Nursing student and Anorexia Nervosa Genetics Initiative (ANGI) research study participant, Lili, 20, Canberra, developed disordered eating habits at 12 years of age.

Three and a half years later she was diagnosed with anorexia nervosa – an illness Lili describes as “a constant scream in your head that sucks all the fun out of life”.

At her mother’s suggestion, Lili enrolled in the ANGI study to help researchers detect genetic variations that may play a role in the illness that affects 25,000 Australians, to which she refers as a “living hell”.

Over the past five years, Lili has lost count of how many times she has been hospitalised from anorexia nervosa.

Prior to her diagnosis, Lili experienced periods of heightened anxiety, until at 15 years of age, she went through a stage of anger and denial.

“At 15 I reached a point where there was no relief from the anxiety and disordered thoughts and behaviours, which led to a lot of conflict over food not only within myself, but also with my parents. I was also in denial about the situation, which resulted in my parents intervening.”

Observing their daughter in this condition, Lili’s parents arranged for her to visit a psychologist.

“When my parents took me to see the psychologist, I refused to talk to her,” said Lili.

“That summer, my parents watched me deteriorate and eventually they took me to an eating disorders clinic in Canberra.”

Lili saw both a psychologist and an eating disorders doctor at the clinic and was diagnosed with anorexia nervosa and provided some treatment options.

“The treatment at the clinic was all forced, and I didn’t want to do any of it.

“I tried a day clinic a couple of times, but that didn’t really work. Over the next few years, I ended up having to visit the hospital a lot. I’ve lost count of how many times I was in and out of hospital,” Lili said.

As part of her treatment, Lili was placed on a Psychiatric Treatment Order (PTO), which required her to attend clinics and undergo treatment in Sydney.
Lili’s illness has compromised her relationships with family and friends, and continues to control her daily activities.

“My whole day focuses around my illness,” said Lili.

“Every morning when I wake up, the first thing I have to do is go on a walk. Whether rain, hail or shine, I’ll be out there.

“Every day my whole mindset focuses around what I can and can’t eat throughout the day, even though I don’t want it to,” Lili said.

“Often what I allow myself to eat is not what I actually want, but something in my head tells me what’s okay.

“I get anxiety around the thought of sitting, not going to the gym or eating too many calories in a day,” said Lili.

“I think when people talk about the physical symptoms of anorexia nervosa, they tend to reel off a list of things they think should be happening to them.

“Physically, I do experience some things regularly. I tend to feel tired all the time, although I’m not sure whether that’s because of the anorexia nervosa or because I don’t get enough sleep,” Lili said.

“My weight fluctuates a lot, and I’m often cold. It drives my family crazy in summer when I want the heater turned on.”

Finding it difficult to break routine, Lilli struggles with a willingness to “put in the hard work” to overcome her illness.

“Emotionally, the struggle I really have is whether or not to put in the hard work, as people tell me there will be a good outcome at the end, or whether to just give in to my illness.

“I feel guilty a lot of the time about what I put my family through,” said Lili.

Lili is not in a period of recovery. To the contrary, Lili explains: “Right now, I would say I’m going backwards than forwards in my recovery.

“I’m currently experiencing a lot of anxiety around food and eating,” Lili said.

“It’s hard. Because I’ve been sick for so long, my family has adapted to my situation. They work really hard to help me. Mum and dad especially go to great lengths to help me recover.

“I want their help, but at the same time, I don’t. They have put up with a lot more from me than they should have to,” said Lili.

“The illness has become a part of who I am, and I don’t know if I’d know myself without it.”

Lili hopes her contribution to the ANGI research study will help researchers identify preventative treatments and ultimately, a cure, for anorexia nervosa, to ensure others don’t have to experience the devastating illness.

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For more information, or to coordinate an interview with Lili, please contact Kirsten Bruce, Mark Henderson or Claire Wright from VIVA! Communications on 0401 717 566 / 0431 465 004 / 0467 415 617.