

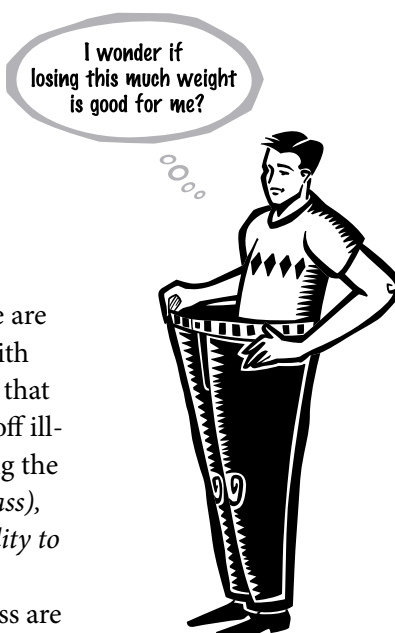
NUTRITION AND WEIGHT MAINTENANCE

A PUBLICATION FROM

PROJECT
inform

Information,
Inspiration and
Advocacy for People
Living With HIV/AIDS

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Good nutrition and weight maintenance are extremely important for people living with HIV. The vitamins, nutrients and energy that nutritious foods provide can help stave off illness. Maintaining weight, and preventing the loss of muscle mass (called *lean body mass*), bolsters general health and the body's ability to fight disease.

That said, malnutrition and weight loss are common problems associated with HIV disease. Malnutrition can result from a loss of appetite due to depression, fatigue, illness or drug side effects. Without an obvious loss in a person's weight, it can persist undetected.

Weight loss can be an obvious sign of malnutrition. It can begin and become severe anywhere in the course of HIV disease. *Wasting* is extreme weight loss—an unexplained loss of 10% or more of a person's normal weight. Some people report wasting despite having very high CD4+ cell counts. However, the risk of wasting and serious malnutrition increases dramatically when CD4+ cell counts fall below 100.

There are many ways to manage your nutrition and weight. A comprehensive strategy for treating HIV should address these areas.

Your weight should be checked with the same watchful eye as your CD4+ cell counts and other lab results. It's critical to prevent, detect and reverse weight loss early. Specialists note that the difference between successfully treating an opportunistic infection and treatment failure can depend on a few pounds of weight.

There are many ways to prevent and treat weight loss. Using different approaches may be needed throughout HIV disease. A healthy person with no obvious signs of weight loss will probably develop a very different kind of strategy than someone with significant weight loss. Similarly, weight loss due to problems in the gut (gastrointestinal distress), diarrhea or other conditions may need different interventions than weight loss due only to drug side effects.

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Finding a nutrition and weight maintenance program that fits both your lifestyle and nutritional needs is critical for success. The following are a few points to consider, which are further explained in this publication:

Include nutrition and exercise as part of a comprehensive treatment strategy

1

The importance of nutrition and maintaining lean body mass cannot be overstated. Good nutrition, combined with exercise, strengthens the body and mind. Together, they can provide a solid foundation to optimize the benefits of therapies to treat HIV and other infections.

Most doctors and people living with HIV do not recognize the early signs of weight loss. Ways to help prevent wasting and malnutrition include careful monitoring of weight, using lab tests to look for vitamin and hormone deficiencies and developing a nutrition and exercise program. Whenever possible, it is far better to correct nutritional problems before they become severe. This may mean intervening with improved diet, appetite stimulants or weight gain supplements.

Your strategy for coping with nutrition and exercise should be checked periodically, adapting it to your body's changing needs. Two people at the same stage of wasting may approach exercise and nutrition differently. Someone willing to follow a workout regimen and careful diet may rebound from wasting by simply adopting better eating habits. Someone who is less inclined to exercise and finds it more difficult to carefully follow a diet may need more invasive interventions, ranging from the use of appetite stimulants and supplements to total parenteral nutrition (TPN). Both people might successfully rebound from wasting, but each intervention reflects individual lifestyle factors and choices. There are pros and cons to each option. Get informed, weigh the risks and benefits, and develop a realistic plan to prevent or reverse wasting.

Many people experiencing weight loss or malnutrition feel frail and avoid strenuous activity. They also tend to feel depressed—a condition linked to malnutrition. These feelings often get in the way of keeping up with good nutrition and exercise. This perpetuates a dangerous cycle. Even if you feel frail, your body is much more resilient than you may feel!

Diagnose and treat the causes

2

It's extremely important for you and your doctor to rigorously diagnose and treat the cause(s) of weight loss. HIV and related conditions can cause weight loss, fatigue, muscle loss and chronic diarrhea. The gut is a major site of early HIV infection, where the virus first establishes itself in the body. Many bacterial, viral, fungal and parasitic infections of the gut grow unchecked once the immune system is weakened. These can contribute to weight loss.

Some doctors test repeatedly to identify the cause(s) of diarrhea and weight loss. Others only treat the symptoms. It's important to do both. Aggressive diagnosis should be accompanied by aggressive treatment.

That said, diagnosing and treating unexplained weight loss and diarrhea can be difficult since multiple causes often occur at the same time. For instance, with testing, a parasite may be identified as a cause of diarrhea, but treating it may only reduce and not resolve the problem. This might be because the parasite was "masking" another infection. More testing and treatment may be needed to deal with the underlying problem(s).

Also, sometimes wasting is due to malabsorption, when the tissue and cells lining the gut have lost the ability to transfer nutrients. Knowing when this is the case helps in selecting the right treatment. Finding the cause(s) of weight loss and diarrhea is always critical to finding the right solution. Treating only symptoms, without knowing the underlying causes, can sometimes do more harm than good.

1. Include nutrition and exercise as part of a comprehensive treatment strategy for HIV.
2. Rigorously diagnose and properly treat causes of weight loss.
3. When necessary, consider using supplements to replenish deficiencies.
4. Follow reasonable guidelines for “safer” food preparation.
5. Learn the pros and cons of various interventions.

Consider using supplements

3

In HIV disease, even when CD4+ cell counts are high and there are no apparent signs of disease, some nutritional deficiency may still exist. Many people attempt to give their bodies an edge over the virus by adding vitamins and other nutritional supplements to their diets.

This may help correct minor deficiencies and may strengthen the body’s natural immune defenses. But much research still needs to be done to fully document vitamin and nutritional deficiencies throughout HIV disease and how supplements affect these problems. Still, using a sensible level of supplements to replenish deficiencies just makes common sense.

Vitamins and nutritional supplements should not be used to replace food. Whenever possible, it’s preferable to take in more vitamins through better eating habits. Supplements can be too expensive for people on strict budgets, disability or other assistance. Some people spend hundreds of dollars per month on these products. This is probably unwarranted in most cases. There are little data to support using “mega” doses of vitamins and supplements in HIV disease.

Some states and counties have programs that help cover the cost of alternative therapies and supplements. To find out if programs exist in your area, call your local health department.

Using vitamins, like nutrition and exercise plans, should be re-evaluated periodically. Your doctor can help with this or can refer you to a registered dietitian, a specialist in these issues.

The body’s ability to absorb nutrients appears to decrease in the course of HIV disease. Therefore, adding amino acids and other enzymes that help digest food

may be useful. In this case, it’s unclear whether taking ever-larger doses of supplements produces any added benefit.

Some doctors who specialize in the use of vitamins and supplements recommend giving vitamins in the vein (intravenously) when absorption becomes a problem. This is not such a far-fetched idea, as conventional TPN formulas (explained later) include vitamin supplements in their mix. Similarly, some hospitals include intravenous vitamin supplements when patients are restricted from eating food.

One difficulty in making decisions about using vitamins is that the vitamin industry is entirely unregulated. This means that when you purchase a product it may not contain what it advertises on its label. One source that may help you evaluate different brands of vitamins is www.consumerlabs.com.

A “brown bag” medical check-up is an important way to monitor your health. When you visit your doctor, put all the meds you take, regularly and occasionally, into a bag. Include vitamins, herbs, nutritional supplements and prescribed medications. Then, ask your doctor or pharmacist to review your therapies for safety, appropriateness, compatibility and instructions for use. This will help avoid harmful interactions and may help diagnose symptoms caused by side effects of and interactions between therapies.

Remember, just because something is available over the counter or perceived as “alternative” or “natural” does not mean it is not toxic or safe to take with other therapies. For more information, read Project Inform’s publications, *Drug Interactions* and *Herbs, Supplements and HIV Disease*, available at 1-800-822-7422 or www.projectinform.org.

Guidelines for “safer” food preparation

4

Properly handling food is one area that can greatly impact your ability to keep up with your nutrition and exercise. Carefully handling and preparing your food while avoiding certain other foods that can easily cause disease may help prevent infections, which can tax your ability to maintain weight. For a complete discussion of safe food handling, read *Home Food Safety*, available through Project Inform’s hotline and website. Meanwhile, some basic guidelines include the following points.



- Wash fruits and vegetables thoroughly to remove organisms, such as *Mycobacterium avium* intracellulare (MAI, the cause of MAC), which are found in soil. Use a vegetable brush to remove soil and chemicals. Avoid eating fresh vegetables and salads at restaurants or

any place where you can’t be certain that the products are washed adequately to meet your needs.

- Avoid eating raw eggs and food containing raw eggs. Each year, thousands of cases of *Salmonella* poisoning come from eating Caesar salads made with raw eggs. If you eat salads at restaurants, ask if raw eggs are used in salad dressings and other foods—avoiding raw eggs whenever possible.
- Cook meat thoroughly. Avoid “pink” meat, including rare steaks or burgers and uncooked meat or fish, including sushi. Diseases like salmonellosis, toxoplasmosis and parasites are found in raw and undercooked meats.
- Avoid raw shellfish like oysters and clams. They may contain organisms like hepatitis A and parasites.
- Use different cutting boards for cooked foods and for raw foods. For example, salads prepared on a cutting board that was just used for preparing meat can become contaminated by organisms in the meat.
- Wash hands, kitchen utensils and cutting boards frequently and thoroughly during food preparation. This will help avoid meat juices from contaminating cheese, vegetables and other foods.
- Keep kitchen appliances, shelves, countertops, refrigerators, freezers and utensils clean. Wash sponges and towels frequently. Properly storing and cooking food can help reduce the risk of food-borne diseases.
- Wash all utensils and your hands with soap and water between handling one food and handling another. This helps prevent cross contamination.
- Boil drinking water between 1–5 minutes to avoid cryptosporidiosis. Some water filters can remove contaminants from tap water, but read your filter’s information booklet to be sure. For more information, read the publications, *Cryptosporidiosis* and *Home Food Safety*, available from Project Inform at 1-800-822-7422 or www.projectinform.org.
- Thaw meats in the refrigerator or microwave rather than in open air. Keep the refrigerator temperature at 40°F or lower.
- Other guides to safer food preparation are available in bookstores that carry materials on nutrition and HIV.

Vitamin supplements

Your doctor or a registered dietitian who specializes in HIV can help you design a nutrition plan that works best for you. The following list is provided simply as something to speak with a doctor or trained nutritionist about. Consider these supplements once a day, preferably at either breakfast or lunch:

- 1x: “Ultimate One” or equivalent vitamin
- 1x: beta carotene (25,000 iu)
- 1x: vitamin B-12 (500mcg)
- 1x: combined calcium/magnesium/zinc (CMZ) (1,000mg/400mg/15mg)
- 1x: iron
- 1x: vitamin E (200mg)
- 1x: selenium (400mcg)
- 1x: zinc (50mg in addition to the CMZ)
- 1x: folic acid
- 1x: vitamin C (3,000mg)
- 1x: capsule acidophilus, 10–20 minutes after meal

At another meal:

- 1x: B-12 (500mcg)
- 1x: vitamin C (1,500mg)
- 1x: acidophilus shortly after the meal

If anyone started all these vitamins at once, they would probably develop stomach problems or diarrhea. If you are considering vitamins and are not currently taking supplements, you’d probably do best by starting with only a good multivitamin once a day. Learn about other options. If you consider other vitamins, add them to your daily routine slowly over time and not all at once. This will diminish side effects. For more information on vitamins, read Project Inform’s publication, *Herbs, Supplements and HIV Disease*.

nutritional concerns of women with hiv

By Marcy Fenton, MS RD and Jeffrey Bowan

Excerpted from AIDS Project Los Angeles' *Positive Living*, Jan. 1996

Women often tend to the nutritional needs of their families and neglect their own nutritional health. For women with HIV, this lapse can lead to increased instances of AIDS-related conditions, a general lack of energy and depression; serious consequences which may result in hospitalization.

By addressing their basic nutritional needs, HIV-positive women can maintain a healthier, stronger immune system; mount a better defense against infections; increase effectiveness of medicines and medical procedures (also minimizing their side effects); prevent the breakdown of soft body tissues and maintain the energy needed to lead an active, full life.

Here are a few conditions affecting HIV-positive women which can be controlled and enhanced through proper nutrition:



HEAVY MENSTRUAL PERIODS

Some HIV-positive women experience heavier bleeding during their periods. This may be due to low platelets. For women taking AZT, there is a greater risk of iron-deficient anemia. Eating lean meats, liver, egg yolk, legumes, green leafy vegetables, whole grains, molasses, fortified cereals and other iron-rich foods may be helpful.

LOW IRON LEVELS

To increase absorption of iron from non-animal sources, combine these foods with those high in vitamin C such as citrus fruits, tomatoes, cabbage, strawberries, green leafy vegetables, broccoli, green and red peppers, potatoes and supplements.

LIGHTER OR MISSED MENSTRUAL PERIODS

This condition often appears in women who are extremely underweight or overweight. When a woman is underweight and under stress, while not getting enough calories and nutrients, the body functions conservatively and slows or stops menstruation (called amenorrhea). To help alleviate this, concentrate on eating "three square meals" a day, including each of the food groups, with additional healthy snacks and weight-gain supplements (drinks or bars are fine). Increase fluid intake and take time for both physical movement and rest each day.

PREMENSTRUAL SYNDROME (PMS)

This condition can be improved through proper diet. Here's the plan: Eat starchy and protein rich foods every three hours to avoid food jags and sharp drops in blood sugar. Choose from each of the basic food groups, including liver, meat, eggs and vegetables for B-vitamin values. Add a bit of vegetable oil (sunflower, safflower or corn) to ensure intake of fatty acids. It may be beneficial to eliminate, or cut back on, caffeine (including chocolate) to reduce breast-swelling and pain. Also, avoid high sodium foods (added salt, chips, processed foods) which can cause bloating. It may be a relief to know it is common to eat 300–500 more calories premenstrually, but choose this food wisely and resume your normal caloric intake after your period.

MENOPAUSE

As with all menopausal women, HIV-positive women at this stage lose bone calcium and need to increase calcium in their diet with calcium (such as Tums). As women get older, they tend to eat more and exercise less. Including a good protein source at each meal and snack, and participating in a physical activity each day, such as stretching and walking, as advised.

Many products and approaches help people with nutrition and wasting, but there are no guaranteed solutions for every situation. Likewise, there's a fair amount of hype and misinformation about them. Supplements and vitamins are often promoted aggressively, whether or not adequate data support the claims they make. The products have varying degrees of effectiveness, side effects and potential interactions with anti-HIV drugs. A good rule to remember is that what works for one person in one situation may not work for the next person. The best solution is to form your own opinions after collecting as much unbiased information as possible.

Weight gain supplements

Many weight gain and protein supplements are available through pharmacies, supermarkets and health food stores. These products should not replace solid food. Protein supplements, like those used by bodybuilders, are sometimes used by people living with HIV to prevent or treat weight loss.

When considering these supplements, look into the kind of calories they add. Calories from protein or carbohydrates are often preferable to fat calories. Look for products high in proteins and low in sugars and fats. Some claim to be better for metabolic weight gain, promoting the development of protein building.

Protein drinks, like Ensure, Advera, Nutren and Resource, are also commonly used by people with HIV. Advera has the lowest fat content and is highest in protein. It is also the most costly. Ensure is less expensive, but higher in fat and sugars. Both Nutren and Resource are less expensive, but have high fat contents. Again, these products should not replace solid food.

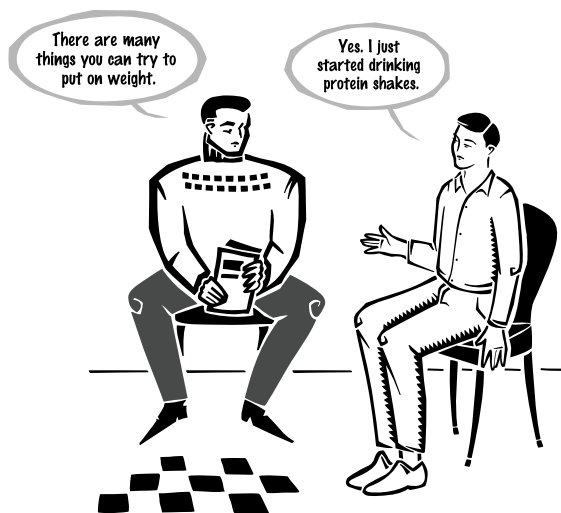
Combining protein and weight gain supplements with exercise is critical for optimal success. Even if exercise is limited to stretching exercises, anything that can help build lean body mass is important. If your diet is limited to liquid nutrition, add fiber from bulking laxatives (like Metamucil) to help clear the colon and control diarrhea.

Appetite stimulants

Some people find they need appetite stimulants in order to maintain their weight and good nutrition. Many people believe that marijuana may help stimulate their appetites and calm their stomachs. Some people prefer baking it into brownies since smoking marijuana can be hard on their lungs.

The chemical in marijuana, THC, has been synthesized. It is the active ingredient in dronabinol (Marinol), approved by the Food and Drug Administration (FDA) as an appetite stimulant for people with HIV. But absorbing dronabinol into the body is problematic. Sometimes it works perfectly; sometimes not at all. At other times it works a little too well, leaving folks too euphoric or "stoned" to carry on with normal activities. These stimulants also may not be appropriate for people in recovery programs. For more information, read Project Inform's publication, *Medical Marijuana*, available at 1-800-822-7422 or www.projectinform.org.

A number of studies show that Megace, a synthetic female sex hormone (progesterone), increases appetite and weight. One study suggests that most, if not all, weight gain associated with Megace is in the form of body fat, not muscle. However, these studies show that people taking Megace reported improved weight and general well being. Side effects include blood clotting (rarely) and breast enlargement in men. Megace should not be used by pregnant women because of possible harm to her unborn child.



Hormone therapy

Recombinant human growth hormone (rHGH, Serostim) is FDA-approved for treating HIV-related wasting. Studies show that people with wasting who use rHGH have increases in muscle mass, energy level and decreases in body fat. People with wasting may not want to lose fat weight, however, so adding in strategies to maintain and increase body fat while taking rHGH makes sense. This might include using appetite stimulants, which usually results in fat gain.

Side effects from using rHGH include joint stiffness, edema, elevated lab markers of sugar and fat processing (glucose and triglycerides) and nausea. In studies these were usually mild and resolved with reduced doses. The drug is extremely expensive but is available through some federal access programs.

Anabolic steroids, like testosterone, may help treat or prevent wasting. (Anabolism refers to building proteins.) Few studies have examined using anabolic steroids in HIV, but doctors routinely correct testosterone deficiencies with testosterone replacement therapy. A broader and largely unanswered question is whether wider use of anabolic steroids helps prevent or treat wasting. There is little information available on how these steroids affect HIV production, but many people are experimenting to see if using steroids can help them maintain or increase their lean body mass.

A study evaluating the testosterone patch (Testoderm) for treating HIV-related weight loss showed that those using the placebo patch actually had better weight gain than those using the testosterone patch. While those on the testosterone patch experienced higher testosterone levels, these increases did not result in improved weight gain. This calls into question the use of testosterone therapy for managing unwanted weight loss and at the very least provides a caution to those considering this approach to set very clear therapy goals.

Women naturally produce testosterone. However, women with HIV-related wasting have lower than normal levels of it. Infrequent menstruation is one of many

symptoms connected with AIDS wasting in women. Results from one study suggest that women who take a replacement dose of testosterone (a dose that brings the hormone to a normal level) experienced weight gain, return of menstruation and improved quality of life. Replacement therapy was generally well-tolerated. However, more studies are needed to measure its effects and safety in women living with HIV.

Another anabolic therapy, called oxandrolone (Oxandrin), is approved for treating unwanted weight loss when its cause cannot be identified. It is an oral drug and can be used by women as it is not as “virilizing” as other anabolics. When women use other anabolic steroids, it can cause them to grow facial hair and other male characteristics.

Anabolic steroids have side effects of varying degrees. They range from kidney toxicities, developing secondary male characteristics in women (like facial hair and enlarged clitoris), and shrinking of the testicles in men (testicular atrophy) to skin problems (including acne), among others. Testosterone therapy shuts down the body’s production of testosterone. This can create a dependency on the therapy. For these and other reasons, anabolic steroids are probably not the best first line of treatment for weight loss, but they may have some advantages before using therapies like rHGH.

DHEA is a product that is sold in health food stores and is believed to help the body produce testosterone. Studies looking at the effect of DHEA on various immune markers, like CD4+ cell counts, suggest that it appears to neither benefit nor harm the immune system. However, some people report that using DHEA has resulted in their improved quality of life. Simply because this product is available over the counter does not mean that it’s not without side effects or potential risks. Indeed, there have been reports that some people using DHEA are more likely to develop certain cancers. None of these products should be used by pregnant women because of potential risks to their unborn children.

final thoughts

Finally, good nutrition and maintaining lean body mass are key parts of a comprehensive anti-HIV strategy. Weigh the pros and cons of your available options and develop a nutrition and weight maintenance plan that fits your lifestyle. Interventions are available if wasting becomes a problem, but as with almost every aspect of HIV, preventing the problem is the best solution.

Cytokine manipulation

Increases in certain chemical messengers (cytokines) produced by immune cells have been associated with increases in HIV production, disease progression, KS tumor progression and wasting syndrome. These cytokines, which include tumor necrosis factor (TNF) and interleukin 1 and 6 (IL-1 and IL-6), are associated with inflammation.

A drug called thalidomide inhibits TNF. Several thalidomide studies have been completed and others are ongoing. One study examined its benefits in treating HIV-related sores in the mouth and esophagus. It showed that the drug is very effective in treating this condition. Another study evaluating its effect for treating HIV-related wasting shows that those taking thalidomide experience greater weight gain compared to those on placebo.

Celgene, the company making thalidomide for treating HIV-related weight loss, has a compassionate use program. The program will cover the full cost of the drug until the company gets approval from the FDA. For more information on this program, people can have their doctors contact the company at 1-800-801-8328.

Thalidomide causes serious birth defects when taken by pregnant women. For this reason, Celgene requires that women and men who access the drug through the program either agree to refrain from reproductive sex or use two methods of contraception (like one barrier and one hormonal). This would cover the period beginning four weeks before, through four weeks after, using thalidomide. The company recommends that men use condoms because researchers do not know if the drug is present in semen.

Thalidomide can cause serious birth defects if taken even once during the first trimester. If a woman taking thalidomide suspects for any reason that she has become pregnant, she should stop the drug and consult her healthcare provider immediately. It's very important that both women and men, engaging in reproductive sex, use precautions to prevent pregnancy if either partner is taking thalidomide.

One side effect of thalidomide is *peripheral neuropathy*—pain and tingling in the hands and/or feet. The drug should be used cautiously when taking other therapies that cause neuropathy, like didanosine, stavudine and zalcitabine. Other side effects include drowsiness, rashes, fever, irregular heart rhythm, low blood pressure and decreases in neutrophil counts (*neutropenia*), which are important cells that fight infection.

Partial or Total Parenteral Nutrition (PPN or TPN)

PPN and TPN are liquid nutrients that are delivered intravenously through a line surgically fixed in a major vein. Some providers use PPN, together with solid food, to treat moderate-to-severe wasting. When wasting becomes severe, TPN is used. Often, due to expense (up to \$13,000 per month), TPN is used too late to help restore body mass. As wasting becomes more severe, it becomes increasingly difficult to treat. Intervening early, even with an aggressive approach like TPN, is important.

An IV diet is hard on the body: the intestines are not “exercised,” and the longer TPN is used the more difficult it is to re-adjust to solid foods. TPN is very high in fatty proteins, and the weight gain associated with TPN is primarily fat and water weight. While this is clearly not the best, it may help someone with severe wasting. TPN should only be used when the intestines have stopped working and other oral interventions are not being absorbed.