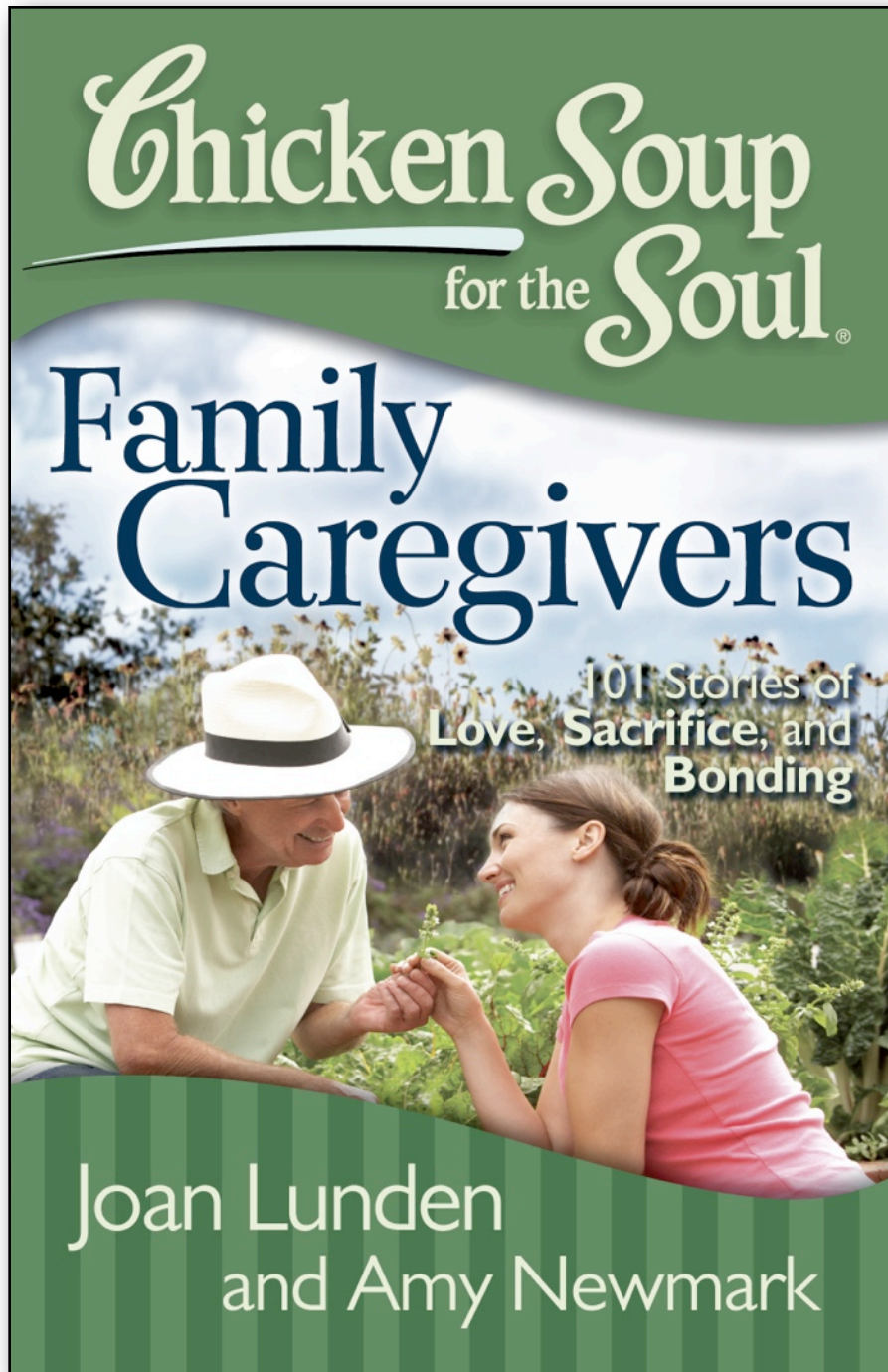


An excerpt from



Introduction

I am a caregiver for my mom Gladyce who is 93 years old, so family caregiving is a subject that is very close to my heart, one that I live every day. Statistics tell us that there are about 46 million Americans, like me, who are providing care to a loved one. However many of us don't identify ourselves as such and therefore we don't always recognize that we are dealing with caregiver issues. In fact, it was only as I sat down to write my story for this book that I truly realized that I first became a caregiver 30 years ago when my brother Jeff began to need my assistance due to his diabetes.

My brother and I grew up in Sacramento, California, where my dad was a cancer surgeon and my mother was a stay-at-home mom. My dad was also an avid private pilot and flew around the country speaking at medical conventions and assisting other doctors with difficult surgeries. When I was 14 years old my dad was returning home from a cancer convention when his plane crashed and he was killed. My mom's world was turned upside down; she suddenly became a single parent to two young teenagers. My mom went to work as a real estate agent to take care of my brother and me. When I was in my twenties I moved east to New York City to work as a television journalist for ABC-TV. My mom and my brother remained in our hometown of Sacramento.

A few years after I left California, my brother's health started failing—he was diagnosed with Type II diabetes. When a person develops Type II diabetes at a young age it can ravage their body, and by the time my brother was in his thirties he was already suffering from migraines and blurred vision, and he later went through numerous surgeries on his hands and feet as vascular problems set in. He found it impossible to stand for long periods of time and consequently he no longer could hold a job.

So when I was in my early thirties, with my brother in ill health, I found myself financially responsible for the lives of both my mom and my brother much sooner than I ever would have anticipated. The time came when I began to feel the financial burden of keeping both of them living in their own homes; I realized that moving them in together would mean one electric bill each month rather than two. So I bought a condominium for the two of them to live together, handicapped designed to accommodate my brother's needs and also for any future needs for my mom. The home had separate living areas so that they would each have their privacy. I even put in separate thermostats and heating systems since my mom liked her home warm and my brother preferred it cool. For the next few decades they lived comfortably with each other in their hometown where they had their roots and their friends—I would pay the bills and I would travel home for visits. Mom and Jeff took care of each other, and I believe that this living arrangement helped to keep each of them well since they had to worry about the other's health. Then as their health began to slip I hired an in-home aide to come each day to help clean, shop, cook and take them to doctor's appointments.

My brother dealt with the details of their daily life, including all of my mom's health care. Unfortunately we never took the time to sit down and have a family meeting or to make a plan for what would happen when the time came that Mom needed more daily care, or as it happened—that one of them would die. We all know the day will come when we have to step in and deal with the demise of a parent, a spouse, a sibling or another loved one. There is no escaping this aspect of life, yet no one ever wants to talk about it. As adult children we seem to find it difficult to press our parents to talk about their twilight years and their end-of-life issues. However dealing with these issues before crisis hits, while our loved ones are still able to provide us with answers, can make this difficult life event so much easier to manage.

I learned this lesson the hard way five years ago when I got the call that my brother Jeff had died suddenly at age 56 from complications of Type II diabetes. My brother and my mother had become

quite comfortable living together and taking care of one another and they enjoyed each other's company. I knew that my mom was beginning to show signs of aging, but what I didn't realize was how seriously my brother's health was deteriorating. He always put on a good face and didn't let on to me that it was becoming increasingly difficult for him to manage their lives. In fact, he had reached the point where he was really not even able to take care of his own health.

When Jeff died, my mother was 88 years old and she was overcome with grief. With my brother gone, everything changed. My 88-year-old mom could never remain living in that condominium all by herself. Mom had also begun to show signs of dementia and was unable to cope with even the simplest of matters. I was left with so many questions and so few answers. Even though my brother's health had been deteriorating terribly, I had no plan in place as to what to do next. I wished that I had talked to my mother and brother about their health, their insurance, their banking, their business affairs, and their end-of-life wishes when they were healthy enough to be able to provide me the information. My mother often feels so helpless, knowing that she simply cannot remember important details about her health or even about our lives growing up.

Frankly, my situation is not all that uncommon. Most of us are not preparing ourselves for the inevitable; we're not doing due diligence, getting ready to take care of older parents or other family members who will require our attention. I think it's fair to say most people are not prepared for the day when it falls to them to be a caregiver. It's usually thrust upon you when one parent dies or your only parent left takes ill. All of a sudden you have to learn how to be a caregiver, instantly.

I'll never forget when I arrived back home in California following my brother's death, how my mom was just sitting there in shock. You could see the pain in her face and the uncertainty as to what would happen next. I knew immediately that I didn't have any time to waste; I had to spring into action and find all of her important documents. I would have to act for my mother, whose dementia had suddenly worsened because of the shock of my brother's death. But

how could I take care of her banking and handle her Social Security checks if I wasn't a signer on her bank account? You know, these are things you need to do and know about ahead of time.

I would ask Mom, "Where's your driver's license?" She would reply, "I don't know, sweetie. I stopped driving quite a long time ago." "Where's your passport, Mom?" Again, "I don't know, honey. I stopped traveling a while ago." "So where's your Social Security card, Mom?" Again, she had no clue. How could it be that I was finding stacks of old mail and newspapers, and books and years of living in every nook and cranny of their condo but not any of the important documents that I needed? After spending hours and hours going through boxes and boxes I figured it out. My brother had long ago stopped keeping any up-to-date financial or medical records.

There I was sifting through hundreds, if not thousands, of papers trying to find Social Security cards, Medicare cards, car titles, bank accounts, insurance policies, etc. When few of them could be found, I literally had to reconstruct my mother's identity in order to get the documents necessary to run her life. I first had to obtain a birth certificate and then a copy of her marriage license from the respective states and then with those in hand, I was finally able to get her a new Social Security card and Medicare card. The bureaucratic red tape was never ending. It took months to track down the details of her life and health, spending many frustrating hours on the phone with government agencies, all while trying to comfort my mother and get her settled into a new living environment. I had always thought that I had everything under control with my mom and brother. Boy was I mistaken. I vowed to use my experience to help others be more prepared for this difficult time.

We all need to know where all those important papers are—mortgages and titles, wills and insurance policies—or you need to know who has all this information. Where is your parents' bank? Are you signed on that account so that you can do their business should something happen to them? Is there is a safety deposit box somewhere? Where's the key and what's the code? When I returned to New York, I conducted my own personal survey, asking everyone I came into

contact with if they knew all of this information about their parents, or even their spouse. Again and again I got a bewildered "Not really." I think it's fair to say that most people don't know all this information. And, quite honestly, you should know it about your spouse as well as your parents. The day that a trauma happens is not when you want to learn about this.

Throughout the initial emotional weeks after my brother's death, along with planning a funeral I had to plan a new life for my mom. I needed to find my mom a new home. I started looking at senior assisted-living facilities throughout Sacramento. I had to become an instant expert on which kind of care home would be the best environment for my mom—and then I learned that there are also different levels of care within each facility. I looked at many different places where I thought she might like to live. Mom was incapable of helping with any details or even rendering an opinion, so in the end I had to make the decision for her and of course all of the arrangements and the move.

But that was the easy part, trust me. Then I had to have that difficult conversation that none of us ever wants to have with our parents—the one where we tell them they must leave the comfort of their home and move into a senior facility. It doesn't matter how pretty the place is or how exclusive it is, it means moving out of the home where they feel safe and secure. Needless to say, my mom didn't want to move. (They never do and you can't blame them.) However there comes a time when it's not a matter of, "Gee, what would they like to do?" That decision must be based on where your loved one will be safe and best cared for. That's where many people make a mistake—it really comes down to what's safe. It's always so difficult when that time comes and you have to make that decision. It was so hard; not only had my mom lost one of her children, but I was about to make her leave her home.

I first moved my mom into a fancy-schmancy assisted-living facility. In my mind, it was a beautiful place where my mom belonged. I thought she would be able to go downstairs to the dining room and be a social butterfly with other Sacramento seniors and then retreat

to a beautifully decorated one-bedroom apartment where she could entertain friends if she wished. The problem with my well-meaning plan is that I was making arrangements for the mom that I used to know, and not who she had become. My mom now couldn't remember who people were, and she would get frightened when taken downstairs to the dining hall. And for the first time, my mom was afraid of being left alone in an apartment, no matter how pretty it looked. As soon as it would start to get dark, she suffered from sundown syndrome, becoming increasingly frightened as the shadows fell into the darkness of night. She had felt safe and secure living with my brother in a familiar setting all those years, but now here she was in this strange place by herself. I thought I was doing what was the best thing for her, but in the end it didn't work out at all.

Less than a year later, I found myself back in California looking for yet another home where Mom would be happy and safe. I tried to talk my mom into moving back east closer to me; however she still had friends in Sacramento who came to see her. She's a California sunshine gal—all the snow and cold weather back east just wasn't her cup of tea, to use her words. I found another lovely facility that provided a higher level of care—but even with more personal attention my mom still felt scared and lonely. In this new facility, aides were coming in and out throughout the day to assist her with personal care; however over the next year and a half she took a number of falls and would end up in the hospital each time. My mom was having issues with balance, and with each fall the injuries got worse; first it was a broken toe, then it was a broken rib, then it was staples in the back of the head. Every time it happened, I jumped on an airplane and flew back to California.

Finally, about two years ago, when she was back in the hospital for yet another fall, and more staples in the back of her head, her physician told me that she really couldn't go back to where she'd been living—the next fall could be fatal. The doctor recommended that I move her to a small residential care facility, a private home where there would be only a few residents. In this kind of living arrangement,

my mom would have her own bedroom but would be constantly watched round the clock, not just checked on occasionally.

Once again I was looking for that perfect place where my mom would be happy and safe. However this search seemed even more difficult to me. In the larger facilities you could see the round-the-clock staffs, and check their schedules. Now I was looking to put my mom into someone's private home—how would I know what they were doing? I wasn't sure where to begin this search. But this time around I was fortunate to secure the help of a “senior advocate,” a knowledgeable professional who could answer all my questions and could show me the residential care facilities available in the area. This made all the difference in the world. I highly recommend obtaining the services of a senior advocate or eldercare advisor to help you navigate this journey. This kind of professional can help save you hours of time and stress by narrowing your choices to locations that meet your specific needs. They help families evaluate issues such as care requirements, finances and amenity preferences. Because of my passion for preserving quality of life for our loved ones, I've recently aligned myself with A Place for Mom, our nation's largest senior living referral information service. The Senior Living Advisors at A Place for Mom are kind and knowledgeable, and easy to talk to about any senior care situation. They can answer all of your questions and help you find the appropriate living arrangement for your loved one.

My senior advocate knew I was nervous about putting my mom into a private home with just a few other seniors, but I remember she looked at me as we got out of the car to check on the first home and she said, “I can show you a dozen places, Joan, but if it was my mom—this is where I would want her to live.” It was a lovely ranch-style house with six residents, each with their own bedroom. My advocate was there by my side to ask all of the important questions (which I really didn't know) and to unabashedly scrutinize the facility (which I was admittedly reluctant to do myself). The residents were sitting together in the living room chatting and watching TV and talking with the care workers who scurried about tending to their needs and getting lunch ready. The home was impeccably clean and

the food being readied in the kitchen smelled yummy. All of my worries began to melt away when I met the owners, James and Rowena Ashley, who were welcoming, warm, knowledgeable and obviously dedicated to their residents.

It has turned out to be a wonderful environment for my mom. They are there with her when she awakens, they get her dressed and they bring her to the dining room table for each meal. The residents are all in their nineties, they don't always talk a lot, but they play Bingo and do crafts projects and jigsaw puzzles. My mom is the reigning Bingo champion right now. She's comfortable, happy and safe, and in this kind of residential care facility you can stay right through to hospice care at the end. Therefore residents don't have to get moved around and that's important because every move can be an emotional, mental and physical setback.

One thing that made this last move much easier on my mom was an idea that my daughter Lindsay came up with. She traveled with me to California to help me get my mom resettled. Any move to a new environment can be upsetting to the elderly, so before you move your loved one, take pictures of where everything is located in their current room or apartment. For example, if there's a bookcase with all kinds of memorabilia, photos and books, snap a few pictures. When we moved my mom into her new room, Lindsay literally went back to the shots in her camera and we recreated my mother's room as identical as possible, putting everything on every single shelf exactly where it had been before—and that made such a huge difference for her.

If there is one thing that I could point to that would have made taking on the role of caregiver more manageable, it would definitely have been **asking more questions when I could still get answers**. Oh how I wish I had had a family meeting! Families really need to have these talks, but of course the tendency by most people is to duck the subject. It's like the elephant in the room, isn't it? Yes, it's the elephant in the room and I think we just can't get the words out of our mouths: "Hey, what are we going to do with Mom and Dad when Mom and Dad can't take care of themselves?"

I got thrown into it all, as most of us do. Suddenly, you're in this world where you are expected to understand the difference between senior care and assisted care and nursing homes—and long-term care insurance... it's all so complicated. My top recommendation to everyone is to **call a family meeting**. If you have older parents or a family member who will seemingly require your care any time soon, you need to schedule this meeting. I recommend that you approach this as you would any other serious business meeting. You need an agenda and you need to think through all of the areas that should be discussed before you all sit down together. Where do we think Mom and Dad should be living as they age? Is there anyone they might move in with when the time comes? You have to ask these questions. And you must go right down that checklist. Is there a will in place? Do you have a power of attorney for their health and business? Is there an advanced healthcare directive? Where are these documents? Do your parents have long-term health care insurance? If not, how will you pay for their care? Do you know their end-of-life wishes?

Many times parents are reluctant to have this conversation, and finances can be an especially sensitive topic. You may need to be less direct with those questions as you start out, but it is essential for all adult children to open this line of communication. Don't make the discussion about what "you are going to have to do for them," since no parent wants to feel like a burden. Make the discussion about what "they want to do and how you might be able to help them towards that end."

It is probably best to have an initial family meeting without your parents present, in order for the grown kids to be honest and forthcoming about what they are really willing and able to do. Maybe everyone can't help equally, but talk about what each of you could do. Perhaps one brother is an accountant; he could be in charge of finances. Is there a stay-at-home mom or an empty nester who might be able to help with day-to-day care? Is there a teenager who loves driving around but needs gas money? There's your chauffeur to doctor's appointments and the runner to the drugstore and grocery store for Grandma. Discuss your options, and have a plan in place—it

will mean having the information necessary to help your loved ones when they need your help the most and it often means that you will also be protecting yourself. And again, remember that caregiving and all of its responsibilities can be complex and overwhelming; I have found much guidance and emotional support from my senior advocate and also from an Elder Lawyer who has counseled me on my mom's legal affairs.

Something else that I have done that I would highly recommend, is that you sit down with a video camera and **interview and record your parents, grandparents and other relatives**. Construct an interview ahead of time; you can start with your own childhood, ask them what life was like when you were a child. What were you like as a child? And don't forget to ask them what life was like for them when they were young, and what the world was like back then. Ask about when your parents met, courted, got married, and first got pregnant with you—all those things that you will never know unless you ask the questions. This kind of video recording of your family history is priceless.

Make sure that you also ask family members about childhood illnesses or family health issues that might affect your own health risks. Once you have them talking, then you can ask about what their wishes are for their older life. Ask questions like: Where do you hope to live as you get older and need more care? How do you envision your Golden Years? And when the day comes, what kind of funeral do you want? I know, a lot of people say that's morbid. Well, it's really not. It's important to make your parents understand that not addressing those issues can create an incredible emotional and sometimes financial burden for their children.

When I got my mom going on the subject of a funeral, or her Bon Voyage Party as I called it, I was surprised by how much she had to say. My mom, who has always enjoyed being in the spotlight, mapped out a funeral for herself like it was a prime time entertainment special. She even selected the songs she wants sung, and who she wants to perform them (fortunately a family friend). My best friend got her mom to have this discussion, and as it turns out her mom had some

very specific requests—including wanting her grandniece to play the flute during the ceremony. It may seem like this would be a terribly awkward subject; however I think you may be surprised if you initiate the conversation, your loved one may welcome this opportunity.

On my many trips back to my hometown to visit my mom, I not only have sat and recorded many conversations with her, but I also arranged to interview family friends and several doctors in Sacramento who were colleagues of my father. They were able to tell me about working with my father in his medical office and next to him in the operating room, as well as about trips they had taken together with my parents. I never got a chance to know my father as an adult; I was only 14 years old when he died, so it's been fascinating to learn more about him. Two of the three doctors I interviewed have since died, so it's a lucky thing I got to have those conversations. These videos are cherished memories that I captured and will treasure forever.

Of all the lessons I've learned through my years of caregiving, I think the most important thing all of us can do, no matter whether we are providing day-to-day care or overseeing the care from afar, is to **keep the love connection going**. Just tell them that you love them again and again and again. You will never say it too much, ever. I try to make sure my mom either hears from me or gets a little something from me often. It can be as simple as sending a magazine with a little note saying "read this article" or "enjoy this." Every time I travel I make it a point to send her a postcard from whatever city I'm visiting.

It's really just about making that connection. I've made my mom a few of those beautiful digital photo books with pictures of our family through the years. I made her one this past year that I titled "It's a Wonderful Life." The album began with the newspaper announcement of when my mom and dad were married, and was filled with photos and holiday cards that told our family story. The best part of making that album was seeing how the photos jogged my mom's memory. As she flipped through pages of black and white images of herself as a young woman being courted by my dad, I saw a glimmer in her eye that I rarely see these days. I was thrilled by how it reconnected her

to her life—it was the best gift I could have ever given her. It was so simple, cost so little, but meant so much. You could achieve the same thing with a scrapbook—I'm just not artsy enough to make one. No matter how you create your book of memories, the bottom line is about helping your loved ones make the connection to their families so they feel as though they still belong.

I feel very fortunate to have had the opportunity to connect with many families and experts for this book and for my television show on caregiving called *Taking Care with Joan Lunden* (on RLTV). I have also heard from many of you on my website, www.joanlunden.com, as well as Facebook and @JoanLunden on Twitter, and I have learned so much from your caregiving stories.

I never cease to be amazed at how many people contact me to tell me how overwhelmed they are as caregivers. They tell me how their lives were absolutely turned upside down when they took on the caregiver role. They talk about its emotional and financial burden, and how they sometimes feel that it squeezes every ounce of strength from them. Now, they say, there is simply no time left over for themselves. They are emotionally, physically and often financially drained. This drives my passion to help families find solutions and resolve.

In fact, studies have shown that there is a real toll taken on the health of a caregiver—that many caregivers may actually die at a younger age because of that toll. It's thought that the constant stress of providing care can take as many as 10 years off a person's life due to greater risks of depression and other health problems. The average caregiver in America today is a 46-year-old woman who has children at home and is working full time. That's a lot for anybody. Many of today's caregivers are part of the Sandwich Generation, like me; they are simultaneously raising children and also caring for parents. People often report that their caregiver role has resulted in less time for family and friends, and a substantial number report giving up vacations, hobbies and social activities as a result of their caregiving responsibilities.

Not surprisingly, studies by the American Academy of Family Physicians show that depression is the most common health problem

among family caregivers. One study revealed that anxiety was present in about 20 percent of caregivers, and those who provide more than 36 hours of care each week are more likely than non-caregivers to experience symptoms of depression. For spouses, the rate is six times higher; for those caring for a parent, the rate is twice as high. And for those caring for a person with dementia, the rates of depression can be as high as 43-46 percent, nearly three times what is found in the general population.

Caregiving can devastate families and marriages and it also has a major impact in the workplace. Many of today's caregivers work either full or part time while providing care. More than half of those working caregivers say they have to go into work late, leave early or take time off during the day in order to provide the care. Some report having to take a leave of absence, shift from full time to part time, quit work entirely, lose their job benefits, turn down promotions, or choose early retirement.

American businesses are reported to lose between \$11 billion and \$29 billion a year in reduced productivity costs related to caregiving responsibilities. That includes workplace disruptions, scheduled and unscheduled absences, leaves of absence, reducing full-time work to part-time, taking early retirements, and leaving work entirely to care for a loved one.

Any way you slice it, caregiving is a difficult role, no matter how much you love your mom, your dad, or whoever you're caring for. When a surviving parent or spouse cannot live alone, we must take charge of finding a solution for their care, sell their home and their cars, and get their business affairs in order. Of course if they don't have a will, when that day comes you won't know how they wish to be buried, or how they wish to distribute their belongings. Without an "Advanced Health Care Directive" you won't know their wishes if faced with tough decisions when their life is in the balance. Without a Durable Power of Attorney, you cannot conduct business for them. If you do not have permission to ask questions of their physicians, doctors cannot give you vital medical information.

It will never be easy emotionally; however it doesn't have to

be such a financial and legal struggle. You just need to take steps in order to be prepared. Don't wait! We never know what life has in store, or when a major event will occur.

People are simply living longer. Today there are more elderly citizens than ever before. Since 1960 the number has doubled from 17 million to 35 million. In the next 20 years, the number of people 65 years old and older is expected to shoot to 70 million, which means more parents will be in need of care and that means that the need for caregivers is going to skyrocket! As baby boomers and their parents get older, so does the demand for better health care. In many cases, the kids or the spouses will be doing the caring. It has been projected that boomers will spend more time taking care of their parents than they did raising their children. Wow! That's a big chunk of time.

The Baby Boom generation is approaching retirement age like an avalanche in terms of volume of people each year, causing what's described as a "silver tsunami." Millions of Americans are now reaching that particular stage in life and will require both medical and non-medical care going forward. Meanwhile, a comparative trickle of physicians and other health care professionals have geriatric training and experience, and shortages of many caregiver types have long been a problem.

According to recent surveys, at least 66 percent of the U.S. population—or more than 138 million Americans—believe they will need to provide care to someone in the future. At the same time, the majority of Americans say they have not taken adequate steps to prepare for the possibility that they will need to be cared for themselves in the future. When asked what steps they have taken, only 4 in 10 adults have set aside funds to cover expenses or signed a living will or healthcare power of attorney. Only a third of all adults say they have purchased disability income insurance or looked into independent or assisted living arrangements, or purchased long-term care insurance. Only 34 percent of Americans say they have talked with a family member or friend about providing care to them in the future.

Family caregiving is most certainly the next big health crisis to face our country. If it's not already going on in your home, it's

probably right at your doorstep. We all need to begin the discussion so that we can be ready, and that is why I am so excited about this *Chicken Soup for the Soul* book. Storytelling has always been a highly effective way to pass on wisdom, and the 101 stories and interviews in this book will open your eyes to the caregiving experiences of other people, and give you some tips about what you can do yourself. You'll also feel comforted when you see how many other people are going through the same ups and downs as you may be experiencing in your role as caregivers, or as the recipient of that care. I hope that this book will expose you to some new ideas, encourage you, entertain you, and above all, help you put your experiences in perspective and make you feel part of that big community of caregivers out there.

~Joan Lunden





Those Sparkling Irish Eyes

A Note from Joan

One of my best childhood friends from my hometown of Sacramento, California is Michele Dillingham. We were in each other's weddings and were there for each other when our children were born.

Tragedy hit Michele's life when her husband died suddenly of a heart attack at only 50 years of age. Her two children were very young at the time, and since then she has raised them as a single parent.

Years later, when her children were grown and off at college, Michele took on the role of caregiver to her mother and father as their health declined. Her mother suffered from Alzheimer's, which of course made the job of caregiving even more challenging. Michele lost both her mom and dad about 12 years ago, but her role as a loving caregiver has continued.

With me living so far away, Michele has made it a point to visit my mom at least once a week back in our hometown. Michele shows my elderly mom with love and compassion. It has been such a blessing for me to know that Michele is there on the other side of the country, keeping a watchful eye on my mom and exchanging

wonderful memories with her. It has also been a blessing for Michele, who once again has an opportunity to make a real difference in the life of another through caregiving.

So often, providing care and emotional support is looked at as a burden. However, those providing the care reap many rewards as well. The smile on my mom's face when Michele goes to see her really says it all. At 93 years old, my mom is dealing with dementia and no longer lives in her home. So she gets great emotional comfort from seeing a familiar face from the past come into the care home; it makes her feel like she is still connected to her life. There are no words that could ever express my gratitude for the time, attention, and compassionate care that Michele gives to my mom. I want to share with all of you, my friend Michele, a model caregiver.

My mother was a real Irish beauty and always quick to laugh. She was actually half Irish and half Italian but she favored the Irish side in looks, with her dark hair, fair skin and those sparkling eyes. My beautiful mother was also a dignified and private person. She loved being with people and she loved to laugh, but all with an incredible dignity about her.

St. Patrick's Day was of course always celebrated in our home, but perhaps the luckiest St. Patrick's Day was the one when Mom fractured her hip. I know that seems odd and even a little cruel, but you see my beautiful mother also had Alzheimer's.

Dealing with a parent who has Alzheimer's or even dementia involves many different steps as the disease progresses. It is very difficult for family members to watch a loved one go through that, and ultimately the child becomes the parent.

My sister and I were like most others coping with the disease. There was frustration, anger, despair, and sometimes even laughter. My son still remembers the time we were all sitting in Mom's living room and suddenly she said, "Where are my lights?" We all stared at her and she went on "These aren't my lights—where are *my* lights?"

Any family dealing with Alzheimer's knows that these moments happen.

Imagine what it must be like for the person *with* the disease... to not know where they are or even who they are. It's a scary thought. It becomes even more difficult when those you love have to be watched carefully so they don't wander off, knowing that they would not be able to find their way home or even let someone know who they are.

Mom, however, didn't want to leave home unless she was with either my sister or myself, and even then, the outgoing mother we had always known became more and more reclusive. On a few occasions she was hospitalized for one thing or another but she would become so agitated that they didn't keep her long.

Looking back on that fateful St. Patrick's Day, I remember how Mom fell. It wasn't unusual for her to fall, but it was unusual for her to be hurt. As we used to say, she had bones of rubber! But this time she fractured her hip, and it immobilized her with pain too great for her to move.

From the hospital she was sent to skilled nursing and it was there that they quickly recognized that she had Alzheimer's. Fortunately they had a wonderful wing that specialized in caring for those with memory problems. Mom wound up being there for the last six months of her life, where she was not only well cared for, but lovingly cared for.

Moving a parent to a facility or care home can be difficult for the parent because they are leaving the security of their own home. Mom would have been terrified if we had just moved her there, but because of her injury it was different, because the pain was so distracting and the people there were helping to ease her pain.

Mom remained bedridden because after the fall she never regained the strength she needed to walk. She had a lovely room, and in her mind she was in her own bedroom in her own home, which made her happy and was a great comfort to her. This not only comforted her but comforted my sister and myself as well. My lovely dignified mother was being impeccably groomed by other people,

which in her case was far better than if we had been doing those very personal tasks for her.

Her memory may have been gone but the sweetness and humor remained with Mom, as did the sparkle in her beautiful eyes. Mother “held court” as everyone was eager to help her. For the last six months of my mother’s life, my sister and I were free to simply enjoy her, and she was comfortable and happy. Seeing her eyes light up when one of us or her beloved grandchildren entered the room still brings such joy to me. It was such a special time and a time that brought my sister and me to a new closeness we had never enjoyed before—a surprising legacy my mom would so have loved.

A fractured hip in most cases would never be considered “lucky,” but for my beautiful Irish mother that fall did make for a lucky St. Patrick’s Day, as it gave the last six months of her life the dignity and happiness she so deserved.

~Michele Dillingham



Cue Ball in the Pocket

*Every gentleman plays billiards,
but someone who plays billiards too well is no gentleman.*

~Thomas Jefferson

When dealing with a disease as difficult as Alzheimer’s, it’s important to look on the bright side whenever possible. Luckily, when it came to my grandpa, we were able to do just that.

I’ve read that Alzheimer’s patients tend to keep the same temperament they had before they got sick. My grandpa fit this pattern. I’d always known him to be fun-loving and easygoing—except when it came to his Buick, which he was very particular about. When I was growing up, my grandparents often babysat for me, so on nice days Grandpa and I would play catch in the back yard. Later on, we would spend evenings shooting pool at the activity center. He’d grown up in a small Illinois town where the local pool hall was the only center of activity. He’d become so skilled that he could almost always hit a bank shot. He would practice such shots just for fun, to give me a chance to catch up with him.

After he needed more care than Grandma could give him, we moved him to St. Joseph’s Home, where the staff of the Alzheimer’s ward was cheerful and friendly. The nuns often strolled around giving extra help to patients. There were extensive grounds so that visitors could take their loved ones on walks around the flower gardens. There was a lounge with a pool table.

My grandmother took an apartment across the street from the facility so that she could visit Grandpa every afternoon. Whenever I was in town, I went with her. On summer days, we would take Grandpa outside so that he and I could play catch. Even though his mind wasn't working properly, his hand-eye coordination was excellent. He would still trick me by looking off to the side and throwing the ball right at me. One visitor often brought a dog, and Grandpa would play with it, too, grinning so widely his teeth shone as he threw a stick for it to retrieve.

When I brought my new boyfriend home to Springfield, I wanted Winslow to meet a family member who was so dear to me. Since he was from Sri Lanka, a country where older relatives are usually cared for at home, he had no qualms about accompanying Grandma and me on our daily visit. Together we walked down to the lounge, and when Grandpa saw the pool table, as usual, he wanted to play. I racked the balls and let Grandpa "break." He then started to shoot, often hitting the balls in, while Grandma read a magazine over in the corner.

"He's not playing by the rules," Winslow observed when Grandpa took a shot even after he missed.

"He can't remember them," I explained. "We just hit the balls around."

Despite this handicap, Winslow and I tried a game of sorts, alternating solids and stripes in between Grandpa's erratic turns.

"We have a small problem," Winslow said. "He put the cue ball in his pocket!"

"Fish it out," I suggested, but by then Grandpa had gravitated toward me, so I fished it out instead, put it on the table, and motioned for Winslow to take his next turn.

As we continued our pseudo-games, Grandpa was enjoying himself thoroughly. Even though he sometimes ignored the cue ball, he studied the angles. And even though he hit solids and stripes indiscriminately, Winslow and I were amazed that he made so many more good shots than we did.

The next time Grandpa pocketed the cue ball, Winslow started to fish it out.

"Does your grandpa wear dentures?" Winslow asked, pulling a pair from Grandpa's pocket.

I shook my head "no" as Grandma shouted "Oh, my God!" from across the room.

Winslow and I couldn't stop laughing, and by now, Grandma couldn't either. Grandpa, undeterred, had gone back to his "game."

"Go take them back," Grandma told me. "I hope the nurses aren't mad."

I carefully carried Grandpa's trophy back to the Alzheimer's ward and searched for the head nurse. "Judy, I'm really sorry, but..."

I tried not to giggle as I held up the fake teeth.

Luckily, Judy took things in stride. "You know, they take one another's things all the time."

I did the rounds with her. Most of the other patients were sleeping, and we found dentures in several glasses as we peeked into the patients' rooms. Finally, we reached MaryLou's room, a bright spot full of pillows and stuffed animals. MaryLou was watching TV, not comprehending anything, with a big, toothless grin.

"Of course," Judy said. "I should have known. I think Mike likes her things the best."

I didn't wait around while Nurse Judy sterilized MaryLou's missing teeth.

By the time I got back to the lounge, Winslow was in the middle of a new game with Grandpa, and Grandma had gotten back to her magazine.

"No worries," I said. "The owner never missed them."

"Thank goodness," Grandma said. "It's so embarrassing."


"Think of the bright side," Winslow piped up. "The next time dentures go missing, the nurse will know where to look!"

My grandpa lived another couple of years after the "dentures" incident, and my grandmother cared for him as best she could. The whole family was thankful he could be in such a loving place as

St. Joe's. Whenever I could get back to town, I continued to take Grandpa on walks, play catch, and shoot pool.

But at the end of every session, I always double-checked his pockets.

~D.R. Ransdell



Losing Gracefully

Loss is nothing else but change, and change is Nature's delight.

~Marcus Aurelius, Meditations

How do you spell old age? L-O-S-S. I know. I was there to bear witness.

After my father-in-law's unexpected death that Independence Day, Velma decided to move to Colorado to join her three sons, to immerse herself in their families. But the cost of love and companionship was high: My mother-in-law traded her rural hometown, her beloved house, and most of her worldly possessions to be with us.

In the process, she chose to leave behind other members of her family—her brother, sister, nieces, and nephews. She waved goodbye to her pastor, her girlfriends, her old classmates, her long-time hairdresser, her Sunday school class. She uttered her final farewells at the headstones of her parents, grandparents, and younger sister.

And her husband.

It was my privilege to spend time in Kansas that winter, helping her dismantle the household she'd established decades earlier when her boys were young, her days full, and her dreams rosy. The idea of old age and ill health in those years was still so distant it hadn't even seemed possible.

"What do you want to do with these?" I nodded toward the kitchen counter where rows of vases stood at attention, soldiers waiting for orders.

She blew a tired breath. “Box ’em. The hospital auxiliary will fill them with flower arrangements.”

“And those?” I pointed at mountains of craft supplies, rainbows of embroidery floss, and packages of straight pins glinting like mica.

“Well, I was thinking some of the ladies at church might use those up. I’ve already set aside my scraps and quilting books. They go with me.” When she reached for a stack of crocheted doilies on her desk, her hand trembled—a symptom of the disease we suspected but was as yet undiagnosed.

Each closet held surprises. The white Tonka truck my husband treasured in his childhood. A vintage game of *Chutes and Ladders*, still in its original box. Brittle photographs of ancient relatives. We unearthed a lifetime of memories and a flea market’s worth of goods amassed throughout six decades of marriage.

“Look here.” Velma leafed through her wedding scrapbook. “These gift cards came from Germany, relatives we hadn’t heard from during The War.” Two heads, one copper and one silver, angled over the pages as we identified signatures and sighed over photographs.

She pawed through boxes and sorted file cabinets, handling each old receipt and rereading every yellowed letter. After a thorough romp through recollections, she left them behind—along with almost everything else she owned.

“No room for any of this in my new apartment at Good Samaritan.”

She was right, of course. Space in her new quarters was limited. Even so, I was stunned at how easily she deserted the possessions she’d spent her entire life accumulating and treasuring and storing.

Velma loved her new digs and segued smoothly into assisted living. She contacted old friends from the 25 summers spent at our local campground. She made new friends at the facility, engaged a hairdresser, and purchased yards of fabric to quilt. She attended church services, sang, and sewed baby quilts for her professional caregivers.

But more loss was on the horizon. In a few short months, the doctor diagnosed progressive Parkinson’s disease. It wasn’t long

before Velma’s physical needs outgrew the parameters set by the assisted-living facility. As a family, we stepped in to take up the slack. As she steadily declined, we drove her to appointments, escorted her on shopping expeditions, mediated with doctors, oversaw dentures, nursed her through a broken hip, purchased an electric cart, gave her “driving lessons,” sat with her at the hospital, and hosted her graduation to a wheelchair.

One by one, she lost her motor skills. Toward the end, we did for her the things her muscles were no longer capable of. We spoon-fed her; we painted her fingernails with her favorite polish—Creamy Carnation—and clipped on her favorite jewelry; we dialed the phone and held it to her ear; and we wiped spittle from the corners of her mouth, straining to catch the words she struggled mightily to speak.

Through it all, she kept up with family near and far. She knew which of the nursing home staff were on vacation, who was expecting a baby, whose teenager was having trouble in school. She read her hometown newspaper and celebrated each victory of the Denver Broncos.

By the time she died, Velma had lost so much—her spouse, her home, and her health. But, ever gracious and accepting of life’s circumstances, she set an example for us all. Without complaint or grieving, she willingly gave UP a lot. Yet she never gave IN.

The real loss, I came to realize, wasn’t hers... it was ours.

~Carol McAdoo Rehme