

HEAL GUIDES

RESOURCES TO HELP,
EDUCATE AND INSPIRE

HIV/AIDS & Depression: Keys to HEALing

HEAL))) Health Education Advocacy & Leadership

A project of AIDS & Disability Action Program/Wellness & Disability Initiative
BC Coalition of People with Disabilities

2010

HEAL Guide No. 1

HIV/AIDS & Depression: Keys to HEALing

The HEAL Guides Series

The HEAL (Health Education, Advocacy and Leadership) framework is a cross-disability, self-advocacy approach developed by the BC Coalition of People with Disabilities (BCCPD).

Through education, advocacy and personal leadership (recognizing and sharing skills, experience and encouragement) people with disabilities discover new strengths, passions and possibilities. This creates a ripple effect into the relationships and communities around us.

HEAL is a path to empowerment and our Guides are intended to “help, educate and inspire” readers to explore their unique HEALing path. For information about HEAL and other HEAL Guides, visit the BC Coalition of People with Disabilities website at <http://www.bccpd.bc.ca> or contact us (please see page 3 for contact details).

How to use this HEAL Guide

HEAL Guides provide information from experts and researchers, as well as people living with chronic health issues and disabilities. They offer a selection of “keys:” facts, research findings, experiences, perspectives and insights about living with a disability or a combination of disabilities or health conditions.

Most keys are one paragraph or two at most. You can begin with any key that interests you or read the Guide from beginning to end.

The source for most keys can be found in parentheses at the end of the paragraph. To read more about each key, find the source in the Resources section at the end of this Guide. Additional helpful articles, books and websites are included. If you are reading this Guide on your computer, the links provided throughout are live and can be used to jump to listed resources.

Disclaimer

While considerable care and effort have been taken in gathering and summarizing the information included in this HEAL Guide, it may have become outdated since publication. HEAL Guides offer a brief and selected overview of research and perspectives on health topics to encourage discussion and participation in your health care, in consultation with your professional care provider. A recurring theme in HEAL Guides is the complex and personal balance that creates wellness. Your health care providers play an essential role and should always be consulted before making changes that may alter the balance for you.

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For more on HEAL, visit us at www.bccpd.bc.ca, under Programs.

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Things we Know

Depression is among the most painful and difficult of all human experiences. It robs those who have it of energy, interest, and the will to make things better. It brings with it a profoundly negative view of the self, the world, and the future.

– Randy Paterson & Dan Bilsker

You're Not Just Feeling Down

Depression is more than “just feeling down.” It’s an illness and can be successfully treated in over 80 percent of cases. (*Depression and HIV/AIDS*)

What are the Symptoms?

Symptoms of depression:

- persistent sad, anxious or “empty” mood
- feelings of hopelessness, pessimism
- feelings of guilt, worthlessness, helplessness
- loss of interest or pleasure in hobbies and activities that were once enjoyed, including sex
- decreased energy, fatigue, being “slowed down”
- difficulty concentrating, remembering, making decisions
- insomnia, early-morning awakening or oversleeping
- appetite and/or weight changes
- thoughts of death or suicide, or suicide attempts
- restlessness, irritability

If you experience five or more of these symptoms every day for at least two weeks and they interfere with your routine daily activities, such as work, self-care, childcare or social life, seek an evaluation for depression. (*Depression and HIV/AIDS*)

Chronic Mild Depression

Depression is a common illness that ranges from mild to severe and is more than the sadness that we all experience from time to time. Chronic mild depression (also called Dysthymia) is characterized by mild, long-term sadness, lack of interest in life, low energy, low self-esteem and feeling hopeless/helpless. People with mild depression continue to function each day, but without joy or enthusiasm. These symptoms last for two years or more. (Aidala et al.)

Depression Can't be "Shaken Off"

Major Depressive Disorder, the topic of this *HEAL Guide*, is a more debilitating depression with the symptoms being more intense. People with major depression cannot simply "shake it off" or "pull themselves together." They need medical treatment, but may find it difficult to get help because of the stigma associated with mental illness. (Aidala et al.)

Insight Can be Affected

"One of the most striking aspects of depression is that many people have little or no insight into the way in which it affects their self-perception, as well as their perception of the past and the future." (Aidala et al.)

Different Causes

Depression can be caused by life events, chemical changes in the brain, medication side-effects or physical illness, including HIV/AIDS.

HIV-specific Depression

Some symptoms of depression can be related to HIV, specific HIV-related disorders or medication side effects. (*Depression and HIV/AIDS*)

🔑 All Parts of Life Affected

Depression is a serious medical condition that affects thoughts, feelings and the ability to function in everyday life. Depression can occur at any age. (*Depression and HIV/AIDS*)

🔑 Slower Information Processing

Depression was once thought to be accompanied by poor memory and difficulty concentrating and paying attention. A new study in the US shows that this is not always the case. Researchers say that, in their review of studies done between 1991 and 2007, “processing speed” was the cognitive or thinking function most often affected by depression. Processing speed is the ability to quickly take in information, process it and act upon it. The ability to do this is slower when people are depressed. (University of Texas Southwestern Medical Centre Press Release)

🔑 Unaware of Being Depressed

It’s possible that you might not even realize that you are depressed. You may believe that feeling sad or down is to be expected because you are living with HIV/AIDS. Families and friends often make this assumption, too, and do not see depression as an illness to be treated.

🔑 Many PWAs Experience Depression

Depression is common among people living with HIV/AIDS. Some research shows that serious depression affects six out of 10 people living with HIV/AIDS. (*HRSA CareAction*) A study of people living with HIV/AIDS in Ontario found that 57 percent had a major depressive disorder. (*HIV & Depression FAQ*)

🔑 Many Undiagnosed and Untreated

Despite the high rates of depression among people living with HIV/AIDS, half are not diagnosed or treated. (*HRSA CareAction*)

🔑 Rural Areas and Isolation

If you are living with HIV/AIDS in a small town or rural area, studies show that you are more likely to experience depression, especially if you are undergoing antiretroviral therapy. Researchers believe this is because of increased social and physical isolation in rural areas. Limited social and emotional support may be related to unstable or intermittent employment. Not only do we gain social support and a sense of community in our workplaces, but insurance benefits and access to community resources may be interrupted during periods when people are unable to work. (Martin)

🔑 Stressful Events as Causes

Depression often follows a stressful life event. Researchers have found that 50 to 80 percent of depressed people experienced a stressful event three to six months before their depression began. (Cohen et al.) Examples of stressful life events include: finding out that you are HIV-positive; disclosing your HIV status to friends and family; physical illness or disability; new symptoms or development of AIDS; death of significant others; and, job or relationship loss.

🔑 Stigma May be Worse than Illness

The stigma surrounding both depression and HIV/AIDS is sometimes described as worse than the illness itself. In fact, stigma has been found to lead to depression. (Venable et al.) Stigma and the fear of being labeled can prevent people from seeking treatment for their depression.

🔑 Rural Areas and Stigma

For people living in rural areas, stigma and discrimination are common in both community and health care settings. This can be especially difficult to cope with because of lack of alternative care providers, social isolation, and lack of transportation and/or resources to travel for services. (Zukoski & Thorburn)

🔑 Age-related Stigma

For older people living with depression and/or HIV/AIDS, the burden of stigma may be made even greater by ageism—judgment and discrimination based on age.

🔑 Stigma Adds to Stress

Stigma causes extreme stress. For people living with HIV, stress has been linked to faster progression of the disease. (Cohen et al.)

🔑 Doctors and Depression

Even your doctor may not recognize and treat your depression. In the same way that depression was once considered a normal part of ageing, researchers say that doctors frequently assume that “feeling blue” is a natural response to an HIV diagnosis and so fail to treat depression as a separate disease. (*HRSA CareAction and Depression & HIV/AIDS*)

🔑 Depression is Difficult to Diagnose

Depression can be difficult to identify even for doctors. A 2009 study found that clinical depression was diagnosed by general practitioners (GPs) only 50 percent of the time. (Mitchell et al.) The researchers gathered data across nine countries and emphasize that their results are not a criticism of GPs. They say these results highlight the importance of a better understanding of depression. They also note that the short time available in a typical medical appointment—usually 15 minutes or less—adds to the difficulty GPs may have in identifying depression.

🔑 Causes are Being Researched

The causes of depression are currently a matter of intense research. An interaction between genetic or inherited characteristics and life history appear to determine a person's level of risk. Episodes of depression may then be triggered by stress, difficult life events, side effects of medications or the effects of HIV on the brain. Whatever its origins, depression can limit the energy a person needs to focus on staying healthy, and research shows that it may accelerate HIV's progression to AIDS. (*Depression and HIV/AIDS*)

🔑 HIV Worsened by Depression

Depression can make HIV/AIDS and other health conditions worse by causing you to miss medical appointments, skip medication doses, eat irregularly, eat unhealthy foods, misuse drugs or alcohol, or withdraw from relationships and social activities.

Things That Help

Medications for Depression

Depression can be treated with prescription medications (antidepressants) which are usually safe and well-tolerated by people taking medications for HIV/AIDS. However, there can be interactions between medications or side-effects which need to be monitored. Antidepressant medications are often used with various types of psychotherapy or “talk therapy.”

Alternative Treatments

Complementary and alternative medicine (CAM) is often used in addition to traditional medical treatment. CAM includes many “natural” or “holistic” approaches to health and wellness, such as guided visualization, meditation, massage/energy therapies, yoga, tai chi, homeopathy, Traditional Chinese Medicine and aromatherapy. (Nambiar)

Important information about herbal remedies

Herbal remedies, a popular complementary and alternative medicine (CAM) option, have been used to treat depression and HIV/AIDS. Although alternative medicines may seem safe because you can buy them over-the-counter without a prescription, it is extremely important that you discuss them with your HIV/AIDS doctor. Herbal or natural remedies can interact with prescription medications, in some cases making them less effective.

For example, St. John’s wort, a shrub-like plant with yellow flowers, has been used for many years in tea, capsule or extract form to treat depression and other health problems. Although many research studies have been done on St. John’s wort, the results are inconsistent. Some studies indicate that the herb may help minor depression. More importantly, the research also shows that St. John’s wort interacts adversely with many medications, including those used to treat HIV/AIDS, depression, cancer and heart conditions, as well as birth control pills. (*St. John’s Wort and Depression*)

🔑 The Power of Stress Management

A study published in 2008 reviewed 35 stress management programs for people living with HIV/AIDS, including training in guided imagery, progressive muscle relaxation, interpersonal skills, medication and other aspects of living with HIV, and coping skills. Researchers found that these strategies improved mental health and quality of life, and reduced fatigue. (Scott-Sheldon et al.)

🔑 Remember Your Strengths

It can be very difficult to feel good about yourself when you are under the stress of having symptoms that are hard to manage, when you are dealing with a disability, when you are having a difficult time or when others are treating you badly. At times like these, it's easy to be drawn into a downward spiral of lower and lower self-esteem which can be a symptom of depression. To begin reversing that spiral, make a list of at least five of your strengths, for example, courage, friendliness or creativity. Next, make a list of ten ways you could reward yourself that are free and not related to food or drink. Examples might include taking a walk in your favourite part of town or in the woods, enjoying a conversation with a good friend, and browsing at the library. When you feel that you need a lift, do one of the activities on your list. (Copeland, *Building Self-esteem*)

🔑 Avoid Drugs, Alcohol and Nicotine

The pain that comes with chronic health problems, stigma, low self-esteem, and other challenges in life can lead many people to “self-medicate”—to use alcohol, nicotine or recreational drugs for temporary relief. However, substance misuse can trigger or worsen depression and seriously affect your HIV/AIDS treatment regimen. *Here to Help* is an excellent starting point for information and support. Developed by BC Partners for Mental Health and Addictions Information, the website provides information in multiple languages (<http://www.heretohelp.bc.ca>). See also the *HEAL Guide* on HIV/AIDS and substance misuse.

🔑 Manage Stress with Meditation

Meditation is increasingly recognized as a helpful strategy for managing stress and depression. Researcher Mark Williams in the UK has been testing a new treatment called mindfulness-based cognitive therapy (MBCT). MBCT combines ancient forms of meditation with modern cognitive behavioural therapy. One way that the treatment benefits people is helping them to live more in the moment, rather than being caught in upsetting memories from the past or worries about the future. (University of Oxford News Release)

Dr. Michael McGee at Harvard Medical School describes meditation as a “practice of psychological weightlifting.” Typically, those who meditate enjoy three immediate results: “increased discipline, regularization of one’s lifestyle and increased commitment to one’s own self care.” (McGee)

🔑 Massage Therapy

Massage therapy has been found to improve overall quality of life and ability to cope with stress for people with HIV/AIDS, especially when combined with meditation or relaxation training. Researchers believe that massage therapy may also increase the body’s ability to fight HIV/AIDS. (Hillier et al.)

🔑 Positive Psychology

Looking for positive aspects of a challenging situation is a way of coping with difficult life events and is called “benefit finding” by psychologists. Researchers have found that people who look for and recognize some of the positive effects or benefits of living with HIV/AIDS feel more optimistic and able to manage challenges they face. Examples of some of the benefits identified include access to medical care and disability benefits following HIV diagnosis; better relationships with family and friends; improved coping skills; and, improved eating habits and nutrition. (Littlewood et al.)

Spirituality

According to researchers, spirituality or religiousness increases after people have been diagnosed with HIV. (Ironson et al. 2006) These individuals also experience less depression and hopelessness, have lower cortisol (stress hormone) levels, smoke less and practice safer sex. (Ironson et al. 2002)

Improve with Exercise

Exercise is commonly recommended for depression. It can reduce stress, and increase energy level, strength and muscle tone. Discuss your exercise plan with your doctor before beginning, to ensure that your medications, physical health and current fitness level are considered. (Bopp et al.) For an overview of how to safely begin an exercise program, see Mooney and Vergel's "Exercise: The Best Therapy for Managing Side Effects."

Recent studies also show that exercise reduces depression and depression-related fatigue in people with chronic illnesses by increasing their sense of achievement or mastery of physical exercise goals. (University of Illinois News Bureau)

Be Your Own Advocate

Living with one or more chronic health conditions means that there will be times when you need to advocate for yourself. Becoming a good self-advocate will also help you when you need to advocate for others. Self-advocacy—protecting your rights and getting the information, care or changes you need—can be especially difficult when stigma, depression and low self-esteem are involved. Effective self-advocacy involves organizational skills to identify what you need, get the facts, plan a strategy and set goals. Good communication skills are needed to explain your situation and gather support from others, to ask for what you want, and to assert yourself calmly. Learning self-advocacy strategies is well worth the effort and will help bolster your self-esteem and nurture patience—two essential ingredients for success. For practical step-by-step suggestions, see Mary Ellen Copeland's *Speaking Out for Yourself: A Self-help Guide*.

The Importance of Connections

Social connections—friends, neighbours, co-workers and family members you can rely on for support—reduce depression and loneliness for people living with chronic illnesses, including HIV/AIDS. A US study found that social connections lowered depression among people living with HIV/AIDS, but only when they appreciated the support provided. A small circle of support is more powerful in reducing depression than a larger and more distant social network of people, *if* the individual interprets the supportive gestures (a neighbour’s ride to medical appointments or a family member’s supportive phone calls) as helpful. Experts suggest that we take advantage of this “social antidepressant” by reflecting on and appreciating the support provided by people in our life and nurturing and appreciating new supportive relationships. (McDowell & Serovich)

Maintaining friendships or making new friends can be extremely difficult when you are living with a chronic illness and even more difficult if you are feeling depressed. *Making and Keeping Friends: A Self-help Guide* by Mary Ellen Copeland offers excellent practical tips to get started finding new friends and maintaining friendships.

Resources

For the source and additional information about the keys above, look for the author's name or article title (which appears in parentheses in the keys) in the resource list below.

The links in this Guide are live, so you can jump to the reference or website directly from the PDF on your computer.

You can learn more about HEAL (Health Education, Advocacy, and Leadership) in BCCPD's magazine *Transition* (Summer 2009) at: <http://www.bccpd.bc.ca/transsummer09.htm>.

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BC NurseLine.

Telephone Anywhere in BC: 8-1-1.

TTY (Deaf and hearing-impaired): 7-1-1.

Call 8-1-1 to speak to a registered nurse 24 hours/day 7 days/week about non-emergency health concerns.

To speak to a pharmacist: call 8-1-1 for medication information between 5 pm to 9 am 7 days/week when your pharmacist may be unavailable.

For nutrition advice, call 8-1-1 to speak with a dietitian.

Translation services are available in over 130 languages on request. Say the name of your preferred language in English to be connected with an interpreter.

- BC Partners for Mental Health and Addictions Information. HeretoHelp. <http://www.heretohelp.bc.ca/> (accessed March 7, 2010).
A partnership of:
Anxiety Disorders Association of BC; BC Schizophrenia Association; Canadian Mental Health Association, BC Division; Centre for Addictions Research of BC; FORCE Society for Kids' Mental Health; Mood Disorders Association of BC
Access information in multiple languages. Publications include: *BC School Resource Guide*; Brochures; Fact Sheets; State of the Knowledge Papers; Toolkits; and *Visions Journal*.
- BC Persons with AIDS Society (BCPWA). <http://www.bcpwa.org> (accessed March 7, 2010).
Resources, support, events/news, advocacy, and more.
Healthy Living Manual and *Living+ Magazine*
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Source of information throughout BC on mental illness; mental wellness; support; advocacy; education; *Visions Journal*; *Mind Matters E-news* and more.
A member of the HeretoHelp partnership.
- CATIE (Canadian AIDS Treatment Information Exchange). <http://www.catie.ca> (accessed March 7, 2010).
Comprehensive and current information about prevention, treatment, living with HIV, news/events, and a directory of provincial, national and international HIV/AIDS organizations.

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Crisis Intervention and Suicide Prevention Centre of BC (Crisis Centre). <http://www.crisiscentre.bc.ca/> (accessed March 7, 2010).

Distress Line Phone Numbers:

Greater Vancouver: 604-872-3311.

Toll free—Howe Sound & Sunshine coast: 1-866-661-3311.

BC-wide: 1-800-SUICIDE (744-2433).

TTY 1-866-872-0113.

Online service for youth: <http://youthinbc.com/>.

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Dial 8-1-1 to speak to a nurse, pharmacist or dietitian.
Open 24 hours/day 7-days/week.

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Telephone 1-800-661-2121.

Vancouver: -604-669-7600.

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