

Grief and Loss

What is grief, what does it look like?

Grief is an emotion we feel when we experience loss. It can feel very heavy, and sometimes it can feel like it will never go away. We can feel grief for many kinds of losses, including:

- Someone we know or love dying
- Someone we know or love changing or getting sick
- Someone we know or love leaving our life (moving away, a support person getting a new job, etc)
- Our every day life changing (job loss, moving, etc)
- Our health declining / aging

People living with intellectual and developmental disabilities (IDD) feel grief when they experience loss, like any other person does.

When people living with IDD feel grief, it can look very typical (crying, sadness, anger, loneliness). **Grief can also look like**: apathy, agitation, confusion, fear, sleep disruptions or changes, and many other individual reactions.



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"How to" support grief and Loss

When supporting someone living with IDD through grief, we should:

- Explain the death or loss as concretely as possible (e.g., not "Sue is an angel now", instead "Sue died, she was sick and her body stopped working. We won't see Sue again.")
- Allow space for the grief we cannot fix grief, and we shouldn't try to (easier said than done!). What is most helpful is to create safe space to feel, share, and express the grief.
- Use visuals and other communication supports if needed
- Be supportive about any **secondary losses** the person may be experiencing:
 - Loss of financial support, material support
 - Loss of routine or activities they would do together
 - Loss of emotional support, friendship

Allowing space for the grief can look like: sitting in silence together, listening, hugs or comforting touch, sensory support, saying things like: "Sometimes I don't know what to say, but I am here if you want to talk or spend time together."



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Rituals of Mourning, Processing Grief

Rituals of mourning can help people process grief. Here are some examples of what those rituals could look like:

- Make a remembrance altar with pictures and/or items that are meaningful
- Plant a garden, plant, or tree in remembrance
- Write letters to the person who has died
- Write or draw a story about the loss and/or the person
- Write in a journal, create a photo journal, or create any type of art about the person and/or loss
- Sing or dance to songs the person liked, or that remind you of them
- Do the activities that used to be done with the person who died/left/is sick, and share stories or memories

Grief doesn't have a time limit. Grief is something we carry with us through our lives, and learn to live along side it.

Sometimes it feels heavier than other times, and certain dates or times of the year can be hard - like birthdays, anniversaries, or holidays.



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Making death and loss concrete

Examples of how to make loss concrete:

- Death "Nana died today. Her lungs were sick and her body stopped working. We won't see her again."
- Support person leaving "Sarah has a new job. Sarah won't be coming to your house anymore. You won't go to the library with her anymore."
- Dementia "Grampie's brain is sick. The sickness in Grampie's brain makes him forget your name and who you are. He can't take you out for lunch any more, but you can go to his house for lunch."

People living with IDD have a right to know what's going on their lives. It's important to be honest, clear, and concrete when explaining death and loss.

When making death and loss concrete it's helpful to think about what the loss looks like in the person's life. What activities, types of conversations, locations, items, and supports (financial, emotional, advocacy, etc) will be missing from their life as a result of this loss?