

NEWS

For people with alexithymia, emotions are a mystery

BY EMMA YOUNG, MOSAIC

22 FEBRUARY 2019

Stephen has been married twice. Two wedding days. Two “I do”s. Yet Stephen has no happy memories from either -- or, in fact, from the marriages or any of his relationships.

He met his first wife on a pre-nursing course when he was just 16. Six years later, they were married. Three years after that, they got divorced; she was never really the right one for him, he says. Almost two decades on, in 2009, he met his second wife through a dating site. He threw himself into the relationship, and the following year, with his father and her two adult siblings present, they married at the registrar’s office in Sheffield, England, where they both live.

He put on smiles for the wedding photos because he recognized that they were expected, but, as he explains: “From an inner-feeling point of view, anything I do that requires an emotional response feels like a fake. Most of my responses are learned responses. In an environment where everyone is being jolly and happy, it feels like I’m lying. Acting. Which I am. So it *is* a lie.”

Happiness isn’t the only emotion that Stephen struggles with. Excitement, shame, disgust, anticipation, even love ... he doesn’t feel these, either. “I feel *something*, but I’m unable to distinguish in any real way what that feeling is.” The only emotions he is familiar with are fear and anger.

Such profound problems with emotion are sometimes associated with autism, which Stephen does not have, or with psychopathy, which he doesn’t have, either. Last year, at the age of 51, he finally learned what he does have: a little-known condition called alexithymia, a word made from Greek parts meaning, roughly, “no words for emotion.”

Despite the name, the real problem for people with alexithymia isn’t so much that they have no words for their emotions, but that they lack the emotions themselves. Still, not everyone with the condition has the same experiences. Some have gaps and distortions in the typical emotional

repertoire. Some realize they're feeling an emotion but don't know which, whereas others confuse signs of certain emotions for something else -- perhaps interpreting butterflies in the stomach as hunger pangs.

Surprisingly, given how generally unrecognized it is, studies show that about 1 in 10 people falls on the alexithymia spectrum. New research is revealing what's going wrong -- and this work holds the promise not only of novel treatments for disorders of emotion, but of revealing just how the rest of us feel anything at all.

Faking it:

After working as a nurse for 10 years, Stephen decided he wanted to do something different. A two-year Access to University course led to a degree in astronomy and physics, and then to a job testing computer games. He built a successful career for himself, working for various companies in their computer-testing departments, managing teams, and traveling around the world to speak at conferences. He had no problem conveying facts to colleagues. It was in the context of more personal relationships -- or any other scenario that would typically involve expressions of emotion -- that he felt things were "wrong."

"At the beginning of a relationship, I'm totally into who that person is," he explains. "I've been told I'm very good at maintaining a honeymoon period for 'longer than expected.' But after a year, it takes a massive turn. It all falls apart. I've put myself on a pedestal to be this person which I'm really not. I react mostly cognitively, rather than it being emotions making me react. Obviously, that is not valid. It's not real. It seems fake. Because it is fake. And you can only pretend for so long."

He and his current wife stopped living together in 2012. He saw a general practitioner and was prescribed antidepressants. Though he was still in contact with his wife, it was clear that the relationship was no longer working. In June 2015, he attempted suicide. "I had actually been posting on Facebook and Twitter regarding killing myself, and someone -- I've never found out who -- contacted the police. I was taken to hospital and treated."

A psychiatrist referred Stephen for a series of counseling sessions and then a course of psychodynamic psychotherapy, a type of Freudian-based therapy that, in trying to uncover unconscious drivers of thoughts and behavior, is similar to psychoanalysis.

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It was in a book called "Why Love Matters" by Sue Gerhardt, which his therapist recommended, that he first came across the concept of alexithymia. "I brought it up in therapy, and that's when

we started talking about how I was very alexithymic. Obviously, I've got a vocabulary. I've got words for emotions. But whether they're the right words for the right emotion is a different point altogether ... I just thought that I wasn't good at talking about how I feel and emotions and stuff like that. But after a year of therapy, it became apparent that when I talk about emotions, I don't actually know what I'm talking about."

The term 'alexithymic' dates from a book published in 1972 and has its origins in Freudian psychodynamic literature. Freudian ideas are now out of favor with most academic psychologists, as **Geoff Bird**, associate professor of experimental psychology at the University of Oxford explains. "Not to disrespect those traditions, but in the cognitive, neuro, experimental field, not so many people are really very interested in anything associated with Freud anymore."

But when Bird read about alexithymia, he found the descriptions intriguing. "Actually, it's really quite amazing." For most people, "at a low level of emotion, you might be a bit unsure about exactly what you're feeling, but if you have a strong emotion, you *know* what it is." And yet somehow, here were people who simply did not know.

Bird started his academic career studying autism, empathy and emotional awareness, which led to his interest in alexithymia. In one of his first studies in this field, he linked alexithymia, as measured with a 20-item checklist developed at the University of Toronto, with a lack of empathy. If you can't feel your own emotions in the typical way, it makes sense that you can't identify with those of others, either.

But what really drew Bird into alexithymia research were his interactions with people with autism. "There has been this perception that people with autism don't have empathy. And that's rubbish. And you can see that immediately as soon as you meet some autistic people."

In a series of studies, Bird has found that about half of people with autism have alexithymia -- it's these people who struggle with emotion and empathy, whereas the rest do not. In other words, emotion-related difficulties are intrinsic to alexithymia, not to autism.

Racing heart:

Bird is passionate about spreading this message. He talks with feeling about one particular autistic study volunteer who did not have alexithymia: "A lovely guy with an IQ we couldn't measure, it's that good. He couldn't hold down a job. But he volunteered to work at a care home because he wanted to do something productive with his time. They said, 'Oh because you've got a diagnosis of autism you can't do empathy, therefore you can't look after our elderly people.' Which is just ridiculous."

Bird has since run a series of studies exploring alexithymia outside the context of autism. He has found, for example, that people with the condition have no trouble recognizing faces or

distinguishing between pictures of people smiling and frowning. “But for a few of our really alexithymic people, while they can tell a smile and a frown apart, they have no idea what they *are*. That is really quite strange.”

Many of the people with the condition whom Bird has met talk about being told by other people that they’re different, though some do recognize it in themselves early on. “I guess it’s a bit like not being able to see color, and everybody’s always banging on about how red this is or how blue, and you come to realize there’s an aspect of human experience that you’re just not participating in.”

As well as better characterizing alexithymia, Bird and his colleagues have also dug into what explains it, taking what could seem to be a circular argument -- Stephen has problems with emotion because he has alexithymia, which is characterized by problems with emotion -- and blowing it right apart.

In situations that Stephen recognizes as being in theory highly emotional -- such as telling someone “I love you” -- he experiences changes inside his body. “I feel my heart race and this rush of adrenaline, but to me that feeling is always scary. I don’t know how to react. It makes me want to either run away or react verbally aggressively.”

Fear and anger -- and confusion -- he understands. “Everything else just feels all the same ... it’s this feeling of, ‘Errrr, I’m not quite comfortable with this -- it’s not quite right.’”

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For **Rebecca Brewer**, a former student of Bird’s and now lecturer in psychology at Royal Holloway, University of London, this makes sense. “With alexithymia, people often know that they are experiencing an emotion but don’t know which emotion it is,” she explains. “This means they could still experience depression, possibly because they struggle to differentiate between different negative emotions, and struggle to identify [positive] emotions. Similarly with anxiety, it might be that someone experiences an emotional response associated with a fast heartbeat -- which might be excitement -- but they don’t know how to interpret that, and they could panic about what’s happening in their body.”

The ability to detect changes inside the body -- everything from a racing heart to a diversion of blood flow, from a full bladder to a distension of the lungs -- is known as interoception. It’s your perception of your own internal state.

Different emotions are associated with different physical changes. In anger, for example, the heart rate rises, blood rushes to the face and fists clench. In fear, the heart rate also rises, but blood

drains from the face. It's generally thought that these changes are not entirely specific to individual emotions, and so context is also important: if you feel your heart racing and you're looking at a spider, you know it's fear that you're feeling, not sexual arousal.

Trauma and neglect:

What Bird, Brewer and others have found in people with alexithymia is a reduced ability, sometimes a complete inability, to produce, detect or interpret these internal bodily changes. People with the condition have normal-range intelligence quotients. They can understand as well as anyone else that they're seeing a spider rather than an attractive potential partner. But either their brains aren't triggering the physical changes that it seems are needed for the experience of an emotion, or other regions of their brains aren't reading these signals properly.

In 2016, Bird and Brewer, along with **Richard Cook** at City University in London, published a research paper that characterized alexithymia as a "generalized deficit of interoception." Here, then, was an explanation for these people's problems with emotion -- but also, in effect, a manifesto stating that the perception of a range of bodily signals is important for the experience of emotion in the rest of us.

It's an idea that we already express in everyday language: in English, for an apology to mean anything, it has to be 'heartfelt.' If you truly love someone, it's with 'all your heart.' When you're really angry, your 'blood boils.' Instead of saying that you're anxious, you might talk about having 'butterflies in your stomach' (thought to be caused by a diversion of blood flow away from the digestive system).

As a child, Stephen suffered extreme emotional neglect. When he was 6, his mother intentionally set fire to their home in Nottingham while she, Stephen, his younger brother and even younger sister were all inside. Fortunately, the children's father, who had left for work, realized he'd forgotten his packed lunch and came home.

Looking back, Stephen says it's clear his mother was suffering from postpartum depression. But she received no treatment, "and all I knew was anxiety and being worried." After the fire, his mother went to prison. His father was a steelworker who worked all kinds of shifts. "A neighbor contacted social services and Dad was told to sort it out or they'd take us away. None of my dad's brothers or sisters wanted me or my brother because we were little shits. We were always in trouble. Robbing shops. All kinds of stuff. So we went into care."

For the rest of his childhood, Stephen was in and out of care homes. The only emotions he remembers feeling, even then, are fear, anger and confusion. "Christmas, birthdays, people out of the blue at care homes being nice to me ... I never really got used to it. I always felt uncomfortable. There's just a mess of feelings inside me that I don't interpret properly or respond to properly."

Alexithymia is often associated with trauma and neglect from a young age, Geoff Bird explains. Twin studies have suggested a genetic component, too. And it's also linked to certain types of brain damage, particularly to the insula, the region that receives interoceptive signals.

As Rebecca Brewer notes, the kind of anxiety that Stephen experiences is common in people with poor interoception. At the University of Sussex, **Hugo Critchley** and **Sarah Garfinkel**, who have expertise in psychiatry and neuroscience, are looking at ways to alter interoception, to bring anxiety down.

Garfinkel has put forward a 3-D model of interoception that has been well received by others in the field. First, objective accuracy at perceiving interoceptive signals -- how good you are at counting heartbeats, for example. Second, subjective report -- how good you think you are. And third, metacognitive accuracy -- how good you are at knowing how good you actually are.

The third dimension is important because various studies have found that the gap between how good someone thinks they are at counting heartbeats, for example, and how good they actually are predicts their levels of anxiety. Lisa Quadt, a research fellow with the Sussex group, is now running a clinical trial with the aim of testing whether decreasing this gap for people with autism can lower their anxiety.

Decreasing anxiety:

In a pilot study, Critchley, Garfinkel and graduate student Abigail McLanachan recruited a group of students who came into the lab for six training sessions. In each session, they first did the heartbeat-counting task. The volunteer sat at rest, with a loose rubber pulse oximeter on their forefingers, and reported how many beats they'd counted. Then McLanachan told them how they'd done so that they got a better sense of how accurate they were.

McLanachan then got them to do a few minutes of jumping jacks or walking fast up the steep hill outside the building -- whatever was necessary to raise their heart rate, to make it easier to detect. ("Because some people really can't feel their heartbeat at all. I can't," Quadt explains.) Then they went back into the lab, did the tasks again and, as before, were given feedback each time.

This was just a pilot study on a general student population. But after three weeks, not only had the students' accuracy improved on all three dimensions of interoception, but they also reported a decrease in anxiety of around 10 percent.

For the main trial, volunteers diagnosed with autism will complete the same tasks as in the pilot, but once at the start and once at the end they'll do them inside a functional magnetic resonance imaging scanner. This will allow the team to monitor activity in the insula, which receives heart-rate data, and look at how changes in that activity may correspond to connections between the amygdala, which detects threats, and the prefrontal cortex, which can work out whether a potential

threat really is or is not dangerous and so whether anxiety is warranted. The hope, Critchley explains, is to see improved connectivity between these two regions, which previous studies have linked to decreased anxiety.

In Oxford, meanwhile, Geoff Bird wants to look at the idea that there are two different types of alexithymia. People with one type don't produce enough of the bodily signals necessary for the experience of an emotion, so they would be unlikely to benefit from the Sussex group's kind of training. People with the other type produce all kinds of bodily sensations, but their brains don't process these signals in the typical way. This second group, which includes Stephen, might benefit more.

Bird stresses that, although people with alexithymia struggle to understand emotion, that doesn't mean they don't care about other people. "For the most part, individuals with alexithymia can recognize that others are in a negative state, and this makes them distressed. The problem is that they can't work out what the other person is feeling, and what they are feeling, and therefore how to make the other person feel better or how to reduce their own distress. I think that's important because alexithymia is different from psychopathy in that respect."

Stephen says that for him, this is certainly true. And in theory, an emotional-training technique is something he would welcome. "I've got several books about emotions and feelings, and they don't make a jot of difference because they're not talking specifically enough about what you actually feel within your body is which emotion."

Feeling empowered:

For now, given the absence of available treatments for alexithymia, Stephen plans to use his newfound understanding of himself, gained through therapy, to try to move forward. At first, he says, he hoped that therapy would fix everything. "I thought every day would be perfect, brilliant ... and I've come to realize that's not going to happen. I'm always going to have problems, always going to have issues."

He's learned valuable lessons, he says. Though he and his wife are still separated, they talk regularly and now he tries not to reject her views on his anxiety. "Rather than go, 'No,' I will listen. I think, 'Well, you know what emotions are about and I don't, so I'm going to listen to you and I'll either take it on board or I'll find a way to deal with it.'" He's also thinking about moving to work with people who are struggling with substance abuse, because he'd like to be back in a career where he can help people.

Most of all, he's determined to use his diagnosis of alexithymia. "For me, it empowers me -- now I know about it, I can read about it. I can find out more about it. And I can develop certain tools that enable me to combat it."

People without alexithymia could probably use such tools as well. Bird has led work showing that people who are more aware of their own heartbeat are better able to recognize others' emotions, a crucial first step in being empathetic. He's planning studies to investigate whether heartbeat training might therefore increase empathy.

Those who want to lower feelings of stress and anxiety in daily life, but who either can't or don't want to change the sources of stress, could focus on changing the signals coming from their bodies instead. Regular physical exercise should dampen down the kinds of bodily signals (from the heart and circulation, for example) that the brain could interpret as being anxious -- so it should dampen down feelings of anxiety, too.

Knowing that signals from our bodies underpin our emotions could be empowering for all of us. Now, how does that make you feel?

*This story originally appeared on **Mosaic**. It has been edited to reflect Spectrum's style.*