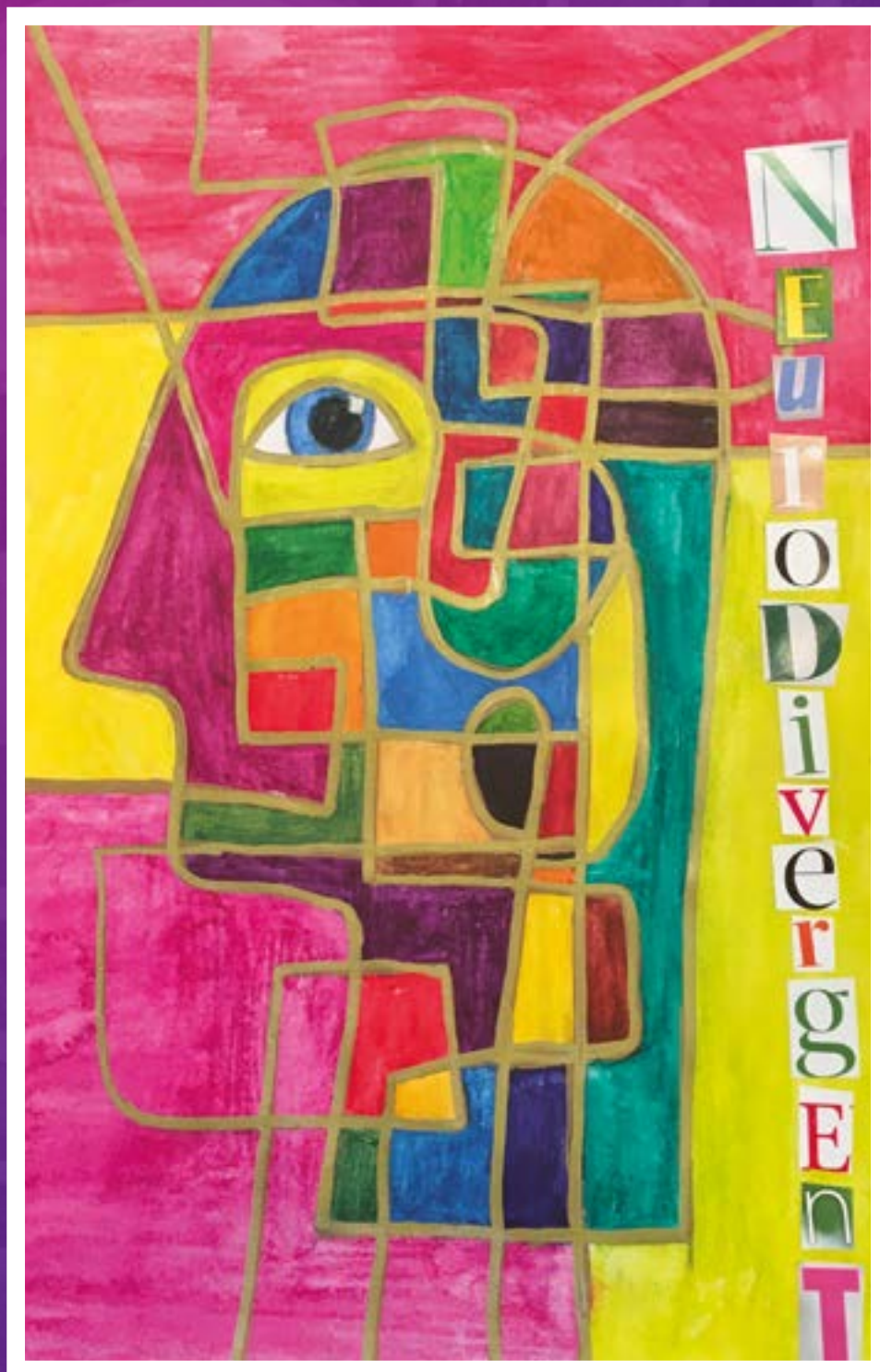


ALTOGETHER AUTISM  
**JOURNAL**  
2023

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Autism and Anxiety

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

## Nau mai, haere mai.

It is my absolute privilege and pleasure to introduce you to our 2023 edition of the Altogether Autism Journal.



Catherine Trezona

What a rich feast of information and celebration we have for you. While Autism and Anxiety can be a heavy topic, our intention is to bring knowledge and hope as our generous contributors share research and insights. If, after reading these articles, you would like more information, research or strategies on autism and anxiety, please contact us on live chat, email or phone with any specific queries or concerns.

The stunning cover artwork from talented artist and author Dianne McLean sets the scene for the articles that follow – thank you Dianne. Tobin Maclean's thoughtful charcoal drawing Perfectionism reminds us that perfect has many ways of being. And we love featuring images from Haz Crawford's Colour Spectrum art exhibition, and thanks to Nicolina Newcombe for interviewing Haz and writing this piece. Jonathan Jensen's story on driving through driving anxiety made me chuckle – I'm sure many will be familiar with the trials of both learning and teaching how to drive.

You will recognise some familiar names and faces in this edition. We are also delighted to introduce to you four new Advisors, Cath Dyson, Anissa Ljanta, Tobin and Karea Sutherland. The Advisors' biographies are on the Altogether Autism website so you can read more about them there.

We sadly say farewell to some of our valued Advisors as they come to the end of their contracts with us in the coming months. Abundant thanks to Rebekah Corlett, Timothy Folkema, Nan Jensen, Crystal Kire, Estelle Pretorius and Daniel Smith.

Check out Anissa's book review of *Unmasking Autism* by Dr Devon Price. As an avid reader, Anissa describes this book as a standout. We have three copies to give away. See how to enter on page 31.

As 2023 comes to an end and we enter into the holidays, I know how stressful this season can be. I wish you moments to delight in the things that bring you joy and peace. Thank you for your continued support of Altogether Autism.

Kia hora te marino, kia whakapapa pounamu te moana, kia tere te rohirohi.

Kia hora te marino, te marino ara mo ake tonu ake.

May peace be widespread, may the sea glisten like greenstone, and may the shimmer of light guide you.

May peace be widespread now and forever more.

Ngā manaakitanga – with best wishes,

**Catherine Trezona**  
National Manager, Altogether Autism

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# Driving through my Driving Anxiety

Embarking on the road to driving, **Jonathan Jensen** shares a personal journey in pursuit of confidence behind the wheel.



Learning to drive was not an easy task. It started off with being given a book that really felt like it made no sense, and questions that I was sure I would not remember the answer to if I were actually in a car.

Honestly, the most useful thing for the learner's licence was free online practice tests. I did test after test and it still wasn't quite enough. The pressure to pass the tests was weighing down on me.

Eventually I just had to brute force the test. I went in with enough money to take the learner's test five times in a row, and fortunately it only took me three tries.

There was a bit of a break between getting my learner's and my restricted licence. The pressure of getting my learner's licence had been so heavy that I didn't really want to try going any further. I felt like I would rather not try than try and fail. Lessons from my parents were of little help — my mother told me I was driving too fast, my father said I was driving too slow; both of them made me feel more nervous and expected me to have memorised the way to places that were several kilometres away. Fortunately, my parents were able to get a driving instructor who acted nothing like either of them. He was able to correct me whenever he needed to and, when something went wrong, he would take control while laughing in a way that prevented me from becoming more nervous. Thanks to him, I was able to get my restricted licence on my first go.

Despite this, I still felt exhausted by the pressure

and found myself unsure if I even wanted to go through the process of getting a full licence. I even considered simply staying on a restricted licence forever. When I finally decided to get my full licence years later, I tried to avoid mentioning it to anyone, as I still had the memories of the pressure my parents put on me when getting my previous licences. Fortunately, I still had the phone number of my driving instructor, and, despite a couple of mistakes, I was still able to pass my test on the first go.

I tended to avoid driving to new areas. Once I found a public car park I would use it as much as possible, even if it was hundreds of metres from where I actually wanted to go. This was because I feared that I would do *something* wrong if I was trying to search for a parking space while driving down roads I wasn't that familiar with, while focusing on every other part of driving process.

I'm still not that confident when driving, but I am managing. I've driven to a lot of places with no one guiding me on the way and sometimes I would drive back with no GPS just to see if I could work out where to go from memory. I also got my forklift licence, so even though I'm not the most confident driver, I've still got one more licence than most people!

*Jonathan Jensen is an Autistic man in his early twenties.*

# Minimising anxiety by designing a life that works for you

## From burnout to your baseline best

An effective strategy for managing anxiety is to build a life around our strengths and energising factors, writes **Anissa Ljanta**, a specialist coach and educator with expertise in multidivergent perspectives.



Anxiety wasn't something I thought I had. Not until my later in life double diagnosis of autism and ADHD. I had thought everyone woke in utter dread and rolled with waves of jittery yuck. Spending time in Autistic communities it was clear that I was not alone. Anxiety is a hot topic in any Autistic space.

Designing a life that works for our Autistic selves is not a choice, it's necessary. It's our right to spend our days in a way that doesn't tip us into burnout on repeat or into mental health trouble.

Sadly, because the source and our embodied experience of anxiety is different, and so many mental health, medical and care professionals are not neurodivergent-informed or affirming, the usual therapies and tools aren't likely to work. Traditionally, the markers of success for treatment for extreme anxiety and / or chronic depression are the resuming of what I call 'the gold standard neurotypical life'. You know, the 9-5 job or full-time attendance at school, active social life, hobbies, sports and ticking all the "appropriate behaviour" boxes sort of success. Problem is, even at our baseline best, that life is not possible for many of us neurodivergent folks to either attain or sustain. Nor should that sort of life be assumed as standard. Shoring up a life that doesn't work for us turns into an unending loop of anxiety and burnout. We need to reframe success, each of us will have a unique definition of what that looks like.

To manage anxiety, we need to build a life on our strengths and prioritise what gives us energy rather than draining us. Wellbeing will look different for each of us but getting good sleep, eating and moving our bodies gives us a good foundation to create a sustainable life. Auditing our sensory diets, allowing ourselves the freedom to stim and buffering sensory-sourced anxiety with external supports like noise-

cancelling headphones can all make a big difference to quality of life but without customising the structure of our lives to suit our unique needs, we have the potential risk of debilitating anxiety and burnout.

### The foundational elements of health are not enough to avoid burnout

Even outside of burnout, a sizable chunk of the neurodivergent population works very hard to manage their anxiety and / or depression. There is a glaring need for more accessible support for Autistic folks to manage anxiety and other mental health issues, and more support people and professionals skilled in guiding us to learn how to structure life that works for each of our baseline capacities, sensory profiles and abilities.

An increase in anxiety levels, or a shift in a person's experience of their anxiety, can flag that something needs to change in the person's life, whether that be in how daily life is structured, the people we have around us, medication/s or the environments we move in. Everyone is different, there's no standard formula for a rockin' Autistic life BUT I've distilled a version of the life mapping process I developed in my neurodivergent specialist coaching practice into six steps to custom design a sustainable life. This can be done solo, with some Autistic friends or a parent or support worker, perhaps a neuro-affirming and informed coach or therapist. Set aside a whole day and make an occasion of it with snacks or set aside time once a week to do it in chunks so there is time to process. Support team folks can customise the Life Mapping process to suit their people.

In my practice, before we get into the big picture work of life mapping, we explore what kind of life the person needs - what their unique Baseline of Wellbeing looks like.

## BASELINE OF WELLBEING

What IS a Baseline of Wellbeing? A baseline is you at your best. It's your ideal state of being. Where you have the most energy, are more able to regulate emotional responses, access your creativity, connect with others in your own way and stand strong in who you are. This is where you are at peak capacity for work and social load.

It's incredibly sad to me that so many Autistic folks haven't had much lived experience of their personal peak wellbeing. If this is the case with you, imagine what your baseline best life might be with the help of those who know and love you. We learn by trial and error so with reflection you'll work out what you need as you go.

In coaching sessions, I represent the baseline as a wide curvy line on a big piece of paper or whiteboard as a reminder that our capacities and requirements of wellbeing shift and change in response to factors like life events, stress and health.

### How to identify your Baseline of Wellbeing

To identify your Baseline of Wellbeing think back to times in your life when life was good, your workload and responsibilities felt manageable and you had a spring in your step. This gives us clues to what life needs to look like. For example, remembering the huge relief I felt when an emergency required me to let go of all responsibilities to be fully present and the fact that I felt best when I lived off-grid and travelled almost constantly for many years showed me I needed a simple life. The absence of feeling overwhelmed in these times informed me that I do best, am more resilient and my struggles more manageable in a simple life, when I am able to tackle one thing at a time.

## Drawing your Baseline of Wellbeing

Draw two big wavy lines through the centre of a big piece of paper or with a digital tool. Between your two lines write **what supports our wellbeing and helps us to live closer to our baseline**. These are the things that light us up, what bring us joy or a sense of contentment, safety or satisfaction.

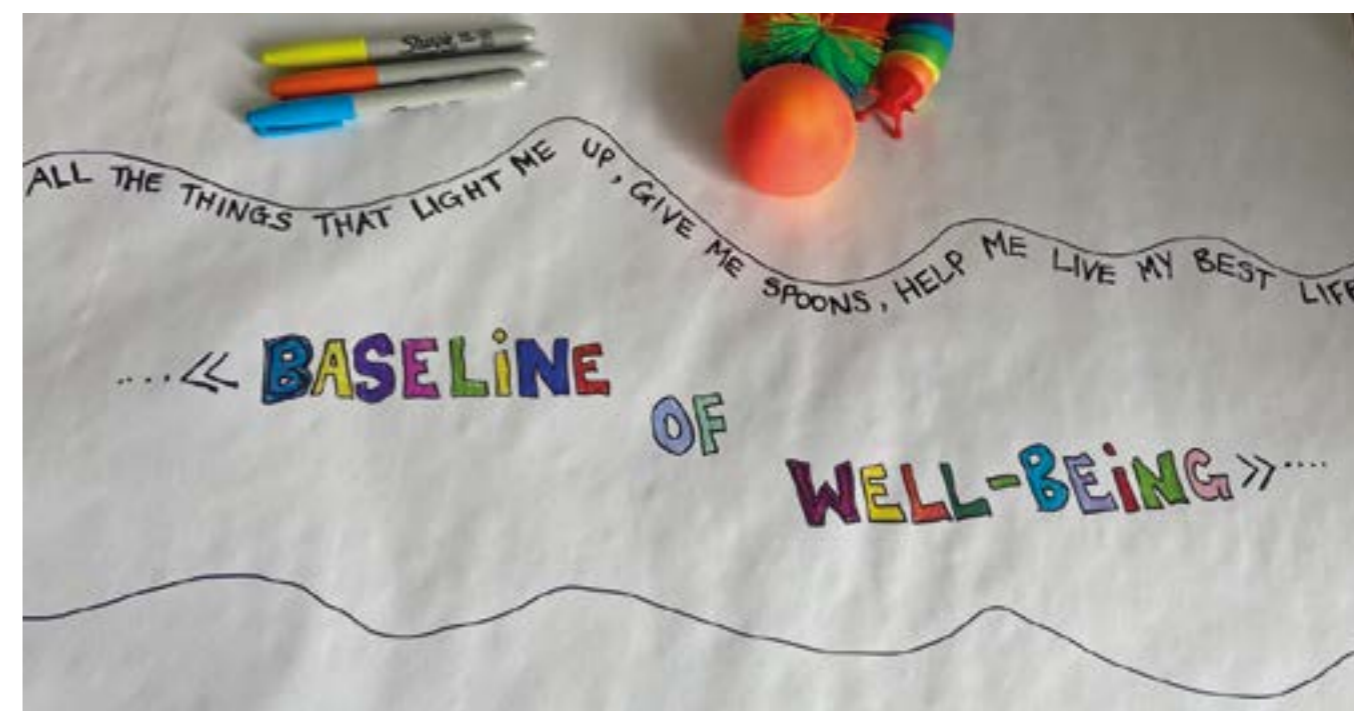
- Some examples of what helps clients stay at their Baseline of Wellbeing: Yoga, cuddling cats / dogs, keeping paid work to X hours a week, watching anime, having a recovery time after a busy afternoon / day, taking meds, gaming, wearing bright coloured clothes, Dungeons and Dragons, reading, crafting, smoothies, going for walks, hanging out in online Autistic communities, sitting in the sun, drinking tea, listening to podcasts / audiobooks, stimming, eating safe and sensory-happy foods.

### What throws us off our baselines and hikes up our anxiety?

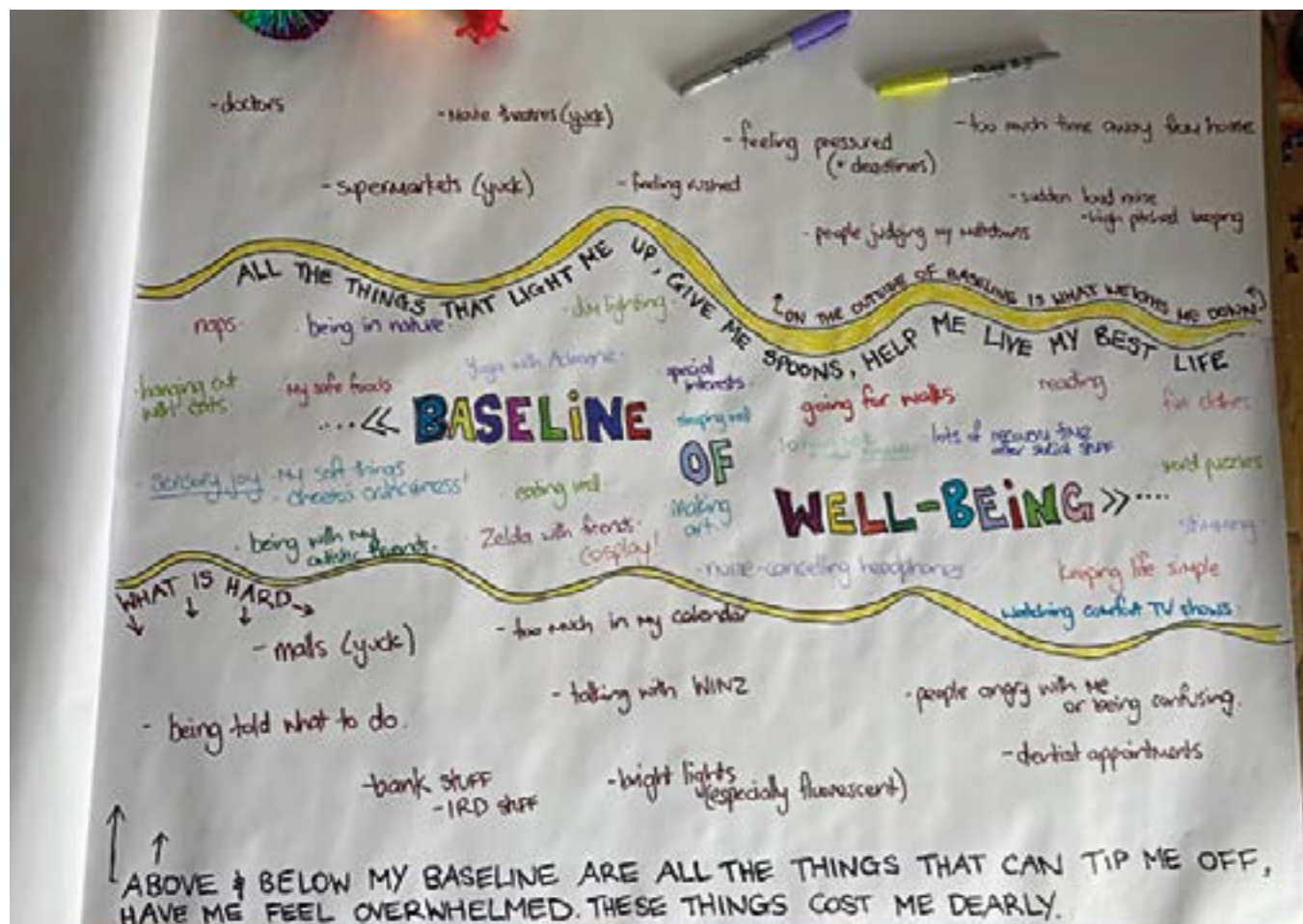
Each of us will have a list unique to us. Trying to maintain a life that isn't designed for us is the main culprit but spend some time noting down some answers specific to you and your life. You can write these on the top and bottom of the piece of paper or board with your baseline.

- Here are some common causes of disruption to wellbeing to many Autistics: time in sensory taxing environments, chronic financial stress, abuse, too much pressure, unrealistic expectations, not getting enough sleep or downtime, physical ill-health, parenting small child/ren without appropriate

Continued on next page »



A canvas labeled 'Baseline of Well-being,' surrounded by art pens and sensory aids for creative self-care.



Customise your baseline for optimal wellbeing.

support, working hours that are not sustainable, menopause, having to suppress stims, the effects of trauma, housing insecurity and the usual life stressors like changes in relationship status, loss of a job and bereavement can be felt intensely. Working with health, care, medical and / or education professionals who don't understand autism is another. It's often a mix of changes and stressors.

**Baselines in summary.** Things that light us up or are soothing and bring joy have us living closer to our baselines, too much stress, unsupported challenges and work that weigh us down have us deviate. When we're off our baselines, neurodivergent traits flare, previously manageable anxiety and OCD or tics can start to spiral and life can start to feel hard.

Once we've established what our Baselines of Wellbeing look like, the next phase is to map out everything in our lives to see if anything needs to change. I've distilled a Life Mapping process I use in my coaching practice for you here but the more numerically minded Excel-loving Autistics might want to google Maja Toudal's energy accounting.

*"We all deserve to love a life that works for our unique Autistic selves."*

## LIFE MAPPING TO DESIGN A LIFE THAT WORKS FOR YOU.

### In six steps.

When serious overwhelm sets in or I'm showing signs of Autistic burnout I get a big piece of paper, hustle up coloured pens, put some uplifting music on and get to work mapping all the elements in my life. This life mapping process provides an opportunity to reflect and get clear on where and who we're giving our precious energy to so we can assess what needs to shift. The mapping helps us get clarity on why we might be so exhausted too.

### STEP ONE.

**Mapping & reflecting. Get everything in your life on a big piece of paper.** Or use a digital tool like Google Jamboard or Miro.

All your commitments, responsibilities and activities go on that big piece of paper or digital board. Grouping in categories of work / study, house, life admin, play, relationships / friends / family, animals and community service can be helpful. Everything goes on there, the bolder the better.

### STEP TWO.

**Traffic lights. What lights you up? What's dragging you down?** Go through your map and mark each life element with a red, orange or green 'traffic light':

- **Red light** = activity, event, relationship or commitment is super taxing / costs many spoons.
- **Orange light** = sort of meh, or neutral. Not terribly taxing but doesn't add spoons to our drawers.
- **Green light** = lights up the person, gives us energy, replenishes our spoon supply. These are the definite keepers.

### STEP THREE.

**Check for balance.** Turn your attention to your red lights. Are there more red than your green lights? Or do you have mostly orange lights? Does the hard stuff outweigh the bright? Pay attention to how you feel looking over your Life Map.

Go back to your Baseline of Wellbeing. Recall what brings you joy or deep satisfaction and keeps you closer to Wellbeing. **How much of that is on your life map? Do you need to add more of what lights you up in your life?** Remember, when you're playing the game of life on hard mode, small changes and joys make a very big difference.

### STEP FOUR.

**Identifying what needs to change.** Go through your Life Map and start with your red traffic lights, assess what stays, what goes and what needs to change or be better supported. Jot down notes on your map as you go. What can you ditch? What needs changing? How can you do more of what brings you joy?

Don't forget to factor in preparation and recovery time before and after social events and work commitments. We also need space in our lives for unexpected things like illness, family emergencies, emotional upsets, support workers coming and going.

It can be helpful to have a trusted person's feedback and perspective for these last few steps.

### STEP FIVE.

**Actioning change.** We're not looking at sudden drastic changes. Transitions and change can be hard for many neurodivergent folks, put plans in place to bridge and scaffold the red lighted things that need to stay part of your life and times of change. Action big decisions gently, in stages, and with support when appropriate. What are the gentle actionable steps to making healthy changes that will have you living closer to your Baseline of Wellbeing?

Make notes about how you might implement plans to stop or carve back various activities, either now or when needed. The sensory load of environments is important to consider too. Does that social meet-up at the noisy cafe come at too great a cost or does the noise mean you can't fully participate? Can we ask for a change of venue? Wear noise buffering ear plugs or just take a break for a while?

When we're struggling or nearing burnout, even the good things like going to yoga, game nights with pals, volunteering, lunch with aunty or social events in general might be in the too-hard basket and we definitely don't need the things that are painful or unhealthy for us. That's okay. To avoid burnout, we need to put ourselves first. We can always reinstate different activities later. Maybe not the super taxing things though, those can get in the bin and stay there.

### STEP SIX.

**Have an anxiety action plan in the wings.** Heightened intensity of anxiety and feeling chronically overwhelmed can be red flags indicating a slide toward burnout. It's helpful to know ahead of time what can be put on hold while you focus on getting back to your baseline. Have a look at your Life Map, what can be carved back if you need to? How would you do that? How can you integrate more of what brings you joy? What support can you identify to help you recover? **It's hard to think creatively when we're struggling, having a plan ready to action has us feel prepared - it's a safety net we're gifting our future selves.**

### Give yourself the green light

A hot tip on integrating our Life Map learnings into daily life is to use traffic lights on your to-do lists, reminder apps and calendars. This allows us to see if we're on track to create the days we need. In burnout you might have only green light items on your list some days.

What we find taxing or enriching will change through life delivering new ways burnout can sneak up on us, but knowing our Baseline of Wellbeing and having a built-in reflection time like Life Mapping can be an important tool to living your best neurodivergent life.

Trying to live a life designed for neurotypical people is a set up. Give yourself permission to live life on your terms.

We all deserve to live a life that works for our unique Autistic selves.

*Anissa Ljanta is an Advisor for Altogether Autism.*

# Autism and social anxiety

Exploring the roots of social anxiety, **Sara Meyer** sheds light on the power of diagnosis and the impact of connecting with other Autistics.



I'm out for coffee with a friend I've known for a long time. I realise, now, that people do this for fun, that they actually like it. I should like it too, but I'm holding the table so tight my knuckles are white. My legs are so stiff they're going to hurt for the rest of the day. There's a buzzing in my ears and I feel slightly faint.

We're here to catch up on our lives, and I have a lot of work to do. I have to make sure I get things right and don't seem weird. I have to make sure I nod at the right time and smile a lot, otherwise my friend will think I don't want to be there. I have to make sure I say "mmhmm" in a sympathetic voice as she talks to me about her struggles with her husband, her kids, and her boss. I've practised that sympathetic voice many times now. Otherwise, I know she's going to come at me with the comments about how I don't care about anyone but myself. How I think I know everything. How I think I'm better than everybody else, just like they did when I was a kid.

I'm working so hard that I can't catch my breath. I realise I'm hungry and I haven't eaten in hours, but it isn't the right break in the conversation to suggest ordering right now. I make it through an hour of listening without accidentally insulting my friend or showing how much I want to go home, I hope. I do like her and want to be her friend; it isn't that. But I have to concentrate harder than I did in any of my three-hour exams at university.

When it's over, I've got nothing left. I get home and shut the blinds and I can't do anything- not play piano, not write, not cook anything for dinner. I know I seemed capable, focused, maybe even empathetic. Most likely hyperactive too, which often seems to happen. But my whole body hurts from the strain of concentration and anxiety.

I look back on experiences like these through the lens of an adult diagnosis of autism, and I don't know how I did it. As a young adult desperate to have

friends so I wouldn't look weird, I forced myself to have these kinds of interactions once or twice a week. Some of them went better than others — especially those where the friend I was meeting was another then-undiagnosed Autistic. It seems I unknowingly collected a fair number of Autistic friends as I grew up. But for the most part, I struggled along, thinking that everyone else felt the same way, and that you just had to keep going to get over it.

I know now that social anxiety is a common experience for Autistic people, perhaps especially for those who have been diagnosed later in life. Just as it sounds, social anxiety involves fear or anxiety in social situations, especially situations where the sufferer might be subject to judgment or scrutiny. Studies report varying statistics, but the prevalence of social anxiety amongst Autistics seems to sit around 50% (Spain et al., 2018). This is considerably higher than in the general population, where social anxiety affects between 5 -10% of people (Koyuncu et al., 2019).

When you understand the double empathy problem, this makes sense. According to the double empathy problem, Autistic people have difficulty understanding the communication and perspectives of neurotypical people, and neurotypical people have difficulty understanding the communication and perspectives of Autistic people (Milton, 2012). This results in mutual disconnects and misunderstandings on both sides — but because Autistic people are in the minority, we are often blamed when things go wrong. These repeated misunderstandings compound, and before long, you have a socially anxious Autistic person with a history of negative social encounters and rejection.

People might tell us that it's all in our heads, but sadly, the fears that socially anxious Autistic people have may come true. A study of first impressions found, for example, that neurotypical people tend to react negatively to Autistic people, rating us as awkward or lacking in empathy (Alkhadi et al., 2021).

Confirming the double empathy model, this only happened with neurotypical people — not when the people giving their first impressions were also Autistic. This suggests that differences in communication style are to blame. We may do things that other people don't expect, struggle with figuring out what to say, and find it difficult to predict what our conversation partner is thinking or feeling (Spain et al., 2020).

I know what that feels like, far too well. And while I'd like to say that I've beaten social anxiety now, and that I'm no longer "painfully shy", that wouldn't quite be true. What I do have, though, is longer and longer moments without social anxiety. And a few more tools in my toolbox to pull out when things get bad. Here are some of the things that have helped me over the years.

## Diagnosis

Diagnosis has been a game-changer in my battle with social anxiety. Like a lot of Autistic people, my social anxiety partly came down to a vague yet ever-present feeling that I was a Very Bad Person. I always seemed to miss how other people were feeling, or say things that were accidentally offensive, and I never could quite respond in the way that people seemed to want me to.

But when I got my autism diagnosis, I was excited to discover that I was just like the other Autistic people I had known and grown up with during my homeschooling years — the people I often secretly aspired to be. I wasn't a bad person; I was just not attuned to the same things as neurotypical people. I noticed other things instead. This process of self-acceptance was facilitated by a formal diagnosis, but I think self-identification could have a similar effect. That isn't my story to tell, but researchers Deborah Spain and colleagues found that an autism diagnosis improved social anxiety symptoms for many Autistic people, including some who were self-diagnosed (2020).

## Feeling understood

As I was able to tell more and more people that I'm Autistic — which I did readily as I was exhausted by the strain of masking — I felt that their expectations of me changed. They seemed more willing to think twice about the things I did, and I now had a good reason to simplify my social calendar.

Looking at more of the research about autism and first impressions that I discussed above, things do seem to get better for Autistic people when others know we are Autistic. When Sasson & Morrison (2019) asked people to describe their first impressions of Autistic people shown in a video, for example, their impressions were much more favourable when they knew the people they were observing were Autistic. For all that talk about not labelling people, which I never got anyway, it seems the label actually helps us out a lot of the time.

## Other Autistic people

Connecting with other Autistic people and sharing common experiences has made a huge difference, too. There is a kind of collective reframing that happens when Autistic people get together and tell stories; we come to realise that there is often a strong logic and meaning to the way we do things. For me, this has helped me feel surer of myself and less prone to changing myself to fit in and please others.

## Simplicity and structure

For Autistic people, social anxiety seems to be worse with friends and family than it is with acquaintances and strangers (Chen et al., 2016). I'm not sure how other Autistic people feel about this, but it holds true for me.

I have quite a few less friends than I had at my peak social chameleon stage, when basically all of my energy went into pretending to be normal. But I have more friends than I did when I was a child and didn't even know that friends were a thing.

When I do see friends, we go to familiar places. Places that are quiet and simple, like the park or the beach. We hang out for a short period of time, like an hour. We usually do the same thing over and over again, once every two months or so, sometimes for years on end.

The structure and simplicity that I've introduced into my life has helped me break out of social anxiety, just for long enough to feel other things instead. Anxiety used to be the only thing I noticed — it got stuck in my joints, buzzed in my head, and messed up my words. But these days, sometimes for the whole hour that I spend with someone, I can actually listen to what they're saying. I can look at the clouds, which have always been my favourite, and I can say some of what I think. I'll still go home and re-run the entire conversation in my head, but for that one hour at least, it can be fun.

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*Sara Meyer was diagnosed with autism not long after she started working alongside Autistic children as part of the Ministry of Education Learning & Support team.*

# Lessons from Autistic burnout

Despite being a well-established concept in the Autistic community, the phenomenon of Autistic burnout has only recently come to the attention of academic researchers. **Rachael Wiltshire** summarises the current research on Autistic burnout, explaining what it is and suggesting some strategies for recovery.



I have always had labels. By seven, I knew that I was shy, and I knew I was a worrywart. What I did not know at the time was that, even at that young age, the worrywart label had already taken on an official form: a generalised anxiety disorder diagnosis. The autism label followed five years later. It helped me find my place in the world as someone who was not shy or a worrywart, but simply different. Nevertheless, even the knowledge that autism explained my differences did not stop me accumulating more labels as I grew up: generalised anxiety disorder again in Year 10, major depression in my first year of university and every two to three years since then. Over time, I came to realise that my mental health just seemed to be cyclic — no matter what I tried, every few years things would come crashing down and I would have to start building back from scratch again. I learned that taking care of my mental health was a balancing act, walking a tightrope between keeping busy enough to not become overwhelmed with boredom, but not so busy that I left no time for rest.

Last year, whilst writing *Altogether Autism's Tertiary Guides*, I stumbled across a new label. Perhaps my experience of cyclic mental health challenges was not separate to my Autistic identity at all. Perhaps what I was really experiencing was Autistic burnout.

## What is Autistic burnout?

The advent of the internet enabled Autistic people to connect online, and discussions of a phenomenon named 'Autistic burnout' soon emerged in these spaces. Nevertheless, it is only in the past few years that researchers have started to pay attention to this phenomenon. Between 2020 and 2022, three papers were published which independently sought

to define what Autistic burnout is (Higgins et al., 2021; Mantzalas et al., 2022a; Raymaker et al., 2020). Collectively, these studies suggest that Autistic burnout is characterised by exhaustion, withdrawal, loss of previously acquired skills and increased intensity of Autistic traits (such as stimming and sensory sensitivity). Burnout can have a significant negative impact on Autistic people's lives: it is often chronic or recurrent, it may lead to the development of other mental health challenges such as depression and it is often associated with suicidal ideation.

Autistic burnout is likely caused by the stress of living in a world that was not designed for our needs. Many Autistic people learn to mask; that is, we hide our true Autistic selves to navigate our way through a world built to neurotypical expectations. We might suppress our stims, force ourselves to make eye contact and wear uncomfortable clothes to get and keep a job, make friends and participate in our communities. This takes significant cognitive effort: it is exhausting! Add in the background hum of an unfriendly sensory environment and everyday life stressors, and burnout is a predictable result. Autistic artist Tzipporah Johnston likens our brains to buckets: masking, sensory stimuli and everyday tasks fill your bucket up, and if it overflows, it fries your brain like a phone dropped in a puddle. This is burnout.

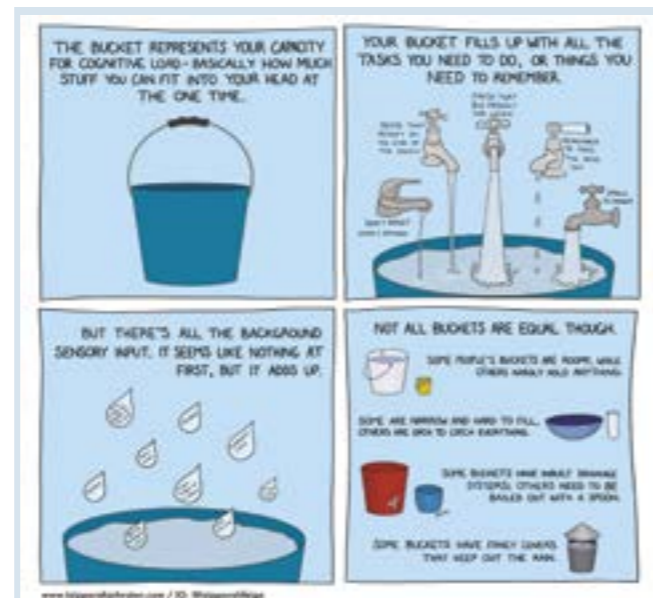


Image source: Creator Tzipporah Johnston, Buckets for Brains, via <https://www.tzipporahjohnston.com/comics>

## Recovery

With research into Autistic burnout in its infancy, no studies have yet been published that investigate the effectiveness of different strategies for recovering from burnout. The following suggestions are drawn from my own experience, and the suggestions of participants in the studies that have sought to define Autistic burnout.

- **Differentiate between burnout and other mental health challenges.** Burnout can look similar to other mental health challenges, like anxiety or depression, but appropriate recovery strategies differ. In particular, reducing social and sensory demands is a useful

strategy for recovering from burnout, whereas this type of avoidance is not seen as useful in treating anxiety and depression. As one participant in Mantzalas et al.'s (2022a) study explained:

*"I was told for years that avoiding things will only make everything worse. And while that is commonly true for my anxiety it absolutely isn't true for my autism related problems. Exposure there makes it WORSE because it causes overload, then burnout. Avoidance HELPS this."*

It is not always easy to tell Autistic burnout apart from other mental health challenges. Researchers have yet to develop any tools for doing so, and burnout can co-occur with challenges like anxiety or depression. However, some factors that may suggest burnout is the appropriate explanation include increased sensory sensitivity, a continued inability to find joy in one's interests and it being possible to identify exhaustion from masking as the cause.

- **Rest.** Rest is the key to recovering from Autistic burnout, although it is of course not always easy to achieve. In some cases, months or years of rest might be needed and recovery may well look like a new normal, rather than returning to whatever your previous normal was. After all, if burnout is a sign that the demands of a neurotypical world have exceeded your ability to cope, recovery must look like changing those demands. Returning to the bucket analogy is helpful here: if you can proactively use rest to reduce social, sensory and task-related demands, you might manage to keep your bucket from overflowing. This might look like making sure to schedule time alone with your interests each day, for example. Some people who receive funded disability supports are able to employ someone to help them with tasks such as cleaning or meal preparation and find this frees up space in their brain that was previously devoted to managing those tasks.
- **Predict when burnout episodes might be more likely and prepare accordingly.** In my own experience, getting enough rest is a balancing act: going too far in the opposite direction and getting bored is also not great for my mental health. One strategy for maintaining this balance is to be aware of times when burnout is more likely and proactively increasing rest at these times. As a phenomenon of chronic overwhelm, burnout is more likely at times when demands increase. For example, many people recall that their first incidence of burnout occurred during adolescence or as they transitioned into adulthood. Thus, as part of planning for major transitions it makes sense to take steps to reduce the risk of burnout. For example, can you schedule more downtime into your week? Reduce social demands for a while? Set aside more time for engaging with your interests?
- **Unmask.** It is the effort of masking that makes Autistic people so vulnerable to burning out. Unfortunately, this does not mean that unmasking is a simple solution to preventing burnout. Indeed, masking is an adaptive strategy that helps us survive in the

world and, in some situations, masking is essential to keeping people safe. However, finding safe times and places where it is possible to be your authentic Autistic self is a key part of recovering from and preventing burnout. *Unmasking Autism* by Dr Devon Price is an excellent resource for exploring unmasking safely in more depth.

## Lessons from Burnout

Ultimately, Autistic burnout tells us two key things about the role of autism in society. First, it underscores the importance of continued efforts to destigmatise, and indeed celebrate, autism. As Mantzalas et al. (2022b) argue, Autistic burnout may be common, but it "should not be accepted as an inherent part of being Autistic." In a world in which Autistic people were safe to unmask, with environments designed with sensory sensitivities in mind and understanding that people's needs, abilities and priorities fluctuate, we would be much less likely to reach a state of cognitive overload, and more able to take the time out to recover when we did. Destigmatising autism to this extent will not be easy, but working towards it is essential to Autistic people's wellbeing.

Second, the story of research into Autistic burnout reminds us of the importance of listening to Autistic voices. Mantzalas et al. (2022a) sought to define Autistic burnout by collecting internet discussion forum posts about it; the first reference they found comes from 2005. It would be another 15 years before anyone sought to define Autistic burnout in the academic literature. Think of where our understanding might be now if studies into Autistic burnout had commenced in the mid-2000s. Think of all the people whose lives might have been different if they had known that the key to dealing with their anguish was rest, not continuing to push through in the hope that it would get better. These are the people we fail when we fail to listen to Autistic voices.

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# Perfectionism

Autistic Advisor for Altogether Autism **Tobin Maclean** hopes that this writing and piece of art helps other people realise they're not alone. He hopes this brings awareness to how anxiety can present as perfectionism, and the impact the deficit model can have on someone's sense of self.

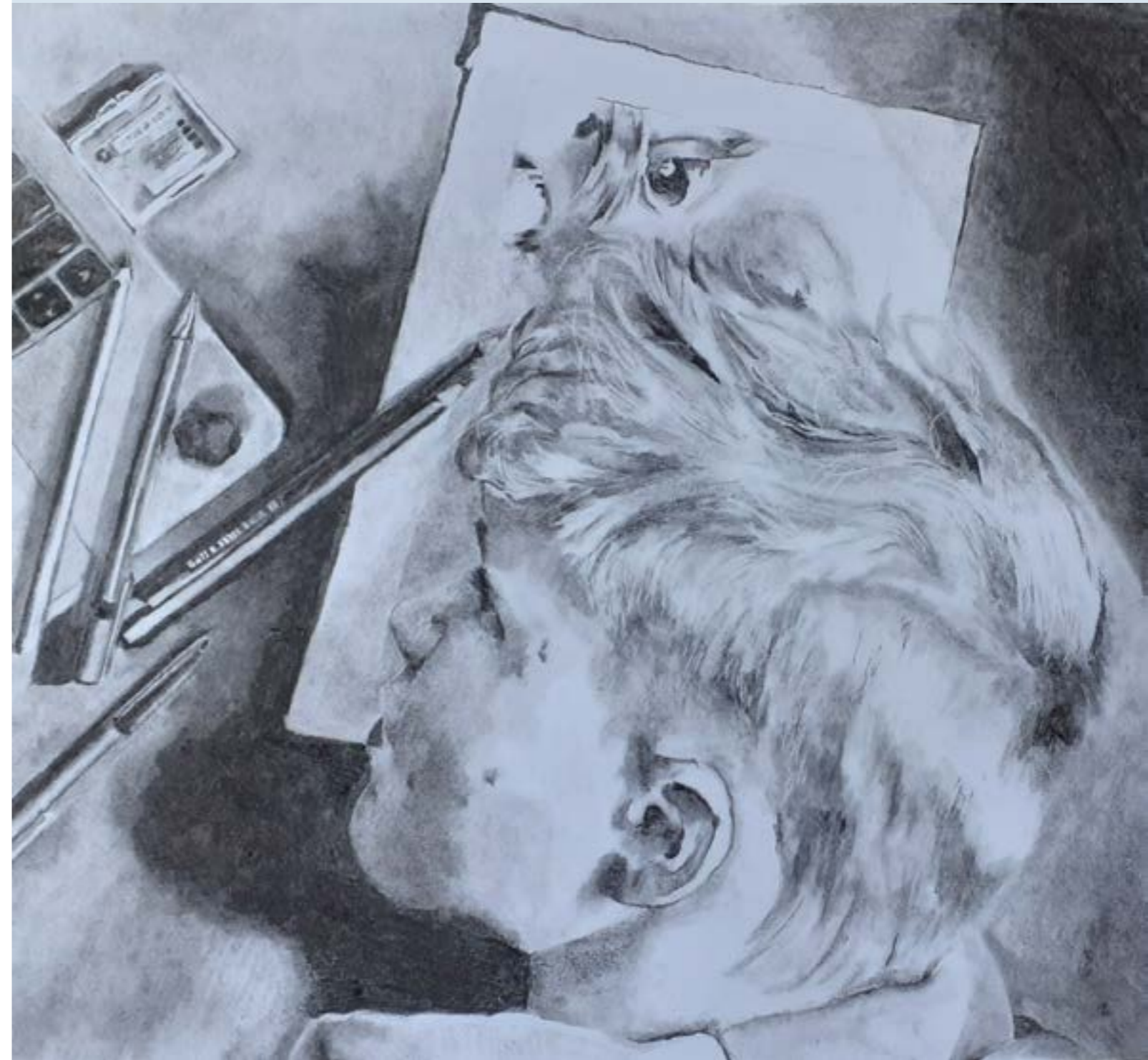


Creating art is difficult for me at the moment. I was a prolific and talented artist when I was younger, I won awards and achieved highly in art classes at school. I have a lot of anxiety about my art being good enough now; every art piece goes through an ugly stage where you need confidence in yourself and the piece to continue, and it is really hard to find that confidence amid perfectionism. I think that being Autistic and the often negative societal messages around autism have contributed to this. The deficit model of autism, where autism is seen as a series of deficits, rather than neurodivergence, has eroded my self-esteem to the point where I think I need to be an extraordinary artist (amongst other things) to make up for my perceived shortcomings. I feel like it is pointless for me to spend time producing art which isn't of exceptional quality, and it leads to so many of my pieces and ideas going unfinished or never even being started. It's a shame because I really enjoyed creating art. For now, I try to reduce the pressure on myself to create and allow that drive to come and go as it pleases.

Yet, I still decided that I wanted to create a new piece of art that somehow depicted what anxiety feels like to me. After over an hour of trying and failing to start anything, feeling like everything I was coming up with was either not very original or didn't feel truthful and therefore nothing was good enough (i.e., perfect), someone pointed out that I was feeling anxious about the task of creating perfect art that portrayed my anxiety. And so, I decided to try and capture the feelings I have around art and used a camera stand made from Sellotape and a ruler to take the reference photo I used for this piece.

I used charcoal because I have found that it is a more free-flowing medium than graphite or watercolour. This lessens my anxiety about making the piece look photorealistic because while you can achieve photorealism with charcoal, it naturally lends itself to being blurry and a bit all over the place. The drawing under my head in the picture is a great representation of what I find hard about art. I had that idea for months, and did manage to finally start it, but now it sits on my desk because I don't want to ruin it. It will probably never be finished.

*Tobin is a lifelong dedicated artist, starting out drawing horses with graphite as a young child. As a teenager, he discovered watercolour, which quickly became a favourite medium along with graphite. Recently he has started using charcoal, as well as branching out into drawing and painting people and planes. He has had pieces in three iNDx art exhibitions, as well as having helped organise it in 2021.*



Perfectionism, by Tobin Maclean

# Autism, anxiety and education: stories from the frontline

As a mother of three Autistic children and an educator herself, Autistic Advisor **Cath Dyson** explores what typically causes anxiety, what anxiety can look like for Autistic students and what is deemed best practice in meeting these students' needs in a typical school setting.

School is typically an environment of unpredictability, pressure around positive peer relationships and a range of sensory stimulation. This can be challenging for many children but is particularly difficult for Autistic children where autism and anxiety frequently go hand in hand. Just going to school can be a battle for these children and staying at school can be a living nightmare.

Autistic students often experience anxiety at times when the demands placed upon them are simply too much. Changes to the normal class routine, a relief teacher, whole school events; these 'normal' school elements can feel anything *but* normal for Autistics. An unmet need to know what is coming up, how long something will take and what it will involve puts the many Autistic learners in a position of feeling very unsafe. Sensory overload is another common reason why these students' anxiety increases.

*“My son has very much struggled to ‘fit in’ at school. He found it challenging to find his place and feel positive about how school operates and the expectations it puts on him.” [Amia, parent of Denny, aged 10]*

How anxiety 'looks' is individual to each Autistic child but there are some commonalities: increased talking and stimming (often hand flapping), leaving their seat, negative body language, refusal to engage in a learning task, leaving the classroom. For some students a phrase such as “this is boring” can be an indicator that their anxiety is on the rise. Certain times of the day are likely to be anxiety-inducing. For Autistic students the unstructured and often unpredictable nature of interval and lunch time can be a minefield. Verbal onslaughts to and from peers and, sometimes, physical altercations can occur because these students do not have the skills or understanding to navigate the social jungle that is the playground.

*“He becomes very agitated in situations where he cannot make himself understood and this makes him increasingly upset. I find it hard to connect with him and calm him at times like this.” [Sally, Year 1 teacher]*

So, what works for Autistic students? How can we ensure that anxiety does not overshadow their educational journey? It is important to note from the outset is that what works for one Autistic student may not work for another. There is evidence-based research, however, around key strategies that are often effective. One that ticks all the boxes is prioritising the home / school partnership. As one parent states: “the line of communication between home and school is so, so important; it should be nurtured, not squashed.” Valuing this communication acknowledges that the parent is the 'expert' of their child and the strategies they use at home are likely to be effective at school as well. Regular and meaningful communication between teacher and parent can go a long way to reducing anxiety for the child as well as the parent and teacher.

Small adjustments can have a major, positive impact in the classroom. Chris, a Year 5/6 teacher in Nelson, “allows students to bring one item from home in case they become worried”. In his experience a student's special interest focus is often the 'one item' which provides support. As Sally notes, her Year 1 student “definitely lights up and is much more engaged” when his learning is based on his special interests. Indeed, for Autistics a learning programme that includes an interest-based element can be successful and research supports this. A strengths-based approach is also critical: for Autistic students to reach their potential, there must be planned, collaborative, strengths-based and person-centred support and intervention (Goodall, 2014; Meer & Evans, 2021).

*“My son's RTLB has advocated for him loudly, from a place of genuine care. She has been able to pull in support to surround Denny with a village. She has educated myself, other whānau and his teachers.” [Amia, parent]*

Removing barriers to learning is key if Autistic children are going to see school as a place that they enjoy and that is free from anxiety. A sticking point for many Autistics is changes to the 'norm' and what they usually experience.

*“Definitely changes to routines can trigger my ākongā (student) to opt out of what is happening which can mean he removes himself and he goes off to do something*

*else - usually running around outside.” [Sally, Year 1 teacher]*

An unfamiliar event such as Athletics Day can become such a source of worry to the student that they think of nothing else and are unable to focus on learning. As Year 5/6 teacher Amie explains, “it is better to ditch cross-country training if it is causing so much anxiety that other learning stops.” A teacher who is willing to be flexible in their approach, therefore, is far more likely to meet an Autistic student's needs and, in turn, reduce their anxiety.

Another barrier to learning can be the teacher themselves. Teachers need to be willing to ensure that learning goals are directly linked to the Autistic student's need. Setting a positive tone for social relationships in the classroom is the teacher's responsibility, as is modelling positive interactions with students. This is facilitated by those teachers who realise that change needs to happen within them as practitioners, rather than the student. It also acknowledges that specialist support, such as RTLB (Resource Teachers of Learning and Behaviour) is sometimes needed and embracing it will be hugely beneficial.

Any kind of transition can be hugely challenging for Autistic students. Home to school, teacher to Teacher Aide, classroom to playground, moving between group rotations, school to home — anxiety is often at its peak during these times. Large-scale transitions such as moving to a new class or new school can cause anxiety for weeks, possibly months. As one mum says: “my daughter has been

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Three young students playing together.



worried about next year since the start of this year.” To forewarn the student is to, hopefully, forewarn them. For example, small-scale transitions within the classroom can be managed through regular check-ins with the student prior to the transition itself.

For larger transitions, such as a change of school, a more specialist service such as RTLB can be employed. The school SENCO (Special Education Needs Coordinator) or LSC (Learning Support Coordinator) can also provide robust support. As one SENCO explains: “we transition Autistic students to their new class and arrange early meetings with their parents. We also help with IEPs (Individual Education Plans) where needed.” This team approach is vital and it should have the student as part of this team. One Nelson RTLB emphasises that gathering a student’s voice around what can help them “can support the student to focus on things that they can control, rather than things they can’t.”

*“My daughter appears to be having a good time and coping at school. Across all of her primary school years we were not believed by her teachers. I feel it is an ongoing battle to help others to understand the specifics of autism.” [parent of a Year 6 student]*

Where educators can become misguided is expecting all Autistic students to be the same in terms of their presenting challenges and manifestations of anxiety. Masking for girls, for example, is common, to the extent that there are almost two different students: the ‘school’ student and the ‘home’ one. The school day can seem to be manageable for some girls whereas, in reality, the anxiety builds as the day progresses. One mum shares that her daughter “comes home from school most days in a big wound-up mess and has many meltdowns and shutdowns due to the anxiety and stress that she has held in at school.” Researchers, RTLB, SENCO / LSCs and parents concur: an increase in teachers’ and school leaders’ understanding of, and response to, autism is key. If a teacher truly understands autism and the individual Autistic student a key shift, or “paradigm shift” as Autistic educator Dr Emma Goodall puts it, occurs. The approach then becomes solutions-focussed, based on the teacher’s belief that the student is capable and has potential (Goodall, 2014).

There is a consensus amongst education and health professionals that there is growing understanding of autism and how it presents differently at different ages and that autism in girls may present differently to boys. Educators, in particular, are realising that neurodiversity is actually very common and they have the responsibility to support the learning needs of these children whether they have a diagnosis or not. This can have a positive impact on parents. Amie, a teacher of twenty years, believes that this increased awareness has “empowered parents to pose inquiries and nurture a sense of curiosity about their child’s development.” Frustratingly, though, increased awareness and empowerment does not equal increased resourcing for teachers. Perhaps, as one parent points out, the future focus should be ongoing professional development: “to have compulsory training in neurodiversity with regular refresher courses would make a huge difference in knowledge, empathy and understanding.”

So, what of the future for our Autistic students in Aotearoa who experience anxiety? It certainly looks brighter. Professionals are more adept at identifying autism and many now acknowledge that autism in girls can look quite different. Schools are more open to making often small adjustments to a student’s day in order to minimise their potential anxiety. Specialist support is often called upon to support teachers in meeting Autistic students’ needs. A child’s sensory needs are increasingly considered to ensure that their learning environment is conducive to learning. Do we have the perfect system? Absolutely not. Can school still feel like a battle? Sometimes. Are we on the right pathway to seeing improved outcomes for our Autistic students? Quite possibly.

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*Cath Dyson is a newly appointed Altogether Autism Autistic Advisor and RTLB in Nelson. She received her autism diagnosis at 47 and ADHD diagnosis at 48.*

A young student and his whānau playing with scarves.



## Therapies for stress relief

**Dianne McLean** first wrote for the *Altogether Autism Journal* in May 2020 with an article titled “Unmasking in the workplace — the late diagnosed Autistic dilemma”. Since then, she has written on Autistic Pride and burnout. In this article she shares practical strategies for relieving stress. She draws on her personal and professional experience as a Diversional / Creative Therapist and shares some simple, creative ways to help manage stress, increase resilience and boost a sense of wellbeing.



I read an article by Chris Schultz on The Spinoff recently. It was entitled “Tempers seem shorter than ever these days. Is it always going to be like this?” It was an interesting read for many reasons. It discussed the long-term effect of global and local events on our nation’s collective ability to be nice to each other — we’re not doing so well, apparently.

Chris Schultz’s article highlighted that many people are feeling disempowered and shaken up by recent weather events and their mental health tanks are getting close to empty. I have a very bad habit of driving around in my car while my fuel gauge flashes a warning at me that I really should fill up soon. I suspect that for many people lately they have been ignoring the warning signs from their overwhelmed nervous systems. They imagine they can keep going for ever without stopping to refuel.

Even without any other influence our modern lifestyles tend to push our bodies into constant fight / flight. Our nervous system has two operating modes: ‘fight / flight / freeze’ and ‘rest and digest’. Sometimes, it is possible for us to get stuck in the fight / flight mode and our bodies never get a chance to return to the rest/digest state, or homeostasis.

The days of encountering a saber-toothed tiger and needing to run for our lives have been and gone but our nervous system still detects things that it perceives as a threat. This could be the experience of lateness due to being stuck in traffic on the way to work or to an important appointment. Our nervous system insists on flooding our body with stress hormones as if we really did need to escape that tiger. And, unlike a real-life encounter with a dangerous animal, there is very little we can do to escape the stressors of modern life; we just have to endure them.

The link between stress and heart disease, stroke and other serious illness is well documented (Steptoe & Kivimäki, 2012). Interestingly, stress also has a profound influence on our immune system and our ability to fight infection as well as our mental and emotional wellbeing (Seiler et al., 2020).

As neurodivergent people we already experience higher levels of stress than the general population. Our particular brain wiring and chemistry means that navigating society can be challenging. Our trauma buckets are much fuller than our neurotypical kin and it does not take much added stress to cause them to overflow resulting in overwhelm, meltdown and burnout. Thankfully, there is a lot we can do to help ourselves reduce our stress levels. Stimming, pursuing our special interests and being empowered to self-advocate can go a long way to making life better.

There are a few other things we can add to our personal wellbeing kits which we can pull out and use when we need an extra bit of soothing. Breathing. Sounds simple and it is. Taking time to concentrate

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on breathing mindfully can really reduce stress levels in the moment when you cannot escape the stressor. Gerritsen & Band (2018) suggest that it is stressors rather than inhalation which activate the sympathetic nervous system, and it is slow and steady breath with prolonged exhalation which activates the parasympathetic nervous system. So, breathing in deeply and paying attention to the sensation of breathing and then breathing out for slightly longer than our inhale will change our physiological responses to the situation. This can mean the difference between coping and melting down completely.

Breathing is like first aid. It is what we can do on the spot to help alleviate uncomfortable feelings. However, sometimes the tension builds slowly over time without us being consciously aware of it until we reach the stage of burnout; this happens to me all the time. By being more aware of our limitations and specific sensory needs there are ways we can be kind to ourselves and fortify ourselves against the negative impacts.

Here are a few things I have found helpful. Since putting these things into practice, I have definitely noticed a huge improvement in my sense of wellbeing and my ability to manage my life stress. This is not an exhaustive list by any means and what works for me may not work for someone else. Hopefully, though, you may be inspired to give some of these strategies a go.

## Movement

I've always been a mover. As an undiagnosed teenager, I used dance to self-regulate. These days it is called stim dancing and I am a big fan of it. I have recently discovered the joys of movement meditations because I struggle with the whole stilling the mind thing. My mind is loud and obnoxious at times so more traditional forms of meditation have been very unrewarding. Movement meditation can take many forms and it strengthens the mind / body connection, relieves stress, calms and energises us. Qi Gong is a form of movement meditation with proven health benefits (Jahnke et al., 2010). If going to a class or group feels too overwhelming, there are plenty of online tutorials on YouTube. I would also like to put in a good word for restorative yoga. Restorative yoga is the practice of yoga designed specifically to soothe and calm the nervous system. Once again, you can find tutorials online if you want to find out more.

Going for a walk and paying attention to your feet and the sensations around you is another way to practise movement meditation.

## Music

We all understand how profoundly music affects us and how many benefits there are in listening to and playing music. You do not need to be a musician or singer to gain benefits from using music as therapy, it's about the process not the performance. There are so many

ways to incorporate music as therapy into your life. The simplest is mindful listening. To listen mindfully is to stop, relax and pay attention to the music as opposed to having it on in the background while you do other things. Listening through headphones is a good way to cut out external distractions and they can also help highlight all the various sounds that make up a piece of music. You may take note of special / different sound effects, allow the music to create a movie in your head, let the music lift your emotions and soothe your anxiety. Just a tip: I can't go straight to listening to gentle, soothing music if I'm upset, anxious or stressed. I have a specific folk metal song I listen to first. I don't need to move, just listening to it works for me. There's something about the rhythm and tempo that allow me to dissipate the stress I am experiencing. My mind can then relax enough for quieter music to do its magic trick on my mood.

There are musical instruments available that you can pick up without any musical training or skill and play to relax and enjoy the process. They are designed so it's impossible to play a bum note, so you'll always sound pleasing (to yourself and those around you). Zen drums, Native American flutes, sansulas and Koshi chimes all work well for this purpose. You can use a small hand drum to pick up some simple rhythms for learning drum meditation.



A shamanic drum rests on the table.

Of course, there's nothing wrong with purposefully learning a musical instrument and it's never too late to learn. There can be, however, a level of frustration involved in learning any new skill which means it may not offer immediate stress relief. Once you've learned successfully though, there's nothing like the sense of accomplishment you get to boost your sense of wellbeing.

## Guided meditation

Guided meditation is listening to someone talk you through a scenario with a specific outcome in mind. There are meditations to help with anxiety, insomnia,

connecting to your higher self and pain relief to name a few. Some guided meditations do rely quite heavily on visualisation, so if you struggle with being able to hold an image in your mind's eye it may be difficult to find one to suit you. I've found these helpful because having someone speaking gives my unruly mind something to concentrate on rather than just sitting there trying to focus on my breath. Some guided meditations are designed to work as you sleep and these will generally have something like 'sleep', 'talk', 'down' or other similar words in the title. Apps such as YouTube and Spotify can help you research and collate a playlist that suits you. Recently, I discovered green noise. This is like the more well-known white noise but at a different frequency. This has helped me to unwind enough to fall asleep. There are several different sound colours all with different frequencies; it is worth experimenting to find one you like. I can't abide brown noise, for example, it makes my brain feel itchy, but other neurodivergent people rave over it.

## Art journalling

This is the one thing that changed my wellbeing the most. I have two systems - my swearsy journal which, as the name suggests, contains more colourful language. It is useful for processing the hard, negative and dark stuff and I don't edit or censor what goes in. Then I have my actual art journal which also moonlights as my gratitude journal. This one I keep purposefully more upbeat and positive. This is because gratitude journalling supports emotional and social wellbeing. Once again, you don't need any artistic experience or skill to do art as therapy. As mentioned before, it is the process and not the end product that is the goal. I've personally experienced this many times. Sometimes the process has been close to achieving a Zen state, which is the highest form of relaxation / meditation. There are lists of prompts available online if you get stuck for what to create a page about. A word of caution: there are people who create art journals to be a work of art so don't get caught up in thinking your pages need to be as intricate as theirs. Avoid articles with '11 mistakes you're making in your art journal and how to avoid them' in the title, for instance. It is important to understand that here's no 'wrong way' to art journal.

The benefits of beginning to incorporate some of these stress-reducing strategies into your life cannot be overstated. Sometimes the changes are gradual but finding something that you gel with initially and then continue with can have a powerful impact. They make us stronger and more resilient to the pressures of the world we find ourselves in. Being creative is not always about being an artist or a musician, it's more about being human. We are driven to create and giving ourselves permission to be so without believing we have to be 'good' at it, heals us on many levels. It strengthens us, too, in ways that will surprise you if you decide to embark on this exciting journey.



Creative Thinker, by Dianne McLean

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# Anxiety communicates — interpreting and responding to anxiety in Autistic children

Identifying both observable and less obvious signs of anxiety in Autistic children, **Estelle Pretorius** highlights the importance of understanding a child's preferences and sensitivities, and the use of sensory-based activities and visual supports.



Anxiety is becoming one of the most diagnosed conditions in young children (Field et al., 2011). Anxiety can be described as feelings of worry, stress or fear that affect how the body and mind operate. For children, these feelings may interfere with their ability to participate in daily activities, such as routines of self-care or participation in family and community gatherings. Anxiety can trigger emotions and children can experience a feeling of being overwhelmed. Anxiety manifests differently in each child: different expressions, actions, emotions, and ability to engage. Research suggests that there is a high prevalence of Autistic children who also experience anxiety (Lai et al., 2019; Middletown Centre for Autism, 2020). Also, while Autistic children may feel and experience

many of the same worries and fears as neurotypical children, they might feel anxious or worry about things that matter less to their neurotypical peers. Sensory sensitivities, uncertainty and change, negotiating social expectations and interpreting emotional responses are common anxiety triggers in Autistic children.

## Sensory sensitivities

Sensory processing is the ability to integrate signals from various sources, such as visual, auditory, taste, smell, tactile, proprioceptive, vestibular and interoceptive signals. When sensory integration works effectively, children can participate and engage with their environment meaningfully by taking an interest, communicating their ideas, and responding to spoken or non-spoken messages. However, Autistic children often experience and process sound, touch, smell, movement and internal body signals differently than their neurotypical peers. Some examples of these differences include heightened reactivity to sound, touch or movement or heightened responses to sensory information that is new or unexpected. These responses can trigger heightened emotional responses, impulsivity or avoidance and resistance. For example, a noisy kindergarten environment or a loud shopping mall can trigger worry or fear responses in the child and these can escalate quickly.

## Uncertainty and change

Another common trigger for anxiety in Autistic children is small disruptions to regular and predictable routines, for example, when a favourite routine or activity is delayed or changed. Uncertainty and change are often unavoidable and can overwhelm and confuse children. Young children often mitigate change and manage emotions during these periods of uncertainty, with the usual support from caregivers. However, this might not be the case with Autistic children, as emotions of overwhelm and confusion may not be so obvious and are often misinterpreted by carers. Similarly, for Autistic children, unplanned or unsupported transitions between activities can often trigger periods of emotional distress.

## Understanding and responding to social expectations

Autistic children can become overwhelmed and anxious when there is an expectation to interact, connect and share in a specific / expected way; however, the rules of social engagement may have not been made explicit or explained to them. Young children are usually introduced to unspoken social rules of engagement early on in their development, through peer-to-peer play and sometimes explicit instruction from adults. However, when these social cues from others are not interpreted or explained, Autistic children might feel overwhelmed when others do not understand them, or they might not understand why others act in a certain way.

## Presentation of anxiety in Autistic children

While anxiety is something we all experience in varied ways, most of us are adept at using strategies and tools to manage our emotions and successfully navigate situations. For example, some people chew their nails when nervous, while others repeatedly flick a pen while thinking or sitting a test. More stressful situations usually require more cognitive or emotional competence, and we actively seek to understand, communicate or describe our experiences. Anxiety presents itself differently in Autistic children compared to non-Autistic children. For some, anxiety shows up in obvious or observable actions; for others, it can be less noticeable that they are experiencing worry, uncertainty, fear or upset feelings.

Observable, obvious clues that may indicate that a child is anxious:

- Physiological responses include sweating, tension, fatigue, nausea, or headaches.
- Sensory seeking or avoiding actions, such as covering the ears to block a particular sound.
- Intense emotional responses, including being angry, irritable or upset, defiant or out of control.

Not-so-obvious clues that may indicate that a child is anxious:

- A lack of engagement or wandering around aimlessly.
- Communicative responses such as being unusually quiet or overly chatty.
- Avoiding or withdrawing from situations.

## Responding to anxiety

Anxiety communicates, whether explicitly or not. Caregivers of Autistic children often intuitively know what triggers their child's anxious responses, but communicating these to other carers, whānau or friends can be challenging. Children respond differently in different settings and a helpful approach is to start with understanding the child's preferences, interests and strengths.

- **Practise observing the child regularly in a range of activities and across settings.** Pay attention to how the environment impacts the child's involvement in activities, routines and ongoing play. Consider what the child needs or enjoys in order to be present and actively engaged. What does 'actively engaged' look like for this child? Does the child have access to preferred activities? How does the child typically show you what they want or need? Are there alternative ways for the child to communicate their intentions, for example, picture boards, communication devices?
- **Learn about the child's sensitivities.** What does the child typically respond to? What do they seek out? Which sensory experiences do they avoid?

- **Consider planning and implementing a sensory diet.** This means creating an individualised range of sensory-based activities that can be performed regularly to give the body the sensory feedback it craves.
- **Teach the child a practical skill** so they can contribute actively to routines in whatever manner works for them. For example, supporting a child to have responsibility for setting the table for family meals might ease their anxiety around the timing and transition to the mealtime routine. Engaging children in everyday routines and activities can reduce anxiety and positively impact their emotional wellbeing.
- **Find a visual support system that works for this child.** Consider a visual system that makes routines and expectations explicit and participation easy. Build in regular breaks and offer options or choices; make these choices explicit and accessible. Anxiety can be significantly reduced when a child knows what is available and how to access it when needed.
- **Relaxation techniques** are helpful and effective in easing anxiety; however, they must be demonstrated and practised. Use fun games throughout the day to introduce a range of relaxation activities such as breathing, bear hugs, listening to music or favourite and preferred activities that are calming to the child.
- **Relaxation or calming spaces** can be set up anywhere at home or in the early learning centre. Consider colour, texture, sound, light and movement when creating a space for the child to go to calm or relax. Consider the child's interests, preferences and sensory sensitivities when creating this space. Think about ways the child can access this space independently; will they have a way to communicate if they need a break?
- **Feelings of anxiety can prompt children to act impulsively or react unsafely.** Suggest or provide alternative ways or places where you know the child will experience calm and become more regulated. Model affirmation and calm wherever possible.

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# Co-design of digital mental health support for Autistic youth with co-occurring anxiety: a research project

Digital mental health solutions, particularly for Autistic youth, lack research attention. **Holly Gray** discusses her upcoming research project which aims to find out: what types of mental health support do Autistic youth desire in digital platforms; what are the barriers and enablers in involving Autistic youth in digital mental health support; and how can digital mental health support be culturally responsive to meet the needs of Autistic Māori rangatahi?



Research estimates that up to 94% of Autistic people experience at least one co-existing mental health condition (Hossain et al., 2020). So, why isn't mental health support more accessible and relevant for tāngata whaitakiwātanga? Despite an increased need for mental health support, there are still inequities between the Autistic community, mental health systems and neurodivergent-specific support systems (Crane et al., 2019; Maddox et al., 2021). Unfortunately, this can lead to Autistic people being turned away from support services. In fact, research shows that over 25% of Autistic participants have been denied mental health support or access to mental health support because of their autism (Hallett & Crompton, 2018). Not only is this an alarming reflection of the large mental health disparity faced by Autistic individuals, it highlights the importance of listening to, and learning from, the Autistic community to ensure their needs and preferences for mental health support are being met (Crane et al., 2019).

Based on emerging research, digital mental health support can be beneficial for youth with anxiety and can improve the accessibility of mental health care (Garrido et al., 2019; Lattie et al., 2022). However, most of this research has been focused on Allistic youth. To our knowledge, there has been no research that considers the specific needs and preferences of Autistic young people in accessing digital mental health supports. Therefore, our project aims to find out: what areas of mental health support Autistic youth would

like to see in digital mental health support; what the barriers and enablers are to engaging Autistic youth in digital mental health support; and how can digital mental health support be culturally responsive to the needs of Autistic Māori rangatahi. As a child and family psychology student, my research interests are centred around promoting child and youth mental health and pushing the boundaries of mainstream delivery of interventions to enable accessibility for those who need mental health support. With the guidance and support of Dr Lisa Marie Emerson (senior supervisor) and Prof Laurie McLay (second supervisor) from the University of Canterbury this project strives to meet these goals.

The need to listen to the Autistic community is clear across literature. Why, then, isn't there a larger focus on creating a space for Autistic people to have their say? The community-led autism research priorities of Aotearoa highlight the importance of understanding the preferences and needs of Autistic people. It is key that this understanding is developed from the voice of Autistic individuals and their experiences across the spectrum of supports (Emerson et al., 2022). Additionally, members of the Autistic community also call for the prioritisation of quality of life, translation of research into real-world change, cultural responsiveness, and mental health in research (Emerson et al., 2022). It is these research priorities which form the foundation of this project.

By considering the mental health experience of Autistic people, described by Autistic people, we can

have a greater acknowledgement of, and can begin addressing the disparities faced by Autistic people. We have sought input from Autistic Partnership Aotearoa New Zealand, the wider Autistic community, and Māori advisors during research and question development, and recruitment phases. We intend to continue utilising their feedback while we carry on recruiting participants, conducting interviews and beginning the analysis phase in the coming months. Being an Allistic student researcher myself, insight from Autistic individuals is essential in creating safe space for Autistic people to voice their needs and preferences. In turn, we intend for this research to inspire a culturally responsive and relevant digital mental health support made by Autistic rangatahi, for Autistic rangatahi.

## Glossary

**Tāngata whaitakiwātanga** Autistic people

**Allistic** Non-Autistic person

**Rangatahi** Young person / people, younger generation

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A youth using an app with headphones outdoors.

# Anxiety prevalence in Autistic youth: an overview

The close link between autism and anxiety reveals unique complexities for Autistic individuals, with the need to explore tailored approaches, writes researcher **Ashe Yee**.



Anxiety is a common human experience that most people will have to deal with at some point. For Autistic people, however, it often takes on a unique and complex dimension. Over the years, research has showcased a close relationship between autism and anxiety, revealing a significant challenge that many Autistic individuals face.

There is a lot of evidence to show that Autistic people have higher levels of anxiety and anxiety disorders compared to the general population. A 2011 meta-analysis conducted by van Steensel et al., (2011) examined 31 different studies involving autism and anxiety disorder assessments and found that approximately 40% of young Autistic people had at least one co-occurring anxiety disorder. To put things into perspective, anxiety disorders in neurotypical children have been estimated to occur in 2.2% to 27% of the population. The prevalence rate of anxiety disorders in Autistic adults is similarly high, with estimates taken from a systematic review and meta-analysis ranging from 27% to 42% for any anxiety disorder (Hollocks, et al., 2018).

## Types of anxiety commonly seen in Autistic youth

Anxiety experienced in autism isn't limited to a single form. Several types of anxiety disorders are prevalent among Autistic children and adolescents, including some of the types listed below. Aside from panic disorder, the prevalence rates seen for the below anxiety disorders are more than double that of the general population:

**Specific phobias:** An intense, irrational fear of something that poses little or no actual danger. Thinking of or encountering the object or situation can bring about severe anxiety or distress. Some common phobias include fear of certain animals and fear of needles.

Specific phobias are the most common type of anxiety disorder seen in Autistic children and adolescents, at a rate of about 30% (van Steensel et al., 2011).

**Social anxiety:** An intense or persistent fear of being watched or judged by others. Autism is often characterised by differences in people's social communication and interaction compared to neurotypical peers. The challenges associated with understanding non-verbal social cues and engaging in social interactions can give rise to social anxiety, which in turn can lead to avoidance of social situations. Roughly 17% of Autistic youth have a social anxiety disorder (van Steensel et al., 2011).

**Obsessive-Compulsive Disorder (OCD):** Uncontrollable, reoccurring thoughts (obsessions) that cause anxiety and behaviours (compulsions) that one feels the urge to repeat to get relief from the thoughts. Both autism and OCD often involve repetitive or ritualised behaviours and a focus on specific interests, which can sometimes make it difficult to tell the two apart. OCD is estimated to affect approximately 17% of Autistic youth (van Steensel et al., 2011).

**Agoraphobia:** A fear or anxiety in which someone believes their environment to be unsafe with no easy way of escape. This often extends to busy public places, like shopping centres or public transport. Agoraphobia causes some people to stay in environments they consider to be safe, like their homes, for long periods of time. In severe cases, some people are unable to leave their homes for months, or even years. Agoraphobia is estimated to impact up to 17% of Autistic youth (van Steensel et al., 2011).

**Generalised anxiety disorder:** Excessive worry or fear about everyday issues with no clear cause or reason. Generalised anxiety disorder is estimated to impact 15% of Autistic youth (van Steensel et al., 2011).



Eva and Alex at an Auckland Good Lives workshop.

**Separation anxiety:** Extreme anxiety due to the separation or anticipated separation from a figure of attachment. This often relates to caregivers or other family members but can also extend to animals or even places. Separation anxiety has an estimated prevalence rate of 9% for Autistic youth and has appears to be more common in younger children (van Steensel et al., 2011).

**Panic disorder:** Frequent and unexpected panic attacks with no clear cause. Panic disorder was the least common co-occurring anxiety disorder found in van Steensel et al., (2011) study, only affecting 2% of Autistic youth.

## Unique aspects of anxiety in autism

Some aspects of anxiety, like automatic and unhelpful thoughts and physiological hyperarousal (e.g., paranoia, jittery feelings, irritability), are shared between Autistic and neurotypical people. However, the experience of anxiety in Autistic individuals can also differ in notable ways from those without autism (Ollendick & White, 2012).

One crucial factor is the interaction between social differences inherent in autism and the anxiety they may induce when interacting with neurotypical peers. The difficulty in navigating social situations, "fitting in", understanding nonverbal cues and managing sensory sensitivities can all contribute to heightened anxiety in everyday interactions and can lead to Autistic burnout. Many Autistic people also rely on routine and predictability, so changes in routines or unexpected events can also cause overwhelming anxiety. This can lead to heightened stress responses and difficulties in adapting to new or unexpected situations.

## Challenges in diagnosis and treatment

Identifying anxiety in Autistic individuals can be challenging due to overlapping symptoms. Repetitive behaviours, avoidance, and communication differences can mask anxiety symptoms, making it difficult to distinguish Autistic features from anxiety symptoms and anxiety symptoms from anxiety disorders (van Steensel et al., 2011). In other words, many Autistic children can display symptoms of different anxiety disorders but may not meet the diagnostic criteria for a specific anxiety disorder. This may be due to their anxiety not interfering enough with their day-to-day life, or to the view that the symptom is already explained by their autism diagnosis.

When it comes to treatment for anxiety, tailored approaches are essential. Autism-specific therapies that acknowledge sensory sensitivities, communication differences and unique stressors are crucial. Despite the substantial overlap between autism and anxiety, research is still in the early stages of identifying effective treatment approaches for Autistic people.

Cognitive Behavioural Therapy (CBT) for example, is often considered to be a first line treatment for anxiety disorders in neurotypical people. However, it has only been in the past decade or so that efforts have been made to suitably adapt CBT for the unique needs of Autistic youth. These modifications can include things like increased caregiver involvement, simplifying or reducing the cognitive restructuring component of CBT, and attempting to personalise the treatment by incorporating the child's interests (Nadeau et al., 2011; Bemmer et al., 2021). The results of modified CBT have been very promising, but research is still being conducted to build a stronger evidence base, particularly for use with Autistic adults.

Medication, like Selective Serotonin Reuptake Inhibitors (SSRIs), is often used to help manage anxiety in neurotypical people. However very little good quality research has been conducted to determine the efficacy of SSRIs or other 'anti-anxiety' medication when used to treat anxiety in Autistic people (Nadeau et al., 2011; Menezes et al., 2022).

Continued on next page »

## Summary

In essence, anxiety and autism often go hand in hand; so much so that even some experienced clinicians have trouble deciding whether it is autism alone, anxiety alone, or both together! Many people experience anxiety at different points in their lives, but Autistic youth may be more than twice as likely to experience anxiety or be diagnosed with an anxiety disorder compared to their same age peers. This higher rate of anxiety can also be accompanied with some challenges and triggers related to autism that can make the anxiety worse. This could be environmental sensory sensitivities, routine disruption, or difficult or confusing social interactions where Autistic people may feel the pressure to mask in order to fit in.

Research on best treatment practices is still emerging, although modified and tailored versions of existing anxiety therapies, like Cognitive Behavioural Therapy, appear to be promising. To be effective, though, they need to be delivered by a mental health professional who is experienced with Autistic clients. If you or a loved one are Autistic, anxious and you want to learn

more about the different types of anxiety Autistic people face, their experiences, and what strategies might be helpful, then this Journal is for you!

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*Ashe Yee (BPsych, First Class Honours) joined the Altogether Autism team as a researcher in 2019 and is passionate about delivering evidence-based information.*



Nilulpul and Nijaya at an Auckland Good Lives workshop.

# He Karu, He Taringa: shining a light on autism through Tahuaroa Ohia's inspiring film

Altogether Autism was proud to feature the groundbreaking film He Karu, He Taringa alongside Maoriland Film during Autism Appreciation Month 2023. **Jamie-Leigh Timoti** was inspired by the firsthand experiences of writer / director Tahuaroa Ohia. This film aims to raise awareness about the challenges faced by whānau during diagnosis and to promote understanding and acceptance of autism within Māori and indigenous communities, as well as among families worldwide.



## A story of Ben and his whānau

At the heart of the film is the story of Ben, a young Autistic boy and his mother's courageous journey as she strives to navigate the complex health and education systems to find support for her son's needs. Tahuaroa's personal connection to this narrative brings authenticity and emotional depth to the film, resonating with families who have faced similar challenges. Through this powerful film, Tahuaroa seeks to extend a hand of support and solidarity to parents and families who may feel isolated and unsure about their child's unique needs.

## Embracing autism as a gift

*"People need to start treating takiwātanga as a gift, not a disease."*

Tahuaroa emphasises the importance of recognising takiwātanga as a gift rather than a disease. By shifting the narrative surrounding autism, the film challenges societal perceptions and encourages a more inclusive approach that celebrates diverse abilities.

*"I want our parents to know that they're not alone. There are so many parents who haven't been helped and they don't know what takiwātanga is, and I really hope that we give that manaaki to them and hope and know that our children are special, they're superheroes." – Tahuaroa Ohia*

## Eyes and ears of a different world

The title He Karu, He Taringa beautifully captures the sensory experiences of Autistic children. It highlights the unique ways in which they perceive the world around them, with heightened senses and a distinctive lens through which they navigate their surroundings.

## Aiming for empowerment

He Karu, He Taringa looks to uplift and inspire audiences worldwide. Tahu's vision of acceptance and understanding is beautifully brought to life, inviting viewers into the world of takiwātanga and promoting autism as a source of strength and unique perspectives. By sharing this film, we hope to amplify the message of compassion, awareness, and support for Autistic people and their whānau, fostering a more inclusive society for all.

Altogether Autism supports the film by offering free information and advice to whānau and tāngata whaitakiwātanga. If you and / or your whānau aren't sure where to find local support, reach out to us and we will try and connect you to your local community support.

## Video for article

<https://maorilandfilm.co.nz/he-karu-he-taringa/>

## Glossary

**Tāngata whaitakiwātanga** Autistic people

**Takiwātanga** Autism

**Whānau** Family

**Manaaki** Support

*Jamie-Leigh Timoti specialises in online creation and engagement at Altogether Autism.*



Poster for He Karu, He Taringa.

# On the Colour Spectrum

The Colour Spectrum art exhibition opened on World Autism Awareness Day 2023 at The Good The Bad Gallery in Glen Innes, Auckland. Curator **Haz Crawford** spoke to **Nicolina Newcombe** about his mission to stun the neurodivergent community with a colourful art exhibition.



## How did the Colour Spectrum project begin?

I wanted to do something to teach the community around us about who we are as Autistic people. There was an exhibition last year called Autistic Expression run by Xabilities, an Autistic-led group for Autistic people. I said to Tamara Grant, founder of Xabilities, that I wanted to do something similar. Tamara and I ended up working on my exhibition together.



Art on easels.

## What is the significance of the name Colour Spectrum?

My mum Belinda Johnston helped me come up with the name. It reflects who we are because we are all different.

## I know you are an artist. Can you tell me about your art at Colour Spectrum.

I have found that art is a way of communicating. It is something we all share. I created an artwork based on my talent for calendar dates. If you tell me a day, month and year I can tell you what day of the week it was on. There is lots of complicated maths behind it, but I can literally do it in my head.

My art is six coloured sheets of paper with tables of all the calendar dates and days. I made it so that other people could figure out calendar dates for themselves. The work is called *Untitled* because it is something I can't put into words. There are multiple meanings behind it.

The opening event for Colour Spectrum was incredible. There was a fantastic turnout from the Autistic community and our supporters. The gallery was so packed I could hardly move. You also put on a sensory space, fire dancers for entertainment, and great kai / food and inu / drinks.

More than 100 people attended the opening night, including two Members of Parliament (MPs): Priyanca Radhakrishnan, Minister for Disability Issues, and Deborah Russell, MP for New Lynn. More than 250 people visited throughout the entirety of the exhibition.



Inside the gallery.

## That sounds like a massive undertaking. Tell me about organising the Colour Spectrum exhibition.

I approached a local gallery called The Good The Bad, which hosts exhibitions showcasing the cultural diversity in the area. Then, I found artists who wanted to participate. I also worked with the venue about how we laid it all out. Most importantly, I ensured that everyone enjoyed it and learnt something to take away as well.

## How did you curate the artwork?

I sent emails out to lots of different people and organisations. I got a broad range of artworks that all these amazing people had done. There were a lot of pieces from Art for All Auckland. Lynda Scott from Art for All also helped out with the exhibition. Some parents from Sommerville Special School, where my mum is the principal, came forward and said their children wanted to showcase some art as well. The youngest artist was 12 years old.

## Were all the artists Autistic?

Yes. It was Autistic Acceptance Month so I decided to focus just on autism.

## Did many pieces get sold?

A few. One of my cousins bought a drawing of an electric train. He works in the transport planning industry and he put that drawing on the wall in his office.

## You said you made sure everyone else learned something. What did you learn from organising this exhibition?

I learned a lot from having a few challenges. I started recruiting the artists a bit earlier than what worked for everyone else. I had already recruited a whole bunch

of artists and I then got a whole bunch of unexpected costs that I had never had to deal with before. That is when I started up a Give a Little page to crowdsource some funding. Xabilities ended up collaborating with me financially as well. There is a lot to putting on an event like this and you have to learn to be resilient and stick to it all the way to the very end.

I also had some anxiety about how others would perceive me. I have grown to be what I call "underneath the radar", so I had to push myself out of my comfort zone to make sure things were organised. I didn't want to be in the spotlight because I thought I wasn't quite ready yet, but I ended up doing it anyway. The outcome was absolutely amazing. I could not have been more proud or more grateful, not just for what I have done, but for everyone else who helped to make it possible.

## You have achieved so much. What is next for you now?

While I got a lot of praise for all the hard work I did, ultimately, it comes down to self-praise, self-love and self-respect. I know I can do greater and better things and it never ever stops, even if it gets tough at times in the future. Overall, I'm really honoured and privileged to have been able to do something like this, not just for myself but for the neurodivergent community. Now I am focusing on what I can do next year.

## Contributors

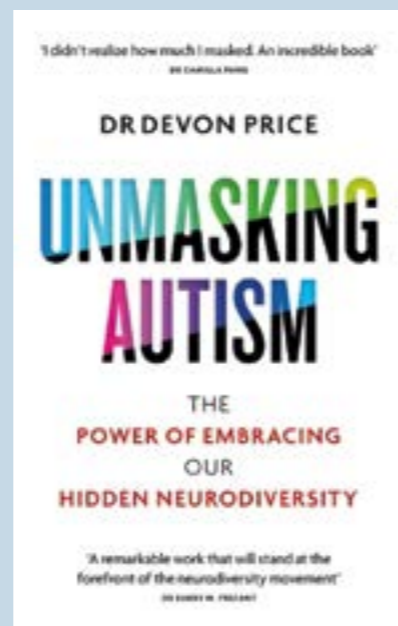
*Haz Crawford (Ngāi Tahu) is an Autistic artist who competes in the Special Olympics, plays for the New Zealand Mini Golf Federation, and volunteers with a community patrol.*

*Nicolina Newcombe (DipJ, BA, GradCertNFP, MMPD) is an Autistic PhD student in Education.*

Book review by **Anissa Ljanta:**

# Unmasking Autism - the power of embracing our hidden neurodiversity

**Dr Devon Price, Harmony Publishing 2022.**



Autistic communities online are on fire with people recommending Dr Devon Price's latest book, *Unmasking Autism*, and with good reason. I consume a lot of neurodivergent content and this one is a standout.

*Unmasking Autism* offers evidence-based tools and insights to support Autistic folks to unpack internalised ableism and live as our true neurodivergent selves while simultaneously educating and broadening society's limited view on autism.

Dr Devon Price is a proud Autistic US-based social psychologist, writer and professor. His work has appeared in numerous publications including NPR (the public radio network of the United States) and the Huffington Post. Active across a range of Autistic spaces and communities, he is also the author of the books *Unlearning Shame* and *Laziness Does Not Exist*.

*Unmasking Autism* reframes autism in the social model of disability. It amplifies stories and commonalities of lived experience, educating readers through Autistic perspectives gleaned from online polls and requests for feedback on Dr Price's online platforms and interviews. This wealth of social wisdom is scaffolded beautifully by clearly cited academic research.

Dr Price demystifies common Autistic behaviours like 'spending hours or days alone sleeping and recharging after a socially demanding event or stressful project' and 'not knowing how we feel, or needing a few days to figure out how we feel about something'. It's super important for those supporting Autistic folks, especially our rangatahi / young people, to know this stuff.

*Unmasking Autism* dissects the reality and cost of masking, explores how to build an 'Autistic Life', addresses common dilemmas like the age-old question of whether to 'come out' as Autistic, highlights the importance of Autistic relationships and sends out a reverberating call for an inclusive neurodiverse world.

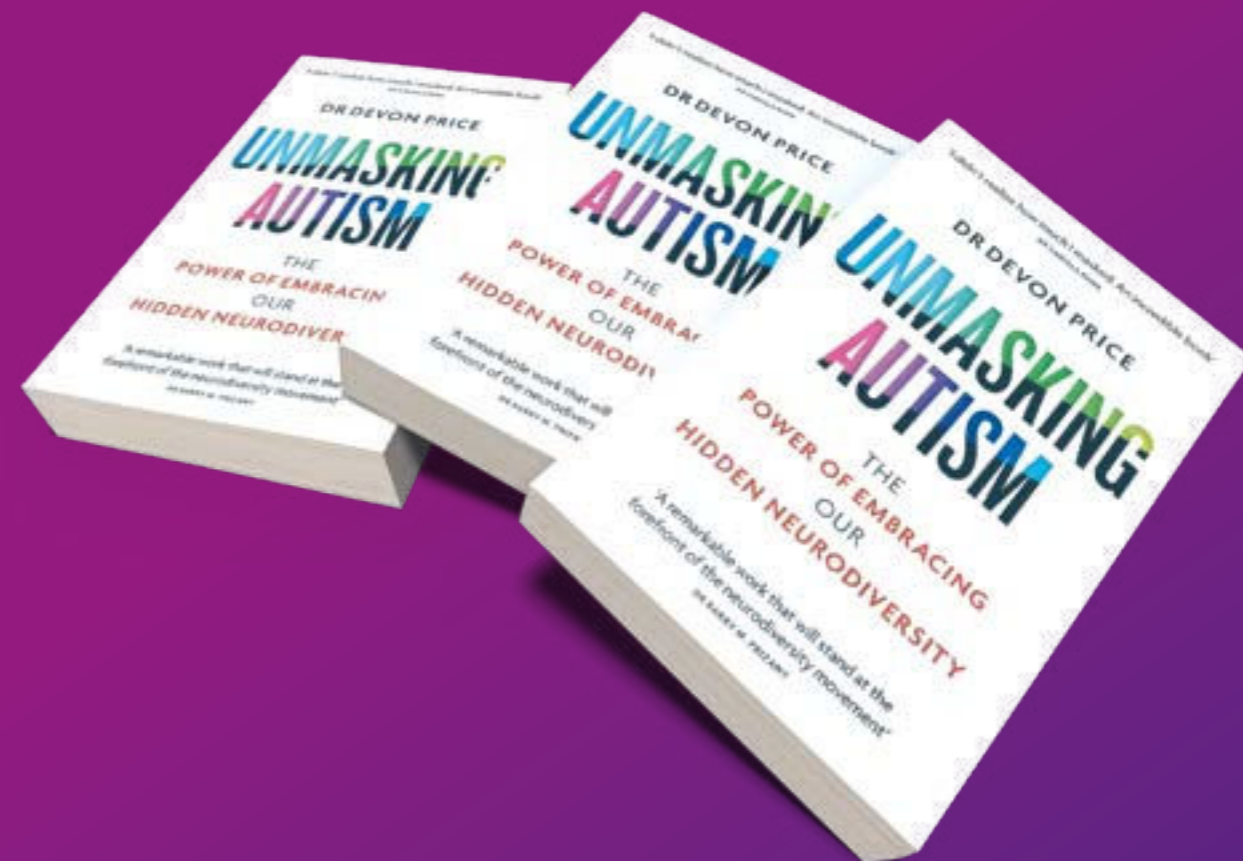
If you're Autistic, or supporting a loved one who is, I recommend taking time to digest and process each chapter. Reading it can be confronting, in a good way, especially for late diagnosed or young folks just starting to embrace Autistic identity.

I'm often asked to recommend books about autism. This one is on the top of my recommended reading list. *Unmasking Autism* is a keeper, a book to return to again and again as we come more fully into our Autistic selves.

*"Autism is a spectrum, a rainbow of different shades and hues that thrive when they stand beautifully together. For too long we have hidden what makes us unique, fearing we're broken or unlovable. Embracing Autism means shedding that mask and finding safe ways to share our vibrant colours with the world."* Dr Devon Price

*"To unmask is to lay bare a proud face of noncompliance, to refuse to buckle under the weight of neurotypical demands. It's an act of bold activism as well as a declaration of self-worth. To unmask is to refuse to be silenced, to stop being compartmentalised and hidden away, and to stand powerfully in our wholeness alongside other disabled and marginalised folks. Together we can stand strong and free, shielded by the powerful, radical acceptance that comes only when we know who we are, and with the recognition that we never had anything to hide."* Dr Devon Price

# WIN WIN WIN



**We have three copies of *Unmasking Autism* to give away.**

Email [editor@altogetherautism.org.nz](mailto:editor@altogetherautism.org.nz) by Wednesday January 24, 2024 and tell us why you would like to win your own copy of *Unmasking Autism*.

All entries will be entered into a draw. The winners will be announced via social media and email in February.



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Join us at Altogether Autism. We have a wide range of workshops for Autistic people, whānau, allies, and professionals. We can also work with you to design and deliver a tailor-made programme to meet your specific learning requirements.

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