

# How to Identify Neuro-Affirming Care and Practice Self-Advocacy





## What is neuro-affirming care?

Neuro-affirming care means understanding and recognizing that neurological differences are natural variations, not deficits to be fixed. Health professionals provide neuro-affirming care when they encourage these differences to flourish instead of trying to reduce them. Even businesses can be neuro-affirming when their work considers the needs of neurodivergent clients and employees.

# Some questions to ask to determine if a care provider is neuro-affirming:

- Are they willing to make sensory accommodations, such as:
  - allowing a client to wear headphones/ear defenders/ earplugs?
  - dimming the lights in their office?
  - keeping their workspace low-scent or scent-free?
- Are they willing to ask for consent before touching?
- Are they willing to walk a client through an exam while they are doing it? (e.g., "I'm going to put my stethoscope on your chest, is that okay? Next you'll feel it on your back.")
- Are they willing to work with a client using non-verbal communication if needed?
- Are they willing to repeat themselves and word things in clear (but not infantilizing) language?

#### **Traits of neuro-affirming care providers:**

- They ask "what do you need?", take your needs into account, and honour your requests.
- They actively listen to your lived experience and honour it, rather than dismissing it because "the research shows..."
- They encourage your special interests and authentic social connections as meaningful skills.
- They're trauma-informed, gender-affirming, and understanding of intersecting identities.
- They accept different ways of thinking, learning, communicating, and experiencing the world.
- They don't try to "treat" or "cure" neurodivergence; for example, they don't encourage you to suppress stims (self-stimulating behaviours like hand flapping, rocking, or swaying), and don't uphold neurotypical social skills as the standard.
- They celebrate your strengths while accommodating areas of difficulty.
- They empower you to make decisions about your care.
- They're willing to keep learning about neurodivergence and use tools designed by neurodivergent people to support you.
- They accept that people might need to use different communication methods; for example, if you experience verbal shutdown, you might rely on text-to-speech assistance.

# What is self-advocacy?

Self-advocacy is expressing what you need or want in a particular situation. This requires clear communication which can be challenging for many neurodivergent individuals, especially when the other party doesn't try enough to understand. Self-advocacy can look like speaking up when a server at a restaurant got your order wrong, or working with grassroots initiatives to bring about societal change.

#### Tips for self-advocacy:

- Practice beforehand, which might involve role-playing, or writing out a script, or creating a social story — all of these things can help you communicate with more ease.
- Request a specific amount of meeting time to ensure you aren't rushed.
- Bring someone with you to help you absorb information or make decisions in the moment. A support person whose communication style is different from yours might also be able to help you build your skills.
- Write down any questions you may have beforehand and take them with you.

- Bring printed cards that help communicate part of your experience and/or what you might need in the moment (e.g., "I need extra time to think when you're asking me questions.")
- Practice communication skills in a lower-stakes environment (e.g., advocating in a social situation with people you know, building up to advocating in a doctor's office).
- If a healthcare provider mainly communicates verbally, ask for written information, or if they will allow you to record the conversation to help you process what they said.

It's also important to know that you can self-advocate without disclosing your diagnosis. Given that not every space is neuro-affirming, there are ways you can still ask for what you need while maintaining your boundaries. For example, you can focus on the trait related to the accommodation you need — "I have auditory processing challenges and need to see the questions written down." This allows you to request your needs without disclosing private information.





# Self-advocacy and after-care

Self-advocacy can be incredibly hard especially when it doesn't go as you had hoped.

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 (https://nedic.ca/contact)
- 988 Crisis Line (call or text 988 to access help any time of day or night)

### **Resources for self-advocacy:**

- <u>Social Stories for Neurodivergent People with Eating Disorders</u> for guidance and a template for creating a social story about self-advocacy
- Self-Advocacy: Taking Action to Meet Your Needs by NEDIC
- Autism Self-Advocacy Network
- Self-Advocacy by Stephen M. Shore
- <u>Create your own "Burnout" plan</u> by the Autistic Burnout, Inertia, Meltdown, and Shutdown (BIMS) Lab (see the Self-Advocacy tool on pages 6 and 7)
- Guava Health Inc. app for making medical visits less stressful and more impactful
- NeuroAffirm directory for locating neuro-affirming care providers around the world

