HIV and emotional wellness





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Introduction



Maintaining a healthy, balanced emotional outlook on life is an important part of living well with HIV. For many people, advances in the world of HIV all help to make this more possible—HIV treatment has improved, people who are on treatment and maintain an undetectable viral load can feel secure that they won't pass HIV to their sex partner(s), and people with HIV now live long and healthy lives. To live as healthily as possible with HIV, it is important to take care not only of your mental and physical health but of your mental and emotional health as well.

The mind-body connection

Our bodies and minds are intimately connected. Living with HIV can be stressful and can challenge our emotional well-being. Similarly, stress and anxiety can affect our bodies. So maintaining "a healthy mind in a healthy body" is key.

Why is our emotional health so important?

When we are emotionally healthy, we are better able to enjoy our life and the people in it. We can love, express ourselves creatively, learn new things without fear and test our limits. We are better equipped to cope with difficulties, disappointments, sadness and stress, secure in the knowledge that, in time, we will be able to enjoy our lives once again. For people living with HIV, our emotional wellness makes it easier to take care of ourselves and others—to take our HIV medications as prescribed, see our doctor regularly, approach our healthcare providers as equal partners, practice safer sex and (if we use drugs) take precautions when using drugs.

"Being an HIV-positive newcomer is one of the most difficult things I ever had to deal with. I was scared and confused, but now it gives me joy to know that there is help out there. I've connected with HIV organizations, a specialist and lots of other people living with HIV. Some of these people are now my 'family."

-Boitumelo

Who is this booklet for?

This booklet is written for people living with HIV, to provide practical information that will help you find and maintain emotional health. It may also be useful for the people who support you—the service providers at your health clinic or HIV organization, your partner, friends, family and loved ones.



Maintaining your emotional health

What do you do to nourish your body and, more importantly, your spirit? Probably a whole range of things: maybe you go for walks, talk with trusted friends, confide in your journal, enjoy a hobby...

Learning how to nurture your emotional health involves trying out various options and finding what works for you and what doesn't. It is an ongoing and dynamic process that requires some experimentation. What works for you may be different from what works for the next person, and what works for you at one time may be different

"What has helped me the most has been getting involved with HIV organizations... Attending meetings, HIV conferences and support groups helps me know that I'm not the only one dealing with this. When I see others with HIV who are strong and confident, I feel like I can handle it, too."

--Kim

from what works later. Through trial and error, you'll find the practices that are most effective for you.

What do we mean by "emotional health"?

Emotional health can be difficult to define because the balance that constitutes emotional health is unique to each individual and varies from one culture to another. In some cultures, talking openly about emotional experiences may be encouraged, while in others it may be frowned upon. Throughout this booklet, we aim to promote a positive, affirming understanding of emotional health and wellness—an important aspect of our health as people living with HIV.

What we mean by emotional health is a balance between the various parts of your life. Emotional health encompasses your physical, mental, emotional, spiritual and sexual well-being. It can be strengthened through love, friendship, social supports and your sense of "fitting in" in your community.

Your emotional health might include such things as your ability to enjoy life without being consumed by things from your past or stressing about things in the future, your ability to manage stress, maintain an optimistic outlook and "bounce back" from difficulties.

When we are feeling mentally and emotionally healthy, we feel more able to juggle the different aspects of our life and make changes when necessary to restore balance among them. We are better able to recognize our strengths and talents and pursue them in a way that allows us to realize our potential. Being in a good place emotionally makes it easier to feel and express our full range of emotions. And we feel better equipped to tackle life's problems.

Practicing "emotional fitness"

Like physical fitness, it can take time, practice and an ongoing commitment to achieve and maintain emotional health. Here are some simple pointers that might not resolve problems but can help you practice "emotional fitness":

 Visualize – Close your eyes and imagine yourself in a peaceful place: a forest, beach or green field. Breathe slowly and deeply. Feel the sensation of peace and tranquility in your body. Or close your eyes and imagine yourself succeeding at a task. Think about the satisfaction you feel. Savour it.

 "Collect" positive emotional moments – Recall the times when you have felt pleasure, comfort, tenderness, confidence or other positive emotions.



- Learn how to cope with negative thoughts – Try to interrupt insistent negative thoughts as they come into your mind, by distracting or comforting yourself if you can't solve the problem right away.
- Forgive yourself and others You may blame yourself for having HIV, or blame the person you think "gave" it to you. Forgiveness can help us live in the present. Through forgiveness, you stop letting the past haunt you and can focus instead on the person you are now.
- Concentrate on one thing at a time – For example, when you are out for a walk, turn off your cell phone and focus instead on the sights, sounds and smells you encounter.
- Exercise Regular physical activity improves not just your physical but also your emotional health and can reduce depression and anxiety. Joining an exercise group, dance class or gym can also reduce loneliness by connecting you with a community of people.

- Taking up a hobby can bring balance to your life by allowing you to do something creative and enjoyable simply because you want to do it. Owning a pet can provide a sense of companionship and help you to get outside and exercise.
- Set realistic personal goals –
 These goals should be doable. You might decide to finish the book you started, take a walk around the block every day or call a family member or friend weekly. Reaching your goals will build confidence and a sense of satisfaction.
- Talk it out or keep a journal –
 Expressing yourself after a stressful day can help you gain perspective and release tension.
- Volunteer Volunteering can make you feel useful, widen your social network and provide you with new learning experiences.
- Treat yourself well Cook yourself a tasty, healthy meal, have a bubble bath, see a movie, sing, dance. Whatever it is, do it just for you.

(Adapted from the Canadian Mental Health Association's Mental Fitness Tips)

In the same way that physical fitness can help us recover from an illness or surgery, "emotional fitness" can make it easier for us to regain our emotional balance and our ability to enjoy life again after a difficult period.

Living with HIV can challenge your emotional health

Living with HIV can be emotionally challenging. You may be dealing with stress and anxiety after being diagnosed with HIV or as a result of disclosing your HIV status to family, friends and sex partners. You may have experienced judgment, rejection or discrimination from those around you. Or if you decided not to tell people in your life, you may feel isolated.

Losses you may have experienced—such as the loss of a relationship—can be devastating.

Perhaps you already struggled with depression, anxiety or other emotional health issues prior to your

HIV diagnosis. Or you have been sexually or physically abused or you are a survivor of a residential school and are experiencing post-traumatic stress. Perhaps you are not entirely comfortable with your sexuality and you are blaming that part of yourself for your HIV diagnosis. Or your use of drugs and alcohol may have gotten out of hand and could be causing problems in your social life or

"Though I tend to become quite depressed in the winter, I won't miss my Friday morning [painting] class—it gets me out of the house and...the creative and supportive atmosphere allows me the freedom to completely relax physically and mentally and enjoy the process without distractions or fear."

---Marlene

"[After my HIV diagnosis]
I thought my life was over—
that nobody would talk to
me again, I would never have
another boyfriend, I would
never find a job or have a
family. I was sure this was
the end."

—Chantale



on the job. To top it off, untreated HIV and some related conditions, as well as some of the HIV medications we take can impact our emotional health.

This booklet provides practical information and tips to help you achieve better emotional health, to maintain it when things threaten to disturb the balance and to return to it after a period of emotional difficulty or crisis. So read on...

"I'm finally at peace with HIV. It's doing its thing, I'm doing my thing—we can live together."
—Devan

"I lived in fear of transmitting
HIV and built walls to keep
others out... I am now aware
that I am much more than a
virus. I can look forward to
meaningful relationships with
others and opening my heart."
—Tom

Emotional health issues in the context of HIV

Self-esteem

Many of the challenges to our emotional health are rooted in low self-esteem. Even prior to an HIV diagnosis, many people have struggled with low self-esteem as a result of experiences in their early life, such as bullying or social exclusion. HIV can add to this feeling. At the same time, many people find that the discovery that successful treatment makes their HIV untransmittable (U=U) has boosted their self-esteem. It allows them to feel more open to love and gives them a sense of sexual freedom.

Low self-esteem can make it difficult to live a healthy and happy life with HIV. Addressing our emotional problems often starts with learning how to

feel better about ourselves.

You may experience unfair treatment (discrimination) as a person with HIV, whether on the job or when applying for services, assistance or housing. You may find yourself confronted with other people's negative ideas about HIV and the people who have it (this is called stigma). Such experiences can harm your self-esteem. It is important

"For years, low self-esteem and a sense of low self-worth prevented me from pursuing my dream as an artist and I listened to people who said it was hard to make it as an artist. More importantly, I listened to myself when I said, "I'm not good enough."

-Ron

to know that there are laws and policies to help you take action if you feel you are being discriminated against as a person living with HIV.

Stress

Stress is very common among people living with HIV. We worry about our health, about telling others about our HIV status, about being rejected in relationships or discriminated against at work.

"When one's immune system is compromised, it is essential to de-stress in as many ways as possible...for me, this means not working and using this time to return to health. I'm learning to live in balance, creating space and time away from my busy life to nourish and recharge myself. Having the courage to say 'no' at times and simplify my life is essential for the restoration of my immune system."

—Rebekka

People cope with stress differently. For some, stress and worries can take over and become chronic. Chronic stress is characterized by tension in our muscles, headaches, an inability to relax or sleep and other physical symptoms. Some people turn to practices that can create more problems, like using alcohol and drugs or engaging in sexual risk-taking.



Telling others you have HIV (disclosure)

It can be stressful deciding whom you can tell about being HIV positive.

To help you decide, ask yourself:

- Who do I feel needs to know?
- Who will not judge me
- Who do I feel safe telling?
- Who is a good listener?
- Who will support me unconditionally?
- Who will respect my privacy and only tell others if I ask them to?
- Who is sensible, reliable and might be able to help me if they knew?

For the most part, you don't have to disclose to anybody until you're ready, and you don't have to tell everyone at once. Though it may seem hard to disclose at first, many people find that it becomes easier the longer you live with HIV.

The one exception is that you have a legal duty to disclose your HIV status to sex partners (and likely the people with whom you share drug equipment) in certain circumstances (to find out more about this, visit www.aidslaw.ca).

Sharing this information can be very stressful. Counsellors at some HIV testing clinics or those who work with Public Health can help you plan how to do this, or even do it for you. Although you may feel judged or rejected when telling friends, families, co-workers, sex partners or people you have shared drug equipment with, people's reactions may not be as bad as you fear. You are a good judge of whom you should tell about your HIV status, so trust your feelings.

The people you tell may need more information about HIV, including how it is and is not transmitted. Many HIV organizations have counsellors who can also give you pamphlets that you can give to the people you tell.

(Adapted from Managing Your Health)

"All of [my friends] were supportive; nobody rejected me as I had feared they would."

—Chantalle

Things you can do to decrease your stress levels now

- Problem-solve If the source of your stress is something you have control over, try to address it and eliminate the root cause.
- Talk about your fears Keeping your fears bottled up makes them worse. Find a friend, a counsellor or an elder you can talk to about your biggest fears and worries.
- Breathe Concentrate on taking slow, steady breaths. Breathe in to the count of four, pause, and breathe out to the count of four.
 And repeat. Find some time every day to focus on your breath and slow it down.
- Relax Tense up each muscle in your body, one at a time, then release it to see how a relaxed muscle feels. A hot bath with aromatherapy oils or Epsom salts

- or getting a massage also helps to relax muscles.
- Laugh Studies show that laughter reduces stress.
- Appreciate the good things –
 Every day, try to count five things
 in your life that you are grateful for.
 This reinforces a positive attitude.
- Learn about stress reduction –
 There are many complementary therapies that teach relaxation and stress reduction. Some community organizations offer free massage, yoga and meditation classes.
- Live in the here and now Life with HIV can be all about living in the past with regrets or with worry about what lies ahead. Find some time every day to try to let go of the past and future and live in the moment.

"What I need to stay away from in order to stay alive is stress. I'm always trying to find balance in my life, so I can fully enjoy it. Part of that balance comes with helping others; I, in turn, help myself."

—Claudia

Anxiety

Some people find it so difficult to deal with stress that they become extremely anxious. They may have panic attacks, develop phobias (intense, specific fears), experience physical symptoms that do not have a physical cause (such as a rapid heart rate, dry mouth or an upset stomach), or feel a nervousness that interferes with their day-to-day activities. To avoid feeling anxious, some people drink alcohol or do drugs.

Stress can have a big impact on the immune system and increase a person's susceptibility to illness, so it's important to deal with anxiety and what lies behind it.

Depression

Everyone experiences short periods of feeling sad or down at some time, but some people develop states of sadness, helplessness and the inability to enjoy things for long periods of time. These states are often accompanied by low energy, problems sleeping, eating or concentrating, and even feelings of wanting to commit suicide. This is known as depression.

"[After my diagnosis, I] became very depressed over the next year... If I had made contact with the AIDS service organization earlier, I might not have spiralled into such a deep depression."

—Terry

Depression is common among people living with HIV. We are much more likely than the general population to develop depression. And, among people living with HIV, depression appears to be more common among women than men.

Depression limits our quality of life and can often affect our ability to care for our health, making it harder to take

our HIV drugs as prescribed and leading to problems with substance use and/or unsafe sex.



Many factors can contribute to depression, such as a family history of depression, experiences of loss, being socially isolated without the support of friends and family, certain medications taken by people living with HIV, or the consequences of prolonged use of street drugs.

Setting small goals can help when you're depressed

- Try to go to bed and wake up at the same time each day.
- Bathe, brush your teeth, comb your hair and get dressed daily when you get out of bed.
- If possible, leave the house and go out for a short walk every day.
- Have short but frequent contact with good friends.
- Engage in activities that you can start or stop easily, such as grocery shopping or some light exercise.
- As much as possible, limit the amount of alcohol and street drugs you consume.

Addictions

The Centre for Addiction and Mental Health estimates that 1 in 5 people who has problems with their emotional health also has a problem with substances, such as street drugs and/or alcohol. Some people use substances to help manage low self-esteem, stress, anxiety and depression. Others may turn to sex, shopping, gambling or other activities. And people can combine these activities—for example, using drugs and having sex.

These activities sometimes come with downsides. Substance use can harm the immune system. It can also interfere with your ability to stay healthy by making it more difficult to stick to one's pill-taking schedule, eat well or get a good night's sleep. Using drugs while having sex can lead people to make decisions they would not normally make, and it can negatively impact one's intimate relationships.

Sometimes these activities become addictions. This can happen gradually: Often people don't realize that their social drinking, drug use or sexual risk-taking is getting out of hand. Education counselling and support groups can help you deal with addictions. For alcohol or drug use, there are things you can do to minimize the negative effects of using these substances (this is called a harm reduction approach).

"I am a survivor of a residential school. I started attending when I was five years old and I was abused before and while at the school. After leaving, I wanted to distance myself from everything that had happened there and I discovered the best way to do that was to use drugs and alcohol."

-Ron

Taking care of ourselves

After recognizing that you need some help, the next step is to get that help. Find people you can turn to for support; take care of yourself by eating well, getting enough sleep and exercising; try complementary and alternative therapies such as yoga or acupuncture; and work in partnership with a healthcare provider to maintain or restore your emotional balance.



Find people to talk to

As a person living with HIV, you may at times feel lonely or isolated. With stress, anxiety or depression, your feelings of loneliness may become even more pronounced. Even though it can be difficult to do so, now is the time to seek out understanding friends, family and community members who can provide a shoulder to cry on, lend a sympathetic ear and help you explore your options.

In addition to, or instead of, friends and family, there may be supportive and nonjudgmental counselling and support services in your community that you can turn to. Community health centres, hospitals and clinics, some HIV organizations, telephone or online helplines often offer such services free of charge.

These services can help you build good coping skills and deal with the issues you are facing. They can provide you with support and help you deal with drug and alcohol issues. You may be able to meet other people with HIV through these services, especially at your local AIDS service organization, where support groups and social events for people with HIV are often held. Meeting other people who have gone through what you are

"Often stress comes because we're carrying this big load that we feel we need to carry ourselves. But I've realized that we can share this load.....
Once I learned to cry in front of others, I was able to express what I was feeling while I was feeling it, without letting it build up to a point where it would become too stressful. A huge weight was released."

—Janet

Through her AIDS service organization, Krista met Ron, another Aboriginal person living with HIV: "Meeting Ron really soothed me inside. It diminished the shame, the pain. I wasn't alone. He lit a fire inside me and I felt that I needed to find a space within the circle. I started to stand up for myself and say, 'This is me. This is my story."

---Krista

"I think support groups are the greatest thing since sliced bread. That's what it's all about—listening to other people who are in the trenches dealing with it."

—Simon

going through can help you develop a positive, hopeful outlook, improve your selfesteem and build a network of relationships with people you can rely on for companionship and support.

Eat well, sleep enough and exercise!

Taking good care of your body will provide a solid foundation on which to build your emotional health. This means eating a balanced and nutritious diet that gives your body and mind the fuel they need to carry out the tasks of daily life. Many people with HIV also find that adding vitamin and mineral supplements to their diet helps them to maintain good physical and emotional health. And, as anyone who has ever been sleep-deprived knows, getting a good night's sleep is also key to our emotional wellness.

Exercise can also benefit our emotional health.

Doing moderate amounts of exercise on a regular basis is something significant that you can do to build not just your muscles but also your emotional health.

Studies show that exercise is effective for treating mild to moderate depression and for reducing anxiety. It helps to counteract the withdrawal, inactivity and feelings of hopelessness that characterize depression and can reduce feelings of anger and nervous tension. It can improve how you feel about your physical condition, enhance your body image and improve your self-esteem. Exercising outdoors can expose you to sunlight, which can help your body synthesize vitamin D and decrease depression. Exercise also brings you into

contact with other people. For the length of your walk or your yoga class, you are engaged with people who share your interest.



"I've been living with the virus for 13 years. Complementary therapies such as massage, acupuncture, Traditional Chinese Medicine, herbs, yoga, meditation and visualization help me to rejuvenate and stay optimistic about my health."

-Rebekka

Try complementary therapies

A number of complementary and alternative therapies can support your emotional health, by either treating the underlying problem or relieving symptoms of the problem (such as sleeplessness or stress). These therapies include, but are not limited to, acupuncture, light therapy, hypnotherapy and aromatherapy.

Aromatherapy blend

- 6 drops of lavender essential oil
- 4 drops of grapefruit essential oil
- 2 drops of ylang ylang essential oil

Add these essential oils to 25 ml of grapeseed oil for an uplifting massage or simply add them to your bath.

Note: Do not ingest essential oils. Use with caution if you are pregnant or have epilepsy.

Some people find that adding more omega-3 fatty acids to their diet reduces depression. Wild salmon and other fatty fish or salmon oil capsules are a good source of omega-3. If your depression is related to vitamin deficiencies, adding a B-vitamin-complex supplement to your diet might help, particularly with anxiety.

While these and other natural health products have been shown to help depression, note that St. John's wort will interfere with how your HIV medications work, so is not recommended for people with HIV. Another

natural health product, called kava kava, can cause liver damage. Although considered natural, many complementary therapies can interact with HIV medications, weaken their effect and/or cause dangerous side effects. It is important that your doctor and pharmacist know everything that you are taking so they can keep an eye out for potentially problematic interactions or contraindications.

Seek professional help

In addition to the support of friends, family and other people living with HIV, you may also want to seek professional help. A trustworthy and supportive healthcare provider may be able to help you navigate your way back to emotional health when you feel like you have lost your footing.

The doctor-patient relationship

You may want to discuss your emotional health with your doctor as issues arise, just as you would discuss your physical health. Your doctor can help you identify the problem, determine the cause and work with you to figure out the best way to deal with it. Or they can refer you to another healthcare professional.

Sometimes our doctors do not ask about our emotional health. Sometimes we don't communicate with them about how we're feeling. We may feel embarrassed or ashamed to bring up these issues, so we don't give them the time that they deserve during our appointment. If this is the case, try to talk about these issues with your doctor. If your doctor is not receptive, look for a counsellor or healthcare provider who is.

"If I don't get good treatment from one doctor, I will find another one. I encourage other people to do the same. I don't allow anyone to tell me what I can't do—whether it's medical or whatever."

-Roberta

Biomedical causes of mental health problems in the context of HIV

If you notice that your mood has changed or you notice signs that could be connected to feeling emotionally unwell—such as problems concentrating, mental fogginess, nervousness, weight changes, disturbances in your sleep patterns—it's possible that the cause is something physical. For example:

- Certain conditions related to advanced HIV disease, such as anemia (low red blood cell count), severe fatigue and HIV-related brain problems, can cause symptoms that feel very similar to depression.
- Nutritional deficiencies
 (particularly vitamin D, vitamin B₁₂
 and other B-vitamin deficiencies)
 can affect our mental functioning
 and make us feel depressed.
- Hormonal imbalances, such as impaired thyroid function, testosterone deficiency, perimenopause, menopause and post-partum changes, can cause anxiety and depression.
- Some medications used to treat HIV are associated with a range of psychological problems. In particular, the drug efavirenz (Sustiva, also found in the combination pill Atripla) is associated with depression as well as vivid dreams and nightmares. Many other medications used to treat conditions not commonly associated with HIV have side effects that include depression, nervousness, mental fogginess and fatigue. These side effects usually diminish over time as the body becomes accustomed to the drugs. In some circumstances where the drug is not tolerable, the only option may be to change it or stop using it, a decision that should be made with your doctor.

The many possible causes of our emotional health problems can make it extremely challenging to tease out the reason for our symptoms. This is why a good doctor-patient relationship, based on trust and clear communication, is so important. Tests to rule out possible causes and identify the actual cause may be required, followed by the addition or discontinuation of prescription drugs, vitamins and/or supplements.

Make sure your doctors and pharmacist are aware of all the drugs you are taking: your HIV medications, medications for other conditions, vitamins and supplements, even street drugs. With this information, they can watch for drug interactions and side effects that may be causing or contributing to problems with your health, including your mental health.



"My GP is a compassionate doctor who spends extra time listening and talking to me, as he knows I've struggled with depression. He's there to help and support me until I can see my psychologist. While applying for medical disability, I was feeling quite depressed, and the overwhelming bureaucracy led to more depression. As usual, my GP was there for me to lean on."

—Randy

"It's important to have support in your life. Find a good counsellor or therapist with whom you can go into the darkest, scariest part of it all and confront your fears."

—James

Once your doctor rules out a biomedical cause, he or she may be able to help you with counselling or refer you to a social worker or counsellor on staff. Your doctor may recommend medications, such as antidepressants, anti-anxiety medications or drugs to treat certain symptoms, such as sleeping aids for insomnia.

Other resource people

Your doctor may refer you to other emotional health resource people, such as:

- a psychologist or psychotherapist
 who can offer talk therapy to
 help you better understand your
 problems and the behaviour
 patterns you have used to cope
 with them, and to learn better
 ways of coping
- a therapist specializing in cognitive behavioural therapy (CBT) who can work with you to identify thought processes that make your emotional health issues worse, along with the situations that trigger them in you, and help you to replace these negative thought patterns with more positive, reassuring ones. This form of therapy has shown much promise in helping people living with HIV.

- a social worker or counsellor who may be able to help you with practical assistance, such as housing and financial support, if these things are barriers to your health
- **a psychiatrist** who can do a psychiatric assessment, offer psychotherapy and prescribe antidepressants or other medications



You may also find it helpful to speak to an **Aboriginal healer** or a **spiritual or religious leader** in your community.

Learning how to take care of your emotional health is an important part of living well with HIV. By maintaining a healthy mind in a healthy body, you can look forward to not only a long life, but also a fulfilling and meaningful life with HIV.

"Now I'm starting to see the light at the end of the tunnel. I never thought I would."

—Darrell

Need more information?

For more information on HIV and emotional wellness, contact CATIE, Canada's source for up-to-date, unbiased information about HIV and hepatitis C. CATIE offers information for people living with HIV and/or hepatitis C, in print, online and by phone in English and French.

To contact CATIE, call our toll-free line at 1.800.263.1638 (all calls are treated as private and confidential). You can also visit us online at **www.catie.ca** or email us at questions@catie.ca

You may also want to check out these resources:

- www.positiveside.ca The Positive Side, CATIE's health and wellness magazine for people living with HIV (available in print and online)
- www.cmha.ca Canadian Mental Health Association
- realizecanada.org Realize, a national organization that responds to the rehabilitation needs of people living with HIV
- hiv411.ca a listing of HIV and hepatitis C services in Canada



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Disclaimer

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

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