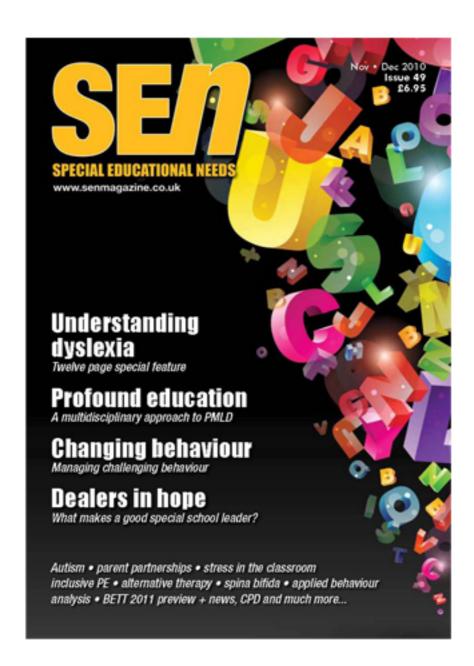
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AUTISM



## The journey of a lifetime

**Wendy Lawson** charts her lifelong struggle with autism, through isolation, obsession and an abusive marriage, on the road to self-realisation and fulfilment

### Early childhood

As a toddler, I was diagnosed as being intellectually disabled. I didn't talk until after my fourth birthday but I got all I wanted by leading my mother by the hand and pointing out what I needed from her. I was an independent child with a real passion for life. I was not shy and I frequently went off with strangers. On reflection, I believe my disposition and the expectation that life would be good and interesting, with exciting things to seek out and explore, held me in good stead. However, while this personality trait has probably been one of my greatest assets, it may also have left me predisposed to being vulnerable, gullible and open to abuse. I didn't receive my

current assessment of high functioning autism until I was 42 years old.

I recently took part in the BBC's Big Personality Test which gave me a summary of my particular personality. One of the things it said was that I scored extremely high on "agreeableness" which was described by the test's authors thus: "Agreeableness relates to a person's ability to understand other people's thoughts and feelings. It may be that this greater awareness of the

I chose to retreat to an inner world that I had control over

feelings of others is what leads them to experience generally higher relationship entirefaction."

However, I interpret my results a little differently. What they call "agreeableness" I see as my difficulty with knowing when and how to say "no". Indeed, I have tended, throughout my life, to say "yes" because it got me into less trouble than saying no. So this was not so much a proclivity to empathy as simply not knowing how to be any other way.

My personality disposition aside, the world went on around me. Even though I was scared of sudden noises and would jump at invasive sounds, I seemed unaware of other people most of the time. I always enjoyed my own company, loved the outdoor life and was forever bringing home animals, expecting that my parents would let me keep them.

I regularly escaped from our home and garden and found myself at the sea or in the company of travellers from a local site who were welcoming, encouraging and accepting of me.

Looking back, I can see that the people who supported me most in my early years included my neighbour, a young twelve-year-old girl, the daughter of two of the travellers and certain teachers in primary school who seemed to understand my need to be on the move. The things that hindered me most were my sensory "hurts", such as sounds, irritating clothing and difficulties with judging depth & distance, which made it hard to interact with other children, cross roads safely or feel at home in my own body.

### Growing up

As I grew older, my strongest attachments were to my pets, and the kitten my grandmother gave me seemed like my only real companion. At school I felt confused and alone. I was often teased and mocked by other children and most of the time I didn't know what was going on. I did my best to please the teachers and would form over-attachments to particular children or teachers.

When I was nearly ten years old, I had to go to hospital for almost a year because of a bone infection in my leg. Although this was a very traumatic time, it was also very stabilizing because the ward routine gave me a measure of security. There were many things that didn't make sense to me, but the structure, the hospital routine and the nursing staff helped me to find a place and a role.

For my tenth birthday the nurses brought in a small cup cake with a large white candle in the middle. All the children sang Happy Birthday and many gathered around my bed. I dived

# After attempting suicide at the age of seventeen, I was committed to a mental institution

under the sheets and pretended to be asleep until they gave up and went away. I couldn't face them because I didn't know what to do. My heart beat fast and I felt really scared, so I did what I usually did: I ignored them and hoped they would go away. This was a common way of coping for me. If I didn't understand something or was unsure of how to respond, I ignored the situation. I chose to retreat to an inner world that I had control over and, when that failed, I returned to various obsessive behaviours that gave me back a sense of connection.

In many ways, routine, ritual and familiarity have been more friend than foe. I still need these in my life and without them I flounder. The only time I cope well with a lack of familiarity is when I am travelling on tour with a lecture program. Under such circumstances, I have to trust others to know what I need, what works for me and to take charge of various arrangements. It is as if I pass my need for structure over to others, and the routine is in letting them do it for me. While at home I eat from a favourite red enamel plate, drink from a favoured mug, sit in my chair and operate from my designated routine, on the road I let all of this go.

### Teenage years

From the age of about thirteen, I began to grasp the reality that I was different to most people around me. I found this realization quite depressing and worked extremely hard to discover how to be like others. I became an ardent reader of books, mostly either about history or animals. I had few friends who tolerated my strange behaviour and when I did find a friend, I latched onto them in an obsessive way. That person then



dominated my existence, which was very difficult for them, as well as for me.

After attempting suicide at the age of seventeen, I was committed to a mental institution, labelled schizophrenic and treated with anti-psychotic medication. For the next 25 years, I lived with that diagnosis and was forever on and off medication whilst going in and out of hospital. However, I managed to study at college, join a church and even have a boyfriend during my late teens.

I received a lot of help from people at church, who seemed open and accepting of my difference, and my life seemed most settled when I was away from home in a structured environment where my daily routine was set out for me. One of the most successful strategies I employed during this period was to write and record events, often as poetry, so that I could read them over and over again. This helped me build up my understanding, particularly of my social difficulties, which were my biggest problems during this period. I did not know how to behave appropriately, struggled with small talk, and caused problems with my obsessive overattachments to others.

#### Adult life

Unfortunately, my gullibility and disposition for forming inappropriate relationships became the driving force behind my choice of partner. I married

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## I could have been closed off for ever if certain people had not taken risks with me

at the age of 20 and eventually had four children. But the partner I chose was a young man with poor self-esteem who needed to be in control of me and was emotionally and, eventually, physically abusive. I established daily routines for our household to operate by and this strategy helped me maintain not only family life, but also my own sanity. However, after nearly 20 years, my husband and I divorced and, although this was a necessary step, I was not used to taking care of daily life on my own, so life seemed very bleak for some time

Recognising and accepting that I am not heterosexual has been a gradual awakening. Today, I live with Beatrice, my partner of 26 years, and her constant support and companionship have enabled me to be the person I am. With her encouragement, and that of many of my friends, I recently completed a PhD in psychology at Deakin University, Australia which has enabled me to fulfil a long-term goal of becoming a psychologist.

As for my family, my middle son was tragically killed at age nineteen by a very drunk driver, but my other three children have grown into independent adults. My youngest son, now 28, also has high functioning autism. He is working as a chef in a busy inner-city deli in Melbourne. I believe my eldest son to be on the autism spectrum too and he also lives with bi-polar disorder. But he keeps his life pretty steady and stable by doing what he loves most: playing music. My daughter is married and has given me two lovely granddaughters.

Through all the difficult years in a mental institution, the time spent in an abusive marriage, the strange years of divorce and the problems of coming to terms with my autism, I always believed life would deliver good things. That I have been able to achieve many of my goals is due, in part, to my own personality, but also, in no small measure, to help from my friends and some family members.

I feel I have woken up over the last fifteen years. It may have taken me a lot longer than most people to grow up, and I still have a long way to go, but it is scary to think that I could have been closed off for ever if certain people had not taken risks with me or had given up on me completely.



Wendy receiving fourth place in Australian of the Year awards, with son Tim, daughter Katy (far right) and partner Beatrice.

### Helping people with autism

A life spent coming to terms with autism has, I believe, taught me a little about some of the practical ways in which people can help those on the autistic spectrum. The foundation for feeling good about who we are and believing that we are worthwhile comes from feeling valued. It is essential that others believe in us to enable us to function to the best of our ability. Building upon this foundation, we can attempt to reach out and take chances and have the confidence to keep trying when things don't go according to plan.

The support of those who help us remember the things we do well, rather than pointing out when things go wrong, can be invaluable. As we build skills and accomplish small things, such as the daily successes associated with self-help or basic goals in education or budgeting, we can build bigger dreams and explore ways to make these happen. And we need others to walk with us in our dreams. While these dreams may, at times, outstrip reality, by mapping out the small steps necessary to achieving our daily goals, such as getting up, having a shower, getting dressed and going to school, other people can really help us build a future we want.

For those of us with autism, our brains are configured to have a single focus and to pay attention to just one thing at a time. This is not a choice but our default setting. By harnessing our unique interests to capture our attention, those around us can help to ensure that our future goals remain within our grasp and achievable. It is also important that our particular learning style is understood and accommodated.

As human beings, we all deserve the right to a future in which we feel valued, accepted and worthwhile. Throughout my journey to date, I have known many helpful people, I have benefited from the application of useful strategies to help me cope and I have made choices which have helped me along the way. I have also encountered people and situations that have hindered my progress and, of course, I have made some bad decisions. Separating all these factors out and understanding their roles in our lives is crucial. We need to evaluate all the events and environmental factors that help or hinder us in achieving our goals, then choose carefully those that support who we each are.

## **The Future**

A poem by Wendy Lawson

Life on earth is but a moment Caught within the crease of time. The seasons come and go again, You have your life, and I have mine.

The seed that's planted within the ground, Cannot choose what to become, A potato, an apple Or a rose for some.

However, for it to be the very best, It needs rich soil, not poor. The sun and the rains must come, To open that seed's door.

I may be born to nourish others,
I may delight the senses.
I may grow tall, I may grow small,
I may stay stunted beneath wire fences.

My future may not depend on my stock,
So much as it does upon sources.
Sources of warmth, sources of care,
I depend on the nurture to be for me there.

Then I can blossom and sing with the birds,
Then I can grow my potential.
So plant me in goodness and all that is fine,
Please keep the intruders away.
Give me a chance to develop, in time,
To become who I am, in life's future, one day!

This poem was originally published in *Build Your Own Life: a self-help guide to Asperger's syndrome* by Wendy Lawson (Jessica Kingsley Publishers, London, 2003).

### **Further information**

Dr Wendy Lawson lives in Australia and is well known in the UK as a conference speaker and campaigner for the rights for people with autism:

www.mugsy.org/wendy

For information about autism and sources of support, visit: www.autism.org.uk

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