FEDERATION OF DEFENSE & CORPORATE COUNSEL

FDCC

DEFENSE LAWYERS. DEFENSE LEADERS.







PATIENCE, PLANNING AND SUPPORT

REFLECTIONS ON DEALING WITH AGING FAMILY MEMBERS

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This book, "Patience, Planning & Support: Reflections on Dealing with Aging Family Members," is a publication of the Federation of Defense & Corporate Counsel ("FDCC"). The articles are authored by FDCC members and reflect their personal stories in honor of their parents.

The book is edited by Defense Counsel members Frank Ramos and Kile Turner,

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ISBN No.: 979-8-218-37254-5

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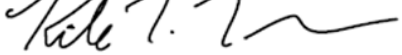
Each of us will have to take care of an elderly parent, grandparent, uncle or aunt, or another family member or friend. There are so many things to consider, address, and tackle, and there is no playbook for it. With that in mind, the FDCC asked its members to share their wisdom and experiences with elderly loved ones.

This book is a compilation of their advice, tips, and hope.

As it moved us, we hope it moves you.



Francisco Ramos, Jr.
Clarke Silverglate



Kile T. Turner
Norman, Wood,
Kendrick & Turner

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"To care for those who once cared for us is one of the highest honors"

Tia Walker, author

The Inspired Caregiver: Finding Joy While Caring for Those You Love

It is usually a normal part of life. Parents pass on before their children. Most of us will face this in our lives, or have faced it, or are facing it now. Here is one who may have cared for you in your childhood, or later as an adult when you were ill, or one who provided advice and solace to you, cheered for you like none other, or just plain was there when no one else was. Here might be one who was not any of that, but was difficult and hard to deal with. No matter, for now they are leaving us. Or have left us.

In the following pages our Federation members pour forth on what they have learned going through it, to ease the burdens of what to do, or how to do it, or how to find help, for those of us going through this, or who may yet begin this path. Some of these articles or chapters speak of tremendous advices: How to convince a parent to move, losing their independence? What of a parent who should no longer drive a car? How to face a parent's terminal illness, dementia, or how to seek help and resources, overcome the emotional loss, and many other situations. All here.

As you read these stories, you will surely appreciate the advices, be struck by the poignancy, learn from the experiences, and come out better in the end for having read this through. If you have already experienced loss of your parents, perhaps some of these related experiences will inspire you to speak with others about your experiences too. Everyone I have discussed this book with who have helped write it, who have helped edit or ready it for publication, is moved.

The idea for this book arose from discussions among some of the FDCC leadership while we all passed through the COVID-19 Pandemic. Life expectancy was dropping. Our FedLife Committee began at about the same time. Many of our members leaped at the chance to write for the book. Members Frank Ramos, Miami, and Kile Turner, Birmingham, undertook the unenviable task of editing the book, and our Executive Director Bernie Heinze and his team at FDCC Headquarters finished it. The unfinished book sat idle for a time after the material submissions, but this year we saw the raw material was good, and so pushed to finish it and pass it along to you. Thank you to Frank, Kile, Bernie, and the many authors, contributors, and workers who brought this together for you.

For all of us.

Together we hope you enjoy this as much as we did bringing it to you.

Thank you.

--- Craig A. Marvinney, February 2024
President, FDCC

CHAPTER 1

THOUGHTS ON CARING FOR AGING PARENTS

by Stacy Broman



My story is not unlike many others

I was an only child. My mother was a teacher, and my father was a farmer living in northeast South Dakota. By the time they began having significant health issues in their 90s, I was a busy attorney living in Minneapolis, about 275 miles away, with small children of my own. My mother was four years older than my father. As my father had weathered some fairly significant surgeries and health scares during his lifetime, both he and I thought that my mother would outlive him. But that was not to be the case. My mother passed away in 2010 at the age of 92. She had spent the last year of her life in a nursing home with moderate dementia and kidney failure. My father passed away in 2019 at the age of 97. At the time of his death, he had spent four years living in a residential living facility with minimal assistance. He was sharp as a tack until the week he passed away, which was both a shock and a blessing.

I learned a few things in caring for my parents and watching my husband care for his 95-year-old mother, which I hope you might find helpful.

1. Have all appropriate legal documents drafted, signed, and stored appropriately

We are attorneys, after all. Have all appropriate legal documents, including a will, power of attorney, and healthcare directive, drafted, signed, and stored in proper locations. I recommend storing copies with your parents, at your home, in your office document management system, and with your parents' doctor's office and hospital. I cannot tell you the number of times I called my office and asked them to send my parents' power of attorney or healthcare directive to a hospital or doctor's office. Other times, I told a doctor or hospital that the documents were already on file with the clinic or hospital. Have those documents prepared, signed, and readily accessible as you will need them. Because I lived so far away from my parents, I made many fast trips to the airport when they were hospitalized for an emergency. You will want to ensure that the hospital has medical power of attorney on file and all needed paperwork. It is also good to review all of the documentation periodically.

2. Know your parents' physicians and their medical staff

Admittedly, this may have been easier because my parents lived in a relatively small community. They were typically hospitalized at the same hospital where I was born. I made it a point to get to know their doctors and their doctors' medical assistants. My parents signed a healthcare power of attorney so that I could speak with their physicians, and I did so regularly. Their doctors and assistants knew me and were happy to talk to me and provide me with information to help me make healthcare decisions. Because the healthcare directive and power of attorney were on file with the doctor and the hospital, when I received a phone call from the hospital when my father suddenly became ill the week before he passed away, the doctor was able to provide me with a significant amount of information.

Make sure your parents keep contact information for you and their physicians in their billfolds. When my mother-in-law fell on the ice in front of a CVS Pharmacy, she had no such information in her billfold. She was taken to the downtown Minneapolis Hennepin County hospital because they did not know if she had insurance. She had a head injury and called me from the hospital, not knowing if she was in Minneapolis or St. Paul or what hospital she was at. Make sure your parents keep your contact information and the contact information of their physicians in their billfolds. They should also keep a list of their medications and dosages in their billfolds. The residential living facility where my dad lived kept this information in an envelope outside of his door so that the emergency personnel could take the medication list along if they were taking him to the hospital.



3. Understand your parents' medical insurance coverage, Medicare prescription drug plans, and even property insurance

Your parents need to have their medical insurance and Medicare cards and any prescription drug cards available in their billfolds. I also kept photocopies of those documents on my phone, in my office document management system, and at home.

Know when the bills are due for the premiums, and make sure you pay them if your parents are incapacitated. Better yet, have the premiums withdrawn automatically from their bank account.

You will also want to understand what coverage is provided. My dad, who I indicated was very sharp until the end of his life, knew the Medicare rules. Make sure you do, too. Medicare will generally pay for a rehab stay in a nursing home following a qualified hospital stay of three nights. Make sure you discuss this with your parents' physician if you believe a stay in a rehabilitation facility would be helpful for their care.

In addition to understanding Medicare, be aware of other insurance coverages your parents may have and when the premiums are due. Make sure the prescription drug premiums are paid. Do they have life insurance? Are there still premiums due? Make sure their property insurance bills are paid. Also, if their residence will be vacant for some time, you may need vacant home insurance. Most first-party property insurers do not cover vacant residences, often defined as vacant properties for 30-60 days. If your parents' place is vacant for some time, check with their homeowners' insurer to determine when the home will be considered vacant. It is better to purchase vacant home insurance than to determine that the policy does not provide coverage after a loss, as the insurer has determined the home was vacated.

4. Hospital social workers are your friends

The hospitals all have social workers who can help locate resources for your family member post-hospital discharge. The social workers can help find an appropriate placement and help determine whether a nursing home rehabilitation stay would benefit your family member. Social workers are in tune with the local residential rehabilitation units

that may have available beds and can assist in finding a placement for your family member. I knew all of the social workers where my parents were typically hospitalized at the hospital. On several occasions, my parents had post-hospitalization rehabilitation stays. The social workers arranged these placements. The social workers are well-versed in the Medicare rules and can speak with the physicians regarding whether a post-hospitalization rehab stay would be beneficial.



We do the best we can and always wonder if it was enough.

In contrast, after my mother-in-law fell on the ice in Minneapolis, a resident at the county hospital discharged her with a fractured patella before a three-night hospital stay. I had asked to speak with a social worker when I got to the hospital. But the overworked county hospital where she was taken, because she had no insurance information in her billfold and no family contact information in her billfold, would not hold her. My husband and his siblings tried unsuccessfully to care for her at home for a few days. She was only about 90 pounds, but with the fractured patella and family untrained in how to transfer her, the experiment of caring for her at home was unsuccessful. My husband started calling nursing homes, trying to arrange a placement, but it was impossible without a referral from a social worker. Finally, I called an orthopedic surgeon who agreed to admit her to a different hospital just so that the hospital social workers could arrange an appropriate placement for her. If your family member is hospitalized and you think they might need post-hospitalization rehab, ask to speak with the hospital social worker early on in the hospital stay.

The social workers are also aware of other programs that might be helpful. My parents were hospitalized in what is considered a rural hospital, and both of my parents could utilize the hospital swing beds for a period following discharge. The Social Security Act permits certain small, rural hospitals to enter into a swing bed agreement. The hospital can use its beds to provide acute or skilled nursing facility care. As defined in the regulations, a swing bed hospital is a hospital or critical access hospital participating in Medicare that has CMS approval to provide post-hospital skilled nursing care and meets certain requirements. Medicare Part A (the hospital insurance program) covers post-hospital extended care services furnished in a swing-bed hospital. Again, the social workers know these programs and whether your hospital participates. https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/SNFPPS/SwingBed.

5. Be your parents' healthcare advocate

Your parents may need you to be their healthcare advocate. For the most part, my parents received excellent care throughout their numerous illnesses and hospitalizations. But there were two situations where I had to advocate for them. One was near the end of my mother's life when she was in hospice. While hospice generally discontinued all life-extending drugs, there was a drug that her physician thought she should have for comfort care. Although it was not on the hospice-approved drug list, with the help of her doctor, I advocated that she be allowed to receive the drug. I had suggested I remove her from hospice to receive the drug, and it was approved.

The other times I needed to advocate related to my dad's diagnosis of colon cancer in 2015. My dad was 93. He was still living alone in his home. He was still driving his F-150 pickup. When the doctors asked him if he was retired, he would say "no." He was unexpectedly diagnosed with colon

cancer. His local hospital did not want to operate as they told us he would not survive the surgery. They sent him to a nursing home to die. We talked about it, and he decided he would like to go to the Mayo Clinic for a second opinion, which we did. We spent about ten minutes with the Mayo surgeon. After the surgeon explained the surgery, he asked if we had any questions. I said I did. "Do you think he'll survive?" The surgeon quickly said, "I wouldn't do the surgery if I didn't think he'd survive. He'll survive." It was a rough recovery followed by four months in a rehab unit, but he survived. He survived four more years. He never went back to his house. He moved to an independent living facility and died of an unrelated cause in 2019.

Sadly, the first rehab facility I took him to provided sub-par care after the colon cancer surgery. They wanted to transfer him to hospice, and I told them to call an ambulance instead. They were insistent on hospice. I said if they did not call the ambulance, I would. When he arrived at the hospital, he was dehydrated and malnourished. The emergency room doctor was very upset, and I quickly said, "he's coming from a licensed facility." Needless to say, when he got out of the hospital, he did not go back to that facility. Before his hospitalization, I called Shalom Home in St. Paul to inquire about transferring him there. Once he was discharged from the hospital, he went directly to Shalom Home, receiving excellent care. Medicare paid a total of 3 months of his rehab stay. At the end of the three months, we did not feel he was quite ready to go home. We paid for an extra month at Shalom Home so that he could get strong enough to go home. He had surgery at Mayo in July 2015. He went back to South Dakota for Thanksgiving 2015. He moved into a residential living facility run by a lovely couple. He stayed there until his final illness in August 2019.

6. "Your memories are in your heart," or in other words, "Your kids don't want your stuff"

My mother was a bit of a collector and had beautiful things. She had a lot of china, crystal, collector plates, and anything else you could imagine. My parents had a 1950 rambler with a full basement. In 2007, their town suffered a severe flood. I kept calling them, asking if they were ok. They were just fine, they reassured me. I asked them if I should come to help them. No, they were just fine, they said. I got a call from a woman from the local Methodist Church who told me that the South Dakota Methodist Bishop had directed the Methodist Church to help my parents clean up from their flood. What? My mother and father belonged to different faith traditions – neither of which was Methodist. How did the Methodist Bishop get involved? Needless to say. I quickly got on a plane and discovered what was going on.

Their basement was flooded. Helpers had moved many of their possessions from the basement to their garage, which was packed. The floodwaters had receded, but many items were still in the basement. The basement needed to be cleaned and bleached to avoid mold.

I was going through a box of my mother's flooded things in the basement with the Methodist Minister and started to cry. I will never forget her words. She said to me, "your memories are in your heart." She was right about that. With a lot of help, I got the basement cleaned out after the 2007 flood, but many of my mother's possessions were still in the house. After my dad suddenly left his home in 2015 due to his colon cancer diagnosis, I couldn't deal with all of the possessions, even on one floor of the house. I kept thinking I would clean it out. But their home was 275 miles away from mine. When I would visit, I would walk around the house, maybe take a few things, and lock the door. I didn't know what to do with all of my mother's things. I had this feeling that I had to go through it all. What if there was something I wanted?

We've all probably seen the articles titled with various variations on the theme "Your Kids Don't Want Your Stuff." "Time to Face Reality: Your Kids Don't Want Your Stuff!" (Kiplinger, March 29, 2021). This is true. Your kids don't want your stuff.

I struggled for two years to figure out what to do with all of my parents' house stuff. In the spring of 2017, I was on vacation with my family when I got a phone call from a young couple who said they wanted to buy my parents' house and tour it. "No," I said. I could not imagine letting anyone tour the house or consider selling it until I had cleaned it out, re-painted it, and generally fixed it up. One of my law partners told me I was "crazy" and told me to hire an estate sale company and sell the house as-is. I'm so glad that I heeded her advice. I sold the house two years before my dad died. I knew he wasn't going back to that house, and there was no reason to leave it sitting. I had to sheepishly call the couple back and tell them sure they could tour the house. I showed them the house and sold it to them the same afternoon in the Spring of 2017.

I hired two lovely women who went through everything in my parents' house and had an estate sale. One of my most significant pieces of advice is don't spend weeks, months, or years going through your parents' home. And indeed, don't store things in a storage unit. One of my friends stored items in a storage unit for years and paid thousands of dollars in storage fees. When she finally did go through it all, most of what was in the storage unit was either donated or trashed. Instead, take what you want and find a reputable estate sale company to sell the rest. Most of these companies will even let you leave a list of what you want if you do not know where it is when you are looking for it. I took three of my mother's yearly collector plates - one for the year we were married and one associated with the years our two kids were born. I made a high school friend take the plate associated with the year we graduated from high school. The rest were sold. My mother's coffee cups that I thought I wanted never materialized. But I did not want the coffee cups. What I wanted were the memories of my mother. I was happy when Pottery Barn and Target sold some reproductions I bought. They remind me of my mother, which is all I wanted. Your memories are in your heart. I asked my kids who wanted my silver service, and the response I got was, "What's a silver service?" The articles are correct. Your kids don't want your stuff.

7. Palliative Care and hospice require tough decisions

The hospital physicians or social workers will likely talk to you about palliative care or hospice. Palliative care is specialized medical care for people with serious illnesses, such as cancer or heart failure. Patients in palliative care may continue to receive medical care intended to cure their illness and, at the same time, care for their symptoms or palliative care. Palliative care is meant to enhance a person's current care by focusing on the quality of life for them and their family. Like palliative care, hospice provides comprehensive comfort care and support for the family, but attempts to cure the person's illness are stopped in hospice. Hospice is provided for a person with a terminal illness whose doctor believes they have six months or less to live if the illness runs its natural course.

My mother had hospice care in the nursing home before she died in 2010. Her hospice nurse was a dear family friend and provided great comfort to her.

My father was ill less than a week. I received a call on a Sunday afternoon that he was ill. Because his hemoglobin was so low, they flew him to Sioux Falls. I had to quickly change my plane ticket from Aberdeen to Sioux Falls, which I did from the airport parking lot. He was in the hospital in Sioux Falls for less than a week before I made the difficult decision to transfer him to a hospice house, where he passed away in approximately 24 hours.

Signing DNR orders for my parents was the hardest thing I have ever done, and it helped me understand what their wishes were. Make sure you have these discussions with your loved ones and have this spelled out in the healthcare directive.

8. Lean on your friends, including your FDCC friends

As an only child, I did not have any siblings to help me care for my parents. In some ways, it was easier as I was the only one to make any decisions. This contrasts with my

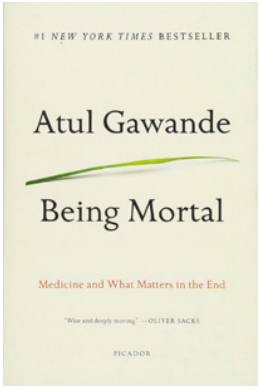
husband's family, where seven kids decide about his mother's care. I was the only one who could make all the decisions. But making all the decisions is very hard, and it is very lonely.

My parents were fortunate to have tremendous friends in their hometown. They had friends who would help them and visit them. Their friends did so much for them, and I am eternally grateful. For the last four years of my dad's life, he lived in a beautiful residential living facility. The owners treated him like family. I would have preferred that he be in the Cities, but he wanted to be in his hometown, where he had lived his entire life. His friends visited him and took good care of him.

I was lucky to have good friends to lean on. I have cousins and sisters-in-law who helped me make decisions about the care of my parents. My law partners helped me with medical decisions and the decisions about selling the house. I leaned on all of them, and I'm very grateful for the help.

Don't be afraid to lean on your FDCC friends as well. When the only lawyer you know where your parents live is representing the other party to your transaction, it is nice to be able to lean on your FDCC contacts for legal advice. I do not practice real estate or trust and estates. While perhaps our FDCC members don't practice in those areas generally, most of them likely have lawyers in their firms who do. Find the FDCC member in the state you need. They likely have partners who specialize in where you need help.

Conclusion



For those who have not read it, I would recommend the book "Being Mortal" by Atul Gawande. The author provides some interesting insights and thoughts on aging.

My mother passed away on January 15, 2010, at 92. She had been a math and physics major in college when women, to the extent they went to college, certainly did not major in mathematics and physics. Before my dad passed away, he established a scholarship for high school students in her name.

My dad passed away on August 18, 2019, at age 97. He had only been sick a week. He and his twin brother were born on the family farm on February 22, 1922. A doctor had braved a blizzard by horse and buggy to attend to the twins' birth. He was sick for less than a week, and he and his twin brother died ten days apart.

I honestly thought that my dad would live to age 100 in 2022 and that I would be contacting Al Roker to get his picture put on a Smucker's jar for the Today show. When he suddenly became ill in 2019, I was shocked. He had pulled through serious illnesses before, and I thought he would pull through this one. But it was not to be.

Making difficult decisions for your parents is not easy. I had to sign DNR orders for both of my parents. I took my mother to the nephrologist when he told her he would not agree to dialysis because her condition was too dire and recommended hospice instead.

I signed the DNR order for my dad when it became apparent that he wouldn't recover, and he slipped into a coma. Those are hard days. But you need to be present.

We do the best we can and always wonder if it was enough.



Stacy Broman is Managing Partner of Meagher + Geer in Minneapolis, MN. Contact her at: sbroman@meagher.com.

CHAPTER 2

THE DIGITAL DIVIDE

SILVER EDITION

by John Buckley



The "Digital Divide" generally refers to the gap between those that benefit from the Digital Age and those that do not. However, within this divide are those who wish to benefit from the conveniences of digital technology but have difficulty navigating the devices that allow entrance to the Digital Age. Frequently, members of the Silent Generation (born between 1928 and 1945) or Boomers (born between 1945 and 1964) – collectively referred to in this paper as the "Silver Generation" - fall within this demographic. While most individuals in this age group use computers, cell phones, and other digital devices and applications daily, when the hardware or applications stop working as the user is accustomed to, they cannot fix the device without assistance. This has given rise to an entire department at Best Buy (the Geek Squad), which also comes at a high cost to those on limited incomes. More likely, before turning to the professionals, members of the Silver Generation reach out to family or friends as technical advisers to keep their systems functional. I currently find myself in this role and thought it would benefit others to share some tips on managing the Digital Divide among the Silver Generation.

Perhaps I am stating the obvious, but sitting in front of a computer when working to correct settings or updating the software makes the job immeasurably easier than telling someone else how to make these changes over the phone. Yet, most amateur technicians have other obligations that prohibit in-person review of their relatives' tech problems at a moment's notice. Software for "shadowing" is available but generally requires the two parties to be on the same network, and using it is complicated.

Trying to give technical advice over the phone can cause many problems. For instance, I am the technical advisor for someone in the Silver Generation, whom we will call "Bob." Bob and I both work on Apple computers, while the rest of Bob's family uses Windows computers. This is, in part, why I became Bob's technical advisor. However, I live 500 miles away from him and often could not work on his system in person. Moreover, my laptop ran a different operating system due to the age and ability to update Bob's computer. Therefore, even though the System Preferences controlled the settings on both machines, the available settings were not identical. While I followed on my laptop to give the best description that I could, Bob did not see the same screen I was describing, so my initial attempts to help him largely failed.

We found a solution to this practical problem by using Facetime to call each other when Bob's computer needed updating or other issues needed to be addressed. Facetime (available on iPhones/Google Duo will work similarly on Android devices) allows users to switch to the back camera to show the computer screen. Seeing the screen also helps when software (as opposed to the operating system) has issues. Bob has a remote desktop for his office. If the remote desktop is occupying the computer when work needs to be done on the host machine, it is easy to get confused about which computer system needs changes or which is even occupying the screen. As a tech advisor, trying to advise what to click without seeing which desktop is currently open can result in hilarious situations (or incredible frustration, depending on your outlook!). By using Facetime, advice about what to open and what settings to change is specific and has made correcting computer issues much easier. In my case, how Bob holds the phone so I can see the screen is a work in progress but is generally a slight but constant impediment to effective technical advising.

Keeping digital devices running well depends on the age of the device but also depends on updating the operating system. Most computers can be set to update the operating system, software, or applications automatically. However, owners need to install these updates (or approve the installation of the software before it installs). This is true for smartphones and tablets as well. It seems updates and patches for applications on these devices are pushed out constantly. Updates are critical in maintaining a secure digital environment. In my experience, many users in the Silver Generation who need technical assistance with their digital machines do not regularly check for or install updates either because they do not understand the importance of updating software or don't know how to update the software (or believe that the software will automatically update but don't realize they need to approve the installation or restart the computer for the updates to take effect). When

visiting or answering technical questions from a distance, checking for available updates may reduce inquiries related to performance, keep the system secure, and avoid problems with incompatible software.

The Silver Generation handles finances, reads newspapers and books, shops, works, engages in hobbies, and generally does most things online like the rest of society. These sites all involve some sign-on and security. A password is the simplest form of security, but different sites may require different rules for passwords, such as password length and the use of capital and lower-case letters, numbers, or symbols. Some sites require Multi-Factor Authentication (MFA) in addition to the password. Resetting passwords involves MFA, answers to secret questions (answered when the original password was chosen), or email addresses. Keeping track of all the different passwords, secret questions, cell phone numbers, or email addresses provided for MFA resets present a daunting challenge for all computer users. Many people keep a list of passwords and other security answers. Fortunately, our devices also often have a password vault that speeds sign-on and eliminates the need to keep track of passwords daily. However, reliance on a password vault frequently eliminates any chance of recalling the password when signing in from another device. This often results in the need to change passwords. If a user keeps a physical password list and needs to change a password, the list can quickly become obsolete. As a technical advisor, it is good to encourage the user to conduct a password audit periodically. They should try to sign in using the passwords on the list and update them as necessary. This includes not only passwords but secret questions and the answers to those questions as well.

Helping to keep devices running efficiently will reduce frustration for the user. This includes avoiding the dreaded "my device has insufficient memory" error. Managing storage should become part of a basic system review. On Apple devices, access General settings – iPhone Storage to examine the amount of storage remaining. It also shows what apps or files use a large amount of storage space. Deleting unused apps can free up space and avoid error messages caused by a lack of storage. The iPhone Storage setting will show the amount of space used by a particular app and indicate when the app was last used. If an app occupies a lot of space but is not being used (Garage Band in Bob's case), it can be deleted to free up space on the device.

Reviewing subscriptions should also be a Standard Operating Procedure for the tech advisor. Helping users avoid charges for long-forgotten or unused subscriptions can be viewed and managed from the Settings – Subscriptions setting, reducing charges for automatically renewing subscriptions. These subscriptions often bury cancellation instructions deep within the app, and the device owner may need technical help canceling the subscriptions. Proactively locating these as part of a system check can avoid the "emergency" call that follows a review of a credit card statement showing charges for a forgotten subscription.

As digital devices allow us to broaden our networks and communicate via numerous channels, the likelihood that a person will receive fraudulent communications has increased. These include phishing emails, text messages, and other attempts to infect the device with a virus, steal passwords, or convince the owner to part with money. Discussing the importance of not clicking on email links/attachments without knowing the source, not clicking on links in text messages from unknown senders, and not sending money to people who solicit via these unsolicited communications should be high on the list of the technical advisor. For instance, another of the people I advised received a pop-up on his computer telling him that this computer had a virus and that he should call an 800 number to learn how to fix it. He called the phone number and was told he would have to buy their costly software to fix his computer. Once he told us about the pop-up and the call, we were able to stop him from sending any money to this scammer. When we ran a legitimate virus scan, the only malware (Adware in this case) was from the company trying to sell him anti-virus software for his computer.

To help avoid spam and scams, add your loved one's number to the Federal Trade Commission Do Not Call Registry (https://www.donotcall.gov). Set up filtering to place text messages from people who are not contacts into a separate folder. Go to Settings - Messages to turn on Filter Unknown Senders on an Apple device. In Android, open the Messages app and turn on Spam Protection in Settings to enable a similar feature. Messages from these numbers can be blocked by tapping the phone number and selecting block messages from that number. Scammers frequently use spoofed numbers and change often, but this will help reduce these scam text messages, albeit one number at a time. Once segregated into the unknown sender folder, the



recipient will not be fooled into thinking the text message is from a known contact and be tempted to click on an attachment.

Physical limitations when using devices can result in frustration for the Silver Generation. Operating systems on personal computers have had accessibility options for some time. If health conditions make devices challenging to use with standard settings, the accessibility options can help users continue operating the digital device. Accessibility features on personal computers include vision, hearing, and motor function challenged options. The accessibility options are found in the computer settings area. They often require changing a setting that is several screens deep in the settings. I have found searching YouTube for what I want to do will produce several YouTube videos in which users or software engineers walk me through how to make the change. When Bob needed to enlarge the type on his MacBook, I found several options available on YouTube. I called Bob on Facetime and walked him through how to make the change and make sure it worked. We tried several options, including different font sizes, until he found the size that he could see. He also had to enlarge the type on his Microsoft virtual desktop. Windows has a magnifier setting that allows the user to magnify parts or all of the screen so someone visually impaired can read the text. These settings are customizable, and so it helps to work with the person to find which settings work best for them. When we used the basic setting, it enlarged the window to the point where the window was too large for the monitor screen. Having the words disappear off the end of the monitor as he was typing was frustrating, so we switched to a "lens" setting that magnified the text in the lens panel that appeared to sit "over" the window on the screen. The lens moved from corner to corner of the window on the monitor and gave the ability to magnify the information on the screen while the window on the monitor stayed stationary. In Bob's case, he preferred the lens view. We were able to modify the size of the lens until he found the right size and right magnification for his vision.

Addressing access to digital devices by memory or judgment-impaired individuals is a decision that needs to be made by entire families. Susceptibility to fraud or parting with money in response to email requests are red flags that need immediate attention. I am familiar with an instance where an elderly widow sent over $100,000 to someone claiming to be a Naval officer stationed in the Persian Gulf who said he needed the money to help the war effort.

Sometimes, a person experiencing memory issues will misuse a digital device. In another case, a person in a locked memory ward called 911 to report she was being held against her will and, at a different time, because she thought something had happened to her adult child. When the police showed up at the memory ward (and at her child's house at 6 AM), they discovered that no emergency existed. While families want to have the convenience of calling a loved one on a cell phone, the loved one's misuse of the phone can be a problem. 911 services can flag a phone number so they do not respond to calls from someone experiencing dementia or confusion.

Discussing the importance of not clicking on email links/ attachments without knowing the source, not clicking on links in text messages from unknown senders, and not sending money to people who solicit via these unsolicited communications should be high on the list of the technical advisor.

Digital devices can offer benefits to people at risk of falling. Apple devices allow the user to designate an emergency contact. If your loved one also has an Apple Watch, the watch will automatically notify both emergency services and the emergency contact in the event of a fall. Android users can add emergency contact information on its lock screen so emergency responders can locate the phone number of the emergency contact without logging onto a phone and notify them in the event of an emergency.

Finally, retiring digital devices or accessing information stored on such devices in the case of death presents many issues. For instance, Bob's wife passed away recently. I tried to help Bob streamline his digital devices. He had his and his wife's cell phone, two iPads, and a 10-year-old laptop that could not run the current operating system and was frustratingly slow. After a discussion with him, he decided to move his number to his wife's larger and newer phone and trade his old MacBook, his old phone, and one iPad to offset the cost of a new MacBook. I backed up the MacBook to an external hard drive, and iCloud backed up all the other devices to the iCloud, wiped the hard drives, traded them, and brought home a new MacBook Pro. We had a password list to access the iCloud account and his wife's email account.

After the trade-ins, I set up the new devices and discovered that I had forgotten a critical step. First, I restored the MacBook from the backup and found that the old MacBook was so old that the software on the old computer was incompatible with the new iOS running on the new laptop. Rather than try to delete all the incompatible software, I wiped and restored the operating system on the new computer. I would still be able to restore the data from iCloud. While the operating system was installed on the new MacBook Pro (and because I am impatient!) I decided to wipe his wife's iPad concurrently and restore Bob's iPad account on that machine. After restoring the MacBook and trying to access her iCloud account, I discovered that accessing the iCloud from a new device also requires Multifactor Authentication. Bob's wife's cell phone number had been surrendered. But MFA's have a backup if the phone number is no longer available. An email can be sent to the email address on file. However, I had just erased Bob's wife's iPad and, with it, her email access. Trying to access the email on the web from a new device also required Multifactor Authentication. Therefore, we could not access the iCloud due to MFA, and we could not access the backup to the iCloud MFA because the email address also required MFA. We had one last chance to recover the data stored on the iCloud; we could answer the secret questions set up when his wife selected her password. Unfortunately, the secret questions his wife chose were not her mother's maiden name or the street where she grew up, for which Bob knew the answer. Instead, she chose "who is the most famous person you have ever met?" The answer on the password list did not work, and while we tried several acquaintances whose accomplishments may have qualified them as "famous," we could not guess the correct answer. I eventually called Apple Support and was told that a court order from a probate court would be required to access the account. The Christmas card list (stored on her



iCloud account) was not worth starting a probate to get a court order to retrieve it.

The lesson learned from my experience is that after the death of a person if the devices are accessible, and before retiring the devices, access the MFA information and change the MFA phone number to one that will remain active. Change the passwords and answers to secret questions to answers that the survivors know. With the number of passwords saved in devices, accessing these sites before retiring the device and changing the password so websites can be accessed is also recommended. Do not rely on physical password lists or answers to secret questions because these may be outdated. Electronic billing of accounts has become commonplace. Accessing email to cancel accounts, paying electronic bills, and assembling documentation for estate administration are all reasons to make sure passwords, MFA numbers, and secret questions are maintained and updated by the survivors. Finally, the passwords and account information must be maintained if the decedent's social media sites are taken down after the owner's death. Otherwise, the deceased will have a social media presence in perpetuity.

The latest operating systems released by Apple have an added option to access data stored in the cloud following a user's death. In iOS version 15.2 and newer, a person can designate a Legacy Contact. To set a Legacy Contact, go to Settings – and click the top of the screen where the user's name appears. Choose "Password and Security" and scroll down to the Legacy Contact choice. The legacy contact receives a key to unlock data stored on the iCloud upon submitting the user's death certificate to Apple. This will be available for iPads and Macs using the most current versions of the iOS software.

Microsoft requires a surviving heir to email a request and submit documentation. The type of documentation is not specified in the information I could locate. However, it is likely that letters of testamentary in a probate proceeding and a certified copy of the death certificate may be required.

The Digital Age provides convenience and accessibility to data, media, and services. However, it has also resulted in complexity, risk, and frustration if the systems do not function. Frequently, those members of younger generations become the family IT department. Learning how to manage device settings or where to educate ourselves to help them will allow those in the Silver Generation to reap the benefits of digitalization and minimize the risks and frustrations associated with using digital devices.



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CHAPTER 3

"HELLO IN THERE, HELLO"

by Scott T. Dickens



John Prine lyric from his 1971 song "Hello in There."

Introduction

If we and our parents are fortunate, they will live long and healthy lives which allow them to witness and to rejoice in the milestones in the lives of their children and perhaps grandchildren and great-grandchildren. But with longevity often comes significant and increasing decline in mental and/or physical health – and decreasing independence. As that happens, we will have the opportunity and responsibility to provide for their care and support in ways we may have never imagined.

My father died in 2013 at the age of 83 after a series of debilitating health problems. He was survived by my mother (who turned 95 on January 17!), me, and my two siblings (both of whom live in other states). My mother now resides in an assisted living community located less than a mile from our home. Because my siblings live far away, it is my responsibility to tend to her day-to-day well-being.

Of course this is uncharted territory for me, and I appreciate this opportunity to share some of my experiences and mistakes, and lessons I have learned along the way. If you also have one or more elderly parents, I hope you will find some of my reflections and suggestions to be helpful – recognizing that no two situations are the same.

Shifting Household Dynamics

If both parents are living, one of them may be in steeper decline than the other. This can upset the dynamics of what may be a long marital relationship in which the one who typically managed such mundane but essential things as finances, taxes, bill payment, insurance, and automobile maintenance is the one in deeper decline. That parent may try to continue to handle those responsibilities for longer than he or she should, both because we humans generally cling to those things that are core to our senses of self-value and identity, and due to the other parent's inability or reluctance to take over those responsibilities.

My parents had been married for 62 years when my father died. He was the one who took care of just about everything other than cooking and cleaning – not unusual for that generation. As my father did, the parent who is in deeper decline may try to mask over problems in an effort to maintain the status quo for the other. As Dad's health and challenges of daily living reached the point that I wanted and needed to be able to visit more frequently and get to him more quickly, I tried to persuade them to move closer to me and my family (they lived about 45 minutes away.) But Mom was still driving and enjoyed being able to go to the local YMCA, shops, and restaurants, and to visit with a group of nearby friends and neighbors whose numbers were steadily declining. As evidenced by the colorful paint transferred onto the corners of her trusty Toyota Camry, she probably had no business driving anywhere, but at least she was familiar and comfortable with the roads and regular destinations surrounding their home. Dad did not want to deprive her of those simple but essential pleasures, so he stubbornly and sacrificially resisted my pleas to relocate.

This eventually led to a situation in which his condition declined to the point that Mom was no longer capable of providing him with adequate care, support, and protection against injury. We became aware of several such occasions over the course of his last couple of years. There were lacerations and bruises caused by falls. He likely dislocated a shoulder. His hygiene was sometimes not the best. No doubt there were other mishaps of which we never learned. At one point I adamantly insisted that the situation was untenable and that they needed to move into an assisted living community near our home as soon as possible, but to no avail.

While I respect that my father was willing to sacrifice his own well-being for the emotional health of Mom, it was at great cost to him both physically and emotionally, and it was difficult for us to watch. But even in hindsight, I struggle to think of what we could have done differently that would have changed the outcome. At least in my experience, trying to balance the desire to respect personal decisions and autonomy with the need to mitigate risk can be tricky business.



The Big Transition

Even after my father passed, Mom remained cold to the idea of moving to an assisted living community. Her house was paid for, and for a Depression-era survivor the thought of having to incur the considerable cost of what we were proposing threatened her sense of economic security. Also, cooking has been one of her lifelong passions, and most assisted living facilities do not permit anything other than a small microwave oven due to safety concerns. She could not face having to surrender what was such an important aspect of her identity and sense of self-worth. And aside from the many other particulars she was clinging to, like most people her age Mom was averse to making such a dramatic change in her very existence.

Eventually we stopped trying to convince her to move. I continued to check in on her daily by phone and would either visit her or bring her to our home most Sundays. She fell at her home at least twice, and of course she was alone. The first time she was able to crawl to a phone and call 911, but because she could not get to the door when the fire department arrived they had to break it open. As a result of that episode, we got her a medical alert device that she wore on a wristband, and we also installed a lockbox outside her front door containing a housekey to be used by first responders. As far as I'm aware, neither was ever called into service but they did afford us some peace of mind.

And then, soon after one Christmas and completely out of the blue, she announced that she was ready. I suppose she had to reach that decision on her own and in her own time, and I am grateful that she finally did.

Because she was moving from a three-bedroom patio home to a much smaller one-bedroom apartment, there was much furniture, furnishings, and other accumulated stuff to be disposed of. We identified a non-profit organization which gratefully removed everything that would not join her in her new home. She insisted on keeping a couple of chairs that now crowd her modest den and are seldom if ever used, but we need to choose our battles wisely so there they shall remain.

The Cost Of Care

Many years before his health began to decline (and at a time when it was readily available and affordable), my father had the foresight to purchase long-term health insurance for both him and my mother. Because his particular disabling health issues occurred intermittently, he qualified for those benefits only a couple of times and for relatively short periods prior to his death. When Mom finally agreed to move into an assisted living community (at a cost of about $5000 per month), the need to draw benefits from her long-term care policy came into focus.

Enter the concept of "Activities of Daily Living." In order for Mom to qualify for benefits under her policy, the insurer had to determine that she was unable to perform at least

two of several articulated ADLs without assistance, such as bathing, getting dressed, and eating. Within several months of moving, Mom met (barely) the requirements of the policy, as determined by a visiting nurse who conducted an assessment. From that point forward and until her policy limits were exhausted, she underwent an annual assessment and the insurance covered the cost of her assisted living residency. (I will spare the details here, but let me know if you want to hear about my attempts to coach Mom for her assessments. As with witness testimony preparation, the results were unpredictable and sometimes comical.)

Qualifying for those benefits had longer-term significance beyond the benefits period, because during the years in which Mom's assisted living costs were being paid under the policy, seed cash comprised mostly of the proceeds of the sale of the patio home and a life insurance payment was allowed to grow in an investment account we had opened for her. Combined with monthly retirement benefits from my father's military and civil service careers, relatively modest withdrawals from that investment account have covered Mom's living and care expenses and should continue to do so for the rest of her life (even assuming that she eventually will transition to a more costly memory care or skilled nursing facility).

Your parent(s) may or may not have long-term health insurance, and they may or may not need it. But if they do not and you have concerns about the cost of their future care, then you may want to look into what products are available and their affordability, sooner rather than later.

Essential Legal Documents

I strongly recommend having aging parents execute wills, living will directives, and durable Powers of Attorney while they are still mentally competent, and updating them when appropriate as circumstances change. In particular, ensure that the POA provides explicit authority to make decisions regarding placement in restricted living arrangements, such as "memory care" (for those diagnosed with Alzheimer's or dementia), in facilities where the freedom to come and go at will and other personal liberties must be surrendered. The details of these POA requirements are usually state-specific.

I also recommend providing copies of living will directives and POAs to healthcare providers in advance to avoid delays in making decisions and taking action if and when the need arises. And keep copies in a readily accessible location (such as on your smartphone) just in case.

Other Practical Tips

- Obtain authority from financial institutions and other service providers to act on your parents' behalf. This includes banks, insurance companies, credit card companies, investment services, and cable TV and phone service providers. In my experience, some companies will grant authority based upon a valid POA but others require an oral grant of permission (by phone) from the parent. Without that authority, those providers probably will not share information or otherwise speak to you about your parents' affairs. I experienced this when I called our local internet provider to have them install wifi in my mother's apartment. They required confirmation directly from her, so I had to be physically present with her when that conversation took place to make sure she understood what was happening and what she needed to tell them. I am also authorized to write checks on my mother's behalf, which has been a huge benefit.

- Make sure their assets and accounts are jointly owned. The primary benefit of doing this is that when one parent predeceases the other, you will avoid having to go through the process of having assets owned solely by the deceased parent transferred into the name of the survivor. You may also be able to avoid having to go through probate court to administer the estate (depending on the language of the will and jurisdiction).

- Install a Nest camera or similar device. I was a little late to this game but highly recommend it. These systems are relatively inexpensive and easy to use – basically plug and play. All you need is a wifi signal. My mom has a Google Nest camera which provides a panoramic, high-resolution view of her main living area. It allows me to check in on her from time to time to make sure all is well (and to see if she is there before I try calling), and to be alerted to and to monitor the activity of any visitors. It allows other authorized persons to do likewise (which in my case is limited to my two siblings). Needless to say, these devices present a degree of intrusion on privacy and therefore access should be limited appropriately.

- Prepare for trips to the ER. One Sunday evening I had to take my mother to a hospital emergency room due to an uncontrollable nose-bleed. Apparently, this is not uncommon in elderly people as their septum weakens with age and many take blood-thinning medication.

Other contributing factors in Kentucky are dry winter air and – in my mother's case – the tendency to keep the apartment thermostat just a couple of notches below the "pits of Hell" setting. Although usually not life-threatening, it is a traumatic experience and can result in significant blood loss.

Over the course of that 7-hour adventure, and when I wasn't praying fervently that I would be protected from the crowd of COVID-infected patients inhabiting the waiting area, I spent considerable time wishing that I had remembered to bring a cell phone charger, some bottled water, and food. Chargers are a scarce commodity in emergency departments, and at least in my limited experience the vending machines were virtually empty. So I suggest keeping a spare charger and some bottled water and protein bars or other sustenance in your vehicle, just for such an occasion.

I also recommend making sure your parents' photo IDs and medical insurance cards are stored in a secure location in their home so that they can be retrieved without delay when needed. I also suggest making photocopies or digital images as a back-up. When my mother had her nose-bleed episode, we were unable to find any of those important items (she had misplaced them in her apartment) and our resulting inability to present them during the intake process at the hospital caused some additional effort, delay, and angst. We now keep those cards in a safe and I also have images saved in my phone.

- Plan to attend medical appointments. When my mother first transitioned into her assisted living community she would go to her occasional medical appointments by herself, with transportation provided by the facility. But eventually it became clear that a family member needed to attend those visits with her, as her ability to understand and to absorb information and instructions provided to her by physicians and others began to wane. We were also concerned that she was not able (or was perhaps unwilling) to provide her medical providers with complete and accurate information regarding changes in her condition or other items of concern arising since her last visit. I now take her to her medical appointments and interact directly with her providers. I also keep a list of her current medications because every provider asks for that information, every single time.

Also, I'm a big fan of using the providers' online patient portals to communicate with Mom's doctors before and after visits. Not only does this facilitate some discrete discussions regarding matters that might be difficult or awkward in the examination room setting, but they also allow you to share information in advance of office visits so that the provider will then have the opportunity to better prepare.



The Struggle Is Real

It is difficult to prepare for something you have never done before and for which there is no universal blueprint. Caring for an aged parent is a serious and demanding responsibility. Preparing yourself both mentally and emotionally will go a long way to help you to fulfill that responsibility to the best of your abilities.

Regrettably, my journey experience has been more reactionary than anticipatory. Along the way, I have had three critical revelations.

Revelation #1 Extraordinary patience is required. Even though it should have come as no surprise, I had

a subconscious resistance to accepting that my mother's memory and overall cognitive function were beginning to fail. So when she would forget something I had told her and stubbornly insist that I had not done so, instead of dropping the issue I would argue with and even chastise her. The typical pattern was "Such and such is happening." "Well you never told me that." "Yes I did." "No you didn't." And on and on. Hack: Don't tell your forgetful parent anything very far in advance. There usually is no real downside to just waiting until just before the event, and you avoid controversy regarding whether you told them about it earlier. You also minimize the time in which they might experience anxiety about whatever is about to happen.

As a person of faith, I have prayed often and earnestly that God would give me the patience – divine patience transcending human understanding – that the circumstances absolutely required but which I could not conjure on my own. He has always answered that prayer. If you believe in God or some other higher power, I would not hesitate to call on them for support.

Revelation #2 Very old people are like young children. Eventually I realized that it helps to view an aged parent as one does a young child. I came to understand that some of the things I learned while helping to raise my four children were helpful in dealing with my mother. I reminded myself that I should not expect more from her than her age naturally permits. In other words, I needed to focus on being patient and remembering that she is a work-in-progress, and her future behavior could be positively influenced by how I handle the current situation. I would be dishonest if I did not admit that there have been times when I reacted inappropriately to things my mother has said or done (just as I did with my children). I think part of the problem stemmed from my difficulty acknowledging and accepting what is happening to her. Eventually, I got there, which led to –

Revelation #3 Very old people are not like young children in one important respect. When raising children, the goal is to address their behavior in such a way that they learn what is desirable and what is not so that they modify their future conduct, and that there are negative consequences for making the wrong choice. After all, they are walking talking miracles who are evolving from helpless infants to independent adults before our very eyes. I don't know why it took so long, but only very recently did I come to realize that unlike a growing child, my mother does not learn from or even retain much of what I try to impart to her. She often seems to not learn from her mistakes or to try to improve or to modify her behavior – not deliberately, but because she is incapable. It reminds me of the movie, "The Curious Case of Benjamin Button." She is physically an adult but her mind is becoming increasingly child-like. With each passing day and ever so slightly, she becomes less independent and rational. Sadly, she is now in a stage in which she seems at times to be aware that this is all happening but there's nothing she can do to slow or stop it. Understandably, she sometimes feels frustrated, angry, embarrassed, and scared. My hope is that she will soon reach the point at which she loses that awareness, no longer passing back and forth across the divide that separates coherence and lucidity from peaceful oblivion.

Closing Reflections

Regardless of any Biblical mandates, I want to honor my father and mother. I believe that by caring for parents in their final years with loving kindness, patience, grace, and understanding, we fulfill that responsibility. I also believe that I continue to honor my father by doing everything in my power to care for my mother. I remind myself that the tables were once turned, and that I was fortunate to have parents who sacrificed and provided for my essential needs during times in which I was wholly incapable of doing so – and that sometimes things got messy and ugly. As difficult and challenging as it may be, it is a true privilege to have the opportunity to repay them in some measure for everything they've done for me. And for those of us with children of our own, we can only hope that the lessons learned while caring for our aged parents will also help us to prepare ourselves and our children for what may lie ahead when we enter the final season of our own lives.



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CHAPTER 4

MEMORIES

FILL THE HOLE IN MY HEART

by Mara Cohara





My biggest cheerleaders taught me how to refocus on the importance of foundation and family as my career started to thrive. I came from a very close family. We moved a lot, and at the start of a new city, my parents and sister were my only friends. Of course, my parents taught us to be independent and adapt, so we quickly found our way with friends and activities. I was harsh on myself and stayed laser-focused on obtaining career success through the years. My parents were always there to catch me when I fell short or encourage me during tough times. They were also the first to cheer me on when I reached my goals. Graduations, weddings, babies, and my success made them happier than anything else. However, I was quickly about to learn the impact aging parents can have on one's life. It all began with Mom's horrible call one evening that she had cancer. I was devastated.

I assured her I would do whatever she needed to do to fight, and we fought hard. It was not easy. I had two children under seven at the time and had just been selected to be the Firm's Tort Group practice group leader. I ran on fumes as I tried my best to be present for my parents during my mom's treatments, my young family, clients, the practice group, and the Firm. It was a long road, but my mom thankfully went into remission, only to learn it was my father's turn to have cancer. I once again pulled up my sleeves and helped him fight hard while trying to keep all my other balls in the air. Once he went into remission, I took a short breath and focused on my career and family. I was earning respect in my firm and was asked to serve on the firm's compensation committee for the first time. The second day after trying to prove I was a valuable member of the committee, my mother called with the devastating news that her cancer had returned. I knew deep down that it was only a matter of time. I did all I could to keep up with work and family and spend time with my mom. I was lucky to be with her in her final days and hold her hand as she took her last breath two months later. Her death took so much out of me. She was my person. The person I called on my way to work each day and on my way home. The second person (after my husband) that I called to share good/bad news with. She was my rock, and now that rock was gone.

I also had to turn my attention to my father, who was lost without my mother. He was also not in great health due to his previous cancer diagnosis and other ailments. It was a trying few years. Thankfully, he agreed to sell his house and move into a retirement community, so I did not have to worry so much about him being alone. But I constantly felt guilty that I was not seeing or talking to him enough. He did take my mom's place as my daily first call, but he was not always as eager to have this new role. I made sure my family



When I reach a goal, get an award, or need a pep talk, I think of my parents, and their memories seem to set me back on track. I also believe they continue to guide my career and cheer on my success.

(especially my kids) visited him as much as possible. For the next year, whenever I was not out of town for work, or one of our kids did not have a practice or game, we visited Papa Tom. It took a toll on my family and my ability to concentrate on my career fully. I was constantly exhausted and felt guilty that I was falling short with family, friends, and my career.

My sweet father finally succumbed to his ailments and passed away three years ago. Before he went to hospice, our final real conversation was that he was so proud of me and that I was an excellent daughter and support to him and my mother. He knew I loved him and that I would do anything for him and my mom. I am thankful for his words and will carry them with me always. Following their passing, I am left with a giant hole in my heart, but with the knowledge that they were my foundation, and I have both of them to thank for my success. When I reach a goal, get an award, or need a pep talk, I think of my parents, and their memories seem to set me back on track. I also believe they continue to guide my career and cheer on my success. I hope that I can do this for my children and will do my best to live a healthier lifestyle so that, hopefully, they will not lose me too early as I did my parents.



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CHAPTER 5

HELPING
A NEIGHBOR IN NEED

by Joseph R. Falasco











Personal Experiences - It Takes a Village

Our experience with aging loved ones comes from a relatively unique standpoint. We moved to our house in 2003, and our neighbors were in their early 60s. We live in a fairly rural area, and we ended up close personal friends with the neighbors. The husband passed away in his late 70s, leaving his widow alone on their property. The widow has no biological children but does have three stepchildren. As the widow aged, it became clear that she needed help if she was going to live out her life in the home she and her husband had built. We agreed to help.

Some Practical Advice

- **Money:** The widow has more than enough money to live comfortably. We decided that it would not be in anybody's best interest for us to handle her money. We ensured the bulk of her funds were under the care of a corporate trustee. Drawing a line between the money has been invaluable in helping us ensure that the widow gets the things she needs without the heavyweight of (a) non-disclosure or (b) figuring out who to keep in the loop.
- **Loneliness:** After spending decades with someone, living in a home alone can be isolating and lonely. As neighbors, our time constraints are limiting. We found a group called Visiting Angels to provide some companionship during the days https://www.visitingangels.com/). We also found a small dog for the widow that keeps her company. The companionship element has made a difference in the widow's mental health.
- **Medical:** We have found that our aging widow needs help understanding and communicating with her physicians. We ensure that the widow always has a liaison to go to medical appointments, help take notes, and communicate with the doctors. Trying to unravel a doctor's visit, new prescriptions, test results, or other items in a conversation with an octogenarian is impossible.

The Benefits

Nothing will pay you more than the earned smile of a person who has lived and aged.



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CHAPTER 6

FACING THE CHALLENGES OF THE ELDERLY DRIVER

by David L. Jarrett



My mom - the family's matriarch, is in her 89th year, still licensed to drive, and is a ball of fiery independence. With the respect I have for my mother's independence comes a dilemma, though. How do we, as her family, make sure she is keeping herself and others around her safe on the road as she continues to age?

I imagine many families are dealing with a similar situation. In 2019, my mom was one of approximately 30 million licensed drivers aged 70 and older, according to the 2020 Federal Highway Administration statistics. The difficulties of the decision likely vary by family. For example, if there is only one child in the family, the difficult decision can be made without working to a consensus. However, like with my family, where there are multiple children, another complication is trying to reach a consensus on the right thing to do.

Some parents recognize their limitations on their own and willingly stop or curtail their driving. Others, understandably, cling to their independence and are unwilling to access or acknowledge their limitations. They may continue driving even when there is a question about their safety or the safety of others while they are driving on the road. My mom falls into the latter category.

It is not unheard of for a member of our family to be driving around town and pass by my mother cruising down the street or looking for a parking space at Walmart. It might be surprising that a nearly nonagenarian woman has retained such independence from those at a distance. But many people who have met my mom are not surprised to learn she still carts herself around town. However, as a son, when I hear she has been driving out of town or getting lost in the high school parking lot, I cannot help but wonder: "Is it irresponsible for me to keep her on the road?"

My mom was born in 1933 and was the oldest of three girls. Her family lived on a dairy farm in Zionsville, Indiana. As anyone who grew up on a farm can attest, the art of working hard is a prerequisite for survival, and the introduction to it starts at a very young age.

In 1957, my mom married my father, a dairy farmer, but she has been on her own for 38 years. Perhaps it was surviving an abusive marriage for 25 years, or maybe it was always working one or two jobs to provide family necessities that her paltry allowance from my dad could not cover. Still, my mom learned to be a survivor. At 5 feet 3 inches tall she is a formidable presence. Some prefer to call it severe stubbornness. But most would agree that it is at least in part fierce independence.

Eleanor Roosevelt may have explained my mom's makeup best when she said, "You gain strength, courage, and confidence by every experience you stop to look fear in the face. You can say to yourself, 'I have lived through this horror. I can take the next thing that comes along. You must do the thing you cannot do.'"

Taking on complex challenges looks slightly different at 83 than at 23, but for the feistiest of women, those challenges can all be faced head-on. For my mom, getting her first smartphone in 2015 was a new challenge for her. She wanted to learn to send text messages to communicate easily with her children and grandchildren, but it was challenging.

Unbeknownst to me, this new little device would grant her unfettered access to me.

My mom loves sports, and commonly, during a Cleveland Browns game or an Ohio State football game, she will be texting me. The commentary almost makes it feel like we are watching the game in the same room. I started receiving text messages from her such as, "Are you watching…."

If I say I'm not watching the game, it will almost certainly guarantee that my phone will spend the next couple of hours buzzing every few minutes with nearly play-by-play texts. It would be easy to be annoyed by the frequent updates, riddled with typos, but I enjoy the interactions because I know she enjoys watching sports and sharing her thoughts about the game with me.

After raising five children, now ranging from ages 53 to 64, my mom lives on her own in a condominium about five



minutes from me and about 20 minutes from one of my brothers. My other three siblings live many hours away, leaving my brother and me, and more often our wives, as the principal caregivers in my mom's life.

At 88, her eyesight and hearing are quite impressive. If my mom uses reading glasses, I have never seen them, even when reading a text from her iPhone. Sometimes, she will even hear me whispering about her, to which she will respond, "Dave, you better stop it. Remember, I brought you into this world."

We live in a relatively small town. It's not uncommon for someone to come up to my wife or me and tell us that they have met my mom. Other than my initial worry about what wild story she has told, I find myself increasingly concerned about the fact that she has been driving.

Maybe it is the proximity, our sharing the streets in our small town, or being a lawyer who is all too familiar with what can happen in a disastrous accident. Still, I feel a strong sense of responsibility to address the issue of her driving.

More than once, my mom has sent me a message asking me about an iPhone feature, such as how to turn off her flashlight or clear a notification. After exchanging a few messages instructing her on fixing her issues, I think the problem was fixed until a couple of minutes later when I received a new text: "I will go to Verizon and ask. Be safe."

The exchange causes me stress because it is another unnecessary trip in the car.

I picture her petite 5-foot, 3-inch body peering over the steering wheel while unnecessarily driving to the Verizon store, and it fills me with dread. The route involves several

turns and a few lane changes across a busy road. Perhaps most concerning, it involves her parking her car amongst many others in a tight parking lot, all of which leave me uneasy.

Recently, a family member received a phone call after my mom went to the hairdresser because the staff at the salon was concerned about her driving herself home. Ultimately, a salon staff member drove my mom's car home while someone else escorted her home in another vehicle.

Not only was the excursion further from her home than Verizon, but she decided to make the outing just days after coming home from the hospital, where she had undergone an operation. She should barely have been eating solid food, let alone driving herself across town.

Knowing she made that judgment call is disheartening but even more frustrating is that the hairdresser offered her a transportation service that she refused. There was a safer option, and she chose not to take it. Again, that fierce independence — or stubbornness — won out over safety.

Sometimes, she will even hear me whispering about her, to which she will respond, "Dave, you better stop it. Remember, I brought you into this world."

She is not without support. In fact, my wife takes her grocery requests at least weekly and delivers whatever she may need to save her the trip to the store. Yet, we will often see her out at Walmart or get phone calls from members of the community who know us and wonder why she's out driving on her own. My siblings, who live across the country, can only remind her that she should not be out driving unnecessarily and let us know when she needs something from the store.

The problem is apparent, and no one dares to take her car away.

While she has never said it outright, I imagine that would be the ultimate disgrace for her. Having the freedom to drive, to get away, even drive around the block, is a freedom that is precious to her. After spending years trapped in an abusive marriage, she cherishes her independence above most other things. To take that away from her might be unforgivable from her perspective.

Per Ohio Revised Code 4507.20, if someone at the Bureau of Motor Vehicles (BMV) has good cause to suspect that a driver is not qualified to be licensed, they can require the license holder to take a driver's exam, a physical exam, or both to prove fitness. In other words, anyone could notify the BMV that my mom should not be driving, and they could require her to undergo the appropriate examinations to retain her license.

Similarly, suppose her physician determines that she may be incompetent. In that case, they can submit a confidential report to the BMV, which then may prompt her to retake portions of the driving skills test or require her to submit to a medical examination to keep her license.

However, upon reviewing Form 2310, "Request For Statement Of Physician," available via the Ohio BMV website at http://www.bmv.ohio.gov/bmv_forms.stm, she does not technically have any of the nine physical impairments listed within the criteria that would prompt a physician to question her fitness to drive. Her doctor would have no more reason to suggest that she is incompetent to drive than my own doctor would have to suggest the same for me.

Still unsure what to do, I decided to dig into the data behind accidents. Are older drivers at a disproportionate risk for causing traffic accidents? I found statistics from Rand.org, that concluded drivers aged 65 and older are 16% more likely to cause an accident than adult drivers between 25 and 64 years old. However, I also learned that drivers under the age of 25 are 188% more likely than drivers over 65 to cause an accident. This means that older drivers pose much less risk to the public than drivers under 25.





After investigation, I was back to where I started.

If my mom's driving poses less risk to the public than my 17-year-old son's driving, who am I to say that she should no longer drive?

I am tempted to stop and leave it like Walter Cronkite used to end his broadcasts, "and that's the way it is." He was sharing the facts, nothing more and nothing less. But I must ask myself, am I simply avoiding the issue? Am I letting my concern for my mom's emotional comfort or happiness overshadow a very real concern for her physical safety and the safety of those around her?

Just as parents should have the courage to make hard choices to do the right thing for their children, ought we, as the children of an elderly parent, have the same courage to do what is best for our parents, too?

Summoning just a bit more courage, I took to the internet, looking for resources, data, or anything I could use for guidance.

A search for "how long to let the elderly drive" brought me to *Seniors and Driving: A Guide by Caring.com*. As I read through it, I found myself checking off the common risk factors as not applying to my mom. Then, a sentence jumped out at me.

"We've developed guidelines that will help you avoid being an alarmist," it assured, "yet also realize when the time has arrived that driving is no longer a safe activity for the person in your care."

This section of the guide held promise. I could envision discussing the steps with my siblings. The most promising was the suggestion to hire a Certified Driver Rehabilitation Specialist (CDRS). They can essentially serve as a driving instructor who could evaluate her driving and possibly make the recommendation all of us are afraid to express.

The report could be discussed amongst my siblings, and we could decide together what should be explained to our mother. If the recommendation is to cease driving, we can refer to the CDRS and hopefully make it feel less like a personal attack on her. If the recommendation is something in between, we could hire CDRS to help her and explain the limitations they observed to her.

In other words, leave it to the professionals.

Caring for elderly parents is not for the faint at heart, and it often requires the courage to tackle tough decisions. I found some ways to broach difficult topics with your parents that may help ease the decision-making. While the issue itself will vary by family, it should always involve being sensitive to the parent's feelings and yet having the courage to do the right thing. And really, isn't that true for most challenges in life?



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CHAPTER 7

BE PRESENT AND AWARE

by Craig A. Marvinney



She was choking. I froze.

The nurse looked over and said, "It's OK, she always does that when I feed her lunch." My mind screamed, "It's NOT OK! This is my mother, and neither she nor anyone else should be choking on her lunch of bits of chicken, beans, and mashed potatoes." I had swung by the hospital to see Mom for a long lunch visit from my law office. As a young partner and a dad with a young family, others largely dictated my life, if not by the billable hour. So, the chance to see my mom over lunch was a welcome change.

Mom, only 63, was fighting diabetes. She'd been in the hospital for over a week with yet another set of infections that kept beating her down. Mostly, they hit her foot. Her health problems accelerated ever since she and her husband (my stepfather, Jack) got caught in their Florida high rise earlier that winter in what became known as a "White Hurricane" that swept to the north, dropping feet of snow across the South. She suffered a heart attack then and had to stay in Florida for weeks as she tried to recover.

Finally, she was healthy enough to travel, so I flew down from Cleveland to drive them the two days home to Ohio for more treatment as she was still deathly ill. Now, over lunch, she was choking, and she was able to clear her throat, and on the next spoon, she choked again. The nurse noted Mom was not eating as she was choking all the time.

My mind jumped to spoon-feeding baby food to my little kids. My youngest would choke on larger chunks of food, too. I mushed up Mom's lunch, so it became as unrecognizable as baby food with that in mind. Mom swallowed. She ate. Almost ravenously. Even the nurse was surprised.

Later that evening, I stopped by on the way home. It was after 11 pm, and the only light in the room aside from the medical equipment lights was a small lamp bathing Mom's face as she lay almost asleep. Hearing a noise, I turned to find the attending physician coming through on his last rounds. He put his hand on my shoulder and noted, "Your mother is shutting down. People do that as they prepare to die. One by one, or sometimes all together, their systems wind down eventually to a stop." While not unexpected, it was still sobering as I considered why and how.

Her grandkids would never know her. She was "young," and I was only 35! The physician noted that her choking was another sign Mom was getting ready to go. But it made no sense to me. I related how Mom ate after I mushed up her food, and the doc said it was no surprise as she was still drinking some fluids but not keeping down any solids. I commented that she was not throwing up but rather coughing up food she could not seem to swallow. It was as if she had a blockage at the top of her esophagus.

In the dim light, I made out the doc's face. He had one of those "so-now-you-think-you're-a-doctor" looks. He strove to ease my mind, "It's part of the dying process," "It's natural," and "often seen." Yet, it still did not make sense the more I thought about it. Finally, I asked him to see her the next day with a gastroenterologist. He pushed back at first but, after some discussion, relented.

The next day, the GE found she had severe esophagitis, an intense infection at the top of her esophagus, blocking her ability to swallow anything but fluids or mush. After treatment with an antibiotic, Mom recovered and lived on.

Keep your common sense and stand up for what is right.

I learned a key lesson. Don't just accept, but question firmly but politely. Allow your common sense to have a role. Physicians ordinarily know their books and are usually adept at putting odds and ends together for a diagnosis that makes sense. Still, sometimes, they get so locked into their assumptions and predetermined beliefs they are unable to see solutions right in front of them.

Another example took place a couple of years later after



Craig Marvinney center, and his parents

Mom finally passed one December morning at age 65. Jack was 81 at that time and fading from what turned out to be a series of minor strokes that chewed away at his mind. Jack was a man's man. Born within a year of the Titanic's sinking, as a young man, he and a friend drove from his native New York City across the United States in the 1930s, long before highways and interstates, and worked on the Hoover Dam as it was being built, and lumber-jacked in Oregon before heading back east. He played a season with the Philadelphia Eagles. After World War II, as a sales manager for a major can company, he saved his company by convincing the soft drink industry to put pop in a can.

By May, after Mom passed, Jack was in decline. One Sunday, he was convinced he was having a heart attack, so I took him to the hospital. He was lightly medicated on check-in the next day, resting comfortably, and the docs said his heartbeat was equilibrating.

As my family finished dinner a half-hour away, I got a call from the hospital. I was needed right away as it looked as though Jack had a major stroke. When I arrived on the floor, Jack was visible in his room at the end of the hall. My younger sister Suzy was there already and was talking with Jack's doctor for the moment. The doctor was a younger resident now dealing with a major stroke victim, Jack. The young doctor noted the stroke rendered Jack a hemiplegic and took away his ability to talk.

The immediate concern, the doctor said, was to calm Jack as he was flailing violently in his bed. The doctor planned to strap him down to the bed and medicate him. It was when "clot-busting" medications were beginning to come into use, and I asked him if he meant that. "No, I'm talking about seriously sedating him," he replied.

We viewed Jack down the hall. Suzy noted he was "reaching for heaven." Watching Jack for a moment, I noticed a pattern in his movements. I asked the doctor if he had told Jack what had happened. The doctor looked incredulous – "He doesn't have a clue. He's just thrashing and would never understand me!" I looked across at Jack.

Jack was focused intensely on his movements. One look at his face told us. He was trying to get out of bed. He was throwing his good leg up, trying to use it as a counterweight to roll his torso up as he threw his good arm forward. All to no avail, again and again. As I explained what I saw, my sister saw it too. The young doctor suddenly seemed to be the one who had no clue.

I blew past the doctor into the room, grabbed Jack by the shoulders, and put my face entirely into his line of vision. The doctor followed us into the room, "You can't do that!" I turned back to Jack, "Jack, Jack!" He looked at me, focusing on my face with his good eye, and stopped thrashing but remained stiff, resistant. I held him firmly and told him what had happened and how sorry I was he had had such a stroke. His stiffness dissipated, and he seemed almost to surrender.

Instead of seeing this calm Jack down, the young doctor responded in anger as if we 'stepped out of line' from the usual passive patient families he dealt with. We were happy to know Jack was not "seriously sedated." More so, we could see he still had a sense of comprehension despite the stroke. The doctor, though, chose not to understand, continuing to talk over Jack as he would over a piece of furniture and not to the man Jack still was. Although Jack passed away two weeks later, that lesson of not simply accepting a physician's point of view, especially when it flew in the face of common sense, stayed with me.

It's not about you.

A loved one's dementia teaches this quite effectively. Upon

discharge following World War II, my father finished college and became a foundry engineer. It was the early 1950s, and anything to do with iron, steel, and molten alloys ruled the roost in American manufacturing. If precision thinking was critical, Dad was THE guy. As the '60s rolled into the '70s, the metals industry moved off-shore, the foundry in the United States withered, and a newfound focus on energy, plastics, and silicates began to dominate manufacturing as hi-tech took root. Dad took early retirement but always maintained his exact nature. Until…

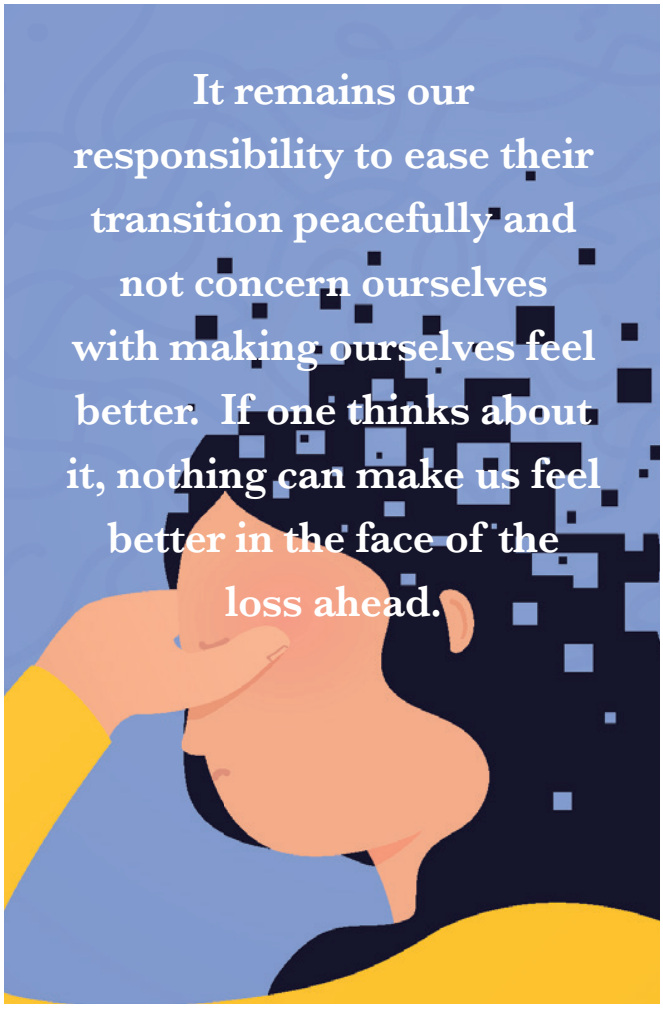
I got a call. From North Carolina. Dad lived in Milwaukee at the time and got into an accident on one of his many driving trips with his late-life companion, Ginny while visiting her extended family. Not just any accident. Somehow, he got his Buick caught between the gate arm and the tracks at a railroad crossing just as a freight train bore down on them. Well, not entirely 'between.'

The train hit Dad's car at high speed, passing about an inch in front of the mainframe cross-member support for the bumper assembly. Miraculously, the train neatly sheared the front-end grill assembly and bumper cover off the front of the car. If the train hit an inch rearward, it would have caught the frame, torquing the car into the side of the train, dragging it along, or worse, all with Dad and Ginny inside.

Afterward, my brother Dave and I questioned Dad hard about how this happened. He was unusually confused and vague about how he became trapped by the gate. We attributed it to the trauma of enduring such a crash. Had we known better, we would have seen the signs.

Other signals. For a man who loved technology, he left a gift portable stereo unopened for years. His temper, never easy, flared up at the drop of a hat or a pill. Or at his toddler granddaughter playing behind a hotel room curtain. These were not typical behaviors. Ginny noted he was medicating to help his mental state. Finally, while attending a volleyball game with his seventh-grade granddaughter, he forgot how to return to the stands in the school's gym after a break. When I found him confused in the atrium, he did not know if he was in our Ohio hometown or in his Wisconsin.

He was 78. A day of testing at the renowned Cleveland Clinic yielded his diagnosis: Dad was already in early-intermediate stage Peripheral Artery Disease-related



dementia, a condition that mimics Alzheimer's disease. Under a watchful eye, he was still largely functional, but soon, a stroke interrupted his ability to walk.

My brother traveled to Wisconsin with my Maryland-based older sister, Diane, a nurse, and together with Ginny, got him on a plane. Suzy and I met Dad and Diane at Cleveland Hopkins Airport and drove Dad to a pre-arranged facility near my brother's home in a Cleveland exurb. He professed no memory of Dave, Diane, and Ginnys' long conversation before leaving Wisconsin about coming to Cleveland. As a result, moving Dad from the car into the Home proved very difficult. Dave stayed over in Wisconsin to begin wrapping up Dad's affairs there.

Dave took care of Dad in the ensuing years, as I did our mother years earlier. Dad slowly deteriorated. He could not engage in normal functions alone. I would take him for walks outside in his wheelchair, showing him trees and

leaves/needles as one would a young child. It seemed innocent enough.

But Dad had other ideas. I got a call. Dad decided to escape. He rolled out of the door he and I usually used for our walks and kept on going. He was already several blocks from the home when his progress slowed on a hill. The home's personnel caught him there. Without a word spoken, Dad unintentionally convinced the facility to install a lock-down security system for residents throughout all the exit doors of the building.

Things grew worse. Dad forgot who his grandchildren were despite their photos in his room. Then, he forgot who his children were. At first, we would correct him, but that would agitate him more. "Dad, how are you doing?" I asked on arriving for a visit. "Why did you call me 'Dad'?" he growled back. "Who are you?" he demanded. I responded, "I'm Craig."

"No, you're not. You're too old."

"How old do you think your son is, Dad?" "He's five," came the response. "Then who do you think I am, Dad?" I asked. "I don't know. You look like one of my uncles, but you're not Craig."

Yet he could hold a conversation on the phone with his older brother (sharp as a tack), where he and Dad would bust chops over where his tee shot landed on Westchester Country Club's par-three fifth hole when they golfed together in New York on Saturday, May 17, 1952. We learned his memory was like a wave receding from a beach. Some of our family took these changes better than others, but it was never easy.

Soon, he spoke only of his childhood as if he was there himself. Later, he lay on his back like an infant for hours, just looking at his hands from all angles as he moved them. Then, one morning, I got a call. Dad passed the night before.

My brother was masterful in securing Dad's grave and full military honors service at a National Cemetery nearby. Weeks later, his headstone was installed. It had the wrong date carved into it. Dave was weary by so much of what he'd done for Dad. Suzy and I felt the headstone error would not sit well with Dad (even though he was gone) – he was so precise. Anticipating a long haul slog with the U.S. Department of Veteran's Affairs, I winced as I initiated the inquiry to get the headstone fixed. To our shock, all we had to do was submit a photo of the stone, both sides and a certified death certificate. Within a month, Veteran's Affairs replaced the old stone with one with the correct date.

Ten years later, my mother-in-law, Lorrie, was diagnosed with Alzheimer's and entered into a spiral similar to Dad's. In the intervening years, courses on dealing with dementia in loved ones sprang up. My wife, Paula, took some, learning in advance much of what my siblings and I learned from experience. Today, Paula deals with her mom's condition like a seasoned vet.

Lorrie went through the gruff temper stage. She resisted moving to Ohio to be near us instead of her hometown, Kansas City. Paula was able to involve Kansas health authorities so that Lorrie did not resent Paula for making her move. Then, during the COVID-19 shutdowns, Lorrie suffered a stroke of some sort, immediately developing aphasia, which left her unable to speak in any meaningful way. She speaks a "word salad." We listen to her cadence and other patterns as she speaks, and while rarely knowing what she says, we see she is calmed, knowing we agree with her most of the time.

While dementia is a classic example of how "it isn't about you," the concept arises in other situations. My Mom, fighting the insidiousness of diabetes in her last year, underwent an amputation of her leg above the knee. Mom became extraordinarily depressed in the rehab facility following the surgery. She was always proud of her appearance, and her mind remained sharp with no doubts or misconceptions about her condition.

One evening, she spoke of how hopeless she felt, having lost her leg. She turned to me and seemed to look right through me, saying, "Touch my leg." I turned paler than my normal beluga complexion. I got a clammy sweat that cold January night. Cool as a cucumber trial attorney, and I suddenly could not move. Did I want to touch my Mom's leg, which was but a still healing, scarred red stump? Could I?

Looking into her eyes, I froze for an instant. Suddenly, I

realized this was a cathartic moment for her. If her son were repulsed by her leg, it would be devastating to her. Trying not to show any unease, I gently pulled the cover and bandage wrap back. I took her lower thigh, holding it as if she was as beautiful and whole as ever. I looked up at her and smiled. Her eyes softened, and tears welled up. She said she feared I would draw back, showing rejection. But instead of following my own initial emotions and fears, I leaned in. It was about Mom, not me.

Her confidence returned. She learned how to walk with a prosthetic and cane. Later that summer, she began speaking to amputee groups about coping with their losses. She helped others overcome the emotions and fears that come from an amputation. Mom flourished for a time before she ultimately passed that December.

My second point comes from all of this: it is not about you. It's about them. It remains our responsibility to ease their transition peacefully and not concern ourselves with making ourselves feel better. If one thinks about it, nothing can make us feel better in the face of the loss ahead. But by stepping out of ourselves and focusing on them, we can ease their path by responding with love at every turn, no matter how tough it can get on us. And that brings the third point to focus.

Learn to depend on resources, for we are not alone in this process in most cases.

We are far better off today than we were thirty years ago when Mom was in decline. Paula leaned on Alzheimer's and Dementia patient care programs to learn what to anticipate in dealing with Lorrie's situation. Resources just seemed to flow once she tapped into these programs.

The information is more understandable than things were with my dad fifteen years ago. This is primarily due to the internet and the ease of finding almost anything about everything. Aside from our faith, these resources impressively show how we are not so alone in these situations anymore.

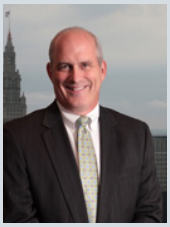
Use the sites from established and dependable facilities, agencies, and journals, and do not depend on information from anything that seems amateurish. Sites from dealing with a disease process to coping, from what to expect to how to reach out to find help, all abound. Information on working through issues with health insurance, Medicare/Medicaid, life insurance, nursing home insurance, and financial coaching can be an ongoing help. What care facilities are out there, and how does one select one? How does one pay for that if no one planned for it in advance? How to deal with the after-death experiences from funeral homes, final memorial or funeral information, gravesite, and cremation info, and how folks grieve.

These resources will help you, and they will help you get through. In addition, most of all, by leaning on such abundant resources, we are not alone. The weight of all that seems to be ahead for those in these situations can and should readily be shared by those who know, are there for us, and can smooth out the wrinkles and get us through.

In the end, these are the three most valuable lessons in my estimation:

1. **Be where you are** calm and collected, aware of what is going on so that you can depend both on your common sense and the doctor's advice in finding the best path forward for your loved one and your family;
2. When it comes to your loved one's transition, **it is about them, not you** – and no matter what, you'll grow from knowing you did your best for them in the end and
3. Know that **you are not alone**, but you have incredible resources for learning and problem-solving if you ask.

None of this part of life is easy; however, it does not have to be as hard as it seems because indeed, there is nothing you will face that someone, somewhere, has not faced before. All you need to do is reach out.



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CHAPTER 8

TAKING CARE OF MY FATHER AND MATERNAL AUNT

by Justi Miller



I was the caregiver for my father and my maternal aunt consecutively, when both were in their mid-90s. Each had their circumstance of health, mental declination, financial means, family/friend support, and expectation of care. These differences led to different lessons and made me more aware that the path in dementia is multivariate and imperfect. Although this is about parents, the lessons learned by my aunt could be informative given my role. I also was the primary caregiver for my mother during esophageal cancer treatment for six months at MD Anderson in Texas. I'll provide some lessons I learned from each below.

My father had attended college and law school at Indiana University, was a successful businessman, and owned/managed his lumber yards and various real estate holdings for 60-plus years. The last lumber yard closed due to arson just a few years before his diagnosis (multisymptom atrophy displayed as dementia and Parkinson's effect). My mother died six years earlier from esophageal cancer. We were incredibly fortunate that he had considerable funds to support his homes in Illinois and Florida. We also knew that he was physically slowing down, particularly after a heart stint surgery at 94 years old, but he was still flying to Florida and playing golf. His physical health was declining, and we had even hired in-home care for him. He had begun to see a woman we knew in town, and she had offered to travel with him down to the Florida home for a few months, which we supported. We fully believed Jane had his best interests at heart.

The issue arose when I received an anonymous phone call from someone in my small hometown. Jane was looking to take his money. She described it as follows, "Jane is looking for an old man with one foot on a banana peel and one foot in the grave. And, she is already taking funds and stealing things from the house." She described a few pieces of my parent's jewelry. I flew home, and my three siblings (who lived there, too) and I began to investigate and ask questions. We quickly realized a few things that weren't necessarily obvious on the phone. Dad was generally confused and described items in the house as worth much more than they were. He explained that Jane was trying to convince him to buy her run-down restaurant, and he was thinking about doing it. She also had his credit cards, cash, and checkbook – and we learned she was taking him down to the local bank to cash checks for five and six thousand dollars. Dad, who typically paid cash for everything, had a large credit card bill from the trip to Florida. We quickly had Dad's mental acuity tested again by his gerontologist, then filed for guardianship and met with the judge who entered it. Part of the petition described Jane's activities, and the judge offered his phone number if we needed additional help. Four of Dad's six adult children, including me, were now fully responsible for his care. We met with Jane at my sister's car dealership along with a police detective and told her that we had obtained guardianship, the gig was up, and that she was to hand over the keys, credit cards, and checking book – and never contact him again or we'd file charges. This seemingly sweet older woman we had known for decades turned into a monster.

We fired the local licensed assisted living company that was sending a new person every day, and as it turns out, some were a bit unsavory and had been working with Jane to steal items from the house. We asked around our small town and found women via contacts at our local churches who had taken care of other elderly people we knew – and we did our background checks by calling all of those folks' families. We landed on having three women rotate through the week on two-day shifts. They were not formally trained or certified but were caring women who fed him, talked, sang, and communicated with us daily.

Sadly, I had to tell Dad what had occurred – that we had obtained guardianship and that he would never see Jane again because she was stealing his money. It was, by far, one of the most challenging conversations I've ever had. Dad's response was, "What time is the Cardinals' baseball game on?" The next day, he asked me to set an appointment with his (and our) long-time family and business attorney "to get rid of this guardianship thing – I want you to tell him why I don't need it." I explained again that I was the one who filed





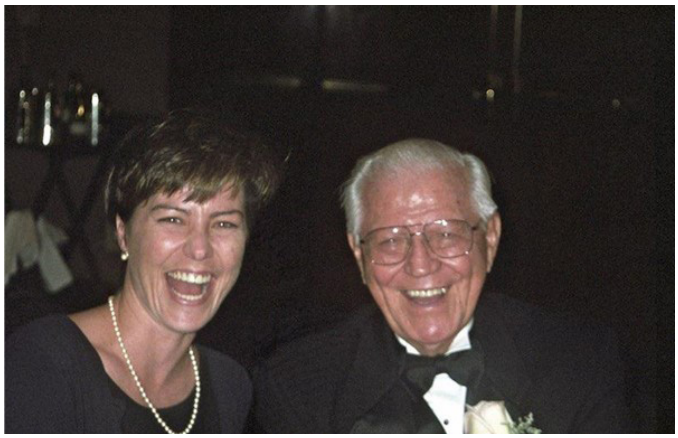
for it via another attorney in town, given the conflict, but that I would set the appointment and take him, which I did. Once we got to his attorney's office, he again asked me to join to "tell John why we don't need this." Having dealt with his own wife's ongoing Alzheimer's, John was incredibly kind and explained to my dad that it was time for him to let the "kids" help him now.

For the next three years, the four of us (three who lived in town and me driving down), with the incredible help of three caregivers, managed my Dad's daily activities, appointments, and every need. My siblings and I are all strong-willed. As a result of stepping on each other's toes in the first months, even if entirely well-meaning, we quickly implemented a strategy that worked for us.

Of the four of us, we began to identify a single "Point Person" who was in charge of all Dad's care and health decisions for a period that they could commit to. Everyone in the family, his friends, and the caregivers were instructed on who the Point Person was that month. Any of us could go to the house and see dad, spend time with him, give the Point Person our thoughts on what we saw, etc., but as to any questions from the caregivers, doctors, or decisions made, the Point Person was in charge. We typically rotated the Point Person role for a month or two. As a result, the caregivers weren't getting mixed messages from every family member who visited or called, and we were each able to visit with Dad on the phone or in-person without feeling like we were on point. The lines of communication were clear, and hard feelings were avoided.

We created a binder with a form for each day that the caregivers needed to fill out that included details about his day, such as blood pressure readings, water intake, medicines and supplements taken and time, output (essential to monitor to avoid bladder infections in the elderly), food eaten, mental state, etc. As a result, any of us could walk in and get a really good read about what was going on with his health. We could also pick it up with Dad when heading to a







doctor's appointment and have a complete record to report. It helped us start to identify patterns and better manage his medications. On one occasion, he was showing symptoms of déjà vu, which was unusual. One of the caregivers had taken him to the chiropractor the day before, giving him a seemingly innocuous over-the-counter supplement. We eliminated the supplement, and the déjà vu disappeared. We found some supplements were beneficial for him and others were not, but only by tracking all of the data could we tease out what was best for him.

My brother was put in charge of the houses in Illinois and Florida, which worked for him. He was not interested in the physical stuff (helping with things such as suppositories, urinals, etc.) that my sisters and I would do, but he could manage the upkeep. Soon, we learned that one of the caregivers was very organized and able to do the shopping, so we increased her hourly rate to keep track of all of the caregivers' hours and grocery expenses. Our local payroll firm took care of all of that headache.

We hired a massage therapist to come in once a week to give him a long massage, which he loved. Like many elderly, he craved touch, and the massage met that need.

We bought him a Sirius radio that had the music he grew up on and had it playing for him. It seemed to give him comfort, and he loved to sing and dance on his feet – even if he was by then bedridden.

We bought a big digital clock that he loved to have sitting on his belly, and he could check the time of night or day.

We kept the phone near him, and he was allowed to call anyone at any time of the day or night to have access to us – and us to him.

We bought a wheelchair van and were able to continue to take him to his favorite eating spots in town and meet his friends. I think he enjoyed those outings even when it was becoming difficult. One of my favorite memories was when I failed to strap down the wheelchair's front wheels fully,

and when I hit the gas, Dad fell backward in his wheelchair. When I thought I killed him, his boisterous belly laugh came forth, and we both laughed until we cried.

Dad always knew who his children were throughout, but between dementia and his failing sight, he was less sure about others, such as his closest friends. He had periods where he was out of it and other periods where he snapped back to total mental clarity. The distance between the mental clarity periods grew significantly over time. At first, it was a few days, then weeks, then months. It was as if it was two entirely different realities for him. When he had mental clarity, he didn't recall anything that had occurred in what I called the "darkness." When he was in the darkness, he was generally just confused.

There was one occasion closer to the end when he hadn't slept in a few days. Sundowners are such a severe side effect of dementia. He ended up in the hospital. We had been trying to reason with him to go to sleep, then cajoling, then begging. But he wasn't having it. He was conversing with himself at the hospital, who he thought was sitting in the chair at the end of the bed. Our excellent caregiver, Peggy, said to Dad, "Mr. Miller, visiting hours are over now. Mr. Miller needs to leave and let you rest, O.K.?" Miraculously, after days of trying to get him to go to sleep, he responded to her, "Yes, O.K. – bye, Ray!" and laid back on the bed, closed his eyes, and went to sleep. Peggy, who we all hoped would be there when we needed a caregiver, was not formally trained but had that amazing ability to put herself in his shoes and make everything better. She had been "caretaking" for people all over town for many years and had a great heart and a fantastic knack for people in their last years, months, and days.

Dad died in September 2008, nearly 97 years old. It was sad to lose him, but we also knew we did everything to make him comfortable, happy, and loved in those last few years.

Aunt Estelle was my one aunt. If I'm honest, I didn't like Estelle much growing up, and my mother's view of her probably influenced me. Aunt Estelle was the oldest of seven children, and my mom was the youngest, and they grew up during the Depression. So, in a six-week trial, I got a call that Aunt Estelle, at 90, had driven her car to an auto dealership in town to get her tires rotated – during a tent sale. Of course, the dealership convinced her to trade in her very gently used car, which worked great and had low mileage for a small SUV that didn't fit in her garage. Her great-nephew on her long-deceased husband's side called me in a panic and had already tried unsuccessfully to resolve it with the dealership. Our aunt had begun down the road of dementia and shouldn't have been driving, but she was making her way through life. Without anyone else able to step up, this began the next four years or more when my cousins and I took responsibility for our aunt while none of us lived nearby. I was the closest, initially residing three states away. She had signed a joint POA naming three of us.

Lessons learned from caring for Aunt Estelle:

1. **Getting the guardianship probably would have been better than a POA.** Some legal papers and issues would have been easier if we had the guardianship versus the joint POA, particularly early when she was in and out of it with her dementia. We chose not to do so because she was pretty independent, but we ended up unnecessarily waiting on some things until she was fully lucid enough to sign documents.

2. **Keep the elder's financial records simple**. Our aunt's funds were in US Bank, but I personally had Wells Fargo, so I moved some of her funds to separate checking/savings accounts in Wells Fargo, thinking it would be easier to manage primarily because I disliked US Bank's bill pay function at the time. I should have just kept them at US Bank or simplified it to one checking account. The savings account interest wasn't worth the headache when I had to apply for Medicaid for three years to take care of her finances. At that time, Medicaid was a five-year look-back period. I'm pretty sure I spent a few hundred hours preparing the application and financial records describing why I moved money from one account to another each time I needed to pay bills. I would also recommend either Quicken or an Excel spreadsheet to track each expense over $50. The state didn't care about more minor expenses than $1,000, but I felt more comfortable detailing each expense, and the application went through without a question.

3. **Communicate throughout the family**. The cousins sat down and communicated expectations and roles early on so that we didn't have missteps. We also communicated well through each financial and medical decision in the process. There was never any jealousy or distrust. We each did what we could for Aunt Estelle and worked hard to make the best decisions for her and help her through the last years.

4. **How do you convince her to move into assisted living**. Our aunt's home required her to go down steep stairs to do laundry and access various items. She had a bad fall years before, so it was time to move. She had been checking out assisted living facilities independently but was scared about the move itself. She was worried she wouldn't like it. My cousin, Dick, came up with a brilliant plan. He told her that the assisted living facility offered a "free two-month stay." We would take her there with a few pieces of her furniture, kitchenware, and favorite clothing. If she didn't like it, she could quickly move back home. We'd help take care of the rest if she did like it. She thought she'd try it as a result – and she loved it. After being a widower for more than 30 years and living in a house that had overwhelmed her, she loved being warm all the time, the available meals, and the company of others, and she could still play her organ or piano there. Even though she couldn't drive, we kept the house and the car available for her for at least six months or more if she changed her mind.

5. **It's ok to trust others to help you**. My aunt met a wonderful younger woman, Pam, at church. Pam considered my aunt like her grandmother and helped her quite a bit. Due to Pam's job as a bank manager in town, she couldn't be involved in our aunt's finances, but she stepped in and helped by visiting Aunt Estelle as often as possible, at least daily. Her mother even began coming to visit. And, since we lived so far away, we hired a young woman to spend an hour a day with Aunt Estelle, initially to make sure she had taken her pills (in the first assisted living home), to talk with her, run errands, read the paper or the bible to her, and keep her company. This group of women was a godsend, and we were fortunate to have their help.

6. **It's never too late to be kind**. This frail little woman, who had very few memories of being kind when I was a child, turned into the most thoughtful woman everyone loved. She called everyone "sweetheart" and said she loved us many times during a visit.

7. **Do the research and fight for them**. She fell twice at the assisted living, likely breaking her leg (hairline fracture) one day and then falling and breaking her hip while struggling with the leg the next day. The surgeon called me in a hurry and wanted to "put a pin in it." I called a hip surgeon friend to understand more and was told that if he did that surgery versus a hip replacement, she'd likely never get out of the wheelchair. The number of years of survival drops significantly if a person is immobile. I asked my aunt's surgeon to "walk me through the options" and then insisted on the hip replacement. There was a chance she'd not make it through the surgery, but relegating her to a wheelchair didn't seem like what she would have wanted. She had the hip replacement and returned to assisted living with a complete physical therapy schedule. She was able to walk with a walker – and I think, a full life for at least another year or more before the dementia worsened.

It's never too late to be kind.

8. **Communicate with the facility team**. I set a quarterly or monthly call with the team to check in on medication, food, weight, emotional, and physical needs for each assisted living, memory care, and nursing care center she stayed in. It typically was a 20-30-minute call, but it helped keep them abreast of issues we all saw and heard about.

9. **All the medication might be suitable, but it could**

be what is holding them back. After a year or more in a memory care center, our aunt quit eating and was moved to a full-time nursing bed in hospice. They took her off all of her meds, and she immediately snapped back and began eating and interacting. She lived for at least 18 months more.

Caring for my mother during her esophageal cancer treatment was – and still is – the hardest, even though it was only seven months from the date of diagnosis to her death. She received the diagnosis and immediately decided to go to MD Anderson because she heard it was the best. It was also in 1997-1998, so my memory of the many lessons I learned have faded a bit, but here goes:

1. **Patience and games**. The entire experience at MD Anderson was one of patience. Waiting in waiting rooms and exam rooms for hours. In the pre-smartphone era, we used electronic games and played volleyball on the exam table with blown-up exam gloves. We read books and played Spite (a card game).

2. **Records**. I kept meticulous records of each appointment, including what was asked and discussed. I began to go to the records room and get the records of each treatment nearly daily to confirm accuracy. With so many doctors, residents, interns, physician assistants, nurses, etc., who were meeting with many patients a day, they often confused her with other patients and made wrong assumptions about her symptoms based on the overarching diagnosis. I was there to make sure they understood where she differed so that the next decisions were customized to her care.

3. **Appointments**. Get the first appointment of the day with the doctor if possible. It eliminates the waiting – and usually resolves the tired doctor errors.

4. **Hotel and car**. At the time, if you stayed in Texas for 30 days, you could claim some residency enough to stay at the Rotary House that was connected to the hospital. The proximity to the hospital was really helpful, particularly on those nights when we needed an emergency visit to the ER or the pharmacy. And everyone there was being treated for some cancer, so it was a built-in community. Having a car was invaluable to escaping that world for lunch, a quick shopping trip, or sitting in the car and singing.

5. **Don't nag**. It seems obvious, but a good lesson. My mom was a smoker. I had been trying to get her to stop smoking my entire life. In my infinite wisdom of 30 years, I thought that she'd stop once she was diagnosed with cancer caused by smoking and start treatment. Nope. She kept smoking all through the treatment – and she was far from the only one. Many patients would stand outside and smoke, hooked up to the IV of pre-chemo fluids. She had a smoking circle of friends that varied in size from five to twelve. They met each day on the patio of the Rotary House, smoked and talked, gave and received advice, and told terrific stories and laughed. As she said, "cancer treatment is stressful; this is the last time in my life that I'd stop smoking." Honestly, looking back, it's my one regret. I wasn't going to change her at this point. Hell, she was 60 years old.

6. **Record conversations**. One last takeaway from losing a parent or loved one: record some conversations with them, keep some of their voicemails for you, and transfer them to DVDs and other places. In particular, I was lucky to have kept the last voicemails of each of my parents before they passed. Each singing to me: my mom's birthday message that I still play 25 years later and my dad's message telling me he loved me. That voice and message will be with you and your loved ones forever.



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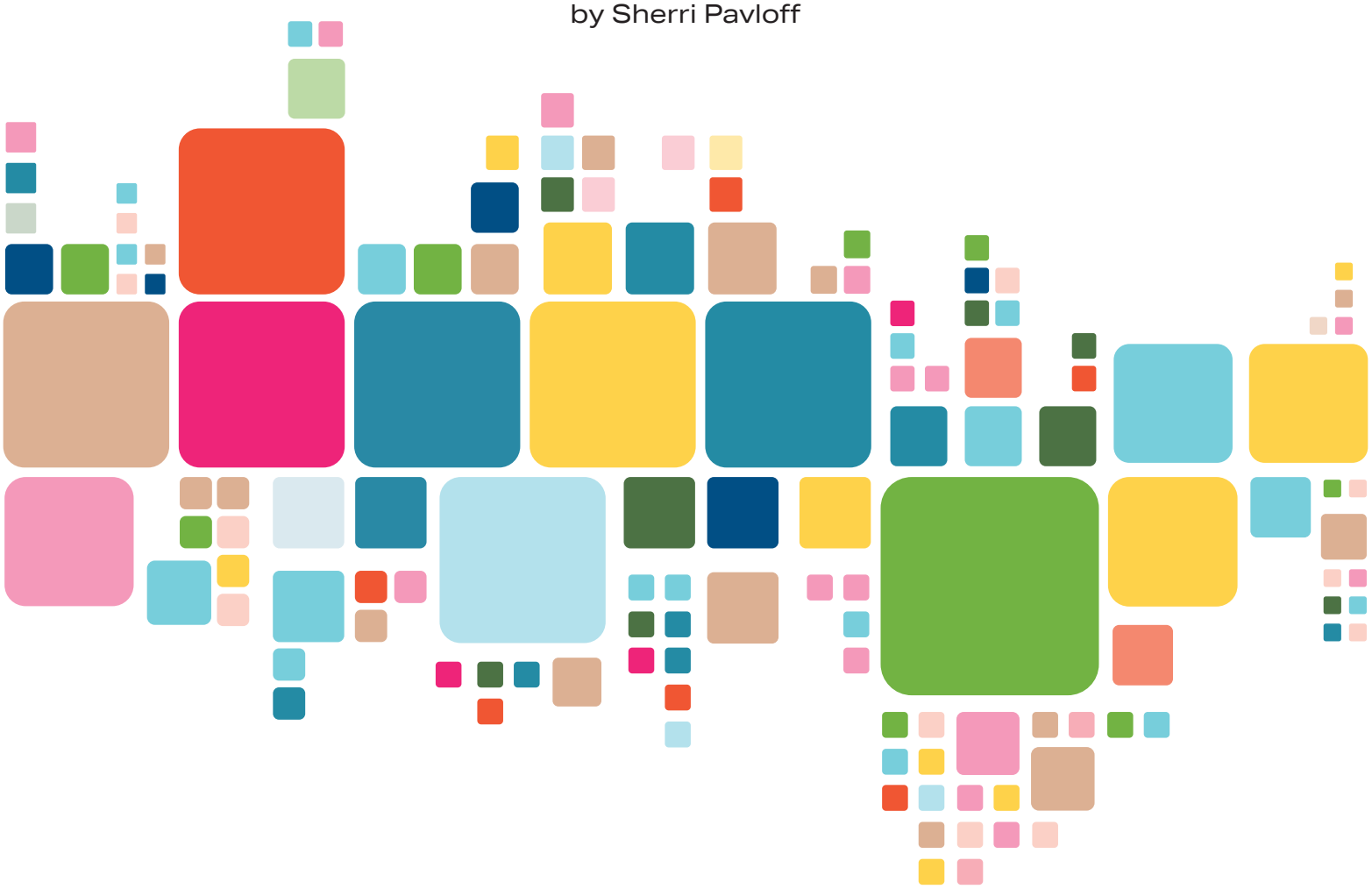
CHAPTER 9

WHEN THE CHILD BECOMES THE PARENT

MY (ONGOING) JOURNEY AND LESSONS I'VE LEARNED

by Sherri Pavloff



My journey caring for my in-laws is complete, but for my parents, it is continuing. It was and remained heart-wrenching. Telling my father-in-law, who was physically deteriorating due to untreated diabetes but mentally alert that he could no longer drive, was one of the hardest conversations I have had…until I had to explain to my mother, who was diagnosed with Alzheimer's, that she could no longer drive. Accepting the unavoidable responsibility of caring for your parents as they age hurts, and yet is the greatest gift of love. Still, finding the fine line between caring and controlling is not easy, particularly if you want to remain sensitive to your parents' need for independence.

After we divorced our first spouses, my husband, Andy, and I met. By the time we met, Andy's mom (Roz) was already ill, and I don't ever remember my mother-in-law as a healthy person. In fact, unbeknown to us, she was undergoing treatment for a rare form of leukemia when we married. As she became sicker, we tried to discuss finding an assisted living facility to take some of the stress of her care from my father-in-law, Murry. Her response: "You want to lock me up and throw away the key!" Upon hearing this, Murry insisted on caring for her until the end and refused 24-hour assistance. But because he was alive, neither Andy nor I participated in her care. My father-in-law? That's a different story.

We knew that Murry refused to follow the proper diet for a diabetic—indeed, we spent one Christmas Day in Delray Hospital with him (he lost his big toe on that occasion). We also knew that he was significantly overweight but did not realize that the combination was slowly killing him until we saw him on Christmas 2018. After he fell asleep at the dinner table and we realized he could no longer walk (although he tried with a walker), we had the "car" conversation, knowing that we took away his freedom by taking away his keys. This was not the first time we discussed this issue. When he called us two years prior, in 2016, to tell us he had struck a fire hydrant, we raised the issue, but our conversation did not seem to affect him. Although we raised the issue periodically after that, we were mindful of the balance between caring and control and did not force any actions or decisions.

In 2018, however, we insisted he stop driving, and he finally listened. To say the conversation was hard understates the anger and hurt we all experienced. When we could see that we were not making any impact, Andy finally asked Murry: "What do you want your legacy to be? That you got off the road a day too late?" Harsh? Yes. Equally hurtful. But we could not have been more omniscient. Shortly after he agreed to stop driving, one of his contemporaries whom he knew well struck and killed two young boys because, in part, his reflexes were not fast enough to react to two teenagers daring each other to step out into moving traffic.

Lesson one: you must have hard conversations with your parent as they age, keeping in mind their perspective.

Shortly after that, Murry caught pneumonia and was hospitalized. When he recovered, he could not return home. He paid all his bills and managed all his doctor/dentist appointments until that point. Andy and I traveled from New York to south Florida every three weeks from January 2019 until he passed in July 2019 (shortly before the FDCC summer meeting). From the change of address forms to creating accounts online to pay his bills to a power of attorney to the "shopping for" an assisted living facility (and the furniture needed), we did it all. We learned about the proper socks he needed, bought Depends, and then bought more Depends.

One Friday night at the airport, I remember Andy on his cell phone and me on mine, trying to explain to the nurses and aides in the nursing home that Andy's Dad was incoherent and needed a doctor, stat!

Lesson two: you must advocate for your parent and be "present"—even if present means daily phone calls.

Lesson three: Patience, and remember to breathe!



Mom and me, 2010



Honey and Stu, 2009

We traveled down to Florida one weekend in July 2019, and Murry asked to go out to dinner with us. This was after he was wheelchair-bound, and we had stopped asking him to join us for dinner because we could not get him in or out of a vehicle. We took him to the Capital Grille, and he thoroughly enjoyed his meal of surf, turf, and wine. He passed in his sleep that night. We arranged the funeral while driving to the airport to travel back to New York. We then attended our first FDCC meeting a week and a half later.

Lesson four: Life is for the living. No matter how hard the situation, you must continue to live your life. Don't forget that you still have a spouse, children, and work.

At the same time Murry began to deteriorate, I watched my Mom, Honey, start to "lose"—glasses, cell phone, keys . . . and then words. She lost her way to a shopping mall in Florida one winter when I visited—and Honey loved to shop and never lost her way! She also began retelling stories from my youth with embellishments I did not remember. She left her keys in the car and left the car running at the clubhouse. Then, she called my Dad (Stu), crying because she could not find her keys to come home.

Despite being preoccupied with Murry, Andy and I took time to speak with my brother (also an attorney) and my dad, first gently suggesting and then, after the car incident, perhaps not so gently advising that Honey needed to see a neuropsychologist for testing. They resisted repeatedly.



Murry, Roz, and Andy, 2004

Return to Lesson One - you must have difficult conversations.

It took a number of those difficult conversations, during which we were met with denial after denial after denial, until finally, in April 2018, Stu finally took her for testing. The diagnosis? Short-term memory loss. Etiology? Unknown. Treatment: exercise the mind and body. But Honey already did that: she played bridge, did crossword puzzles, practiced chair yoga, and walked.

Christmas - or Chanukah for us - 2019 - was the last time I remember her conscious of the world around her. Sure, the word loss was more prominent. But she prepared dinner and went clothes shopping, although this time I drove!

And then . . .Covid. The isolation caused a rapid deterioration, and in April 2019, the formal diagnosis was Alzheimer's. After numerous discussions with Stu, we finally found a memory care unit 5 minutes from my brother, with an independent living facility for Stu.

From July 2019 to November 2019, when he moved, I asked my father the same question multiple times. . . "Dad, do you need me to come down and help you move? If so, please let me know so that I can isolate first." His answer, repeatedly, was "no". . .—until two nights before the move when he called me and said, "I need your help."

Honey was not only "lost" when I arrived, but she was also ill, with swollen feet and gastrointestinal problems. The day we moved her into the memory care unit was when I insisted on meeting the Director of Nursing, and I sat outside her office for almost an hour until she realized I was not leaving until I spoke to her.

Return to Lesson Two - You must be an advocate.

In addition to Honey's memory loss, Stu also suffered and continues to suffer the loss of his wife and marriage. And so, I have become a therapist. Every night on the phone--many nights as long as 45 minutes—as Stu processed and still processes his loss.

Return to Lesson Three - Patience and remember to breathe.

While Stu pays his bills, does his own shopping, and is self-sufficient, I am sure that the day will come when he needs help, and the cycle will begin again.

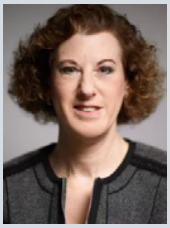
And as time passes, I remind my father of Lesson Four. Life is for the living. No matter how hard the situation, you must continue to live your life. Unless he wants to be sad, he needs to make a life for himself. It's a tough message—for both him and me.

Yes, I cry. . . for the loss. The loss of Murry, who knew that Andy and I loved each other and loved me as a daughter, although he did not understand divorce. The loss of my mother, who was perhaps my biggest advocate and why I went to law school. The decline in my father—a man I thought was invincible, who now flounders with indecision.

I never found any book or article with clear guidance, probably because every family dynamic and situation differs. The best help came from a therapist, who let me unload my frustrations and my fears, learned about me as I spoke, made concrete suggestions, continually reminded me that I can only control myself, how I react, and my feelings, and then provided the best words for coping: what you are going through is complex, and the pain does not "leave"—it just becomes easier to manage. Learning that my contemporaries are going through the same problems and being able to share, even though there is never a "right" answer, helps. Running, biking, hiking, and other forms of physical exercise also help relieve stress. Yoga continually reminds me to breathe and to accept "what is." Sometimes, the logic of the law is the best escape. And sometimes, all I can do is take a break.

My Lessons?

- You must have hard conversations with your parent as they age, keeping in mind their perspective.
- You must advocate for your parent and be "present"—even if present means daily (or twice daily) phone calls.
- Patience, and remember to breathe;
- Life is for the living. No matter how hard the situation, you must continue to live your life. Don't forget that you still have a spouse, children, and work.



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CHAPTER 10

OPEN DIALOGUE

ON DEALING WITH AGING RELATIVES

by Marcus Snowden



What I've prepared in the narrative section below is more a "story" than advice in the "war stories" tradition we are familiar with in our professional lives. However, the story can certainly wait until you have time for those who need some direct input. In response to the request for some practical thoughts and pointers immediately below, I've compiled a few which readers may see echoed by contributors to other chapters of this work – repetition is why we "practice" law, and so hopefully, these assists when you need to focus:

Here are a few thoughts to open a dialogue on dealing with aging relatives:

We're lawyers, and we tend to think we can do it all, but we'd often be wiser to look up a classmate or get a referral from a trusted colleague to a lawyer who does estate planning. Why?

- You need someone objective to assist and who you can trust to give some required counsel to your relatives without you looking like you are self-serving, controlling, etc., which can get in the way of constructive discussions about planning and care.
- Depending on the local business and legal environment where your relatives reside, certain institutions require paperwork (in my instance, powers of attorney for both property, which includes finances, and personal care, which includes healthcare decisions) when addressing the needs of aging relatives.
- Because, whether aging parents or others (in my instance, I had my father's siblings in addition to my parents, and my parents were more remote on the west coast while the siblings were all here in my home province – more on managing from afar below), you should want **the best** for them – and you're not at your best when acting in this capacity – so get someone who can act and more importantly be seen by your relatives as that objective and practical trusted advisor.
- Discuss this now, *before* it's needed –
    - It's a difficult discussion for most North Americans as we tend to avoid bad news –
    - But however bad it might seem in theory, it can be so much easier or more difficult depending on whether you've already had or avoided the "discussion."
    - This should include personal preferences in the event of incapacity of one or both parents or relatives, geographic concerns, local resource concerns, and simple logistics (which can be the most challenging where distance is a factor).
- When you cannot "be there" to assist:
    - Do not be afraid to lean on those who your aging relatives know best, whether they be in the local community organization, church, synagogue, etc.
    - We're often reluctant to impose and even more so when it comes to enlisting help for others when we feel we should be "in charge" of caring for them.
    - Yet the mirror image of "it takes a village to raise a child" is also true at the other end of the timeline: "It takes a village to care for a senior," and you'd be surprised at who in that village is ready, willing and able to assist – apart from having a classmate out west who practices estates law and so was able to help with the paperwork and counseling required.
        - in my late parents' case, it was their local church that, recognizing my inability to manage from a distance of almost three thousand miles without their help, stepped in.
        - Members of the parish were quick to arrange for meal delivery, checking in occasionally and reporting to me on needs, etc.
        - When my late father was no longer able to operate a car safely, the church knew he liked his freedom. So, with my input, he took on the responsibility of





arranging a senior's bus pass – which I reimbursed them for out of his account on an agreed periodic basis – and which, in turn, gave my late father some sense of control even though he was frustrated at no longer being behind the wheel.

- Don't fight City Hall:
  - While you may feel you're now "the adult," remember that aging does not and should not be made to take away your parents' or other relatives' grace and dignity.
  - Respect must remain, and perhaps it is most beneficial to consider them objectively, as you would a client – they have the right to be wrong, and unless it is genuinely endangering them, there is no need to "control" – provide that sage advice, but let the client decide.
  - As with a reluctant client, guiding with a suggestive narrative sometimes helps – like the witness who eventually owns the idea and theme you are developing at trial. This requires work, and while it is not always successful and is often frustrating – rarely garnering a "thank you," you'll feel more "in your zone" by borrowing a little from your honed professional skillset.
- Overall, the effort to treat them "professionally" and compassionately will ensure our elders maintain a graceful and dignified presence in their worlds, regardless of whether they appreciate what we do for them. Be sure you consider and discuss their "end-of-life" preferences with them – doing so while they can still express them will take the burden of decision-making off your shoulders. And remember: This is not about us. It's about them.

These are my practical pointers. They are in some respects amplified in the war story below, and I hope that, along with the other contributors to this work, what follows lends some comfort and context to the difficult subject of elder care.

Some thoughts on managing aging in place from a distance

This is a war story in three parts, the first being the longest, the second shorter, and the last the shortest:

I. Suddenly, a gradual condition made apparent.

I grew up as the son of parents who were not immediately an obvious match.

Mom was born near Newcastle-upon-Tyne in the northeastern part of England, one of two siblings and

the only daughter of a coal miner who, my older brother explained, was one of the very few crew leaders after each shift to bring all of his crew back to the surface without a fatality. He was likely at least Scottish rather than English. Still, given his, my late uncle's, and my late mom's modest height,[1] the best bet is that she was most likely neither – my brother contends and is likely correct that his parents were descended from the Picts, a fierce tribe formerly inhabiting the northland near Hadrian's Wall between England and Scotland.

While you may feel you're now "the adult," remember that aging does not and should not be made to take away your parents' or other relatives' grace and dignity.

My maternal grandfather's housemaker spouse was born in Scotland and counted both the Stuart and Blair clans in her lineage. This resulted in my middle name, which has some distant relation to the Rhodes family, from which my brother gets his middle name. She was never in good health and passed away when my mom was still in her teens. Mom always aspired to more than the hardworking life of industrial northern England, and after her mom's passing, she resolved to become an actress. Ultimately, she was admitted to and a graduate of London's Royal Academy. She first emigrated to Canada with her first husband to participate in regional theatres. She returned home to give birth to my older brother before returning to Canada. After her divorce, she worked factory and bank clerking jobs to support her acting career whenever they were available. After marrying my dad, she later worked as a bookkeeper and ultimately as a city librarian before she retired.

Dad was the fourth son of a Canadian-born black father who worked variously as a general laborer and factory worker and a US-born black mother with a fascinating history of their own, space, and time, which we don't have here. For our purposes, suffice to say, he had a physical presence but a quiet demeanor.[2] He and his younger sister were the first and last in their generation of the family to earn university degrees. His older brothers stayed close to home, working in factory jobs until retirement. His older sister also worked in various jobs, including at a local candy factory and later as a custodian at the local hospital. Her younger sister had been the head of a time nurse. This older sister remained in the family home to help out their parents while using her savings to travel, often with a local singing troupe, including overseas to places in Europe.[3] Space does not permit saying more here on these relatives.

Dad's undergraduate degree earned from what was then Sir George Williams University in Montreal,[4] funded by the Young Men's Christian Association, was in social work, and he started his career with the "Y" in what is now Thunder Bay, Ontario as a specialist in teen and adult education. After my arrival on the scene, he was posted to a new "Y" facility in Edmonton, Alberta, which my mom later told me was one of the largest in the country at the time. While he was posted there, the federal government's Department of Indian Affairs & Northern Development approached my dad to develop an adult education program designed for our Canadian first nations people. He was later required to compete for the privilege of administering the program he

1 Mom's passport record, when she left the dock in England, listed her at 4'11½" – when she arrived at the Pier in Halifax, the immigration officials remeasured her and erased the ½"! When I later met my uncle, he was no taller.

2 Although standing a full 6'1" tall and just under 300 pounds, he was known as "shorty" by his siblings.

3 My chapter contribution for this work was delayed in part by duties owed as this aunt's estate trustee upon her passing on October 27, 2021, one month shy of her 99th birthday, the last of this generation of my dad's family.

4 Now Concordia University.



had designed. Still, he was successful and went on to have a 30-plus-year federal civil service career before his retirement.

I was somewhat oblivious to the challenges of raising a young family in my youth, but I did take note that we were seemingly always on the move. I suspect I contributed modestly to this experience. Though I have no recollection of it, my older brother recalls that at about the "terrible twos" stage very early in my life, I escaped for a short time from our rented suite into the corridors of their Edmonton high-rise apartment building. A few more such episodes prompted a move to a rental home much closer to the ground as my mom resolved that she would no longer be chasing me up and down the corridors.[5]

This began a life of moves, first within Edmonton and then during my dad's civil service career, to Frobisher Bay on Baffin Island, in Nunavut Territory [6], and then down "south" again to the prairies and Canadian shield country, which makes up the Province of Manitoba. There, we had stints in Winnipeg, Dauphin, and Brandon before settling back in Winnipeg. During much of the time in Manitoba (from 1973 to 1980), I attended boarding school in Winnipeg, which gave me some stability. Mom had attended such a school to keep her from under her dad's feet when her mom was ill, so it was not as strange for her as it might be nowadays. I shared my mom's restlessness. Upon graduating from high school, I struck out for the east coast to study for undergraduate and graduate degrees in Halifax, Nova Scotia, before moving to Kingston, Ontario, for law school and Toronto to start my legal career.

For their part, once retired, my parents moved in the opposite direction to the small town of Nanaimo on

5 Her athleticism was still challenged after our move as I do recall her chasing me around the kitchen of the rental house, wooden spoon in hand, because I'd managed to get my hands on the brown sugar jar left within reach. Ultimately, my boundless energy won over her fierce determination to mete out justice – perhaps helped by my constant laughter, which eventually brought a smile to my mom's formerly angry face. All of which is to say, though rambunctious, mischievous, and quick on my feet at an early age, I was well and truly loved.

6 For readers old enough to recall the first voyage through the Northwest Passage of a ship called the USS Manhattan, my parents knew this was an historic "moment" and so hustled me along with my Inuit friends to the shores of Frobisher Bay at a low tide to bare witness – albeit from quite a distance – to a long black line moving slowly across the mouth of the bay, preceded by a much smaller red line with a white top. The former was the Manhattan, the latter one of our sturdy Canadian icebreakers cutting a path forward.

Vancouver Island in British Columbia. They did so to meet my mom's desire to retire to a more temperate climate like her home in the north of England and, in part, to be with and assist my older brother in raising their granddaughter. Ironically, Nanaimo is a former coal-mining town like the place where my mom grew up. Once they moved to the west coast, visits to my parents were fewer and farther between than had been the case when I was in undergrad and graduate school. The demands of a legal career combined with distance and cost of travel meant trips west were cherished, planned well in advance, and always with less time to visit than was needed or desired.

Pausing here, readers may wonder why sharing such early life details is of any moment for a piece addressing the care of elderly parents and relatives. My purpose and message are simple:

- To fairly inform what you do requires recognizing why, and of course, your immediate answer is "because I care."
- But to know how deeply you care about and for your aging loved ones, you are best served to take a bit of time to recall the memory of when they cared most deeply about and for you.
- This is to recognize that even in the angry moments, the not-so-pleasant encounters, the "I wish you had never been born" diatribes every self-respecting parent (or aunt or uncle) has thought in vivid detail not said out loud, there is underlying and unconditional love.

The impish grin hopefully leavens all of these challenging moments remembered, giggles, and laughter, which remind us why we parent (or are the patient aunt or uncle) and what we once were when we were, in turn, parented (or in the case of uncles and aunts, loosely supervised) by those we are now so challenged to care for...

But I digress... moving to the more recent past, the first inkling of anything amiss was shortly after I made it to the arrivals area at the Toronto airport to meet my parents on a rare visit east. They were flying in for a visit to spend time doting on their two granddaughters, then only in grade school. Given the distance, cost of travel, and busy lives, particularly after the girls were born, we had only been out to the west coast to see them a handful of times for family trips. The technology back then was not what we all now take for granted. So periodically taking videos with a video camera and couriering videocassette recordings of our daughters out to my parents for them to review was the substitute.

As I looked through the baggage collection zone each time the automatic opaque sliding doors opened, [7] I felt vaguely disturbed. I could see my dad pushing a baggage cart, which was normal, but his and my mom's conduct was somehow "off." The first glimpse was not a concern, but when the doors opened again, I could see that he had a slightly vacant look in his eyes as if somewhat confused or lost. When the doors opened again, I could see mild frustration on my mom's face, and dad appeared to be the source. No surprise there. After a long flight, but while I could not then place my finger on it, I would later realize what I had seen was an example of my dad's deteriorating mental state.

They eventually emerged with their baggage duly loaded on the cart, and we made our way to the car rental kiosk. Their dad went through the motions he'd been familiar with as a seasoned traveler for the federal civil service.[8] They followed me home, about a 15-minute drive from the airport in non-rush hour traffic.

The next sign of anything untoward was somewhat more alarming and out of character for Dad, who had always been a skilled driver in the city and on the highway. In my youth, I learned a few good lessons that came back to me when driving on highways – once, when a rear tire blew while I was driving my soccer teammates and coach in a long passenger van returning from a game in rural Nova Scotia, and another time when I hit white ice at about 60

7 At the time, following the horror of 9-11, this was a new development in travel security, thus preventing hosts from directly meeting passengers at the baggage carousel to assist with luggage.

8 His duties often took him on long flights or where highways permitted, longer drives by car to remote communities, first in the eastern arctic and later in central and northern Manitoba.

mph on my way to visit clients in rural Manitoba. In short, I trusted my dad's driving skills without question based on the lessons learned at his knee.

As parents, we worked full-time, and the girls were generally in summer camp during the day. My parents wanted to visit my dad's family in his hometown, a drive that was about an hour and a half out of the city. We all agreed it would be a nice adventure away from day camp for the granddaughters. Dad had flown into Toronto to stay briefly with us once before when we lived in an apartment with only one child. He was then attending to the details of his younger sister's sudden passing and funeral, which we attended in separate cars. Returning from the roughly 1½ hour drive to his hometown, he noticed the significant changes to the highway exits and layout since his last visit a decade or so before.

Remembering this, and before leaving for work on the morning of their adventure with granddaughters in tow, I reminded him, but otherwise, he had no concerns or worries. When I arrived home that evening, all seemed fine. I asked our eldest daughter about the trip. She cheerfully replied that grandpa got lost a few times on the way home, amongst other details. I assumed from this that perhaps he had ignored or forgotten my caution about the changes to the highway layout and so thought nothing more of it... until further details came out about just what my daughter had meant about getting lost.

As it turns out, the problem was not on the highway or in his hometown, both of which he seemed fine navigating.[9] Instead, it was in our neighborhood where he got "lost." Since the street we lived on was only two blocks long in a section of old Toronto laid out on a grid pattern, there is not much to mystify an out-of-town driver, and certainly not one with my dad's driving experience. As later relayed to me, it was, in fact, my eldest daughter who eventually guided grandpa back to the house. This was, Mom later told me, after dad had at least twice driven past our marked and signed street.

This was before the days of Google maps or other navigation software – and so mom, who relied on dad to do the driving, was quite panicked but did her best not to show it to the girls. To hear it from my eldest, this was no big deal – just another part of the adventure – but Mom had quiet discussions with my then-spouse, who became more than a little concerned about how Mom was describing Dad's behavior. I was encouraged to "go for a walk" with Mom in the strongest possible terms.

Pausing here, readers may wonder why I did not pick up on anything unusual much sooner – why my mom did not alert me to the markedly different behavior, etc. Indeed, if I knew my parents well, I'd have seen the signs earlier, asked questions earlier, etc. I later wracked my brain to remember if I had seen or should have seen any earlier warning signs from our all too infrequent family trips. But the truth is, I was not in any position to "see" or appreciate the situation firsthand with that distance.

Nor was his conduct yet troubling enough locally for my older brother to notice or alert me. My brother lived in the same town on Vancouver Island. Still, he often worked either in the Alberta oil patch as a field inspector or abroad as a safety officer on an oil rig in the Persian Gulf – which made raising his daughter as a single parent a challenge. My parents, therefore, spent a lot of their time helping with that once they moved out. If anything, with his work commitments, my brother was likely less informed than me, even with an address much closer to my parents.

But the most important bit of information to share and for readers to understand is that I relied mainly on my parents to let me know how they were doing. And we must recognize and account for the fact that we all do this. Our parents, after all, have historically been the ones who told us what to do, how to do it, etc. In this context, our natural inclination is to assume they can take care of themselves unless they tell us otherwise. Now, about that walk with my mom:

It took some doing, and I resorted to "turning on" my well-honed litigator skills to tease out the story from the "witness" – my mom. What started as her complaining about the state

9 For those not familiar, the tendency in dementia patients is an ability to retrieve with sometimes remarkable clarity longer term memories while having more difficulty with short term memories.

of her marriage, how dad was not treating her very nicely, and her not understanding what she had done wrong at any given point in time to attract his mood changes, sudden about-faces in decision-making, etc., became a theme which I recognized only because I had not heard it before. Pulling it all together for the summary notes at the bottom of a figurative client intake sheet, she described the gradual symptoms of a problem with dad's health and not, as I had first thought, some problem in their marriage. For lack of a better term, I will call the symptoms of dementia.[10] Once I realized we were no longer having a conversation about their marriage problems or even the dad I knew, loved, and remembered, I realized what a burden Mom must be carrying. And so I was then at pains to explain to her that all of this behavior was collectively looking like a mental health issue, which was most certainly not her fault. She had trouble understanding, and so, to help her own the narrative, we went over her description of a few instances where Dad was not treating her nicely.

One memorable instance she described that solidified it for me was their trip to the local department store. At home that day, they had discussed, and he was firmly settled on buying her a new winter coat since the lining in her current one was getting worn through – so this was something dad had concluded was needed, not mom. While in the store and as Mom was trying one of a few coats she quite liked, he suddenly turned and looked at her almost as if he was angry. He asked why she was trying on coats and said they would not be buying a coat that day, insisting that they leave the store at once. Mom relayed this in the tentative way of a person who struggles to understand what she said or did to make him change his mind. There were other such instances.

Without belaboring, suffice it to say what started as a dialogue, decision, and conduct aimed to do one thing would, for no apparent reason, suddenly not be what Dad wanted or what he remembered being interested in doing. To Mom, who was seeing this gradually on a continuum over time, I explained it was like the frog in the pot of water slowly brought to a boil – she did not notice it. To me, by contrast, seeing this unusual track record of behaviour suddenly and for the first time, it was like the frog which jumps into and then immediately out of the already boiling pot of water.

I explained to Mom that she was slowly and gradually but unknowingly witnessing my dad's cognitive decline because of some health disease or disability. I was presented in short order with key facts that did not add to the dad I remembered. This made it much easier for me to conclude this than for my mom, who struggled with misplaced guilt over what she perceived as dad's dissatisfaction with her shortcomings in her marriage.

As we discussed more, I asked her to recall anything odd about their trip out to Toronto. She reported that when they were preparing to go to the Nanaimo regional airport for the connecting flight to Vancouver, she had taken out her passport and put it with her purse on their bed. She then left the room to attend to something else, but she could not locate the passport while her purse was still there when it came time to go.[11] She did manage to find an expired passport in a rush, which was accepted in the circumstances as proof of identity at the airport. At the time, she only questioned her own memory and did not think anything was amiss otherwise. She then related her side of the experience I had observed at the airport: Dad, it turned out, had "forgotten" what to do about retrieving their luggage off the carousel, and so was pushing the empty cart aimlessly around the luggage zone, uncertain what to do until mom persuaded him that their bags were right there on the carousel to be picked up.

Their trip was ending, so I told Mom it was most important

10 Note: I'm no doctor and my dad was never officially diagnosed – more on that frustration below – so I use this term in a general rather than clinical sense to encompass the broad spectrum of sometimes irrational or without cause turns in mood, behaviour and character we lay people learn to recognize as symptoms of a degenerating mental capacity. The current site, https://alzheimer.ca/en continues to include valuable information. Readers should look up their local equivalent if dementia symptoms are a concern, as there are many supportive resources to lessen the feeling of being overwhelmed.

11 For domestic flights within Canada at the time, a driver's licence sufficed as identification, but mom didn't drive and had not held a driver's license since leaving Winnipeg for the west coast.

that she not continue to blame herself. I also advised her that she must not lose patience with Dad as this was not "him" so much as whatever was causing him to act this way. She should not take it as normal, although she had been living with it as if it was – like the frog in the pot slowly brought to a boil – for some time now. My mom was slow to accept it but started to see the logic of my advice and my more "immediate" appreciation of the history. It would be confirmed by the circumstances leading to and upon their return home.

Their departure raised concerns and also a challenge for my brother and me:

1. At the airport security screening, Mom went through the scanner with no problem. I was at the point of leaving but had enough residual concern that I lingered nearby to make sure Dad made it through, too. He went through the first time and began collecting his things when the security staff stopped him and asked if he had anything in his pockets – he shook his head no, so they asked him to go through again. On his second pass-through, the scanner detected objects again – this time, he removed his belt and then was instructed to go through a third time. When the scanner again detected objects, they pulled him aside and patted him down and then politely but firmly asked him to empty his pockets – at which point he expressed some frustration and pulled out his nail clippers, a pen knife, and a pipe-cleaning tool – all forbidden items since 9-11 and in any event items which should have gone into the tray for personal items.

2. This is something my dad would typically have known had he been acting as I remembered him, and I sensed that now he was at risk of creating an incident that would jeopardize their flight home. So, when it was clear that he would raise a fuss about relinquishing these items, I decided to intervene. At the same time, I had never raised my voice to my dad in my life. I put on my best courtroom bark and effectively ordered him to do as he was told – and then, when I had his attention, firmly but politely explained I would send the items to him in the mail. He stared at me with the same vacant look I had first seen in the arrivals area when he pushed the cart into the baggage collection zone. He nodded meekly in agreement, seemed confused, but allowed the security people to take his items, which they handed over to me with a knowing smile. He turned slowly to join my mom, who looked embarrassed but relieved about their flight home.



3. Back at home, a web search on the Alzheimer's Society information page disclosed the anticipated symptoms of those with dementia. Dad's conduct, as my mom had

described it and as we had now witnessed, "ticked all the boxes" to raise significant concerns. One symptom stood out for me: there is a tendency to misplace, hide, or move household items from their regular place to inappropriate places.

Sure enough, when my mom called later that evening to report their safe arrival home, she also shared a remarkable discovery in a somewhat doubtful voice. As if, for the first time now, seeing what she had been living with my dad's behavior in the same way I had explained to her, she explained that dad went in ahead of her when they got home. Not unusual, and she thought nothing of it. But when she went to the bedroom, her passport was on their bed, where she remembered leaving it. She knew it had not been there when they left, meaning only dad could have taken it in the first place and put it there upon their return. This gave Mom some comfort and then presented us with a considerable challenge – what to do about it.

II. Distance makes for a fonder heart but a difficult dilemma

I am not ashamed to say I cried myself to sleep that first night after somewhat distraught calls to my brother and Dad's older sister, my aunt. At the time, my then-spouse had trouble understanding why I was so upset. I calmed down enough to explain that, effectively, with almost no notice and no chance to say a proper "goodbye," I had lost the dad I knew. He was not dead, but there was likely no way to recover that version of the person I had called my dad for all of my life. All we could do was learn to cope and attempt to manage what would likely become a more marked decline in his abilities over time.

The collective challenge for Mom, my brother, and I was how to make this journey with Dad given our current state of being: Mom was there but only just coming to grips with what she now could see was a medical condition, not a problem in her marriage. While always willing to assist, my brother was not in a position to be present most times when it might be needed, given his work commitments. He also had the additional issue of being a stepson and not wanting to intervene too much. Yours truly had the challenges we all have in raising a family while juggling a professional career, to which was added roughly 2,700 miles of highway or flight time separating me from the task and parent at issue.

One piece of good fortune was a dear friend I'd first met in law school and his spouse. He practices in Victoria, BC, the major city on Vancouver Island, about two hours drive south of where my parents lived. His spouse works in the pharmaceutical industry with a territory that includes the area where my parents lived. Of course, sometimes having a friend closer to the scene is helpful only because they might know of local resources or be in a position to point you in the right direction or refer you to someone local, etc. However, I received my friend's best legal advice. His law practice focuses on estate planning and related matters while also tapping his spouse's advice based on her reasonably close knowledge of the medical profession in and around where my parents lived.

As discussed in the next part below, just like me, you are also lawyers or have lawyer spouses, and we should remember the adage: "who acts as counsel in" their "own case has a fool for a client." So heed the advice, and get yourself some good counsel.

The point to take away here, though, is that when you discover your loved ones are in a bind, it makes good practical sense to step back and look at what your education and training in practice can do for you. Making connections, which is much easier these days on social media platforms, can be the difference between a challenge becoming overwhelming and a merely difficult challenge. I won't sugarcoat it to say it ever becomes easy – it never does, and there's no way to get around it. But lightening the load and stress can start with a phone call or email to an old classmate or friend, walking down the hall at your firm and consulting a trusted partner, or grabbing lunch with a colleague in your town that you know and trust.

I'll digress only briefly to highlight just how this can work and how little it takes in a connection to make something actionable. I heard on the news one day of a small plane going down in the province of Newfoundland and Labrador, which is on the Canadian east coast for those unfamiliar. At the time, it made the news across Canada as they were mounting a search and rescue operation. However, it

soon became known in the emergency services world as a "recovery" effort – no survivors. The plane had been located, but the weather and terrain in the remote area of the crash site made it a challenge. This became suddenly very immediate and closer to home when passengers were the husband and son of a lawyer in Chicago I had only "met" through like-minded coverage lawyers. I had only recently been introduced to the organization she kept current called the Armadillos. She knew I lived in Canada, and so reached out seeking assistance as she was concerned about first finding and then repatriating the bodies of her late husband and son. I advised her promptly by the reply that I would do what I could, involving another Canadian FDCC member out west. Together, we pooled resources and tracked down colleagues on the East Coast to get her in touch with, all so that she could have "eyes and ears" on the ground in addition to the official police and other authorities working diligently in challenging conditions.

That she had the presence of mind to reach out by email during what can only have been the most traumatic time for her and her family is an example of what we can each do for ourselves in less traumatic and dramatic circumstances. I was only too happy, along with my FDCC colleague, to be of assistance, a small effort that I suspect went some way to put this friend in need in the hands of those who could best assist. We should all remember that collectively, a little effort can lighten an otherwise unbearable load – a load we might be too distant, too ill-prepared, or too overburdened to carry alone. Lesson: Don't be afraid to reach out to your fellow professionals. But I digress...

That good friend and classmate explained that if my parents could make it down to Victoria, he would assist them with an estate plan and powers of attorney. There was built-in trust because he and his spouse had also previously helped my parents when they needed a lawyer to close on their real estate purchase. What started as a discussion about planning quickly became a discussion about them needing my friend's best counsel. Fortunately, it did not take too much to persuade my parents, so he first met with them in his office down in Victoria. Once he had a sense of their preferences and desires, he then called, and we arranged for me to fly out to meet him at my parents' home.

After several hours of explanatory discussion, my dad signed the paperwork for powers of attorney over property and health care. My mom did likewise. Though time-consuming and the result of a little gentle persuasion as to its necessity on my part, this one step proved invaluable going forward. Initially, I had fewer concerns about their finances as Mom was quite capable in this area. The challenge was to make certain Dad was not spending all their resources improvidently. Tracking his bank account, it became apparent he habitually would go to a bank machine for cash. It was unclear where this money went, so I had to limit what amount was in the account.

Later, I set up a separate account to hold his share of their retirement funds. However, for readers, what is key here is this: None of these steps would have been nearly as easy to accomplish on their behalf if my friend had not first established the powers of attorney that gave me this legal authority. Institutions like banks and municipal offices will often do nothing but politely commiserate with you if you do not have the proper legal authority to act on your loved one's behalf. The best time to get this paperwork in place is now while your loved ones are still competent to instruct counsel. Depending on your (or, again, their) jurisdiction, the alternative can mean a trip to the courthouse and a much longer and more involved process to be appointed by the court.

Lesson: Don't think that because you are your parents' most beloved daughter or son (substitute niece/nephew, etc.), you have the authority to act as a lawyer. We may long ago have vaguely studied this in law school. A brief refresher: Blood may be thicker than water, but kinship is not necessarily the appropriate relationship to assert for helping your loved ones when dealing with their financial and other affairs. Your authority as a family member may only go so far depending on your (or, more importantly, their) jurisdiction laws. So it is essential to consult and have your loved ones consult a trusted professional to ensure when the time comes, they have put you in the best position to do your best for them. This does not mean controlling what their wishes are,

however. Instead, it means simply ensuring they know why it is necessary, and the trusted counsel will explain this – it's to ensure you are in the best position to carry out their wishes if required on their behalf.

Another resource for my parents was also immediately ready and willing to help in the form of my niece. She loved her grandparents dearly and went above and beyond to ensure they had help when they needed it. However, she did not have a car and needed one to get back and forth efficiently from where she lived in town to where my parents lived. At one point, my brother and I concluded Dad was no longer fit to drive – but to our great frustration, we could not get Dad's doctor to see that Dad was a danger to others on the road, given his often erratic driving behavior. Very briefly, despite several attempts to have my dad assessed by the required specialists, he seemed to know that the purpose was to impact his freedom intuitively. So, although he dutifully attended, often reluctantly, he never completed any of the myriads of tests that would have permitted the professionals to diagnose him firmly. He was, in a word, stubborn. And this was in character for him from the dad I knew. So, we had to work around the fact that we could not point to a firm diagnosis. Rattling off a list of symptoms, while helpful, does not make a diagnosis for certain vital purposes, one being to authorize the suspension or cancellation of a driver's license.

This is where you must not give up hope. Instead, get creative. Recognizing the liability Dad faced was not going to be addressed by his doctor, who, without a diagnosis of inability to operate a vehicle, was not prepared to lift Dad's license. We did a bit of self-help. In speaking with the dealership where Dad had his car serviced, I learned the manager who had dealt with Dad knew him well. He spoke knowledgeably about both my dad and his recent mental decline. He freely related, having had a similar experience with his father. I explained the plan to trade in Dad's car to purchase a newer model for my niece. He understood immediately, so getting them on the side was not difficult. We then explained to my dad that his car needed repairs, which it did. We left out that it would stay in repairs and eventually became unrepairable with the dealership's assistance until he forgot about it and learned to get around using local transit.

On the dealership's recommendation, I took him to the local insurance appraisal shop, where, by chance, the appraiser recognized the car. I explained who I was, and he explained he had dealt with Dad a few times previously. I outlined our plan to have the car brought up to saleable condition to trade it into the dealer and buy a car for my niece to use and asked if insurance might cover some of what looked like damage caused by others. I showed him my power of attorney documents, and he paused to explain he had been in the same position as his parents, so he knew what we were going through. Upon checking the database for Dad's car, he realized there were records of a few not-at-fault accidents he had been involved in, which would permit the repairs to be processed through insurance. He went the extra mile to ensure we could get the car appraised and off to the repair shop that afternoon to bring it up to top saleable repair. This allowed the dealership to take in a trade against a newer vehicle for my niece. Again, none of this would have been doable without the paperwork giving me the authority over Dad's property. Still, it was also more manageable by the combined goodwill of both the manager at the dealership and the appraiser at the insurance appraisal shop.

Lesson: While it's often difficult and embarrassing to share one's circumstances, do not underestimate the goodwill of your fellow citizens where your loved ones are concerned. You may be surprised to make a connection that unlocks a treasure trove of assistance or even a small gesture that eases the process. Remember you're acting for your loved ones, and you might find others are more than willing to help out.

It takes a community...

Apart from family, there are also community institutions to consider. My parents had been long-time members of the Anglican Church despite the church's original refusal to marry them. That's another story for another day, but my parents were regular and faithful contributors to their church's good works wherever they lived. I would rely heavily on the good grace, patience, and generosity of the local priest and members of the local parish in ways I could

not have imagined when first coming to grips with the situation my parents were in.

I am not a particularly religious person, but I knew my parents were. That helped as I also knew the church they belonged to would at least have some additional resources to share. Did they give any less because I was not myself a card-carrying member? No, of course not – their focus, and properly so, was on the well-being of their parishioners in a time of need.

This community-based outreach can take many forms, not always religious and not necessarily requiring that your loved ones be "members." Therefore, the practical point here is this: explore your parents' personal and community connections. Like yours, theirs will almost always be solid and well-tended. Like yours, their connections will stand them in good stead even in your absence.

So, just as you should not be reluctant to reach out to a colleague locally or across the country, you should also not ignore the built-in community that your parents have. Who do they have lunch, dinner, or coffee with on a regular basis? What pastimes, groups, or clubs do they enjoy? Here, you will find the friends and close-knit connections they've made, both old and new, who can provide much-needed support, particularly if, like me, you cannot "be there" in any meaningful way other than by occasional visits.

III. When being a "professional" isn't enough

Here's the difficult pill to swallow: You've studied hard, worked hard, and are a respected senior member of your profession – used to finding and fashioning solutions to your client's problems. And yet, nothing in your studies or work may have prepared you for this very personal challenge. The immediate reaction may be to treat the challenge as you would a problematic file at the office.

And this has its merits, to be sure – it forces a focus and attention to detail you might not otherwise bring to the challenge at hand. For example, conducting a walk and talk with my mom while also turning the time we had together into a witness interview to learn more about my dad's situation, while challenging at first, soon came as second nature. This was partly because I realized we only had a short period before my parents would be flying back west. And there are some self-help steps we as lawyers can take with less trepidation – walking into the local bank to present the paperwork for powers of attorney (or your local equivalent) while daunting for the layperson is much less so for counsel who appears regularly before our local courts. Insisting on the proper and full disclosure of assets in that context takes persistence and sometimes a "polite but firm" tone when institutional inertia is working against the interests of your loved ones.

But there comes that moment – and it matters not whether you're an experienced courtroom litigator or seasoned appellate counsel – when you not only should but must step aside in your loved one's best interests to let those with a dispassionate, objective view take the reigns. This may not always be in the legal arena. We like to think we're pretty good at knowing the facts, finding the theory of the case and pressing the advantage to gain a ruling or settlement in the client's best interests. However, being the "lawyer" as opposed to the son or daughter (nephew or niece) can get in the way of what's best.

We don't like to be told we don't know what we're talking about, but in the case of elder care and meeting the needs of your loved ones, often we're in precisely this predicament: we don't know. We best serve our loved ones by knowing when it's not enough to be the "lawyer," when another professional is required, and when we must step back to respect and let that other person or team of persons do their good work.

I'll briefly describe why there's no sugar-coating it to end the war story. War is not pretty, and often, elder care involves some not-so-pretty moments. I cannot say it was an easy journey – there were some tough calls with my mom as she struggled with her dad's deteriorating condition, and there were end-of-life decisions to make for both of them.

My mom called one evening as I was at my desk at home, preparing for a hearing – and what was strange was that her doctor was on the line to start and then passed the handset over to her to speak with me. She relayed in halting words that she had been diagnosed with pancreatic cancer, which takes its victims down relentlessly and quickly. I flew out to

see her immediately and raced about to arrange for my dad's continued living in place.

While the tempting and easier path would have been to get him admitted to some form of nursing home, I knew this would not suit the dad I remembered at all. So, I met with the parish priest and concerned parishioners to see if we could fashion a plan to let him live and age in place. Apart from the above-mentioned arrangements to get him a bus pass, they also arranged to deliver meals, and some knew my parents well and agreed they could check in on him.

It was clear Mom would not last longer than a few months. And so the community cared for my dad when I knew my brother and I could not. I asked if Mom would make it home again, but the doctor said she could only recommend putting her on a palliative care waiting list at this stage. The doctor said it was hard to judge, but Mom's expected life was predicted for a few weeks. She told me I could fly back for my court hearing, and Mom would last long enough for me to fly back. However, she strongly suggested I should be sure to get my daughters out for the last visit soon. So, with help from a friend in management with one of our national airlines, I managed to fly my family out to see Mom. Mom's final words to me before I left to fly back for the hearing were: "Don't get your dad upset, son. See that he doesn't get aggravated..." My family spent an overlapping day in the local hotel before I flew back east to Toronto to do final preparations for and attend the week-long hearing.

At about mid-day on the third day of the hearing, I felt a strange sense of a shadow lifting – I don't know how to describe it. When I arrived home, there was a message from the hospital advising that Mom had passed earlier that day.

My niece had been there, and somehow, my dad also made it there, perhaps guided by his faith to be at her bedside when the time came. Neither my brother nor I can get that missed time at my mom's bedside, but I am not going to blame myself or the doctor for the fact that I flew back east for the hearing. My brother headed back to the Alberta oil patch – to echo the advice I give in my closing thoughts below, we did our best and did it based on what the doctor had told us. Her prediction of mom's remaining lifespan turned out to be mistaken, but no one's perfect.

My dad outlived my mom by about 18 months, which was both a blessing and truly challenging to manage from a distance. The church and parishioners were more blessed because they were also more challenged: they struggled to keep track of him and ensure that he was taking care of himself. I started to second guess the decision to let him age in place, given the challenges he presented to those who tried to assist. My niece continued to help him as and where she could. My brother also checked in on him but had moved up the island about an hour by this time.

Without belaboring, suffice it to say I made trips out myself but had little ability to control them except through those from the local parish who could report back on him. It was frustrating, but it was what I was able to do for him. And it was better for dad than putting him in a nursing home or other long-term care facility.

The war comes to an end.

Then, one day, I received a call from the Nanaimo hospital advising that Dad had fallen and hit his head on a curb stone.[12] I spoke with the attending doctor, who explained that they had to put him into an induced coma to prevent his brain from swelling. I was quickly on a plane out to see him, and it was apparent the man who was my hero, who had been a dad to me for all of my life, and who had been lost and confused in the baggage area at the airport a few years previously, was in a bad way.

I sat down with the doctor in charge of his care. He asked what I wanted to do. I asked him what the possible outcomes were, and he explained they had already done a scan that showed Dad had suffered several mini-strokes. In this condition, therefore, even if he regained consciousness, Dad would be completely bedridden and dependent on 24-hour care. The doctor held out very little hope of Dad even regaining consciousness. Again, he asked what I wanted to

12 As explained to me by elder care professionals, dementia can also diminish the body's response time so that a person who would normally raise their arms and hands to protect their head when falling, cannot do so nearly as quickly. This appears to have been what happened when they found my dad.

do. In short, I had to make decisions both formally as Dad's power of attorney for personal care and personally as his only surviving next-of-kin.

The dad I remembered had always cherished his freedom, his ability to go where he pleased and to do the things he enjoyed in life. The dad I remembered, the dad who loved and cared for me and who was quietly proud of all that I had accomplished in life, would not want to be in 24-hour bedridden care.

And so, I said to the doctor that day in words I still remember vividly: "Just keep him comfortable, please." The doctor looked very relieved and thanked me so much for this guidance. I was puzzled and so asked why he was thanking me since, in my mind, it was I who should thank him and his colleagues for the care and services provided to Dad. What he explained to me and what each of us must consider carefully in our contexts is worth sharing here, regardless of your end-of-life beliefs:

- Given the limited resources they work with, it becomes a real challenge to meet a family's wishes to maintain a life in these circumstances when all the evidence points to an end-of-life decision.
- And yet, because they have sworn an oath, they are duty-bound to follow the family's wishes, absent court intervention or the like.
- So often, they are instructed and duty-bound to make herculean but pointless efforts to keep a person alive to meet their oath and a family's wishes.

He was thanking me, he explained, for not putting him and his staff through that effort. I had no hesitation in saying that Dad would not want such an effort wasted on him if it might be better used to save or make another life better. He had a good life, and for the dad, I remembered, all he would want and all I wanted for him was a peaceful, comfortable, respectful passing.

I later asked the parish priest if I had put everyone through too much trouble and made the wrong decision to let Dad age in place, given his condition. He assured me my dad would not have done well in a nursing home. While Dad was a bit of a character, stubborn, and no doubt a handful to deal with, all in the parish were content to see him have his freedom. And that's the dad I remember.

Some final thoughts about managing aging in place from a distance:

1. Remember to preserve with respect the dignity and grace that they have earned and deserve – using the trusted counsel, guidance, other family members, and local help available where and when appropriate, deferring to the professionals for truly objective assessment when it counts.

2. Know that distance, while a challenge, is not insurmountable when you remember to ask what assistance you can get from the good people you know. Those your parents or loved ones likely had the good sense to surround themselves with when they could while you were living your life as they wanted you to.

3. And finally, you should not worry as much as I did – we lawyers, as "A" types, can tend to let the details overwhelm us. My best advice when addressing the needs of your aging loved ones is to remember one overarching theme: Remember where you came from, and the memory will guide you. You can and will do your best – and that will, in every instance, be far more than anyone, including your loved ones, expects of you. So if you do your best, you will have done more than enough, both for them and you.

Take care, be well, and remain safe.



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CHAPTER 11

MEMORY

& THE CHANGING PARENT/CHILD DYNAMIC

by M.C. Sungaila



As we get older, the parent-child dynamic changes. And when our parents reach a certain age, that dynamic changes once again. Change is hard. And few changes are harder than when our parents have memory issues, whether as a natural consequence of aging, stroke, or various forms of dementia, including Alzheimer's.

Here are a few tips for those starting on the caregiving journey.

1. **Be an advocate.** As lawyers, we are skilled at advocating for others. You will need to be your parent's representative of medical professionals and be proactive and assertive with the medical system. You will need to coordinate treatment amongst various providers, be present at most medical appointments, and nudge doctors' offices to provide specialist referrals and fill prescriptions. Please plan to attend most medical visits with them. Memory issues make folks unreliable narrators; if a medical professional does not get the complete or accurate story of how your parent is being impacted, the professional cannot treat them properly.

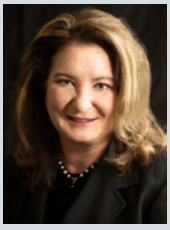
2. **Be prepared for the impact on you and the entire family**. Life is changing for the loved one with memory issues. But it is also changing for the whole family. As a child, you will grieve the loss of your parent – when we lose portions of our memory, part of our history is lost, and so are part of our relationships. In many cases, depending on which part of the brain is impacted, the parent may honestly believe that they are perfectly fine and have no memory issues at all. This gap in perception can create a lot of conflicts. And, as our parent's ability to do things is increasingly impacted, so is the entire family dynamic. If your mother always handled the financial aspects of the family, for example, your father will need to learn how to do so. The partnership between our parents must adjust, which also means our role within the family may need to expand to fill the gap.

3. **Do your research.** If you are going to assist with your parent's medical treatment, you will need to study up and be a knowledgeable source of information. Medical doctors will take your input and suggestions much more seriously if they know you did not get your information from Wikipedia or WebMD but from reading actual studies. This will help you ask about new treatments or inquire about the impact or side effects of recommended treatments. Some terrific podcasts like Peter Attia's Drive or the Huberman Lab share cutting-edge research and thinking, including around Alzheimer's Disease.

4. **Look for a doctor who treats your parent's memory issues as unique**. Some doctors will throw up their hands and say there is no treatment and that decline in all cases is inevitable. Avoid them. Look for those few specialists who treat the disease as it should be treated: as unique in each individual and capable of at least being slowed down if caught early enough. Do not give up. And do not waste time finding a doctor who will try. Brain capacity cannot be fixed once it is lost; however, the speed of degradation can be slowed down. The faster you can become proactive, the better.

5. **Be open to alternative treatments.** Alzheimer's and other forms of dementia have minimal traditional treatment options. Three primary prescription medicines are available, each with varying effectiveness and sometimes worse adverse impacts than the disease. Those doctors who try to arrest the disease's progression often rely on nutritional supplements that reduce inflammation or lifestyle recommendations like exercise. They are open to considering those because those are their tools.

6. **Be proactive for your future, too.** If your parent has memory problems, you are more likely to get them later. The best treatment we have is prevention, and visit a doctor to get tips on preventing or delaying the onset of any disease.



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CHAPTER 12

CAREGIVER FATIGUE

IT IS REAL, AND IT CAN BE DANGEROUS

by John C. Trimble



One of the facts of life, if you and your parents live long enough, is that you may reach a day when you are looking after aging parents in the final years of their lives, or you will be caring for your spouse or a family member. Sometimes, the circumstances are such that you end up as the caregiver, but often, we find ourselves observing as one aging parent becomes a caregiver for the other. The latter has been my experience, and it is the experience I will share with you here.

My subject, caregiver fatigue, is one that most of us know nothing about unless we observe it firsthand. We may hear a loved one expressing frustration or describing fatigue, but we don't know how to characterize it as a recognized medical condition. However, we need to know about it because it is real, and it can be dangerous.



If you Google "caretaker fatigue," you will find dozens of articles from major medical institutions about the subject. They all define it as emotional and physical "burnout" caused by the stress of caring for another person. It is generally caused by someone who is shouldering the entire burden of caregiving and not taking any breaks or time off. The list of disorders that the stress of caregiver fatigue can cause is long, but the common symptoms are a feeling of worry and being overwhelmed; sleeping too much or not enough (usually not enough); fatigue; weight loss or weight gain; irritability or anger; loss of interest in activities and human interaction; headaches, body aches, elevated blood pressure, or other physical problems; and, abuse of alcohol or drugs. Many healthcare providers will tell you that the risk of death of the caregiver is real and that many elderly caregivers die before the person for whom they are caring.

My wife, Ann, and my sister, Lisa, and I had the opportunity to see caregiver fatigue firsthand with my father and mother, and we almost lost my father. That is why I wanted to share our story so that you will know and recognize caregiver fatigue before it happens in your life.

My father was a college professor, and my mother was a local elected official, artist, and homemaker. They met in college and were married in 1954. Dad retired from teaching in 1994 at the age of 64. Upon his retirement, they embarked on world travel, and for 15-20 years, they began spending their winters in South Florida. They were happy and healthy and had comfortable savings and life was good. Both were social extroverts who loved entertaining and loved being around others. They played in bridge groups and enjoyed eating out with friends multiple times a week. In Florida, my mother loved to hang out by the pool with her many friends, and she volunteered to assist in planning and hosting community activities.

In January of 2010 my mother was 78, and my father was 79. One night my mother got up in the middle of the night and tripped over the hem of her nightgown as she was returning to bed from the toilet. The fall caused a fractured hip. Fortunately for her, she was in excellent health with strong bones. The orthopedic surgeons gave her a partial hip replacement that involved the replacement of the femur head but left her with her natural hip socket. The surgery was successful, and she recovered very quickly with minimal pain or disability and only modest physical therapy. We were ecstatic that she did so well, and we believed that she and we had dodged a bullet. I was well aware because of my occupation that a hip fracture in a senior citizen could result in a spiral down and premature death.

After Mom recovered, my father was ready to see the two return to their usual activities in Florida. But Mom became

reclusive and paranoid, and she did not want to leave their apartment or welcome visitors to the apartment. Our plan to visit them for spring break was canceled because Mom did not want us to come to visit. A full two months before their lease was up for the winter, Mom began planning and packing to return home. An entire month before they loaded the car to drive back to Indiana, she was fully packed. Furthermore, it appeared to be clear from her comments and her packing that she did not intend to return to Florida the following year.

When my folks returned from Florida, Mom continued her paranoia and reclusive behavior. She did not want visitors, and she would not leave the house except for doctor visits. Surprisingly, she would not allow Ann and me to come to spend the night or have a meal at her home. She explained that the cooking, laundry, and bed changing were too much for her. It did not matter that we offered to make and change the bed, bring the food, and cook the meals.

Mom had always paid the bills, planned and cooked their meals, and went grocery shopping with Dad's help. However, Dad reported that Mom could not perform executive tasks within a very short time. She could not write a check, compile a shopping list, or plan and prepare a meal. On one occasion, they went to their favorite local restaurant (at Dad's urging), but she could not read a menu or order her meal. These characteristics were entirely out of character for a woman who had been the Clerk/Treasurer of our town and the president of the League of Women Voters and other community groups. She had been the life of the party, but now she wanted to sit at home and work crossword puzzles all day and all evening. In addition, she became paranoid about everything. When Dad would leave to go grocery shopping, she feared that he would die in a car wreck. She feared that they would run out of money, and she feared that strangers, friends, or family would come to their house and steal from them.

As this developed, we knew that something was seriously wrong. With the help of a close friend in medicine, we identified a doctor at the Indiana University Medical Center who specialized in elder care and dementia. With great difficulty, Dad convinced Mom to attend an appointment in Indianapolis (which was 100 miles from their home where we live). I met them for the appointments and assisted my father in explaining the history of her fall and the change in her personality. After a brain MRI and neuropsych testing (which Mom resisted), it was determined that she had likely suffered a cluster of mini-strokes at the base of her brain when she fell. The effects of the strokes were not fully reversible, but with medication, she could expect improvement, and they could prevent more strokes.

I will never forget sitting in the meeting and observing the doctor turn to my father and hand him a three-ring notebook. The doctor patiently explained caregiver fatigue to my father and implored him to take the binder home and study it. He insisted that Dad get daytime help a few days of the week to stay with Mom so that Dad could take some time off from caregiving. My mother rolled her eyes and announced that they would not need help, that they could not trust strangers in their home, and that they would run out of money if they paid for help. Dad went home and put the notebook on top of the refrigerator and never looked at it.

Over the next few months, Dad did it all himself. He would complain to my sister and me that the act of planning and preparing three meals a day was exhausting to him. He was having trouble sleeping, and his blood pressure began to rise. As it got worse, he would faint when he stood up from a chair, and several times a day, he would regurgitate food into his mouth. He began keeping a paper towel and a plastic bag in his pocket because the throwing up was so spontaneous. He started losing weight.

All of our efforts to offer help were rebuffed. Mom would protest about having anyone in her home, including Ann and me. Dad would not stand up to her protests because standing up to her made her more upset, and the upset made him feel sick. I reminded Dad about the issue of caregiver fatigue and urged him to do something about it but to no avail.

One day, Dad called to let me know that he had had a minor car accident. He was driving through the parking lot of his local pharmacy when he ran head-on into a light pole in the parking lot. He told me they must have repositioned the pole or that his car had malfunctioned. The truth was that he was getting tired and starting to lose control of his own functions.

After conferring with my sister, I drove down to my hometown, and Dad and I went to see his family doctor. We discussed the state of affairs, and his family doctor asked him

if he was taking any breaks, but of course, he was not. The doctor instructed us to check Dad into assisted living at a local nursing home for two weeks to rest and recuperate. Dad and I went straight there, and within a few hours, Dad had a furnished room and a meal plan for two weeks. As I left to go home, where Ann was spending time with Mom, Dad asked, "John, tell me the truth. I am going to die here, aren't I?" I assured him that he would not die but rest and get better, and we would change his living arrangement.

Many healthcare providers will tell you that the risk of death of the caregiver is real and that many elderly caregivers die before the person for whom they are caring.

That day, my sister flew home from Arizona, where she lived, and for the next two weeks, we looked after them. Mom was not happy, but because of her paranoia, she would not leave the house to visit Dad. She was afraid it was a ploy for us to get her into the nursing home. For the first two days, Dad slept almost non-stop. On the third day, he got up and about and started eating. We took him newspapers and books, and he began reading. By the end of the week, he was roaming the nursing home halls and visiting community friends there. His blood pressure stabilized, and his vomiting stopped. He was regaining strength and vigor, and his head was clearing. By the end of the second week, we had reached an understanding that he would go home, but at least three days a week, he would leave for most of the day and do something relaxing.

While Dad was in the nursing home, we found a local home healthcare agency with an excellent reputation, and we interviewed their employees. We let Mom know what would be happening and that if she protested, we would have no choice but to put her in an assisted living facility. Initially, she was standoffish to the helpers who came to our home, but eventually, she relaxed and grew accustomed to having them there.

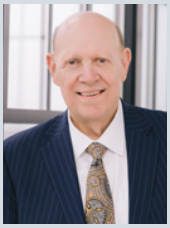
To take the burden of preparing meals three times a day off Dad, we contacted the local college where Dad taught, and we found a fraternity house cook who was willing to make extra meals for Mom and Dad for $4 a meal. Each afternoon, Dad would drive over and pick up their dinner. As it turned out, the meals were wonderful, and my folks enjoyed them a great deal. During the summer and during breaks in the school year, the main college kitchen remained open, and Dad could get meals there.

Over time, Mom's medications helped her, and she regained some of her executive function. Further, once she no longer had to worry about my dad, she relaxed, which helped her too. She never completely lost her paranoia, but she began welcoming an occasional visitor, and she let Ann and me come again for overnights and weekends. (She still would not agree to let me cook in her kitchen even though she knew I was an accomplished cook.) While they did not return to their prior social life, they often got out for restaurant lunches or dinners and came to Indianapolis to visit us. Dad remained healthy and rested, and the cost of in-home health was not a burden to them.

In June of 2015, five and a half years after Mom's fall, Mom was diagnosed with heart failure that was probably linked to the sedentary life she had been living with her crossword puzzles. She died shortly after that diagnosis. She was 83. Today, Dad is 92. He is in great health, has good hearing, and a perfectly sound mind. He is living contentedly in a nice assisted living facility. He may live to be 100.

We still talk about the caregiver fatigue that nearly ended his life. He does not remember asking me if he would die in the nursing home, but he does remember being there. And, off and on, I have heard him caution a friend or family member about caregiver fatigue.

I hope that this account of our experience will remind you about this serious subject if and when you are confronted with a similar situation. Caregiver fatigue is real, and, as we learned, it can be dangerous. Don't let it happen to you or your loved ones.



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CHAPTER 13

CARING

FOR A FAMILY MEMBER WITH ALZHEIMER'S DISEASE

by Bill Whitfield



You never really see it coming, but brain cell by brain cell, it sneaks up upon your loved one, in this case, my mother, until it becomes noticeable in ways that sadden and portend darker days ahead. When it became noticeable and suspicious, only because I had handled cases where certain signs were dead "giveaways," I immediately reached out to a neurologist friend. My physician friend was more than accommodating and inserted her into his schedule within a short time.

I picked up Mom [and Dad]. Mom mainly was "herself," but obviously "slipping" with names, dates, and events. I attended the appointment with her, and the encounter seemed strangely like an "intervention." My father had health issues, so I insisted he remain out of the room. He had always shown himself to be in denial of "issues" that were clear indications of a cognitive decline in his wife of 60 years. Awkwardly, I asked him to stay clear of this physician encounter so that it could be conducted as "objectively" as I could manage it. The emotions would obscure data exchange with him in the room, and events muddle the conclusion or diagnosis. I cared deeply about my mother, but someone had to approach this situation as objectively and analytically as possible, and among my siblings, that responsibility fell to me.

The notion that I would take my mom to a physician's visit solely for her long-term help, only to allow the encounter to be skewed with emotion and tears, was frightening. Dad was not happy with me for excluding him, but by that time in his life, the father-son dynamic had essentially reversed so that he was mainly deferring to me on these and other matters.

He was mortified that the doctor would confirm my worst fears, which signaled a new beginning for him, which, in the end, it did. He was a retired [kind of] Southern Baptist minister, and his wife was the consummate "mate" for him. She participated with him in nearly every function that he participated in. Mom went with Dad to make hospital visits, home visits, scheduled events, and parties, and in some ways, the two of them were more active in his "retirement" than when he was "full time."

Dad always doted over Mom, even doing things for her that were, in my mind, way over and above the "call of duty." Even though he was a Southern California boy who met my Mom while he was stationed at Pensacola Naval Air Station, he quickly adapted to the expectations of the "South" [Alabama] when it came to his relationship with my mother. It started with him rising early in the morning for some "quiet time," then he'd make coffee and take it to her while she was still in bed. Subject to their endless activities, the day usually ended with him turning the bed down for her even though she could physically do it herself. The relationship between the two was unique to being uncharacteristically



1954



1957

"storybook" in today's times. They would travel, visit, and entertain others in their home to the point of breathlessness. They made me tired just watching them! Given my appreciation and protection of their relationship and having gotten resistance many times from Dad when I raised the subject of the possibility of a mental decline, his participation in this physician visit was not advisable.

My memory of my mom is that I had the best that God could have supplied.

We entered the room, and all seemed to be quite normal. Dr. "Jones" [only for the sake of anonymity] began the encounter with "Why are you here." In all graciousness with my dear mother, I explained to Dr. Jones that we kids [my two younger sisters] had begun to notice some things in Mom that were alarming in nearly every facet of her life. Dr. Jones asked for more detail, and it started with what I believed to be the earliest sign that Mom was not very attentive to her safety. A year or more ago, she had gotten into a wreck on a busy street by turning in front of an oncoming car. By all accounts [law enforcement as well], Mom did not have the right of way and had only a slight memory of doing it. While that alone would not have been worth mentioning, and in isolation, it probably was not, her explanation to me about what happened was of concern. At the time, I chalked it up to inattention, but over the next year, it was followed by curious confusion (slightly at first) and then the conversational miscues where she would account for things that were partly or not true. But the most alarming thing that motivated my concern was one thing my Mom was the proudest of: and that was her cooking.

Aside from a preoccupation with her appearance and hygiene, which was always immaculate, Mom loved to schedule family gatherings that could have included children, spouses, their children, and even children's children. She would cook for any occasion, and the entire family was invited and sometimes demanded. The usual holidays were only a minimum. She would cook for any event and make enough for everyone to take home. She was a great cook, and my memories of our family, even from the earliest days, we're all about the food! So, when I began to suspect that something was amiss, food became involved. Mother always insisted on cooking even as the disease noticeably progressed, but the results of her cooking at first were less than optimal but progressed to the catastrophic. My mother's most notable gift had now slowly turned into a game of Russian roulette as to which entree would be scorched, or even uncooked, or still sitting in the fridge. The proverbial "straw that broke the camel's back" was an occasion when I was late for a semi-special family gathering. As I walked in and proceeded to my seat at the table, there was a look on most of my family's face of unusual resignation that the fare would be unappetizing. It was lasagna, which I love.

I cut and parsed myself a portion only halfway, noticing that there was way too much left to eat even though I was late. In the "good old days," if I were only a little late, I would have to rely mostly on my siblings to protect my interests at the table. This time, though, there was way too much uneaten. My first bite earned a scowl from my Dad that only my Mom could not decipher. My Dad's eyes were immediately rebuking, and he "telepathically" warned me to hold my tongue. I meticulously picked around the heaping portion of my meal, looking for any portion I could consume without offense to my senses, regretting that I selfishly grabbed a larger-than-normal portion. My Dad's reaction then only affirmed for me the very reason that he must be excluded after that from any effort to arrive at a diagnosis of his bride's cognitive condition.

Accounting to Dr. Jones of the wreck, the common miscues of Mom's apparel, hygiene, cooking, and the conversational vacuum that sometimes characterized our family visits would have been more than my Dad could have endured discussing. Plus, the necessary frankness from me could have sullied me for a time, even though my relationship with my Dad was always excellent. While I was summoning every bit of lawyer training to maintain my composure about my dear mother with Dr. Jones, my insides were hopelessly a wreck. I did not think my sisters would be emotionally built for this foreboding encounter, and my Dad could not be a part of this process. He and I would talk over the phone often, even after the decline was obvious, and typically, there were moments of silence and a struggle to speak. The

toughest part of watching my Mom's decline was what was happening to my Dad. He was still vibrant, healthy, active, and hypersensitive to every little thing that would happen that affirmed the inevitable. It became so overwhelming to him that for a time, my sisters and I each took a day or two during the week to liberate Dad to get him out of the house and do something that he enjoyed: playing golf with lifelong friends. The change of scenery for him was necessary for his mental health. The greatest challenge in caring for a loved one with Alzheimer's is caring for the one caring for them. Our failures often matched my successes and those of my sisters in that department because of work or other family engagements.

After Dr. Jones heard from me, he turned to my mother and asked her some questions. His questions were his effort to probe some of the details of my observations, and even though my Mom was surprisingly aware of what was happening, she, at times, would completely make up events, people, and places that I was hearing for the first time. The gaze of my doctor friend slightly in my direction indicated that I should just let these exchanges play out. Dr. Jones patiently allowed Mom to finish what she had to say. Dr. Jones did some exams that required my mom's participation. It appeared to test her strength, balance, gait, and whether there might be some early deterioration in balance and overall sturdiness. Once done, my ever-optimistic physician friend reassured Mom that he felt that she had early signs of "age-related" dementia and that new medications on the market could help hold them at bay. He wrote out a script, handed it to me, and asked me to walk Mom to rejoin my Dad. I returned only to be told that Mom was indeed showing early signs of dementia but that the medicine that he gave would, he thought, help stave it away in the short term (whatever that meant), but that the long-term effects of dementia, even with medicine, were not very promising.

I rejoined my parents in the lobby, and we walked to the car. My Mom was unfazed at what we had just done, and as much as she could be, she was talkative, complimentary, and always planning the rest of her day. We all went to Cracker Barrel for a "debrief" and some food, but the medicine thing was lost on Mother. Yet, if I said she needed some medicine, she was more than happy to oblige. I left later to return to my office, and Dad took Mom home and called in the script.

As time went by, her mind incrementally became more troublesome to us all. We didn't see any difference in her with or without the medicine, even though Dad was religiously making sure that it was taken. She was slipping, and we knew it. One could hardly tell from day to day just how much, but it was very discernible over time. As far as the medicine was concerned, my family would often discuss how it was that any caregiver could even know whether any medicine was truly working because it would require knowledge of the outcome without it. But, my blind trust in my physician friend early on would trump my natural suspicions about the medicine and whether the pharmaceutical industry could present any empirical data to justify marketing it.

As time went by, excursions away from home for the two of them became less spontaneous since plans always had to be made for handling hygiene issues. Over time, Mom's ability to walk without falling was an issue, so considerations of independence became a larger factor than before. Dad would most times take Mom with him to do the family shopping and business because he couldn't leave her alone at home, and on rare occasions at a store, Mom would "give him the slip," and then he'd panic looking for her. In some ways, Dad was still hoping that things would level off and even get better, but in the end, that proved to be false optimism. He and I often talked about stopping the medicine because of what he felt were "other" complications of taking it, and he would discuss his "hopes" that she would return to normal someday. We were always a part of the conversation. He would later get a referral for another neurologist and made an appointment for Mom that he wanted me to attend. I did, and the diagnosis seemed to rely more on conversation than anything else. After an initial encounter with another physician, the doctor took me aside and confirmed that he thought Mom had Alzheimer's. He recommended a "new " medicine for her, which was as good as the other. Over time, Dad had me pinging from one doctor to another in a frantic attempt to find someone who would give him any hope that things would get better, and of course, they did not. I didn't dare push back on his efforts since doing so would risk ruining my special relationship with my father.

A time came when Dad was at a point when he wanted answers that none of us children or doctors could give. He

knew a friend from working with a local seniors organization who considered herself an expert in how to manage a loved one with Alzheimer's. All of us kids and Dad went to see her at her home. We talked for hours, and while she was profoundly kind, she was a little more direct than I felt then was necessary. In retrospect, she was pretty darn close. One takeaway that struck me most was her suggestion that the medicine that each of the doctors had been prescribing should be stopped. Wow, that was a stunner. Her rationale was that, at best, the medicine might extend the diminishment of the mind over time but that it also seemed to prolong that time. It does not cure, and in some ways, the side effects are comparable, if not worse, than the disease itself. It made little sense to me then, but perfect sense today. Yet, the "elephant in the room" was, does the medicine prolong life and maintain quality? At least to us, then, the answer was "it's possible."

The medicine may lessen some of the mental diminishment in some unquantifiable ways. Still, the disease marches on in other ways, and while it may prolong life, it does little for the diminishment, which at best may be slowed slightly. As we concluded our meeting, we were essentially told that there is no cure for Alzheimer's. As harsh as it may seem, we were asked to consider the reality that Alzheimer's ultimately results in the body's withering, and it seems too the soul. Her advice was for us to allow it to run its course on its own predestined timetable and continue to be loving and supportive, yet always reflecting upon the relationship as it was. Early in the disease, there are more good days than bad. In the middle of the disease, there are as many good and bad days, and the bad days endlessly string together toward the end.

My belief, though unscientific, is that the first manifestations of mental diminishment to ultimate death for her were about four years. Over that time, my social butterfly Mom went from a tireless shopper and visiting fanatic to someone so dependent upon Dad that she would not even speak. In her last weeks, she would not even eat. Mom didn't seem to know what was happening to her, but for all of her apparent ambivalence, I would see my Dad sometimes so despondent that I mainly worried for him. The crushing weight of having to tend to every single need of his wife was suffocating him. At some point, all of the children pitched in to hire outside assistance, and then some VA benefit kicked



2014

in, which gave him a welcome reprieve. It got to the point that caring for Mom was the easy part, but caring for Dad, who was predominately caring for her, was the hardest part.

In the summer and fall of 2018, Mom's illness had progressed to the point that special equipment had to be obtained. Her condition had become hopeless and inevitable. I would often travel to see them and sit and talk to her with no response. I would sometimes have to fight back the tears because of Mom's unfamiliar gaze back at me. I sensed that she was now so mentally gone that she had no idea who I was. Late one night, December 18, 2018, I got a call from my sister, who lived close to my parents, that she didn't think that Mom would make it through the night. I quickly dressed and got in my car for the hour and 30-minute drive from my home to theirs. The night was miserable. It was raining steadily as I drove, navigating one country highway after another. By the time I arrived, she had passed. I missed being there with her by about 15 minutes. I spent some time with her there, thinking only of my childhood with her, her presence at my wedding, and my children's birth. Her deserved "wippins" for sassing her was as much of a memory as the presents under the tree. There was no better Mom that a boy, and then later, a man could have ever wanted.

Over time, it seemed that Dad could recover from the depression he'd been under caring for Mom, but he never forgot about her for a minute. Family gatherings would continue, and Mom would always be a topic of discussion at some point. Dad even mistakenly called one of my sisters by our mother's name. Dad was so committed to Mom's care from day one that little did I know, he had kept a journal of



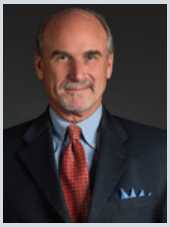
2015 (at the beginning of the disease)

most of the events only referenced in passing here. After she died, Dad began to compile his journal into a book that he later published, hoping that some caregiver would gain just a little insight into the dynamic of caring for a spouse with Alzheimer's.

Now, I have friends and acquaintances who have a spouse or loved one diagnosed with Alzheimer's. It seems that every patient with the disease develops differently. Their personality, mental acuity, and physical well-being seem to diminish at different rates over time. My Mom's slightly reliant and then dependent phase began about 2+ years before her death. I have heard of others lingering for a decade or more. But, that short 2+ year time brought our family, in some ways, closer to caring for our parents. While there were constant frustrations, we all knew that Mom's illness made her incapable of knowing better. The farther she progressed into the darkness in which she spent nearly her last year of life, the more and more we would make an effort to do anything to nudge a smile from her or even a sincere gaze. While words from her were few, when they came, they were priceless. My Mom died on December 18, 2018. Her mind and body were ravaged by a cruel disease that was unrelenting and determined.

Caring for someone with Alzheimer's requires extraordinary patience and understanding. In our case, we were able to manage my Mom's care mostly with my Dad and my very "devoted sisters," [one of whom lived close by] but also with "in-home" assistance as well. It has to be a family effort if possible. With Mom, it would have been unthinkable for my Dad to place her in some memory care facility, but there are other situations where the care and even safety of the loved one must be there. There is no "cookie-cutter" approach to caring for a loved one with Alzheimer's disease. Every situation is as different as a "snowflake." In our situation, we were focused as much on caring for the caregiver as we were "the patient" and managed to pull off that balance reasonably well. When the disease showed its ugly side, we had assumed the approach that we were now taking care of a child with very similar needs. Then, when the disease is all-consuming, it is genuinely taking care of someone dependent.

My account of events is unique to us [our family], and there has never been a short supply of regrets since Mom's death. There is no authoritative "textbook" on personally caring for your particular family member with Alzheimer's disease. It is truly a "learn as you go" process since the patient and the resources will always be different, and patients require different responses and resources. Suppose you are caring for a parent or loved one with Alzheimer's. In that case, you will likely get to "the end," or that time when your care stops and you look back with some regrets, and my only advice to most would be to make sure that you fill that time with as many fond memories as those times where challenges were frequent because the challenges will sometimes be daunting. At the end of the process, your memory of YOU should be that "I did my best" for that loved one- forget the challenging days and fill your memory with fondness of your long-term relationship with that loved one. My memory of my mom is that I had the best that God could have supplied. The challenges were there, and they will be there while caring for that loved one, but no matter the difference in circumstances, be able to look back on that process with fondness, having "honored" your mother and [or] your father! Ex. 20:12



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CHAPTER 14

WHAT TO DO

DURING/AFTER A MAJOR SURGERY OR LENGTHY HOSPITALIZATION FOR YOUR LOVED ONE

by Ketia B. Wick



Unprepared. Even though you know it's coming, your parent (or your loved one) tries to assure you they're ok…so you don't prepare, and you put it off. You put it off because you are afraid. You put it off because you think they will be angry and resist. You put it off because you don't know how to solve the problem. In hindsight, I genuinely believe that preparing can be done with dignity and respect out in the open with participation or maybe in secret because of denial. You need to do it. If you first try to do it out in the open with participation and involve your parent or your loved one, they may resist, argue, or deny and try to convince you that they are OK. This may cause you to feel like you need to back off or wait to make decisions or have further discussions. In reality, you need to move forward with what you know and what you think is best, in the open or behind the scenes, based on your knowledge and some outside research. At first, it may be painful, and there may be hurt feelings. In the end, it will be the right thing, and you will be more prepared.

My father is 75 years old. He was largely healthy and active his whole adult life. He did sports, went to the gym, ate well, and drank minimally. He was no stranger to surgery but could avoid or reasonably manage many of the chronic illnesses common for his age group. Last year, he began to have disabling back pain and right foot weakness. It reached the point of needing surgery. The telltale sign for me, although I would not have recognized it at the time, was his belief and expectation that the surgery and recovery would be like the prior surgeries years before, including a quick recovery with minimal pain. He underestimated both his age and his resilience following an intensive L2-S1 fusion. My mom and I did, too. We learned a lot from this experience, and there are many things we would have done differently or better. We can now share those with you in the hopes that you will be more prepared when your parent or loved one falls ill or has a long hospitalization.

Lesson 1: Expectations and Pre-Planning following a hospital stay/surgery

Although you cannot always manage the expectations of your loved one, reasonable or unreasonable, you can work towards planning for success and managing your expectations. My father was a Medicare patient with Part A and Part B. Medicare does not begin to cover hospitalization until day 3. Had we known this ahead of time, we may have spoken to his physician about keeping him in the hospital longer to help manage his post-operative pain, rehabilitation, and chronic medications. Instead, we were surprised when he was discharged on day two home instead of to a rehabilitation facility. We could have checked this coverage ahead of time and then weighed the cost of a 2-day hospitalization versus a 3-day hospitalization covered by Medicare. For you, it may be best to determine the approximate amount of these costs ahead of time to prepare for amounts that may not be covered and speak with your loved one's physician to determine a more manageable length of stay.

Once you know the discharge date and plan (you may need to check with the attending physician many times along the way, so be prepared to do so), help prepare for the event by asking yourself the following questions:

1. **Can I care for my loved one at home during this period largely uninterrupted?** Although you may think that you can take breaks between conference calls, a working spouse or child cannot care for an aging loved one after major surgery or hospitalization, where recovery requires 24-hour care and monitoring. You will find that trips to the bathroom take upwards of 30-45 minutes. This sometimes relates to the physical act of getting to the bathroom but may also relate to an accident that happens along the way, the need to go back to the bathroom after a failed first attempt, and the time needed to "clean up" after bathroom use. Sleeping is disrupted constantly with medication management for pain, and cooking and preparing food and snacks sometimes need to be coordinated with taking medications and providing assistance with eating and drinking. This means that a 15-30 minute time period for preparing food becomes a 1-hour commitment multiple times per day.

2. **Can I physically assist my loved one up from bed to the bathroom, around the house, shower, and do home physical therapy?** When my Dad first came home from the hospital, physical therapy could not start until later, so my Mom and I had to help. My Mom and I are strong and athletic, but we often struggle to help my Dad with the activities of daily living because of his size and lack of strength. This was a two-person job, and sometimes we felt it should be a three-person job. We often needed to ask my daughter for help. Having other people available in the home to assist or close by was important.

3. **Is the space where the patient will stay after the hospitalization functional for limited mobility?** This question should include whether a walker can easily move from a bed/recliner to the bathroom and whether there are grab bars or a pole by the bed/toilet. Is the shower accessible for two people (the patient and the person holding and washing them)? Is the toilet high enough to use, and are there bars for stability? Is there a need for a lift recliner, an adjustable bed, or a hospital bed? Will a walker with a seat be needed for longer ambulation? There are medical supply rental companies in most large community locations. The more you can plan the space and the needs ahead of time, the more prepared you will be.

4. **Can I troubleshoot if something goes wrong?** We had to make a last-minute run to the drug store many times, and we sometimes had to go to multiple drug stores to find something. We could not have left my Dad at home to do this, but he also was not well enough to go with us. We would ask my brother or daughter to run food/medication errands when necessary. Having sufficient help at home or close by is essential and something you may not think of. Three or more people may be necessary if the patient needs transfers, is heavy, or has any unique care needs.

5. **Do I have the ability to provide the necessary health care at home during the recovery period?** This includes having a sufficient number of supplies and the training necessary to help with the care. If your loved one has diabetes, do you have adequate supplies? If your loved one takes multiple medications, you will need to speak with an attending physician or primary care provider to discuss drug reactions and interactions.



If there are problems or concerns at home, what is the plan for getting to the ER, calling 911, or seeking advice or help for a medical issue? All of these things require preplanning. It is challenging to manage this last minute or alone if you are not prepared.

6. **Once the discharge is imminent, what services will you need and or have available for the patient at home?** Once the patient is discharged, the discharge is what triggers the need for home health or physical therapy. We learned very quickly that communication between the hospital and home health could be lacking. What care is needed at what intervals, and what needs to be done to arrange or schedule these services? Will the social worker arrange these services? When can you expect them to start? When do they need to start? Ensure you have the list of all of the services that will be needed, the telephone number for that service, and confirmation from a physician that the service is being ordered and is necessary.

Lesson 2: What About the Unexpected

Despite my Dad being a fairly healthy 75-year-old, staying in the hospital has risks like having surgery. First, he developed bladder retention and needed a catheter, which we had to learn how to empty/clean when he was discharged home. Then, he had a surgical infection and became so ill at home that we had to have him transferred to the hospital via 911. It happened quickly. At about 9:00 am, he was speaking and joking. By 11:00 am, he had mounted a fever, was barely able to move, and was incoherent. He went back to the hospital and spent the next month in the ICU. During his time in the ICU, he almost died. It was scary, but we discussed his wishes for medical care and funeral arrangements beforehand. It was not a discussion you necessarily wanted to have, but it was necessary. When your loved one passes, it will be sad and stressful. The more you can plan and know ahead of time, the more manageable it will be.

When the unexpected happens, try to keep a routine for your loved one. If they usually have oatmeal on Monday and Wednesday morning for breakfast, try to do the same. If they read a book each night, have someone read to them from that book each night. A routine means normalcy, and sometimes, that is precisely what is needed to help get them through the day. A wipe-off board with daily goals is a great idea, too.

Lesson 3: Start Now by Defining the Goal of Aging

Is the goal to bring your loved one home from the hospital versus a nursing home or rehabilitation facility? Is the goal to keep them in their home (for as long as possible)? These topics need to be shared in a discussion and preferably agreed upon so that your loved one can provide input and "own" the things they will need to do to reach the goal. Depending on the goal, you will need to define what physical and mental characteristics they will need to meet it. Do they need to walk on their own without assistance? Do they need to be able to feed themselves and make their needs known verbally to a caregiver or someone they might not know? Do they need any assistance (walker, cane, or wheelchair)? Is the environment they are going to from the hospital set up sufficiently enough to help assure them of success (grab bars, single-story access in/out of the house of bathroom (tub/shower)?

When my family went through the list for my Dad (and it was long), we decided to think about the positive. We wrote down the things my Dad could do (breathe on his own, see us and respond, say his name, say our names, swallow water by mouth, etc.). The sooner you determine what they can do on their own, the easier it will be to determine where the "gap" is (what they need help doing, what they can improve, and what they can do already). NOTE: If you have different goals from those of your loved one (for example, they want to come home, but you don't believe that will ever happen), it is up to you to try to determine an attainable shared goal. Maybe it is over a period of time, or perhaps it has multiple steps. The important thing is that everyone agrees and that the discussion comes from a place of mutual respect.

Lesson 4: Don't Forget to Take Care of Yourself

While you're taking care of your loved one, your life still must continue, and you need to leave room for others. The "others" may be your spouse, children, work colleagues, or close friends/extended family members. Those other



people in your life need to give you a window of time to ask for "grace" and allow you to skip things or cancel things (even at the last minute). Sometimes, that window feels like it doesn't exist. Sometimes, it is a short window, but seldom is it a lengthy period of time. If you are caring for a loved one for a longer period, remember that you may need to change how you respond to your new life (it will never go back to the old normal). It's up to you to balance all your needs with your family/work. Define for yourself what is essential and what is not necessary. You need to ask yourself how much you can give to each other without losing yourself or becoming so tired that you also fall ill.

Balance is important. Be present at the moment, whether you are with your loved one or trying to meet the needs of your family, friends, or work colleagues.

Lesson 5: Be an Advocate

You can see, experience, and know what your loved ones cannot see or understand when they are ill or medically disabled. During those times, you have to become their advocate and their spokesperson. Don't be afraid to ask questions. Ask for an explanation. Take notes about the treatment they are receiving and their prescribed medications. Take photos and videos. Make a chart to track the medications. This was especially helpful to my Dad in the hospital. In addition

to having a surgical infection, he also developed a reaction to his medications. We tracked when he was receiving his medications and what medications he was taking. Each day, he would have a new hospitalist taking care of him in the hospital, so it was difficult for them to see a pattern, and they sometimes didn't have time to do a lengthy review of his records. My Mom and I were able to look back at our medication "notes" and identify the problem medication, and the doctors discontinued it. Had we not tracked this information, I doubt that his treating physicians would have figured it out as quickly as we did.

Don't just document the medications. Take videos of your loved one's behavior or activities if you are concerned. This helps document what is going on when the doctor or provider is not in the room. My Mom and I often sent videos to the physicians to "show" certain behaviors that were not present when they visited for a short time once a day. This ended up helping a lot.

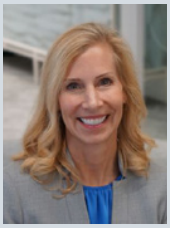
Make an effort to surround yourself with as much knowledge as possible. This may come from the treating doctors or friends or family who have medical experience. Finally, utilize your support systems. If you are at the hospital all day, take a walk, get a cup of coffee, or make a phone call to a supportive friend or family member. If you have faith, utilize it and pray.

Most importantly, let your loved ones know you are there for them by respecting them and their presence in the situation. For example, during my Dad's care, people would often walk into the room and start talking about him without addressing him. Even if your loved one is medically ill or disabled, always make sure that their presence is respected. For example, if a doctor or professional walks into the room or home and begins to talk about your loved one, be respectful and apologize. Say, "Dad, this is Beth, your physical therapist, and we are talking about you now… We would like you to hear and participate if you can." All decisions (unless beyond their abilities mentally) should be made to include their input and listen to their goals. Most importantly, it's about respecting the person and ensuring that they are included in important decisions about their health needs.

Summary

Most people who need this level of support and care are concerned and frightened that things will never get better and worried about what will happen in the future. Challenges present themselves in the hospital, when they come home, and even during recovery. You want them to feel safe and feel loved. They want to feel your touch. They want to complain (I think you get mad at them because they're upset with themselves). It may feel like they want to push you away, but they want attention and caring. They may challenge you hour by hour, day by day. To get through this, keep focused on the person and their goal. When you feel like you need a break, take a break (your loved one won't want you to and may punish you when you return), but you need one. When my Dad was in the hospital, and I was there with him, I used to tell him that I was going to Starbucks for my "daily cup of coffee." He knew that I loved that, and it was a treat for me. He got used to it, and it became "routine." For me, the cup of coffee could also turn into a phone call for support or a brisk walk around the block.

Guilt is a big concern for caregivers. You ask yourself: Did I give enough? Did I do enough? Can I do more? Avoid these questions in your head because, in the end, you are one person who is there to help your loved one get through a very difficult time. Doing your best is the best you can do. Balance is important. Be present at the moment, whether you are with your loved one or trying to meet the needs of your family, friends, or work colleagues. Remember that you can only do your best. Live and behave with no regret because you don't know how much longer you may have with them.



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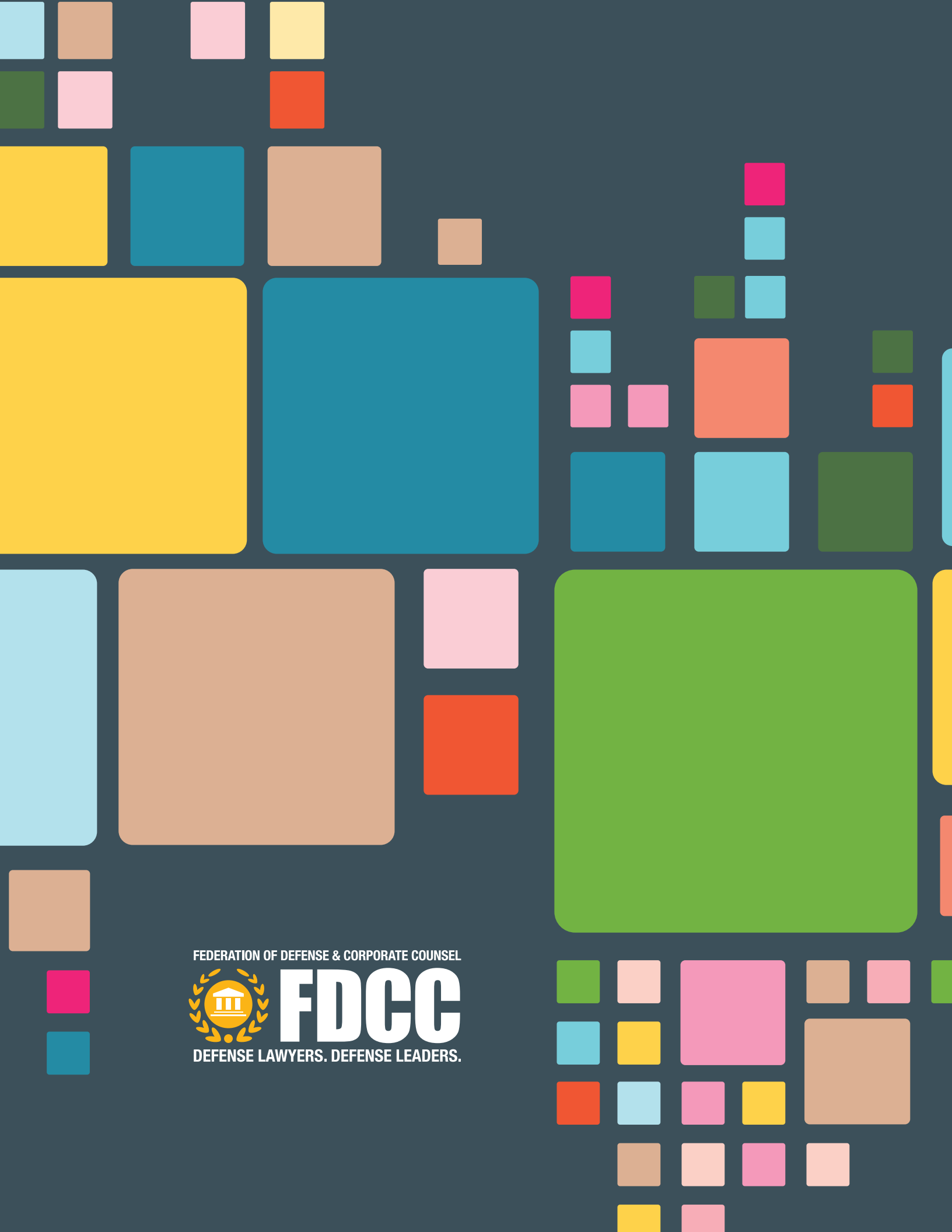
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