Living With Lipo

Lipodystrophy, or abnormal changes in fat distribution, is a common problem among people living with HIV, especially those who have been treated with the earliest antiretrovirals.

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When Linda Sidle was at the local vehicle license bureau near her home in Van Wert, Ohio, to get some paperwork on a truck she'd recently sold, her pants suddenly fell all the way down around her ankles. A tough-as-nails straight shooter with a salty, class-clown sense of humor, she took the gaffe in stride. It helped that no one else was around and that the one employee could only see Sidle from the chest up, so she didn't realize that the 58-year-old was standing there half-naked.

"As I bent down to pull my pants back up, the girl behind the counter asks, 'You OK?'—and I said, 'No, I just dropped $100,'" Sidle recalls with a "what, me worry?" way of laughing it off.

"My mom used to say, 'There's something funny in everything that happens, including death,'" Sidle reflects. She takes this maxim very much to heart, and it has helped her rise above considerable heartache and various health challenges that she's faced during more than a quarter-century of living with HIV.

"You laugh loudest when you laugh at yourself," says Sidle, a former IRS manager, now retired and raising hell as an avid gardener, bowler, junk-sale scrounger, and HIV activist and educator.

Sidle's wardrobe malfunction may ring a bell for others who are also living with HIV-related lipodystrophy. In her case, the condition means she's got practically zero fat in her legs and buttocks while being saddled with so much extra fat in her abdomen that she says she could be mistaken for pregnant if she weren't a senior citizen.

"I just look like a pear with toothpicks stuck in it," she quips.

It turns out such physical attributes are hardly a winning combination for finding pants that fit right, or that even cooperate. Sidle, however, isn't one to passively accept changes to her body, and has spent some two decades looking for answers in her typical headstrong fashion. In recent months, she's finally found one.

Changes in body fat became a signature struggle among the HIV population during the early years of the modern era of antiretroviral (ARV) treatment, which began in 1996 with the introduction of

the first of the triple combination drug cocktails. Lipodystrophy, which refers to an abnormal distribution of fat in the body, soon replaced wasting and Kaposi's sarcoma (KS) lesions as the most prominent physical manifestation of HIV. It was a cruel irony that some of the very drugs that helped return so many HIV-positive people to robust health during that time wound up making many look sick, at least in the eyes of the uninformed.

Lipodystrophy can be a disfiguring and emotionally devastating condition, one that is fortunately less common in people living with HIV today thanks to advances in ARV treatment. Included in this umbrella term are two conditions: lipoatrophy, which refers to the abnormal loss of fat; and lipohypertrophy, or the abnormal buildup of fat.

HIV-positive people who develop lipo-atrophy may experience the loss of what is called subcutaneous fat (just below the skin) in the limbs, including the buttocks, as well as facial fat loss, specifically in the cheeks, temples, eye sockets and smile lines. The limb fat loss can make veins look especially prominent.

HIV-related lipohypertrophy can mean increased fat in the abdomen, known as visceral fat or visceral adipose tissue. This fat accumulation can lead to a hard, protruding belly—"You could bounce a quarter off of it," Sidle says of hers—and raises the risk of heart attack and diabetes. Other possible forms of lipohypertrophy among people with HIV include fat buildup in the breasts (which can occur in men and women), a fat pad on the upper back and back of the neck known as the "buffalo hump," enlargement of the neck, and round lumps of fat beneath the skin known as lipomas.

Such bodily changes can lead to physical pain, the loss of range of motion, and even impaired breathing. Brenda Goodrow can certainly attest to these challenges. At 19 years old, she's a member of the first wave of young people who contracted HIV at birth to reach adulthood after a lifetime on combination ARV treatment. She has severe back pain as a result of excessive breast fat, which exacerbates the effects of scoliosis—itself a result of her cerebral palsy.

Lipodystrophy often goes hand-in-hand with certain so-called metabolic abnormalities that can raise the risk of cardiovascular disease or diabetes. These abnormalities may include high cholesterol, as well as insulin resistance and high blood sugar.

Research has pointed to three ARVs in particular as major contributing factors to the development of lipoatrophy: Retrovir (AZT, or zidovudine), Videx (ddI, or didanosine) and Zerit (d4T, or stavudine). Retrovir was approved for HIV treatment by the U.S. Food and Drug Administration (FDA) in 1987, while Videx and Zerit got the nod in 1991 and 1995, respectively. They all became components of the early combination cocktails once protease inhibitors came along in the mid-1990s, and a considerable proportion of HIV-positive people who took them wound up with lipodystrophy. Retrovir was also packaged into the combination tablet Combivir (zidovudine/lamivudine), which was released in 1997, and also into Trizivir (abacavir/zidovudine/lamivudine), which was approved in 2000.

Research into non-ARV causes of lipodystrophy hasn't provided the clearest answers. The science is particularly uncertain when it comes to sussing out why the condition develops. HIV itself is apparently to blame for lipodystrophy in general, along with the damage that the virus, as well as some ARVs, causes to mitochondria, which are the energy centers of cells. Other potential factors that contribute to the development of lipodystrophy include genetics, hormonal changes, diet and obesity, shifts in hormones and the body's metabolism of fatty acids, as well as the seesaw effect on the immune system as it's depleted by the virus and regenerated by HIV treatment. People at greater risk for lipodystrophy include whites, older individuals, those who have been living with the virus longer, those who start treatment with a lower CD4 count or higher viral load, and people who are obese or have wide fluctuations in body weight.

Those who aren't familiar with lipodystrophy may incorrectly think that an HIV-positive person's loss of facial fat, often the most noticeable change, is a sign of their poor health, rather than a reflection of a complex interplay between ARVs, the virus and other causes. Back when the health condition was a newer phenomenon in the HIV population, this false impression may have been compounded by the fact that wasting, in which people with HIV experience uncontrolled weight loss, was a well-known major complication of AIDS, and was highly prevalent in the HIV population in the 1980s and early '90s. Confusing matters more, "facial wasting" is a common term for facial lipoatrophy. However, the fat loss associated with wasting does not typically follow the same patterns as seen with lipoatrophy.

For Goodrow, her peers' misperceptions about the reasons for her gaunt face and wiry limbs (she has taken all the meds known to cause lipo) made the typical travails of junior high school more challenging for her.

"That's when people start thinking about appearance and fitting in," says the Milford, Pennsylvania, resident. "People would be like, 'Oh, you're really skinny, don't you eat? Why don't you gain weight?' It became this whole 'I have an eating disorder' thing."

To those in the know about facial lipo-atrophy, on the other hand, sunken cheeks and temples and deep smile lines can be instant indications that someone is HIV positive. In essence, HIV becomes etched into people's faces, robbing them of their control over when, how and to whom they disclose their serostatus.

"I've always envied the people who could keep HIV a secret," says Goodrow. "I never really could."

Facial lipoatrophy in particular "can be so stigmatizing," says Camille Introcaso, MD, a physician at the Pennsylvania Centre for Dermatology in Philadelphia who sees a considerable HIV-positive patient population. "I think it's very hard in social situations if you're meeting people, you're trying to date."

Like many people experiencing lipodystrophy, Goodrow has experienced depression as a result. (This particular drag on mental health can lower adherence to ARVs as well.) Her depression got so bad her first semester in college that she stopped going to class and ultimately dropped out. (She

is hoping to go back.)

“I didn’t want to leave my room,” she says. “I didn’t want people to look at me. I felt like they just saw everything bad about me.”

“It really is difficult to function with a face that doesn’t reflect what’s inside,” says Sydney R. Coleman, MD, a New York City plastic surgeon with many years of experience reconstructing the faces of HIV-positive patients who have had lipoatrophy.

“The good news is we’re seeing less lipoatrophy than we used to,” says Gerald Pierone Jr., MD, an HIV specialist in Vero Beach, Florida. “I tend to see it more in the people who have been living with HIV for 20 or 30 years.”

Indeed, the introduction of newer, less toxic ARVs during the 2000s greatly reduced the risk of lipoatrophy. Such HIV treatment alternatives have been great news for people just starting meds, and today many HIV-positive people are fortunate enough not to experience any lipodystrophy. But the hard truth is that, for those who had already suffered from troubles with body fat distribution, switching off the culprit meds has tended to offer only modest improvement, if that. For reasons that are poorly understood, lipodystrophy is a typically permanent condition. It remains a lasting legacy among many long-term survivors of their having lived through those rocky early years of ARV treatment.

This permanence doesn’t mean, however, that there aren’t available treatments to help people reconstruct their faces and to reduce fat buildup elsewhere in their bodies.

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If you have lipodystrophy, or you are concerned that you may have the condition, a good first thing to do is to have a comprehensive check-up with your physician. This starts with expressing your questions and concerns to him or her.

“With your own body, you can feel subtle changes, as little as two or three pounds,” says David Parks, MD, an HIV specialist in St. Louis, Missouri. “So it’s really important that patients talk to their doctors about how they feel: How they feel their body is changing, and how they feel about fat accumulation or fat loss.”

Part of this conversation may include distinguishing lipodystrophy symptoms from those related to wasting. While wasting is uncommon in the HIV population these days—thanks to antiretroviral treatment—it still can occur, even in those with higher CD4 counts and lower viral loads. So it’s important to determine the precise cause of any unexplained weight loss, which in the case of wasting means more than 10 percent of total body weight, occurring along with diarrhea or chronic weakness and fever for at least a month.

Other topics on the table may include your personal and family medical history, especially any high cholesterol or triglycerides, diabetes and insulin resistance, and heart disease. Along those

lines, your doctor will likely want to run blood tests to screen for the metabolic abnormalities associated with lipodystrophy.

How your symptoms affect you psychologically is equally important. Your clinician may refer you to counseling or suggest other ways to help you cope with any changes in your body.

Aaron Blashill, PhD, is an assistant professor of psychology at San Diego State University who is researching psychological treatment paradigms to help HIV-positive people cope with symptoms of lipodystrophy. He has found that for some people with the condition, the common psychotherapeutic practice of challenging so-called “faulty” ways of thinking may not always be helpful. Instead, trying to reduce the baseline importance of physical appearance in the lives of people living with lipodystrophy may provide a greater benefit in the effort to reduce depression and body dissatisfaction.

“Sometimes I will tell patients that maybe our goal at the end of treatment isn’t necessarily for you to love your body more,” Blashill says, “but that you don’t necessarily have to hate it. Trying to get to a place of neutrality for some people can be a really important goal.”

When it comes to looking for physical solutions with your medical doctor, a good place to start is by examining any lifestyle changes you can make to improve your overall health.

“Eating a good, healthy diet and exercising will certainly help for both the lipo as well as diabetes prevention,” says Janet Lo, MD, an assistant professor of medicine at Harvard Medical School who researches heart disease in people with HIV. These healthy habits can also help regulate cholesterol, triglycerides and sugar in the blood. “Because muscles utilize insulin,” Lo notes, “it’s good to maintain good muscle strength.”

In addition to a strength training program to build muscle mass, Lo recommends regular cardiovascular exercise. That means getting your heart rate up for 20 to 30 minutes at least a few times a week. The exercise may help you cut down your belly fat accumulation, and it will likely do so without affecting any lipoatrophy you may be experiencing.

There are, unfortunately, often singificant limitations to how much lifestyle changes can affect your body’s fat levels, as Sidle knows all too well. After her belly first ballooned in the mid-1990s, her weight shooting up from about 175 pounds to 225 (she’s 5’4"), she started a major physical fitness kick, running 10 miles a week and seeking help from a personal trainer. Ever determined, she was able to drop 70 pounds in only five months. But the belly proved more stubborn than she was. (In general it’s not a good idea for people with lipodystrophy to lose weight too rapidly, as that can raise their risk of losing important lean muscle mass.)

If diet and exercise shifts don’t have enough of an impact on your various metabolic levels, your clinician may want to try certain medications to address those concerns. For example, Lo says that if glucose levels are still abnormal she may prescribe the drug Glucophage (metformin), which has been shown to help lower blood sugar and prevent diabetes, and may also reduce visceral

abdominal fat in people with HIV.

If one of Lo's HIV-positive patients has significant abdominal fat buildup but does not have diabetes or other blood sugar problems, and if six months of diet and exercise haven't helped slim their waistline, she will consider prescribing the drug Egrifta (tesamorelin). This daily injectable drug, approved by the FDA in 2010 to treat excess belly fat in people with HIV, works by prompting the release of natural growth hormone, which leads to the burning of visceral fat in the belly. On average, the medication reduces abdominal fat by about 18 percent over a one-year period. A major downside, aside from potential side effects such as joint pain, is that once you stop taking Egrifta the belly fat will rapidly return.

"I drew the line when my belly was bigger than my boobs," Sidle recalls of her motivation to try the drug. "I couldn't stand it anymore."

Sidle has been one of the luckier ones, experiencing a considerable fat reduction while taking Egrifta. In a few months she went from 223 pounds to below 200 and lost three pant sizes. She's also seen significant shrinkage in the fat pad on her upper back and neck that she's endured for years.

Liposuction is another option for those looking to deal with that upper back fat. However, it often returns. The procedure is not an option for visceral belly fat, because it's too dangerous to try to reach fat that's around the organs.

Breast reduction surgery is another possibility for both women and men with fat buildup in the chest. Goodrow has been investigating this as a solution to her back pain. She's also been talking with plastic surgeons about the possibility of using various kinds of facial fillers, including a transfer of her own fat from one part of her body into her face. Her hope is to look in the mirror and see a fuller face that's more along the lines of what her HIV-negative siblings have. She's run into a lot of walls, though, thanks to the high expense of reconstructive treatments. Patient access programs from the pharmaceutical companies that make Radiesse and Sculptra, the two fillers that are FDA approved for treating HIV-related facial lipoatrophy, were once quite generous; in more recent years they have taken a stingy turn.

Some clinicians have been able to secure insurance coverage for such treatments, by classifying them as reconstruction, like for a breast after a mastectomy. But garnering reimbursement tends to be a rare feat, requiring a considerable amount of time and effort on the part of doctors' offices.

Blogger and HIV activist Mark S. King, 55, who lives in Baltimore, is one of the luckier ones. After living with severe facial lipoatrophy for years, he began receiving periodic injections of Radiesse and Sculptra and regained much of the lost volume in his face. (Check out his video blog covering these treatments on his website, MyFabulousDisease.com.) His clinician was able to secure a cut rate for him, and he's fortunate enough that he can afford to pay the difference. After enjoying success with these temporary fillers—they do fade over time—he decided to take the plunge and undergo treatments with the semi-permanent Bellafill. Part bovine collagen, part permanent

synthetic filler, the treatment requires a series of injections, after each of which the collagen portion gradually fades, leaving behind the synthetic base.

King, who in his younger days as a commercial actor and gay man in West Hollywood “got a lot of mileage” out of his fresh-faced look, says he has “mixed emotions” over having reconstructive procedures done to his face. He’s all too aware that many other people living with HIV and lipoatrophy don’t have access to these treatments, while still others wear the look as a badge of honor.

“In some ways, I feel like I just wasn’t up to it,” King says of maintaining his visible battle scars. “I’d rather have it fixed. It’s too painful of a reminder. I’m too self-conscious.”

As for Sidle, she’s adjusting to the positive changes in her body, still not quite sure what to make of her good fortune in experiencing so much waistline improvement after all these years of struggle.

“Slowly I’m going to thrift stores and finding clothes I can wear,” she says.
The first order of business: pants that stay up.

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