

## Overcoming adversity

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Robert Spicer has lived with HIV for 20 years and with HIV-related vision problems for 10. But despite losing most of his sight, he remains fiercely independent and has an inspiring outlook on life. Robert spoke with his partner, Bernie Slagtman.

I spoke to Robert sitting outside our motor home, in the rays of a sunny 23-degree day sipping on a lovely brewed cup of coffee at the Kings Canyon resort in the Northern Territory.

Robert was diagnosed with HIV on the first day of spring 1986. Since then he has suffered from a number of opportunistic infections, the worst being Mycobacterium avium complex (MAC), which nearly took his life in 1993.

But it's Cytomegalovirus (CMV) infection that creates the greatest challenge for Robert today. A relatively common viral infection, for most people CMV causes no illness, but in people with severely compromised immune systems, it can lead to a number of AIDS-defining conditions, most commonly CMV retinitis, an infection in the retina of the eye.

Robert's CMV retinitis, originally diagnosed in 1995, has rendered him legally [blind](#) [1]A randomized trial is "Blind" if the participant is not told which arm of the trial he is on. A clinical trial is "Blind" if participants are unaware on whether they are in the experimental or control arm of the study; also called masked.. He has no light perception in his left eye, and only about 12 percent blurred tunnel vision in his right eye. Fortunately for Robert, [combination therapy](#) [2]Highly Active AntiRetroviral Therapy ??? aggressive treatment of HIV infection using several different drugs together. has seen good immune restoration, but the future for his remaining eyesight is uncertain: further deterioration has occurred over the last few years.

I asked Robert about the impact of his vision impairment on his life.

"It has been life changing," he said. "Every time something goes wrong with your physical health, it impacts on you big time. But there are many positive things that come out of these changes – not realised at the time, but later on when you look back and see how you can still do things."

Exploring this idea further, Robert gave the example of how his HIV "was a great initial shock to his family, but then it actually brought them closer together."

Coping with such a profound loss of vision hasn't been easy. But, Robert says, "life is always changing. It's a roller coaster – health, emotions and feelings – nothing stays the same whether you are living with HIV or not. I just treat my vision impairment as a change in my life's journey. It's how you approach these changes that determines how it will impact the future."

Robert gave up driving eight years ago, which seems to have been the biggest challenge, impacting on his independence, where he lives and his mobility. "It so restricts and narrows the places and services that I have access to," he said.

But it hasn't dampened his love of travelling. When the opportunity arose for Robert to join me on an 'escape the winter' motor home trip, he jumped at the idea. Robert said it was "a big upheaval and change coupled with the uncertainty of not knowing whether it was going to work" as it involved relocating from his home and friends in Perth, but, "sometimes you have to grab an opportunity when it comes along."

"Great things start with one small step and a decision to do something," he said.

We left Melbourne in late May, travelling via Adelaide through the Flinders Ranges and along the Oodnadatta track to Lake Eyre and onto Coober Pedy. From there to Uluru and Kings Canyon. As you read this we'll be heading for Alice Springs, Darwin and across the Kimberley before heading south along the west coast to Perth and finally back to Melbourne.

Robert chose this route in order to climb Uluru and Kings Canyon, experience the Mingil markets in Darwin, take a helicopter ride over the Bungle Bungles and see some of the many national parks in Western Australia where he has lived for 22 years and never got to go.

So far, Robert has joined me on various tandem bike rides including around Uluru, he has climbed to the top of Uluru, walked the Valley of the Winds at the Olgas and completed the rim walk up and around the Kings Canyon.

(The Anangu people, traditional owners of the land around Uluru, do not restrict, but rather prefer that tourists not climb Uluru – for safety and men’s business reasons. However, we thought that getting Robert to the top was also pretty important men’s business and hoped that the elders would not object.)

In case you were wondering, Robert didn’t do the ‘Priscilla’ thing by climbing to the top of King’s Canyon in drag. As he explained, “my cane is a much bigger drawcard than stilettos.” I can personally vouch for that as people stood in bewilderment at his achievements, several asking for his photo. He would calmly say to them (most were out of breath and struggling): “sure, but what’s the big deal?”

At the rock, I overheard a man say to Robert, “you’re a hero, mate.” Robert calmly explained “it’s about putting one foot in front of the another. If you slip or stumble, just stop, reassess and try again.” The going has been tough at times and has required real endurance and persistence. Robert explains: “hard as it might be, sometimes I just have to ask for assistance, at the same time trying to keep my independence. Getting this mix right can be hard and frustrating for myself and others around me.”

Our big trip continues and so we go forth together. Robert’s future vision is as uncertain as life can be. But as he explains, “great things start with one small step and a decision to do something.”

- [CMV](#)
- [personal stories](#)

**Links:**

[1] <http://www.napwa.org.au/glossary/term/474>

[2] <http://www.napwa.org.au/glossary/term/96>