

Eating disorders and autism spectrum disorder link needs more research, experts say

By Larissa Romensky for the Sydney Morning Herald published on 13th of October 2019

Experts are calling for more research into the link between eating disorders and autism spectrum disorder to come up with better treatment and support services.

Key points:

- Nearly a million Australians have an eating disorder, according to the Butterfly Foundation
- One expert wants more research into what proportion of people with autism have an eating disorder
- He says it could be possible that autism may be a risk factor in developing an eating disorder

Nearly a million Australians are living with an eating disorder, according to the Butterfly Foundation, and anorexia nervosa has the highest death rate of all

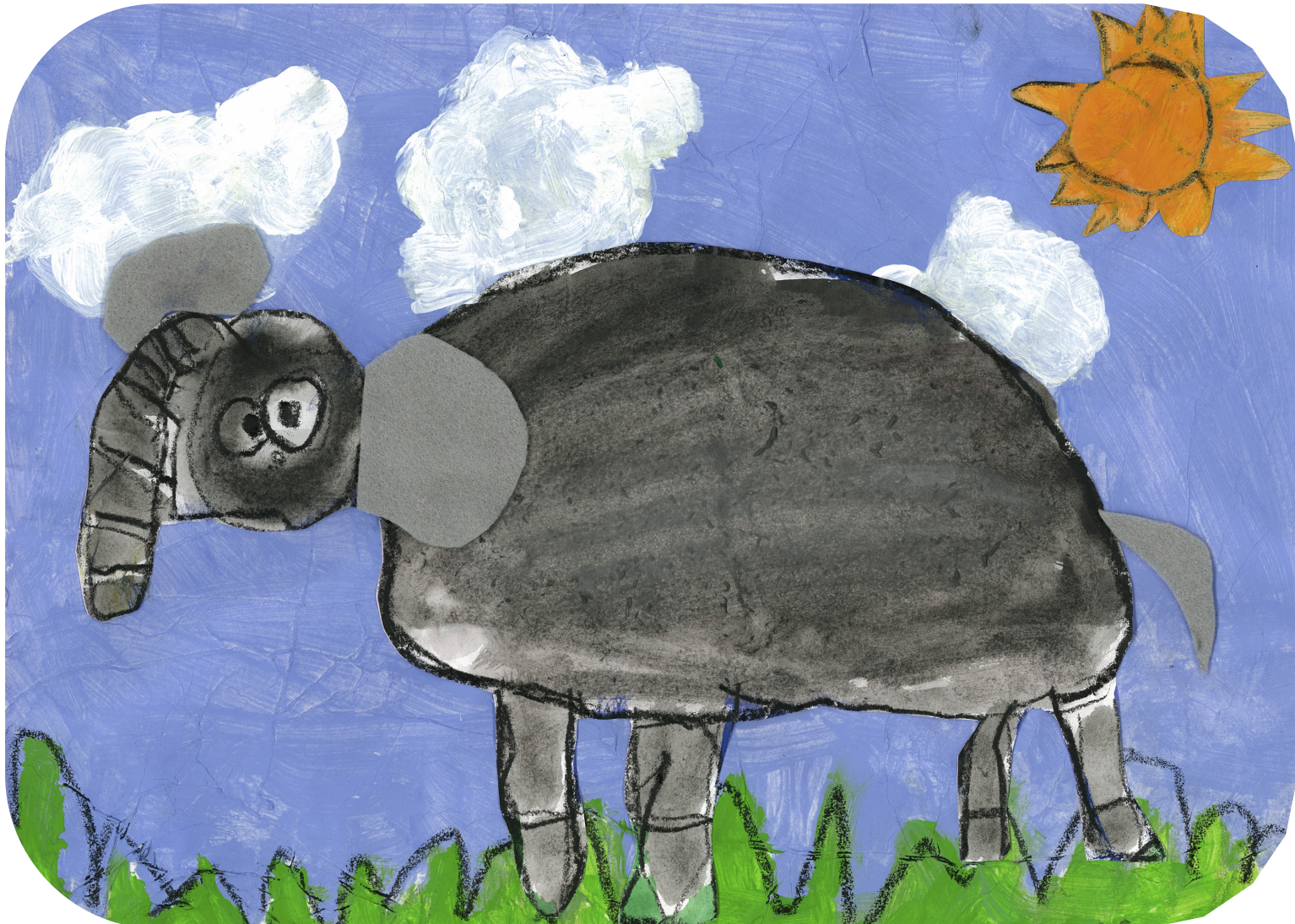
mental illnesses.

Single mother of two Carrie, whose teenage daughter has been diagnosed with anorexia nervosa, said it was an all-consuming, isolating illness beyond most people's understanding.

"When you go out it's like having a toddler, you've got to pack everything, because you can't be guaranteed that anywhere you go there is something they will eat," she said.

"You could stand in a bakery for one hour and she would end up in hysterics, in tears because she couldn't decide what she wanted."

Carrie's 16-year-old daughter was diagnosed with anorexia by a psychiatrist two years ago after a lengthy



search for answers, but her mother said she probably had it for eight months prior to the diagnosis.

Living in Bendigo in central Victoria, Carrie had struggled to find the right support services.

It was only after reaching out online to a parents' support group that she was thrown a lifeline from a parent in Melbourne who helped her access the right services.

At times, Carrie's daughter's sheer force of resistance to eating was often matched by an angry determination.

"My daughter has tried to jump out of a car. We were going about 80 kilometres an hour at the time," she said.

Recently a new doctor asked Carrie if her daughter was on the spectrum.

"Maybe if she is on the spectrum, then maybe the eating disorder is a direct result of her anxiety," she said.

At a cost of close to \$2,000 for a full report from Autism Spectrum Australia, Carrie said she would "try anything" and has begun the process of diagnosis.



Photo: Carrie had to quit work and take her daughter out of school for two months to make sure she was eating. (ABC Central Victoria: Larissa Romensky)

“More children are being diagnosed with both anorexia and autism spectrum disorder”

More girls being diagnosed with both anorexia and ASD

More children are being diagnosed with both anorexia and autism spectrum disorder (ASD).

According to a senior social worker at The Children's Hospital at Westmead Eating Disorders Service, Colleen Alford, the prevalence is well known worldwide with more than 20 per cent of adults diagnosed with anorexia also having ASD.

"Now the research is about how do we adapt treatment to help these young people who have both conditions," she said.

Most of the research has come out of the United States and the United Kingdom, and Ms Alford said more research was needed in Australia, especially around treatment.

Westmead Hospital in Sydney has just started a small focus group and pilot project looking at adjunct treatment for children with ASD and anorexia.

"Families that have a child with this comorbidity feel even more isolated than families that have a child with anorexia without autism," Ms Alford said. She said having both disorders tended to amplify each other.

"They feel really stuck around how to support their child," Ms Alford said.

Is autism a risk factor for other eating disorders?

If you need help with an eating disorder, contact:

Eating Disorders Victoria 1300 550 236

The Butterfly Foundation 1800 33 4673

National Eating Disorders Collaboration 1800 33 4673

Lifeline on 13 11 14

Kids Helpline on 1800 551 800

Associate Professor in clinical psychology at University College London Will Mandy said the link between women with serious eating disorders and undiagnosed ASD was first written about in a Swedish study in the 1990s.

"Between 20 and 30 per cent of these people with anorexia nervosa were also autistic," Dr Mandy said.

Despite there being some initial concerns with the results, in terms of effective autism assessment and the psychological effects of starvation often mimicking the



characteristics of autism, subsequent research has found the same figures.

"When you do these studies properly with diverse methods you tend to come back to that figure," Dr Mandy said.

What was lacking was research looking into what proportion of people with autism also had an eating disorder.

"They've done it the other way round, they've said, 'What proportion of people with an eating disorder are autistic?'," he said.

He said it could be possible that autism was a risk factor for other eating disorders, such as bulimia nervosa.

“What was lacking was research looking into what proportion of people with autism also had an eating disorder”

'Maybe autistic women restrict eating to manage unbearable emotions'

Christine Naismith is the founding board member of Eating Disorders Families Australia (EDFA), a volunteer organisation made up of people with lived experience of being a carer of somebody with an eating disorder – and the parent who helped Carrie seek help.

Ms Naismith has two daughters, a 23-year-old who has recovered from anorexia and a 17-year-old-daughter diagnosed with Avoidant Restrictive Feeding Intake Disorder (ARFID).

"It's picky eating gone crazy," she said.

"She'll only eat certain brands of foods or it has to be cooked in a certain way or she won't touch foods that touch other foods on the plate.

"It doesn't have the body image side of things that anorexia or bulimia do."

But one of the common traits of people exhibiting both ASD and eating disorders is anxiety.

"We're investigating the idea that, in many cases, maybe autistic women develop very severe restrictive eat-

ing as an attempt to manage unbearable emotions that are associated with being autistic and not getting the support they need," Dr Mandy said.

"It's almost like the weight loss is a secondary consequence of that."

'Girls better at 'pretending to be normal'

Dr Mandy said the main barrier in diagnosing women with autism was the current conception that autism was based on a "male-typical presentation" that made up most of the studies.

"There's evidence to show that autistic girls and women are on average somewhat more socially motivated than autistic boys and men," he said.

Women were also more adept at masking or social camouflaging.

"They invest a lot of effort in learning how to pretend not to be autistic in social settings — many call it 'pretending to be normal'," Dr Mandy said.

He said there tended to be gender-specific patterns with ASD, with boys more likely to have difficulties with their behaviour, particularly at school, and girls more likely to experience anxiety and depression.

"So girls were less likely to come onto [the teacher's] radar and less likely to get the assessment they need," Dr Mandy said.

He said a timely diagnosis was crucial in providing the necessary support to girls, and he said more understanding around the precise nature of the eating difficulties of people with ASD was needed.

"We need to get a much better understanding of what mechanisms are causing and maintaining these really serious restrictive eating problems in autistic people," Dr Mandy said.

'Being around people who get it'

Ms Naismith said the biggest impact on families was exhaustion and a feeling of isolation and hopelessness.

"It's a long journey. The average time to recovery for anorexia is five years," she said.

For the first time in regional Australia, EDFFA has started a new support group in Bendigo for parents and carers of teenagers and young adults with eating disorders run by facilitators with lived experience.

"It was amazing," Carrie said.

"It's being around people who get it, who understand

what you're going through, who know exactly how horrific it is and how restrictive it is and how terrible it is.

"It just makes you feel you're not alone."

Recently EDFFA put in a submission to the Federal Health Minister for funding to allow them to roll out a pilot program of 15 support groups nationally.

Reference

<https://www.abc.net.au/news/2019-10-13/more-research-needed-into-eating-disorders-autism-link/11593828>

Further Reading

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