Grief
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Ways to Help Support Someone with Down Syndrome who is Grieving:

1. **Acknowledge and normalize the person’s feelings.**
   It’s important for someone to know that their feelings, whatever they are, are normal and they are not alone. It can help just to say “you are sad” when someone is crying and remind them “I’m sad, too. We are all sad because Mom died.” Remember that feelings of anger are also a normal part of the grief process. It’s important not to say or do things that convey the message “you should be over this by now.” Remember that people with Down syndrome often go through a longer grief process and take more time to process and grieve a loss than people in the general population and that everyone’s grief process is different.

2. **Keep familiar routines.**
   The aftermath of a significant loss is not a good time to make significant changes in a person’s living situation, school, or day program. Unfortunately, due to changes and events surrounding the loss, these significant changes may be necessary. Do whatever you can to keep the person in a familiar routine with familiar people. This may include planning ahead for big changes you know are going to happen as a result of the loss, such as needing to move out of the home of an elderly parent when they die, and trying to make these changes happen prior to the death.

3. **Use the person’s support networks.**
   It’s important for everyone involved in the person’s life, including staff at school and the day program, to know that the person has experienced a loss or that a loss is imminent. Staff and peers at a day program or group home are often a very significant source of support for people with Down syndrome and should not be discounted. Also, think about other important sources of support in a person’s life, such as friends and religious leaders at church or synagogue or even staff at a monthly social club or summer camp they’ve attended for many years. Everyone has a role to play in supporting the person as they grieve a loss. Sometimes people feel more comfortable sharing their feelings with people outside the family who were not directly affected by the loss.

4. **Realize your own limitations.**
   You may be dealing with a situation in which the loss of someone close to the person with Down syndrome was also a significant loss for you. You may be going through your own grief process and not be in the best place to support your family member with Down syndrome. Don’t be afraid to realize your own limitations and ask others for help. It’s important for you to go through your own grief process as well. Remember that you have to take care of yourself before you can assist others effectively.

5. **Consider professional help.**
Some people with Down syndrome do benefit from counseling to help them process feelings of grief and loss. Some are very verbal and able to participate in “talk therapy” to talk through their feelings. Those who have fewer verbal skills can still benefit from expressive therapies, such as art therapy, play therapy, and movement (dance) therapy. Family members may need professional help to work through their own feelings in order to support the person with Down syndrome in the most helpful way.

Resources for Parents and Caregivers

Helping People with Developmental Disabilities Mourn, Practical Rituals for Caregivers by Marc Markell
This is a particularly helpful book for caregivers. It contains suggestions for rituals that a person with Down syndrome can do with a caregiver to remember the person who has died. The rituals described can be used with people who do not communicate verbally.

How to Break Bad News to People with Intellectual Disabilities: A Guide for Carers and Professionals by Irene Tuffrey-Wijne
This book covers how to break all sorts of bad news to people with intellectual disabilities and can be applicable to a variety of situations. It includes suggestions for people with limited verbal skills and describes how to use a person’s support networks in the process of helping them cope.

Supporting People with Intellectual Disabilities Experiencing Loss and Bereavement: Theory and Compassionate Practice by Sue Read (Editor)
This book is aimed at professionals but could be useful for family members or other caregivers. It focuses on practical suggestions that are supported by evidence-based research. It includes chapters from different contributors with a range of personal, academic, and professional experience.

Books about Loss to Read Together

I Miss You: A First Look at Death by Pat Thomas
This is a book with simple explanations about death and common rituals around death. The pictures describe the process but are not overwhelming or frightening. I often use this book in counseling with people who are experiencing grief and loss.

Lifetimes: The Beautiful Way to Explain Death to Children by Bryan Mellonie and Robert Ingpen
This is a “classic” book that explains death in a simple way. It presents death as being part of life and can be tailored to people of different belief systems.

The Fall of Freddie the Leaf: A Story about Life for All Ages by Leo Buscaglia
This is another “classic” book about the “circle of life.” It is about how Freddie and other leaves change with the seasons and the passage of winter. It can also be used with people with different belief systems.
I’ll Always Love You by Hans Wilhelm
This book is about a boy that loses a dog who has grown old and died. It can be used as a way to talk about other types of loss or can be useful when a pet dies.

The Tenth Good Thing About Barney by Judith Viorst
This is another book that describes the loss of a pet and can be a springboard for discussing other types of losses.

Other Resources

Books Beyond Words (booksbeyondwords.co.uk)
This is a series of books that explore different topics entirely through pictures. These resources are helpful for people with intellectual disabilities and communication difficulties who may find it easier to understand pictures rather than words. Three books in the series are specifically about death, including When Mum Died, When Dad Died, and When Somebody Dies. They also have a YouTube channel as well as other resources on their website. Some of the books are available on Amazon.

Other Helpful Online Resources

Tips and Resources for Helping People with Intellectual Disabilities Cope with Loss

Loss and Grief Within Intellectual Disability by Owen Doody

Bereavement and Intellectual Disabilities: Suggestions for Support by John McEvoy

Managing Grief Better: People with Intellectual Disabilities by Professor Sheila Hollins
http://www.intellectualdisability.info/mental-health/articles/managing-grief-better-people-with-intellectual-disabilities