

Autism & Grief Project

Self-Care for the Caregiver Tip Sheet



Being a caregiver is tough. Grief is tough, and it can affect us in many ways—physically, cognitively, and spiritually. Caring for ourselves helps us personally and also helps us be gentle with others. Yet caring for another person can also result in a loss of independence, a loss of friends and social activities, and/or a loss of financial security. Whether we're grieving alone or grieving while also caring for another person, self-care is essential.

If you are experiencing loss while also caring for an autistic loved one, we offer the following basic rules of self-care.

Sleep

Grief often disrupts sleep. You may find yourself sleeping too little or much more than usual. You may have been in a caregiving role for a dying loved one and already be sleep deprived, so grief may make you feel even more exhausted. Try to avoid sleep aids if possible, as they may disrupt sleep cycles even further. If sleep is severely disrupted, ask a doctor about taking a natural sleep aid such as melatonin.

Some grief counselors recommend taking a hot bath or shower before bed, sleeping in a cool room, and using plenty of blankets. The weight of blankets can be a comfort and helpful for sleep. Others find that limiting screen time before sleep, aromatherapy, or a sound machine can help with falling and staying asleep.

Healthy Eating

Food may be the last thing on your mind following a loss. Often people who are grieving may eat too little or too much or rely on unhealthy food that temporarily makes them feel better. A nutritious diet for you and for your loved one with autism is essential. Try to choose foods that provide nutrients, are comforting, and easy to digest. It is also important to remember to stay hydrated by drinking plenty of water or non-alcoholic, low-sugar beverages without caffeine.

Identify and Use Your Support System

Whether you look towards your personal network or an organized grief support group, there are people who can help. Your family, friends, co-workers, faith community, and neighbors are often willing and happy to offer assistance, so don't be afraid to ask them. Most people in your intimate network will want to help but may not know what to offer or how to ask.

Often, the bereaved hear comments such as, "Let me know whatever you need." Specific requests from you, such as asking a friend to pick up a prescription, shovel

snow, drive you to appointments, or walk the dog, can go a long way toward helping you in the first weeks following a loss and will also help your friends feel like they are helping. If in-home professionals are working with your autistic loved one, use that

support to its full advantage. Consider accessing respite care, which can give you a needed break.

Some therapists recommend reflecting on how those in your support network can best help and suggest using the DLR coding system. One of the greatest strengths of the autism community lies in its ability to network with other families. If you have a support network, it may not specifically be centered around grief, but chances are good that several people in your moms/dads/siblings group have experienced loss. Reach out and connect with those people.

- “D” for people who are good doers and are able and anxious to help with specific chores and tasks.
- “L” for listeners who are people you can turn to who will always listen without judgment.
- “R” for respite friends who you can relax with and who will provide the necessary “time off” from grief.

Exercise and Exposure to Nature

It may feel hard to get motivated to exercise after the death of a loved one. Taking the first step toward intentional movement can reduce stress and bring about positive brain chemistry changes. A walk around the block, a swim, gentle yoga, or any kind of physical exercise, can be a good way to get a change of scenery while recharging physical and mental batteries. Getting outside and into the calming presence of nature has been shown to have positive effects on mood. You don’t need to take a rigorous hike if that’s not your thing; but any exposure to the outdoors is, for many, enough to instill tranquility and calm.

Educate Yourself

Understanding your own feelings after loss and knowing about the grieving process that you may be experiencing can offer validation and tools to manage grief. For example, knowing that everyone grieves differently and that grief does not occur in prescribed stages can help you be kinder to yourself and those around you. Sometimes it can help to read current books or authoritative websites about the grieving process. The resources section of this portal has some suggestions you might find helpful.

Joining a grief support group may also help. Many hospice providers offer access to free or reduced cost grief support through groups and individual counseling to all community members, whether the death occurred in hospice or not. In the wake of COVID-19, many support groups are now accessible online.

Avoid Alcohol and Drugs

It can be tempting to turn to alcohol and other drugs to numb your pain, but these will only delay and complicate your grief reactions and leave you less able to help others around you. If you or others around you are concerned about your reliance on these substances, seek professional help right away.

Grieve Together

Any or all of these strategies that are useful to you may also be useful for your loved one with autism. They also represent ways that others could help the autistic adult, rather than taking it all upon yourself. There may be ways to make a plan that spreads out some of the responsibility, for example, questions like these may be helpful:

“We both need sleep, so how can we help each other get some?”

“We both like to walk outside, and sometimes we like to walk with others or by ourselves. Would you like to walk alone, with me, or with your aunt today?”

Consider Journaling

Writing down your feelings can help untangle emotions, help you track your grief journey, and give you a much-needed outlet of self-expression.

Monitor Your Physical and Mental Health

In the days and weeks following a significant loss while supporting your loved one with autism, your own health may seem trivial. Remember that while it is not unusual to be physically or mentally affected by loss, it is essential not to ignore symptoms that could indicate illness.

When is it time to seek professional help? While loss is difficult and painful, most people are resilient even in the face of loss. However, a small percentage of people develop more serious reactions that can impair their functioning. If, after several months, you find yourself unable to function in key roles at work, school, or home; or are unable to find pleasure or participate in previously enjoyable activities; or experience sustained feelings of depression or anxiety, get help from a trained grief professional. Seek immediate help or call 911 if you feel you wish to hurt yourself or others.