



a survivor's story

From the Australian Cancer Survivorship Centre



James Williams' story, as told by Meg Rynderman, a consumer representative for the Australian Cancer Survivorship Centre

October 2015

'Never good news'

James Williams

James Williams describes himself as a 'blackfella'. He is a proud 54-year-old Waka Waka man. He was born in Goreng Goreng country in South East Queensland near Bundaberg. He is one of seven children.

His parents, who recognised the power of education, encouraged James and his siblings.

"My Mum and Dad were poor blackfellas from the bush basically. They didn't have a very good education and not much opportunity and they said, 'Make sure you take advantage of all your talents and make the most of them'."

Following their advice, James has, for more than 30 years, explored his talents and skills up and down the east coast of Australia. He apprenticed and worked as a watchmaker, followed his musical talents in a successful band, trained as a chef and worked as an actor.

Along the way James married and fathered the three children who are the joy of his life.

He came to Melbourne about 10 years ago. While working for Melbourne Water, an opportunity arose to further his knowledge.

"I had an opportunity to go and study a lot of Aboriginal culture and heritage. I was sort of their

Aboriginal culture and heritage adviser, plus I worked with the traditional owners of the Melbourne area, the Boonwurrung, on their country, doing site surveys and stuff like that. So I'm now a Cert 4 in Aboriginal culture and heritage management." This complements his practical experience on country.

James' pride in his culture now connects with his professional skills. Self-taught initially, he has become the only Aboriginal computer engineer/IT manager in Australia.

His IT work ignited a desire to help young Indigenous community members learn and explore more about their traditional heritage. A position with the Catholic Education Office allowed James to pursue this aim.

"I was able to use technology to benefit my people. I was running a project where I bought 300 iPads for Koori kids right throughout Victoria. I was training them how to use them, and with other trainers and a lot of other Aboriginal community members to come in and tell stories and teach them about storytelling. I'm proud of my Aboriginal heritage and I believe it's very important to all Aboriginal people to be proud of their heritage and to not let it die off."

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Currently James travels the country, working with a very large not-for-profit organisation, supporting its remote Aboriginal community programs and IT systems.

I met James recently at Peter MacCallum Cancer Centre when he came to tell me his story – not just the story of his journey to assist his community, but also of his cancer journey.

Five years ago, in late 2009, James noticed changes in the way his body was functioning.

"I went to my medical centre and I'd been losing a lot of blood and I had to have blood tests. It was here in Melbourne at my local Aboriginal medical centre, The Gathering Place, in Maribyrnong.

"I liked going there because they were always very supportive. You go to an Aboriginal health service and you feel more comfortable because everyone there is Aboriginal. I'd feel almost as comfortable in a white surgery but it does make a



difference – you feel culturally safe, you know."

"I remember the oncologist saying 'I'm sorry, this is never good news. I'm sorry to tell you but you've got cancer'. And that's exactly how I felt – never good news. Actually, my first thoughts were 'Gee, I thought I'd die of a heart attack, I never thought I'd die of cancer'."

Rapidly admitted to Western Health Footscray Hospital, where he was diagnosed with metastatic colorectal cancer, James was scheduled for an operation to remove his sigmoid colon, to be followed by nine months of chemotherapy.

"I remember the oncologist saying 'I'm sorry, this is never good news. I'm sorry to tell you but you've got cancer'. And that's exactly how I felt – never good news. Actually, my first thoughts were 'Gee, I thought I'd die of a heart attack, I never thought I'd die of cancer'."

During his treatment James suffered side effects from the chemotherapy, including pins and needles in his hands and feet, which are only now dissipating. He says he was thankful that he'd made the decision to seek medical help.

"I'd actually done something about [my health] when the first symptoms came up. I did something about it fairly early, so I had a fairly good chance of surviving [the cancer] with the treatment. And I'd never really believed that, until after the first all clear, I thought, 'Wow, you can actually survive cancer'."

James slowly recovered and returned to work. He implemented the health messages he had learned during his experience.

"I've never had to worry about not eating properly, which is something

that they always stress to make sure that you have a good diet. But that was never a problem because that was why I became a chef.

"I tried to exercise and get fit for health reasons. I did cut down on drinking alcohol more, but I never really thought I'd get [cancer] again."

Following a number of clear scans, in 2012, James' doctors discovered spots on his liver and he was diagnosed with cancer, spread to the liver.

"When they told me I had cancer spots on my liver, I said, 'No, that's got to be wrong, you must be wrong, I don't believe you'. It was probably about a year or 18 months after. I couldn't believe it and I knew how bad it was the first time and then when they told me what they were going to do the second time I thought, 'My god, this is going to be twice as horrific as it was the first time' and sure enough it was!"

His preferred treatment involved a liver resection. He had two operations over a number of months to remove the affected liver, half at a time to allow regeneration, as well as a lengthy chemotherapy regime.

For James, the side effects and his reactions to treatment the second time were dramatic. He experienced anxiety, panic attacks, anger management problems and depression. He suffered panic attacks during treatment and his chemotherapy was modified as a result. These reactions continued for almost 12 months.

Leading up to and during this same period, James' relationship with his wife had been under enormous stress and his marriage finally ended.

"There's a lot that talks about stress as a cause of cancer and I had to put up with a lot of stress. I probably



could have handled it if I didn't have cancer, but because of the fact that I was suffering from panic attacks and depression ... it was because of the cancer treatment that I couldn't deal with it." James is now seeing a psychologist to assist him with his panic attacks and anger management issues.

During his treatment, while being aware of the side effects he was experiencing, James did not ask for help. "I probably should have, but I'm pretty stable and pretty happy. I think they all thought I was fine. I bought in the latest album from my band and I gave it to the oncology clinic and said, 'You need to play this, it will cheer you up'. So I think they all thought I was fantastic, I was fine, I didn't need any help."

James explained that he was a very private person and had not confided in many people about his cancer diagnoses.

"I was almost ashamed before to tell people that I had cancer. I'd only told a small number of people. It's silly, because there's no reason to be ashamed of it, because so many people are getting cancer these days, it's not unusual. I think if I was to try and think of something

it would be that I don't want to go and tell everyone that I've had cancer and have pity on me and feel sorry for me. I'm not like that. I don't want you to come and help me, I'm the kind of person to come and help you. And that's what I'm like. That's why I work for the organisation that I work for, because I want to help people."

"I don't want to hide any more. I'm happy to be on a brochure that says I'm a survivor because I think I'm encouraging people, I'm telling people, 'You can survive and there is hope'"

His children were too young to understand what was happening: they knew he was sick but didn't understand the implications of the cancer.

James had a limited social network and family were far away. "I had no one. I just dealt with it by myself. Would have been a lot easier for me if I'd been home where my Mum is at least. My Dad's passed away, but I've got brothers and sisters and cousins and nieces and nephews. I've got a family there.

"I don't like talking on the phone or over email. I like talking face to face. You can have a better conversation, I think."

With little additional support, he managed his surgeries and other treatment, his side effects, his inability to work consistently and the subsequent financial difficulties that often go hand in hand with cancer treatment.

He did, however, contact 13 11 20 Cancer Council Information & Support, who helped him with financial advice and assistance. Subsequently he has confided in a number of his work colleagues and a member of his band.

His attitude to his cancer experience has changed with time.

"I don't want to hide any more. I'm happy to be on a brochure that says I'm a survivor because I think I'm encouraging people, I'm telling people, 'You can survive and there is hope'. And that's probably my main motivation. I wouldn't have told anyone before, but I don't care about telling anyone now because I see that there's a positive outcome for me telling everyone."

James talked about encountering ingrained attitudes towards his Aboriginality – in workplaces and from people in authority. But, during his cancer journey he has felt a shift. Many hospitals employ Aboriginal liaison officers to assist Indigenous patients through a system that is often complicated and difficult to negotiate.

"There was an Aboriginal liaison officer at the hospital. I was referred to them and did speak to them, but only the once. It was very good to speak to an Aboriginal person, I think for a lot of Aboriginal people in hospital they would be extremely important."

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He has strong views about cancer in our society and the need for healthy lifestyle messages.

"It's a modern society disease and we all live in modern society (now), Aboriginal people as well. In some instances it's a lot harder for them. I'm talking about Aboriginal people because they've got this whole different life to what a white person would have.

"It's a humanity problem – it doesn't matter if you're black or white. But you need to try twice as hard with the Indigenous community; it needs twice as much work because they're so disadvantaged. There are those things that affect Aboriginal people that don't affect the rest. These could be things that are causing cancer. And that may impact on health."

"I know that once you start hitting 45, 50, you need to keep looking after your health a bit better. So I think I was lucky that from 45 I started to go and get regular checkups"

James stresses that other men can learn from his experience – to be aware of and not ignore changes in their bodies

"I know that once you start hitting 45, 50, you need to keep looking after your health a bit better. So I think I was lucky that from 45 I started to go and get regular checkups. I think that is a problem with particularly men who get stage 4 cancer or they're diagnosed with something bad. They've probably had a problem for years and they

haven't done anything about it – just ignored it."

Footnote: James has two unfulfilled ambitions – to obtain his pilot's licence and, having worked on state and federal Aboriginal and Torres Strait Islander policies, to run for election in state politics.

Further information:

How we can help you - Victorian Aboriginal Communities

<http://www.cancervic.org.au/how-we-can-help/victorian-aboriginal-communities>

Living with cancer - telling a child

<http://www.cancervic.org.au/living-with-cancer/telling-a-child>



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A Richard Pratt Legacy



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