Fat Chance

Whether old-fashioned wasting or newfangled lipodystrophy, relief is possible.

April 1, 1999 By Lark Lands, PhD

I was standing in Grand Central Station, looking for the train that would take me to an AIDS conference in upstate New York. A total stranger walked up to me and said, 'Hey, going to the conference?' That's when I knew I had AIDS stamped on my forehead," says Monterey, California, PWA Jay Sheldrake.

What he had was The Look -- that frighteningly familiar facial gauntness that once pervaded the world of AIDS. Accompanied by a generally skeletal appearance in the rest of the body, wasting foretold the beginning of the end for many. The general rule was that quality of life and physical appearance went downhill hand-in-hand, and loss of life soon followed.

For Sheldrake, the result was emotional devastation and social isolation. "I'd been a ballet dancer with a six-pack stomach for years," he says. "With this, I could no longer bear to look at myself -- or to see the looks I got from others. And a social life became impossible. Who wants to be looked at with horror instead of attraction?" As his condition worsened, he became more withdrawn and depressed, ultimately resigning himself to dying. "I felt like a leaf in autumn, shriveling more and more, and just waiting to fall," he says.

Luckily, the many thousands of PWAs who might once have reached this point of hopelessness can now benefit from a range of therapeutic approaches. When doctors decide not to wait for someone to qualify for an overly conservative official definition of wasting, both they and their patients report that the most successful line of attack is an integrated approach. It combines anti-wasting drugs and exercise to stimulate muscle growth with measures to boost calorie intake and treat infections -- including HIV itself -- and the intestinal problems that may exacerbate wasting.

As a result, The Look is now far less common. Along with other opportunistic infections (OIs), wasting has declined dramatically. Once affecting two-thirds of PWAs, it now strikes only a third. But in one of those odd HIV-land twists, the effective new antiretroviral therapies that have contributed to these declines have brought with them a new kind of wasting -- associated with lipodystrophy.

This nasty new syndrome, seen in many on HAART, may also include elevated blood fats and blood sugar. Although the precise causes of this newest kid on the wasting block are still being defined, the physical effects are unmistakable: Most commonly, there is a redistribution of fat away from

the limbs and buttocks and into the belly, an increase termed “protease paunch.” In some, a “buffalo hump” develops behind the neck, and in women, there is often severe breast enlargement. Protruding veins may appear in the skinny arms and legs, lumpy fat deposits almost anywhere. And in the face, there’s a new version of The Look -- a loss of fat, often with deepening wrinkles -- that has become the new AIDS-identifying tattoo.

Picture a blond, buffed and buoyant soccer mom. That was San Antonio PWA Sharon Mars (not her real name) pre-HAART. “I’d never had anything that marked me as having AIDS,” she says. “But protease inhibitors changed that. Lipodystrophy started with obvious lumps of fat on my thighs. Then over time, my arms and legs shrank to sticks while my belly and breasts blew up.” Her dress size increased from 10 to 14 and her bra size from a C cup to an E. “I looked like I was seven months’ pregnant. When I went to get a new bra, they sent me to a specialty store. I figured that soon I’d need crutches for my breasts.”

Researchers believe that both forms of wasting may occur in the same person, and that clinicians may mistake one for the other. Kathy Mulligan, PhD, a wasting expert and assistant professor of medicine at the University of California (San Francisco), says: “We have people come in with supposed lipodystrophy who turn out to be suffering from old-fashioned wasting and vice versa. And sometimes they’re occurring together.”

For more accurate diagnosis and assessment of treatment effectiveness, Mulligan says that it’s very important to have baseline measurements of weight as well as of body cell mass (BCM) -- the tissue in muscles and organs that is crucial for survival. BCM is measured by bioelectrical impedance analysis (BIA). Both BIAs and weight measurements should be standard parts of an HIVer’s medical appointments.

A regular top-to-bottom physical assessment is important, too. With lipodystrophy, neither weight nor BCM may change much, if at all. But simply looking at the person may show the fat redistribution. Mulligan says, “Just ask the person -- self-assessment is often accurate.” Regular monitoring by both HIVers and their docs will mean that significant changes won’t escape notice.

Many experts now agree that a “significant” weight change would be an unintentional loss of 5 percent or more of body weight over six months’ time, or 10 percent or more in a year. But a CDC wasting diagnosis requires a 10 percent loss of weight, along with persistent fever, weakness or diarrhea and no underlying OI to explain such symptoms. That definition should be changed, says longtime wasting researcher Sherwood Gorbach, MD, professor of medicine at Tufts University.

“We need to identify wasting at an earlier stage,” he says. “Studies have tied a 5 percent weight loss to significantly increased risk of OIs and death. But many clinicians’ assessments of the need to treat -- and drug reimbursements -- are tied to the current CDC formula.” The result, he says, is that “people are going untreated because of a bad definition.”

Other scientists believe that BIA results showing a 5 percent to 10 percent loss of BCM should also trigger concern about wasting. Last year, leading wasting researcher Norma Muurahainen, MD, PhD, reported that HIVers could have a 9 percent to 10 percent loss of BCM while remaining at 95

percent to 105 percent of ideal body weight. Regular BIAs, she says, could spot losses early, promoting the interventions needed to prevent a downhill slide into serious wasting.

Gorbach emphasizes that despite the CDC definition, wasting can occur without infections, cancers, diarrhea or fever, although all can be contributing causes. Wasting may just be part of the HIV disease process. Physicians who remain unconcerned about wasting unless those other problems appear may not even be monitoring the basics. Gorbach is shocked by how many clinics don't bother to weigh patients regularly. "Progressive weight loss is a considerable concern," he says. "Every clinic or physician's office should have a policy to weigh everyone on every visit." Mulligan adds, "It's also useful to have a history of BIAs so that when weight is being regained, you'll know whether it's fat, muscle mass or both."

Both are eventually lost with traditional wasting, and both need to be regained for optimal health. Restoring fat to appropriately healthy levels is important since fat is the body's energy store. But, Mulligan says, "It won't get you up and down the stairs. For that you need your muscle tissue back." To restore both, and especially BCM, she says you may need help. But what that should involve is not well understood. Gorbach fears that there's a myth out there that HAART cures or prevents wasting. "It doesn't," he says. "Effective antiretroviral therapy may control virology and clinical symptoms, but it doesn't prevent wasting or put flesh on people." Research backs him up, showing limited, if any, weight gain (most of it fat) in people who begin HAART. In one current wasting trial, of the 100-plus PWAs with greater than 10 percent weight loss, more than 70 percent are on HAART.

HAART may help prevent wasting by reducing the risk of wasting-inducing OIs, but it is certainly not enough. Instead, experts agree on the need for a multipronged approach, something we'll call FAT: Feeding the body; Anabolic therapies (the ones that boost muscle growth); Treatment of OIs, HIV, diarrhea and malabsorption.

Feeding

Food intake can be low in PWAs for many reasons -- drug side effects or infections that cause nausea or appetite loss, mouth problems that make eating painful, depression that creates disinterest in eating -- all of which should be eliminated where possible. Since weight maintenance requires a balance between energy (calories) taken in and energy expended, decreased intake can be a major contributor to wasting. Boosting nutrition is crucial. And the focus should be on stimulating appetite and adding nutrient-rich foods that are high in calories, not junk. (For tips, see "All You Can Eat") Taking a potent multivitamin daily is also important, since many studies show multiple nutrient deficiencies even in unwasted HIVers. Supplementation of vitamins and minerals can help enhance supplies of the micronutrients required for rebuilding the body.

Taking the amino acid glutamine may be key. Research by Harvard's Judy Shabert, MD, RD, has shown that PWAs diagnosed with wasting who were given adequate doses of glutamine (30 to 40 grams per day) gained both weight and body cell mass. "Glutamine is the major fuel for the immune system and the gastrointestinal tract," Shabert says. "Since the muscles, largely made up

of this amino acid, are the body's glutamine supplier, HIV's constant demands on the immune system can erode muscle. When this and other factors lead to wasting, the daily demand for this fuel can quickly exceed the supply." The results can be decreased immune defenses, reduced intestinal absorption of both nutrients and drugs, and worsening muscle loss. That's why Shabert calls a combo of good nutrition and extra glutamine "the first line of defense against wasting." In a recent double-blind, placebo-controlled study, Juven -- a glutamine-containing, over-the-counter nutrient mixture that also includes the amino acid arginine and an amino acid derivative called HMB -- showed significant weight gains. PWAs who were wasting gained an average of six and a half pounds in eight weeks, most of it muscle.

Anabolics

Anabolic therapies tell muscles to grow. Progressive resistance exercise -- the kind you get with weight training -- is one such muscle booster. Gorbach's research group recently completed a study showing that after 12 weeks of supervised weight training, with three hour-long sessions per week, PWAs had significant gains of both weight and muscle tissue. Normalizing levels of testosterone, frequently deficient in people with HIV, can also help. Testosterone is one of the body's two most important anabolic hormones (see "Raging Hormones"). The other is human growth hormone, a genetically engineered version of which (Serono Laboratories' Serostim) is approved for HIV wasting. Despite its high price, Serostim has a large PWA fan club. Sheldrake, with his traditional wasting, and Mars, with her lipodystrophy, both used it as part of their body restoration programs.

Shocked by his Grand Central Station outing, Sheldrake was determined to do everything necessary to reverse his downhill slide. He improved his diet, began weight training, started swallowing fistfulls of vitamins and minerals along with his meds, and enrolled in an early Serostim trial. With daily hormone injections, he saw a turnaround. He says, "It was definitely the whole combo that worked, but if I had to pick one thing, I'd call growth hormone the miracle maker."

Meanwhile Mars was desperate for an answer to her protease paunch. Although preliminary research has now shown Serostim's usefulness for reversing lipodystrophy, in May 1998 there were only a handful of anecdotal reports about its possible benefits. Nonetheless, Mars talked her doc into prescribing it, using her wasted limbs as justification to get the drug's high cost covered. After three weeks of daily 6 milligram (mg) Serostim injections, she noticed that her stick-thin arms and legs were beginning to fill out. Continuing with 5 mg daily, within three months her paunch was mostly gone and she was back to a svelte size 10. Unfortunately, her breast size did not decrease, a problem that still causes her much distress.

San Francisco treatment activist and ACT UP/Golden Gate member Matthew Sharp has used growth hormone for both kinds of wasting. After a slow weight loss had left him at 138 pounds in 1994, a week of Serostim (6 mg daily) put back a third of his lost weight. After a month, he was at his normal 165. As is often the case, Sharp experienced no side effects. But some people develop temporary arthritis-like stiffness in their hands and feet, a problem that less-frequent dosing can usually eliminate. Blood glucose can rise and should be monitored during Serostim treatment,

especially in those on HAART or with a family history of diabetes.

Sharp continued on 6 mg of Serostim daily for a year and added weight training. After beginning HAART in 1996, he dropped the frequency to three times per week, but added high-dose glutamine, protein powders and testosterone, plus cycles of other anabolic steroids (nandrolone decanoate [Deca Durabolin] and oxandrolone [Oxandrin]). This aggressive combo boosted him to a muscular 185.

His first two years of HAART caused no lipodystrophy, but three months after insurance problems forced him to discontinue Serostim, his belly began to increase and his face to thin. He went back on the drug at 3 mg every other day. The results were again impressive. “Within a week, my belly began to shrink, and by the end of one month, it had mostly returned to normal.” Sharp has maintained the growth hormone dosing ever since, along with testosterone replacement, good nutrition, exercise and cycles of nandrolone decanoate. Although his facial gauntness has never disappeared, his energy is better than ever, his sex drive is great, his muscles are buffed and his friends tell him he has never looked better. He says, “I guess I’m the poster boy for Serostim. Twice it’s been the magic bullet that’s reversed serious syndromes. I just wish they’d lower the price so the magic would be available to everyone who needs it.”

After numerous protests against Serostim’s maker, Serono, few in the AIDS world remain unaware of the drug’s cost ($1,200 to $1,800 *weekly,* depending on dose) -- figures that have left many physicians (particularly those in HMOs) disinclined to prescribe it. But Karyl Thorn, a Los Angeles nurse and independent case manager who has carefully studied the costs associated with wasting, thinks this penny-pinching is shortsighted. “The costs of wasting -- additional hospitalizations, extended hospital stays and increased OI incidence -- are very high.” She says that it’s simply a matter of doing the math. “If you don’t spend the money on effective therapies -- and in my experience growth hormone is best -- in the end you’ll often spend even more for those extra hospital stays and OI therapies.” Most state Medicaid programs cover the drug, and insurance plans are more likely to do so if the doctor consults first with Serono’s Patient Assistance Program (800.714.2437). Both Thorn and Mulligan emphasize that Serostim shouldn’t be thought of as a lifetime therapy for conventional wasting. Instead, they see it as a kickstart that propels people out of wasting (three months’ use is the standard protocol, but some benefit from more long-term use). After that, PWAs may be able to maintain their bodies with exercise and nutrition.

Just over the treatment horizon may lie two considerably cheaper wasting treatments, already available in buyers’ clubs. One is a high-dilutional cytokine mixture called Cell-Signal Enhancers (see "Less Is More," *POZ,* April 1998). This experimental, nontoxic treatment has shown good results in small wasting trials, and research is continuing. The other is peptide T, a drug once studied as an antiretroviral that has resulted in significant weight gains in some users. With recent research indicating it may improve the body’s ability to use its own growth hormone, wasting trials are planned.

Some treatment advocates support a more controversial approach to reducing costs: substituting much less expensive anabolic steroids for growth hormone. For Houston PWA Nelson Vergel, the founder of the Program for Wellness Restoration (PoWeR), using testosterone plus nandrolone

decanoate was a lifesaver. “After watching 38 of my friends die from wasting,” he says, “I was terrified when my weight dropped by more than 10 percent in 1989.” Using the steroids along with weight training and a high-calorie, high-protein diet quickly restored a healthy body. And getting his body back was tied to other improvements. His thrush, diarrhea, skin problems, night sweats and fatigue all vanished. “I never felt or looked better in my life, even when I was HIV negative,” he says.

Vergel and PoWeR research director Michael Mooney have found that such integrated approaches work not only for “traditional” wasting but also for the lipodystrophy variety. “There’s no single magic component,” Mooney says. “What works is a combo of the nutrients that provide muscle building blocks, the progressive weight training that tells the muscles they need to grow and the anabolics that signal muscle cells to increase in size.”

Anabolic steroids are powerful drugs that must be used with care. PoWeR recommends combining testosterone replacement -- when tests indicate the need -- with cycles of the drugs that they have found to work best (most often nandrolone). “Use the least amount that gets the desired effect for the shortest period of time that works,” Mooney says.

The standard PoWeR program recommends 12 weeks of nandro-lone followed by a break from all anabolic steroids for 16 weeks or more. This cycling is intended to reduce the chances of possible side effects, including unhealthy increases in red blood cells (a risk factor for heart disease), impotence, acne, high blood pressure and swollen prostate. For anyone on anabolic steroids, it is advisable to monitor blood pressure, hematocrit blood levels, liver function tests and blood fat levels.

Treatment

Treating OIs and intestinal problems is the third crucial aspect of wasting therapy. Infections boost the level of cytokines, the HIV-elevated cell-produced chemicals that promote weight loss and fevers, both of which further raise the elevated metabolic rate of PWAs. Diarrhea rapidly throws needed calories into the toilet. And malabsorption prevents nutrient uptake. Thus, aggressive diagnosis and treatment of any underlying infections and diarrhea, along with maximum possible suppression of HIV viral load, are musts. And using digestive enzymes and glutamine may help with malabsorption.

Regardless of their disagreements on certain specifics, almost all treatment advocates would agree on two things: the need for a multipronged integrated approach to wasting and a preference for early intervention to prevent it. “The future of wasting therapy -- whether for traditional wasting or for the body composition changes seen with lipodystrophy -- lies with prevention,” Mooney says. “Beginning at diagnosis, hormone levels should be monitored quarterly, followed by appropriate replacement of any found deficient. This should be combined with exercise, optimal nutrition from both a good diet and supplements, and glutamine to protect the intestines and ensure good absorption.”

Sheldrake has maintained just such an approach for four years. “When I reversed my wasting, I

got my life back," he says. "I'm never going down that black hole again." Today, the only strong reactions he gets from strangers are wolf-whistles from those appreciative of his muscled, tanned body.

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