

For Family Caregivers

Snapshot

- This section highlights advice and tips from our Autistic advisers for family caregivers on how to help them maintain their well-being.
- This section also highlights what Autistic people would like their caregivers to know.
- Autistic caregivers experience parenting differently than non-Autistic caregivers.

“Until our daughter was diagnosed with autism, I didn’t feel like much of a caregiver. I didn’t understand what the world looked like, sounded like, felt like or smelled like for her. She needed help, and we felt helpless. Our family has always had lots of love and an abundance of patience. Unfortunately for our daughter, love and patience helped, but it wasn’t enough. When she was diagnosed at 17, we became armed with information and we started to speak the same language. It was like being handed a key to unlocking how to communicate with each other. Since becoming aware that we are the parents of an Autistic female, we have had the joy of seeing the world from a different lens. The stress and trepidation that accompanied every vacation, outing and family celebration has been replaced with sensitivity, tolerance, flexibility and calm. Parenting an Autistic child (now adult) has allowed us to visit her beautiful world: a world where numbers are colours and music has movement. We have learned that life doesn’t end if we miss a concert or a flight and that sometimes it is even better to stay home. We have learned that some things do not need to be fixed, and sometimes a silent cuddle is the most perfect answer.”

What Autistic advisers would like caregivers to know

“Give tools and opportunities for Autistic people to politely and firmly communicate what they want for any short- or long-term wants/needs/goals they have.”

“If you think we have done something wrong (in what you would consider as an error), please be careful of how you address the issue with us. As Autistic people, we are often keenly sensitive to being corrected. This may be because of a lifetime of being corrected by everyone—caregivers, teachers, relatives, siblings, peers, co-workers, even strangers.

“This constant experience of being corrected may be tied to the different aspects of the Autistic experience. For example, we often take longer to learn our life skills, we may move slower than you expect (especially when anxious) and we may struggle with executive functioning skills and social interactions. When our slower speed inconveniences others or we do a task of social approach that does not meet with approval—we are caught, and our shortcomings are pointed out. In any case, **please use positive language to help us gain skills and confidence**. Just as important: figure out how to teach us the skill and understanding that resulted in what others would consider an error.”

“Sensory issues are not ‘all in my head’ (and they bothered me long before I understood their nature, or even what the issues were). Sensory differences can cause behavioural and emotional responses in Autistic people.”

“If an Autistic person seems to be experiencing a higher degree of mental health problems/distress or low positive mental health, do not automatically pinpoint it to autism as the cause. We are all formed and informed by a variety of factors (e.g., social, biological), all of which impact us positively and negatively as human beings.”

“Do not shame us for our social-communication skills or make excuses for our communication skills. It may not seem right to you, but it is right to me. It can be very challenging for us to live our lives knowing that we may tick someone off on any given day and have no idea why or what we did. These interactions can end employment, personal relationships and friendships.

“Remember: Autism is a different way of communicating and interacting with others. We often have to be taught directly what non-Autistic people simply pick up intuitively. If there is something we did that others found inappropriate or offensive, this may mean there is a social expectation that we were not taught or need to adapt to. Prepare us for new situations. Sometimes simply telling us in advance about the hidden social rules of an upcoming social situation can improve our skill and confidence. This helps us avoid being shamed and blamed when our responses are misunderstood.”

“Do not let your Autistic family member be bullied by a sibling, a caregiver or any other relative. **Home needs to be a safe space.** When a caregiver or sibling is a bully or an abuser, it can ruin the relationship we have with that person for life. We often don’t address interpersonal conflict, so if these family members hurt us, that may define our relationship and how we respond to that relative for a very long time (forever, even).”

“A good rule of thumb for when it comes to supports (e.g., medical, therapy): really try to use more than one method. It doesn't necessarily mean having to switch therapies or support (although, that might be needed too). It may be a matter of doing a different activity (e.g., mandala colouring books and yoga are two current prominent, different and viable options for promoting relaxation).”

“Be mindful of how you advocate and how you approach advocacy. Learn about autism, not just in the sense of what autism is, but . . . what disability is socially. What’s our history? What social implications does that have on people? Because autism isn’t living separately from humans, it’s a part of us. And humans—even Autistic ones—have social culture.”

Family relationships

Caregivers

Being a caregiver to Autistic people is a journey. Some caregivers of Autistic people work to co-ordinate services and care for their family member. Caregivers can also struggle to cope when their Autistic family member experiences mental health problems or low positive mental health. They can describe feeling frustrated, sad, angry, hopeless, stressed, or overwhelmed.

However, they can also report feeling empowered, content, loved, hopeful, happy and secure in their role as caregivers to support their Autistic family member. Each caregiver and family reaction depends on the situation at hand and resources, coping skills, strategies and other life events surrounding the family.

Caregivers may feel a sense of responsibility about their family member's care and well-being across the lifespan. Caregivers of Autistic people have the potential to grow as people, increase their patience and change their priorities. They may learn to pick their battles wisely. They can find allies in other families, advocacy groups and helpful professionals.

Some family members may find it difficult to soothe their own anxieties and to disengage themselves from their life stresses. They may feel unable or too guilty to take time for themselves to relax, care for their own emotional and physical health and rebuild their coping resources. In some cases, there might be a lack of available respite opportunities, especially in disadvantaged communities.

"I have never felt angry or resentful of the things I do for my son, or the amount of support that he needs. He is one of the best human beings I have ever known in my life. Where it has impacted me is my relationship with others who do not understand my son. They may see support with life skills as enabling, or his inability, so far, to master certain life skills as a weakness of character rather than a visual motor issue, fine and gross motor difficulties, executive functioning differences that mean poor attention, focus and working memory. If someone is not respectful and kind to my son, I cannot have them in my life. This is true of partners and of any extended family members."

Sometimes family members may feel guilt when they experience negative emotions. It is important for caregivers to notice and accept when they feel extremely tired or have negative feelings. Ignoring these negative emotions may seem to help in the short term, but it can lead to exhaustion, depression, isolation and hopelessness. This will not be helpful for them or their Autistic family member. Remember that many family caregivers can experience difficult circumstances and negative feelings related to their caregiving roles or responsibilities.

Caregiver experiences with Autistic family members

“Being the caregiver of two Autistic sons has helped me see that you don’t have to be ‘neurotypical’ to make an important contribution to the world. I am more patient and accepting now. I am better at assessing and accepting the world as it is, as opposed to how I might want to see it. I am learning that ‘success’ means different things to different people. Our family defines it in terms of personal well-being and purpose as opposed to material things (although we love some nice material things!).”

“I would want my Autistic sons to know that I accept them and see them just as they are and [that I] want to make a place (or help them make/find a place) where they can live a life that is meaningful to them. I treasure how kind and empathetic they are. I sometimes forget that we experience the world differently, and I wish I could experience it the way they do. I am trying to teach them as much as possible how to navigate on their own.”

“My relationship with my adult Autistic child is not one of unbalanced power where I make decisions. Everything is collaborative with ultimate decisions falling to him. It has been very empowering and useful for my son to be an equal part of the process. By ‘process,’ I mean deciding on next steps in life, in gaining skills and ability or in seeking mental health support. I am present and connected to give information, to question, to guide—but he has to decide.”

Caregiver stressors

As each family is unique, specific reasons for stress differ from family to family. However, families do report some common sources of caregiver stress. We discuss some of them below.

Frustrations with systems, funders and programs

Dealing with different systems (government, health, education, social services, employment counselling, etc.) is time-consuming, stressful and hard to navigate:

- There is a lot of paperwork involved.
- It's not easy to figure out and work with the system, and at times the information provided is not clear.

Lack of appropriate services

Autistic people often fall through the gaps in services and funding. Even when services are available, professionals may not understand the needs or support necessary for Autistic well-being.

Worries about the future

When thinking about the future, caregivers are concerned about the vulnerability of their loved ones. Some common concerns include:

- Dependence on funding and/or services that might not be offered consistently.
- Lack of safety and security when the time comes when they are unable to care for their family member, due to their own poor health, aging or death.
- Lack of family or friends to be alternate guardians or trustees when they are not able to care for their family member.
- The challenge of making a will and participating in estate planning to provide for a person with a disability (and also wanting to be fair to any other children).
- Will they find love? Maintain lasting relationships and social connections?

Personal stress

Many caregivers can report being exhausted and unable to perform self-care. This can be especially true for caregivers whose Autistic adult-age children have very high physical support needs (those who are not independent with toileting or bathing, who cannot control their body or whose responses to the environment can be a safety risk). At times, only one caregiver may end up doing all the advocacy, support and care for their Autistic family member.

Other stressors may include a lack of access to affordable, knowledgeable professionals who work with Autistic people and their families, or not being able to go to work, take care of other family members or attend to other things in their lives.

Receiving a late diagnosis

For caregivers who have late-diagnosed Autistic family members, they may face the following challenges:

- It can be difficult and expensive to get an assessment or re-assessment.
- There are long wait-lists to get assessments.
- Once a diagnosis is received, it can be a lot of work to understand what is involved, what to do to help, what services are available and how to access them.

Financial stress

Caregivers of Autistic people may earn less money or have to work fewer hours than other caregivers. At times, they may have to take off unpaid workdays to support their Autistic family member. Caregivers may also have added expenses such as therapy, medicine and housing. These challenges may be especially experienced by single-caregiver households or households with other medical difficulties.

Social stress

Some caregivers may have difficulty connecting with other family members because they may not understand autism or how to support Autistic people.

At times, extended family members may be critical of the caregivers or their family member. Some people experience pressure from relatives to be a “perfect” caregiver or family. Some caregivers may be unable to connect with their friends or community because they may be occupied or because social attitudes toward disabled people are too negative.

“We have lost many friends and much of my family because of our differences. We were never well-off, but we struggle financially because of choices my husband and I have had to make, to stop working in full-time jobs (with pensions) because we needed to be available during workdays to meet our sons’ needs. There’s guilt associated with this—not being able to provide as well as we’d like to, because of having to make these choices.”

You can use the **Brief Family Distress Scale**¹ to quickly decide where you are in terms of distress, which is often the result of on-going stressors without support. This scale is like a “distress thermometer” and offers a quick way to communicate to others, including service providers, how well you think you are managing and how urgently you feel you need help.

Brief Family Distress Scale¹

On a scale from 1 to 10, rate where you and your family are right now in terms of crisis by picking one of the following statements:

- 1 - Everything is fine, my family and I are not in crisis at all.
- 2 - Everything is fine but sometimes we have our difficulties.
- 3 - Things are sometimes stressful, but we can deal with the problems if they arise.
- 4 - Things are often stressful, but we are managing to deal with the problems when they arise.
- 5 - This is very stressful, but we are getting by with a lot of effort.
- 6 - We have to work extremely hard every moment of every day to avoid having a crisis.
- 7 - We won't be able to handle things. If one more thing goes wrong – we will be in crisis.
- 8 - We are currently in crisis, but we are dealing with it ourselves.
- 9 - We are currently in crisis and have asked for help from crisis services (emergency room, hospital, community crisis).
- 10 - We are currently in crisis, and it could not get any worse.

Marriage and partnerships

Marriages and partnerships can be affected by daily stressors. There can be stress for many reasons, and the following are potential strategies that have been suggested to maintain positive relationships during times of stress.

Caregiver strategies for relationships

1. Keep the lines of communication open between partners.
2. Rely on each other for support.
3. Seek help from each other or from others outside the relationship, such as couples' counselling.
4. Make time for family members, like going to a movie or another activity to nurture your relationships.
5. Attend some of your family member's appointments together.
6. Give each other time to deal with stress in your own ways.
7. Try hands-on activities instead of only talking.
8. Learn about your family member's difficulties together.
9. Ask for information to share with each other.
10. Increase your partner's involvement slowly, rather than expecting too much too soon.
11. Connect with other families of people in the same situation as you.
12. See yourself as a "team."
13. Remember the big picture of what your common goals are.
14. Recognize that family members may have uneven parenting responsibilities. Caregivers should communicate with each other about what their expectations are.

Siblings

Siblings may worry about mental health problems, or they may have the same diagnoses. They may worry about the stress and strain that their caregivers are experiencing and may take on some of the roles in helping. At the same time, siblings may sometimes resent the time that caregivers spend supporting an Autistic sibling. There may be feelings of guilt for not being able to support their sibling in the way that is needed or they may not understand them.

How can caregivers help siblings cope?

1. Help them learn about autism and mental health and how they interact and affect each other.
2. Share feelings and encourage your family members to talk about how they feel. For example, what they are experiencing and how their Autistic sibling's experiences affect them.
3. Help them build a new relationship with their Autistic sibling and create different ways of being with them.
4. Explain that other extended family members may feel uncomfortable or embarrassed, but that doesn't mean they need to be uncomfortable or ashamed of their Autistic sibling.
5. Help them develop realistic expectations of themselves, as some siblings may feel like they have to behave perfectly or excel at different parts of their life.
6. Celebrate the accomplishments and achievements of all family members.
7. Discuss the issue of stigma and why it happens, as well as effective ways to deal with it and address it with others.
8. Spend alone time with each family member, talking or doing their preferred activities.
9. Encourage siblings to have interests outside of the family. An outside activity can help build friendships, skills and self-esteem.
10. Help siblings connect with a peer group of other siblings.
11. Strengthen your family members' support system. Sometimes it's important for siblings to have an adult outside of the family (e.g., friend, support team) to confide in.

Sibling experiences

“As an #ActuallyAutistic and also a sibling of a non-Autistic brother and sister, their experiences with me are different than my experiences. My brother and sister were good with me most times, but of course, we fought as most siblings did. They did a lot of exposure and exploring with me and would engage with me when I was younger; played games and looked after me very well. That has helped with my overall growth in my very younger and later years as well.”

Autistic caregivers

Autistic caregivers are often forgotten in conversations about parenting. Autistic caregivers can experience times when their roles as caregivers can be difficult.² These difficulties include but are not limited to: a lack of tailored support, challenges communicating with professionals (e.g., doctors, teachers), low opinions of parenting from others (e.g., being judged by other caregivers) and perhaps being at a higher risk for depression after birth. Executive functioning difficulties may make the smooth running of a household difficult.²

It also can be common for Autistic caregivers to feel isolated and judged. Their social struggles and unique differences can make fitting into parenting groups difficult, leaving them feeling alone. Their struggles and differences can also make them feel “less than” non-Autistic caregivers. Some Autistic caregivers live in fear that they will be judged “unfit” to be caregivers and will have their children taken away from them due to discrimination and misunderstanding.²

Strengths of Autistic caregivers

Neurotype alone (e.g., Autistic or non-Autistic) does not decide anyone’s capability of doing anything, including parenting. Autistic people can be good caregivers who raise fantastic kids, Autistic and non-Autistic alike. Similar to non-Autistic people, Autistic caregivers find parenthood rewarding² and are able to prioritize their child’s needs above their own and seek ways to boost their child’s self-confidence.

Autistic people can be incredible caregivers to Autistic children. They know what it is like, because they think and experience the world differently also. They may understand why their child is doing something that other people may not understand—because they know their child’s way of thinking and perceiving the world.³ Autistic caregivers can provide their family member with autism-specific coping skills and things that have helped them get through the non-Autistic world.

Autistic caregiver needs

Below are several things that may help support Autistic caregivers:

- A support system among Autistic caregivers for the sake of solidarity and idea-sharing. Being an Autistic caregiver is a unique experience; having other Autistic caregivers to turn to for social support and validation is essential.

- Awareness and understanding to reduce stigma and stereotypes and foster compassion and empathy.
- Education/mentoring programs that could help Autistic caregivers with things that don't come naturally to them. For example, help with family communication, including between caregiver, child and partner.
- Some parents may feel that they could benefit from structured coaching or mentorship. For instance, advocacy groups, parenting support groups, peer-to-peer supports or parenting programs.
- An advocate to aid in communication with schools, doctors and other professionals. Situations where parents are expected to advocate for their children can be intimidating or hard to navigate.

Autistic caregiver experiences

“Being an Autistic parent helped me to be a better parent to my Autistic child and has made me a better person as well. For example, he cannot tolerate raised voices, so from the time he was two years old, I did not holler in the house. I would find calm ways to express my urgency, upset or excitement. Raising him allowed me to immerse myself in the autism culture in hope of finding ways to address his learning, sensory and social-interacting needs. I read every book, paper, website I could get hold of and never stopped. When I discovered something that helped him, I felt compelled to share it so that other children could benefit. I am an Autistic advocate whose strength is in navigating school supports and identifying learning challenges to help Autistic students thrive in school. I am able to do this because of the gift of raising my Autistic son. It is worth noting that Autistic traits, including tenacity and focus on areas of strong interest, helped me to help him—and now to help others.”

Strategies for caregivers

Activity 8.1 below is an activity you can do to check how different areas of your life are doing. It may help you to communicate with professionals about your support needs.

Activity 8.1: Personal Impact Log

This log will help you think about your situation and how it affects your physical, emotional, social and spiritual health.

Physical health	Emotional health
Social life	Spiritual life

There are no easy answers for coping with caregiver stress. Many families know exactly what they need to relieve stress, but what they need may not be available. Following are some suggestions and advice our caregiver advisers have suggested. These tips on coping are offered knowing that they don't work for everyone and that they are a lot easier said than done.

Learn and celebrate Autistic culture

Autistic culture is the shared history of Autistic people and how they move, communicate, experience and understand the world around them in their own way.⁴ Learning about your Autistic family member's culture can help you to appreciate, accept and enjoy them as they are.

There is no right or wrong way

Keep in mind that there is no one right or wrong way to be a caregiver. It is okay if you do not have all the answers. Many caregivers find that there is a lot of trial and error involved in building a good life.

Find the humour in life

Take time to laugh daily, even if it's simply through reading, social media or television. Humour can be a great stress reliever.

Remember you are not alone

Connecting with other families and support groups is a source of support that many caregivers find useful. You may find inspiration, hope and creative solutions to problems by communicating with other families. If it's not possible to connect, there are books, films and websites written by Autistic adults and caregivers. Accessing these types of materials can also make you feel less alone.

Make use of supports and funding

Some families may not take advantage of financial support, such as the disability tax credit, because they think they are not entitled or that others deserve it. You do not need to be in the worst possible situation to deserve funding or a tax break. It can be okay to accept help.

Access respite care

Accessing respite services can allow caregivers an opportunity to engage in a hobby or other relaxing activity, spend some time alone, get chores and errands done, visit a friend or participate more fully in other activities.

Respite (or relief) can be found from multiple sources. Through your personal network is often a great way to find a person that is a good match for your family. This means letting others know what you need. The other way is through respite agency services.

Take time for yourself

Self-care is essential, it is not selfish. If the caregivers are burnt-out, everyone can suffer. Refer to **Section 6** of this guide for some activities to try.

Take care of your health

Caregivers may neglect their own health, particularly when they are overwhelmed by the needs of others. Caregivers can be prone to stress-related challenges (experiencing distress or low mental health) or physical problems such as chronic pain and headaches. Remember to try and find time for some exercise (even if it's just a for a short walk) and to get enough sleep—these can improve your mood and outlook.

Pursue activities with your Autistic family member

Caregivers can join clubs that are of interest to them and their child. Sharing interests can build a deeper connection and relationship—it allows you to get to know them more as people.

Develop advocacy and assertiveness skills

Learn how to advocate effectively on behalf of or with your Autistic family member. You may find workshops on how to effectively advocate useful. You can also contact disability organizations for help or read literature on the topic. Below are some suggestions on advocacy.

When advocating, start by explaining your family's vision of a good life (especially your Autistic family member's vision). One way to advocate effectively is to explain your child's strengths. When you advocate, it be helpful to be assertive, rather than aggressive or passive. Aggression may result in being dismissed as unreasonable or it may elicit a variety of other resistive responses. Passivity may result in you or your family not receiving important resources and services.

When attending a meeting where you expect to advocate:

- Try to start on a positive note—do not attack or blame.
- Clearly state your concern.
- Be clear in your own mind what you want from others.
- Bring a list you can refer to.
- If a new idea or surprise is introduced during a meeting, don't be pushed into making a decision—ask for a day or two to think about it.
- Bring someone with you to serve as a support and to take notes when at meetings with professionals.
- Record who has agreed to do what and when it will be done, and send a copy to everyone who was at the meeting.

What family caregiver advisers would like caregivers to know

“If one caregiver is impatient, rude or hostile to their Autistic family member, it causes harm and often has implications that can last a lifetime. If your partner is contributing to or even causing your Autistic family member's mental health challenges, please do something to protect your child. Autistic people deal with enough bullies out there in the world. Home should be a safe place.”

“There are very few professionals who really understand what it means to be Autistic. With that in mind, only seek help from professionals with a high degree of knowledge, experience and understanding of Autistic culture.”

“Never accept advice you know is wrong. Trust your gut. Reach out to Autistic-led support groups to learn more about the Autistic experience. Increase your understanding, and you will naturally change your support for and actions on behalf of your Autistic family member.”

“Live your life. Model how to handle mistakes. Show, by example, how to work through disappointment, frustration, anger and being overwhelmed. Narrate your experiences when your Autistic family member is with you and when it is appropriate to do so. This will help the Autistic family member to grow up and know what to say and do when these feelings take root.”

“One of the most under-appreciated aspects of the Autistic experience is the intolerance of uncertainty. Be respectful of this reality: let your child know in advance when plans change, when plans are being made, when their help may be needed with a chore. Last-minute demands can, by nature of the Autistic experience, be very difficult. Now you know this. Now you can find another approach. This one small step can help your child to feel more at ease in your presence, and less anxious as a result.”

“Sensory differences are real. Learn what they are and respect them. Don’t make a big deal out of accommodating them, and don’t make excuses for your difficult relatives who interpret sensory needs as whiny, dramatic or bad parenting. If anyone doubts you, ask them to wear a mohair (type of fabric) sweater on a hot day and challenge them to maintain a cheerful, focused demeanour.”

“Autism is a different way of learning, interacting with others and experiencing the sensory world. That may sound very abstract, but if you can learn what each of these mean for your Autistic family member, it can make all the difference in the world. It can help you view any hurdles your Autistic child may be experiencing from an autism perspective. Educated caregivers who respect Autistic culture can be very effective and appreciated allies.”

“Keep your Autistic family member’s strengths and positive attributes in mind, especially when times are hard and there is a lot of conflict in the relationship.”

“Seeking professional support and strategies on how to communicate with your verbal Autistic family member may reduce conflict or arguments and escalation because of frustrations.”

“If your Autistic family member (especially pre-teenagers) seems to be struggling with mental health challenges, especially increasing isolating behaviour, rumination, social anxiety and/or paranoia, ask your health care practitioner and/or mental health professional about autism.”

“Self-care is essential for caregivers and siblings. It is one of the ways to ensure resilience and empathy for your child/sibling.”

“Plan for the future, especially when it comes to securing affordable, independent, supported housing for your Autistic teenager as they emerge into adulthood. Families experience two critical periods with their Autistic family member: early adulthood and early seniorhood, and stresses can be reduced with advanced planning.”

“Teach the adult Autistic person how to advocate for themselves in a scaffolded way. Parents will not always be there. This will help them to feel more confident. It will also alleviate stress and worry from the caregivers, who worry endlessly about how their adult child will manage without them. ”

“The Autistic person is not trying to be malicious—they are trying to express a need of some kind. Imagine if you didn’t speak the language everyone else spoke and people consistently misunderstood what you needed. Try not to take ‘behaviour’ personally—try to step back and assess what the person’s goals are.”

“Always remember to give your Autistic family member space if they need it. Sometimes it takes time to process difficulties and expressing their emotions.”

References

1. Weiss, J. A. & Lunsky, Y. (2011). The Brief Family Distress Scale: A measure of crisis in caregivers of individuals with autism spectrum disorders. *Journal of Child and Family Studies*, 20, 521-528. <https://doi.org/10.1007/s10826-010-9419-y>.
2. Pohl, A. L., Crockford, S. K., Blakemore, M., Allison, C., & Baron-Cohen, S. (2020). A comparative study of autistic and non-autistic women's experience of motherhood. *Molecular Autism*, 11(3), 1-12. <https://doi.org/10.1186/s13229-019-0304-2>.
3. Crane, L, Lui, L. M., Davies, J., & Pellicano, E. (2021). Short report: Autistic parents' views and experiences of talking about autism with their autistic children. *Autism*. <https://doi.org/10.1177%2F1362361320981317>.
4. Ed Wiley Autism Acceptance Lending Library. (n.d.) *Autistic Culture*. Retrieved from: <https://neurodiversitylibrary.files.wordpress.com/2017/01/autisticculture.pdf>.