

THE LITTLE THINGS, AND LIFE AFTER LOSS

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Every evening, he made her a cup of tea.

It was a simple gesture, part of the familiar rhythm of their life together. Now, after his death, evenings are the hardest part of her day. The absence of that cup of tea carries the absence of the person who made it.

When I spoke with six widows and two widowers about losing their spouse after living with Parkinson's, it is often these small moments that bring the depth of their loss into focus. A little squeeze around the waist. A song. Something ordinary that happened during the day and would once have been shared.

"I miss the nothingness," one person tells me. "Random little things that happen during the day just don't anymore."

There is humour, too. One participant recalls the "nonstop running of the vacuum," adding, "don't miss that." There is room for an affectionate laugh alongside the sadness. Remembering someone means remembering their habits, their quirks and all the everyday things that made a life together.

Each conversation is different. Yet there are shared experiences: lives changed by a diagnosis, years of adapting, the complexity of saying goodbye, and the question of what comes next.

A future that changed

For these couples, Parkinson's changes life in ways both large and small.

One couple chose to retire so they could spend as much time together as possible. Their future had changed, and time together became the priority. Their experience is a reminder to make memories while you can.

For others, even interactions with people outside the family can become complicated. Facial masking can mean a spouse is repeatedly asked whether they are angry or sad. People see an expression without understanding the person behind it.

Some participants also describe feeling unsupported by the health care system. One recalls a difficult experience with a physician that made the diagnosis the worst day of their lives. Others speak about the exhaustion of feeling that every step requires a fight. Support for the care partner matters within that experience. Knowing their spouse has someone to turn to can also bring comfort to the person living with Parkinson's.

The diagnosis changes conversations within families, too. Being open and honest with children

becomes more important, and that openness continues after the loss. Hearing children and grandchildren bring up memories of Mom, Dad, Grandma or Grandpa brings happiness. Their loved ones still have a place in family conversation.

More than one feeling

For some, grief begins long before their spouse dies.

As Parkinson's progresses, there are losses and changes over time. Couples adjust expectations, routines and the ways they spend time together. Some participants feel that this gradual grieving has made the final goodbye less heavy than they might otherwise have expected. That is their experience; it is not everyone's.

After death, sadness can sit alongside relief that their loved one's suffering has ended.

Guilt is also part of several conversations. There are questions about whether more could have been done, about the circumstances of the death, and about what their adult children had experienced. Those questions can remain even after years of devoted care. But there's also an enormous sense of relief that comes from knowing your loved one is no longer suffering.

Then comes another adjustment. For someone whose partner lived in care, being at home alone may already be familiar. But there is a difference between living alone and being alone. Their spouse is no longer somewhere they can visit or call.

The end of caregiving can also leave a loss of purpose. After being needed for so long, what does a day look like when those responsibilities are gone?

Finding a different way

A common theme is the importance of allowing life to take a new shape.

Several participants speak about choosing new experiences instead of trying to recreate those they had shared with their spouse. Familiar activities and places can feel different now. Giving themselves permission to do things another way helps.

That includes family traditions. Something that has always been done together does not have to continue in exactly the same form. "Used to" isn't your responsibility.

There is permission in that thought: to change a celebration, make a new plan or decide that something no longer works. Memories can remain meaningful without becoming obligations.

Music holds a particular place in remembering. A familiar song can bring a smile one day and overwhelming emotion another. The same memory can feel different depending on the moment.

People trying to help do not always find the right words or actions. Participants speak about remembering that most mean well. At the same time, their experiences show how individual support needs can be.

Staying connected

The advice they offer is practical: get outside, find a hobby, join a group, volunteer, consider a pet. Reach out when you need to - people often want to help.

"Don't disappear" is a message that stays with me.

For some, the relationships built in care partner support groups continue naturally after their spouses die. They have already shared so much. Remaining connected as widows and widowers means being with people who understand that history. Others find those connections too painful and choose to step away from the Parkinson's part of their lives. Both choices deserve respect.

What emerges from these conversations is room for different ways of grieving and living. There can be comfort in company, purpose in helping others, or pleasure in trying something new. There can also be difficult evenings and songs that still bring tears.

The invitation from those who share their stories is to live your life and do the things you want to do, with space for the person you miss.

And sometimes, that person is remembered most clearly in the smallest thing: a laugh about the vacuum, a squeeze around the waist, or a cup of tea. ■

