



Coping with Serious Illness

The diagnosis of a life-limiting illness is a difficult time for families. Whether the loved one is a family member, close friend, direct support staff, or pet, a serious illness can cause distress, confusion, and worry.

While various professionals will have different roles, everyone involved with an autistic adult experiencing the serious illness of a loved one should communicate clearly about the illness and explain any changes that may occur as a result. The prognosis should be shared clearly and honestly, and information should be given regarding treatment and care. Honest communication may help alleviate anxiety about the unknown and likely disruptions to routines. It can also help the autistic begin to think about how things may change in the future and to prepare a plan for coping.

Recommendations for Providing Support

- Keep the individual informed throughout the course of the illness, providing updates as they are available. Examples of sharing information over time include:
 - “Your mom hasn’t been feeling well. She is going to the doctor to see if she can get some help.”
 - “Your dad’s doctor is trying a new medication/treatment, but we don’t know yet if it will help.”
 - “The new medication doesn’t seem to be helping. Your grandmother is going to die, but we don’t know when. We are going to try to make sure she is very comfortable, doesn’t feel sick, or feel any pain.”
 - “Your grandfather won’t be alive much longer. Other family members are sharing with him how much they love him. Would you like to visit/call/write to him?” (This can and should be offered at multiple points.)
- If it is appropriate and possible, provide numerous opportunities to connect with the dying person. This could involve preparing for the interactions, such as practicing what to say.
- Allow the autistic individual to set their own boundaries. Don’t pressure them to see the dying person if they express discomfort. Do offer alternatives for “leave taking,” such as sending a message, writing a letter, or drawing a picture.
- Reach out to others in any support network the individual may have to let them know that this is a good time to check in.
- Invite conversations with anyone in their support network to help the autistic understand what could or likely will happen when their loved one dies.



- Use clear and honest language. Avoid euphemisms when discussing the illness, treatment options, and prognosis.
- Provide ample time and space to address any questions.

Hospice and Palliative Care

More than half of all deaths in the U.S. occur in hospice care. Nonetheless, many adults are uninformed or have misconceptions about the role of hospice, differences between hospice and palliative care, and differences between treatment and supportive care. Helping an autistic understand the goals of hospice and/or palliative care may ease their concerns.

Hospice Care

Hospice is an approach, not a place; most hospice care is delivered where the person lives, whether in a private home, in a nursing home, or in another residence. Eligibility for hospice requires a doctor's certification that the patient has a life expectancy of six months or less—although of course this expectation is difficult to determine and some hospice patients live longer than six months.

Hospice care is provided by a team of professionals including a nurse, a social worker, a chaplain, and others. The goals of hospice care are to manage pain and other symptoms, and to improve quality of life. Treatments aimed at curing the primary diagnosis discontinue when the patient or healthcare surrogate elects hospice care.

Hospice does not imply “giving up on” the person. Hospice care means that there is no curative option available or that the patient has elected to discontinue treatment—typically due to debilitating side effects of treatment that has failed to alter the disease progression significantly. Hospice is about comfort rather than cure.

Hospice professionals treating a patient with an autistic adult in the home should recognize potential stressors that the idea of hospice, as well as the presence of the hospice team, may bring. Additional equipment and multiple new people entering the home at strange intervals all can create distress for an autistic and may exacerbate the anticipatory grief that person may already experience. These potential stressors could be alleviated somewhat by including the autistic in conversations about expectations and care plans, and by asking directly about their specific needs during this strange and confusing time.

Because hospice care at home allows the dying loved one to remain present with their family, their continued physical presence may be helpful and comforting to adults with

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autism. Being able to assist in caregiving may also provide a sense of purpose and control during an otherwise uncertain time. Hospice professionals should maintain boundaries yet also be aware of any available support system of family, friends, or others who could provide critical help in supporting the autistic during their grief journey.

Palliative Care

Palliative care differs from hospice care in that it provides supportive care for anyone who is experiencing suffering or is in pain, but it is not restricted to those who are terminally ill. Palliative care can be provided along with curative treatment for the underlying condition in the home, at an outpatient clinic, or in the hospital.