



LOVE, DIGNITY & PARKINSON'S

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FIVE DEMENTIA CAREGIVER STRATEGIES THAT PROTECTED MY MIND AND SPIRIT

For years I struggled with caregiving.

I thought I had to ignore my needs.

I wasn't alone in this.

I see this with so many caregivers.

Some of us believe we must sacrifice everything else we love to the responsibilities of caregiving.

We have been influenced by the myth that our love for a person with dementia requires that we only think of their needs. The myth that it's never ok to put ourselves and our own needs, or the needs of other family and friends first.

Somehow we imagine that if we are struggling and sacrificing everything it makes the person whose mind is in decline more comfortable and somehow better.

To this, I say...
NO.



Now, I did not know this when I first made the shift from care partner to caregiver. But then I learned that there are two separate roles.

The first was the role of loving and honoring my husband, who had Parkinson's dementia: of spending time with him, enjoying time together and helping him to feel loved and secure. The second role involved meeting his hands-on needs.

As my husband lived and eventually died with Parkinson's he had all my love every day. At the same time, he received support, care, encouragement, and companionship from me and from others as well. Learning this difference gave me so much relief.

I realized that not only was it allowed for me to pay attention to my own well-being, it was necessary. And I started to learn how to do that.



Today I am the bestselling [author of a book on being a Parkinson's caregiver](#) and I have another one in the works that will help caregivers get help.

I communicate regularly with many many dementia caregivers to help them distinguish their loved one's need for love and their need for loving care.

It's not exaggerating to tell you that caregivers regularly let me know how my work helps improve their day. I am determined to make my customers' lives better. I hear from them nearly every day about how much they appreciate the work I do.

I'm committed to making dementia caregivers' lives easier and less isolated.

I know there are things that I offer that can be helpful if you are looking to ease your life while giving even better care to your loved one.

Here are five things that transformed the way I lived the caregiving life. These five things made my mood and energy better, gave me better clarity about my role as a caregiver, and freed me from guilt, exhaustion and isolation as I walked the dementia path alongside my husband.

1. SELF RESPECT

Each case of dementia is unique and this is especially true of Parkinson's, which we experienced. But in any form of brain failure, people can lose touch with more than memory and knowledge.

As dementia progresses a person can lose their empathy for other people, their capacity for relationship.

I know this was an important discovery for me as a caregiver. When I first realized that my husband could not care about me anymore, it was wrenching.

But over time, I looked inside myself, understood that this was not his fault, and that if someone, somehow, was going to care about me, I had to do it myself.

It took me thought and insight to recognize that caring for myself was doing something my husband could not do for me.

Not anymore.

He always had cared about me, and if he could still do it, I knew that he would. So, like driving, and cooking, and buttoning his shirts, and dozens of other abilities that dementia had stolen, this ability was gone too. This was something I had to do for him.

As your loved one's mind fades, they too may have stopped being able to recognize or care about you. About your reality. About how hard you're working to help them. About how tired and sad you are.

This is not a moral failure.

Your relationship may have always been deeply loving. Or perhaps it has not. But as dementia progresses, your loved one, husband, wife, partner, parent, child, may lose touch with their relationship with you.

They may no longer recognize your feelings. What you need. What worries you. What gives you joy.

You start to feel invisible.

And when this happens when the person in brain failure loses the ability to see what other people want or feel, the caregiver must do it for them.

You, the caregiver, must hold on to your own needs, wants, and feelings.



This means you need to know yourself. To know your own feelings, wishes, wants, worries, and needs.

Caregivers need self-respect.

Being a caregiver means you cannot only *serve* your own needs. That is probably not good for the person you are responsible for.

But it does mean this:

As a self-respecting caregiver you must never lose touch with your own humanity.

Each situation you face must include awareness of both people's needs.

I always feel so sad when a caregiver says, "I'm at the end of my rope." or "I am worn down and burnt to a crisp."

What an awful feeling for the caregiver.

What an awful experience for the person with dementia.

It seems to me that such a caregiver is treating self-care as selfish. Like there are little children somewhere who are arguing "My turn!" " No, my turn!"

As if self-care and caregiving are opponents.

These caregivers seem to think "if I notice what I feel or what I want, I'm a bad caregiver."

I surely do not agree with that. And it's important to know that our suffering does not improve our loved ones' lives.

Now, if you struggle with keeping your own needs in the picture, you might want to use this recorded meditation.



[Click here to listen to the meditation.](#)

(It's free, or you can choose to leave a gift to support the work).

Listen to it to reconnect with the feeling of being respected and valued. It's based on the way I helped myself to remember that what I was doing was hard, and deserved respect.

2. CONNECTION AND KINDNESS

I heard a story years ago about a very old woman. She had been lying in bed for weeks, never speaking, not even opening her eyes. It seemed that she was simply waiting for the end to come.

An aide came in one day to give this patient a sponge bath.

She was careful as she cleaned the woman. She described each step as she did it, and even refilled the basin to keep the water warm.

The bath over, the aide cleaned up her supplies, and turned back to the patient to smooth her sheets. Then before she left the room, she paused. She let her hand rest on the old woman's head.

That's when something unexpected happened.

The old woman opened her eyes to look into the aide's face. Her smile was clear, and with a voice creaky from disuse she said, "you care."

Care is so important.



And people with dementia need to feel safe and cared for. No matter how disorderly and disconnected and discouraging their behavior is.

Your relationship with this person may have been deeply loving. Or it may have been more complex or even difficult. But with dementia, that past relationship can be fractured, diminished, and even completely lost.

In our caregiving we must release these past connections, both the positive and negative ones. Then we can find a way to approach each caregiving encounter with the unspoken question. "How can I be loving to this damaged, diminished, person who is here with me right now?"

You don't even have to get it right. You just have to care.

There is one thing I had said to my husband many times over as his brain failed. When he was very frustrated and angry, I would say this:

"Peter, this is me. I am your wife. I didn't cause your Parkinson's, and I'm so sorry you have to go through all of this. I'm right here to help you. We will do this together."

I reminded him that I loved him. That I recognized his struggle, his unhappiness, and his fear. I told him that I wouldn't leave him to manage it on his own.

I remember sitting with my husband in the last months of his life in a waiting room after a strenuous medical appointment.

We were waiting for the transport van to bring us back to his memory care home. As we sat, he became increasingly distressed and agitated. He started to shout that he didn't trust me. That he was angry. That he did not want to be here anymore and wanted to get away.

At first, I felt surprised. Then I felt embarrassed. But when I slowed myself down to listen, what I heard was his fear.

And connecting with him made it easier to know what to do.

I used his name and spoke to him. Slowly, without agitation in my voice, I told him, "I know you're scared. I know you don't want to be alone. I can't fix your Parkinson's. But I will make sure that you are not in pain, and you are never afraid."

I said this to him gently but intensely. I am sure that my tone, my desire to connect with him mattered as much as in the words. It took repetition for him to truly hear me and to absorb what I was saying.

Once he heard me, he became calm. He looked right at me and said, "That's what I want. That's what I want."

Out of an episode of agitation and anger grew a deep, personal, and intimate moment.

I could not stop his Parkinson's.
I could not stop his dying.



But I could do everything I could to make sure that it was a loving and accompanied experience. My desire to be connected and kind enabled me to offer him the best that I had in the last months of his life.

3. HUMILITY

Where did we get this idea?

That as caregivers we can and should single-handedly do everything that our loved one needs. That this is true from the moment that we learn about the diagnosis through the end of their lives.

Is it a boost to our self-esteem if we believe these things?

That we don't need anyone else.
That I, Super-Caregiver, can do it all.
No one else can help like I can.

Well, most experienced caregivers will tell you that just ain't so.

In almost every case you're going to need help of some sort. And isn't it strange that once we finally turn to others for help, we feel a sense of loss? We feel that we have failed somehow?



This is unnecessary. Why give yourself that disappointment? Why do we expect ourselves to be stronger than our person's diagnosis?

I know that there are a lot of T-shirts and slogans that suggest "you got this" or "you're stronger than you think."

Well, I want to say this, Let that stuff go!

Yes, you want to preserve your love and relationship with your PWP. Especially if the PWP is a beloved spouse.

But I am convinced of this. There is little benefit in viewing this caregiving life as a pitched battle against dementia.

So here is a T-shirt slogan I like better:

"You were supposed to climb that mountain - not carry it on your back."

4. CURIOSITY

When your loved one's mental abilities start to fade, it can be tough to stay calm. It's only natural to crave order, familiarity, and predictability. But the truth is, our loved ones will change.

They might say or do things that seem unpredictable or even irrational. And these changes can leave us feeling disappointed or frustrated.

When you take on the role of dementia caregiving, you can expect that such things are going to happen. There will be new behavior, new symptoms. Ones that you don't expect and don't recognize.

That's why curiosity is a huge asset for us as caregivers.

When something pops up that we don't recognize, instead of asking "how can I fix this?", we can ask ourselves different questions. "Now what is this new thing? How can I figure it out?"

When we respond with curiosity, it means we don't try to resist or fight against the unchangeable. We're not undone or devastated by it. Instead, we're simply curious. That gives us serenity—like in the familiar prayer—to accept what can't be changed.

Sometimes, you can figure out things on your own.

But it often helps to check out online communities. These resources can provide valuable insights from other caregivers.

They can give you a better idea of what to expect. And these welcoming places let you ask other caregivers directly for their ideas to help with the specific questions you have.

Other places to find answers include web pages, [books like the one I wrote for caregivers](#), or ones with a more medical focus.

And when the time comes for more one-on-one support a coach, consultant, or counselor can lend a helping hand. These professionals can help you keep your own needs and well-being in mind and build your sense of curiosity as well.

Curiosity served me well at times when my husband did not know who I was.

He didn't remember me.

He did not recognize me.

With curiosity I was able to imagine that he may have been thinking this: *I don't know who this person is. I feel her taking care of me as tenderly as a mother, so maybe she is my mother.*

And thus, he asked "Are you my mom?"

Wow!

Being curious about this new and frankly unnerving development helped to soften this blow. It helped me say "Oh no, I'm not your mom . But I do love you and I'm here to take care of you."

My response made this new loss much easier and less painful.

I'm sure I felt wounded in this new moment. Still, I was able to focus on the deeper truth in the moment. That he could tell I was loving him and caring for him and he was trying to sort out the details.

There is freedom in approaching the behavior of a person with dementia with this kind of curiosity. With the wish to understand.

Since we know life is changing, we don't have to immediately know what to do. We can simply be there to listen deeply and attempt to understand.

Being open to change allows you to approach each encounter with your loved one, each day of caregiving, with a sense of wonder and curiosity and readiness to listen and learn.

5. OPENNESS AND ACCEPTANCE

The advances of modern life, and especially modern medicine can make us believe that everything can be fixed if only we try hard.

But human life is frail. We are not robots, made of stainless steel and plastic. We are fragile, made of flesh and blood, love and spirit. Aging and sickness are a natural part of being a human being, just as death is a natural end of human life. But loving and spirit last.

Being a caregiver brings change and loss. There's no getting around this fact. But. If your benchmark is always "the way things used to be," if you stay focused on trying to get your partner back to some past that you remember, or trying to finally achieve some way of life that you have hoped for, then you're facing an unrealistic set of expectations.

Being a dementia caregiver means living with today's losses and the awareness of more to come. Therapists call it anticipatory grief - the sadness of losing someone who still seems within reach.

Will you experience loss? Absolutely. Sadness? Yes, indeed.

But if you combine curiosity, humility, connection, and self-respect, you create space to acknowledge the reality of the present. Both the reality of the loved one's condition along with the reality of your own feelings, wants and needs.

The question is not *whether* our loved one is ill with a disease that has no cure--we have no choice over that.

The question is not *why* our loved one is ill with the disease that has no cure. Or why our loved one (like all of us) will die - certainly we have no choice over that either.

Instead, we can face the how question much more easily and with greater health, greater grace, and greater happiness. Not what we will do – but how we will be.

How are we going to accompany our loved one in this experience--this fully human and perfectly natural experience of illness? This is where we can choose.

Thank You.

I hope you've been helped by reading this and have found value in these 5 things that helped me reset how I lived my days in caregiving. (My husband died four years ago, but I'm still doing caregiving at times.)

I appreciate you taking the time to read this. I hope you got value out of this document, and I appreciate you being in my world.

Your suffering does not benefit your loved one.

It's your giving of care and attention and love—however you choose to do these—that honors the world and your loved one.

And for these, I honor you.

Terri (Your Work Matters) Pease

