

Remembering someone you love who has died and healing the hurt.

Anne Masters, MA, FAAIDD Pastoral Ministry With Persons With Disabilities for the Archdiocese of Newark



www.rcan.org/disabilities

When someone you love suffers a loss, it hurts to seem them struggle. When that person has a hard time communicating how they feel or processing complicated emotions, it makes it more difficult. Individuals with intellectual and developmental disabilities (IDD) experience loss and grieve for lost loved ones, just like everyone does. Like everyone else, each person with IDD grieves in their own way, though there can be some general patterns that are typical for individuals with IDD. For example, it is not unusual for their grieving process to be as long as ten years. However, this could be because they are often excluded from the typical and ordinary rituals of healing. The hardest part can be finding the ways to understand and express what they are feeling.

All loss is a death of some kind. Moving to a new home is the death of life in your current home with all the security and familiarity that goes with it. Even a positive experience like starting a new job means leaving something behind. Change involves replacing the comfort of known routines with the unknown.

All people grieve, but each person grieves in his or her own way, and each person will grieve differently for different losses. Also, the experience of grief is impacted by more abstract elements of the loss. For example, when a beloved grandparent dies, the impact of their relationship has an important impact on the grieving. If they felt really good about themselves when with the grandparent, they have not only lost a beloved grandparent, but also a cheerleader and supporter. This is particularly difficult for someone who often encounters judgment rather than encouragement. The sense of loss can be compounded if they had regularly scheduled time and/or regular activities together.

It is important to provide time to acknowledge the loss, and in the case of death, to provide time and space for remembering the person or beloved pet. Rituals are very healing, so include them in these, or at least provide the opportunity and invitation. But do not force it, always respect the person's preference and understand that it will take time.

I hope the following pages are helpful. Put the name of the lost loved one in place of ..... and adapt for different needs, for the death of a pet or moving, etc. As Catholics we are a sacramental people. So even if there is not a Memorial Mass, as in the case of a pet, you should still plan some ritual of remembrance. Also, with technology today, you can create tributes in many different mediums, photo, video, etc., or in whatever format that is meaningful for the person.



Remembering someone you love who has died and healing the hurt.

I Love You ..... and I Miss You.

## Love,



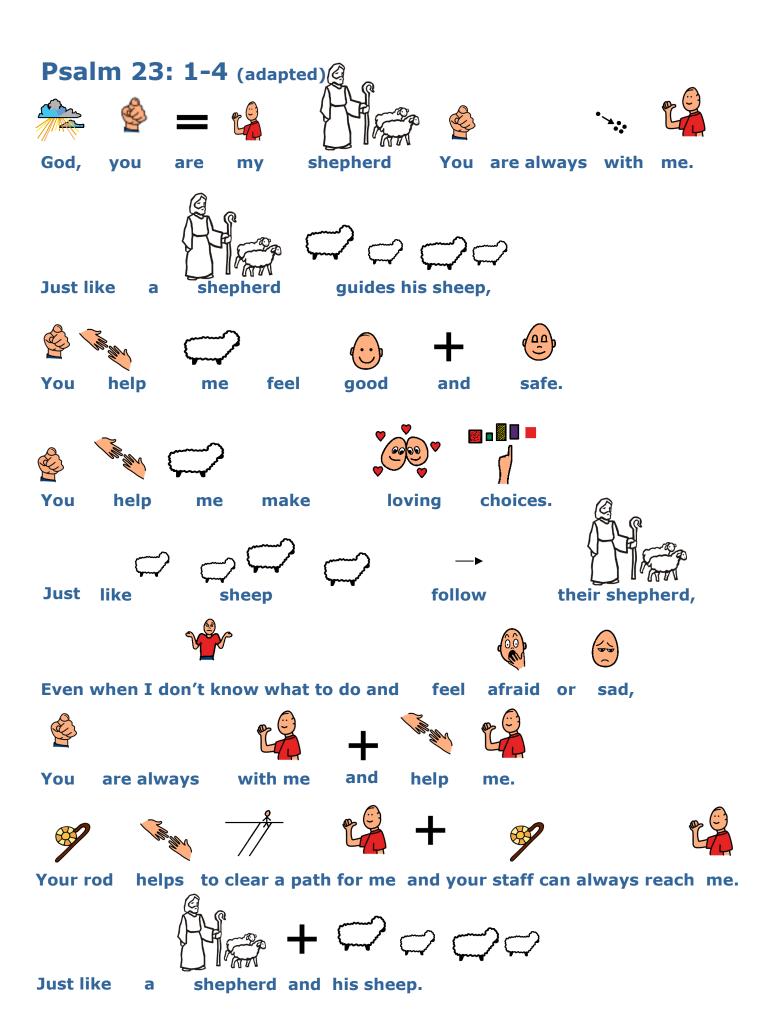
When we are happy or sad, we can pray to Jesus and ask him to help us. He knows what it is like to feel afraid, sad and happy.

Jesus was afraid and sad before he died. He prayed to God. You can pray to God too.

The prayer on the next page is from Psalm 23. Jesus prayed the psalms all his life. This helped him feel God with him and to feel better.

It can help you feel better too, even though you will still miss ..... Maybe you want someone to read it with you.

You can still talk with ..... too. Remember ..... 's love for you and the things you did together, the happy and the sad things. It's not like being together and talking face to face. But we believe that when the people we love die they are in heaven with God, and also still with us in a special way.

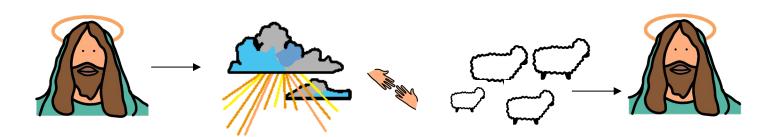


### We call Jesus the Good Shepherd

Jesus said,

"But I am the Good Shepherd. God knows me and I know God. And in the same way, I know my sheep and my sheep know me. And I am willing to die for my sheep. John 10:14





| Fun things I remember doing with: |  |  |
|-----------------------------------|--|--|
|                                   |  |  |
|                                   |  |  |
|                                   |  |  |
|                                   |  |  |
|                                   |  |  |
|                                   |  |  |
|                                   |  |  |
| or Dicturgs of Eup Timos with     |  |  |

or Pictures of Fun Times with ......

## Use your crayons to show how you feel right now about . . . . .



or Pictures of Special Times with ......

# My favorite part of the Memorial Mass was:

| <br> |
|------|
|      |
|      |
|      |
| <br> |
| <br> |

# I think ..... would have liked these at the Memorial Mass:

## I think ..... 's favorite song of the Memorial Mass would have been:

My favorite was:

| When I am sad and missing         |  |  |  |  |
|-----------------------------------|--|--|--|--|
| 1. Give a hug to                  |  |  |  |  |
| 2.Play with my [dog, cat, friend] |  |  |  |  |
| 3. Play Ball.                     |  |  |  |  |
| 4. Pray.                          |  |  |  |  |
| 5. Read.                          |  |  |  |  |
| 6                                 |  |  |  |  |
| 7                                 |  |  |  |  |
| 8                                 |  |  |  |  |
| 9                                 |  |  |  |  |
| 10                                |  |  |  |  |
|                                   |  |  |  |  |



| <br> |
|------|
|      |
|      |
|      |

# Or use your crayons to draw what you like when you think about this.

More favorite pictures of . . . . .



# Jesus is always with me.

#### <u>Tips to Help Heal People with I/D Disabilities in Grief through Certain Situations</u> Adapted from Robert L. Morasky, PhD

| Sample Situation  | How You Can Help   |
|---|--|
| <ol> <li>The individual did not attend the wake or<br/>funeral or did not comprehend the meaning<br/>of the event(s)</li> </ol>   | Help the person conduct a goodbye ritual<br>(personal funeral ceremony) that would be<br>concrete and personally meaningful  |
| 2. The individual may not have conceptualized<br>death or may have a simplified notion of it.<br>Given his/her level of understanding s/he may<br>be confused if people seem hesitant to talk<br>about it | Describe death concretely. Avoid euphemisms<br>like "passed on," "went to sleep," "no longer<br>with us." Do not avoid talking about the what's<br>and the how's to a reasonable degree  |
| 3. The individual may be feeling emotional pain<br>that is unlike anything s/he has ever experienced<br>and s/he may think it will never go away  | Assure the person that s/he will not always feel<br>the pain s/he currently is experiencing. Be a<br>reflective <b>listener</b> to verbal and non-verbal<br>communication & avoid saying "stupid things":<br>"I know how you feel" "You'll just have to be<br>grown up about this" "What you need to do<br>is" "You'd feel worse if" |
| 4. The individual may believe that other people s/he knows are going to die also  | Explain that others are not going to die just<br>because one did. Point out that people continue<br>to be around. Use an example if available (i.e.<br>"It's like when one of the fish in the tank dies,<br>the others keep living.")  |
| 5. People may not know what to ask or how to get information about what has happened. Even the idea of getting information may not occur to them  | Help them to ask questions: "Do you<br>want to know about?" and encourage them to<br>do so. Notice when they are trying to get<br>information from you   |
| 6. In their grief, people may ask questions repeatedly.<br>The same question may be asked often in a short<br>period of time  | Keep answering the questions as it is the feelings of grief, not a lack of information, that is causing the repetition.  |
| 7. The individual may be searching for the missing person. The search could be actual (looking for the person in a variety of places) or virtual (talking about the person, asking for the person)        | Support them while they search but again<br>explain the concept of death and help the<br>person ritualize the goodbye. Pay<br>attention to anniversaries   |

| 8. The person says s/he saw the deceased person.<br>This may have occurred in a dream or in his/her<br>imagination, but the person was seen and was real<br>to her/him | Listen to him/her. Process with him/her. Do not contradict or correct  |
|--|--|
| 9. Grief may show up in behavioral communications  | Reflect back to the person that her/his actions<br>are a way of expressing the hurt and pain of<br>grief: "You threw your clothes all over your<br>room and broke those things because you're<br>missing and don't know what to do<br>with all the anger and hurt and loneliness. I<br>know you're hurting inside (touching your heart<br>to show hurt there)" |
| 10. The feelings of grief cause fear   | Listen to the fears. Don't contradict them or deny them. Just acknowledge them   |
| 11. The feelings of grief cause anxiety  | Use relaxation techniques  |
| 12. A new experience renews the person's feelings of missing someone   | Know that grief comes and goes and that there<br>are numerous triggers for it. Respond to each<br>cycle of grief in the same way you did the<br>previous cycle. Each one will need healing as<br>much as the ones before it.   |
| 13. There is an increase in ritualized behavior  | Recognize that rituals provide security. Be alert<br>to the possibility that a ritual could arise out of<br>any activity (taking a coffee break and talking,<br>looking at a picture book or magazine, etc.).<br>Help the person maintain and practice the<br>rituals they select  |
| 14. Anniversary, holiday, birthday, etc.   | Important "grief-triggering days" need to be<br>anticipated and supported. Help the person<br>carry out a memorial tribute/ritual that<br>acknowledges the significance of the day   |
| 15. The individual may want to remember the deceased in a special way  | Give him/her choices about how to memorialize<br>the person and how to express his/her feelings.<br>The choices may be expressed in physical<br>behavior rather than words (pictures, dance,<br>volunteering). Expect that the senses of smell<br>and taste may influence the objects and/or<br>activities used in memorialization                             |

### Helping People with Intellectual/Developmental Disabilities Navigate Loss

- Use picture cards that concretely depict feelings, emotions, etc. about \_\_\_\_\_\_
- Engage is drawing activities to convey events, feelings, emotions, etc. about \_\_\_\_\_\_
- Create together a memory box of items that remind him/her of \_\_\_\_\_\_ (don't forget items with smells—lotions, soaps, spices, coffee)
- Make a photo album or scrapbook about \_\_\_\_\_\_ or times with \_\_\_\_\_\_
- Take a trip together to the graveside or previous home or former workplace or place of accident or \_\_\_\_\_\_
- Have the person help with taking care of the ill loved one or with funeral preparations or to have a role in memorial or goodbye celebration(s)
- Do something together that the person used to do with the now gone person or in honor of the now gone person
- View videos or newspaper/magazine articles that show people being honored after death or show people moving away, starting new jobs, etc. to make it more concrete
- Designate a "space" to keep a memorial item(s)—this may be used in conjunction with a calendar that marks significant dates
- Use colors to symbolize feelings
- Help the person illustrate (pictures/drawings/etc.) what qualities they miss in the person/place/thing he or she has lost
- Create a "remember journal" that can be added to over time
- Brainstorm ways to celebrate the person's life or the time enjoyed with him/her at a significant place(s)
- Write letters to the person or thing and bury them/burn them/etc.
- Set a place at the table, set a photo visibly, name the person in the grace or in memory before the shared meal for a holiday remembrance
- Have a ceremony, show photos, tell stories, say what you'll miss and say good bye (person, place or pet)
- Take an hour each month, on the anniversary day of a loss to handle objects, look at photos, or to write about the loss experience
- Use videotapes and recordings to capture the person or place before death, move, etc. t
- Make an anonymous donation in honor of your loss
- Plant a tree or flowers to honor the occasion of a loss

- Plan a Ritual:
  - Because of the nature of their disability, people with developmental disabilities generally benefit from more concrete experiences such as those rituals allow
  - To benefit from rituals, they tend to need fairly explicit directions
  - o To benefit from rituals, they benefit most from simplified activities
  - Rituals that are too abstract or open-ended may be confusing, frustrating and of little value to them
  - o It is important to maintain an element of symbolism
  - Rituals can also be used when PWIDD experience other significant losses in life which may include moving, change of a job, staff leaving, etc.
- To make Rituals impactful design them around (Adapted from <u>Helping People with</u> <u>Developmental Disabilities Mourn: Practical Rituals for Caregivers</u> by Marc A. Markell,

Ph.D.

- o Use of Photos
- o Use of Storytelling
- o Use of Memory Objects
- o Use of a Plant or Tree
- o Use of Drawing
- o Use of Music
- o Use of Writing
- o Use of Stones
- o Use of Photos of the Death Process
- o Use of Space & Location
- o Use of daily objects
- o Use of Daily Memory
- Use of Packing up Belongings
- o Use of Pendant or Ornament
- o Use of a Heart Picture
- o Use of Light
- Use of Burying an Object
- o Use of Memory Gift
- o Use of Play-Doh or Modeling Clay
- o Use of Food

#### Reference List

Bower, Crystal, Jeanne Dicke, and Stacey Stoppenhagen. *Remembering: Grief and Loss Scrapbook*. Bethesda Lutheran Homes and Services, Inc. Watertown, WI. <u>http://bethesdalutherancommunities.org/services/faith-supports/faith-resources/</u> accessed January 3, 2008 (original title *Grief and Loss Workbook*.)

Gilbride, Margaret T., JD, CT. "Loss and Grief in the Lives of Individuals with Intellectual and Developmental Disabilities." Workshop presented at Academy 360, March 21, 2017.

Kravitz, Murray J. "Helping Children Cope with Grief and Loss: A Special Education Perspective." Channels, 1997. pp 35-37.

Rivas, Marsha. "When Persons with Intellectual Disabilities Grieve." <u>http://www.ncpd.org/sites/default/files/When%20persons%20with%20intellectual%20disabilities%20grieve%200410\_0.pdf</u> accessed May 10, 2010.

Tilton, Adelle Vancil. "Johnathan Lost His Dad." What You Need To Know About Autism/Pervasive Developmental Disorders. <u>http://autism.about.com/library/weekly/aa040102a.htm</u> accessed June 3, 2002.

Scripture:

Brusselmans, Christiane, Sr. Paule Freeburg, C.C., Rev. Edward Matthews, Christopher Walker. *Sunday Weekly Leader Guide. Year B.* Treehaus Communications, 2002. p. 51

Images: Christian Clik Art, Broderbund.

PCS, *Boardmaker Plus* by DynaVox Mayer-Johnson, 2100 Wharton Street, Pittsburgh, PA 15203, Phone: 1 (800) 588-4548, Fax: 1 (866) 585-6260, Email: mayer-johnson.usa@mayer-johnson.com, Web site: <u>www.mayer-johnson.com</u>.

The Picture Communication Symbols ©1981-2013 by DynaVox Mayer-Johnson LLC. All Rights Reserved Worldwide. Used with permission.

Anne Masters, MA, FAAIDD Anne.Masters@rcan.org

Office for Pastoral Ministry with Persons with Disabilities Archdiocese of Newark www.rcan.org/disabilities

