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Body shape change (lipodystrophy) can be a challenging experience. It is important to support personal well-being and establish a sense of control over the situation by drawing on a range of useful resources and strategies. Lipodystrophy may or may not be a concern for you personally. Either way, you might like to find out more about how some people experience and deal with body shape change. The voices presented here highlight important themes and issues, but should not be seen as representing all the diverse experiences of people with HIV and lipodystrophy.

Lipodystrophy

Since its introduction in 1996, highly active antiretroviral therapy (HAART) has significantly reduced AIDS related deaths and greatly improved life for many people with HIV/AIDS, but some also experience a range of side effects from antiretroviral drugs, including *lipodystrophy syndrome*. This metabolic disorder involves an unusual process of fat redistribution which can manifest in a variety of body shape changes. The most common of these include: fat loss (*lipoatrophy*) in the arms, legs, buttocks, and face, and fat accumulation on the abdomen, breasts, shoulders, and back of the neck. Prominent veins on legs and arms are also common due to loss of subcutaneous fat. Other symptoms include metabolic abnormalities such as elevated levels of harmful fats in the blood and insulin resistance, which can increase the risk of heart disease and diabetes.¹

It's different for everyone

It is important to emphasise that lipodystrophy does not happen to everyone who takes antiretroviral drugs. There is still a great deal that is unknown about lipodystrophy in terms of its causes, mechanism and prevalence. Nor is it clear whether lipodystrophy is one or several overlapping conditions. The dominant theory is that protease inhibitors play a role in lipodystrophy, and possibly the nucleoside analogues as well, particularly in relation to lipoatrophy. However, two people taking the same HIV drugs do not necessarily experience the same kind or degree of symptoms, if any at all. It is also unclear to what extent these symptoms are caused by

living with body shape

change

antiretroviral drugs or by HIV itself, or a combination of both. In addition, some changes in body fat are a common feature of normal ageing. Generally, most experts agree that the possibility of developing lipodystrophy increases with age and length of HIV treatment. On the whole, it is likely that lipodystrophy is a result of a number of complex co-factors that are yet to be fully understood.

Having lipodystrophy often means having to adjust to a new body image and a new way of being HIV positive. Because of different personal circumstances, this experience is not the same for everyone. Certain circumstances may lessen the impact of lipodystrophy, such as being openly HIV positive, engaging with the HIV sector or peers, being in a supportive relationship, and being older.

Ludwig: Well, to me it's a bit like a badge of honour in a way because it says that I'm positive and I'm out and all that sort of business ... I think it's important that positive people be seen as out there. And this is a side effect of being HIV positive and taking medication.

But it is also important to acknowledge that body shape change can sometimes be a challenging experience that may affect personal well-being and everyday life in numerous ways.²

Talking about lipodystrophy

Little is understood about the lived experience of body shape change. Social avoidance and silence are common, and for those who are affected, finding support or people to share their experience with can be difficult:

Max: We talk about it happening, but we don't necessarily talk about how we feel about it happening. I haven't experienced a lot of discussion, really meaningful discussion.

Adam: I think the effects of lipo have to be factored into this whole sort of approach to managing HIV ... I think there is all this avoidance about it. You don't have any role models and positive people with lipo coming out and saying, you know, I have lipo and this is the effect it's had on me. You hear about what it's like to be positive and all that stuff. But you don't hear about what it's like to have lipo, you know ... There is a silence around it. Get the community to talk about it in some way. Maybe, you know, some education campaign.

Body image

Body shape change can have a negative impact on body image, making you feel you look different, unattractive, 'bizarre', or prematurely aged, a feeling that might be triggered by comments and looks from others:

Matthew: The fact that I get comments all the time means there's something about my appearance that looks out of place. So, I'm sure I look abnormal in some way ... It's just the fact that they know that you're different. I don't want to be different. I just want to be one of the crowd, you know.

Duncan: I feel like the ageing process has been sped up. It's just suddenly happened. I mean everyone is organic, you have to age. But to have it happen so quickly and so bizarrely is quite deeply psychologically horrible, you know, even something you can hardly talk about.

Living with a body that does not conform to cultural ideals can be a challenge. Society is saturated with images of young, healthy-looking, buffed, and largely unattainable bodies. Messages that play on fears and insecurities are everywhere in the visual and print media and feed a hugely profitable industry.

Ann: Lipo can really sort of knock you around self esteem-wise as a woman, particularly the belly thing, because women are not supposed to have bellies, or so I've been told.

Mandy: When [lipodystrophy] started to happen, it just kind of flipped me straight back into being a teenager and being totally unattractive and being the wrong shape and not being what society says is beautiful.

Advertising in the gay media and the body-conscious Sydney gay 'scene' can be particularly unhelpful and may exacerbate the difficulties of lipodystrophy:

José: The community seems to be geared towards people with beautiful bodies ... All the ads for call services and sex, and ads for the saunas, they're all people that have got beautiful bodies and they're all youthful. I don't think that helps at all in trying to come to terms with something like lipodystrophy. It just makes it that much worse.

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Damien: As long as you're still on the 'scene', they're going to judge you on the way you look. So, that's really disappointing and it makes those little things, like the lipodystrophy, far more significant than they should be. You know, it's not a really big problem except in this context, in this body beautiful competitive scene. It's sad the way it is.

Personal reminder of HIV

Regardless of individual health and viral load, lipodystrophy is sometimes experienced as a visual manifestation of HIV on the body. This may force you to confront or reassess your HIV status:

Rick: It's something you can't hide anymore, you know, whereas for a long time you could just sort of bury it or be in denial about it. It brings about a change where it leads you to recognise 'I do have something'.

Ann: What I look at is the disease in my body. The way I look is like a visual reminder that I actually do have HIV ... I've never looked like a person with HIV until I got lipodystrophy ... There was no visual thing on my body that related to HIV, you know, apart from a band-aid from a blood test. Like that was as much as my body expressed HIV.

Forced disclosure of HIV

It is also common to experience concerns that your body shape change (in particular facial fat loss) makes it obvious to others that you are HIV positive:

Jim: It just makes you feel like, you know, the face of HIV. It's like people can look at you and know that you're HIV positive. It sort of decreases my self-worth.

Feeling 'outed' by your own body can undermine the sense of control over your HIV status in social situations or the timing of disclosure to friends, workmates, or family:

Adam: I'm quite close to my family, but I want the choosing to be mine, like when I choose to tell and if I've got lipo bearing down on me then I lose a bit of that decision making ... like my decision to disclose my status and not have it sort of overrun by physical appearance.

Concerns around HIV disclosure and identification may be strongest in relation to gay community because of an assumption that lipodystrophy is well-known among gay people:

Rick: I mean people know what's going on, you know, people in the gay community know what lipodystrophy is and pretty much know now what it looks like.

This sense of forced disclosure of HIV within gay community can increase feelings of social stigma. While overt discrimination is relatively rare, many experience a subtle division within gay community between HIV positive and HIV negative people:

José: You see in adverts, in the personals: 'clean, healthy'. Well, I'm healthy. I just happen to be carrying a virus around with me. Yeah, so there's a lot of discrimination there and that doesn't help. If there was more support in the community, I think it would be easier to adjust to [lipodystrophy].

If you live in a regional area, disclosure can be a concern in relation to the local population as a whole because of the higher degree of visibility and 'talk' that comes with living in a smaller community:

Vincent: There's less people like you around and so maybe you're a bit more visible. And there's less people around overall, so you probably are more visible than you would be if you were walking around Oxford Street.

Social life, relationships and sex

Poor body image and low self-esteem can impact negatively on quality of life and lifestyle, such as avoiding particular social interactions and places like the beach, saunas, parties, or the gym, to escape potential stares and questions:

Matthew: Well, it puts a lot of restrictions on my life. Things that I would like to do, but I won't, like going to the beach ... I love swimming and stuff like that. But I haven't been swimming for three years and that's a direct result of lipoatrophy.

Eddy: Certainly, at the end of the day, if you feel uncomfortable about your looks it doesn't assist your social interaction skills and all those sort of confidences.

Feeling unattractive, and fearing rejection by potential partners, can sometimes become an obstacle to relationships and sexual intimacy:

José: I remember one day looking in the mirror and I'd lost a lot of muscles and fat from my legs and I've got very prominent veins in my legs and in my arms, and my face. And I remember looking in the mirror and I just broke down and cried because I thought, 'who is going to want me?' I mean, I was just horrified.

Wanting to protect yourself from potential hurt and rejection may even lead to self-imposed social and sexual isolation:

Duncan: I've isolated myself. Things are switching off bit by bit in my social life. Feeling like, you know, kind of non-sexual and like I'm not really 'part', you know ... You have to feel good to go out and I never feel good. I never feel I look good.

José: It's all part of this feeling of not wanting to be hurt. It's protection, not wanting to put myself in a situation where I can be rejected, you know. I'm afraid of that.

HIV therapy: weighing it up

The lack of a cure for lipodystrophy is a concern for many. Several substances, such as steroids, human growth hormone, and rosiglitazone (a diabetes treatment), have been tested with mixed results.³ **Before you consider these therapies, you should consult your doctor about their effectiveness and suitability for you.**

In some cases, changing those HIV drugs that contribute to lipodystrophy may alleviate some symptoms, but is unlikely to reverse them fully.⁴ Furthermore, stopping or switching drugs is not an option for everyone:

José: I've had a long history of treatments and monotherapy and dual therapy. I'm concerned about how many changes I can now make and for the drugs to work as well as they are working. And at this late stage, how reversible is it anyway?

Body shape change can cause resentment or ambivalence towards HIV therapy:

Max: I just think it increases the mental work of taking the medication because, you know, it's that paradox of taking something that is supposed to be good for you and yet you're also witnessing some stuff that shows that the body is also being really damaged at the same time ... You're taking really, really powerful drugs to have a desired outcome and there are costs to that outcome.

In light of these present limitations, you may have to consider lipodystrophy in a broader health context and weigh the adverse effects of HIV therapy against its more positive outcomes:

Leroy: I know a lot of people say to me, 'oh the side effects with these drugs', and I say, 'yeah one of the big side effects is that it keeps you alive'. You've got to look at it like that as well.

Ludwig: I think containing the virus is number one. Lipodystrophy is sort of, you know, a bit further down that list. Provided I can have the current quality of life and contain the virus, I'll put up with lipodystrophy.

Dealing with body shape change and taking control

Anger or frustration can be common reactions if you feel you have little choice but to 'put up with it'. Making a conscious decision to come to terms with the experience of lipodystrophy or to actively deal with it somehow can be a useful way to establish a sense of control over your situation:

Trevor: I think I was quite traumatised at the beginning and now I think I've grown into it more. So, yes, it had a major impact, but I think the impact has lessened with time as I've grown used to the face I see in the mirror, as I've grown used to the person that I am ... I mean, I don't think I could stand spending all my time hating myself, because that's all I am. So, I've grown to accept it to a large extent.

Walter: Time was the cure and also empowering myself to do something about it ... So it was a bit of a road to discovery, because I wasn't willing to think you can just change body shape and not do anything about it.

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Diet, exercise, and making friends with your body

There are a number of non-medical strategies that you can use to deal with body shape change, the most common being a healthy diet and exercise. A nutritionist can help you work out a suitable diet to maintain your weight and reduce cholesterol levels. While lack of money and energy levels can be an obstacle, a regular exercise routine, such as walking, swimming, yoga, or the gym, can help to counteract some of the body shape changes, to maintain cardiovascular health, to change your body image, or simply to 'feel better':

Jim: Doing exercise, especially doing exercise with a group of guys who are HIV positive, you know, it's almost like adding a different dialogue, you know, the internal dialogue that you're having with your body. After a while, when you can say, 'oh gee my biceps are getting bigger', that increases your self-esteem, you know, so then you're not so overly critical of other bits that aren't so good. You can sort of try and push your attention a little bit more to things that are good and happening, you know ... It makes you feel better about yourself.

Matthew: I feel a lot less fatigued and have a lot more energy because I go to the gym regularly, which probably has been my number one treatment since I've been diagnosed ... I know that if I don't go to the gym on a regular basis my weight just starts to plummet very quickly. I can't put on weight, but I can maintain where I'm at ... Going to the gym keeps me stable at least.

Physical contact and touch can also be helpful, especially if there are feelings of physical isolation and discomfort. Massage for example can be a great way to relax and to care for your body and yourself.

Lisa: Massage is a natural therapy that I always do, because I think it's very important that people with this virus be touched ... Just that element of touch is really, just really important.

The cosmetic option

In terms of facial fat loss, some find cosmetic procedures such as the New-Fill[®] injections into the cheeks effective and are generally pleased with the results.

Ben: Oh it makes me feel like I look younger. It makes me feel like I've got a fuller face. It makes me feel fabulous. Like in the last few months, wherever I've been, people say how well I look and they haven't said that for a long time. So, yeah, self image. Worth it. Worth having it done.

George: Whoever sees me now says, 'oh you're looking much better'... I know that I don't like people looking at me and that's why I never go out. But if my face fills up I think I will start going more to the pictures, even sitting down having a coffee in the open air.

The effect of New-Fill on self-esteem is promising. Currently, the cost of this procedure, which requires repeated treatments, makes it out of reach for many. It is important to remember that while New-Fill can have very positive effects, it is a temporary solution and it may not resolve every issue related to lipodystrophy, HIV or body image:

Aif: I think that things like New-Fill are incredibly important. But, you know, what I am saying is that, it's not going to fix all the inadequacies and all the probs. It's just going to fix the cheeks ... I think if we actually looked more at why people felt uncomfortable about it and dealing with some of the basic behavioural stuff around it and looking at people's anxieties and the reasons why they're so anxious about it, we'd actually achieve a hell of a lot more.

Covering all bases: the broad approach

Because of the impact that lipodystrophy can have on self-esteem and well-being, it is important to consider a broad approach that takes emotional and social needs into account along with physical strategies:

Jim: I use techniques to actively make sure I'm not sliding into depression. So I stop negative thoughts and, you know, 'my glass is half full rather than half empty' stuff, and that's important. And, you know, trying to make a strategy against social isolation, so remaining engaged by doing volunteer work and seeing community groups and organisations and stuff. And physiologically, I think going to the gym keeps you as fit as you can be, you know ... Also, I go to the metropolitan community church periodically so that spiritually my needs are met. So, you know, I really keep working at it, keep it in check.

Friends and peer support

It may be difficult to find people to talk to about your experience, and you might feel hesitant to approach others with lipodystrophy in case you 'touch a raw nerve' or draw attention to it. Taking steps to break down that barrier can be rewarding, as friends and peers can provide a valuable source of support:

Ann: I have a couple of female friends who are also unhappy about their bodies. My HIV negative female friends are just as good to talk to, because women are just good at talking about bodies ... So there's a level of peerness that I find from other women, like just around the body image stuff. That's helpful.

Rick: I discuss it with friends who are HIV that have [lipodystrophy] as well. The way it looks. You don't need to go there with your friends as far as how it's feeling, because you know what they're feeling ... Quite often it's a subtle acceptance, you know. It's like, 'you're okay, it doesn't change the way I feel about you. It doesn't change the way I look at you', yeah.

Humour and focusing on the positive

Maintaining a sense of humour, and staying focused on the positive, including positive aspects of lipodystrophy, can put things into perspective and make it easier to cope:

Ann: It's not all grimness. Like if I go out anywhere I'll wear mini skirts and take great delight in the fact that I've got these gorgeous thin thighs for the first time ever in my life. But that's really kind of playing around the edges of it.

Jim: I actually try and jolly myself and maintain my positive optimistic nature with telling myself things like 'look at this fantastic six pack of abs, you know, I barely needed to work on it all, all thanks to lipoatrophy'. Because like to me humour is a way of coping, you know. Yes, it's grim and gallows humour, but that's just my nature, to try and be optimistic.

Take me as I am: resisting negative messages

Actively resisting those cultural body ideals and negative messages that contribute to the difficulty of lipodystrophy is another valuable strategy, either by refusing to participate in the beauty industry or refusing to let lipodystrophy stop you from doing what you want to do:

Ann: Having other women to talk to helps. Having cartoons on my bathroom wall which take the piss out of that whole thing. Not going shopping in stores that I know won't have anything that I can [wear] ... I don't buy fashion magazines or stuff. Yeah, just refusing to participate.

Jacob: I still walk around in a pair of shorts as though I've still got footballer's legs, even though I don't ... I still walk up the street as though I was the same as yesterday ... I've always had the attitude that if you can't take me the way I am, then don't take me at all. I'm not going to do somersaults to try and impress you. What you see is what you get.

It is important to remember that lipodystrophy is not necessarily something negative in and of itself. It is the culture we live in that makes it so. The language around lipodystrophy is loaded with words like 'disfiguring' and 'abnormal' which can make it easy to forget that beauty is very subjective:

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Aif: There's a lot of discussion about lipodystrophy always being bad and I don't think it is always bad. I think there are a lot of men who look heaps better with a bit of lipodystrophy than they ever did before they got it, to be perfectly honest. I mean it's an aesthetic thing which is in the eye of the beholder ... I don't necessarily think it makes people look worse. I think that in many cases it makes people look really interesting.

How lipodystrophy is seen and represented is also linked to the ongoing stigma of HIV, another important reason to challenge negative messages:

Aif: I have survived and I am a middle aged gay man who is out and is known to have HIV. I mean, it's just part of having the disease and people know that I have the disease and, you know, in a way it's a statement, a confirmation of who I am and what I am ... I'm pretty comfortable about it, you know. I don't care who knows I'm positive ... I'm pretty upfront about all that sort of thing. If people have a problem with that, that's their problem. It's not my problem. I refuse to take that sort of stuff on.

While the emotional and social effects of body shape change are increasingly acknowledged, there is a need to further develop support systems and strategies to assist people dealing with these effects. The personal stories in this factsheet describe how some people deal with body shape change by using a number of positive strategies that are well worth considering and building on.

Remember that help is available.

- Talk to your doctor, nutritionist, counsellor or ACON Treatment Officer.
- Peer support – talking to another HIV positive person can help.
- ACON has developed Healthy Life +, a twelve week gym program for HIV positive gay men around exercise, general health and diet that runs regularly during the year. Phone ACON to find out when the next program starts, or ask for the accompanying booklet.
- The Positive Access Program at FitXGym (ACON) is a program exclusively for HIV positive clients. Call ACON (02) 9206 2000 or Ingrid Cullen on 0400 712 964.
- Contact the Positive Living Centre, the Sanctuary or a community health centre for information on their lifestyle enhancement programs (yoga, exercise, nutrition).

References

- 1 Carr, A. et al. (1998) *AIDS*, 12: F51–58; Carr, A. et al. (1999) *Lancet*, 353:2093–99.
- 2 Power, R. Tate, H.L. McGill, S.M. and Taylor, C. (2003) A qualitative study of the psychosocial implications of lipodystrophy syndrome on HIV positive individuals. *Sexually Transmitted Infections*, 79:2:137–141; Collins, E. Wagner, C. Walsley, S. (2000) Psychosocial impact of the lipodystrophy syndrome in HIV infection. *The AIDS Reader*, September, pp.546–550; Persson, A. (2002) 'People can tell you're positive': Lipodystrophy and forced disclosure. Paper presented at The Australasian Society for HIV Medicine Conference, October, Sydney.
- 3 Gold, J. et al. (1996) *AIDS*, 10 (7): 745–52; Wanke, C. et al. (1999) *AIDS*, 13:2099–2103; Nass, H. "Metabolic Complications", *AIDS Community Research Initiative of America Update (ACRIA)*, Spring 2003, Vol.12, No.2. This is a good resource which can be accessed on: ww2.aegis.org/pubs
- 4 Carr, A. et al. (2001) *AIDS*, 15:1811–1822; Ruiz, L. et al. (2001) *Acquired Immune Deficiency Syndrome*, 27:229–236; Carr, A. et al. (2002) *JAMA*, 288:207–215.
- 5 New-Fill (polylactic acid) is a cosmetic intervention and procedure, which is injected into the cheeks or temples, to 'fill out' the trademark hollows caused by lipodystrophy.

The Side Effects and Lipodystrophy Project

The discussion presented here is based on interviews with research participants in The Side Effects Project, a study by Dr Asha Persson at the National Centre in HIV Social Research at the University of New South Wales. This qualitative study documents and explores how some people experience and manage lipodystrophy and other HIV treatment side effects, with particular focus on body image, social and sexual relationships, and decisions around HIV treatment and health priorities. **All names have been changed.**

For support and information

Services provided by the AIDS Council of NSW (ACON):

- **Counselling and Assessment Team** ☎ (02) 9206 2000. Outside Sydney 1800 647 750 between 10am–6pm Mon–Fri. Trained and professional staff offer a free & confidential service to people living with, affected by or at risk of HIV/AIDS as well as gay men, lesbians, bisexuals and transgender people, regardless of their sero-status.
- **Treatment Information Officers** ☎ (02) 9206 2013 or (02) 9206 2036. Freecall 1800 816 518. Call for up-to-date information about treatments for HIV.
- **ACON's Women's HIV Peer Support** ☎ (02) 9206 2012. Information, education, support and referral services for women living with HIV/AIDS.
- **Men's HIV Support** ☎ (02) 9206 2037. Information, education, support and referral services for men living with HIV/AIDS. They will also have information on Healthy Life +.

Services from other organisations:

- **People Living with HIV/AIDS (NSW) Inc.** ☎ (02) 9361 6011. Freecall 1800 245 677. A non-profit community organisation representing the interests of people living with HIV/AIDS in New South Wales.
- **Heterosexual HIV/AIDS Service (Pozhet)** Project Coordinator ☎ (02) 9515 3095. Freecall 1800 812 404 (national) between 10am–5pm Mon–Fri. Peer support, workshops, social activities and retreats, freecall phone counselling for positive heterosexual men and women, their partners and family members.
- **Multicultural HIV/AIDS Service** ☎ (02) 9515 3098. Freecall 1800 108 098. 9am–5pm Mon–Fri. Bilingual/bicultural co-workers providing emotional support, advocacy and information to PLWHA from non-English speaking backgrounds.
- **Albion Street Centre Psychology Unit** 9am–7pm Mon–Fri Psychology Unit Manager ☎ 9332 9600. 24hr Crisis call 9382 2222 (ask for Albion St counsellor on call). Free and confidential psychological and counselling services to HIV positive people, their partners, carers, family and friends.
- **Albion Street Centre Nutrition Department** ☎ (02) 9332 9600 Customised services for health care workers and people affected by HIV/AIDS and Hep C.
- **Positive Living Centre (PLC)** offers programs on complementary therapies for people living with HIV/AIDS. ☎ (02) 9699 8756.
- **The Sanctuary Newtown** offers massage, shiatsu, meditation, yoga and social activities. ☎ (02) 9519 6142 (Mon–Fri by appointment).

- **FitXGym** Call ACON ☎ (02) 9206 2000 or Ingrid Cullen (Positive Access Program instructor) on 0400 712 964. The Positive Access Program offers positive people an opportunity to exercise in a comfortable, supportive environment, where individually tailored programs are implemented for HIV positive people who may not feel comfortable in the commercial gym environment.

For regional NSW HIV/AIDS and related services:

- **Contacts. A Directory of Services for People Living With HIV/AIDS.** Available from People Living With HIV/AIDS (NSW) Inc. ☎ 02 9361 6011. Freecall 1800 245 677.

Useful websites:

- AIDS Meds: HIV+ owned and operated www.aidsmeds.com
- Team Sydney: Contacts for gay and lesbian sports groups in NSW www.teamsydney.org.au
- Aidsmap www.aidsmap.com
- Amfar AIDS Research www.amfar.com
- The Body: An AIDS and HIV Information Resource www.thebody.com

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