

curePSP®
UNLOCKING THE SECRETS OF BRAIN DISEASE™

Life After Loss

Navigating the Journey of Grief



“The reality is that you will grieve forever. You will not ‘get over’ the loss of a loved one. You will learn to live with it.

You will heal, and you will rebuild yourself around the loss you have suffered. You will be whole again, but you will never be the same, nor should you be the same, nor would you want to be.”

—Elisabeth Kübler-Ross
and David Kessler,
On Grief and Grieving

Understanding Grief, Mourning, and Bereavement

We experience grief in diverse ways.

Grief is a process, without a roadmap or time limit, and involves emotional, physical, social, and spiritual responses and experiences along the way.

Common grief feelings include shock, anger, guilt, anxiety, sadness, fear, and even numbness. Many people have “grief bursts,” where reactions and emotions can quickly come and go—one moment you’re laughing, and the next you’re crying. Some cry frequently, at least in the first few days, weeks, and months following the death, while others never cry at all. Triggers can bring about intense waves of emotion and are part of the typical grieving process. Some face physical changes, such as difficulty sleeping, appetite changes, challenges with concentration, and even generally not feeling well.

Many share that the grief journey can feel lonely at times, and it is common to experience changes within friendships and other relationships after a death. Some find themselves questioning their faith or simply searching for meaning and making sense of what happened.

As you travel through grief, your experiences may change in different ways. Many people are familiar with Dr. Elisabeth Kübler-Ross’s five stages of grief model: denial, anger, bargaining, depression, and acceptance, though David Kessler writes about finding meaning as the sixth stage. There is no set order in which one might encounter the stages of grief. Your stages may be in a different order; you might skip some, and you could experience several simultaneously. J. William Worden identified tasks of bereavement: actualizing the loss, working through the pain of grief, adjusting to a new reality,

and staying connected in some way with your loved one. You may never relate to stages or tasks or any other process, and that is OK, too.

Overall, what is important to keep in mind is that there is no normal or abnormal way to grieve. Grief is a delicate balance of both holding on and letting go. This is a powerful, complex, and often confusing journey. What it looks like for you and how you navigate through it is personal and is an important part of your story.

There can be a range of everyday experiences that change and evolve throughout the grieving process. If you find that you are neglecting your physical self-care and emotional well-being, please reach out. There are many experienced, caring, professional support resources to help along this challenging journey.

Develop a plan to stay connected to your loved one.

The experience of grief and mourning can affect us in profound ways. Though your loved one's physical time on earth has ended, the love you feel for this individual never ends. Finding ways to honor their legacy and, with the intention, to maintain a connection can be helpful as you work to move forward in your life. Examples include:

- *Lighting a candle in their memory*
- *Framing a letter they wrote*
- *Making a quilt from their old clothing*
- *Contributing to a cause they supported*
- *Crafting a piece of jewelry from one of their items*
- *Tending to their garden*

You can memorialize and honor your loved one in many ways. Try not to deny but rather incorporate the loss into your life. The progression of neurodegeneration is often slow and can be painful to witness, typically involving anticipatory grief and ambiguous loss over a number of years. This process is different from other terminal diseases, and the physical and emotional toll can be overwhelming. You have learned about strength, courage, and resiliency as you cared for your loved one through their illness,

and you can use those same tools to continue on your life journey. We hope these personal stories of grief and mourning and life after loss in the CurePSP community serve as sources of strength, support, inspiration, and hope.

Sharing Our Journeys in Grief

JANET RICE FINNEY

Your journal, your journey

Journaling comes easy for me. It's where I go when I have been unable to verbalize my feelings. When my husband died, the pen and paper on my nightstand were old friends waiting to hear my story.

I write what I am feeling. I write as if no one else will read it. That helps me to be more honest with myself. I know I need to dig deeper into the guilt, anger, fear, or sadness to help myself. I use words to come to the hard stuff. At the beginning of my grief journey, I found expressing myself through words to be fairly easy because my feelings were raw, and I wanted to ease them. Some people find rereading the journals therapeutic. I did not and still don't six years later. It takes me back to the places where I was at my most vulnerable, and I'm not ready to do that. Not yet.

As I continue to write about the thoughts and stressors I've harbored, I finally come around to the healing power of gratitude. I list the things that make me feel better about the world—comforting thoughts that help me sleep better.

Journaling works better for me as an unplanned activity, rather than sticking to a daily or weekly schedule. There's no reason to put more pressure on yourself, especially early on in your journey. Every word counts. Maybe you'll write two lines or two pages. Just keep going. Perhaps you'll write a book or a series of poems—the writing may start a new chapter in your life.

Don't worry about what you say or how you say it. You are not passing an exam because no one's going to read it, remember?! This is your journal and your journey, and no one else will feel exactly as you do or express it as you will.

As you read the stories that follow, you can use the note pages to start your own journey.

If I could forgive myself for something, it would be...

ALLEN NIXON

I spent over 70 percent of my life with Eileen.

Eileen and I were married for 52 years. We shared four married daughters and five grandchildren. Sadly, Eileen died three weeks before our 53rd anniversary. Eileen's PSP journey lasted six years, from first recognition something was terribly wrong, through two years of misdiagnosis until her passing from PSP, confirmed by her brain autopsy, as she had directed.

Shortly afterwards, I joined a grief support group and saw a grief therapist. I took notes after each session so that I could reflect on what we discussed and use the knowledge to help in my grieving process.

About two and a half years after her death, I summarized my notes. I added the actions I had taken as I struggled with my grief and included things I was grateful for.

When grieving, one takes three steps forward and then two back, and on some days, it is four steps back. That is normal. It isn't easy to know on a day-to-day basis if you're making progress or not. Only after I reviewed my notes did I realize I was making progress. That understanding was cathartic, and it consoles me to this day when I grieve.

Unbeknown to me, my regular note-taking was a form of journaling. Had I been aware of journaling's benefit, I would have done a more complete job of it. I strongly recommend if you are in the throes of grief, keep a journal of what you are experiencing, both the good and the bad, and you, too, will be surprised by the progress you make.

This is my journey of grief. Hopefully, it will help with yours.

*Only after
I reviewed my
notes did
I realize
I was making
progress.*

*I place
photographs
of Eileen
prior to
PSP around
my home.*

The first six months, I'm in a fog.

- While I was Eileen's 24/7 caregiver, I never got sick. Right after her death, I was sick for two weeks, then again a few months later.
- I am emotionally numb with difficulty concentrating.
- I feel relief. Eileen is no longer suffering, and I am no longer consumed with her care.
- I feel guilty that I am relieved. Am I in denial?
- I have trouble sleeping.
- My memories only center on Eileen's illness.

My actions:

- I see a grief therapist who explains that because PSP is a prolonged and terminal disease, I suffered from anticipatory grief during Eileen's illness. Feeling relief is a normal caregiver reaction.
- I stop watching the national and local news on TV because it is adding stress to my grief.
- My pastor lost his wife five months prior to Eileen's death. He and I meet twice monthly for lunch.
- I visit family and out-of-town friends.
- I place photographs of Eileen prior to PSP around my home, trying to remember her when she was healthy.
- I speak with my daughters about their journey of grief.
- I settle Eileen's estate.
- I donate Eileen's wheelchair, shower bench, and other items.

The next six months, reality sets in.

- I experience a fresh wave of grief remembering the wonderful life Eileen and I shared.
- I cannot believe Eileen is gone; I am now alone.
- I still have trouble sleeping.
- Sudden temporary upsurges of grief come out of the blue, triggered by a song or a familiar place.
- Could I have done more to help Eileen? Did I tell her "I love you" enough? I regret being short-tempered at times.

- Well-meaning friends want to fix me up with dates.
- I'm not ready to sort Eileen's clothing and belongings.
- My daughters have their own lives to live; I will not be a burden.

My actions:

- I join a bereavement support group and rejoin a volunteer organization I had been active in.
- I reconnect with my coffee group and resume golf and walks.
- My daughters clean out Eileen's belongings. I save a few favorite items.
- I'm "being strong" for my daughters and family.
- I'm slowly coming to understand that I did all I could for Eileen. It was the PSP I was short-tempered with, not my loving wife.

Surprises:

- On several occasions, birds, especially cardinals, arrive at the moment I am grieving. I believe Eileen is with me in spirit, and it is very comforting.
- I think I see Eileen on three occasions; however, when the woman turns around, it is not Eileen.
- I learn who my true friends are. Some "good friends" have not contacted me since her death; others keep in contact and are really helpful, inviting me out to dinner.

The second year, I am told, is the toughest time.

- I am grieving less frequently, but when I do, it is much deeper.
- I realize Eileen will never return. I have no one to confide in or share day-to-day life.
- Three close friends die, adding to my grief.
- I still have trouble sleeping.
- Holidays and anniversaries are difficult, but my grandchildren's special events are even more so since Eileen enjoyed them so much.
- I stay busy, but I have lost my sense of purpose. Nothing seems to matter.

*I'm coming
to understand
that I did
all I could.*

- I go to dinner with “couple friends” and feel like a fifth wheel.

My actions:

- My pastor asks me to start and facilitate a church bereavement support group, and I accept.
- CurePSP calls and asks me to co-facilitate a new Connecticut PSP support group. I accept and join the Patient Carepartner Advocacy Committee to continue Eileen's legacy of clinical trial participation and brain donation.
- The facilitator of my first bereavement support group asks my pastor and me to help a woman and her pastor start a similar group.
- A good friend asks me to join the board of directors for a community television station, a field of which I know little, but I join.
- I spend more time with my four daughters and their families.

Surprises:

- I now feel as though I'm making a meaningful contribution working with organizations that help people.
- The woman I assisted in setting up her church's bereavement support group is a widow close to my age. After our second meeting, I ask her out for lunch. We continue to enjoy each other's company, sharing day-to-day joys and disappointments, and we have a safe space for both of us to discuss our grief.
- I now express my grief and ask my daughters to do the same. "Being strong" wasn't working.
- I had the wedding ring I had worn for 52 years resized and now wear it on my right hand.

The third year and beyond, acceptance begins.

- I have many more good days than bad; the wound is not as raw.
- I have fewer upsurges of grief but still have trouble sleeping.
- I am not “moving on.” I am “moving forward.”
- I still think about Eileen every day.
- I am learning to live with life’s joys and sadness.
- I am alone, but I am not lonely.

I can honor my loved one by:

Al was my kindred spirit.

My husband, Al, and I shared 34 magical years raising our son and daughter, enjoying our grandchildren and extended families.

Al's PSP journey ended peacefully at age 69. The grace and bravery that Al demonstrated during his journey and in his final days, well, those things just came naturally for Al. As tough as the PSP years were, Al harnessed every small joy, and I was blessed to have made his final years with PSP good quality years.

Early months of bereavement: in shock

- As I transitioned from anticipatory grief to loss, I felt numb, physically and emotionally exhausted. The loss of his presence was immense. A month prior to losing Al, I lost my father. After these collective losses, I developed my own medical issues. With my family's support, I took time out to heal and regain energy.

First holiday season: unexpected gifts

- My spirits are lifted with the birth of our third grandchild, Ruby. I felt Al's happiness looking down on this blessing.
- I dread the upcoming holidays. An awesome friend presents me with an unexpected gift—a glass heart with a photo of Al in his pre-PSP days and Al's words "I love you" etched into the glass.
- I plough through paperwork and sort through Al's clothing for donation.

The new year: venturing out

- I accept a dinner invitation with a close-knit group formed during the PSP years. While caring for Al, I co-planned a movement

disorder exercise class for patients and caregivers. The group was great for our physical and emotional needs—an unexpected gift.

A refresh

- In February, I make a solo trip to the West Coast to surprise my grandchildren and meet Baby Ruby. I fly on Valentine's Day and look at photos from our last Valentine's Day together. I feel Al is guiding me on this trip.
- I bond with my new grandchild and once again feel joy. My daughter and grandchildren, unable to travel for Al's service, grieve with me. We take walks, reminisce, and go to the beach where the kids create hearts in the sand and collect rocks for Grandpa's resting place back east.

Finding purpose and support

- CurePSP reaches out to inquire if I am interested in working on a project. I am grateful to help others in the PSP community and meet the clinicians, professionals, and caregivers behind this impressive organization. I rejoin the workforce, attend a hospice support group, and reach out to others during COVID-19 isolation.

Takeaways so far:

- *I must care for myself by walking and gardening.*
- *Loss stays with you, but joy can be part of life again.*
- *Achievements are small steps forward.*
- *It's okay to not be strong and resilient every day.*
- *Life goes on; responsibilities do not go away.*
- *Getting support is essential to moving forward.*

*I feel Al
is guiding
me on
this trip.*

*The loss of his
presence
was immense.*

*I took time
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A loving one-year memorial to my father, Al

It's been one year since my father's passing. What wouldn't I do to get him back, have one more conversation? Ask him some questions I never got a chance to. His wisdom and knowledge were incredible. His love and devotion to helping anyone he could was admirable. All he ever wanted was the best for everyone, no matter if it was family, friends, or a complete stranger. His strength was incredible.

Today, one year later, it still feels like it was yesterday. I still can't believe he is gone, but although physically he may not be here, I know he is here in spirit, watching down on all of us.

A comforting memory of my loved one is:

ROXI PADRID

Grief has its own timetable.

When asked to write about losing my mother to PSP, I started and stopped many times; reliving the journey was just too painful. My mother died five and a half years ago, and I'm still surprised how raw my feelings are.

When my mother first developed symptoms, she was misdiagnosed with Parkinson's disease for five years. After testing at the Mayo Clinic, her diagnosis was progressive supranuclear palsy, a disease we had never heard of.

My mom, Lu, was my best friend. She was very beautiful and always looked much younger than her age. She was a local model in Kansas City and was very active. My stepbrother and stepfather were mom's primary caregivers in Kansas City. I lived in Albuquerque with my husband and went home every six weeks. Looking back, I don't know how my stepbrother and I survived. Unfortunately, my stepfather didn't, dying four years before Mom.

At first, my mom was still Mom. As the disease progressed, her speech became unintelligible, she began falling, and her ability to walk was severely compromised. I watched PSP chip away at my lovely, strong mother, and I grieved the loss of her every day. This type of grief has a name I had never heard of—anticipatory grief.

Four years before Mom died, I began seeing a grief therapist and learned I had to walk through pain—not run from it. I looked for a local support group. Not finding one, I started a group for families, caregivers, and loved ones of people with PSP, CBD, MSA, and LBD.

When Mom died, she had a feeding tube and a catheter, and was unable to speak, walk, or move. I was relieved—she was finally free of PSP—but felt guilty because I was relieved.

For me, loss came in waves. After my mother died, I frequently wrote down what I was feeling.

A few thoughts:

- *The sadness is always waiting... brought on by a smell, a song, or my reflection in the mirror, my expression so like hers. I will never see her or speak to her again. Ever.*
- *Watching a parent die is like ripping the mask off your illusion of safety. You realize in the not too distant future, this could be you. I am an orphan.*
- *Sometimes the grief is so heavy I can hardly hold it.*
- *I even miss the things about my mother that irritated me. I wish I'd been a better daughter, taken more time to be with her. I miss her unconditional love.*
- *I have learned that time doesn't heal all wounds. It has, however, allowed me to remember the good times, to enjoy life, laugh, and live without her.*
- *I will always be her daughter; she will always be my mother. I will always remember and love her. And life goes on.*

I wish I'd been a better daughter and taken more time to be with her.

Four years before my mom died, I began seeing a grief therapist.

I feel most connected to my loved one when:

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NANCY FREHILL

I will never not miss my mom.

I write from the viewpoint of an adult daughter who lost her mom, Janet Jean La Rosa Hohn, to PSP and the effect her death had on my dad, Harry. My dad wanted to fix things so that they could be Harry and Janet again—a team since they met at a New Year’s party at the age of 16, but he had no power over the devastating disease called PSP.

Mom ran the home, raised four daughters—Harry’s Harem—and volunteered. Dad attained the American Dream, tirelessly working long hours for his family, and became a captain in his industry.

Like many, my mom was first diagnosed with Parkinson’s disease. When she finally received a PSP diagnosis, my grieving began. I memorized the description: “progressive supranuclear palsy (PSP), a neurodegenerative disorder with no known cause or cure.”

I panicked. Was the diagnosis accurate? Were there other, perhaps better, doctors to care for her? People describe this mode, this attitude as denial.

I became consumed with caring for my mom, almost to the neglect of my own young family. At first my mom was adamant about not needing help. My mom and my dad would manage “just fine, thank you very much!” When safety issues emerged, uncomfortable conversations were necessary. With the assistance of a social worker, my family muddled through these difficult conversations.

On a quiet and still morning, my mom, who had been hospitalized for pneumonia, passed away, ten days before her 83rd birthday. I feel honored to have been by her side and let her know that it was okay to let go. Her experience with PSP had been long—at least ten years—and she had given it a good fight.

*I became
consumed
with caring
for my mom,
almost to
the neglect
of my own
young family.*

Losing my mom was incredibly difficult because she loved me unconditionally and was my biggest fan and loyal supporter. She taught me right up to the end of her life to be brave and face challenges head on, to love fiercely, and to have the grace to accept what you cannot change.

The year was filled with sad firsts. Holidays, birthdays, and summer beach weekends were profoundly different without my mom. Dad seemed older and more frail. My dad was hospitalized, and within weeks, he died, nineteen months after mom had died. My sisters and I were shell-shocked.

After my parents' deaths, I learned to adjust to my new reality. As a CurePSP peer supporter, I have the opportunity to share my mom's story to help others. I appreciate the opportunity to offer thoughts about my grief process. It has been therapeutic for me, and I hope it proves helpful to others.

Living life to the fullest

My Grandpa Jaja was diagnosed with PSP in June but had developed symptoms as early as almost three years prior. I was just 13 years old and didn't fully understand what was happening.

What I remember is my mom telling me one sunny, summer day about grandpa's PSP. My first thought was that there was a cure, and it would be just a couple of months for Grandpa Jaja to return to himself. Except that didn't happen. The crazy disease of PSP was gradually taking Grandpa Jaja away from me.

The beginning

At first, when Grandpa Jaja stumbled, he usually managed to catch himself. As the disease progressed, falling and getting back up was a challenge. Grandpa Jaja was 5'11" and weighed about 290 pounds, and when he fell, he fell hard. Once, I was at his house in the country, and my grandma, whom we call Busia, went out to cut the Christmas tree. We were gone for only a short time, and, of course, Grandpa Jaja got up because he wanted some crackers. Instead of crackers, he found the floor. We ended up in the ER, where my grandpa got seven stitches.

As PSP progressed, Grandpa Jaja barely talked. He listened a lot and nodded for what he wanted. The one thing he always did when I was around was sing. He sang "You Are My Sunshine" and "Do-Re-Mi." I loved it.

Grandpa Jaja would already be in bed when we arrived on Friday nights. I would jump on his bed, and we would sing. Neither of us had good voices. But, singing was a way for me to hear his voice, and it made me feel like we shared something special. Those singing

moments hold a very special place in my heart, and every time I hear those songs, I think of Grandpa Jaja, and I smile.

Grandpa Jaja, my hero

Even as PSP progressed, Grandpa Jaja was brave, and despite setbacks, the harsh realities never took his spirit. He used to say, "It's not over until God calls me home." I cherish those memories and the love we shared. PSP took so much from him, yet he showed me things I will never forget, and that is how I want to be when I grow up.

He showed me that happiness is created. Always do the right thing and work hard. Enjoy life and give thanks to God. Think before you talk. Sing when you can't speak, and always be warm, happy, loving, and forgiving.

From Grandpa Jaja, I learned what living life to the fullest means. We must gather our strength and face challenges with a smile on our faces. Life is short, and later is never promised.

Singing with him was a way for me to hear his voice.

My Personal Journey:

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About CurePSP

CurePSP is the leading nonprofit organization working to improve awareness, education, care, and cure for devastating prime of life neurodegenerative diseases. These include progressive supranuclear palsy (PSP), corticobasal degeneration (CBD), multiple system atrophy (MSA), and others. They often strike when people have careers, family responsibilities, and active lives. Their symptoms are incapacitating, and there are no known causes, treatments, or cures.

Research has shown that there are important links between prime of life diseases and more common neurodegenerative conditions, such as Alzheimer’s disease and Parkinson’s disease. Your support will help advance this research, provide resources for families and caregivers of patients, and better educate the healthcare community. Together, we are unlocking the secrets of brain disease.

CurePSP is a not-for-profit 501(c)(3) organization. Gifts and pledges of support are encouraged, and donations are tax deductible to the extent allowed by law.

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