



The Hepatitis C Trust Post-Treatment Survey

Executive Summary

The Hepatitis C Trust held a web-based survey from April 2006 to September 2007 that asked about people's experience of anti-viral hepatitis C treatment and in particular how they felt up to 3 years after finishing the treatment. 500 respondents completed the questionnaire.

Key findings:

- 90% of people reported ongoing symptoms/side effects for longer than 12 months after treatment ended.
- The five most frequently reported post treatment symptoms/side effects were fatigue, joint aches/pains, brain fog, depression and mood swings.
- Regardless of SVR (sustained virological response), 40% of people felt worse after treatment than before and 31% felt better.
- For those who had attained SVR 37% felt better and 36% felt worse
- For those who hadn't attained SVR 18% felt better and 50% felt worse.

This was a retrospective survey and therefore contained the potential for bias for a number of reasons. Nonetheless, the hugely varying experiences of treatment reported here, particularly the severity of side effects and how long they last, the apparent persistence of side effects in a large majority and the comparatively low correlation between SVR and feeling better clearly indicate that considerably more research is required into the longer term physical and psychological impacts of hepatitis C treatment.

The Hepatitis C Trust recommends:

- 1) The development of considerable further research, including a large scale prospective longitudinal study which monitors people's experiences in the periods before, during and after treatment and when and why these differ.
- 2) That the findings from such a study be utilised to assist in the development of more appropriate support services for patients, both for those who have not yet undergone treatment, those who have attained an SVR and those who have not.
- 3) That the findings should also inform improved guidance for physicians and other medical staff in preparing people for treatment and assist in people's decision-making processes before treatment as well as assist in how treatment and post-treatment follow-up is understood and managed.