



Tips for Caregivers

- Sorting through the complex challenges and issues related to caring for a child or children with autism spectrum disorder (ASD) can be challenging. Adding employment demands, the care of other family members, maintenance of a household and other personal matters, caregivers have little time or energy for self care and personal interests. Although it seems difficult to ask others for help, it is important for caregivers to seek assistance to reduce these demands.
- Try to identify the issues which are most difficult to handle. Local governmental agencies that focus on family members who have disabilities can help. Local libraries and the special services department of school districts have a list of these agencies readily available.
- Life may be different for families caring for a child with ASD. With these differences, it is still possible to enjoy various aspects of life with planning and support. As difficult as it may seem to involve a child with ASD in recreation, leisure, and family activities, the more a child with ASD is out in the community, the more he or she has opportunities to become familiar and comfortable. These outings can be pleasant diversions from many of the stresses of everyday life.
- Many children with ASD exhibit challenging behaviors and may not respond to discipline methods effective for other children. Caregivers should seek professionals and resources to help modify these behaviors and develop coping skills. Lists of local service providers can be found on many autism websites, from local libraries, or from the child's school district.
- Connecting with other families who have children with ASD can help. Spending time with other caregivers who have similar interests, challenges, and experiences can reduce anxieties and feelings of isolation. Look for people or support groups that provide positive input and reliable resources. These connections can reduce isolation and help caregivers feel empowered.
- Many hospital and doctor offices have staff who are also parents of children with special needs. Caregivers can contact a social worker or representative from the facility and ask to be connected with staff who have this background and understanding.
- It is helpful for caregivers to set consistent routines as part of daily life. As appointments and meetings are common, try to let the child know about schedule changes ahead of time to help alleviate challenges with disruption in the routine.
- Find areas in the home where the child with ASD feels comfortable and engaged in an enjoyable activity. Caregivers can find comfort near the child to read, exercise, write, or other activity of personal interest.
- Respite care is a basic need for families living with ASD. Respite means finding the time to take a break from many of life's demands. This supports caregiver well being and helps preserve family balance. Respite, in small or large amounts, can happen in or out the home. Caregivers can contact their local school district, college, community organizations, neighbors, religious communities, family members, case manager, and their physician to find people who could provide respite care. Governmental agencies may also be able to provide respite workers or financial support for the respite needs of families.
- When a respite care worker has been identified, start with small amounts of time. Both need to become familiar with each other as well as preferences and routines. The respite time can be expanded once there is a comfort level. Respite can begin while the parent or caregiver is in the house in another room. Then it can be expanded for a short trip out. The goal is for caregivers to have multiple respite providers in place on order for the caregivers to have sufficient time to get the rest and leisure activity they need and for the person with ASD to get used to a variety of helpers.

- Many times caregivers may not realize they are neglecting their health and well being. Family members and friends may suggest counseling or medical intervention. It is all right for caregivers to get the help that they need. Family and friends may want to help in many ways, but may not know how. Caregivers should let them know the ways that they can be helpful in practical and meaningful ways. There is no shame in getting the help needed if it makes the helper feel needed and wanted.

