



SPOTLIGHT ON

Supporting the Mental Health of Autistic Girls and Gender Diverse Young People

A comprehensive guide to supporting autistic girls and gender diverse young people informed by and developed by the neurodivergent community.

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About Yellow Ladybugs:

Yellow Ladybugs is an autistic-led non-government organisation with strong bridges to the community. We are dedicated to the happiness, success and celebration of autistic girls, women and gender diverse people. We recognise that autistic people are the true experts on autism, and their lived experience is a critical factor in Yellow Ladybugs' commitment to being an organisation that can advocate for its autistic members of all ages.

Disclaimers

The autistic lived experience observations found in this resource have primarily been drawn from the Yellow Ladybugs Mental Health and Safety Conference 2021 and specifically the following panel discussions: Can We Do Anything to Protect Mental Health?; Understanding and Supporting Meltdowns and Shutdowns; How Can We Better Understand and Support Complex Behaviour; Supporting Neurodivergent Parents; What to Do When Facing a Mental Health Crisis. All content attributed to individual speakers has been shared with permission. Supporting evidence drawn from other sources has been referenced throughout the document.

The content of this resource are for information purposes only and not intended to replace medical or professional advice.

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Yellow Ladybugs uses identity first language ('autistic person') to reflect the preferences of the majority of the autistic community and because we believe being autistic is an integral part of our identity.

Yellow Ladybugs is also an inclusive organisation, and while this document has particular focus on autistic girls, we use the term 'girls' broadly to include cis-girls, transgender, non-binary, and gender diverse individuals, and anyone who was socialised, or identifies as female. Information in this resource may also be relevant to autistic cis-boys and male-identifying autistic individuals, and equally may not always be applicable to all autistic girls/women.

With thanks to our village

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A special thank you to all our lived experience contributors, who shared their insights, so this resource has a strong autistic voice.

This guide aims to

- ✦ Delve into the complexities of mental health and wellbeing of autistic girls and gender-diverse students
- ✦ Highlight some of the challenges when it comes to the mental health of autistic young people
- ✦ Provide practical strategies for how parents and schools can help support improved mental wellbeing of autistic girls/students and encourage positive autistic identity
- ✦ Draw on personal, professional and academic knowledge with an emphasis on lived autistic experience
- ✦ Amplify, empower and validate the diversity of all autistic experiences



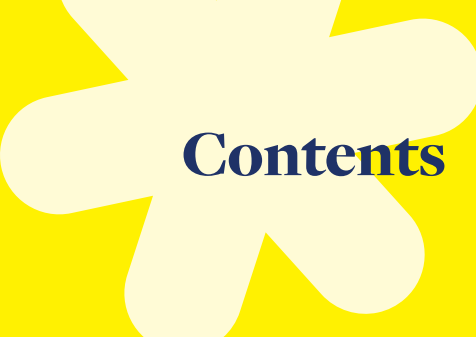
Understanding the Mental Health Risks for Autistic Girls and Gender Diverse Young People

This guide delves into some of the common struggles and challenges that can impact the mental health of autistic girls and gender diverse young people. It explores topics including internalised autism, masking, distressed behaviour and mental health crisis. It offers lived autistic experiences and neurodiversity-affirming strategies for both parents and schools, with the aim to help inform and support the mental health of autistic students and their carers.

Our society is still geared to think about autism in a narrow and stereotypical way that doesn't take into account the full diversity of autistic experiences. In particular, we have a long way to go in understanding about internalised autism, and as a result, many

autistic girls and other autistic individuals who don't meet our stereotyped expectations may end up going unrecognised and under-supported. This is due to many factors including misconceptions, social expectations, masking, and a lack of knowledge of internalised traits, all of which tend to result in reduced supports and a diagnosis process that is less likely to favour girls.¹

It is estimated that 80 percent of autistic females remain undiagnosed or misdiagnosed at the age of 18.² Recent statistics are also showing that it takes 2-3 years longer, on average, for a female to get diagnosed compared to their male peers.³ The implications of this discrepancy are significant, and make autistic girls particularly vulnerable to mental health struggles.



Contents

Seven key areas for supporting the mental health
of autistic girls and gender diverse young people

1	Understanding Internalised Autism	3
2	Understanding Autistic Masking	8
3	Understanding Meltdowns and Shutdowns	14
4	Reframing Distressed Behaviour	18
5	Understanding Autistic Burnout	25
6	What To Do in a Mental Health Crisis	27
7	Protective Measures for Good Mental Health	30



Understanding Internalised Autism

This section of the resource explores how autistic girls and gender diverse young people often have their needs overlooked because of their more internalised or hidden presentation of autism, and examines the impact this has on their mental health and wellbeing.

Although autistic people of all genders can share many traits, girls often present differently, which can result in them being misdiagnosed, misunderstood or missed completely.

This is not to say that there is a 'female presentation' of autism, however. Rather, it is necessary to look more closely at how the internalised autistic experience commonly found in girls differs from the more stereotypical and widely understood externalised autistic presentation.



INTERNAL

Freeze | Appease

EXTERNAL

Fight | Flight

DID YOU KNOW?

Body Responses to Stress

*When presented with a perception of danger or stress, the body will respond in one of four ways. **Fight** and **flight** have external behavioural presentations, while **freeze** and **appease** [also known as **fawn**] are internal.⁴ Many autistic girls will display internal responses to danger and stress.*

External vs Internal Autistic Presentations

There are two types of broad behavioural presentations when it comes to autism; externalised and internalised. Externalised autism, which can be observed as outward-facing behaviour or traits in response to stress or stimuli, is more recognisable, as it is the presentation that is visibly different to non-autistic peers. Externalised autism is what is generally thought of as autism. In other words, it meets our society's stereotyped understanding of what autism looks like.

The internalised autistic experience is much less widely understood. It describes the experience of

autistic individuals, who internalise, or hold their stress and anxiety inside. This may involve freezing up, possibly becoming non-verbal/situationally mute, or shutting down. On a day-to-day basis it often involves hiding natural autistic traits in an attempt to appear like everyone else. Internalised autism is generally hidden and unseen, and therefore, it can be harder to discern when an autistic person needs assistance. **More often than not, autistic girls will display an internalised presentation of autism.**⁵

DID YOU KNOW?

Internalised Autism at School

In a school setting, the needs of autistic students who have an internalised response to danger or stress often do not come to the teacher's attention, due to their being less disruptive. Autistic girls with an internalised presentation are often seen as shy or simply anxious, and as a result, they are less likely to receive needed supports within the school environment.

For tips on how schools can support autistic girls, see page

16

Common Features of Internalised Autism⁶

Some of the more common features of the internalised autistic experience, often found in autistic girls and gender diverse young people, are listed below.

Overview	Internalised Autism in Social Settings
- More likely to have an internal stress response to sensory stimuli in complex environments [e.g. freeze or fawn/appease] - Able to cope better with predictable and low sensory environments - Amount of effort required to cope in complex environments often hidden to the observer - Outwardly appears to be coping well, therefore less likely to receive supports - More likely to experience depression and anxiety due to appearing to cope while internalising their stress	- More likely to be bullied - May struggle to understand social structures - May be very dependent on one or two friends - People pleaser or fawner – more likely to be taken advantage of - Strong sense of social justice - Interested in socialising, but can struggle or experience barriers in making connections amongst neurotypical peers (the Double Empathy Problem) - May be controlling in social play, or extremely passive - Strong language skills, but may interpret language literally
Internal Autism at School	Emotional and Sensory Internalisation
- May appear shy, not wanting to raise hand or answer questions - May be outwardly compliant, rarely causing disruption - May struggle with group work – prefers working only with friends - May struggle with unstructured times at school - May struggle with lunch times, due to sensory overload - May struggle with classroom transitions and change - May use compensation techniques, including perfectionism, to hide their stress - May struggle with sensory aspects of the school uniform - May shut down or go situationally mute in situations of perceived stress - May seem fine throughout the school day, and then unravel once home - May be startled or scared by teachers' raised voices	- May have intense empathy and attachment [including to animals and objects] - Can appear younger/less mature than some of their peers - May have Alexithymia – difficulty identifying/naming their emotions and the emotions of others - May display strong sensory responses: noise, smells, touch, and clothing sensitivities are all common, and can have a severe impact on daily life - May stim, however stims may not be as noticeable or are seen as more socially acceptable [i.e. picking nails, twirling hair] - May have poor interoceptive awareness – the ability to recognise and identify internal physical sensations in the body - May have an intense focus on subjects that are of interest to them, but this may be overlooked if these interests are 'socially expected' for girls [e.g. animals, fashion or make-up].

This list is for information purposes only. These experiences and traits are not specific to any gender, and may not be relevant or applicable to all autistic individuals.

Why is Internalised Autism Misunderstood?

It is not uncommon for many autistic girls to be questioned about being autistic and their need for additional accommodations to be ignored because they appear to be fine.

These misunderstandings, combined with outdated ideas of what autism actually is, have resulted in ongoing stigma and discrimination around who is “autistic enough” to receive support.⁷

When an autistic girl or young person feels that they are different, not accepted or discriminated against, or they have experienced negativity or aggression in the past as a result of who they are, they may, as a self-protective measure, attempt to hide their autistic characteristics, often at the expense of their mental health.

Common Gender-based Misconceptions

She just has an imagination

Talks too much

Well even if you are autistic, you are just mildly autistic, right?

**How can you be autistic?
You can talk / make eye contact / are social, etc**

She has an anxiety disorder

She's just sensitive

She doesn't need support, she's not having outbursts

She has friends/has an imagination/ has empathy/ doesn't line up toys

Internalised Autism and Risks to Mental Health

- ★ More vulnerable to exploitation and predators
- ★ More susceptible to autistic burnout
- ★ Poor self-esteem
- ★ Increased anxiety and/or depression
- ★ Eating disorders or restricted eating patterns
- ★ Greater risk of mental health crisis if struggles not addressed
- ★ May experience mental health issues including situational mutism, self-harm, school refusal/ can't, and other mental health conditions

See
page
25



Autistic Perspectives on Internalised Autism

“Just because you experience my autism mildly, doesn’t mean I experience it mildly.⁸ I mask to the point that I make everyone else feel comfortable, yet inside I’m trying to hold everything together.

Frances Brennan, *autistic speech pathologist*

“When I am in class and I can’t follow what’s going on, or I start to feel scared, I just freeze. I want to run to the bathroom and cry, but I can’t. I don’t want anyone to think I am a baby. So I hold it in and pretend I’m ok.

Maya, *autistic child, age 8*

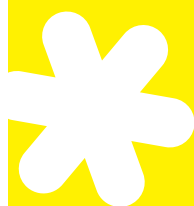
“For years I thought there was something seriously wrong with me, because everyone else in class seemed to manage ... I am constantly self-regulating my emotions to meet society’s at times unrealistic expectations.

Summer Farrelly, *autistic advocate, age 15*

“‘Mild autism’, as some call it, is really just internalised autism. It’s us, trying to please all of you, sometimes at a huge cost to our own selves.

Amanda Buckland, *autistic psychologist*





Tips for parents and teachers

Internalised Autism

As parents and teachers, one of the most powerful ways in which we can support our autistic girls and young people and their mental health, is by actively overturning the many persistent fears and mistruths about autism. Here are some steps which all of us can take which will help replace the common stereotypes and misconceptions with a more nuanced and acceptance-driven understanding of autism.



Listen to autistic voices

There are many organisations and individuals wanting to “help” autistic children and adults, but not all do so in a way that is supportive of the neurodivergent community. Choose to support organisations that are neurodiversity affirming, meaning that, they are led by, or otherwise prioritise advice and input from the “actually autistic” community.



Accept self-identifying or late diagnosed autistic adults

There are many barriers to getting diagnosed as an adult, especially for women, and many within the autistic community have chosen self-identification. This is a valid method of diagnosis within the autistic community.



Start the conversation about diversity and neurodiversity early

For more information on this





Understanding Autistic Masking

This section explores autistic masking, which is one of the most common experiences of internalised autism, and is often seen in autistic girls and gender diverse young people. Masking, sometimes also called camouflaging or compensation, is when an autistic person either consciously or subconsciously suppresses or hides their natural autistic behaviours and responses.⁹

Many autistic girls have a desire to fit in, and as a result, they will observe and copy neurotypical behaviour within social settings, in an attempt to blend in and make connections. Masking can take on many forms – it may change depending on the social situation, tends to be more prevalent amongst autistic girls, women and gender-diverse individuals, and is one of the main reasons autistic girls are diagnosed less often or later in life than autistic boys.¹⁰ Masking is also one of the most common contributing factors to the mental health challenges experienced by autistic girls and young people; this is due to both the exhaustion and the loss of authentic identity that results from masking.

Examples of Masking

Forcing/Faking eye contact

Mimicking gestures, smiles and body language

Practising social scripts

Saying “I’m fine” when stressed

Suppressing discomfort over sensory stimuli

Hiding personal interests

Suppressing stims

Case Study

Tayla, autistic adult

I'm 24 years old and I was diagnosed last year.

For the majority of my life, I have felt different, wrong somehow, and I never understood why.

No matter how much I tried to be like everyone else, I just couldn't seem to get it right.

Getting diagnosed was a weight off my shoulders, an understanding that I'm not broken or wrong, but that I'm just different – and that different is okay. I still have a long way to go, though. Although I'm proud of who I am, and comfortable with my differences, I still struggle when it comes to unmasking. It's become ingrained in me that I need to act a certain way, talk a certain way, or else I won't fit in.

I mask when at work, when out in public, and when out with friends. I do it so often that sometimes I'm unsure who I really am underneath. My mask has been so carefully crafted that most people in my life seem to forget that I'm autistic – then when I slip up and struggle with the things others don't, I'm treated as if I'm making excuses when I try to remind them the reason why not everything is easy for me. Ironically, it is often because I mask that I am more prone to these slip-ups, to struggling with basic tasks or having days where I have the inability to function.

Masking is exhausting, and it often leads to burnout, which then results in me taking poor care of myself and struggling with my physical health and daily functioning. Sometimes I think that by trying so hard to hide my struggles and differences, I end up creating them.

What can Happen When Autistic Young People Mask at School?

The Coke bottle effect is an analogy used to explain the effects that internalisation and masking at school can have on autistic children. It explains why some autistic children, including many girls, appear to be “fine” whilst at school, yet as soon as they get home (or sometimes sooner), they become dysregulated and melt-down.

Imagine your child is a bottle of Coke. Every time the child experiences something stressful, the bottle is shaken. As the stresses of the day go on, the bottle is shaken over and over again. On the outside, it looks like not much is happening. But on the inside, the pressure is building.

When the child gets home and they begin to feel safe, the lid comes off, all that pressure explodes out, and the child appears dysregulated.

“The Coke Bottle Effect”¹¹



Masking can lead to some common after-school behaviours

It is not uncommon for autistic girls and young people who mask at school to present very differently when they get home, and teachers are often surprised to learn that the quiet and non-disruptive student they observe at school, is overwhelmed and ‘explosive’ at home.

Some common stress-based after-school behaviours are listed on the right. It is important to understand that these types of behaviours are indicators of exhaustion and the stress build-up that comes from internalising and masking during the school day.



Meltdowns and escalations

Anger, quick temper

Mood fluctuations

Amplified sensory sensitivities

Withdrawal or disinterest

Shutdown and disengagement

Extreme exhaustion

For strategies on how to assist with after-school meltdowns, see page

14

DID YOU KNOW?

Autistic Girls and Internalised Anxiety¹²

It is not uncommon for many autistic girls to present with anxiety while at school, especially when they are internalising and masking in an attempt to fit in. The demands of school, combined with the social pressures of female friendships, can leave many autistic girls feeling anxious throughout the school day, followed by meltdowns, shutdowns or anxiety attacks once they are home. Though the anxiety may be quite subtle within the school environment, it can result in ongoing issues, including school avoidance and situational mutism. Working with the school to develop an anxiety care plan may help to alleviate some of the stress that is brought on by the school day.



Autistic Masking and Mental Health

As research into autistic masking continues to emerge, we are increasingly understanding how the experience of prolonged masking can lead to negative outcomes for autistic people, including late, missed or misdiagnosis, exhaustion, burnout, and high rates of mental health issues and suicidality.¹³

For many autistic girls and gender diverse people, this is a process that starts in childhood.

Adaptive Morphing?

What makes autistic masking different?

We all make small adjustments to our behaviour from time to time, to accommodate varied social situations (e.g. how we act at a formal dinner party may be different to how we act at a casual dinner with friends). For autistic individuals, however, masking can be much more prolonged and intense, and can take an incredible amount of energy to maintain. If an autistic person is not able to unmask, the toll on the body can become too much, which increases the risk of serious ongoing mental health issues.¹⁵

Recent evidence states that for autistic individuals, and often for autistic girls, masking may be an unconscious act, where the subconscious mind takes over and masking is no longer a choice. Known as adaptive morphing, this is the body's way of coping when there is an overwhelming need "to hide us from harm, enabling us to ... feel safe."¹⁴ When the act of masking becomes instinctive, removing the mask becomes very difficult. If autistic girls and women continue to feel the need to mask, the long-term effects may include emotional and physical exhaustion, burnout and a loss of the autistic person's sense of identity.

Long-term Dangers of Masking¹⁶

- ★ Burnout
- ★ Anxiety
- ★ Depression
- ★ Meltdowns and escalations
- ★ Eating disorders
- ★ Trauma
- ★ Loss of identity



What about Unmasking?

Although the cost of masking is well understood, unmasking can be a complicated process for autistic individuals. There are many challenges that come with attempting to remove a mask, especially one that has been in place for a long time. Many women who have recently discovered they are autistic say that it is extremely difficult to remove the mask and live as their authentic self. Some women have reported a complete loss of identity, a struggle with self acceptance, negative responses by friends and family, stigma, and questions surrounding needed accommodations.¹⁷

For anyone supporting autistic girls or gender diverse young people, one of the best protective measures for mental health is to start an open conversation with them about masking and unmasking as early as possible, and to help them identify and build their own awareness of when they are masking. Other steps can include encouraging them to explore their authentic autistic identity, connecting them with their peers, and advocating for accommodations to their external environment - all things which may help them feel safe enough to more openly embrace their autistic identity.

Autistic Adult Perspectives

A lot of women who have recently had their autism identified say they don't know who they are, because it's so hard to unpack the layers of collecting different identities as a result of camouflaging.

Dani Boucher, late diagnosed autistic adult

It is our role as parents and carers of autistic children to provide a safe, judgement-free environment where our children can learn to be themselves and grow into their true autistic identities. This will hopefully prevent future generations from needing to learn to unmask, instead embracing who they are as an autistic individual.

Amanda Buckland, autistic psychologist

DID YOU KNOW?

Masking as a Protective Factor

There are some autistic people who feel that masking is not always a negative trait, and that it can be an important component for overall mental health. Masking, for some, can contribute to achieving socially desirable outcomes, including developing a social circle or performing better in some social situations like job interviews and work.¹⁸ But while there are times when masking can be beneficial, prolonged masking is a survival instinct used to blend in and avoid stigma, discrimination and trauma, and takes an emotional and physical toll on the body.

Case Study

**Audrey, 38 and parent
to two autistic children**

I spent over three decades building up multiple masks in an attempt to fit in. As a child, I copied my friends; how they talked, dressed, what their interests were.

I remember having posters on my wall of the young “stars” all my friends swooned over.

I remember not being interested in these people in the slightest, but copied my friends so I could be a part of them.

As I grew older, the masks changed to fit in with school, and then work. It has only been in the last couple years, learning that I am autistic, that I have begun to accept who I really am. It has been a difficult and slow process, one that I am still working on. How do you learn who you truly are, when everything about you has been put on for the benefit of others? But I am committed to learning how to unmask and fully accept myself, and I am hoping that my journey of my own self-discovery will guide me in teaching my children that they do not have to mask, and that they are enough just as they are.



Understanding Meltdowns and Shutdowns

This section of the resource delves into autistic meltdowns and shutdowns which are a relatively well understood aspect of autism, although still surrounded by stigma and misunderstanding, particularly for autistic girls or gender diverse young people who have a more internalised presentation of autism.

Shame around experiencing meltdowns or shutdowns can have a direct impact on the mental health of these young people, especially when they are met with judgement and disbelief. Regular meltdowns or shutdowns may also be an indicator of declining mental health and can be a clue that something in the child's external environment needs to change, and that the demands on them need to be reduced.

This section of the resource explores how parents, carers and teachers can:

- ★ Understand the function of meltdowns and shutdowns, including the neurobiology behind them
- ★ Take a neuro-affirming, respectful and connection-based approach to supporting autistic young people through meltdowns/shutdowns
- ★ Look at both the young person's external environment and their internal signals of building stress, and remove whatever stresses and demands are possible
- ★ Understand that meltdowns/shutdowns often can't be prevented and may be a necessary release
- ★ Know how to safely support young people through a meltdown/shutdown and through the aftermath

Autistic Adult Perspectives

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Meltdowns and shutdowns aren't a negative thing. We need to stop thinking of meltdowns as the worst possible thing and instead look at them as communication.

Dannielle Wilson, *autistic parent*



Meltdowns and shutdowns are an intense response to overwhelming circumstances, and occur when an autistic person's brain, sensory and nervous systems become so stressed and heightened that they lose control of all of their reactions. They are involuntary, and often consist of emotional, cognitive and physical components.¹⁹

A Meltdown is



an outward expression of stress build-up, which is usually an explosive physical release. Autistic individuals often describe a meltdown as needing to happen in order to regulate the body and mind and rest the body's stress levels.²⁰

Signs of a Meltdown

- ★ Rage
- ★ Sobbing
- ★ Screaming
- ★ Hitting
- ★ Kicking
- ★ Self-harm
- ★ Running
- ★ Throwing

A Shutdown is



an internal response to stress. Although the stressors may be the same for both meltdowns and shutdowns, a shutdown may be less noticeable, as it becomes a protective inward retreat from the outside world, and is done as a coping mechanism to stay calm and escape from what is causing the stress.

Signs of a Shutdown

- ★ Non-responsive, unaware of surroundings, or overly attentive to surroundings
- ★ Dissociation or withdrawal
- ★ Exhaustion/falling asleep
- ★ Unable to speak clearly, or at all (situational mutism)
- ★ Zoning out/retreat into self
- ★ Hiding or displaying obsessive behaviour patterns

Autistic-approved Tips for Preventing or Reducing the Overwhelm that Leads to Meltdowns and Shutdowns

Have an open dialogue

with parents and collaborate with the student to understand their signs of stress, their sensory profile, and the things they find stressful within the classroom environment.

Allow for breaks

If an autistic young person is saying that they need a break, listen to them. Autistic students should never have to 'earn' a break.

Note: High masking or internalising students may not show any build-up of distress. They will do everything that they should be doing, and will appear calm and in control. But if they say they need a break, believe them. By removing themselves from a situation they are finding stressful, a meltdown or shutdown may be avoided.

Presume competence

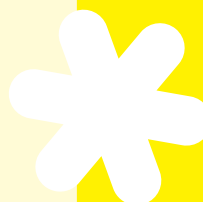
that autistic students have an awareness of what they need, and empower them to be able to communicate when they need it.

De-stigmatise needed accommodations

so that children have the confidence to ask for help.

Ask simple, yes or no questions

if an autistic child is in a heightened state of arousal. A child in a heightened state may not have the ability to answer open-ended questions.

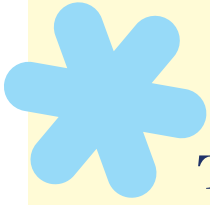


Tips for schools

For strategies on how to assist with after-school meltdowns

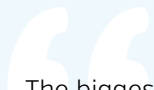
See
page
17





Tips for parents

Autistic Adult Perspectives



The biggest game-changer for me personally was when I started to think of having a meltdown as being part of a cycle. The meltdown itself wasn't what I needed to focus on, or the thing that I needed to manage or fix. The meltdown was simply the result of not meeting my own needs, or the needs of my children.

I started shifting my focus away from the meltdowns themselves, and started focusing on what could be done to better support me, and my family, and I learned that meltdowns are not the problem. Meltdowns are simply the by-product of a whole realm of overwhelm that is going on.

Allison Davies, *autistic parent*

Allow time to decompress

Recognise that there is a recharge that needs to happen following stressful events like school, social engagements and outings.

Create a safe space at home for children to unmask

You are their safe space. Let them know it is ok for them to be who they are.

Do what works for your family

If your children need some screen time to decompress, let them on their screens for a bit. Then following that you may have a child that is more receptive and agreeable.

Allow extra processing time

Many autistic children need extra processing time. Do not expect an immediate answer or action and give them time to register and process.

Model supportive mental health

Show your children through your actions how to handle stress in a way that doesn't hurt themselves or others.



Reframing Distressed Behaviour

This section of the resource reframes our understanding of behaviour as one of the most important means of supporting autistic girls and gender diverse young people in a way that acknowledges where they are struggling, and that contributes to better mental health outcomes.

Knowing how to respond to 'challenging behaviour' or 'behaviours of concern' is a frequently misunderstood aspect of supporting autistic children in general. For autistic girls and gender diverse young people, it is another example of where their internalised and less obviously disruptive presentation can result in their needs being overlooked.

By embracing neuroscience, it is possible to look at complex or challenging behaviour differently, to overturn conventional thinking and the traditional approaches often recommended to 'manage behaviour'. As teachers and parents, we have an opportunity to reframe behaviour as something not to be managed or stopped, but as the gateway to understanding what our children's needs are.

Why Conventional Approaches to Managing Behaviour Might Not Work

Many of the systems and approaches to managing behaviour sourced by parents and schools come from the 'behaviourist' theory of psychology.²¹ In these settings, a child exhibiting complex or challenging behaviours may be seen as being deliberately naughty, oppositional, disruptive, or otherwise non-compliant. The 'challenging behaviour' is seen as something that needs to be stopped or redirected.²² This is usually through some form of reward and punishment system - where desirable behaviour is rewarded [often through reward charts and positive reinforcement], and undesirable behaviour is met with consequences, discipline systems, detention, behaviour contracts, or is deterred or ignored. The focus is on changing the external behaviours, rather than on the internal state of the child or young person. These traditional approaches to behaviour management usually do not work for autistic children.

Kids Do Well When They Can: Embracing Neuroscience²³

Through the lens of modern neuroscience, instead of looking at how we can 'fix' or replace the outward behaviours, we can start to understand that these types of behaviours are a clear indicator that the child has unmet needs, and that their internal nervous system has gone into one of the survival-based stress responses of fight, flight, freeze and fawn/appease. A child in this distress state is no longer in control of their behavioural or emotional responses. For them in that moment, no amount of logic or positive reinforcement of desirable behaviour is going to help them to regulate and choose to 'control' their behaviour.



We don't give children and adolescents enough credit - that if they could do it, they would be doing it. Why wouldn't they? And if they're not, then it means they need help. It means that they need to be taught or supported, because their brains are not letting them do it, because it gets too scared or too reactive or it internalises. And they're not able to speak out for themselves. Understanding this is so crucial. But we often don't start from there. Instead, we start to 'manage' or 'treat behaviour' and do all this other stuff that isn't actually starting from what they're going through. **Dr Alberto Veloso**, *psychiatrist*



Distressed behaviour can look like:

- ✦ **Disruptive behaviour, acting out**
- ✦ **Absconding, escaping**
- ✦ **Defiance and oppositional behaviour**
- ✦ **School refusal (better described as school can't)**
- ✦ **Demand avoidance**
- ✦ **Risky, impulsive behaviour**
- ✦ **Physical aggression, destroying property**
- ✦ **Self-harm**
- ✦ **Autistic meltdowns and shutdowns**

One of the most powerful things we can do as parents/carers or teachers is to be a detective and figure out what is behind a child or young person's distress behaviour, and to ask ourselves 'what are their unmet needs?'.

What can cause distress behaviour in autistic girls and gender diverse young people?

- ✦ Exhaustion from masking
- ✦ Autistic burnout
- ✦ Trauma and shame from surviving in a world built on neurotypical expectations
- ✦ Sensory overwhelm
- ✦ Emotional overwhelm (alexithymia, interoception, hyper-empathy and executive functioning challenges may all be contributors to this)
- ✦ Bullying and social exclusion
- ✦ Being denied the accommodations they need

Distressed behaviour needs to be met with connection

When challenging behaviour is reframed as distressed behaviour, it is possible to bring a more compassionate and informed approach to supporting the needs of young people, and to do so in a way that doesn't undermine their most basic need for safety, and instead builds on a foundation of security, compassion and connection.²⁴

See
page
21

For connection-based strategies for supporting distressed behaviour



When we're helping our young people we need to remember which part of their brain function they're using at any one time. If their frontal lobe is connected and they're logical, then we can have logical conversations and even debate. But if those arousal or stress levels come up and they're functioning only from their emotional states, we need to respond to them differently, and that is where connection comes in. **Dr Alberto Veloso**, psychiatrist

What Else Can Contribute to Distressed Behaviour?

When examining the underlying causes for distressed behaviour in autistic girls and gender diverse young people, it can be worth exploring other co-occurring conditions or factors that come under the wider neurodiversity umbrella. Some of these are introduced below. It is also helpful to consider the external environment more generally and the internal stress response that comes from being a neurodivergent young person having to function in a world built for and by neurotypical culture.

Interoception	Rejection Sensitivity Dysphoria
Many autistic individuals have poor interoception i.e. knowing what is going on inside our body.  Impacts emotional regulation skills Hard to notice the internal physical states of the body i.e. racing heart Can trigger anxiety as it's hard to know what the body needs Impacts self-awareness, self-advocacy and problem solving Difficulty detecting hunger, fullness, thirst or full bladder Impacts self-care, sleep and overall well-being	Rejection Sensitivity Dysphoria is extreme emotional sensitivity and pain triggered by perceived or real rejection or criticism.  Criticism and correction leads to extreme feelings of frustration, rejection and failure It can impact learning, relationships and well-being It does not need to be real, it can be perceived or imagined It can cause physical reaction or pain Very sensitive to tone - even neutral - can be seen as a threat or rejection It is difficult to know and express sensory needs, likes and dislikes
Alexithymia	Pathological Demand Avoidance
Alexithymia comes from the word 'without words for feelings or emotions'. Many autistic individuals have difficulty identifying or expressing emotions.  It's really hard to identify, articulate or label emotions It can impact learning, relationships and well-being It is tough to tell the difference between emotional and physical sensations It's often described as an emotional blindness Describing feelings to others is hard. 'I don't know' is a common answer. It is difficult to know and express sensory needs, likes and dislikes	Persistent Drive for Autonomy (better description) involves the extreme avoidance of perceived or actual demands and expectations.  I experience high levels of anxiety when demands are placed on me Demands can be invisible and hidden to others. What I perceive and experience as a demand, might not look like one to you The expectations and pressure from perceived or real demands are scary Even if I want to do the thing and look forward to it, I just can't do it if demand rules Relationships and negotiation work better than routines and time tabled events (a demand) Anxiety and intolerance of uncertainty can compel us to avoid demands

Inspired by the work of Dr Wenn Lawson





Strategies for Supporting Distressed Behaviour

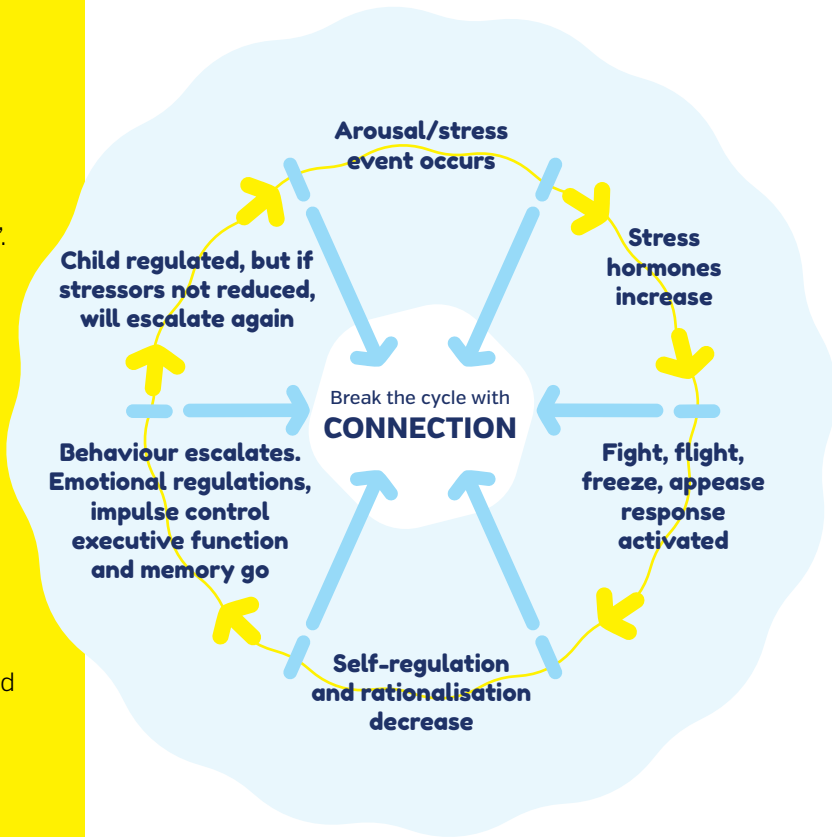
Connection Before Correction

The build up to distressed behaviour tends to follow a cycle. It begins when the stress hormones within the body begin to increase, until the child moves into flight, fright, freeze, or fawn/appease mode. In this moment, the body's defence mechanisms have taken over, and the child may start displaying signs of distress, irrationality and 'challenging behaviour'.

In this state, the child will not respond to any corrective measures, and therefore the issuing of punishments or promising rewards at best will achieve short-term compliance, but otherwise will leave the underlying causes of the distress behaviour unaddressed. Eventually, the child may de-escalate, however if the stressors are still present, the cycle of escalation is likely to continue.

It is possible for this cycle to be reduced by understanding that connection needs to come before correction. When connection is introduced at any point within this cycle, the chances of genuine de-escalation, which addresses the distressed child's innate need for relationship-based safety, are far greater. By introducing meaningful connection and support, this distress cycle can be minimised.²⁵

Life Cycle of Behaviour Escalations



Note: These strategies are also an important component to assisting with meltdowns and shutdowns.

See
page
14

Autistic girls and gender diverse young people (along with any children) who are experiencing distressed behaviour will benefit from a compassionate response, that prioritises their most basic need for safety. PACE, which is a connection and co-regulation based method for supporting distressed behaviour, is one such approach.

PACE

Originally developed by clinical psychologist Daniel Hughes, PACE is a connection-based and trauma-informed approach to assist children who have complex behaviours to begin to de-escalate. It stands for playfulness, acceptance, curiosity and empathy. PACE is a tool meant to guide the adults to think, feel, communicate and behave in a way that builds trust within the adult-child relationship.²⁶

Playfulness	Acceptance
★ Stressed brains respond to calm, playful faces and tones of voice. Introducing playfulness into the situation can defuse arousal and conflict, and promote connection. When a young person feels connected, they are less likely to experience an escalation. More Connection = Less Escalation	★ Total acknowledgement that the child's feelings, thoughts, urges and perceptions are their truth in that moment. Acceptance is truly listening to what they are saying and ensuring that the emotions driving the behaviour (not the behaviour itself) are judgement-free. Truly Listened To = Reduced Defences
Curiosity	Empathy
★ Being curious about where the behaviour has come from by attempting to understand the situation from the child's perspective. Done by asking open-ended questions and allowing the child to speak freely. Aids in self-reflection. Child Feeling Heard = De-Escalation	★ The genuine attempt by carers to understand a child's position, by demonstrating that they understand how difficult the experience is for the child in that moment, and letting them know that they do not have to deal with their distress alone. Validation of Feelings = Security + Trust

Unconditional Positive Regard

Unconditional positive regard is the mindset that people are doing the best they can with what they have available. If an autistic young person is struggling, or acting out, even if it seems deliberate, it is about understanding that they are coping to the best of their ability, while recognising their effort, and working with them to come up with solutions to best assist them. Unconditional positive regard allows for connection in a judgement-free manner, and can be a powerful protective factor for good mental health.

Case Study

**Frances Brennan,
autistic speech pathologist**

I was the kid that breezed through primary school with no effort. But come high school, with the changing classes, organising myself to have the right books and belongings, and all the other executive functioning tasks you need to get through the day, things fell apart.

In spite of me trying my hardest, the school assumed I must just be naughty.

They put me on an organisational contract that consisted of teachers signing off that I had my materials for every class. I tried to figure out how to organise myself, but was still not able to do what was expected of me. When I still failed to come with the right stuff, I was put into detention, and I was put into detention so much, that I then decided that if I was going to be in trouble, I would give them a real reason. My behaviour escalated, and high school became really tough. In all that time, no one asked me how I was coping or noticed that I was actually really trying.

But what I think would have made a difference was someone recognising that I was doing the best I could, in spite of how it may have looked. Had someone talked to me and tried to help the original problem of just being overwhelmed, perhaps my school journey would have been different.

Two-Handed Approach for Setting Boundaries



Taking a relational or connection-based approach to distressed behaviour does not mean setting no limits and letting children and young people do whatever they want. But a balance is needed between establishing limits and building connection. The 'Two-Handed' approach to complex or distressed behaviour recognises that on the one hand, limits are necessary to ensure the child or young person's safety. But on the other hand is connectiveness, empathy and acceptance.

The more limits and boundaries that are put in place, the more it becomes necessary to increase connection and care. When a young person is struggling with behaviour, and needs more limits within the home or school setting, it is important to ramp up playfulness and connectivity to match those demands. When the 'two hands' are balanced, this is a key step in reducing distressed or challenging behaviours.²⁷

DID YOU KNOW?

PACE and the Two-Handed approach are only two of the recommended neuro-affirming and trauma-informed approaches to supporting autistic girls and gender diverse young people who are experiencing distressed behaviour. Other trauma-informed approaches that are founded on

a current understanding of neuroscience include: Dr Mona Delahooke's work on the body-brain connection, Dr Ross Greene's Collaborative and Proactive Solutions (CPS) model, Dr Stephen Porges's work on Polyvagal Theory and Dr Stuart Shanker's Self-Reg programme. All of these approaches are focused on understanding 'challenging behaviour' as a stress response that needs to be met with connection, co-regulation and relational-safety.²⁸

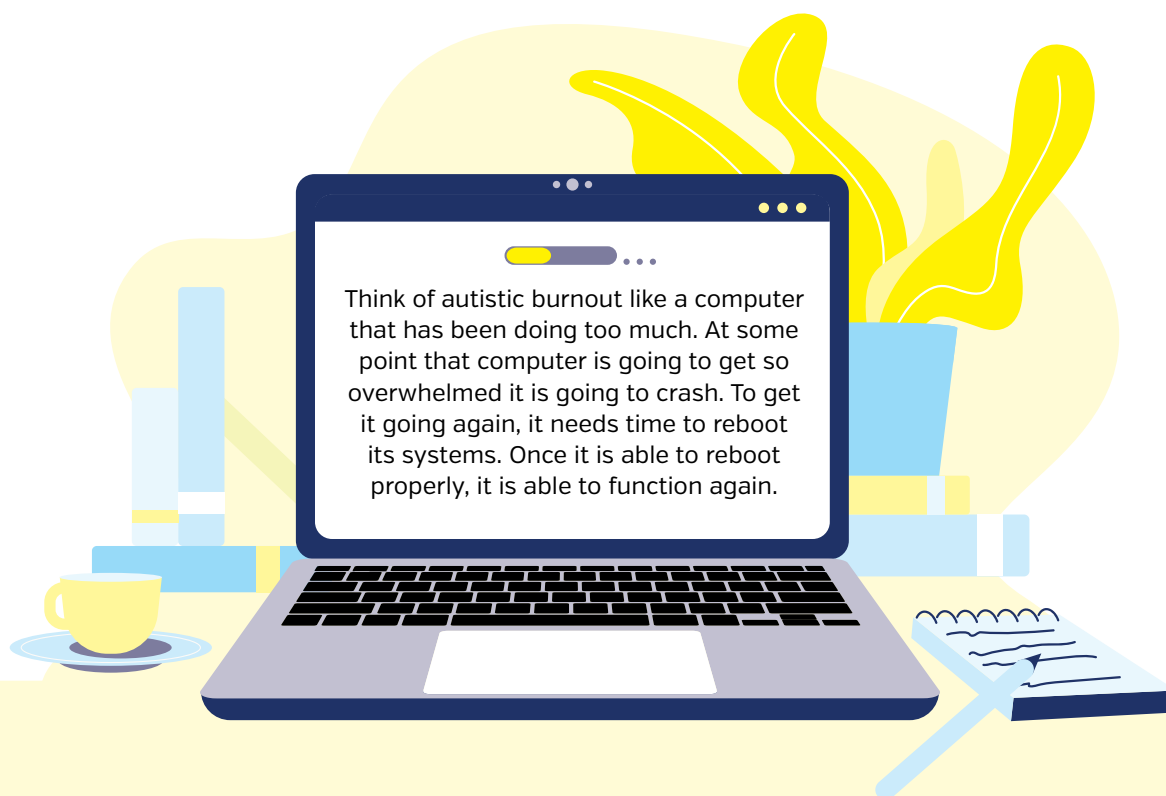




Understanding Autistic Burnout

This section examines autistic burnout which is one of the most important factors to consider when understanding the specific mental health needs of autistic girls and gender diverse young people, especially when they are beginning to struggle and their mental health is in a state of decline.

Autistic burnout is a state of intense mental and/or physical exhaustion, and is usually a direct result of masking and feeling completely overwhelmed from navigating a world not designed for autistic people. Autistic girls, who are more likely to mask, may also be more likely to end up in burnout. During an autistic burnout, the mind is so completely overwhelmed and tired, that it is no longer able to cope with even the basics of life. For some, it is a complete shutdown of all physical and mental abilities.



Signs of Autistic Burnout²⁹

- ★ **Extreme exhaustion**
- ★ **Increased meltdowns/shutdowns**
- ★ **Constant/increase in anxiety**
- ★ **Disinterest in things that brought joy**
- ★ **Loss of skills including difficulties in communication**
- ★ **Reduced memory capacity**
- ★ **Decreased self-care**
- ★ **Quickly overstimulated**
- ★ **Heightened sensory activities**

It is important to distinguish between autistic burnout and depression. Many autistic women speak of being misdiagnosed with depression when in fact they are experiencing burnout. Much of the advice relating to depression is not applicable to burnout – for example the recommendation to get regular exercise as a treatment of depression does not apply to the experience of burnout where complete rest is required as a necessity.

Strategies to Help Someone Through Autistic Burnout

Allow them to rest

Autistic individuals in a burnout state need significant time to rest and recover.

Reduce all demands

This may include a break from activities, school, work, etc.

Do not force communication or socialisation

Often these are the reason a burnout has occurred in the first place.

Encourage stimming

Stimming is an autistic individual's way of self-regulating.

Encourage self-care

But do not force self-care.

Safe and accepted

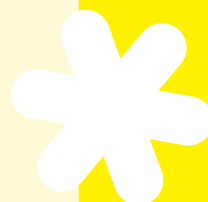
Try to stick with foods that you know are safe and accepted.

Encourage going outside/ into nature

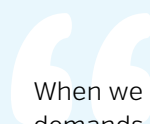
But only when ready.

Special interests and activities

Encourage engagement.



Tips



When we talk about reducing demands, including taking a break from school, we need to break down the stigma that we're 'reinforcing the behaviour of school avoidance' and instead, see this as a necessary mental health option, to allow our children to recharge enough to be able TO go to school

Sandhya Menon

Neurodivergent Psychologist

Neuro-Affirming Perspective



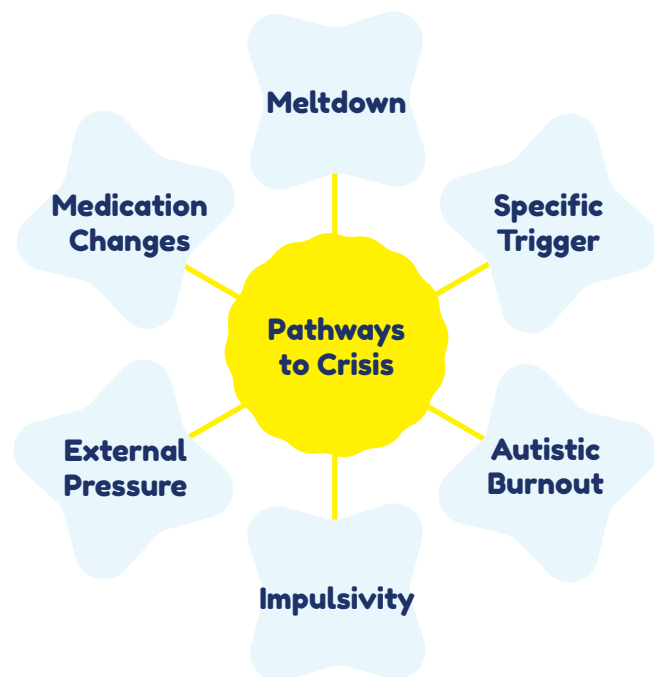


What To Do in a Mental Health Crisis

Content warning: This section of the resource makes reference to various aspects of complex mental health including self-harm, eating disorders, risky behaviour and suicide/suicidal ideation.

This part of the resource looks into the difficult topic of mental health crisis. There may be times when, despite all the protective and supportive measures in place, your autistic child may experience an acute mental health crisis.

A crisis situation exists any time you think that the child is in immediate danger of causing harm to themselves or others. It can occur as a result of a sudden, unanticipated trigger; a slow, relentless build up to autistic burnout, or a combination of both.

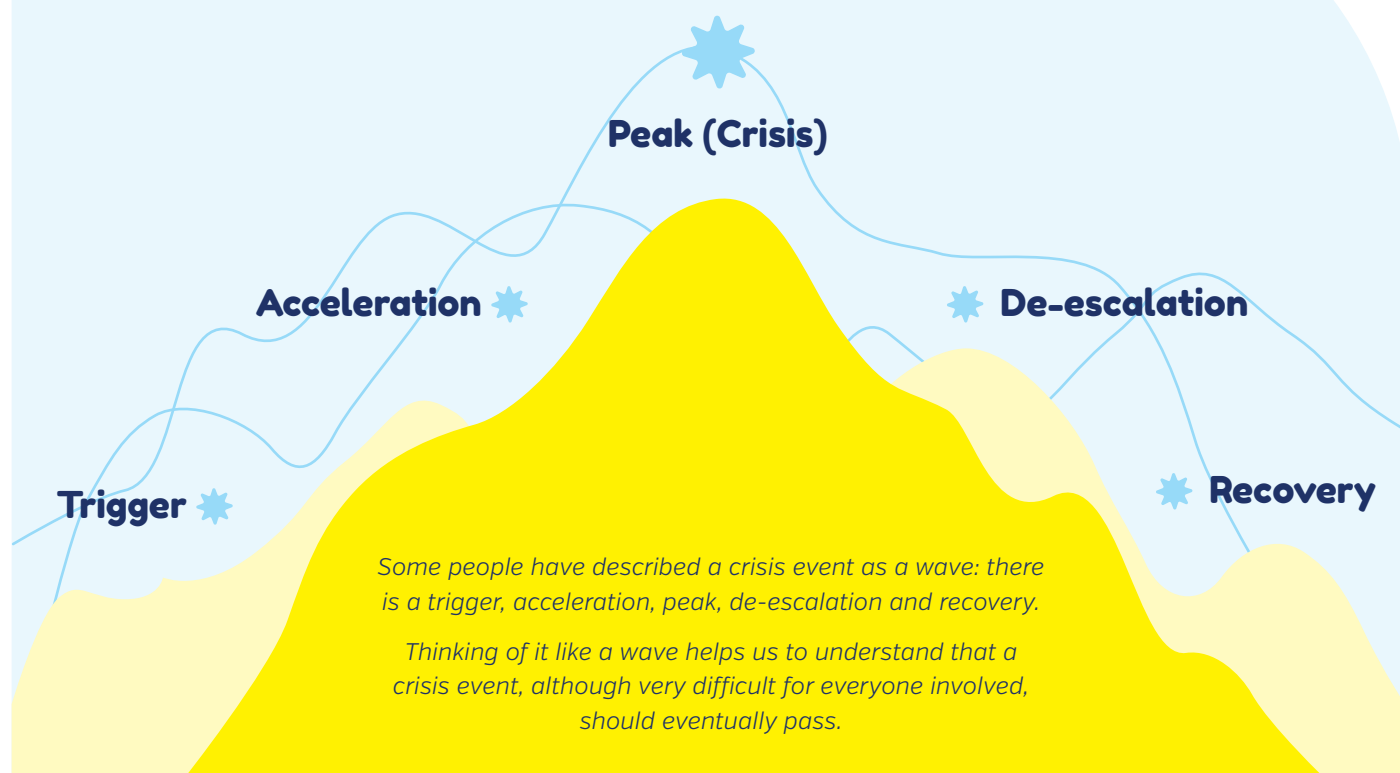


Signs That Your Child May Be Experiencing a Mental Health Crisis

- ★ **Rapid mood swings**
- ★ **Changes in eating patterns and/or rapid weight loss or gain**
- ★ **Dramatic changes in energy or sleep patterns**
- ★ **Threats to themselves or others**
- ★ **Isolating themselves from friends and family**
- ★ **Withdrawing or disengaging from preferred activities (this may be subtle)**
- ★ **Suicidal thoughts, statements or attempts**
- ★ **Self-harm**
- ★ **Calling 000 or other support services themselves**

Disclaimer: We understand that a mental health crisis can encompass a range of complex issues including self-harm, eating disorders, suicidal ideations, and other complex mental health presentations. We also recognise that supports for autistic young people going through a mental health crisis are extremely limited and that systemic change is needed as a matter of urgency. Although this resource does not go into specific detail on experiences that often drive a mental health crisis, it is our intention to acknowledge and validate the lived experience of our community. Yellow Ladybugs is committed to continuing to advocate and educate about the complexities and challenges surrounding a mental health crisis, in the hope that through this understanding, greater supports will be allocated to supporting the mental health of autistic girls and gender diverse young people on an ongoing basis.

Life Cycle of a Crisis Event



Parent Perspective

Content warning: Self harm

I sit here ... waiting ... waiting for the waves to come. It's the kind of wait that makes you feel sick - because you know what's coming. You remember the last time it knocked you both off your feet, and it still hurts. It starts off small. The swell grows, and moves in a familiar way, and you notice the once calm waters changing. Maybe she is sleeping more, or talking to herself, or her voice sounds different. You can't pinpoint it, but you feel it, deep in your gut.

You can see the ripples hitting the surface. You notice she isn't talking to you as much. She might begin hurting herself, or she loses her appetite. It's not always the same, and with each ripple getting bigger, you sense the impact growing stronger. You know you need to prepare yourself. You doubt yourself, and question if you have the energy to stay afloat this time. But you know you have no other choice. You need to be prepared for anything, just in case.

Each crisis wave is unique. It has its own path it's going to take, and you can't stop it (as much as you try). You might be lucky, and this crisis wave will be small enough to jump over or through. It's easy enough (you've been there, done that) and you know what you need to do to get through it. Other times, it's sneakier.

It looks calm on the surface, and you think you are safe, but it's a hidden current that drags you both under. This time, you didn't expect it (or notice it) and the crisis comes from nowhere. One minute she is fine, the next thing you know, you are both at emergency.

Then there is the tidal wave of crisis. The one that just wipes you both out. You can't catch your breath - it's relentless with its fury and impact. Maybe this tidal crisis lasts for a long time - or it's more heartbreaking than normal to witness. Maybe it just feels like that, because you are so broken and tired from the cumulative distress of caring for someone in pain for so long (and seeing them in pain for so long). It actually feels more like a tsunami - a tsunami of pain, not being able to rescue someone when they need it the most. You both feel like you are drowning. Drowning in a world not built for them, and a system that is constantly failing them.

And then somehow, you catch a break. The sun comes out, you see the shore. You both find your feet and catch your breath. You take a moment, and breathe in the calm. And then, you get ready to wait. And you wait again ...

Autistic parent of autistic teen



Tips for Supporting an Autistic Young Person Through a Mental Health Crisis

Content warning: Specific references to dangerous items/substances and suicide.

When a Crisis is Suspected

If there is a crisis escalation but you are able to manage at home, the following are some steps to consider:

- ★ Remove all dangers/lethal substances the child can access (this can include alcohol, illicit drugs, medicines, household cleaners, poisonous materials, knives, razors or other weapons, ropes, belts and plastic bags)
- ★ Check for triggers that may be specific to your child/young person – this may help you navigate the situation
- ★ Administer any prescribed medications if required
- ★ Consult your safety plan (see page 31 for further discussion)
- ★ Seek immediate help if needed – See page 37 for a list of numbers you can call if you or your child are in crisis
- ★ Keep an open dialogue with your child – if they are unwilling to talk to you, see if they will open up to another person that they trust [i.e. another family member, psychologist, teacher, etc]. Remember there are options other than verbal communication (e.g., your child may prefer to communicate via text)
- ★ Current evidence suggests that if you suspect a person is suicidal, it is recommended to be direct and ask 'are you feeling suicidal?'. Then you are then in a better place to assess where you are at within the safety plan and best actions including calling 000 if required.³⁰
- ★ **If your child is in immediate danger, call 000**

A Note on Social Media

- ★ If there has been a sudden onset of a crisis with no other explanation that is obvious, it is advisable to check your child's social media content. It is preferable to have set boundaries and expectations with your young person in advance, that you as the adult can check their social media content. Lived experience advice is to follow your instincts if you feel unsure about content or contacts that may be triggering your child.

Important Note

- ★ If you suspect a crisis is imminent, it is highly recommended that you also contact your child's care team (paediatrician, and/or psychologist/psychiatrist), who can help support you and your child during and after the crisis.

DID YOU KNOW?

Understanding Impulsivity

Impulse control can be a significant challenge for autistic young people, especially if they have co-occurring ADHD. Feelings and emotions come across very intensely for autistic individuals and can feel overwhelming, while ADHD minds may believe the way they feel now is the way they will always feel. In a mental health crisis, emotive behaviour, self-harming, or suicidal thoughts/attempts may come on very quick, fuelled by impulsive thoughts and feelings that the young person is not able to process fully.

Guide to Presenting to Emergency in a Mental Health Crisis

If you are concerned about the safety of an autistic young person who is experiencing a mental health crisis, you always have the option of taking them to an ER for a mental health assessment.

- ★ When you first arrive, stick to a factual account and ask for a Mental Health Risk Assessment
- ★ Inform the triage nurse that the young person is autistic. You can ask for a private waiting room [although this is not guaranteed].
- ★ Once triaged, you may be observed and/or interviewed by hospital staff
- ★ The hospital may want to interview your child separately
- ★ If your child appears calm, you may not be deemed a priority and you could be sent home
- ★ If your child escalates or is escalated upon arrival, the hospital may offer medication to try to calm the situation
- ★ In some instances, physical/chemical restraints may need to be used
- ★ Noise and sensory sensitivities in an ER environment may trigger or escalate certain behaviours. This may be mitigated by ensuring comfort items are brought to the hospital with you.
- ★ If any behaviour changes for the worse, or you disagree with the doctor's assessment, voice your concerns and ask for a reassessment.

Hospital Bag Checklist	Please Note
★ Phone/charger ★ Headphones ★ Comfort items [soft toys, fidgets and other sensory accommodations, etc] ★ Safe food items to snack on ★ Change of clothes/personal items ★ Regular medication ★ Copy of any care plans you may have	★ ER departments are often established to deal with physical injuries and emergencies. As a result, mental health crisis does not rate highly on their triage list. With limited facilities and limited mental health staff in hospital ERs, there may be significant wait times before being assessed. In general, most ER services will not admit a young person for mental health reasons only. ★ Be aware that emergency services have their own strict protocols when dealing with high-risk situations. If a situation is deemed to involve physical risk to the child in crisis, or aggression to others, then protocol will typically require that the police are sent to attend first.



Managing an Ongoing Mental Health Crisis at Home

Following the peak phase of a mental health crisis, the priority should shift towards the post-crisis recovery phase (see diagram on page 28) during which the child or young person experiencing the crisis will continue to need significant ongoing support.

Here are some practical considerations for parents/carers and families, to help with navigating the ongoing wave of a crisis, in the days and weeks immediately following a crisis peak. These suggestions will depend on the individual situation, but are relevant, whether or not they follow a hospital or Emergency Department visit [acknowledging that may not always be possible or appropriate to the situation or individual circumstance]. These strategies also recognise that a mental health crisis does not happen in isolation, and that wider family support [for siblings and parents/carers] is an important part of the process of recovery.

Strategies for Parents During the Recovery Phase

- ★ First, you need to be sure that the crisis is over. This may be hard to define, and will look different for everyone. The situation might go back and forth between crisis and recovery, but you may begin noticing patterns that can help you identify what stage you are at.
 - ★ Consider who needs to be contacted from your child's allied health support team (e.g., psychologist, paediatrician, psychiatrist) or whether additional allied health support is needed on an ongoing basis.
 - ★ Other children (i.e., siblings of child in crisis) may also require professional support. They will process this experience in their own way, and may be experiencing strong emotions such as guilt, fear, resentment or sorrow. They might feel alone, isolated, ignored or even embarrassed by their sibling – but not wanting to burden you with extra challenges, given what the family is going through. It is equally important to make a plan to support siblings through this process, or a plan for respite (if that is possible).
 - ★ Don't forget to ask yourself whether you as parent/carer require professional counselling or support. Even if you may not have the mental energy to do that right now, enlist those around you to help connect you with someone. If you don't have anyone, try your local council, even your MP, or local carers organisations, to see if they can arrange this for you. Finding an affirming support group, either online or in-person, can also help with feeling less alone, especially when other people in your network may not 'get it'.
 - ★ Try to access post-crisis therapy support for your child/young person that is trauma-informed and can support them through this process of crisis recovery. This may be in the form of psychology-based support (e.g. DBT or ACT)*
 - ★ Draw on your professional support and personal or local networks to find out what (if any) additional mental health supports and services are available for your child. Who else can you call? Consider your local CAMHS, police proactive unit (if there is a link with violence or behaviours of concern), your local council or MP. You can search for 'post crisis local support' to see if there are any funded outreach programs in your area.
 - ★ Look at whether there any ongoing adjustments needed to make your household environment safe.
 - ★ Consider implementing a safety plan for home. This plan should be created in collaboration with your child. Your allied health professionals or mental health support team may have a template for this. Otherwise, safety plan templates are widely available online.
 - ★ Contact your child's school to make key staff aware of situation and to ensure appropriate safety measures are in place. This may include developing a safety plan specifically for school.
-

* Dialectical Behaviour Therapy (DBT and Acceptance and Commitment Therapy (ACT) both have their origins in Cognitive Behavioural Therapy (CBT) but with their greater emphasis on acceptance, values-based strategies and techniques for building distress tolerance, are reported to be more effective forms of therapy by the neurodivergent community), but depending on the young person's individual needs may involve things like art therapy, animal-assisted therapy, or similar.



Protective Measures for Good Mental Health

This section of the resource explores some of the broader protective measures which can contribute to better mental health outcomes for autistic girls and gender diverse young people.

It draws on the lived-experience expertise of the autistic community, and offers neuro-affirming perspectives on the topics of radical acceptance, supporting parents (including neurodivergent parents) and tips for both families and schools to celebrate neurodiversity and actively embrace autistic culture.

Radical Acceptance and Neurodivergent Parenting

Radical acceptance, when it comes to parenting, means choosing to parent in the way that works best for your family, regardless of the expectations society may place on what 'proper' or expected parenting is. It is about recognising the individual needs of each family member and saying 'mine and my children's mental health is more important than what society wants, so I am going to raise my children the way that works best for them and us as a whole, so that their mental health is protected'.

Radical acceptance therefore says that it's okay to disregard the societal expectations, and do what works for your family. By instilling a radical acceptance philosophy into your parenting, it enables you as their carer, to accept and celebrate who they are as individuals, while attending to their specific needs.

Examples of Radical Acceptance

- ★ **Allowing additional screen time to help with regulation**
- ★ **Meals that accept each person's individual needs. Also allowing meals to be eaten at times and locations according to individual needs (rather than requiring the whole family to eat dinner at the dinner table, at a prescribed time)**
- ★ **Going to the same restaurant and ordering the same meal**
- ★ **Separating siblings on the weekend to meet everyone's needs**
- ★ **Having downtime after school rather than engaging in typical after-school activities (this includes homework)**
- ★ **Choosing not to participate in extended family celebrations, or modifying the way in which your family does participate**



Case Study

**Allison Davies,
autistic adult**

Growing up, it was the expectation in our family that we would all eat our meals together, we all had our same spots, the table was always set the same way, and meals became almost ritualistic.

When I had my family, and dinners were not working, and everyone was getting stressed, it took me a LONG time to get over thinking that I was a bad mum for not doing dinners the way that society says you ‘should’.

But I have completely let go of the idea of eating together at night time, because one of my children needs to move constantly, and the other one needs to be completely away from all of us, and I had to learn that it is ok if we don't all sit together. Now, my kids happily eat where it works for them, and my husband and I have our own mini-date at the dinner table every night. If I had never tried this, I never would have seen that removing this expectation of ‘family dinners together’, actually means that everyone is happier.

Supporting Parents of Autistic Young People

Parents of autistic girls and gender diverse young people often find themselves navigating a unique set of parental challenges, many of which may not always be understood by others. Some of the additional demands include advocating for supports, services and accommodations for our children (and frequently advocating to change the system), and the significant administrative load of coordinating appointments, managing finances, paperwork etc. Add to this a frequent lack of understanding from external family or friends, and expectations to meet the demands of the neurotypical world, and it can easily become overwhelming, especially when your young people are struggling with their mental health.

In addition, many neurodivergent children also have neurodivergent parents (whether they know it or not), and as a result, sensory sensitivities, masking, meltdowns and shutdowns, hyper-empathy, rejection sensitivity and burnout can be experienced by both children and adults alike. As parents it is important to remember to take care of yourself as well. The mental health of your children will be best protected if you are also taking care of your own mental health.

Seek out neuro-affirming support networks

Autistic-led support groups (whether in person or online) can be a great asset, and can often offer listening ears and advice from people in similar situations, and most importantly, a lived experience perspective.

Schedule time for yourself

Just like you would for your children's appointments, doing what you need to do to help maintain your own mental health.

Utilise electronic resources

Make good use of technology like your phone to help with things like scheduling, reminders, timers, etc

It's ok to acknowledge your difficulties

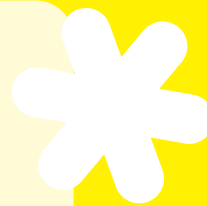
It's ok to need your own time out. Supporting children who have complex behaviour, conflicting sensory needs or mental health challenges is hard. Every parent needs a break sometimes.

Don't be afraid to advocate

if an autistic child is in a heightened state of arousal. A child in a heightened state may not have the ability to answer open-ended questions.

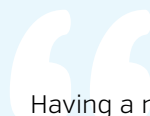
Practise radical acceptance

Do what works for you and your family.



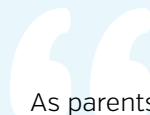
Suggested strategies for parents

Autistic Adult Perspectives



Having a neurodivergent family and being an autistic parent requires so much shedding of who we thought we were, while being present with what we need right now ... It's really hard, but also the thing I love.

Allison Davies, *autistic adult*



As parents, we may need to review our own triggers with a counsellor or psychologist. A lot of the time we know our children have different needs, but it can trigger us when we expect things to be done a certain way, and we may need some support to shift to radical acceptance.

Sandhya Menon,
neurodivergent psychologist and parent



Celebrating Neurodiversity

Autism - A Label to be Embraced, not Feared

Many adults who are discovering their own autism, often because of a self-reflection when their children are diagnosed, have said that knowing that they are autistic has actually given them a better understanding of their own self-identity, and most wish they had obtained the diagnosis sooner.³¹ Teaching younger children about who they are, with total acceptance of their neurodiversity, is one of the best ways to break down the stigma, and build acceptance at both an individual and societal level.

Start the conversation about neurodiversity early – at home and at school

Adding Diversity into the Conversation

One of the best measures to help protect the mental health of neurodivergent young people is to begin the dialogue about diversity, including neurodiversity, as soon as possible. Discussing diversity early lays the foundation for embracing individuality and destigmatising difference, thereby opening the door for acceptance of all neurotypes.

Some Tips on Introducing the Concept of Neurodiversity to Children

- ★ Begin by openly exploring similarities and differences within a family unit
- ★ Extend the conversation into the wider community, country and the world looking at similarities and differences
- ★ When children have a general understanding about diversity and how this benefits us all, it is possible to incorporate neurodiversity into the conversation by discussing how everyone also has different brains.
- ★ As children mature, conversations around mental health can also be included, to help open dialogue and de-stigmatise mental health conditions.

Autistic Adult Perspective

When it comes to autism, there often remains a fear of labelling and discrimination that hinders some parents from seeking a formal diagnosis or pursuing the supports that are needed for their autistic children. I think we need to move away from the idea that an autism diagnosis is something to be feared or mourned, and instead think of it as an identification or clarity into who we are and see this identity as a beautiful wonderful important essential thing.

Allison Davies, autistic adult



Autistic Adult Perspective

Neurodiversity needs to be part of the school curriculum from the first year of school. When we teach children from a very young age that we all have different brains (just like we all have a different favourite colour), and that these brains all do what they're supposed to do, but they work differently - even just acknowledging this at a very early stage gives children the understanding that it's okay to have a different brain and it's okay to think in different ways. It also introduces the parents to these concepts early in their parenting journey.

Mandar Nelson, autistic parent

How Can Schools Become More Neuro-affirming?

One of the most powerful ways schools can support better mental health outcomes for autistic students is to develop a school culture that openly celebrates neurodiversity and all types of differences. This can be achieved by embracing autistic (and otherwise neurodivergent) culture; learning directly from autistic people; supporting autistic young people to connect with their peers within the autistic community; and by 'normalising' accommodations that help autistic students to feel safe, supported and understood.

Allow for needed accommodations to be accessed with dignity. When other students see that accommodations are being accessed easily, it normalises diversity.	Provide an open space with quiet activities during recess and lunch, so that the children who may not have someone to play with always have somewhere to go.
Build rapport with your neurodivergent students – Autistic children need more support in a variety of areas, and they need to feel like they are supported and listened to.	Source autistic-led training around neurodiversity and mental health so that staff can develop better knowledge in those areas, and are better equipped to understand these students.
Develop a school culture where issues around mental health are openly spoken about, and maintain an open dialogue with students and families so that supports can be put in place as soon as an issue is identified.	When able, run special interest activities that anyone is free to join in during breaks. Even if autistic children choose not to participate, they are still around others, which can be important to ensuring that the mental health of children is being taken care of.
Implement diversity into the curriculum.	Provide safe/quiet spaces or breakout rooms to allow neurodivergent children the time they need to re-regulate.
Remove 'motivators' like reward charts. They may not work. See also Reframing Distressed Behaviour on page 18.	Seek connection, not correction.

Autistic Adult Perspectives

“It is important for teachers and parents to be aware that even if your child doesn't have friends ... they still need people ... who they can associate with ... so they feel they have others around them.

Ebony Birch-Hanger
Autistic Adult

“While all children deserve to be treated with respect and supported according to their needs, we need to remember that autistic and neurodivergent children have especially sensitive nervous systems. Safety through secure relationships is an absolute necessity in order to support their regulation. We can do this by showing interest in their special interests/passions, developing open lines of communication and respecting how they choose to communicate.

Sandhya Menon
Neurodivergent psychologist and parent



Additional Resources

Important Numbers

- ★ Kids Help Line 1800 551 800
- ★ Lifeline 13 11 14
- ★ Youth Beyond Blue 1300 224 636
- ★ Suicide call back service 1300 659 467
- ★ Royal Children's Hospital Mental Health Ward (BANKSIA) - a 16-bed inpatient unit for 13-18 years, where young people are assessed and treated for a range of mental and psychological disorders
- ★ Monash Mental Health Unit - Psychiatric Triage Service for people 0-64 years - 1300 369 012
- ★ Austin Mental Health Unit (13-17 years) - 9496 5108, after hours 9496 5000
- ★ **If your child is in immediate danger, call 000**

Resource List

- ★ The Brain Forest - Sandhya Menon
- ★ Same Same, But Different - Jenny Sue Kostecki-Shaw
- ★ Different Not Less - Chloe Hayden
- ★ Supporting autistic girls and gender diverse youth – Yellow Ladybugs (launching mid 2023)
- ★ The Yellow Ladybugs Podcast Series
- ★ I will die on this Hill - Jules Edwards and Meghan Ashburn
- ★ Intune Pathways Podcast

References – Lived Autistic Experience

Most of the autistic lived experience observations that are quoted in this resource have been drawn from the following panel discussions that took place during the Yellow Ladybugs Mental Health and Safety Conference 2021:

- ★ Can We Do Anything to Protect Mental Health?
- ★ Understanding and Supporting Meltdowns and Shutdowns
- ★ How Can We Better Understand and Support Complex Behaviour
- ★ Supporting Neurodivergent Parents
- ★ What to Do When Facing a Mental Health Crisis.

We would specifically like to acknowledge the following individuals, whose contributions to these panels have been quoted or paraphrased in this document: Ebony Birch-Hanger, Dani Boucher, Frances Brennan, Amanda Buckland, Allison Davies, Mandar Nelson, Dannielle Wilson, and Dr Alberto Veloso.

Reference List

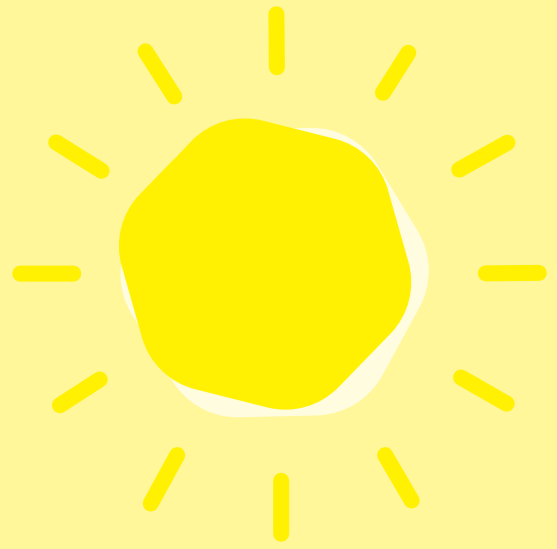
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Notes





A Positive Future

Creating greater awareness of the unique mental health challenges our ladybugs face- both at school and at home - opens the door to better understanding, support and ultimately, to their educational, social and emotional well-being.

The current obstacles facing autistic girls and gender diverse young people are many and varied - but they can be supported with deeper knowledge, more effective neuro-affirming systems in place, open and honest communication between schools and families, and strategies that encourage families and schools to work together towards positive outcomes. Teachers and support professionals can be powerful allies in helping our ladybugs feel understood, safe and accepted at school. This is an incredible protective factor for mental health concerns, along with celebrating and understanding autistic identity and culture.

These are all important steps in the lifetime journey of our ladybugs. Having a positive, validating learning experiences can help provide the foundations for them to thrive.



