your guide
to understanding

Lipodystrophy

syndrome

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This brochure is intended to assist individuals in their decision making with their physician. It is not medical advice. Please consult your physician before starting, changing, or stopping the use of any drug mentioned in this publication.

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Introduction

Our bodies are an important way that we present ourselves to others. One of the ways our friends, families, and colleagues know us is by the look of our bodies and how we carry ourselves. How others perceive us—those unavoidable first impressions—can affect how we feel about ourselves. Luckily, by accepting our bodies and placing in perspective the perceptions of others, we may come to a greater appreciation of who we are as individuals.

Most people are in touch with how their bodies look and feel; those living with HIV sometimes more so than others.

Most people are in touch with how their bodies look and feel; those living with HIV sometimes more so than others. As you probably have come to learn, your body is a barometer for the various signs and symptoms that can accompany HIV disease. It responds in numerous ways to treatment with antiretroviral drugs and other medications. Chances are you already keep careful watch for any body changes that may mean a change in the course of your HIV disease or treatment.

During the past few years, attention to body fat changes in people with HIV infection has increased. Many people are also seeing their **cholesterol*** and **triglyceride** levels rise abnormally or are starting to have trouble with their **blood sugar**. In many cases, they have relatively high levels of **CD4⁺ cells** and low **viral loads**, and they feel healthy. As more people with HIV develop these body fat and **metabolic** changes, there is much debate over what causes these difficulties. Some have placed the blame on the use of antiretroviral drugs such as **protease inhibitors (PIs)** or **nucleoside reverse transcriptase inhibitors (NRTIs)**. Others believe that the HIV disease process may play a significant role in the development of these problems.

As scientists sort out the reasons behind these body fat changes, people with HIV want to know what they can do to avoid these problems, or find effective treatments once they experience them. That's what this patient guide to **lipodystrophy** (pronounced lip-oh-DIS-troh-fee) and body fat changes is all

*Throughout this brochure important words or terms are highlighted in **bold print**. They are defined in the Glossary, starting on page 21.

about. Lipodystrophy is the medical term used to describe changes in how fat is distributed throughout our bodies. In the following pages, you will read the latest information surrounding the possible causes and treatments of this syndrome. By reading this guide, you may be better prepared to deal with such changes in your body and weigh all options before deciding on an effective course of action for prevention, as well as possible treatments, should these changes occur.

What Is Lipodystrophy?

At the moment, there is no official definition for this **syndrome**, although researchers continue to work toward developing one so that when we talk about it, we know we are talking about the same thing. Changes in the distribution of body fat and abnormal laboratory findings linked with these changes are commonly grouped together under the term lipodystrophy. While lipodystrophy is frequently used as an umbrella term to describe these diverse body fat changes and laboratory abnormalities, the term better describes fat loss only. The term fat redistribution, or fat **derangement**, more properly describes the loss of fat in one area (*ie*, legs, arms, face) and the accumulation of fat in other areas (*ie*, upper back, abdomen).

Reports on these changes began surfacing in late 1997. They came after encouraging news about PIs and **highly active antiretroviral therapy (HAART)** started to fill the AIDS community with hope and promise. Today, more individuals are reporting body fat changes, lipodystrophy, and abnormalities in blood fats and **glucose** levels. Since there is no set definition for this collection of symptoms, it is difficult to determine how often people living with HIV are developing them. Estimated prevalence rates vary widely, from a low of 3% to a high of 83% of people on HAART.

Changes in the distribution of body fat and abnormal laboratory findings linked with these changes are commonly grouped together under the term lipodystrophy.

In general, three different types of body fat and metabolic changes have been reported to take place in some people—

- Elevated lipids (**hyperlipidemia**)—abnormal increases in fat particles (triglycerides and cholesterol) found in the blood.
- Glucose intolerance—an inability of the cells to use sugar (glucose) as fuel to power the body. This may be the result of **insulin resistance** or the development of **diabetes**.
- Fat redistribution—the gain or loss of fat within various areas of the body. While fat may increase in the breasts or abdomen, it may also be lost in the legs, arms, buttocks, or face (lipodystrophy). Some people may develop large deposits of fat on the upper portion of their back, a condition known as buffalo hump (see Figure 1).

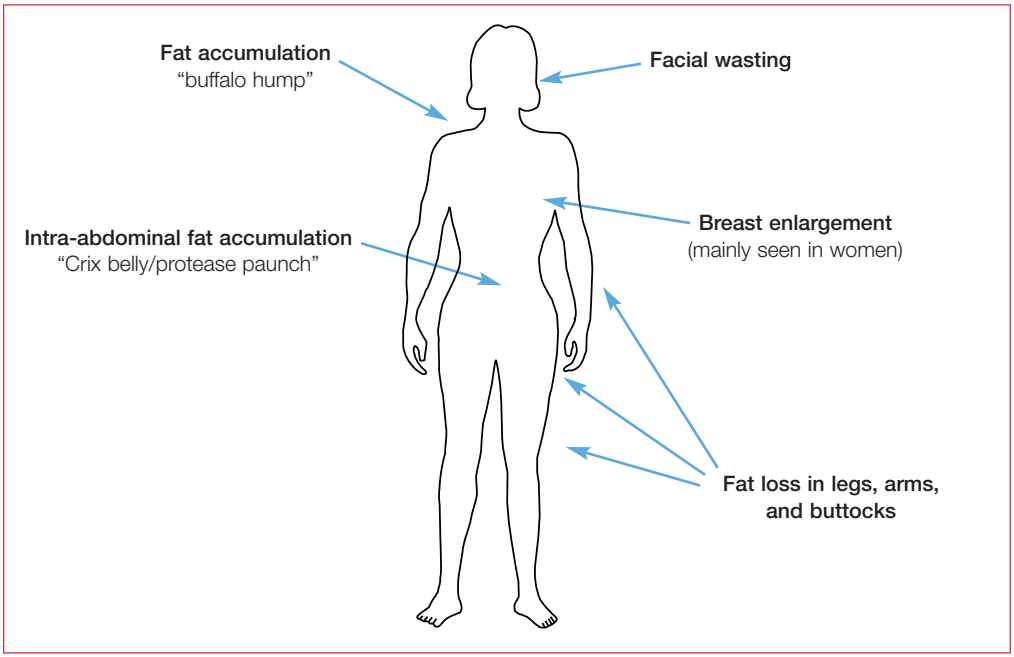

Figure 1 Main areas of fat changes.

This syndrome is not the only condition that can cause body changes in persons with HIV infection. A serious illness, such as **AIDS wasting**, can also result in significant body changes, particularly if the illness has happened within the last three months.

Elevated Lipids

Among individuals with HIV infection, there have been wide reports of increases in the level of lipid (fat) particles in the blood. This condition is called hyperlipidemia. Cholesterol and triglycerides are two types of lipids that are elevated in individuals with hyperlipidemia.

Since individuals with HIV are living longer, the early onset of heart disease has become a growing concern when these lipid abnormalities develop.

Made by the liver and also brought into the body from the foods we eat, cholesterol is a building block for cell membranes and certain hormones. You may have heard people talk about "bad" cholesterol and "good" cholesterol. Bad cholesterol, called low-density lipoprotein (LDL), can stick to the walls of blood vessels, causing problems such as poor circulation, high blood pressure, blood clots, and heart attacks. Good cholesterol, called high-density lipoprotein (HDL), keeps harmful LDL particles from collecting in the blood stream by bringing them back to the liver where they are broken down. High levels of LDL cholesterol in the blood can lead to an increased risk of heart disease and stroke, while high levels of HDL cholesterol can reduce a person's risk for heart disease and stroke.

Table 1. Risk Factors for the Development of Heart Disease

- Older age
- Men are at higher risk than women
- Family history of heart disease or diabetes
- Smoking
- High fat diet
- Inactive lifestyle
- Being overweight
- High blood pressure

Triglycerides are fatty particles that are used by the body to store energy. HIV infection, in general, can cause elevated levels of triglycerides. Individuals suffering from fat redistribution tend to have higher than normal levels of triglycerides in their blood. High triglyceride levels in the blood can lead to heart disease. Since individuals with HIV are living longer, the early onset of heart disease has become a growing concern when these lipid abnormalities develop.

Individuals who take PIs may also have raised levels of LDL cholesterol and triglycerides. Their HDL cholesterol levels, however, may remain the same or even decrease. This reduces the protective effect of

HDL cholesterol, thus increasing the risk of heart disease. It is also known that HIV itself can damage the heart muscle and cause decreased levels of HDL cholesterol.

People with HIV may have one or more risk factors for heart disease unrelated to HIV infection (see Table 1). They may also be taking other medications, such as testosterone and anabolic steroids, that can cause the blood to clot, further increasing their risk. All of these factors can work together to increase one's chances of developing heart disease.

Glucose Intolerance

Along with the metabolic problems the body may develop with using and storing fats, there can also be difficulties with the way the body uses glucose. Glucose is the fuel that the body uses to produce energy. **Insulin**, a hormone produced by the pancreas, allows the entry of glucose into the cells. Insulin resistance may develop in some people, which means their bodies become unable to properly **metabolize** glucose. When this delicate balance between insulin production and blood glucose levels is changed, individuals can develop type II diabetes, commonly known as adult-onset diabetes. This is a disease with many possible complications, including nerve damage, kidney failure, and blindness, if it is allowed to progress without treatment.

Fat Redistribution

Men, women, and children living with HIV infection have reported various changes in the normal distribution of fat in their bodies. This redistribution of body fat may take on one of several presentations involving the gain or loss of fat within the body. Individuals may experience one or more of these appearance problems; sometimes all of them are present in one person. Women, for example, may experience an enlargement of their breasts; in contrast, this occurs much less often among men. Individuals may also find fat building up on the back at the base of their neck, often referred to as buffalo hump (see Figure 2). Overweight men and women with HIV are at an increased risk for developing this problem. There may also be a collection of fat deep in the abdomen (see Figure 3). This type of intra-abdominal fat is different from the fat that normally collects just under the skin (subcutaneous) around the waist and is more dangerous to the individual. Someone with intra-abdominal fat accumulation usually has a hard belly, while a person with normal fat accumulation around the waist has a belly with a soft, dimpled feel to it.

Less frequently, some individuals may see a buildup of lumpy fat tissue, similar to cellulite, on their backs below the shoulder blades. Some have even reported small, lumpy fat deposits on the forehead.

Along with the accumulation of fat in these areas, there may be a loss of fat just under the skin in the face (see Figure 4), limbs (see Figure 5), and buttocks. With fat loss in the arms and legs, veins may show through more easily. Individuals with fat loss in the abdomen may also experience bulging veins in this area along with an increase in abdominal girth. The loss of fat in the face may create a gaunt look (particularly in the cheeks and temples), and may make existing wrinkles more evident. Some individuals with HIV may only experience fat loss without fat gain. Having a low weight when starting PI therapy, or being on antiretroviral drugs for long periods of time, may make someone more likely to experience these types of fat loss.

Figure 2. Buffalo hump.[1]

Figure 3. Fat accumulation in abdomen.[1]

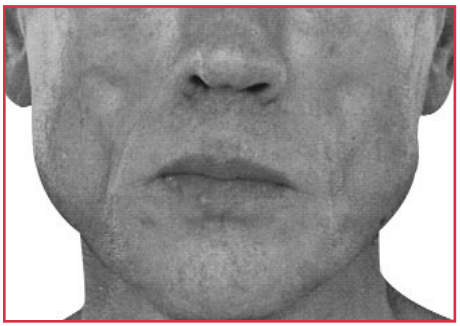

Figure 4. Fat loss in cheeks.[1]

Figure 5. Fat loss in legs.[2]

Depending on their severity, these body fat changes can become quite disfiguring. Aside from genuine cosmetic concerns, these changes can also interfere with the body's ability to function normally. For example, a large fat deposit around the neck may cause severe migraine headaches, poor sleep, and the inability to turn the neck in a normal fashion. Deep abdominal fat may place pressure on internal organs, resulting in gastrointestinal problems such as bloating and pain. Fat loss from the buttocks may make sitting for long periods painful.

It can be emotionally or psychologically challenging to deal with this syndrome.

It can be emotionally or psychologically challenging to deal with this syndrome. People with HIV who experience these changes may suffer from anxiety or depression, as these various body changes are difficult to hide once they develop. People who come into frequent contact with a person with this syndrome may notice these changes, prompting questions as to what may be wrong. For some, such body changes can create a forced outing of their HIV status to friends, family, and coworkers.

What Causes Lipodystrophy?

Debate continues as to the exact causes of body fat gain and/or loss and metabolic changes among people with HIV. It was once thought that PIs caused this syndrome. Today, however, it is thought that these changes are caused by a number of factors and may be a function of age, duration of HIV infection, length of therapy, and/or some specific therapies. A person's immune function and fluctuations in hormone levels may also contribute to the condition. None of these individual factors have been proven to cause this syndrome, but a number of theories continue to be offered. Understanding these theories may help you make informed choices. You should know, however, that the cause of body fat changes has not been established and none of these theories have been proven true or false.

The Possible Role of HIV Disease

Fat abnormalities have also been seen among individuals suffering from chronic diseases other than HIV. For a number of reasons, some researchers believe HIV

infection and disease progression play roles in producing these changes. Fat redistribution may be associated with the degree of viral load reduction and restoration of the immune system that often occurs with effective HAART. Additionally, lipid abnormalities have long been observed among people with HIV infection. As early as 1989, people with HIV-related wasting were shown to have abnormally high triglyceride levels when compared with uninfected people. Lower than normal levels of HDL cholesterol have also previously been noticed in people with HIV. Now that some people are living longer due to the use of HAART and PIs, some researchers believe that people who had risk factors for heart disease prior to starting antiretroviral treatment are now living long enough for cardiovascular problems to develop.

Antiretroviral Therapy

Some scientists believe that PIs, or other antiretroviral drugs, may be the cause of fat redistribution and the appearance of metabolic abnormalities. Those who believe this theory feel that most people taking these drugs will, at some point, experience these problems, commonly after one to two years of therapy. There is no proof that one PI causes more of these changes than another. In those individuals taking PIs who experience these changes, it is difficult to determine to what extent PIs, or other therapies, are causing these physical and/or metabolic changes.

Individuals taking PIs, who seem to be most at risk of experiencing these symptoms, include those who start therapy with lower total body fat, those who have been on anti-HIV therapy for a long time, and those who have a lower body weight prior to starting therapy. Other factors affecting this risk in people taking antiretroviral medications are the duration of therapy, the duration of HIV infection, an individual's disease status, and his or her age. Higher than normal levels of **fasting triglycerides** and C-peptide concentrations have been found to predict the severity of the syndrome many months later. Generally, the syndrome is more severe in individuals who have better responses to antiretroviral therapy, such as increases in $CD4^+$ cell counts and decreased viral loads.

This association between fat redistribution and antiretroviral therapy may have emerged because the greatest numbers of cases continue to occur in patients treated with PIs. Some researchers believe the HIV protease enzyme has a similar composition to two enzymes in the body involved in fat metabolism.

PIs may interfere with these **enzymes**, resulting in fat redistribution or metabolic problems. However, other research has shown that this may not be the case.

Table 2. Approved Antiretroviral Drugs

Class	Abbreviation	Generic Name(s)	Brand Name
NNRTIs	DLV	delavirdine	**Rescriptor®**
	EFV	efavirenz	**Sustiva™**
	NVP	nevirapine	**Viramune®**
NRTIs	**3TC**	lamivudine	Epivir®
	3TC + AZT	lamivudine + zidovudine	**Combivir®**
	ABC	**abacavir**	Ziagen™
	AZT	zidovudine	Retrovir®
	d4T	stavudine	Zerit®
	ddC	zalcitabine	Hivid®
	ddI	didanosine	Videx®
PIs	APV	amprenavir	**Agenerase™**
	IDV	indinavir	**Crixivan®**
	NFV	nelfinavir	**Viracept®**
	RTV	**ritonavir**	Norvir®
	SQV-HGC	**saquinavir** hard gel capsule	Invirase®
	SQV-SGC	saquinavir soft gel capsule	**Fortovase®**

Most commonly used names are in **bold** type.

These theories, however, do not explain the body fat changes, nor the changes in lipid metabolism, seen in individuals who do not take PIs. For example, 25% increases in cholesterol levels have been reported in individuals taking the combination of AZT + 3TC + efavirenz. Fat loss in the extremities, abdominal fat gain, and buffalo humps have also been reported in individuals taking only nucleoside analog combinations, such as AZT + 3TC or d4T + 3TC.

Some researchers believe that NRTIs may be toxic to mitochondria if they are used for long periods of time. Mitochondria are small structures found inside our cells. Often called the cells' powerhouses, mitochondria are where the cells produce energy for use by the body. Individuals with diseases that affect the mitochondria

also develop a syndrome similar to that affecting people with HIV infection and lipodystrophy. Some researchers believe NRTIs may affect the mitochondria in fat cells, leading to changes in the distribution of body fat.

All of these various theories suggest a role both for PIs and for NRTIs in contributing to fat redistribution and metabolic complications. The longer individuals receive antiretroviral therapy, the greater their risk for developing this syndrome. Additional work is needed, however, in order to determine if these theories are true.

Other Risk Factors

Certain people with HIV infection may be at greater risk for fat redistribution, lipodystrophy, and metabolic changes. Men have a higher rate of peripheral fat wasting and a higher frequency of laboratory abnormalities. Women, on the other hand, are less likely to have fat wasting in the extremities, but are more likely to have central fat deposits in the abdomen or breasts. Men and women who are overweight are at higher risk of developing buffalo hump. Overweight men have less facial fat wasting, while overweight women have more breast fat accumulation. Individuals with HIV infection over 40 years old, and especially over 50, also seem to be at greater risk. In addition, people who eat high-fat foods or who live sedentary lifestyles are also more prone to experience this syndrome. Finally, there may be some genetic factors yet to be determined that increase a person's chances of developing these changes. For example, some people are more genetically prone to being overweight or underweight. These natural differences in our bodies may influence whether fat gain or loss occurs as a consequence of this syndrome.

In addition, people who eat high-fat foods or who live sedentary lifestyles are also more prone to experience this syndrome.

In summary, the syndrome may be caused by a number of factors all working together. Aspects of HIV infection itself, as well as the way in which it is treated, may combine in several ways to produce these changes in fat distribution and metabolic abnormalities.

What Can You Do About It?

Given the fact that the syndrome remains poorly understood, there is limited knowledge about how to treat this condition in patients with HIV infection. This is little consolation to someone who has lost a significant amount of facial fat. The long-term health impact of fat redistribution in HIV disease is currently unknown. The disfigurement and consequent impact these changes have on self-esteem, however, can create a great deal of stress and anxiety.

There are significant health risks associated with elevated cholesterol and triglyceride levels, as well as with the body's inability to process glucose correctly. Most individuals living with HIV infection take an active role in their healthcare and would like to do something about these metabolic abnormalities. Traditional treatments used in individuals with high cholesterol levels and diabetes are being tried. Other, less common approaches are also being used with varying degrees of success.

In consultation with his or her provider, each individual must weigh the risks associated with stopping therapy—such as disease progression, or a diminished ability to successfully resume therapy at a later date—with the possible benefit of halting fat redistribution.

In an attempt to reduce body fat changes, some individuals with HIV elect to stop their antiretroviral therapy or eliminate certain drugs from their regimen. In consultation with his or her provider, each individual must weigh the risks associated with stopping therapy—such as disease progression, or a diminished ability to successfully resume therapy at a later date—with the possible benefit of halting fat redistribution. It may be better to live with the effects of this syndrome and the benefits of an effective antiretroviral regimen until a treatment for fat redistribution comes along, or until we better understand this complication.

Lipid-Lowering Medications

A group of drugs, known as statins, are widely prescribed to thousands of people in the general population who suffer from elevated cholesterol and triglycerides. Three of the most common of these drugs, atorvastatin (Lipitor®), lovastatin

(Mevacor®), and simvastatin (Zocor®), have been used to treat individuals with HIV infection who have hyperlipidemia as well. Unfortunately, the liver metabolizes these statins in the same manner as it does PIs and NNRTIs. For instance, one recent study showed that when atorvastatin or simvastatin were given at the same time as ritonavir and Fortovase, blood levels of each of the statins were increased too much. This creates the potential for liver toxicity and side effects. Safer statin options include fluvastatin (Lescol®) and pravastatin (Pravachol®), which are not metabolized by the same route in the liver.

Another class of lipid-lowering drugs is the fibrates. One fibrate, gemfibrozil (Lopid®), is somewhat effective for treating high triglycerides in individuals taking HAART. Some individuals have found success in combining statins and fibrates. Combining gemfibrozil and atorvastatin, for example, has been shown in one study to substantially decrease lipid levels in about half of the individuals who try this combination. However, combining statins and fibrates is not without certain health risks, such as **myopathy**.

Recombinant Human Growth Hormone

Some individuals living with HIV have used recombinant human growth hormone (Serostim®) as a treatment for AIDS wasting. Studies are currently testing this therapy as a possible treatment for fat redistribution. Human growth hormone has been shown to promote restoration of lean body mass. However, it also may affect triglyceride or cholesterol levels.

A number of individuals report good results with growth hormone used to treat buffalo hump. Unfortunately, some people using it have also noticed that their buffalo hump and abdominal fat return if they stop therapy or lower the dose. There is also a risk of developing **hyperglycemia** and elevating pancreatic enzymes. Hyperglycemia is a condition that often occurs before the onset of diabetes, and elevated pancreatic enzymes can often lead to pancreatitis, a potentially fatal inflammation of the pancreas. Since individuals already taking antiretroviral therapy may also be at risk of developing diabetes, caution should be used when taking growth hormone. Diabetes is a serious metabolic condition in which the body cannot properly process sugar. If untreated, diabetes can lead to blindness and heart disease, among other life-threatening problems.

Because of these potentially serious complications, growth hormone may not be suitable for all individuals, particularly for people already affected by hyperglycemia. Other side effects include tissue swelling, joint pain and stiffness, carpal tunnel syndrome, and flulike symptoms. Cost is also an issue—growth hormone is very expensive—and many health insurance plans do not currently cover its use.

Insulin-Controlling Drugs

Individuals experiencing insulin resistance and high blood sugar levels may benefit from medications designed to help the body utilize insulin more effectively. An example of one of these drugs is metformin (Glucophage®), the same agent used to treat people with type II, adult-onset diabetes. These drugs have been shown to reduce insulin levels and resistance, as well as lower blood lipids. One recent study showed that metformin therapy resulted in some decreases in intra-abdominal fat accumulation among people with that condition. In general, however, data from studies of people with HIV-associated fat redistribution are limited, and more studies involving larger numbers of patients are needed to determine the true utility of these drugs in helping to manage the syndrome.

Switching Therapy

Since body fat derangements and metabolic abnormalities were first thought to be associated with PIs, some physicians thought that switching patients from PIs to NNRTIs would help the problems. For example, some individuals have tried replacing the PI portion of their regimen with an NNRTI such as nevirapine. This switch has been shown to significantly lower cholesterol, triglycerides, glucose, and fasting insulin levels. In one small study, a majority of patients maintained undetectable viral loads after switching from a PI to nevirapine, although not all patients did. Patients should be aware that there is a risk of viral breakthrough or decline in $CD4^+$ cell count if the NNRTI-containing therapy does not prove to be as effective as the previous PI-containing regimen. Also of note, switching from a PI to nevirapine does not seem to improve the problems with body fat redistribution. Another NNRTI, efavirenz (EFV, Sustiva), has also been substituted for a PI in some patients, but results were mixed in terms of improvements observed in metabolic values.

Changing the antiretroviral regimen may be only moderately successful in improving body shape. After switching, some individuals report reductions in fat deposits around the abdomen; however, not everyone sees a return of fat in their legs and arms. Switching may produce a decrease in cholesterol and triglyceride levels, as well as a reversal of insulin resistance. If factors other than PIs are behind the development of these changes, then other specific measures must be taken in order to fully correct the condition.

Changes in Diet, Exercise, and Lifestyle

Individuals at risk of heart disease because of diet and lifestyle should consider making changes in these areas to improve their health. Such changes can include the following—

- Stopping smoking
- Eating low-fat foods
- Losing weight when necessary
- Getting adequate **aerobic** and **weight resistance** exercise on a regular basis

The possible benefits from these lifestyle changes as far as improving HIV-associated body fat problems or metabolic abnormalities are unknown, but appear to be limited at best. However, small decreases in average cholesterol and triglyceride levels may be achieved, and general benefits can also be realized from regular exercise, including a reduction in total body fat and trunk fat. One recent study found that weight resistance (lifting) training increased muscle strength and lean body mass, and decreased triglycerides in a group of HIV-infected men receiving anti-retroviral therapy. However, changes in body fat composition and distribution were not observed. Regardless of their specific, lasting impact on lipodystrophy, healthy eating and exercise can increase your energy level and promote a greater sense of well being.

Regardless of their specific, lasting impact on lipodystrophy, healthy eating and exercise can increase your energy level and promote a greater sense of well being.

Other Interventions

Some individuals with buffalo hump have elected to have their fat surgically removed through liposuction. More than likely, any benefit from surgical removal will be short term as fat deposits may reappear, sometimes within months. Having such procedures can also be very costly, as most health plans do not cover them. Surgical removal for abdominal fat deposits is not possible. This is because these deposits are deep within the abdominal cavity, surrounding the organs rather than being just under the skin's surface. Some women with breast enlargement have had their breasts reduced surgically, particularly when they are large enough to produce back pain or difficulty walking.

For those experiencing the loss of fat from the face, there may be the temptation to have fat injections or silicon implants in the cheeks. Implanted fat can disappear, while silicon implants may erode inside the body. In addition, there is a risk of infection from having these procedures performed.

There is continued discussion within the HIV community about the use of anabolic steroids and testosterone to reduce fat abnormalities. Anabolic steroids produce only a minimal amount of change, and while a testosterone deficiency should be treated, it remains unknown as to how helpful testosterone and anabolic steroids are in the treatment of lipodystrophy. In some individuals, these agents may actually promote hyperlipidemia or create problems with blood sugar.

Keeping Track of Changes

There are a number of things individuals can do to help them monitor changes in body fat distribution. First, before starting any antiretroviral regimen, ask your doctor to get a baseline fasting blood lipid profile and a glucose tolerance test. These should then be performed on a regular basis as you continue your prescribed therapy. Getting these tests done before starting antiretroviral therapy will let you know about your lipid levels (LDL cholesterol, HDL cholesterol, and triglycerides) and if you are having any existing problems processing glucose properly. By performing these tests periodically during therapy, your doctor can identify early on any risk you may have for developing the syndrome. A chart is

included for you to fill in your laboratory results to help you keep track of changes over time. You will see that healthy/normal ranges are listed in the left-hand column. However, these values may be different from the reference ranges listed on your laboratory results form.

Laboratory Results Diary

Fill out the laboratory values of each of these measurements each time you have your blood work done (every 2–6 months). Consult the glossary for definitions of these terms.

Remember that for cholesterol, triglycerides, and glucose, it is best to have fasting values. These are taken from blood samples drawn at least two hours after your last meal. You may want to speak with your provider about having your blood drawn in the morning before you eat breakfast.

Test	Date	Date	Date	Date	Date
CD4$^+$ count >600 cells/µL					
CD8$^+$ count 140–1,080 cells/µL					
CD4% 26%–68%					
CD4:CD8 ratio >0.6					
HIV RNA (Viral load) <25, <50 copies/mL ultrasensitive <400, <500 copies/mL standard					
Cholesterol, total Desirable: <200 mg/dL Borderline high: 200–239 mg/dL High: ≥240 mg/dL					

Test	Date	Date	Date	Date	Date
LDL cholesterol 60–130 mg/dL					
HDL cholesterol Men: 35–65 mg/dL Women: 35–80 mg/dL					
Triglycerides 10–190 mg/dL					
Glucose (fasting measure) 70–110 mg/dL					
Hemoglobin A_{1c} 4%–7%					
Testosterone Men: 4.0–8.0 ng/mL Women: <0.6 ng/mL					
Weight*					
Bioelectrical Impedance Analysis (BIA)* Total body water Intracellular water Extracellular water Body cell mass Extracellular tissue Fat free mass Fat mass					

*Normal ranges for weight and BIA values vary according to age, height, gender, and other factors. Keep track of changes over time to identify trends.

These are some of the standard laboratory tests most people with HIV regularly obtain, as well as some values obtained from a standard chemistry panel that pertain to the topics covered in this brochure. Some tests listed here may not be performed at every visit, as they may only be ordered in special circumstances. Of note, some laboratories have different reference ranges for these tests. Try to use the same laboratory over time so that results are standardized.

By keeping track of your body's changes during therapy, you are in the best position to identify any changes that might indicate body fat redistribution. In fact, most individuals are able to accurately pick up the first signs of this syndrome and have them later confirmed by their doctor. One way to do this is by having a friend take photographs of your face, full body, and profile every one to three months. Chances are you will be able to notice right away any changes, especially fat loss in the face, legs, and arms.

By keeping track of your body's changes during therapy, you are in the best position to identify any changes that might indicate body fat redistribution.

It is also a good idea to have your doctor include regular **body cell mass** measurements. An excellent way to do this is by measuring total body and regional fat, particularly central abdominal fat, with **dual-energy x-ray absorptiometry (DEXA)**. Central fat on DEXA shows both declining subcutaneous and accumulating intra-abdominal fat. Imaging studies, such as **computerized axial tomography (CAT or CT scan)** or **magnetic resonance imaging (MRI)** can also be used to visualize and measure body fat, particularly central fat. Although not nearly as accurate as the above methods, your doctor may also use routine **anthropometric measures** of your body mass index and waist–hip ratio to help determine if any changes are taking place. Estimating fat mass before and some time after the start of antiretroviral therapy may be helpful in determining the development of body fat redistribution or lipodystrophy.

Finally, it may be a good idea to meet with a dietitian or nutritionist who can help plan a complete diet and exercise program for you.

As was mentioned earlier, a number of lifestyle changes can be beneficial. Even making moderate changes in these areas can go a long way toward making you feel better. If you smoke, you should make every effort to quit. Reduce or eliminate your intake of alcohol. Eat low-fat foods, reducing your intake of dietary fats and sugars whenever possible. Participate in a regular exercise program that combines strength training with aerobic activity to improve the health of your heart. Finally, it may be a good idea to meet with a dietitian or nutritionist who can help plan a complete diet and exercise program for you.

Staying Informed

In addition to asking your doctor and other healthcare providers about any of your concerns, you may also want to seek out other sources of information on this syndrome. Your local AIDS service organization can provide you with additional resources, support groups, and literature. You may also want to keep track of clinical trials related specifically to the treatment of body fat redistribution, lipodystrophy, and metabolic abnormalities. This can be done by calling 1-800-TRIALS-A to hear the latest information about AIDS clinical trials in your area. If you have a computer, you may also want to subscribe to LIPIDLIST, a free Internet e-mail discussion list. Here, individuals can discuss current research and treatment, as well as share their own experiences and concerns. To subscribe, send an e-mail request to: listproc@critpath.org. In the body of the message, type: *subscribe lipidlist*, then add your name. NAPWA's Information and Referral Service can also point out other resources that may be of assistance; call (202) 898-0414, ext. 113 for more details.

There is a great deal more to be learned about this syndrome. Research is currently underway to accurately define the condition and to determine its exact causes. In addition, a number of studies are looking at better ways to treat these body changes when they develop and, more important, to prevent them from happening in the first place.

Until more information becomes available, nothing can take the place of the relationship you have with your primary care provider. Working together, the two of you can learn more about this syndrome and develop appropriate treatments that are just right for you.

Glossary

Aerobic exercise: exercise that benefits the cardiovascular system, such as running, cycling, swimming, or aerobics classes.

AIDS (acquired immunodeficiency syndrome): the late stage of HIV disease, which is diagnosed by the development of specific opportunistic infections, cancers, or $CD4^+$ counts of less than 200 cells/mL, in the presence of HIV infection.

AIDS wasting: an AIDS-defining condition, generally defined as the unintentional loss of greater than 10% of normal body weight.

Anthropometric measure: a technique to measure body fat with the use of calipers and other devices.

Bioelectrical Impedance Analysis (BIA): a simple test performed in your doctor's office that provides information such as how much water and fat are contained in your body.

Blood sugar: also known as glucose, a simple sugar used by the body's cells as the main fuel for energy.

Body cell mass: the amount of lean muscle and organ tissue in a person's body. Body cell mass is often measured to determine if someone is suffering from HIV-related wasting or lipodystrophy.

CAT or CT scan (computerized axial tomography): a diagnostic technique that uses a computer and x-rays to produce clear, cross-sectional images or slices of the tissue being examined. It offers a more detailed image than traditional x-rays.

$CD4^+$ cell: also called CD4 lymphocyte or helper T cell. It is a part of the immune system—a type of white blood cell that helps the body fight infection—and a main target for HIV infection. Chemical messengers released by these cells regulate other immune system cells.

CD4:CD8 ratio: the ratio between these two types of infection fighting cells. In a healthy individual this is usually greater than 1, in someone living with HIV it is usually less than 1.

CD4%: $CD4^+$ cells are only some of the infection-fighting cells in the body. The CD4% shows how large a portion of these types of infection-fighting cells are $CD4^+$ cells. A healthy person, uninfected by HIV, will normally have a CD4% of 45% to 55% of these infection-fighting cells. Below 14%, one is considered to be at higher risk for opportunistic infections.

$CD8^+$ cell: an immune cell that fights cells that are already infected.

Cholesterol: a fatty substance necessary for cell membrane development and nerve fiber insulation. There are two types of cholesterol in the blood. Low density lipoprotein (LDL), commonly called "bad cholesterol," can cause heart disease. High density lipoprotein (HDL), commonly called "good cholesterol," protects a person from heart disease.

Derangement: a disturbance in the normal functioning of a body process.

DEXA (dual energy x-ray absorptiometry): a technique used to measure total body and regional fat that is much more accurate than anthropometric measurements.

Diabetes: a disease resulting from the body's inability to produce insulin or respond to its effects on glucose in the blood. Diabetes produces high blood glucose levels (hyperglycemia) in the blood. Type I diabetes most often develops during childhood, and is sometimes called juvenile diabetes. Type II diabetes most often develops during adulthood, and is the form of diabetes that has been associated with the metabolic problems observed among people with HIV.

Enzyme: a protein that regulates chemical reactions in the body.

Fasting triglyceride: a triglyceride measurement taken at least two hours after the last time food was eaten.

Glucose: a simple sugar used by the body's cells as the main fuel for energy. A fasting measure is taken at least two hours after the last time food was eaten.

HAART (highly active antiretroviral therapy): this is a treatment regimen that is typically thought of as two NRTIs plus a PI or an NNRTI.

Hemoglobin A_{1c}: a measurement of longer-term blood glucose. Its levels are increased when blood glucose is uncontrolled; for example, in untreated diabetes.

HIV RNA: see **viral load**

Hyperglycemia: abnormally elevated levels of glucose (sugar) in the blood that may be a consequence of diabetes or other conditions.

Hyperlipidemia: a condition characterized by high levels of fat (cholesterol, triglycerides) in the blood. Hyperlipidemia is considered a risk factor for the development of heart disease.

Insulin: a hormone secreted by the pancreas that enables cells in the body to absorb glucose efficiently.

Insulin resistance: decreased effectiveness of cells to respond to insulin, resulting in high glucose levels (hyperglycemia) in the blood.

Lipodystrophy: the loss of fatty tissue, particularly in the legs, arms, and face. The term is also frequently used to describe any type of body fat redistribution.

Metabolic: adjective form of metabolism (see metabolism).

Metabolism: the chemical changes in cells which provide energy for the body.

Metabolize: verb form of metabolism (see metabolism).

MRI (magnetic resonance imaging): a diagnostic technique that produces high-quality, cross-sectional images of organs and structures in the body without using x-rays or radiation.

Myopathy: any disease of the muscle. Myopathy may be caused by a number of factors such as alcoholism or use of certain medications, among others.

NNRTIs (non-nucleoside reverse transcriptase inhibitors): a class of antiretroviral drugs similar to NRTIs. Drugs available in this class are delavirdine, efavirenz, and nevirapine.

NRTIs (nucleoside reverse transcriptase inhibitors): a class of antiretroviral drugs used to treat HIV infection. NRTIs suppress viral replication by interfering with the reverse transcriptase enzyme found inside HIV. Drugs available in this class are 3TC, abacavir, AZT, d4T, ddC, and ddI.

PIs (protease inhibitors): a class of antiretroviral drugs used to treat HIV infection. Protease inhibitors block the action of the HIV protease enzyme, resulting in a reduction of viral replication (the reproduction of HIV). Drugs available in this class are Agenerase, Crixivan, Fortovase, ritonavir, saquinavir hard gel capsule, and Viracept.

Syndrome: a group of symptoms that occur together to define a particular condition or illness. AIDS (acquired immunodeficiency syndrome) is an example of a syndrome, because it is defined by any number of infections with which one may be diagnosed.

Testosterone: a hormone produced by both sexes that is associated with male sex characteristics such as beard growth, larger muscle mass, etc.

Triglyceride: a type of fat particle that circulates in the blood. High levels of triglycerides increase a person's risk of heart disease.

Viral load: this refers to the quantity of HIV found in the blood. Viral load is determined by measuring the level of HIV RNA, an indicator of how much HIV is reproducing in the body. Changes in viral load are used to determine whether or not antiretroviral therapy is working.

Weight resistance exercise: weight lifting or other exercise that increases muscle size.

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The National Association of People with AIDS (NAPWA) advocates on behalf of all people living with HIV and AIDS. Through education, public policy, community development and training, we are working to end the HIV pandemic and the human suffering caused by HIV and AIDS.

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