

# Coping with a Diagnosis





# Who is this tool designed for?

Anyone who has just received a diagnosis of ADHD or Autism (or possibly a different type of neurodivergence), and/or an eating disorder.

This tool aims to help you better understand neurodiversity, neurodivergence, and eating disorders. The hope is that this will help you advocate for yourself and get the support you need.

You are not alone.

### What is neurodiversity?

Neurodiversity is the natural variation in brain development and ways of thinking among human beings. Just as biodiversity strengthens the Earth's ecosystems, neurodiversity helps make societies healthy and vibrant.

## What is neurodivergence?

Neurodivergence is an umbrella term that refers to the wide range of ways that people's neurodevelopment differs from typical patterns. It encompasses the diverse ways people experience, understand, and respond to the world. This includes individuals with ADHD, Autism, mental health struggles, and learning differences.

# What does neuro-affirming mean?

Being neuro-affirming means understanding and recognizing that the differences in how brains work contribute to a thriving society. It means seeing neurodivergence as natural rather than a deficit to be fixed.

Healthcare providers are neuro-affirming when they support these differences, encouraging people to flourish as unique individuals. Businesses are neuro-affirming when their work considers the needs of neurodivergent clients and employees.

# How can you tell if you are getting neuro-affirming care?

Your provider:

- Makes your goals the priority, not theirs
- **Listens** to and **learns** from your lived experience, as well as the broader community they are supporting
- Focuses on **reducing distress**, not neurodivergent traits
- Respects your definitions of what is meaningful, distressing, and functional instead of sticking to neuronormative standards
- Prioritizes connection over compliance
- Values different ways of communicating, paying attention, and learning
- Presumes **competence**, regardless of your diagnosis
- Focuses on the 'why' behind your responses, behaviours, and distress
- Teaches and encourages self-advocacy
- Accommodates you whether or not you have an 'official' diagnosis
- Acknowledges the intersections of your identity
- Respects your **autonomy**, both body and mind

Adapted from Sonny Jane Wise @livedexperienceeducator

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#### What is an eating disorder?

Eating disorders are complex mental illnesses that negatively affect physical health, mental health, and/or functioning in daily life. They include anorexia nervosa, bulimia nervosa, avoidant/restrictive food intake disorder (ARFID), binge eating disorder, pica, rumination syndrome, and other specified feeding or eating disorder (OSFED). Eating disorders do not discriminate. They can affect anyone, no matter their body size, ethnicity, age, gender, and more.



#### When eating disorders and neurodivergence meet

Below is a list of ways that being neurodivergent can impact a person's experience with an eating disorder or how they recover:

- Preference for sameness, rituals, and routine
  may lead to disordered eating patterns that
  help them cope or self-regulate. However,
  these patterns often increase dysregulation,
  creating a cycle that is very difficult to
  break free of.
- Executive function struggles can make tasks such as grocery shopping, meal planning, and food preparation overwhelming.
- **Sensory differences** can make certain environments, experiences, or foods intolerable.
- **Decision paralysis** can result in choosing not to eat as it feels less overwhelming than trying to figure out what to eat.
- Struggles with perfectionistic tendencies can be worsened by societal expectations and feeling like one is not living up to them.
- Masking or camouflaging to appear more neurotypical can lead to the development of disordered eating and body dysmorphia.
- Sensory processing differences, such as strong sensitivities and low interoceptive awareness (i.e., awareness of internal body sensations like hunger, fullness, and pain), can complicate eating.

- If they have alexithymia, it can be difficult for them to identify, understand, and express emotions.
- **Medications**, such as stimulants for ADHD, can impact appetite and food intake.
- They may experience fluctuating capacity levels that can lead to burnout, inertia, meltdown, and/or shutdown.
- If they were labelled a 'picky eater' and faced forceful feeding practices, they may have food-related trauma.
- They may experience intense distress in response to being or feeling rejected

   this is known as Rejection Sensitive

   Dysphoria (RSD).
- If they have Pervasive Drive for Autonomy, also known as Pathological Demand Avoidance (PDA), any kind of request or expectation can trigger intense anxiety that leads to avoidance.
- Gastrointestinal issues, chronic illnesses, and mental health challenges (e.g., obsessivecompulsive disorder, anxiety, depression) are often also present. These can make eating and self-care more difficult.

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#### **Disclosure**

Letting other people know about — or disclosing — a diagnosis that you have received can take many forms. You may want to disclose your neurodivergence or eating disorder to healthcare providers, friends, family, or others in your life. This often comes with having to educate them about your diagnosis and how it affects you. Start with someone you trust. Pre-planning, or even scripting, can help make the disclosure easier.

#### **After-care**

Disclosing any kind of diagnosis can be hard. Intentional time for stimming and self-regulating activities can help bring down the intense emotions you might experience before, during, and after a disclosure. Consider planning time afterwards for a comforting activity, even if it goes well.

#### For additional support, you can also reach out to:

- NEDIC (<a href="https://nedic.ca/contact">https://nedic.ca/contact</a>)
- 988 Crisis Line (call or text 988 to access help any time of day or night)

#### **Masking**

Masking, also known as camouflaging, is a behaviour that neurodivergent people may adopt to appear more neurotypical and cope with being different. It can be conscious or unconscious. For example, a child may copy the behaviours of neurotypical peers in social situations to fit in and avoid being bullied, without even realizing that they are actually masking. As they become aware of their neurodivergence, they may choose to 'wear their mask' in specific situations to protect their safety or privacy. However, over time, masking takes a significant toll and can lead to burnout and other mental health struggles.

#### **Burnout**

When someone is pushed beyond their physical, emotional, and/or mental limits, they may end up without the energy or motivation they need even for their routine activities. This burnout may be the result of overworking, socializing, masking, or sensory overload. Recovering from burnout takes time and may require you to be extra kind to yourself. Strategies that promote recovery include:

- Setting boundaries
- Decreasing your workload and expectations
- Limiting masking

For more information on burnout, inertia, meltdown, and shutdown, check out <a href="https://www.bimslab.ca/burnout-adults">https://www.bimslab.ca/burnout-adults</a>.

#### Late diagnosis

Many ADHDers and Autistic people, especially women and those who are gender non-conforming, are diagnosed late — long after their neurodivergent traits show up — due to the lack of understanding of how ADHD and Autism look. Before diagnosis, they can often tell that they experience the world differently from others, but don't have the language to explain it. This can lead to struggles with their mental health, as well as with their identity. A diagnosis, even if late, can help a person finally discover and celebrate who they are 'under the 'mask', and truly begin to heal.



For information, support, resources, and referrals, chat with us online at nedic.ca or toll-free 1-866-NEDIC-20 (416-340-4156 GTA).