

ART **OF**  
CAREGIVING

WORKBOOK

GROWING  
**BOLDER**

# Growing Bolder's Art of Caregiving **REAL PEOPLE. REAL STORIES. REAL INSPIRATION.**

What comes to mind when you think of the word “caregiving”? Do images of nursing homes pop in your head? Maybe a nurse pushing a wheelchair down a hallway? Perhaps it’s a scene from a movie with white-haired elderly folks playing cards and watching TV at round tables in the community room at an assisted living facility?

It’s time to shatter those images and stereotypes. Sure, some caregiving looks like that but most caregiving happens at home with more and more people requiring care than ever before. A national caregiving crisis is unfolding in America thanks to a desire to “age in place” along with the rising cost of nursing care. Homecare is the fastest-growing occupation in the country. The care is often unpaid and family caregivers have become some of the most stressed and overworked members of our society. As families and friends step forward to provide care, they often sacrifice their own needs, and the emotional, physical and mental strain can be highly destructive.

But there is hope! There is help. There are tools and training, relief and respite. You just need to know where to look, whom to ask and what to do.

The definition of “care” needs to be rewritten. Life is about living. It’s not about being alive. How can we push the boundaries of possibility when it comes to engaging in and creating moments of joy for those in our care? How can we help turn the caregiving journey into a life enriching blessing for the caregiver rather than a stress filled, demoralizing experience it becomes for millions of people?

There are more than 50 million unpaid caregivers in the U.S. and 50% of them don’t even realize they are one! Caregiving isn’t only for elderly parents. ALL CARE COUNTS! A caregiver is a person who has responsibility for the care of another. Today, in the age of COVID-19, even more people are stepping up as caregivers. Just this year, 61% of the U.S. population said they were caring for a loved one in some way and 55% of those are new caregivers, only beginning this new journey since the global pandemic began.

## Caregiving by the Numbers

- ▶ 45% of caregivers are men
- ▶ 1 in 4 caregivers are millennials (born in the early 1980s to the mid-1990s)
- ▶ The value of unpaid caregiving equates to about \$470 billion per year
- ▶ Caregivers are twice as likely to develop a chronic illness and twice the rate of depression
- ▶ Caregivers average more than 20 hours per week of unpaid care for loved ones
- ▶ 84% of caregivers report a negative impact to their state of mind
- ▶ The average duration of a caregiver’s role is 4 years
- ▶ Only 30% of caregivers provide care for less than a year
- ▶ 24% of caregivers provide care for more than 5 years
- ▶ 15% of caregivers provide care for 10 or more years  
Higher-hour caregivers are twice as likely to have been in their caregiving role for 10 years or more

## MOST CAREGIVERS (85%) CARE FOR A RELATIVE OR OTHER LOVED ONE:

- ▶ 42% care for a parent (31% for a mother, 11% for a father)
- ▶ 15% care for a friend, neighbor or another non-relative
- ▶ 14 % care for a child
- ▶ 7% care for a parent-in-law
- ▶ 7% care for a grandparent or grandparent-in-law

## INDIVIDUAL ADULT CAREGIVERS IN THE U.S. IDENTIFY THEIR RACE/ETHNICITY AS THE FOLLOWING:

- ▶ White: 62%
- ▶ African-American: 13%
- ▶ Hispanic (non-White, non-African-American): 17%
- ▶ Asian-American: 6%

# Caregiving Tips: Keys to Remember

## ▶ **STAY INFORMED**

Do the things you know work. Wear a mask. Use the right kind of mask (3-ply, non-vented). Get a face shield if necessary.

## ▶ **TAKE CARE OF YOURSELF**

You need to be healthy before you can care for someone else. Diet, exercise, good sleep.

## ▶ **ASK FOR HELP**

Ask your doctor or neighbors or family and friends for help. Call a local or national helpline.

## ▶ **LAUGH**

Keep your mind healthy. What makes you happy? Concentrate on staying positive and not getting caught up in all the negativity.

## ▶ **CONNECT WITH OTHER CAREGIVERS**

Caregivers are everywhere. Take advantage of what other caregivers can offer you. They have tips that can help you and you have tips that might help them. If you're feeling helpless, remember there is no better feeling than connecting around a shared reality.

## ▶ **A NORMAL ROUTINE IS KEY**

If you don't keep some normalcy in your routine you'll find yourself at risk of losing it.

## ▶ **STAY ACTIVE**

Anything is better than nothing – even just pacing. Staying at home doesn't mean staying inside. Get out and get active!

## ▶ **CONNECT WITH FRIENDS**

Don't withdraw from your friends. It's important to stay socially connected.

## ▶ **FORGIVE YOURSELF FOR FEELING FRUSTRATED**

Caregiving can feel frustrating under the best of circumstances. Take a deep breath. Give yourself a break. Caregiving is never perfect. Everyone makes mistakes.



# Real People. Real Stories.

## Kim Campbell – Gentle On My Mind

Kim Campbell was married to legendary musician Glen Campbell for 34 years. When they met, she was just 22 and he was 44. Kim shared with Growing Bolder intimate details from their star-studded story including Glen’s early battle with alcohol and drug addiction and later, his diagnosis, decline and death from Alzheimer’s disease in 2017 at the age of 81. Kim says their roller coaster marriage survived thanks to a combination of faith in God, a sense of humor and a strong circle of family and friends.

Kim talked about confronting Glen when she first realized he had a drinking problem. “Initially, when I tried to discuss it with him, it made him really angry. He forbid me to talk about it with anyone. I suffered in silence.” She continued, “It was painfully obvious to everyone around us that he had a problem, but I wasn’t allowed to talk about it or reach out for help.” Deep down, Kim knew she could not do it alone. Of course, Glen was the only one who could beat the addiction, but Kim couldn’t sit back and suffer in silence by his side. She needed help. She needed resources. She needed advice and support and understanding. She needed to pull in others who knew what was really going on. Kim read books, researched, and learned how to be his partner, but not his enabler. Eventually he was ready to talk about it and after five years of setbacks and relapses, Glen finally got sober.

What Kim didn’t know then was the skills she obtained by helping Glen overcome alcoholism would later be her lifeline in navigating his Alzheimer’s. “I have always been the kind of person who educated myself,” she explained. “I read my books about alcoholism and then I did the same thing for Alzheimer’s. I read about the disease, the science and even caregiving. Education is so important.”

They decided to go public. They put his disease out front for all the world to see and come alongside. They opened the discussion and used his experience to inspire others. Kim and their three children cared for Glen at home for five years until it became impossible. Because people with Alzheimer’s can’t communicate verbally, they tend to lash out and become combative. Once Kim realized Glen had moved into this stage, she located a memory care community. “I didn’t even know these communities existed. I only knew about stereotypical nursing homes which terrified me.” Kim said she didn’t want Glen to be isolated or lack socialization, so this was a perfect option. Researching helped her find the support she and Glen both needed.

Kim made it her mission to improve the quality of life for not only people with dementia but also their caregivers. In 2016, she launched CareLiving, which she describes as “a lifestyle guide and social movement designed to support and advocate for caregivers, and to encourage them to care for themselves while caring for others.”

### 1. To which part of Kim’s story can you most relate?

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### 2. Kim says her faith in God, good friends, and a sense of humor helped her manage caring for Glen. What are the things you have in your life to cope with the pressures of caregiving?

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### 3. What lessons from your past can you apply today to caring for yourself?

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**KIM CAMPBELL’S CARELIVING**  
[careliving.org](http://careliving.org)

**FOLLOW CARELIVING ON FACEBOOK**  
[facebook.com/carelivingorg](https://facebook.com/carelivingorg)

Kim’s book *Gentle on My Mind: In Sickness and In Health with Glen Campbell* is available in stores and online now. The documentary *I’ll Be Me* (2014) is available on Amazon Prime Video.



### Dottie Gray

It was remarkable that 94-year-old Dottie Gray competed in the 50 and 100 meter dashes at the 2019 National Senior Games, but when discovering she broke her hip less than a year before, it seemed nearly impossible. Dottie's daughter Mary said it was questionable if her mom would even make it through the surgery. "We didn't know if she would be in a wheelchair for the rest of her life or if she'd use a walker forever." Mary and Dottie fought the group mindset that she was done exercising, or even walking. Doctors and physical therapists encouraged a surplus of safety around Dottie and didn't want her walking without help. Dottie was determined to ditch the walker. She overcame pain, fought through rehabilitation, and shattered people's expectations that no one over 90 could bounce back from hip surgery. When asked about her secret, Dottie explained, "I am determined to keep going as long as I can." From playing ping pong in the driveway to picking berries with her daughters, Dottie stays active and rarely just sits. "My mom has led a rich, exciting life," said Mary. "I want to see her continue to enjoy these years ahead."

To watch the entire video of Marc's interview with Dottie at the Senior Games go to [GrowingBolder.com/caregiving](https://growingbolder.com/caregiving).



### Ruth Hamilton

Ruth Hamilton lived an incredibly full life. Born in 1898, most of her 109 years were filled with teaching and learning, excitement and adventure. She was married to a Major League Baseball player and was one of the first women to host a radio show. As a teacher, she taught diction to Hollywood starlets and traveled the world giving lectures. In 1937 she came face to face with Adolf Hitler and tried to warn the world. Ruth was also the first woman elected to the New Hampshire State Legislature.

Like so many supercentenarians, Ruth outlived her spouse, children and friends and wound up in a nursing home, in a wheelchair, with little engagement with other residents. That's where her friends from Growing Bolder found her and began a conversation. Those conversations started one-sided but quickly turned into passionate discussions, with Ruth taking on the role of teacher. She shared her wisdom from a lifetime of learning. Soon Ruth was recording videos on the internet (with a little help from Growing Bolder) and, at the age of 108, became the world's oldest video blogger.

People around the world were able to hear about Ruth's experiences and be inspired by her example. She beamed with pride over the comments left on her videos. This new connection gave Ruth purpose. She felt useful and important. She went from nearly comatose to waiting for her video sessions camera-ready, in a dress and jewelry and a smile on her face.

Ruth died shortly before her 110th birthday but she maintained her quick wit and positive spirit until the end. She was a perfect example of what happens when people connect. Talking, sharing and interacting interrupted and disrupted her monotony. Her attitude and demeanor transformed.

Caregiving matters. It's important. And maybe it's just caring enough to give someone a chance to communicate. Who is your Ruth?

Watch Ruth's full story at [GrowingBolder.com/caregiving](https://growingbolder.com/caregiving).



### Banana George Blair

George Blair, best known as "Banana George," holds two spots in the Guinness Book of World Records: oldest barefoot water skier at the age of 87 and oldest snowboarder at 86. His nickname "Banana" came from his love of yellow. From his pants and shirts to his curtains and bedding, everything around George was yellow. He didn't just like yellow. He claimed to be "in love" with the color yellow. Even his car and drum set were, you guessed it, yellow.

Banana broke his back four times and nearly drowned twice, but that didn't stop him from doing what he loved. He lived his life with passion, never looking back. "I don't wait for the next thing," Banana explained. "I make the next thing happen." He skied on 7 continents in 69 different countries, continuing to ski barefoot into his 90s.

Banana George Blair passed away in 2013 at the age of 98. Growing Bolder was there for his final barefoot adventure when he was 93. Despite a long battle with pneumonia and constant pain from six back surgeries, he found a way to get up on his two feet on the water again. "I am proud of the fact that I made an impression on a lot of people about taking care of your body. That means exercise and good food every day." Banana was always quick to share his best advice, "You gotta take care of your body. Without your body, where are you?"

Visit [GrowingBolder.com/caregiving](https://growingbolder.com/caregiving) to see the video from Banana's final barefoot water skiing adventure





### Eugenia Zukerman

Eugenia Zukerman is by all accounts a brilliant woman. She is smart, she's creative, and she's caring. She's a world-class flutist. She was a long-time television correspondent on CBS Sunday Morning, and now she's come face to face with Alzheimer's disease.

With the time she has, she is doing everything to reach out to those who are dealing with things like dementia or even isolation and loneliness. She wrote a book called "Like Falling Through a Cloud," full of poems with heartfelt, eye-opening insights into what it's like to face a life-threatening challenge.

Eugenia doesn't look at her Alzheimer's disease with fear. There is no physical pain. While she'd like to live a longer life, she says the knowledge of her disease motivates her to be positive and find joy every day.

Visit [GrowingBolder.com/caregiving](https://growingbolder.com/caregiving) to hear more from Eugenia on what it's like to live with Alzheimer's disease.



### Amy O'Rourke

Amy Cameron O'Rourke M.P.H., CMC is a dedicated care manager with a passion for helping people and their loved ones find peace and joy as they age. O'Rourke is a licensed nursing home administrator and certified care manager with 40 years of experience helping families and individuals navigate the care giving journey. She is the friend we all need to help navigate the caregiving journey.

Watch Amy's caregiving tips at [GrowingBolder.com/caregiving](https://growingbolder.com/caregiving) and get her book, **The Fragile Years: Proven Strategies for the Care of Aging Loved Ones.**



### Teepa Snow

Teepa Snow's life mission is to shed a positive light on dementia. Snow is one of the world's leading educators on dementia and the care that's needed to cope with it. In this eye-opening conversation, she explains what caregivers and loved ones need to know about what is going on in the minds of those with dementia. Her insights can help you better communicate with and care for your loved one. Plus, she offers tips for taking care of yourself during this journey.

Snow is the founder of a company called **Positive Approach® to Care**, which offers training, services, and products to make the journey a little easier and understandable.

For more with Teepa Snow visit [GrowingBolder.com/caregiving](https://growingbolder.com/caregiving).



### Molly Middleton Meyer

Molly Middleton Meyer was called to the mission of innovative caregiving for very personal reasons. After both of her parents were diagnosed with Alzheimer's disease, she totally changed the trajectory of her professional life, dedicating herself to improving the quality of life for those in memory care.

Among other life-enhancing programs, she's created a unique poetry facilitation process that triggers memory and imagination. The program has a unique and, in many cases, an unprecedented ability to engage those with dementia – even many who were previously non-verbal. Her work has been featured in U.S. News and World Report, PBS, NPR, Huffington Post, and major daily newspapers across the country. Through her advocacy, she's destigmatizing memory loss and helping redefine elder care.

Step Inside one of Molly's facilitation sessions to watch a group of Alzheimer's and dementia patients come alive through poetry at [GrowingBolder.com/caregiving](https://growingbolder.com/caregiving).

# The Conversation Project

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Despite 10,000 people turning 65 every year, there is still a deafening silence when it comes to talking about end-of-life care. We are mortal beings. We decline. Ultimately, death is inevitable. The inability to talk about death can lead to confusion, frustration, pain, suffering and guilt.

Having a conversation about end-of-life matters is vital for loved ones. That is why The Conversation Project was born: to help all of us have the important conversations with those we care for and those who may need to help us in our final days. According to The Conversation Project, 92% of people say that talking with their loved ones about end-of-life care is important and yet only 37% have actually done it.

## TRY THESE DISCUSSION STARTERS FROM THE CONVERSATION PROJECT:

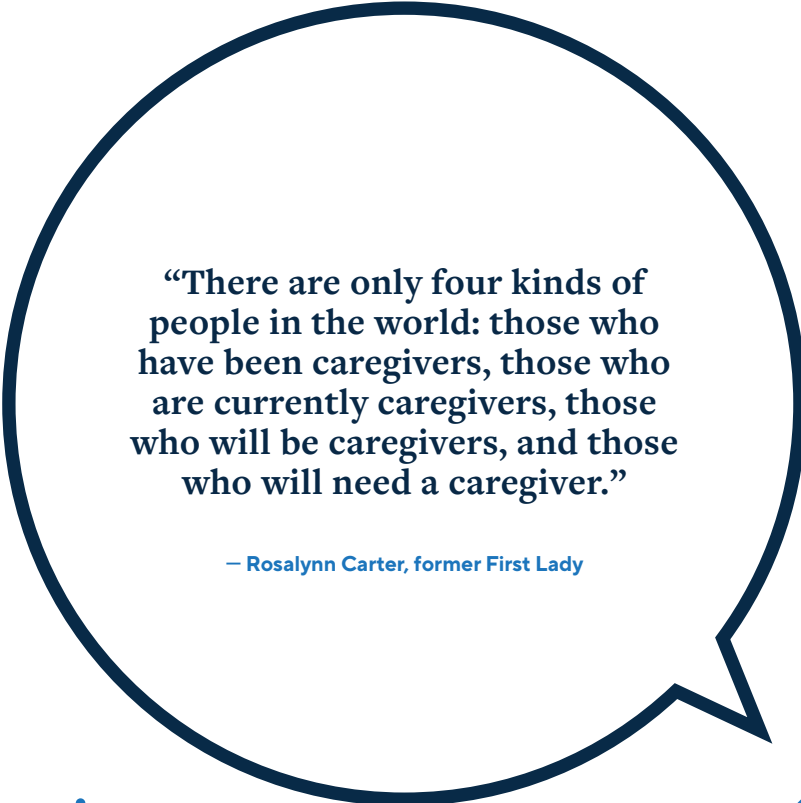
- ▶ When you think about the last phase of your life, what's most important to you? How would you like this phase to be?
- ▶ Do you have any particular concerns about your health? About the last phase of your life?
- ▶ What affairs do you need to get in order or talk to your loved ones about? (Personal finances, property, relationships).
- ▶ Who do you want (or not want) to be involved in your care? Who would you like to make decisions on your behalf if you're not able to? (This person is your health care proxy).
- ▶ Are there important milestones you'd like to be there for, if possible? (The birth of your grandchild, your 80th birthday).
- ▶ Where do you want (or not want) to receive care? (Home, nursing facility, hospital).
- ▶ Are there kinds of treatment you would want, or not want? (Resuscitation if your heart stops, breathing machine, feeding tube).
- ▶ When would it be okay to shift from a focus on curative care to a focus on comfort care alone?



You can download the entire  
Conversation Starter Kit here:  
[THECONVERSATIONPROJECT.ORG](https://THECONVERSATIONPROJECT.ORG)


# Quotes on Caregiving

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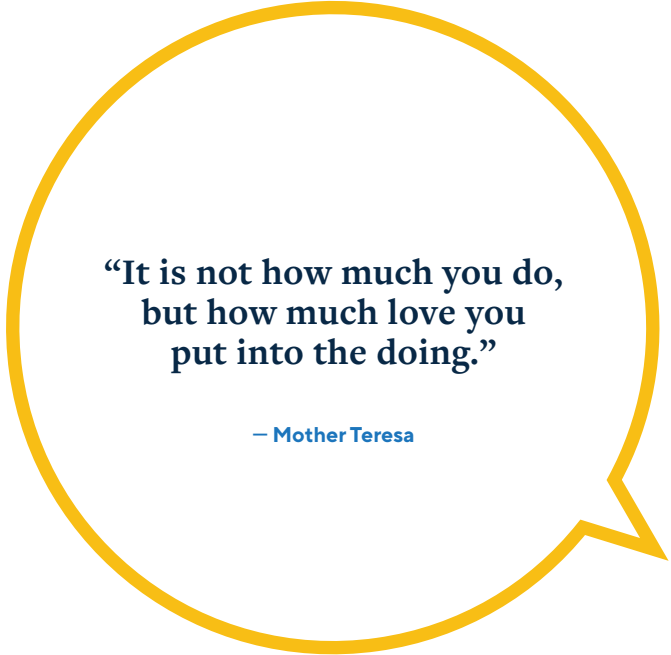
“There are only four kinds of people in the world: those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need a caregiver.”

— Rosalynn Carter, former First Lady



“Caregiving often calls us to lean into love we didn’t know possible.”

—Tia Walker



“It is not how much you do, but how much love you put into the doing.”

— Mother Teresa



# Taking Care of Yourself

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As a caregiver it is vital that you care for yourself. Too often caregivers think they are being selfish when they put themselves first. It's important to discern between selfishness and self-care. Sometimes caregivers forget to breathe and come up for air. They are so busy doing the caring that the basics of a healthy life get pushed by the wayside.

## WHICH OF THESE THINGS ARE YOU DOING OR NOT DOING? WHAT WILL YOU START DOING TODAY?

- ▶ Eating healthy
- ▶ Staying active
- ▶ Getting fresh air
- ▶ Exercising
- ▶ Taking time for yourself doing what YOU want to do
- ▶ Connecting with friends
- ▶ Receiving enough sleep
- ▶ Joining a caregivers support group
- ▶ Sharing responsibilities with family or friends
- ▶ Participating in a hobby or activity that makes you happy
- ▶ Talking to your doctor about your physical and mental health concerns
- ▶ Dealing with frustration and guilt

## SHARING CAREGIVING RESPONSIBILITIES

Caregivers cannot do it alone. It often requires teamwork. But how do you build the team? How do you get everyone on board to help with the care? Here are a couple of simple steps from the National Institute on Aging to get you started:

### TALK ABOUT IT

Set up a family meeting and include the care recipient if it makes sense to do so. It's best to do this at a calm time, not in the middle of an emergency. Try to define the responsibilities. Write down what kind of care is wanted and needed. Figure out what needs to happen now and might be needed in the future. This can help avoid confusion and resentment.

Decide who will be responsible for which tasks. Usually it's helpful to name a primary caregiver, even if it's not needed right away. This helps if there is a crisis and the primary person can step in. The most important part is to agree ahead of time which tasks are best suited to everyone's skills and interests. Figure out how each person involved can best use their abilities to become an effective team.

# Taking Care of Yourself

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## WHAT ARE YOUR STRENGTHS?

### WHAT ARE YOU GOOD AT AND HOW CAN THAT HELP WITH THE CAREGIVING RESPONSIBILITIES?

- ▶ Are you good at finding information, keeping people up-to-date on changing conditions, and offering cheer, whether on the phone or with a computer?
- ▶ Are you good at supervising and leading others?
- ▶ Are you comfortable speaking with medical staff and interpreting what they say to others?
- ▶ Is your strongest suit doing the numbers—paying bills, keeping track of bank statements, and reviewing insurance policies and reimbursement reports?
- ▶ Are you the one in the family who can fix anything, while no one else knows the difference between pliers and a wrench?

## WHAT ARE YOUR LIMITS?

### ONCE YOU DECIDE WHAT YOU'RE WILLING TO DO, YOU MUST THEN FIGURE OUT WHAT YOU AREN'T ABLE TO DO. WHAT TASKS WOULD BE BETTER SUITED TO SOMEONE ELSE ON THE CAREGIVING TEAM?

- ▶ How often, both mentally and financially, can you afford to travel?
- ▶ Are you emotionally prepared to take on what may feel like a reversal of roles between you and your parent — taking care of your parent instead of your parent taking care of you? Can you continue to respect your parent's independence?
- ▶ Can you be both calm and assertive when communicating from a distance?
- ▶ How will your decision to take on caregiving responsibilities affect your work and home life?

The National Institute on Aging recommends being realistic about how much you can do and what you are willing to do. Think about your schedule and how it might be adapted to give respite to a primary caregiver. For example, you might try to coordinate holiday and vacation times. Remember that over time, responsibilities may need to be revised to reflect changes in the situation, your care recipient's needs, and each family member's abilities and limitations.

Sometimes the caregiving team may live in the same area but sometimes the team (siblings, parents, friends) may live far away. Long-distance caregivers can have an important role, too, providing relief and support to the primary caregivers.

# Food for Thought

1. Who is on your caregiving team?

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2. What kind of care is needed and wanted?

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3. What needs to be done now?

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4. What might need to be done in the future?

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5. Who will be the primary caregiver?

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6. What are your strengths? What would you be willing to do in your role as caregiver?

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7. What are the strengths of others on the caregiving team? What are they willing to do?

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8. What are your limits?

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9. If you are a long-distance caregiver, how can you help provide relief and support to those nearby?

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# Art of Caregiving

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This companion guide was produced to support Growing Bolder’s Art of Caregiving initiative designed to smash the stereotypes associated with caregiving and celebrate one of life’s greatest blessings — growing older.

Art of Caregiving brings together national thought leaders, corporate decision makers, and ordinary people engaged in the one relationship that defines us all — caregiving.

“Caregiving is a celebration of life and we are pushing the boundaries of possibility when it comes to engaging and creating moments of joy for ourselves and those in our care, said Growing Bolder CEO, Marc Middleton.

**“Growing Bolder is working to fundamentally reframe how caregivers are seen, celebrated and supported. Yes, caregiving is challenging in every way imaginable but it’s also enormously meaningful, enriching, important, and often filled with moments of great joy and laughter.”**

**GROWING BOLDER CEO, MARC MIDDLETON**

# Resources

## GROWING BOLDER

### **GrowingBolder.com**

Growing Bolder: *Defy the Cult of Youth, Live with Passion and Purpose* Book by Marc Middleton

**GrowingBolder.com/bookstore**

Follow Growing Bolder on Facebook:

**facebook.com/GrowingBolder**

## GRANDPAD

Based in Minneapolis, GrandPad is a digital health company that develops engagement solutions to improve the health and well-being of older adults by reconnecting them to families, friends, and caregivers through technology that is safe, reliable, and easy to use. The GrandPad purpose-built tablet for people over the age of 75 — the first mobile device of its kind — addresses usability, security, and connectivity issues that are often roadblocks for integrating remote monitoring and telehealth into professional and familial caregiving settings. To learn more, visit **GrandPad.net** or connect with us on LinkedIn, Facebook, and Twitter @GrandPad\_social.

## AMY O'ROURKE

Amy Cameron O'Rourke (M.P.H., CMC) is a dedicated Care Manager with a passion for helping people and their loved ones find peace and joy as they age. A Licensed Nursing Home Administrator and Certified Care Manager, Amy has a Master's Degree in Public Health and Master's Certificate in Gerontology. With over 40 years experience as a patient care advocate, she has helped tens of thousands through the confusing maze of home care, assisted living, nursing homes, Medicaid, Medicare, hospital administrators, pharmacists, hospice, and the Veterans Administration. She is the friend we all need to help navigate the caregiving journey, and the author of the ground-breaking book, **The Fragile Years: Proven Strategies for the Care of Aging Loved Ones.**

## ALZHEIMER'S & DEMENTIA RESOURCE CENTER

For over 38 years, the Alzheimer's & Dementia Resource Center (ADRC) has served as a Central Florida based grassroots nonprofit and community resource center dedicated to providing support and hope for families and individuals caring for a loved one with some form of dementia. ADRC empowers caregivers with the knowledge, support and programs to help them prepare for and cope with the challenges that lie ahead. **Adrc.org**

## OTHER RESOURCES FOR CAREGIVERS

Family Caregiver Alliance, National Center on Caregiving  
**caregiver.org**

National Family Caregivers Association  
**nfcacares.org**

Alzheimer's Association  
**alz.org**

Follow AA on Facebook: [facebook.com/actionalz](https://facebook.com/actionalz)

U.S. Administration on Aging's Eldercare Locator  
**eldercare.acl.gov/Public/Index.aspx**  
1-800-677-1116

National Institute on Aging: Caregiving  
**nia.nih.gov/health/caregiving**

Follow NIHAging on Facebook: **facebook.com/NIHAging**

Caregiver Action Network  
1-202-454-3970  
[info@caregiveraction.org](mailto:info@caregiveraction.org)  
**caregiveraction.org**

Follow the Caregiver Action Network on Facebook:  
**facebook.com/CaregiverActionNetwork**

American Red Cross Information about COVID-19 for Family Caregivers  
**redcross.org/get-help/how-to-prepare-for-emergencies/types-of-emergencies/coronavirus-safety/family-caregivers.html**