

# Constructive Conscious Caregiving

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by Robin Gilmore, M.F.A.

She labors with each breath, mouth agape, chest heaving. Her head is fixed in an extreme backward tilt. The rasping exhalations turn to moans as the pace of respiration accelerates. She is dying. She is my mother. As we breathe together for the next few hours I have the mental clarity to notice myself in this shared act of letting go.

We arrived at this moment after eight years of health crises and the cumulative wasting effects of Alzheimer's disease. My mother was a physician and had been a talented athlete. She had a nose for adventure and was fearless in her many pursuits. As her only child I inherited many of her traits and those served me well in the role of caregiver, case manager and patient advocate. I was not intimidated by any medical professional and became a quick study in financial planning and eldercare. These intellectual tests were interspersed with the heavy physical labor of sorting through and paring down fifty years' worth of cluttered belongings in order to sell my mother's house.

Throughout each challenge I drew deeply from the well of Alexander principles. Thirty years of studying the Alexander Technique helped me adapt to my shifting responsibilities as my mother's mental and physical capabilities disintegrated. F. M.'s phrase "analyze the conditions present" became a mantra when prioritizing the many demands upon my time. If something *could* wait, it did. I learned to conserve my energy for the numerous emergencies along the way. In an emergency, then what?

Ask my fight or flight muscles to release, find my back, feel my feet on the ground. Take a breath and take action with as much clarity as can be mustered. Once the crisis has been stabilized, allow time for the adrenalin rush to subside. Exhale fully and wait for the air to come in through my nose. Find a place to lie down with maximum support. Drink lots of water.

There were days when my interactions with my mother left me exhausted and drained. Despite telling myself, "Do NOT argue with dementia," I would on occasion fall down that rabbit hole in a pointless effort to be right. I wanted my mother to agree with what was obviously fact when she was unable to grasp reality. Arguing with Alzheimer's was end-gaining on a grand scale. Because my mother was losing her capacity to reason through a sequence of thoughts or activities, I needed to adapt my own means-whereby in relation to her condition. Her health and safety trumped my ego and timetables.

When I successfully slowed down and let go of a predictable outcome, I was able to observe and listen to my mother with compassion. Whether or not she was making sense didn't matter and was certainly beyond my control. What I could control, at least most of the time, was my demeanor. Not surprisingly, the quality of my own use sometimes seemed to have an affect on my mother. Even when that was not the case, I felt better and had more energy. Caring for a loved one with Alzheimer's is a marathon rather than a sprint. There are certainly crises along the way that require swift and decisive action, but mostly there are mounting responsibilities coupled with letting go of certain activities and types of interaction.

I will give myself credit for doing the best I could on any given day. If I caught myself forgetting Strategy #1: Do NOT argue with dementia, I would pause and redirect the conversation along with my own use. There were some colossal failures along the way, and I had to learn not to beat myself up afterward.

As a female physician of her generation, my mother had to aim for perfection at all costs. If she didn't meet expectations, there would be no second chance given. Any mistake could have severe consequences. Growing up with that model, I developed into quite the perfectionist. How fitting that I would gravitate to the Alexander Technique in which there is no right or wrong but only better or worse. Rather than the absolutes of Western medicine, Alexander's principles operate along a flexible continuum. We do not treat symptoms but look at causation and psychophysical patterns. There is no end point at which we say "case closed." There is always more to learn about ourselves and how we respond to stimuli.

The Alzheimer's Years provided a steady stream of "unfamiliar sensory experiences" as there was no telling what my mother might retain from day to day or moment to moment. At the beginning, we had some epic tests of will over major issues including her ability to drive a car, manage her medications and handle her finances. I sometimes resorted to creative trickery in the interest of safety. On the day she moved grudgingly into Baywoods, an assisted living facility, my mother told anyone within earshot that she was there temporarily until her physical therapy ended. She insisted that her recent hospitalization had been due to misdiagnosis and that the reason she kept losing her balance was due to lying around not getting any exercise. Fine. Do NOT argue with dementia! The medical team, social workers and I knew she was never going to return to her home. Alzheimer's moves in one direction only.

In the middle stages of her decline, my mother gradually accepted her living situation and became the "poster child" for participating in every activity Baywoods offered. She remained stubborn about physical mobility, refusing to use a walker or cane despite falling many times. No matter how often she fell, my mother miraculously never broke any bones, but her stubborn disposition became magnified by dementia. I never knew when the phone would ring with a report from the nursing staff that she had fallen and needed to go out for x-rays or a CT scan. We then performed our pas de deux in which she resisted my help transitioning from the assisted living facility to the car while I pretended to let her move under her own steam. I stayed in close proximity, kinesthetically attuned to her shuffling and unsteady gait. On the occasions when she was in a wheelchair, she would try to stand up before the brakes were set. I had to be ready to receive my mother's weight when, not if, she lost her balance. My

Alexander training and years of Contact Improvisation served me well whenever we left the relative safety of Baywoods.

During this period my cell phone was turned on at all times. My Alexander students understood that I might have to interrupt or cancel a session on a moment's notice. I revealed more about my personal life than usual out of necessity. With professional boundaries somewhat softened I had to monitor my own use as well as divert students from becoming overly concerned about me. The focus remained on them and their reasons for studying the Alexander Technique. One of the trade secrets among Alexander teachers is that we feel better after working than when we began. If not, then we had better address our own use before thinking about anything else. Amidst the ordeal of my mother's decline, teaching became a mini-vacation. No matter how well or how poorly I may have been handling the stress at a particular juncture, being able to teach the Alexander Technique and work on myself allowed me to recover and restore equilibrium time and time again.

Notice the balance of my head on top of my spine. Connect from sitting bones to heels. Breathe into my back. Scan the horizon. Go for a brisk walk or take a nap. Drink lots of water. Cry often and ardently.

How much can a body take? In my mother's case, more than even her daughter could imagine. Along with the visible signs of weakness and deteriorating reflexes, her nervous system went haywire. Unlike the localized neural damage of stroke or head trauma, Alzheimer's attacks the brain globally. Beyond the signature trait of memory loss, the disease can affect speech, taste, smell, balance, sense of time, comprehension of sights and sounds, recognition of loved ones and regulation of bodily functions. TIA (transient ischemic attack- like a mini-stroke) occurs frequently causing all the systems to break down. My mother was tough as nails, but these lightening strikes in her brain eventually got the best of her.

When a loved one has Alzheimer's the grieving process begins while the person is still alive. I mourned the loss of a brilliant mind while continuing to interact with my mother in whatever ways were available moment to moment. One day she asked where her husband was. Here was a bellwether moment. My father had been dead for twenty-five years and my mother had never remarried. Her question to me had no relevance to time or sequence of events. I caught myself mid-gasp and closed my lips and waited for the air to come in through my nose. I softened my neck muscles, looked at my mom and formulated an answer. That was the extent of constructive conscious control at that juncture. The collapse around my heart was not subject to change.

I awoke that morning *knowing*. This would be the day her struggle ended. I lingered in bed planning to phone Baywoods when the day shift nurses came on duty. Before I could make the call, the phone rang. It was the head nurse essentially speaking my thoughts aloud: Let her be. Don't transfer her from the bed to her lounge chair. Do not force her to eat or drink. Give her morphine hourly.

We were on the same page regarding end stage care. In the previous few days my mother's condition had deteriorated swiftly. She could no longer walk or support her own weight. She

had difficulty swallowing even a milkshake. Trying to coax her to eat had begun to feel like torture to me as well as the skilled staff. One of the last full sentences I heard her say had to do with going home. My mother, known as one tough customer, had no fight left in her. It was time for her to rest.

In a state of hyper-awareness I prepared for the final visit. I decided to take a feline companion. Scout had been my mother's cat and now lived with me. The nurses were happy to see the cat carrier as they knew how much my mother loved animals. They walked with me to mom's room explaining each aspect of the care they were providing to the woman they affectionately called "Doc." By that point their routine consisted of monitoring vital signs, repositioning Doc hourly to prevent bedsores and administering pain medication. When we got to my mother's room I could hear her arduous breathing from around the corner.

The nurses performed their duties and left, closing the door so that Scout could roam freely. Mom's eyes were closed and she was no longer able to speak, but she knew I was there. I spent the next hours talking to her, stroking her with the lightest touch and intuiting my part in our final breaths together. My mother had never been a "touchy-feely" person, and despite her intellectual curiosity, the Alexander Technique was simply *that thing* that her daughter claimed to do for a living, something to do with movement and too abstract for a physician of her generation. Well, what was happening in that room could not have been more tangible.

I spoke to her of family members and the many adventures we'd had together. I told her she had worked hard for so long and deserved to rest. Scout participated as well. Once she had investigated the room thoroughly, Scout jumped up on the bed and gradually settled down near mom's feet. By this point mom was moaning with each shallow breath. Amazingly, Scout stayed put and purred. I began to hum. Then I switched to whispered "ahs" and placed my hand at the back of my mother's head. These would be our last breaths together. I knew she would not let go with me in the room, so I chose when to leave.

My apartment was close by, and I returned home to await the inevitable phone call. That call came just a few hours later from the night nurse. I had a feeling that "Doc" had held out until the day shift had left because they had become like family. She was not going to die on their watch just as surely as she was not going to die in front of her daughter.

Within minutes I arrived back at Baywoods. Unlike the usual bustle of daytime activities, it was eerily quiet. I had never been there after all the residents were in bed. The nurse was waiting for me, and she walked me to mom's room. Total silence. The whirring motor of the air mattress had been turned off. No water was running in the pipes. And there was no sound of agonized breathing. My mother was at peace.

## **POSTSCRIPT**

I began writing this piece on the one-year anniversary of my mother's death. The words had been formulating in my head for a while, and at some point I realized a book was in order. This article is the first drop in the bucket and is written for an audience familiar with the Alexander Technique. I didn't want to get bogged down in explaining concepts such as end-gaining but wanted the writing to be a bit raw. I can honestly say that AT principles became survival skills

that helped me navigate the Alzheimer's maze. It is my hope going forward to bring some of those principles to a broad population of caregivers and health care professionals. I envision a book about the somatic aspect of caring for a loved one with dementia.

There are a number of excellent resources on practical matters including healthcare services, advanced directives, power of attorney, etc. I found this information to be most helpful. These books do encourage caregivers to take care of themselves and offer advice such as getting enough rest, asking for help, eating well and joining a support group. They describe wide-ranging emotions that may arise in response to dealing with dementia and assure the reader that these responses are common. What is missing from the literature is a psychophysical component, a set of strategies for embodied, kinesthetically aware caregiving. That is what we in the Alexander Technique and other somatic disciplines can offer.

The following self-care activity can be done in bed during bouts of sleeplessness. Chronic insomnia is common for family caregivers, particularly women in menopause. Rather than turn on the lights and get out of bed in the middle of the night, I find it helpful to keep the room dark and remain relatively still with my eyes closed. That way my tissues can be at rest even if my brain does not want to turn off.

Here is the **INSOMNIA MANDALA**:

- Lying on your back, place your left hand at the bottom of your ribs below your sternum. Place your right hand at your pubic bone. If your abdominal cavity were a clock, your hands would be at 12 and 6. Let your hands be soft and weighty. Remain here for several minutes sending warmth to your organs.
- Slowly slide your hands in a clockwise direction to 2 and 8 o'clock. Allow your hands to spread over your organs and rest here for a while.
- Slide your hands to 4 and 10 o'clock. Your right hand can send energy to your liver, a vital filter for toxins. The clockwise path of your hands follows the direction of your ascending and descending colon and will encourage good digestion.
- If after several minutes you are still awake, ask your eyes to soften deeply into their sockets and take your hands on another slow journey around your abdomen. Rest well.

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