

Submission to the Hep C commission

Dear commissioners

I write to you as the wife of a Hep C carrier and as a mother of two daughters aged six and eight.

My husband has been suffering the effects of his Hep C infection since well before we meet in 1998. In 1999 I saw him struggle through a trial of high dose interferon/ribavirin in an attempt to clear the virus from his system. With incredible courage he continued to work, although he could scarcely make it through the commute and in the front door every day. Despite battling the terrible side effects of these drugs, as for many, the treatment was not a success.

The effect of the experience of the trial treatment made him reluctant to seek treatment for many years. However, for the past three years he has been with the doctors at St Vincent's hospital in Sydney. It is of course for our children that he continues to present himself at the clinic, undergoing endless testing and meetings with his doctors only to hear that there is a new treatment option that has vastly improved outcomes and far less brutal side effects, but that he cannot get it. Apparently he is not yet sick enough to have any hope of receiving the treatment that could prevent the progress of his disease. And so he has surgery to cauterise the tumour on his liver- but no treatment to prevent further deterioration. He lives with constant nausea, fatigue and gut troubles and still goes to work every day and looks after his family.

We all wait, not just my husband, but myself, his sisters, his mother and my two daughters. We hope with each appointment that he will finally be given his chance at better health and potential to see his daughters grow up. It is unbelievably frustrating not be given a treatment, not because it is not ready for use or that he is not a good candidate, but because the Government is unwilling to bear the cost. This is a great irony as we all know, because the real cost-if only we consider the cost to the public health system and not our own personal cost-is far higher if we calculate the probable expense to the Government of my husband's long term treatment for chronic liver disease.

We live a modest hard-working life. We both work full-time to cover the cost of a mortgage and raising a family. We would, if we could, absolutely re-mortgage our house to fund the treatment ourselves. What is any of it worth if my husband is not here to be part of our lives? I have no doubt his sisters and his mum too would also contribute in a heart-beat. But no, we are not allowed to fund the treatment ourselves.

This is our lives living with Hep C-not just the person with the disease, but a family supporting, loving and hoping that this commission finds a way forward out of this poorly considered situation, for us all.