



Dr. Gordon Arbess, MD, CCFP

Dr. Arbess specializes in HIV primary care at The Health Centre at 410, St. Michael's Hospital, Toronto. He also teaches in the Faculty of Medicine, University of Toronto.

## Can you have Quality of Life and also be on treatment?

People on treatment for HIV want to live longer and have a good quality of life. Balancing treatment needs with quality of life issues is a critical factor in achieving this goal.

If you are living with HIV/AIDS, you may be taking what is known as a “cocktail” – a combination of three or more antiretroviral drugs. The cocktail aims to help you live longer by reducing the amount of HIV in your body as much as possible – for as long as possible – and by strengthening your immune system to protect you from infections.

The challenge is to find the right combination of drugs that will reduce the amount of HIV viral material in your blood (known as “viral load”) and strengthen your immune system while avoiding unwanted side effects (“drug toxicities”).

In the early years of the HIV cocktail, emphasis was placed mainly on reducing viral load and strengthening the immune system. As new drugs have been introduced and more experience gained in using the cocktail, the overall health and survival expectations of people living with HIV/AIDS have improved. This has allowed for more attention to be paid to improving the quality of life of people on the cocktail.

### What do we mean by “Quality of Life” and can it be measured?

Quality of Life (QOL) generally refers to your physical, psychological, emotional and social well-being. If you're on treatment, measuring QOL is important. Why? Because the cocktail can have side effects that impact quality of life and, in turn, affect the way you follow your treatment regime (known as “adherence”).

A number of methods have been developed to assess QOL for people living with HIV. These include the MOS-HIV questionnaire,

which asks questions in eight areas: physical activity, social activity, work activity, pain, mental health, emotional well-being, energy level and self-perception of the state of health. You may have been asked to complete one of these surveys by your doctor or as part of a research study.

### How does a doctor typically assess QOL within a treatment plan?

One of the aims of treatment is for you to feel better and to function better in your day-to-day activities. In discussing HIV/AIDS treatment options, you and your doctor should take into account all physical, psychological, social and spiritual aspects of your life. Some common issues that have an impact on QOL may be your living situation, your job status, your financial situation, your energy level, your level of

pain and how you sleep. Concerns about confidentiality, feelings of isolation and the fear of having to disclose a diagnosis are all issues that can significantly impact your sense of well-being, even before you have begun to think about starting on medications. Feelings of low energy, chronic fatigue, depression, anxiety and low sex drive can also affect quality of life – some related to being HIV+ and others related to being on treatment.

### How can treatment affect QOL?

Some of the above-mentioned issues may affect whether you choose to go on the cocktail and which specific drugs you take. There are people living with HIV who experience significant improvements in their QOL after they start the cocktail. For example, a recent French study has

### Definitions of Some Terms Used by Doctors in HIV Treatment

**Adherence** – Taking all the pills in the cocktail, at the right times of the day, every day, as prescribed by your doctor.

**Cocktail** – Common term for a combination, usually three or more, antiretroviral drugs that fight HIV.

**Lipodystrophy** – Changes in body fat that may affect appearance (like fat loss in the face and arms, or gain around the waist) or increase fats in the blood that could lead to heart disease.

**MOS-HIV** (Medical Outcome Study-HIV Health Survey) – This questionnaire measures quality of life by asking questions in eight areas: physical activity, social activity, work activity, pain, mental health, emotional well-being, energy level and self-perception of the state of health.

**Peripheral neuropathy** – Numbness, tingling or pain in the hands and feet, especially the fingers and toes.

**Toxicities** – Unwanted side effects from drug treatments.

**Viral load** – The amount of HIV viral material in the blood.



demonstrated that the majority of people taking a protease inhibitor-based antiretroviral therapy had stable or improved health-related QOL a year after starting therapy.<sup>1</sup>

However there may be instances where quality of life is negatively affected because of antiretroviral therapy. Treatment could produce unpleasant side effects such as chronic diarrhea, changes in body fat (“lipodystrophy”), problems sleeping and numbness, tingling or pain in the hands and feet (“peripheral neuropathy”). These symptoms can lead to social isolation, shame, anxiety and depression. It is critical, therefore, that you discuss such side effects with your doctor in an open and honest way. You might also want to consult two easy-to-read guides: “Living Better with HIV,” which provides practical suggestions on how to manage unwanted symptoms, and “A Practical Guide to HIV Drug Side Effects.” Copies are available from your local HIV/AIDS organization or the Canadian AIDS Treatment Information Exchange (CATIE).<sup>2</sup>

### **How can you improve your chances for maintaining Quality of Life while on treatment?**

1. **Educate yourself first.** If you have not yet started taking HIV medications, educate yourself about the positive and negative aspects of antiretroviral therapy. Starting the cocktail is an important step for an HIV+ person. Are you able to accept the fact that HIV is a part of your life? Not feeling ashamed of HIV and knowing both the benefits and side effects of treatment, before you start the cocktail, can make you feel more comfortable with your choices. And that can help you feel more in control of your life.
2. **Learn about new guidelines.** It may be possible to start treatment later in the course of your disease, which can help delay side effects and toxicities. Ask your doctor about new guidelines that recommend starting treatment when your viral load is higher and CD4 cell count is lower than was previously recommended.

3. **Simplify treatment.** When you start treatment, choose something that will have the least impact on your daily life. For example, you may want to choose a combination therapy that has the fewest number of pills, or the fewest doses per day, or treatments that you can take with or without food and liquids. The idea is to make it as simple as possible to fit into your work or leisure schedule and your life in general.
4. **Select side effects.** Try to choose a cocktail with side effects that will be least damaging to your quality of life. For example, could you more easily tolerate dry skin than problems sleeping or diarrhea? Some people can cope with having diarrhea by modifying their diet or taking medications to control it. Talk with your doctor, pharmacist or treatment counsellor – they may be able to help reduce the impact of side effects on your daily life. Changing your diet and exercising can also help reduce some side effects.

5. **Change or modify your meds.** Depending on your situation and the number of medications you have been on in the past, you may be able to change your treatment in consultation with your doctor. For example, you might be able to reduce the number of pills or take fewer doses per day with a different cocktail, or switch certain medications that may cause lipodystrophy, diarrhea or other symptoms that are harming your quality of life.
6. **Take care of your mental health.** Living with HIV can be stressful, which can lead to feelings of isolation and shame, depression and anxiety. Make sure you talk about your feelings with people you care about and trust. If necessary, try to reach out and seek professional help from a counsellor or psychiatrist. You may also require medications to relieve feelings of depression and anxiety, so don't hesitate to discuss the best way to address your mental health with your doctor.

### **What other resources could help?**

Discussing issues related to your quality of life and how living with HIV/AIDS affects you is important. Other resources that may be helpful are HIV/AIDS community organizations and support groups, a social worker, a pharmacist, a nurse and a psychologist or psychiatrist. They may be able to help you address how living with HIV affects you as an individual. They may also help to address the spiritual, social and psychological aspects of living with HIV – subjects that your doctor may or may not discuss with you.

If you're living with HIV, it's crucial to identify and understand what issues related to quality of life are most important to you. Every person is different, and everybody will have different priorities. Make sure you talk to your doctor regularly and work with him or her to develop – and adjust as necessary – a treatment plan that is right for you.

1 Carrieri P et al. Health-related quality of life after 1 year of highly active antiretroviral therapy. JAIDS 2003; 32: 38-47.

2 Contact your local HIV/AIDS organization, or the Canadian AIDS Treatment Information Exchange. 1-800-263-1638. [www.catie.ca](http://www.catie.ca)

**This information is provided solely as an educational resource.  
Always consult your physician before initiating or changing any treatment regimen.**