Ben's Fragile X journey

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There's a sense of relief in Jo Ryan's voice when she talks about her son, Ben, 25, and how he's playing golf, going to the gym, swimming and meeting people in his own community thanks to the NDIS.

"It's a completely new world for us," the Tasmanian mum said, still mesmerised her son, who has Fragile X Syndrome (FXS) is achieving all this without her.

FXS is a genetic condition causing intellectual disability, behavioural and learning issues and people born with it have various physical characteristics.

According to the Fragile X Association of Australia, it's also the most common single gene cause of autism worldwide and it appears in people no matter what nationality.

"Now Ben is a NDIS participant we've been able to tailor his supports to best suit his needs," Jo said. "It's something I feel like I've lobbied for forever and it's something I didn't think I'd see in my lifetime but I'm just so glad it's here.

"Ben's never been able to go to the gym or play any type of sport. I remember a few years back I tried to get him into a gym but they wouldn't accept him knowing he had to have someone with him every minute but thanks to the NDIS that's all changed.

"Now Ben has joined a gym; he's swimming and he's joined the local golf club where his amazing and very patient carer has taught him how to play golf. It's great. He's meeting new people every day in our community, even one's I don't know!" Jo added with a laugh.

"He's out and about five days a week doing great things and we're not stuck at home together for days on end. It's just been an incredible change for both of us," she adds.

"I think the NDIS has really opened up the community's eyes. Places, like the golf club, are more accepting and they understand Ben needs a carer with him at all times, and even though he has a disability they can see he has other valuable attributes and abilities to offer.

"The NDIS has been great for me too," Jo said. "I've returned to work two days a week at Newstead College. I enjoy my job and it's good for me. I've just joined the gym and I'm able to go when Ben's out and about.

"We're also enjoying each other more because we're not in each other's face all the time," Jo said with a laugh. "Our home is so much happier."



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