

Lipodystrophy and Body Changes ^[1]

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What Is Lipodystrophy?

Lipodystrophy means abnormal fat changes. It is used to describe a number of changes in body fat that are experienced by many people living with HIV (HIV+). Lipodystrophy can also include changes in fat and sugar levels in the blood of people living with HIV. Although there is no official definition of lipodystrophy in HIV, it is generally broken down into two categories:

- Body shape changes ? Includes fat loss (lipoatrophy) and fat gain (lipohypertrophy) or movement of fat from one area to another (redistribution) in particular areas of the body
- Metabolic complications ? Includes increases in fats and sugars in the blood

People living with HIV can experience both body shape changes and metabolic complications. This is sometimes called lipodystrophy syndrome.

Body Shape Changes

Changes in the shape of your body can be caused by fat loss, fat build up, or fat redistribution.

Fat loss may happen in the:

- Arms and legs (fat loss may cause veins to appear larger in the arms and legs)
- Buttocks
- Face (sunken cheeks)

Fat build up may happen in the:

- Stomach
- Breasts
- Back of the neck ("buffalo hump")
- Front of the neck ("turkey neck")
- Round lumps of fat may appear under the skin (lipomas)

Some studies show that lipodystrophy affects men and women differently. Women are more likely to see fat gain in their breasts and stomachs while men are more likely to see fat loss in their legs, arms, buttocks, or faces. However, many men and women suffer from both symptoms. It is not clear why there might be differences based on sex. It may have something to do with hormones or with how men and women burn fat differently.

Lipodystrophy can dramatically change your appearance. These changes can leave some people with feelings of poor self-image and low self-esteem. Some people may want to stop taking their HIV drugs. Others may put off HIV treatment due to fear of experiencing lipodystrophy symptoms. If you are feeling this way, it is important to talk to your health care provider so that you take the necessary steps to improve your health. It is also important to

know that many newer HIV drugs are less likely to cause lipodystrophy. If you are taking HIV drugs that do cause lipodystrophy, you and your provider can consider switching to HIV drugs that may reduce these symptoms.

Metabolic Complications

Changes in fat (lipids) and sugar (glucose) in your blood are called metabolic complications and include:

- Increased lipids in your blood such as cholesterol and triglycerides ([hyperlipidemia](#) [2])
- Increased blood sugar or glucose levels (hyperglycemia)
- Insulin resistance or [diabetes](#) [3]
- Increased [lactic acid](#) [4] in your blood

Metabolic changes cannot be seen with the naked eye; they can only be confirmed through blood tests. Without treatment, they can cause serious long-term health problems.

- Increased levels of cholesterol and triglycerides can put you at a higher risk of developing [heart disease](#) [5] or having a heart attack or stroke
- Increased blood sugar and insulin levels greatly increase the chance of developing [diabetes](#) [3], a disease that can cause vision and kidney problems and may be life threatening
- Increased lactic acid can lead to a rare but dangerous condition called [lactic acidosis](#) [4]. Symptoms include nausea, vomiting, or stomach pain; feeling very weak and tired; and shortness of breath.

It is important that you and your health care provider make sure you get regular [lab tests](#) [6] to check for metabolic complications. Call your health care provider right away if you are experiencing symptoms of lactic acidosis.

What Causes Lipodystrophy?

Scientists have many theories about what causes lipodystrophy and research in this area is ongoing. However, the exact causes of lipodystrophy are still unknown. There may be different causes for different symptoms. It is important to know that the HIV drugs that are most likely to cause the different types of lipodystrophy listed below are older HIV drugs that are rarely used today.

- **Fat loss:** Research shows that certain HIV drugs from the [nucleoside reverse transcriptase inhibitor \(NRTI\)](#) [7] class are the main cause of fat loss. These drugs are Retrovir (zidovudine, AZT or ZDV) and Zerit (stavudine, d4T).
- **Fat gain:** It is less clear what causes fat gain. Taking [protease inhibitors \(PIs\)](#) [8], another class of HIV drug, may increase the risk of fat accumulation. Another theory is that insulin resistance and increased lipid levels play a role in fat gain. Insulin resistance occurs when your body does not respond to normal amounts of insulin and produces more insulin to try to get your body to respond. The higher levels of insulin may increase fat accumulation.
- **Increased lipids:** Some of the PIs are believed to increase lipid levels, especially the first available, older PIs, such as Crixivan (indinavir) and Kaletra (lopinavir plus ritonavir)
- **Increased blood sugar levels, insulin resistance, and diabetes:** Both PIs and NRTIs

have been linked to insulin resistance and diabetes

- **Lactic acidosis:** Some of the NRTIs are associated with lactic acidosis, especially Zerit and Videx (didanosine, ddl)

Not everyone taking HIV drugs develops body shape changes or problems with fat or sugar levels in the blood. Researchers have been looking for other factors that may cause lipodystrophy. The following appear to be risk factors:

- Starting HIV treatment with lower CD4 cell counts and/or higher viral loads
- Starting HIV treatment at an older age
- Being on an HIV drug regimen containing certain PIs and NRTIs (the longer the time on the regimen the higher the risk)
- Being white
- Smoking [9]

Can Lipodystrophy Be Treated?

At this time, there is no simple treatment for lipodystrophy. However, there are a number of approaches that are being used to treat some of the symptoms.

Fat loss

- **Switching or avoiding Zerit and Retrovir:** People who have not developed fat loss should avoid taking the NRTIs Zerit or Retrovir to prevent the condition. Zerit is a much older HIV drug that is rarely used today. People who have fat loss may consider talking with their provider about switching these drugs for others in the same class. The results of switching drugs are uncertain and may take some time; you and your health care provider may decide that changing medications is not right for you. Be sure to talk with your health care provider before stopping or switching any medications.
- **Injections, implants, and plastic surgery:** Some people have procedures done to restore fullness in the face. Injections of fat or synthetic fat substitutes can fill out sunken cheeks, as can cosmetic cheek implants. However, many of these treatments are still being studied and have not been approved by the US Food and Drug Administration (FDA) for HIV-related lipodystrophy. If you are considering plastic surgery, research the options carefully. Some treatments are short-term, can be very expensive, and do not work for everyone. It is important to consult with a plastic surgeon or dermatologist experienced in treating HIV-related lipodystrophy. Also find out if your insurance plan or country-sponsored health service will cover plastic surgery.
- For more information, see our fact sheet on [Lipodystrophy Treatments and Fat Loss](#) [10]

Fat gain

- **Human growth hormone (HGH):** HGH may reduce excess fat build up in the stomach; however, it can also cause fat loss in the arms, legs, or face. Two drugs, a synthetic human growth hormone (Serostim) and a synthetic growth hormone releasing factor called Egrifta (tesamorelin), have shown the ability to reduce fat build up in studies. The FDA approved the use of Egrifta for HIV-related lipodystrophy in 2010. The most commonly reported side effects of HGH are joint and muscle pain, swelling of the hands and feet, and glucose intolerance (which can lead to diabetes).
- **Liposuction:** Liposuction is a plastic surgery procedure that can be used to remove fat

from the back of the neck and around the breasts, but not usually in the stomach (since fat gain caused by lipodystrophy in this area is deep, internal fat). Liposuction tends to be a temporary solution and the removed fat frequently returns. It can also be painful and is generally not covered by health insurance plans, although some people have had some success getting reimbursed for this expensive procedure.

- In February 2014, the FDA approved the use of Myalept (metreleptin, the drug form of the hormone leptin) for lipodystrophy. Leptin is a hormone produced by fat cells. High levels of leptin suppress appetite and cause more fat to be used up. The most common side effects of Myalept include headache, low blood sugar, and belly pain. In addition, Myalept can increase people's risk of developing lymphoma, a type of blood cancer.
- For more information, see our fact sheet on [Lipodystrophy Treatments and Fat Gain](#) [11]

Increased lipids

- **Switching HIV drugs:** Switching to other HIV drugs may lower cholesterol and triglycerides. Speak to your health care provider about this option before stopping any medications.
- **Lipid-lowering medications:** There are drugs available to reduce lipid levels. Some lipid-lowering medications [interact](#) [12] with HIV drugs, so it is important for your health care provider to review all your medications before prescribing anything.
- For more information, see our fact sheet on [Lipodystrophy Treatments and Metabolic Changes](#) [13]

Increased glucose levels, insulin resistance, and diabetes

- **Switching HIV drugs:** Switching to other HIV drugs may reduce blood sugar levels. Speak to your health care provider about this option before stopping any medications.
- **Medications:** There are a variety of drugs that can be used to treat these conditions; talk to your health care provider about which ones might be right for you.
- For more information, see our fact sheet on [Lipodystrophy Treatments and Metabolic Changes](#) [13]

All symptoms of lipodystrophy

- **Diet and physical activity:** Increasing [physical activity](#) [14] and improving your [diet](#) [15] may help with all of the symptoms of lipodystrophy. Physical activity can help reduce fat gain, build muscle, and reduce elevated lipid and glucose levels.

Reducing the amount of saturated fats you eat may help reduce cholesterol levels. Saturated fats are found in animal products. Reducing the amount of fats and carbohydrates you eat may help reduce triglyceride levels. Increased fiber in the diet can help control insulin resistance and may help decrease stomach fat from lipodystrophy.

While there is no definite proof that these methods will improve lipodystrophy, there is no down side to eating right and staying physically active. It is a good idea to speak with a nutritionist or dietician about the steps you can take to improve your diet and level of physical activity.

Caring for Yourself

If you are experiencing lipodystrophy it is especially important to take care of your body. It is important for you to keep all of your appointments with your health care provider, get regular [lab tests](#) [6], and tell your provider about any changes in the way you feel or in your body shape. Recording body measurements and weight on a regular basis, whether or not you are taking HIV drugs, may give you valuable information down the road.

Some of these body shape changes and metabolic problems have been linked with heart disease and strokes in people living with HIV, so make sure you are checked regularly. Other factors, such as high blood pressure, may also contribute to the risk of heart attacks and strokes and need to be treated. You can also support your body, and especially your heart, with a healthy [diet](#) [15], [regular physical activity](#) [14], and [stopping smoking](#) [9].

Even though the physical changes of lipodystrophy can cause [emotional distress](#) [16], no researcher has suggested that people with lipodystrophy should stop taking their HIV drugs. The benefits of taking HIV drugs to preserve your health far outweigh the small risk of lipodystrophy. If you are concerned about your appearance, talk to your health care provider about treatment options. There are many things that you can do to stay healthy and feel good about your body.

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Additional Resources

Select the links below for additional material related to lipodystrophy.

[Body Shape Changes \(AIDS InfoNet\)](#) [36]

[Changes to Your Face and Body \(Lipodystrophy & Wasting\) \(POZ\)](#) [37]

[HIV and Lipodystrophy \(AIDSinfo\)](#) [38]

[Lipodystrophy and Women \(The Body\)](#) [39]

[Treating body fat changes \(AIDSmap\) \[40\]](#)

[How Common Is Lipodystrophy? \(AIDSmap\) \[41\]](#)

[US Treatment Guidelines, Table 12h: Antiretroviral Therapy ? Lipodystrophy, Lipohypertrophy, Lipoatrophy \(NIH\) \[42\]](#)

[Managing the Effects of HIV and Meds on the Body \(CATIE\) \[43\]](#)

[Lipodystrophy Syndrome \(Patient UK\) \[44\]](#)

[Facing Facts: Dealing with Lipodystrophy \(POZ\) \[45\]](#)

[Body Weight and Body Shape Changes \(CATIE\) \[46\]](#)

[The Benefit of Treatment Has Outweighed the Clinical Impact of Lipodystrophy, Conference Hears \(AIDSmap\) \[47\]](#)

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Links:

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[7] <http://www.thewellproject.org/hiv-information/hiv-drug-chart-overview#NRTIs>

[8] <http://www.thewellproject.org/hiv-information/hiv-drug-chart-overview#PIs>

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[11] <http://www.thewellproject.org/hiv-information/lipodystrophy-treatments-part-i-treatments-fat-gain>

[12] <http://www.thewellproject.org/hiv-information/drug-interactions>

[13] <http://www.thewellproject.org/hiv-information/lipodystrophy-treatments-part-iii-treatments-metabolic-changes>

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- [36] http://www.aidsinonet.org/fact_sheets/view/553
- [37] <https://www.poz.com/basics/hiv-basics/changes-face-body-lipodystrophy-wasting>
- [38] <http://aidsinfo.nih.gov/education-materials/fact-sheets/22/61/hiv-and-lipodystrophy>
- [39] <http://www.thebody.com/content/art5101.html>
- [40] <http://www.aidsmap.com/Treating-body-fat-changes/page/1730137/>
- [41] <http://www.aidsmap.com/How-common-is-lipodystrophy/page/1730148/>
- [42] <http://www.aidsinfo.nih.gov/guidelines/html/2/pediatric-arv-guidelines/97>
- [43] <http://www.catie.ca/en/practical-guides/nutrition/2-a-la-carte/2-2#lipodystrophy>
- [44] <http://www.patient.co.uk/doctor/Lipodystrophy-Syndrome.htm#>
- [45] <https://www.poz.com/article/lipodystrophy-treatment-24184-8626>
- [46] <http://www.catie.ca/en/practical-guides/hiv-drug-side-effects/3-body-changes>
- [47] <http://www.aidsmap.com/The-benefit-of-treatment-has-outweighed-the-clinical-impact-of-lipodystrophy-conference-hears/page/3094561/>