5.1 Living with HIV and ART Over the Long Haul

When HIV treatment was first introduced, nobody really knew how well or for how long it would work. Now, with the advances that have been made, it seems that treatment is more successful than we might have dared to hope at first. Many experts are predicting that HIV drug treatment may allow people with HIV to live out nearly normal lifespans. While that remains to be seen, and some people might be more skeptical than optimistic, we do know that people with HIV are living longer than ever before.

Of course, that means dealing with the consequences of growing older, as well as dealing with the long-term effects of treatment and of the underlying HIV infection. The relationship between aging, HIV and drug treatment is the subject of much research, and it is not always clear which is most responsible for some health problems. However, we do know that as people with HIV age, they are more at risk for cardiovascular disease, kidney disease, thinning bones and certain types of cancers.

Some people with HIV develop lipodystrophy—the visible loss of body fat (called lipoatrophy) or buildup of body fat (called lipohypertrophy). Lipoatrophy includes the loss of fat in the face, arms, legs and buttocks, causing a gaunt and veiny look. Lipohypertrophy involves the buildup of fat in the breasts, belly or base of the neck. This can sometimes occur together with fat loss in other areas. Many people are very concerned about developing “lipo” because it is so visible. Although many people think of lipo as purely a side effect of treatment, it is probably due to a combination of treatment toxicity and long-term HIV infection. Experts do not have a complete understanding of what causes lipodystrophy or how to treat it. However, experts have identified d4T, and to a lesser extent AZT, as two drugs likely to cause lipoatrophy. Because of this, other drugs from the same class (called nukes) are often used instead.

For nine years, my motto was: ‘If it ain’t broke, don’t fix it.’ That’s why, despite worsening lipodystrophy, I clung to the drug regimen that was keeping me alive. Though my viral load was still below detection, my doctor was urging me to make a change. She wanted me to replace d4T [with another drug] because of increasing evidence that d4T was responsible for my sunken cheeks and stick-like arms and legs.

—Maggie

Cardiovascular disease (CVD) includes diseases of the heart and blood vessels, including coronary heart disease, heart attacks and strokes. Among people with HIV—as for anyone else—smoking is the number one factor that increases the risk of CVD. CVD also becomes more of a risk for everyone as they age, although there are many other risk factors. One risk factor—high levels of cholesterol in the blood, especially LDL cholesterol—has received particular attention in HIV care because many antiretroviral drugs (including several of the protease inhibitors) can raise cholesterol levels. Other risk factors for CVD include being overweight, a family history of CVD, diabetes, alcohol use, physical inactivity, high blood pressure and a high-fat diet. HIV-positive people should limit their risk factors for CVD as much as possible. While this may include choosing antiretroviral drugs that don’t raise cholesterol levels, it can also mean eating healthily, getting moderate amounts of exercise and watching your alcohol intake. For smokers, quitting smoking is the single most effective means of lowering risk. There are also drug treatments that can lower cholesterol levels if heart-healthy changes to lifestyle are not enough.

Because some people on HIV treatment have abnormally high levels of blood sugar (or blood glucose), your regular lab tests will likely include a test to measure your blood sugar. The same “healthy living” measures that help keep your heart healthy can also help to keep blood sugar under control. If there are concerns about your blood glucose levels, you may have to take special care with the food you eat. In more extreme cases, glucose-controlling medications may be needed.

Thinning of the bones is another problem that is often seen in people as they age, especially in women after menopause. As bones slowly lose minerals—mainly calcium—they become less dense and more porous and sponge-like. When bone loss occurs too quickly, it can lead to osteopenia and, in more severe cases, osteoporosis.
The bones become fragile and more prone to breaking. Osteoporosis is common among people with long-term HIV infection—men as well as women. The process of bone loss is painless and may go undetected until a person breaks a bone.

Bone scans can detect whether bone loss is taking place. Find out from your doctor whether it is possible to get a bone density scan in your area. If you get a scan now, it will allow you and your doctor to track any changes that may occur in the future. Ideally, you’ll get this “baseline” scan when you first test HIV-positive and then have follow-up scans at regular intervals thereafter.

Vitamin D₃ is important for bone health and a lack of it can lead to bone loss. Studies have found a deficiency of vitamin D₃ to be very common among people with HIV, and many experts recommend taking vitamin D₃ supplements regularly. Talk to your doctor to find out more.
Disclaimer

Decisions about particular medical treatments should always be made in consultation with a qualified medical practitioner knowledgeable about HIV- and hepatitis C-related illness and the treatments in question.

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