

# CATHERINE'S NDIS JOURNEY

On an icy August afternoon in Melbourne I sat down over a cuppa with my sister Catherine to discuss her experience of the NDIS. Catherine lives in the eastern suburbs of Melbourne. Until recently she lived with her son. Her son has moved out and Catherine now shares her home with her cat, Misty.

Catherine likes where she lives: "I like living here because it's nice and quiet. It's close to transport and doctors. My neighbours are nice and they help me if I ask them. Like the other day I asked a man from down the road to help me pull out some conifers".

Catherine works as an Easy English Consultant at Scope Australia and recently was awarded the Scope Quarterly 'Doing it right' Award for this work. She was also a member of the team who took out the prestigious Victorian Disability Excellence in employment outcome award for 2018.

When Catherine found out about the NDIS back in 2017 she was very excited. In November 2017, Catherine and her sister Sharon began investigating her eligibility for the scheme. Catherine and Sharon completed the paperwork together and Sharon sent it off to the NDIS in Canberra for consideration. Catherine described the process of ascertaining her eligibility for the NDIS. "Sharon helped me with all the paperwork. There were so many bits of paper and it took a long time to fill them all out. I had to give so much information and it was hard to work out what they wanted to know. Some of the questions were really hard to understand. If it wasn't for Sharon, I wouldn't have understood what the questions were. I wouldn't have had any hope. If people like me didn't have someone to help them, I reckon they would give up".

In January 2017, Catherine received notification that she was eligible for NDIS funding. This was great news for Catherine and our family. However we were in the dark as to how this new system of funded support was going to work. Collectively, our family has had decades of experience providing or receiving disability support services. Despite this familiarity with the system, we were anxious about what lay ahead. Catherine described how she felt once she received notification that she was eligible. "I was really relieved. I could do some things that I wanted to do. But I felt anxious, because it was all so unknown and new to everyone. I wanted things to change straight away".

In late January, Catherine had her first planning meeting with her Local Area Coordinator (LAC). Sharon and I went with her. Catherine's planner, gave us a lot of time and tried her best to answer our many questions. I thought she was very helpful. Catherine described how she found the meeting.

"I was a bit flustered. I didn't understand what was happening. She used such big words and it's really hard to understand. When people talk like that, I get flustered, I can't understand and then I just give up. Not everything was clear, so it helped to have Sharon and you [Jo] there".

During the planning meeting we discussed the pros and cons of self-management. Catherine decided that self-management wasn't for her.

Once Catherine's plan was approved it was time to put it in place. This was daunting for us all, especially Catherine. "I didn't know what I was supposed to do. Who to ring? How to get started?" Despite Catherine having opted out of self-management, there was no funding allocated in her plan for service coordination. This was problematic as Catherine needed support to make her plan a reality. We as a family soon became overwhelmed, finding that we didn't have the time and ability to take on the responsibility of coordinating Catherine's plan. Catherine felt like she had been given a gift but didn't know how to open it. "I felt like I just wanted to give it back".

Catherine and I applied for a review of her plan and as a consequence three months later her plan was amended to include funding allocation for service coordination to be provided by her service provider. Catherine's plan has been in place for approximately four months. She has begun working with her service provider to achieve her goals. These goals include improving her independence at home and in the community, improving her physical and mental health and furthering her education.

Catherine has joined a social group which she enjoys. Her needs have been assessed by an Occupational Therapist, and she now has some assistive technology to assist her in the kitchen. The travel allowance Catherine receives through the NDIS allows her to go out in the evening with family and friends, expanding her opportunities to socialise and strengthen her friendship circle.

One of Catherine's main goals is to develop her computer literacy skills. "Computers are the way of the world, and it is the way everything is going. Everyone is always doing things on them with their friends and family. I feel left out and left behind". Catherine has had a computer assessment through her package, however, is yet to have any lessons accessing the computer. "I really want to learn how to use the computer, and we made sure that was in my plan didn't we? But there's nothing happening. I'd really like to learn how to use the computer". Catherine has tried contacting her service coordinator to discuss this with him, however he is yet to return her call.



*Catherine (left) and her sisters, Sharon (middle) and Jo (right)*

Although Catherine's service provider has been allocated funding for service coordination she is yet to hear from her service coordinator. "I felt really happy that I was given a support coordinator, but I've heard nothing from him. So I don't know whether I'm Arthur or Martha. I want to give up again. What's the point of it all if I don't know what's going on? I feel like I had been swept under the carpet to work it all out by myself".

Catherine's NDIS journey has had its ups and downs. As our third cup of tea began to disappear from our cup, I asked Catherine what key message she would like to give the NDIA and her service provider. "I wish people would just communicate with me so I can understand what's going on". I share Catherine's frustrations. Although, I can see that the NDIS has provided Catherine with some wonderful new opportunities, without consistent and responsive service coordination, I can't see her goals being achieved.

**by Joanne Watson and her sister  
Catherine Catarinch**

### **OUR TIPS FOR THE NDIS AND THOSE PROVIDING SERVICES TO NDIS PARTICIPANTS**

- Keep working on making the NDIS system easy to understand. Catherine says: "It is very complicated at the moment. Sometimes I don't know if I am Arthur or Martha"
- Communicate to participants in a timely and responsive way. Catherine says: "Why does it always take so long for someone to get back to me?"
- Build the capacity of service coordinators. Catherine says: "I don't know what the service coordinators job is, I have never heard from them".