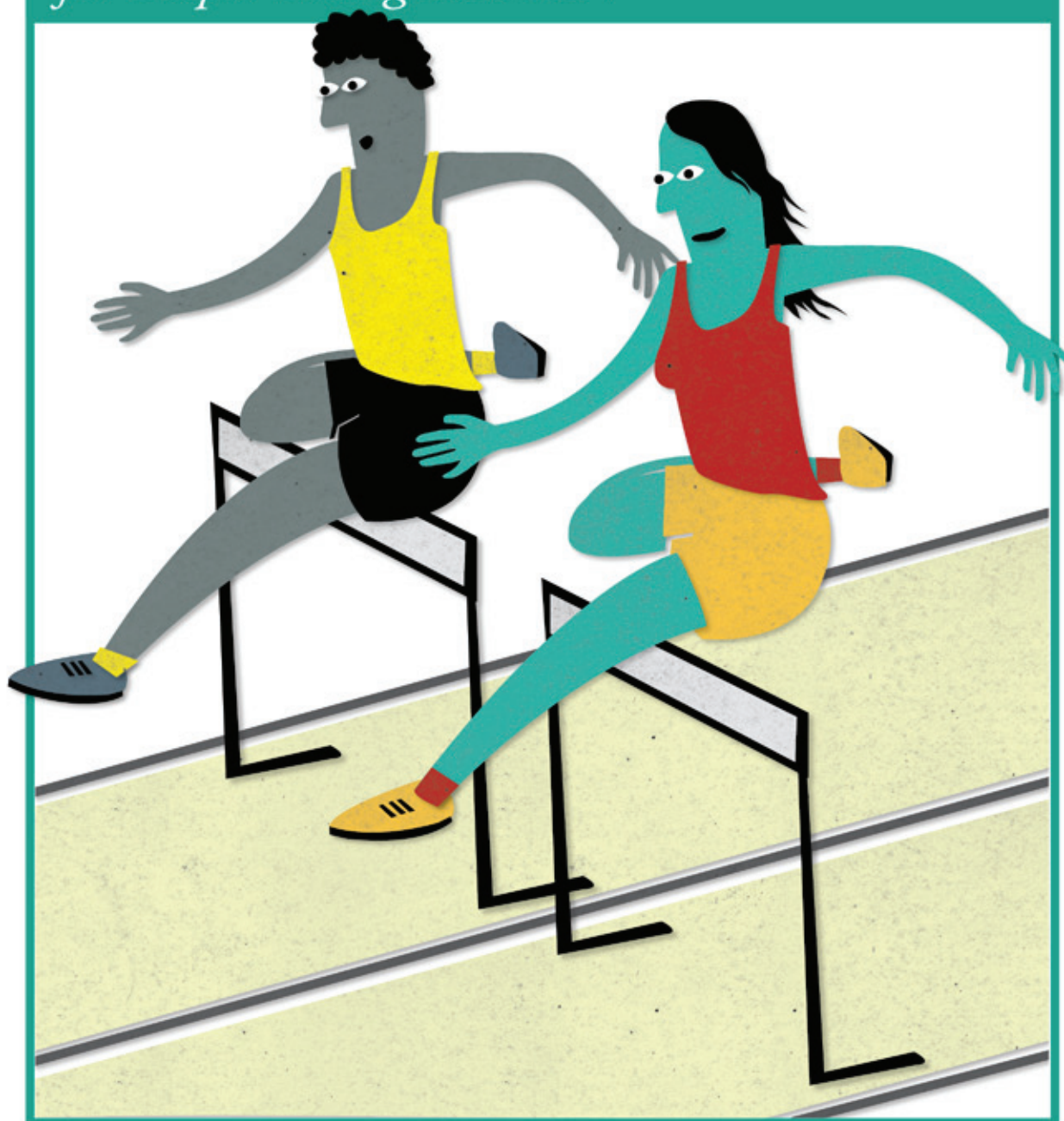


A Practical Guide to
HIV Drug Side Effects

for People Living with HIV



Canada's source for
HIV and hepatitis C
information

A Practical Guide to HIV Drug Side Effects for People Living with HIV

Second edition, 2013

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About CATIE

CATIE is Canada's source for up-to-date, unbiased information about HIV and hepatitis C. We connect people living with HIV or hepatitis C, at-risk communities, healthcare providers and community organizations with the knowledge, resources and expertise to reduce transmission and improve quality of life.

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Disclaimer

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

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Information on safer drug use is presented as a public health service to help people make healthier choices to reduce the spread of HIV and hepatitis C. It is not intended to encourage or promote the use or possession of illegal drugs.

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This Guide Is One Tool to Healthy Living

Welcome to the second edition of *A Practical Guide to HIV Drug Side Effects*, published by CATIE (Canadian AIDS Treatment Information Exchange).

Thanks to ongoing improvements in HIV treatment, the future for people living with HIV is better than ever before. Many of the problems that were common with the treatments available early in the epidemic have been eliminated or at least minimized.

Despite great improvements in the treatment of HIV, many people living with HIV continue to experience changes and problems in their body as a result of the drugs they are taking to treat HIV and, in some cases, as a result of the virus itself. The changes and problems caused by medicines are called drug side effects, and they can range from mild to annoying to life-threatening.

As you will see in the sections to follow, there are many possible HIV drug side effects, and many possible ways to resolve them. In this guide we hope to help you understand more about the various types of drug side effects: what each drug side effect looks or feels like, what could be causing it and how the side effect may be managed. Some of the treatments suggested in this guide will be ones that you will need to access through your doctor or other healthcare provider. In other cases, this guide will suggest over-the-counter remedies and things you can do to help yourself.

As the title says, this publication is meant to be a practical guide. Feel free to use it any way that suits you. You may want to read it from beginning to end, or concentrate only on the sections that relate to side effects you are experiencing.

THE FOUNDATIONS FOR HEALTH

Speaking of things you can do to help yourself, there are a number of practices for healthy living that lay the foundation for living well with HIV, regardless of the treatments you take or the side effects they can cause. First of all, a trusting and honest relationship with your **doctor** is very important for your overall health. Two of the most significant decisions you and your doctor will make together concern when you go on antiretroviral therapy and what combination of drugs you decide to take.

Antiretroviral therapy helps to slow the body's production of HIV and is responsible for changing HIV from a disease that was once fatal to a chronic, manageable illness. If your doctor prescribes antiretroviral drugs for you, be sure to take the medications exactly as directed, every day. Missing doses increases the chance the drugs will no longer work to control HIV as the virus becomes resistant to them.

Eating a healthy, well-balanced diet consisting of lean proteins, whole grains and colourful fruits and vegetables provides your body with the nutrients it needs to function best. Consider supplementing your diet with vitamins and other nutrients. You'll find lots of information about supplementation in the sections of this guide.

Regular **exercise** boosts your metabolism, builds muscle, stimulates feelings of hunger and contributes to a feeling of overall wellness. Getting a good night's **sleep** helps your body to regenerate and heal. Finally, **reducing stress** through positive social interactions, calming techniques like meditation or deep breathing, counselling, or participating in enjoyable activities ensures that you have a healthy mind and a healthy body.

STAYING UP TO DATE

The information about HIV drugs and their side effects is constantly changing as research provides new information. However, a lot of the underlying issues — the types of side effects, how they look and feel, what can cause them and how to describe them to your doctor — stay largely the same. We've tried to focus on information not apt to change quickly.

For the most up-to-date information on specific drugs and their side effects, refer to **CATIE News** and **TreatmentUpdate**, two publications that provide timely reporting on the latest developments in HIV treatment. CATIE's website www.catie.ca provides a wealth of information, as well as links to many other reputable online sources of HIV information.

If you don't find an answer to your question there, you can email or call CATIE with any questions, and we'll do our best to answer them. Get in touch with us at info@catie.ca or **1-800-263-1638**. Most importantly, don't forget that none of this information can replace the advice of your doctor.

We've also tried to make this practical guide work with other CATIE publications and resources, including our indispensable ***Managing Your Health: a guide for people living with HIV***. *Managing Your Health* covers a lot of ground, including some of the issues discussed here. While you may notice many similarities between the two publications, this practical guide provides more detailed information about the side effects of HIV drugs.

Author Lark Lands has provided expert, holistic and practical advice for healthier living with HIV for more than 30 years. You can find more of Lark's great writing at www.larklands.net, including in-depth resources on specific HIV drug side effects.

Dealing with Side Effects



WHAT ARE SIDE EFFECTS? WHY DO THEY HAPPEN?

Medications often produce more than one effect in the body. In the case of antibiotics, for example, there is the desired effect (killing a bacterial infection) and there are also unintended effects (the nausea or changes in taste that antibiotics can cause.) These unintended effects are called drug side effects, and they can range from mild to annoying to life-threatening.

Some side effects will create obvious changes you can see or feel; others will not. Instead, they will cause changes in lab results. For example, you might not feel it if a drug stresses your liver. But your lab results will show changes in liver enzymes or liver function tests that will tell your doctor the drug has a negative effect on your liver.

Other side effects can be more difficult to determine since they can develop very slowly over time. For example, it is thought that some antiretroviral drugs can cause or contribute to bone disease. However, this is something that can often not become obvious for many years. As a result, the relationship between a particular drug and a particular side effect can be hard to pinpoint.

In this guide, we focus on the short-term side effects commonly faced by people living with HIV. There are other, long-term health issues that can also affect people with HIV more often than HIV-negative people. These include heart disease, bone disease and brain function issues. CATIE has other information on those topics. Visit www.catie.ca or call 1-800-263-1638 for more information.

STARTING TREATMENT, ADJUSTING TO TREATMENT

Many antiretroviral drugs that keep HIV under control have side effects, causing changes of various kinds. But not all people with HIV who take antiretroviral therapy or other medications for HIV-related conditions will experience side effects from their drugs. We are lucky to be living in an era in which many of the newer medications used to treat HIV cause far fewer side effects than were seen in the early years of the HIV epidemic.

Many people are able to stay on their medications for years with few, if any, side effects. When side effects do occur, they are often only temporary and will disappear after a few days or weeks. There can, however, be side effects that last as long as the drugs are continued; in some cases, these side effects will remain even after the drugs are stopped.

People who are considering antiretroviral therapy are often concerned about side effects. Here's something to consider: If you talk to your doctor about possible side effects *before* starting treatment, you will be better prepared to deal with temporary, minor problems that can happen as you adjust to treatment. If there is a side effect that can be severe or life-threatening, you will know what to watch for.

People sometimes experience headaches, nausea, muscle pain, diarrhea or dizziness while their bodies adjust to a new medication. These side effects may disappear in two to six weeks. The same can hold true for other, more specific symptoms. In general, as the body adjusts to a medication, many symptoms can diminish or become more manageable.

Many people who start antiretroviral therapy find the side effects to be much more manageable than they expected. At the least, knowing the side effect will improve over time can make it easier to convince yourself to stick with a particular medication.

If side effects are a problem for you, remember you are not alone. Countless others are feeling the same thing. Even if your symptoms seem too awful to handle, talk to others and ask what has worked for them. Try to hang in there for at least six to eight weeks after your medication is introduced, if you possibly can.

Even if you've been taking a drug for a while, new side effects can appear at any time. Never say to yourself: "I've been on this drug combination for three years so what I'm feeling couldn't possibly be tied to the medications." It could.

FIGURING OUT THE CAUSE OF WHAT YOU ARE FEELING

Always seek a full diagnosis from your doctor regarding all symptoms. What you're feeling could be from your medication, but it could also be a hormone problem, a nutrient deficiency, an infection, depression, HIV infection itself or something else.

Determining what could be contributing to a given side effect can be difficult, and an obvious place to start is by discussing the problem with your **doctor**. Doctors who have worked with many people living with HIV are usually familiar with the majority of likely drug side effects.

You can also look at the information available on a particular drug. The **product monograph** or prescribing information for a drug — the official, approved document that summarizes what is known about it — will normally contain a fairly comprehensive list of all known side effects. In some cases, these lists can be very long and seem to include every possible side effect known. However, if you see a symptom you are experiencing listed as one of the common side effects, this is a hint your drug could be the cause.

Two other things are important to remember. First, it is always possible that you could be the first patient to ever experience a particular side effect. This isn't likely, but it is possible. The fact you don't see a side effect listed does not mean it is impossible the drug is causing this problem *in you*.

Second, even if a drug does contribute to a particular problem, it might not be the sole cause. Many symptoms, like diarrhea, fatigue, headache and others, have many possible causes. Before you conclude that a drug is the only cause of your symptom, consider the other possibilities. If a drug is otherwise working well for you, you don't want to discontinue it needlessly.

In each section of this guide, we discuss the possible contributing causes of symptoms to help you untangle what's causing what.

TALKING TO YOUR DOCTOR

Many people don't bring up all of their current problems when they meet with their doctors. This can be because of the limited time available during an office visit. Some people feel that all they have time to discuss with their doctors is their latest lab results, and not all doctors will specifically ask questions about side effects.

If you feel you want more time to discuss the side effects of your treatment, book a separate appointment to discuss the issue. Or consider your pharmacist as another source of information. Pharmacists have a broad base of knowledge about drug side effects and most have computerized systems that put a great deal of information at their fingertips. Your pharmacist can be a valuable resource.

It is crucially important that you bring up the topic of side effects. If you don't mention that you regularly experience diarrhea or that your fatigue never seems to go away, then your doctor can't offer help. Do not minimize your symptoms when you are discussing them. Be very clear on the extent of the problem. Feeling like you don't want to make a fuss, or vaguely mentioning a problem without really describing how difficult it is for you, is not appropriate in this situation. Your doctor could conclude the problem is minor when, in fact, it's a big concern for you. The one problem that is certain *not* to be addressed by your doctor is the one that you don't mention.

With full information, your doctor can fully understand what could be contributing to a side effect and develop a plan to treat it. This can include multiple steps, depending on what possible causes have been identified.

TRACKING HOW YOU'RE FEELING

You must be in touch with your body so you're clear on what you are experiencing and can describe it to your doctor. This leads us to the two most important rules:

Rule #1: Tell your doctor everything, from beginning to end. If a symptom appears, changes, disappears or reappears, tell your doctor what's up. Write it down so you do not forget.

Rule #2: Always apply Rule #1.

It can be helpful to keep a symptom diary so you can show your doctor a record of everything you have been experiencing. Keeping a daily record as you experience symptoms is better than trying to remember them later.

We have included here *My Health Map* (page 8), which is a simple way to track what you're feeling by drawing on a silhouette of a body and answering a few questions. Photocopy the map and use it to keep track of your symptoms over time. Or use a personal health record, which you can use to record many aspects of your HIV care. A good example of this type of health record is found at: www.catie.ca/en/sideeffects

The key things to report to your doctor about any given symptom are these:

Frequency: How often do you experience it? Is it something you only notice a couple of times a month? Multiple times every day? All day, every day?

Intensity: Is this a minor problem or something severe? If you rank it on a scale from one to five, where does it fall? If the intensity varies, noting this in detail with each occurrence can be part of the daily record you keep.

Duration: Is this a problem that lasts only a few minutes or does it continue over many hours or days? When it happens, does it come and go, or does it continue without a break?

Pattern: Can you identify any pattern related to when and why the symptom occurs? Does it only happen at a certain time of day? Does it occur shortly after you take your drugs? If it's a stomach or gastrointestinal symptom, is there any pattern related to eating particular foods or beverages? Does your level of physical activity affect it? Does it only occur at night?

Treatment: Is there anything you have found that helps?

Perhaps most importantly, tell your doctor if a side effect is adversely affecting your life in important ways. If you have taste changes that make food unappealing, with the result you don't want to eat, that's important. If you have diarrhea so often it keeps you from leaving the house, that's important. This is true for the whole list of symptoms that can cause undesirable changes in your life.

THE BENEFITS OF SUBDUING SIDE EFFECTS

The goal here is to create an approach that will allow you to benefit from your drugs while avoiding the side effects that can make taking them difficult. There are two potentially huge benefits to this approach:

First, you are much more likely to properly **adhere** to your antiretroviral therapy, which means sticking to your drug schedule and taking your drugs exactly as prescribed and directed. Always taking your drugs as directed (instead of skipping the Sunday morning pills because you've been invited to brunch and don't want to be sick to your stomach) means you're much less likely to experience drug resistance. That means the ability of your drugs to keep you healthy can remain effective for years.

And last, but most assuredly not least, your **quality of life** can be immensely improved when difficult side effects are eliminated or lessened. It's all about living *well* with HIV, not just longer.

NOT ONLY MEN LIVE WITH HIV

It seems an obvious statement, but the fact is that men have made up the large majority of people who have taken part in clinical trials of antiretroviral drugs. Therefore, much of what we know about how well a drug works and what side effects it causes really only applies to men. There has long been a concern that many clinical trials enrolled too few women to be able to detect any difference in how women react to drugs. However, most recent studies have not found significant differences between men and women. Unfortunately, we know almost nothing about the impact of antiretroviral drugs in trans people.

One major known exception is that women have a higher risk of both liver toxicity and rash with the antiretroviral drug **nevirapine** (Viramune), a risk that is related to their CD4 count. For this reason, nevirapine is not recommended for women with CD4 counts over 250 (for men, the cutoff is 400). Nevirapine

is a drug that is less commonly used in Canada now. As discussed in the section on *Body Weight and Body Shape Changes*, there can also be some differences between men and women in the body shape changes known as lipodystrophy syndrome.

The other consideration is the possibility of drug side effects on the developing fetus in someone who is **pregnant**. Canadian guidelines recommend antiretroviral therapy during pregnancy, both for the health of the parent and to help prevent HIV transmission to the baby. However, certain drugs are known to cause side effects in pregnancy and others may harm the fetus and so should be avoided.

Drugs that we currently know should be avoided in pregnancy include delavirdine (Rescriptor), nelfinavir (Viracept) and the combination of ddI (Videx EC) and d4T (Zerit). However, it is important to always check the latest treatment guidelines for current recommendations. In addition, there is good information on this subject in CATIE's publication *You can have a healthy pregnancy if you are HIV-positive*, available at www.catie.ca.

DRUG INTERACTIONS

Sometimes when people take medications for more than one condition at the same time, these medications react with each other. This reaction is called a drug interaction. An example of a drug interaction occurs when one medication affects how another is absorbed, used or flushed out of the body. In some cases, this can be a problem.

Drug interactions can have several effects. One is that one drug can slow down the breakdown of another drug in the body. This can increase the level of that drug in the body, which can improve its efficacy but can also lead to more intense side effects or even toxicity. A drug interaction can also have the opposite effect: sometimes one drug will speed up the breakdown of another. In this case, the second drug's effectiveness can be diminished. If the affected drug is an antiretroviral medication, this can lead to drug resistance and fewer treatment options for the future.

Drug interactions are not always obvious and can take various forms. Some occur immediately after the drugs are combined; other interactions do not cause any noticeable problem for weeks or longer.

Ask your **doctor, pharmacist or naturopathic doctor** to check for possible interactions with other drugs or treatments, including herbs and supplements, you may be using. Many pharmacies now have on-line programs that check for possible drug interactions. However, if you obtain your prescriptions at more than one pharmacy, be sure each pharmacist is aware of all the other drugs you are taking.

You can look into drug interactions on your own with other resources. At www.aidsmeds.com, place your cursor over *Treatment* and then click on *Check My Meds*. You can then enter all your medications, nutrients, herbs and various foods (like garlic or grapefruit, both of which are known to cause drug interactions). The tool will then give you information on all the possible interactions known to occur among these factors.

The University of Toronto provides drug interaction tables at www.hivclinic.ca. Click *Drug information* then look for the drug interactions link. Or, you can go to www.hiv-druginteractions.org and click where it says *Click Here* under the *Drug Interactions Charts* heading. After you click to enter all the antiretroviral drugs you are currently taking, it will tell you about any possible interactions.

My Health Map

1. Name

2. Date

3. How am I feeling?

- Choose a number from 1 to 10 to describe how you feel: 1 = feeling bad 10 = feeling great
- Think about your body. What feels better or worse physically? Do you have any specific symptoms or pain? Draw this on the body: Mark these spots and add words or symbols to describe what you feel and where.
- Think about your mood. Are you feeling more happy or sad these days? Draw this on the body: Mark these spots and add words or symbols to describe how you have been feeling.

4. Encouraged by/Discouraged by

- Write down what have you done this week that made you feel encouraged about your health and wellness. For example, you may have eaten a healthy meal, taken your medication on time, attended a support group or exercised.
- Write down what happened this week that made you feel discouraged about your health and wellness. For example, you may have missed a dose of your medication, had unpleasant side effects or did not exercise.

5. Life happenings

- Think about any important happenings in your life this week. Write down what you feel hopeful about and what you are worried about.

6. Medications and other substances (herbal therapies, vitamins, marijuana, alcohol, etc.)

- List any medications or other substances you are currently taking or want to take.
- Write down whether you missed any doses this week.
- Write down any challenges with taking your medications. For example, you may have had difficulty remembering to take them or were unsure whether to take them with food or on an empty stomach.
- List fatigue, nausea, depression or other side effects you had.

7. Questions to ask my doctor

- Write down any question you would like to ask your doctor. For example, you might want to know how to deal with side effects, get test results, or find out about your reproductive health.

8. Extra info

- Write down any extra information. This information could include, for example, your CD4 count or viral load.

My Health Map

1. Name

2. Date

3. How am I feeling?



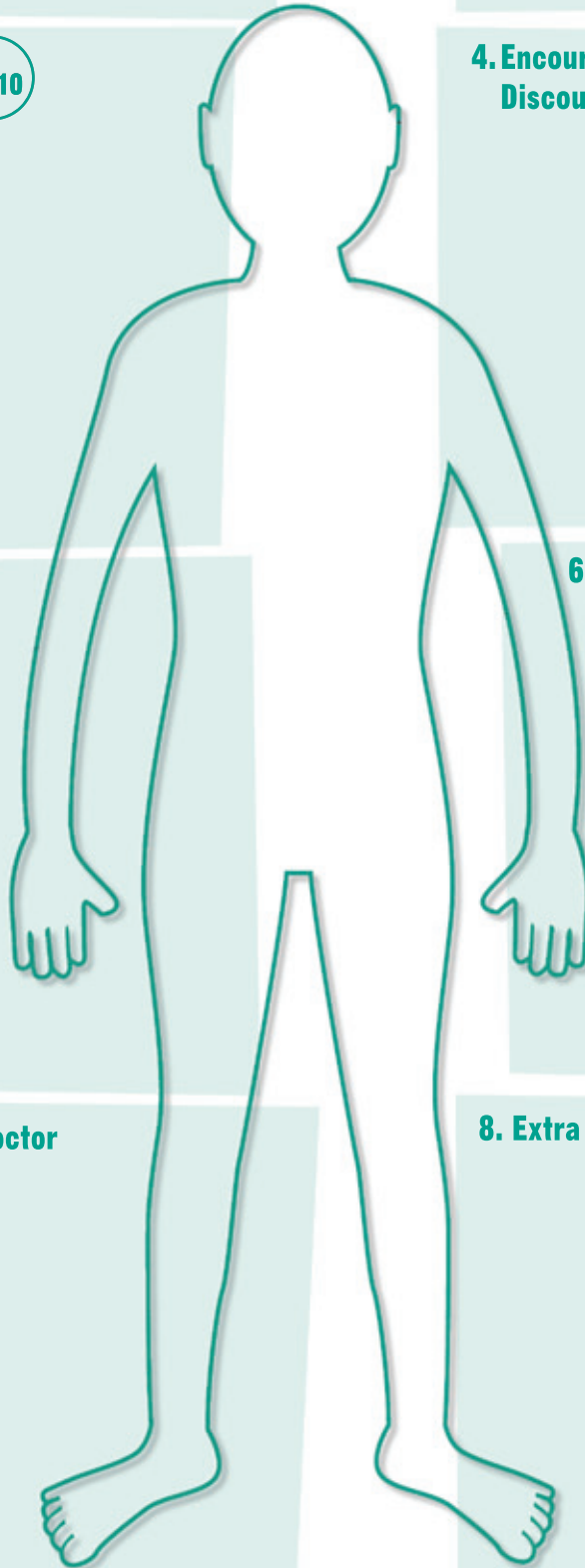
4. Encouraged by/
Discouraged by

5. Life happenings

6. Medications and
other substances

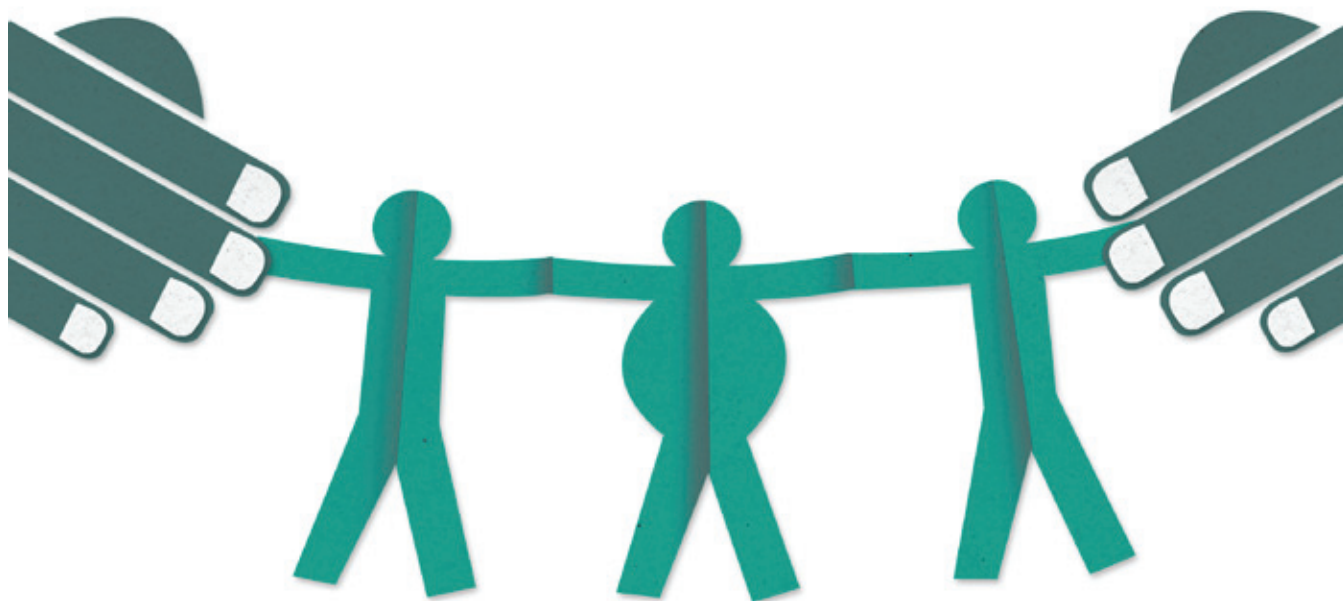
7. Questions to ask my doctor

8. Extra info



Body Weight and Body Shape Changes

There are a number of changes in body weight and body shape that can occur in some people with HIV, from regular weight loss or gain to unintentional wasting. Not all the underlying causes of such changes are directly related to HIV infection or antiretroviral drugs. The good news is that newer antiretroviral drugs are much less likely to lead to lipodystrophy, a specific type of body change. People with this condition look to surgeries or other cosmetic therapies to address the visual effects of these changes.



FIGURING OUT THE CAUSE

The causes of body changes in HIV are not fully understood. In some cases, body changes may result from some combination of drug side effects, changes in the body that occur when antiretroviral therapy leads to a stronger immune system and the effects of HIV disease itself, especially how HIV affects the ways in which the body stores and uses blood fats. In other cases, these body changes are the same type seen in HIV-negative people and are the result of an unhealthy diet, lack of exercise and aging.

Along with the gradual slowing of metabolism that is common as we grow older, **weight gain** can happen in people with HIV in the same way and for the same reasons as it does in people who do not have HIV. People with HIV, like everyone else, can simply gain weight as a result of eating too much of the wrong

foods, not exercising or both. However, there are several factors related to HIV disease that can lead to the weight and body changes that are part of the lipodystrophy syndrome (see below).

Some people with HIV will lose weight. Planned weight loss can be the result of exercise and diet.

Unintentional weight loss has many possible causes and can be HIV-related or not. Common causes include:

- depression, which can cause you to lose interest in eating
- hyperthyroidism, a condition caused by an overactive thyroid that causes you to burn calories quickly
- problems with your mouth, teeth or throat that make eating painful
- using street drugs
- infections, including those caused by parasites
- cancer.

The most extreme form of weight loss is **HIV-associated wasting**. Although this is seen much more rarely than in the past due to improvements in HIV diagnosis and treatment, it does occur, especially in those who are diagnosed late. HIV-associated wasting is a complex problem that requires a multi-step approach, including antiretroviral therapy; appetite stimulation, if needed, and appropriate diet supplementation to boost calories and provide nutrients; hormone replacement therapy, particularly testosterone, as appropriate; glutamine supplementation; treatments for anything that affects food intake and absorption, such as nausea or problems of the mouth; treatments for any infections; and in advanced cases, human growth hormone therapy.

LIPODYSTROPHY SYNDROME

Lipodystrophy syndrome is the term used to describe a range of symptoms that include changes in body shape and metabolism. Lipodystrophy-associated body changes can involve fat loss and/or fat gain in specific parts of the body.

Lipoatrophy is the loss of fat in the face, arms, buttocks and legs. This fat loss can cause veins to protrude in the arms and legs and create sunken cheeks, along with loss of fat elsewhere in the face.

Lipohypertrophy is the accumulation of fat that results in enlarged breasts, an enlarged belly, as well as fat on the base of the neck and shoulders known as a “buffalo hump.” Some people also develop lipomas, which are round, moveable lumps of fat under the skin. These are sometimes called fatty tumours but they are not cancerous.

Some studies report that lipodystrophy may be different in men and women. Women may be more likely to see fat gain in their stomachs and breasts. Men may be more likely to see fat loss, particularly in their face, arms, buttocks and legs. However, many men and women have both fat loss and fat gain. Researchers are not sure why this difference exists. It may be related to hormones or to how fat is burned differently in the male and female body.

Although some people consider fat changes to be a “cosmetic” issue, they can cause considerable discomfort when:

- the buffalo hump leads to difficulty sleeping, headaches and neck pain and makes it harder to turn your neck or shoulders, which can affect

- side vision and makes driving difficult
- the abdominal fat causes breathing, digestive and back problems
- the facial fat loss and body changes cause emotional distress, isolation and non-adherence to medications.

ANTIRETROVIRAL DRUGS

Several classes of antiretroviral drugs have been associated with **fat accumulation**. Protease inhibitors (PIs) may alter the function of certain enzymes needed for maintaining healthy, functional fat cells and healthy levels of blood fats. The result is fat accumulation. The older PIs may be more likely to cause fat accumulation, whereas at least two of the newer PIs, atazanavir (Reyataz) and darunavir (Prezista), have not been associated with fat accumulation in studies to date.

Nucleoside analogues (nukes) can cause fat accumulation in some people, possibly because they contribute to insulin resistance, which is associated with an increase in gut fat. Non-nucleoside reverse transcriptase inhibitors (non-nukes) and integrase inhibitors have much less commonly been associated with fat accumulation.

Fat loss has most commonly been associated with two of the oldest nukes, d4T (Zerit) and AZT (Retrovir, and in Combivir and Trizivir). Researchers believe these drugs damage mitochondria, which are your cells’ energy factories. This damage can cause fat cells to lose their ability to function normally and can distort their shape. In some cases, the cells can die. If enough fat cells are affected by this mitochondrial damage, it can cause wasting of fat tissue in the face and other parts of the body.

Nukes that have *not* been linked to fat loss include:

- 3TC (lamivudine, and in Combivir, Trizivir and Kivexa)
- FTC (emtricitabine, in Truvada, Atripla, Complera and Stribild)
- tenofovir (Viread, and in Atripla, Truvada, Complera and Stribild)
- abacavir (Ziagen, and in Trizivir and Kivexa)

Whether ddI (Videx EC), which is rarely used in Canada today, causes fat loss is not clear.

Fat loss has also been associated with the non-nuke efavirenz (Sustiva, and in Atripla) though it is not known how efavirenz causes this fat loss.

Reversing changes in fat distribution associated with lipodystrophy is difficult. The best option is to choose drugs that have a lower chance of causing fat changes.

Also, monitoring closely for changes — some people regularly take pictures of their face or body and then compare them for changes — means any issue that arises can be caught early before significant damage has occurred.

For people who have developed lipoatrophy, clinical trials have found that discontinuing the older nukes and substituting either tenofovir or abacavir can help. Fat loss will usually stop after the problematic drugs are stopped, and in some people fat loss may actually reverse somewhat. Restoration of fat is usually only partial and generally occurs very slowly, with visible changes taking six months to several years. People who have the best results with fat restoration after switching drugs have generally been those who had not been on the problematic drugs very long and had not experienced serious fat loss.

SUPPLEMENTS

Because of the link between lipoatrophy and mitochondrial damage, some people seek to prevent or reverse mitochondrial damage by taking a combination of:

- a potent multivitamin that includes the whole B complex of vitamins and a broad spectrum of antioxidants (vitamin C, carotenoids, selenium and others)
- acetyl-L-carnitine (500 mg, three times daily with meals).

A separate supplement of N-acetyl-cysteine (NAC; 600 mg, three times daily with meals) can be added to boost glutathione levels, since glutathione is an antioxidant that can be deficient in HIV disease. Talk to your doctor or pharmacist about any supplements you plan to take so they can help you make the right choice based on your other health conditions and treatments.

ANABOLIC STEROIDS, EXERCISE AND GROWTH HORMONE STIMULATORS

The use of **anabolic steroids** combined with exercise can help boost “lean tissue,” including muscle size, but this combination does not significantly improve fat loss or accumulation. In studies of people using the steroids oxymetholone or nandrolone, muscle size increased but there were no reductions in accumulated fat, and there were worrisome decreases in HDL cholesterol (the healthy kind of cholesterol). In those using oxymetholone, there were also increases in liver enzymes, indicating possible toxicity to the liver. Neither oxymetholone nor nandrolone is available by prescription in Canada.

Exercise alone has generally been shown to have either a small benefit or no benefit in terms of losing the fat associated with lipodystrophy. But exercise does have many other benefits, including boosting cardiovascular fitness, mental well-being and self-esteem.

At the time of publication, the synthetic growth hormone-releasing medication called **tesamorelin** (Egrifta) was not available in Canada. It is approved for the treatment of HIV-associated fat accumulation in the United States. Clinical trials showed that Egrifta reduced visceral gut fat, but also that it would have to be used long-term; when the drug was stopped, gut fat returned.

SURGERIES, FACIAL FILLERS AND RELATED THERAPIES

Liposuction can remove fat in some areas of the body. It has been used successfully with buffalo humps and lipomas. Standard surgery can be done for breast reduction, although the fat sometimes returns over time. Neither liposuction nor other surgical techniques can be used in the belly because of the high risk of bleeding.

To help fill out sunken cheeks and restore a fuller appearance to the face, a variety of facial fillers and other therapies have been used. Results have varied. In fact, some have serious drawbacks and possible complications, so it is important to choose carefully. These surgeries can be costly; talk to your doctor to find out if there is any coverage for these surgeries in your region.

Two **non-permanent facial fillers** available in Canada are **poly-L-lactic acid** (Sculptra) and **calcium hydroxylapatite** (Radiesse). Both require multiple injections into the areas of the face with fat loss. These fillers stimulate the production of collagen around the areas where it is injected. The collagen grows for several months after the injections, helping to fill the face out.

The change in facial appearance usually lasts for around one year to 18 months, after which another treatment is required to maintain the results. Although some people have thought of its lack of permanence as a disadvantage, it can actually be an advantage. If excess collagen develops in a given area, it will gradually fade over time. If your own fat cells begin to recover, you will not end up with too much bulk under the skin. It is important to choose a plastic surgeon or dermatologist very experienced in the use of these fillers.

There are two other non-permanent fillers sometimes used for facial wasting. **Hyaluronic acid** is a substance that is a normal component of connective tissue. Synthetic forms of hyaluronic acid (such as Juvederm or Restylane) are injected into the face. The length of time the results last varies. **Collagen** has long been used as a treatment for facial wrinkles.

Results vary widely among individuals using these fillers for facial wasting, and are not generally long-lasting. The skill of the doctor injecting these substances is important for the best results. There have been no studies of these products in HIV-associated facial wasting, but there are anecdotal reports of improvements lasting up to six months.

A number of **permanent fillers** are available to treat facial wasting, including polyalkylimide, polymethylmethacrylate, implants and silicone oil. **Polyalkylimide** (Bio-Alcamid) is a synthetic product approved in Canada for the treatment of facial wasting. It requires multiple injections into the face. There have been reports of very serious problems with this product, including infections that develop in the area where the substance was injected, sometimes well after the initial procedure. This product has also been reported to migrate from the site where it was originally injected. Bio-Alcamid can also result in lumps and bumps in the face. Although removal is possible, it is painful and expensive and becomes increasingly difficult the longer the product has been in the face. Due to greater awareness of the many problems associated with Bio-Alcamid, many plastic surgery societies no longer recommend the use of this product.

Polymethylmethacrylate (PMMA; Artefill, Precise, Metacrill) is a synthetic compound used in cosmetic surgery as a permanent facial filler. All of these products contain small particles of PMMA. Multiple injections of PMMA into the skin are normally done but alternative techniques have been used in other countries.

Expanded polytetrafluoroethylene (ePTFE) implants (SoftForm, Gore-Tex) and **hard silicone implants** are solid implants used for large sunken areas in the face. These implants can be problematic in people with serious facial fat loss because the edges of the implants may be visible. Some doctors recommend these implants be used in combination with a product that boosts collagen production. The idea is that over time, with enough collagen production, the solid implant might be less visible. There is a risk of post-operative complications, including infection and scarring. The cost for implants can be very expensive.

Silicone oil has been used to treat HIV-associated lipoatrophy but the use of injected liquid silicone remains controversial. Case reports and one study have shown positive results for reversal of HIV-associated facial lipoatrophy, but there is concern about the potential for side effects, including long-term inflammation, migration of the product and inflammatory reactions called granulomas. Once injected, liquid silicone cannot be removed. The cost is variable, depending on the amount of silicone oil needed and the fee for injections, but can be very high. Silicone oil implants are not widely used in Canada and their long-term safety in HIV-positive people is not clear.

Finally, an **autologous fat transplant** involves taking fat from another part of the body and injecting it into the face. Since people with lipoatrophy may have lost a lot of subcutaneous fat, it can be difficult to find enough fat for use in the face. Nonetheless, this process can be effective in restoring facial appearance when done by a skilled plastic surgeon. Only one or two treatments are required initially, but later treatments are required to maintain the benefits. Results last for as short as three months in some people and as long as a year or more in others.

Diarrhea, Gas and Bloating

Diarrhea, gas and bloating can be inconvenient and embarrassing. They can also be painful and dangerous for your health. Don't be afraid to talk with your doctor and other healthcare providers about these conditions, and don't accept that nothing can be done about these problems. It is almost always possible to control them with a comprehensive approach.



NO LAUGHING MATTER

Diarrhea is an increase in the frequency and decrease in the consistency of stools. It is a side effect that can arise when starting treatment. It often goes away after a few weeks, though, for some people, it remains an issue for years. Gas and bloating, sometimes to an uncomfortable extent, are also common in people with HIV. Many of the causes of gas and bloating are similar to those that cause diarrhea.

Diarrhea, gas and bloating can cause pain and embarrassment, particularly when their timing is unpredictable. They can make people unwilling to leave home because they don't want to risk a humiliating incident in public. Diarrhea can become life-threatening when it causes the body to lose too much fluid or too many electrolytes (normal chemical compounds in the blood) or it contributes to wasting (serious, unwanted weight loss).

There are many benefits to fully addressing the issues of diarrhea, gas and bloating, including an improvement in your quality of life. When you get rid of diarrhea or excessive gas:

- You reduce the painful irritation caused by diarrhea and you reduce the pain that accompanies bloating from gas.
- You normalize your daily life since you don't have the constant interruptions and embarrassment of these conditions.
- Your sleep improves since you aren't running to the bathroom in the night.
- You improve your body's nutrient status since you are no longer flushing away unabsorbed nutrients that maintain weight and immune function.
- Your drugs work better since these medications will be absorbed at the levels needed for effective viral control.

- You can stay on your antiretroviral therapy longer since gastrointestinal problems, including diarrhea, gas and nausea, are some of the main reasons people stop or switch therapy.

FIGURING OUT THE CAUSE

It is important to report to your doctor any diarrhea that is frequent, watery, lasts for more than a couple of days or contains blood. Also report any on-going problems with gas or bloating.

These conditions have many causes and can be complex to address. HIV itself damages the gut by attacking immune cells there. Many HIV medications are a common cause of diarrhea, gas and bloating. However, they can also have causes unrelated to HIV disease, such as functional bowel disease (irritable bowel syndrome and inflammatory bowel disease), lactose intolerance or gluten sensitivity. Infections, including bacterial and parasitic infections, can also cause diarrhea. These causes can be dangerous and lead to severe health problems, such as wasting. The best approach is to see your doctor for a full workup to determine the specific cause or causes and to develop a comprehensive treatment strategy.

Many **medications**, including antiretroviral medications and other medications used in the treatment of HIV, list diarrhea, gas and bloating among their possible side effects. Often these will be short-term side effects that will disappear after a few days or weeks of treatment. In some cases, however, these side effects continue long-term.

The number of medications often taken by people with HIV can make it difficult to tease out the cause of gastrointestinal symptoms. If the onset or sudden worsening of diarrhea, gas or bloating is tied to starting or switching to a medication, it's a likely suspect. It is usually worth waiting for a few weeks to see if the problem clears up, especially if you are on otherwise effective antiretroviral therapy. If these side effects continue, however, it is important to discuss this with your doctor.

Since diarrhea, gas and bloating have many causes, truly effective treatment requires thorough diagnosis. In addition to medications, these conditions can be the result of:

- infections and parasites that require treatment

- fat intolerance and malabsorption; can be improved by cutting back on dietary fat and taking lipase, the fat-digesting enzyme, with meals
- lactose intolerance; can be resolved by eliminating or decreasing the consumption of dairy products and by taking enzymes to break down lactose or casein when dairy products are eaten
- excessive sugar or caffeine, legumes (dried peas and beans) and raw broccoli or cauliflower
- recently taking antibiotics
- stress.

MEDICATIONS AND NATURAL THERAPIES

When the causes of diarrhea, gas and bloating cannot be entirely eliminated, an over-the-counter **anti-diarrheal agent**, such as Imodium (loperamide), Kaopectate or Pepto-Bismol, may help relieve symptoms. Check with your pharmacist and doctor to ensure they will not interfere with any other medications you are taking.

Crofelemer (Fulyzaq) is a prescription drug derived from the extract of a tropical plant. Clinical trials have found it useful in cases of HIV-related diarrhea not caused by another infection. At the time of publication, the drug had been approved for use in the United States and was available in Canada through a special access program. Check with your doctor or pharmacist for the most up-to-date information.

Other **natural therapy** options for diarrhea include:

- The amino acid L-glutamine can heal damaged intestines and reduce diarrhea by enhancing water and salt absorption across the wall of the small intestine.
- Gut-friendly bacteria, such as *L. acidophilus* or *S. boulardii*.
- Ground flax seeds sometimes help to relieve diarrhea and heal the intestines.
- Calcium may work to reduce or eliminate diarrhea caused by protease inhibitors, but check with your pharmacist or doctor to make sure it will not interfere with other medications you're taking and that you are not taking too much calcium.

DIETARY CONSIDERATIONS

It is crucial to **prevent dehydration** when you are suffering from diarrhea. As long as diarrhea continues, consume plenty of calories and drink plenty of healthy fluids, such as water, juices, herbal teas, broth and fruit

juice smoothies. You should consume at least 1.5 litres of fluids every day, and more if the diarrhea is ongoing and causing substantial fluid loss. Also, be sure to consume enough high-quality calories. Diarrhea causes food to move faster than normal through the digestive system, meaning all nutrients may not be absorbed.

Foods that contain **soluble fibre**, such as apples, peaches, pears and bananas, grains such as oatmeal and white rice and psyllium-containing supplements like Metamucil, can help with diarrhea. They absorb water, expand and bind together the intestinal contents, bulking up the stool and slowing its passage. Fibre intake should be increased slowly because it can cause gas. Bananas and avocados contain fibre and potassium, which can help to replenish electrolytes (see below). In some cases, cheese can also help bind loose stool and control diarrhea; however, if you are lactose intolerant, cheese could actually contribute to diarrhea.

Foods and liquids **to avoid** when you have diarrhea include coffee and other caffeinated beverages, alcohol, chocolate, fried and fatty foods, spicy foods and high-sugar foods or liquids. A registered dietitian can be a good source of advice on how to deal with diarrhea. Check www.dietitians.ca for a list of registered dietitians in your area.

REPLENISHING ELECTROLYTES

With serious diarrhea, it is important to rebalance the body's **electrolytes**, including sodium, potassium and chloride. Drinking juices or broths, diluted with water to enhance absorption, can help. Avoid Gatorade and other sports drinks, which contain a lot of sugar that can make diarrhea worse.

Concentrated sources of electrolyte minerals may be needed. Oral **rehydration salts** are one option that is available through many pharmacies at low cost. You can make your own rehydration solution. Start with one litre of orange juice and then add 5 ml (1 tsp) of *light* salt (which contains potassium mixed with sodium). Sweeten with 15 ml (1 tbsp) of pasteurized honey if desired. To add soluble fibre to this mix, add rice water to the juice. Make rice water by boiling four parts water and one part rice until the rice is tender, and then straining off the rice water. This rice water can also be drunk on its own as a source of both hydration and soluble fibre.

Emotional Wellness

Emotional wellness is often overlooked. But as people with HIV live longer, healthier lives, their emotional health is increasingly important and effective communication with their doctors about this issue is needed. Unhealthy stress, depression and anxiety are more common in people with HIV than in the general population. Emotional issues can have multiple causes, including HIV infection and the medications used to treat it. There are many treatment options to improve emotional wellness, including self-help strategies, talk therapy and prescription medications.



FIGURING OUT THE CAUSE

Some people with HIV experience **emotional** problems such as anxiety, depression, sleep disorders and nightmares, or **mental** problems such as foggy thinking, memory difficulties and loss of the ability to concentrate or focus. If you are experiencing these symptoms or have friends, family or coworkers telling you they are observing such problems in you, it is important to work with your doctor and possibly other health professionals to obtain an accurate diagnosis and to establish a treatment plan.

There are a number of possible causes of emotional problems in people living with HIV. Sometimes, multiple causes can interact to create problems. The causes may or may not be associated with HIV disease and its treatments.

It is particularly important to discuss symptoms of anxiety or depression with your doctor. It is normal to have feelings of worry or **anxiety** about different issues in your life from time to time. However, if anxiety persists, symptoms can intensify beyond general worrying and include irritability, changes in appetite and weight, difficulty falling or staying asleep and sexual problems. Anxiety is a health problem that can and should be treated. Moreover, if anxiety does not resolve, it can, in some cases, turn into depression.

People may say they are **depressed** when they experience sadness or “the blues;” such short-term feelings are part of everyday life for most people. True clinical depression is a serious condition that has emotional, physical and behavioural effects, including long-term feelings of sadness, the inability to feel pleasure, disinterest in previously pleasurable activities, low self-esteem, the loss of the ability to

concentrate on tasks, fatigue, poor quality of sleep, feelings of hopelessness and, in the most extreme cases, thoughts of suicide.

Many people with HIV at some point experience depression, anxiety or other mental problems not caused by HIV disease but rather by their life experiences, lifestyle or biochemical imbalances in the brain. However, it is very important to remember that there are specific HIV-associated causes that should always be considered as you seek answers for depression and other emotional or mental problems. If any of the following HIV-associated issues are contributing to your emotional or mental symptoms, they will need to be addressed in order to restore your emotional health.

ANTIRETROVIRAL DRUGS

Many antiretroviral medications can cause emotional or mental problems as side effects. These side effects may diminish or disappear after a period of days, weeks or months but can also remain long-term. In some cases, changing drugs may be the only option.

The drug most likely to be a cause of mental health problems is the non-nucleoside analogue **efavirenz** (Sustiva and in Atripla). This medication can cause fatigue, unfocused thinking, feelings of paranoia and disorientation, depression, anxiety, insomnia, vivid dreams and nightmares. Though many people do not experience any of these side effects on this medication, in those who do these side effects typically disappear gradually after several weeks on the drug, so waiting out the problem for at least a month is advisable, if possible. For others, the problems continue and changing drugs may be the only solution.

Consider beginning efavirenz on a weekend or taking a few days off from work since it can take a few days to get used to this drug. Also, it is best to avoid street drugs and alcohol when starting efavirenz because they can worsen some of the central nervous system side effects of this medication. Taking efavirenz on an empty stomach can also help, as food (especially fat) can increase levels of the drug in the blood and thus worsen side effects.

Although rare, serious psychiatric disorders have occurred in some people taking efavirenz, including severe depression, aggressive behaviour, delusions, paranoia, psychosis-like symptoms and suicide attempts. Patients with a prior history of psychiatric disorders appear to be at greater risk for these serious problems.

HEPATITIS C TREATMENT

Interferon, a drug often used to treat hepatitis C (and some cancers) can often cause symptoms of anxiety and depression. These symptoms can range from mild to very severe. Some doctors find it useful to treat people who have hepatitis C with an antidepressant before beginning their treatment with interferon.

NUTRIENT DEFICIENCIES

Deficiencies of certain nutrients, especially vitamin D, vitamin B₁₂ and other B vitamins, are common in people with HIV and can cause a variety of emotional and mental symptoms.

Vitamin D deficiency has been linked to depression. It is very important to get your vitamin D level tested regularly and use supplements when necessary to boost vitamin D to an optimal level. Studies have shown that vitamin D deficiency is a common problem in people with HIV, so this is a possibility in anyone who has developed depression, especially in the winter. With proper supplementation, depression and associated problems caused by vitamin D deficiency can usually be reversed. See the appendix for more information about this important vitamin.

Vitamin B₁₂ has been shown in studies to be deficient in many people with HIV, and the deficiency can begin early in the disease. Vitamin B₁₂ deficiency can result in a deterioration of mental function that can cause symptoms such as foggy thinking, memory loss, confusion, disorientation and psychiatric disorders, including depression and paranoia. If you have developed such emotional or mental symptoms, especially when combined with chronic fatigue, it is very possible that vitamin B₁₂ deficiency could be contributing. If you also have other symptoms this deficiency can cause, such as neuropathy, weakness and difficulty with balance or walking, it is possible vitamin B₁₂ deficiency is a problem. See the appendix for more information about this important vitamin.

Other B vitamins are also sometimes deficient in people with HIV. Deficiency of almost any individual B vitamin or of the whole B complex can cause anxiety, depression, lack of focus or difficulty concentrating. Most important in this regard is vitamin B₆. Always accompany an individual B vitamin supplement with another supplement that contains the whole B vitamin complex in order to maintain the proper balance of these important vitamins.

UNTREATED HIV DISEASE

In untreated HIV disease that has advanced, certain opportunistic infections, as well as HIV itself, can affect the brain in a way that causes symptoms of depression, memory loss and other serious mental and emotional symptoms. If your CD4 count is low and symptoms like this become noticeable, be sure to discuss this with your doctor right away. Such symptoms could be an important sign of another infection for which treatment is urgently needed. If you are not currently on antiretroviral therapy, beginning effective treatment will be very important to control the virus and help restore your immune system.

HORMONE CHANGES AND DEFICIENCIES

Testosterone deficiency frequently causes depression, fatigue and loss of sexual desire in both men and women living with HIV. The appropriate use of transdermal testosterone patches or gels to return testosterone to optimal levels can help eliminate depression and fatigue if testosterone deficiency is the cause. A Columbia University study showed that 79 percent of HIV-positive men who had been diagnosed with depression and had low blood levels of testosterone had their depression reversed and their mood improved with testosterone replacement therapy.

It is possible for the hormonal changes that occur during and around **menopause** to cause depression or anxiety. Testing of hormone levels followed by discussion with your doctor of what can be appropriate for replacement therapy is very important. See *Menstrual Changes* for more information about menopause.

Thyroid hormone deficiency (called hypothyroidism) is a problem for some people with HIV. It can cause fatigue, depression, foggy thinking and difficulties with focus and concentration. Talk to your doctor about whether thyroid function tests should be a part of your regular blood tests. In people who have low thyroid hormone levels, restoring their thyroid hormones to optimal levels can create mental focus and physical energy, though it may take weeks to months of supplementation before these levels return to normal. Hormones tend to work slowly so patience is necessary.

REDUCING STRESS

Stress may be causing your anxiety or depression. Many people face stressors in their relationships, finances and work. Living with a disease like HIV or other chronic

illness can add to that stress. Stress reduction can come from a combination of behavioural strategies and counselling with a good mental health professional, along with meditation, other relaxation techniques or homeopathic remedies. See the discussion of St. John's wort below, and check with your doctor or pharmacist about any potential drug interactions between the medications you take and any complementary therapies you are considering.

There are many simple **self-help techniques** that can help deal with anxiety, including:

- Deep, slow breathing – Concentrate on taking slow, steady breaths. Breathe in to the count of four, pause and breathe out to the count of four. Repeat. Find some time every day to focus on your breath and slow it down.
- Relaxing – 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.
- Laughing – Studies show that laughter reduces stress.
- Living in the here and now – Life with HIV can be all about living in the past with regrets or in the future 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.
- Appreciating the good things – Every day, try to count five things in your life that you are grateful for. This reinforces a positive attitude.
- Problem solving – If the source of your stress is something you have control over, try to address it and eliminate the root cause.
- Talking 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.
- Learning about stress reduction – Many complementary therapies teach relaxation and stress reduction. Some community organizations offer free massage, yoga and meditation classes.

EATING, SLEEPING, EXERCISING AND SOCIALIZING

A healthy lifestyle contributes to mental and emotional health. Eating a nutrient-rich healthy diet is important for mental and physical health in people with HIV. Many studies have shown that regular exercise can help to improve mood and counter anxiety, stress and depression. Getting a good night's sleep is also very important for maintaining a good mood in general, as well as for ensuring you have sufficient energy to address your health and well-being.

Socializing with friends and family and finding social support can contribute significantly to emotional wellness, too. People with HIV who are isolated or have little social support are more likely to experience depression and anxiety. Making the effort to socialize, or joining a peer support group can be very helpful for restoring and maintaining good emotional health.

SEEKING PROFESSIONAL HELP

In addition to finding support within your circle of family and friends, you may want to reach out to healthcare providers. A good place to start is with your family doctor or HIV specialist. They can work to uncover any medical causes, and they can refer you to mental health professionals such as counsellors, psychologists or psychiatrists for more help.

Talk therapy, either one-on-one or in a group, can be very effective in dealing with emotional problems. If you are feeling emotionally unwell, it is crucial you have someone to listen to you, understand your feelings, give you support and help you understand what is troubling you. Antidepressant medication may also be part of the solution.

USING ANTIDEPRESSANT THERAPIES

Antidepressant medications may also be needed to treat depression, anxiety and other mental health issues common in people with HIV. There are many different antidepressant medications available today; you may need to try more than one to find the medication that works best for you.

Medications that are most commonly used today for the treatment of depression are called selective serotonin reuptake inhibitors (SSRIs). They work on serotonin, the brain's "happiness chemical." Because it is a serotonin precursor, **5-HTP** (5-hydroxy-tryptophan, related to tryptophan) may also work for countering depression. (See *Sleep Problems* for more on 5-HTP supplements.) Many people have found that combining 5-HTP supplementation with other emotional wellness strategies is a successful solution for depression. However, 5-HTP should *not* be taken by people who are also taking medicines to treat depression or anxiety.

Be sure to tell your pharmacist or doctor about all the medications, over-the-counter drugs, supplements and herbal therapies you take. These products can interact with your antiretroviral drugs, causing them to become less effective or increasing the risk you will experience side effects.

The herb **St. John's wort** is widely used as a natural antidepressant but it can interact with many medications, including antiretroviral drugs. It should never be used without consulting with your doctor or pharmacist regarding the possibility of drug interactions.

Fatigue

Fatigue can be characterized as tiredness, lethargy or a lack of energy and is a common symptom in people with HIV. Fatigue can have physical effects, leaving you unable to do the things you used to do. It can also have mental effects. Fatigue can have many causes, not all of which are related to HIV disease. The good news is that by addressing the things that are dragging them down, many people are able to return to full energy.



FIGURING OUT THE CAUSE

Fatigue is different from sleepiness or simple tiredness from a busy schedule or hectic lifestyle. Fatigue usually goes on for weeks or months and is not always relieved by getting enough sleep or taking breaks. Fatigue can occur in people with HIV, especially those who are not taking treatment. Some people wake up each day feeling like they don't want to get out of bed and spend the whole day exhausted. For others, fatigue comes and goes. They have reasonable energy on some days but not on others. Fatigue can have physical effects, leaving you unable to do the things you used to do and making simple tasks seem overwhelming. It can also have mental effects, making it difficult to focus on your work or leaving you without the motivation to carry out the tasks of daily living.

It is very important to discuss fatigue with your doctor since it could indicate an important health problem that needs attention. Because fatigue can develop very gradually, you may not realize how exhausted you truly are. In order to assess your current level of energy, think back to years past, perhaps to a pre-HIV time, and ask yourself whether your energy level now is similar to the past. Are you able to work a full day and still

have the energy for a fulfilling social life? Or do you come home so exhausted that you collapse on the sofa? Do you have the energy to exercise as often as you would like, or is just the thought of hitting the gym exhausting?

How do you feel when you wake up in the morning? Are you getting out of bed feeling great, or are you dragging yourself out and forcing yourself to keep moving? Do you find yourself dozing off or perhaps reaching for yet another cup of coffee just to stay awake? In general, think about how your level of energy affects your daily life, and describe this to your doctor.

In addition to the conditions described below, a medical evaluation to exclude other potentially serious non-HIV-related illnesses is also important. This is especially true with advancing age.

INFECTIONS

As long as any infection continues, whether it is HIV-related or simply a cold or flu, it is likely to contribute to fatigue. Long-term infection by viral hepatitis, such as hepatitis C, is one possible infection to be tested for. If you have not been diagnosed with an infection but

have fatigue, especially along with any other symptoms that might indicate an infection like fever, chills, body aches, sweating or weight loss, work with your doctor to determine if you have an ongoing undiagnosed infection. If you have been diagnosed with an infection, be sure that it is fully treated. It may not be possible to return to good energy until an infection has been fully addressed.

If you are not on antiretroviral therapy, it is important to know that HIV infection itself can contribute to fatigue. Many people find that one of the great benefits of starting on antiretroviral therapy is a tremendous return of energy. As your viral load drops to undetectable levels, your energy level will often increase.

DIET, NUTRITION AND HERBAL THERAPIES

What you eat can contribute to fatigue. Nutrient deficiencies can occur in people with HIV, especially when their infection is not treated. Many people with HIV take a **multivitamin-mineral**. Other **supplements** can also help ensure your body has all the nutrients it needs for health and energy. For example, vitamin B₁₂ is important for good energy and studies have shown a high rate of B₁₂ deficiency in HIV disease. See the appendix for more information about this key vitamin for people with HIV. The **herbal therapies** rhodolia, licorice and ginseng may also be helpful in alleviating fatigue.

Some people who are fatigued get themselves through the day with constant servings of **sugar** and **coffee**. This can temporarily give you more energy, but this boost is often followed by a crash. Getting off this rollercoaster can help you regain a more steady level of energy in the long run.

Drug and **alcohol** use are a common cause of persistent fatigue. If substance use has become a problem for you, seek help and referrals through your doctor or through your local AIDS service organization. Obesity can also contribute to fatigue; maintaining a healthy, balanced diet can help here.

HORMONE DEFICIENCIES

Inadequate levels of certain hormones can occur in people with HIV, especially those whose infection is untreated. It is important to test for hormone deficiencies if you have persistent fatigue. If test results

show low hormone levels, replacement with hormone therapy can improve the fatigue. **Testosterone** can be deficient in people with HIV and deficiency can be a major contributor to fatigue. **Hypothyroidism** (a deficiency of thyroid hormones) is also possible. Talk to your doctor about checking your TSH level (this is an indirect indicator of thyroid function) and your thyroid hormones (especially free T3 and free T4) levels if you have persistent fatigue. Proper thyroid hormone replacement therapy can be a very important step in restoring good energy levels.

DEPRESSION, STRESS AND NOT GETTING ENOUGH REST

Depression almost always causes fatigue, and fatigue may be the first symptom of depression. Talk therapy, and sometimes medication, can help alleviate the depression. (The section *Emotional Wellness* provides more detail.) In addition to emotional and social factors, causes of depression in people with HIV, especially in men, can include testosterone deficiency (see above). Vitamin D deficiency may also be a cause. Consider having your vitamin D level tested. See the appendix for more information about this key vitamin for people with HIV.

Stress can contribute to fatigue, so do your best to avoid it as much as possible. Where you can't avoid it, try to find ways to counter it using whatever combination of approaches works best for you. Meditation, yoga, breathing exercises, talk therapy and herbal or homeopathic remedies are all ways to counter the effects stress has on your body and mind. Regular light exercise can also help improve symptoms of persistent fatigue. Check with your doctor before starting any exercise regimen. Read also the section *Emotional Wellness* for more information.

If you are **not sleeping** well or not sleeping enough, it is very important to address insomnia in order to restore a good night's sleep. Sleep apnea (the slowing or stopping of breathing while asleep) can also lead to not getting enough sleep. It can be helpful to take naps, especially when the previous night's sleep was inadequate. For a full discussion, see the section *Sleep Problems*.

ANTIRETROVIRAL MEDICATIONS

Antiretroviral medications can cause fatigue in people with HIV. Luckily, with the newer antiretroviral medications, this problem is less common than it once

was. If you do experience this side effect, your fatigue will sometimes disappear after you have been on the drugs for some time. You may want to consider waiting to see if the fatigue passes. If it does not disappear or lessen with time, you may want to talk to your doctor about changing your combination. The fatigue should disappear fairly quickly once your medications are changed. The medications most likely to cause fatigue are those that can contribute to the development of anemia (see below).

OTHER MEDICATIONS

Many drugs, including over-the-counter medications, can cause fatigue. Antihistamines, often used by people with seasonal allergies, can cause drowsiness and are a common cause of fatigue. But there are many medications that can contribute to fatigue, so consult with your doctor and pharmacist about whether any prescription or over-the-counter medication you take could be causing your fatigue.

ANEMIA

Anemia is a problem of the red blood cells (RBC) and is indicated by decreases in blood test results for hemoglobin, hematocrit and RBC count. Blood cells are produced in your body's bone marrow. When your bone marrow isn't functioning properly, the result is anemia. Accompanying fatigue is highly likely. Medications that can suppress bone marrow and lead to anemia include:

- antiretroviral drug AZT (Retrovir, and in Combivir and Trizivir)
- cytomegalovirus (CMV) drug valganciclovir (Valcyte)
- sulfa antibiotics (Septra/Bactrim, Dapsone)
- anti-hepatitis C drugs alpha interferon (PegIntron, Pegasys), ribavirin, boceprevir (Victrelis) and telaprevir (Incivek)
- anti-malarial drug pyrimethamine (Daraprim)
- various anti-cancer drugs.

Anyone with fatigue should have their red blood cell levels checked. Anemia is experienced by more than three-quarters of people with HIV whose disease has advanced because they are not on antiretroviral therapy. It is less common in people who are on therapy. In either case, treating anemia is critical. A large study found that regardless of CD4 count, the risk of death was substantially higher for people with anemia, and that recovery from anemia, by whatever means,

significantly lowered that risk. Unfortunately, anemia too often goes untreated. Symptoms of anemia include:

- fatigue and weakness
- shortness of breath
- heart palpitations
- increased susceptibility to infections.

Medications are not the only cause of anemia. Other possible causes include:

- heavy bleeding during menstrual periods
- deficiencies of folic acid and vitamin B₁₂
- iron deficiency (less common in men, but fairly common in women)
- infections such as *Mycobacterium avium* complex, tuberculosis, CMV colitis, parvovirus B19, cryptococcal meningitis and other fungal infections
- kidney disease
- cancers such as lymphoma and Kaposi's sarcoma
- late stages of hepatitis C infection.

HIV itself can also cause anemia. That is the Catch-22: the drugs you are taking may cause anemia, but left untreated, HIV will impair the production of red blood cells. If you are not currently on antiretroviral therapy and are diagnosed with anemia, consider starting antiretroviral therapy.

Some people with severe anemia associated with cancer, kidney disease or hepatitis C medications will benefit from injections of **erythropoietin** or related drugs (Epo, Aranesp or Eprex), which promote the production of red blood cells. It will often resolve anemia within four to six weeks (the time needed for the new red blood cells to be created) and return energy to your life. However, erythropoietin cannot work alone. It provides the stimulus for the bone marrow to produce more cells, but the actual building blocks for the cells include iron and the B-complex vitamins folate and vitamin B₁₂. You should always accompany use of erythropoietin with the B vitamins and, if testing shows the need, with an iron supplement. Blood transfusions can provide short-term relief in severe cases.

Headaches

While people with HIV develop headaches for the same reasons as everyone else, headaches can sometimes be related to HIV disease and associated conditions and infections. They can sometimes be the result of antiretroviral medications, occurring at the start of drug therapy and disappearing gradually over the first weeks of treatment. Sometimes headaches continue over the long-term and a more involved investigation is needed.

FIGURING OUT THE CAUSE

Some headaches are due to the activation of pain nerves in the head. Tension headaches and migraines are examples of these kinds of headaches. Other times headaches are a symptom of another condition. These other conditions include hangover, low blood sugar, allergies or sinus congestion, ear infections, dental problems or over-use of pain medications. Headaches can also be a side effect of a prescription drug.

Some headaches can be a symptom of a serious or even life-threatening condition, such as:

- encephalitis (inflammation of the brain) or meningitis (inflammation of the membranes around the brain and spinal cord), often due to an infection
- depression
- syphilis
- bleeding around the brain
- stroke
- cancer.

Headaches that are severe, last for more than a few hours or recur should be taken seriously. This is especially true if these symptoms are new. For instance, severe headaches lasting for hours are certainly problematic, but potentially less concerning if you have a history of migraines and your symptoms are identical to your previous episodes.

That said, certain **headache “red flags”** should be addressed urgently when they occur. A severe headache that comes on very suddenly or reaches its maximum intensity within minutes could be a sign of a very serious problem. See “Stroke and aneurysm” below. In these cases, people should get medical attention right away.



If you have recurrent or severe headaches, talk to your doctor. He or she may refer you to a neurologist or HIV specialist for a comprehensive diagnosis. It is best *not* to treat such headaches with pain medications until the problem has been diagnosed and the treatment prescribed. If you cover up a headache with pain medications, it can make the diagnosis of something serious more difficult.

Be sure to describe to your doctor how often your headaches occur, how severe they are, whether there is any pattern to their occurrence (for example, time of day, after eating certain foods or doing certain activities), and whether you experience any other symptoms, such as neurological symptoms (for example, physical weakness) or fever.

Don't forget the possibility that your headache may be related to something other than HIV. Healthcare practitioners sometimes use diagnostic procedures that focus too much on opportunistic infections and HIV-related conditions, forgetting that people with HIV are also susceptible to other conditions.

ANTIRETROVIRAL THERAPY

Headaches can sometimes be a side effect of **antiretroviral therapy**. In some cases, headaches will only occur during the beginning of drug therapy and will gradually disappear over the next few weeks. In other cases, they may remain long-term, and the only solution may be to switch drugs. Medications should be particularly suspected as a cause of headaches when a new drug treatment has recently been started. Note, however, that such reactions can occur even after months of using a particular drug.

Another possible cause of headaches is **lactic acidosis**. For anyone taking one of the nucleoside analogues (such as AZT or d4T) or other medications associated with them, lactic acidosis should be considered. Newer agents like abacavir (Ziagen and in Kivexa and Trizivir) and tenofovir (Viread, and in Truvada, Atripla, Complera and Stribild) are much less likely to cause lactic acidosis than their older counterparts, so this has become less of a concern in recent years. Lactic acidosis may be suspected especially if the headache is combined with other symptoms of this condition. These include fatigue; nausea and vomiting; pain in the stomach, abdomen, or liver; unexplained weight loss; difficulty breathing; cold hands and feet; blue skin colour; and sudden symptoms of peripheral neuropathy. For a full discussion of this condition see the section *Less Common Side Effects*.

INFECTIONS AND OTHER CONDITIONS

Headaches can also be a symptom of many different infections and conditions that are important to diagnose and treat, including:

- advanced syphilis called neurosyphilis
- herpes outbreaks
- endocarditis (heart infection)
- cryptococcal meningitis
- toxoplasmosis
- CMV encephalitis
- progressive multifocal leukoencephalopathy (PML)
- primary central nervous system (CNS) lymphoma.

STROKE AND ANEURYSM

With any severe headache, the possibility of a stroke (the loss of blood flow to a part of the brain) or the rupturing of an aneurysm (a bulge or ballooning of a blood vessel in the brain) should always be considered. As people with HIV live longer lives, their risk of cardiovascular disease increases. Cardiovascular disease can occur at a younger age in HIV-positive people than is typical in the HIV-negative population.

Common symptoms of a **stroke** are: sudden paralysis or weakness in the face or limbs, especially on one side of the body; sudden problems with balance or walking; sudden vision problems; slurred speech; and sudden confusion or problems understanding simple statements.

With a ruptured **aneurysm**, a headache — sometimes described as the worst headache ever — often comes on quickly and reaches maximum intensity in minutes. It can be accompanied by confusion, numbness, trouble seeing, speaking or walking, a stiff neck, a high fever or nausea or vomiting.

If you experience one or more of these symptoms, seek medical attention immediately. Call 911 if your region has that emergency service.

STABILIZING YOUR BLOOD SUGAR

Blood sugar problems may also contribute to headaches. As people with HIV age, they may develop insulin resistance and diabetes, which can result in serious blood sugar problems. When your blood sugar drops too low, it can cause a headache that may not resolve for a number of hours. If you are having recurrent blood sugar ups and downs, this can cause recurrent headaches. These headaches can be resolved by stabilizing your blood sugar. Eating frequent small meals that are nutritionally balanced, with fibre, complex carbohydrates and protein can help, as can exercising regularly.

MAGNESIUM DEFICIENCY

Magnesium deficiency can occur in people with HIV and can cause headaches; supplementing with magnesium can eliminate this problem. Magnesium supplementation should not be substituted for immediate medical attention for severe or recurrent

headaches. If no other cause for your headache is found, keep the possibility of this deficiency in mind. Be aware that doses of magnesium above 350 mg per day can cause diarrhea. Magnesium glycinate may be better tolerated than other forms.

PAIN MEDICATIONS

It is important to remember that if you are treating your headache with pain medication, your choice of drugs should be made in the context of all the other factors currently affecting you, including:

- other medications you are taking, because of possible drug interactions
- medical conditions such as liver problems, which would weigh against acetaminophen (Tylenol) because it can be hard on the liver
- other medical conditions such as stomach ulcers, gastrointestinal bleeding problems, intestinal Kaposi's sarcoma, low platelets, kidney dysfunction or low serum albumin levels (common in those with wasting), which would weigh against non-steroidal anti-inflammatory drugs (NSAIDs).

Talk to your doctor about which pain medications are right for you. A drug from the class called non-steroidal anti-inflammatory drugs (NSAIDs) is one choice.

NSAIDs include ibuprofen (Advil, Motrin), naproxen (Aleve) and acetylsalicylic acid (Aspirin). Long-term use of Aspirin or other NSAIDs can cause damage to the lining of the stomach and intestines and can lead to gastrointestinal bleeding. Also, people taking tenofovir should talk to their doctors about taking NSAIDs as there is a risk of kidney injury. In general, only use these medications when you need them to relieve headaches, and avoid long-term use if possible.

Acetaminophen (Tylenol) is another common painkiller and is found in many over-the-counter medications. Because it is widespread, acetaminophen **overdose** is a concern. It is the most common cause of acute liver failure in North America, and alcohol consumption or liver disease, such as hepatitis C, can substantially increase the risk. The standard maximum

short-term dose is 3,000 mg per day (or only six extra-strength 500-mg tablets). In people who drink alcohol, liver damage may occur with consumption of only 2,600 mg of acetaminophen a day. It is strongly recommended that people who drink alcohol regularly limit their use of acetaminophen to a maximum of 2,000 mg per day. This means taking no more than two to four standard-strength pills within a 24-hour period.

Acetaminophen is also an active ingredient in many other medications, including popular headache and cold remedies such as Dayquil, Nyquil, Anacin 3 and others. It is important to read the labels of all over-the-counter medications and prescription medications very carefully in order to be certain you never take more than the recommended dose.

Some people who take acetaminophen regularly also take the supplement N-acetyl-cysteine (NAC; 500 to 1,000 mg, twice daily) to help normalize levels of the antioxidant glutathione. During acetaminophen overdose, glutathione is depleted in the liver and can lead to liver toxicity. By taking NAC whenever you take acetaminophen, you may decrease the risk of liver toxicity, although you should still *never* exceed the recommended daily limit of acetaminophen.

COMPLEMENTARY THERAPIES

Some kinds of headaches can be treated with other types of therapy, including **deep-tissue massage**, **acupuncture** or **acupressure** and herbs. The herb **feverfew**, for example, may help. It contains parthenolide, an agent that reduces spasms in blood vessels in the head. Feverfew has been shown to work for both migraines and tension headaches.

Be sure to tell your pharmacist or doctor about all the medications, over-the-counter drugs, supplements and herbal therapies you take. These products can interact with your antiretroviral drugs, causing them to become less effective or increasing the risk you will experience side effects.

Menstrual Changes

Menstrual changes may or may not be directly related to HIV disease. Any changes related to your menstrual periods should be thoroughly checked out by a primary care doctor and, if necessary, by a gynecologist. Once the source of the problem is identified, it can be treated appropriately. Even if there is no clear cause, there are many treatments to relieve symptoms associated with menstrual irregularities.



WHAT IS “REGULAR”?

For many people who have a menstrual cycle, their period occurs monthly at a predictable time, lasts for the same amount of time from one month to the next and has with a flow that they come to recognize as typical for them. Others do not have a particularly regular cycle and this irregularity is their “norm.” Most tend to develop a good sense of what is normal in terms of their menstrual cycle and can identify changes. At various times in their lives, most people with a menstrual cycle experience changes in their cycle, regardless of whether they are HIV-positive or not.

Some of these changes are considered “normal,” signalling pregnancy, menopause (the point in later life when your periods stop permanently and you are no longer able to become pregnant) or perimenopause (the period prior to menopause when changes occur in your reproductive hormones and your body transitions into menopause).

But sometimes, some changes are unexpected and may indicate a health problem. Periods may become irregular, occurring either more or less frequently than usual, and are sometimes skipped entirely. Or the menstrual flow changes, with either heavier or lighter bleeding during some periods. The amount of bleeding may not be consistent from one period to another. Some people who are not pregnant (or going through perimenopause or menopause) may have no period for a number of months, a condition known as amenorrhea. Others find that their premenstrual symptoms become more difficult than they were previously.

While many cisgendered (non-transgendered) women, as well as trans men who are not on testosterone therapy, bleed during their periods, some trans women on hormones experience a “bloodless period” characterized by regular monthly abdominal pain, cramping and other symptoms. Though the cycles of trans people are poorly understood, information in this chapter on premenstrual symptoms may be useful to you.

WHAT IS THE IMPACT OF HIV?

Early studies of HIV in cisgendered women reported a number of differences between the menstrual cycles of HIV-positive and HIV-negative women. More recent and better designed studies have more clearly identified those menstrual irregularities tied directly to HIV status. These studies seem to show that although

menstrual irregularities occur with HIV infection, they are common in the general menstruating population overall, leading to the conclusion that HIV may have less impact on menstruation than originally thought.

Studies report no significant differences in the rates of excessive menstrual pain (also called dysmenorrhea), the development of perimenopausal symptoms or the development of early menopause. However, some studies have shown an increased likelihood of missed periods (amenorrhea) and delayed periods (oligomenorrhea) in women whose HIV disease has advanced because they are not on antiretroviral therapy. In particular, one large study found that cisgendered women with CD4 counts below 200 were about 50 percent more likely to have irregular cycles with 90 days or more between periods.

FIGURING OUT THE CAUSE

Reporting any menstrual changes to your doctor is very important since these changes can indicate **health problems related to the reproductive organs**, including cervical dysplasia (early changes in cervical cells that can lead to cervical cancer), pelvic inflammatory disease or endometrial conditions. Of course, menstrual changes can also indicate pregnancy. During pregnancy, unexpected bleeding could indicate miscarriage.

Menstrual irregularities can occur as a result of various sexually transmitted **infections** or almost any serious infection, HIV-related or otherwise. Some people with HIV develop low levels of platelets (thrombocytopenia), which can contribute to heavier than normal menstrual bleeding.

Many **other health issues** can contribute to menstrual irregularities, including stress, eating disorders, hormones (not only changes in estrogen and progesterone but also in thyroid, pituitary and adrenal hormones), excessive weight loss, excessive exercise or the presence of other chronic diseases, including diabetes, kidney or liver disease and inflammatory bowel disease.

Many **medications** can cause menstrual changes, including various anticoagulants (blood thinners), narcotic pain medications, methadone/heroin, corticosteroids and others. Some of the early protease inhibitors (high-dose ritonavir (Norvir), saquinavir (Invirase) and indinavir (Crixivan)) have also been associated with increased menstrual bleeding. Because

Aspirin can thin the blood, making it less likely to clot, long-term use of high doses of Aspirin can contribute to longer, heavier periods. Some herbal supplements can copy or mimic the effects of estrogen and taking these can also result in menstrual irregularities.

A Canadian study found a higher risk of **magnesium deficiency** in people with HIV disease. Magnesium deficiency can cause many problems, including a worsening of several premenstrual symptoms. In turn, some menstrual problems can worsen other HIV-related conditions. For example, HIV-positive people have a high incidence of **anemia** (low red blood cells), and the risk is higher during menstruation because the loss of blood during this time is added to other contributing causes. Since there is already an increased risk for anemia in HIV disease, heavy bleeding should be discussed with your doctor as it can further worsen anemia. More information on anemia is found in the *Fatigue* section.

Treatment for menstrual irregularities varies depending on the problem and what is causing it. In people with **untreated HIV disease** who are not yet on antiretroviral therapy, beginning effective treatment can be very important to raise CD4 counts. Lower counts have been associated with higher risk of menstrual irregularities. Beginning antiretroviral therapy with any level of wasting will help restore weight, which may help restore normal periods.

The bottom line is that changes in your menstrual pattern should always be discussed with your doctor so appropriate tests can be done to determine the cause.

HORMONAL THERAPIES

Low levels of the hormone testosterone have been linked to HIV-related wasting syndrome. Although testosterone is usually thought of as a male hormone, cisgendered women's bodies also produce it in smaller amounts. Researchers tested a daily testosterone skin patch on a small group of cisgendered women with wasting syndrome and low testosterone. The dose used was just enough to bring their testosterone levels up to normal. Six of the women had no menstruation before they took part in the study. After 12 weeks of treatment, periods returned in five of the six women.

For irregular periods, the use of birth control pills to help restore regularity and reduce heavy bleeding may be recommended. Hormone replacement therapy is sometimes recommended during perimenopause

or early menopause, especially when symptoms are very severe. Because of concerns about the possible risks of cancer with long-term hormone replacement therapy, short-term use for the specific relief of symptoms is preferred. Any hormone replacement therapy should be thoroughly discussed with your doctor. Possible interactions with other medications also need to be discussed.

PREMENSTRUAL SYMPTOMS

Physical and emotional symptoms can develop during the week leading up to your period and can continue throughout it. Although almost all people who menstruate experience some degree of premenstrual symptoms, many people with HIV have reported increased and more intense symptoms. There are many remedies for relief of premenstrual symptoms; you may have to try several different ones before finding something that works for you.

The good news is that it is possible to greatly decrease or even eliminate premenstrual symptoms. Whatever approaches you decide to take, it is helpful to keep a diary of how you feel, both emotionally and physically, before you start anything new and for several months afterward. This can help tell you what's working and what isn't so you can choose the elements of your approach more wisely.

EXERCISE AND DIET

Regular physical **exercise** can help to relieve premenstrual symptoms. A regular exercise program is an important part of a healthy lifestyle; if exercise is not currently part of your lifestyle, knowing that it can help reduce premenstrual symptoms can be a reason to add it.

Many experts recommend cutting down or cutting out caffeine, sugar, salt and alcohol to help with premenstrual symptoms. Reducing **salt** in the diet has been shown to help cut down on water retention and the sensation of being uncomfortably bloated. It can be difficult to find salt-free foods, but by cooking from scratch, looking for salt-free foods and reading the labels on food packages for sodium content, it is possible to reduce the daily salt content of your diet.

Cutting back on **caffeine** can also help since caffeine can increase the anxiety and irritability associated with premenstrual symptoms. Remember that caffeine is found not only in coffee and tea, but also many soft drinks, chocolate and many over-the-counter

medications. **Alcohol** has also been shown to worsen headaches, fatigue and depression in people with premenstrual symptoms. If alcohol is part of your lifestyle, cutting it out during the premenstrual week can be helpful.

Research has found that consuming a combination of **carbohydrates** results in an increase in serotonin (the brain's "happiness" chemical) and can help to reduce tension, depression and anger in people suffering those premenstrual symptoms. Any combination of foods that raises the blood levels of **tryptophan** will work because tryptophan stimulates the production of serotonin. High-carbohydrate foods, such as whole-grain toast or hot cereal, as well as protein foods that are high in tryptophan, such as dairy products and turkey, will raise serotonin levels.

Adding carbohydrate-rich snacks for a few days before or during your period can sometimes help lessen the emotional distress that can accompany periods. However, if you add these carbs day after day, weight gain can occur unless you increase your level of exercise. Don't forget to speak to your doctor about persistent emotional problems and safe ways of finding relief from them.

SUPPLEMENTS

Several micronutrient supplements can be helpful with premenstrual symptoms.

Magnesium can help some people reduce or eliminate painful cramping. It can also be useful to counter irritability and moodiness. A safe dose to start with is 250 to 350 mg per day. Higher doses can cause diarrhea, but may be needed for effective relief. Magnesium glycinate may be better tolerated than other forms.

For painful or swollen breasts/chest, **vitamin E** is often very useful. A daily dose of 800 to 1,200 IU taken the week before your period starts and during your period may reduce symptoms. The dosage required to counter these symptoms varies from person to person, so speak to a naturopathic doctor. Be sure your supplement contains the full range of compounds (called mixed tocopherols) that belong to the vitamin E family.

The supplement **5-hydroxytryptophan (5-HTP)** is related to tryptophan (mentioned above under "Exercise and diet") and converts directly to serotonin.

See *Sleep Problems* for a discussion of 5-HTP. It can help relieve the emotional symptoms of the premenstrual period. It is important to take 5-HTP with vitamin B₆ because this vitamin is deficient in many people with HIV and is used to convert 5-HTP to serotonin. Many 5-HTP products contain vitamin B₆. However, 5-HTP should *not* be taken by people also taking medicines for treating depression or anxiety.

A daily supplement of **vitamin B₆** can help reduce water retention and bloating. It should be taken along with a B complex supplement to help keep B vitamins in balance. It also seems to help reduce moodiness associated with premenstrual symptoms.

Gamma-linolenic acid (GLA), found most cheaply in borage oil supplements as well as in evening primrose oil supplements, may help with breast/chest pain, bloating and emotional symptoms such as irritability and depression. A dose of 240 mg, twice daily, is a common recommendation from naturopathic doctors to reduce premenstrual symptoms.

According to a 1991 study, women who consumed 1,300 mg of **calcium** daily in foods like milk or yogurt reported an easing of symptoms such as water retention and moodiness. Since the average person gets only 550 mg daily from their diet, temporary supplementation may be useful. However, before taking calcium supplements, it may be best to try and eat more calcium-rich foods. If this is too difficult, speak to your doctor about your calcium needs.

HERBS

Herbs like **black cohosh**, **raspberry root** or **rue** can help relieve premenstrual symptoms in some people. However, some herbs can interact with various medications. Before starting any herbal therapies, consult a naturopathic doctor or herbalist in addition to your doctor and a pharmacist highly knowledgeable about HIV.

OVER-THE-COUNTER AND PRESCRIPTION DRUGS

Naproxen (Aleve, Anaprox), mefenamic acid (Ponstan) and ibuprofen (Advil, Motrin) are **anti-inflammatory drugs** that relieve cramps and can reduce premenstrual symptoms. They are available over the counter from your pharmacist. Talk to your doctor about using these sorts of drugs, especially if you are taking tenofovir (Viread and in Truvada, Atripla, Complera and Stribild) as there is a risk of kidney injury.

As well, several prescription drugs are sometimes recommended for severe emotional symptoms associated with your period. Some antidepressants can improve mood swings, irritability and depression by boosting serotonin levels in the brain. These medications have the potential for serious side effects so be sure to discuss your options thoroughly with your doctor.

DRUG INTERACTIONS

Make sure you discuss your use of any products, including multivitamin-mineral supplements, herbal and other complementary therapies, over-the-counter products and prescription drugs, with your doctor and pharmacist before taking them. Some products can interact with HIV medications and lead to increased side effects or cause the antiretroviral drugs to be less effective. Mineral supplements, including calcium and magnesium, may need to be taken separately from certain drugs. Speak with your pharmacist and doctor to understand how best to take all your medications and health products.

Mouth and Throat Problems

It is important to pay attention to the health of your mouth, teeth and throat. Problems in this area can be a sign of a more serious infection or underlying condition. In addition, they can cause pain, make it difficult to eat properly or to take your medications. Tell your dentist and doctor about any mouth or throat problems you have. This section describes mouth and throat problems in people with HIV, with an emphasis on common problems, including canker sores, dry mouth, taste alterations, dental problems and periodontal disease.

FIGURING OUT THE CAUSE

There are a number of causes of mouth and throat problems, including infections, antiretroviral drugs and other medications, nutritional issues, oral cancer or other medical conditions and poor dental hygiene. A trip to a doctor or dentist is needed to determine the cause. Developing a treatment plan will depend on the specific problem. Below we discuss common issues such as infections, canker sores, dry mouth and dental problems. Most of the time, once the underlying issue is resolved, the mouth problem clears.

Note that changes in the mouth can be a sign of a rare but serious allergic reaction to a drug. The reaction, called Stevens-Johnson syndrome, usually develops within two weeks of starting a new drug, including some antiretroviral drugs. This reaction results in rash, fever, nausea and other allergy-like symptoms accompanied by tingling, inflammation and blisters in the nose or mouth or on the lips. This reaction is very serious and potentially fatal. The section *Rash and Other Problems of the Skin, Hair and Nails* has additional information on this reaction. A person experiencing these symptoms should seek medical care right away.

INFECTIONS

In people with HIV who are not on antiretroviral therapy, mouth problems — and more specifically mouth ulcers — can be a sign of a weakening immune system that has left them vulnerable to an **opportunistic infection** or other condition. Opportunistic infections and conditions that can

affect the mouth include Kaposi's sarcoma, oral and esophageal candidiasis (commonly called thrush), hairy leukoplakia and mouth or throat ulcers caused by herpes simplex or cytomegalovirus (CMV). More rarely, mouth lesions can be caused by *Mycobacterium avium* complex (MAC) and oral fungal lesions can be associated with histoplasmosis, geotrichosis or cryptococcus.

People with these infections require immediate attention and need to start antiretroviral therapy. Antiretroviral therapy allows the immune system to rebuild itself, at least partially, resulting in a dramatic decrease in the risk of these infections.

Other mouth and throat infections and conditions can occur in people with HIV **regardless of CD4 count**. These include herpes simplex, which causes painful cold sores on the lip or ulcers on the palate, and herpes zoster, which is the cause of chicken pox and shingles. Shingles can cause pain and multiple lesions on one side of the mouth, with the mouth pain lingering long after the initial lesions have healed.

Human papilloma virus (HPV, the cause of warts), bacteria — either an overgrowth of bacteria normally found in the mouth or newly introduced bacteria — and lymphoma can also cause mouth and throat conditions. Some **sexually transmitted infections**, including chlamydia, gonorrhea and syphilis, can also infect the mouth or throat and produce sore throat, tonsillitis or oral ulcers. Some of these lesions, especially with primary syphilis, are not painful, making them easy to miss. Proper treatment of such infections or conditions is key to clearing up these mouth or throat problems.

CANKER SORES

Mouth sores such as **canker sores** (also called aphthous ulcers) are common and usually form on the soft pinkish-red tissue inside the lips and cheeks and on the bottom or sides of the tongue. It is thought that the hyperactivity of the immune system in HIV disease can contribute to the development of these painful sores. Antiretroviral treatment counters this hyperactivity, so very severe forms of canker sores are less common today than in the past. It can be helpful for people who are experiencing recurrent, severe canker sores and who are not on antiretroviral therapy to begin such treatment. The antiretroviral drug saquinavir (Invirase) can cause mouth ulcers, but it is not commonly used nowadays.

Certain **micronutrient deficiencies**, specifically in iron, zinc, niacin, folate, glutathione, carnitine and vitamin B₁₂ can occur in people with HIV and can predispose them to canker sores. Regular use of a potent multivitamin mineral formula can help prevent most of these deficiencies. Glutathione deficiency can be countered with 600 mg of N-acetyl-cysteine, taken three times daily with meals. The most efficient way to boost carnitine levels is the use of acetyl-L-carnitine (500 mg, three times daily with meals). Note that this nutrient is seldom included in multivitamins. See the appendix on vitamin B₁₂ for more information about this key vitamin for people with HIV.

Consuming too many **acidic foods** can cause canker sores in some people. Cutting back on tomatoes and products made with them, citrus fruits and their juices, coffee, pickled products, vinegars and other acidic foods can help. Canker sores can also be caused by local injury to the mouth, such as when you accidentally bite the inside of your cheek or tongue. There may also be a genetic link since canker sores are more likely to occur in people from families where they are common. **Emotional stress** and lack of sleep are also known to cause canker sores. Some people find they occur more often at certain times during their **menstrual cycles**.

TREATING CANKER SORES

As a first step, many people treat canker sores simply by rinsing their mouth with salt water several times a day. The rinse is gargled in the mouth for one to two minutes then spit out before repeating one or two times. Although canker sores will usually go away

on their own within a week to 10 days, topical and oral treatments are available when the sores are frequent or cause significant pain or difficulty eating. Don't be afraid to raise the issue of ongoing canker sores with your doctor.

The use of **topical corticosteroid creams and gels** is the most common treatment for canker sores. These work by suppressing the immune activation that contributes to the development of these lesions. Such products must be used carefully, however, since the resulting localized immune suppression can lead to an increased risk of oral infections.

As long as the sores remain, **topical anesthetic sprays** can be used to numb the area and lessen pain when eating or swallowing. A **mouth rinse** consisting of viscous lidocaine, Benadryl elixir, and nystatin can help eliminate the pain of mouth sores. This rinse is prepared by a pharmacist. An opiate painkiller is sometimes added if the ulcers are particularly painful. If the lesions are only in the mouth cavity, this rinse can be swished and gargled for the two minutes, then spit out. If the lesions extend down into the throat, it can be used as a "swish and swallow" agent, rinsing it around the mouth for a couple of minutes and then swallowing it.

Dexamethasone, a corticosteroid, can also be added to the mixture. But before treatment with dexamethasone is begun, it is important to make sure the lesions are *not* caused by herpes viruses or other infections that could worsen with use of a steroid agent. If dexamethasone is added to the rinse, it is better not to swallow the mixture but to spit it out after the two-minute gargle. This will avoid the possible immune suppression that such a steroid agent could induce.

Another rinse sometimes used is called **Miles mixture**. It consists of hydrocortisone, nystatin and tetracycline. This mixture should not be swallowed, since hydrocortisone also suppresses the immune system. Some doctors and pharmacists have found that brushing the colouring agent **gentian violet** over mouth sores is a useful treatment. Again, it is important to be sure these sores are not caused by fungi or viruses.

For people with very serious canker sores that recur frequently, thalidomide has been shown to be effective. Thalidomide has serious side effects, including severe birth defects if taken during pregnancy. It should only be used under the close care of a doctor.

DRY MOUTH

Decreased saliva production resulting in dry mouth can develop as a side effect of medications, changes in salivary gland production, dehydration or radiation or chemotherapy used to treat cancers. Medications known to decrease saliva production include antidepressants, antihistamines, many opioid painkillers, foscarnet (used to treat cytomegalovirus) and the antiretroviral drug 3TC (lamivudine, also in Combivir, Kivexa and Trizivir). The chance of developing dry mouth increases with the number of different medications a person takes.

Saliva protects tooth enamel, so any decrease in saliva production can result in increased tooth decay. Normal saliva flow helps protect the lining of the mouth, so decreased saliva production makes mouth lesions more likely. It can also make eating and swallowing difficult.

TREATING DRY MOUTH

Drinking lots of water can help with dry mouth, especially if you are dehydrated. However, when there is seriously decreased saliva production, especially due to salivary gland damage caused by radiation treatment, drinking water may not help. When saliva production has been decreased by radiation or chemotherapy, the prescription medication pilocarpine can stimulate saliva production. The herb prickly ash bark has been shown to increase salivary production. It is often sold as a tincture, and a common dose is five to 10 drops placed under the tongue before meals. Herbal bitters can also help increase saliva production.

If your saliva production cannot be returned to normal, there are **saliva substitutes** that can be used to moisten the mouth. These products can moisten the mouth and throat for one to two hours, making swallowing or chewing much easier. One study found that Mouth Kote was the most effective of these products. It is available over the counter, has no side effects and is naturally sweetened with xylitol. There are also chewing gums available that can help to increase saliva production and toothpastes for people who have dry mouth.

Dentists usually recommend the use of topical fluorides and very careful dental hygiene to reduce the development of cavities in people with long-term saliva deficiency. Moistening food is also helpful for those with dry mouth.

DENTAL PROBLEMS, PERIODONTAL DISEASE AND GINGIVITIS

Some people with HIV may develop dental problems, including **periodontal disease** (inflammation in the tissues surrounding the teeth), **gingivitis** (inflammation of the gums, indicated by a red line where the gums meet the teeth or a generalized reddening of gum tissue) and **accelerated tooth decay**. It is very important to prevent such problems when possible, or treat them effectively when they occur. They can worsen if left untreated, causing pain and difficulty in chewing, bad breath and bleeding or sore gums.

Brushing and **flossing** your teeth is an obvious step for preventing dental problems and can help with some problems such as gingivitis. However, brushing and flossing will not usually resolve severe problems. When brushing your teeth, brush every tooth surface thoroughly, as well as the tongue. If your tongue or any area around your teeth is too sore to brush with a regular toothbrush, you can use one of the disposable foam sticks available in pharmacies for cleaning these areas.

TREATING DENTAL PROBLEMS

The first step in resolving gum and dental problems is usually a **professional tooth cleaning**, which removes tartar above and below the gum line. Dentists usually also recommend the use of **antiseptic mouthwashes**. Sometimes they also prescribe a short course of antibiotics to get rid of bacteria in the mouth.

If minor gum problems are not resolved, they can progress to more serious periodontal disease. The bone that holds the teeth in place can be damaged, as well as the fibres that hold the gums to the root of the teeth. Symptoms of more serious periodontal disease can include bleeding gums, loose teeth, bad breath and even tooth loss. In some people, a condition called HIV periodontitis may develop. This condition involves serious inflammation, rapid deterioration of the tissues surrounding the teeth, and very rapid loss of bone around the teeth.

There are certain **nutrient supplements** that may be very helpful with gum and periodontal problems. These include coenzyme Q₁₀ (CoQ₁₀), bioflavonoids, vitamin C and vitamin D. **CoQ₁₀** has long been used

in Japan as a treatment for periodontal and gum problems with considerable success. Since levels of CoQ₁₀ can be low in people with HIV, this nutrient deficiency may be a factor in the development of periodontal problems. CoQ₁₀ supplements, in doses of 100 to 300 mg daily, may help to prevent or resolve gum and periodontal problems. **Vitamin C** is needed for healthy gums, and bioflavonoids such as **quercetin** have capillary strengthening qualities that might reduce gum bleeding. Vitamin C taken to a maximum of 2,000 mg per day, the upper tolerable limit, and quercetin taken in doses of 500 mg, twice daily, may be helpful in maintaining oral health.

ALTERED TASTE

Antiretroviral drugs and other medications can sometimes cause abnormal tastes, dry mouth or mouth lesions. Antibiotics such as clarithromycin (Biaxin), azithromycin (Zithromax, Zmax) and metronidazole (Flagyl) can cause a metallic taste or sensation in the mouth. A number of antiretroviral drugs can also cause abnormal taste, including Kaletra (lopinavir/ritonavir), ritonavir (Norvir) and indinavir (Crixivan). These changes may diminish over time, or they can last for weeks or months even after the drug is stopped.

If altered taste is a problem, try the following:

- Use plastic utensils to decrease a metallic taste.
- Use sugar-free gum and candies to cover up a bitter taste.
- Talk to your pharmacist about tips to deal with medicines that alter taste.

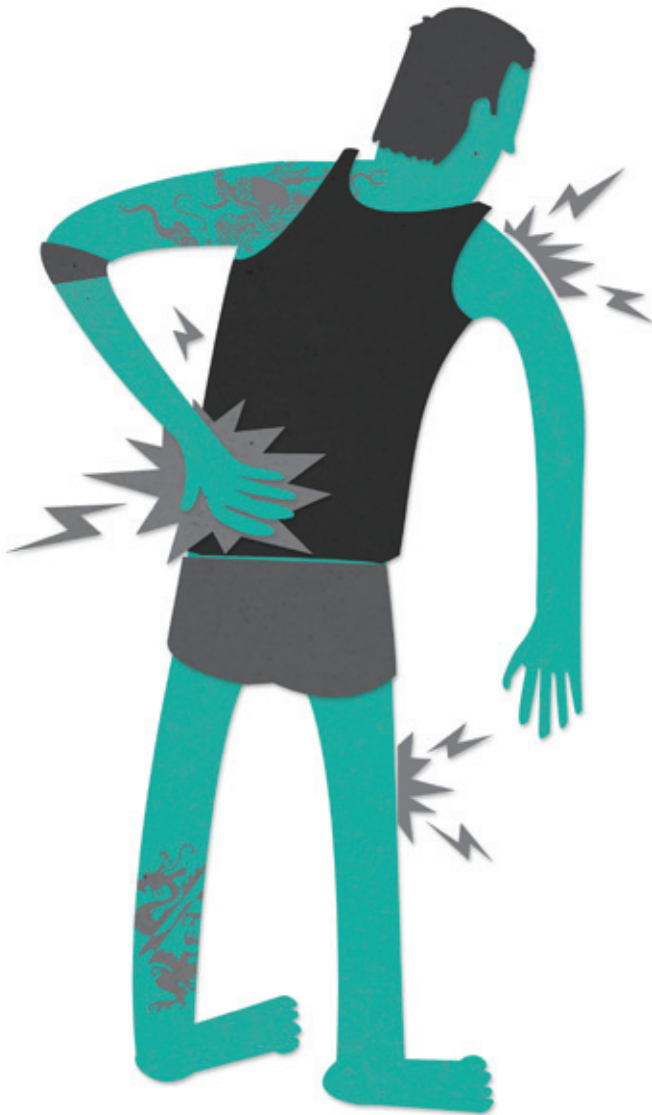
TIPS FOR DEALING WITH PAINFUL CHEWING

The mouth and throat problems described in this section can cause painful chewing or difficulty swallowing. Here are some practical tips that can help you to adjust your diet if you experience pain when eating, drinking or swallowing:

- Try foods that are soft and smooth in texture; they are easier to eat. Remember that you can mash or blend many foods, even if that's not how you would normally eat them. A food processor can give almost any food a smooth consistency. Commercial baby food is already well blended and comes in a wide variety. You can make an easy-to-drink breakfast or snack by blending a mixture of non-acidic fruits with milk and protein powder.
- Moistens foods. Add gravies or sauces to food before eating, or mix them into a soup base. Soak breads and cookies in liquids before you eat them. Take sips of a beverage with every bite of food.
- Avoid citrus fruits, tomato products, pickles, coffee and vinegars because their acidity can irritate mouth lesions.
- Avoid highly seasoned or peppery foods.
- Avoid carbonated beverages if they irritate the mouth or throat.
- Avoid foods that are hard or salty, such as certain raw fruit and vegetables, chips, popcorn or salted nuts.
- Avoid foods that stick to your mouth, such as peanut butter.
- Avoid hot foods and liquids. Room-temperature or cold foods and liquids are often less irritating.
- Use a straw to drink liquids.
- Try to avoid smoking and alcohol since both irritate tissues in the mouth.
- Limit or avoid sweets if thrush (*Candidiasis*) is a problem, as this fungus thrives on sugar. If you do consume sweets, clean your mouth well afterwards.

Muscle Aches and Pains

Muscle aches and pains are common, especially as we age, but they can be a sign of something that needs medical attention. Tell your doctor about ongoing muscle pains; they can be very serious. This section examines the possible causes of muscle aches that can develop in people with HIV and offers complementary treatment options.



FIGURING OUT THE CAUSE

Everyone has the occasional muscle ache, especially as they age. And many people who exercise or play sports know the benefits of stretching to counteract muscle tightness that comes with physical activity. But people with HIV can experience more serious muscle conditions, including muscle pain, muscle cramping and muscle disorders that result in weakness. The pain often involves the back, hips or lower limbs.

In order to distinguish between minor and more severe muscle problems, it is very important to visit your doctor when any muscle problems develop. This is not a time for self-diagnosis. Your muscle problem could be something relatively minor, but it could also be the result of a serious problem only a doctor can properly diagnose.

Tell your doctor about any muscle weakness, aches or pains you develop so that a proper workup can determine the cause. In particular, it is very important to rule out any neurologic diseases (whether related to HIV or not) that could be causing your symptoms.

MYOPATHY

Myopathy is a muscle disorder that results in weakness, often leading to musculoskeletal pain involving the back, hips or lower limbs. Myopathy can be caused by:

- AZT (Retrovir, and in Combivir and Trizivir), d4T (Zerit) and other nucleoside analogues
- lipid-lowering drugs (statins)
- vitamin D deficiency
- essential amino acid deficiencies
- testosterone deficiency
- neurological problems.

In rare cases, the use of integrase inhibitors, including raltegravir (Isentress), elvitegravir (in Stribild) and dolutegravir, can lead to fatigue and muscle weakness.

Changing or stopping a problematic drug can solve muscle problems related to that drug. However, this may not be an option when the medication causing the problem is needed as part of your antiretroviral combination.

Although Aspirin and other over-the-counter pain medicines such as acetaminophen (Tylenol) can help counter muscle aches and pains, they don't really solve the underlying cause of muscle problems (see the warnings about these medications in the *Headaches* section).

LACTIC ACIDOSIS

It is also important to rule out lactic acidosis, a problem that can be caused by some nucleoside analogue medications, particularly d4T. In Canada, d4T is not commonly prescribed. For more info about lactic acidosis, check out the section *Less Common Side Effects*.

AMINO ACID SUPPLEMENTS

Amino acid deficiencies can sometimes be the underlying cause of muscle weakness. Muscle is mostly composed of protein and protein is made up of amino acids. Thus, essential amino acid deficiencies can cause muscle weakness. Deficiencies sometimes result from poor protein digestion. Gas or bloating after meals can be a sign of poor protein digestion, so if this is an ongoing problem for you and you are experiencing muscle weakness, talk to your doctor about the possibility of amino acid deficiency. In some cases, a supplement that includes all of the essential amino acids can help reverse muscle weakness.

Look for a supplement that contains all eight **essential amino acids**: isoleucine, leucine, lysine, methionine, phenylalanine, threonine, tryptophan and valine. The total daily requirement for essential amino acids is a minimum of 50 to 60 grams daily, though this varies based on your weight and activity levels. You will get a lot of this from the food you eat if you have good digestion. However, in order to bring your level back up to optimal and help reverse muscle weakness, you may

need to take five to 10 grams daily of an essential amino acid supplement. Talk to a health professional about what dose is right for you. It can take several weeks to notice a change, but if you don't see any improvement in muscle strength within three to four months, then amino acid deficiency is probably not the problem causing your muscle weakness.

Glutamine is a specific amino acid often deficient in people with HIV. Glutamine is involved in many aspects of healthy body function, including maintaining antioxidant levels, building and maintaining muscle tissue, strengthening immune function and repairing and maintaining intestinal tissue. Although glutamine is classified as "non-essential," meaning the body can normally synthesize what it needs, it may be deficient in some people with HIV. The deficiency can result in both muscle weakness and actual wasting away of muscle tissue.

Glutamine researcher Dr. Judy Shabert recommends at least five to 10 grams of glutamine daily to maintain optimal levels in HIV disease. People with HIV who have muscle wasting will have depleted glutamine stores since it is found mostly in the muscles. In these cases, Shabert recommends up to 30 to 40 grams daily. Glutamine is available in powdered form and is best mixed into water or juice and taken on an empty stomach (at least a half hour before eating), with the total daily dose divided into at least three doses.

Research has shown that doses of the amino acid **L-carnitine** can help with myopathy. In these studies, 3,000 mg daily of L-carnitine usually reversed the myopathy and left people taking it feeling substantially better. L-carnitine may help to reverse the mitochondrial toxicity caused by nucleoside analogues. (For a more complete discussion of mitochondrial toxicity, refer to the section *Body Weight and Body Shape Changes*.)

A more effective form of L-carnitine is **acetyl-L-carnitine**. The usual dosage is 500 mg taken three times daily with meals. Doses of acetyl-L-carnitine can be lower than doses of plain L-carnitine because the acetyl-L-carnitine releases four times as much free carnitine into the bloodstream using equivalent doses. But be careful about taking too much carnitine: it can cause diarrhea.

VITAMINS

Vitamin D supplements may be helpful in some people with muscle weakness and associated pains. Multiple studies in HIV-negative people have shown that deficiency of vitamin D can cause serious muscle weakness and associated musculoskeletal pain involving the back, hips or lower limbs. Several studies have shown that vitamin D deficiency is a common problem in people with HIV, so it is very important to consider vitamin D deficiency in anyone who has developed muscle weakness and pain.

The link between vitamin D deficiency and muscle problems and pain is not known by all healthcare professionals. For this reason, talk with your doctor about having your vitamin D level tested, and then consider taking vitamin D supplements. The cost of the test may not be covered by all provincial or territorial healthcare plans or may be covered only in certain situations. Check with your doctor for availability in your region. For more information, refer to the appendix on vitamin D.

Magnesium supplements can sometimes help relieve muscle problems, especially muscle cramping. If you have recurrent muscle cramps or the Charley horse type of cramping in your calf muscles that can occur during sleep, magnesium deficiency may be the cause. Constipation is another symptom that points to the possibility of magnesium deficiency. Painful menstrual cramping is another indicator. Any combination of such symptoms indicates you may need magnesium supplementation.

Because individual needs can differ widely, you will have to experiment to see what dose of magnesium solves your problems. Naturopathic doctors often suggest starting with a dose of 250 to 350 mg daily taken with food. People who are at risk of having too low levels of magnesium and who are also taking calcium supplements often take the two supplements at different times of the day, since calcium can block the absorption of magnesium.

If the initial dose is insufficient to resolve muscle cramping, then try gradually increasing the amount you take. If you take too much magnesium you will get explosive diarrhea, so watch for this as a sign you are taking too much. Magnesium glycinate may be better tolerated than other forms. Epsom salts, which contain magnesium, dissolved in a hot bath may also help ease muscle pain and cramping.

Nausea, Vomiting and Appetite Loss

Nausea or vomiting can make it difficult to get through day-to-day life. When nausea leads to repeated vomiting, it can cause serious health problems. Vomiting can also result in less than ideal levels of antiretroviral drugs in your bloodstream and the possibility of drug resistance. For all these reasons, it is important to control ongoing nausea and vomiting as quickly as possible. Appetite loss can substantially contribute to malnutrition, weight loss and wasting, and it can be difficult to overcome.



FIGURING OUT THE CAUSE

Nausea, or feeling sick to your stomach, is something everyone feels sometimes. It can also lead to vomiting, or throwing up. Sometimes it passes after a few hours or within a day. When nausea causes repeated vomiting over time, it can result in serious malnutrition, dehydration and imbalances in some of the normal chemical compounds, called electrolytes, in the blood.

Appetite loss, or not feeling the urge to eat, can accompany nausea, but it can also occur on its own. It may be harder to notice, but it can be even more serious when it leads you to not consume enough nutrients to maintain your health.

Keeping notes that detail your problems can help your doctor know how to successfully address them.

Keep track of:

- How often you feel nauseated each day, how long the nausea lasts, and whether you vomit on any of these occasions. If the feeling persists through much of the day, note this. Also keep track of how many days of the week the nausea occurs.
- Any pattern you notice about when nausea occurs. Does it occur when you first wake up, after you take your medications, when you smell food, when you begin eating, after meals, or in response to anything else you can identify?
- Any ways that nausea changes how or when you take your HIV medications. Do you end up skipping doses of your antiretroviral drugs or other medications because you feel too nauseated to take them? Do you have difficulties keeping down your medications because of vomiting? If so, how often does this occur?
- Everything you eat and drink over the course of a few days. This can help you and your doctor assess whether your total intake of calories and nutrients is sufficient for optimal health.

While medications can cause nausea, vomiting or appetite loss, there are other things that can also cause these symptoms. Your doctor should run blood tests and carry out an overall medical workup to see if liver problems, infections, hormone deficiencies or other medical conditions are contributing to your nausea or appetite loss. There are many possible causes for these symptoms; often, more than one factor will be contributing to them.

Not all doctors approach the problems of nausea, vomiting and appetite loss aggressively. If you feel your symptoms are not being effectively managed, tell your doctor

they are seriously affecting your life and your ability to eat a healthy diet. Emphasize that the search for a cause or causes of your symptoms must continue.

INFECTIONS

Appetite loss and nausea can be caused by infections. Almost any infection can result in decreased appetite, along with fever, fatigue and generally feeling lousy. Nausea can be caused by certain infections, including many common bacterial and viral ones. The organisms that cause food poisoning will often cause sudden and sometimes severe nausea, so food poisoning should always be considered.

Some infections and cancers that can also cause nausea in people with HIV include *H pylori* gastritis, secondary syphilis, cryptococcal meningitis, cryptosporidiosis and other parasitic infections, viral hepatitis, *Mycobacterium avium* complex (MAC), severe toxoplasmosis and lymphoma. Some of these are uncommon in people whose HIV is well treated, but it is always important to consider the possibility that an infection is contributing to nausea and appetite loss, and take all necessary steps to diagnose and properly treat it.

ANTIRETROVIRAL DRUGS, OTHER MEDICATIONS AND SUPPLEMENTS

Nausea is a common side effect of antiretroviral drugs, pain medications, cancer chemotherapies, radiation and many other therapies. Virtually all the currently available **antiretroviral drugs** can cause nausea, though some (for example, protease inhibitors) are more likely to cause this problem than others. It is also one of the symptoms of the rare abacavir hypersensitivity reaction. See the section in *Less Common Side Effects* for more information.

Drugs used to treat many infections can cause nausea. One nausea-causing drug that people with low CD4 counts can be taking is the antibiotic **Bactrim/Septra**, used to prevent *Pneumocystis* pneumonia and some other germs. Most people tolerate this drug well, but some people develop significant nausea and may need to switch to a different preventative drug.

Pain medications cause nausea in a large percentage of people. If these drugs are possibly contributing to your nausea or appetite loss, discuss possible alternatives with your doctor. Cancer chemotherapies and radiation can also cause very severe nausea and it is very important to address this in order to continue to treat the cancer.

Some people experience nausea from certain **supplements**, such as fish oil. This can be more common if the supplement is taken on an empty stomach. Pharmacists advise people to watch for side effects when they start a supplement and not to begin taking a new supplement when they are changing any other medication.

LIVER PROBLEMS, PANCREATITIS, TESTOSTERONE DEFICIENCY, DEPRESSION

Testing to assess the possibility of **liver problems** is important in determining the cause of nausea and appetite loss. If tests show the possibility of liver damage, therapies to support the liver and reverse damage or prevent its worsening are important to counter nausea and appetite loss.

People with HIV are at an increased risk of developing **pancreatitis**, and this risk may be higher when people take certain medications or drink a lot of alcohol. If severe abdominal pain starts suddenly and accompanies nausea and vomiting that lasts several hours, especially after eating or an alcohol drinking binge, pancreatitis is a possibility. These cases need immediate medical care. For more information on this serious condition see the section *Less Common Side Effects*.

Testosterone deficiency is common in both men and women with HIV and can lead to decreased appetite. It is important to have your testosterone level tested for many reasons. If testing shows your levels to be low, testosterone replacement may improve your appetite. For a full discussion, see the section on hormone changes in the *Emotional Wellness* section.

Depression occurs in some people with HIV and, when present, frequently causes appetite loss. If depression is a problem for you, it is very important to get the treatment you need. For a full discussion, see the section on *Emotional Wellness*.

CHANGING YOUR MEDICATIONS OR YOUR MEDICATION SCHEDULE

If the nausea or appetite loss you are experiencing appeared just after you began taking a **new medication**, your drug is a possible cause of your symptoms. If the problem doesn't improve over the next few weeks, talk to your doctor about it. In many cases, these side effects diminish or disappear after a short time on the medication, so it may be worthwhile to stick it out rather than immediately stopping

or switching drugs. Remedies that can help with short-term nausea or appetite loss, including anti-nausea drugs, are listed later in this section.

Another factor to consider is the **timing** of your medication. Consult your doctor or pharmacist to determine whether taking your drug at a different time of day could help. Some drugs cause less nausea when taken with a full meal; others should be taken on an empty stomach.

CHANGING YOUR EATING HABITS

To cope with ongoing nausea or appetite loss, try changing your **eating habits**. Eat on a schedule and substitute smaller meals and frequent small snacks for three big meals. Allowing your stomach to remain empty for too long tends to increase nausea. This approach will also help prevent low blood sugar, which can worsen nausea. Even if you don't feel hunger pangs by the next scheduled meal or snack, do the best you can to eat at that time. Anything that perks up your appetite and doesn't make you feel nauseated should be tried. For example:

- Try different seasonings or sauces to find one that improves the taste of food without creating nausea.
- Ginger can be very useful for helping to control nausea. Powered ginger in capsules, ginger ale (made from real ginger), ginger tea or candied ginger can all be helpful.
- Lemon can suppress nausea, so before a meal slice a fresh lemon and sniff it for a minute or two. Or drink water with lemon in it before eating.
- If you have more appetite or less nausea at certain times of day, try to eat then, and put the focus on nourishing foods so that every bite counts.
- Smells can sometimes trigger nausea and cold foods generally have less smell, so try making a meal out of cold foods.
- Sip liquids through a straw in order to limit their smells.
- If cooking smells trigger nausea, try to stay away from the kitchen when food is been cooked; open windows and turn on fans to blow cooking odours away.
- Keep tasty snacks around so that any moment of appetite can be used to your advantage.
- Use dry and/or salty foods like crackers, bread or toast, to calm the stomach.
- Protein foods can improve nausea and sweet foods can sometimes worsen it, so avoid sweet foods at breakfast. Instead, start your day with a small amount of protein such as a hard-boiled egg or leftover chicken.

- Sip cool beverages such as juice, or carbonated beverages such as fruit juice spritzers. Some people find carbonation can worsen nausea and can prefer flat or non-carbonated drinks; try both to see what works for you.
- Chew food thoroughly so the stomach can handle it more easily.
- Avoid spicy foods, fried foods, high-fat meats, sauces or gravies, sour cream, caffeine-containing beverages and alcohol.
- Eat bland foods like broth, miso soup, mashed potatoes, rice, oatmeal, toast, naan or plain yogurt.
- Eat sitting up and try to remain in an upright position for at least two hours after eating. This can help reduce the tendency to vomit.

If you experience recurrent vomiting, it is very important to rebalance your electrolytes. See the suggestions in the section *Diarrhea, Gas and Bloating*.

COUNTERING NUTRIENT DEFICIENCIES

Ongoing nausea or appetite loss can lead to a vicious cycle where reduced food intake results in inadequate levels of nutrients. That lack of nutrients creates malnutrition-induced appetite loss, which results in continuing reduced nutrient intake. When this cycle occurs, it is necessary to restore your body's nutrient levels to normal. The solution usually involves a combination of appetite boosters, high-nutrient foods and supplementation.

A **multivitamin mineral** supplement can help make up for not getting enough micronutrients. If nausea makes taking pills difficult, liquid multivitamins are an option. The micronutrient deficiency most known for causing appetite loss is zinc. Although zinc is contained in most multivitamins, you can restore levels more quickly by adding it as a separate supplement (75 mg daily, taken with any meal). People often add a copper supplement (5 mg daily, taken at a different meal) to reduce the risk of heart problems. However, too high levels of copper can lead to liver damage, so talk to your doctor before starting a copper supplement.

Drinking a **liquid meal** may seem a lot easier than eating one. Try a home-made blended soup or a nutrient-rich, high-calorie smoothie. Experiment by blending together the following ingredients:

- Regular milk or rice or coconut milk plus non-acidic fresh fruits like banana, apple, peaches or blueberries
- Coconut oil or nut butter, if you need more calories
- Vanilla or other natural flavorings for variety

- Frozen fruit (instead of fresh) or ice, if you like an icy smoothie
 - High-quality protein powder, if you need more protein
- Among the best of the available protein powders are the whey protein products. Just don't overdo protein powders. Remember that too much protein can actually strain the kidneys and cause diarrhea.

If you don't want to create your own supplement, look for supplemental drinks that are low in sugar, use predominantly medium chain triglycerides (MCTs), are moderately high in good-quality protein and high in calories overall.

Check out CATIE's *A Practical Guide to Nutrition* for more suggestions.

ANTI-NAUSEA AND APPETITE-STIMULATING DRUGS

When all of the above suggestions fail to resolve your problems with nausea or appetite loss, it is very important to discuss with your doctor or pharmacist the use of medications to counter them.

The most commonly used drug in Canada for nausea, even in hospital emergency rooms, is **dimenhydrinate** (Gravol and its generic equivalents). You may find you can get effective relief from mild to moderate nausea with a children's dose of Gravol rather than the adult dose. The children's dose also helps to avoid drowsiness. If you are taking an adult dose of Gravol and not getting relief from nausea, you should see your doctor or pharmacist as soon as possible.

There are a large number of prescription medications used in the treatment of severe nausea and appetite loss. If one does not work, another one might; or a combination of medications may do the trick. The best results are sometimes seen using drugs that act in different ways. For example, some drugs work by emptying your stomach more quickly, while others block the signals to and from the brain that otherwise result in nausea.

Talk to your doctor or pharmacist before switching drugs. Drugs can interact with one another to cause side effects or other problems. Always ask your pharmacist to check for **drug interactions** with your current antiretrovirals and other medications before trying any of these agents.

Some of these anti-nausea medications can be given in different forms. For people with severe nausea that makes keeping pills down difficult or impossible, quick-dissolve tablets, suppositories, patches, injections or intravenous infusions are important options.

One warning on medication choices: **megestrol acetate** (Megace) was prescribed in the past for appetite stimulation but it can suppress production of testosterone, which is already low in many people with HIV. Testosterone deficiency can contribute to appetite loss and can also cause breast enlargement in males. Talk to your doctor about alternative medications that may be right for you.

OTHER ANTI-NAUSEA AGENTS

Studies have shown **ginger** to be an effective anti-nausea agent, even in chemotherapy-induced nausea. Because the anti-nausea effect of ginger requires it to be physically present in the stomach, consume it a few minutes prior to eating, drinking or taking medications. It can be taken in capsule form or as a ginger syrup that is added to water to make a beverage you can drink throughout the day.

Or make ginger tea by chopping or grating 30 to 45 ml (two or three tablespoons) of fresh ginger root and adding it to 250 ml (a cup) of boiling water. Simmer for five to 10 minutes and drink throughout the day. Chopped ginger root can also be added to many dishes where it will add flavour, as well as help counter nausea.

Medicinal marijuana is effective as an appetite stimulant and anti-nausea agent, so it can be a good choice for people who need both. Preparing a healthy meal prior to using marijuana can help ensure its appetite-stimulating effects are used to the best nutritional benefit. The cannabinoid drug **nabilone** (Cesamet) is sometimes used for severe nausea and vomiting. Smoking marijuana can be hard on your lungs, so some people prefer it baked into brownies or cookies. All cannabinoid agents can leave people feeling "stoned." There is controversy over the link between marijuana use and the medical condition called psychosis. People with a predisposition to psychosis should talk to their doctor before using marijuana.

ACUPUNCTURE AND ACUPRESSURE

Both **acupuncture**, which uses needles at energy points in the body, and **acupressure**, which uses physical pressure on energy points, can be helpful for nausea. Acupressure bands, most commonly sold as remedies for motion sickness, are one simple way to get help with nausea. These bands are available at many pharmacies, health food stores and from some health practitioners.

Nerve Pain and Numbness

Peripheral neuropathy is a type of nerve damage that causes changes to sensation in the toes, feet and legs, and sometimes in the hands and arms. It can be caused by HIV itself, some antiretrovirals and other medications, by common nutrient deficiencies and medical conditions such as diabetes and hypothyroidism. Peripheral neuropathy is much less common nowadays thanks to newer antiretroviral drugs. However, it still affects some people who have been living with HIV for a long time. It can become permanent, so it's best to deal with it early.

FIGURING OUT THE CAUSE

Peripheral neuropathy can cause numbness, tingling, burning and sometimes severe pain. It most often occurs in the toes, feet and lower legs, but can also arise in the hands and arms. Normally, both sides of the body are affected. It is important to identify the cause so it can be addressed, and your doctor may want to order some tests.

If your nerve symptoms appear to be caused by a medication, it should be stopped as soon as possible. Delay could result in permanent problems. When medications causing the problem are stopped shortly after symptoms begin, pain and numbness usually subside over time. Too many people have ended up with permanent pain, numbness and burning because the symptoms of peripheral neuropathy weren't identified soon enough or they continued too long on the medication after the pain started.

ANTIRETROVIRAL DRUGS AND OTHER CAUSES

The **antiretroviral drugs** that were once the most frequent cause of neuropathy in people with HIV — d4T (Zerit), ddC (Hivid), and ddI (Videx EC) — are no longer in common use in Canada. Much less commonly, neuropathy can be caused by 3TC (lamivudine, and in Combivir, Kivexa and Trizivir) and T-20 (enfuvirtide, Fuzeon). Many other drugs can also cause this condition, so if you begin to develop symptoms of peripheral neuropathy, it is important to discuss with your doctor and pharmacist the possibility that a medication is contributing to the problem.

There are other factors that can cause or contribute to peripheral neuropathy as well. These include diabetes, hypothyroidism, alcohol, cocaine or amphetamine use, vitamin B₁₂ deficiency and HIV itself.

NUTRIENT SUPPLEMENTS

Anecdotal reports and clinical trials in people with diabetes and people with HIV have shown the following nutrient supplements to be useful in preventing or reversing peripheral neuropathy:

- **alpha-lipoic acid** (in doses of 300 mg, one to two times per day; preferably using an extended-release form)
- **gamma-linolenic acid** (in doses of 240 mg, twice daily)
- **acetyl-L-carnitine** (in doses of 500 mg, three times daily with meals).

Antiretroviral drugs, particularly the older nucleoside analogues (nukes) listed above, can damage mitochondria, the power plants of cells. This is thought to contribute to neuropathy and other health problems. Fortunately, the newer nukes appear not to cause the extent of mitochondrial damage seen with the older drugs.

Because of the link between mitochondrial damage and neuropathy, some people seek to prevent or **reverse mitochondrial damage** by taking a combination of antioxidants, B vitamins and the amino acid acetyl-L-carnitine. One way to get this combination of nutrients is to take:

- a potent multivitamin that includes the whole B vitamin complex and a broad spectrum of antioxidants (vitamin C, carotenoids, selenium and others)
- a supplement of acetyl-L-carnitine (500 mg, three times daily with meals).

When B complex vitamins have been determined to be too low, some people have reported it helpful to supplement, especially with vitamin B₆ (25 to 50 mg daily taken as part of a B complex supplement) and vitamin B₁₂ (see the appendix for more info about this vitamin). Taking very large amounts of vitamin B₆ has been linked to nerve problems. The recommended maximum daily dose is 100 mg. Vitamin B₁₂ is generally safe, even at high doses.

Some people also take magnesium, a mineral essential for nerve function. The recommended maximum daily dose for magnesium is 350 mg daily, though doses of 500 to 600 mg per day may be needed by some people to see benefit. Doses above 350 mg of magnesium daily can cause diarrhea. Magnesium glycinate may be better tolerated than other forms.

Vitamin D may also be helpful. Multiple studies have shown that vitamin D deficiency is common in people with HIV. A study in people with diabetes showed that the pain of peripheral neuropathy was cut almost in half after three months of supplementation with vitamin D. See the appendix on vitamin D for more information.

REDUCING PRESSURE ON FEET OR HANDS

Anything that soothes and reduces pressure on hypersensitive feet or hands can help to reduce pain caused by peripheral neuropathy. This includes:

- limiting the amount of walking
- avoiding wearing tight-fitting shoes and socks
- avoiding standing for lengthy periods
- avoiding repetitive pressure on the hands
- soaking your feet or hands in ice water regularly
- raising your heels or hands off the mattress with a small pillow to help prevent increased pain while sleeping
- keeping heavy covers off painful areas
- exercising regularly
- getting acupuncture or acupressure.

If you are experiencing numbness or lack of sensation in your feet, it's a good idea to get in the habit of checking your feet every day when you remove your shoes and socks. Sometimes neuropathy prevents you from feeling cracks and sores on your feet. A visual inspection can help you identify any problems early to prevent them from getting worse.

DRUG AND ALTERNATIVE THERAPIES

Although they have mostly been studied for diabetic neuropathy, the following medications and treatments can help some people with HIV reduce the pain of peripheral neuropathy, although they won't eliminate numbness:

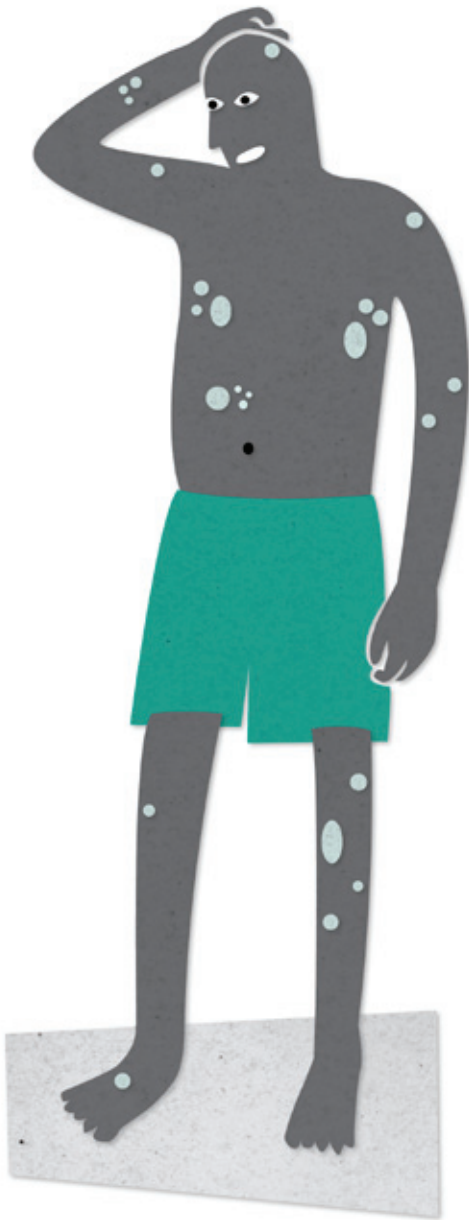
- **Antidepressants** such as amitriptyline (Elavil) and nortriptyline (Aventyl) may be useful. Side effects can include drowsiness, dry mouth, constipation, lack of urination and low blood pressure upon suddenly sitting up or standing. Nortriptyline tends to cause less drowsiness than amitriptyline and can be useful for daytime pain management, while amitriptyline can be helpful for pain that is worse at night. Duloxetine (Cymbalta) is a newer antidepressant used for nerve pain; it can cause nausea and sleep disturbances initially as well.
- **Antiseizure medications** such as gabapentin (Neurontin) and pregabalin (Lyrica) can also be useful for nerve pain. These medications can cause drowsiness, dizziness and weight gain in some people. Other antiseizure medications, such as carbamazepine (Tegretol) and phenytoin (Dilantin), are often used to treat nerve pain, but these have significant interactions with antiretroviral drugs, including non-nukes and protease inhibitors, and should not be taken if you are using these medications.

All of these medications are usually started at a low dose and increased gradually to minimize side effects, especially sedation and dizziness. It is important to note that pain relief is not immediate with these medications; it can take as long as six to eight weeks before the full benefit of antidepressant or antiseizure medications is felt, so try to be patient and don't give up too soon.

- **Anti-inflammatory drugs** such as ibuprofen (Advil, Motrin) may help with mild neuropathic symptoms. **Opioid pain killers** can be used to help manage more severe pain that doesn't respond to other medications.
- **Capsaicin**, derived from chili peppers, applied as a cream or patch directly over the painful areas, has been shown to help reduce neuropathic pain. Capsaicin cream will only result in a temporary reduction in pain so it must be used regularly to provide prolonged pain relief. Some people feel significant burning sensations on the skin when the cream is applied, so not everyone can tolerate it.
- **Marijuana** and its synthetic version, nabilone (Cesamet), are sometimes helpful for treating pain related to neuropathy. For a full discussion of approaches to using these drugs, see the section *Nausea, Vomiting and Appetite Loss*.
- **Geranium oil** has been reported by some people to help when rubbed onto the skin of the painful area.

Rash and Other Problems of the Skin, Hair and Nails

Most problems of the skin, hair and nails are not as common as they once were in people with HIV because effective and better tolerated HIV therapy is more widely available. However, rashes that follow the initiation of HIV drug therapy are common and can indicate a problematic drug sensitivity. Any rash that appears after a new drug is started should be reported to your doctor or pharmacist right away; some rashes can be serious, while it is safe to try to wait out other rashes while you continue treatment.



RASH

A rash is a change in the colour and texture of the skin that shows up as an outbreak of red patches or bumps. Mild rashes consist of flat, red patches appearing on a small area of the body. Moderate rashes spread over a larger area of the body and consist of flat, red patches and/or small, raised red bumps or lesions. Severe rashes are widespread and include blisters or ulcers.

Possible causes of rashes include infections, allergic reactions and medications. Rashes can be caused by many different medications. Sometimes the rash is mild and it disappears on its own. Other times the rash can be severe or a sign of an allergic reaction to the drug, called a hypersensitivity reaction. In these severe cases, the drug should be stopped.

Since it's hard to know if it's safe to continue taking a medication when a rash develops, you should report all rashes to your doctor or pharmacist. This is especially true if the drug is known to cause severe reactions. If your doctor or pharmacist is not available, go to the emergency room of the nearest hospital. If ignored, a lower grade rash may progress into a potentially fatal hypersensitivity reaction.

Most rashes show up within the first four to six weeks after a new drug is started. However, they can sometimes develop later. Some people develop a rash when they start taking **antiretroviral therapy**, most commonly if their combination contains certain protease inhibitors or non-nucleoside analogues (non-nukes). Women are more likely than men to develop a rash related to non-nukes.

The protease inhibitor atazanavir (Reyataz) causes a mild rash during the first two months in about 10 percent of people with HIV, but the rash usually disappears within a few weeks of being on the drug. In rare cases, darunavir (Prezista) and fosamprenavir (Telzir) can also cause rash, and people who have an allergy to sulfa medications may be at higher risk of an allergic reaction with these medications. Occasionally, rash has also been reported with raltegravir (Isentress), maraviroc (Celsentri), and Stribild. Medicines used for treating hepatitis C can often cause rash.

At one time, serious rashes caused by hypersensitivity to the drug **abacavir** were somewhat common, but it is now routine to test for this reaction before abacavir is prescribed. For a full discussion of abacavir hypersensitivity, see the section *Less Common Side Effects*. Rashes associated with other anti-HIV medications can also sometimes be very severe, and screening for hypersensitivity to these other drugs is not available.

Any rash with the drug **nevirapine** (Viramune) should be checked out. It could be just a mild, temporary side effect or it could be sign of a serious hypersensitivity reaction, especially if the rash is moderate to severe, or associated with liver toxicity, fever and feeling unwell. There is no screening test available to predict hypersensitivity to nevirapine, though women are at higher risk than men, and generally people with higher CD4 counts are at higher risk. This reaction is very serious and can be fatal if it is not recognized and the drug is not stopped. Always report rash with nevirapine to your doctor right away.

Though rare, **Stevens-Johnson syndrome** and its more severe form, toxic epidermal necrolysis (TEN), have been associated with antiretroviral drug sensitivity. Stevens-Johnson syndrome usually begins with fever and flu-like symptoms: aches, pains, sore throat, headache and fatigue. There can also be respiratory symptoms such as difficulty breathing and a cough.

Within a day or two, a burning rash develops, often first over both sides of the face and upper parts of the torso, then sometimes progressing to the arms, legs, face and the hands and feet. The rash can progress rapidly. It can include ulcers or blisters on mucous membranes (for example, in your mouth, on your lips or genitals), or irritation of the eyes. This reaction is life-threatening, so anyone experiencing these symptoms should go immediately to the emergency room of the nearest hospital.

Fortunately, most medication-induced skin rashes are mild to moderate, and many do not require stopping the medication. However, the only solution for severe skin rashes related to a drug is to stop taking the drug causing them. Although some drugs can be tried again after a mild rash, usually at lower starting doses, this is not the case with rashes caused by abacavir or nevirapine; these drugs must never be used again.

Milder medication-caused rashes are less likely to develop into severe problems but should still be reported to your doctor. They may disappear without treatment. If they do not, antihistamine drugs are one treatment option. Do not take antihistamines without checking with your pharmacist or doctor about the possibility of interactions with your other medications. Locally applied creams, often containing a corticosteroid, can help suppress inflammation associated with a rash, but long-term use of these is not recommended because of their potential to weaken the immune system when they are absorbed.

Less serious rashes can also be caused by a bacterial, fungal or viral **infection**. A syphilis infection can cause a rash, and that rash can appear when someone starts antiretroviral therapy, so a workup by an HIV-knowledgeable dermatologist is a good idea if possible, as is regular testing for syphilis in sexually active people. Diagnosing and treating any underlying infection should cause the rash to clear up quickly.

SKIN AND NAIL PROBLEMS

One skin problem that can be related to antiretroviral drugs is **hyperpigmentation** of the palms of the hands, soles of the feet and occasionally the face. This condition is uncommon and can be caused by FTC, found in Truvada, Atripla, Complera and Stribild. Hyperpigmentation related to antiretroviral medicines occurs most frequently in dark-skinned people.

Hyperpigmentation of the skin, tongue or nails has been linked to AZT (Retrovir, and in Combivir and Trizivir), peg-interferon alpha-2b (Pegetron) and hydroxyurea (Hydrea). Dry skin, cracked lips and ingrown nails can be caused by the protease inhibitor indinavir (Crixivan), which is rarely used today. The hepatitis C therapies boceprevir (Victrelis) and telaprevir (Incivek) are also known for causing rash, dry skin and itchiness.

When **dryness** or **itchiness** is part of the problem, drinking plenty of fluids, especially water (if dehydration is the cause), and applying a non-perfumed moisturizing cream or lotion can help. Some people break open a vitamin E capsule and rub the liquid, along with moisturizer, on dry skin and cracked lips. Vaseline also works well for dry, cracked lips. Zinc oxide cream, sold as a diaper rash cream or sunblock, can help eliminate some rashes.

Essential fatty acid supplements such as fish or borage oil can sometimes help with rashes and dry, itchy skin by supplying fatty acids needed for skin health and because of their natural anti-inflammatory effects. Essential fatty acid supplements can complement a multivitamin mineral supplement to provide the vitamin E, vitamin A, zinc and B vitamins necessary for good overall health, which includes good skin health.

Avoid harsh soaps that contain antibacterial chemicals and fragrances and choose hypoallergenic products. Avoid hot showers or baths. Sticking to lukewarm water will help prevent moisture loss from the skin and prevent the irritation of a rash that hot water can cause. Applying moisturizer right after bathing can help lock in moisture. Oatmeal baths can also provide relief. Wearing only soft natural fabrics, especially cotton, can help. When a rash feels irritating, calamine lotion can be soothing.

HAIR LOSS

Hair loss, also called alopecia, is a common experience, particularly in men as they age. When hair loss is new, rapid or severe, it is considered abnormal. There are many medical treatments that can cause hair loss, including cancer drugs and some arthritis drugs.

Hair loss can also be caused by some **antiretroviral medications**, particularly 3TC (lamivudine, also in Combivir, Trizivir and Kivexa), though this is not a common side effect. The protease inhibitor indinavir (Crixivan, rarely used today) and some hepatitis C treatments have also been implicated in some instances of hair loss. Unfortunately, no one seems to have found a perfect solution for medication-induced hair loss other than switching or discontinuing the problematic drug. Even then, in some cases, hair regrowth may be slow and incomplete.

Other causes of hair loss include:

- malnutrition, particularly low protein intake
- thyroid problems (these can also cause hair to become coarse and brittle)
- B vitamin complex deficiency
- testosterone levels that are too high
- syphilis.

It is important to note that androgenic steroids such as testosterone are often implicated in hair loss, particularly when high doses are used. If you are considering using testosterone, speak to your doctor about its pros and cons. In general, doses that replace normal levels of testosterone, using gels or patches, are considered best. High doses, especially by injection, should be avoided.

For some people, products that boost hair growth, such as minoxidil (Rogaine) or finasteride (Propecia), can help with hair loss. As with all medications, check to make sure there are no possible interactions with your other medications before taking such products.

Sexual Difficulties

Loss of sexual interest, also known as decreased libido, erectile difficulties in men and difficulties reaching orgasm in both men and women are frequently ignored problems in people with HIV. Try not to be embarrassed about sexual difficulties. Discuss any problems you are having with your doctor or other counsellor. A healthy, fulfilling sex life is part of a life well lived and something all people with HIV deserve.

FIGURING OUT THE CAUSE

It will be helpful if you can provide your doctor with information on when your sexual difficulties began, exactly what your problems are, and to what extent you are experiencing them. It may be helpful to ask yourself how your current libido and sexual functioning compares to the past. If your sex drive has always been strong and you realize that recently it is not, tell your doctor. If you never had problems having sex and now you do, this is something your doctor needs to know. The more specific you can be in describing your sexual difficulties, the better.

Sexual difficulties can have a number of different causes. Sexual function often changes as people age. Some people consider this a natural part of life, while others seek to address it. Prescription medications can also be a cause. Sexual difficulties have been reported in many people taking protease inhibitors or antidepressants. If your troubles started shortly after the introduction of any new medication, consider that it could be causing or contributing to the problem. Finally, other factors can contribute to changes in sexual function, including:

- smoking
- alcohol
- hormone problems
- emotional issues, including stress.

When a physical exam and laboratory analysis appear normal, the search for other possible causes should continue. Autonomic neuropathy, a nerve condition that may occur in people with HIV and often remains undiagnosed, has been found to cause impotence in some men with HIV. Nutrient therapies for peripheral neuropathy (see the section on *Nerve Pain and Numbness*) may help some people.

Not only is it important to find solutions for sexual difficulties, but some can indicate conditions that are very important to address for overall health, such as diabetes, heart disease or thyroid gland disease. If your sexual difficulties persist, a consultation with a urologist, gynecologist or sexologist could be in order.

HORMONE DEFICIENCIES

Testosterone deficiency can contribute to loss of sexual interest in both men and women. In men, it can lead to decreased ability to function (impotence), a loss of muscle mass and overall body cell mass, as well as to fatigue, lack of energy and depression. While testosterone levels drop naturally with age, a deficiency can happen at any time for HIV-positive cisgendered men (non-transgendered men). An evaluation of your testosterone level is important if you are experiencing a decline in sexual interest, erection difficulties, or inability to reach orgasm.

Appropriate hormone replacement can return testosterone levels to normal and reverse sexual problems when testosterone deficiency is the underlying cause. At the same time, restoring normal testosterone levels can help to reverse or prevent other serious problems related to a deficiency. Testosterone gels, creams or patches are preferable to injections because injections can shut down your own remaining testosterone production and can actually cause sexual problems.

Menopause may start earlier, so it may be worth testing levels of **estrogen** and **progesterone** in cisgendered women. Deficiencies can contribute to sexual arousal disorder, vaginal wall thinning and dryness, the combination of which can cause difficulty with intercourse and reduced pleasure. Based on your

test results, you should discuss with your doctor whether hormone replacement therapy to reverse your symptoms is appropriate. For more information, see the section on *Menstrual Changes*.

ANTIDEPRESSANT AND SLEEP MEDICATIONS

Stress, anxiety and depression are frequently accompanied by sexual problems. Some people find the emotional impacts of living with HIV can affect their sexual function. These issues should be treated through effective counselling and medications as needed.

However, if you are taking medications for depression or chronic anxiety and you develop sexual problems, your medication may be the cause. On the other hand, the antidepressant Wellbutrin (bupropion) can increase sexual desire and function, including ability to reach orgasm in both men and women. Discuss this with your doctor. Check the section *Emotional Wellness* for more information about possible causes and treatment options for depression.

Sleep medications can also be a problem; they diminish sexual desire significantly in some people. Since many different medications and natural alternatives are available to help with sleeping disorders, many people are able to find an effective substitute. For a full discussion of these possibilities, see the section on *Sleep Problems*.

LIFESTYLE CHANGES

Some common sense recommendations to improve your sexual health include:

- Eat well and avoid heavy meals before sex.
- Cut down or quit smoking, which inhibits the sexual reflex.
- Cut down how much alcohol you drink; alcohol is a sexual depressant.
- Look into ways to reduce your stress; stress lowers libido.
- Get enough rest; 7.5 to nine hours is enough for most people.
- Avoid using street drugs or party drugs that diminish your sex drive.

DRUGS TO TREAT IMPOTENCE

The erectile dysfunction drugs Viagra (sildenafil), Cialis (tadalafil) or Levitra (vardenafil) can be an option for some men with impotence. However, these drugs interact with a number of other drugs, including some antiretroviral medications and heart disease drugs. These drugs should *not* be used by anyone taking the heart drug nitroglycerin or other nitrate medications. Nor should they be used along with poppers (amyl nitrite and other alkyl nitrites). These combinations can sharply decrease blood pressure and lead to shock or death. Also, lower doses of erectile dysfunction drugs are recommended in anyone on an antiretroviral treatment that includes a protease inhibitor or a non-nucleoside analogue (non-nuke).

People should use Viagra, Cialis or Levitra only after consulting with their doctor, who can identify possible health issues and potential drug interactions. Erectile dysfunction drugs bought without a prescription — often from friends, the Internet or other sources — can be counterfeit and contain ingredients that could be harmful or interact with HIV medications.

Sleep Problems

A good night's sleep is crucial for maintaining good health. Unfortunately, some people with HIV can experience sleep problems, including insomnia, vivid dreams, nightmares and night sweats. Sleep problems tend to be undertreated so it is very important to discuss them with your doctor. They can be signs of another medical problem, and they are certainly a barrier to living well.



FIGURING OUT THE CAUSE

If you are experiencing sleep problems, **keep a sleep diary** for the week before you see your doctor. It may provide useful information to help diagnose some of the problems. Keeping a sleep diary can be as simple as having a pen and paper by your bed to track some or all of the following:

- how often you experience sleep problems
- how much sleep you actually get each night
- the quality of your sleep
- whether you experience disturbing dreams or nightmares
- whether you have trouble falling asleep, staying asleep, falling back to sleep
- whether you wake up one or more times during the night
- whether you wake up too early
- how you feel when you wake up; for example,

whether you get out of bed feeling rested and refreshed or find it difficult to get up because you still feel groggy and tired

- whether the sleep you get each night is sufficient to give you full energy for your day
- any factors you are able to observe that may be related to your sleep problems.

Sleep problems may be linked to lifestyle choices. Examples of lifestyle choices include the time at which you eat, whether you drink alcohol or use street drugs, whether you work or party late, and whether you travel frequently. A sleep diary can help identify these activities.

The sleep diary might also give clues to help your doctor identify insomnia (the inability to sleep) and sleep apnea (slowing or stopping breathing while asleep), two conditions that can occur regardless of HIV infection.

However, it is important to remember that there are also specific HIV-associated causes that should be considered as you seek answers for restoring a good night's sleep.

ANTIRETROVIRAL DRUGS

Sleep problems are possible side effects of certain antiretroviral drugs. Of all the antiretroviral drugs now in common use, the most likely to cause severe sleep problems is the non-nucleoside analogue **efavirenz** (Sustiva, and in Atripla). This medication can cause insomnia, vivid dreams and nightmares. For some people, the nightmares can be intense and terrifying and can cause repeated waking in the night. Returning to sleep can be difficult. In many people, these side effects disappear gradually after several weeks on the drug, so waiting out the problem for at least a month is advisable, if possible. For other people, the sleep problems caused by efavirenz continue and stopping the drug is the only solution.

Consider starting efavirenz on a weekend or taking a few days off from work, since it can take a few days to get used to the changes this drug can produce. Generally speaking, it is best to avoid alcohol and street drugs when starting efavirenz. Alcohol and drugs such as marijuana, cocaine and speed can worsen some of the central nervous system side effects of efavirenz.

Doctors often recommend taking efavirenz before bedtime since many of its side effects, such as dizziness, impaired concentration and lightheadedness, are strongest within a few hours after taking the dose. However, if you find that the drug keeps you awake or causes nightmares, taking it in the morning may be better. If you want to take it at night but find that sleep problems continue, try all the standard recommendations for improving sleep listed below. Or try reprogramming your dreams. Sleep researchers have found that most recurrent nightmares can be reprogrammed by repeatedly visualizing the unpleasant dream, and then mentally changing it into something pleasant.

Much less commonly, sleep problems, such as insomnia and abnormal dreams, may be associated with the following **other HIV drugs**:

- abacavir (Ziagen and in Kivexa and Trizivir)
- 3TC (lamivudine and in Combivir, Kivexa and Trizivir)
- AZT (Retrovir and in Combivir and Trizivir)
- tenofovir (Viread and in Truvada, Atripla, Complera, and Stribild)

- FTC (emtricitabine, in Truvada, Atripla, Complera and Stribild)
- rilpivirine (Edurant and in Complera)
- T-20 (enfuvirtide, Fuzeon)
- d4T (Zerit)
- ddI (Videx EC)

As with taking efavirenz, sleep problems may lessen or disappear after a period of days, weeks or months on any of the drugs listed above. Other times, the problem may persist and other options must be considered.

EMOTIONAL PROBLEMS

It is important to look honestly at your life to see if stress, anxiety or other emotional health issues could be contributing to your sleep problems. Just living with HIV can cause stress for many. Problems related to relationships, work, family and so on can contribute to sleep problems. Although it can be impossible to fully eliminate all the sources of stress, there are many things that can help reduce the effects of stress on your body, including meditation, deep breathing exercises, yoga, biofeedback and other relaxation techniques. At times, therapy with a good mental health therapist or psychologist can work wonders, especially if you have a lot going on in your head and your life.

Depression is another possible cause of sleep problems. Addressing depression or related emotional problems may help with sleep problems, including insomnia or fatigue. For a full discussion of approaches to treating depression, see the section on *Emotional Wellness*.

FATIGUE

If you are feeling too fatigued for normal life activities and are not being active during the day or not exercising enough, you may find it difficult to sleep normally at night. For a full discussion of approaches to treating fatigue, see the section on *Fatigue*. With restoration of good energy, you may again be able to do regular exercise (though well before your usual sleep time!).

INFECTIONS

There are certain infections, including *Candida* overgrowth, that may be accompanied by insomnia. If you develop insomnia, see your doctor, especially if you have any other symptoms that could indicate an infection. In some cases, insomnia can be your earliest warning of an infection in need of treatment.

NUTRIENT DEFICIENCIES

Deficiencies of certain nutrients, especially vitamin D and vitamin B₁₂, are very common in people with HIV and can contribute to sleep problems.

Vitamin D deficiency has been linked to depression. Since that can, in turn, cause sleep problems, restoring vitamin D to optimal levels may be very important for improving sleep. See the full discussion of this vitamin in the appendix.

Vitamin B₁₂ has been shown in studies to be deficient in many people with HIV, and the deficiency can begin very early, even in the asymptomatic stage of HIV. Deficiency of vitamin B₁₂ can result in serious problems, including depression and chronic fatigue. Each of these can, in turn, contribute to sleep problems. Some people do not realize they are fatigued because they are driving their bodies with their minds. They plow ahead, more or less refusing to acknowledge their fatigue. Giving these people sufficient B₁₂ may actually help them to slow down, feel more peaceful inside, and get better sleep. For an expanded discussion on the need for vitamin B₁₂ in people with HIV, see the appendix.

Other B vitamins are also frequently deficient in people with HIV and deficiency of almost any individual B vitamin or of the whole B vitamin complex can contribute to the development of anxiety or depression that, in turn, can cause sleep problems. The best approach to ensuring you have all the B vitamins you need to prevent such problems is to take a supplement that contains the whole B complex.

HORMONE CHANGES

A number of hormone changes common in HIV disease can contribute to the development of sleep problems.

It is important to consider the possibility that **menopause** could be contributing to sleep problems. It is not uncommon to develop sleep problems at this life stage. Hot flashes and night sweats can disrupt normal sleep sufficiently to cause fatigue the next day. They can occur during the night without causing waking, making it difficult to identify it as the source of the problem. In such cases, testing of female hormone levels followed by discussion with your doctor of whether hormone replacement therapy is appropriate will be important. Although long-term use of hormone replacement therapy is not generally

recommended because of possible increases in the risk of heart attack, stroke and several cancers, short-term use can sometimes be useful for improving sleep.

In addition, optimal doses of vitamin E may reduce or eliminate hot flashes. Although the effective dosage is very individual, it is certainly worth trying supplementation with vitamin E to see if it can help. A reasonable starting dose to manage hot flashes and resulting sleep problems would be 1,000 IU daily of a natural form of vitamin E (d-alpha tocopherol with added mixed tocopherols). Increases of up to 2,000 to 3,000 IU daily have helped some people to eliminate hot flashes.

Inadequate levels of **testosterone** or **thyroid hormones**, which can be deficient in both men and women, are a frequent cause of depression and fatigue in people with HIV. Since both of these can contribute to sleep problems, measuring natural levels and, where necessary, providing replacement therapy to restore the hormone to optimal levels may be very important for restoring good sleep. Tests of thyroid function should be a standard part of your regular blood tests. Be sure to ask your doctor to check the results of these tests. Checking for testosterone levels requires a separate blood test you can ask for.

COMPLEMENTARY THERAPIES

Melatonin is the body's natural sleep promoter. People with HIV may have decreased levels, so supplementing melatonin may improve sleep. Research has shown that for insomnia, taking the melatonin two to three hours before your desired bedtime is optimal. It is best to start with a low dose of melatonin and then increase it if necessary. Doses of only 100 to 300 mcg (0.1 to 0.3 mg) will be sufficient for most people.

The traditional glass of warm milk helps because it provides a dose of tryptophan, a precursor to the chemical serotonin, which is involved in the induction of sleep. A more effective boost to serotonin is the supplement 5-hydroxy-tryptophan (5-HTP). **5-HTP** is an effective sleep aid. Doses of 50 to 150 mg of 5-HTP one hour before bedtime work for many people. It's important to take it with 50 mg of vitamin B₆ because vitamin B₆ is used to convert 5-HTP to serotonin. (However, 5-HTP should not be taken by people who are also taking medicines for treating depression or anxiety.) The addition of glycine (500 mg) to this package may also help since it is a calming amino acid and seems to increase the overall effect in summoning sleep.

Aromatherapy may also help induce sleep. Essential oils of lemon balm, lavender or chamomile are considered calming. Using these can be as simple as putting a few drops on a cotton ball and leaving it in the room or near your pillow. These oils can also be put in bath water or added to a small vaporizer or humidifier.

There are **homeopathic remedies** that may help with sleep problems. *Calms Forté* is a homeopathic remedy that many people find useful in relaxing them enough to allow them to drift off to sleep. Another possibility is the Bach Flower Remedy called *Rescue Remedy*, a plant essence preparation that many people have reported seems to help reduce anxiety. A few drops under the tongue summons a calming effect.

Acupuncture has also been found to be very helpful for people experiencing sleep problems. A qualified acupuncturist can choose the right combination of points to treat.

There are several **herbal remedies** that may help with sleep. The traditional cup of chamomile tea before bedtime can be quite useful. Other herbs that can have a calming effect to help you drift off to sleep are valerian root, hops and passion flower.

PRESCRIPTION AND OVER-THE-COUNTER MEDICATIONS

Ask your pharmacist about effective, non-addictive, **over-the-counter medications** available for short-term use. Gravol, an anti-nausea medication, or Benadryl, an antihistamine, often cause drowsiness as a side effect. However, these should not be used for more than a few days as prolonged use can raise the risk of developing anxiety and depression. Benadryl can also cause dry mucosal membranes.

Talk to your doctor about **prescription sleeping aids**. Sleeping medications should normally only be used short-term and in the lowest effective dose in order to help re-establish a good sleep pattern. They are not recommended for long-term use. Medication possibilities include zopiclone (Imovane), lorazepam (Ativan) and temazepam (Restoril). The antidepressants trazodone (Oleptro) or mirtazapine (Remeron) can help some people. Some of these drugs can interfere with antiretroviral drugs, particularly protease inhibitors, so ask your doctor and pharmacist about possible interactions.

TIPS FOR BETTER SLEEP

- Avoid drinking or eating anything with **sugar or alcohol** for four to six hours before bedtime. Avoid **caffeine** eight to twelve hours before bedtime.
- Try to eat your **last meal of the day** at least three hours before bedtime.
- Avoid **nicotine** for four to six hours before bedtime, though many smokers know this can be difficult.
- Avoid **strenuous exercise, bright lights, Internet activity and television** one to two hours before bedtime.
- **Relax before bedtime** by doing peace-inducing yoga or breathing exercises, indulging in a soothing bath or doing relaxation techniques.
- **Create an environment that promotes optimal sleep**. In general, this means a room that is dark, quiet and removed from any distractions.
- **Maintain a regular sleep pattern**. That way your body will expect to sleep at that time.

DEALING WITH NIGHT SWEATS

Night sweats are common when people with HIV are not taking treatment, but they can also happen even when people have been on successful therapy for a long time. Night sweats may also result from other serious infections or cancers. You should tell your doctor if you begin to have night sweats since they could be an early sign of a serious problem.

Night sweats can be very uncomfortable and disrupt sleeping. Putting towels on the bed and having an extra set of sleeping clothes handy can limit the disruption of having to deal with soaked bedding. People who consistently sweat extensively during the night can lose considerable electrolytes (normal chemical compounds in the blood), including sodium, potassium and chloride. See the section on *Diarrhea, Gas and Bloating* for suggestions on replenishing electrolytes.

Less Common Side Effects

Lactic Acidosis, Pancreatitis and Abacavir Hypersensitivity

Three drug side effects, although rare, require immediate medical attention:

LACTIC ACIDOSIS: damage to mitochondria caused by your antiretroviral medication or toxicity from other medications can cause a build-up of lactic acid in the body called lactic acidosis

PANCREATITIS: mitochondrial damage or drug toxicity can also cause a painful inflammation of the pancreas called pancreatitis

ABACAVIR HYPERSENSITIVITY: abacavir can cause an allergic-like reaction called a hypersensitivity reaction.

These side effects are severe and can be fatal.

LACTIC ACIDOSIS

Lactic acid is produced by the body's cells as they use energy to function. Minor increases in lactic acid are fairly common after exercise but are usually temporary. But when lactic acid reaches a higher level, there is a risk of a serious condition called lactic acidosis.

Although other medications can cause lactic acidosis, most cases have occurred in people using nucleoside analogues (nukes). These include: d4T (Zerit), AZT (Retrovir, and in Combivir and Trizivir), ddC (Hivid), ddi (Videx EC) and tenofovir (Viread, and in Truvada, Atripla, Complera and Stribild). Cases have also been reported with the hepatitis C drug ribavirin, as well as the drug hydroxyurea (Hydrea), which raises the concentration of many nukes inside cells.

Researchers think these drugs can damage mitochondria (your cells' energy factories), leading to a dangerous buildup of lactic acid. Lactic acidosis causes non-specific symptoms, including:

- fatigue
- nausea
- vomiting
- abdominal pain
- sudden unexplained weight loss
- shortness of breath or difficulty breathing (respiratory symptoms)
- neurologic symptoms (including difficulty moving)
- changes in blood circulation indicated by cold hands or feet or blue colour in the skin.

If you experience these symptoms tell your doctor what you're feeling.

Because mitochondrial damage is thought to be an underlying cause of lactic acidosis, some people take supplements with the goal of preventing or reversing mitochondrial damage. It is not clear how effective this approach is in preventing lactic acidosis. These supplements are:

- antioxidants (vitamin C, carotenoids, selenium and others), which can be found in some multivitamin-mineral and/or antioxidant formulas
- B vitamins, found in a B complex formula or a multivitamin that contains the whole B complex
- acetyl-L-carnitine (500 mg, three times daily with meals).

A separate supplement of N-acetyl-cysteine (NAC; 600 mg, three times daily with meals) is sometimes added to boost glutathione levels, since glutathione is an antioxidant that can be deficient in HIV disease.

PANCREATITIS

Pancreatitis is an inflammation of the pancreas, the organ that secretes digestive enzymes and insulin. Pancreatitis can be caused by many drugs, including nukes such as ddi (Videx EC), ddC (Hivid) and d4T (Zerit), which are no longer in common use in Western countries, as well as by hydroxyurea and rarely by 3TC (lamivudine and in Combivir, Kivexa and Trizivir). Protease inhibitors and the non-nucleoside analogue efavirenz (Sustiva, and in Atripla) have also been rarely

associated with pancreatitis. In addition, high levels of blood fats can put people with HIV at increased risk for pancreatitis. Other possible causes are gallstones, alcohol, street drugs and other medications or infections.

Pancreatitis may cause symptoms such as:

- severe nausea
- vomiting
- severe abdominal pain.

The risk of pancreatitis may be higher when people drink a lot of alcohol. If severe abdominal pain starts suddenly and accompanies nausea and vomiting that lasts several hours, especially after eating or an alcohol drinking binge, pancreatitis is a possibility. If left untreated, pancreatitis can be fatal. If there is any suspicion of pancreatitis, it is crucial to get immediate medical attention.

ABACAVIR HYPERSENSITIVITY

Without screening, an allergic-like reaction called a hypersensitivity reaction occurs in up to eight percent of people who start taking abacavir (Ziagen, and in Trizivir and Kivexa). A screening test is available that identifies the version of the gene HLA-B*5701 linked to the hypersensitivity reaction. This test can identify most people who are susceptible to this problem, reducing the risk of a reaction to less than one percent. Anyone considering therapy with any abacavir-containing medication should be screened with this test before starting treatment. Now that screening is standard practice, abacavir hypersensitivity reactions are extremely rare.

When an abacavir hypersensitivity reaction does occur, it usually appears during the second week of therapy, although in some people it can take up to six weeks for symptoms to develop. Very rarely, the reaction can develop much later in people who have taken the drug for an extended period with no symptoms.

The most common symptoms of abacavir hypersensitivity are fever and rash, as well as a combination of flu-like symptoms: fatigue, headache, nausea, vomiting, diarrhea, sore throat, cough, shortness of breath, and aches and pains. These symptoms usually get worse over time. In anyone taking abacavir, such symptoms should be reported to a doctor immediately.

If you are experiencing a hypersensitivity reaction, you will be told to stop the drug immediately. Anyone who has had this hypersensitivity reaction will never be able to take medications that contain abacavir again, since restarting the drug could cause severe illness or death.

Other drugs can cause hypersensitivity reaction. For more information, see the section *Rash and Other Problems of the Skin, Hair and Nails*.

Appendix: Vitamin B₁₂ and Vitamin D

People with HIV often have lower than normal levels of micronutrients, and doctors often recommend that everyone with HIV take a complete multivitamin-mineral supplement daily to maintain optimal levels. However, two specific vitamins, vitamin B₁₂ and vitamin D, are of particular concern because of their many effects in the body.

VITAMIN B₁₂

A number of studies have shown that vitamin B₁₂ is deficient in a large percentage of people with HIV, and the deficiency can begin early in the disease. Vitamin B₁₂ deficiency can result in neurologic symptoms — for example, numbness, tingling and loss of dexterity — and the deterioration of mental function, which causes symptoms such as foggy thinking, memory loss, confusion, disorientation, depression, irrational anger and paranoia. Deficiency can also cause anemia. (See the section on *Fatigue* for more discussion of anemia.) It has also been linked to lower production of the hormone melatonin, which can affect the wake-sleep cycle.

If you have developed any of the emotional or mental symptoms mentioned above, especially combined with chronic fatigue, vitamin B₁₂ deficiency could be contributing. This is especially true if you also have other symptoms that this deficiency can cause, including neuropathy, weakness and difficulty with balance or walking. On the other hand, these symptoms can also be associated with HIV itself, with hypothyroidism or advanced cases of syphilis called neurosyphilis. A thorough workup for all potential diagnoses is key to determining the cause.

Research at Yale University has shown that the standard blood test for vitamin B₁₂ deficiency is not always reliable. Some people who appear to have “normal” blood levels are actually deficient, and could potentially benefit from supplementation.

The dose of vitamin B₁₂ required varies from individual to individual and working with a doctor or naturopathic doctor to determine the correct dose is recommended. Vitamin B₁₂ can be taken orally, by nasal gel or by injection. The best way to take it depends on the underlying cause of the deficiency, so it’s important

to be properly assessed before starting supplements. For oral therapy, a typical recommendation is 1,000 to 2,000 mcg daily.

One way to know if supplementation can help you is to do a trial run of vitamin B₁₂ supplementation for at least six to eight weeks. If you are using pills or sublingual lozenges, the most useful form of vitamin B₁₂ is methylcobalamin. Talk to your doctor before starting any new supplement to make sure it is safe for you.

Some people will see improvements after a few days of taking vitamin B₁₂ and may do well taking it in a tablet or lozenge that goes under the tongue. Others will need several months to see results and may need nasal gel or injections for the best improvements. For many people, supplementation has been a very important part of an approach to resolving mental and emotional problems.

VITAMIN D

Some studies show that vitamin D deficiency, and often quite severe deficiency, is a common problem in people with HIV. Vitamin D is intimately linked with calcium levels, and deficiency has been linked to a number of health problems, including bone problems, depression, sleep problems, peripheral neuropathy, joint and muscle pain and muscle weakness. It is worth noting that in many of these cases there is a link between vitamin D and the health condition, but it is not certain that a lack of vitamin D causes the health problem.

A blood test can determine whether or not you are deficient in vitamin D. If you are taking vitamin D, the test will show whether you are taking a proper dose for health, while avoiding any risk of taking an amount that could be toxic (although research has shown that toxicity is highly unlikely, even in doses

up to 10,000 IU daily when done under medical supervision). The cost of the test may not be covered by all provincial or territorial healthcare plans or may be covered only in certain situations. Check with your doctor for availability in your region.

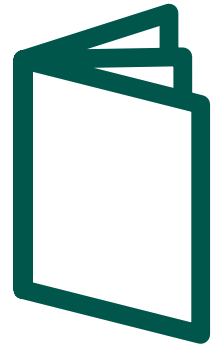
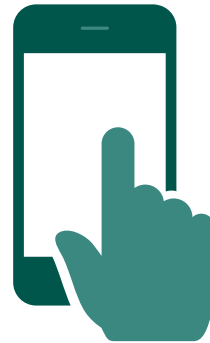
The best test for vitamin D is the 25-hydroxyvitamin D blood test. There is some debate about the best levels of vitamin D, but most experts believe that the minimum value for health is between 50 and 75 nmol/l. Many people use supplements to boost their levels to more than 100 nmol/l.

While sunlight and fortified foods are two possible sources of vitamin D, the surest way to get adequate levels of this vitamin is by taking a supplement. The best dose to take depends on the person. A daily dose of 1,000 to 2,000 IU is common, but your doctor may recommend a lower or higher dose for you, depending on the level of vitamin D in your blood and any health conditions you might have. People should not take more than 4,000 IU per day without letting their doctor know. Look for the D₃ form of the vitamin rather than the D₂ form. Vitamin D₃ is the active form of the vitamin and there is some evidence that people with HIV have difficulty converting vitamin D₂ to vitamin D₃. Historically, vitamin D₃ supplements are less commonly associated with reports of toxicity than the D₂ form.

It is best to do a baseline test so you know your initial level of vitamin D. Then, have regular follow-up tests to see if supplementation has gotten you to an optimal level and that you are not taking too much. Regular testing is the only way to be sure you attain — and then maintain — the optimal level for health.

With proper supplementation, problems caused by vitamin D deficiency can usually be efficiently reversed.

More Resources



CATIE is Canada's source for HIV and hepatitis C information. We offer a full range of resources on healthy living for people with HIV. Check www.catie.ca or call our confidential information line toll-free at 1-800-263-1638.

The following resources may be of particular interest to people living with HIV looking for information on managing drug side effects:

- www.catie.ca/en/sideeffects
- **YourDocTalk** – CATIE's HIV treatment talking tool available online at yourdoctalk.catie.ca and as a smartphone app
- Other guides in CATIE's **practical guide** series:
 - A Practical Guide to Nutrition
 - A Practical Guide to Complementary Therapies
 - A Practical Guide to HIV Drug Treatment
- CATIE **fact sheets** – concise overviews of conditions, symptoms, medications, side effects, complementary therapies, vitamins, supplements and other treatment issues
- **Treatment Update** – CATIE's flagship digest on cutting-edge developments in HIV and hepatitis C research and treatment
- **CATIE News** – CATIE's bite-sized HIV and hepatitis C news bulletins

Other CATIE resources for people living with HIV include:

- **Managing your Health** – CATIE's guide for people living with HIV
- **The Positive Side** – CATIE's health and wellness magazine for people with HIV
- **HIV and Emotional Wellness** – a booklet exploring how people with HIV can cultivate their emotional well-being
- **You Can Have a Healthy Pregnancy if You Are HIV Positive** – plain language information about HIV and pregnancy
- **HIV and Aging** – healthy living tips for people 50 and over living with HIV

A Practical Guide to
HIV Drug Side Effects

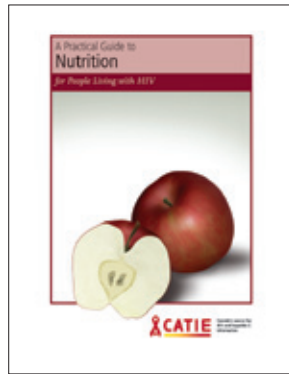
for People Living with HIV

This guide is one of a series of practical guides
for people living with HIV. Other titles in the series are:

A Practical Guide to HIV Drug Treatment

A Practical Guide to Nutrition

A Practical Guide to Complementary Therapies



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