

A Thousand Pin Pricks

This article is dedicated to the courageous caregivers who stand guard with watchful and caring eyes over the tragic loss of their loved one from the diseases of Alzheimer and dementia.

By Sharon Fox

A thousand pin pricks describes the tiny little losses that the caretakers observe as they see their loved ones slip away. Not wounds from injury, but little bits of function and personality that are gone due to the diseases that robs humans of memory, without their own ability to control and usually an inability to recognize they do not remember what they do not remember.

The caretakers of parents or spouses see the diminished capacity from initial symptoms to the inevitable closure of life. Like a black sheer curtains dropping layer by layer, the essence of what was cherished about the loved ones grows more distance. Each day a grief event evolves in layers as well. Causing not only the surety of the pending death of the loved one, but the loss of the companionship, the partnership, the shared memory pool and the expectation of a future that could have been shared and enjoyed are now gone.

Perhaps the stages of your loved ones has been a recent diagnosed. Or perhaps you are well into the functional loss of memory stages where your awareness of every aspect of their life and in fact of your life are requiring your full focus.

Locks and sound systems on door, reminders of how and when to bath, where the bathroom is located, how to use the phone, and who you are all prick the soul of the caregiver. It is in these isolated and sometimes desperate moments that knowing that you are not alone is the only sane and calming thing you have to hold on to.

As a Christian, the belief that from the very announcement of the birth of Christ his promise was proclaimed. “Emanuel. God with us.”, we have been assured that we are not alone – ever. There is no doubt about that. Clearly pronounced to all who believe, God does not forsake those that serve and care for others through the faithfulness of love. You are NOT alone. Even in the early morning hours when your exhaustion, both mentally and physically has lapsed, you are into the bone aching collapse of attempted sleep, God is with you. Financial and living accommodations as well as your health may be pressing in to the point that it feels like breathing will take too much energy to accomplish. God is with you.

Psalm 46: 1-3 reads: ***God is our refuge and strength, an ever-present help in trouble.*** *Therefore, we will not fear, though the earth give way and the mountains fall into the heart of the sea, though its waters roar and foam and the mountains quake with their surging.* NIV.

How do you cope? How do you feel? What can you rely upon to lean into for hope?

Because of the disease, the isolation of the caretaker becomes more acute. You know you cannot travel, cannot go out for a few minutes for a quick errand, cannot enjoy social events due to the limited capacity of the loved one. Impairment affects you too. The isolation becomes a way of life to the point that when interaction occurs some will describe the one who is “missing in action” your loved one, who is not there, literally physically or mentally results in a need to explain or redirect the conversation with others.

But to say that you are frustrated, feel cheated, angry, resentful of others, lonely, frightened for your loved one and for yourself is normal, does not help you cope. The fears you feel seem to wear “caution flashers” of “What if something happens to me?” or “What if no one knows that I am hurt or dead?” or “What will happen to my beloved if I cannot provide for them?” Or the little voice that says, you are the only one who cares for them. How can that be when we were once surrounded with friends and family? Daily the pin pricks mount up, not creating a flowing wound, but an ongoing hurt that is unhealable as long as your loved one is alive. Those words and thoughts reflect the common condition of caregivers across the world.

Let's look at statistic:

Dementia related disease is a National and International epidemic. Across all nationalities, and cultures and food supplies, we are living longer. What might have developed as dementia related diseases a century ago, are now rising in numbers because we have won the battle of polio, smallpox, treatments for pneumonia, and some cancers. The days of “they took sick and died” are gone. We can elongate life, but the result is the increased number of years of life has given rise to the number of dementia patients.

Currently these are over five million dementia patients. (Or 5-8% of the population according to data released in 2020.) The research on the cause and possibility of finding a cure is considered underfunded and strategically behind the oncoming demand to address the illness.

What do you do?

Dearest caregiver, you have one more important job. Self Care! Simple steps are critical for your life to be in a healthy balance.

- Eat nutritious and balanced meals
- Drink lots and lots of water to stay hydrated
- Stay on a schedule as best you can. Sleeping/resting is important
- Get your personal finances and Wills organized
- Plan the funeral
- Use your phone to stay in contact with family and friends
- Seek support from Alzheimer community organization if possible.
- Consider day care if that is affordable to ease your 24 hour duty hours
- Consider respite care or other options for hours, daily, overnight if available and possibly covered by insurance.
- Lean into prayer. These are not easy waters, but God offers the lifeline to keep you afloat. Even if the tasks do not change and concerns do not lessen, God cares about you and can lift the burden you carry. Ask Him.

These is an amazing gift given by God to those who suffer. It is the unexplainable gift of rising above the chaos of the current situation and seeing it through God's eyes. He has the ability to lift you out of the trauma but, not away from the situation. Prayer makes that possible. His gift of peace in the storm is miraculous. Reflect on this.

Sometimes God calms the storm. Sometimes God lets the storm rage and calms his child.

In the hands of the Savior.

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