When push comes to shove

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Why do some of us refuse treatment? And how far will we go before we finally relent? JAMES MAY tells us his story.

I guess I was always reluctant to start treatment.

My thinking was shaped by my own fears and doubts and the friends and peers who informed me. I didn't really know anyone with HIV before my diagnosis and never kept an eye on what was happening behind the scenes. Most people I knew in Sydney moved in the party/drug scene and were suspicious of the whole thing. Maybe they didn't wanna know? Maybe they didn't wanna let it spoil the fun?

When my diagnosis hit in 2000, I didn't know what to believe. Unaware of any treatment advances, I took it as a death sentence. My consulting GP gave me a brochure about treatment options but I assumed it was experimental [1](Of a drug) Not licensed for use in humans, or as a treatment for a particular condition. Experimental drugs are studied in clinical trials to determine their safety and efficacy, and are sometimes made available via Special Access Schemes prior to their approval. stuff and threw it away. Other HIV physicians I met at the time were far from informative or encouraging. They were critical and judgmental and fuelled my belief that it was the 'end of the world', so I didn't go back.

The only knowledge I had of HIV treatments was through a messed-up partner who thought taking an HIV test was foolish in the first place. He wasn't giving up his diet of crystal meth for HIV drugs. He said his mate was positive and doing fine without them: 'he drinks beetroot juice all week and parties on crystal all weekend.'

I wanted to believe it was just a benign illness but I knew it wasn't. The seroconversion knocked me on my arse for weeks and my health never fully recovered.

I moved to Melbourne after that and had my first contact with an HIV doctor in over a year.

I rocked up saying I just wanted to monitor the virus [2]A small infective organism which is incapable of reproducing outside a host cell., explore my options and that I'd only take the meds if absolutely necessary. He ran some tests —viral load [3]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. 50,000, T-cells 350 — and was adamant I begin treatment right away otherwise I'd have AIDS within a year. I thought he was being alarmist and seemed more concerned with my infectiousness than my wellbeing.

I felt pushed around. So, I contacted the Positive Living Centre, sought counselling, started yoga and meditation. I adopted peak nutrition and a healthy lifestyle. I saw a naturopath who gave me potions that resolved a few symptoms.

The blood tests played on my mind but I felt physically well so I got on with life.

My visits to GPs were always confrontational. They weren't impressed that I'd taken matters into my own hands. I told them I was concerned about the toxicity of the meds and I didn't want to be driven by fear. I wanted to have control over my body for as long as possible. There was no meeting each other half way; so four years after the diagnosis I ceased contact with them.

> I surrounded myself with people who supported my choices — positive people who were doing things a similar way. It was great but it brought its own challenges.

Life revolved around my health and wasn't much fun. It felt a bit competitive, too. No one wanted to be the first to

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'crack' and go on the meds. We tried coffee enemas, juice fasts, wheat/dairy/sugar-free diets. We boiled yucky vegetables, drank stinky potions. I danced around living rooms with women with cancer and eating disorders, beating drums and chanting.

Fatigue and skin infections cropped up but most of the time I felt healthy. I guess I was hoping I could stay on top of HIV without drugs. 'It was all in the mind,' I kept telling myself. By the time things started to unravel, this idea was so ingrained in me that it was impossible to let it go. I saw taking the meds as a failure. I couldn't face defeat. And in some strange way, I thought I didn't deserve help. Going on the meds seemed harder to face than the diagnosis.

Six years down the track I started to experience chronic fatigue, severe night sweats and weight loss. I could hardly eat or sleep with the acute anxiety and depression that came with it. I felt like I was going round the bend. Some weeks later I was hauled off to emergency with HIV-induced psychosis. I had ten CD4 cells, highly active PCP (Pneumocystis jiroveci pneumonia [4]An inflammation of the lung, usually caused by infection with bacteria or other microorganisms, in which the air sacs of the lung become filled with inflammatory cells which solidify and inhibit breathing.) and MAC (Mycobacterium avium complex). It was almost impossible to swallow any meds at that stage.

My first combination messed with my kidneys but the next worked fine and I've been on it ever since. Taking it relieves some of the burden that I felt going it alone and the fear of getting sick.

In many ways, it's made life easier. I get a few side effects but they respond well to complementary therapies [5]A broad range of healing philosophies, approaches, and therapies that Western (conventional) medicine does not commonly use to promote well-being or treat health conditions. Examples include acupuncture, herbs, Traditional Chinese Medicine, etc..

Although I gained a lot of willpower and faith, I wouldn't wish getting sick on anybody. The meds helped pull me through that crisis and continue to sustain what is a good quality of life.

Treatment is no magic bullet. Living well with HIV takes effort. So, I still put a great deal of time into yoga, gym and meditation.

The emotional burden remains. But, despite the tough times I value the personal development that has come from living with HIV.

I do believe in freedom of choice, especially regarding your health; but people need to be informed. HIV health educators need to make sure there is accurate information in the public domain to break down myths around HIV and treatment. HIV physicians need to be careful and compassionate in the way they communicate with us about our treatment options.

People need to feel like they have a voice. It made a huge difference when I found a GP and others in the sector who didn't scoff at my beliefs.

We need to feel empowered and make our own decisions.

- starting treatments

Links:
[1] http://napwa.org.au/glossary/term/491
[2] http://napwa.org.au/glossary/term/125
[3] http://napwa.org.au/glossary/term/416
[4] http://napwa.org.au/glossary/term/351
[5] http://napwa.org.au/glossary/term/478

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