

**DEFEATING CANCER
HOBART CANCERIANS COMMITTEE
HER EXCELLENCY PROFESSOR THE HONOURABLE KATE WARNER AC
GOVERNOR OF TASMANIA
CLARENCE ON THE BAY, ROSNY PARK, SUNDAY 15 NOVEMBER 2020**

I begin by paying my respects to the traditional and original owners of this land: the palawa people. I acknowledge the contemporary Tasmanian Aboriginal community, who have survived invasion and dispossession, and continue to maintain their identity, culture and Indigenous rights.

Thank you for the invitation to speak to you today and for the opportunity to support the work of the Australian Cancer Research Foundation. I feel so grateful that medical science has enabled not just me, but my husband Dick and other close family members and friends to defeat cancer or if not to defeat it, to hold it a bay. And of course the many millions for whom thanks to medical science, cancer has not been the death sentence it once was.

This is my cancer story, the details of which I had rather buried but am revisiting for a good cause – although given you gave me a choice of topics, I was tempted to talk about something entirely different!

In late September-early October 2018, I felt pain in my left hip when I got out of bed one Saturday or Sunday morning. I assumed I had just pulled a muscle and so continued to use it normally although I had a bit of a limp.

When it did not get better and I was limping noticeably, I went to see my GP and he ordered an X-ray and an MRI which I had on Friday 2 November. The radiologist rang me on the way home to warn me to be careful over the weekend because I had a cracked pelvis. The next week I had CT and some days later a bone density scan.

My GP Rob White referred me to orthopaedic surgeon, Mike Prichard. He thought that the fracture was possibly an insufficiency fracture (osteopenia) although there was a bit of blob he was a little concerned about and he advised a follow-up appointment on 17th December after another MRI to clear me to

walk up Bishop and Clerk in January! Meantime he advised that it was okay to use it, standing and walking and cycling as long as this did not hurt.

I had the follow-up MRI in mid-December at Calvary. Mike Pritchard's surgery rang me the next day as he wanted to see me that afternoon about the MRI. The fracture in the pelvis had not healed. Although I was no longer limping, I still had pain which had moved from the groin to the lower back. So began a flurry of appointments and tests: blood tests, a PET scan and a bone biopsy at St Vincent's in Melbourne on Friday 21st December.

We had flown over on Thursday afternoon after Rhiannon's graduation and had a nice dinner at the Florentino Grill quite confident that the scan would show no abnormalities. On Friday morning the oncologist from St Vincent's rang me. He told me the results of the PET scan were not good and apologised for giving me this news by phone. The scan showed hot spots in the bone of my left pelvis and spots in my liver and lungs. I asked him if this meant I have cancer, which he confirmed. He warned me that as a result of the PET scan they would probably do a biopsy of other organs as well as the pelvis. I asked him what I should say to family and work colleagues. He advised merely to say that I have had a bone biopsy and we are awaiting the results.

Dick and I went for a walk down Bourke Street, viewed the wonderful Christmas window at Myer – an Alice in Wonderland theme that year and had a lovely long browse in the Hill of Content bookshop and purchased some distractions.

When we got to St Vincent's, the radiologist explained that they would only do the bone biopsy as they are experienced with the procedure and he thought it highly likely that this would tell them all they need to know without a biopsy of the lungs or liver. However, there was a slight risk that the scan would be non-diagnostic. All went well. The narcotic administered made me feel deliciously floaty. Results are normally available in 48 hours although because of Christmas there may be delays.

Christmas Eve: Received the Speaker Sue Hickey and Clerk of the House of Assembly Shane Donnelly to approve amendments to Standing Orders in relation to a new Code of Conduct. In the morning. Kept my phone with me all day in case there was a call in relation to results. Just before 7pm Rob White

rang to say that there were no results yet and we would not get them until Friday 28th or possible the day before.

Call from Rob White on Friday 28th to say no results yet, a problem with analysis which would be done again on Monday 31st NYE.

New year's Eve: Mike Pritchard rang when we were passing Constitution Dock on the way to the Derwent Sailing Squadron for the Launceston to Hobart presentations to report that I have B-cell Lymphoma, which he was relieved to hear because it is treatable. He then met me at DSS entrance as he was down at the club, having just completed the Melbourne to Hobart race. So good of him to keep in touch with things while involved in the race. The oncologist from the Royal rang with an appointment at 4.15 so we left the Sydney to Hobart presentations a bit early and cancelled attending the Melbourne to Hobart presentations – phoned Mike Pritchard to apologise for not presenting him with the Line Honour's trophy!

Anna Johnston explained that there are 20 types of B-cell Lymphoma and I would need a liver biopsy to determine which type I had to determine the appropriate treatment.

So we got back to Government House soon after 5 pm and I told my elder daughter Emily who was at Government House with our grandchildren (who were staying the night) until we returned. This was the most difficult part – telling our family and seeing them so upset.

One of the people I confided in first was my friend and colleague Julia Davis who was diagnosed with metastatic breast cancer in 2011 and whose strength and courage was an inspiration to me. We were chief investigators in a research project which attracted a lot of funding – including three year grants in 2013 and 2014 all complicated by uncertainties caused by Julia's illness and my appointment as Governor in December 2014.

On Wednesday 2nd January, Julia emailed from Adelaide:

This “diagnosis and telling people” part is one of the difficult parts – oddly enough, once the treatment starts and the shock of the diagnosis wears off, things do get better.

Later that day she emailed with the following advice:

1. Make love not war

Everyone talks about cancer battles and about fighting the disease. I don't do that. I leave the fighting to my oncologist and my radiotherapists — i.e., the healthy, trained, objective, expert fighters. I don't think that being in "fight mode" is good for ordinary human beings. I have always focused my energy on staying connected to the people I love and doing the things I love because that goal keeps me in a sustainable frame of mind (and it is a "battle" that you can win!). It's much better to focus on who you are and staying true to your authentic self than to focus on "fighting cancer". Leave the fighting to the experts and do the things that make you, you.

This means that you need to make sure that your specialists understand you and your goals too – they can't fight effectively on your behalf if they don't know who you are and what you value. These talks are one of the worthwhile parts of the therapeutic journey.

2. Find a way to deal with the anxiety

(Three points: anti-anxiety drug; treat it like a new puppy and train it; get a psychiatrist.)

I did not need anxiety drugs, visualising it as a new puppy or talking to a psychiatrist – having such an optimistic diagnosis was such a big difference between my situation and Julia's "It's not a matter of if it would kill her but when."

3. Don't worry about what caused it

Draw on your legal training to recognise that the cancer is just a "bad fact" — it does not mean that you are a bad person or that you did something to cause it. It just means that it's something that needs to be dealt with. One thing that I have noticed, is that many people agonise about why this is happening to them — they try to make sense of it in moral terms and hunt around for something or someone to blame. Usually they end up blaming themselves — but cancer does not raise a question of blame or fault. It's just a bad fact that you have to deal

with. Don't agonise over why — it's a waste of good brainpower that you need for other things.

4. Anger

Another thing I've noticed is that some people end up enraged by the disease. Sometimes it seems to me that they end up in this unhappy state because they have some unresolved anger in from the past that finds its way "out" through the avenue of the cancer. It is socially acceptable to be angry with cancer but not other aspects of our lives. If this happens to you – it's worth pondering.

5. Live in a smallish "slice of time" – and don't get ahead of yourself

Many people say live day by day (or even worse to "live every day as if it's your last") –but that is not how human minds work. We see ourselves in a time continuum and as someone with a past and a future. I read this piece of advice a few years ago and it helps:

Don't agonise about the past, in the sense that you can't change it. Live in the slice of time that's the now. You can't live in the moment; it's too short. The slice is richer. It contains a little of past, present and future.

6. Treat statistics with care

You can get obsessed with the numbers and the statistical chances of success. Remember that they hold good ONLY over large numbers of people — they don't hold any magic power over you because you are an individual.

7. Learn to live with uncertainty

Once you get cancer, the only certainty you get is the bad kind! So, learn to live with the fact that you do not know what is going to happen or what it will be like when it does happen. Don't hanker after certainty.

And finally:

8. Get equipped (maybe an iPad and maybe a port)

Heart scan on Wednesday and liver biopsy on Friday 4th.

I had the biopsy on Friday and the doctors were not delighted about our plans to head off to Maria the next day in case of bumping the biopsy site and bleeding

and strongly advised to delay it for 24 hours and no vigorous exercise for a few days, not even kayaking! We had to be back by the following Wednesday.

Wednesday 9th January: On-duty RHH oncologist explained the diagnosis (relieved there was one and so no need for a surgical biopsy and further delays). It was “diffuse large B-cell lymphoma”, high-grade and Stage 4. This is the most common form and is curable! I quickly understood that the fact that there are “hot spots” in lungs and liver with the lymphoma is not equivalent to saying that the “primary” has metastasized. The hot spots are just all over the place because lymph is everywhere and so the spots are just manifestations of the primary, which if you have a curable kind of lymphoma, should go away as a result of the treatment.

The basics are that there would be 6 cycles of harsh chemo every 3 weeks. At the end of 6 cycles I would have two cycles of a different type of chemo to avoid risk of the cancer spreading to my brain or spine. These will involve admission for 3-5 days.

The overall message was that I had a good chance of being in remission and although there is a higher risk of it recurring because I have it in my bones the prognosis is very positive.

Next we had a follow up meeting with the nurse (Deborah) who gave us a lot of material; went through the side effects and what I need to do. No sex without a condom!

Thursday 10th January: Had a morning coffee with Julia which was lovely who was visiting here from Adelaide. In the afternoon we met with Will Hodgman and David Owen to discuss. We went through the options if I am not well enough for engagements such as the appointment of a Deputy Governor.

It was decided that we should do a press release on Sunday morning (13th, inviting the press to be here at 10.30am) with me speaking, then the Premier and then David. Meantime David would contact Government House staff and then a list of people to be told before the press release.

Sunday 13th January: The press release went quite well. I spoke followed by Will and then David. Fiona Blackwood was the ABC journalist and she did an excellent job with her story and it was so nice to have a familiar face in the

audience. It was also lovely to have Government House staff members Ainstie Wagner and Leigh Millington in my line of sight while making the announcement.

Monday 14th First cycle of treatment: R-Chop 21. We walked to the Royal from the Silos – a most glorious morning which I relished, not knowing when I would next feel so well! All went smoothly, the Irish nurse, Martina, was excellent and also looked after by Jessie whose husband Ian is associated with Cancer Council Relays.

Thursday 17th: Managed the Neulasta injection (to increase the production of neutrophils) at breakfast but went and checked with Grosvenor St Practice that I had managed to inject all of the syringe contents. This is to stimulate the production of neutrophils, a type of white blood cell which help fight infection.

Wednesday 23rd January: Consultation with Rosie Harrup, who will be my oncologist and she confirmed that the latest tests from the liver biopsy have come in and the treatment regime we had started was the right one.

Generally coping with the treatment well. No neutropenia; no mouth ulcers and blood test monitoring to check that blood cell count has returned to normal all fine. The steroid medication (prednisolone) has affected my voice.

Julia remembered to email me before each infusion – on 6th February she said:

Dearest Kate, I'm thinking of you today – it's hard to force yourself into the chair when you know that they are dripping poison into your veins. After today you will be able to tell yourself that you have done a quarter of your treatments.

I replied,

Darling Julia thank you! Back from the hospital! Dick and I walked in this morning so I could relish feeling so well knowing that I would be a bit wobbly this afternoon. Am terrified of nausea especially as I have some Wooden Boat festival boating to do on Friday and Monday! They have given me a prescription for Ondansetron which I can take if I need it. I do have a real hair wig which is okay – fringe is compulsory apparently and although I have had it thinned to be more like my hair as it was, it is still like a furry helmet and itchy so I feel as though I have Pekinese on my head with fleas! I am thinking of having what

remains of my hair just shaved off! God knows what I will wear on boats and at the Cup on Sunday!

After cycle 3 I had two tests; one to check my heart (Calvary nuclear medicine) and a CT scan of chest, abdomen and pelvis and so I could report to Julia:

22 March

Dearest Julia,

All going well with treatment—had some scans this week and chemo today. Got results from scans just before today's treatment and the CT results are very encouraging, reductions in liver lesions etc and no new osseous lesions! It all makes feeling a bit average worth it! And I was pleased I managed to get back in time for a St Johns Investiture this afternoon which involved the wearing of capes and me knighting Greg Melick with a sword – I had to actually wield the sword from his right to left shoulder and back again which I managed it without slicing either of his ears! I have to have another heart scan before next treatment as the chemo has had some kind of adverse effect on it - but nothing to worry about and it just might mean adjusting the next infusion if this continues.

Second heart scan on 8 April showed further reduction in heart function so this means an adjustment to the chemotherapy cocktail on Friday substituting a different drug which will need to be infused on Saturday and Sunday as well.

3 May

Dearest Kate,

I am writing to send you love for the latest infusion. For me the last few were always the hardest, so I hope everyone is helping you through the next few weeks!

I have had a good scan, showing that this new stuff is working and has cleared the lesions in the liver. This is a relief, but while it is good news, it doesn't mean the end of my treatment. I am stuck with having these infusions for the foreseeable future, and the side effects are getting worse. Still, at least it's working, so it feels worthwhile.

Best love, Julia x x x

25 May

Dearest Kate,

I am writing to send my love — I hope these final treatments are not too awful and that you can see some light at the end of the tunnel.

I have been enjoying Meg's book SO MUCH!!!! I don't find Susannah too angsty –and I can understand why Dick can't bring himself to read it :)))

Mid-June

Oh dearest Julia, 141 infusions! I just cannot contemplate how awful that would be! Perhaps I understand it better than someone who has none though!

My methotrexate in-patient treatment was pretty awful! I had hoped to be out of the RHH in 2 or 3 days but had to stay six and even then the levels were still not down as much as they would have liked but there was a gastro outbreak on the ward so walking around was banned – I felt as though I was imprisoned in gloomy bunker and so they let me out. Last week Rosie decided no more methotrexate for me and out came the PICC line. I have been feeling pretty tired and SO thirsty but water tastes pretty awful and nothing has seemed to quench my thirst. I have managed to continue with most things – Dick had to host an ambassadorial dinner and fill in for a couple of things and when I can I have been in bed by 7.30 or 8pm. How can one sleep so much! Blood tests yesterday showed white blood cell count and neophils still dropping so have decided not to go to Sydney tomorrow to Bob Hawke's state funeral as it would have been a very long day.

I will have the PET scan to see how (if) things have gone in mid-July and then Dick and I are on leave from 20 July until 3 August so I hope not to miss you when you come down! We are going to Broome and the Kimberley with Jane and Peter Evans which I am very much looking forward to. Even if I need radiotherapy it can wait until we get back.

Julia responded:

It would be very nice if you could avoid the radiation, but once we get on this particular rollercoaster it's sometimes hard to get off! I remember reading

someone's blog on living through cancer and she said something that I have taken to heart. It was along these lines: At each stage of cancer I keep thinking, "if only I'd known it was going to come to this, I'd have been really happy with the stage I was at before." So, I do my best to find something to make feel happy each day and to make sure that I'm not wishing for things that I can't have. It is very bloody tricky to find things to be happy about when you are feeling nauseous and the digestive system is doing its best to ruin your peace of mind, but most days I can find something!

So, I got through the six months of treatment, by the end of the year I even had very short hair, eventually a few eyelashes and now a year later and at last, toenails! I am so grateful for the treatment and support I received and also for the fact that I did have a form of cancer that is curable, that I the treatment was mercifully short in comparison with so many. I was also so lucky to have many distractions and for the most part being well-occupied distracted me from feeling anxious and from dwelling on the side effects – which I soon forgot. So, I managed to cancel very few engagements – we had plenty of notice about the timing of the treatment and so could juggle events around it.

Keep busy – if you can, keep working. Get plenty of fresh air and exercise – even if you feel awful, you WILL feel better if you can go for a walk or bike ride in the fresh air. For me I preferred not talking about it, except with Julia and another colleague who was also having treatment at the same time. Otherwise, I tried to put it right out of my mind as much as possible – and to leave it to the medical experts to fight it for me. As Julia also advised, using my legal training I treated it as a bad fact and put it in a box, in its own compartment and got on with my life as much as I could, remembering, as she advised, to focus on things that make me happy.

Thank you.