

Living with Multiple Myeloma: A Patient's Story



Dot and Terry Arnold were teenage sweethearts who drifted apart but found themselves happily reunited in later life. Both had been married, but Terry was divorced and Dot had been widowed. On Terry's retirement, they dreamed of travelling Australia in their "old caravan with new curtains", even managing a few short trips to South Australia, New South Wales and Queensland.

Their contented new life however, was marred when doctors finally discovered why Terry was lethargic and breaking bones so easily – even by just getting out of bed. Terry became one of the estimated 1800 Australians diagnosed every year with the blood cancer, multiple myeloma¹. After a stem cell transplant, chemotherapy and a clinical trial, Terry is doing well. He knows he won't be cured "but I am hoping to keep this disease asleep and get another five or ten years."

Terry's Story

I worked in the plastics industry for 25 years and I was enjoying retirement. Dot and I did a few trips in our van but then I went to see a local doctor because I had a really sore back and I was starting to break ribs just getting out of bed. I had always been fairly fit, but one morning I got out of bed and my ribs started to crack.

It was so painful. So we went to the doctor and she ran all the tests.

When they told me it was myeloma I was shocked, we knew nothing about myeloma.

In my case, the body attacked the bone marrow. The myeloma could have been in my system for a long time. I might have had it 5 to 10 years. What triggered it, I don't know. It was so quick.

We were that shocked and we did have a little cry. But then we went to see the haematologist and he was very honest. He said we can't cure it, but we can put it to sleep for a while.

It certainly put a dent in my travelling plans!

They put me straight on to chemo and then prepared me for a stem cell transplant. I had the cell collection but about two weeks before it was due to happen my (paraprotein) levels were up and we had to put the transplant off. Then they asked me if I wanted to go on to a new trial, which meant another lot of chemo.

Our doctor Michael thought it was a good idea, and we trusted his leadership.

We got the levels back to where they should be and then I had the cell transplant. This was a tough time; I was in hospital for about a month.

I have been in remission for about 4 months now. It's all going very well. I go back to the doctor at the end of every month for a blood test and you do worry about what it's going to show up.

At the moment I am on a lot of steroid and hormone pills. Once I get off them, we want to head up north.

I don't think I would have got through any of this without Dot. She has been marvellous. I want to keep this disease at bay and I am hoping we get another five to ten years.



Dot's Perspective

Terry and I were childhood sweethearts. We weren't together very long, but I dumped him. I always felt sorry about it and I always wanted to apologise, because he was really a lovely guy.

After my husband died, I asked a mutual friend how he was going. The friend put us back in touch and we caught up for dinner. I was shaking so much my cutlery

was rattling.

I was worrying about how old I looked!

We got married four years ago and were looking forward to retirement.

I knew nothing about myeloma when he was diagnosed and we were shocked.

It has been tough. After the cell transplant, I did not think he would be coming out of hospital, he was so sick. Now, I just feel so relieved. He has been through a tough time and to see him suffer like this has been terrible. So, we are dusting the caravan off and I have made her some new curtains to freshen her up. We are planning on going up north.

You need to make the most of every day. None of us knows what is around the corner.

Dot and Terry would like to thank Dr Michael Lowe, Professor Andrew Spencer “and the amazing team at The Alfred for their dedication and for giving us a second chance at life”.

** Dot and Terry shared their story in February 2018.*