



Grief and Loss

*Explaining death to an individual
who has an intellectual disability*



Prince Edward Island
Association for
Community Living
Diversity includes.

It is imperative that all people have access to appropriate supports, where required and where requested, for dealing with grief and loss. People with intellectual disabilities may require additional supports that are sensitive and cater to their specific needs. The provision of appropriate support needs to consider the social, cognitive, and communication factors that may have an impact on how a person with an intellectual disability experiences and expresses grief and loss.

We hope that *“Grief and Loss: Explaining death to an individual who has an intellectual disability”* will provide people with intellectual disabilities and their supports an overview and an understanding of the grief process. This grief kit highlights the range of needs people with intellectual disabilities may have while grieving, while providing effective strategies for supporting them as they process grief and loss.



Thanks to Jill Stewart and her team at *Your Life Design Inc.* for working with us in creating a grief and loss booklet and pulling together additional resources for us.

For more information or support, please reach out to Prince Edward Island Association for Community Living at www.peiacl.org



YOUR
LIFE
DESIGN INC.

Grief And Loss Booklet

FOR CAREGIVERS OF GRIEVERS WITH
INTELLECTUAL DISABILITIES

GRIEF AND LOSS BOOKLET

FOR CAREGIVERS OF GRIEVERS WITH
INTELLECTUAL DISABILITIES

Foreward

The grieving process due to loss, separation, or death can be an emotionally painful time, especially in the life of a person with intellectual disabilities.

It can be so overwhelming to the griever creating confusion and difficult transitions.

This grief and loss booklet for caregivers provides guidance, practical activities, encouragement, and hope for those grieverers with intellectual disabilities.

Jill Stewart
Your Life Design Inc.



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WHEN DEALING WITH LOSS, SEPARATION OR DEATH

1 Be honest, inclusive and involved

Caregivers find themselves unable to be honest or to include a person with intellectual disabilities. The griever should be offered the choice as to whether they wish to attend a funeral or memorial service. If the griever is unable to choose due to cognitive limitations, it is normally advisable to involve the griever as much as possible in all rituals being arranged.

- ✓ Remember to provide accurate and honest information about the loss. (For example, do not say, “we lost them”)
- ✓ Remember to enable maximum involvement in social, cultural and/or spiritual activities surrounding the loss.

2 Listen and be there

Be available to listen and provide support. This must occur as soon after the loss, and most importantly, in the weeks and months following as understanding the permanence of loss comes slowly for some.

- ✓ Remember that people with intellectual disabilities respond to bereavement and loss in essentially the same way as anyone else.
- ✓ Remember to provide support to process the grief.
- ✓ Remember to maximize opportunities for the expression of grief and condolences.
- ✓ Remember to consider counselling or additional support to help someone process their grief.

WHEN DEALING WITH LOSS, SEPARATION OR DEATH

3 Seek out nonverbal rituals

Picture books may be helpful when explaining what happens after a loss.

- ✓ Remember to make a book or a memory box about the loss.

4 Photos and memories

In the early stages of bereavement, it is common to avoid pictures and possessions, but as time passes, such mementoes may come to be treasured. People with intellectual disabilities may need help choosing some mementoes, and these should be offered at a later date when their emotional pain has subsided.

- ✓ Remember to promote conversations about the loss - to honour a lost life, to remember the love that was shared, and to think about what the person who has died might want for the griever.
- ✓ Remember to give the griever something that belonged to the person who has died.
- ✓ Remember to visit places they used to go together.
- ✓ Remember to talk about how much the person who is gone would be happy about a present activity.
- ✓ Remember that pets are an important part of peoples' lives and that similar conversations, etc. should occur.

WHEN DEALING WITH LOSS, SEPARATION OR DEATH

5 Minimize change

Minimize changes in routine, accommodations, or caregivers at the time of grief whenever possible. A suggestion is all major changes should not occur for at least one year, if possible.

- ✓ Remember to keep connections with key supportive relationships.
- ✓ Remember to provide reassurance - that there is no blame - on the ways things will be different.

6 Avoid assessment

If it is a caregiver that has died, situations arise to assess the person with the disability to “fit” them into the replacement service or supports. However, this is likely the worse time to assess a griever as their behaviour and skills may have regressed due to the loss.

- ✓ Remember that the effects of bereavement may be prolonged with people with intellectual disabilities experiencing more anxiety, depression, irritability, and other signs of distress.
- ✓ Remember that while grief may be obvious such as sadness, crying, or depression, it might also express itself through behaviors such as irritability, sleep problems, anxiety, or expressions of fear.

WHEN DEALING WITH LOSS, SEPARATION OR DEATH

7 Assist in searching behaviour

By revisiting the cemetery, caregivers can assist with appropriate searching behaviour to support grief recovery. If a person is found wandering, they may be trying to find their lost home and family.

- ✓ Remember to provide opportunities for the griever to make connections to the past, present and future by looking at pictures and sharing memories.

8 Support the observance of anniversaries

Anniversaries should be formally observed.

- ✓ Remember to include the griever in deciding how an anniversary may be observed.
- ✓ Remember to not judge how someone is grieving or wants to remember their loss.

RESOURCES

CLICK THE TITLES TO OPEN

O. Doody 2014

[**"Loss and grief within intellectual disabilities" in Frontline 95**](#)

Funeral Guide 2021

[**Supporting someone with an intellectual disability through grief**](#)

Hrepsime Gulbenkoglou. 2007

[**Supporting People with Disabilities Coping with Grief and Loss: An easy-to-read booklet**](#)

Vanderbilt University Medical Center 2021

[**Coping With Loss**](#)

Sudden 2021

[**Supporting bereaved people with learning disabilities**](#)

RESOURCES

WEBSITES

www.theifod.com/the-give-skill/

www.virtualhospice.ca

www.intellectualdisability.info/mental-health/articles/managing-grief-better-people-with-intellectual-disabilities

www.aging-and-disability.org/en/grieving

www.sesamestreetincommunities.org/topics/grief

www.sudden.org/tools/supporting-bereaved-people-with-learning-disabilities/

YOUTUBE VIDEOS

Sesame Street: [Coping with big feelings](#)

Living with loss for the developmentally disabled [part 1](#) and [part 2](#)

Bill Gaventa, [“Coping with Grief in the lives of people with intellectual disabilities and/or Autism”](#)



RESOURCES



CALMING MUSIC

[Weightless](#)

BOOKS

A Hug From Heaven, Anna Whiston-Donaldson (for children) and on [YouTube](#)

Books Beyond Words. These are picture books (for children) from www.booksbeyondwords.co.uk

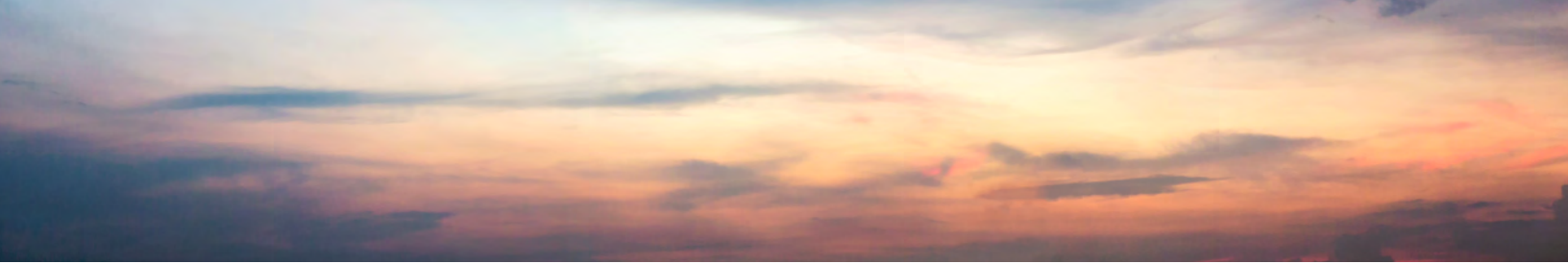
When Dad Dies, Sheila Hollis, Lester Sireling

When Somebody Dies, Sheila Hollis, Sandra Dowling, Noelle Blackman

HELPING PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES PROCESS GRIEF

Professionals in the field of grief and loss suggest direct support professionals become familiar with the ways grief and loss impact people with intellectual and developmental disabilities (IDD). The accumulation of losses over a lifespan can cause serious health concerns if unacknowledged/unsupported. The ideas below are stated in terms of helping individuals process the death of a person they valued but can be adapted to assist in processing any significant experience of loss or change. What is critical is that people have their loss and accompanying feelings acknowledged and be provided opportunities to experience the feelings and move, at their own pace, to their “new normal.”

- Use pictures (magazines/computer searches) to allow a person to concretely depict feelings, emotions, etc. about the deceased
- Engage in drawing activities to convey events, feelings, emotions, etc. about the deceased
- Create together a memory box of items that remind the individual of the deceased (don't forget items with smells—lotions, soaps, spices, coffee)
- Make a photo album or scrapbook about the deceased or times spent with the deceased
- Take a trip together to the graveside or previous home or former workplace or place of significance shared with the deceased
- Have the individual help plan the memorial or have a role in the memorial or goodbye celebration(s)
- Do something together that the person used to do with the deceased or do something that is in honor or in tribute of the deceased
- Use YouTube or TV shows/movies that portray people grieving to help illustrate and normalize the experience and its feelings
- Designate a “space” to keep a memorial item(s)—this may be used in conjunction with a calendar that marks significant dates
- Use pictures/photos to tell /share stories about the deceased
- Use colors to symbolize feelings
- Help the person illustrate (pictures/drawings/etc.) what they miss about the person

- 
- Create a “remember journal” that can be added to over time
 - Brainstorm ways to celebrate the deceased person’s life or the time enjoyed with him/her at a significant place(s) using an object of meaning and/or symbolism
 - Write letters to the deceased and bury them/burn them/etc.
 - Set a place at the table, set a photo visibly in that place, name the person in a “memory share” before the meal for a memorial and/or a holiday remembrance
 - Have a ceremony, show photos, tell stories, share what you’ll miss about the deceased and say good bye
 - Take an hour each month, on the anniversary day of a death to handle objects, look at photos, or to write about the loss experience
 - Plant a tree or flowers to honor the deceased or the occasion of a loss
 - <https://www.pinterest.ca/kmatitich/grief-activities/> for over 300 activities from which to choose

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RESPONDING TO GRIEF REACTIONS

OF PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

ADAPTED FROM ROBERT L. MORASKY, PHD

For many reasons, people with intellectual and developmental disabilities (IDD) are often not included in the usual conversations, cultural rituals, and other means of personal and/or communal acknowledgement of loss and grief. As a result of not being included, their grief reactions can be complicated and/or prolonged. Additionally, the language of grief for people with IDD, whether or not they are verbal by nature, is primarily behavioral. In order to help people process their grief, we first need to recognize it as the source of the thoughts, feelings, and/or fears which their actions convey. Below is a table designed to help you identify specific situations griever with IDD may experience and behavioral communications that may be grief related. For each situation or communication there is a strategy to employ that may promote healing.

SITUATION OR BEHAVIORAL COMMUNICATION

The individual was not able to attend the wake or funeral or ethnic/cultural equivalent or did not comprehend the meaning of the event(s)

You are not certain the individual understands "death" or think s/he may have a simplified notion of it (e.g., not realize its permanence). Given his/her level of understanding s/he may be confused if people seem hesitant to talk about it

STRATEGIES TO ASSIST

Help the person conduct a goodbye ritual that is concrete and personally meaningful. A ritual that acknowledges the person's loss and allows them to say goodbye

Describe death concretely. Avoid phrases like "passed on," "went to sleep," "no longer with us." Do not avoid talking about "the what" and "the how" within reason. Use items/experiences to teach the body "no longer works," "can't be fixed," "the person won't come back."

SITUATION OR BEHAVIORAL COMMUNICATION

The individual may be feeling emotional pain that is unlike anything s/he has ever experienced and s/he may think/fear the pain will never go away but not have the words to express that fear

The individual believes/fears that other people s/he knows are now going to die

The individual may not know how to ask for information about what happened (or what will happen). Even the idea of asking for information may not occur to him/her

In their grief, people may ask questions repeatedly. The same question may be asked often in a short period of time

The individual appears to be searching for the deceased. The search can be actual (looking in places) or virtual (talking about the person, asking for the person) The individual says s/he saw the deceased person. This may have occurred in a dream or in his/her imagination, but the person was seen and was real to her/him

Shortly after a known death or significant loss, an individual begins to behave differently than s/he did prior to the event

STRATEGIES TO ASSIST

Acknowledge the pain and assure the person that s/he will not always feel it so strongly. Be a reflective listener to verbal and non-verbal communication. Avoid saying, "I know how you feel..." "You have to be grown up about this..." "What you need is..." "You'd feel worse if..." It can help if you name the feeling: "You feel sad. You feel mad." Use of a feelings chart may be helpful.

Explain others are not going to die just because one did. Point out that people continue to be around. Use an example if available (i.e. "It's like when one of the fish in the tank dies, the others keep living.")

Help the person to ask questions: "Do you want to know about...?" and encourage them to do so. Notice when a person is trying to get information from you

Keep answering the questions. It is the feelings of grief and not a lack of information that is causing the repetition

Support the individual in the search but again explain the "foreverness" of death. Acknowledge the loss. You may want to ritualize another goodbye. Anniversaries, holidays, seasons can trigger searching

Reflect back to the person that her/his actions are a way of expressing the hurt and pain of grief: "You threw your clothes all over your room and broke those things because..."

SITUATION OR BEHAVIORAL COMMUNICATION

STRATEGIES TO ASSIST

...(cont'd) you're missing _____. I know you're hurting inside(touch your own heart to show hurt there)." Suggest doing one of the other grief processing activities

Grief causes fear

Listen to the fears. Don't contradict or deny them, just acknowledge them. If fear persists over time, or interferes with life activities, refer for counseling

Grief causes anxiety

Use deep breathing and other relaxation techniques

A new experience (personal or the witnessing of someone else's loss) renews the individual's feelings of missing someone

Know that grief comes and goes and that there are numerous triggers for it. Respond to each cycle of grief in the same way you did the previous cycle. Each one will need healing as much as the one(s) before it

There is an observed increase in ritualized behavior

Recognize that rituals provide security. Be aware that a ritual of comfort can arise out of any activity (taking a coffee break, looking at a photo album, etc.). Help the person maintain and practice the rituals they select

Anniversary, holiday, birthday, etc.

Important "grief-triggering days" need to be anticipated and supported. Help the Individual carry out a memorial tribute/ritual to acknowledge the significance of the day

The individual may want to remember the deceased in a special way

Give him/her choices about how to memorialize the person and express his/her feelings. The choices may be expressed in action rather than words (pictures, dance, volunteering). Smell and taste are tied strongly to memory and are important tools in memorialization



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RITUALIZING GRIEF

WITH PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

When discussing person-centered thinking and practices, the topic of rituals often surfaces: the need to capture the rituals of relationship (e.g. I always have a cup of tea when I visit with Rose) and the rituals of comfort (I like classical music and a burning candle when I relax) important to an individual. Rituals motivate and move us. They help us define our families, build community, make transitions, and mark important life events. Through ritual we express our joy and sorrow. We do so alone, in private, and together, in relationship with others. In no circumstance is ritual more important than in acknowledging, experiencing, supporting, and healing the grief experienced because of the death of another. Mourning rituals are universal. There is such a wide variety held by different ethnicities, cultures, faith traditions and families, that they can even be contradictory. People perform mourning rituals in an effort to alleviate their grief – but do they work? The research of Francesca Gino and Michael I. Norton, first published on May 14, 2013 in Scientific American, showed that they do. What follows is a guide to planning a grief ritual and some suggestions for items or activities around which a ritual can be designed. These are rooted in neither cultural nor faith traditions and are not meant to replace either; they are meant merely to provide the opportunity to express personal and communal loss in a safe, symbolic, participatory and meaningful way.

HOW TO PLAN A RITUAL FOR PEOPLE WITH IDD

- Make the ritual concrete rather than abstract: because of the nature of their disability, people with IDD generally benefit from more concrete experiences that include activities or include the use of physical, representative items
- Use explicit directions, with few words. When possible, providing picture illustrations of the directions and/or modeling should be used
- Keep the ritual simple: rituals that are too complicated or open-ended may be confusing, frustrating and of little meaning
- It is important to maintain an element of symbolism—to have the activity done, or the object used, represent something beyond its literal meaning



TO MAKE RITUALS IMPACTFUL DESIGN THEM SO THE PERSON PARTICIPATES THROUGH SYMBOLIC GESTURE OR OBJECT

- Use Photos (of the deceased or from magazines/computer images in representation)
- Use Storytelling (“I remember when...” or “What I will miss the most about...”)
- Use Memory Objects (“I brought this cup today because...” or “This reminds me of...”)
- Use a Perennial plant or Tree (“Let’s plant this tree in her memory and whenever we want to talk to her we can come here” or “Every time this plant flowers we will remember...”)
- Use Drawing (“Draw what he meant to you” or “Color your paper heart with a color that shows how you feel right now.”)
- Use Music (“Let’s sing/play her favorite song.”)
- Use Writing (“Write what you would say to him right now” or “Write one word about him.”)
- Use Stones/Seashells/Tee shirts/Pottery/Modeling Clay for a keepsake (“Paint whatever you want in her memory on this” or “These playing cards were hers, each person take one.”)
- Use Light (a candle that can be lit on special days, a nightlight, etc.)
- Use the act of Burying an Object (personal item, goodbye notes, something symbolic of the deceased or of the feelings of the griever)
- Use Food (share a favorite dessert or favorite meal “in honor of”)

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The griefHaven Word Exercise

A Powerful Exercise For Post-Traumatic Stress

by Susan Whitmore

[Excerpt from talk on “Dying Alone” at the 2020 International Day of Hope and Healing.
Read or watch this talk on the griefHaven.org website.]

Today I’m going to teach you an exercise that is very powerful. We use this exercise at griefHaven, and I’ve taught it all over the world. It has to do with those looping thoughts that cause us to keep re-living a traumatic event over and over again.

In my work as a grief expert with griefHaven, I have had the honor of working with hundreds of people who are grieving, and many of them have had their loved ones die alone. This is usually because of an unexpected event, such as unknown illness, accident, suicide or timing when someone is at the end of life. Today, we are seeing this in great numbers with the current pandemic, where people are saying goodbye to loved ones by cell phone or while standing behind a window watching their loved ones die. We also see great numbers of people who have PTS for other reasons surrounding the death of their loved one, such as the moment they received the phone call, when the paramedics came to the house and tried to revive their loved one, watching their loved one suffer, and dozens of other scenarios. Even though most studies of PTS have not included loss and grief trauma, such trauma is highly prevalent in our world today and is finally starting to receive much needed attention.

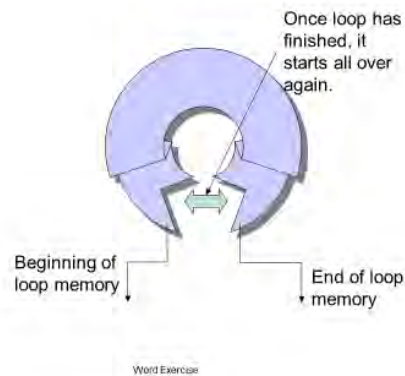
A certain percentage of those who have experienced their loved ones dying alone end up with post-traumatic stress, either because they imagine what their loved one went through while dying alone or because of what they actually experienced while their loved one was dying.

It is those traumatic moments that people ruminate over again and again, moments they just can't stop thinking about. I refer to this as "the loop," and this loop has a beginning and an end. People with PTS may get caught up in the loop and play it out from beginning to end relentlessly. They often tell me it is driving them crazy, keeping them from being able to sleep or eat or have a sense of peace.

So what do we do about it? What we want to do is *interrupt* that loop. We don't want to fight it or judge it or struggle with it, because that only makes it worse. We want to simply work *with* it by sending a message to our brain that says, "Let's not go around this loop this way—let's go out of this loop that way."



Illustration of How PTS Loop Works



How Do We Interrupt the Loop?

Several years ago, I was involved with studies being done at UCLA where the researchers were using functional MRIs (fMRI) to look into the grieving brain. At the time, two studies had been completed: one for the death of a parent, and the other for the death of a spouse. I was there to work on the third one, which was the death of a child.

During my time at UCLA, I came up with an exercise which I felt was already helping me with my own PTS, PTS that resulted from watching my daughter Erika die. I was continually re-living over and over the loop of watching her death. Over time, I worked with this exercise, tweaked it a lot, and started teaching it to others. It not only worked for me, but everyone I shared it with found it worked for them.

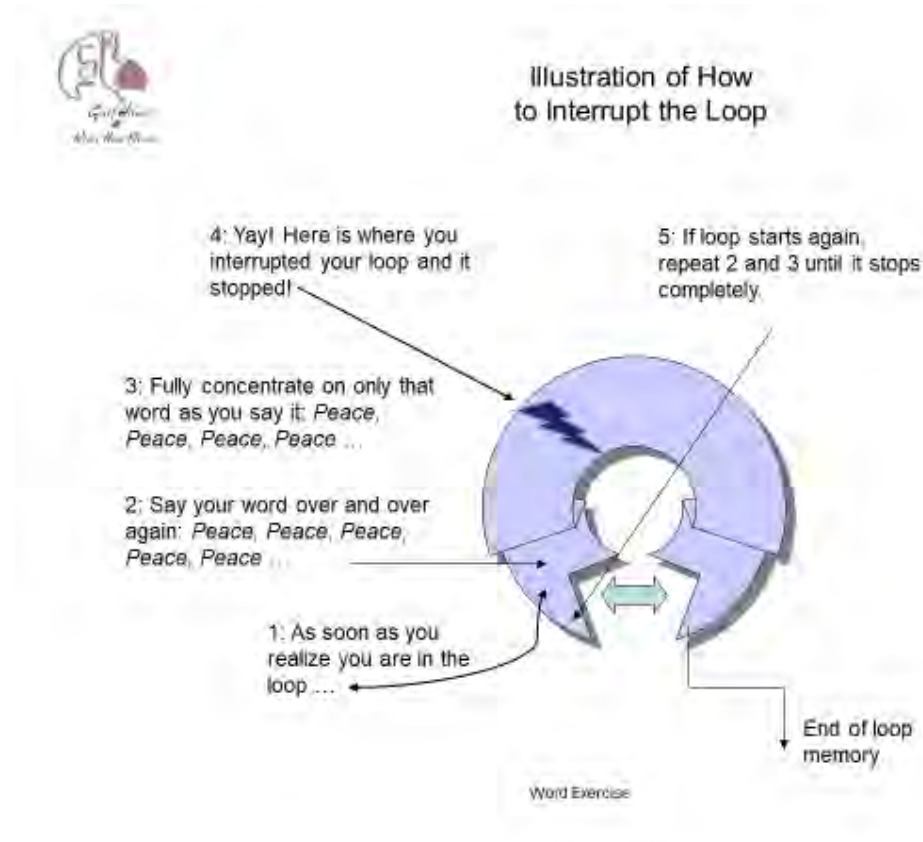
This exercise is so deceptively simple that it is hard to believe it is as powerful as it is. Yet, when you understand how the brain works, it makes perfect sense. That loop is your brain's way of trying to work out what has traumatized you, so you keep going over and over it. It is similar to having that imaginary conversation that you *wish* you had had when a person said something upsetting to you. You keep having the imaginary conversation with them you wish you had had because you are trying to work it out. But by interrupting the loop and sending the message to your brain that you are stepping out of the loop by doing something else, you create a new neural pathway that moves away from that traumatic memory. This process weakens the loop and will eventually stop it.

Now, I am going to explain exactly how this technique works so you also can use it. If you use it and practice it regularly, you will find that it is extremely effective.

THE WORD EXERCISE

1. You pick a word. One word.
 - a. The word has to be one syllable.
 - b. The word has to be a positive or neutral word.
 - c. The word cannot be a person's name or in any way remind you of your loved one who died.
2. Some word examples: love, hope, peace, God, white, gold.
3. The minute you find yourself in that loop where you are re-living that traumatic experience, you start saying your word. Say it out loud or to yourself and keep repeating it over and over until the loop stops. (To view a physical demonstration, visit griefHaven.org, Home Page.)

MOST IMPORTANT: When you say your word, focus 100% on only that word. See it. Hear it. Focus on it. Many people see it in front of them or in their imagination, or they hear it as they think or say it. **Strong focus on your word is the main key to this exercise**, because you cannot fully focus on more than one thing at a time. So bring all of your attention to your word, and keep saying it several times over. This is what takes you out of the loop and into a different direction.

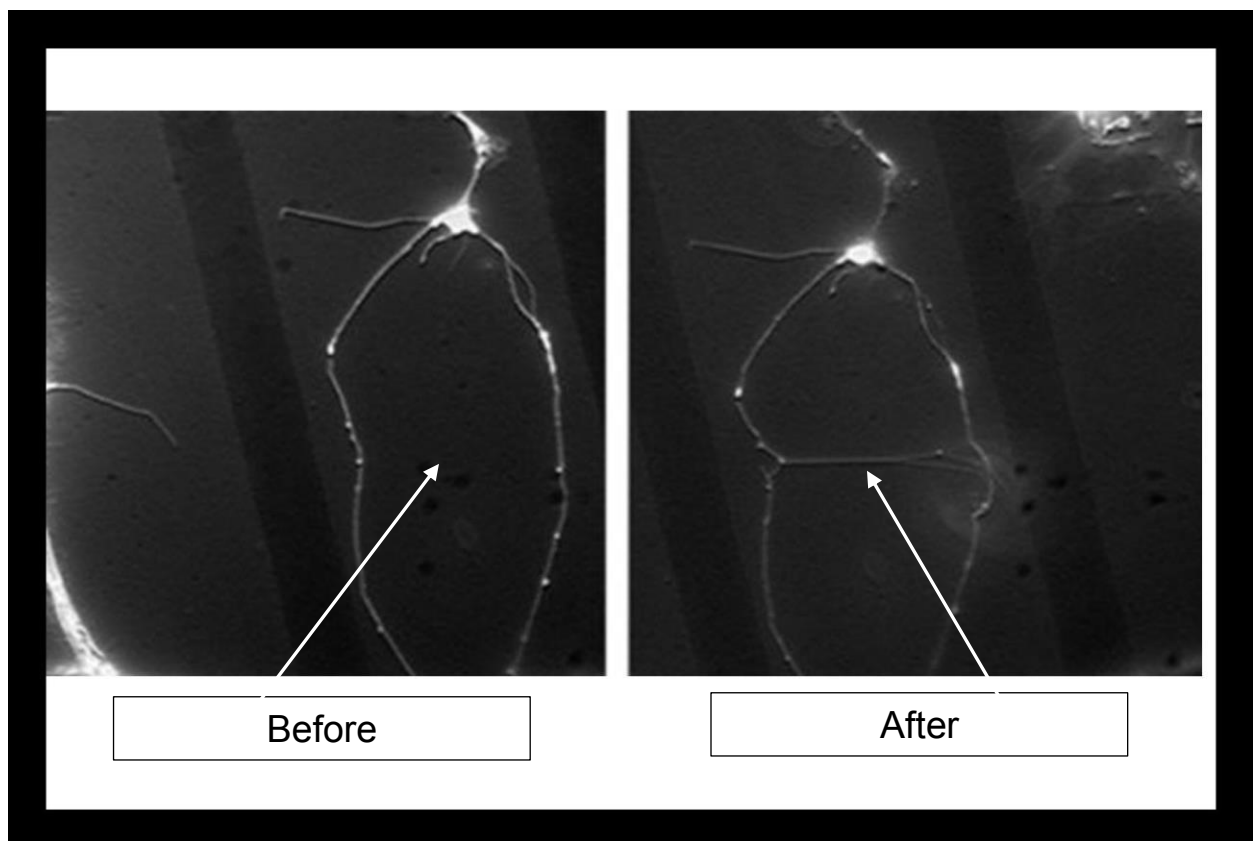


Often, as soon as you stop saying your word, your loop will start up again. Do the word again and keep doing it until the loop stops. If you are in bed at night, you may fall asleep saying your word. Some people choose to go to sleep this way at night, using their word like a meditation, prayer or mantra.

4. This exercise can work immediately, but you will need to use the practice consistently, over and over again. It is a powerful and useful tool that you can use for the rest of your life and teach to your children and friends.

Using this technique, you will stop reinforcing the traumatic circuit, the loop, and you will create a new neural pathway as seen in the remarkable photos below.

Microscopic Photo of New Neural Pathway Being Formed



As published in *Scientific American* magazine.

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What to Say What Not to Say to Someone Who is Grieving

OVERVIEW

Someone you care about is grieving because someone they love has died. What do you say or not say to this person? Does it make a difference if what you are saying is found to be caring and comforting or, conversely, hurtful and upsetting? Yes, it does make a difference. In fact, science has shown repeatedly that the type of grief support a person receives is a key component in that person's ability to deal with the everyday struggles of picking up the pieces of the lives they used to have and rebuilding a new life without their loved one there. So think of it this way: When you say something to someone who is grieving, you want what you say to them to be comforting and show that you care. Yet, how are you supposed to know what is safe and helpful, especially if you haven't had your own experiences with loss. That's why we have compiled this information for you.

So what do you say; what don't you say? Here we have made it easy for you.

This guide is comprised of actual comments made to people who were grieving—the ones that were helpful and the ones that were not. If you follow our guidelines, you will know what a person who is grieving can handle hearing, wants to hear, or finds comforting to hear, and you can safely and lovingly share those comments. Conversely, you will also know what is upsetting to someone who is grieving, and you can avoid those comments. Of course, as with grief itself, everyone is different, so don't ever hesitate to simply ask the person to let you know if you ever say anything they don't find comforting or if you are not saying something they would like to hear.

WHAT TO SAY (Comforted if these are said)



1. Say the person's name—forever and ever—and keep saying it for the rest of the griever's life. Talk about the person whenever the opportunity is there to do so.

This is one of the most important recommendations of all. We cannot stress this enough. Because a person died does not mean that the relationship with that person died, too. Just as we don't stop talking about a person who is alive but unreachable in a



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remote location somewhere in this world, we also don't stop talking about a person who has died. That's because the love and relationship with the person who died is still very much alive, only shifted in nature and form. The memories and the deep need to keep them a part of their lives is also alive. You can help them do just that. For instance, is a brother or sister whose sibling died still that child's brother or sister? Of course they are, and they will tell you that is true. They will forever refer to their brother or sister, share stories, and let others know they have x number of siblings, always including the one who died. Death may end a physical life, but it never ends the love nor the relationship. We never stop loving someone just because they died, and we never stop having a relationship with them. The relationship just changes in form. This is a healthy thing for people to do. You can help them.

Saying the name of the loved one means so much to those who are grieving. It's like music to their hearts. This remains true for the rest of their lives. If the name comes up, you can just listen, add something about the person as part of the conversation, or share a memory you have. Just let it happen naturally. In other words, you don't have to force it. Be careful that, when the person brings up their loved one, you don't squirm, go quiet, or act as if something was said that shouldn't have been said. Your discomfort can be felt. Rather, just know that bringing up the loved one is a natural part of keeping their memory alive, and that it is a positive and good thing.

2. "I am so sorry" or "I am so sorry for your loss."

This is one you hear regularly. Generally, it means a lot to most people who are grieving, but only if you say it with sincerity, from your heart, not just like the "thing" to say. Say it from a place of compassion and love, and it will be sincerely felt.

3. "I can't imagine what you are going through" or simply "I can't imagine ..."

This is a truthful and heartfelt thing to say to someone who has experienced a loss that you have never experienced. For instance, if you are speaking with someone who tells you their child died, you would say, "I can't imagine." Of course, if you have had the same loss, you would change this accordingly, since you have walked many miles in those grief shoes. You could even say, "I'm so sorry. I lost my child 12 years ago ..."

4. "I want you to know how much I care."

Again, this is where speaking truthfully and from your heart comes in. If you stay away from platitudes you usually can't go wrong. You can create your own similar, kind words.

5. "I miss him/her, too."

This is very nice to hear if you knew the person. This is a nice thing to say on anniversaries, birthdays, or just whenever you have a moment you are thinking about the person and want to share it.

6. "I have been thinking about you and want you to know I care."



This can be sent in an email, text, or left as a message on their phone. Just be sure there is no expectation of a reply.

7. “I want to do or say something that you will find helpful because I want you to know how much I care. I am just concerned I might do or say the wrong thing. Please know how much I do care and that you and your family are loved.”

These are our words of course. You would come up with your own. Here’s why something like this is important. Oftentimes because people are concerned about saying the most thoughtful words that can be taken in by the person who is grieving, and/or because people are concerned about saying or doing the wrong thing that upsets the person, they don’t say or do anything at all. Not saying or doing anything is extremely hurtful. So just be honest. Let them know that you care and that you truly don’t know what to say or do at such a time. You can even ask them if there are words that they find caring.

8. “I was remembering that time...”

Share a special positive or personal memory. Grievors often learn a lot of wonderful things about their loved ones listening to other people’s stories. They will be forever grateful.

9. “I wish I had known him/her” or “I’m glad I’ve gotten to know him/her through you.”

If you have never met the loved one but are a friend of the griever, these are lovely things you can say.

10. “It’s good to talk with (or see) you” or “What have you been doing?” or “Just calling to say hello.”

These are replacements for asking, “How are you?” Most grievors find the question “How are you?” annoying and upsetting because they feel like you are asking them a rhetorical question that has an obvious answer: “How do you think I am? My child just died!” Losing someone you love is painful, and just getting through each day is often a challenge. Also, when you ask, “How are you?” you put the person in a difficult position of either having to politely pretend (“Fine” because they don’t want to upset you OR because they believe that you don’t actually want to hear how they really are) or delve into painful details they may not wish to recount at that time. A question that is more concrete and specific is better. The person can more easily answer the specific question and then elaborate further if they choose. That’s why we suggest when you are checking in with them, you say something specific like “How was your day so far?”

FINAL THOUGHTS ON WHAT TO SAY:

A person grieving is in a place that is usually foreign to him or her. Even if they had other losses, each loss is new and unique. Just a text or phone call (without ever expecting a response) saying that you care is thoughtful and comforting.



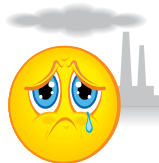
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Once the services are over, life continues on as ever before for everyone else, but not for the grieving person. For them, their lives become more and more difficult and challenging with time. Grievors often say that things get worse and harder as time moves onward. That's because they have had time to live with the realities of life without their loved one. The griever needs people to understand that they are continuing to grieve, even when it seems like it has been a long time.

No one "gets over" losing someone they love, and, as time goes by, they want their loved one to be remembered. You can be a supportive part of the griever's journey so they don't feel abandoned or misunderstood, sending the message "You are not alone." So, over time, keep in touch and remember that birthdays, anniversaries of the loss, and holidays can be especially challenging. If you simply acknowledge on those days that you know it is a rough day, or that you are thinking of the person, it can be very helpful. Of course, if you are so inclined, by inviting the person to lunch or to go for a walk can be an additional source of comfort, even if they should decline.

Finally, research shows that the type of love and support you give someone who is grieving makes a difference in their ability to pick up the pieces and rebuild their lives. A person who is grieving needs to create a "new normal," which includes figuring out how to live life without their loved one here. At the same time, they are creating a new relationship with the person that is no longer about their loved one's physical presence. This is one of the most challenging things a person has to do, and it takes time, hard work, and lots of love and support. You can make a huge difference.

WHAT NOT TO SAY (Sad if these are said)



OVERVIEW:

Platitudes about grief have made their way through all our lives, and generation after generation continues to use them. Grief platitudes are those comments you have heard over eons of time, such as "Time heals all wounds," "Everything happens for a reason," "What doesn't kill you makes you stronger," and "It must have been part of God's plan." However, those who are grieving will tell you they don't find those comments comforting or helpful, and sometimes they find them downright infuriating. Some of them are not true at all, some might be true for you but not the griever, and some are actually hurtful.

Let's see if together we can break the pattern of using these platitudes and make the grief journey a little softer for those on it.



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Below we have chosen several of the most often heard statements by griever. Again, these are all actual comments made by people who thought they were helping, but in the real course of the griever's life, the comments were found not to be comforting.

1. "I know how you feel."

In reality, no one can know how anyone else truly feels. Only the griever had that relationship with the person who died. This comment also sends a message that you are comparing your loss to theirs. If you have actually had the same loss, try saying something like, "I also lost my daughter. Losing a child is so terrible." Or this, "I also lost a brother, so as much as anyone can, I understand your pain." Otherwise, best to avoid this comment.

2. "Time heals all wounds."

Even though people who are grieving learn that their grief softens and becomes more manageable over time, it's really what they do with the time that matters. The "time heals all wounds" statement says that there isn't anything you need to do with your grief except wait it out. It also implies that grief is like a "wound" that will heal in a linear fashion. Grief doesn't work that way. Grief needs to be given a voice, which means that it needs an outlet. Last, a statement like this is minimizing what the person is experiencing. It's as if you are saying, "Oh don't worry. Time will make you all better."

3. "At least she's no longer in pain."

Even though this is true, the problem with this comment is that instead of acknowledging what the griever is experiencing (*I miss him so much I can hardly stand it*), you are making a statement that feels as if you are trying to point out why the person should be grateful, "At least she's no longer in pain." This is what we call the silver lining statement. Silver lining statements are not loving and comforting to a person who is grieving. The person knows that their loved one is no longer in pain. They are also longing and yearning for their loved one, and that longing and yearning lasts a very long time.

4. "It must have been her time." "God only takes the best ones." "She's in a better place."

All of the spiritual comments you might believe or find comforting should someone you love die are not necessarily comforting or even true for the person to whom you are talking. Even if the person does believe anything said about the spiritual essence of a person's death, they still might not find these comforting at the time.

We suggest you are careful with saying anything religious or spiritual unless you know for sure the griever **will** be comforted by what you say. Keep in mind that sometimes the death of someone beloved results in people questioning previously held beliefs. They just need the space to do that.



5. "Call me if there is anything I can do."

This puts the responsibility on them to (1) know what they might need from you (which they usually don't); and, (2) actually reach out and ask you for something. Better if you just call them and just "do" what it is you think they might need. For instance, "I would like to drop dinner off tonight. Would that be okay?" or "I would love to come by, pick up your laundry, and bring it back to you the next day. Would that be okay?"

6. "How are you?"

You know how they are, so avoid this one. If you want to know how they are doing, try saying something specific they can address, such as "What did you do this morning?" or "Did you go to book club last night?"

7. "Did you try this...?" "You should do this..."

Making suggestions to the person who is grieving about all of the things they should try or do is typically not very helpful. Comments like these send the message that the person should change, so it's best to avoid anything where you are trying to change the way they feel. These comments are annoying to those who are grieving because they just want people to "be" there with them, not give them advice. For instance, people say, "Are you exercising? You should exercise. Those endorphins will really help." Or, "You should get out more. It will really help you." Avoid giving advice or using "the *shoulds*." Just listen without interjecting your remedies. The one exception to this would be if you have also had a loss and found something that really helped you, such as a grief group you attended or a book you read, but only as a suggestion.

8. "Be thankful because it could have been worse."

A logical or reasonable comment like this is not comforting at all. A person who might compare something that happened to someone else as being so much worse is implying that the griever shouldn't feel as bad as they do because, after all, much more awful things "could" have happened. But a person only knows their own experience—their own pain.

9. "Be strong." Or to a child whose parent has died, "You need to be strong now for your family." Or "You are now the man of the family."

This is one of the most important things never to say. First, what does "be strong" mean? Don't cry? Keep busy? Don't show your emotions in the "inappropriate" places? Pull yourself up and get on with life? Everyone who is grieving IS strong in their own way. Sometimes just to get out of bed and get dressed is the best they can do. Further, it takes great strength to face and deal with losing someone you love, so they are already doing the best they can.

With regard to the additional comments, never, ever tell a child or teen that they need to be strong or that they are now the head of the family or that they need to take care of their mother or anything like that. Children need to grieve and be children. Letting



out their grief and getting back to their normal routines as quickly as possible is what is most healthy for them.

10. "Don't cry."

This is another one never to say to anyone who is grieving. I know it's tempting to say with love, "Oh, don't cry. It will be okay." Don't say anything when they are crying; hand them a tissue. OR, better yet, you just cry right along with them. In fact, always remember that your tears show how much you care. Just make sure it doesn't turn into the griever having to take care of you.

12. "What 'stage' are you in?" Or "Sounds like you are in the 'such and such' stage."

There are no stages of grief. This is a myth. There are not five stages of grief. There are not any stages of grief. Grieving is like being on a roller coaster ride, up and down and all around, and that is normal. Grief does not come with nice, linear stages that a person has to get through before they are done with their grief. If you haven't watched the *Now You Know*™ grief myths on the website, this is covered there.

13. "I hear that most marriages end when a child dies. How are you guys doing?"

One of the biggest grief myths is that most marriages end when a child dies. This is absolutely untrue. In fact, most marriages go on to be deeper and richer than ever before. If you haven't watched the *Now You Know*™ grief myths on the website, this is covered there.

14. "You need to put this behind you so you can go on."

A person never puts the death of someone they love behind them because it's always with them. In fact, what they do is bring their loved one with them into the new life they are creating since their loved one's death, for losing a significant person in life changes everything. Remember that they are having to completely rebuild their lives without that person in this world. With that process, they are also creating that new relationship with their loved one, which means the person who died will come with them into that new life that is created and will always be a part of their lives. This is healthy and good.

15. "Don't think about that." or "Think of the good times."

Again, this shows that you are trying to change the way they are grieving. Some people can think of the good times right away and find peace in those memories. Others find that thinking of the good times only reminds them of what they've lost, so for a while they need to avoid doing that. Again, steer away from giving advice where you are trying to change what the person is doing or feeling.

16. "Are you dating yet?" or "You will fall in love again one day."

A person whose spouse has died may never want to fall in love or date again. That is up to them. They will get on with life at the pace that works for them. With that, it's best to never suggest someone start dating whose spouse or significant other has



died or even to suggest that one day they will find love again. Maybe they will, but they need to come to that realization on their own.

17. "What happened?"

Oftentimes when people first find out a person has died, they will want to know how the person died and what happened. Curiosity is normal, but in this case, it's a very inappropriate question. If the person wants you to know, they will tell you.

18. "When my mother died...when my father died...when my pet died..."

If someone has just shared with you about their loss, it's a normal response to want to share with them your losses as a way of bonding so that the griever will see that you also understand grief; however, instead of using it as time for you to share your story, try to listen to what they are saying and share some of the "what to say" comments above. At least let the person finish sharing whatever it is that they want to say about their loss and then see if they can handle hearing about your losses. The griever feels you weren't listening and/or they now have to comfort you when you share your stories of loss.

19. "He wouldn't want you to be unhappy." Or "She would want you to be happy."

Even if you know the person who died and you know for sure he or she would want their loved one to be happy, this is not a comforting thing for you to tell someone who is grieving, in pain, and struggling. Essentially you are adding a burden to their grief and saying, "He/she would not like it that you are not happy." It is also sending the message that they "should not" be sad. How can they be happy right now? They are grieving. One day they will be happy again, but right now it's appropriate for them to be sad.

20. "You were lucky to have had her at all."

What year would you be willing to give up your loved one to death? No need to remind them how lucky they were to have had their amazing loved one. They already know that. Yet, they miss and long for that person, and that is normal.

21. "Thank God you have other children." Or, "Have you thought about having other children or adopting?"

This implies that the child they lost is replaceable or that somehow having another child will fill the hole in their hearts. Some parents have said they feel like the person who says things like this is saying, "Just get another kitten and you will feel better."

22. "Something good always comes out of every tragedy." Or "There's a silver lining in everything."

That may be true about many things in life, yet these statements are sending a message to the person that, even though it is sad that their loved one died, regardless of how horrific the circumstances of their death might have been, you know that something



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good and amazing will come from it, and you know that this silver lining or good thing that will eventually happen would not have happened had their loved not died. Yikes! Something wonderful does not actually come out of every tragedy. What does come out of every tragedy is a new person who slowly rebuilds his or her life. With your love and support, they will find that new way of living without their loved one there.

FINAL THOUGHTS ON WHAT TO SAY:

Did you notice the pattern in almost all the comments?

We suggested you avoid three major categories:

(1) Don't try to change what the person feels, thinks, or believes or how the person is grieving. This includes any comments that are judgmental or giving advice about what they should be doing differently;

(2) Stay away from sharing what you would find comforting or what you believe to be true, including spiritual or religious comments, and instead share what the griever will find comforting or believes; and,

(3) Avoid sharing your stories of loss too soon when someone is first sharing theirs, especially if theirs is new and you have had time to deal with yours. Instead, as much as you can, just listen.

Everyone is different, so if you stick to the basic loving, nonjudgmental, thoughtful comments, you will be a part of those who help the griever as they find their own way of picking up the pieces and rebuilding their lives. We promise that they will do exactly that.

With your help and love, those who are grieving will find comfort in your presence and be able to hold onto that as the days, weeks, months and years move onward. You will be a positive part of their grief journey, and they will be eternally grateful.

From our hearts to yours,
thank you for caring enough to learn about
what to say and what not to say.

Watch our *Now You Know*™ videos and blogs right on our website.
There's lots there for you!

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The BIG LIST of Grief & Loss Resources



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Health Support & Resources.*

Have a Resource to Add to This List? Email us at: hello@joinmentallyfit.com

RESOURCES RECOMMENDED BY OUR COMMUNITY

Here are some resources recommended by our community...

Community

- [Mentally Fit Community](#) - a group for anyone and everyone who is interested in learning about mental health and peer support. All are welcome.
- [Therapist Toolbox Community](#) - a group for therapists to get support from experienced peers and mentors; connect to our massive (and constantly growing) resource library; and connect with tools to improve your practice.

Articles & Handouts

- [The Mourner's Bill of Rights](#)
- [The Process of Grief](#)

- [Kubler Ross Stages of Grief Handout](#)
- [5 Stages of Grief Handout](#) (Ok.gov)

Websites

- [Grief.com](#) - Website by grief expert, David Kessler.
- [Grief Share](#) - GriefShare is a friendly, caring group of people who will walk alongside you through one of life's most difficult experiences. You don't have to go through the grieving process alone.

Books:

- [The Grief Club: The Secret to Getting Through All Kinds of Change](#)
- [When Dinosaurs Die: A Guide to Understanding Death](#) (Children)
- [When Someone Very Special Dies](#) (Children)
- [Creative Interventions for Bereaved Children](#)
- [Healing Your Grieving Heart for Teens: 100 Practical Ideas](#)
- [Tear Soup](#)
- [Moving Through Grief: Proven Techniques for Finding Your Way After Any Loss](#)
- [The Fall of Freddie the Leaf: A Story of Life for All Ages](#)
- [It's OK That You're Not OK: Meeting Grief and Loss in a Culture That Doesn't Understand](#)
- [How to Survive the Loss of a Love](#)

- [Bearing the Unbearable](#)
- [The Wild Edge of Sorrow](#)
- [Disenfranchised Grief: Recognizing Hidden Sorrow](#)
- [I Wasn't Ready to Say Goodbye: Surviving, Coping and Healing After the Sudden Death of a Loved One](#)
- [In the Presence of Grief: Helping Family Members Resolve Death, Dying, and Bereavement Issues](#)
- [Grieving Beyond Gender](#)
- [Treatment of Complicated Mourning](#)
- [The Invisible String](#)
- [Recovering from Losses in Life](#)
- [Swallowed by a Snake: The Gift of the Masculine Side of Healing](#)
- [Unattended Sorrow: Recovering from Loss and Reviving the Heart](#)
- [Permission to Mourn: A New Way to Do Grief](#)

Workbooks

- [Transforming Grief & Loss Workbook](#)
- [The Invisible String Workbook](#)

Exercises

- [Activities for Grieving Children](#)

(Memory Box, Handprint, Grief Maze & More)

YouTube Videos:

- [The Invisible String by Patrice Karst \(Author\)](#)

Podcast Episode:

- [Pandemic of Grief: Surviving Loss During Covid19 with Dr. Alan Wolfelt](#)

Organizations

- [The Dougy Center for Grieving Children and Families](#) - The Dougy Center provides support in a safe place where children, teens, young adults, and their families grieving a death can share their experiences. We provide support and training locally, nationally, and internationally to individuals and organizations seeking to assist children in grief.
- [National Alliance for Grieving Children](#) - The National Alliance for Grieving Children (NAGC) is a nonprofit organization that raises awareness about the needs of children and teens who are grieving a death and provides education and resources for anyone who supports them.
- [Whats Your Grief](#) - What's Your Grief offers online and in-person continuing education training for grief support professionals. Using an

accessible approach and a combination of practical and creative tools, we strive to help participants utilize relevant and useful theories, tools, and techniques in their work with people grieving a wide range of losses.

- [Center for Loss & Life Transition](#) - Founded in 1984 by Dr. Alan Wolfelt, the Center for Loss and Life Transition is dedicated to “companioning” grieving people as they mourn significant transitions and losses that transform their lives. We help mourners, by walking with them in their unique life journeys, and both professional and lay caregivers, by serving as an educational resource and professional forum.

People to Follow

- Dr. Alan Wolfelt - Dr. Alan D. Wolfelt is a noted author, educator, and grief counselor. Recipient of the Association for Death Education and Counseling's Death Educator Award, he serves as the Director of the Center for Loss and Life Transition in Fort Collins, Colorado. He is also a faculty member of the University of Colorado Medical School's Department of Family Medicine.
 - [Website](#)
 - [Instagram](#)

- [YouTube](#)
- Megan Devine - Megan Devine is the author of the new book, "It's OK That You're Not OK: Meeting Grief and Loss in a Culture That Doesn't Understand" (Sounds True, October 2017). She was born and lived in Maine for many years and holds a master's degree in counseling psychology.
 - [Website](#)
 - [Twitter](#)
 - [Instagram](#)
 - [YouTube](#)

Tools:

- ["The River" set and "Roads" deck](#) for adult/teenager clients and "The World of Trains" set for children. The guidebooks describe numerous ways to encourage clients to share and process issues using these projective cards, both in individual therapy and group sessions. For example: A client can use the river cards to represent periods in her life, to describe stages in her process of grief or to examine her relationship with her late spouse over time.

United Kingdom

- [Cruse Bereavement Care](#)

Shareable Graphics

- Stages of Grief ([Download](#))
- Stages of Grief Graphic 2 ([Download](#))

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We offer resources like this for free, so we can support as many people as possible!

Please SHARE this resource with therapists, clients or anyone else you know who would benefit from having access.

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