

The Long Goodbye: Living With and Caring for Those Suffering from Alzheimer's Disease and Other Forms of Dementia

Author unknown

Alzheimer Prayer

Please grant my visitors
tolerances for my confusion
forgiveness for my irrationality,
and the strength
to walk with me into the mist of memory
my world has become.

Please help them take my hand
and stay awhile,
even though I seem unaware
of their presence.

Help them to know how their strength
and loving care will drift slowly
Into the day to come
just when I need it most.

Let them know when I don't recognize them,
that I will, I will...

Keep their hearts free of sorrow for me
for my sorrow when it comes
only lasts for a moment, then it's gone.

And finally, Lord,
please let them know
how very much their visits mean
how even through this relentless
mystery, I can still feel their love.

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By Rev. Charlotte Brown



As the elevator doors open, I step out on the 3rd floor. This area is what we refer to as the enclosed or secure unit in our 247 bed long-term care facility in London Ontario. The secure unit is for the safety of residents who suffer from Alzheimer's disease or other forms of dementia, especially those who are prone to wander if they were to manage to get outside by themselves.

I have come with my guitar and musical instruments to provide a weekly program which incorporates a spiritual theme as well as music and singing, including the old familiar songs and hymns. It is amazing how many of the residents remember the songs and hymns long after their ability to communicate in words has declined. It is as if there is a place deep within that enables them to recall those hymns they likely learned as children and have known all of their lives. Each week the group concludes by saying the Lord's Prayer together. Most are able to say the prayer word for word.

The residents respond in many ways. One resident, who was raised in Scotland and can remember attending church every Sunday as a child, often says, "I just love the old hymns". She is a joy to visit. She told the chaplain one day, "I know when I see you that I can trust you and tell you anything I'm worried about".

At every weekly group meeting, another resident always says "Jesus loves me this I know for the Bible tells me so". It was her favourite hymn. And in the final hours of her life, it was that hymn that the family asked the chaplain to sing with them as they gathered around her bedside. It offered a sense of comfort, not only for this beloved mother and grandmother but also for the family.

When one gentleman, a retired minister, was first admitted to the 3rd floor, he would often say "what can I do to help others". It seemed natural that he would ask this, as caring for others was something he had always done his whole life in his church ministry. We found that he was sometimes able to offer a prayer at the end of the program and was also able to pray at the bedside of a sick resident. I expect it gave a sense of purpose to his life.

A woman with Irish roots always says to me, without fail, when we meet, "you have nice eyes". One day I wore a skirt instead of my usual slacks at our weekly group. All of a sudden, with her best Irish accent, the resident looked right at me with a smile and said, "you have nice legs". She caught me off guard as it was such an unexpected comment from her. But we enjoyed a good laugh together.

Another resident who lives on a different floor is in the beginning stages of Lewy Body dementia. We met in the hall one day and she asked me if I would come and see her. When I arrived in her room later she said, "I just wanted to let you know that I had a very good day yesterday and wanted to share that with someone. I knew you would understand." This resident is confused most mornings now. She is at the stage where she is able to understand the seriousness of her disease and what the future will hold for her. To have a whole day spent with friends in the community without any confusion was something to celebrate with the chaplain who visits with her regularly.

I have recently developed spiritual/religious reminiscence packets with significant religious objects, one for Roman Catholics and one for Protestants. The idea, which I have found helpful in my work, came from a book by Larry VandeCreek titled *Spiritual Care for Persons with*

Dementia - Fundamentals for Pastoral Practice. One day after showing a crucifix to one of the residents, her response was “this is precious”. Sometimes the use of tactile objects seems to be helpful in the remembering.

Another aspect in my ministry as chaplain to those with dementia is to offer support to family members. I am always touched by the love and faithfulness between residents and their spouses who come daily to visit. One couple sit together every day holding hands, heads touching as they lean towards each other. They have been married for over sixty years. Their love and devotion for each other is obvious, despite the changes that Alzheimer’s disease has brought to their relationship.

Many times I have heard family say with sadness or tears, that she or he doesn’t recognize me anymore. When that time comes, there are some who find it too difficult to come and visit their loved one. It is then that the staff often become like family for those residents. However, one day I remember hearing beautiful violin music being played down the hall on the 3rd floor. When I got there, there was a young woman sitting by a resident, playing the violin for her. When I spoke with the woman afterward, she told me the resident was her mother. Although the resident no longer recognized her, the daughter came and played her violin for her mother regularly in the hope that the music might somehow evoke past memories within her.

I believe it was Mother Theresa who once said, “we can do no great things, only small things with great love.” Small acts of love and kindness shown to others... receiving so much more in return...a smile on a face when they see you even though they don’t remember your name but know you only as someone who cares...a hand held that doesn’t want to let go...praying together...singing from the heart...listening to stories about family or the longing to go home...calming and quieting a restless soul...

This is my ministry and so much more. I give thanks every day and consider it an honour and privilege to serve as chaplain in this meaningful ministry with the elderly and their families.

Rev. Charlotte Brown has served for many years as a diaconal minister in congregations in Chippawa and St. Thomas, Ont. and in regional work with the Atlantic Mission Society. She graduated from Knox College and was ordained in 1996, serving for five years as the Executive Secretary for the Women’s Missionary Society. After completing training in chaplaincy, she worked as chaplain at St. Joseph’s Health Care in London and is presently in her fourth year as chaplain at Chelsey Park Retirement Community, London. She has also completed the Jubilee Program in Spiritual Direction and hopes to expand her spiritual direction ministry in the future.

The Alzheimer’s Society Book Mark - “10 Absolutes Of Caregiving”

Never argue,
Instead agree.

Never reason
Instead, divert

Never shame,
Instead, distract

Never lecture,
Instead, reassure.

Never say, remember,
Instead reminisce.

Never say, “I told you,”
Instead, repeat.

Never say, “You can’t”
Instead, “Do what you can.”

Never command,
Instead ask, or model.

Never condescend,
Instead, encourage and praise.

Never force,
Instead, reinforce.

Author unknown

The Alzheimer’s Society
www.alzheimer.ca/english/index.php

Letters addressed to the Alzheimer's disease

By Elizabeth Jobb

The following letters addressed to the Alzheimer's disease were written as an assignment from my support group for caregivers. We were instructed just to let our feelings flow. I resisted writing the first letter but after it was written I felt so much better. The support group offered by the Alzheimer's Society has been a Godsend in my life. The social workers have been encouraging, instructive and deeply caring. The teaching is not only about the disease but also instructive in self-care. I would encourage anyone who is coping with Dementia to phone your local Alzheimer's society and ask about the support groups and day-away programs. I have learned to reach out and ask for help because caring for someone with Alzheimer's or any form of dementia is very demanding and time-consuming. I have learned that care does not need to be provided by one person alone. I pray that one day soon there will be a cure found for the disease. Elizabeth Jobb.

To The Alzheimer's disease. Letter #1

You are a thief! You are stealing my partner from me day by day. I am becoming a single mother with an adult child. I am 61 years old with a full-time job and huge responsibilities and I no longer have a husband who is able to support me... However, I am not powerless and you do not have any power that is greater than my love for my husband. Love never ends! Eventually your destructive powers will end. Even if my husband forgets who I am, I will never forget who he is and his love for me will always remain in my heart.

My faith will get me through the rough times ahead as it has already helped me up until this time. I will stand on God's promises that tell me that, "I can do all things through Christ who strengthens me and that in my weakness, God's strength is made perfect."

I will follow my shepherd and allow Him to comfort and nourish me. I will follow his leading to still waters for rest when things get rough. Even though I am currently walking through the valley of the shadow of death, I will not be afraid because the Lord is and will be with me.

You ultimately have no power, even if you take Herb's life because we are an Easter people and death has no hold on us. One day Herb will be renewed. He will be given a body that is perfect and can never be destroyed.

The commandment given most often in scripture is "Do not be afraid," so I will trust that no matter what you can do, God will not let us go and will continue to hold us in the palm of His hand. Life is a walk in trust, we don't know what is going to happen from one day to the next, but we do know that God walks with us and will care for us, no matter what.

Rev. Elizabeth Jobb graduated from York University with a B.A. majoring in Judaic Studies. She then went on to Knox College. Following her graduation from Knox she did her C.A.P. E. internship and Residency at St. Michael's hospital in Toronto. Following her C.A.P. E. training she was called to Knox, Guelph where she ministered for eight years. She met her husband Herb while she was in Guelph and they married in 1999. Elizabeth is now the minister at St. Andrew's Amherstburg. She has been there for nine years and loves the old and historic congregation and village situated on the Detroit River at the mouth of Lake Erie. Herb and Elizabeth have seven children between them and sixteen grandchildren. They also have a miniature poodle named Susie who is a great companion and comfort.

Elizabeth and Herb in past years loved to fish, go camping and just be outdoors. Herb was diagnosed with Alzheimer's disease four years ago and is now waiting for a placement in a nursing home in Amherstburg.

Letters addressed to the Alzheimer's disease cont.

To The Alzheimer's Disease. Letter #2

I just finished reading the letter that I wrote to you last year and I am still standing on God's promises to get me through whatever it is that you throw at me. You are a thief and you have robbed us of many things, physically, emotionally and financially but it is still true that you cannot steal our love for each other.

You cannot take away my friends and the members of St. Andrew are who have been such a great support for both of us. You cannot steal my memories of Herb when he was well. You cannot steal the beautiful poems that Herb wrote for me. You cannot take away the recording that I have of his wonderful tenor voice.

Each day that I have with Herb is precious and I will not allow you to steal those moments from us. When I awake in the morning with his arms around me, I can sometimes believe that you are just a bad dream, but when I come fully to my senses I realize that I have to face one more day with you. I have to face the blank look on my husband's face as the world becomes increasingly difficult for him to understand. I have to take on the role of detective in order to find out why Herb behaves the way he does, what he is needing and what he is trying to tell me. I have had to learn to think outside of the box for our safety and sanity. The one very good thing that has happened is that I have had to learn to laugh at so many things that used to make me cry, like Herb putting his pants on backwards, wearing the dog's leash for a belt and putting on my clothes instead of his own, including my clerical shirt that he put on underneath his sweater.

One day they will find a cure for you and when that day comes I will rejoice with so many other people who have been affected and afflicted by your stealing ways.

To The Alzheimer's Disease Letter #3

Another year has passed and you don't let up, do you, in depositing more and more plaque in my husband's brain? So much now that he has wandered into a stranger's home, totally confused as to how he got there. The house didn't even look like our home. How frightened he must have been when he was escorted out onto the street and told that he didn't belong there. I have no idea how he found his way home. He can no longer be alone even for a short while. This has certainly made me into a good juggler, trying to find people to fill the gaps when I am not at home. The evening is the worst time for Herb. He has "sundowning" which is the term used when Alzheimer patients become more anxious and agitated when the sun goes down. It's difficult to find people in the evening who want to deal with this.

You have certainly taught me a great deal over these years but I am currently very aware that much of the way I conduct worship services in nursing homes needs to be reconsidered. We are people of "the way" and people of "the word" but for people with dementia, the word is not necessarily good news as it cannot be understood. Ritual, sacrament, the taste of bread and wine, music, pictures, the holding of hands with a blessing must take a much greater role in how we praise God together. I have even thought of using flannel board as we did in Sunday school when I was a child.

More and more your presence will take its toll bringing the news of slow death to thousands of people. What you cannot do however is stop the church from ministering to people with Dementia and Alzheimer's disease. With the help of the Holy Spirit, as a minister, I will continue to explore new ways to reach these people in their confusion with God's love for them. Just try and stop us. You won't win.

Care for the Caregivers

Elizabeth Jobb is a minister in The Presbyterian Church in Canada. As such, she is part of a "helping" profession. Her work involves caring for others, sharing their burdens as well as their joys, and helping them through troubled times. But who cares for the caregiver? As Elizabeth continues to look after her husband Herb, she has recognized that she herself is in need of care. Her feelings of fear, sadness and anxiety are very real and she needs to be ministered to during this difficult time. Elizabeth wishes to stress that clergy in this kind of situation must seek spiritual assistance of their own. Elizabeth and Herb are currently both receiving Pastoral Care from the Anglican priest in Amherstburg, whose mother-in-law is in a nursing home with Alzheimer's disease. He very much understands the challenges.

By Terri Ross

My mother was diagnosed with Alzheimer's in 2004 only a few months after I was married. My husband and I became her full-time caregivers until 2008. The disease progressed to a stage where we could no longer provide the care she needed. I wrote this poem for my mother and me. Our favourite thing to do was chat about everything and anything over a cup of tea and a cookie. Even when she lost her words. I miss her.

In my mind I wander through the years long left behind.
And lately I find I am becoming lost there.
I stroll through the memories in search of familiar faces.
What time erases I replace and rename.
The way that I have renamed you.
You are someone I once knew
when I didn't need to be reminded of my own name.

The stranger in the mirror is stealing my money
and thinks it's funny when I can't find the bedroom door
I'm trapped in my room until you come and set me free.
Like a child with a night scare you rescue me from the darkness.
We shared tea time conversations, confidences, and reminisced.
I couldn't resist a bit of gossip or the way you made me laugh until we cried.
Then the conversations died
when I lost my words.

We said we would save our tears until we've parted.
We would not let go until I'm gone.
Then I slipped away and moved on to those years long left behind.
Search my stare but you will not find me.
A promise made is not a guarantee.
It's just as well we didn't try.
It is such a long good-bye.

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