

**A summary of @MarieMcInerney's Twitter thread from a presentation by Lyn Swinburne at #GiantThreads19. How one person can change the world**

**This nine-page compilation was produced for Croakey News, November 2019.**

First keynote for Day 2 [#GiantSteps](#) is Lyn Swinburne, founder [@BCNAPinkLady](#) and [@thewomens](#) Board Chair on: How one person can change the world. She was [honoured](#) with AO in 2019 Australia Day Awards





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“My overriding fear was that I was not going to be there when my kids grow up.” Lyn Swinburne on being sideswiped with cancer when she least expected it. Remembers being told her tests were positive and thinking ‘isn’t that a good thing?’ [#GiantSteps19](#)



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For a start I was lucky: in a metro hospital, English speaking "but it was still excruciatingly difficult. Imagine if I was a single mum in a high rise flat, or a widow on her own, or imagine if I couldn't speak the language (of oncology & English)." Lyn Swinburne [#GiantSteps19](#)

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Lyn Swinburne began to amplify issues for women through the Breast cancer Network Australia newsletter: "pretty grassroots-y. Important though because women needed to talk about their issues and how they got through them." [#GiantSteps19](#)

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Then we started to get a bit "antsy, bit problematic", so were going to lose funding. Were offered one last conference, "the first ever for women with breast cancer, there's been plenty for doctors and scientists": Lyn Swinburne [#GiantSteps19](#)

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Lyn Swinburne didn't even know if people would come. "They came and they came and they came," she remembers. Once women had permission to tell their stories, they told them." [#GiantSteps19](#)

1998 – 1<sup>st</sup> National Breast Cancer  
Conference for Women, Canberra



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It wasn't just saying women are unhappy, they had to vote on what was important for them: the number one thing they wanted was breast care nurses to help women navigate the system, with advocacy and support: Lyn Swinburne on the 1st women's breast cancer conf [#GiantSteps19](#)

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Women began to work with researchers and other organisations, put their own issues on the agenda for breast cancer research. Longterm issues, including relationships, physical, emotional and financial issues: Lyn Swinburne [#GiantSteps19](#)

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"As time went on we found better ways to reach women across Australia who had been diagnosed, incl an online presence for women who needed to reach out at 2am in the morning." Lyn Swinburne [#GiantSteps19](#)

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These visions went around the world, became a very powerful message - because on the MCG, also got message to men about how to support their partners: Lyn Swinburn [#GiantSteps19](#)



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Lyn Swinburn led a strong movement from an advocacy group trying to change the system, now also provide services to women with breast cancer across the country. Big question:

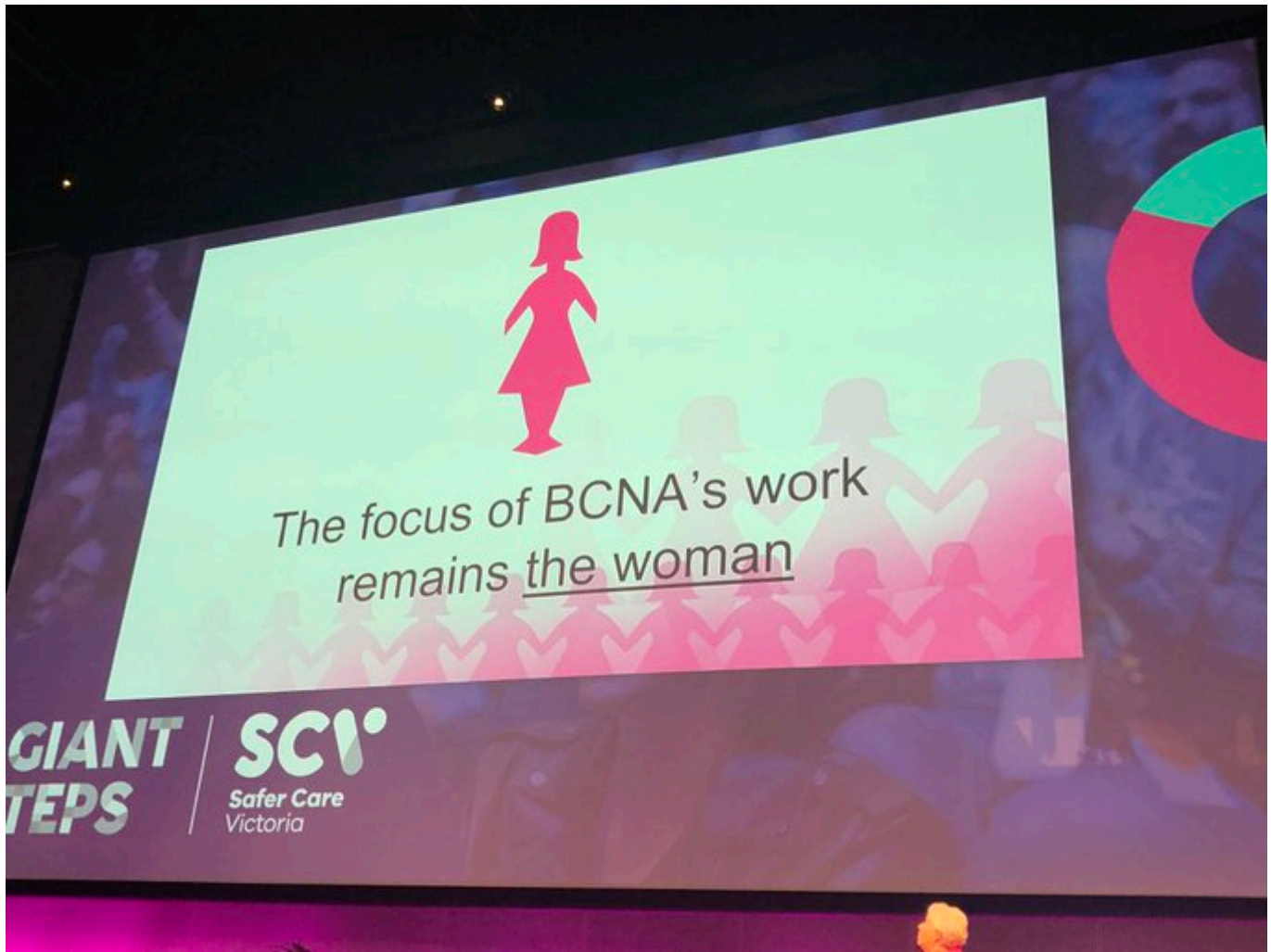
“what does this mean for the woman?” [#GiantSteps19](#)

[@BCNAPinkLady](#)

## **BCNA Now**

- 130,000+ Members
- 300+ Member Groups
- A strong, influential and respected national organisation
- Provides direct services and programs to women with breast cancer and their families
- A trusted source of independent information.

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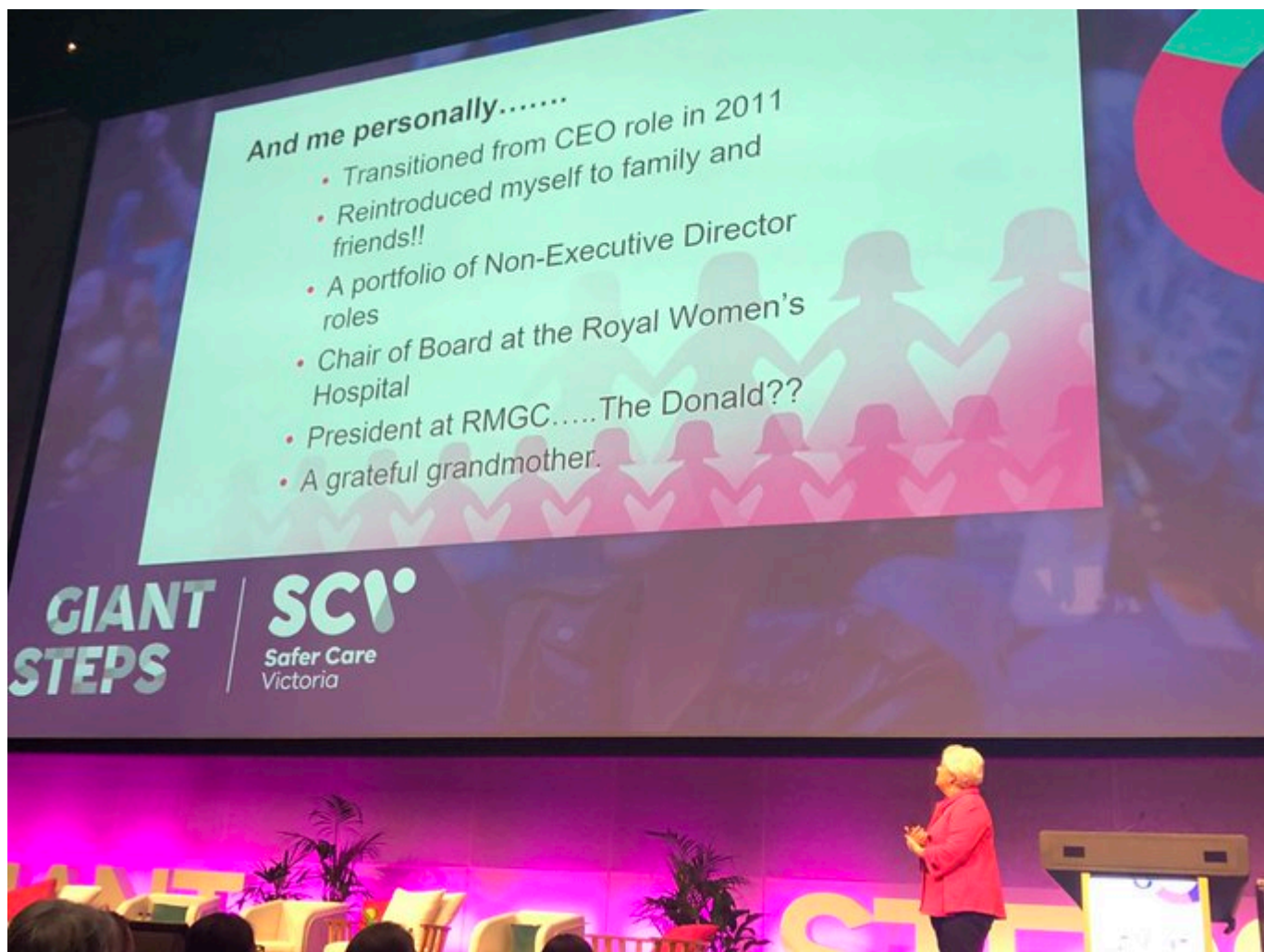


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But it also has a toll to undertake such advocacy: Lyn Swinburn says she has spoken at too many funerals, farewelling people who have worked with her on breast cancer work

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Lyn Swinburn had thought it would be easy to make change in breast cancer advocacy, to say "hey, it's not best to tell me my diagnosis at work on the phone when I'm supervising children at the morning break." Long journey, but now she is chair of board at

[@thewomens](#)

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"I'm now a very grateful grandmother", Lyn Swinburn recalls her fear she would not be around as her children grew up after breast cancer diagnosis. "That phone call totally changed my life," she says on her legacy of building

[@BCNAPinkLady](#) Lyn Swinburne pays tribute to women who helped with [@BCNAPinkLady](#) work to change the system, as they were dying [#GiantSteps19](#)

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Sometimes relied on being "ballsy and angry" other times on being "charming and nice": Lyn Swinburn's lessons on advocacy [#GiantSteps19](#)

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Q: how manage the fear. Lyn Swinburn remembers urge to make quick decisions - "get this breast off". Doctor presented options. Urges clinicians 1. acknowledge fear 2. present the evidence/options clearly. "You don't want fear to be driving your clinical decisions".

[#GiantSteps19](#)

