

Treatment breaks: an individual perspective

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The announcement of the premature end of the SMART study has come as a body blow for many people living with HIV. The conclusion drawn by the researchers behind the study – that treatment breaks have more risks than benefits – suggests, on the surface at least, that those of us on treatment will be taking pills every day for the rest of our lives. It's a depressing piece of news, to say the least.

Doctors have long hoped that structured treatment interruptions might not only be safe, but could actually prime the immune system to deal more effectively with HIV. SMART and other studies have shown that this is not the case, but is there still a role for treatment breaks in our lives?

There's really no doubt now that, from a medical viewpoint, treatment breaks are not a good idea but, like everything in HIV, medical evidence is only part of the picture.

There are many reasons why positive people might decide to take a break from treatments apart from the medical reasons that guided SMART. Problems coping with side effects, overseas travel, fear of long-term toxicities or just the desire to have a break from the daily ritual of pill-popping are all reasons why some people have interrupted their treatment. Doctors sometimes recommend treatment breaks for people who have short-term problems with adherence, or for those who have few treatment options but aren't in immediate danger of AIDS-related illnesses.

Peter (not his real name) is a 35-year-old gay man living in Melbourne who spoke to *PL* about his decision to take a treatment break. After five years on his first drug combination, he and his doctor decided to try a treatment break after his CD4 count rose to about 800 and his [viral load](#) [1]A measurement of the quantity of HIV RNA in the blood. Viral load blood test results are expressed as the number of copies (of HIV) per milliliter of blood plasma. had been undetectable for a long period.

"I raised the issue with my doctor and he was really happy to support my decision, as long as I came in for regular checkups during the time off treatment," Peter said. "I'd been on a combination of nevirapine and Combivir for several years and I was worried about the long-term effects of the AZT in the Combivir. We discussed changing to another drug but I wanted to see if I could take a break from the pills altogether for a while, and he agreed to give it a go."

Because nevirapine remains in the bloodstream much longer than most other drugs, Peter wasn't able to simply stop the pills. Instead, he had to switch to Kaletra for a couple of weeks to cover the period while the nevirapine washed out of his system. Doing this helps to prevent the emergence of [resistance](#) [2]HIV which has mutated and is less susceptible to the effects of one or more anti-HIV drugs is said to be resistant. to the nevirapine during the wash-out period – because Peter was still responding well to nevirapine, his doctor wanted to be especially careful that he had the option to go back on it in the future if he needed to.

Peter found the switch to Kaletra very hard on his system. "I'd had some side effects from the drugs I was on, but nothing like this. Nausea, diarrhoea, stomach cramps and generally feeling lousy all the time. I found it really hard to take the Kaletra; I had to keep reminding myself that it was only for two weeks."

With the wash-out period behind him, Peter was able to start his treatment break in earnest and was generally happy with the decision to grant himself a holiday from pill-popping. His doctor asked him to come back for checkups and blood tests after one month and every three months after that. He told Peter to expect that his viral load would rise and CD4 count could fall during the treatment interruption, but hopefully not so greatly that he would have to resume treatment too soon.

"It took a little while for my body to become used to not taking treatment," Peter said. "I was expecting to feel much healthier without the drugs circulating in my body, but instead at first I found the reverse was true. I had a few problems with sore throats and feeling fluey in the first month after I stopped the pills, but then that seemed to settle down."

After three months off treatment, Peter started noticing other minor problems, such as mouth ulcers, sinus

infections and skin problems which he'd not had before. "I knew from my doctor that these are signs of lower immunity, so I went back for another check-up. My T-cells had gone down to just over 300 and my viral load was through the roof, so now I'm about to go back on treatment."

Peter says he's generally happy he took his treatment break, but disappointed that it wasn't able to be maintained for a longer period, and that he didn't feel as well during the break as he expected to.

"With the Kaletra, the initial period of adjustment and then the last few weeks of dealing with all these annoying health problems, I guess I only had a month or so of being off treatment and feeling OK. I'm still glad I took the break – at least now because I have a real idea of the difference between being on and off treatment, and I wanted to change treatments anyway, so maybe I would have had to deal with some of this stuff regardless."

Peter says he's still worried about the long-term effects of his treatments and he still hopes that one day he'll be able to take a longer break, but for now his experience has made him aware that treatments are likely to be a daily feature of his life for the foreseeable future: "I guess it showed me that the grass isn't necessarily greener on the other side of the fence," he said.

- [drug holidays](#)
- [treatment interruption](#)

Links:

[1] <http://www.napwa.org.au/glossary/term/416>

[2] <http://www.napwa.org.au/glossary/term/109>