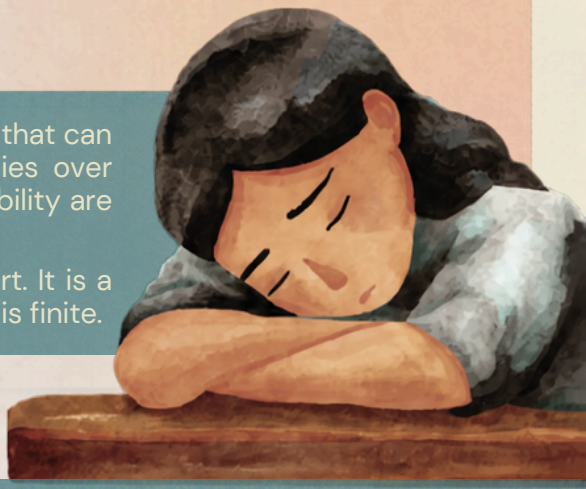
CARING FOR THE CAREGIVER

Caregiver fatigue, mental health, and supporting people who care for neurodivergent loved ones

You can deeply love someone and still become tired from caregiving.
Those two truths can exist at the same time.

WHAT IS CAREGIVER FATIGUE?



Caregiver fatigue is the physical, emotional, and cognitive exhaustion that can develop when someone carries substantial caregiving responsibilities over time, especially when support, respite, resources, or shared responsibility are limited.

It is not proof that a caregiver does not love the person they support. It is a sign that caregiving itself involves real labor and that human capacity is finite.

WHY THIS MATTERS IN NEURODIVERGENT FAMILIES



Neurodivergent people are not inherently a burden. The strain often comes from the amount of work surrounding care, advocacy, coordination, uncertainty, and navigating systems that may not be designed around the person's needs.

Research in this area often focuses on parents and caregivers of autistic children or children with developmental disabilities. These studies consistently treat caregiver well-being as an important part of family support, and WHO now includes dedicated caregiver well-being content within its Caregiver Skills Training materials.

THE INVISIBLE WORK OF CAREGIVING

Remembering appointments, medications, schedules, forms, school or workplace needs, and follow-ups





Providing emotional co-regulation or support while managing one's own emotions

Advocating with schools, healthcare providers, employers, relatives, or service systems





Coordinating multiple professionals and translating information between them

Researching accommodations, services, benefits, therapies, or community resources





Making repeated decisions about safety, independence, support, and long-term planning

Anticipating triggers, sensory needs, transitions, communication needs, or changes in routine





Carrying responsibility that may continue even when the caregiver is technically "off duty"

CAREGIVER GUILT CAN MAKE EXHAUSTION HARDER TO ADMIT

Caregivers may judge themselves for needing rest because the person they support is also struggling. Common thoughts can include:



"They are the one having a hard time. Why am I tired?"

"I should be more patient."

"I should not need time away."

"If I say I am overwhelmed, will it sound like I see them as a burden?"

"I chose to be their parent, partner, sibling, or caregiver. I should be able to handle this."

WHY THIS MATTERS IN NEURODIVERGENT FAMILIES

Supporting caregiver mental health does not compete with supporting the neurodivergent person. A family or care relationship is a system: when one person is chronically depleted, the effects can spread through communication, patience, decision-making, connection, and daily functioning.

This is why caregiver support should not be reduced to "be more resilient" or "practice self-care." Some problems cannot be solved by an individual coping strategy when the underlying issue is lack of time, money, respite, services, or shared responsibility.

WHAT MEANINGFUL CAREGIVER SUPPORT CAN LOOK LIKE



Practical Assistance:
Help with transportation, appointments, paperwork, meals, household tasks, finances, or service navigation.

Peer Connection:
Spaces where caregivers can speak honestly with people who understand the role without being judged for mixed emotions.



Clear Information and Training:
Useful, accessible guidance about the neurodivergent person's needs, communication, accommodations, crisis planning, and available services.



Mental Health Support:
Access to therapy, counseling, support groups, or other appropriate mental health services that focus on the caregiver as a person, not only as an extension of the person receiving care.





Supportive Systems:
Schools, workplaces, healthcare services, and communities that do not require the caregiver to fight repeatedly for every reasonable support.

Respite and Shared Responsibility:
Regular opportunities to step away from caregiving without guilt, plus practical redistribution of responsibilities where possible.





Respect for the Caregiver's Own Identity:
Time and permission to remain a partner, parent, sibling, friend, professional, or individual with interests and goals beyond caregiving.

UNAWA CIRCLE

WHAT CAREGIVERS MAY NEED TO HEAR



Needing rest does not mean you love them less.

You are allowed to have needs that are separate from the person you care for.



Asking for help is not the same as abandoning responsibility.

Mixed emotions can exist alongside love and commitment.



You deserve support before exhaustion becomes a crisis.

A NEUROAFFIRMATIVE REMINDER

Caregiver well-being should never be used to frame neurodivergent people as problems to be managed. Good support looks at the whole environment: the neurodivergent person's autonomy, dignity, communication, and accommodation needs, and the caregiver's capacity, mental health, practical needs, and right to support.



The goal is not to choose whose needs matter more. The goal is to build enough support around the relationship that neither person has to disappear inside it.

QUESTIONS FOR REFLECTION

- What parts of caregiving are currently being carried by one person alone?
- Which responsibilities could be shared, simplified, automated, or supported by someone else?
- Does the caregiver have regular time when they are genuinely off duty?
- Can the caregiver talk honestly about exhaustion without fear of being judged?
- Are services supporting the whole family or only responding when someone reaches crisis?



SOURCES AND FURTHER READING

- **World Health Organization. (2026).** Caregiver skills training for families of children with developmental delays or disabilities: Caregiver well-being: Facilitators' and participants' guides. WHO.
- **World Health Organization. (2022).** Caregiver skills training for families of children with developmental delays or disabilities. WHO.
- **Mo, S., Bu, F., Bao, S., & Yu, Z. (2024).** Comparison of effects of interventions to promote the mental health of parents of children with autism: A systematic review and network meta-analysis. Clinical Psychology Review, 114, 102508. https://doi.org/10.1016/j.cpr.2024.102508
- **Pereira, T. L.-B., Wichaikhum, O.-A., Nantsupawat, A., Rajendrana, P., Baladram, S., & Shorey, S. (2024).** Recognising the parental caregiver burden of children with mental disorders: A systematic mixed-studies review. International Journal of Mental Health Nursing, 33(6), 1941–1961. https://doi.org/10.1111/inm.13417

