

Jon, 63

Living with a rare blood disorder

Jon Beauchamp was diagnosed with Paroxysmal Nocturnal Haemoglobinuria (PNH) and Myelodysplastic syndrome (MDS) mid-2009. Since then, health complications associated with both diseases have snowballed and significantly compromised Jon's quality of life. He has given up work and is now too tired to weed his garden or take his dog for a daily walk. When Jon's mother passed away recently, he was so sick in hospital that he couldn't attend her funeral. There are days when Jon feels so lousy that he just wants to give up on life. This is his story.

What symptoms were you having before your PNH diagnosis?

Before being diagnosed with PNH, I was extremely fatigued. I was a private painting contractor and was so weak that I could barely take the ladder down and get it into the back of the truck at the end of the day. I experienced this extreme fatigue for about four weeks before I visited my GP. It was then that I was diagnosed with PNH.

What were you told to expect when diagnosed with PNH?

I was told that I would die from PNH in about five years – not from the disease itself, but from the complications associated with it. Now I have been told that I have less than two years to live.

How did you feel when you were diagnosed with PNH?

I was fairly shocked when the doctor told me I had PNH because I have always been a pretty healthy person, and most of my family members have lived long and healthy lives.

How has PNH affected your health?

Nine years ago I was diagnosed with Crohn's disease. Until the PNH and MDS diagnoses last year, I had never had a single problem from Crohn's, but now I experience all sorts of complications such as severe stomach cramps, blood clots, bouts of diarrhoea, endless fatigue and rapid weight loss. I have dropped from 92kg to 68kg in the last seven months.

How has PNH affected your quality of life?

PNH has forced me into early retirement. I am breathless just walking around the house, let alone working and there have been times that my brother, Kevin, has had to carry me to or from my car because I was too exhausting to walk by myself.

I am now living on a small disability pension. I plan to sell my house at the end of the year because I can't afford the repayments.

Living with PNH means that I can't perform activities that I used to. I haven't taken my dog for her daily walk for about three months and I have to get someone to mow the lawn.

How do you manage your PNH?

I currently treat my PNH by replacing the destroyed red blood cells through blood transfusions at least once a fortnight. There are times when I require transfusions twice a week, usually with two bags of blood and one bag of platelets at a time. This procedure must be performed at the hospital and can take up to six or seven hours.

What would Government funding of PNH treatment mean to you?

Government funding of the PNH treatment is the only way that I could achieve any sort of quality of life without it, the rest of my life – however long that may be – will be a struggle.

How did you feel when you heard about the Government's recent decision not to fund PNH treatment?

I was really disappointed when I heard that the Government would not fund PNH treatment. I had a gut feeling that the Government wouldn't sign off on it due to its expense.

Some of the other PNH patients in Australia are on the treatment through a temporary Compassionate Use Program, but I missed out because I was diagnosed too late. If I had been diagnosed about three months earlier then I may have been included on this program. My doctor has tried tirelessly to get me onto the program, but we have had no luck.

I guess it is a classic case of 'what you don't see, you don't feel.' The Government doesn't see us living with PNH so they don't know about the dire predicament which our patient community is facing. We desperately need their help.

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To arrange an interview with Jon, please contact Kirsten Bruce or Sarah Mathiesen from VIVA! Communications on 02 9884 9011 or m. 0401 717 566 / 0400 712 861.