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11th February 2015

Committee Secretary
Standing Committee on Health
PO Box 6021
Parliament House
Canberra ACT 2600

Dear Sir/Madame

I am writing this as my submission to the Australian Government's Fourth National Hepatitis C Strategy, the Standing Committee on Health inquiry into and reporting on:

Part c. The costs associated with treating the short term and long term impacts of Hepatitis C in the community.

I recently completed the PBAC Online comment as part of my contribution to the discussion about how HepC is managed. Primarily I have an interest in this discussion as I have HepC and there is a lot of talk about new medications having good outcomes for people like me without the side effects. After pressing the submit button I was emailed the following receipt:

Date: 11th February 2015

Contact:

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Disclaimer:

Submission1:

Submission2:

Submission3:

Submission4:

Submission5:

I understand that the reply from Health was a standard format but it also reminded me of my experience with the NSW health system in the mid 90's. I had spoken with _____ Hep C NSW then about my dealings with the Red Cross and Health. I did not resent so much the fact that the health system gave me this virus, but what I did resent was their hit and run response to me after it got out they had.

I was transfused with infected blood in October 1990 that was screened for Hep C, though this was news to me. The idea when they originally found out after I donated blood myself in 1992, was that I had some 'risk factors'; that is IV drug use I suppose. I never touched drugs and the only risk factor I had was a blood infusion for an operation in October 1990. This could not be though they said as the blood was screened. They found out later through a 'look back' investigation and I hope that my input then may have had something to do with causing them to 'look back' and stop infecting others. Do you see why "submission1" etc. brings it all back? It feels like I was listened to but not heard.

I wrote to my local Member twice who wrote to Andrew Refshauge (got a reply) and Jillian Skinner (no reply) and found out this was my baby so to speak. Interferon in the late 1990's was okay and I kept working though it did not clear the virus. The combination therapy that followed after saw me sleeping all weekend and nodding off while driving the work car (I was working in child protection then). The system had it that "Jeff could not cope with [the side effects of] the medication" and I guess they are right; I need to work to pay the mortgage not sleep all the time.

I still work two jobs as I like the idea of being in the helping professions (I am a social worker). I need to work anyway as my wife and we were blessed with a daughter four and a half years ago. We were both old at the time and it was a surprise; I was also told that something else in all likelihood would kill me before the Hep C did. The specialist seemed more shocked then me when we got the results from a scan I think he ordered to show me it was all okay after my alpha feta protein levels were a bit high in 2012. The surgeon who did the operation in August 2012 to remove the 5 cm tumour told

me that people seem to be getting cancer after about 22 years of infection. I was infected in October 1990 so I guess this is pretty correct.

I did a short letter that was published in the Hep C review around 1996(?) using my full name. Since then I have completed my second undergraduate degree, two post graduates, TAFE teaching qualifications, and am two subjects away from my Masters in Social Work. Would have completed the Masters but for the cancer. I have worked all the time since being told I have Hep C apart from having a liver resection in August 2012. My alpha feta levels are up again though I am told this happens anyway; but with me the last time it happened in 2012, the 5 cm tumour was found. So scans and blood tests are the go that the tax payer funds. Having chronic active Hep C is a risk factor for HCC so I guess having the virus cleared may allow me to live and provide a lot longer.

More specifically, the costs associated with treating this illness

All my learning tells me that treating health concerns is best done as a primary endeavour; if you can prevent or cure something in its early stages, then why not? We all know that, but don't mention stuff about needle exchanges or how on earth anyone can pay for Sofosbuvir.

My wife worked as a radiographer and radiotherapist in a poor Latin American country where health concerns are left so late. Everyone is that poor they cannot afford primary care where a recovery may be gained, instead all the expensive radiotherapy cancer treatment is directed towards necrotising wounds the cancers have been allowed to become. Is this a model of Primary care or palliative care? It's a waste really, and one that we can duplicate here with hepatitis C if we like.

Hard choice, a quid up front to keep a working bod working and paying taxes, or lets have everyone of a Disability Support Pension instead. When this happens we can blame them as well by insinuating they are drug users – like I felt I was in the 1990's.

Some added private thoughts:

1. I have a great respect for people involved in treating Hep C - someone has to shout into the wind and look after us. Support them in giving them a wider range of affordable options to treat us.

2. I work in mental health and do the same shouting type thing; my nemesis is drugs though.
3. I do relative kinship care placement assessments for children in Out of Home Care on the side. The primary interventions I was used to when I worked in DoCS have all gone; now kids just come into care and the tax payer pays the Carers Allowance. In hindsight, the only benefit here is to me in that I am so proud of the work I was able to do in the 1990's to keep kids safe at home.
4. Significant cohorts of patients I see have Hep C (maybe they find out after admission?). Do we treat their mental health and let them carry a virus that will kill them in the next not so many years?
5. I have met a lot of people (some I knew already but I did not know their HCV status until I mentioned mine) who made some dumb choices when younger. Like me, they deserve better.
6. The person who donated the infected blood I got was doing a 'good thing' with the intention to do his bit for society to allow people who needed blood to live. Any other insinuation or interpretation about any moral blame for this illness or justification for treating someone is just plain crap.
7. The prison system appears to be an incubator for these types of epidemics. Who is going to manage all the sick people who cannot work (I can use my brain to get around the lethargy) and who end up with liver cancer.
8. What about the families who miss out on a full life while some family member is crook with this illness and not able to fully provide. I don't want my daughter believing that living on a handout is something Australian; I want her to, and will provide for her while I still can, to aspire to contribute and not be dependant.

Recommendations

1. Focus on primary care up front whatever the perceived cost; it will be cheaper in the long run both financially and morally.

2. On the question of Gilead's ownership of Sofosbuvir, our government needs to lobby harder for the health of Australians. The recommendation here is to do so.

I see on the Doctors without Borders web site India is able to look after its people, why can't we? Why is problem not addressed more forcibly by my government so that Australians are looked after? Individuals cannot address this; their elected representatives need to for them.

Yours sincerely

Jeffrey Paterson