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Commentary

When the Parents are Gone: Grief, Responsibility, and the Future of Autistic Adults

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Abstract

Taking into account the results and actions performed during the previous COVID-19 pandemic waves, it seems that in the last wave in our Region, the decision-making process that concerned patients, both surgical and those who required intensive or critical cares, have been adapted and changed, based on modifications suffered in care indicators, both in terms of available resources and in the volume of activity demanded by both COVID-19 infected or non infected patients operated on.

This article aims to offer some new perspectives on this issue.

Keywords: *COVID-19 Pandemic; SARS-CoV-2 Infection; Safety Management; Surgery*

One of the most difficult questions facing families of autistic children is rarely discussed openly.

What happens when the parents die?

For many families, a parent is much more than a mother or father. The parent may also be the autistic person's primary caregiver, interpreter, advocate, transportation provider, financial manager, medical historian, behavioral support, and source of emotional security. When that parent dies, the autistic individual does not experience only one loss. The person may suddenly lose a relationship, a routine, a home, a communication partner, a caregiver and the structure that made daily life understandable.

Understanding death

Autistic individuals vary greatly in their ability to understand death. Many autistic people understand death fully and experience grief in ways similar to anyone else. Others—particularly those with significant intellectual, language or cognitive disabilities—may have difficulty understanding death's permanence and irreversibility.

A person may repeatedly ask when the parent is coming home. A nonspeaking individual may search the house, wait near the door or continue expecting the parent to appear. Even when someone cannot intellectually explain death, that does not mean the person is incapable of grief. Research indicates that people with autism and developmental disabilities experience genuine bereavement, although changes in routine, concrete thinking and communication differences can affect how that grief is understood and expressed.

Grief may appear as sadness, anxiety, anger, withdrawal, irritability, increased dependence or major behavioral changes. These reactions can sometimes be incorrectly labeled as "autistic behavior" rather than recognized as expressions of loss. People with intellectual disabilities are also at risk of having their grief underestimated or excluded from traditional mourning and support practices.

Families should therefore prepare autistic individuals for death in a truthful, concrete and developmentally appropriate manner. Euphemisms such as "went to sleep," "passed away" or "went to a better place" may create confusion. Some individuals benefit from visual stories, photographs, calendars, repeated explanations and opportunities to participate in funerals or memorial activities at a level they can tolerate.

The sibling's double burden

The surviving sibling may experience two major events at the same time.

First, the sibling is grieving the death of a parent.

Second, the sibling may suddenly become responsible for the future of an autistic brother or sister.

While other family members are allowed to grieve, the sibling may be expected to locate legal documents, contact government agencies, arrange housing, manage medications, communicate with service providers, handle finances and decide who will provide daily care. The sibling may feel there is no time to emotionally process the death because another vulnerable person immediately needs protection.

This can create resentment, guilt, fear and exhaustion.

The sibling may love the autistic individual deeply while still feeling overwhelmed by the expectation of lifelong responsibility. These two feelings can exist together. Love does not eliminate stress, and reluctance to become a full-time caregiver does not mean the sibling is uncaring.

No brother or sister should discover after a parent's death that the family quietly assumed they would take over everything.

Legal and financial struggles

The death of a parent can expose serious gaps in planning. Depending on the autistic person's needs and legal status, the surviving family may have to address:

- Guardianship or alternatives such as supported decision-making.
- Appointment of a new Social Security representative payee.
- Supplemental Security Income and Medicaid eligibility.
- Social Security survivor benefits.
- Special-needs trusts, wills, life-insurance beneficiaries and inherited assets.
- Housing, residential placement and home- and community-based services.
- Medical consent and access to health information.
- Transportation, employment support and daily supervision.

Guardianship does not automatically transfer from a deceased parent to a sibling. Court involvement may be necessary, and guardianship is not the only option. Supported decision-making allows some people with disabilities to retain decision-making rights while receiving

assistance from trusted individuals. The appropriate structure depends on the person's actual abilities and needs, not simply the autism diagnosis.

Social Security also selects the person or organization that will serve as representative payee when an individual cannot manage benefits independently. A parent's death may therefore require a separate process to establish a new payee.

Inheritance can create additional complications. Directly leaving substantial money or property to a person receiving means-tested benefits can affect eligibility unless the estate is structured appropriately. Social Security specifically advises families to consider instruments such as properly established special-needs trusts and ABLE accounts.

Some adults whose disability began before age 22 may also become eligible for Social Security survivor benefits based on a deceased parent's work record. However, these benefits generally require an application and should not be assumed to begin automatically.

Because these rules vary by program and jurisdiction, families should consult a qualified disability or special-needs attorney before a crisis occurs.

The risk of exploitation

After a parent dies, an autistic person may become especially vulnerable. The individual may depend on unfamiliar caregivers, lack the communication ability to report mistreatment or have difficulty recognizing financial or physical exploitation.

This is why a future plan should never rely entirely on one replacement caregiver. A stronger system includes several trusted people, professional oversight, written instructions, financial safeguards and regular checks on the individual's welfare. People with intellectual and developmental disabilities can face heightened risks when they are financially or physically dependent on others and socially isolated.

Planning must begin before the emergency

A responsible transition plan should document more than legal arrangements. It should explain the autistic individual's daily life:

- How the person communicates.
- Medications and medical history.
- Sensory sensitivities.
- Foods, routines and sleeping patterns.
- Behaviors that communicate pain, fear or illness.
- Calming strategies.
- Important relationships.
- Religious or cultural preferences.
- Housing and support needs.
- What creates happiness, comfort and purpose.

Whenever possible, transitions should begin while the parents are still alive. Future caregivers should spend time with the autistic individual. Overnight stays, respite arrangements, financial-management practice and gradual changes in responsibility can reduce the shock of a sudden transition.

The autistic person should also be included in planning to the greatest extent possible. A person may not be able to understand every legal detail, but can still express preferences about where to live, who provides support, which routines matter and what makes life feel safe.

The central message

Planning for a parent's death is not an act of pessimism. It is an act of protection.

Parents must protect the autistic individual from abrupt abandonment, service disruption and exploitation. They must also protect the siblings from inheriting an unspoken and unmanageable obligation.

The goal should not be to force one sibling to replace the parents. The goal should be to create a sustainable circle of support in which legal authority, financial responsibility, caregiving and emotional support are shared.

Every autistic individual deserves continuity, dignity and security after a parent dies. Every sibling deserves the opportunity to remain a loving brother or sister without automatically being required to surrender their own future.

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