



**ADULT AUTISM:
HIDDEN**

IN

PLAIN

SIGHT

Sometimes the condition is not diagnosed until well into adulthood. The news can be both a shock and a relief.

BY Lisa Fields



AFTER A PARTICULARLY stressful day at work three years ago, Jo Bervoets, 51, an engineer from Antwerp, Belgium, headed home, only to discover the train station was noisier and more chaotic than usual.

"I was already a little bit lost in my head before I went to the train station," says Bervoets. He had recently started a new job, and the fact that he couldn't connect with his new coworkers had left him feeling anxious. "I just took whatever train was going in the direction of Antwerp."

When the train pulled into his station, Bervoets headed for the shared-bike station where he usually grabbed a bicycle to pedal to his neighborhood, but there was none available. Feeling overwhelmed, he suddenly realized that he didn't know how to get home.

"I phoned my wife, and somehow I got home," Bervoets says. After three months at his new job, he'd burned out. "I completely crashed, and it was black." He says his memory is still fuzzy about what happened that day.

Too upset to return to work the next day, Bervoets consulted a psychiatrist. She decided to send him to another specialist for testing. After two months of evaluation, he received a formal diagnosis: autism.

"It was a surprise," says Bervoets. He and his wife, Els, did some online research and quickly realized that the

diagnosis explained some of his odd behavior, such as insisting that things had to be in a certain place and turning off the lights in a particular order. "Very quickly, it made sense," he says. "It was a relief."

ABOUT AUTISM

Autism is a developmental disability that impacts the way that people interact and communicate with others throughout their lifetimes. Experts are not sure what causes the condition, but people may have a genetic predisposition toward autism, which sometimes runs in families. Autism is also more common among people who have sensory processing disorders, which makes people abnormally sensitive to things that affect any of their five senses, such as loud noises.

Autism was once believed to be rare, but studies show that it affects about 1 in 100 people. An estimated seven million people in Europe have some form of autism.

Males are more likely to be diagnosed than females, although experts aren't sure why. Some theorize that females may be less likely to inherit the condition, while others hold that autism presents differently in females, leading to underdiagnosis.

"It seems that there might be a 'female autism phenotype,' which doesn't fit with the profile usually associated with men and boys on which assessment tools are usually based," says Aurélie Baranger, director of Autism-Europe,

a Brussels-based advocacy group.

Symptoms include a wide range of disabilities, which appear early in childhood, with diagnosis after the age of four, on average. Doctors use the term "autism spectrum disorder" to encompass everyone who's been diagnosed. At one end of the spectrum, symptoms are so severe that people who don't get the right support are unable to communicate, and require lifelong assistance. At the other end of the spectrum, people have such subtle symptoms that they may function like anyone else (perhaps with some odd habits), and their autism may go undetected well into adulthood.

People with autism may follow strict routines and focus on their own narrow interests. But this is not true for everyone with the condition.

"I don't think you can generalize anything with regards to autism, but many have this idea of hypersensitivity and the world being too much," says Kristien Hens, an autism researcher at the University of Antwerp. "The world is too fast and they have to take more time to process the information that they receive."

Although everyone with autism experiences the condition differently, people may have certain traits in common. Many, for example, have trouble making decisions, are confused by facial expressions, and have trouble navigating social situations.

"Many autistic people have difficulty with executive functioning," says Baranger. "They may have trouble with



Says Diederik Weve, a chemical engineer from The Hague, "Accepting it gave me a new perspective on life."

certain skills like planning, staying organized, sequencing information, and self-regulating emotions. It can have a significant impact on their daily life."

BLENDING IN

Autism awareness has become more widespread this century, and greater numbers of children with subtle symptoms are now diagnosed at young ages. But decades ago, doctors rarely diagnosed people toward the subtler end of the spectrum.

"Fifty years ago, nobody would call autism what we call autism today—they would just be considered quirky,"

ILLUSTRATION, PREVIOUS SPREAD: ©SHUTTERSTOCK

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says Hens. “We no longer see autism as this kind of condition where children are completely locked up in themselves and have no contact; it has become a condition with a very wide definition.”

Those who were diagnosed as adults often blended into society during childhood.

“They were able to manage daily life by learning social rules through observing others and using logic and reasoning to develop ‘scripts’ or ‘formulas,’” says Victoria Russ, a psychology researcher at Southampton

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University in the UK. “This method of learning social behavior helps individuals to develop strategies to fit in.”

Imitating the behavior of their peers is often effective, says Dr. Bojan Mirkovic, a psychiatrist who studies Asperger’s syndrome at University Hospital Pitié-Salpêtrière in Paris. But, he adds, “It involves a very large cognitive effort that may become exhausting and lead to depression.” Asperger’s is an autism condition characterized by the desire to focus conversations on specific intellectual interests. Current

practice is to phase out the diagnosis of Asperger’s in favour of autism spectrum disorder.

It can be exhausting, says Bervoets. “You go to receptions, and you need to think about how many kisses are given, where to stand, when to make eye contact. All of these things normal people don’t have to think about, we need to think about.”

Indeed, Bervoets believes that the feelings of depression he struggled with throughout his life might, in reality, have been exhaustion caused by “trying to cope and to compensate” for his undiagnosed autism.

REACHING SIGNIFICANT MILESTONES

Many people graduate from college, have meaningful careers, get married and become parents before learning, in middle age or beyond, that they’re on the autism spectrum.

“A career which harnesses an individual’s strengths, and one which creates a level of predictability, routine, and structure to life, can enable someone to have a fulfilling and successful life,” Russ says.

Diederik Weve, 62, a safety engineer from The Hague, Netherlands, sought a diagnosis ten years ago after friends recognized similar behaviors in a friend’s autistic child. He received an Asperger’s diagnosis.

“The autism fitted me,” he says. “Accepting it gave me a new perspective on life.”

Before he even knew he had it, Weve says, autism shaped his career “in a way.” He recognized that he functioned best when he was able to solve things on his own. “I always found in my career that it was best to be a specialist in a niche area so that people would come to me rather than the other way around.”

AUTISM IN THE WORKPLACE

Although many autistic people find jobs that suit them, the condition is associated with underemployment. Some people take positions beneath their abilities because they can’t handle the stress of too much responsibility or because depression, anxiety, or autism-related disabilities may prove too challenging.

Peter Street, 71, of Wigan, England, was diagnosed with autism at age 64. His problems started in childhood. “I couldn’t do English, maths—couldn’t do anything in the classroom, really,” he says. “I’d end up with ink all over me, and I kept wondering why the other children could do things—simple things—and I couldn’t.”

He was held back twice during school, then dropped out at age 15. He worked as a gravedigger for years, then became a gardener and later a forester. He didn’t become literate for years. In 1982, Street was hospitalized after an accident and befriended a fellow patient, a literature teacher, who tutored him and encouraged him to write. Street has since published four



Peter Street didn’t do well at school when he was a boy. He is now a published author.

volumes of poetry and a memoir.

Inability to connect meaningfully with colleagues or go with the flow may limit people’s upward mobility or earning potential, even if they’re successful professors or engineers. A 2017 British survey of 2,471 people, published in the journal *Molecular Autism*, found that autistic traits were negatively related to income.

“Although there are some roles where technical skills are paramount, it is hard to imagine a workplace or role for which it is not also useful to be skilled at processing social information,” says study author William Skylark, senior lecturer in psychology at Cambridge University.

Researchers have also found that autistic adults are less empathetic, which may limit their success in social or professional situations. A 2018 study published in the *Journal of Autism and Developmental Disorders* studied 173 adults who were sent for autism

PHOTO BY JOHN BENTLEY

assessments. It found that those who received an autism diagnosis tended to have lower scores on a questionnaire that measured how well someone understands others' feelings.

Research has demonstrated that people with autism also have difficulties with understanding what one person thinks about another person's thoughts, understanding non-literal expressions, and understanding the beliefs, intentions, and meanings of indirect remarks or sarcasm.

Empathy is a core skill needed for social interactions; without it, people may have trouble making friends or dating. Street is glad to have met his wife of 50 years through a mutual friend.

"Dating was an absolute nightmare for me," Street says. "I hadn't a clue about it."

DIAGNOSIS CAN BE A RELIEF

Some adults, like Bervoets, are diagnosed after seeing a mental-health professional. Others seek diagnoses because they recognize autistic qualities in themselves after learning about the condition. "They can discover that they are on the autism spectrum when their own children are being diagnosed," Baranger says.

The news comes as a relief for many adults, who suddenly understand why they've always felt differently than others. "For some people," Baranger says, "it alleviates the sense of guilt that

they have experienced throughout their life, notably because they have been blamed for their behaviors since childhood."

Bervoets' diagnosis helped him realize that he'd rather study philosophy, a lifelong passion, than continue working as an engineer. He's working toward his PhD.

Diagnoses may help people redefine previous experiences. "They finally manage to explain why...they have often messed up their job in interviews or why they are accused of failing to express their emotions or understand jokes," Dr. Mirkovic says. "This is an essential step toward improved well-being."

Street's belated diagnosis provided a much-needed explanation of his youth. "When I was diagnosed, I started crying happy tears," Street says. "That's made me realize that none of it was my fault."

PROS AND CONS OF SOCIAL SUPPORT

When children are diagnosed with autism, they may receive social support to help them fit into society more readily. Similar services may not always be available to help newly diagnosed adults.

"What follows the diagnosis is very variable depending on the impact the disorder has," Dr. Mirkovic says. "Some will need to undertake behavioral psychotherapy to help them find compensation strategies, while others will need to work on social skills or on a career

reorientation."

Some people are set in their ways, content with the lives that they have. "I have had people who said, 'This is me, take it or leave it,'" says Hens.

After Bervoets was diagnosed, he was advised to do talk therapy, but stopped because it wasn't helping. "The more I reflected on my behavior, the worse I felt," he says. "I try to understand why other people sometimes get upset, but I do not reflect too much on changing further."

The couple accept that the condition is, and always was, a part of their lives. Says Bervoets' wife, Els, "He was always a certain kind of person, and he still is that person. That doesn't change."

"I'm a philosopher now," Bervoets says. "I'm an engineer. I'm a father. I'm a good husband, I think. I'm a lot of things. I'm also autistic, and I'm proud to be autistic. But focusing only on autism diminishes the horizon you have on the world." ♦

WERE THEY ON THE SPECTRUM?

Long before autism was recognized, notable historic figures were busy contributing to math, science, philosophy, art and literature while exhibiting autistic traits. Michael Fitzgerald, adjunct professor of psychiatry at Trinity College Dublin, has studied the lives of prominent historic figures and concluded that several may have had autism.

♦ **Charles Darwin** was obsessed with his interests, rarely swayed from his daily routine, and reportedly had a lack of empathy.

♦ **Thomas Jefferson** was socially awkward, lacked empathy, followed strict routines, and obsessively focused on his interests.

♦ **Isaac Newton** couldn't interact with his peers, was hyperfocused on

his work and couldn't understand facial expressions or body language.

♦ **Gregor Mendel** followed strict daily routines, was obsessed with his work and was socially awkward.

Their enduring achievements stand as a testament to their ability to accomplish great things despite—or perhaps because of—their condition.