

WHO ARE YOU?
[written in oral form]

Ecclesiastes 1:2, 11:5-10, 7:10
Topical - Dementia

Gordon Allaby
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Dementia can be caused by a number of things. Alzheimer's disease is one we are most familiar with. Also, dementia affects people in different ways. Those with Alzheimer's disease respond diversely, too.

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Except for offering a few helpful suggestions for responding to someone with dementia, I will not present a clinical study on dementia.

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For a spouse or loved one dealing with someone suffering from dementia, it feels like a long, painful death of the one you love. The sense of loss and isolation can be intense. Moreover, it is too demanding to be the sole caregiver. Help is definitely needed.

Family of someone with dementia are often slow to grasp the depth of what is happening. Periodic perceived symptom-free moments can delay loved one fully accepting the risks and needs caused by dementia. In the early stages, denial in family caregivers is typical.

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I will share four insights that I've learned that may be helpful in responding to one who has dementia.

1. Try not to remind the person about the memory loss, such as saying, "you already told me" or "You already did that."  
Venting the painful frustrations should be done on others.
2. Try to respond with creative calming answers, such as "Let me help you, toasters can be very difficult to use."
3. Think ahead and anticipate. Make the environment safe, and guide the sufferer into positive situations, such as doing things the person enjoys, and that joy may change, too.
4. As the dementia progresses, he/she will no longer realize who you are. This is a painful loss, yet it can be tormenting to the sufferer when told they are your spouse or your parent. We have to go with their ever changing new reality, while trying to present a peaceful presence.

Still, there is no template. Everyone is different.

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I won't refer too much to the passages that were read. However, I will highlight a few observations.

“Vanity of vanities All is vanity.”

The Hebrew word for vanity is hee beh, breath or vapor. Basically, it means futility, meaninglessness, emptiness; here for just a moment, but soon gone.

The writer is saying life is brief and futile, with no enduring significance.

The author, repeated the phrase twice for emphasis stressing utter despair and total futility. The passage raises the question “what’s the use?” and grievously petitions for reliable gain from toil and work. It's a protest to being unable to control one's destiny.

It's a complaint about finitude and the limitations of life, revealing the desire for control.

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Chapter 7 continues the protest, yet with the veiled hint that our past was Not as glorious as our fond memories declare.

In chapter 11, there is the advice to just let go and do the best you can do, and don't expect to control the outcome.

The writer seems to admonish the youth, but it is more a criticism of naiveté and self delusion.

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I don't think the youth today are naive. Their lives are a lot harder than mine was as a youth.

Unfortunately, they understand the futility that radiates from this text.

The lesson here is not an age issue, but an attitude, an awareness,....or better, a philosophy of life, that affects us– rendering despair.

The writer is saying we delude ourselves if we think that we can control our lives or predicate results. We can be young or old and embrace that delusion. The torture comes when we enviously look back, still filled with the delusion, and see the futility of it all!

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Sure, most of us know better; we **know** that we aren't in control but few of us really believe it or live that knowledge.

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Verses 9-12 of chapter 12 illuminates that inconsistency by mocking the pedantries of the wise and learned teacher, the author himself.

To be sure, we know better, but we still protest claiming if we suffer and pay for our errors, thenwe should be rewarded for our self discipline and hard work!

We deserve what we work for; we should be able to affect tomorrow.

But, life rarely unfolds that way; we can't determine our future.

We can't secure our rewards.

All the best efforts won't guarantee our safety, we can't guarantee our children will survive or even turn out as we had hoped they would. And so, we are left with a sense of helplessness, and life seems futile. Therefore, “All is vanity.”

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*Boy, on the surface, ...these passages Sound depressing. However, the author may be trying to prompt us to a higher level of awareness?*

And, Sometimes, awareness is best shared through a story.

So, I'll share a story.

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October, 23 years ago, after a fog delay, the plane I was on, lifted off the ground up **into the clouds** heading for Florida.

Life was not unfolding as planned.

I thought that I had things all in order: Jessica was beginning her first year at university, I had just started as pastor at my first Mennonite church, and marriage with Leslie was just a couple months away.

Things were looking good, but now I was gazing out the window into the clouds heading to Florida. My father was in the hospital, there in Florida– a victim of caring for my mother who was suffering from Alzheimer's disease.

The constant, draining devotion to her had taken its toll, and was **killing him**. He **thought** he could care for her by himself.

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She couldn't be left alone, so my sister, Carolyn, had rushed down there to care for her, but she needed to leave because her son was getting married. So, it was my turn to be there.

In the plane, my thoughts were spinning.

**This was not on my agenda! I had other plans!**

Plus, I was scared to death of what I was about to experience. Carolyn, had called a number of times, in tears from the tremendous drain of caring for my mother in her condition. And, Carolyn was much better at that sort of thing, than I was.

I thought, **can** I handle it, and .....what if I can't?

Then my thoughts leaped into angry accusations:

We tried to get my father to yield to professional care for mom but no, "I can handle it", he would say. We tried to persuade him to move back close to us, but he, also balked at that, too.

He had planned for a long time to retire in Florida, and he wanted to stay there. He would not let go of his perceived destiny.

This whole scenario should not have happened.

The whole thing was insane.

He had a grand vision for retirement, but instead he ended up spending every ounce of his energy caring for my mother.

**And**, in no way did my mother deserve such a brutal disease ,nor did we, and I was too young to lose both my parents.

Vanity of vanities, all is futile.

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As the plane rose above the clouds, I saw only blue sky, which temporarily pulled my bitterness away.

I took a moment to look around the plane: mostly men, BIG MEN, HUGE MEN, all were muscle-bound men.

I asked Mr. Steroid, sitting next to me, “what’s the deal?”

He was too buff to pivot in his seat, so he spoke out of the side of his mouth, explaining, “ we are going to the Mr. Universe contest in Orlando.”

I thought to myself, “great, just great, if this plane makes a crash landing, I’ll definitely be the last one off.

Even their presence added to the insanity:
all those hours in a weight room, to build muscles, and for what reason?”

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The plane descended back into the clouds, symbolic of what was before me.

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I was picked up at the airport and driven to the retirement community in Winterhaven.
That was the shortest hour of my life, and soon that tempo would be reversed.
Carolyn had caught an earlier flight, and the neighbours were watching my mother.
They greeted my arrival with great relief, and handed my mother to me.
I said a quick prayer, which I repeated often, “God help me.”

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According to the Global Deterioration Scale Assessment of Primary Degenerative Dementia, my mother was at level seven– an advanced stage full of delusional behaviour, personality changes, and cognitive and motor breakdowns.

The synapses and connectors in the brain were being destroyed, rendering recall on demand, almost impossible.

Yet, sometimes the brain finds a channel, and the person momentarily converses coherently.

Emotions are very present, and even heightened.

Time is not understandable, and silence is an eternity.  
Attempts to link thoughts together can result in panic and rage. Moreover, memory is floating somewhere, ....as if playing a game of tag with the brain.  
It is a brutal disease for all affected.

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The care giver will try to monitor and keep the person busy, and that **isn’t easy**. **All the while**, trying to treat the person with respect because the victim of the disease is NOT a child.

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For example, we looked at the same photographs, that were in her purse, over 50 times.  
And, I had to respond to each showing as if it was the first, because for my mother it was the first, and any other reaction would have been insulting to her.  
To state, "You already showed me that" is insulting and can cause an explosion of panic.

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I could not relax; I was always on! And she was always in my face!

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When we met out in front of her module Florida home, we hugged, and She asked “how are your girls?”  
At the time, I only had one daughter, but replied, “They’re fine.”

And, with heavy steps I entered the house with her, as she asked, “where are you from?” and "Who Are you?"

That was the first of 100 times I heard those two questions.

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Who are you? Who are you? Who are you?

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The interior of the house added to the weight of the occasion; it was a museum of family heritage mementoes and photos everywhere.

I took a heavy breath– more of a groan.

She commented, “that man is not well, we need to go see him.”

I replied, “Yes we’ll visit dad, soon.”

Then she asked, “Who is your dad, do we have to visit him, too?”

I tried to explain, “my dad is Ken, the man in the hospital, your husband.” That was a BIG mistake.

A Blank reaction followed, then confusion, then anger.

“If he is my husband, then,..... then,..... if he is your dad, ..... then we are related.”

“Someone should have told me this,” her voice rose into a fury.

I quickly tried to redirect her thoughts, with, “let’s look at the pictures.”

This time she followed my lead, most of the time she did not.

In the future, I called him, “that man in the hospital.”

We looked at pictures, too many pictures, photos of another time, photos of when Jessica was young, when life was simpler.

My eyes started to blur with tears. So, I prompted, “Let’s go see that man.”

I drove very, very slowly, she did well while she was in the car.

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Each day consisted of: eat, walk, drink, chat, hospital visit, snack, walk, tour the house, eat, walk, go to the hospital, snack then bed time around nine pm.

She would sleep soundly for the first hour, long enough for me to make my anguished filled phone call to Leslie.

Around 10:00 or so the real torture would begin.

The medication she was on, disrupted her sleep.

My bed was the living room couch. From 10 pm onward, every half hour, I would be awakened by her standing over me, firmly asking, , “who are you. what are you doing here?”

Then, she'd begin her morning routine of opening all the blinds.
To calm her down, I would say, "I'm so sorry for waking you up in the Middle of night. I'm your friend, let me walk you to your bed."

She was a mature lady, and would not respond to being told what to do.

All night long, about every half hour, we went through this ordeal.
I would get her settled in her bed, and then try with all my might to fall asleep before it all happened again.

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Things got worse.  
The third day, Saturday, was a leap into hell.  
She had an attitude; She was very mean.  
The comment, "oh what a beautiful day, didn't work" She just grunted, "too hot." She paced about;  
tried to escape a number of times, and screamed at me for being the prison guard.  
Finally, I let her go, and followed from a distance.

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Who was this woman? What happened to my mother?

The world was nuts.

Neighbours kept their distance. In fact, the whole place looked bizarre: fake flowers, pink flamingoes and plastic rabbits were everywhere.

It wasn't fair. A long faithful life should NOT end this way!
We should go out in glory, not fizzle out.

Life isn't fair, and all seems futile; what's the point?
Why try? Nothing is guaranteed.
Old painful injustices flashed back.
So futile so futile.

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The next day, we went to church— that seemed to help, the music and all.  
During the afternoon, she had a spell of despair.  
She just walked in circles. I asked, "what's wrong?"  
She mumbled, "it hurts."  
"Where?" I asked. She replied, "you know, the confusion it hurts."

"Yes I know, ..... I know."

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That evening, at the hospital, she had an accident. Even bearing the obvious aroma, she carried herself with dignity, until we got back to the house. There, I cleaned her up.
How strange: there was a time she did that for me, how strange? She was broken: so embarrassed; she wept and wept, and then cried herself to sleep.

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**THE PAIN. THE PAIN.**

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It is a gift to see into one's soul. A small benefit of Alzheimer's is you often see into the soul. I was seeing raw, unedited emotions, and that was a gift. In addition, when I would ask my mother to say grace, she would pray with perfect clarity: remembering events and family members. But, the "amen" brought a return to her dreadful disease.

How strange? I struggled to form a theology of Alzheimer's disease. And,.....I was amazed that my father lasted as long as he did.

He thought he was strong enough to do it alone, but he was Not. No one is.

Before the strain took away his physical life, it stole his rational thinking. The years of care giving had whittled him down to the point of the delusional thinking that God would rescue him by letting him win the Reader's Digest Sweepstakes.

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A few days later, my sister arrived to relieve me. We had a few good, insightful conversations about life. We admitted that we both struggled with the "entitlement" attitude of "Why Me"? Protesting to God, "Why did you let this terrible thing happen?" is often really asking, "Why me? It wasn't in MY plans." Assumptions / Expectations can really blur one's vision and narrow the focus.

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To be sure,....when a loved one has dementia, it causes a tremendous sense of loss and isolation,.... and..... alters one's identity. A new role of protector and caregiver is formed, and the identity of mutual partner is no longer possible. The loss is terribly sad.

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Ecclesiastes ends with a call to look beyond ourselves and our turmoil, and focus on God, and the things that are of God: creation, love and those around us, now.

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Something to ponder:
Take away expectations, potential and the aspect of time.
In a freeze frame moment,.... How /..WHY is it different to care for a toddler, than an adult with special needs and limitations?
Both situations demand love.....all around.

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The next day, I was preparing to leave. My mother was in a good mood. She was repeating, as she often did, "God is so Good, we have so much to be Thankful for, God is so God." Her mantra stood as a testimony, in stark contrast to the reality most of us were seeing. I wonder..... who was seeing more clearly?

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As I was packing up, Carolyn was explaining to her that I would soon be leaving. The roles were reversed. We were now the guardians, and had to direct and let her know what was happening.

As Carolyn was talking, my mother slipped into her bedroom, grabbed her purse, carried it out, and started rifling through it, as she approached me. It was mostly empty for her protection.

I was by the door, suite case in hand.

With great apology, she pulled out a dollar bill, and said, "I don't know why, but this is all I have, and you need take this for your trip."

All she had was more than enough; ..... it was a gift!  
For one last time I experienced my mother being my mother to me.

That moment is a precious, frozen moment.  
I still have that dollar bill. [show dollar bill]

It was a moment in the present, in the now, in the clear blue skies.

And it is still **now, very much so.**

Life as it really is, ...is in the now!  
Not futile but, open for and in need of love and peace.

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Who are you?

Who are we?

Are we God's children, loving and caring for each other....as we also need to be loved and cared for?

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May we find peace in the Now... depending on God's love to comfort and sustain us.