Change of Face: Should Government Pay for Lipoatrophy Treatment?

The Centers for Medicare and Medicaid Services is accepting public comments until February 16 to help it decide whether to cover treatments for facial wasting. Sharing your story, or the story of a loved one, could help secure coverage of these therapies for HIV-positive people who need them.

February 3, 2009 By David Evans

Study after study shows that HIV-related facial fat loss has a profound effect on a person's life, ranging from isolation and depression to HIV treatment adherence problems. While the condition, called lipoatrophy, also affects the arms, legs and buttocks, it's facial wasting that is often most visible and, as a result, the most stigmatizing. "Facial wasting is like the scarlet letter of HIV. It takes away your anonymity and declares to the world that you're HIV positive," says Nelson Vergel, a Houston AIDS activist.

The face is also the part of the body that's easiest to restore with temporary or permanent filling agents, at least for those with the cash or credit to pay several thousand dollars to a trained plastic surgeon or dermatologist. Until now, the government has considered HIV-related facial reconstruction a cosmetic procedure and therefore not coverable by Medicaid, Medicare or private health insurance. All of that could change very soon—with your help.

Only rarely does the average person living with HIV receive an open invitation to help the federal government shape its health policy. Between now and February 16, the Centers for Medicare and Medicaid Services (CMS), a branch of the federal Department of Health and Human Services, is accepting public comment on reconstructive treatments for HIV-related facial wasting. AIDS activists who've long advocated for the government and private insurance to cover such treatments say that a groundswell of comments from individuals and organizations could finally make this hope a reality. Of course, it will be critical that such comments make the strongest case for coverage of this vital treatment. Following is a primer on the causes of facial wasting, the impact it has on people's well-being, and the rational for ensuring that everyone with the condition has access to reconstructive treatment.

Causes and Conditions

When doctors first noticed that people with HIV were losing body and facial fat, they thought it was

due to the wasting syndrome that was so common in the late 1980s and early 1990s. Then, because protease inhibitors had recently been introduced, experts feared they could be the cause. Ultimately, numerous studies proved that three of the older drugs were the culprits. The worst offender turned out to be Zerit (stavudine), followed by Retrovir (zidovudine). If a person stopped taking the offending drug, the fat loss usually halted, but the fat almost never returned.

Vergel, who has led the charge for better access to treatments for facial wasting and runs a web forum on the topic, says people contact him all the time and tell him they are terrified to start HIV treatment for fear of facial wasting and ask him how to avoid it. “There is enough data to show a huge impact on quality of life, depression and anxiety, suicidal thoughts and [poorer] adherence [to antiretroviral medication] among people with facial wasting,” Vergel says.

Vergel believes that this research demonstrates that treating facial wasting is medically necessary—the standard that must be met if it is to be covered by both government and private health insurance.

The only treatments approved by the U.S. Food and Drug Administration (FDA) for HIV-related fat loss are injectable artificial fillers that help collagen form under the skin, and these are approved only for the face. Both fillers act in a similar fashion and are considered semi-permanent. It usually takes several courses of treatment to restore the face to normal proportions, and people often need to repeat the treatment within a couple of years. Each course of treatment can run in excess of $5,000 when the cost of the fillers is added to the cost that most trained practitioners charge for the consultations and injection procedures.

The CMS process of collecting public comment will help the government determine whether facial wasting treatment meets the medical necessity threshold. “It’s critical that people make the point that facial wasting can be totally debilitating and that facial reconstruction is just that, reconstruction of something that the [HIV] drugs took away. This is not cosmetic. This is not about vanity,” Vergel says.

Vergel also makes that point that private health insurance companies usually follow whatever course the government takes with Medicare and Medicaid. He says that even people with private insurance should send in comments.

To share your story, advocate for a loved one or make a declaration on behalf of your organization, visit the CMS web site here and click on the orange “Comment” button in the title. Vergel says that comments should make the case that the treatment is reconstructive, rather than cosmetic, and elaborate on the mental and physical toll that facial wasting can have on a person.

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