

Pathways

SERVING FAMILIES AND CAREGIVERS OF BRAIN IMPAIRED ADULTS AND THE FRAIL ELDERLY

Mothering Mother *by Carol O'Dell*

My mother and I were in what I call "agreed denial" about her growing health concerns.

My adoptive mother—50 years older than me, widowed, with Parkinson's and a mild heart condition, fiercely independent and determined to live alone—was noticeably declining. Me—in my late 30s, married, raising three daughters, founder and director of a private school in an Atlanta suburb, juggling all of my responsibilities—lived in perpetual worry about my mother. My mother and daddy took me into their hearts and homes when I was adopted at the age of four and I had promised Daddy in his last moments that we would, "be good and take care of each other."

I started noticing bruises on her arms and legs—was Mama falling and not telling me? She grew paranoid, calling 911 and claiming someone was trying to get in her house all hours of the day. Then came the car dings, the crashed mailbox and excuse after excuse. She was losing weight, mumbling, and although I had patch-worked together a rotating schedule of caring neighbors, willing



church members, extended family, visiting home health aides, and my husband and myself to come and go from her house more days than not, I knew it was time. She needed to be with me—with us—her family.

"What's close got to do with it? Do we always get along? Hell no. Will I take care of my mother? Hell yes."

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Pathways

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Mothering Mother . . . continued from page 1

To say that my mother was bigger than life, domineering and demanding as I used to chide, a queen without a country, would be kind. People asked with a smile if we were close when I mentioned we were all – kids, pets, my mom, two households, more personalities than a clown car could hold—moving from Georgia to Florida due to my husband’s transfer. I’d smile back at them and reply, “What’s close got to do with it? Do we always get along? Hell no. Will I take care of my mother? Hell yes.”

I stepped down from the private school I’d created and left it all behind. I’d dreamed of one day becoming a writer and had already published numerous short stories and essays and was working on a novel. Just as I was stepping into my own, becoming who I longed to be, I had to let it all go. We had a family meeting and agreed that caring for my mother was needed and that, yes, we would all have to make room and sacrifices in our lives. My husband started by building on my mother’s “suite.”

From the day we moved in together I knew that my mother was much worse than I had allowed myself to see. She froze at doorways and couldn’t manage her own basic hygiene. Most of her days were acts of sheer nonsensical repetition. Something else was going on. I knew it before it was diagnosed—dementia.

Mother spiraled. She wandered at night, agitated, confused and inconsolable. She trashed her suite breaking beloved antiques and starting into the faces of her family with absolute terror, wondering, “Who are these people?” I learned the name for this the hard way—sundowners. She started referring to me as “little girl.” I asked my family to forego my 40th birthday. I couldn’t blow out candles and look into the face of my mother knowing she did not know who I was. I asked my heart, “Who am I if not my mother’s daughter?”

I floundered. We floundered. My children and my marriage suffered. I withdrew, snapping at anyone who came near. I was beyond scared. I didn’t know how to do this. I had made a vow as a child that I would

“Never, ever, ever put you in one of those nurse’s homes, Mama.” Would I have to break that vow? Was my mother beyond my care?

My daughters stepped forward, making meals. My husband took them to swim practice, the movies and to church most times without me. My children sat with their grandmother so I could bathe or go for a walk and cry. My husband picked my fallen mother off the floor and cradled her in his strong arms. We got help, but it wasn’t enough. My heart broke every time I looked at her blank eyes, so very lost, and realized nothing I could do would comfort her.

“I looked at my mother who no longer knew me and resolved, “It’s okay. You might not remember me, but I remember. I remember you. I remember us. I will tell our stories.”

And then it changed. One ordinary day I looked at my mother who no longer knew me and resolved, “It’s okay. You might not remember me, but I remember. I remember you. I remember us. I will tell our stories.”

My mother died one quiet June afternoon. It took quite some time to figure out who I was without my mother on this earth, but the more I wrote our stories, the more I shared our journey, the more I felt her with me. My family was tested in ways I never could have imagined but we endured and it made us all better people. I see in my daughters a sense of compassion far beyond their years.

Caregiving changed me. I did not—and could not—go back to who I was before. That time was over. I am someone different. And I decided I wanted something different for my career, too. I returned to college and

earned my degree. Now I write, blog, speak and am a family and caregiver advocate in my community. I also serve as a contributing editor and thought leader at Caring.com. I have new plans and new dreams. I am not who I was, and I am not who I will be.

Through caregiving, I have learned a thing or two, I hope. I've learned to pace myself. I've learned that it's really easy to get caught up in the drama and trauma at hand, and the danger of setting yourself aside too much. I've learned that guilt, anger,

resentment and frustration will eat you alive if you don't find a way to release it, and that if you don't practice profound self-care you won't have anything to give anybody.

I've learned to be a strong advocate for those I love, even if this means taking on the medical and insurance powers that be to ask for help, and then to ask for more help from community sources because doing it solo is just plain stupid. We need each other. We need to be needed. I've learned that our elders, children, and the poor and marginal-

ized need us to be their voice. While standing up or pushing back to get the help, funding and resources they need is not going to be easy, it will make all of us—individuals, families and communities—stronger and better if and when they receive it.

Reprinted with permission. Carol D. O'Dell's is the author of Mothering Mother: A Daughter's Humorous and Heartbreaking Memoir, written for the "sandwich" generation and all those who find themselves caring for a loved one. Carol is a health and wellness blogger, and her blog, Mothering Mother and More has been featured as 2012's top ten health care blogs in the country by ShareCare.com.

CAREGIVER'S COLUMN

My Last Wish

By Bob Oyafuso

Dear family, friends and those
who care.

Throughout this time I have
been wordless

But mindful of your love and
concerns.

I am grateful for those hands that
cleaned and fed me

then gently rolled my inert body
side to side.

I am grateful for the lovely voices
that sang to me

then offered prayers to ease
my pains.

I have lost loved ones to this
dreadful disease.

I understand what it must be like
for you.

Please accept my final wish that
my body

be gifted to the UC Davis School
of Medicine

so I may continue to support this
cause after I'm gone.

To our future healers I commend
my body to you

and charge you to study and bear
witness to my ills.

Let me be that vessel of knowledge
to see you

you through your most difficult
journey.

Let me bring you joy

as you uncover the wonders to
be human.

Finally preserve my dignity for

I have given you my greatest
treasure.

Loneliness

By Bob Oyafuso

Where have all the children gone
They came for candy and ice cream
to pet Bella and run their fingers
over her silky fur then screamed
with delight as Bella kissed away
morsels of ice cream from their lips.

They came to sit with Grandma
or to watch an artist at work
and learn from the master
the art of drawing.

They came for Grandma's
unconditional love and attention.

Then came Alzheimer's
now she is strange and distant
Grandma can only smile at them.
the house is silent.

INVITATION TO CONTRIBUTE TO CAREGIVER'S COLUMN

Please submit your contributions via email to crc@deloro.org. Please be sure to include your source(s), unless it is your own work. Additionally, please share how this information was beneficial to your caregiving journey.



13th Annual Cook-off and Fundraiser, benefiting Del Oro Caregiver Resource Center

Date: Wednesday, June 20, 2018

Time: 5:00 – 8:00 p.m.

Location: Divine Savior Catholic Church
9079 Greenback Lane
Orangevale, CA

Please join us for this festive event featuring a cook-off by local chefs, live entertainment, silent auction and raffle prizes!

To purchase tickets please visit <https://www.eventbrite.com/e/12th-annual-cruise-around-the-world-cook-off-and-fundraiser-tickets-29796615479> or call Del Oro Caregiver Resource Center at (916) 728-9333

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We hope your heart is with Del Oro Caregiver Resource Center, serving family caregivers of brain-impaired adults and the frail elderly in our region.



Visit: <https://www.bigdayofgiving.org/delorocares> to give!

SAVE THE DATE

MARK YOUR CALENDARS! Alzheimer's Association Care Partner Education Forum

Thursday, April 19, 2018
9 a.m. – 2:30 p.m.
Citrus Heights Community Center
6300 Fountain Square Drive
Citrus Heights, CA 95621



Interested in Sponsorship and Exhibitor opportunities for the 2018 forum? Call or email our Program Coordinator, Denise Davis at denise.davis@alz.org or 800.272.3900

Come join us for this Care Partner Forum, designed to fit the needs of care partners and families caring for those with Mild Cognitive Impairment, Alzheimer's disease, and other forms of dementia. Learn more about the diseases, the latest updates on research, strategies in communication and tips on self-care.

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