

Where's that spoonful of sugar
when you need it?

The Importance of Being Adherent



BY DEREK THACZUK

Are you like me—sick and tired of the same old song: “Take *all* your pills, *all* the time”? This mantra is shoved down our throats so often, who can blame a person for saying, “Take *ALL* your pills and shove ’em!”? The problem is that playing loose with HIV therapy can lead to drug resistance, causing treatments to fail. Why do we PHAS have to walk such a tightrope, and how do we manage to pull it off?

Drug adherence (or compliance) means taking your HIV medications exactly as prescribed—in the right number, at the right time, with or without food, *every* time. Understanding why adherence is crucial can help you stick to the pill drill.

DRUG RESISTANCE 101

Once HIV is in your body, it's there for good (until medical science finds a way to exterminate it). Drug therapy—antiretrovirals, HAART, the cocktail, whatever you call it—is not a cure, but it can reduce the risk of life-threatening infections and improve survival.

HAART (highly active antiretroviral therapy) keeps HIV under control—throwing monkey wrenches into the “assembly lines” the virus uses to re-

produce. But a dose here and there won't succeed: It takes constant, adequate amounts of drugs to keep HIV under control. Think of HIV as a gushing river, and HAART as the dam holding it back. Half a dam won't work—it's either high enough or not. Biologists describe antiretroviral drugs as a “genetic barrier” to HIV reproduction. If you don't keep enough meds in your body, all the time, that barrier wears away under viral pressure and eventually breaks, allowing HIV to reproduce.

HIV is sneaky, finding weak points in our defenses, such as low drug levels. The virus can change shape to sneak around a drug: The change is called a **viral mutation**, and the mutated virus may be **drug resistant**. Once a certain drug no longer works for you, drug-resistant HIV can reproduce and grow, even if you keep taking the drug. Even worse, **cross-resistance** can sometimes make the virus resistant to other drugs in the same class—even if you've never taken them before.

Prime example? Moi: I started monotherapy (single-drug therapy) with AZT back in 1995, before we knew that taking just one med was a recipe for drug resistance. We did a lot of things wrong back then—adding on 3TC (Epivir) and then Crixivan (indinavir) only made me resistant to them as well. Thanks (or no

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thanks) to cross-resistance, many other new meds became useless too, and for a while my prospects didn't look good. Luckily, the *five* antiretrovirals I switched to in 2000 finally got my viral load under control, but believe me, you don't want to paint yourself into that corner.

What does all this have to do with adherence? Simple: **drug levels.** Whether you're taking too few meds or taking enough but not *often* enough, the result is the same: inadequate drug levels. Your body is constantly clearing medications *out*, so you have to keep putting them *in* to maintain sufficient levels. Hence, once-, twice-, or even (bleah!) three-times-daily pill-popping schedules.

WE'RE ONLY HUMAN

As you can see, there's good reason to be adherent—it's not just doctors being bossy. In fact, one often-quoted study found that chances of keeping the virus suppressed for a long time start to slide if you miss more than 5% of your doses. If you pop your pills twice daily, that means not missing more than two or three doses a month; for three-times-daily poppers, not more than one dose a week.

Taking 95% of your doses for peak effectiveness is an incredibly high target. Most negative people don't come anywhere near it. So what are we PHAs supposed to do out here in the busy and messy human world?

Take my less-than-perfect self: I can spout stats 'til the cows come home, but I still find missed doses in my carefully organized pillbox. My own personal pitfalls?

- Falling asleep before pill time (because, dammit, I'm tired!).
- Being depressed and not feeling like eating, which makes a "with-food" dose a problem.
- Losing track of one of my nine prescriptions, and either forgetting to get one of my HIV 'scripts refilled or running out of repeats.

COMPLIANCE CULPRITS

Working at the Toronto People With AIDS Foundation for eight years, I've found that there are as many different adherence challenges as there are people on meds. Laura, a single mom whose kids don't know she has HIV, has to keep her meds hidden. Luis went for weeks taking only half-doses because he thought that would lessen the side effects. Jimmy does really well until he lights up his crack pipe, then it's game over for the next three or four days. And I can't even begin to count the people who show up at our agency, out of meds and panicked, because their drug coverage plan has screwed up—again.

Out of this assortment, some common culprits emerge:

- **Side effects.** Who wants to feel sick? If the side effects are nasty, switching meds may make adherence easier. Talk to your doc about how to deal with them.
- **Depression or anxiety.** Ever ask yourself "why bother?" Because your life *is* worth it, that's why. Depression can be treated in a variety of ways. Don't be ashamed or afraid to seek help.
- **Lack of structure.** This is often tied to alcohol and drug use

or mental illness. Or just trying to hold a hectic life together—as a single parent can tell you.

- **The "oops" factor.** "I just forgot" or "I was late"... hey, it happens! Finding *some* stable point amid the daily chaos can be the key (see "Forget-Me-Nots" for practical pointers).
- **Access issues.** You can't take your meds if you can't fill the 'script—and too many coverage schemes have cracks that people fall through. You may need to work with your health care team or AIDS agency to get the drugs you need.

GETTING AHEAD OF THE GAME

While there's no single magic solution, take heart—most people can handle the challenge of adherence once their issues are addressed. Best up-front advice? *Be prepared.* Going from no pills a day to *any* pills *every* day is a big leap. If you're thinking about starting HAART, work through your feelings about taking HIV drugs. Be aware of any potential side effects *before* you start taking meds and practice with jellybeans or Smarties to see where the trouble spots may lie. Talk with other HAART takers.

Once you're on HAART, adherence problems can sneak up—even eager beavers may drift after awhile. If you feel like you're slipping, don't wait: Talk with your doctor, pharmacist or clinic nurse—your health is their job. Simpler schedules, such as once-a-day dosing, often make adherence easier, but they may not work for everyone.

If you do miss the occasional dose, don't beat yourself up. Nobody's perfect; just do the best you can. If you space out, don't double up your next dose to make up for it—get back on track by taking your next dose on schedule.

I've been taking HIV drugs for a long time now and, like everyone else, there have been times I've wanted to ditch 'em. But in the end, while taking meds may be complicated, one thing is simple: My life is worth the trouble. +

Derek Thacuk tested positive 12 years ago. He provides treatment information at the Toronto People With AIDS Foundation and as a freelance writer. His pill schedule can't keep him off the bike trails.



Web Wee-minders

- CATIE's *Practical Guide to HAART*, www.catie.ca/PG_HAART_e.nsf/ (See the sections on "Issues to consider before starting treatment" and "Continuing Treatment: making it work long-term")
- "Tips on scheduling medications," www.thebody.com/treat/adherence.html, lists many other useful articles, including an "Adherence Attitude Inventory," www.thebody.com/aacm/aa_i_survey.html
- "The Importance of Adhering to Your Treatment Regimen," www.aidsmeds.com/lessons/Adherence1.htm
- "Adherence: Keeping up with your meds," www.projectinform.org/fs/adherence.html



What the Science Says

Research into HIV drug adherence may produce ways to make it better and will hopefully help doctors and scientists see the point of view of the people taking the medications. However, considering how heavily HIV is studied, there's less research on drug adherence than you'd expect. One reason is that it's so complex, says Laura Park-Wyllie, a Toronto pharmacist and researcher with St. Michael's Hospital's Inner City Health Program: "A huge number of factors affect people's adherence. As a researcher, you have to make sure you're doing the science carefully, but it's important to remember you're dealing with real human beings."

DIFFERENT STROKES

Park-Wyllie, along with Dr. Elizabeth Phillips of Sunnybrook and Women's College Hospital, recently reviewed the research on adherence for the *Canadian Journal of Clinical Pharmacology*. Examining why people have trouble sticking to their regimens, they found everything but the kitchen sink: depression, stress, unstable living conditions, recreational drug use, complex and demanding med schedules, side effects, the number and frequency of daily doses, poor or inconsistent medical care, travel, changes in daily routine, and just plain forgetting.

This grab-bag of troubles led to the notion of a "toolkit" of support techniques: working closely with each individual to assess what's most likely to help, then drawing on existing tips and tools to form a highly customized adherence support program.

PHARMA KARMA

A recent study from the B.C. Centre for Excellence, published in *AIDS Care*, found that pharmacists can help with adherence. People who got their meds from pharmacies in hospital clinics, where pharmacists work very closely with PHAs, were most likely to be highly adherent and have lasting viral suppression as a result.

STAART BEFORE HAART

Psychologist Louise Balfour and others at Ottawa Hospital are currently studying a program they call "Supportive Therapy for Adherence to Anti-Retroviral Treatment" (STAART). Providing psychological and educational support

before people pop their first pill is proving useful to head off potential problems with adherence, especially for PHAs suffering from depression.

A FULL-TIME JOB

Other Canadian researchers say that adherence has a lot to do with how we as PHAs *feel*—about ourselves, our medicine and what we have to do to stay healthy. Eric Mykhalovskiy and colleagues at Dalhousie University in Halifax use the term "health work" to describe the ongoing daily effort demanded of PHAs, recognizing that just getting through a typical day, with its medication and other health demands, requires constant effort.

MIND OVER MEDS

James Gillett and colleagues at Hamilton's McMaster University are talking to PHAs about their views of drug treatments and all that they symbolize. The McMaster team calls this a "rarely straightforward" headspace where treatments may symbolize hope, health and a future—or intrusiveness, toxicity and "feeling like a lab rat."

A FINE BALANCE

Sergio Rueda, from the (now-defunct) Community Research Initiative of Toronto, found that while some people sing the praises of their meds, many more see them as, at best, a necessary evil. This "stoic" view reflects an ongoing struggle: to keep HIV and taking pills from ruling your life. +

—Derek Thaczuk

Forget-Me-Nots

- **Piggyback.** Pick something you do habitually every day—brushing your teeth, watching the nightly news, putting contact lenses in. Get in the habit of taking your pills at the same time.
- **Get your ducks in a row.** Doses—daily or weekly pillboxes with different compartments—can be had from the drugstore or perhaps your local AIDS organization. Doling out your doses at the beginning of the week saves time and bother.
- **Put drugs in your pocket.** Keep a dose or two on you in case you come home late (or not at all).
- **Stockpile.** It can't hurt to have a little extra stash on-hand in case a prescription renewal hits a bump.
- **Don't be afraid to ask.** For help, that is. Your doctor, pharmacist, AIDS organization, PHA pals—somebody is bound to have suggestions. You don't have to go it alone.
- **Put yourself in charge.** Nobody likes being told what to do. Ditch "Yes sir, took my pills, sir"—do it for yourself.
- **Come clean.** Be honest about adherence problems. Your doctor should be able to help you, not scold you.
- **Put it in perspective.** If you're bummed out about meds running your life, here's how one PHA puts it: "I think about being HIV positive for 15 seconds a day—when I take my pills." It takes longer than that to shower and shave!