

Linda's NDIS story

"We just don't fit into their square boxes!"

Linda lives with fatigue and hearing loss caused by mitochondrial disease. She lives with her adult children and her husband in NSW and works part time.

When Linda needed new hearing aids, she applied for access to the NDIS. Her first plan came back with funding for allied health therapies and other supports that Linda has not asked for, but didn't include funding for hearing aids! After two reviews, Linda now has a plan that has improved her wellbeing and allows her to be more present and involved in the day to day lives of her family.

Some of the supports Linda receives through the NDIS are:

- Exercise physiology and boxing
- Support around the house, including cleaning and home maintenance
- Hearing aids and other supports relating to her hearing loss

Linda self-manages her plan. This gives her maximum flexibility, but also means she has needed to learn about the sometimes confusing terminology and funding rules.

Linda did find it difficult to think of herself as having a disability. "Having to focus on all the things I used to be able to do that I couldn't do anymore did bring up my grief around having mito. But I also think it helped me to accept some of my challenges. Learning how to get the supports I needed was empowering."

We asked Linda what she's learnt that might help others in the mito community to navigate the NDIS.

"When preparing for your planning meeting, write a list of everything that could help you. Make sure each of these is backed up by a report from a professional. I particularly had to explain the impact of fatigue on my day to day life, as the decision makers were not familiar with mito.

To get the best outcome, you will need to advocate for yourself right from the beginning. I had to ask for a new local area coordinator (LAC) to get one that 'got it' – this LAC understood my situation and my need for support. But even with a great LAC, I had to be persistent."