



TWO

OF US

STORY AND PHOTOGRAPH BY Rosamund Burton

Ned Travers, 16, has suffered from severe epilepsy since he was 12. In 2014, he moved with his mother Carolyn Travers, 55, from Sydney to Tuscany. The same year they walked an old pilgrim route, which was his path to better health.

CAROLYN: Just before his 12th birthday, Ned was on a school excursion. The principal rang to say he'd had an epileptic seizure. I met him in the ambulance. He spoke like he'd had a stroke. Four days later, I was outside the school gate. I saw everyone running and knew Ned had had another one. I found him on the ground.

He has a rare condition called congenital bilateral perisylvian syndrome. The medical team put him on six drugs, twice a day. He was having 10 seizures a day, so couldn't go to school. I decided life needed to change, so in 2014 we bought this 300-year-old barn near Lucca in Tuscany. Ned and I live here full-time with my daughter, who's at university in Florence. My husband and oldest son come and go from Australia.

I'm an outdoor person, so I thought walking the 400-kilometre Via Francigena pilgrim route from Lucca to Rome would be great, because Ned could do that and we could go slowly. We started in November 2014 and it took us 30 days.

On the first day we ended up in an ambulance, because he had a seizure and fell. He was having 10 seizures a day when we set off, but by

the end he was only having them when he ate and drank. He became fit very quickly and walked so fast, which inspired me, because he was sporty before he got sick. He also became interested in life again. I felt I had lost the Ned I knew – and now I was getting him back.

After we finished the walk, I found an Italian doctor. He said, "It's better to live a great life with a few seizures than to have no life due to drugs." Now Ned is on half the medication he was on previously. He's made an amazing transition. He goes to the local school and he's slowly learning Italian.

Ned's a very gentle soul. He wants to be friends with everyone. When he was younger, he was always so happy, and he's retained that. I admire his resilience. When he wakes up after being unconscious, surrounded by people, he doesn't feel embarrassed or sorry for himself.

With the epilepsy and the brain syndrome come learning difficulties. It takes him a long time to get ready, and he doesn't understand personal space, which upsets some people. Also, if he's having a great time, he'll clap. He comes home from school and says, "I embarrassed

myself today, Mum. I started clapping." I would like him to be sportier, but he loves music and comedy. He lip-syncs to all the latest songs on the radio and adores comedian Dave Hughes.

If I play tennis I leave him for an hour, otherwise we're always together. Last August we did a 178-kilometre walk through the hills around Florence, and because I've started a walking business, we did many day walks to perfect the itineraries. Since then, Ned's moved up a class and started Scouts, and now catches the school bus, which he wasn't able to do earlier this year.

He struggles with friends because they often don't get him, but he's got a family who absolutely adore him and he's got a life now.

NED: Walking with my mum was strange at first, but I got used to it. We didn't fight at all, which was good, considering we were stuck with each other for a month. Me and Mum have always been close. I'm the youngest.

I got to experience new things, a new language, and waking up to Franciscan friars. We stayed in monasteries and saw some beautiful places. Every night when we checked in to our monastery, I'd change into my pyjamas and lie on my bed. It would be completely silent, then Mum would say, "I can't wait until tomorrow."

The walking was tiring for the first four days. The first day was a shocker. We were walking 19 kilometres and were about half way when I came up with a really bad idea. I said, "Why don't we run one kilometre and walk five?" So I started running. Mum thought it was a joke, but I kept running, so she started running. I had my kilometre done when my epilepsy started to kick in. I fell over and had a seizure at the side of the road.

Mum was screaming, "Ned, Ned, Ned." She ran over and sat next to me. All the cars stopped. Mum didn't have enough Italian to explain what was going on and no one spoke English. But they all had a friend who spoke a little bit of English, so each person rang their friend to try to translate, and the friends called their friends who spoke better English. Then the ambulance came, and I was put in it. I was feeling fine by this time and Mum was sitting in the ambulance trying not to laugh. We both know because we've been in this situation a lot: a seizure happens and then five minutes later I, like, reboot.

The more I walked, the less I had seizures. I didn't train. I literally got off the couch; I was watching movies non-stop. I really was fit by the end. I hope I've kept that fitness. Before this illness I was extremely energetic and sporty. I was playing rugby and tennis. My face was getting red from running, not passing out. It was great.

Moving to Italy was big for me, but I didn't want to complain too much. I wanted to stay in Sydney, because of my friends there, but I knew I couldn't. Now I really like Italy.

I would describe my Mum as caring, energetic, enthusiastic and funny. She is one of those people who always tries to put you into groups that you don't want to be part of. She's always trying to involve me in sports activities that I don't really like. Before the epilepsy I once said I didn't like karate and Mum put me in karate classes. She's just waiting for that one activity that I say, "I love this." Mum's great. Mum being Mum makes me laugh. ■

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