Tasmanian grandfather finds support for rare condition through NDIS

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For Tasmanian grandfather Tim Howard, his diagnosis of Spinocerebellar Ataxia Type 6, or SCA6, was very difficult to deal with.

After 58 years of living a very active lifestyle from playing AFL and running or riding his bike to and from work, Tim and his wife Fiona had no idea what was to come as his SCA6 progressed.

“I think Tim is one of one or two people with SCA6 in Tasmania but we’re unsure of the exact figure because there’s no local support group. We know it’s very rare,” Fiona said.

SCA6 is a hereditary neurological condition that slowly progresses. Tim experiences difficulty in his mobility, uncontrollable shakes, slurred speech and epileptic seizures.

“Tim’s diagnosis was a very difficult situation for us because no one knew anything about it and it was especially hard to find information here in Tasmania,” Fiona said.

“We went online just to get some information and we understood the basic medical background for it but we weren’t fully aware of how it was going to progress.”

What helped them was joining online support groups for people living with SCA6.

“From what we read, there was a high chance that Tim was going to be permanently using a wheelchair,” Fiona said.

“As time went on, Tim got worse and worse to a point where he couldn’t walk without an aide. We then became aware of the NDIS.”

“The NDIS has been great,” Tim said.

“Before I used to use a walker to get around but it was very tiring. I would need to take a lot of breaks.”

Tim now uses his NDIS supports for assistive technology, home modifications, physiotherapy, speech therapy and occupational therapy specialising in neurological conditions.

“The NDIS has put in a stair lift in our house so Tim can get on there with his power chair to actually leave the house. The NDIS also helped us level our house so Tim could move around his own backyard,” Fiona said.

“We feel very fortunate because we speak to other people living with SCA6 around the world and they get nothing compared to us. We are so grateful to be living where we are. Since joining the NDIS, we’ve been full steam ahead.”

For Tim, the best thing about the NDIS is he now has the freedom to just do things, like go to Bunnings.

“Tim loves going to Bunnings. It’s so easy for him now. Before he was slow but since we got a motorised wheelchair from the NDIS, he just goes and I lose him for half an hour because he is just enjoying himself!” Fiona said.
With three sons, five granddaughters and another grandchild on the way, Tim and Fiona can focus on living how they want to.

“Now we can do what Tim loves to do whether it’s fishing, being with his family or doing some travel.

None of this would have been possible if it wasn’t for the NDIS,” Fiona said.

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