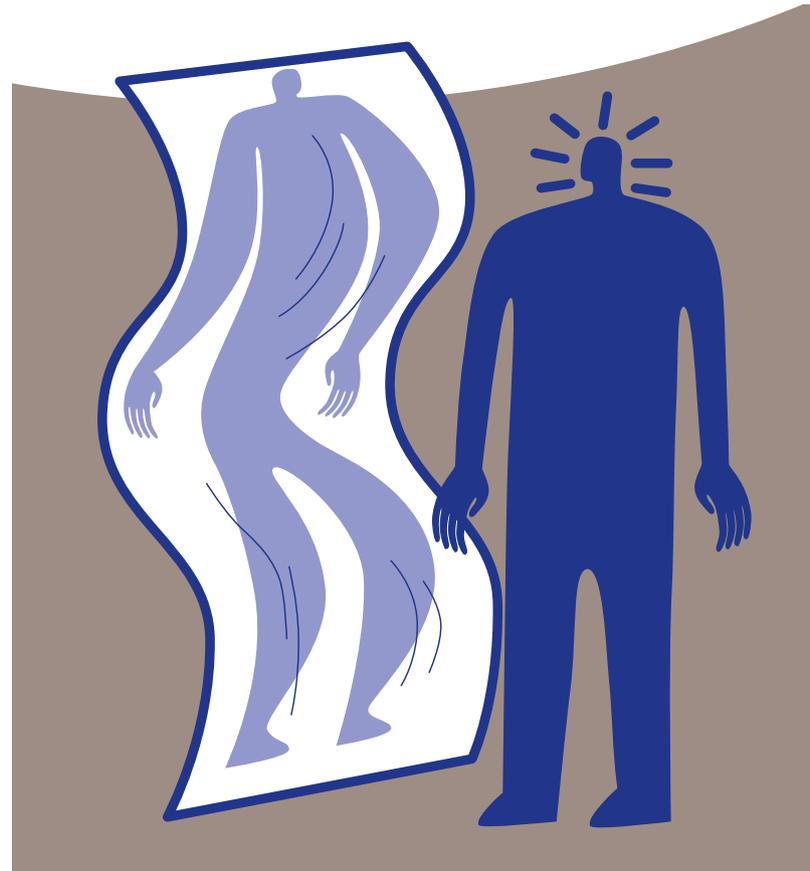




Your shape



The HIV and sexual health charity for life

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Lipodystrophy is a side-effect of some anti-HIV drugs. It can mean losing some fat from our face, legs, arms or buttocks, or gaining fat elsewhere.

It can be a difficult side-effect to live with, as it can affect the way we see ourselves. We may be concerned that other people notice these changes.

Also, these visible changes may happen at the same time as increases in the amount of fat and sugar in our blood. If this happens, we may be more likely to suffer heart disease and diabetes in the future.

This booklet is part of a range of publications produced by Terrence Higgins Trust to support you in living well with HIV. Most of these publications are designed to be suitable for you whatever your race, nationality, gender or sexuality.

This project has been made possible as part of the Treatment Information Providers Initiative, which is funded by the London HIV Commissioning Consortium.

What are the symptoms?

Some people get just one of these symptoms – others get several of them at the same time.

Fat loss (also known as lipodystrophy):

- from the face, leading to sunken eyes, cheeks and temples
- from arms and legs, making the veins more visible
- from the buttocks

Fat gain:

- around the belly
- in the breasts
- on the neck and between the shoulder blades
- small lumps under the skin, called lipomas

If we eat too much and put on weight, the fat will be just below the skin: this is known as 'sub-cutaneous' fat. But the fat gain from lipodystrophy is 'visceral' fat, which means it is deeper inside the body, around organs such as the bowel or the liver. It can make the belly feel hard and taut.

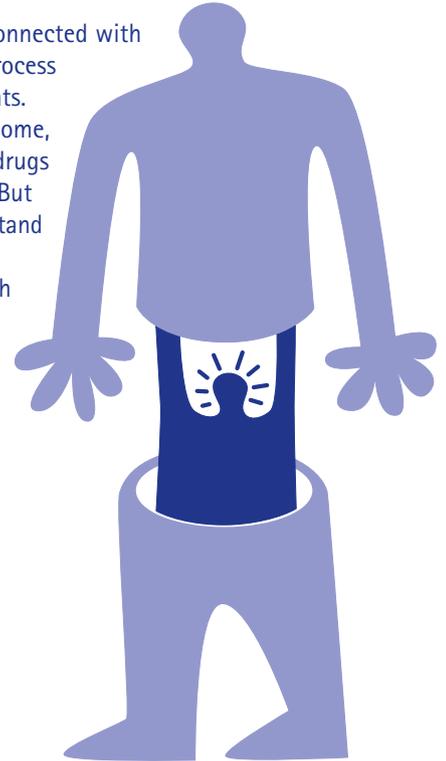
Raised blood fats:

Our blood naturally contains cholesterol and triglycerides, which are types of blood fats (also known as lipids). Doctors use blood tests to check the quantity of blood fats – higher levels of some of them can increase the chance of heart disease and stroke.

Raised blood sugars (also known as insulin resistance):

It's normal for us to have glucose, a form of sugar, in our blood. But if our body cannot process and remove this sugar, we may feel tired, thirsty and have problems concentrating. We may develop type 2 diabetes, which also puts us at more risk of heart disease and stroke. Sugar levels can be tested by blood tests.

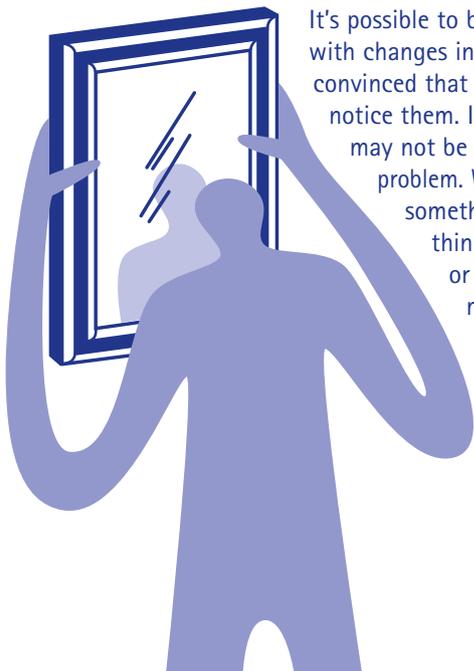
The changes are all connected with the way our bodies process and use sugars and fats. Doctors believe that some, but not all, anti-HIV drugs cause these changes. But they still don't understand exactly how and why this happens. Research is continuing.



Living with fat changes

Fat loss and fat gain can be difficult to live with. Many people with HIV find these changes harder to accept than other illnesses and side effects.

We may notice body shape changes when clothes no longer fit, or when we see ourselves in photos. Looking and feeling healthy or attractive may be important to us. And we may think that other people judge us on our appearance.



It's possible to become preoccupied with changes in our appearance, convinced that other people always notice them. In fact, other people may not be so conscious of the problem. When people do notice something, they may simply think we look older, fatter or a little unwell. They may not realise that HIV is the cause, but things they say can be embarrassing.

But if the people we meet are knowledgeable about HIV, they may recognise the signs of lipodystrophy. We may not want people to know that we have HIV, and no longer having control over who knows can be hard to accept.

All of this can affect self-confidence and the way we feel about ourselves. We may avoid meeting new people or situations that might become embarrassing. Meeting new sexual partners can be particularly difficult.

When we'd prefer to forget about having HIV, our appearance can remind us of it. Having these side effects can also lower our motivation to take treatments regularly.

Some people, on the other hand, are not troubled by fat loss and fat gain. They can accept changes in their appearance and the reactions of others as the price to pay for the benefits of anti-HIV drugs. In this case, it's not helpful for other people to make them worried.

But many people are disturbed by these changes. Getting support from partners and friends is often important. Professionals can also help. If fat changes are getting you down, or are making you anxious, it may be particularly important to get their help.

Staff at your clinic, a local HIV organisation or **THT Direct (0845 12 21 200)** will be able to suggest who you can turn to.

Why do raised blood fats matter?

High levels of blood fats increase the risk of heart disease, heart attack, stroke, high blood pressure and other types of cardiovascular disease.

Cardiovascular disease is one of the main health problems for the general population. As people with HIV live longer, it has become a problem for us too.

Several factors increase the risk of developing cardiovascular disease. Some of them cannot be changed:

- older age (men over 45, women over 55)
- being a man
- a family history of heart disease

But some of the risk factors can be changed:

- smoking
- high levels of blood fats
- lack of exercise
- high blood pressure
- high levels of blood sugars

If you have two or more risk factors, it is worth considering how you can reduce the risk by changing your diet, getting more exercise or stopping smoking.

Why do raised blood sugars matter?

Anti-HIV drugs may cause problems with the way our bodies process blood sugar, meaning that we have too much blood sugar. This is known as 'insulin resistance', and may progress slowly to the more serious 'type 2 diabetes'.

High levels of blood sugar can damage blood vessels, nerves and organs. If left untreated, diabetes can lead to a wide range of health problems. These include:

- heart attack
- stroke
- kidney problems
- damage to the back of the eye and blindness
- nerve damage
- for men, problems getting an erection
- for women, pregnancy complications

Several factors increase the risk of insulin resistance:

- liver damage or co-infection with hepatitis C
- a family history of diabetes
- being overweight
- lipodystrophy-associated fat gain or fat loss
- lack of exercise
- being aged over 40
- high blood pressure
- high levels of blood fats
- having had raised blood sugars in the past

If you have two or more risk factors, it is probably worth considering how you can reduce the risk by changing your diet, getting more exercise or keeping your weight down.

Treatment choices

It seems that some, but not all, anti-HIV drugs cause lipodystrophy. Although our knowledge is still incomplete, it makes sense to avoid those drugs which are associated with problems.

Problems with fat loss and fat gain have been particularly noticed with two drugs from the NRTI (nucleoside or 'nuke') class of drugs:

- **d4T (brand name Zerit) – a lot of problems reported.**
- **AZT (brand name Retrovir, also found in the combined tablets Combivir and Trizivir) – fewer problems reported.**

There may be more of a risk of fat loss and gain when these drugs are combined with drugs from the protease inhibitor (PI) class. But doctors are not sure of this, and research is continuing.

Protease inhibitors are listed in the box opposite.

Protease inhibitors can also cause problems with raised blood sugars and blood fats, especially when one PI is taken with a smaller dose of a second protease inhibitor called Ritonavir (Norvir). Taking the two PIs together means that the drug is more powerful and you don't need to take it so often, but the disadvantage is the risk of raised blood sugars and fats.

“Doctors now know more about which drugs cause problems”

Protease inhibitors

Saquinavir (Invirase, Fortovase)

Fosamprenavir (Telzir)

Lopinavir + Ritonavir (Kaletra)

Ritonavir (Norvir)

Nelfinavir (Viracept)

Indinavir (Crixivian)

Darunavir (Prezista, TMC114)

Atazanavir (Reyataz) is also a protease inhibitor, but fewer lipodystrophy problems have been reported with it.

It's sometimes thought that newer anti-HIV drugs do not cause problems, but it may simply be that we haven't had enough time to see problems emerging. A few people have had problems with lipodystrophy, without taking any of the drugs mentioned here.

Nonetheless doctors think that fewer people are having problems with fat gain and fat loss than a few years ago. This is because they now know more about which drugs cause problems, and try to prescribe other drugs. For example, d4T is taken by fewer people than before.

Treatment questions

I'm taking one of the drugs linked to lipodystrophy. Should I change treatment?

It's certainly worth discussing this with your doctor - switching to a different drug combination may be an option. On the other hand, there may be a good reason to stick with the drugs you are taking:

- you have been taking the drug for some time already without any difficulty,
- the other drugs available have other side effects,
- the other drugs available are more difficult to take, or
- you have virus which is resistant to the other drugs available.

I have lipodystrophy. Will the problems go away if I change treatment?

Unfortunately, if the problem is fat loss or gain, improvements can be very slow and difficult to notice. If the problem is raised blood sugars or blood fats, the results may be better. But you still need to be sure that the new treatment will be as effective against HIV as the last one.

Or could I stop treatment?

Again, improvements to fat loss and fat gain may be minimal. Moreover, if your CD4 count drops or is already low, there is a real risk of getting sick from HIV.

I don't want to start treatment, because of lipodystrophy. How long can I put it off?

British treatment guidelines suggest delaying treatment until we're sure it's medically necessary. The guidelines are based on our CD4 counts - the immune system is stronger when the CD4 count is higher.

- CD4 above 350 - treatment is not usually recommended, as it may unnecessarily increase the risk of lipodystrophy and other side effects.
- CD4 between 200 and 350 - treatment should be considered.
- CD4 below 200 - start treatment before the CD4 drops below 200. There is now a strong risk of getting sick from HIV, and the benefits of treatment outweigh the risk of lipodystrophy.

My treatment is easy to take, and generally it's working well. The only problem is that I've lost some fat from my face. My doctor has suggested changing the treatment, but I'm not sure I'm ready for that.

It's up to you. If fat changes don't particularly bother you, then make sure your doctor understands this. It may not be worth changing treatment for this reason alone. On the other hand, if the fat loss is troubling you, this may be a good reason to change treatment.

Lifestyle changes to minimise lipodystrophy problems

Ways to completely reverse fat losses and gains have not yet been identified, but there are some lifestyle changes that are worth considering. If you have raised blood sugars or blood fats, they may help prevent the development of cardiovascular disease, diabetes and other problems. These lifestyle changes are all low-risk and good for your health generally.



Exercise regularly

Helps with fat gain, raised blood sugars and raised blood fats.
May sometimes help with fat loss.

Most lipodystrophy problems can be improved by regular exercise. Some doctors also believe that exercise may help prevent lipodystrophy problems developing in the future.

It's usually recommended to combine two types of exercise:

- **AEROBIC OR CARDIOVASCULAR EXERCISE** strengthens your heart and includes things like walking fast, running, swimming, cycling and dancing.
- **RESISTANCE TRAINING** strengthens your muscles, for example by using weight machines in a gym.

Both types of exercise will help you lose fat. Increasing your muscles will increase the amount of fat you burn off, even when you aren't doing anything. In fact, resistance training is thought to be particularly effective for people gaining fat in the belly or abdomen.

Regular exercise usually leads to better blood sugar and blood fat levels.

If you have fat loss in your limbs, exercising will mean you lose more fat. But a carefully planned programme of resistance training could help you build muscles to improve the appearance of your arms and legs.

If you're not used to exercising, you should start with moderate activity, and build up to something more challenging. Your doctor can advise you on what is safe and appropriate for you. He or she may also be able to suggest a gym that has experience in developing exercise programmes for people with lipodystrophy.



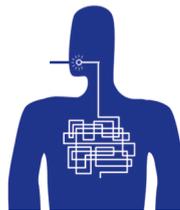
Change your diet

Helps with raised blood sugars and raised blood fats. May also help with fat loss and fat gain.

A healthy diet can help you deal with raised blood sugars and fats. It may also help prevent fat changes happening in the first place.

You are recommended to eat a 'Mediterranean diet'. In other words:

- **Make sure you are getting your five portions of fruit and vegetables each day.**
- **Eat more fibre by cutting back on sugars, fast food, white flour and potatoes. These should be replaced with vegetables and wholegrain versions (wholemeal bread, wholewheat pasta, brown rice).**
- **Avoid saturated fats. They are found in fatty meat, in dairy products, coconut milk, palm oil and ghee. Olive oil, vegetable oils, and spreads based on these oils are healthier alternatives. If you replace red meat, sausages and burgers with lean poultry, tofu and Quorn, you will also be eating less saturated fat.**
- **Try to eat lots of oily fish like mackerel, salmon, swordfish and fresh tuna. It contains omega 3 oils which are good for your heart. If you don't eat fish, linseeds and flaxseeds also contain omega 3 oils.**



Stop smoking

Helps with raised blood fats. May also help with raised blood sugars.

Stopping smoking is the most important thing you can do to reduce your risk of heart disease. It's well known that people who smoke are more likely to have heart disease, which is also more likely if you have raised blood fats.

Tobacco smoke contains carbon monoxide and tar – these are the chemicals which contribute to heart disease and cancer. Nicotine is less damaging, but is addictive.

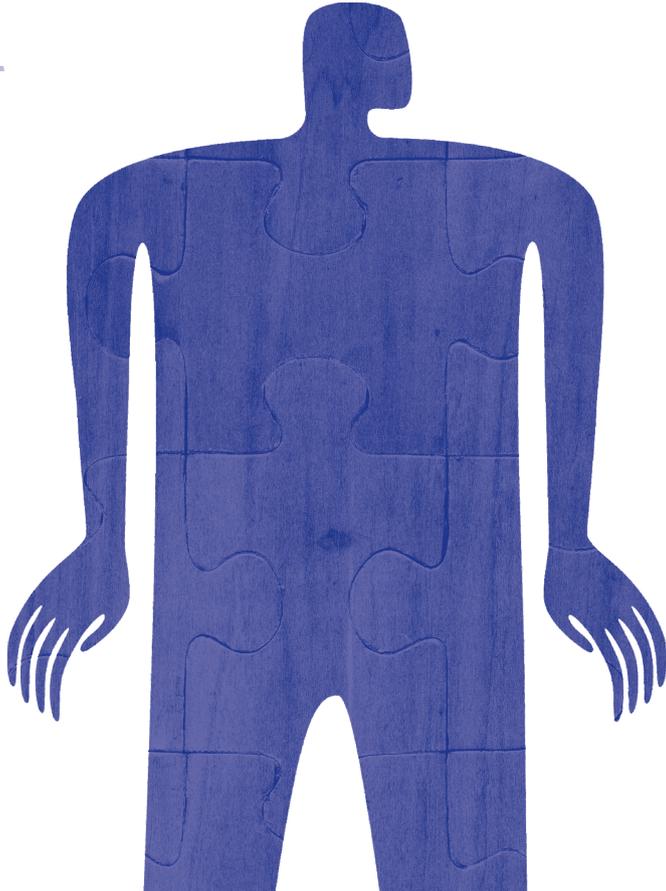
You can use nicotine patches, gums, tablets and sprays to help you get over the addiction to nicotine gradually, whilst you get out of the habit of smoking. Research has shown that we can double our chances of quitting if we use these nicotine replacements. They are available from GPs or chemists.

Stopping smoking is also a question of wanting to do it, planning for it and having lots of will-power.

There's more information about diet, exercise and stopping smoking in *Your body*, another booklet from Terrence Higgins Trust.

Medical treatments for lipodystrophy

Few of these treatments have been tested in large groups of people, and we can't always be sure how effective or safe they are. But some individuals have benefited from them.



New Fill

Helps with fat loss from the face.

New Fill is a product which is injected into the cheeks. It stimulates growth in the skin and reconstructs the normal thickness and shape of the face.

For many people, fat loss from the face is the most distressing problem with lipodystrophy, as it affects the way we see ourselves and other people see us. Many people who have taken New Fill say that as well as their appearance, they also get their self-confidence back.

New Fill injections can be a little painful, and it takes around four different sessions (with up to 40 small injections in each session) to achieve a good result. You also need to massage the face afterwards. Its effects may last for one or two years.

Unfortunately not all NHS hospitals offer treatment with New Fill, and waiting lists can be long. Private treatment is available, but can be expensive. For good results, it's important that the doctor or nurse is trained and experienced in using the product.

There are other products which work in a similar way but may be even more difficult to get hold of. For example Bio-Alcamid is a filler with a permanent effect.



Statins and fibrates

Help with raised blood fats.

These are two main types of drugs which have been shown to reduce levels of blood fats.

- Statins are most effective against cholesterol.
- Fibrates are particularly effective against triglycerides.

However there is a risk of drug interactions between statins and protease inhibitors.

Metformin

May help with fat gain and raised blood sugars.

Metformin is a drug used by people with diabetes, and early studies suggest it can help control blood sugar levels and reduce fat gain around the waist. But it can have some unpleasant side effects, and is not recommended if you have fat loss in another part of the body, or if you are overall a 'thin' person (with a low body mass index).

Hormones

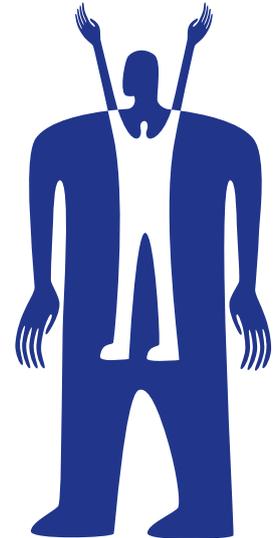
May help with fat gain.

Human growth hormone can reduce fat gain around the waist and between the shoulder blades. Unfortunately, it can also raise blood sugar levels. It needs to be taken on a long term basis, and has side effects.

Nucleomaxx dietary supplement

Could help with fat loss.

Research is continuing into a dietary supplement called Nucleomaxx (Uridine). It may help some people restore fat to their arms and legs. But not enough research has been done yet – speak to your doctor to find out more.



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