

## **Hepatitis C: a death sentence?**

Despite my hepatitis C infection I have always had an active life in community service in addition to this working life, but in the past four years, hepatitis C has caught up with me. I am now suffering badly with decompensated cirrhosis of the liver and is waiting to be on the liver transplant list, behind 28 other people. I feel hopeless, and useless and longs to be a contributing member of society again. But without access to treatment, hepatitis C could be his death sentence.

With three goes at interferon treatment, under my belt, I have faced the fact that I am one of the many who are not responsive to interferon based treatments. I was always hopeful new treatments would come along before things got serious, but in in the last four years things have gone from bad to worse. The diabetes, constant fatigue, encephalopathy, and other health issues related to the liver disease gave my Specialist reason to tell me that enough is enough and I needed to take a medical retirement at only 50. First it was the onset of diabetes. Then it was my gall bladder not working properly, and then my bile duct kept blocking up causing gall stones. An operation was considered too dangerous because of the condition of my liver and so a stent was inserted. The stent has to be changed every 12 weeks and each time it is changed I end up with pancreatitis and have a day or two in hospital. Right now I am hanging on by a thread with encephalopathy affecting my thinking as a result of the extent of his liver damage.

But a painful abdominal attack in the middle of the night recently brought this whole horrible history to crisis point. Rushed into hospital in by ambulance, I was diagnosed with a strangulated umbilical hernia and an immediate decision was made to do surgery. I have recently undergone extensive testing in preparation for the removal of his the hernia, gall bladder, bile duct, as well as a liver transplant. It's a dangerous operation and of course I have to wait for a suitable liver to become available.

It seems livers are in short supply -it is not enough for people to just tick the organ donation box on their licence. People need to register with Australian Donors online and tell their family of their intentions in order for their organs to be saved for transplant in the event of their untimely death.

Life has become a matter of day to day survival for me. My body is in a state of disrepair following all the illness and I have significant muscle wasting as I have been immobile for such a long period. Even after the liver transplant, I will be facing the rest of my life on anti-rejection medication, which carries its own side effects and requires adherence to a strict diet.

I am hoping I can cheat death and regain some semblance of life back within 12 to 18 months. But for many in my position it is too late. 630 Australians died of hepatitis related liver disease last year.

Just recently I have been lucky enough to be given a chance at treatment with Sofosbuvir and Daclatasvir, on a compassionate access program and I'm hoping that this will give me a better chance at living after my liver transplant.

These drugs are really life saving. It shouldn't matter how people acquired Hepatitis C, or how far along they are everyone needs fair access to treatment. Please look on this favourably, living with this insidious disease is at best horrendous at worst it makes you question whether you want to keep living with it.