Talking About Depression, Anxiety and HIV/AIDS
Acknowledgements

The Canadian AIDS Society (CAS) adopts a holistic approach to health as part of its core values and beliefs; that good health encompasses physical, emotional, mental and spiritual well-being. This holistic approach guides the work of CAS as it supports communities and organizations that address the needs of people living with and affected by HIV/AIDS. CAS is committed to reducing inequity, stigma and other social factors driving the epidemic by working with all levels of government, community organizations, and people living with and affected by HIV/AIDS.

“Talking about Depression, Anxiety and HIV/AIDS” was developed to be a resource for people living with HIV/AIDS (PLWHIV/AIDS) and the people who support them. It examines two specific mental health issues, depression and anxiety, in the context of HIV/AIDS. Drawing upon resources developed for people living with HIV/AIDS, depression and/or anxiety, as well as for the general public, it provides general information about depression and anxiety, and how these mental health issues interact with HIV.

This document provides general information only, and cannot substitute for the advice of a medical professional. If you think that you or someone you care about might be living with depression or anxiety, consult with your health care or mental health care provider. With appropriate care and treatment, we bring ourselves closer to a state of well-being in which we are better able to cope with the stresses of life, to make a contribution to our communities, and to enjoy our lives.

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About the Canadian AIDS Society

Representing community-based AIDS organizations across the country, the Canadian AIDS Society (CAS) strengthens the response to HIV/AIDS in Canada and enriches the lives of people and communities living with HIV/AIDS. CAS accomplishes this by:

- promoting education and awareness
- mobilizing communities
- amplifying the voices of Canadians living with HIV/AIDS
- engaging with Canadians on public policy
- providing information and resources
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Introduction

Canadians are talking more and more openly about mental health and illness. There are several national mental health awareness campaigns and increased public attention being given to a wide range of mental illnesses. Perhaps you have heard this statistic recently: that 1 in 5 Canadians (20% of the population) will experience a mental illness in their lifetime.¹

But, did you know that people living with HIV/AIDS (PLWHIV/AIDS) are more likely than the general population to be affected by depressive disorders² and general anxiety disorder³?

There are many types of mental illness. “Talking about Depression, Anxiety and HIV/AIDS” will examine two of the most common and treatable mental illnesses affecting PLWHIV/AIDS today: depression and anxiety.

This document will help readers identify depression and anxiety, and it will explain the most common treatments that are currently available for these conditions. It will look at how living with HIV/AIDS can have an impact on a person’s mental health, and how PLWHIV/AIDS can also be living with depression and/or anxiety.

Readers will learn how they can build on the knowledge provided in this document by sharing information with others and by drawing upon other resources. Finally, it highlights the importance of communication with their care providers when it comes to care and treatment issues relating to mental health and HIV.

NOTE: This document provides general information only, and cannot substitute for the advice of a medical professional. If you have concerns regarding mental illness and HIV, consult with your HIV specialist, your health care provider and/or your mental health care professional.

Depression, Anxiety and HIV/AIDS
What do we mean when we use the term Mental Health? The World Health organization describes mental health as “a state of well-being in which the individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his own community”.

The term Mental Illness is used to describe disease that significantly affects a person’s thoughts, mood and behaviour and impairs their ability to function and cope in their day to day lives. The term also distinguishes certain conditions from physical illnesses – although they are both happening in the body, the symptoms of mental illnesses do not always present themselves physically like an infection might. However, just like physical illnesses, there are a wide range of conditions that fall under the term mental illness.

What causes mental illness? We do know there is rarely one single cause. Mental illnesses are thought to be the result of a combination of a variety of factors: genetic, social, economic, biological and psychological. We know that mental illness does not discriminate: it can affect anyone and no one is immune.

Mental Illness in Canada

It is estimated that 1 in 5 Canadians – 20% of us - will experience a mental illness or issue in their lifetime. The remaining 80% of the population will likely be affected by mental illness after someone close to them develops a mental illness, like a family member, a friend, or a colleague. This means that over the course of their lives, almost everyone in Canada will experience mental health issues directly or indirectly.

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5 Canadian Mental Health Association, 2014.
Mental Health and Illness in Canada

Mental and Physical Health and Quality of Life

Our minds and bodies are linked, and the connections between our physical and mental health and our quality of life can be seen in our day to day lives.

Researchers now know that people with serious mental illness are at greater risk of experiencing a range of chronic physical conditions, and conversely that living with chronic health conditions can have an effect on your mental health. They have learned that good mental health is associated with – if not essential to - better physical health.

Like other mental illnesses, undiagnosed and untreated depression and anxiety can limit our quality of life and interfere with our immune system’s ability to fight diseases like HIV.

Did you know…?

There are many famous Canadians who have publicly shared their personal experiences related to living with depression and/or anxiety:

- Comedian/actor Jim Carrey
- Comedian/actor François Massicotte
- Multiple Olympic medal-winning cyclist and speed skater Clara Hughes
- Singer/songwriter Amy Sky

Anxiety:
- Singer/songwriter/actress Alanis Morissette
- Singer/songwriter Stefie Shock
- Comedian/actor Howie Mandel
- Comedian/actor John Candy
Factors Relating to Mental Health

There are known factors that relate to mental health and the chance of developing or recovering from mental illnesses.

Protective Factors: Protective factors are those things that help to reduce the probability of developing mental health problems and illnesses, and that aid in maintaining good mental health. They include having a sense of belonging, good relationships, problem solving skills, and the feeling of being in control of one’s life. They also include structural factors in society that reduce adversity and promote a sense of security (for example, having safe housing and a stable income).6

An example of a protective factor is resilience. Resilience refers to our ability to rebound after experiencing a set-back or series of challenges. Resiliency is an inner strength that helps you cope with life’s challenges and traumas. Being resilient can help you see past problems and better handle stress. Resiliency can be learned and strengthened over time.

Risk Factors: Risk Factors are things that increase the likelihood that people will develop mental health problems or illnesses. They can include genetic predisposition, economic, social and psychological factors, trauma, isolation, incarceration, personal or family drug or alcohol use, family conflict, and the experience of discrimination.7

Most people have a combination of these protective and risk factors – and by themselves, they do not indicate whether or not you have a mental illness. They are indicators or signs that have been related to mental illness through research.

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7 Ibid.
Depression, Anxiety and HIV/AIDS
There are many types of mental illness. In the pages that follow, this document will look at two of the most common types of mental illness: depression and anxiety.

**Note:** The following sections will identify different ways to recognize depression and anxiety. The presence or absence of certain signs, symptoms or thought patterns by themselves is not sufficient evidence to diagnose the presence of a mental illness. Screening tools for both depression and anxiety do exist, and they can be easily obtained from different sources. Whether using the information in this document or using screening tools obtained elsewhere, do not rely on that information alone to determine the state of your mental health. If you would like to have your mental health assessed, make an appointment with a mental health professional in your area. They are trained in the use of reliable screening tools, and more importantly, can offer needed supports regardless of the outcome of screening, testing, retesting or diagnosis.

### Depression

As a term used to describe a range of mental illnesses, “depression” is sometimes confused with depressed feelings or moods. The mental illness known as clinical depression is different from the “blues” or from merely feeling sad or down. As human beings, we are not always happy, and there can be good reasons why people may feel unhappy. Consider how you might feel at the moment of being rejected for a job or a date, losing a loved one, experiencing a change for the worse in your financial circumstances, or even receiving a diagnosis of HIV infection. Experiencing grief or unhappiness alone, however brief, does not mean that you have one of the conditions that are categorized under the clinical term of “depression”. In other words, having a depressed mood that lasts even a few days is not the same as living with depression.

When you have clinical depression, you can live with feelings of severe despair for an extended period of weeks, months or even years. It can affect almost every aspect of your life, including your emotions, your physical health, relationships and work or school. Living with this mental illness can leave you experiencing a sense of hopelessness, and even unable to imagine ever feeling better again.
Many people living with symptoms of depression never seek treatment. However, clinical depression is a treatable mental illness, and people who do seek help have a very high chance of recovery.\(^8\)

Depression may be one sign of your body’s response to dealing with an unmanageable burden. Depression is not a sign of personal or moral weakness.

### Symptoms of depression

Some of the common symptoms of depression are:

- feelings of guilt and worthlessness;
- sadness and loss;
- extreme impatience, irritability, or a short temper;
- loss of interest or pleasure in usually-enjoyed activities;
- changes in weight or appetite;
- fatigue and/or changes in sleeping patterns like insomnia;
- reduced ability to think clearly or make decisions;
- difficulties in concentrating or with short term memory loss;
- noticeable lack of motivation;
- anxiety and restlessness, sometimes leading to panic attacks;
- muscle and joint pain;
- stomach aches, and other gastro-intestinal problems like constipation;
- frequent headaches;
- recurring thoughts of suicide or self-harm;
- withdrawal from friends and family.\(^9\)

Everyone who lives with depression experiences it a little bit differently. For example, one person’s symptoms may not be the same as those of another person living with depression. Still, if you have been experiencing 5 or more of these symptoms for more than 2 weeks, consider talking to a medical professional about your mental health.

If you are experiencing thoughts of suicide or self-harm at any time, with or without these symptoms, it is recommended that you seek immediate medical attention.

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Beyond the list of symptoms

While a list of symptoms can be helpful, they are not only the things to consider when looking for signs of depression.

It may be hard to match the sensations and thoughts a person may experience and think while living with depression to a list of symptoms. Some people have an easier time identifying their own experience of depression when they look at lists of negative thought patterns. They may not identify with ‘feelings of guilt or worthlessness’, but they may immediately recognize themselves making repeated statements like, “Why bother—who cares?”, “I’m no good”, “I’m a total failure”, or “I’m to blame”.

Social and cultural differences may significantly impact how a symptom presents itself, how it is experienced and how it is communicated. Information may get lost in the communication between a medical practitioner and their patient if they are not aware of different understandings of terms, ideas, practices or norms. A person may not fully disclose relevant information because of past experience with the medical profession, or because they fear it will impact their community or social status.

How we are able to function (or not) plays a key role in determining whether our experiences are indicative of clinical depression. Linguistic differences may also play a key role, as how we express what we are feeling is often a large part of the evidence used by medical professionals to make diagnostic determinations. This is not just limited to speaking different languages. Even the difference between medical jargon and street slang can create confusion for both the person expressing their experience and the medical professional looking to identify or rule out the presence of a mental illness.

Causes or Co-factors of Depression

Depression can be brought on by many different causes or co-factors. Stressful or traumatic life events such as the death of a loved one, the ending of a relationship, losing a job, or being diagnosed with a medical condition can trigger symptoms of depression. Depression can also be a side effect of certain medications including some steroids, narcotics (including opioids sometimes found in strong painkillers), benzodiazepines (used to treat insomnia, anxiety and seizures), and hormones (like progesterone used in hormone replacement therapy). The over use of alcohol can also trigger symptoms of depression. While some forms of depression may be event related, not all forms or symptoms of depression are triggered by outside events or substances. Some may have organic origins.
Anxiety Disorder

Anxiety, fear and worry are emotions that we can all experience at certain times in life. Some people describe the experience of anxiety as having “butterflies in their stomach”- a mixture of excitement and fear. You might feel this at a job interview, or on a first date. In situations that are more challenging, such as in a heated argument, the sensations may become stronger. In the presence of a stressor or a perceived threat, our mind and body exhibits different signs of fear such as increased heart rate, rapid and shallow breathing, and a feeling like we have to decide whether to “flee” or “fight”. If these reactions are temporary (lasting only as long as the stressor or threat seems to exists), if they would not be considered as overreactions to the actual or perceived threat, and if they do not interfere with your daily activities, then chances are that you are experiencing feelings of anxiety – but this does not mean that you have an anxiety disorder.

An anxiety disorder is diagnosed when anxiety creates significant distress and interferes with a person’s life, their relationships, their performance at school or work, and/or in their social activities. A person with an anxiety disorder experiences fear and worry, but may do so to a degree that is out of proportion to the perceived threat or stressor.

Many individuals do not get help for their anxiety disorder. Sometimes this is because they think that their symptoms are normal, and that they can manage the anxiety they feel without treatment. They may also feel embarrassed by their symptoms. Other times the symptoms of anxiety themselves can make seeking help seem terrifying and overwhelming.

People with anxiety disorders may avoid situations in life that they feel might trigger symptoms of extreme anxiety. They might also develop rituals and habits to help lessen anxiety and manage their responses to life’s events. However, the sensation of anxiety may overwhelm the person and their ability to use these survival techniques at all, and leave them feeling frozen or paralyzed and unable to act.

In the absence of treatment, the techniques some people use to address their anxiety disorder (such as avoidance, suppression, escapism or sedation) may work too well, resulting in alleviated symptoms but an untreated and ongoing anxiety disorder. Other times, they may not work at all. Most people who get help and treatment for their anxiety disorder are able to recover fully.
Signs and symptoms of anxiety

Anxiety can appear by itself or in the presence of another mental illness (like depression). The most common symptoms of anxiety disorders are often physical, such as dry mouth, upset stomach, increased heart rate, rapid and shallow breathing, shaking, headaches, dizziness, and sweating. Increased agitation and panic attacks are also common symptoms of anxiety disorders. These symptoms can interfere with your quality of life, your ability to function and your ability to take care of your health.

Causes and co-factors of Anxiety Disorders

Anxiety can be brought on by many different causes or co-factors. Certain medications, including some HIV medications and those used to treat depression, have been shown to cause anxiety. Often, it is our perceptions of events (real or imagined) that can trigger or aggravate symptoms or episodes of anxiety.
Depression, Anxiety and HIV/AIDS
Let’s look at some treatments that are commonly used for depression and anxiety:
- medications;
- talk therapy;
- peer and caregiver support;
- complementary and alternative medicine; and,
- hospitalization.

Many mental health professionals find that some combination of treatments (like medications and talk therapy, for example) can achieve better results than relying on one of these treatments alone. Some people may be living with both depression and anxiety, and they may be surprised to hear that some treatments can work for both conditions. With all forms of treatment, we and our care providers should be vigilant for any side effects, or any interactions with other treatments that we may be taking.

Note: Some people take non-prescribed drugs and/or alcohol in an attempt to find relief from the symptoms of depression and/or anxiety. It can feel as though those substances ease the symptoms for a short period, but this feeling of relief is usually brief and unsustainable.

Some may think that this information is not important enough to share with their care providers. However, using non-prescribed drugs and/or alcohol can be relevant for treatment. Some mental health treatments and approaches that are tested and proven to work in most cases will not achieve even a small degree of recovery if the person on treatment is taking non-prescribed drugs or alcohol at the same time. The only way that a care provider can ensure you are being given the best possible treatment is when you reveal as much relevant information as you are comfortable sharing with them.

It is important to discuss whether you use recreational drugs, even on a casual basis. Recreational drugs can interfere with medications, often in unpredictable ways. Some recreational drugs have been associated with symptoms of depression and/or anxiety, especially as the person comes down from the high produced by the drug. This makes treatment very challenging, as the care provider has to determine if the treatment can even be safely prescribed in the presence of recreational drug use. Having a frank discussion with your care provider on the subject of recreational drug use is one way to ensure that you and your care provider have the information you both need to make the best treatment decisions for your care.
By having an open, trusting relationship with your professional care provider, and by following prescribed therapies and treatment plans as agreed-upon by you and your care provider, you are increasing the likelihood that treatment of your depression and/or anxiety will be successful in the long-run.

**Medications**

Talk with your doctor to see if prescription medication is right for you. If you do decide to take medication for depression, be sure to tell your doctor about all other treatments that you are taking so that you can find a medication that works best for you and will have the fewest side effects and/or interactions with other treatments, including HIV medications or complementary therapies.

Medications for mental illness can take several weeks to start to work well. Sometimes it takes a few tries to find the medication or dosage that will work best.

**Medications for depression**

There are different classes of anti-depressant medications. The most common are:

- **Tricyclics**, named for the fact that their chemical structure is based on three rings of atoms. This class includes drugs like amitriptyline (Elavil);
- **MAOIs** or monoamine oxidase inhibitors, including drugs like phenelzine (Nardil);
- **SSRIs** or selective serotonin re-uptake inhibitors, including drugs like fluoxetine (Prozac); and,
- **SNRIs** or serotonin-norepinephrine reuptake inhibitors, including drugs like venlafaxine (Effexor).

The first two classes (tricyclics and MAOIs) were among the first generations of antidepressant medications. Many of these came with side-effects and had interactions with other medications, but they are still in use because they have proven success in treating depression. Newer drugs in these classes have been developed that have reduced the number and frequency of side-effects and interactions.

The last two classes (SSRIs and SNRIs) are most frequently prescribed because these have the least side-effects and interactions with other drugs.

The most common side-effects associated with anti-depressants are dry mouth, weight gain, sleep problems and loss of sexual interest or ability. Tell your doctor about any side effects that you experience as most of them can be minimized if addressed.
Medications for anxiety

Anxiety disorders have been successfully treated with both anti-depressant medications and anti-anxiety medications. In addition to the different classes of anti-depressant medications already described above, there are a range of classes of anti-anxiety medications. The most common medications for anxiety are:

- Benzodiazepines, so called because the chemical structure fuses rings of benzene and diazepine. This class includes drugs like diazepam (Valium)
- SSRIs, or selective serotonin re-uptake inhibitors, including drugs like fluoxetine (Prozac);
- SNRIs, or serotonin-norepinephrine reuptake inhibitors, including drugs like venlafaxine (Effexor), and,
- Azapirones, another name based on a distinct chemical structure. This class includes drugs like buspirone (Buspar).

Benzodiazepines are most commonly used for anxiety, but they have been connected to symptoms of withdrawal when stopped. Azapirones are often used to boost SSRI medications, but do not usually result in withdrawal when stopped.

Talk Therapy

Talk therapy (also known as psychotherapy) can be an important part of treatment for depression and anxiety. It involves talking about ourselves and our lives, including our emotional lives. There are a range of professionals who offer talk therapy, and they may be known by different professional names, from psychiatrist to counsellor. Their training may be different, but they are similar in that they follow professional guidelines for the therapies they offer.

Talk therapy can help us develop our ability to ask for help, and to learn how to receive it. It can also help us better understand our illness, as well as give us opportunities to learn and practice new coping skills and strategies that can be used throughout life’s more difficult times, and not just in relation to depression or anxiety. Talk therapy does take a time commitment and can require very hard work, both emotionally and mentally – but many people who have committed to follow the directions of their therapists can attest to the difference talk therapy has made in their quality of life.

Talk therapy can include group counselling, but it is more often associated with one-on-one treatment, using established psychotherapy approaches. There are a wide range of psychotherapy approaches, and most therapists use one or a combination of approaches in the treatment they offer.
Psychodynamic therapy is based on the idea that there is an unresolved conflict that is being worked out in our conscious and unconscious mind. This can be related to past experience or current stressors, including projections or fears of what the future holds for us.

Interpersonal therapy helps people link their mental illness to interpersonal stressors that may arise due to the death of a loved one, a change in life role, or interpersonal disputes. This kind of therapy is usually one-on-one. Couple therapy and family therapy options may also be considered. These types of therapies acknowledge the roles of others in treatment, and bring them into the therapeutic process. An example could be therapy for couples to help both partners manage the impact of a new diagnosis, or family therapy where children may be the central recipient of care, but where families learn to share the burden of care.

Cognitive behavioural therapy focuses on how we process and organize ideas in our brains (cognition) and how these processes can be connected to behaviour and action. For treatment of anxiety, cognitive-behavioural therapy helps people turn their anxious thoughts into more rational ideas that are less likely to produce anxiety. In depression, it can help identify stressors that trigger emotions which lead to negative behaviours, and offer other ways to respond to those same stressors without resorting to negative behaviour. One example of a cognitive behavioural therapeutic approach is mindfulness.

**Mindfulness**

Mindfulness teaches skills that can alleviate cognitive symptoms of depression and anxiety. Mindfulness-based cognitive therapy, (or MBCT), is one specific form of cognitive based therapy. In cases of depression, the treatment assumes that one part of depression depends on a steady stream of negative thought patterns.

Consider the effect of constantly thinking thoughts like, “Why bother-who cares?” “I’m no good”, “I’m a total failure”, or “I’m to blame”. Some people with depression experience a steady stream of negative thoughts like these while they are doing everyday activities. Negative thinking can also reinforce anxiety. Thoughts like “I couldn’t” or “It’s impossible” can obscure realities that demonstrate clearly that “it is possible” and “you could”.

These thoughts often have little to do with the activities at hand. It is often described as feeling like you are on auto-pilot, with the body functioning but the mind unable to acknowledge what is happening because it is overwhelmed by negative thoughts.

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Mindfulness means being aware of what you are doing while you are doing it – this means no longer letting your thoughts run on auto-pilot. MBCT teaches people to practice being mindful of what they are doing in the moment they are doing it. The idea behind the therapy is that by being present in the moment, people will recognize that their old perceptions of the world (as described by the negative stream of thoughts) do not match up with the actual world as it is being experienced in the present moment.

MBCT focuses on practicing mindfulness on a regular basis. Mindfulness is not easily mastered, especially if the negative streams of thoughts are strong and established. With practice, the hope is that over time, mindfulness weakens the power of repeated negative thought patterns, replacing them with thoughts that are grounded in the present reality. In this way, people who experience small letdowns during the course of a regular day will be less likely to let that letdown be followed by a stream of negative thinking – the downward spiral. With mindfulness, they will be more likely to accept the letdown as it happens, and then be able to move on to what life has in store after the letdown has come and gone.

Peer and Caregiver Support

Peer groups take many forms, from informal get-togethers to more structured forms such as support groups and one-on-one peer guidance. In all these forms, the key benefits are often the same: seeing that you are not alone in what you are experiencing, hearing how others cope, and sharing valuable and useful information. Peer support can be invaluable to people living with depression and/or anxiety. Finding peers or a peer group who you can relate to and can be open with can help you learn more about your illness and how to live and cope with it.

Peer support can be safely combined with other forms of treatment, and is usually provided in the community rather than a health care setting.

Caregiver groups for couples, friends and families can also help loved ones develop the tools for coping with the symptoms and mitigating their effects.

Complementary or Alternative Medicine

Many people use complementary or alternative medicine (or CAM) as part of their treatment, either on their own or along with the health care they receive from medical and mental health professionals. Many people living with mental illness find that practices like exercise, meditation and/or yoga have had a positive impact on both their physical and mental health. Others have attributed improved health and mental outlook to other traditional practices of medicine, like ayurvedic medicine, Reiki and traditional Chinese medicine including acupuncture. The range of complementary therapies is constantly growing, as new ways of healing are tried, tested and shared.
You can learn more about complementary therapies by looking at reliable resources, or by sharing with your peers. You may find that some complementary therapies work well for some people, but not for others. Before trying a therapeutic approach for the first time, it is always wise to discuss these approaches with professionals: specialists in complementary therapies (like registered naturopaths), your mental health care provider, and your HIV specialist.

Many people have also experienced positive effects from herbal therapies (substances derived from plants, such as teas, tinctures, or oils). Studies on the effects of herbal medicines are ongoing, but it is important to note that some herbal medicines can interfere with other medications, such as HIV, depression and anxiety medications. Recent research has shown that St. John’s Wort (an herbal product sold over-the-counter and promoted as a treatment for mild depression) can have severe interactions with other medications, including those prescribed for HIV, as well as those regulating cholesterol (statins), benzodiazapines and oral contraceptives. Before starting any herbal remedy, look for reliable resources that identify any known interactions with other medications you may be taking, and be sure to discuss your interest in taking herbal medicines with your health care professional.

**Hospitalization**

As mentioned at the beginning of this section on treatments, it is often a mix of treatments that will produce visible results. Sometimes, in order to aid recovery, adding the type of intensive, personal care available in a hospital to the treatment mix is necessary. If the condition’s symptoms or the effects of treatment are severe enough to be putting someone’s life, or the lives of others, at risk of danger, hospitalization might be required.

Hospital care can come in different forms:

- **Outpatient care** refers to visits to the hospital that do not require admission or staying at the hospital. Another form of outpatient care exists where the mental health professional who works for the hospital will visit the patient at their home for a series of regularly scheduled visits.

- **Inpatient care** refers to the care provided to people who are admitted to the hospital and stay at the hospital for a period of time.

- **Emergency care** refers to the care provided at times of urgent need, usually at times of crisis.

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Over time, researchers have observed that mental illness and HIV are closely connected. The World Health Organization (the WHO) found that people with serious mental illness are at increased risk of contracting HIV. There are different reasons for this, including increased behavioural risk factors among people with serious mental illness, and the potential for mental illness to interfere with our ability to receive or use information about how to protect ourselves from HIV infection.

The WHO also acknowledged that PLWHIV/AIDS are more likely to have mental health issues than people who are not living with HIV/AIDS. There are many different reasons given for this, including increased stress at diagnosis and the chronic nature of HIV disease generally. Researchers are still discovering the effects of HIV on the brain, the side-effects of some medications used to fight HIV and their impact on mental health.¹²

Some studies have found that many PLWHIV/AIDS can expect to experience depression and/or anxiety at different points in their lives. They show that depression is under-recognized in PLWHIV/AIDS, with less than 10% receiving treatment for their mental illness. They also show depression as a factor affecting adherence to HIV treatment.¹³

Our knowledge about HIV and mental health is growing, but these findings show why it is important to be aware of the effect of mental health on our lives when we are living with HIV/AIDS.

**HIV Diagnosis and Life Beyond**

With or without the presence of mental illness, traumatic life events (like the diagnosis of a physical illness such as HIV) can negatively impact our mental health. Diagnosis with any serious illness can be a very traumatic experience and the way that you manage the experience can contribute to your mental health.

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In Canada, where HIV treatment is generally accessible, PLWHIV/AIDS are now expected to have long, productive lives. In fact, most Canadians living with HIV/AIDS who are receiving treatment can now expect to live as long as their peers. However, this fact may escape us at the moment of receiving an HIV diagnosis. Our emotions can sometimes overwhelm our ability to reason and think things through.

While depression and anxiety might seem like unavoidable reactions to being diagnosed with HIV/AIDS, it is important to know that there is a difference between strong emotional reactions that follow receiving challenging news, and mental illnesses that can exist at the same time as HIV.

It is normal to feel a lot of different emotions when you are first diagnosed with HIV. These emotions can range from fear and sadness to surprise and anger. A person could have many questions following a diagnosis, and in the beginning, there may not be many concrete answers. A newly received diagnosis of HIV disease can be perceived as a major threat to your life plans, or a major stressor on your relationships. Living with HIV/AIDS often causes you to think about and question your place in the world: the past, the present and the future. Strong feelings often follow these thoughts and questions. Some people are able to face these emotions as they happen, and other people may try to suppress those emotions, at least until a time when they feel they can safely face them.

It is important to learn how to manage feelings so you can express them in a healthy and appropriate way. No matter how you may be feeling, it is important to give yourself the permission to experience those feelings at some point. Continuously suppressing emotions can interfere with your daily activities.

Talking about your feelings, with an understanding family member, friend or a mental health professional such as a counsellor, social worker, or nurse, is one way to lessen the impact of the diagnosis of HIV on your mental health. Talk to your healthcare provider or local AIDS Service or Community Mental Health Organization about it. If you are not ready to talk today, they will be there to help when you are ready.

It is still possible that receiving a diagnosis of HIV infection can trigger symptoms of mental illness. In that case, it is even more important to talk about what you are experiencing with a mental health professional. They can help us determine whether what we are experiencing is related to strong feelings or to mental illness, and they can review the range of treatments that exist for HIV, depression and anxiety which can greatly improve our outlook and quality of life.
After diagnosis, PLWHIV/AIDS face unique stresses that will affect their mental health. Some of these stresses could include issues around disclosure of HIV, stigma and discrimination related to HIV, HIV and/or medicine fatigue. These stressors can be compounded by the effects of HIV on the brain. The section that follows will begin to examine all of these issues.

**Disclosure, Life Adjustments, Relationships**

PLWHIV/AIDS often experience strong feelings as they adjust to having been diagnosed with HIV and as they face new realities in their lives. These new realities frequently include dealing with disclosure and changing relationships with family and friends. It also leads to changes in future plans, and changes in everyday life. These changes and stresses can have a negative impact on our mental health.

**Disease and Treatment Fatigue**

Many PLWHIV/AIDS have spent years and decades carefully maintaining and monitoring their own health. They may have lost friends and loved ones to AIDS, have had ups and downs with their own treatment and health, experienced body-changing side effects, loss of jobs, and/or loss of income. More recently, they have had to come to terms with a positive new reality of having the prospect of living a normal lifespan when formerly being sure that they only had a few years left to live.

Taken together, these experiences can be quite draining, even exhausting. They can be burdensome to our mental health and physical well-being. They can require support to work through even without concurrent conditions of depression or anxiety.

Similarly, people living with depression and/or anxiety can tire of the vigilance required to notice any negative changes in their mood or outlook.

Treatment fatigue is a common concern of people living with HIV/AIDS and/or depression and anxiety who have been on treatment for many years. It can be challenging to accept living with HIV/AIDS or depression or anxiety and it can be even harder to accept that treatment may entail taking medications every day for the foreseeable future.
Stigma and Discrimination

Even though we have made significant progress in Canada in recent years, HIV-related stigma and discrimination continue to be present here and around the world. Despite science’s better understanding of the virus, people continue to experience prejudice and rejection because of their HIV status. Feelings of isolation and marginalization relating to HIV stigma and discrimination can negatively affect a person’s self-esteem and mental health.

Stigma and discrimination also exists for mental illness. In certain cultures, discussion of mental illness is anti-social, impolite, unacceptable, and even taboo. Recently in Canada, there has been a movement towards greater openness and understanding of mental illness as society begins to appreciate just how prevalent mental illness is, and how important it is to face it without prejudice or misunderstanding.

In addition to experiences of discrimination encountered from the outside world, many people living with HIV/AIDS and mental illness wrestle with self-judgement, self-blame and shame. These internal and external expressions of discrimination and judgement can prevent people from seeking the help that they need for their physical and mental health.

The Effects of HIV on the Brain

While depression and anxiety can co-exist with HIV, it is important to remember that HIV disease by itself is known to have effects on the brain.

In the past, advanced HIV disease often led to neurocognitive problems such as HIV-associated dementia or HAD, where persistent troubles with memory and concentration impaired the person’s ability to function, and was often followed by a loss of control over different bodily functions and behaviours, as seen in slurred speech, increased clumsiness and other types of behaviour changes. In the years since the introduction of Highly Active Antiretroviral Therapy (HAART), there has been a dramatic drop in rates of HIV-associated dementia, but it has not been eliminated entirely. HAD is now considered to be at the upper extreme of a range of neurological disorders the may affect PLWHIV/AIDS, from Mild Neurocognitive Disorders or MND (such as having trouble concentrating and/or remembering things), to HIV encephalopathy (a variety of brain disorders arising from HIV disease) to HAD. This range of HIV related neurological disorders is now known under the umbrella term of HIV-Associated Neurocognitive Disorder, or HAND.

Talk to your health care provider if you are experiencing changes in your mood or thinking, or any other symptoms relating to your mind and brain. They will be able to help you sort through what is causing the symptoms and how to manage, or even reverse them.
When a person experiences two or more illnesses or diseases at the same time, the illnesses are known as concurrent conditions. This section examines some of the known issues relating to diagnosis and treatment of concurrent conditions of HIV and depression or anxiety.

## Diagnosis

Mental health professionals and health care providers must diagnose or confirm the presence of a disease or disorder before determining the best treatment to follow. Their diagnosis is based on information provided by the patient through conversations, assessments and tests. This information is then compared to existing knowledge about a disease or disorder to determine if the patient’s symptoms indicate the presence of that particular condition. Having more than one condition can make diagnosis more challenging.

One issue includes figuring out what condition a particular symptom is a sign of. For example, did you know that many of the physical symptoms of depression and anxiety are similar to the physical effects of HIV disease? Healthcare providers who are knowledgeable about HIV and mental illness can help identify the likely sources of your symptoms.

## Treatment

A number of interventions have shown promise in dealing with mental illness in PLWHIV/AIDS, such as a combination of medications and talk-therapy. Also helpful are individual, family or group counselling; stress management sessions; improving your knowledge and understanding of HIV and depression and anxiety; home visits and respite care. Particular success has been seen with peer support programs where the person receiving care can relate to other people in the group and/or with the caregiver.
Medication Side Effects and Interactions

Today, medications used for depression and anxiety and for HIV/AIDS are generally well tolerated and safe, and are becoming more “user friendly” as multiple medications are combined in one pill to reduce the number of pills taken every day.

However, there are still medications with side effects that may make that treatment less “user friendly”. Side effects can vary from one medication to another as well as from person to person. For example, some HIV treatments can cause symptoms of depression and anxiety; others have an effect on the central nervous system that results in vivid dreams.

If you experience side effects, let your health care provider and pharmacist know right away. You can keep a record of the side effects you experience including the severity and duration and report these to your health care provider; they may be able to help you find ways to minimize or eliminate the effect, or even consider an alternative treatment.

There may also be potential interactions with other medications, even complementary and alternative medicine. Many complementary therapies have been shown to have no interaction with other treatments, but others can have severe interactions and may not be recommended for use. An example of this is the herbal product St. John’s Wort, which has been shown to cause severe interactions with certain other medications.

Consult with your health care provider or pharmacist about the potential for side effects and interactions, and what you can do if you experience side effects or interactions with your medications.

Adherence, Drug Resistance, and Future Treatment Options

While medicines for HIV have improved considerably in recent years, treatment is most effective if taken as prescribed. In order to continue to effectively fight HIV, the schedule and dosage of prescribed medication must be followed carefully. When doses are taken as scheduled, every time, that is called treatment adherence. Some medications for depression and anxiety also require treatment adherence, especially when starting a new treatment, as the effects of the medication may not be obvious for several days. Research has shown that people who follow their prescribed treatments are less likely to develop drug resistance.14

Drug resistance occurs when an organism (such as a virus, like HIV) changes or mutates just enough to no longer be affected by the presence of a medication. When this happens, the medication is no longer effective in controlling the replication of the virus.

One of the main causes of drug resistance is irregular or interrupted treatment, usually from successive missed doses or not taking medications as prescribed. In the case of HIV, where there are a limited number of medications and combinations available for treatment, drug resistance can severely limit the range of available treatments.

Having more than one illness can make it more difficult to seek help and to maintain health. It can also make it difficult to adhere to prescribed treatments. Having more than one disease or disorder can affect a person’s ability to follow treatment schedules and can negatively affect their health and quality of life.

The best way to avoid drug resistance and to see results from treatment is to improve our adherence to all our treatments. Alone, this can seem challenging – but we can overcome these challenges when we work with others who are interested in our health and well-being. Doctors can adjust prescriptions, especially if we tell them about any unexpected results that come from taking them in combination with certain foods, on an empty stomach, or with other medications. Pharmacists can help explain what the medications do and how to organize them so it is easier to follow treatment as prescribed. It is important to share with all our medical professionals the same information so everyone is able to determine the best course of action.

We can help those professionals and ourselves in our own ways. Pill organizers and calendars can help us take medications at the same time each day, every day. Keeping a record in our diary of how we feel after taking our medications can help us be more mindful of changes that occur when there are changes to our treatments. Sharing this information with your health care professional will help them make any adjustments to optimize your treatment and increase the likelihood of recovery.
Depression, Anxiety and HIV/AIDS
From the beginning of the AIDS pandemic, most doctor-patient visits looked at disease markers (like blood tests) and how to manage different symptoms. Ever since the arrival of HAART for HIV treatment, they now also deal with HIV disease management as it intersects with one or more of the following themes:

- long-term complications of HIV infection, many of which may be related to ongoing inflammation;
- aging-related issues;
- the physical, biological and psychological burden of having a chronic health condition;
- medication-related side effects, and;
- co-infections and concurrent conditions.15

Looking at these themes, and what we have learned about concurrent conditions of mental illness and HIV, it is clear that we need to have good communication with our care providers, including mental health professionals.

Taking control of your care means being an active participant in the process. Remember that in the process of giving and receiving care, you are part of a relationship: you have as much input as your health care provider in that relationship.

Proactive steps you can take when talking to your mental health care provider:

- Define your priorities. You can even create a ranked list if you like, but don’t try to address everything on the list all at once. Focus your attention on a few of priorities at the top of your list.
- Concentrate on what is most important to you regarding your mental health
- Try to specify main points you want to discuss and think about how you want to do so.
- Consult with mental health care workers other than your psychiatrist or doctor, specifically nurses, social workers, specialists, pharmacists or community care agents. These professionals may be better placed to answer some of your questions.

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Self Awareness and Empowerment

Have you ever had good friends and family members ask you about how you are doing and feeling? Sometimes, our friends and family can help us recognize problems in ourselves that we cannot see, and can support us to take the first steps towards getting the help we need. In the public parts of your life, they probably know you very well – however, you are the person living your life. In that sense, you are best placed to know what is going on for yourself. Knowing what is happening to you is part of being self-aware.

Some of us may have had the habit of blindly trusting health and mental health professionals to know what’s best for us - we do as we are told and hope for the best. The patient empowerment movement, led by PLWHIV/AIDS, has broken that habit for many people. People are informing themselves with knowledge and self awareness before talking to their health professionals. We are arriving at medical appointments ready to talk about what is troubling us, what has worked for us in the past, what hasn’t and what we think might be best for us now. We are no longer passive – we are empowered to take action.

If you are self-aware and empowered, you are able to take charge of your own life, illness and care. Because you know yourself best, you can best assess when something is wrong and when you are not feeling like yourself – and you can take a leading role in your own care and treatment.

People living with any illness can benefit from seeing themselves as the experts about how their illnesses affect them, what they need and what is involved in taking care of them. Many PLWHIV/AIDS have learned how important it is to advocate for their physical health. It is equally important to be able to advocate for your psychological and emotional health, while continuing to be monitored and supported throughout all phases of care and treatment. Beside the benefits of improved mental health, stronger mental health and well-being leads to improved outlook and treatment outcomes.

Empowerment means that you become an active partner with medical and mental health professionals. Together you determine what’s best for you, and what course of action you wish to take for your treatment. HIV/AIDS revolutionized how many of us interact with health care professionals. This change in attitude from being passive patients to active consumers of care might have been uncomfortable for some people as they adapted to a new way to think about care, but it is now largely welcomed and is recognized as one of the first steps of recovery.
**Being self-aware**

You are being self-aware when you can refer to your own history with your illnesses for examples of how you have coped and what has worked for you (or not) in the past. You may be surprised by how much your experiences can tell you, and by how much you know about yourself.

**Empowerment through knowledge**

Moving beyond yourself, you can gather knowledge about your condition(s) and the variety of treatment options available to you. You can do this by talking with peers, by studying medical websites or reading books and journal articles about your conditions.

**Assembling your own health team**

Keep in mind that no amount of reading will replace the need for knowledgeable health professionals and not all doctors will appreciate your knowledge and expertise. It might take some effort to find professionals who work best for you or to get your professionals to respect the role that you want to play in your own health. Empowering yourself will shape your experiences with your doctors and will help build your self-confidence and feeling of control.

**Your role in your treatment**

People living with HIV/AIDS and depression and/or anxiety should talk with their health care providers about current or proposed medications. You need to be clear with your medical professionals about your lifestyle, and any other treatments you’re using, including complementary therapies. Take the opportunity to ask all the questions you have about drug interactions and side effects. Having a full and open discussion about all the treatments you are taking can help you and your health care professionals make the best assessments about your care and treatment options.

If you are being asked to start or change treatments, you have to make up your own mind. In the end, it’s your decision.
When you are being asked to start or change a treatment, find out as much as you can before making a decision. This means researching and talking to others.

1. First, ask why you are being advised to start or change a treatment. It will help you to know the reasons behind the change.

2. Research the medication. Look on the internet, contact local, regional or national resources, and talk with your peers.

3. Bring your questions to your care provider. Writing out the questions and concerns you have will make you better prepared and less likely to forget something.

4. Once you have information from your care provider, weigh the risks and benefits of treatment. Are there other medications that might be better for you? Do you need to start or change right now or can you wait? You can continue your research before you make any decisions about your treatment options.

5. Don’t make a decision until you’re ready and confident that it’s the right one for you.

Keep in mind that all treatments require commitment. Following treatments as prescribed is very important, and you need to stick with them to see the positive effects over time. If you have problems (side effects or other concerns) you need to talk with your care providers. You can also talk with your peers. Taking control of your care and treatment also means seeking the support you need to work through the tough times.

If you aren’t feeling ready to start or change your medications, this means saying “no”. It’s easier said than done, especially if we think that our professional care providers always know best. But remember, the decision is yours. If you decide that you need more information, you can talk it through with your peers and with your care professionals and you can look for more options.

**Being assertive with care professionals**

When dealing with care professionals, acknowledge that you are both in a relationship. As in all relationships there is some give and take, so you both will have to listen to each other as much as talk to each other. When it is your turn to talk, you have the right to be assertive in managing your care and treatment options.

There’s a difference between being assertive and being aggressive. Being assertive means you can express your thoughts and opinions clearly and firmly in order to claim (or assert) your key role in your care relationship. Assertion makes room for your role, but also leaves room for the other person to respond in their role. When you are assertive, those responses from the other person usually show respect for your role and opinions.
Aggression may make your point all too clear, but may leave no room for any other opinion. The other person may feel that you do not respect their role in your care relationship. This places the other person in a defensive position. Unless the situation is defused right away, aggression usually leads to arguments, where people are more concerned about defending their positions separately rather than finding solutions together. Be assertive and look for solutions, together.

Always remember that you are in charge of your care and your options. You have rights and responsibilities and so do your care providers. By being proactive and involved in the decision making process you will maintain your control over your treatment and care.

It may take some work, but being informed about your options is the first step toward developing meaningful and respectful relationships with your care providers.

**Can We Talk?**

Looking for more information on how to communicate with your mental health care provider? Take a look at “Can We Talk? Treatment and Options, A New Dialogue”. “Can We Talk? Treatment and Options, A New Dialogue” is the title of the eighth module of the “One Foot Forward” series found here on the Canadian AIDS Society website: [http://www.cdnaids.ca/CanWeTalk](http://www.cdnaids.ca/CanWeTalk)

“Can We Talk?” was designed to provide a starting place for conversations about health care between people living with HIV/AIDS and their health care providers. It contains the Patients and Health Care Providers Agreement for PLWHIV/AIDS and the People Living with HIV/AIDS Patient Bill of Rights, two documents that provide a foundation for communications between a care provider and a care recipient.

“Can We Talk?” was not exclusively designed to focus on people living with HIV/AIDS and depression and/or anxiety. However, it can be used as a reference point as you consider the following questions:

- Does the Patients and Health Care Providers Agreement for PLWHIV/AIDS and the People Living with HIV/AIDS Patient Bill of Rights offer a good starting place for conversations between people living with HIV/AIDS with their mental health professionals? Why, or why not?
- What would you change or add to these documents to make them more appropriate for people living with depression and/or anxiety?
Depression, Anxiety and HIV/AIDS
Finding information locally

There may be resources in your community that can help you in making informed decisions about your treatment and care options.

Larger centres may have treatment information available at an HIV/AIDS or mental health agency. Some agencies may have libraries of information that can help you research the treatments and weigh your options.

In rural and smaller communities, you may need to speak to your health care provider, mental health professional or pharmacist. Alternately, you may be able to access information from an HIV/AIDS or mental health organization in a community nearby.

Internet Resources

Searching for information about treatments online is another way you can educate yourself to make informed decisions. Remember that not all information on the internet is reliable: make sure you have a source for relevant and reliable information. Treatment information changes frequently, so beware of any information that is more than a few years old.

When it comes to medications, some websites will tell you about medications, how they work and the potential side effects. They may even list those side effects that are experienced by a very small percentage of people. However, they may not be able to tell you how a particular medication may interact with any of the other medications or substances you may be taking while on treatment.

You may find out more about the treatments you are prescribed by searching for people who offer “user reviews”. User reviews are submitted by people who have actually taken the treatment and are offering their personal experience. Some people may only have had a negative experience, even though there may be people who have had a positive experience with the treatment in question. Remember that other people may not be using the treatments in the same way or in the same combination. For example, when it comes to medications, others may not be using some medications in the same dosage, on the same schedule or as part of the same combinations as you may be considering.

You’ll need to sift through the information to make up your own mind. Use good judgment when looking up information online and be a cautious and careful observer of the claims that are being made.
HIV Resources

There are national, regional and local organizations in Canada that offer information on HIV/AIDS. Many of these groups have websites with searchable information and some have toll free numbers that you can call to ask questions about HIV, peer supports, HIV treatment and access to HIV treatment. These organizations will also offer links to other groups that offer treatment information and support.

Looking for a local, community-based AIDS Service Organization near you? The Canadian AIDS Society (or CAS) represents community-based AIDS organizations across the country. There are local organizations in Canada that are run by and for PLWHIV/AIDS. These groups can offer you information as well as peer support. Look up the CAS members in your area at www.cdnaids.ca/members.nsf/members!Openview&languagesenglish.

CATIE (previously known as the Canadian AIDS Treatment Information Exchange) offers online publications, a listing of treatments and information about the treatments as well as a magazine written for PLWHIV/AIDS. In addition to its website, www.catie.ca, CATIE also has a toll free line at 1.800.263.1638.

Mental Health Resources

These resources are all available for free online:

- Canadian Mental Health Association
  - On mental health - www.cmha.ca/mental-health
  - On mental illness - www.cmha.ca/mental-health/understanding-mental-illness
  - On mental and physical health - www.ontario.cmha.ca/public_policy/the-relationship-between-mental-health-mental-illness-and-chronic-physical-conditions

- Canadian Network for Mood and Anxiety Treatments - www.canmat.org

- Déploie tes ailes - www.deploie-tes-ailes.org (in French only)

- Mental Health Commission of Canada - www.mentalhealthcommission.ca

- Mood Disorders Society of Canada - www.mooddisorderscanada.ca

- Revivre - Quebec Anxiety, Depressive and Bipolar Disorder Support Association - http://www.revivre.org/home.php
Self-Care and Mental Health Management

- Self-Care Depression Program: Antidepressant Skills Workbook

- MoodGYM – An independent resource developed and delivered by the Australian National University, MoodGYM is an online self-help program to teach cognitive behavioural therapy skills to people vulnerable to depression and anxiety. Note: Access to MoodGYM is free of charge, but requires registration. Registered MoodGYM users may deactivate their account anytime. [www.moodgym.anu.edu.au](http://www.moodgym.anu.edu.au)

- Positive Coping with Health Conditions a Self-Care Workbook

Caregivers

- Mental Health Commission of Canada on Caregiving
  [http://www.mentalhealthcommission.ca/English/issues/caregiving?terminitial=52](http://www.mentalhealthcommission.ca/English/issues/caregiving?terminitial=52)

- La boussole (in French only)
Self Assessment

After completing this booklet I learned:

I still need more information about:

My next steps will be:

I can complete my next steps by:

Rate the statements below by circling the number that you think fits.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Very confident</th>
<th>Need to work on this</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resources - I know where to go to find more information.</td>
<td>1 2 3</td>
<td>4 5</td>
</tr>
<tr>
<td>Relationships - I know or can find a person to help me out.</td>
<td>1 2 3</td>
<td>4 5</td>
</tr>
<tr>
<td>Readiness - I know how to apply what I learned.</td>
<td>1 2 3</td>
<td>4 5</td>
</tr>
</tbody>
</table>
Adherence: Following a prescribed treatment regimen, according to the correct dosage, the number of doses a day, and dietary restrictions if any.

Anxiety Disorder: Persistent and excessive anxiety and worry which is far out of proportion to the actual likelihood or impact of a feared event(s). The worry is often about everyday circumstances.

Complementary Therapies: Complementary medicine is the name generally given to those medical and health care systems, practices, and products that are not presently considered to be part of conventional Western medicine. Well known examples include herbal and other nutritional supplements, acupuncture, aromatherapy, homeopathy, exercise, meditation and yoga. Complementary medicine can be used together with conventional medicine.

Concurrent Conditions: A term used to describe the presence of two illnesses or disorders at the same time.

Depression: Depression is a common mental disorder, characterized by sadness, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, feelings of sadness, and poor concentration.

Drug Resistance: The mutation of a microorganism in such a way that it loses sensitivity to a drug.

HAART: Highly Active Antiretroviral Therapy (HAART) is the name given to aggressive treatment regimens used to suppress HIV viral replication and the progression of HIV disease.

PLWHIV/AIDS: Person Living with HIV/AIDS (see also: PHA, PLWHA, PLWHIV, HIV-positive person)