

While death is a part of life, experiencing and accepting the death of a loved one often requires support and resources to help during this difficult time. We have compiled resources available for people with Intellectual/Developmental Disabilities, their siblings and parents, as well as family members and caregivers.

This Fact Sheet provides a broad array of general, introductory information on the subject. Families should consult with their primary doctor, health clinic or counselor to determine what works best for your loved one.

Grief Resources for People with I/DD

The Boggs Center on Developmental Disabilities, New Jersey's UCED (University Center for Excellence in Disability) at Rutgers' Robert Wood Johnson Medical School, has put together significant resources on grief and loss specifically tailored for people with intellectual and developmental disabilities. Resources available in both English and Spanish. Resources about Grief and Loss (rutgers.edu)

Children's Hospital Los Angeles & National Center for School Crisis and Bereavement: a one-page publication on Grief Support for Children with Intellectual and Developmental Disabilities that includes guidance for children diagnosed with Autism Spectrum Disorder. Grief-Support-Intellectual-and-neurodevelopmental-disabilities 1Page.pdf (grievingstudents.org)



The Dougy Center (National Grief Center for Children & Families) has a podcast on Grief and Developmental Disabilities and includes a list of resources at this link: <u>Grief & Developmental Disabilities (dougy.org)</u>

E-book "Supporting People with Disabilities Coping with Loss and Grief" includes simple language and pictures in a social story/PECS style format. grief and loss_bookletV2.indd (anglicarewa.org.au)

Grief resources for Children and Siblings

"Grief is felt by a large percentage of children: An estimated 1 in 14 children in the U.S. will experience the death of a parent or sibling before they reach the age of 18. Over 5.2 million youth will become bereaved, and that number more than doubles by age 25 to 13.2 million. All too often, children are forgotten grievers. Some feel they are not old enough to feel loss. But if a person is old enough to love, then that person is also old enough to mourn and to grieve." -Buddy's Place website: Childhood Bereavement Program | Pillars Community Health

Pillars Community Health offers Buddy's Place for childhood grief. Online resources available. Located in western suburbs of Chicago. **Childhood Bereavement Program | Pillars Community Health**

The SIBS Network, a group for Adult Siblings of individuals with IDD, provides a Grief Adult Sibling blog on their website: <u>Sibling Grief | S.I.B.S Network</u> (sibsnetwork.org)



Grief resources for Children and Siblings

The Sibling Grief and Bereavement Toolkit for Children and Teens was created to address the needs and concerns of children and teens who have experienced the death of a sibling with medical complexities. From the Pediatric Palliative Care Coalition (PPCC): Sibling Grief and Bereavement (ppcc-pa.org)

The Stepping Stones Bereavement Camp provides a safe place for campers to explore their grief emotions, balanced with plenty of fun. Stepping Stones camp is open to any child who has lost a loved one, not only those who were served by BJC Hospice. Stepping Stones Camp Grief Support for Children BJC Hospice

General Resources

From Healthychildren.org, an article on **Childhood Grief: When to Seek Additional Help: Childhood Grief: When to Seek Additional Help - HealthyChildren.org**

The National Alliance for Children's Grief is a national organization of professionals dedicated to supporting children and the networks and communities that surround them by connecting to resources and local support if you are supporting a child who is grieving. NACG



Grief Resources for Parents and Loved Ones

Resource guide: When a Child Dies: Planning Acts of Love and Legacy from the Funeral Service Foundation offers downloadable guides in both English When a Child Dies Planning Acts of Love and Legacy (adobe.com) and Spanish Cuando un Hijo Muere Planificando Actos de Legado y Amor (adobe.com).

Willow House: The mission of Willow House is to provide grief support and education for youth, families, schools and other communities grieving the death of a parent, sibling, or child. Our free services are where hope lives and healing begins, providing space for people to grieve in companionship with others who share a similar loss. Our vision is that no child, teen or parent grieves alone. Willow House

Faith-Based

Faith-based initiatives and programs may be available from your own faith community to support the grieving process. Consider seeking out any support available from your local mosque, synagogue, church, or other house of worship. We've provided some examples of faith initiatives below.

GriefShare: GriefShare's parent ministry is a Church Initiative. Church Initiative is a nondenominational, nonprofit ministry serving more than 20,000 churches worldwide. From its headquarters in Wake Forest, North Carolina, the ministry creates and publishes video-based curricula to help churches minister to people experiencing life crises.

<u>GriefShare - Grief Recovery Support Groups - GriefShare</u>



Grief Resources for Parents and Loved Ones

My Jewish Learning website: Finding Support at Each Stage of Grief What Jewish mourners can expect at each stage of the bereavement process. <u>Finding Support at Each Stage of Grief | My Jewish Learning</u>

042025

This is a resource that may be covered by your health plan; there are other hospice organizations that provide continuing and ongoing support.

JourneyCare: At JourneyCare, we understand that it can be helpful to talk about the loss of a loved one and the adjustments that follow after your loss. While there are no simple answers, our experienced, licensed counselors can help you discover healthy ways of dealing with your feelings and provide support after the death of your loved one. **Grief Support | JourneyCare**