

Kaye's Story

KAYE: Before this diagnosis I was very fit and strong, and very active, and funnily enough I've spent my life maintaining good health status, good diet, always exercising, and so it came as an absolute shock when I was diagnosed with mesothelioma.

Mesothelioma is caused by asbestos fibres and in my case it's quite a rare form of meso. I've got peritoneal mesothelioma which involves my entire abdomen having tumours throughout.

In my mind it was almost like a betrayal, people were happy to make thousands of us sick in order to earn extra dollars and so that is a huge thing to have to come to terms with.

The surgery was an 11-hour operation and a team of doctors do this operation called a peritonectomy, and they remove many organs and as much as tumour places as possible.

They removed my appendix, spleen, gallbladder, ovaries and tubes. They removed a tumour from my diaphragm, two sections of bowel. They stripped my peritoneum after and I had a ileostomy bag, and after that they pour hot chemo into your abdominal cavity and rotate your bed so that the chemo flows over your organs, and then after that was period of two months, two and a half months in Saint George's Hospital in Sydney to recover from the operation.

It was horrendous. I had to stop for a while. It's the hardest thing you would ever have to do. It's just a huge amount of pain and I think you survive on your will alone.

It was also terrible for my husband Geoff. He's a farmer, he's used to being in the outdoors and he was there beside me every day for three months.

GEOFF: Getting up each morning and just didn't know whether she was going to be there or not because she was running a fairly fine line at that stage and watching her in just the most horrific pain even though she was on painkillers.

KAYE: ...and at that point I was unaware of palliative care. In between doctors visits I was really feeling alone and wondering what would happen next, and once again that feeling of free falling without a net is the only way I can describe how I felt.

I spoke to the oncologist who felt that I was not really yet ready for palliative care, however I knew that I needed them in my life and so I spoke to our GP about it and he very willingly and readily referred me.

From my experience I believe the moment a person is diagnosed with a life-threatening illness – that would be the ideal time to link them to palliative care.

Palliative care has provided me with incredible, emotional support. Each person involved in the team has just been so well trained and so professional, so supportive. I'm amazed at the difference it's made in my life.

There seems to be an attitude in the medical profession that people don't need to be referred to palliative care until the last months or weeks of their life, but that's definitely not the case speaking from my experience, definitely not.

It's a frightening, lonely place to be and all of a sudden with palliative care around me I feel secure and safe and I fully understand that they will be supporting me through the last period of my life.

They constantly assisting my progress so they can see with each slight downturn, they address that instantly and my pain control is now wonderful. I'm getting the emotional support. I've actually used pastoral care, the social worker, the dietician and the nurses, and we need all of that to support us.

Just to be able to still be engaged in life, I appreciate nature, just to be doing the simple present things that I enjoy doing on a daily basis. Gardening, walking, swimming, just the little gentle pleasant things. But most of all being with family and friends.

Palliative care is everyone's business, we all need to know about it.

From one day to the next we don't know whether we will be the next person diagnosed with a life-threatening illness and so if we all know about it then we're all aware and able to take the steps to enjoy the benefits of it.