

# HIV treatment breaks?

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## JUDY'S STORY

### TIME WILL TELL...

"I AM CURIOUS TO SEE HOW THINGS PAN OUT FOR ME "

## THE BOTTOM LINES IN THINKING ABOUT OR TAKING A BREAK FROM YOUR HIV TREATMENTS ARE:

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2. Find out more – talk to your doctor or local treatments officer, get the more detailed treatments break booklet
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4. If side effects are a big part of the reason for thinking about a HIV treatments break, stress this with your doctor – there may be alternative combinations or treatments for your side effects.
5. Monitor your health if you take a break

The issues for you in taking a break from your treatments vary depending on whether you started treatments soon after getting HIV, and your current CD4 cell count and viral load.

While there is not yet evidence to support taking a break in any setting, treatment breaks are currently under investigation and study around the world.

Most HIV-experienced GPs now realize that treatment

breaks are often a fact of life for people with HIV.

What happens when people take a break from treatments varies for each individual – your experience will not necessarily be the same as everyone else. Some people can experience a very rapid decline in their CD4 cell count. Others won't. You can't tell what your experience will be – nor can you tell from 'how well' you feel. This is why monitoring

your health which includes regular testing of your viral load and CD4 cell counts is so important.

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"I contracted HIV in 1995 from a man I was in a relationship with. After being told that there would be an asymptomatic phase, I waited and waited....."

"Seven years later it has become clear that I fit into that group of approximately 5% of PLWHA who don't really recover from the initial infection onslaught. Within the first 18 months of living with HIV, my T-cells had steadily dropped to 100, and it was then that I started treatment. Since then my CD4 cell count has basically stayed between 100 and 200."

"Although to this point I haven't experienced a major illness, my general well-being has been at quite a low ebb with ongoing fatigue, digestive

problems, skin problems and periods of weight loss."

"On the whole I have been a reliably 'good patient' rarely missing any medication doses. At present I am working again part-time and am happy with where I am in life. My weight has gone up, although it has appeared in a few of the wrong places! Subtle effects of lypodystrophy have certainly become apparent over the past couple of years and have perhaps contributed to the decision to take a treatments break."

"It has been a decision that took almost one year to make, and I suppose that simply put, it just felt like the right time. I needed to change my medication anyway, and my doctor has continued to be

supportive of any decisions I make regarding my health. I psychologically needed a break – and having to change medication was good opportunity."

"I have to admit that it's a bit scary given that I don't have too many T-cells to play with, but I really feel for so many reasons that I needed to do this. Although the agreement was to take a six week break, I think at this point I will be leaving it as long as I can – while carefully keeping an eye on my health."

"After 6 years of swallowing pills morning and night, I am currently on my 7th day combination-therapy-free. I am very curious, nervous and excited to see how things pan out for me...time will tell."

**To find out some of the answers to the questions raised by Judy's story talk to your doctor, your local treatments officer, get a copy of the more detailed HIV treatments break booklet from your doctor, AIDS Council or local PLWHA group, and read the summary overleaf**

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### CAMERON'S STORY

"I CAN DANCE IF I WANT TO"

... THE CASE OF SLOPPY

TREATMENTS INTERRUPTIONS

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After 4 years of being on pills for HIV infection and missing about 3 doses, Cameron puts it like this: "I was at a point in my life where I felt like I had to get out and about more. So I decided to go clubbing every second or third weekend. I had been such a 'good' person with HIV for so long, as far as I was concerned it was time to reward myself. I had read about the interactions of some of my anti-HIV drugs with recreational drugs. I'd also heard about people doing OK after breaks from their treatments – and some of my friends seemed to have done this without much harm – although one friend

after six months off his pills got suddenly sick – but I was only having a break on occasional weekends."

A while later Cameron's doctor asked him if he was aware of the potential interactions between one of the drugs he was on and recreational drugs. Cameron had a quick answer: "Yeah, but I'm having a break from my pills every second or third weekend for a few days. And I've read about this new interest in treatments breaks so I decided it was OK."

"My doctor then explained to me the difference between unplanned breaks, the sort of 'do it yourself'

breaks I was having, and what Structured Treatment Interruptions or Strategic Interrupted Treatment are and how it was different from what I was doing which he called 'sloppy treatment interruptions'. Well being called 'sloppy' doesn't thrill me – it's the same as being called 'slack'... so I guess I sat up and took notice."

"I had my viral load done and it had gone from 20 to 400... not a huge increase but... – and as it's now winter I've taken a break from clubbing. But next summer I've pre-warned my doctor that I want a break and we are going to talk later about the best way to do this."

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## RON'S STORY

“ I THINK I DID AN OOPS...”

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Ron became HIV-positive "in the dark ages".

"At the beginning of the 1990s I was down to 200 CD4 cells. After postponing starting HIV treatments I couldn't any more", says Ron.

"I did all right. But the early 1990s were a horrible time. It seemed like a funeral every week."

Ron managed to keep his CD4 cells around 250. Then the earliest interleukin-2 trials (a still experimental HIV treatment) were announced. "I was just lucky enough to qualify."

"The trial was a real grind... but whether it was interleukin or the new

protease drugs or both... my CD4 cells count went to levels I'd never had since they were first tested. Over 700."

After 4 years on interleukin Ron had what he describes as "treatments burnout". "Something basically snapped. People weren't dying all the time any more. AIDS was no longer the big story – and I think the previous ten years hit me."

Ron threw all his treatments in the bin, put his furniture in storage, and drove north and ended up staying in Northern Queensland for 8 months.

"For most of the time I felt physically better than I had for years. But I did notice

I was losing weight. I had been thinking more and more about going home to Melbourne – but I kept putting it off. Then I got a cough...and ended up in hospital with a nasty lung infection that wasn't considered to be AIDS related. However, as a result my counts went down – and the picture was not good."

Ron's CD4 count had dropped to 50.

"When I got out of hospital I went back home...and since then it's been a real struggle maintaining my health.

I think looking back I did a big oops..."

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## MARK'S STORY

// 5 YEARS, 18,250 PILLS //  
LATER....

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Mark had his first positive HIV antibody test result in 1992. He had regularly tested for HIV and other STDs and doesn't remember any seroconversion illness.

In 1992 the time the treatments picture was confusing – combination trials of 2 drugs were common, but the first drug, AZT, was mired in controversy. After talking to a number of people Mark decided that treatments was a future issue for him... and he

would just regularly monitor his health. "I guess after then I had a four year party. My attitude was the clock was ticking and I was going to have fun."

Then in 1996 Mark read banner headlines across the front page of the local gay newspaper announcing the arrival of seemingly effective antiviral treatments for HIV.

"It changed my life. I had to rethink my future and that was actually

really scary. A year later, instead of dance parties, I was career oriented – and instead of recreational drugs... it was 10 pills a day of antiviral drugs."

Mark has started to hear more and more about long-term side effects so he decided to begin having discussions with his medical practitioner about stopping his drugs for a while.

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