the right time
 - A diary or note system to remember past events
 - Routines to help complete daily tasks
- Being tired can have a negative impact on your memory. The treatments listed in the section on fatigue might be helpful.

Complementary Therapies

- A naturopath can
 - suggest supplements to improve memory
 - suggest diet and exercise changes to improve memory

12. Insomnia

Having insomnia means having trouble getting to sleep, or staying asleep. Some HIV+ people report having trouble with insomnia, either because of their HIV medication or for reasons unrelated to HIV. In either case, rehabilitation professionals can help.

- An occupational therapist can help improve your sleep in several ways¹¹.
 - Helping you find a schedule that promotes good sleep.
 - Suggesting changes to the sleeping space to encourage sleep, such as white noise machines and light-blocking curtains.
- An occupational therapist or physiotherapist can create a physical activity plan to help you feel tired at bedtime.
- An occupational therapist or social worker can help you remove barriers to sleep, such as stress and the use of caffeine or cigarettes before bed.
- An occupational therapist can teach you coping techniques, such as:
 - Getting up and doing something else when you cannot sleep.
 - Using relaxation techniques.

Complementary Therapies

- Massage therapy can help reduce tension and improve sleep.

- A naturopath can create a plan that may include supplements such as melatonin.

Day-to-Day Challenges

13. Self-care

Self-care challenges include bathing, dressing, and eating. These challenges could be due to:

- A lack of strength which can make it hard to do things like dress yourself, get in and out of the bath or shower, or move around your home.
- A lack of energy or stamina which can make it hard to finish all of the things you need or want to do in a day.
- A lack of balance, which can make it difficult to complete self-care tasks safely.
- A lack of motivation, which can be due to physical, cognitive, or emotional challenges.

Treatment involves overcoming these challenges:

- The treatments for weakness described earlier can help you build the needed strength.
- The treatments for fatigue described above can help you conserve your energy so you can complete all of your self-care tasks.
- An occupational therapist can suggest tools like grab handles that will make getting in and out of the bathtub or shower easier.
- A speech-language pathologist can help if you have trouble eating due to difficulties swallowing.

Other Rehabilitation Therapies

- A dietitian can help you create a menu that is healthy and tasty to keep you eating properly.
- If you are facing a lack of motivation, a social worker can explore that with you and suggest some ways to overcome it.

14. Household activities

Household activities include cooking for yourself, keeping your home clean, and doing repairs around your home. These challenges could be due to:

- A lack of strength which can make it hard to do things around your home.
- A lack of energy or stamina which can make it hard to finish all of the things you need or want to do in a day.
- A lack of balance, which can make it difficult to complete home care tasks safely.
- A lack of motivation, which can be due to physical, cognitive, or emotional challenges.

Treatment involves overcoming these challenges:

- The treatments for weakness described earlier can help you build the needed strength.
- The treatments for fatigue described above can help you conserve your energy so you can complete all of your home care tasks.

Other Rehabilitation Therapies

- If you are facing a lack of motivation, a social worker can explore that with you and suggest some ways to overcome it.

15. Getting around

Challenges in getting around can include:

- Pain or weakness making it hard to walk or climb stairs, use curbs and step over obstacles.
- Fatigue making it hard to walk for long distances.
- Challenges with eyesight, hearing or reaction time can make it difficult or unsafe to drive a vehicle.

Treatment involves overcoming these challenges:

- The treatments for pain described earlier can help you move with less pain.
- The treatments for weakness described earlier can help you build the needed strength.
- The treatments for fatigue described earlier can help you conserve your energy so you can have the energy to get around the way you want.
- An occupational therapist can assess if driving is a safe activity for you.
- If driving is unsafe, an occupational therapist can work with you to find other ways of getting around that meet your needs.

16. Running errands

Errands can include getting to doctors' appointments, doing your shopping, and paying your bills.

Challenges can be due to:

- Pain making it difficult to get out to doctor's offices, stores, and banks.
- Weakness and fatigue can also make it hard to get to the places you need to, and/or to carry the stuff you buy.
- Memory problems can make it hard to remember when your appointments are, when your bills are due, and/or what you want to buy.

Treatment involves overcoming these challenges:

- The treatments for weakness described earlier can help you build the needed strength.
- The treatments for fatigue described earlier can help you conserve your energy so you can have the energy to get around the way you want.
- The treatments for pain described earlier can help you move with less pain.
- An occupational therapist can help you with memory tools to remember things like doctors' appointments and shopping lists.

Challenges Doing Activities that are Meaningful to You

17. Work-related or school-related issues

Because HIV is a condition with ups and downs, you might face uncertainty about how you will feel and what tasks you will be able to do on any given day. This uncertainty can make it hard to hold down a typical job (paid or volunteer) or go to classes. When you are in a down phase, you may feel too tired and weak to do work- and school-related activities.

- An occupational therapist can help¹² with:

- Finding solutions to challenges related to returning to or staying in work.
- Developing a daily routine that includes work tasks.
- Suggesting adjustments of work tasks.
- Learning to communicate with your employer.
- A physiotherapist can help with:
 - Developing an exercise routine to increase your fitness and strength so the down periods have less of an impact on your ability to do work and school activities.

Other Rehabilitation Therapies

- A vocational counsellor can help¹³ with:
 - Figuring out what challenges you might face in the workplace.
 - Creating a list of goals for returning to or staying at work.
 - Creating an action plan to overcome challenges.
 - Improving communication between you and your employer.
 - Building job search and retention skills.

18. Social Life Challenges

A person's social life includes a number of areas:

- Interactions with family and friends, which can include romantic partners, children, brothers and sisters, parents, and extended family.
- Interactions with people and organizations related to your health conditions (e.g., ASOs, support groups).
- Interactions with people and organizations of interest to you, such as hobby groups and churches.

Challenges in your social life may be due to a number of factors:

- Fatigue or weakness making it hard to leave the home or to stay out with friends as long as you might like.
- Pain making it difficult to engage in regular social activities.
- Digestive issues that make you worry about leaving the home or having people over.
- A lack of motivation to go out and get involved.
- Feeling down or anxious might make it hard to get out and interact.

Treatment involves overcoming these challenges:

- The treatments for fatigue described earlier can help you improve your fitness and conserve your energy so you can get around the way you want.
- The treatments for weakness described earlier can help you build the needed strength.
- The treatments for pain described earlier can help you move with less pain.
- The treatments for digestive issues described earlier can help you feel more confident leaving the home.
- The treatments for feeling down/depressed and anxious listed earlier can help with those issues.

Other Rehabilitation Therapies

- If you are facing a lack of motivation, a social worker can explore that with you and suggest some ways to overcome it.

Chapter 4 How do I get rehabilitation services?

How do I decide I need rehabilitation?

1. Identify the health challenge or problem.
2. Be able to describe the health challenge or problem and how it impacts your life.
3. Recognize these issues as something rehabilitation can treat.
4. Identify the rehabilitation professional(s) who can help you.
5. Ask for a referral from your doctor, if needed.

After I decide I need rehabilitation, what do I do?

- If possible, you should first make an appointment with your doctor or HIV specialist to discuss your rehabilitation needs. Your doctor knows your medical history, can help to pinpoint the nature of your problem and the rehabilitation professional(s) needed, and can help you to find rehabilitation services in your area (if available).
- In case your doctor is not aware of how rehabilitation can help HIV+ people, you should arrive at your doctors' appointment prepared to tell your doctor about your problem, how your problem impacts your life, and which rehabilitation profession you think might be able to help you. You could bring this e-guide with you or tell your doctor about it and where it can be found on the internet.
- If you cannot access a doctor, you can try to find rehabilitation services on your own using the tips outlined later in this chapter.

What kinds of rehabilitation services are available to a person living in the community?

- **Publicly** funded out-patient rehabilitation services are available in many communities. These services are usually provided in out-patient clinics in general hospitals or community health centres and require a referral from a family doctor. The cost is covered by the healthcare system.
- You will need a referral from your family doctor to see a physiatrist¹⁴, who is a specialist. Because physiatrists are doctors, their services are covered by your provincial health insurance plan.
- **Publicly** funded homecare services, where rehabilitation professionals visit you in your home, are available in many communities. These services are only provided to people with the greatest need and require a referral from a family doctor. The cost is covered by the healthcare system.
- **Privately** funded out-patient rehabilitation services and complementary therapies are available at private clinics in many communities. Physical therapy is the most common rehabilitation therapy privately available. You can make your own appointment and the cost is covered by you or through your health insurance.
- Your local AIDS service organization may offer some complementary therapies.
- Your local AIDS service organization may have some suggestions for accessing local services.
- Larger cities have more rehabilitation professionals, on average, than smaller towns.

How do I find the rehabilitation services that I need in my area?

You can find local rehabilitation services in several ways:

- Your doctor may have rehabilitation professionals that he or she recommends.
- Most professions have associations or colleges on a national or provincial level. You can find a list of these in the “Resources” section. Many of these associations and colleges have a directory of their members, where you can search by location and specialty.
- You can ask family and friends for recommendations – this has the benefit of getting a review of the clinician at the same time.
- A search through your local yellow pages. Best results will likely come from searching by profession such as physiotherapy or occupational therapy.
- An Internet search using your town and the services you are looking for is likely to give you much information. You should review the information carefully, as not all information on the Internet is of the same quality.
- AIDS service organizations may also have information about complementary therapies in the community.

What should I look for in a rehabilitation professional?

You have a right to choose the care that best works for you. Before choosing a rehabilitation professional, you should feel free to ask any questions that would make you feel comfortable. Some questions may include^{15,16}:

- What is your educational background?
- How do you stay current, that is, on top of new research and skills since certification?
- What experience do you have with {your symptom or challenge}?
- What experience do you have working with people with HIV (if you choose to disclose)?
- What is your plan of action?
- What will be expected of me – in the sessions and outside the sessions?
- What is the usual outcome for someone with my condition?
- In general, how many visits do people with my condition need?
- Is there a cost for your services? Are they covered by my provincial health insurance plan? If not, do you provide a sliding scale?
- Can you provide me with references?

How am I going to pay for these services?

In some areas, publicly funded rehabilitation services may not be available or there may be long waiting lists. People may then consider paying for private rehabilitation services which may be a challenge. Talk to your doctors, other HIV+ people, and staff at AIDS service organizations to get some ideas. Some possibilities for paying for rehabilitation include:

- For people on government provincial income assistance, some rehabilitation services may be covered. Your doctor or the local AIDS service organization may be able to tell you more.

- Private insurance: If you are still working, or are on an employer’s disability benefits plan, the employer’s group insurance policy may cover rehabilitation services. If you have private health insurance, the plan may cover rehabilitation services. Read your employee benefits guide over carefully, as there might be limits to what services are covered, what percentage of the costs is covered, or a maximum dollar amount per year.
- AIDS service organizations (ASOs): Some ASOs provide rehabilitation services or complementary therapy on site. Often, this is through a partnership with student clinicians, who provide free services to HIV+ people in return for the experience hours. Some ASOs may provide full or partial repayment of some healthcare services, including rehabilitation.
- Provincial health plans: Coverage varies from province to province. Some provinces may cover some non-prescription treatments for HIV+ people. Check with your ASO to learn more about these treatments¹⁷.
- Sliding scales and payment plans: If you cannot get coverage, you should have a talk with your rehabilitation professional. Some therapists offer a sliding scale fee based on what you can afford to pay. Others might let you make small payments over a longer period of time to access their services.
- You might be eligible for a tax rebate for treatments that you pay out of pocket. Keep your receipts and check with a tax expert or your local ASO for information on what might be eligible¹⁷.

How do I express myself to the rehabilitation professional?

To give you the best help they can, rehabilitation professionals need to have a clear and full picture of your challenges. But it’s not always easy to explain everything perfectly when you’re on the spot. You might want to sit down before your meeting, and work out exactly what you want the rehabilitation professional to know. In working out your explanation, think about:

- Are the challenges you face constant, or do they come and go?
- Do the challenges change based on the time of day?
- What have you tried to cope with the challenges in the past, and did it work?
- Is there anything that makes these challenges worse? Is there anything that makes them better?

Managing multiple healthcare providers

Many HIV+ people are already familiar with the challenges of coordinating multiple doctors’ visits, and adhering to a medication schedule. You can add your rehabilitation service visits to your current system. If you do not have a system yet, or if you want to improve your current system, consider these tips:

Visit tracking

- You can put future visits into a calendar (paper or electronic) to ensure you do not forget any.

- Some people have found it helpful to keep a record of past healthcare appointments, to give themselves a review of how their health has changed over time. This can be as simple as a notebook where you write down each visit:
 - name of clinician
 - date
 - reason for visit
 - steps taken at visit
 - any medications, supplements, or treatment suggested
 - how you felt about the result
- This visit record is also a good place to jot down any questions or concerns between visits.

Medication tracking

You can find medication trackers on the Internet. Simply type the phrase “medication tracker” into a search engine like Google. You can download your favorite, or use them to make your own.

- Most medication trackers include:
 - name of drug
 - dosage
 - what time you take it
 - how you should take it, such as with food
 - how it makes you feel
 - when you started the medication
 - the last time the dosage changed
 - when you need your next refill
 - which doctor prescribed it
- You should include supplements and over-the-counter (OTC) medications in your tracker.
- You should bring a paper copy of your medication list to all healthcare and rehabilitation service appointments. Your healthcare professional might need that information.
- You can keep an electronic copy in a word processing or spreadsheet file for easy updating.
- If you have a smart phone, there are several apps that can help you track your medication. Some will also remind you when it is time to take your next dose.

Important

Some over-the-counter medications and supplements, and naturopathic treatments can interact with prescribed medications in negative ways. Please consult your doctor or pharmacist before starting any OTC medications or supplements.

Other trackers

- Chapter 9 of CATIE’s (2015) *Managing Your Health* focuses on monitoring your health and can help guide your own tracking plan: <http://www.catie.ca/en/practical-guides/managing-your-health>.

Chapter 5 How do I work with rehabilitation professionals?

What happens during a visit with a rehabilitation professional?

An appointment with a rehabilitation professional may take place in various settings, including at a hospital (both inpatient and outpatient), at a clinic, or at home. Often, the therapist will provide a short summary of what to expect when you book an appointment. Alternatively, you can ask questions about the process before the first meeting.

- Bring any questions you have about your issue or treatment. It is easy to forget little things, so having it written down will help.
- Wear clothing that allows easy access to the affected body part (e.g., loose fitting pants if you have a knee problem). Many clinics have a place to change if you would prefer to bring a change of clothing.

What information would it be helpful to give the rehabilitation professional?

The first step any clinician undertakes is to get a clear, complete picture of the problems you face. Some things your clinician will ask you about^{18,19} include;

- Your current issue (e.g., when did it start? does it change over time? what have you used to treat it in the past?)
- Previous instances of the same problem
- Other current conditions or injuries
- The needs of your daily life
- Past conditions or injuries
- The medication(s) that you take
- Family health history
- Your goal(s) for treatment

If you have had many health issues in the past, you may want to make a list, including dates, in advance to make sure you have everything straight. While it is your choice how much of this information you share, this information will help the clinician decide the best course of treatment. You should decide in advance what information you are comfortable sharing.

Why should I disclose my HIV status to my rehabilitation professional?

You do not have to tell rehabilitation professionals about your HIV status²⁰. All healthcare providers have to take “universal precautions,” which are steps they have to take to protect them from all blood-borne infections. For example, all health professionals must wear gloves when working near a patient’s open cuts.

However, there are some instances where your status might be relevant to your issue or treatment. HIV is an episodic condition, which causes periods of feeling well and feeling unwell. A physical therapist who knows you have HIV will be able to understand why it may be challenging for you to adhere to an

exercise plan, and will tell you what to do when you feel well or unwell. An occupational therapist who knows you have HIV will understand why you may have changing levels of fatigue, and will help you plan your activities so you do not get overtired. If they know your HIV status, rehabilitation professionals can also consult material on treatments that work best for HIV+ people, such as the e-module published by CWGHR on HIV and rehabilitation, which can be found [here](#). If you disclose to your clinician, you can trust that your information is safe; the law requires healthcare providers and their staff to protect your information.

Why would the rehabilitation professional ask me about *that* (e.g. sexual or substance use history)?

As we noted in the last chapter, sometimes symptoms can have many different causes. For example, muscle tremors can be due to weakness after an injury, but it could be due to a change in medication, or use/withdrawal from a prescribed or recreational substance. A thorough clinician will ask questions about these possible experiences so that he or she can account for these in your treatment.

Remember that you have the right to make an informed decision about what you choose to disclose. If you have any concerns about the questions that a clinician is asking, do not hesitate to ask what part that information might play in your treatment. Their answer might convince you of the value of sharing that particular information, and if not, you do not have to provide it.

My clinician did... {examples below} Is this okay? What should I do about it?

...Refused to treat me

In Canada, HIV is considered a disability²¹. Human rights law in Canada forbids healthcare professionals from refusing to treat a patient or client based on a disability. However, healthcare professionals are allowed to refuse to treat clients or patients for other reasons, such as having a full caseload. If you believe you have been refused treatment because of your status, please see the “discriminated against me” section.

...Moved me to a different clinician in the same profession

Clinicians are not all trained or experienced in the same ways. Your clinician may have felt that their colleague had more experience with your condition. He or she should have explained their reasons when they made the referral. If they did not, you may want to contact them to ask for an explanation, and/or follow the “discriminated against me” section.

...Wore gloves or a mask

In Canada, we have “universal precautions,” which are steps healthcare professionals must take with all patients. One of these steps is that they have to wear gloves if they might touch blood, other bodily fluids, or any cuts or sores. If you have a cut or a rash, the healthcare provider should put on gloves before touching you.

The healthcare provider also has to help prevent the spread of respiratory illnesses²². During cold and flu season, your healthcare professional may wear a surgical mask to avoid spreading an illness from one client to another.

If you feel the actions taken went beyond universal precautions, you can ask the clinician to explain why he or she took that action. If the answer does not satisfy you, please see the “discriminated against me” section.

...Discriminated against me

The Canadian HIV/AIDS Legal Network (<http://www.aidslaw.ca/site/>) has helpful information for HIV+ people. If you believe that a healthcare professional has discriminated against you, and talking to them has not resolved the issue, keep a careful, complete record of what happened. If the clinician has a supervisor, speaking with them would be a first step. Some institutions like hospitals have a Patient Relations Office or Ombudsmen that you can speak with. If that is unsuccessful, or if they do not have a supervisor, you may wish to file a complaint. This complaint can be with the regulatory body for that profession, such as the College of Physiotherapist of Ontario, or your provincial Human Rights Commission.

Your local ASO may have information and resources on dealing with discrimination in healthcare.

Chapter 6 How do I stick with the treatment?

Sometimes, you might find that you are having a hard time making it to your sessions with the rehabilitation professional, or doing the homework they assign you. You are not alone. Below, we outline some challenges you may face in trying to stick with your treatment, and suggestions for overcoming them.

Feeling Unwell

Rehabilitation professionals consider HIV an episodic condition, which means that there are periods of feeling well and periods of feeling unwell. Sometimes these periods can be weeks or months at a time, and sometimes it can be that you have more energy in the morning, but feel tired in the afternoon. Feeling unwell could be related to physical things like pain or energy levels, or it could be related to mood. If you have periods of feeling well and unwell in your life, you should share them with your rehabilitation professional. They can give you suggestions for dealing with periods when you are feeling unwell, and may be able to tailor your treatment plan to take advantage of when you are feeling well.

Pain

When treatment involves physical activity, the treatment may cause pain. This can cause some people to stop treatment, either because the pain is too intense, or because they fear that they are causing further damage²³. If you experience pain during or after your rehabilitation session, please talk to your rehabilitation professional. They can determine if it is typical (that is, there is no chance of causing further harm) or they can modify the activity to make it safer and easier for you. They will also recommend strategies to ease the pain.

Fatigue

Treatment can also leave you feeling more tired than before. It might be hard to make yourself go to an appointment if you think you will be too tired to get through it. Mention the issue to your rehabilitation professional. They can modify the activity to make it easier, and/or give you strategies to fight fatigue.

Depression

One common symptom of depression is being unable to “get going” – to do what you want or need to do. So it is not surprising that feelings of depression have been linked to challenges sticking with a treatment plan²³. If depression is getting in your way, it is a good idea to speak with your rehabilitation professional. They may have some ideas for working around the challenge, or they may be able to suggest another healthcare professional who may be able to help.

Memory

Some people may have trouble when it comes to things such as remembering their next appointment, or remembering what homework assignment they have been given. If this is a problem for you, please discuss it with your rehabilitation professional. Some things they might be able to do if you tend to forget appointments is to provide a reminder card with the day and time of your next appointment, or

to call you that morning to remind you. If you forget what you need to do as homework, they could give you a handout with your tasks clearly listed. Also, they may be able to give you tips to help work around memory challenges, such as writing things down in a calendar or day planner.

Work Responsibilities

If you have a paid or volunteer job, you might find that you have a schedule that makes it hard to find a time when both you and your rehabilitation professional are free. Either their office/clinic is only open during the same time you are working, or your days are so full with work and other responsibilities that fitting in another appointment seems impossible. Discussing the issue with the rehabilitation professional might help. They might be able to show some flexibility in appointment times so you can attend when you can. They might also have suggestions to help you talk with your employer to get time off for your appointments, and/or to manage your time more effectively to fit more into your day.

Family Responsibilities

Similar to work responsibilities mentioned, sometimes it is your responsibility to your family that makes getting to your appointments difficult. You might find it hard to find extra time in your day after taking care of your children, parents, or partner. You may have challenges with finding child care if your children are still young. You might need to have a family member come with you to appointments. As with work challenges, talking with your rehabilitation professional can help you find ways to fit your appointments into your busy schedule.

Cost

The issue of cost of treatment is outlined in the “How am I going to pay for these services?” section of Chapter 4. If anything changes for you financially that would get in the way of attending appointments, discuss it with your rehabilitation professional to explore possible solutions. If the cost of transportation is a barrier, you can look into whether your disability benefits would cover the costs, or if any local support groups can help to offset the costs. Making plans to run errands before/after your appointment can help you get more value from the cost of your trip.

Accessibility of Treatment

If it is hard to get to your treatment sessions, it is more likely that you will start skipping them. You will want to consider location before you choose a rehabilitation professional – to make sure you can get to and from his or her clinic regularly. If you live in a remote area, you could talk with the rehabilitation professional to see if some meetings can be done over the phone or the internet. Finally, you should speak to your rehabilitation professional and try to work out strategies together, such as fewer in-office visits, but more email check-ins.

Lack of Support

Support can come from a number of places; friends, family, or staff/volunteers at AIDS service organizations and other community organizations are just some places to find support. Support you get from these people and places can take many forms; financial help, favours, someone to talk to, etc. If you find that you do not have the support you need to handle your daily tasks and your rehabilitation

work, please discuss it with your rehabilitation professional. They may be able to suggest community groups that can provide what you need, or ways to discuss your issues with your friends and family.

Chapter 7 Balancing self-management and rehabilitation

What is self-management?

Self-managing your health means taking charge of your health. This means doing the right things on a daily basis related to diet, sleep, medication, and exercise, and getting the health services you need to stay healthy. Therefore, taking charge of your health also means seeking out rehabilitation services when you are faced with a problem that you cannot manage on your own. Rehabilitation professionals can also help you build the skills to prevent or cope with future challenges. Self-management training is included in most rehabilitation plans.

What do I need to self-manage my health?

In this e-guide, self-management refers to you using your knowledge, skills, and the right attitude to stay as healthy, happy, and active as possible. This includes not only keeping healthy and dealing with health-related challenges to avoid needing healthcare professionals, but also knowing when to seek help from healthcare professionals.

To self-manage your health successfully, you must be able to:

- Understand HIV and its treatment.
- Understand other health conditions you are living with.
- Engage in health behaviours to minimize health issues and maximize health and well-being.
- Be aware of changes in your body and your health.
- Understand how to cope with the physical and emotional impact of issues and setbacks.
- Understand where and how to get medical or social support to deal with challenges.
- Be confident in your ability to handle your challenges.

Example

- After starting a new HIV medication, you notice that you are starting to put on weight.
- You do some research on the Internet, and find out that weight gain is a common side-effect of the medication.
- You speak with your HIV specialist about the weight gain, and together you decide to stay on the medication, as the benefits outweigh the side-effects.
- You decide to work with a dietitian to create a healthy meal plan to help lose the extra weight and then maintain a healthy weight.
- You develop an exercise plan for yourself, using techniques and skills you have learned from previous treatment by a physiotherapist and tips you found on a reputable Canadian health website.

Where do I start with managing my health?

CATIE has provided a wonderful guidebook for HIV+ people called, “Managing your health” (<http://www.catie.ca/en/practical-guides/managing-your-health>). Chapter 4 focuses on healthy living, and touches on many actions you can take at home on your own. Many of these complement the rehabilitation techniques discussed in previous chapters. The highlights include:

- Eating a healthy, balanced diet.
- Maintaining a healthy weight.
- Getting the proper vitamins and minerals.
- Exercising regularly / getting regular physical activity.
- Dealing with stress.

The Canadian Working Group on HIV and Rehabilitation has a few self-management tip sheets on its website: http://hivandrehab.ca/EN/resources/people_HIV.php. These tip sheets cover:

- Exercise and HIV
 - What to do before starting exercise
 - Suggestions on types of exercise
 - Suggestion on duration of exercise
- Fatigue and HIV
 - Pacing
 - Positioning
 - Planning
 - Prioritizing
 - Problem-solving
- Mental Health and HIV
 - Coping strategies for memory challenges
 - Coping strategies for stress

What should I know about exercise?

- Exercise can be anything from walking a bit more than usual, to going to a gym or joining a sports team.
- Exercise can make you feel better physically and emotionally, and may help offset weight gain.
- For more tips, see the self-management tips at CWGHR: http://www.hivandrehab.ca/EN/resources/people_HIV.php
- If you are thinking of starting an exercise program, talk to your doctor and then your local fitness centre or YMCA for an exercise program that might be right for you.
- This e-guide has plenty of valuable information on how rehabilitation professionals can help you put together the right exercise plan for you.

What can I do about feeling tired?

- Conserving your energy when you can will allow you to reach the end of your day without draining yourself.
- The Canadian Working Group on HIV and Rehabilitation (CWGHR) created a short flier on avoiding fatigue.
 - Set priorities, to be sure you get the most important tasks done, and postpone less important ones if needed.
 - Break large tasks into several smaller ones, and doing them slowly over the course of the day or even over several days.
 - Plan to do activities when you are feeling most energetic, and plan to rest when your energy is low.
 - For more tips, see the self-management tips at CWGHR:
http://www.hivandrehab.ca/EN/resources/people_HIV.php
- Chapter 3 of this e-guide provides a list of rehabilitation professionals you can work with to develop an energy conservation plan that works for you.

What can I do to sleep better?

- A National Health Service organization in the UK has a helpful self-help pamphlet on overcoming sleep problems.
 - Try not to worry when you are unable to fall asleep. You will fall asleep eventually.
 - Talk to someone you trust about any feelings you might be having that are affecting your sleep.
 - Speak to your doctor about any health issues that may be interfering with your sleep.
 - Avoid caffeine and nicotine a few hours before bedtime.
 - Make sure your sleeping space is conducive to sleep (e.g., dark, quiet, comfortable).
 - Try to keep a regular bedtime.
 - Make sure you get enough activity during the day to be tired at bedtime.
 - For more information, download the pamphlet at the following address:
<http://www.ntw.nhs.uk/pic/selfhelp/>.
- You can use the information on insomnia in Chapter 3 of this e-guide to decide if the services of a rehabilitation professional can help you deal with your insomnia.

What can I do to manage stress?

- The American Heart Association has suggestions for dealing with stress that may be useful to HIV+ people.
 - Try to use positive self-talk (e.g., “I can do this.”).
 - Use “stress stoppers” to instantly improve stress levels. These include taking a walk, taking a few deep breaths, and meditation.
 - Regularly do things that make you happy. Pursue a hobby, enjoy a movie or TV show, spend time with family and friends.

- Engage in relaxation techniques.
- Visit http://www.heart.org/HEARTORG/GettingHealthy/StressManagement/FourWaystoDealWithStress/Four-Ways-to-Deal-with-Stress_UCM_307996_Article.jsp for more information.
- Centers for Disease Control and Prevention also provides several tips for managing stress:
 - Avoid drugs and alcohol.
 - Find and use a support system.
 - Stay active – physically and socially.
 - Take care of yourself.
 - Visit <http://www.cdc.gov/features/handlingstress/> for more information.
- You may choose to consult with the rehabilitation professionals that work with anxiety, as listed in Chapter 3 of this e-guide.

What can I do to manage work?

- Research into managing work demands with chronic low back pain²⁴ outlined self-management skills that may be useful for people living with other chronic conditions:
 - Changing work and home schedules and routines to make sure you can complete work tasks. For example, doing stretching exercises at the photocopier to avoid tense muscles.
 - Reducing symptoms, perhaps by keeping medications and non-medicinal pain relievers in your work space.
 - Breaking big jobs into smaller tasks that are easier to focus on.
 - Communicating with the employer to get adjustments in the work setting, such as a standing desk, being able to take frequent short breaks, or having a flexible work schedule.
 - Communicating with coworkers about specific issues, such as pain or stomach upset, to get help and understanding.
 - Recognizing when you need time off to recover and negotiating time off.
- You do NOT have to disclose your HIV status to anyone at work to get workplace adjustments (accommodations).
- Chapter 3 has information on rehabilitation professionals that may be helpful in managing work challenges.

What can I do to stay on top of my issues and treatments?

- The best way to manage your health is to stay informed.
- Your local AIDS service organization may have workshops or presentations on topics relevant to you.
- You can also find booklets and brochures on HIV-related topics at your ASO, or online at websites like CATIE (www.catie.ca).

- The internet is a good place to find a large amount of information, but examine the material carefully to assess its quality. You may want to visit this webpage for information on how to judge a website: <http://usm.maine.edu/library/checklist-evaluating-web-resources>.
- You can also look up suggestions for tools to help with your challenges, such as getting a day planner if you have trouble remembering appointments.

Barriers to self-management

Several barriers to self-management that might impact people living with chronic conditions include²⁵:

- Motivational barriers. Sometimes it is tough to do things even when we want to do them. Working with a rehabilitation professional can help you figure out what type of motivation would work best for you. An occupational therapist may be helpful in this role.
- Behavioural barriers. Sometimes we go about meeting our goals in the wrong way. Sometimes we set goals that are too hard, or we organize our lives in ways that do not support success. This is another place that an occupational therapist can help – helping you set achievable goals, and work out a plan to realize them.
- Emotional barriers. Low self-esteem and low confidence can interfere with meeting your goals. We are less likely to keep up with healthy behaviours like eating right and exercising when we are feeling down. A social worker can help you work through issues that might be getting in your way.
- Relationship barriers. Sometimes, we can become sidetracked by people in our lives who are not as supportive as we would like. Good communication skills can help you get the support you need from your loved ones. Rehabilitation professionals like occupational therapists and social workers can help you build your communication skills. Rehabilitation professionals can also provide the support you need as you work towards your goals.
- Environmental barriers. Our environment can also sometimes provide barriers. For example, healthy food is often more expensive than unhealthy food. The right rehabilitation professionals can help you find a way around your barriers, for example:
 - Dietitians can help you find inexpensive healthy meal ideas.
 - Physiotherapists can create an exercise plan that does not involve a gym membership or expensive equipment.
 - Local recreation centres may have flexible payment plans.

Self-management programs

If you are looking to learn more about self-management, or to create your own plan, you might want to explore the following:

- *Self Management Ontario* <http://www.swselfmanagement.ca/SMTOLKIT/>
- The Online Chronic Disease Self-Management Program <https://bc.selfmanage.org/onlinebc/hl/hlMain>

Chapter 8 What rehabilitation-related resources are in my area?

In this chapter are some web resources to help you learn more about rehabilitation, and/or find specific rehabilitation services in your province or territory. You can also use some of the strategies listed in Chapter 4 to find a rehabilitation professional.

Rehabilitation

Canadian Working Group on HIV and Rehabilitation (CWGHR): <http://hivandrehab.ca/>

- This site provides information about what part rehabilitation can play in the life of people living with HIV.

Employment Action: <http://employmentaction.crescan.com/>

- This site provides information and help to HIV+ individuals who are looking to return to or stay in the workplace.

WORKink: <http://www.workink.com/>

- This site helps people with health-related challenges such as HIV (described on the site as disabilities) to find and keep work.

Many of the links below are to national or provincial colleges or associations/societies. While both the colleges and associations/societies have some information in common (e.g., where you can find a rehabilitation professional in your area), there are some differences as well. The college is where you would go to file a complaint against a rehabilitation professional, and would find information such as any rehabilitation professionals who have been suspended. associations/societies generally have information for the public about what the rehabilitation profession does, and the benefits of their treatment.

Physiotherapy

Associations and Societies

Canadian Physiotherapy Association: www.physiotherapy.ca

Physiotherapy Association of British Columbia: <http://bcphysio.org>

Physiotherapy Alberta College + Association: <http://www.physiotherapyalberta.ca/>

Ontario Physiotherapy Association: www.opa.on.ca/index.shtml

Manitoba Physiotherapy Association: <http://mbphysio.org>

Ordre professionnel de la physiothérapie du Québec: <http://oppq.qc.ca/>

Nova Scotia Physiotherapy Association: <http://www.physiotherapyns.ca/>

Nunavut Department of Health Rehabilitation Services:

<http://gov.nu.ca/health/information/rehabilitation>

Colleges

College of Physical Therapists of British Columbia: <http://cptbc.org/>

Saskatchewan College of Physical Therapists: <http://www.scpt.org/>

College of Physiotherapists of Ontario: <http://www.collegept.org/Home>

College of Physiotherapists of Manitoba: <http://www.manitobaphysio.com/>

Nova Scotia College of Physiotherapists: <http://nsphysio.com/index.html>

College of Physiotherapists of New Brunswick: <http://www.cptnb.ca/publicE.html>

Newfoundland and Labrador College of Physiotherapists: <http://nlcpt.com/>

Prince Edward Island College of Physiotherapists: <http://www.peicpt.com/>

Occupational Therapy

Associations and Societies

Canadian Association of Occupational Therapists: <https://www.caot.ca/>

Canadian Association of Occupational Therapist – British Columbia:

<http://www.caot.ca/default.asp?pageid=4125>

Society of Alberta Occupational Therapists: <http://www.saot.ca/>

The Saskatchewan Society of Occupational Therapists: <http://ssot.sk.ca/>

Manitoba Society of Occupational Therapists: <http://www.msot.mb.ca/>

Ontario Society of Occupational Therapists: <http://www.osot.on.ca/imis15/>

Ordre des ergotherapeutes du Quebec: <http://www.oeg.org/langues/english.fr.html>

The Nova Scotia Society of Occupational Therapists: <http://www.nssot.ca/>

New Brunswick Association of Occupational Therapists: <http://www.nbaot.org/main.html>

Newfoundland and Labrador Association of Occupational Therapists: <http://www.nlaot.ca/>

Newfoundland and Labrador Occupational Therapy Board: <http://www.nlotb.ca/>

Prince Edward Island Occupational Therapy Society: <http://www.peiot.org/indexot.html>

Prince Edward Island Occupational Therapists Registration Board: <http://www.peiot.org/indexrb.html>

Nunavut Department of Health Rehabilitation Services:

<http://gov.nu.ca/health/information/rehabilitation>

Colleges

College of Occupational Therapists of British Columbia: <http://www.cotbc.org/>

Alberta College of Occupational Therapists: <http://www.acot.ca/>

College of Occupational Therapists of Manitoba: <http://www.cotm.ca/>

College of Occupational Therapists of Ontario: <http://www.coto.org/>

College of Occupational Therapists of Nova Scotia: <http://cotns.ca/>

Speech-Language Pathology

Associations

Speech-Language and Audiology Canada: <http://sac-oac.ca/>

BC Association of Speech/Language Pathologists and Audiologists: <http://www.bcaslpa.ca/>

Alberta Speech-Language Association of Private Practitioners: <http://asapp.ca/>

The Saskatchewan Association of Speech-Language Pathologists and Audiologists:

<http://www.saslpa.ca/>

The Ontario Association of Speech-Language Pathologists and Audiologists: <https://www.osla.on.ca/>

Ordre des orthophonistes et audiologistes du Quebec: <http://www.ooaq.qc.ca/index.html>

New Brunswick Association of Speech-Language Pathologists and Audiologists: <http://www.nbaslpa.ca/>

The Newfoundland and Labrador Association of Speech-Language Pathologists and Audiologists:

<http://www.nlaslpa.ca/pg.php?p=1>

Speech and Hearing Association of Nova Scotia: <http://www.shans.ca/>

Prince Edward Island Speech & Hearing Association: <http://www.peispeechhearing.ca/>

Nunavut Department of Health Rehabilitation Services:

<http://gov.nu.ca/health/information/rehabilitation>

Colleges

College of Speech and Hearing Health Professionals of BC: <http://www.cshhpbcc.org/>

Alberta College of Speech-Language Pathologists and Audiologists: <http://acslpa.ab.ca/>

The College of Audiologists and Speech-Language Pathologists of Manitoba: <http://www.caslpm.ca/>

College of Audiologists and Speech-Language pathologists of Ontario: <http://www.caslpo.com/>

College of Audiologists & Speech-language pathologists of Newfoundland and Labrador:

<http://www.caslplnl.ca/>

Physiatry

Canadian Association of Physical Medicine & Rehabilitation: <http://capmr.ca/>

Search for specialists in physical medicine and rehabilitation within the college of physicians and surgeons of your province:

College of Physicians and Surgeons of British Columbia: <http://www.cpsbc.ca/>

College of Physicians and Surgeons of Alberta: <http://www.cpsa.ab.ca/>

College of Physicians and Surgeons of Saskatchewan: <https://www.cps.sk.ca/>

College of Physicians and Surgeons of Manitoba: <http://www.cpsm.mb.ca/>

College of Physicians and Surgeons of Ontario: <http://www.cpsso.on.ca/>

College of Physicians and Surgeons of Quebec: <http://www.cmq.org/>

College of Physicians and Surgeons of New Brunswick: <http://www.cpsnb.org/>

College of Physicians and Surgeons of Nova Scotia: <http://www.cpsns.ns.ca/>

College of Physicians and Surgeons of Prince Edward Island: <http://www.cpspei.ca/>

College of Physicians and Surgeons of Newfoundland and Labrador: <http://www.nmb.ca/>

Complementary Therapy

The Vocational Rehabilitation Association of Canada: <http://vraCanada.com/>

Dietitians of Canada: <http://www.dietitians.ca/>

Canadian Chiropractic Association: <http://www.chiropractic.ca/>

Canadian Massage Therapy Alliance: <http://www.crmta.ca/>

Canadian Association of Naturopathic Doctors: <https://www.cand.ca/>

Canadian Contemporary Acupuncture Association: <http://www.contemporaryacupuncture.ca/>

Canadian Association of Social Workers: <http://www.casw-acts.ca/en>.

AIDS Service Organizations – HIV related resources

These organizations may be able to help you learn more about your challenges, and help you find and/or access rehabilitation services.

CATIE- Canada's source for HIV and hepatitis C information: <http://www.catie.ca/>

Canadian Public Health Association: <http://www.cpha.ca/en/programs/portals/hiv.aspx>

Canadian AIDS Society: <http://www.cdnaids.ca/>

- Local AIDS service organizations can be found on the members page:
<http://www.cdnaids.ca/members.nsf/members!Openview&language=english>

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