



Helping an Autistic Adult Cope with Someone's Serious Illness

The diagnosis of a family member's serious illness can send shockwaves through the entire family and bring about many feelings, emotions, and reactions. It can be difficult to identify and balance your own emotions while also trying to help an autistic loved one cope with theirs.

The suggestions below may help reduce the impact of some of the changes and disruptions that a life-altering illness can bring to an autistic individual's life.

- **Communicate and plan** — Be clear about what will change, what will stay the same, and why. Change is difficult but change without warning is even more so. Involving the individual in making plans, lists, and calendars so they know what is coming can be particularly helpful. Ask what kind of information about the situation would help them feel more comfortable.
- **Address sensory challenges** — Prepare the autistic adult for what they may see, hear, and smell. Honest and appropriate communication is important. An ill loved one going through chemotherapy may lose their hair and change in appearance. Weight loss, bloating, scars, or connections to tubes can be frightening to see. Hospitals can be full of unfamiliar smells and sounds, and equipment such as monitors and oxygen tanks make sounds that can be disturbing. Bright hospital lights and the presence of strangers can lead to sensory overload. Communicate about what to expect in these environments and validate their sensory experiences. If possible, reduce or eliminate exposure to sensory challenges. Allow your loved one to determine their own level of comfort as they cope with any sensory concerns.
- **Model** — One tactic that can help reduce stress and anxiety during a serious illness or hospice is modeling. For example, if the ill person requires oxygen, ask their provider for a spare length of tubing and nasal cannula. Encourage your loved one with autism to hold it, and smell it, and show them how the tube will blow gentle air into their family member's nose to help them breathe. In this way, you are modeling comfort with the new apparatus, and helping to make the unknown more familiar.
- **Role-Play** — Role-playing can be used to practice for unfamiliar situations they may encounter, so they may comfortably respond to them. "Aunt Susan, there's a tube by your nose. What's that?" Having the opportunity to try out unfamiliar phrases and conversations may help your autistic loved one feel more comfortable in a new environment.



Helping an Autistic Adult Cope with Their Own Illness

When our bodies are fighting illness and injury, we are simply not capable of being our best selves. For an adult with autism who is coping with their own serious illness, regressive behaviors are common. They may exhibit increased self-stimulatory behaviors and emotional outbursts as well as decreases in their ability to cope with change, verbal ability, listening comprehension, and ability to follow instructions. It may be difficult for them to communicate their level of pain, understand the need for tests, or accept treatment from medical personnel.

Tips to Provide Support

- Advocate for the autistic by sharing information with healthcare providers about what would help. For example, talk with providers about ways to minimize sensory overload during hospital stays. Small modifications such as minimizing needle sticks or lowering the lights in their room are simple ways to make hospital time easier. Arranging for a single room may significantly decrease stress and anxiety. You can model for providers how to ask the autistic about what they need or what might help them and encourage them to do so.
- Determine if there are things that you could do, such as staying overnight in the hospital with the autistic adult, that would provide support during hospitalization. For example, when adults with autism and other disabilities were hospitalized with COVID-19 many medical facilities allowed a caregiver to be present, even overnight, despite a general ban on visitation.
- If possible, identify individual providers or medical or hospice facilities that have experience caring for patients with autism to treat your autistic loved one. Seek to maintain routines or supports that have provided comfort and support in the past, such as favorite objects, music, and activities.
- Most importantly, be present. Isolation and anxiety among people who are ill, including autistics, can be alleviated simply by your presence.

Coping with Anticipatory Grief

When we're focused on a serious illness and possibility of death, we can sometimes begin to grieve before the death occurs. The grief that may arise when facing a serious and potentially life-limiting illness is referred to as *anticipatory grief*.

Grief and its effect on the neurotypical population has been extensively researched; countless studies help us understand its impact. In contrast, the study of the effect of grief on adults on the autism spectrum is just emerging.



Here are some important considerations regarding anticipatory grief:

- **Tangible and intangible losses** —Serious illness can bring about both tangible and intangible losses for the person who is sick as well as for family members. Losses could include physical and/or cognitive abilities, one’s living situation, a sense of safety in the present, or hopes and dreams for the future.
- **Importance of validating losses** —Anticipatory grief may have similar impacts as grief after a death, including physical, emotional, behavioral, and spiritual impacts. Similar to the grief experienced after a death, our reactions can be varied and unique as we think about the inevitable losses to come. It is important to recognize and validate these anticipated losses as well as the grief they may cause when we are helping someone cope with pending losses and associated feelings of anxiety.
- **Effects on the family** — Anticipatory grief can be experienced by family members as well as the person who is dying. Family members anticipate the death of their loved one and the known and unknown consequences. The person who is dying grieves losses that signal their own approaching death, including the loss of abilities and independence.

Ease Your Loved One’s Anticipatory Grief

Here are some guidelines to support an autistic adult as they cope with anticipatory grief:

- **Look to past experiences to guide you** — How they coped with other challenges will provide insight to help with this current struggle.
- **Be deliberate and clear with your words** — It is always best to be honest in comments and explanations. “Your grandmother is very sick and she will die soon.”
- **Offer choices for coping strategies** — “Let’s think about some of your memories with Grandma and look through photos of her to find some of your favorites.” You could also suggest ways of helping or comforting the patient: “What can we do for your grandmother today to remind her that we love her?”
- **Provide reassurance** — “This is hard and we will be sad after your grandmother dies, but we will get through this together. We’ll take care of each other. You’ll be with me.”