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Lisa Curry AO

Triple Olympian, mother, grandmother, wellness entrepreneur & author, **SUNSHINE COAST**

Grab A

Those times in the pool was so significant for me. They were a stepping stone to everything else that I did in my life, and the dedication required to do what I did, particularly going to three Olympics and the last one as a mother with two daughters at home, was quite incredible when I look back on it. But the, the hard work, the work ethic is what I'm so proud of.

Grab B

We were weighed every day while we were away. And that in itself was frightening for a teenager because we would get in trouble if we were a little bit over what we were yesterday, you know, and if you eat a meal and you're point two over, they're going to come down hard on you.



So we had those fears instilled in us probably between the ages of 15 and 18.

But it even happened to my daughter here when she was trying to make a team, in the outrigger team. I don't know for the life of me why they were weighing these kids for an outrigger race.

Grab C

Family is everything to me, & it always has been. And now more so than ever. It's not until you lose someone that you, you know, you hold tighter. You, you love more, you want more.

Grab D

I know Jaimi would say to me often, mum, what is wrong with me? & I'd say, well, we know what's wrong because we're seeing it every day. But she'd say, no, but where did it come from? Why am I like this? I couldn't answer those questions. Nobody could answer those questions. & that's what made it so hard.

Grab E

When Jaimi was like 14, 15, 16, I knew something was going on, but we couldn't really put a finger on it. She didn't really say anything, but she'd have these massive mood swings, and would inhale everything out of the fridge, and then would disappear. So we kind of thought something was going on, but didn't really bring it up because it created World War III, because there was so much stigma and shame attached to it that it wasn't spoken about.

Grab F

Jaimi was told she wouldn't make her 30th birthday, so she was very excited to have 30 candles on her cake. She said, mum, I made it. Okay, let's go for another 30. You know, trying to keep everything really positive. & there was so many visits to the hospital, like I'm talking three or four times a week, some weeks that we never knew when the last one would be.

Grab G

I do know that I have a voice, so I have to be able to use it for the good to help other parents not go through what we've been through, you know, so that they can say good night to their kid every night.

Grab H

The Eating Disorders Genetics Initiative 2 or EDGI2. When I first heard about it, I thought, this is really great, this is going to be great research. I think it's really important that we start to understand what the causes might be.

Grab I

I've decided to lend my voice to EDGI2 , because of course, it has a personal attachment to me and my daughter is not here to tell her story. I am here to help tell her story, and to help prevent it from somebody else, & help prevent another parent from losing a child.

Grab J

So if people want to volunteer for EDGI2 and be part of the research and part of the solution, which is fabulous, they just have to go to EDGI2.org.au and fill in the online assessment. & then if they qualify, they will be sent a saliva test, send it back, and it goes into the research. So it's I think it's fabulous & the more people that do it, the better.

Professor Nick Martin

Lead Investigator, EDGI2 Australia, Geneticist & Head, Genetic Epidemiology, QIMR Berghofer, **BRISBANE**



Grab A

What is an eating disorder?

Eating disorders are severe, mental disorders that, can have drastic physical consequences.

Grab B

How many Australians are currently living with an eating disorder?

The number of Australians living with an eating disorder is huge. It's about 1 in 23, almost 5 per cent of the population.

Grab C

How many genes are involved in an eating disorder?

The number of genes involved in these complex, disorders we've found, where we've had large enough sample sizes is huge. It's, often, in the hundreds. And we've actually found nearly 500 genes for depression. About the same number for schizophrenia.

Grab D

What is the Eating Disorders Genetics Initiative (EDGI) 2 & what is its aim?

EDGI2, Eating Disorder Genetics Initiative 2 is, part of an international collaboration, which includes other countries, including, Sweden, Denmark, Mexico, US, New Zealand, Australia. Aiming to collect a very large sample. We'd like eventually to get to 100,000 people, with these eating disorders. And we need to get that number to really understand the particular genes that are contributing to these conditions.

And we need to do that because, that will enable us to, design new medications, to have a much better understanding of the biochemical basis of these disorders, and also to actually make predictions about which people are most, liable, most susceptible to these conditions.

Grab E

How many genes does EDGI2 aim to identify, that influence a person's risk of developing an eating disorder?

Our work so far on eating disorders has defined eight genes. That's up from zero before, so we're very pleased with that. But we know, comparing with other complex trait disorders, including psychiatric disorders, that there are most likely to be hundreds of such genes. And we also know that the number we find is directly proportional to the sample size we get.

Grab F

How many adult volunteers, & who specifically, are you aiming to recruit into the Australian arm of EDGI2?

We're aiming in Australia to recruit at least 4000 participants in our study. These would be people, people over 18 years of age, who have experience either now or in the past, of anorexia, bulimia, binge eating or ARFID.

Grab G

What does participation in EDGI2 involve?

Participation in our study is quite simple. Just go to a website **EDGI2.org.au**. That would give you all the information you need about the study. A short questionnaire, and then information about donating a saliva sample.

Professor Sarah Maguire OAM

Chief-Investigator, EDGI2 Australia, Clinical Psychologist & Director, InsideOut Institute, **SYDNEY**



Grab A

How many Australians are currently living with an eating disorder?

Conservative estimates suggest a million Australians have an eating disorder.

Grab B

Who is affected by an eating disorder?

Eating disorders occur across the lifespan. The earliest reports are about age six, and they go through to end of life. But you are at the highest risk in the adolescent and early adult years.

Grab C

What are some common eating disorders?

The eating disorders that are marked by binge eating, bulimia nervosa and binge-eating disorder are actually more common than eating disorders marked by restriction, like anorexia nervosa and ARFID. ARFID is an eating disorder marked by pathologically picky eating. Um, people colloquially might refer to it as very fussy eating, but it's an extreme version of that.

Grab D

Why is it important to identify the genes that contribute to eating disorders?

Well, genes are the building blocks of human existence and experience, including the experience of an illness, like an eating disorder. We've been, I suppose, researching, understanding and treating eating disorders from the top down. For a long time, we've been looking at the outside symptoms of weight, shape, food and treating the illnesses as such, and we've been really quite unsuccessful. We need to look at biological mechanisms and biological drivers so that we can develop targeted therapies.

Grab E

What is the Eating Disorders Genetics Initiative 2 (EDGI2) & what is its aim?

The Eating Disorders Genetics Initiative 2 or EDGI2 is part two of a very large international consortium of researchers that are trying to gather enough genetic samples from affected people, to determine the genetic architecture, of a range of eating disorders.

Grab F

Do you need to have received a formal diagnosis of an eating disorder to participate in EDGI2?

You don't need to have been given a formal diagnosis of an eating disorder to participate in the EDGI2 study. If, across your lifetime, you think that you've had an experience of any eating disorder – anorexia nervosa, bulimia nervosa, binge eating disorder or ARFID – then go to the EDGI2 website, fill in some questionnaires. Your diagnosis can be confirmed through those questionnaires.

Grab G

What does participation in EDGI2 involve?

Participation in EDGI2 is really simple. It just involves some online questionnaires, then we'll mail a spit kit to the house, and you can give us a saliva sample, and we give you a prepaid envelope to mail it back to us.

Grab H

What is your message to people aged 18+, living in Australia, with experience of an eating disorder?

To adult Australians who believe that they've had an experience of an eating disorder, anorexia, bulimia, binge eating disorder, or ARFID at any point in their life, please help us be part of the solution. Go to the EDGI2 website, fill in some brief questionnaires, give us a sample of your saliva and let us determine the drivers of these illnesses.

Elise, 39

Corporate breathwork & meditation facilitator, mindset coach & counsellor who lived with anorexia nervosa for 23 years, **SYDNEY**



Grab A

Self-introduction

My name is Elise, and I'm 39 years old. I live on the Northern Beaches of Sydney, and I'm a breathwork facilitator, ice bath coach and empowerment coach.

Grab B

When were you diagnosed with anorexia nervosa & for how long did the illness continue to pervade your life?

I was diagnosed with anorexia nervosa at the age of 14, and this continued on until my early 20s. But then I had a couple of relapses after that, later on in my 20s.

Grab C

How does it feel to live with anorexia nervosa?

Living with anorexia nervosa is so extremely isolating and it's all consuming. Every thought is related to the illness around to how much you're going to restrict that day, how much exercise you're going to do, and it becomes really, really lonely.

Grab D

What were your symptoms of anorexia nervosa & how long did you experience them?

My symptoms of anorexia nervosa were extreme food restriction. So sometimes going all day or days without eating any food, I also would engage in extreme levels of exercise. So going for really long runs, going to the gym, doing sit ups in my room, you name it, as I would do as much exercise as I could possibly do.

Grab E

How did you symptoms affect you?

My symptoms were causing me to be extremely tired and lethargic and terribly moody. I remember having really big rageful outbursts towards my parents, my mum in particular. And I think because of the lack of food and the amount of exercise that I was doing, that I just had no energy for my brain to be functioning at its best and for my moods to be stable.

Grab F

Do you have a family history of an eating disorder?

Yes, there is a family history of mental illness & potentially an eating disorder.

Grab G

How did living with anorexia nervosa affect your life from a physical, mental and social perspective?

Living with anorexia nervosa impacted my life significantly, particularly on a social level. I missed out on so much, and I reflect back at moments in time where I could have shared a beautiful meal with family, where I could have celebrated a birthday and enjoyed some cake with my loved ones and all that was surrounding those experiences was anxiety around the food that was being served, and it was just so isolating for me and so extremely stressful at the same time. In moments that I really could have just been experiencing joy and love and all the really amazing, delicious things that life has to offer.

Grab H**Why is the Eating Disorders Genetics Initiative 2 (EDGI2) important to you?**

EDGI2 is so important to me because the idea that we could identify whether someone has a genetic predisposition to an eating disorder would then mean that they wouldn't have to endure what I endured as I was growing up, if we could put in place things to avoid that eating disorder being triggered, that would mean that someone doesn't have to experience what I did.

Grab I**What is your message to other Australians living with an eating disorder?**

You can get through this. That life can be so much more than it is right now. Life can be so absolutely incredible and you are so much more than your body. You have so much more to offer this world. And just believe in yourself. You can get to the other side of this.

Shannon, 48

Lived experience educator & dog lover who grappled with anorexia nervosa & bulimia nervosa for more than three decades, **PERTH**

Grab A

For how long do you suspect you had been living with anorexia nervosa & bulimia nervosa before your diagnosis?

I would say I probably started to experience forms of disordered eating or some forms of symptoms of an eating disorder, probably about the age of 10. You know obviously you start to grow up, and your body starts to change, and it wasn't something that I certainly could change or have control over so I would say around it was about then I was becoming more aware of the physical changes within my body, but also becoming more aware of societal pressures where people were, obviously influencing their weight and size around me all the time.



Grab B

What events led to your diagnosis of anorexia nervosa & bulimia nervosa?

I was hitting puberty, and I had a few health issues at the time, so medication influenced my weight and how I felt physically, so I think the ripple effect of that, and also potentially feeling powerless around circumstances around me, all sort of overlapped, and I think probably led to developing symptoms and then exacerbating over time.

Grab C

What were the long-term health impacts of living with two eating disorders?

I had developed osteoporosis particularly having an eating disorder for so long. I was in pain all the time and I also developed major gut issues. So I had three abdominal surgeries over the years and that was something that was really difficult to recover from.

Grab D

Despite being severely unwell, you struggled to accept your diagnosis. Can you reflect on this?

I did find it really hard to accept the diagnosis in itself. There's something about an eating disorder that, um, tries to convince people that they're not sick enough. And I felt that I didn't meet the norm of what I understood to be an eating disorder. And if I'm honest, I only ever really thought of an eating disorder as anorexia nervosa or bulimia nervosa. And, perhaps I was looking for what it, how it was perceived, not realising that, much of how it impacts a person is behind closed doors.

Grab E

Do you have a family history of an eating disorder?

So I was aware that my aunt had anorexia nervosa. But if I reflect back on my experiences, I think in hindsight, and maybe understanding a bit more about eating disorders, I can certainly say I think there was definitely traits of disordered eating in my family and potentially undiagnosed eating disorders as well.

Grab F

Can you explain the potentially devastating consequences of living with anorexia nervosa & bulimia nervosa?

I think having eating disorders to the degree that I did took away everything that mattered the most to me to the point where I nearly lost my life.

Grab G

Why is the Eating Disorders Genetics Initiative 2 (EDGI2) so important?

The Eating Disorders Genetics Initiative 2 is such an important study. Not only does it touch on anorexia nervosa, bulimia nervosa and other eating disorders, but it's going to help understand and gain more insight and information not only to the environmental factors that cause eating disorders, but also potentially the genetics behind what influences people to become so unwell from eating disorders.

Grab H

What is your message to other Australians living with an eating disorder?

I'd just encourage you to reach out to somebody that you can trust, whether it's someone in your family, a GP, a teacher at school, and let them know what's going on. I think the sooner that you can get the right supports, the sooner you can start to live your best life. Eating disorders can take away so much from you, and no one deserves that, but I think the right support and potentially treatment, I think you can start to live the life that you deserve.

ends#

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