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Recovery from Hepatitis C Treatment

A Study into Life after Hep. C Treatments

by Dr. Max Hopwood, reprinted from *The Hep. C Review* (September 2010)

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My study into life after Hep. C treatments came about through a mix of three things. First, I wanted to hear about people's perspectives on their treatment experience, particularly those whose treatment had failed them after they had time to step back and think about it. Second, I identified a gap; except for a small amount of clinical literature, mainly case reports, there are hardly any research studies into the post-treatment period. These reports show that a small number of people treated with interferon experience a persistent neurotoxicity - in other words, the effect of the drug on the central nervous system can linger for prolonged periods, making people unwell. Case reports also show that, in some instances, new symptoms can emerge in the weeks or months after treatment has finished. Finally, anecdotal reports from people in the sector (and testimonies on various websites) indicated that some people were having problems with their health after treatment. People often described symptoms which resembled their treatment side-effects.

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How the study was conducted

To be part of this study you had to have finished Hep. C treatment at least six months prior to being interviewed. I had no trouble finding people who wanted to talk about their experiences after treatment. I advertised the study in *The Hep. Review* and *Good Liver* magazines, thanks to Hepatitis N.S.W. and Hepatitis C Victoria. I was then surprised how quickly people contacted me and how eager they were to talk about their post-treatment experiences.

It is important to remember when reading the results of this study, however, that it used a small sample of people who applied to be part of the research, and as such the findings do not represent the average experience of life after Hep. C treatment. Instead, studies like this one show the diversity of people's post-treatment experiences. So, although these reports are likely to be uncommon, they are important to document in order to understand the range of all possible outcomes from treatment.

Brief overview of main findings

Clinicians and health workers usually assume that patients will feel at least as good a month or so after treatment finishes as when they started, and probably much better if treatment clears their infection. In most cases this assumption seems to be true but several people in my study reported that their health had not returned to pre-treatment levels, and this included people who had been cleared of Hep. C infection. Some people reported feeling so unwell at the time of their interview (at least six months after completing treatment) that they were unable to return to work, while others were finding it difficult to socialise with friends or form new relationships.

Individual accounts of well-being are influenced by many factors in a person's life, and this type of study cannot identify all those factors. But for many participants, one explanation they had for their ongoing poor health was the continuing effects of the treatment drugs. These people perceived that the side-effects they had during treatment were still happening long after their treatment had finished. In people who did not respond to treatment, or who relapsed shortly after treatment, some thought that their ongoing ill-health might also be caused by underlying liver damage from years of living with Hep. C infection, and the ongoing effects of infection. These are indeed plausible explanations. Nevertheless, underlying liver damage seems unlikely to explain why some people reported feeling worse after treatment than they did before treatment.

The study also highlighted how people had difficulty dealing with the fallout of a slower than expected recovery. Some were too sick to return to work when expected after finishing treatment and had run into financial problems as a result. Some people with partners and children felt that they were not meeting their family responsibilities for long periods after treatment. Participants talked about separating from partners and/or having to repair close personal relationships which were damaged during and immediately after treatment.

Some in this study were annoyed by their clinics' lack of interest in post-treatment issues and health problems; they were frustrated in their attempts to find information about the ongoing effects of treatment; they expressed disappointment in the lack of referral for medical care to address ongoing symptoms; some needed counselling for problems in readjusting to life after treatment; and nearly all participants wanted further support to help them get back on their feet after treatment.

For the majority of this study, their clinics provided no support after treatment. When treatment was finished, people were told not to return to the clinic. It is hardly surprising that people in this study were so concerned about finding avenues for support; they had been through a very challenging time during treatment and often they felt fragile, and sometimes ill, for months afterwards.

Could this happen to me?

How common are types of post-treatment problems? It's a question many people want answered.

Currently, we don't know. We need a study that uses a representative sample of people in the treatment, then measures how well people feel before they start treatment and during treatment, and compares this data with those collected six months to two years after finishing. The results could tell us a lot about the long-term benefits and risks of Hep. C treatment. Even if the worst problems identified in this study are shared by only a tiny minority of people, it is a risk that clinicians should warn their patients about before they start.

Implications of this study

Ideally, after treatment is completed, feedback and support systems should be in place for people with ongoing health problems so that they can have continued medical care through their treating clinic. People need access to more and better organised information, both before and after treatment. Referral systems need to be in place at the end of treatment where people can easily access other health professionals and/or services if required, and there need to be opportunities for obtaining further social support for those people who feel they need it.

One possible way to increase support after treatment is to develop a survivorship program, similar to existing programs for cancer survivors. A post-hepatitis C survivorship program would be available to anyone who felt they needed further medical care, information, counselling, referral or other means of support. It would aim to help people to psychologically re-adjust to everyday life after treatment. In some cases it might be as little as referring people to the community-based hepatitis organisations for information, support or advice. For others, it might mean a period of face-to-face counselling until they feel able to adjust to life after treatment or a period of further medical care until their symptoms settle down.

If better systems can be put in place to organise appropriate levels of support during and after treatment then people on opiate substitution programs and/or who currently inject are more likely to consider having Hep. C treatments.

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