

Living with hepatitis C: from self-loathing to advocacy

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Compassion for those with hepatitis C and accurate information about preventing its transmission will also benefit the wider community

MY GP'S ROOMS were the last place I would have expected to feel like a leper because I was sick, but that's my story, and unfortunately it's a fairly common one among people living with hepatitis C (HCV).¹ Discrimination against people who are HCV-positive is not confined to healthcare settings, but this is where it is most often reported,² partly because it's the context in which affected people are most likely to disclose their condition. Discrimination also rears its ugly head at home, in social situations, at work, school, in the media and when we attempt to access services, such as insurance. It even clings to people beyond death, with families of people with HCV sometimes being refused viewings of their loved ones' bodies, even though this is inconsistent with public health regulations.

Several Australian government reports and a growing body of social research identify hepatitis C-related discrimination as an epidemic in its own right,³ and show that stigmatisation has detrimental effects on people's health and quality of life,¹ as well as significant social and economic costs.⁴

When the NSW Anti-Discrimination Board announced its world-first enquiry into hepatitis C-related discrimination in 2001, I decided to make a submission about my experience of being diagnosed with HCV. The Hepatitis C Council of NSW knew my story and that, as a journalist, I would be comfortable dealing with my colleagues, so I was asked if I would talk to the media to raise awareness of the enquiry and the issues it was investigating. Although there are an estimated 225 000 people in Australia with hepatitis C,⁵ many fear the consequences of disclosure in their daily lives, so very few are prepared to publicly identify themselves as HCV-positive. Since agreeing to talk to the media, I have been invited to tell my story many times. It is always rewarding work, because, as HIV/AIDS-positive speakers throughout the world have demonstrated,⁶ presenting a personal experience of living with an infection like HCV not only educates audiences about the disease and prevention strategies, but also challenges negative stereotypes that result in discrimination.

I was diagnosed in March 2000 by the GP I had consulted for 7 years. She was used to me complaining of extreme tiredness, for which she diagnosed "some sort of virus" and recommended a few days off work. However, in January 2000, I felt as if I had aged 60 years in a couple of months.

Vomiting after lunch was becoming routine. I had three weeks off work, but it made little difference to how I felt.

I went back to the doctor in March to request a hepatitis C test because I had met a woman who was HCV-positive. She had described the debilitating symptoms that had forced her to give up her career as a medical practitioner, and I identified with them all, so I knew I had to be tested.

Back in 1985, before hepatitis C got its name and before there was a test for it, I took heroin for a few months. When I sought help, my drug use was treated in a non-judgemental way by my family, a fabulous GP and a psychiatrist. I received excellent care and emerged with my self-respect intact and my body in good shape. Or so I had thought for 15 years.

In 2000, my doctor's response to my request for an HCV test was "you wouldn't have that". My subsequent admission of injecting drug use all those years ago was met with silence, but she ordered the test. When I went back for the results it seemed that she didn't want to know about me or my illness, despite the fact that I was very sick. She offered almost no information at all about the virus, explaining that she "just doesn't see it" in her surgery, and handed me a brochure produced in 1991, which said there was little in the way of treatment, that the prognosis was not good, and that the highest risk group was homosexual men. All of this was simply untrue in 2000, but I did not know that then.

I felt that my GP's diagnosis was not that I had a serious liver disease, but an untreatable moral malady. If I had been one of the many people who are diagnosed before they experience any symptoms, I would have left her rooms, not told a soul and tried to forget all about it.

I didn't go home filled with righteous indignation and contempt for my doctor that day. I was consumed with self-loathing — I felt like a piece of human debris, unclean and totally unworthy. But the gods were smiling on me. It was 27 March 2000 — the day the New South Wales Health Department launched the world's first hepatitis C mass media public awareness campaign. On the news, doctors were talking about treatment and there was some discussion about discrimination. I rang the Hepatitis C Council of NSW helpline the next day and received accurate information, support, and referral to my local liver clinic.

I was on the road to recovery, but the shame I felt about my positive status was hard to overcome. After my experience with my GP, I was wary of people finding out about my illness. Sometimes I still am. In the past four years I've met lots of people with hepatitis C, and many of them express shame and fear because they have had such negative experiences when they disclosed their HCV status. There were

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people in my treatment support group who expressed the medieval notion that their illness was direct punishment for their "sins" and that they deserved to suffer and to be treated poorly because they had injected drugs in the past.

The NSW Anti-Discrimination Board enquiry into hepatitis C-related discrimination in 2001 found two reasons for discrimination.² It heard evidence of many cases of stigmatisation as a result of ignorance about the virus and how it is transmitted, but it was the close association between injecting drug use and HCV infection that was found to be the main reason why people with hepatitis C were treated in a discriminatory manner. Its report, *C-change*, says much more needs to be done to educate the general community, and especially healthcare workers, about what hepatitis C is, how it is contracted and who contracts it. This requires the political will to change things, but is not an insurmountable problem. However, the enquiry found that the perception of people with hepatitis C as being "somehow deviant and automatically engaged in illegal or criminal behaviour" is far more difficult to tackle.²

It is acceptable to vilify very few groups within society these days, but people seem to feel it is quite reasonable to denigrate injecting drug users because their behaviour is illegal and highly stigmatised. In his introduction to the NSW Anti-Discrimination Board report, former president Chris Puplick comments: "Were this nexus to be severed, either by means of legislative change or by changes in perceptions, attitudes and responses, then most of the problems identified in the *C-change* report would be more easily resolved".²

There is little hope of this vision being realised in the short term. I believe the Australian Government's proposed Disability Discrimination Amendment Bill⁷⁻⁹ aims to overturn a Federal Court decision in 2000 that found addiction to a prohibited drug could be regarded as a disability.¹⁰ If the bill becomes law, illicit drug users (and their families) could, in some circumstances, face legalised and institutionalised discrimination. Healthcare workers have voiced concerns that such an amendment may result in the increased spread of bloodborne viruses, such as hepatitis C, and limit access to drug treatment programs.⁷ The illegal status of injecting drug use already results in negative health outcomes for many people with hepatitis C, especially if they are current injecting drug users.¹¹ Quite simply, many do not attempt to seek medical treatment unless they absolutely have to, and, when they do, they sometimes report receiving very shoddy treatment.

The Disability Discrimination Amendment Bill and the Federal Government's rejection of evidence-based recommendations, such as harm minimisation, for combating the HCV epidemic stand in stark contrast to Australia's highly successful response to HIV/AIDS. This response depended to a large extent on legislative action by Australian governments, in particular the repeal of laws that made homosexuality illegal and discrimination acceptable.

A recent study has found that discrimination against people who are already vulnerable because they are ill can be "a profoundly negative experience".¹¹ This is so not only for the person with hepatitis C, but for the wider community as well, because access to information about preventing transmission is compromised when people are afraid of dealing with healthcare services.¹¹

Around 40% of the relatively small number of people who undergo treatment become free of the virus.¹² I consider myself extremely fortunate to count myself as one of them. The side effects of treatment¹² were extremely difficult during my 48 weeks of therapy, but it was worth it. I have been free of the virus since 2001, and feel better than I have for many years.

It's wonderful to have a happy ending to share when I talk publicly about living with hepatitis C, but I hope the audience understands that it was not just the medicine that made me better. Love, understanding and compassion are great healers that many with hepatitis C just don't experience.

Competing interests

None identified.

References

- Zickmund S, Ho EY, Masuda M, et al. "They treated me like a leper". Stigmatization and the quality of life of patients with hepatitis C. *J Gen Intern Med* 2003; 18: 835-844.
- C-change: the report of the enquiry into hepatitis C related discrimination. Sydney: Anti-Discrimination Board of New South Wales, February 2001. Available at: www.lawlink.nsw.gov.au/adb.nsf/pages/hepcreport1 (accessed Feb 2004).
- Treloar C, Hopwood MN, Loveday SK. Hepatitis C-related discrimination in healthcare. Report of the Third Australasian Conference on Hepatitis C, Melbourne, March 2002. *Med J Aust* 2002; 177: 233-234.
- Australian National Council on AIDS, Hepatitis C and Related Diseases. Hepatitis C Sub-Committee. Hepatitis C Virus Projections Working Group. Estimates and projections of the hepatitis C virus epidemic in Australia. Sydney: National Centre in HIV Epidemiological and Clinical Research, The University of NSW, 2002. Available at: www.ancahrd.org/pubs/pdfs/epidemic_02.pdf (accessed Feb 2004).
- National Centre in HIV Epidemiology and Clinical Research, HIV/AIDS, Viral hepatitis and sexually transmissible infections in Australia. Annual surveillance report 2003. Available at: www.med.unsw.edu.au/nchecr/surv_anrep.html (accessed Feb 2004).
- Arnold W, Bard M. HIV-positive speakers' bureau educates the community. 6th International AIDS Conference. San Francisco, Cal: June 20-23, 1990. Available at: www.aegis.com/conferences/06wac/ThD907.html (accessed Feb 2004).
- Disability Discrimination Act Amendments, 2003. Available at: www.disabilitydiscrimination.info/pages/1/index.htm (accessed Feb 2004).
- Commonwealth of Australia. Hansard, House of Representatives, 3 December 2003, 23171 (Philip Ruddock, Attorney General).
- Explanatory memorandum, Disability Discrimination Amendment Bill 2003 (Cwlth).
- Marsden v. HREOC* [2000]. FCA 1619.
- Hopwood M, Treloar C. The 3D project: diagnosis, disclosure, discrimination and living with hepatitis C. Sydney: National Centre in HIV Social Research, 2003.
- Dore G. Therapy decision making for people with chronic hepatitis C. In: Crofts N, Dore G, Locarnini S, editors. *Hepatitis C: an Australian perspective*. Melbourne: IP Communications, 2001: 172.

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