

'It feels like you're

Amy Hill is a successful professional with a husband and two sons. She is effervescent and outgoing, with a million-watt smile.

She seems like the type of person who makes friends wherever she goes.

Yet at night, as her family sleeps, Hill spends hours wandering the house "like a little ghost" counting switches and checking everything is turned off. She feels something bad will happen if she doesn't complete these rituals.

"It's always this intense fear that if I'm not diligent enough, something's going to happen that I could have prevented."

The checking rituals started at about age 7 when she would go through her house counting the lights a certain number of times and checking there was nothing on top of the lamps that could cause a fire.

The light switch-counting ritual remains, even though the intermediate schoolteacher knows it doesn't make sense.

"It's not rational but certain things need to be done seven times or four times or three – I don't know why."

When her life feels settled, the rituals may take only 15 minutes. At other times – hours.

"The numbers work for me on a good night, but on a bad night, it's sets of those numbers. I will repeat that counting. I never feel better. It's just when I get brave enough to walk away."

Rock-bottom came last year with the rituals and compulsions taking so long to complete that she was only getting a few hours of sleep a night.

"I can recall being in the bathroom counting for an hour at the same point, the same switches until I felt okay enough to leave that room. Then I'd go to bed and worry and be up until 3 or 4 o'clock in the morning.

"You feel stuck and you can't move out of it or your mind. You're trying to convince yourself, 'If I get to this number then this awful doom will leave me.'"

"But you get to that number and it's still there."

Hill says at times like these, re-counting would not make the fear go away.

"I feel like something bad is going to happen and it might be my fault because I didn't count to seven, three times. It's illogical and unrelated."

Her OCD doesn't affect her at work. She says it's made her more empathetic to kids who are having mental health struggles, and she has great support, "love and care" from the colleagues she has opened up to.

She feels it affects her husband and that if she put herself in his shoes and saw him "tormented by a freaking plug" it would break her heart.

"It would be hard seeing me on a bad night."

Seeking answers last year when at its worst, Hill tried acupuncture, meditation therapy, medication, a detox and sleep clinic, a psychologist and alignment massage. But the most healing thing she's experienced is hearing others share their journeys with OCD and hopes her story can help someone else feel less alone.

Staying up for hours at night checking and rechecking the house is safe, washing the body and clothes after using the toilet, and backtracking steps until a 'good thought' has entered the mind are some of the compulsive behaviours three women with Obsessive Compulsive Disorder (OCD) live with. **Catherine Sylvester** finds out what it's really like to live with this 'exhausting and debilitating' condition.



Ashley Bertelsen says at its worst, living with OCD was unbearable and debilitating but therapy 'saved her life'.

While everyone will experience intrusive thoughts, they will feel "catastrophic" and "very real" to those with OCD, says Jim Sterner, director and founder of The Gateway Institute in America, which specialises in treating the condition.

"If I were to give an OCD sufferer a PET scan during an episode, it would look exactly like a PET scan of someone being held up at gunpoint," Sterner says.

"It feels so real because the same physiological manifestation that is occurring when someone is in real danger is exactly what's occurring in the brain of someone with OCD," even though the "vast majority" will

recognise their thoughts are irrational.

Sterner, who holds a Masters of Clinical Psychology, says this makes treating OCD "profoundly challenging".

With 2.5 per cent of the population affected by OCD, and clients taking "seven to 10 years to seek out treatment", Sterner says there are certain variables recognised as exacerbators of OCD.

"If there is a genetic variable of OCD, then particular stressors can bring it to the surface", such as life transitions, physical or emotional trauma, PTSD, general stress and paediatric autoimmune neuropsychiatric disorder associated

with streptococcal [Pandas].

"Pandas is a fancy way of saying if someone has strep throat and they have that genetic variable [also], the inflammation in the brain causes OCD to surface."

Once OCD has surfaced, it's "chronic for the rest of one's life", Sterner says.

"It can change and metastasise over time depending on the age and life stage you are in."

The institute offers very specific strategies for learning to manage the disorder.

Before Ashley Bertelsen travelled to California in October 2022 to receive

treatment at The Gateway Institute, her life had become consumed with the compulsions and rituals of her OCD.

She first exhibited obsessive compulsive thinking and behaviour as a child.

At age 7, the Tauranga local had to have her schoolbag on a certain hook or "something bad would happen".

"When I was 10, the brother in a family of YouTubers I used to watch suddenly passed away and his favourite number was seven," she says.

"So in my 10-year-old brain, I was like, 'Oh, if I do anything seven times, that means that I will die like he did.'"

being controlled'

Aggressive obsessions	Somatic obsessions	Contamination obsessions	Sexual obsessions	Hoarding or saving	Religious obsessions	Symmetry or exactness	Others
Examples include fear of harming self or others or being responsible for something terrible happening.	Examples include fear of illness or disease.	Examples include concern with getting ill because of contaminant, excessive concern with bodily waste.	Examples include forbidden or perverse sexual thoughts, images, or impulses.		Examples include concern with sacrilege or blasphemy.	For example, with or without magical thinking (concerned another will have an accident unless things are in the right place).	Examples include fear of losing things, lucky/unlucky numbers, intrusive (non-violent) images.

Herald graphic

She also developed an intense fear of throwing up.

By the time she was 14, she was experiencing many mental compulsions and rituals daily. So much so, that getting ready for bed could take hours, resulting in only a few hours of sleep a night. The resulting fatigue necessitated a move from regular to online schooling.

"I had to tap a wall a certain amount of times before bed, and think of a certain memory before I could move on and do something else until it felt right and complete."

By the end of 2021, when she was 16, Bertelsen had developed even more compulsions to alleviate the obsessive fear that if she didn't, she would throw up or her mother would die.

When she was walking and had a "bad thought", her OCD would tell her to stop, go back to where she'd experienced the bad thought, and replace it with a "good thought" before moving on. At its worst, this was happening up to four times a minute. A walk on the beach, which might usually take 20 minutes, could take up to an hour.

"It feels unbearable... like you're trapped or being controlled. It's very lonely, frustrating and exhausting."

Exhausting their options seeking help in Aotearoa – "there were either really long waiting lists or we couldn't find anyone that helped" – they chose a three-week intensive outpatient programme in California, at The Gateway Institute, in 2022.

"I learned how to respond to the OCD, how to make it smaller because it's not something you can 100 per cent recover from."

Where once Bertelsen was unable to engage in conversation or do her schoolwork due to how "busy" her head was, she is now undertaking a full-immersion French course in Canada and doesn't engage with the intrusive thoughts that once dominated her life. However, she does remember how "exhausting, challenging, difficult and debilitating" her OCD once was and hopes people remember to be patient and supportive towards those with OCD as they "don't get a break from it".

Like Hill and Bertelsen, Hilda Foo exhibited symptoms of OCD as a child, wiping her feet before sitting on her bed, using her feet to open a door so that she wouldn't have to touch it, and washing her hands a lot.

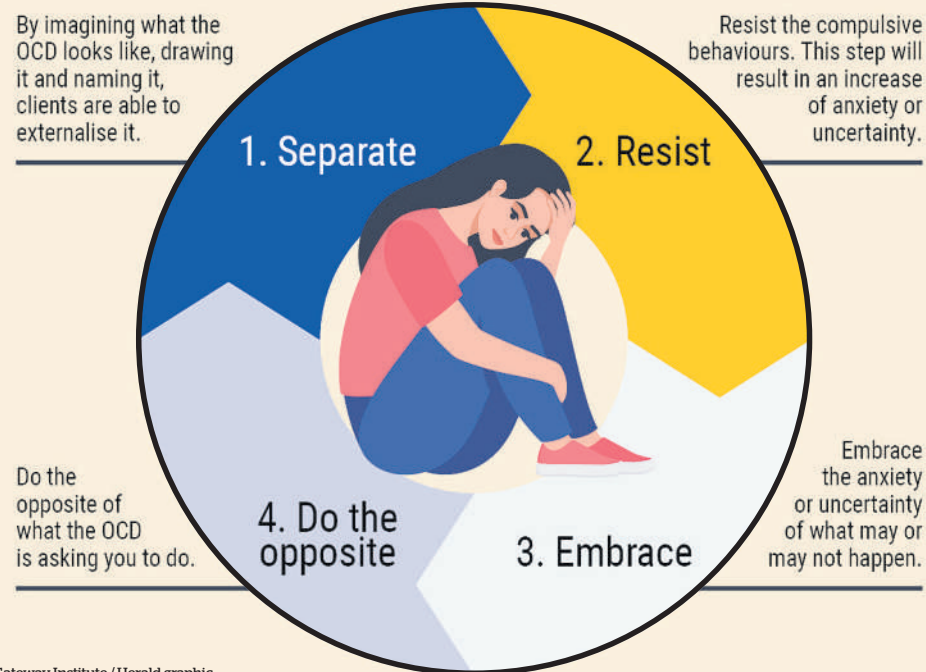
But it was when her 3-month-old son was hospitalised with unexplainable high fevers in November 2021 that Foo's "germophobia" really increased.

When the doctors found E. coli in his system, and someone suggested she may not have been cleaning him properly, Foo became more "fearful of bacteria and germs".

Eventually, her son was diagnosed

Obsessive-compulsive disorder

The Gateway Institute's four-part strategy for treating OCD.



Source: The Gateway Institute / Herald graphic

with vesicoureteral reflux, a condition where urine moves backward from the bladder to the kidneys, which reinforced the young mother's desire to "keep things clean".

Before her son's illness Foo, already concerned about germs, would bathe him after he was held by others. However, once home from the hospital, she would not allow people to visit the house, hold or touch him, other than his grandparents and her sister – with a caveat.

"I would get very anxious and ask them to always wash their hands and

make sure their clothes were clean before they carried him as a baby."

She feels it was at this time that her husband and family became frustrated with her requests and actions.

Foo says her rituals and cleaning then increased. Her cat, who had once been "the love of her life" was now "scary to interact with" as all she could think about was the germs he may have been carrying. Seeing her house as her clean sanctuary, she would wash her feet outside before entering her home and stopped using public toilets or at others' homes.

"I was very convinced that when you flush the toilet, there will be water coming out from the toilet bowl because I've seen it happen before and then everywhere around the floor is contaminated. This was a very specific fear of fluid."

She says she's very fearful of others' bodily fluids.

Now, if she uses a public toilet, she will change and wash her clothes when she returns home, and bathe. When using her own toilet, she makes sure she washes her body afterwards.

If the family has been out together, then they all must bathe and change

their clothes when returning home as she feels outside clothes are contaminated.

Foo says she is "okay with it affecting" her life as her desire is to keep her son from getting sick. However, she has now been taking medication for more than a year and feels able to allow her son to play outside of the home.

Marion Maw is one of the administrators for the Facebook page Fixate. It's a closed group for people with OCD and those who support someone with the condition.

From this group, OCD NZ was created to provide resources and information about the mental health condition.

Maw says it's essential when seeking treatment, that people ask practitioners what experience they have with OCD as some therapies may exacerbate symptoms.

"You really want to hear them talking about exposure response prevention."

She explains this comes under the umbrella term, cognitive behaviour therapy (CBT).

Mental health nurse practitioner and CBT therapist Anna Elders says it's the pervasiveness of the intrusive thoughts and the "catastrophic sense of what could happen" if the compulsions weren't carried out that hallmark OCD.

"It's incredibly hard, unless someone's done some work, to be able to ignore [the thoughts] and get over them."

Elders is the clinical lead for Just a Thought – a website offering free, evidence-based mental health courses. Last year they launched a tailored, specialist treatment course for OCD with the same content "you would get if you saw an OCD therapist face-to-face".

Elders says not all therapists or counsellors have specialist training around OCD.

"That becomes a problem because there's an evidence-based specific approach that you need to run it with exposure and response prevention to be able to really work on the major crux of what drives OCD."

There are many sub-types of OCD such as contamination OCD, symmetry and ordering, moral OCD where the person fears they will act immorally, and aggressive obsessions, which may manifest as a fear of harming oneself or others.

Elders says people living with OCD often feel self-stigma and stigma from others, and a high level of guilt and shame due to their intrusive thoughts and the "fear of what [they] mean about them".

However, once they learn about what is actually happening and understand how to use effective treatment, they can "make massive leaps and bounds of changes".



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Amy Hill, OCD sufferer