



A survivor's story

From the Australian Cancer Survivorship Centre

Alison Button-Sloan's story, as told by Meg Rynderman, a consumer representative for the Australian Cancer Survivorship Centre

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"We are Australia's cancer"

Alison Button-Sloan is a health professional who became a patient. Alison, who trained as a midwife and is currently working as a practice nurse, has converted her experience with melanoma into a crusade to help others.

A diagnosis of suspected cancer led Alison from her GP to a dermatologist, and the rollercoaster of surgery and pathology familiar to many. Results revealed a large primary nodular melanoma and surgery was hastily arranged to remove it and tissue surrounding it.

Melanoma is a type of skin cancer that can occur on parts of the body overexposed to the sun. It is the third most common cancer diagnosed in Australia and is more likely to affect women than men.

Alison reflects on the confusion and speed with which events occurred: "I was angry at being caught in a situation as a patient, as a health professional now turned patient, where things were happening around me and I didn't have any information and I was making decisions."

She was anxious for her husband and her children. "I'm thinking 'Oh my God, these stats, I'm going to be dead in a couple of years, he'll be left on his own, what about my children?' It was just a whole gamut of emotions, all these thoughts start escalating."

Living in Brisbane at the time of diagnosis, Alison decided to have her post-treatment check-ups at the Melanoma Institute of

Australia in Sydney. She moved with her family to Melbourne the following year but travelled to Sydney regularly over the next five years for subsequent follow-up visits, ultrasounds and CT/PET scans.

Over that period Alison spent much of her time learning about melanoma and what was available for those with melanoma undergoing treatment.

"Knowledge is protection"

"My way of coping was to read and to gain knowledge. Knowledge is protection and once you know that there is something better out there or you know how things work, you can then have a reason to agitate for it."

She discovered Melanoma Patients Australia (MPA), established in Brisbane in 2006, and along with another patient set up a small group in Melbourne. She began an ongoing journey with MPA, which sees her currently volunteering in a variety of roles as an educator, advocate and vocal supporter for all those diagnosed with melanoma. She sits on numerous committees, boards and reference groups and is sought out as an inspirational



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speaker and individual support. She describes herself as an activist and an advocate.

"I guess I've become a go-to person with the knowledge and a greater awareness of the cancer community and the cancer system that patients need to navigate."

Australia and New Zealand have the highest rates of melanoma in the world

Alison bemoans the inequity of funding around different cancers, lamenting the lack of services and support for people with melanoma, despite it affecting many thousands of Australians each year.

She reflects "We are Australia's cancer."

Australia and New Zealand have the highest rates of melanoma in the world; in Australia, **over 15 000 people are diagnosed** each year and **more than 1700 people die** from melanoma.

"We are Australia's cancer"



Alison feels that there is often a lack of understanding of melanoma, frequently hearing: "After all, it's only skin cancer and it's cut out and its gone." As a result she has developed a personal philosophy around improving the journey for other patients.

For those newly diagnosed, she emphasises:

-  finding a trusted GP
-  searching for information
-  finding the confidence to ask questions
-  seeking support
-  finding ways to deal with the fear about cancer coming back.

Not all of these are instantly achievable, Alison acknowledges. "There are supports, but it's hard, you don't know where to look. You're dealing with a life-threatening illness. Nearly every cancer has surgery, so you've got recovery, then you've got drugs or radiation coming on top of that. You're dealing with all of that and all the family stuff, you're off work, there's money, there's the finances – you haven't got time to think".

Information and support, in her opinion, are the key to better understanding for both patients and their families. "Get yourself educated, find a good GP that you trust – knowledge is protection because that gives you the information to discuss things intelligently and to be able to make better informed treatment decisions if you have some knowledge".

Sharing information and peer support is essential, Alison says. "You need to talk

about it – give them [patients and their families] resources they could read; there are a number available."

Alison has developed routines to manage the stresses surrounding follow-up appointments.

"The best thing you can do is write your questions down before you see the doctor and these days take a recording, ask them first, and record the consultation. Because that way you don't have to concentrate so intently on what they're saying to you, you can let the conversation flow more naturally.

"Don't be frightened to seek a second opinion: they are really common, the doctors don't mind, they understand."

It is during a discussion around fear of her cancer coming back that she becomes most passionate, explaining that "those ruminating thoughts can start to interfere with your quality of life, and you need help to think of strategies to overcome those".

"Get yourself educated, find a good GP that you trust"

"Talk to the doctor and say, 'I'm really worried about this coming back and I can't get it out of my head' and depending on who they're seeing, the GP might be able to give them a mental health care plan to a psychologist for up to 10 visits per calendar year or you can go with a GP management care plan for five a year or if they're in a big hospital like Peter Mac they can be referred to the psychology department.

"One thing I've found [worthwhile] is doing something that takes you out of yourself. So, when you're helping other people, or you're going to work, there's the distraction of work, there's the distraction of going out with your friends. I've found that eventually that distraction takes over and the thoughts diminish; they may come



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back, often they do, but I've learned that by mixing with people and not totally cutting myself off that's a good strategy."

Alison does not use the term "survivor" for herself. "I don't say I've survived cancer, because I don't know whether it's going to come back. Melanoma is sneaky and unpredictable. I'm just trying to get on with my life."

"I have to be positive, too. You know I have a 25% chance that it will come back, [but] that gives me a 75% chance that it won't. So, I have to do things and get on with life, otherwise I'll be stuck in a rut and I won't be able to move forward."

"I don't say I've survived cancer, because I don't know whether it's going to come back"

She speaks with pride of her family: their support and their knowledge of melanoma, acquired through her experiences. "They're very sunsmart now, almost paranoid! I don't mind paranoia when it comes to sun safety behaviours."



Resources

- **Australian Cancer Survivorship Centre**
www.petermac.org/cancersurvivorship
- **Common Survivorship Issues Directory**
<https://www.petermac.org/survdirect>
- **Cancer Council 13 11 20**
This service can answer any questions you have about cancer and surviving cancer.
- **What to expect, Melanoma**
<https://www.cancer.org.au/about-cancer/cancer-pathways-what-to-expect.html>
- **About Melanoma**
<https://www.cancer.org.au/about-cancer/types-of-cancer/skin-cancer/melanoma.html>
- **Melanoma Patients Australia**
<https://melanomapatients.org.au/>
- **National Melanoma Support Line**
1300 884 450
- **Melanoma Institute Australia**
<https://www.melanoma.org.au/>

