It’s 10 O’Clock. Do You Know Where Your Meds Are?

If your dream AIDS drugs have become the regimen from hell and you’ve got those “can’t live without them” blues, Julie Boler can tell you where to go from adhere.

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It all comes down to standing at the sink and swallowing. Again and again and again.

When the novelty of the most technologically advanced pill-dispenser wears off. When the last version of “10 Adherence Tips” yellows under your refrigerator magnet. When the ritual focused on that pretty glass pill bottle from Pier 1 holds no more magic. When the choice between the seafood platter and your no-fat Crixivan meal blurs. When the ill effects of a drug holiday become as theoretical as your contribution to global warming when you use aerosol. Then it comes down to the will to swallow. Again.

What if you flush the dose?

Will you tell anyone? How many times will you do it before you issue a cry for help to the ones whose job it is to remind you, reinvigorate you, chastise you, educate you, beg you, empathize with you, and then leave you alone again at the sink?

Or will you take the knowledge that you do this and bury it like a guilty secret, answer “OK” when asked how you’re doing with your regimen, and then dread your lab results as much for their evidence of your “bad adherence” as for their news of your health?

Or will you swallow, again and again and again, because you always do as you’re told?

Welcome to the new world of adherence high-anxiety. Surely many people on complicated HAART regimens are down with their drug-taking schedule. They may be never-miss-a-dosers who have studied their options, set up a support system and selected the best time to begin. Even many not-so-adherents have come to terms with their drug-taking highs and lows -- whether it’s been a week of clockwork dosing or one when every pill is washed down late with the wrong food. And while an anal temperament or an unambivalent relationship to these toxic compounds can give a leg up, nothing eases adherence like access to resources.

Bill Cagle, a California adherence-hotline specialist, rarely misses a dose and has little anxiety

when he does. Educated, informed and empowered, he also has little use for AIDS service organization-trained “adherence buddies” or the proliferation of pill dispensers and other such products. “Those are geared more to people with multiple life problems -- money, housing, substance use,” Cagle says. But adherence anxiety hardly breaks down along class lines. Cagle reports having taken plenty of calls from educated, informed and empowered folks who missed or skipped doses and were “totally freaked out.” (For a list of hotlines that can help you with compliance complaints, see “Adhere’s the Number”)

For many HIVers struggling with drug schedules, adherence anxiety is a part of daily life. The misery is more than just fear of the consequences of not keeping the right levels of the right drugs in their blood, including resistance, treatment failure and a downward health spiral. Also present is the performance anxiety that accompanies all behavior-change initiatives. With so much at stake, expectations are high; neglecting to “do the right thing” can cycle into guilt, shame and failure. And often the very people in an HIVer’s life who intend to promote adherence are the ones producing anxiety. As Project Inform’s “Discussion Paper on Adherence to HAART” points out, “Most health care providers have little or no training in the self-adherence tools that might help people who are undertaking a new treatment regimen.” Doctors expect their patients to follow prescriptions. Therapists and counselors derive professional satisfaction out of getting their clients to implement successful problem-solving strategies. Drug-makers have a vested interest in the success of their drug, which plays out in the bodies of consumers. And, above all, families, partners and friends count on a loved one’s drug compliance to ensure that his or her health lasts as long as possible.

No one knows how much adherence is necessary for the drugs to do their job, and few will hazard a guess. The research on resistance is in early, specialized stages, and bedeviled by variables. A doctor may base recommendations for compliance to a regimen on the half-life of one particular drug. A study may look at how viral load affects susceptibility to resistance. Drug interactions may play a role, as may specific strains of the virus. To err on the side of caution, the treatment establishment has told the hapless drug-taker, “Just say swallow.”

Because the science is still so ambiguous, the official approach to adherence resembles nothing so much as early HIV prevention campaigns: “One slip can be fatal.” This “never miss a dose” edict, drawing on a crisis mentality, calls for the immediate adoption of drastic behaviors to be maintained for a lifetime. And like the absolutism of “use a condom every time,” this adherence line may have measurable success in the short term but result down the road in the same kind of disconnect between what people are told to do and what they can do.

This prevention/adherence likeness can trigger an unnerving sense of déjà vu. These days the exhibit halls at AIDS conferences are as attention-grabbing as they’ve been since ASOs unveiled their “safe sex is hot sex” posters more than a decade ago. Of course, at the glitzy booth displays of Merck, Glaxo, Abbott and the rest, the message now is not about getting off, but about staying on -- your meds, that is. In the words of one company’s guide, “Every time you miss a dose of anti-HIV medication, you may be doing the virus a big favor … . Don’t skip doses. Don’t endanger your health status -- and maybe your life … . The next time you’re tempted to skip a dose or two, think

again ... ."

Back when condoms were queen and harm reduction the ugly stepsister, researchers, doctors and public-health officials prioritized their energies to look at worst-case scenarios and certain danger; out of their urgency, limited information and the tools at hand, a genre of social marketing arose. It was designed to halt people in their tracks and turn their behavior around, and for a time it did. Now we're all older and wiser about HIV prevention. We're learning to integrate realistic, individually tailored and sustainable safer-sex strategies into our lives. But people whose prevention needs are aimed not at such pleasure-seeking acts as sex but at downing pills are still expected to adopt a drop-everything-and-live approach. It's no wonder some question whether a long life under the rule of the regimen is worth the price.

We do have the benefit of all our previous prevention trials and errors. Adherence pros pay increasing attention to the multiple barriers a person faces in trying for a high level of compliance, and the latest behavior-change theory is sometimes applied to programs. Even as "100 percent adherence 100 percent of the time" is touted as the goal, experts admit that 80 percent compliance to the simplest antibiotic regimen is hard to achieve. With most studies showing that the average HIVer gets his or her pills down between 60 percent and 80 percent of the time, it's worth asking: What if doctors, drug companies and friends based their adherence expectations on a recognition of this reality? What would we call an approach whose premise is that HIVers shoot for taking most of their meds most of the time, and so be less anxious about performance, less likely to drop treatment in the long run and -- just maybe -- better able to stick to dosing schedules today?

We'd call it harm reduction. Health care providers recognize its benefits in preventing HIV transmission, yet their ability to apply it to adherence counseling varies. When Tony Valenzuela, 31, a Los Angeleno on combo therapy, asked his nurse "How much adherence is adherent?" he was told, "Take 90 percent of your meds 90 percent of the time." In discussions with other HAART-takers, he searched for perspective. "How does my nurse know that's effective treatment?" Nobody knows, was the consensus, it's just common sense. At the other extreme is the experience of a New York City HIVer who was open with his doc about his hopelessness over frequent missed doses, only to be told that his behavior was "suicidal," a cry for help. The doc suggested hospitalization.

A harm-reduction approach may be the only way to make it to the next treatment breakthrough. If we arm people with accurate information, acknowledge the gray areas and help them to assess their own treatment goals and integrate their chosen strategies into their lives, they have the best chance to sustain them, and survive. That's important, says Michael Pugh, a 38-year-old North Carolina PWA, because "the drugs we have now are just the best thing until something better comes along." Pugh used to ritualize his drug-taking and make an art out of adherence. Now he just does the best he can, and is convinced this is healthier, if less compliant: "The anxiety I felt around adherence was as threatening to my health as missing doses." He watches for new research that forecasts a change in the current treatment climate, including the introduction of planned drug holidays, or Structured Treatment Interruption (see "Happy Holidays?"). While

studies of STIs tell us little about the effects of spontaneous dosing irregularities, they do suggest that there's more to the picture than "Just say swallow" for the rest of your life. "The future," Pugh says with a sigh of relief,"is likely to allow for drug holidays."

For now, though, we must make do with the drugs we have -- and with their toxicities and scheduling miseries. And because the best effect of any drug is realized by maintaining optimum levels in the bloodstream, efforts to help people achieve this are vital. That's why adherence is an activist agenda. The time is ripe for HIVers on HAART to demand honest, realistic and client-centered support, along with research to make these unholy regimens a thing of the past. Activism could take a creative turn, with HAART-driven HIVers marching in the streets for a smaller Videx tablet, nonrefrigerated Norvir and better resistance studies. PWA consumer advocates could train doctors to see 80 percent adherence as successful and to be curious and flexible when a patient is less regimented. AIDS service organization clients on regimens could volunteer to train "buddies" to drive home the complexities of compliance and urge nonjudgmental listening as the standard of care.

After all, once the world has gone to sleep and you're standing alone at the sink with the last dose of the day, what is it you need? All the timers and sectioned plastic boxes and charts and snack tips in the world won't make you take your pills if you don't want to. These devices can help to keep you from forgetting your meds, taking them at the wrong time, getting confused about which goes with which and what to choke it all down with. But what puts you in the right frame of mind to fill the pillboxes, set the timer, use the chart and open wide, day after day? It still comes down to you, choosing to wrap your throat around six more lumps of bitter, chalky chemicals. And only you know what it will take to make you swallow. Again.

How To Be Adherence-Able

1. Plan Ahead
Before you run out of pills, before a hectic week, before a doctor visit, before you even start HAART: think it through, talk it out, write it down, make a plan.

2. Set up a System
Ask your druggist for the consumer 800 numbers of the makers of your pills and call for any adherence freebies -- pill boxes, calendars, beepers. Ask the pharmacy, ASO, your case manager and the clinic. Gather all your tools, a pad and pen, and then organize your drugs by dose and put them where you'll see them, or organize your days by drug and set a time to take them.

3. Get Support
Make a date with a friend to talk meds miseries monthly. Identify a fellow HIVer on your regimen and swap notes. Ask your ASO to start training for "treatment buddies," then become one -- and get one! Tell your boss, partner, friends and family what you need. Speak up!

4. Honor Thyself
Understand that what you're doing is tough. You're treading an uncharted, solitary path, and no one knows better than you how to walk in your shoes.

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http://beta.docker.poz.com/article/It-s-10-O-Clock-Do-You-Know-Where-Your-Meds-Are-1550-2481