ALTOGETHER AUTISM
JOURNAL
2025

ALTOGETHER AUTISM
TAKIWĀTANGA

Autistic and… making the invisible visible.

Altogether Autism is a free, nationwide autism information and advisory service provided as a partnership between Your Way I Kia Roha and Parent to Parent New Zealand.

With a vast amount of material available online, finding credible information on autism can be a challenge.

Altogether Autism provides tailor-made, relevant, evidence-based information, individually researched and collated by our information and research team.

Our team has the skills and experience to provide trusted information and can refer your more complex requests to our Advisory Group. This Advisory Group includes Autistic people, family/whānau and professionals.

Whether you are Autistic or you are family/whānau or a professional supporting an Autistic person, our service is free.

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We aim to include photos of Autistic people but those pictured may not be Autistic.

Photo credit: Luella Wheeler

We are pleased to be issuing this journal under our past National Manager, Catherine Trezona and new National Manager, Altogether Autism, April Johnson. We are very grateful to Catherine Trezona for her many years' contribution to Altogether Autism.

Nau mai, haere mai.

Catherine Trezona

In 2025 our Autistic Advisors chose a powerful theme for our Journal: "Autistic and… Making the Invisible Visible."

While there is much to celebrate about being Autistic, this theme highlights many overlooked aspects of autism—those complexities and experiences that so often come with autism. Or, as Tyrone Cook describes in his article, the 'flatmates' that live with his Autistic self.

We are deeply grateful to everyone who has shared their stories, artistic talents, insights and expertise. Together, we explore some of the unseen realities that are part of daily life for many Autistic people.

Ngā manaakitanga – with best wishes,

Catherine Trezona
National Manager, Altogether Autism

April Johnson – National Manager, Services and Altogether Autism

April Johnson (Waikato Tainui) has been appointed as the National Manager of Services and Altogether Autism at Your Way | Kia Roha.

April's leadership is deeply influenced by her family's lived experience of disability. With 14 years of experience working in the disability sector, April brings a combination of strategic leadership, cultural depth, and sector expertise to the role. Guided by the principles of manaakitanga and kaitiakitanga, she works to create environments where everyone feels respected, valued, and empowered to thrive.

Having previously served as an Information Advisor, Community Manager, and National Manager of Services, she is energised by the opportunity to bring her skills and lived experience to this new position. April says,

"I can't wait to dive deep into Altogether Autism, champion equity of outcomes and to see the voices of Autistic people heard."

April Johnson

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Cover art by Róisín Kelly

"Neurodivergence is not a puzzle to be solved, but a living, breathing spectrum to be honoured."

Created in response to Xabilities' call for designs that reflect neurodiversity in Aotearoa, Róisín Kelly brings the infinity loop to life as a guardian creature — adorned with kōwhai and pōhutukawa, grounded in Aotearoa, and coiled within a cosmos of diverse experiences. Each word floats like stardust, neither defining nor limiting the being at the centre. Instead, they orbit it, part of a vast and intricate constellation. This artwork invites us to look beyond categories and into the beauty, complexity, and strength of neurodivergent lives.

To learn more about the kaupapa visit: www.xabilities.com/colouring-competiton

Róisín Kelly Bio

Róisín Kelly is a professional illustrator, background, and storyboard artist based in Auckland, New Zealand. She holds a Bachelor's degree in Digital Design with a focus on 3D animation and has over eight years of experience in the animation industry. Currently, Róisín serves as a 2D Background Artist at Mukpuddy Animation, contributing to various projects such as "Badjelly," "Maia," and "Quimbo." Beyond her animation work, she has collaborated on medical illustrations and educational materials, showcasing her versatility across different artistic disciplines. Róisín's passion lies in background and concept art, storyboarding, and illustration, where she brings creative visions to life with depth and detail.

To see more of Roisin's art, visit www.rkcreator.com

My Autism has Flatmates

By Tyrone Cook

Being Autistic and having several co-occurring conditions is like living with some very unpredictable flatmates! Tyrone Cook shares this light-hearted look at how his Autisic self shares space with epilepsy, deafblindness, and a nervous system that sometimes has a mind of its own, leading to some hilarious (and frustrating) "flatmate disagreements".

Tyrone Cook sitting in his garden

Hi, my name is Tyrone. I am 45 years old (will be 46 in August), and I am Autistic. But as well as being Autistic, I have two rare syndromes called PHACES Syndrome and Functional Neurological Disorder (or FND). Because of these two syndromes, my autism shares my body with co-occurring conditions.

My autism lives with deafblindness, epilepsy, cardiac issues, skeletal and nervous system issues, diabetes, and limbs that work when they want to!

Sometimes, just like in an average flatting situation, there will be disagreements between the "flatmates" and the Autistic self. For example, my Autistic self wants to eat its favourite food that has been put in front of me for dinner. Epilepsy, on the other hand, decides "No, that's totally unacceptable!" Next thing my food is threatened to be thrown everywhere!

Another example of flatmate disagreement is while writing this article. My Autistic self was determined to have all these words written and get it in on time, my brain on the other hand was thinking "Nah, she'll be right".

There are also times when the flatmates get on just fine too, like they ALL love water. In water my body tends to behave (most of the time, though epilepsy does sometimes get a little too excited, and I will go absent). In water, my Autistic self gets to express itself, but when it's time to get out again it's all on because the flatmates know it's going to be cold!

My heart sometimes annoys my Autistic self too. We will be in our happy place and enjoying some TV or getting some sleep and my heart says "I think I will go faster than a racing car."

My nervous system likes to join in too, so I tell anyone dealing with my feet that they may want to stand to the side, or they may get a smack by a foot that unintentionally kicks them!

Yup, my Autistic self has flatmates and if I could share everything that goes on in the "flat", you would be reading a book!

The acronym PHACE stands for:

Posterior fossa brain malformations

Haemangiomas, particularly large, segmental facial lesions

Arterial anomalies

Cardiac (heart) anomalies and coarctation of the aorta

Eye and **E**ndocrine abnormalities

Tyrone Cook is a legally deafblind, minimally speaking, Autistic Christian from Hamilton, New Zealand. He finds joy in discussing topics like cats and space. His experiences during the COVID-19 lockdown were featured in the publication "Life in a Pandemic," published by Life Unlimited Charitable Trust in September 2020.

Obsessive Compulsive Disorder: another dimension of neurodifference

Content note: OCD themes discussed include fear of suicide, health anxiety and moral scrupulosity.

What happens when being Autistic interacts with having obsessive compulsive disorder (OCD)? Here four members of Fixate, a Facebook-based OCD community for Aotearoa, share their experiences.

A growing national community for individuals and their families

Fixate is a Facebook group that acts as an online community for people throughout Aotearoa who live with OCD or support a friend or family member living with OCD. Individuals connected via Fixate have begun to advocate for better understanding of this mental health condition, which can also be viewed as a form of neurodifference. If you would like to learn more, please visit the **ocd.org.nz** website or email ocd.org.nz@gmail.com.

OCD NZ – it's not the thought that counts …

Illustrations on the following four pages are by Róisín Kelly

It is not always autism: repetitive unwanted thoughts are a hallmark of OCD

Zara (He/Him/His, They/Them/Theirs) is a queer disabled Autistic person currently studying towards an Honours Degree in Sociology. They are passionate about disability justice and hope to do their Honours thesis on some facet of disability justice or representation. In his free time he enjoys reading almost anything he can get his hands on, especially queer literature.

When Zara was 16, he was convinced that he would die in his sleep. Every night he would spend hours working into rumination spirals and would go bug his mother to seek confirmation that he was safe and okay.

The scary intrusive thoughts, known as obsessions, are OCD's hallmark. They are the opposite of what the individual believes, values and wants. Compulsions are actions that an individual feels they must do, such as repeatedly seeking reassurance, to counter the unwanted thoughts and to relieve associated anxiety.

Zara was not suicidal and yet was panicking every day that they could potentially end their own life. They distinctly remember telling their GP about having intrusive suicidal images when walking over a bridge, when taking medication for physical health issues, and when chopping vegetables in the kitchen for dinner. Zara perfected compulsive avoidance to an art form; he did not trust himself to carry his medication nor to be in the kitchen unsupervised.

Zara had already figured out that he probably had ADHD and autism. Now, courtesy of accidentally stumbling across advocacy content about harm theme OCD, he realised that he also had OCD. They cried when they realised that they were not suicidal and not broken, and started learning everything they could about the condition.

A month later, Zara walked out of a psychiatric appointment with autism and ADHD diagnoses, but not an OCD diagnosis. The psychiatrist believed that the 'obsessive-compulsive traits' were attributable to their autism diagnosis, evidence of mental rigidity and self-regulatory behaviour/stimming, especially because they didn't have any major stereotypical physical compulsions.

Zara was told that they should imagine a big red stop sign to distract themself from anxious thoughts. By then Zara felt certain that what they were experiencing was not solely attributable to being Autistic and had learnt enough about OCD to understand that such a coping mechanism could, in time, become a mental compulsion.

They say that "I am lucky that by then I knew that, so I did not heed the advice."

Zara said that being unable to get the help that he needed for OCD impacted his ability to cope with autism. When OCD consumes your every waking moment, Autistic traits such as overstimulation and meltdowns become far harder to cope with, and simply existing feels like a chore.

Eighteen months later, Zara called their grandmother crying, unable to cope any longer with the disturbing thoughts and unwanted compulsions. He asked for approval to access some money from a bank account that was not supposed to be touched until he was older. In December 2023, they walked into an appointment with one of the best OCD specialists in the country. Twenty minutes later, the clinical psychologist agreed with the diagnosis that Zara had found and clung to like a lifeline: they had textbook OCD.

Zara regards himself as one of the lucky ones.

"I had the option to go private and seek the diagnosis that I needed. But so many of us are overlooked by the public system, especially if we have co-occurring conditions that overlap, as in the case of autism and OCD."

Zara Sheard (He/Him/His, They/Them/Theirs) is an Autistic Honours student studying Sociology who enjoys figure skating and reading.

Zara reading a book titled 'Honouring Our Ancestors: Takatāpui, Two Spirit and Indigenous LGBTQI+ Well-being'

OCD targeted my uncompromising personal ideals, courtesy of autism

Alyssa is a 21-year-old Autistic with a passion for astronomy and astrophysics. Her interest in space began when she was very young. Her family recalls fondly the memory of a determined baby crawling with a very particular purpose, come sunset, towards the moon as it became visible in the twilight.

By the age of 11, Alyssa says that self-protective mechanisms in her mind had effectively malfunctioned and turned against her. She had become her own judge and jury. The punishment anticipated for failing to complete 'simple' tasks: an excruciating and graphically detailed torment that awaited both Alyssa and her family for all eternity. For example, Alyssa believed that if she didn't do certain things in specific ways, such as looking in the corner while swallowing or tilting her head to the side and saying a certain phrase like Port Hills or Andromeda galaxy, she and her family were at risk of being tortured or harmed. That feared consequence was how her child's mind justified making her spend hours on repetitive compulsions and so pulled her further into a spiral of mental distress.

With hindsight, Alyssa has realised why intrusive thoughts with a moral theme were so persistent and increasingly intense and nasty. They were, in part, due to a strict moral compass that had become ingrained while growing up in a Catholic environment. They were also related, in part, to staunch personal ideals about what it meant to be a good or bad person, courtesy of autism. Failing to protect herself and her family by any means necessary would mean Alyssa was evil for allowing bad things to happen.

It wasn't until Alyssa was 19 and seeing a new psychologist that she was diagnosed with autism and learned what it meant to be takiwātanga. She began to receive treatment for OCD that was tailored with autism in mind and, for the first time in twelve years of therapy, she began to get somewhere.

Alyssa says, "My relationship with OCD began to shift dramatically, and at the same time, I finally felt like I was okay with being myself."

OCD no longer controls Alyssa and the intrusive thoughts that do occasionally pop up simply hold no weight. She has found friends in the Autistic community and has met new people through a shared passion for games like Dungeons and Dragons.

> *Alyssa is an Autistic young adult who is interested in astronomy, philosophy and artificial intelligence and enjoys the outdoors.*

Alyssa with pounamu pendant

Neurodivergence is a family affair

Jacqui Eggleton is a solo mother of four children who is doing a Diploma in Early Childhood Education. Jacqui has OCD, as did her Nana. Two of her three sons are Autistic with Intellectual Disability and her daughter has Tourettes.

One way and another, over the years, Jacqui, her children and the extended family have experienced a lot. She says, "The things we have been through have made us a very strongly connected family, being able to appreciate each other's quirks and support each other."

For Jacqui, OCD flared up during a very stressful period in her life. The birth of Jacqui's second child was difficult, and she experienced postnatal depression. There was also the death of a dear friend and financial struggles. This was the beginning of an ongoing battle with OCD, although looking back now she can see smaller episodes as far back as her teenage years.

Jacqui's OCD can make day to day life in her house extra challenging. Everything must be done in small steps. She can only put one item of clothing on the clothesline, take one peel of a potato or mow one strip of the lawn before panic and anxiety overcomes her and she needs to walk away. Furthermore, everything that is thrown into the rubbish bin or recycling must be spotlessly clean. Her Autistic children can easily do the jobs that she finds hard and can stay on task better than Jacqui.

The household functions by utilising the strengths of each other.

Fifteen years ago, when Jacqui was formally diagnosed with OCD, she had hoped that would open a pathway to getting help within the home in the way of a therapist working alongside and helping her with the anxiety and panic attacks. Instead a lot more agencies became involved with the family.

Jacqui says, "It felt as though it was expected that I could just flick a switch and the OCD would be gone and the house would be tidy."

Jacqui reluctantly agreed to have her two youngest boys live with their Dad. This was an incredibly hard adjustment. She says, "I wish that I could have been in a better mental health space to keep the house cleaner so that my children could have had friends over without feeling embarrassed."

Jacqui is now 53 years old and her children are teenagers and young adults. Jacqui has had counselling from both the public and private system over the years. It has been a case of taking suggestions and piecing together what works for her. By using self-calming techniques and methods from Exposure and Response Prevention (ERP) therapy she can quieten the OCD thoughts.

She says, "I have started to tackle my OCD slowly but surely and have turned a major corner where I am gaining control and we can have people over without feeling a sense of embarrassment."

Jacqui Eggleton has volunteered in various roles over the years and is currently Chair of the Waitaki Local Advisory Committee for CCS Disability Action.

Jacqui with her two sons – Zane (left) and Hayden (front) – and her daughter Tyla

Many people with OCD are unable to access formal diagnosis and treatment

Te Aroha Harrison-Kaa (Ngāti Porou) is an Autistic artist and Screen Arts student majoring in Concept Art and Design.

Te Aroha's earliest 'OCD memories' are from when she was around six years old. Her first obsession was about heart attacks. She was terrified of the idea that your heart could just "stop" at any moment and so started holding her breath for a certain amount of time. She would tell herself things like "If I hold my breath for 10 seconds I won't have a heart attack."

At age eight, Te Aroha was hospitalised because she refused to eat. Prior to that her eating had gradually become very restrictive. She rationalised that if you don't eat, you don't get fat and if you don't get fat, you won't have a heart attack. Initially she compulsively checked food labels for fat and sugar content and eventually just stopped eating food all together. Her parents didn't know what was wrong, neither did the doctors or nurses and, being a child and Autistic, Te Aroha had no idea how to explain what was happening.

Te Aroha has a lot of mamae (pain) about this time. As far as she can recall there was never any kind of psychological assessment. Instead she was given laxatives and various physical tests. The reason Te Aroha started eating again, initially in small amounts and slowly, was the distress shown by her parents.

As a young adult, Te Aroha had another bad bout of OCD. This time the obsessive thoughts were all over the place, but the major one was a fear of developing schizophrenia. Te Aroha lived with her family for quite a few months and met with a counsellor who was and continues to be supportive.

During this time Te Aroha described her experiences in a post on Reddit to a forum on anxiety. Someone replied suggesting that she may have OCD. Her initial reaction was, "Nah, that's the cleaning disorder."

"At the time I genuinely thought, and excuse my past ignorance, that OCD stood for 'Over Cleanliness Disorder'. YIKES. So I guess that serves to highlight the severe misunderstanding that I had and a lot of people have about OCD."

Once Te Aroha learned what it really was, everything clicked. However, she quickly realised that there was restricted access to OCD specialists in this country and that any overseas options were too expensive. So she determined that she'd learn about ERP therapy and treat herself.

She says, "Of course my whānau and friends supported me hugely, but you know, no one knew what OCD was really - we all had to learn. I did, thankfully, begin to recover and am now in a much better space."

> *Te Aroha Harrison-Kaa (Ngāti Porou) is an Autistic artist and Screen Arts student majoring in Concept Art and Design.*

Te Aroha attending the Hikoi mō te Te Tiriti in Gisborne

Peer groups: Building a Connected Autistic Community in Aotearoa

By Nicolina Newcombe, Emma Cox, Sarah Hoefhamer, and Alta Sacra

Autistic experiences intersect with all aspects of life, from health and identity to relationships and community. For many Autistic people connection opportunities provided by peer groups can support the often-invisible challenges through a shared journey of visibility, understanding, and empowerment. We are four Autistic peer group leaders sharing our journeys, and offering inspiration, practical insights, and support for Autistic and neurodivergent people looking to establish these much-needed groups across the motu (nation). Two of our groups include anyone who feels unique or different, although all four authors are Autistic.

In this article, we define peer groups as being by and for Autistic and neurodivergent people, with neuronormative people involved by invitation only. According to Wise (2023), neuronormative people are those who align with the most common ways of thinking and behaving in capitalist colonial societies, while neurodivergent people have neurological differences that set us apart from those norms.

As Damian Milton (2012) explained in his groundbreaking Double Empathy Problem theory, social and communication differences exist between Autistic and non-autistic people. However, our ways of thinking and being are normal among our own group. It is well-known that Autistic-to-Autistic interactions are more likely to be validating, restorative, and easier, while also celebrating our shared interests. We have the right and the inclination to connect and build our community together, like any other cultural group.

We have found connection, acceptance, friendships, opportunities, community, support, problem solving, leadership development, and mana among our groups. As one member said, “It’s about belonging.” Our ideal future has an Autistic group in every city and town, with us coming together for regional and national events. Here are some steps we are taking towards this vision.

Our four groups are all very different. Nicolina runs the Matamata Autistic and Neurodivergent Social Group, who meet for two hours once a month and have ad hoc meals and activities. Autistic Adults Aotearoa NZ is an Autistic-led and neurodiversity-affirming mutual support network for Autistic adults led by Alta. Mainly online, the group is a vector for discussions, resource sharing, and peer support. Emma’s group is called Island of Misfits Community. It is a safe space for Tauranga-based neurodivergent and marginalised late teens and young adults to belong, while building friendships and bridging to the wider community. They eat

together and have deep discussions about life, faith, worldviews, neurodiversity, and everything else. Sarah leads a group of Autistic women and genderqueer adults called Kirikiriroa Autistic Women + Co. From small town to whole country, our groups all began from one person who saw a need and decided to do something about it.

Relationships and community are at the core of everything we do. Alta created their group to provide a dedicated space for Autistic adults, addressing dissatisfaction with many other online spaces where our experiences are often overshadowed by the narratives of parents, carers, and professionals. Emma found many people in the autism and neurodivergent communities were isolated and wanted to bring people together to find a renewed sense of hope and purpose. Being involved in the Autistic peer group, Voices from the Spectrum, Sarah identified the need for a complementary space for women and genderqueer folk. we all began our groups for different reasons, for Nicolina, it was moving to a new town and wanting to make some friends. So how did we go about getting our groups started?

Our groups have been running from four months to four years. After approaching a support group for parents, Emma formed connections with their teen and young adult children. Island of Misfits started with five people in her lounge at home. Now over 80 people have gone to an Island of Misfits event! Emma is also part of a few networks of support groups and service providers that help each other out and many recommend Island of Misfits to their clients. For Alta, recruitment has relied on word-of-mouth, with an emphasis on nurturing the kaupapa (initiative) rather than increasing numbers. Nicolina put an ad on a community Facebook page. After that, she also approaches people who seem Autistic. Some people have found that spending time with Nicolina one-on-one helps them grow the confidence to join her group. Other people have found it easier to start online before meeting up in real life. Sarah has also found members via autdar (Autistic radar, the ability to perceive autism in other people). Between us, we have also gathered friends and acquaintances, asked Enabling Good Lives and Altogether Autism to send out group details, utilised Facebook Marketplace, publicised our groups through social media, and invited people from events. Emma also made a print publication.

We have each grappled with drawing boundaries around who can join our groups. All our groups are for adults (18 years and over). Sarah and Alta lead Autistic-only groups, while Nicolina and Emma include people with other forms of neurodivergence. Acknowledging there is no right way to do this, Sarah's group is for adults who do not require ongoing supervisory care and support, on the basis that her group does not have the capacity to supervise people and neuronormative support workers often cause Autistic people to mask. Nicolina, on the other hand, is staunch about unifying all Autistics and

By Misfits for Misfits 2024 – left to right Nicolina, Tamara, Maisie, Emma, Erik, Bridget

By Autistics For Autistics 2022 – left to right Jonny, Sophie, Tamara, Holly, Scott, Jack

has a BYO support policy. While her group is for adults, being a parent herself led Nicolina to ask her group if they could welcome people who needed to bring their children because they did not have alternative childcare, and everyone was happy with that. She will exclude any person who threatens or actions physical, sexual, or psychological violence to anyone, whether inside or outside the group, to maintain our safe space. Emma often likes to meet with people and get to know them in person before they come to the group. Alta's group membership is focused on Autistic adults and those who are exploring if they might be Autistic, along with their chosen supports. Non-autistic professionals, whānau, and friends are added only in specific circumstances.

Each of us has insights to share with people interested in starting a peer group. Sarah explains the importance of understanding that we all have trauma from living as Autistic people in a neuronormative world (plus many times other traumas as well), and that this should be front of mind when navigating difficulties. She wants everyone to know that people really want these Autistic-led spaces, so you will have people coming even if it takes a bit of time to get off the ground properly. Note: it only takes two to have a quality interaction, so if only one other person shows up, that's still great. While funding is out there if you need it, Emma reminds us that it does not have to cost a lot to bring people together. Make a Facebook or Discord group or event, find someone's house or a free venue to host it at, have a potluck where people bring food (or supply some cheap snacks), bring some board games or a discussion topic, and there you have it. Food is a good way to break the ice, and fidgets are good too. Alta reflects on the importance of clear parameters, trust, and active engagement—ensuring that we contribute to the things we want to build. Nicolina aims to encourage other members to organise activities and get togethers as well and tries to āwhina (support) and attend these. It is a good idea to have a back-up leader for times when you are away. In summary it is about whanaungatanga (relationship) – when people feel connected to something and they feel loved and cared for, they will invest more into that community and get more out of it!

We extend an invitation to prospective group leaders and advocates to contact us using the details below, so that we can offer encouragement in pursuit of our vision for a more connected future.

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Contacts

Nicolina Newcombe

Dr Nicolina Newcombe is Autistic and has a PhD in Education and a Master in Māori and Pacific Development. She works as an Inclusion Advisor for IHC.

www.linkedin.com/in/nicolina-newcombe

Connect with the Matamata Autistic and Neurodivergent Social Group at www.facebook.com/groups/matamata.ansg

Sarah Hoefhamer

Sarah is a chronically ill Autistic parent of Autistic teens. She was diagnosed after hesitantly self-identifying for five years. She leads Kirikiriroa Autistic Women + Co, hosts Altogether Autism A4A Zoom sessions once a fortnight, and is an advocate on the ground for Autistic rights and needs.

A4A sessions are hosted by Autistic adults. Sessions can be found and booked at www.altogetherautism.org.nz/events

If you'd like to join Kirikiriroa Autistic Women + Co, connect with us

Facebook group: kaw.org.nz

Email: sarah@kaw.org.nz

Emma Cox

Emma is passionate about hospitality and creating spaces where people can come together. She works full-time running Island of Misfits, a project that brings a sense of community to neurodivergent individuals, which she sees as an incredible privilege. As an Autistic person, Emma has found joy in creative outlets like painting, playing the ukulele, and other artistic pursuits, in addition to cooking and traveling. Over time, the support of those around her and her faith have played a crucial role in helping her embrace her identity as Autistic—something she once felt ashamed of but has since learned to accept and celebrate.

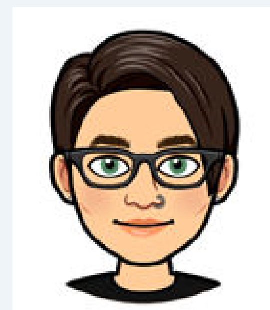
emma.cox@steiger.org

Facebook: Island of Misfits Community

Instagram: islandofmisfits.tauranga

Booklet of Neurodivergent Stories

Alta Sacra



Alta Sacra (BA, MScEd) is an Autistic person and parent to an autistic child, dedicated to enabling access, inclusion, and well-being for Autistic people. They work for VisAble, run a part-time consultancy, and are completing a Master of Applied Social Work in 2025.

Connect with Alta Sacra, on LinkedIn: www.linkedin.com/in/altasacra

Find the group on Facebook: www.facebook.com/groups/autisticadultsaotearoa

To learn more, read: bit.ly/AutisticAdultsAotearoa

Autistic and navigating chronic health challenges

By Luella Wheeler

Chronic illness and co-occurring health conditions are a common part of Autistic experience. In this article I share some of the bigger health challenges I've experienced and how understanding my underlying health and wellbeing needs helped to significantly improve my quality of life.

In 2020 I was in the depths of chronic illness. At times I was unable to walk or speak and was having regular severe migraines. I had chronic pain, extreme chronic fatigue, tinnitus, blurred vision, dizziness, intense brain fog, and was barely able to eat. I struggled with basic daily tasks like dressing myself and my life was very small and limited. In the years preceding I had experienced a variety of other health challenges, several of which led me to the emergency department.

Now, in 2025, I am energetic, well, and living a full and busy life.

There are many things that took me from one state to another. Recovery is part of some aspects of my health journey, and I would like to acknowledge that stories of recovery can bring discomfort for those living with chronic illness. I invite readers to take from my story what feels useful, validating, and supportive and leave what is not.

Some health professionals have described my experience as a journey "to hell and back".

When unwell, I suffered due to a variety of symptoms, but what made it worse was the experience of attempting to seek insight and support and often being badly let down. There were many reasons for this, including the limits of diagnostic testing and a mixture of empathy and invalidation from various health professionals. I received well-intentioned but unhelpful advice from some people and judgement-disguised-as-advice from others. I also struggled with my own internalised ableism and feelings of shame. I know that many of these experiences will be familiar to those who have experienced similar health challenges. There are depths of loss, grief, trauma, and disconnection that are often not understood by those who haven't lived through chronic illness, who often fail to imagine the extent of the impacts. I didn't understand the extent of loss myself until I was on the other side looking back and safe enough to be able to see just how bad it had been. Even now, four years later, there are still things I'm rebuilding and reclaiming. I still have a path ahead of me.

There are a lot of things I didn't know about myself in 2020 that I know now. The long version of the story is complex and involved years of making sense of what I was experiencing and why, trial and error, progress and set-backs. One of the most fundamental discoveries relevant to my wellbeing was finally recognising that I am Autistic. After I realised my Autistic identity and started to connect with other Autistic adults and learn our stories,

I learned my lifetime of health challenges was a shared pattern through our communities. There is a devastatingly long list of health conditions that we experience at higher rates than the general population (Al-Beltagi et al, 2021; Davies et al., 2023). Healthcare systems are full of accessibility barriers for us as Autistic people. Additionally, as patients we are often not believed or our presentation is misinterpreted. It is, sadly, no wonder we frequently have poor outcomes.

Autistic burnout is a widely shared experience but awareness of it is often limited.

"Autistic burnout is a syndrome conceptualized as resulting from chronic life stress and a mismatch of expectations and abilities without adequate supports. It is characterized by pervasive, long-term (typically 3+ months) exhaustion, loss of function, and reduced tolerance to stimulus." (Raymaker et al., 2020, Defining autistic burnout section).

Looking back, I now see that I had cycled in and out of burnout over the course of my life in ways that had cumulatively impacted both my mental and physical wellbeing. Autistic burnout is highly interlinked with the chronic health challenges I've experienced. Repeated and prolonged periods of Autistic burnout took a toll on my wellbeing and created risk for developing health problems. For me, burnout included significant fatigue and more disconnection from perception of my physical self, which interfered with me being able to do things that supported my long-term wellbeing. Experiencing chronic health conditions and the ways they create stress fed into more Autistic burnout. I spent years caught up in this damaging feedback cycle, but at the time was unable to name it for what it was.

It was only last year I finally recognised that hypermobility is also a factor for me, as it is for a lot of neurodivergent people (Glans et al., 2022). Knowing I am hypermobile has given me the opportunity to adjust how I manage my physical needs and to get more appropriate advice from physiotherapists, osteopaths, and those with insight about hypermobility. I've had much better outcomes in the months since.

At my lowest point I concluded I may need to try to accept that pain and fatigue were going to dominate the rest of my life. But I found I couldn't reach that acceptance without first trying everything I could feasibly do to regain some health.

I was not hopeful, but I was determined. That anger fuelled my determination.

I have been surprised, and very grateful, by how much recovery I have experienced. I recognise that I have some things in my favour, including supportive and safe whānau and a spouse by my side whose income meant we could live without me working. My background in science meant I could wade through information of mixed quality and accuracy to find what was evidence-based, low risk, and could help. I also live in an urban centre with access to medical care and options. If any one of these factors had been missing, I could be in a different position today. While I had many negative experiences with health professionals, I also had some very good ones. I have had a whole team of people providing support and care along the way and some people I'll always be grateful to.

The things I recovered from include:

- Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) – I had this severely for two years following an infection and stressful event, and like other people with ME/CFS I had a period of chronic fatigue following Epstein Barr Virus infection earlier in my life. In my conversations with professionals and researchers about my recovery we have speculated that my community-sourced management strategy, including careful pacing within energy limits, good nutrition, and use of supplements, allowed my body to recover. More research is needed to understand the role of neutraceuticals and pacing (Maksound et al., 2021; Nilihan et al., 2023).
- Functional neurological disorder (FND) – this is a widely misunderstood diagnosis, particularly within chronic illness communities, and understandably so because it's too often misunderstood and misrepresented by clinicians. It is a real illness and can be positively diagnosed by skilled clinicians (Richardson, 2024). I was fortunate that there is an excellent rehabilitation team in my city and I had full recovery of symptoms that had included loss of vision and loss of the ability to walk and speak.
- Migraines – I had regular, severe migraines for years and while things like sensory exposure and hormone changes could trigger them, I discovered that the underlying cause was neck misalignment and tension in my neck

and jaw muscles related to hypermobility. I worked with a skilled physiotherapist and I've never had a migraine since. It may be that this adjustment of anatomical structure also led to improvements in other symptoms via reduced compression of cranial nerves and blood flow. The role of the neck and cranial nerves in ME/CFS was studied by Matsui et al. (2021).

Things that are part of my life today:

- Being Autistic – I am happily and proudly Autistic and actively support my sensory needs and executive function challenges. I receive support, and live life in a way that works for me. When seeking healthcare I'm now aware of the accessibility barriers I have to navigate.
- Hypermobility – I have yet to receive a formal diagnosis but I have a team who accept hypermobility is a factor and modify their approach to take it into account. I use support garments when necessary, and I put a lot of work into doing exercise to improve joint stability. I have learned better ways to approach stretching and the release of muscle tension that don't destabilise my joints. The Muldowney exercise protocol has been particularly helpful (Muldowney & Muldowney, 2015).
- Scoliosis as part of hypermobility – I am working to improve core strength and symmetry to reduce pain and muscle tension.
- Asthma – I have a good asthma plan that I built with a community asthma nurse and I have worked on my breathing pattern with a respiratory physiotherapist.
- Sleep apnoea – I sleep with a CPAP (continuous positive air pressure) machine.
- Perimenopause – managed with menopausal hormone therapy. I was fortunate to be at a good baseline of wellbeing when I started to notice symptoms because it's possible I wouldn't have attributed them correctly had I still been experiencing chronic illness.

Te Whare Tapa Whā

Wellbeing for me does include a lot of managing and looking after myself via a medical approach, but in reality my wellbeing is experienced by and drawn from my entire self. Connecting with both my Māoritanga and takatāpuitanga has also been essential to having an ongoing sense of wellbeing. I find Sir Mason Durie's Te Whare Tapa Whā model very useful for thinking about my whole self within my context.

TAHA TINANA

Pace and rest that is right for my way of being

Appropriate approaches for hypermobility

Management plans for chronic conditions (asthma, sleep apnoea)

Nourishing kai

Rebuilding a safe connection and trust between self and body, becoming a good kaitiaki of my tinana

TAHA HINENGARO

Knowing and affirming my identity

Trauma healing via various modalities

Self-compassion and pragmatism

TAHA WHĀNAU

Authenticity in relationships

Being safe to be myself with whānau and friends

Connecting with other Autistic people

Connecting with all my communities

Having wonderful and kind people in my life

TAHA WAIRUA

Being at home within my takiwātanga, takatāpuitanga, and Māoritanga

Connection with reo and mātauranga Māori

Connection with te taiao

Acknowledging wairua and mauri

TAHA WHENUA

Deepening connections with whenua

Knowing the stories of my iwi, hapū and tīpuna

Strengthening a sense of belonging

Time in te taiao

Hi 5 wellness plan

A Hi-5 wellness plan is a guide in Easy Read format to help you think about your health and well-being. It focuses on five important parts of wellness, based on Te Whare Tapa Whā.

Photo credit: Luella Wheeler

In a book written for clinicians who work with Autistic women Sarah Hendrickx (2015, p.199) writes: "I have never yet met an [Autistic woman] whom I believe to be fabricating their health concerns or making an unnecessary fuss. If anything, the opposite is true: these women are often just getting on with life in considerable discomfort and pain, without seeking medical help." What I have observed of myself, and among my Autistic peers, is a tendency to endure and tolerate things far beyond what many people would. When we do seek help it is often desperately needed.

Navigating life as an Autistic person is not always easy and we so often do it while managing other challenges. This can mean we carry a heavy load. I long for a world where Autistic health needs are well understood, where none of us end up so unwell, where we don't have to fight so hard to be believed, where support is available and easy to access, and where understanding and compassion flow to us freely.

Kotahi karihi nāna ko te wao tapu nui a Tāne.

The creation of the forests of Tāne comes from one kernel.

Start small and grow from there.

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Luella Wheeler is a late-identified Autistic adult who has lived through severe chronic illness and is currently living well, actively managing health conditions, and passionate about better health outcomes for all Autistic people in Aotearoa.

Active coping and self-advocacy strategies

By Luella Wheeler

In this article I share from my own experience some shifts in thinking, habits and self-advocacy that have helped me to navigate managing chronic health conditions. I have been fortunate to experience a significant improvement in quality of life, so I am hopeful some of what I learned is of use to others navigating similar health journeys and all the challenges they bring.

Living with a chronic health condition means experiencing impacts on many, if not every, part of life. These experiences can have unique features for Autistic people because of the ways we sense ourselves and navigate our worlds. Living with a health condition means developing coping strategies. There are a variety of ways people cope with health challenges, with some strategies being associated with better quality of life than others (Kristofferzon et al., 2018; Siegel et al., 2016).

While I personally do find this research insightful and validating of my experiences, I feel a strong sense of resistance that a professional might expect me to simply and suddenly feel better about my situation or symptoms, especially when they have not experienced what I have. In sharing the shifts in thinking and approach that have worked for me in my own context, I am very conscious that you, the reader, may feel a similar resistance. I welcome and encourage you to take what seems helpful and leave what is not. You are the expert in your own life and experiences. I think it is useful to imagine every suggestion or piece of advice being followed by "if that feels right for you". Kā mihi nui kia koe.

An active coping strategy

Below I list some examples of shifts of thinking that I have observed within myself as my ability to actively manage chronic health conditions has improved. It is after-the-fact that I have realised these shift are reflected in research and theoretical models such as quality of life research in chronic disease patients (Megari, 2013) and shifting perspectives in chronic illness (Paterson, 2004). Siegel et al. (2016) describe active coping as "seeking information, problem-solving efforts, deciding to fight" based on the Freiburg questionnaire on coping with illness. Given there are additional barriers to accessing healthcare experienced by Autistic people, it is important to recognise there is an extra layer of difficulty in employing some coping techniques.

Some of the shifts in thinking and approach I describe below happened over years and took a lot of work. While I can see now the limitations of some of my old ways of thinking, I have a lot of compassion for all the reasons why I was like that and what it took to shift my perspective and practice. The "Things that were less helpful" list is not a judgement of my thinking or anyone else's, but a recognition of what has been limiting for me. I also think it's important to recognise that so often we are required to be reliant on ourselves because society and its systems are letting us down. In addition, don't assert that in every case it was a shift in perspective that changed my circumstances. Indeed, in many cases those shifts happened hand-in-hand and it was an improvement in circumstances that shifted my thinking. When navigating chronic health conditions there are natural ups and downs - it is natural and okay to experience ups and downs in perspective and emotional experience too.

Illustration by Róisín Kelly

What active coping and being well-supported in healthcare looks like for me as an Autistic person

THINGS THAT HAVE HELPED ME	THINGS THAT WERE LESS HELPFUL
Self-compassion	Self-judgement
Nurturing all aspects of my self	Ignoring aspects of myself, not acknowledging their significance to wellbeing
Understanding and meeting my needs	Trying to meet societal expectations that I had internalised
Pragmatism and problem-solving	Waiting to feel better, waiting for ideal circumstances, waiting for rescue from professionals
Having good support, both natural supports and support workers	Being unable to accept support and using hyper-independence to avoid showing vulnerability
Being proactive and committed to making appointments, attending appointments and being supported to do so in a way that works for me	Not prioritising or having support to access needed care
The right next step at the right time	Rigid expectations and "should" thinking
Reinvesting back into wellbeing – allocating a portion of my time, energy and resource (including financial, which is not always an option)	Expecting myself to be able to perform constantly in all circumstances
A pace of life that works for me, with lots of time for proactive rest and decompression	Living to neuronormative expectations of life and occupation
Good nutrition, including supplements (acknowledging these have a financial cost)	Not managing interoception challenges and not eating regularly
Pulling back, paying attention, giving myself space	Pushing through, ignoring messages from my body
Listening to and responding to my body's needs with care and regard, building interoceptive perception	Devaluing my body, resenting it and tuning it out
Recognising some symptoms as my body's inherent wisdom and signs of it fighting and working towards wellness	Seeing all symptoms as evidence that something is 'wrong' with my body
Working with health professionals who listen and collaborate	Wasting time on health professionals who invalidate and dismiss
Information from professionals who have insight and understanding	One-size-fits-all standard advice that ignores my reality
Seeking support and information from groups of people who share the same challenges (e.g., Facebook groups)	Relying only on professionals and others in my life, who sometimes lacked specific insight and knowledge
Small adjustments to habit or routine, one at a time, perhaps starting with one or two times per week	Expecting or enforcing dramatic and rigid changes in habit or routine
Using my tendency towards being very habitual as a chance to add care habits	Not doing enough to recognise and disrupt or limit habits that aren't helping
Flexible, deliberately inconsistent, and responsive approach	Rigid, rule-based, inflexible approach
Long, slow progress	Quick fixes

THINGS THAT HAVE HELPED ME	THINGS THAT WERE LESS HELPFUL
Giving my body/self space and resource to find recovery when ready	Attempting to force recovery
Setting achievable milestones and celebrating them (including small things)	Frustration (natural and unavoidable but I try to let it pass)
Using glimmers and stimming to feel present in my body in a comfortable way	Meditation, gratitude, affirmations, and some mindfulness practices are effective for some but have not been for me, at least not without significant alterations
Distraction for short periods when pain or distress is elevated – with favourite TV shows or games	Being overly reliant on distraction to the point it becomes avoidance and I miss opportunities for care
Visual reminders for medication when I'm unwell and/or overwhelmed – e.g., a checklist	Not having strategies for loss of memory when unwell and/or overwhelmed

Doodle by Luella Wheeler

I used to spend long periods of time drawing and doodling as a way to distract myself from pain. Now that I have better understanding of my sources of pain and the potential impact that long periods of being still has on hypermobile bodies it is not a strategy I would use again.

Self-advocacy in healthcare settings

Navigating healthcare well is a big part of managing chronic health conditions. Healthcare environments, systems, and professionals often operate without Autistic people and our needs in mind. I have found the following useful, but different people may need different sets of strategies:

- Building self-advocacy skills with support from a therapist.
- Having people who will advocate for me if I'm unable to – whānau and support workers who are well-informed about my preferences and goals.
- Taking a written list of questions or concerns to appointments – this can be read from or even passed to professionals if speech becomes inaccessible.
- Knowing my rights and expecting them to be met.
- Working with professionals in collaboration and partnership, finding support from those who will work with me. I do better if I am not just a passive recipient of care but am exercising self-determination over my body, my health, and my life.
- I walk away from professionals who won't listen or don't believe my experiences, who are not curious and who are not willing to understand and learn.
- I ask a lot of questions. It is within our rights as users of health and disability services to have the information we need in a form we can understand. Asking questions can also

Photo credit: Luella Wheeler

be a useful way of steering conversations, and I personally prefer a lot of information.

- I speak up if something is not right. Sometimes in the moment it is hard to process what has happened and say something, so in those cases I will get some support and make contact afterwards to resolve the matter.
- I find it easier to communicate pain by discussing the impact on sleep, mood, daily activities, and by the amount of pain medication I am using. My face, body language and tone of voice don't convey what I'm feeling and pain scales don't make sense to me, so historically I've had times when my pain level was underestimated greatly.
- Having pre-prepared "about me" documents if needed. One is a very basic note on my phone I can use for brief explanation and self-advocacy if I am in distress. A more detailed document can be created as a Health Passport booklet.
- If I know I will be receiving care in hospital I find out if they will record information about accessibility and communication needs in my patient file so they are available to all practitioners.
- I use online patient portals (such as Manage My Health) as an alternative to using a telephone where possible. For me telephone is less preferred but I know for some Autistic people it is entirely impossible. Some practitioners may also be able to offer email communication.
- Sometimes it is possible to wait in alternative spaces (other than the main waiting room), or to request changes to lighting or any radio or television playing. I usually rely on tinted glasses and ear plugs for more sensory comfort.
- I sometimes wear my sunflower lanyard, but my experience has been that few professionals understand what it means. I know there are initiatives in some parts of the country to make sure clinicians do recognise and respond to these.

While I found solutions as an individual, many of these were based on having the right circumstances and support, and some may be less of an option for some people. Autistic people are diverse, our needs are diverse, and so our strategies must be too. Coping strategies and self-advocacy can serve us well, but it must also be recognised that changes are needed in our public policies, systems and services to ensure everyone is supported in their wellbeing.

> *Luella Wheeler is a late-identified Autistic adult who has lived through severe chronic illnesses and is currently living well, actively managing health conditions, and passionate about better health outcomes for all Autistic people in Aotearoa.*

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AUTISTIC GLIMMERS

Source: Bec Secombe, Occupational Therapist at The ND OT www.thendot.com

Doodle by Luella Wheeler

Autism and ADHD in education and beyond

By Cath Dyson

Cath Dyson explores the complexity of autism and ADHD in the education setting.

Being neurodivergent with one or more co-occurring conditions is very common. According to the 2023 New Zealand Household Disability Survey, two percent of children over five years old have been diagnosed with autism and three percent of children over five have been diagnosed with ADHD (Whaikaha – Ministry of Disabled People, n.d. - a). However, it is difficult to source statistics on the number of people with a dual diagnosis of autism and ADHD.

In my role as an RTLB (Resource Teacher of Learning and Behaviour) I frequently work with students who have co-occurring autism and ADHD diagnoses. Indeed, two of my three children have this dual diagnosis, as do I. Navigating the complexity of autism and ADHD is challenging and, often, the education space is where our struggles are at their most prevalent. According to Whaikaha – Ministry of Disabled People, 51% of disabled people (that's 48,000 people) have at least one unmet need in terms of educational support (Whaikaha – Ministry of Disabled People, n.d. - b). Examples of these needs vary, but include a range of options, from access to assistive technology to requiring adapted learning tasks.

Being Autistic and ADHD can mean experiencing significant challenges in the school setting. There are some overlaps between the two forms of neurodivergence, such as sensory challenges, but how these are shown and supported can be quite different. Often ADHD students seek sensory stimuli (sensory seeking behaviour), and Autistic students often avoid it (sensory avoiding behaviour). This can cause great (or immense) tension for a student who has conflicting sensory needs. Abby, mum of two boys who are both Autistic/ADHD, notes that one of her boys often makes a lot of noise, but cannot handle when it is coming from another source. This can cause conflict with peers. Having a quiet place to do their work helps Abby's boys focus on the task at hand. Kathryn, a teacher in Nelson, ensures her neurodivergent students' sensory needs are met through having a calm corner in her classroom, along with providing noise-cancelling headphones and fidget toys for those students who need them. Michelle McLeod, SENCO at Nelson Christian Academy, encourages teachers to facilitate brain breaks for their neurodivergent students, along with access to the swings when they need it. Michelle ensures that learning assistants are available to support students at assembly time. Rather than 'making' them go to assembly (a common school activity which has the potential to cause sensory overload for Autistic/ADHD students), learning assistants take students to the swings. Meeting these students' sensory needs means that the students are more likely to go back to their classroom in an emotionally regulated and calm way – which is exactly what we want for both students and their teachers!

Social challenges, whilst commonly linked to autism, are also present with ADHD. The neurotypical social world can be puzzling for Autistic/ADHD students. The unstructured and unpredictable jungle of the playground can be a huge source of frustration and,

at times, distress. The challenges with executive function (decision making, sequencing, prioritising and critical thinking) are exacerbated for Autistic/ADHD students. Learning can be incredibly hard if accessing the 'thinking' brain is not always possible.

Despite the challenges there are some things that can make a huge difference to the school experience for Autistic/ADHD students. Abby says the key thing is structured support at school: "A typical day is full of highs and lows, there is not a lot of middle ground", so having structured time is key for both boys. Time blindness is amplified with some Autistic/ADHD students, so ensuring they have support with time management is essential. This could be a visual timetable (both at home and school), a timer or 'blocks' of time crossed off on a piece of paper. The best strategy is the one that works for the student. This kind of support promotes emotional regulation; supporting/allowing the student to 'see' how long is left of a class or activity can reduce potential heightening of emotions.

Meeting the needs of Autistic/ADHD students has to come from 'the top down'. That is, a school's senior leadership team has to recognise that neurodivergent students (as do all students) have the right to have their particular needs met. At Hampden Street School in Nelson, a sensory room has been funded to give those students who need it the space to meet their sensory needs. As the LSC (Learning Support Coordinator), Tracy McLaren, says: "Our senior leadership team is amazing. We now have 'Huka Falls', which is a sensory space designed to promote students' emotional regulation."

A whole-school approach to inclusive practice is also something that senior leaders can invest in. The recently launched Ministry of Education Inclusive Design Modules are designed to be applied as a whole-school approach, driven by a school's senior leadership team (Te Kete Ipurangi, n.d.). In addition to this, PLD (professional learning and development) can be delivered to the whole school staff or a select group. This year in my role as an RTLB I am working with learning assistants at Nelson Christian Academy and Waimea College, delivering regular PLD around meeting the needs of neurodivergent students.

A key area of challenge for Autistic/ADHD students is transition: both large-scale transition from school to beyond school and smaller transitions, such as task-to-task or subject-to-subject. Achieving predictability and routine, structure, and relational safety in a secondary setting can be particularly hard for students. As Waimea College's SENCO Ali Browning acknowledges, it is bigger picture thinking that is needed: "Multi-agency support is often required to provide a holistic lens to support a student's transition." With smaller students need to be forewarned and reminded frequently prior to the move between tasks/subjects to ensure they are prepared. Ali uses two common strategies together: the 'When/Then' structure in a picture format, e.g. When maths is over, then I go to the library. She makes up a key ring which has each subject presented visually: "The idea is to support the student to take this out in the last 10 minutes of each period to give them warning of what is coming".

People I have spoken to working in this space all agree that strategies which support neurodivergent students are actually best practice for all students."

A snapshot of these strategies is:

- Setting high expectations for each student
- Creating a predictable, routine-driven classroom with clear expectations
- Encouraging teachers to be relational i.e., have the teacher/student relationship at the forefront of their mind, knowing that for students to learn they have to feel safe
- Prioritising the home/school partnership: parents/whānau know their children best and can guide understanding of what works for their children
- Making learning accessible: use an inclusive design approach, which will ensure each student's needs are met and all students experience success
- Adopting a team approach, sometimes requiring external specialist support e.g., RTLB.

Autistic/ADHD students can bring a unique perspective to any classroom. If nurtured they will flourish. As mum Abby says: "My child is unique, creative and quirky, he is so much fun, he often surprises us with his 'out of the box' thinking". If educators can harness the strengths of neurodivergent students, we will be setting them up for a successful pathway. As Dame Whina Cooper said, "Take care of our children. Take care of what they hear, take care of what they see, take care of what they feel. For how our children grow so will be the shape of Aotearoa" (Wootton, n.d).

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Autism and… making the invisible visible

Kelly Robyns is a parent and researcher in social policy and neurodiversity. This article highlights the complexities of autism and other co-occurring invisible conditions.

As a parent I have experienced many barriers to diagnosis and support for my neurodivergent son and through my research I have discovered that these barriers are significant worldwide.

In this article I have used term such as 'condition', 'diagnosis', and 'disability', but I want to make clear that I believe, autism for example, is a neurodivergence/difference. My son is Autistic and neurodivergent; he is not visibly disabled, however his ability to function can be dis-abled because society is not set up for his Autistic ways of thinking and being. While he does have a 'diagnosis' – this was necessary to access support and funding - I prefer to use the term 'diagnostic recognition' as he has always been Autistic. However, it took 15 years to reach the point of recognition by a 'professional'.

Invisible conditions are those that can disable a person yet may not be visible to the casual observer.

Some examples include anxiety, autism, attention deficit hyperactivity disorder (ADHD), sensory processing disorder and epilepsy in some forms. While these 'conditions' may have some visual features common to more than one person, they may not be visible to others until a person is in crisis. Anxiety can be invisible until someone has a visible panic attack, and focal epilepsy can be unnoticeable unless you know what to look for. Invisibility of such conditions can cause challenges when seeking diagnosis and further support. Behaviours that are sometimes associated with these conditions can also be difficult to pin down to one singular diagnosis as co-occurring invisible conditions are common.

Co-occurring invisible conditions are common within the neurodivergent population, which can add complexity when a person seeks diagnosis and tries to access suitable support. A few examples of co-occurrence are:

- 25% of people with a primary diagnosis of ADHD also have dyslexia (McBride, 2019).
- Among dyslexic people, 25-40% also have ADHD and 25% have dyscalculia (McBride,2019).
- The percentage of Autistic people who also have epilepsy varies between studies; however, the median is 14.2% (Pan et al., 2021).
- In a New Zealand study of 9555 Autistic young people the rate of co-occurring mental health or other related problems was 68% (Bowden et al., 2020).

The co-occurrences for my son are all invisible - he is Autistic, ADHD, coeliac and asthmatic, and he has focal epilepsy, anxiety, long covid and chronic fatigue syndrome (CFS). On a good day, when he leaves the house and may engage in conversation,

it can be very difficult to see any of these conditions; oftentimes it is only me that sees them.

*Neurodivergent children with co-occurring conditions are at greater risk of being held back academically, encounter more social difficulties extending to the workplace and potentially have more engagement with the law. (*Germano et al., 2010).

Runswick-Cole (2008) quotes the reality that one mother faces: "If ADHD is unaddressed and untreated and particularly if a person is on the low IQ side… the prognosis is horrific and it includes depression, suicide, being in trouble with the law, jail, you name it. The worst things that happen in our society happen to people with ADHD…" (p. 179).

Kiernan and others (2019) interviewed 10 mothers as part of a qualitative study for perspectives on their lived experience with children diagnosed with an intellectual disability who have behavioural needs. There were several different diagnoses represented in the study, including autism, ADHD, oppositional defiance disorder, and cerebral palsy, however the overarching theme of exclusion emerged from every mother's interview. The services and schools these families visited were often unable to meaningfully meet the needs of their children or provide adequate support in a timely fashion. The lack of support and understanding by some of the professionals they encountered was exacerbated by the complex nature of a child's behaviour on a day-to-day basis, which produced multilayered stigma and multiple ways in which their children could be excluded from both services and events (Kiernan et al., 2019). This study highlights the challenges faced by children with multiple diagnoses, including invisible conditions, and the lack of understanding among professionals.

Only by understanding how co-occurring neurodivergence and other health conditions play out for each individual can we provide support in a way that is best suited to them (McBride, 2019). This is particularly important when conditions are invisible. Which diagnosis comes first can be tricky as Bonfirm et al. (2020, p. 6) noted that in a UK study "professionals have difficulties in recognising the main developmental delays". In relation to autism the professionals also lacked training and knowledge. This becomes problematic if any or multiple diagnoses have a medication treatment option that parents want to try. Interactions between medications need to be closely monitored.

It has been evident throughout my research that the power and knowledge gap between parents and professionals can create barriers to recognising what it takes to care for a child with invisible disabilities.

Caring for a child with multiple invisible disabilities creates an alternative way of living life that society and policy has not acknowledged. Parents of such unique children are often not asking for anything other than support; our children are square pegs that do not fit society's round hole. While seeking diagnostic recognition should provide a gateway to better support and understanding, my experience is that it can lead to parental blame and shame. When neurodivergent children are masking it can make invisible health conditions more difficult to identify in professional settings. Our children often hold it together and only show their true selves in the company of parents; that doesn't mean it's the parents' fault.

Diagnostic tools and policies worldwide working from a deficit model do not serve our children and families well. Coupled with the busy caseloads and working environments of medical and mental health systems, this does not allow time for professionals to truly see and understand who they are working with. It's time for change.

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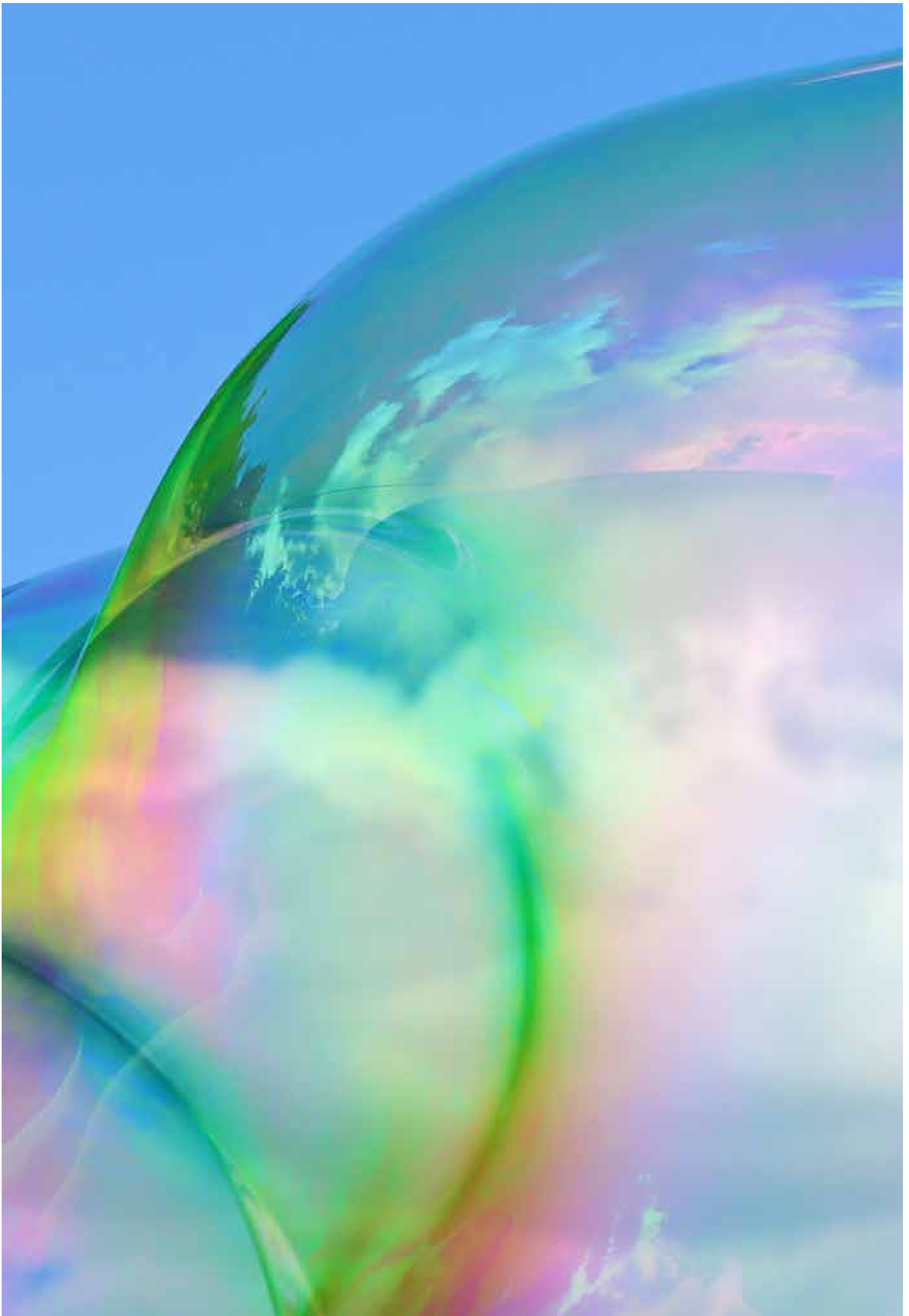

Photo credit: Luella Wheeler

Autism, Menopause, and Reaching Breaking Point: A Hidden Crisis

Content note: this article mentions self-harming, suicide and abuse.

Menopause has been identified as a major life transition point at which people are vulnerable to mental and physical ill-health, as well as stress-inducing environments or events. Autism research has disproportionately focused on children and young people, but in the past few years a small body of work has drawn attention to the experiences of Autistic people in later life, including at menopause. Please note that some of the research and anecdotes discussed here make for heavy reading and may be upsetting to some readers.

Many Autistic people have highlighted menopause in their stories about diagnosis, suggesting that menopause was the point at which life went "off the rails" for them. For some, this meant looking back at their lifestyle and mental health history and recognising that they had been Autistic all along. For people who already knew they were Autistic, meanwhile, menopause has been described as the point where they became "more Autistic". These individuals found it more difficult to "hide" their autism after menopause and experienced a general loss of coping skills.

The small amount of research that has been done on this topic mirrors these anecdotal accounts. There is evidence, for example, that rates of mental illness and suicide risk peak at menopause for Autistic women (Moseley et al., 2021). Other studies pinpoint menopause as a period of broad vulnerability for Autistic people, where employment difficulties, physical and mental health, and social isolation come to a head (e.g., Brady et al., 2024). Autistic people may also find it especially difficult to cope with the hormonal and physical changes of menopause, although their experiences are often highly variable.

Some of the research exploring the unique challenges that Autistic people face during menopause is discussed below. Please note that some studies describe the experiences of women, while others also include perspectives from people with a broader range of gender identities. Our language when discussing each study reflects the participants that were included.

Mental health, physical health, and victimisation

Moseley and colleagues (2021) interviewed 17 Autistic women about their experiences of menopause and later-life transitions. For many of the women participating, there was a baseline of mental health challenges and isolation that they felt set them up for difficulty at menopause. Many had been diagnosed with depression and anxiety earlier in life, and others had experienced eating disorders, digestive issues, and chronic pain conditions such as fibromyalgia. Some reported a history of sexual abuse and trauma.

This is consistent with other research looking

at the mental health and general vulnerability of Autistic adults, which points to high rates of childhood abuse, sexual abuse, maltreatment and exploitation amongst Autistic individuals (Reuben et al., 2021). In a 2019 paper, for example, Griffiths and her colleagues found that Autistic people were more likely to face abuse of nearly every type imaginable. Conditions such as chronic fatigue syndrome, joint hypermobility and fibromyalgia have also been found to be more common in Autistic people (Ryan et al., 2023; Grant et al., 2022).

This underlying vulnerability and history may mean that by the time menopause hits, Autistic people are already exhausted and overwhelmed. The physical and hormonal changes of menopause may then introduce more de-stabilisation, leading in some cases to a mental health collapse.

Women in the study by Moseley and colleagues (2021) reported experiencing increased emotional lability/instability, outbursts, and worsening anxiety and depression at menopause. One woman said, *"whereas previously I'd be a little bit grumpy…I was psychotic, like my emotions have been turned up a notch"* and another said she experienced meltdowns where she "sat in a corner naked, rocking and bashing (her) head against a wall" (Moseley et al., 2021, p.718). Still others described self-injury and suicidal ideation. Participants in another study of 24 menopausal Autistic people also described heightened negative emotions at menopause (Brady et al., 2024).

Menopause was also a time when underlying health conditions tended to flare up. One woman in the study by Moseley and colleagues commented that "I feel like I can't live like this…I can't do anything really…I don't have the energy" (Moseley et al., 2020, Physiological symptoms section). In another study, Autistic women who experienced more physical symptoms and challenges at menopause were found to have worsening symptoms of anxiety and depression (Groenman et al., 2022).

Isolation and Exclusion

Many Autistic women in the study by Moseley and colleagues felt that the way their autism presented did not match the public perception of autism (2021). For these women, this meant that their needs and preferences were often not recognised or acknowledged by people around them, including health professionals. A few had had positive encounters with medical professionals, but many were distrusting and felt their difficulties were too easily dismissed.

One woman shared that: "I suspect that GPs etc thought that the symptoms weren't that bad because I wasn't breaking down and crying or giving any emotional detail… When you can't describe what's going on, you can't really ask for help" (Moseley et al., pg.718).

All participants pointed to a need for autism-specific resources around menopause.

Autistic participants in a study by Piper and Charlton (2025) shared similar experiences with health professionals, especially their GPs. One described their GP as "unresponsive", while others talked about having to "fight" to access medical care such as hormone replacement therapy (HRT) (Piper and Charlton, 2025, p. 10). Research has shown that Autistic people face numerous barriers when accessing healthcare in general (Doherty et al., 2022).

General social isolation also meant that many women in the study had no-one to talk to about the changes of menopause. They felt menopause was a "taboo" topic anyway; one said she was largely "on my own with my body and my feelings" (Moseley et al., 2021, p.716).

For many women in the study by Moseley and colleagues (2021), tolerance for social interaction and other people also reduced at menopause due to a lack of energy and motivation. Fewer women felt able to mask or conceal their Autistic traits, which for many was a positive outcome. Others felt, however, that losing the ability to mask pushed them further into social isolation. Communication difficulties also increased for many Autistic women at menopause.

Challenging Symptoms and Heightened Autistic Characteristics

Autistic women going through menopause reported an uptick in a number of different symptoms, including:

- Standard physiological symptoms of menopause, such as hot flashes, fatigue, and insomnia
- A feeling of being "out of control" emotionally

- Flare-ups of chronic illnesses such as fibromyalgia
- Brain fog
- Challenges with executive function (organisation, planning, attention and memory)
- Poor work performance
- Increased sensory issues
- Autistic burn-out/exhaustion

(Moseley et al., 2021)

Generally, Autistic research participants report experiencing menopausal symptoms very intensely (Brady et al., 2024; Karavidas & de Visser, 2022). In addition, according to a survey of 508 Autistic people from 24 countries, many participants described their menopausal symptoms as unexpected, with 62% surprised by changes in memory and concentration span, almost 60% surprised by changes in mental health, and 47% surprised that they experienced disturbed sleep during menopause (Jenkins et al., 2024).

For women in the study by Moseley and colleagues, these symptoms culminated in a feeling of being "more Autistic" at and around menopause. For some, this meant that they pursued an autism diagnosis for the first time; for others, this meant an end to camouflaging and masking. As in the title of one paper, some Autistic women identified menopause as the time point "when my autism broke" (Moseley et al., 2020).

A 'Storm' Of Transitions

Autistic people in the study by Brady and colleagues (2024) also reported that menopause was associated with a 'storm' of other life transitions that collectively created overwhelm and dysfunction. Some of these transitions included ageing parents dying or being diagnosed with illnesses, children leaving home, retiring from work or changing careers, health challenges, and relationship breakdowns. For some Autistic people, dealing with these changes on top of the hormonal instability of menopause led to a period of crisis (Brady et al., 2024).

Positive Experiences and Silver Linings

It's important to note that while many Autistic people report heightened challenges at menopause, some feel that this is a positive transition that improves their mental health. Most women in the study by Moseley and colleagues (2020) welcomed the cessation of periods, for example. Others reacted positively to reduced pressure on women to "look good" and appreciated the reduced attention they received from men.

In addition to these gains, some participants felt that menopause had given them permission to be "more selfish", pursue better self-care, let go of toxic relationships, do activities they had always wanted to do, and work out better coping strategies.

For five women in the study, menopause was ultimately the reason they began to recognise themselves as Autistic. This realisation allowed them to reframe their lives with self-acceptance and compassion, and to start learning to accommodate their needs.

Still other women felt that not much changed at menopause. They reported minimal symptoms and disruption and simply identified the transition as a natural part of ageing. This marked variability highlights a need for further research and exploration of Autistic experiences at menopause.

What Helps Autistic People Get Through Menopause

Several supports, services and tools emerged as critical resources for Autistic people in the studies discussed here. These included:

- Access to knowledge about menopause and what to expect at different stages
- Self-advocacy resources and support
- Connection with other Autistic people
- Autism-informed healthcare
- Communication supports to help them express and describe their needs and challenges
- Social media groups
- Recognition of the way menopause, health conditions, and autism may interact

Generally, however, both professionals and Autistic people lacked knowledge about menopause. Healthcare services were also found to be inadequate and inaccessible. (Brady et al., 2024; Jenkins et al., 2024). Autistic participants in all of the studies described here pointed to a need for autism-specific research led by the Autistic community. In particular, there is a significant gap when it comes to the experiences of Autistic people with learning disabilities or communication differences, who may struggle to recognise and report their symptoms.

Better understanding of Autistic menopausal experiences can help Autistic people recognise the signs of menopause sooner and provide reassurance and direction about what they are going through. This can, in turn, inform clinicians and policy-makers of key service gaps and barriers to supporting this vulnerable community.

Menopause Survival Guide

If you're Autistic and going through menopause, check out the following resources and supports:

NATIONAL AUTISTIC SOCIETY GUIDE TO MENOPAUSE:

NAS_MenopauseGuide.pdf

TOOLKITS FOR ADVOCATING FOR YOUR HEALTH AS AN AUTISTIC PERSON:

AASPIRE Healthcare Toolkit for Autistic Adults

Know Your Normal | Ambitious about Autism

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The Autistic Perimenopause

Content note: this article mentions self-harming, suicide and abuse.

Sam Galloway shares her lived experience of ongoing Autistic perimenopause.

My experience of Autistic perimenopause is complex but not unique. The menopause is a life transition that is inevitable for all people with ovaries. I will soon be turning 44, and my life is still characterised and limited by hormonal fluctuations.

I was diagnosed Autistic aged 37, alongside my children's emerging neurodivergence. This was the time when my perimenopause symptoms began to appear. My symptoms began at a younger age than is average, so my doctors didn't take my concerns seriously when I told them I felt unstable and wanted to trial hormone replacement therapy (HRT). HRT is also known as menopausal hormone therapy (MHT). The first symptoms I noticed were extremely dry eyes and constant sensory overload. My moods became unpredictable, I would experience what I refer to as 'The Rage', and have more frequent meltdowns and shutdowns.

My energy was very low, and I began to develop insomnia, which also affected my mood. This impacted my whole family, and the dreams I had had for my childrens' childhoods became out of reach as I had to instead focus on managing my menopausal mental health challenges.

I regressed frequently, with bouts similar to Autistic burnout, including loss of self-care and executive functioning skills. I became unable to cook family meals or wash my own hair and even had frightening episodes of forgetting how to drive or where I was going whilst driving.

My hormonal fluctuations were extreme and when they dropped they took my mood and capacity down with them. I experienced suicidal ideation and intrusive thoughts of how to end my life. When my hormone levels soared I was euphoric and felt capable of achieving anything.

I did not have the capacity to educate my family doctors on perimenopause so I looked for a private doctor to help me save my life. I was exhausted and feeling desperate. I waited months for an appointment since menopause doctors are in high demand in Aotearoa New Zealand. The Australasian Menopause Society has a database of doctors with an interest in menopausal and midlife medicine.

I was fortunate to find a trusted doctor who specialises in women's health and has an interest in neurodivergence, perimenopause, and how they intersect. Although she is not local to me, she offers remote consultations via telephone, video calls, emails, and a secure medical consultation portal.

Under her guidance my HRT was titrated to a level that manages my mental health symptoms - the most significant of all my menopausal issues. My other symptoms have included heart palpitations, tinnitus, breast pain, vaginal atrophy, disordered eating, insomnia, lethargy, loss of energy, memory loss, slower processing and reduced cognition, bloating, weight gain, emotional

dysregulation, receding hairline, reduced tolerance for sensory inputs, and many more.

My HRT regimen currently includes oestrogen gel, oestrogen patches, vaginal oestrogen cream, testosterone gel and micronised progesterone capsules. It takes a lot of executive functioning skill to remember when to use each treatment, so I use timers, reminders on my phone and establish them into my daily personal hygiene routines.

Other treatments that I have trialled to manage my autistic perimenopause are the Mirena intrauterine device (IUD or "the coil"). It was beneficial because it stopped my constant bleeding that had been ongoing for months and had been causing me distress from sensory overload. However, the Mirena also caused extreme bloating, depressed mood and never felt right for me. I now think I may have progesterone intolerance, and that using progesterone aggravates my body and mind. Yet it is essential that people with a uterus who are using oestrogen HRT also use progesterone to maintain the health of the uterine lining.

I was diagnosed with premenstrual dysphoric disorder (PMDD) recently and am now using hormone blockers to stop my own hormone production from my ovaries. This is because the rapidity of the hormonal fluctuations that occur for me in perimenopause trigger mood changes, cognitive regressions and risk of suicidal ideation. It is not the specific hormone levels that are the problem so much as the fact that they change so fast from one hour to the next. Due to hormone blockers I am now in a temporary chemical menopause state so that I do not ovulate or bleed.

I am awaiting an appointment with a gynaecologist. I am self-advocating for a hysterectomy and bilateral oopherectomy, which will mean that my uterus and ovaries are removed. This would put me into a surgical post-menopausal state. This is a procedure for PMDD patients whose extreme hormonal fluctuations are so debilitating that they put them at increased risk of suicide.

My doctor explained to me that HRT is not a replacement of the hormones. HRT provides a buffer for our own changing hormone levels, so that our bodies and minds have a more consistent baseline.

Other ways I manage my Autistic perimenopause include lifestyle changes. I have a consistent bedtime and get up at the same time every day, although I still co-sleep with my neurodivergent 10-year-old. I do two 30 minute strength training sessions at home each week with a personal trainer who is also neurodivergent and in perimenopause. I try to eat a range of plant-based meals with lots of protein sources at regular times of day. I stop eating before 7pm and don't eat again for at least 12 hours overnight. I stay hydrated throughout the day and don't drink caffeine after midday. I listen to yoga nidra tracks to promote rest in the daytime, and sleep stories at night to encourage deep sleep.

I ask others for support when I need it and I drop commitments if I realise that I don't have enough energy. I have a cleaner who maintains household hygiene and I have support with food preparation as and when needed.

I write because I find it cathartic and I work hard to build community and understanding around autistic perimenopause. Advocacy is important to me and is one of my core values. I have been fortunate to be motivated by communication with research academics on the topic and by sharing insights with my online community at The Autistic Perimenopause: A Temporary Regression at Substack.

I am trying to find the motivation and cognitive capacity to start interviewing experts on my podcast and to write a book about neurodivergent menopause. In the meantime, I am focusing on preserving my mental health so I can continue to care for myself and my whānau, whilst advocating on the side.

Sam Galloway (BSc Psychology with Hons, Primary PGCE, MA in Education) is a late diagnosed Autistic and ADHD midlife woman. She advocates for Autistic and neurodivergent menopause as a distinct life phase that can lead to fluctuations and temporary regressions in functioning, mood and cognition.

Sam is the creator of The Autistic Perimenopause: A Temporary Regression on Substack, where she: supports others to self-advocate for their needs in Autistic perimenopause; has a growing community of readers and email newsletter subscribers; hosts her Auti Peri podcast (also available on Apple Podcasts); and offers a platform for others to share their lived experience in a regular feature called The Auti Peri Q&A Series.

Autistic and pregnant – the Neurobirth podcast

Luella Wheeler reviews the Neurobirth podcast - a podcast about neurodivergent experiences of pregnancy, birth, and early parenting - created by two neurodivergent midwives, Bronwyn Rideout and AmyTaylor.

Launched in November 2023, the Neurobirth podcast covers autism, ADHD and the journey parents take, from preconception, through pregnancy and birth, to the early weeks of parenthood. Hosted by neurodivergent midwives Bronwyn Rideout and Amy Taylor, the podcast covers the following topics:

- Neurodiversity 101
- The senses
- Communication
- Autistic and ADHD health
- Antenatal, labour, and birth care
- Postnatal care and early parenting

The series begins with an introduction to the neurodiversity paradigm, covers the many neurotypes that are considered neurodivergent, and provides guidance for language and framing. There is also discussion of LGBTQ+ identities and the intersection with neurodivergence.

Two episodes are dedicated to sensory experiences. These are enormously relevant to experiences of pregnancy and birth. Understanding someone's sensory profile and how this might impact their experience gives practitioners an opportunity to provide accommodations and reduce distress. Sensory needs have implications for management of the environment in hospitals and birthing suites and what will be the most suitable pain management for each individual. Bronwyn and Amy cover differences in interoception – the ability to perceive and respond to the body's internal signals – and what that may mean for a person during pregnancy and birth. The use of fidget and sensory aids such as weighted blankets, and the ways they are perceived, is also discussed.

The third episode is dedicated to communication and the challenges Autistic and ADHD individuals may experience when interacting with healthcare professionals. This includes the relevance of the double empathy problem and how much Autistic masking can interfere with communication. The importance of clear and direct language and mindful use of figurative language, as well as the need to adapt to augmentative and alternative communication (AAC) users, is also covered.

In other episodes Bronwyn and Amy discuss numerous topics including executive function and accommodating any processing and decision-making time needed, the increased rates of numerous health conditions that co-occur with neurodivergence, the experience of meltdown or shutdown during birth, and the strengths neurodivergent people bring to parenting.

The episodes draw on extensive research and the research references can be found

on the website. Each episode has a full transcript available for accessibility.

I personally find this podcast and all work in this area very heartening. My own experiences through pregnancy and birth were incredibly difficult, in ways that made so much more sense when I later realised my Autistic identity. I had a very hard time and there were multiple missed opportunities for my care to have better met my needs. It created fallout for my wellbeing that lasted for years.

The Neurobirth podcast covers essential and relevant information for midwives and anyone involved in caring for Autistic or ADHD people through pregnancy and birth. The information is also useful and validating for neurodivergent people themselves.

The podcast can be accessed on the Neurobirth website: www.neurobirthpodcast.wordpress.com

Or from Amazon Music/Audible, Deezer, Spotify, or Spreaker

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Chronic Fatigue, Fibromyalgia, and Autism

By Sara Meyer

Many Autistic people experience chronic fatigue and pain. In this article, Sara Meyer reviews current research and offers some practical strategies.

There is growing interest in the relationship between autism and various conditions that cause chronic fatigue and generalised pain. These include fibromyalgia, joint hypermobility, and chronic fatigue. While research in this space is still emerging, there is some evidence that all of these conditions are more common in Autistic people, as well as in people with ADHD and anxiety (Ryan et al., 2023).

It is not clear how these conditions are related to autism, but evidence suggests that Autistic people are particularly vulnerable to fatigue. Both Autistic people and people with chronic fatigue experience higher rates of sleep disturbance, for example, and appear to share a common physiological sensitivity to stress. This sensitivity is thought to arise from differences in the hypothalamic-pituitary-adrenal (HPA) axis, which regulates our nervous system and hormone levels.

In addition, some Autistic people are known to be highly sensitive to sensory stimuli and pain (Chen et al., 2017), to the extent that they process pain sensations differently to non-Autistic people. Abnormal pain processing is thought to be the main cause of fibromyalgia (Hoffman et al., 2023; Clauw, 2009).

In a recent study of central sensitivity syndromes including chronic fatigue syndrome, fibromyalgia, irritable bowel syndrome, restless legs syndrome, and migraines, Grant and her colleagues (2022) found that 21% of a large sample of Autistic adults had been diagnosed with a central sensitivity disorder, and over 60% met criteria for one. In this study, fatigue and pain symptoms were strongly related to sensory sensitivity and anxiety (Grant et al., 2022). In a follow-up study, participants with a diagnosed central sensitivity syndrome also reported more Autistic traits than people without a central sensitivity condition (Grant et al., 2024). The authors suggest that fatigue and pain may be a common and sadly chronic experience for many Autistic adults.

In another study of Autistic women and women with ADHD, chronic pain and fatigue were reported by almost 77% of participants. Approximately 24% of Autistic women and 39% of women with ADHD described experiencing chronic pain that was widespread, affecting both sides of the body for 3 months or more (Asztely et al., 2019). The women in this study were 5 times more likely to report pain and fatigue than women of the same age in the general population. This suggests that neurodivergent women may be more likely to live with these symptoms than neurotypical women. The same pattern has been found to apply to children and adolescents, pointing to symptoms that start early in life (Lipsker et al., 2018).

There are several different reasons that Autistic people could experience higher rates of chronic fatigue and pain. These include sensory sensitivity, joint hypermobility, and POTS/dysautomnia. I will briefly discuss how each of these could contribute to pain and chronic fatigue. Research in this area is in its early stages, and we are only just beginning to uncover some of the connections described here.

Sensory sensitivity

Many Autistic people have sensory sensitivities, including differences in the way they perceive pain. According to one review (Moore, 2015), the following differences in Autistic pain processing have been noted:

- Some Autistic people are over-sensitive to pain (hypersensitive), while others are under-sensitive (hyposensitive)
- Autistic people may experience more anxiety around pain
- Tactile sensations may be processed differently
- Autistic people may take longer to recover from pain or exertion

Autistic people may also have difficulty regulating their emotions after a painful or distressing sensory experience. Research (Ibrahim et al., 2019) has shown, for example, that Autistic people exhibit over-arousal in the amygdala (the brain area associated with negative emotion) and under-arousal in the ventromedial prefrontal cortex (which helps us calm down and process our emotions).

For an Autistic person, this may mean that painful or disruptive events are experienced more intensely, resulting in extreme emotional arousal that is difficult and overwhelming for them to deal with. An Autistic person may be simultaneously less able to activate the part of the brain that could help them manage and calm these emotions. This may leave them "stuck" in extreme negative emotion, which accumulates and causes fatigue and pain.

Finally, other sensory sensitivities may contribute to fatigue and pain. Most environments other than the home are busy, noisy, and overwhelming. An Autistic person may expend a lot of their available energy managing sensory challenges, leaving little left over for anything else.

Joint Hypermobility

Recent research has suggested that the link between autism and chronic pain can be partly explained by joint hypermobility. Joint hypermobility occurs when joints can stretch farther than usual or even "pop out" of position during daily activities. This is enabled by exceptionally soft or fragile connective tissue in the body. Joint hypermobility is commonly associated with pain, stiffness, fatigue, frequent sprains, poor balance and coordination, thin skin, and bowel and bladder problems. Rates of chronic fatigue and fibromyalgia amongst people with joint hypermobility range from 25-86% (Ryan et al., 2023). Joint hypermobility is often associated with Ehlers-Danlos Syndromes.

According to one study, Autistic people were estimated to have a 4.5 fold increased risk of joint hypermobility compared to the general population (Csecs et al., 2023). Joint hypermobility was even more common in Autistic women. In another paper, joint hypermobility was found to partly account for the link between autism and chronic fatigue/fibromyalgia (Ryan et al., 2023). It is not clear, however, why Autistic people are more prone to joint hypermobility, although genes may play a role.

In other research, for example, 42% of people with joint hypermobility were found to have Autistic or neurodivergent relatives, as well as other relatives with fibromyalgia and chronic fatigue. This suggests that there may be a genetic link between these conditions. A further project noted that while many Autistic people reported fatigue, brain-fog, and sleep disturbance, those who also had joint hypermobility tended to have the most severe pain and fatigue symptoms (Ryan et al., 2023).

POTS/Dysautomnia

Finally, it is possible that POTS or other forms of dysautomnia can partly account for pain and fatigue in Autistic people.

The autonomic nervous system is responsible for regulating involuntary body functions such as breathing, heart-rate, and digestion. Dysautonomia refers to a group of conditions where the autonomic nervous system does not function properly. One specific type of dysautonomia is Postural Orthostatic Tachycardia Syndrome (POTS). It is characterized by an excessive increase in heart rate upon standing up

from a sitting or lying position. People with POTS may experience symptoms such as dizziness, light-headedness, fatigue, and sometimes fainting.

A detailed investigation into autonomic dysfunction in autism has not yet been undertaken, but there are some indications that Autistic people may have a profile of sympathetic nervous system excitability. The sympathetic nervous system is associated with rapid heart-rate, anxiety, and fight-or-flight responses, and people with sympathetic nervous system excitability may experience sudden surges in heart-rate. This can in turn cause headaches and feelings of exhaustion. More research is needed to work out how autism affects nervous system functioning (Owens et al., 2021).

Seeking support

It can be very difficult to live with these conditions, and affected individuals may find themselves unable to work or take care of themselves. According to Grant and colleagues, chronic fatigue and fibromyalgia are also associated with depression in Autistic individuals (2024).

It can be challenging for service providers and clinicians to understand what is going on for Autistic patients affected by these conditions, and some medical providers may be dismissive of cases of chronic pain and fatigue that present with no known cause. For some Autistic people, the fight to access appropriate care and support may consume much of their available energy, leaving little left over for other activities. There is a critical need for service providers to understand these debilitating conditions and how they present in Autistic people.

If you are an Autistic person affected by one of these chronic conditions, it may help to:

- Keep a diary of symptoms, rating pain and fatigue on a consistent scale each day
- Take note of times when you struggled to perform daily living activities due to pain and fatigue
- Take pictures or videos of times when you are in pain
- Record what a typical day looks like for you
- Ask for alternative communication tools to help you describe your symptoms accurately - for example, visual supports, electronic communication devices, sign language, or written communication (notes, emails)

- Follow a predictable routine using energy accounting. Energy accounting is a framework where you define your daily activities as either energy deposits (things that increase your energy level) or energy withdrawals (things that decrease your energy level). This should be seen as a subjective exercise, based on how that activity typically makes you feel. You can see an example of how to do this below:

DAILY ENERGY ACCOUNT FORM			
Withdrawals		**Deposit**	
Activity/experience	(0-100)	Activity/experience	(0-100)
Going to the mall	-60	Spending time on special interests	+50
Being misunderstood	-40	Quiet, uninterrupted time	+60
Being overtired	-80	Watching a lava lamp	+60
Hungry	-30	Touching soft materials	+30
Withdrawal Total	-210	Deposit Total	+200

An editable Daily Energy Account Form resource is available to download

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He pō, he pō. He ao, he ao.
Tākiri mai te ata, korihi te manu,
Ka ao, ka ao, ka awatea.
Tihei mauri ora!

We emerge from the darkness into the light.
The morning dawns, the birds sing.
A new day begins.
There is life!

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