





Talking Body
Image with Autistic
Young People For Professionals

This factsheet has been produced for Butterfly by Yellow Ladybugs, an autistic-led, non-government organisation supporting autistic girls and gender diverse youth. Butterfly and Yellow Ladybugs acknowledge the neurodivergent individuals and their families who contributed to this resource by sharing their lived experience. We affirm their identity, honour their wisdom, validate their feelings and recognise their strengths, as together we work toward a more inclusive world for autistic and neurodivergent individuals.

#### A bit about language

This factsheet uses identity-first language
– meaning we refer to 'autistic' and young
people rather than people 'with autism'.

Many autistic people prefer to use identityfirst language as they see being autistic
as intrinsic and a core part of their identity.

Autism is a lens through which autistic people see, experience and process the world. Being autistic means that a person may experience differences in ways of thinking and feeling including sensory processing, communication, language and social interactions. Every autistic person however, is unique and has particular strengths and challenges.

# Body image and eating disorders

Eating disorders such as Anorexia Nervosa, Bulimia Nervosa, Avoidant/Restrictive Food Intake Disorder (ARFID) or Binge Eating Disorder (BED) are complex mental illnesses that require specialised support to assist recovery.

Negative body image is one of the factors that can play a role in the development of eating disorders, in addition to environmental and genetic factors.

Developing a positive body image may help to prevent the development of eating disorders among young people.



## Autism and eating disorders

Research shows that neurodivergent people are disproportionately affected by feeding and eating difficulties, with many experiencing eating disorders.

It's estimated that 20-37% of individuals with anorexia are also autistic<sup>1</sup>.

Delayed diagnosis of autism may leave young people highly vulnerable to developing mental health challenges including eating disorders, as they struggle to fit in with a world not designed for them.

Some research suggests that both eating disorders and autism are integrally linked to sensory processing differences, such as difficulty recognising emotions (alexithymia), difficulty reading internal body cues (interoception), challenges with emotional regulation, proprioceptive differences (sensing the body in space) and sensitivities to textures, smells and tastes<sup>2</sup>.

Autistic young people may report feeling hyper-sensitive to rejection or criticism particularly in relation to their bodies.

They may more rigidly seek to apply rules that are taught by caregivers or modelled through social norms in relation to food, eating and physical appearance or they may utilise control over food choices and obsessive-compulsive traits as a way to feel safe in a world that may reject and overwhelm them.

Additionally, many autistic young people may have experienced trauma which can increase the likelihood of the development of an eating disorder.

Some autistic young people may feel as though they have to mask/camouflage to be accepted and may seek to change their body in order to fit in. Finally, challenges with executive function (cognitive control of behaviour) can also impact eating patterns, mental health and body image.

I describe being autistic in this way: I feel more intensity, more often than others, and that emotional intensity lasts longer. I'm the overly sensitive one. The hyper-vigilant one. Struggling to filter all of the noise of the world, all of the time".

<sup>&</sup>lt;sup>1</sup>Eating-Disorders-and-Neurodivergence-A-Stepped-Care-Approach.pdf

<sup>&</sup>lt;sup>2</sup> https://www.ncbi.nlm.nih.gov/pmc/articles/ PMC5098957/

### Avoidant Restrictive Food Intake Disorder

Avoidant Restrictive Food Intake Disorder (ARFID) is commonly misdiagnosed or missed completely among autistic young people. Unlike Anorexia Nervosa, ARFID isn't linked to distress about body shape or size.

Children and young people with ARFID may have a very restricted diet due to having little to no interest in food, having fears about eating, swallowing or vomiting and/or sensory aversion to eating.

While the research is still emerging as to exactly why autistic young people are more likely to develop eating disorders, what is clear from those with lived experience is that acknowledging and understanding the autistic identity and experience in conversations about body image and eating disorder recovery is vital.

After four years of struggling through secondary school without support or accommodations, I finally hit autistic burnout in Year 11 and developed a severe case of ARFID. I was misdiagnosed with depression and anorexia.

The treatments were ineffective and traumatising, worsening my burnout and ARFID. Ultimately, I ended up in emergency and hospitalised. Learning about my neurotype, unmasking, shedding shame and connecting with my Autistic community has been integral to my wellbeing."

My dad thought I was attention seeking. My friends thought I was being dramatic. I didn't hurt myself for any of those reasons.

In fact, I didn't really know what I was – but maybe it was because I was trying to gain some control in a world that made me feel uncomfortable and unsafe."

### Factors that influence body image

Body image is a feeling state influenced by many factors including **cultural norms**, **family attitudes**, **life experiences and neurotype**. It is important to understand that even though we can aim to support the development of positive body image as a pathway to preventing eating disorders, what happens at home is only part of the picture. Experiencing negative body image is likely due to an interplay of all the factors listed above.

Interestingly, I have very few body image issues. I see my body as part of my machine that is working or not working. When bits get damaged I make efforts to make them better."

I believe my fixation on changing my body was simply an extension of my masking – I needed to look like the other girls because I couldn't BEHAVE like them as effectively anymore."

#### A Neuro-Affirming Approach

Being neuro-affirming means that you validate and acknowledge neurodivergent culture and do not see neurodivergent individuals as wrong, broken or needing to be fixed. At its core, adopting a neuro-affirming approach is about listening to the lived experience of the person standing before you, holding unconditional positive regard, and believing what they are telling

you even if you can't understand it from where you stand.

Being neuro-affirming means putting aside what may work for other individuals in relation to body image, and getting curious about what might work for the people within your own home, care setting or family. What works for many neurotypical people can be harmful and even traumatic for autistic people.

I have body dysmorphia and eating disorders. I'm also non-binary. Part of my eating disorder is driven by keeping my curves away, keeping myself safe inside my own skin.

However, that safety also drives my eating disorder. I'm working with an amazing team and I'm now very well supported." I hate the narrative around loving your body, it seems like too much pressure for me! I prefer accepting my body for what it is."



#### When supporting an autistic person, do

- environment and setting is as neuro-affirming as possible. This includes checking in with the individual as to whether they are comfortable with the lighting, seating arrangement, noise levels, temperature, appointment method (some may prefer telephone or online appointments) and appointment time.
- Establish trust with the individual first and foremost. Safety is paramount to an autistic person so make space to genuinely connect and get curious about their special interests.
- Stay within your scope of practice and refer to neuroaffirming, neurodivergent professionals and specialists if necessary.
- Be trauma-informed in the way you work, centering choice and consent for the autistic individual and working at the pace chosen by them.

Recognise that many autistic people will come with medical or other trauma so share the process in advance, explain everything in detail and offer written instructions if they are struggling to process the information verbally.

 Get a sense of what their strengths, challenges and goals are with regards to health and wellbeing. • Normalise that other autistic or neurodivergent people also struggle with body image or disordered eating (citing the reasons above) and that their perception of their body may change according to their mood, where they are in their menstrual cycle (if they have any), the season or in relation to other environmental stressors.

This acknowledgement, or normalisation helps reduce feelings of isolation or shame.

- Validate and provide

   a safe space for them to
   share fears about their body
   shape, size or weight.
- Be curious about their food choices even if they seem unusual to you. Acknowledge and validate food sensitivities and preferences. Many autistic people want to be able to eat a wider variety of foods, for example, but can't due to sensory reasons.
- P Be curious about the relationship between executive functioning challenges and eating/movement habits.

For example, many ADHDers may not be able to remember what's in their fridge, to be able to make a list and shop, or feel confident cooking from a recipe. Other neurodivergent people may be overwhelmed by choice and may need strategies to help them develop a smaller list of safe foods they can go to when hungry.

- Consider practical tips
   for helping individuals that
   have difficulty recognising
   when they are hungry or full
   and what steps they can take
   to respond to their internal
   cues without becoming
   overwhelmed.
- Help the neurodivergent person to name the feelings they have about their body and explore the reasons why they may feel that way (e.g. cultural or familial factors, media, peers).

Remember that alexithymia and interoception differences can make this tricky.

Help them to critically analyse cultural norms and standards of beauty as portrayed in the media.

- Model talking kindly about bodies of all shapes, sizes, genders and abilities and minimise pathologizing language.
- Understand that recognising the relationship between their neurodivergence and their body image/disordered eating is crucial.

Help them to more deeply understand the way their brain works and to understand why certain things may be difficult.



#### When supporting an autistic person, do

 Normalise body functions and experiences – explain things that happen in the body explicitly, so they don't feel so scary.

> Give more information than you think you need, use visual aids if appropriate and avoid using metaphors or sarcasm if possible.

 Avoid asking openended questions – the individual may feel like they are being tested and that there is a wrong or right. Neurodivergent individuals experience Rejection Sensitivity Dysphoria which means they are hyper-sensitive to being ridiculed or shamed.

Instead, give choices or offer scales to help them explain their internal experience.

Provide context in talking about food, movement or body image – try to avoid rigid rules.
 If there are things that are important to recovery, then share the reasons why they are important and encourage the individual to share their ideas and ask questions.

- connection with
  other neurodivergent
  individuals through
  podcasts, books, videos
  and meet-ups, so they can
  develop an understanding
  of neurodivergence and body
  image from those with lived
  experience.
- Unpack your own triggers, conditioning and expectations around autism, neurodivergence and disability.
   Listen to the lived experience of autistic individuals and become interested in what creates safety for them internally.
- Look at pathways to lower stress and demands to ensure lots of space for processing to reduce overall anxiety.
- Reframe behaviour –
   instead of seeing the person
   as angry, consider that
   they may be overwhelmed.
   Instead of seeing them as
   dramatic, consider they may
   be crying out for help.

- Have conversations about what foods and movements feel good and why for different bodies and brains
  - for example, coloured foods look fun, bouncing feels happy, crunchy foods make a good sound.
- Celebrate body and neurodiversity (including for our gender diverse/trans young people) in the materials, books and resources that you use and recommend.
- Support body autonomy

   respect the individual's
   choices around their body
   and try not to apply neuronormative expectations on
   them (for example, sitting around a dinner table eating the same food as everyone else).
- Offer pathways to engage in movement in non-competitive settings

   or honour the ways in which they choose to move.

I've had extensive body dysmorphia and eating disorders. Growing up with family members who constantly criticised my weight and criticised others contributed deeply as I'm so literal and I was worried about getting in trouble. I've cried countless times looking back on photos where I looked healthy but was being told to lose weight.'



#### When supporting an autistic person, don't

- Disclose their autism diagnosis without their consent.
- Minimise their fears.
- Make decisions about them, without them.
- Talk about the individual in a de-humanising way.
- Talk about disability as

   a deficit it's possible to
   acknowledge the challenges
   without perpetuating neuro-normativity (the idea that all brains and bodies work the same).
- Shame weight gain or loss or restrictive/avoidant/ repetitive/obsessive behaviours around food or movement.

- Blame the individual
   for physical or mental health
   issues or attribute physical or
   mental health issues to certain
   foods or behaviours.
- Create a wellbeing or treatment plan that doesn't acknowledge their neurodivergence.
- Set new expectations or goals that are unattainable.
- Project harmful cultural norms around beauty, health or wellbeing.
- Label food as good or badn – punish 'bad' food or reward 'good' food.
- Comment on others' food choices, weight or body shape or size.

- Invalidate their feelings about their body or tell them to be positive if that's not how they feel.
- Force eating or restrict food.
- Encourage dieting.
- Look only at the behaviour – be curious about what is underneath.
- Talk about autism as a condition with symptoms that need to be 'treated'.
- Shame non-cis gendered bodies.

As a late-diagnosed autistic, now reflecting on my childhood, rules around eating at home have led to not knowing the difference between hunger and feeling full.

That it is not OK to not finish my plate. My parents did the best they could with the knowledge they had back then, but now as an adult I can see that I don't know when I'm hungry and when I'm full."

For me, I found safety in unhelpful patterns and control that restriction brought me. While autism and eating disorders often co-exist, I found great difficulty in accessing neuro-affirming treatment that would consider my extra challenges around sensory considerations and thought processing."

#### Support and referral services

Eating Disorders Neurodiversity Australia LifeLine

edneuroaus.com 13 11 14 Crisis Support | Suicide Prevention

Autism Connect Yellow Ladybugs

National autism helpline | amaze.org.au | Supporting Autistic Girls and Gender | Diverse Youth

As a child of the 1980s, I was surrounded by diet culture.

Jane Fonda workouts, "light" food options – an enormous amount of rules and boundaries, that I took as very rigid and black and white. Good and bad. Food was bad. Being fat was bad. Dieting however, was good. Losing weight was something to be so proud of.

I often joked as a teenager, that people would be more proud of me losing weight, than getting accepted into medicine at university – that's how it honestly felt."

This factsheet has been produced for Butterfly by Yellow Ladybugs, an autistic-led, non-government organisation supporting autistic girls and gender diverse youth. Butterfly and Yellow Ladybugs acknowledge the neurodivergent individuals and their families who contributed to this resource by sharing their lived experience. We affirm their identity, honour their wisdom, validate their feelings and recognise their strengths – as together we work toward a more inclusive world for autistic and neurodivergent individuals.





