Hepatitis C: When a Virus Creates a Community

July 15, 2014 By Lucinda K. Porter RN

"It takes community to maintain a human." - Earon Davis

Getting support has helped me live with hepatitis C more than anything else has. Not drinking alcohol and developing healthy habits were also important, but I needed support in order to be able to stay on track with my health goals. I have participated in at least one hepatitis C group since 1997.

Support groups work. They may sound touchy-feely, but a good group empowers people to make choices about their health, by providing solid information and insight on how to live with their disease. The potential value of support groups is not just theoretical--there is evidence for it.

In the 1970's and 80's, Harvard-trained psychiatrist David Spiegel became interested in the emotional aspect of illness, specifically cancer. He could see the advantages of using the mind to assist people with aspects of their illness. However, Spiegel was uncomfortable with claims made in alternative medicine about the power of positive thinking.

Spiegel decided to put the issue of "mind-body" to rest by proving that giving positive emotional support would have no effect on the course of disease. He collected data from a research project conducted at Stanford, where Spiegel had co-facilitated a breast cancer support group.

The good news for us is that Spiegel was wrong; his research revealed the exact opposite.

"...Dr. Spiegel was troubled by the assertion that you one could "wish-away-your-illnesses."...In the 1980's his well-designed study of women with breast cancer shocked the medical community. Those in support groups lived on average twice as long as those who had not been in a group - an 18-month extension. (Published in The Lancet, 1989) However, the group model emphasized confronting cancer and death rather than "wishing it away." The focus was on living better, not on living longer." David Spiegel*, Living Beyond Limits*

Somewhat stunned, Spiegel conducted further research and concluded:

1) *Support groups can improve quality of life - reduce anxiety and depression, increase coping skills, and help symptom management*

2) *A thorough understanding of illness affects physical and psychosocial factors that affect response to treatment and resistance to disease progression*

3) The most effective techniques involve facing the illness directly

4) There is no evidence that these techniques will cure an illness, but there is evidence that these may prolong life with cancer, heart disease, and other chronic diseases

David Spiegel, *Living Beyond Limits*

I still participate in hepatitis C groups, and hang out quite a bit at the Hep Forums. Now that I don't have hepatitis C, I could pass my time in other ways, but there is magic and joy in being part of a group filled with people brought together by hepatitis C. At first, I joined to help myself. I stayed because it felt good to help others. Now I remain because being there reminds me that we are all connected. In short, I am still there to help myself.

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