

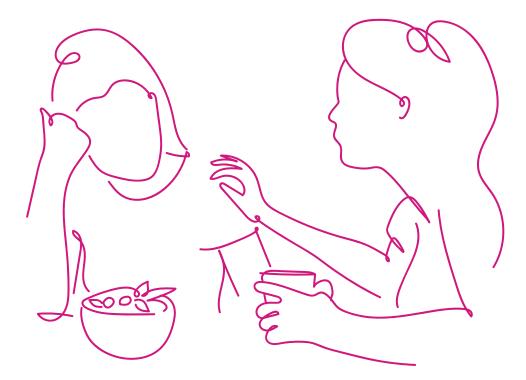
NEURODIVERSITY AUSTRALIA

CARERS



Overview

Accompanying and having to advocate for a loved one through eating disorder treatment and recovery can be very challenging and isolating for carers. This document is meant for carers of neurodivergent people who experience feeding difficulties, disordered eating, and/or eating disorders. Carers often play a critical role when it comes to helping their unwell loved ones. Therefore, carers' support needs are essential to be understood and met to allow them to advocate for their loved ones. Important considerations for meeting the support needs of neurodivergent people within the context of eating and feeding, as well as through eating disorder treatment and recovery are provided. In addition, some tools for advocacy are also included.



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- Avoid commenting on neurodivergent persons' food preferences (e.g., sensory aversions or cravings, samefoods) and ways of eating (e.g., slow, fast, clumsy). For example, neurodivergent individuals may sometimes struggle with motor skills and coordination (e.g., dyspraxia, apraxia), which may lead to 'clumsiness' while eating. Therefore, it is important to remain patient and understanding.
- Avoid referring to 'healthy' versus 'unhealthy' foods. Allocating dichotomous moral attributes to food items can be processed in a literal manner by neurodivergent people, which may contribute to obsessiveness about eating 'healthy' (e.g., orthorexia). If concerns exist about the food intake habits of a neurodivergent person, it is best to refer to a trained neurodiversity-affirming dietitian.
- Avoid making comments about weight or body shape (e.g., body shaming, fat shaming, promoting non-medically required diets).
- Be aware of distinctive contributors to the development of eating disorders for neurodivergent individuals (e.g., double empathy problem and masking/camouflaging, minority stress and internalised ableism, alexithymia, neurodivergent burnout, sensory processing, executive functioning).

Accommodating neurodivergent traits related to eating and feeding

- Understand the influence of neurodivergence on eating habits and food choices (e.g., eating the same foods for prolonged periods of time, sensory aversions or cravings, separating foods on the plate, using preferred cutlery and/or plastic plates, eating at specific times, eating alone, using sensory-regulating tools such as noise cancelling headphones and/or sunglasses while eating).
- Be willing to challenge neuronormative food rules and mealtime expectations (e.g., sitting still at a table for family meals, eating out,

social eating, eating a wide variety of foods in the absence of clear medical necessity, eating the same meal as the rest of the family).

- Adapt the physical eating environment to meet sensory support needs (e.g., noise reduction, dimmed lights, reduced smells). If in doubt about the sensory profile of the neurodivergent person, consider a sensory profiling assessment by a neurodiversity-affirming occupational therapist.
- Allow the neurodivergent person access to distractions/self-regulating stimuli while eating (e.g., viewing content on an iPad, eating while standing up or stimming).



- If you notice any major changes in food choices (obsessiveness around 'healthy' eating), eating patterns (binge eating, restriction, rumination, ingestion of non-edible items), attitudes towards nutrition (emergence of, or increased focus on, calorie or carbohydrate counting) that are concerning, please seek advice from a health professional. A first point of contact can be a general practitioner (GP) or the <u>Butterfly Foundation</u>.
- Understand that neurodivergent people may experience an eating disorder even in the absence of associated body image issues or insecurities (e.g., avoidant/restrictive food intake disorder, orthorexia, rumination, pica). If you have concerns, seek advice from a health professional experienced in neurodiversity-affirming eating disorder care.
- Many neurodivergent people have restrictive eating disorders while not being in the 'underweight' diagnostic range for anorexia nervosa (i.e., 'atypical' anorexia nervosa).

Post-identification support



Free support, including information and consumer advocacy, is available through lived experience advocates across Australia if needed (e.g., <u>VMIAC</u> in Victoria). In addition, there are organisations that provide free individual support and advocacy for disabled people (<u>1</u>).



The development of a positive neurodivergent sense of self is a key element of recovery, which emphasises the importance of using a strengths-based approach to ongoing recovery support (e.g., highlighting personal strengths rather than focusing on perceived 'deficits').

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The early stages of treatment represent a vulnerable period that may require additional sensory and interpersonal support, and reduced expectations or demands (e.g., chores, booking appointments, school homework, socialising and going out) to prevent escalating anxiety and burnout.



It is important to allow neurodivergent people to connect with other members of the neurodivergent community as this can assist in finding a sense of belongingness. Therefore, it may be useful to link your neurodivergent loved one with neurodivergent-led organisations (e.g., Yellow Ladybugs, I CAN Network). In addition, the Council for Intellectual Disability, the Dyslexia Association, Developmental Coordination Disorder Australia, and the ADHD Foundation Australia can provide resources and recommendations for community peer support groups.



For neurodivergent individuals, the conceptualisation and understanding of recovery may differ from that of neurotypical individuals, underscoring the importance of asking directly rather than making assumptions.

Remember that healthcare professionals are legally required to accommodate disability support needs in accordance with the Disability Discrimination Act (2). If you feel that your loved one's healthcare provider is not accommodating disabilityrelated support needs, you can seek advice from the Australian Human Rights Commission (3). You may also look into notifying the Australian Health Practitioner Regulation Agency (4) of your concerns if appropriate.

References

(1) https://www.dana.org.au/find-an-advocate/

(2) https://www.legislation.gov.au/C2004A04426/2018-04-12/text

(3) https://humanrights.gov.au/our-work/complaint-information-service/ make-enquiry

(4) https://www.ahpra.gov.au/About-Ahpra/Complaints.aspx

Further reading

- Eating Disorders and Neurodivergence: A Stepped Care Approach https://nedc.com.au/eating-disorders/types/neurodivergence
- Parenting an Autistic Child: A Practical Guide https://reframingautism.org.au/parenting-an-autistic-child-a-practical-guide/
- Adapting Intuitive Eating for Neurodivergent People https://www.rdsforneurodiversity.com/blog/adapting-intuitive-eating-for-neurodivergent-people
- What does it mean to be neurodiversity affirmative? https://www.bps.org.uk/psychologist/what-does-it-mean-be-neurodiversity-affirmative
- Craving inclusion: a systematic review on the experiences and needs of people with disability eating out https://www.tandfonline.com/doi/full/10.1080/09638288.2023.2295006
- Barriers to healthcare and a 'triple empathy problem' may lead to adverse outcomes for autistic adults: A qualitative study https://journals.sagepub.com/doi/10.1177/13623613231205629