Adherence All-Stars

Diane Peters meets a group of PHAs with “chaotic lifestyles” and finds out how, despite major obstacles, they adhere to their meds.

“My doctor says I’m her star patient,” Dwight Barker brags. He’s got a right to: He takes his HIV meds like clockwork and his viral load has been undetectable for almost three years. “No matter what, I take my pills every day. It helps that as soon as I open my eyes I can see the pill bottles on my night table and I take them before I get out of bed.”

Reaching star status has not been easy for Barker, who’s 46. He was diagnosed with HIV in 2010, but suspects he contracted the virus the previous summer when he was living in Vancouver and injecting drugs.

Barker eventually moved to the Edmonton area to get away from the Vancouver drug scene but he started using again. During a five-month relapse, he was unable to take his HIV meds for 12 days straight because someone stole his pills and he couldn’t get to a doctor for a new prescription. But he was lucky: His high CD4 count and low viral load remained unchanged.

Before starting on HIV meds Barker’s health was in decline, so he knows how bad things could get without them. He’s seen friends get sick quickly after tossing their medications aside. And he’s extra-motivated when he’s dating someone—he does not want to pass the virus on to a sex partner and knows that when his viral load is low, his HIV transmission risk stays low, too.

Drug-free since 2014, Barker now has a part-time job and does peer support for HIV Edmonton. He still has his struggles with anxiety and with fractured relationships in his family, but his ability to stick to his meds through chaotic times is helping experts understand how people can stay adherent even when the odds are stacked against them.

What’s your secret?
University of Alberta School of Public Health instructor Megan Lefebvre conducted a unique study with the Northern Alberta HIV Program (NAHIV) to find out just why Barker and 12 others with self-described “chaotic lives” adhere so well to their meds.

The participants have indeed struggled with obstacles: homelessness, drug addictions, mental health issues, abuse, jail and co-infections. But NAHIV clinic staff had noticed that these clients were superstars when it came to adherence. Lefebvre decided to find out more. “The research always asks, what are the barriers?” she says. “We wanted to ask them: What’s your secret to success? How can you do this? We wanted to learn from them.”

Lefebvre’s community-based, participatory research project involved in-depth discussions with the 13 members of this group, who, along with clinic staff, helped develop the interview questions.

Working around the central question, “What is your secret for taking your HIV medication all the time?” Lefebvre learned about people’s motivations and strategies for staying adherent. Common explanations included not wanting to die from HIV, family ties, wanting to protect others from the virus and having something to look forward to in the future. “I don’t want to hurt the people that love me,” confided one participant, while another stated simply, “I’m moving into a new apartment next month.” Through these interviews, Lefebvre discovered that what’s considered a chore for many people with HIV is actually an opportunity for success and celebration for others.

It all boils down to a sense of control, according to Lefebvre. “These people felt they had little or no control over their daily lives. But by taking their HIV meds regularly, they could have control over something.” Experiencing that sense of being in charge, in turn helped them make other positive life choices, such as renewing relationships with estranged family members or volunteering.

As a result of Lefebvre’s research, clinical practices at NAHIV have changed. Lefebvre recounts how one of the clinic’s nurses had remarked, “I didn’t know about my client’s families. I didn’t ask about that. I believed I didn’t have time.” But, once staff understood the importance of family in motivating patients to stay adherent, they began to ask regularly about people’s partners, kids, parents and siblings. If patients didn’t have families, the clinic staff tried to act more like “family” to them, learning about patients’ lives and goals, and keeping this conversation active from one visit to another. As a result, many in this group of adherence VIPs felt closely connected to their healthcare team and relished the support they got for their great adherence record. “Society often tells them negative things about themselves,” Lefebvre says “but this is something they can do and get recognized for.”

Simpler HIV drug regimens

Treatment for HIV gets better all the time. Today’s medications are easier to take, cause fewer side effects and many formulations require just one dose a day. But there’s still a big catch: Adherence has to be high or the virus can start reproducing, leading to drug resistance, fewer treatment options and, eventually, illness. Studies from the past decade or so have indicated that an adherence rate of about 95 percent is ideal for achieving the best health outcomes. “That means if you take 30 pills a month, you can only miss two, not even,” says Linda Robinson, an HIV clinical pharmacist in Windsor, Ontario.

Some of today’s meds are longer acting, so if you miss a dose, there may still be enough drug in the body to keep the virus under control. “But it’s a fine line,” Robinson says—and experts don’t know the precise point at which the drugs will stop working for an individual. People with existing drug resistance, co-infections or other underlying health conditions not related to HIV likely need to be more careful.

The bottom line is that getting into the routine of taking pills every single day exactly as prescribed and directed is still key and missing pills here and there can lead to drug resistance, health problems and the risk of HIV transmission.

Barriers to adherence

Taking a pill once or twice a day may sound simple, but over a lifetime of pill-taking, it is a challenge, especially for those who face additional obstacles.

Research in the past decade has established that certain factors impact adherence rates. Between 2007 and 2010, British Columbia’s LISA (Longitudinal Investigation into Supportive and Ancillary Health Services) cohort enrolled 566
participants with HIV who were taking antiretroviral therapy. Their research found that only 316 participants (55.8%) were “optimally adherent,” or took their meds at least 95% of the time. In particular, they noted that women and people using injection drugs struggled most with adherence.

Depression and other mental health challenges can put people at risk for poor adherence. The BC study found that this was particularly so among women. Not surprisingly, going to jail can disrupt a medication schedule, as can moving from one province to another (and therefore one provincial medication coverage plan to another) or periods of homelessness. “Where are you going to keep your meds?” asks Dr. Stan Houston, professor of medicine and public health at the University of Alberta and director of NAHIV. “Someone can steal your backpack at the shelter. But also, all your energy is devoted to what you are going to eat and where you are going to stay tonight. Taking pills may drop down on the priority list.”

Immigrants and refugees in Canada who are living with HIV face considerable hurdles, including access to medications and privacy concerns that impact their ability to store and take meds. And, of course, HIV meds can cause unpleasant side effects—gas, fatigue or sleep problems— which can be real de-motivators to popping those pills.

Adherence tips

- Take your medication at the same time(s) each day.
- Use the alarm on your cell phone, a pager or other reminder device.
- Use a pill box to take extra doses of medications with you when you are out.
- Get your pharmacy to put your medications in a weekly dosette or blister pack.
- Keep backup supplies of your meds at places where you regularly stay (like your workplace or partner’s home).
- Plan ahead for weekends, holidays and travel.
- Make sure you don’t run out of your medications.
- Talk to other people with HIV and learn from their experiences.
- Develop a supportive network of people who can help remind you to take your medications.

New approaches to adherence

To address these issues, healthcare providers can offer extra help to reduce the barriers to taking medications. This may mean changing meds to avoid certain side effects, or creating a more convenient medication schedule. Dosettes and blister packs available through the pharmacy can help organize a complex medication schedule, as can assistive adherence apps.

But many HIV healthcare providers are beginning to look more closely at adherence as an acquired habit or behaviour. “People’s circumstances dictate their ability to adhere,” says pharmacist Linda Robinson. “That, combined with their own personality or behaviour patterns. Adherence is a behaviour.”

Some people are creatures of habit and have a set routine, no matter what’s going on in their lives. Others change what they do and how they do it daily. Most people have points in their days that are more predictable than others. So the most successful approaches to adherence take into account the whole person with a very individualized adherence approach (see opposite page). “It’s a question of figuring out a way of integrating a habit into your life,” explains NAHIV’s Dr. Stan Houston.

Tackling side effects

An individualized approach to adherence often starts with tackling side effects. Dr. Houston always questions his patients closely about side effects and how they are impacting their lives. “Ask. Never assume,” he cautions. Some people don’t mind digestive concerns while others, perhaps because of their work or living situation, really struggle to keep taking meds that cause these side effects. Again, these issues are so individual that doctors need to listen closely as their patients explain how certain aspects of their meds affect them and let that determine the next move.

Establishing motivation

Next, it’s about establishing motivation. To help people grasp how their meds work and the benefits of sticking to
their regimen, Robinson uses props like a balance scale to show how HIV drugs hold the viral load down and allow CD4 counts to rise.

Effective healthcare providers make sure their message is about teamwork and support, not judgment. “You have to be non-judgmental with your patients,” Houston says. “You have to convey the idea that we both know adherence is important and it’s part of both of our jobs to support it.”

**Playing piggyback**

Then, it’s on to finding a trick or technique that works. Some clinics send emails or text reminders to help patients adhere. But perhaps the ideal is to identify a daily routine on which to piggyback pill taking. One of Dr. Houston’s patients with great adherence picks up his HIV meds every morning from the pharmacy on his daily trip to the liquor store.

**Slip, fall and get back on your feet**

The best-laid plans can fail, and those taking meds for many years are at risk for slipping—particularly when life changes.

That’s what happened to Alexandra de Kiewit. She took her HIV meds regularly for six years. Then, last fall, she started treatment for hepatitis C. A former injection drug user, de Kiewit was also working nights at a Montreal needle exchange. “The morning pill for HIV became so hard for me to take,” she says. “Sometimes in the morning, I’d be fast asleep.” Taking her evening pill, which she always did with dinner, stayed firmly entrenched in her routine.

Finally, six months later, she realized her medication schedule was not working and never would. A visit to her doctor resulted in a new regimen with a single HIV pill she could take at dinner.

Now, de Kiewit has been able to adhere well again, and is extremely motivated to keep it up, as she and her HIV-negative partner are trying to get pregnant. After discussions with the doctor, they both understand that de Kiewit’s viral load has to be undetectable in order to have the best chance of conceiving naturally without her partner becoming positive. “At first I took my medication for me, because I don’t want to get sick,” says de Kiewit, “but now I take it because of my relationship as well.”

**Research that keeps on giving**

Back in Edmonton, Megan Lefebvre’s research became more than just a PhD thesis. She and six study participants decided to take what they discovered about superstar adherence and share it with others—healthcare workers, researchers and people who are HIV positive and struggling with medication adherence.

They made a video called Living with HIV and it’s OK and screened it at HIV Edmonton at a series of pizza parties. Study participants acted as peer educators and HIV Edmonton clients enjoyed learning from “the celebrities” themselves. “It really humanized the issue of adherence,” Lefebvre says. The pizza nights became so successful that the study participants continued to show this video and animate conversations about the importance of adherence throughout their communities.

To see Megan Lefebvre explain her research at the Northern Alberta HIV Program, check out “**Adherence Among Chaos**”

Diane Peters is a Toronto-based freelance writer, editor and teacher. She writes about health, business, parenting and other issues.
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