



# a survivor's story

From the Australian Cancer Survivorship Centre



Ian Allen's story,  
as told by Meg  
Rynderman,  
a consumer  
representative  
for the Australian  
Cancer Survivorship  
Centre

June 2016

## 'At the end of the day it's my body'

Ian Allen

Silver hair brushed back, wearing his signature corduroy jacket, at 71, Ian Allen OAM looks very much the ageing rock 'n' roller.

We chatted recently at Peter MacCallum Cancer Centre (Peter Mac), where Ian told me the story of his cancer journey. I soon learned that music has been one of the twin passions of his life, and has included touring with international artists, playing electric bass in various bands.

"I was running pretty big rock and roll dances in the four corners of Melbourne. There was Ringwood, Moorabbin, Yarraville and Preston. And each location four times a year, so there were 16 of those going on."

Music has acted as a counterbalance to Ian's busy life. He is involved in an executive capacity with a well-known Melbourne family, active in their philanthropy and major event management. He described his role as "doing what has to be

done"— a mantra that extends into all aspects of his life.

Ian explained to me that he has a long history with Peter Mac.

"I was born here. And here's a weird story. Then it was St Andrew's Hospital. When I met [my haematologist], his office was the old delivery room. I thought I'd done the whole cycle."

Ian traces the beginnings of his cancer journey to 2001, a period in which he was focused more on caring for his frail, ageing mother, immediately prior to her death, than concerning himself with his own health.

"As her son and her medical power of attorney, we had this situation of effectively unresolvable stress. It was just a few months after that that the cancer started. The symptoms were dry coughing, shortage of breath."

# a survivor's story



From the Australian Cancer Survivorship Centre

Ian visited his GP, who initially treated his symptoms. With little change, he was soon hospitalised and referred to a variety of specialists. Investigations included a series of X-rays, tests and scans, and finally a PET scan and biopsy.

Referred to Peter Mac, Ian soon met the haematologist who, after repeating the tests, arrived at a definitive diagnosis. He was to become Ian's collaborator in his 15-year journey.

With a diagnosis of aggressive diffuse large B-cell lymphoma situated in the chest, Ian recalls being told there were no guarantees. If nothing was done, he might have six months; with treatment the outcome was uncertain, but better than six months.

He spoke openly of his reaction to receiving his diagnosis.

"I sort of felt then that I may never come back out of this. So that realisation sort of hit me. Then there was a little time before I could get an appointment with [my haematologist] and before we started the treatment. So here was I charging around working like nothing was wrong and largely putting it out of my head. I guess one could have sat down and said, 'Well, I'm sick, I've got cancer, I'll sit in a chair and waste away'. It's not the way I work."

Ian explained that both his academic training and his



nature led him to question the thinking behind every decision made around his cancer care.

**"At the end of the day it's my body. I'll listen to their advice like I would other professionals, but I'll make my decisions."**

In consultation with his haematologist, a treatment plan was developed, involving an immunotherapy trial (rituximab also known as MabThera) and six cycles of chemotherapy. The effect of the treatment was to be assessed with PET scans. Radiotherapy would follow if required.

"So by the time we had two cycles of a six-cycle program there was no cancer, it had gone. So I say to [my haematologist] of course, 'Well, why are we keeping on doing this?' He proposed we continue through the six cycles just to be safe."

From the outset, while he would question his doctors and his treating team and be involved in the decision-making, Ian viewed his cancer journey as a collaborative exercise with his haematologist: his 'team leader'.

"We need to do this as a team, you're the team leader and I will guarantee you I won't put anything in my body that you're not aware of. I guarantee you that. But I'm going to ferret information out and drive you crazy with it."

Ian investigated Chinese and complementary medicine, exploring what benefits they might offer his recovery, and obtaining approval from his haematologist before commencing a vitamin regime that he maintains to this day.

He presented his haematologist and his treatment team with a daily record of how he managed between treatments.

# a survivor's story



From the Australian Cancer Survivorship Centre

He recorded his consumption of food and drink and his temperature, which he took three or four times a day. He wanted to give his haematologist every item of information he needed. "And it worked well."

He managed his treatment and recovery with a simple formula introduced by his haematologist.

"[The haematologist would say] 'Just listen to your body, if you're tired lay down'. So if I was feeling tired I'd just go and lie down and I might lie down for a whole afternoon and let the treatment take over. But I didn't fight it at all, there's no point, you're stupid to do that, crazy."

Ian said that his wife and his adult sons supported him physically and emotionally during his treatment and recovery. At times, though, they



disagreed with his methodology.

"Everyone was very concerned. There's no question, very emotional. [But] their expectation of someone being sick is a bit different [to mine]."

[They would say] 'Don't you think you're going over the top?' and 'do you really think you need to do this?' Well actually I think I do."

Ian describes himself as like an 'unreasonable man', calling on a quotation from George Bernard Shaw:

*The reasonable man adapts himself to the world; the unreasonable one persists in trying to adapt the world to himself. Therefore, all progress depends on the unreasonable man.*

"I think it's how some people see me. It's being a bit unreasonable to the model where you've got doctors and people wanting you to do what the doctors say. I come in and say, 'Hang on, I hear what you say, but I'm not going to do what you tell me, unless you can convince me. I'm going to have a say in this. It's my body!'"

Following the completion of his treatment and recovery, Ian's haematologist warned of potential long-term side effects. Ian commented on the importance of survivors taking charge of their health after treatment.

"So I've managed now to get a team of specialists to monitor long-term side effects and the information about me is shared between them all. So they treat a patient and not a symptom. It just seemed to me to be sensible." He sees his GP about once per year and has all his own medical records.

His message to other cancer patients and survivors incorporates this same advice.

**"You've got to find the best person to look after you, you've got to then hear what they say and challenge them and keep asking questions and be the one who evaluates the answers and makes a decision. You can't expect someone else to be making the decisions on your behalf and then something goes wrong and you blame the doctor—that's not fair."**

Taking time off work for treatment, returning to work and financial problems are issues many survivors struggle with. Ian recalled that he was overwhelmed with the level of support and flexibility he encountered.

He was encouraged to take whatever time he needed and invited to return to work when he felt able.

"I was getting around on a walking stick. Probably before the fifth cycle of chemo, [with] no hair—and a family

# a survivor's story



From the Australian Cancer Survivorship Centre

member called me up one day and sought my help with an event. The positive impact was enormous and never forgotten."

Post-treatment, Ian became involved with the Peter Mac Consumer Advisory Committee, the Board and later the Foundation. The involvement has evolved into a lengthy journey focusing on cancer survivorship.

"When I was appointed to the Peter Mac Board I closed all those dances [I had previously organised] and sent a note out to all the patrons saying how much I appreciated what they'd done and their support [explaining] now I'm hoping to try and help others. And I just work on the simple premise to do good for people."

Ian talked about the tools that survivors might need to enhance their journey. They include using lists of questions to ask their doctor, taking part in educational sessions and getting a second opinion.

A vital tool for patients, Ian felt, was a survivorship care plan—a document to be distributed to the patient and all their treating doctors, including their GP. The

care plan outlines information about diagnosis, treatments, possible ongoing side effects, healthy living messages, and contact details for easy referral back into the system. Ian's approach meant he effectively devised his own survivorship care plan, but for other people, a formal plan would be a critical tool.

**"Because ... the GP, the specialists ... all have a common document and they start to look at the patient as a person and not as a symptom. I think that a survivorship care plan is critical."**

Ian explained that if he becomes aware of a cancer patient who seems in need of reliable information, he visits the Australian Cancer Survivorship Information Centre, a Richard Pratt legacy, collects the relevant information and delivers it to the patient. "It is always very well received."

And his personal definition of survivorship? "I view survivorship from diagnosis onwards; it doesn't make any sense otherwise. It means 'I'm living ... I'm not dead'."

## Further information and support:

### Peter MacCallum Cancer Centre

Survivorship and life after cancer resources

[Dealing with cancer-related fatigue](#)

[Questions you may wish to ask after treatment](#)

[Australian Cancer Survivorship Centre](#)

[Practical and Social Support Services for Survivors](#)

[Survivorship Care Plans](#)

[Livestrong](#)

[Survivorship Care Plan generator](#)

[Cancer Council Victoria](#)

[Cancer, work and you](#)

## Australian Cancer Survivorship Centre

A Richard Pratt Legacy



Locked Bag 1 A'Beckett Street, Melbourne VIC 8006

Email: [contactacsc@petermac.org](mailto:contactacsc@petermac.org)

[www.petermac.org/cancersurvivorship](http://www.petermac.org/cancersurvivorship)

