

## Why are so many of us over-sensitive?

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When a gentle glow feels like a spotlight and everyday sounds hurt your ears, life can get anxious and painful. But, discovers Emma Young, there may be an upside to being highly sensitive.

At the age of six, Jack Craven started telling his mother he wanted to die. "God made a mistake when he made me," he would say. "Why can't I just die?" His mother, Lori Craven, says she didn't even know that kids his age could think such things: "Can you imagine your child saying that?"

Jack, now 12, has sensory processing disorder (SPD). It's a contentious diagnosis. Some doctors will argue that it doesn't really exist, while those who recognise it estimate that sensory issues affect between 5 and 16 per cent of us. For some people, this means they are over-sensitive to lights or sounds, but there are others for whom a caress feels like sandpaper tearing their skin, and there are babies who will scream and won't sleep unless they are held tightly and bolt upright. It can make what many of us take for granted as 'normal' life practically impossible.

As a toddler, Jack had found it unbearable to be anywhere loud: "There was a lot of screaming if it was noisy," Lori recalls. "Actually, there was just a lot of screaming from him." At school, "he was like a deer in headlights". Jack is a bright boy, but the environment was so overwhelming he couldn't perform well. He would come home and tell Lori that the other kids were saying he was "stupid", "a dummy". Now she schools him at home herself and every day, in everything they do, they have to consider Jack's sensitivities, she says.

Despite the difficulties, however, some adults and some parents of kids with SPD report an upside. As well as being more reactive to physical sensations, they're also more sensitive to other people's emotions. To researchers, this is intriguing. Could sensory processing help explain the personalities of people we might otherwise just think of as 'sensitive'? Might people with SPD even be at the extreme end of a spectrum of sensitivity that developed as an evolutionary advantage?

"How am I feeling in this room right now? Horrible. This is a terrible room. I'm trying not to focus on the lights and let them bother me. I'm trying not to listen to that echo – because I'm hearing my voice in my throat, and in the air and bouncing off the walls. And we are sitting with this gap behind us, so I'm floating in the middle of the room and a piece of me is going, 'I hope this doesn't screw me up for when I have to be on stage'... I guess the door is locked? No one's coming in, right?"

It's a little after midday on a bright cold Tuesday in Chicago, and Rachel S Schneider is describing what it's like for her to be in what to most people would seem a bland ante-room to the hall in which she will shortly be speaking. If being in here is so discomfiting, the flight from New York, where she lives, must have been torture? She nods.

Schneider was 27 when she was diagnosed with SPD in 2010. For her, it means she's particularly over-sensitive to sights and sounds. No one likes a spotlight in the face or the sound of nails on a blackboard, but to Schneider a glow can feel like a spotlight. For her, an echo is as intrusive and attention-seizing as scraping nails. She also struggles with a lesser-known sense called proprioception – the sense of where your body parts are in space. For this reason, she thinks, she enjoys pressure on her body ("I'm a hugger!").

She's been hyper since she burst into the room, fuelled by excitement (relating to the symposium she'll shortly be addressing) and anxiety

(relating to her talk, the travel, this interview, this room). When we get on to talking about recent neurological research into SPD, she practically bangs her fist on the table. "It was pivotal!" she says. "PIVOTAL! When I first heard about it, I was so excited, I wanted to throw a parade!" She pauses for a moment. "And I don't like parades."

The parade would have been for Professor Elysa Marco at the University of California, San Francisco (UCSF). Marco is a paediatric neurologist and is now regarded as a leading expert on SPD. Back up six years, though, and she hadn't even heard of it. She was, however, starting to think more about the role of sensory problems in the symptoms of many of her young patients.

In her consulting rooms, she was seeing kids with a range of brain-related difficulties. "And what I realised was that the families were coming in, and I would want to talk about the kids' seizures or their headaches or their language problems in the case of, say, kids with autism," she says. "And the parents wanted to talk about that also.

"But what they really wanted to talk about was the minute by minute, the day by day, which was so hard because they couldn't get their kids into the shower to wash their hair because the kids wouldn't let them touch their heads, or they couldn't get a shirt on them because they would scream bloody murder, or they couldn't make soup in the kitchen with the blender because the kid would cover their ears and run out the door."

In the 1960s, Jean Ayres, an occupational therapist and educational psychologist working in California, first identified SPD (or sensory integration disorder, as she called it then) as something distinct. For people who accept SPD as a disorder, what unifies patients is that while their sense organs work normally, their brains do not respond typically to the data those organs send on. Some people with SPD are 'under-responsive' (they crave the stimulation of one or more senses), while

many are 'over-responsive' to one or two senses, or more. Some people are under-responsive in some senses and over-sensitive in others.

Lucy Jane Miller was one of Ayres's students, and has researched SPD for more than 30 years. Now a professor of paediatrics at Rocky Mountain University of Health Professions in Colorado, and the founder of the Sensory Processing Disorder Foundation, she has developed assessment scales for diagnosis, coordinated research into therapies and done all she can to spread the word that SPD exists. But the recognition she has long fought for – the recognition that a listing in the Diagnostic and Statistical Manual of Mental Disorders (or DSM, sometimes called the 'bible' of psychiatrists and psychologists) would provide – still eludes her.

In the summer of 2008, Miller gave a presentation at the UC Davis Medical Investigation of Neurodevelopmental Disorders (MIND) Institute about problems with sensory processing. Elysa Marco was in the audience. "It was as though a big bright light turned on for me," Marco recalls. "I was very excited. I thought: okay, this is the way I need to think about and study my kids."

After the talk, she went up to Miller and told her she was already planning a study at UCSF to image the brains of children with autism; perhaps she could use brain imaging to investigate SPD too? Miller helped Marco get the funding she needed, and the "pivotal" research that followed changed Rachel Schneider's life.

The first experiments, whose results were published in 2013, used magnetic resonance imaging (MRI) to look at the brains of kids with SPD and a group of controls without any disorder. The results showed measurable differences in brain structure, primarily in areas towards the back of the brain that connect regions involved in processing visual, aural and touch data. (A bigger follow-up supporting these findings was

published in 2016.)

A second paper, published in 2014, compared children who had SPD with autistic children, because there are overlaps between the two conditions. According to some estimates, as many as 90 per cent of people with autism have sensory processing problems, but Marco wanted to confirm that SPD could also occur without autism.

While there were some similarities, she also found significant differences: the SPD kids had less white matter – the 'wiring' that connects parts of the brain together – in some sensory-related regions, whereas the children with autism had impairments in brain circuits essential for processing the emotions on people's faces, which the SPD children did not. Or, as Schneider puts it: "The first study said, 'Cool, we established SPD exists', and now, 'Here it is compared to autism, and – guess what – it looks different in the brain, guys!'"

These studies are crucial for Schneider because they provide evidence that SPD is a neurological disorder. Her whole life, she explains, she has struggled with her symptoms. She's a warm, friendly, outgoing person, but she shrank from family outings as a kid, found it hard to fit in at school because social gatherings like parties were overwhelming, had what she calls 'shutdowns' in the street that were diagnosed as panic attacks, and had to wait until she was 27 even to hear about SPD – only to learn that it was not well-understood or widely accepted. Then the brain-imaging studies were published. "For the first time in my entire existence, there was proof that I am different."

There was still resistance to the idea of SPD, however. In 2012, the American Academy of Pediatrics put out a statement saying: "It's unclear whether children with sensory-based problems have an actual disorder related to the sensory pathways of the brain, or whether these problems are due to an underlying developmental disorder," such as

autism, ADHD (attention deficit hyperactivity disorder) or anxiety disorder. Even since Marco's ground-breaking papers were published, caution has persisted among many paediatricians.

Thomas Boyce, a professor of paediatrics at UCSF, is sceptical but not dismissive: "I think there's undoubtedly something there," he says. "And it may well be that there is a sensory processing disorder... I just think we don't understand enough yet."

Sensory sensitivities are not uncommon in childhood. One survey of parents in the USA found that 16 per cent of children were 'over-responsive' to some form of sensory stimulus, while another found that based on their parents' responses, at least 5 per cent of school-age kids met the criteria for SPD. "If you can take your child to the fireworks and they cover their ears and they make it through, then they go home and they are back to normal and everything is fine... then bring earplugs," explains Marco.

"But if you can't take them anywhere there might be a popping noise, or every time you vacuum the house they are screaming for hours on end, or you put diapers on them and they scream and claw at their skin, then you cross the line."

When Jack Craven was 10, his mum Lori took him to see Marco in San Francisco. They found themselves staying in a rough part of town. "As soon as we walked out of the hotel, Jack would grab our hands really tight and he was shaking, he was terrified," she recalls. "He said, 'I don't like San Francisco! There are too many sad people!'" At home, Lori, her husband and their daughter can never react with anything other than warmth to whatever Jack does or says, no matter how hurtful it is. If they react with disapproval, "we've got an explosion on our hands".

Our senses provide information about our world, including other people.

We constantly offer each other visual and auditory clues to our emotional states through our facial expressions, our tone of voice, our posture. Our brains pick up this information instantaneously and subconsciously. In one experiment, Tania Singer, a director at the Max Planck Institute for Human Cognitive and Brain Sciences in Leipzig, Germany, and a pioneer in the field of social neuroscience, found that about a quarter of volunteers experienced a surge in their levels of the stress hormone cortisol just by watching other people undergoing a stressful experience. This is called subconscious 'emotion contagion'.

And if visual and auditory data provide information about someone else's fear or anger, for example, it doesn't seem a great leap to think that people with pronounced sensory sensitivities, like Jack, will get more of this information and respond to it more strongly. When Rachel Schneider says, "Someone can walk into a room, and right away, I'll know how they're feeling, and how I'm going to feel around them," that fits too.

Emotion contagion is thought to be the basis on which empathy – an understanding of how someone is feeling and a sharing of their emotion – is built. There is research suggesting a link: Singer has found that people who are more susceptible to emotion contagion also score higher on empathy questionnaires.

Singer has not studied people with SPD. But Elysa Marco is receptive to the idea that over-responsive SPD kids and adults fall at the extreme end of a spectrum of general sensitivity to the environment that includes other people. And for her, there's yet another way of thinking about them: as extreme 'orchids'.

Ask a non-psychologist what a 'sensitive' person is like, and they might say someone who's easily hurt by a jibe, who cries at sad (or sometimes happy) moments in movies, who prefers the company of a single friend

or a book of poetry to a party. Psychologists don't define the word in quite the same way (though crying over a film, enjoying poetry and avoiding parties can still fit right in).

At a café in Tiburon, a quiet town in Marin County, just across the bay from San Francisco, psychologist Elaine Aron is explaining what being a 'sensitive' person means to her. "The most important aspect is that they process information more deeply and thoroughly," she says. "The things people notice about some of them are the surface behaviours, like being upset by too much noise or crying easily or not liking to be rushed on a decision, but underneath that there is this depth of processing."

Aron has pioneered the scientific study of the 'highly sensitive person' (HSP), which she thinks is a distinct personality type – underpinned by what she terms 'sensory processing sensitivity' – and one that can be identified not only in humans but in over 100 different species of animal. It's not the same as introversion (about 30 per cent of the people she has studied are extravert). But highly sensitive people and animals generally approach situations, including social interactions, more cautiously. They 'pause and reflect' rather than rushing in. They notice more about their environment, and can use that information to help them to survive and, ideally, thrive.

Her 27-point checklist, used to find out if someone falls into this category, asks you to tick statements that apply to you, such as 'Other people's moods affect me', 'I make it a point to avoid violent movies and TV shows', 'I seem to be aware of subtleties in my environment', 'I am made uncomfortable by loud noises', 'I am conscientious' and 'I make it a high priority to arrange my life to avoid upsetting or overwhelming situations'.

"I think I'd probably tick every one," Aron smiles. In fact, it was being called "sensitive" by a therapist back in 1990 that originally sparked her



curiosity about what that means scientifically.

Based on her work and that of others, she thinks that perhaps around 20 per cent of the population are HSPs, and that within that group there's a spectrum of sensitivity – but that the rest of us don't fall on it. Most of us, she argues, are simply not 'sensitive', and the difference this makes is as big as gender. "How it impacts people is enormous," she says.

It isn't only Aron who divides people into sensitive and non-sensitive types. Thomas Boyce classifies kids as either 'dandelions', who will do pretty much the same anywhere, provided their environment isn't excessively harsh (about 80 per cent of kids), or as 'orchids', who are highly sensitive to their environment (the other 20 per cent). Orchids are more "permeable", Boyce says, to their surroundings. In difficult environments, they do badly. But in supportive environments, they actually do better than dandelions.

Both Aron and Marco admire this work. Aron thinks Boyce's orchids are her HSPs, and Boyce agrees. "What she sees in her primarily adult patients is very close to what we are seeing in orchid children," he says.

Aron and Boyce believe there's an evolutionary benefit to having different psychological types in the population, including HSPs. Those who pay close attention to their environment – notice more, take more in – will do better in some circumstances, while bold, adventurous, thrill-seeking types will be more likely to succeed in others. The observation of more-sensitive, environmentally aware and also bold, less-sensitive individuals in a wide range of animals, from birds to fish, supports this idea.

But where do people with SPD fit in? Marco thinks that some of her over-sensitive patients sit on the extreme end of the orchid spectrum. Aron is not so sure; her feeling is that they are different in kind. People

with SPD who are over-responsive are more distracted by sensory input than able to use it to garner useful information about their environment, she argues. Boyce is not convinced either. While sensory sensitivity is a hallmark of an orchid child, he thinks there are other differences in orchid brain functioning – differences that mean they process information about their environment more deeply.

Still, Michael Pluess, a senior lecturer at Queen Mary University of London, who studies the same groups as Boyce but uses the term 'environmentally sensitive' rather than 'orchid', comments: "I would expect that people scoring high on HSP are more likely to also be diagnosed with SPD."

Once a patient is diagnosed, the next step is treatment – not to remove the sensitivity, given its potential benefits, but to make living with it less traumatic. At the moment, occupational therapy is often used to design specific programmes depending on the symptoms. Schneider says that, for example, jumping on the spot and doing 'push-ups' against the wall helps to calm her, as does using a 'skin brush' to brush her limbs and torso (she uses such a brush before she sits down with me).

Treatments can also include drugs for anxiety or those used in ADHD, but other options may be on the way. With colleagues, Marco is involved in work on a computer game, called Evo, designed to help train attention. About 40 per cent of kids with SPD also meet the diagnostic criteria for ADHD, and if you can use Evo to improve someone's attention to a stimulus, you should be able to improve their ability to process it accurately, Marco argues. A research study of using this game hasn't yet been published, so she won't reveal details, but she does say that "we're showing some really nice improvements, and some brain changes". Jack Craven was one of the kids who took part in the study – anecdotally, his mother reports big improvements in his ability to take in visual information.

Marco is also investigating the genetics of SPD and how it compares to autism and ADHD. While these are all distinct diagnostic labels, they apply to groups of symptoms that often overlap. It's easy to see how a child who can't concentrate at school because her SPD means she's focusing on the clicking of a fan or the scratch of her neighbour's pencil might get labelled as having attention deficit disorder; or how a child who wants to run around endlessly because he craves sensory input about the location of his body parts in space might get labelled as hyperactive; or how a child who cannot properly process visual information about a face might struggle to understand what someone else is thinking and be diagnosed as autistic.

"There are overlapping genetics for all these brain-based conditions," Marco says. "The labels are simply behavioural descriptions."

For Rachel Schneider, recognising SPD as a distinct disorder is essential, because it would cut the number of people who grow up, as she did, not understanding what is wrong with them – and being dismissed, or worse, as a result. She is now well-known as an advocate within the SPD community – she's written a book, and has a blog and a Facebook page through which many fellow sufferers contact her.

She puts me in touch with Sean (not his real name) in Florida, who has just turned 21. He's lived with what he now knows to be SPD ever since he can remember. At school, he wouldn't say the lights were painful because he thought it would sound weird, so he'd say he had a headache, but his parents and teachers came to think he was just looking for ways to skip class. At the start of 2016, he tells me, he finally summoned the courage to describe his everyday experiences to his mother. "She said, 'Sean, that sounds like a crazy person'... She told me she deserves a better son than me."

Sean's experience is far from unique, according to Schneider. And it was

the stories of people like Sean, as well as their own experiences, that persuaded Schneider and Kelly Jurecko – who runs SPD Parent Zone, an organisation that provides information to parents of SPD kids – to launch a new initiative called Sensory Is Real in April 2016. "We, the people of the Sensory Community, decree that sensory issues exist and are worthy of your attention, understanding, and acceptance," its manifesto says.

When I meet Schneider, she's in Chicago to talk at an event on how to improve the accessibility of places like museums, theatres and zoos for people with [sensory processing](#) problems. The large sunlit hall is already packed with representatives from local cultural institutions. She's waiting nervously in the ante-room, worrying about the disturbing reflections off the hall's highly patterned marble walls. But she knows that afterwards, her husband Josh (whom she only half-jokingly calls her 'handler') will rub her back in broad circles to help calm her.

"So many SPD adults have secondary anxiety," she tells me. "There are a lot of psychological conditions affiliated with this, because for so long, the sentence in your head is: 'I can't do this, what is wrong with me, I can't do this, everybody hates me, I'm embarrassing, life is painful and difficult, I can't do this.' So I'm trying to change the dialogue to: 'It's a little bit difficult, you have to change how you do things... but yes, you can.'"

Then she goes into the hall, overcomes the reflections and the anxiety, and starts to speak.

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