

CHOICE
AND DIGNITY
End-of-Life Advocacy

Choice and Dignity, Inc.

End-of-Life Advocacy

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Please share this newsletter with a friend or neighbor to help spread the word.

What to Say (and Not Say) to Someone Who's Grieving

**Come to C&D's "Small Group Social Gatherings"
to learn more about this.**

Finding the right words when someone is grieving can be difficult, but being honest and allowing them to be heard is a good start.

Grief, while uncomfortable, is inevitable — everyone experiences grief in some form or fashion throughout their life.

Grieving is a natural part of life and can occur after a loss of:

- a loved one — whether by death or a changed relationship
- a job
- a childhood home
- autonomy or independence due to illness or ageing
- less tangible things, such as opportunities or prospects for the future.

For those experiencing grief, support from co-workers, acquaintances, family, or friends, can be very important. But many find themselves at a loss for words — unsure of what to say (or not to say).

Everyone grieves differently

Grief can show up in various ways, from anger to extreme sadness and everything outside and in-between.

There's no one "right" way to cope with grief. It's a normal, healthy response to losing someone you love.

What to say to someone who is grieving

It's not anyone else's responsibility to take someone's pain away. And it's OK to feel not OK. Don't dismiss their pain.

One can simply help them feel heard, not feel ignored or left on their own. Don't be afraid to bring up the topic: They haven't forgotten their loss!

Say something

It can be as simple as:

"Hey, I heard and wanted to ask if you needed anything?"

"I heard and I'm really sorry. Can I do anything?"

Consider offering to pick them up a meal or bag of groceries, or helping them with phone calls or household chores.

Be honest

The most important thing is letting your loved one know that you're there, so it's best to be upfront. Try saying something like:

"I don't know what to say, but I love you so much and I want you to feel heard."

"I'm unsure of what to say, but I'm here to listen if you need me."

Embrace their feelings

• Don't attempt to soothe or change them.

• Validate their feelings.

Don't fear the worst

It is unlikely that you will cause someone to feel sadder.

It's best to be true to who you are and what your relationship with that person is.

What not to say to someone grieving

These statements can feel dismissive:

"At least you had them for as long as you did."

"They're in a better place now."

"At least now you know what's really important in life."

"This will make you a better person in the end. You won't always feel this bad."

"This is all part of the plan."

"Everything happens for a reason."

WHAT TO SAY *continued on next page*

Don't blame:

“Now you know better.”

“Maybe you should have listened to your intuition that day.”

Are you grieving?

Do not treat the human condition as if it's a disease: Realize that negative feelings are going to occur. Shaming people for having natural responses to hard situations is not going to change that.

Grief is not a problem to be solved, it's an experience to be carried.

Being honest about where you are and leaning into your feelings can be aided by:

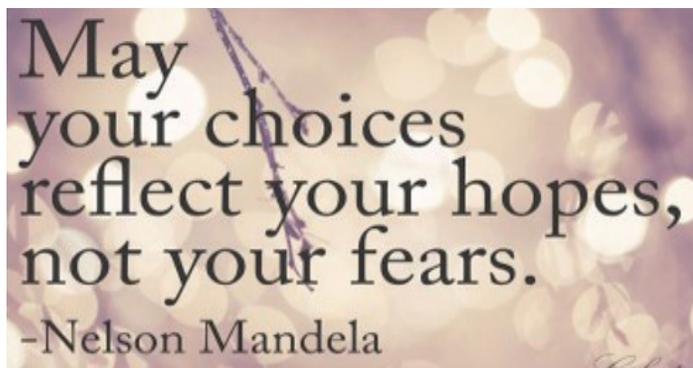
- support groups
- talk therapy
- books
- podcasts

Looking ahead

It's not your responsibility to end anyone's hardship. Just show up and be straightforward about where you could fall short.

If you just want to let a loved one know you would like to be present, but are not sure how to help — it's OK to tell them so.

You probably can't make it worse. Tell your friend that though you might get it wrong sometimes, you're there for them.



What Is Anticipatory Grief and How Does It Work?

Anticipatory grief, also referred to as anticipatory loss or preparatory grief, is the distress a person may feel in the days, months or even years before the death

of a loved one or other impending loss. It is knowing that a change is coming, and starting to experience bereavement. Sometimes we experience anticipatory grief without knowing there's a name for it.

Anticipatory grief can lessen the pain of post-loss grief.

It's Okay to ask for help!

Who Has Anticipatory Grief, and When

Patients with a terminal illness, as well as their friends, caregivers, or family members. Any kind of looming change can bring on anticipatory grief.

Those diagnosed with a degenerative disease, such as Alzheimer's disease, or Parkinson's disease.

End-of-life care

Anticipatory grief may affect the caregiver, the patient or both. (We with C&D experience this when a member chooses to exit.)

Caring for children with chronic disease or hereditary cancer risk.

The patient imagines when a cancer diagnosis may come and how it will change their quality of life.

Awaiting an organ transplant

Besides grieving the possible scenarios of their own death, patients on a heart transplant list also grieve for their potential heart donor and their death.

Amputation

The time before the operation can be the most upsetting -- unknowns surrounding their future.

Impending loss of a pet (*I had to have my dog euthanized in August. John Abraham*)

A new job, a new relationship, a geographic move or a teen leaving home for college

Even planned, desired life changes can prompt anticipatory grief related to the prospective loss of friends, identity, or routine. Anticipatory grief can also surface around pregnancy and childbirth, including:

In-utero complications.

Parents who learn that their unborn baby may not survive or experience.

Premature birth

Parents mourn the loss of their wished-for baby. The mother may think that the inability to bring her baby to term is a personal failure.

Anticipatory Grief and Age

The younger a person is, the more severely they may experience anticipatory grief, particularly as it relates to death. Younger people view death as extinction.

Anticipatory Grief vs. Conventional Grief: What's the Difference?

Think of conventional grief as grieving backward: Grieving for something we might lose.

Remember that the worst may not happen.

What You Might Feel When Experiencing Anticipatory Grief

Anger or irritability, anxiety, denial, the desire to withdraw from social situations, desperation, dread, guilt, an intense preoccupation with the dying person, lethargy or lack of motivation, loneliness, loss of control over one's emotions, sadness, tearfulness.

The Stages of Anticipatory Grief

There's no set order for anticipatory grief, and there's no finishing.

Phases a person with anticipatory grief may experience, in any order:

Accepting that death is inevitable; Feeling concern for the dying person --Maybe having regrets in regrets;

Rehearsing the death -- A person may become focused on funeral arrangements, saying goodbyes and other concerns;

Imagining the future -- Envisioning what life will be like without their loved one. The person dying may think about similar scenarios, wondering what it will be like for their loved ones to experience life without them. The dying person may also imagine what their own experience may be like after death—what, if anything, comes next?

Potential Benefits of Anticipatory Grief

It doesn't necessarily reduce pain after loss.

The preemptive processing of a loss could help a person better cope once the loss occurred, such as dealing with unfinished business, saying good-byes, or clarifying misunderstandings.

One doesn't choose to feel anticipatory grief. More important than considering its benefits is making sure one gets the proper help to work through it.

How to Deal With Anticipatory Grief

It's important to talk about it with someone.

Talk about the dimensions of it. Talk about where it moved into their lives and filled in cracks and crevices, or was taking over their day-to-day lives and their relationships.

Maybe find a mental health provider who specializes in grief.

Do active listening. Out-loud musing can help a person process their grief.

Perhaps use cognitive behavioral therapy. It focuses on managing distressing emotions and encouraging actions to help a person experience pleasure and a sense of community.

Express empathy and validation.

They always say time changes things, but you actually have to change them yourself.

—ANDY WARHOL, ARTIST

Grief Can Strike Even Before a Loved One Has Died

Feelings of grief are expected after the death of a loved one, but having those feelings when your loved one has a terminal illness is also real and can fluctuate over time. Individuals can adjust to their emotional pain of "pre-loss grief".

With medical advances, people are going to be living longer with life-limiting illnesses, so there will be a bigger issue with grief before the person dies. Symptoms of pre-loss grief can predict long-term negative outcomes after a loved one's death, so this is a good intervention target that we would do well to learn more about.

In one study participants completed questionnaires assessing their symptoms of grief: depression, post-trau-

GRIEF CAN STRIKE *continues*

matic stress and caregiving burden. These included 28 people whose loved ones had dementia who responded to both the initial and follow-up questionnaire and 33 of those whose loved ones had cancer. The initial survey was answered by 138 people.

The first questionnaire revealed substantial pre-loss grief among participants. One month later, symptoms of pre-loss grief decreased for 69% of participants, though women and those with heavy caregiving burden were more likely to feel more intense grief.

Family members of patients with dementia were more likely than family members of cancer patients to have severe pre-loss grief, though some people anticipating the loss of a loved one to cancer also had unexpectedly high levels of grief. Symptoms were similar, no matter how long the individuals had known that their loved one had a life-limiting illness.

People in this study had pre-loss grief at a very high rate even after many years. That was shocking, because one might think that time would abate one's grief. But with Alzheimer's disease, it can get harder, and with cancer there could be a similar trajectory, starting with hope at the beginning but feeling worse over time. Perhaps the lingering grief was the caregiver burden, or the loss of their identity as a couple, or that they're not engaging in pleasurable activities anymore.

Pre-loss grief was added to the Diagnostic and Statistical Manual of Mental Disorders released this year. Symptoms include preoccupation with thoughts or memories of the lost family member combined with symptoms such as intense emotional pain, a sense of disbelief and difficulty moving on with life.

A better understanding of preparing for the death of a family member may help prevent mental health problems for their survivors.

Why I joined Choice and Dignity, Inc.

I was originally hired by Choice & Dignity, Inc. in January 2021 to take meeting notes at the board Meetings. By February 2021 I decided to join Choice & Dignity as a board Member. The reason I joined the board was because I am passionate about individuals having a choice on when and how their life on earth comes to end. I spent eight years as a Victim Advocate volunteer for the Pima County Attorney's

office, so death and dying is something I am very comfortable with, and I have received significant training on how to handle death over the years. I feel Choice & Dignity gives people the tools and support to make the decision for themselves when it is time. I also like the fact Choice & Dignity reaches people all over the country and not just the people of Pima County.

-- Susan

More than one-third of nonprofit groups' income comes from bequests – generous members who want to help others after they are gone.

Please add us to your legacy.

We certainly would appreciate your putting us in your will:

Tax ID# EIN- 84-4667788

Choice and Dignity, Inc.

PO Box 86886, Tucson, Arizona 85754

Donations can easily be made on our website.

As you're thinking about your charity giving this year, please consider including a contribution to support the critical work of Choice of Dignity, Inc. There are many tax-advantaged and easy ways to make a gift with cash and these non-cash assets: stocks and securities, mutual funds, cryptocurrency, real estate, or automobiles. Your employer may match your contribution or, if you have a Donor Advised Fund (DAF), you can speak with your DAF advisor about setting up recurring grants to C&D. You can also add C&D as a beneficiary to your DAFs, life insurance, or retirement policies.

Other Ways to Maximize Your Impact for Choice and Dignity



Appreciated Stocks & Securities



Appreciated Cryptocurrency



Recurring Grants from your DAF



Vehicle Donation



Employer Matching



Life Insurance Beneficiary



Retirement Plan Beneficiary



Real Estate

And More!

We recommend that you consult with your attorney, tax or financial advisor for the various tax benefits and restrictions to determine which method of giving is best for you.