Cancer Inquiry. Diane Shepheard

Thank-you for the opportunity to respond to such an important inquiry. I have only just received the terms of reference and have very little time to respond, nor to do drafts and corrections, but I feel it is important enough to make time in a hectic schedule to give my point of view.

Both my husband are well-educated professionals who have both had cancer. I was diagnosed with ovarian cancer in 1996 at the age of 37 and was very quickly rushed to Melbourne from my country town for surgery where I had a hysterectomy and my ovaries removed. It was a whirlwind diagnosis and surgery with little time for any input from us. We were both so traumatised that we did whatever we were told without question. It would have been good to have the option to discuss whether I wanted a hysterectomy and my other ovary removed but there was a presumption that they would do what they needed to do to ensure that the cancer was halted. I have been clear of cancer ever since and am glad for their care and treatment. As I was treated in the city I had to have regular visits to Melbourne for check-ups. After a year I was told I needn’t return. I had to ensure that I did my own follow up treatment and I have had to work out how to regulate my oestrogen levels through trial and error with different deliveries of the drug. I have kept copies of all of my treatment, blood tests, etc. and have been able to show doctors what has happened but I have only just found a local doctor who has told me that he will find out whether I should still be having blood tests and check ups.

I have four children; my youngest at the time was three. Motherhood was very important to me and I grieved the loss of my uterus and ovaries, as they were an essential part of my womanhood. I was and never have been offered counselling. I have never been followed up by the hospital, nor the gynaecologist. It has concerned me for a while that as an educated, articulate and well supported person I have been able to pick my way through the often brutal maze of oncology without too much scarring. I feel for those who do not have my skills and wonder how they survive, if not the cancer, the psychological and clinical desolation of oncology treatment.

My husband was diagnosed with melanoma three years ago, after being misdiagnosed three years earlier. We were on the same treadmill of panic and submission, even though we were well informed, reading medical texts and extracts, clutching at the very slim straws that were being offered. It took the two of us, taking notes at medical interviews, keeping our own records of blood tests, xrays, CT scans etc, to case manage his treatment. There were a number of people who were involved in his treatment, two different surgeons, his GP, the radiologist, his oncologist, Peter MacCallum Clinic, his naturopath, the local hospital, the Melbourne hospitals. We kept each of them informed of what was happening and carried a very large folder to all of our appointments.

After going through the conventional medical treatment of surgery and radiation we were offered Interferon, which my husband self injected for a year. I have condensed this time but these two years were filled with much anxiety and despair. Our options were very limited and the prognosis was grim.

When the cancer returned after the year of Interferon, we were at a very low period and could not see our way out of what seemed a doomed outcome.
With the help of family, who looked after our children and paid some of the fees, we both went to the Gawler Centre in the Yarra Valley.

It was here that we found the hope and peace of mind to continue on our mission to conquer my husband’s cancer.

We met other people, very much like ourselves who were seeking answers from what seemed, from conventional medicine's viewpoint, to be an open and shut case. Conventional medicine left us thinking that my husband was certainly going to die, and quite quickly.
At Gawler we were able to discuss our feelings with others who had been through the same things. We were taught to meditate, to find peace and quiet in the middle of stress and anxiety. We were updated with all of the scientific data of other ways of treating cancer. No one-way was pushed, it was seen that cancer was a chronic condition caused by multifactorial issues and we were shown how to explore the different things that can help cause cancer. We had many moments of laughter, singing and even dancing, we began to feel normal and were able to stop and look around at our options. We became empowered again to ignore the prognosis and get on with living. It was an invigorating experience and it changed my husband's attitude to his disease.

We have become fish eating vegetarians, do yoga and qigong, my husband gave up his business and we travelled around Australia with our children. We sought out a doctor who supported our positive mental attitude and didn't scoff at our attempts to improve my husband's outcomes. We have been able to minimize the fear and get on with living with cancer, with the hope of conquering it.

As conventional medicine is now unable to offer him any treatment, we feel no compunction in declining some of the treatments, eg CT scans to see whether the tumour has grown. It's pretty useless if there is nothing they can do about it.

My husband has been back twice to the Gawler Centre for follow up sessions and he has found them to be very useful.

Even though our oncologist is a friend, he still felt it necessary to warn us of being duped, because as cancer sufferers we were vulnerable. I explained to him that we were as every bit as intelligent as him and able to sift and sort through all that different people had to offer. We find it amusing that conventional medicine offers us Interferon, with many major side effects, with little idea of how it works, with very little statistical support of it doing much good but scoffs at changing our diet to cut out coffee, tea, meat and alcohol.

We were amazed to find 18 months after the Interferon treatment that my husband's white blood cells were still very low. Who's job is it after chemotherapy to get the patient's blood levels back to normal? Who's looking after their mental health, encouraging them to stay fit and healthy, to be positive, to be informed.

There is much to improve in the treatment of cancer. Cancer is a life changing event, it can even be a change for the better, amazingly enough. It is certainly an enriching journey. You can die having panicked, run scared, leaving chaos behind you or you can live, knowing that death is inevitable, eventually, and enjoying every moment. The Oncology Department doesn't offer you the second option.