

Te Aho o Te Kahu’s Disability and Cancer Project is supported by three Lived Experience Advisors. The Agency appointed Amr, Dairne and Wendi through an external Expressions of Interest process in 2023.

Their knowledge, connections, and experiences, along with research and data matching, is building a stronger view of the inequities and barriers within the cancer system affecting disabled people with cancer.

Wendi, Amr and Dairne spoke to one of the Agency’s kaimahi | staff, Tommy Livingston, who wrote up their experiences and why they applied to join this project. All three articles are available on Te Aho o Te Kahu website project page at [www. teaho.govt.nz/reports/our-projects/disability](https://teaho.govt.nz/reports/our-projects/disability). You can read Wendi’s one below.

**Wendi – Lived Experience Advisor for the Disability and Cancer Project**

Wendi Wicks has dedicated her life to advocating for people who live with a disability.

Her own life changed when she was diagnosed with a brain tumour in her early 30s. The diagnosis left Wendi with multiple disabilities.

“At the time the cancer system was less accessible with few resources or support to help people in my position. I seemed okay but there were gaps - like work.”

A trained radiographer, Wendi was unable to continue with her work following the diagnosis. She decided to retrain as a social worker.

“I looked for some other things I could do that would use my brain and my skills. I ended up doing a social work degree, then a Masters and from there I moved into disability policy via employment equity. So many disability issues needed attention.

“I worked for a disabled persons organisation that was focused on advocacy. It often involved representing disability to government departments, ministers, and anybody else who could benefit from listening.”

In 2021, Wendi was again diagnosed with cancer – this time the tumour was in her breast.

The cancer in her breast was picked up during a routine mammogram. Because the cancer was detected early, the outlook is a lot better.

“The experience of the health care system this time around was different. Not everything was perfect, but things were explained to me in a straight-forward way, and where there were options, the pluses and minuses were explained.

“Despite pandemic lockdowns I got timely treatment and support. I was lucky, so many others hit barriers of various kinds.”

It was these experiences that drew Wendi to want to work alongside Te Aho o Te Kahu to improve the experience of disabled people in the cancer system.

“Having heard so many stories from other people in the disability community - and knowing what it is like from the inside – I thought I had something to offer.

“I have a very strong sense of giving back to a disability community that has given me so much. There’s a lot of disability discrimination built into the system so it is incredibly important we try to ensure we make improvements for disabled people where we can.”

“Disabled people make up 25 percent of the population – right now I do not think we are fairly represented or looked after. The disability-cancer project is so useful for the wider community.”

Wendi has some simple advice for disabled people trying to navigate the cancer system – don’t do it alone.

Taking someone along to listen and take notes can make a big difference.

“I regretted that I did not always have people surrounding me when I went through my breast cancer treatment. It is a very useful thing to have.

“My cancer outlook is promising, so if my work with this project improves the outlook for other disabled people, I will be pleased to have been part of the enterprise.”

For more information about this work please email the Agency at info@teaho.govt.nz.