

# *Final Care:* Boomers for Parents

As one parental care-giver puts it, “There were phone calls at all hours requiring one of two responses: ‘I’ll take care of it’ or ‘I’m on my way.’ It was the hardest thing I’ve ever done.” And, it cost her her marriage, as well.

STORY AND PHOTOS BY DAN SMITH

**THE DEFINING** characteristic of the baby boom generation might well be its size, but eldercare is rapidly becoming its biggest challenge, both for the generation’s parents and for its members.

It is yet another baby-boom ripple that has become a tsunami. As the largest generation in American history nears 70, brags on grandkids, cashes in on Medicare and Social Security, downsizes and discovers new hobbies, a new reality is settling in. Millions of boomers are caught in the eldercare vice, taking care of aging and infirm parents who have, for one reason

or another, lost self-sufficiency; and/or on the other end, being the recipient of that care.

Many relish the role of caregiver, others see it only as a responsibility of “family.” Some resent it. Siblings often quarrel and sue over the estate. One sibling will often be put in the position of doing the bulk of the work.

Raw statistics (mostly from AARP\*) tell the story of a defining moment of a generation:

- Twenty-nine percent of the adult population takes care of someone who is old, ill or disabled. That’s 65.7 million



**Above:** Sandra McCown: "Old hurts melt away, and the clarity of needing to make it right comes through. Mom and I made it right. We are at peace."

**Below:** Kathleen Boggs (with daughters Brucie and Sara): "... So many precious memories of a woman who loved poetry and ... to sing."



caretakers.

- Of those cared for, 43.5 million are older than 50 and 14.9 million have Alzheimer's Disease.

- The value of the care is \$450 billion a year, up a third in the five years before the study was completed in 2012.

- Most of the care-givers (66 percent) are women and their average age is 48. The number of men in the role of care-giver is increasing.

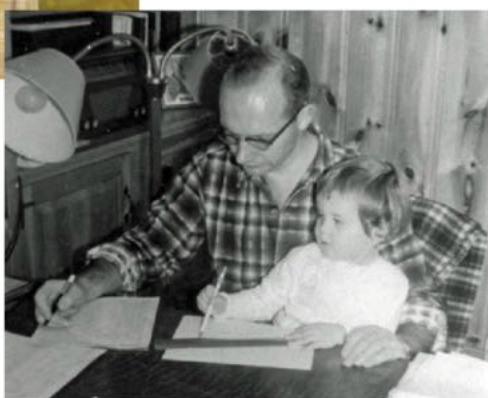
- Women do the hard work (toilet, bath, dressing), while men often concern themselves with the finances and the like. Women put 22 hours a week into care on average and men 17.4.

"Goals of care mean different things to different



**Above:** Janeson Keeley: "I had to deal with attorneys, bankers, contractors, real estate agents, and estate appraisers."

**Left and below:** Baby Janeson Keeley with her father, Dr. Allen Duvall, and with Janeson Keeley's mother, Joann.



people," says Dr. Brian Unwin, section chief in geriatric and palliative care services at Carilion Clinic. "Some patients want to live to see a grandson graduate; others want [to employ] every technological advance until they are brain dead."

It is, says Unwin, the quandary of late life: "We don't do dying well, expecting cure instead of care." And it is a family expectation, sometimes—often—divided among relatives, depending on their closeness, goals and philosophies.

It is not always about the division of money upon death, though it often is. Recent examinations by the National Institute of Aging and the University

**SANDRA MCCOWN'S TIPS  
FOR PARENT CARE**

Following are tips for caring for an Alzheimer's patient from Sandra McCown, who took care of her father during his bout with the disorder. They are based upon her experience. She is a registered nurse.

- A baby monitor is good for keeping track of someone with dementia. I slept with the monitor the whole time.
- Do not move furniture or change the decor of the home. Change is not good for dementia.
- You are who they say you are and it's better not to argue.
- When your relative gets to the point when they are not safe to drive, take the distributor wires off the engine because they will not remember. It is easier to say the car is broken than to go through the whole explanation of why they cannot drive any more.
- There are Alzheimer's support groups. Join one and talk to people. Do not isolate yourself.
- Take care of yourself. Whether your parents are in a facility or at home. This sometimes takes you to scary places. You must care for yourself because you are all that they have. —DS



**Both photos:** Ray Cox and Leila Albrecht. *"We went through hardship, but I treasure those days. I spent more time with her in the last five years than in the 20 years leading up to it."*

**ONLINE**

Visit [TheRoanoker.com/Silent](http://TheRoanoker.com/Silent) to read the gripping saga of a person who spent more than a decade caring for aged parents, only to have that process end all contact with siblings.

of Michigan's Health and Retirement Study show that Americans who die between 65 and 74 have a median net worth of \$205,000, 80 percent of that in their homes.

"When people die with estates, there is often a knife fight," says Unwin. But not many die with estates. Medical debt eats up a lot of the net worth: People spend \$38,000 out of pocket on

health care in the last five years and a fourth of us spend all of our money during that period. "It's more if you're single," says Unwin, "and the government doesn't pay for dementia."

"It's never easy," says Kathy Wolford, a social worker and practice manager at Carilion's Center for Healthy Aging and Infectious Disease Clinic.



*Belinda Ayers: "Regardless of our relationship, I would have been there to help."*

If there is no specific health directive, says Unwin, "in the middle of all that stuff, the family is asked to make decisions. The clinician tries to sort it out and advise on where to go with [treat-



*Concetta Yuhasz and her sister Denise Altice: "Family is what we know how to be."*

ment and decisions]. Often the treatment [alternatives are] very sensitive."

Family members are frequently left with "the say," says Wolford. An advance directive and some intelligent planning can help, but those don't necessarily deal directly with family dynamics which, says Wolford, "are sometimes driven by guilt; sometimes making sure I get my part" of the estate. Ultimately,



*Kathy Wolford and Dr. Brian Unwin of Carilion: "When money is involved, invariably the most bitter and awful [disputes arise]."*

she says, "it is rooted in patient autonomy.

"It is not so much nerve-wracking as heart-wrenching," says Wolford.

"When money is involved, invariably the most bitter and awful [disputes arise]. But that is in the minority," Unwin says. "Every family is different, but in America we tend to plan for life—the good times—and not for the bad times. We prepare pre-natal by painting rooms, buying clothing; we plan for vacations. Do Americans plan

to retire, plan for bad times, how life will end? No."

### Legal problems

"Equitable is not always equal," says Mark Dellinger of the Roanoke law firm of Rhodes, Butler & Dellinger, which specializes in family law. "People attach love to inheritance but sometimes one child makes a much greater contribution to the life of the parent

#### AVOIDING PROBLEMS

Mark Dellinger, a Roanoke attorney with the Rhodes, Butler & Dellinger law firm who specializes in elder law, lists five suggestions on avoiding serious end-of-life conflict for caregivers and their families. Here is his list.

1. Visit your parent regularly.
2. Occasionally meet with your siblings without your spouses present.
3. Hire professionals and have all interested persons be involved, subject to the confidentiality wishes of parent.
4. If a sibling offers to show you a history of transactions or to make something transparent, take him up on it.
5. Do not assume the worst motive of your sibling upon learning of some change in circumstances. —DS



Lawyer Mark Dellinger:  
"Equitable is not always equal."

a parent is going to leave less in a will or trust to one child than another, I advise clients to write a letter to the child who is receiving less explaining why ... and reiterating that it has nothing to do with love."

The will is crucial. "There is a growing consumerism attached to wills and powers of attorney," says Dellinger. "Non-lawyers want to make a profit and so they offer 'products' at a cheaper rate than

in the years close to the time of the parent's death.

"The parent may love the child who lives in Kansas City and sees the parent one time a year the same as the child who lives down the street. However, the time and attention the child living in town provides dwarfs that provided by the out-of-town child. Should the child in town inherit more? ... If

#### *'I LEARNED THAT LOVE HAS NO BOUNDARIES'*

Concetta Yuhasz watched her mother die slowly, but in the end there was sweet closure for her, her mom and the rest of the family.

"It profoundly affected all of us," she says. "We were going to lose our mom, my momma, gam-gam, our gammie, and we felt absolutely helpless to save her. The chemo wasn't going to work. After two treatments her legs swelled so badly, they were oozing fluid.

"It was then my mom decided to finish out what time she may or may not have had her way, with dignity, the way she wanted to. That's my mom. My girls and my sister's two girls were all greatly affected.

"When my mom was having a better day, not all that [often], all our kids would visit her. It helped make my mom's day. She got to hold her great granddaughter, Carmella, who was just a few weeks old at the time. Absolutely priceless.

"My sister and I talked about what we needed to do for our mom. We honored her decisions in limiting her

what the lawyer's price may be." Most often, says Dellinger, you get what you pay for.

Indecision and suspicion are important stressors, Dellinger says. A well-advised parent is prepared to tell her children what she would like to see happen prior to the events that cause the stress, he says.

"I think the families most likely to have legal difficulties are those that do not take the time to think

through the 'what ifs,'" Dellinger stresses. "... It is not fun to sit around considering your death or incapacity. However, it is a gift to those serving under a power of attorney or handling an estate."

Herewith are some stories from the Roanoke Valley of those who have cared for parents in their final years. As you might imagine, the diversity is wide ranging.

### Forgiveness

Janeson Keeley, a 55-year-old website developer with her own home-based business (JTKWeb), took care of both her mother and father, who were divorced, during prolonged illnesses. The illnesses ultimately led to their deaths. Her father, noted Roanoke veterinarian C. Allen Duvall, Jr., died in 2005, and her mother, Joann Shoaf Duvall, died in 2009.

The stress was often intense, says

visitors. My mom, as much as she loved all her friends and co-workers, did not want them to see her like this. She had lost weight, her head was shaved in preparation for the chemo she decided to end after a couple treatments. It was very hard on my mom to turn her close friends away, especially knowing how much they loved her and wanted to be there for her. They loved my mom so much.

"We had staff members at Springtree help my mom, great nurses, my sister Denise of course, and myself. My mom's sister, Aunt Adele, who had just lost her husband a couple months before, traveled to Virginia, along with my son, Adam, and his fiancé, Kelly. They stayed a whole week to visit my mom and help look after her. My Aunt Adele, has been suffering from lupus for many years, traveled a long way to be with her sister."

"I learned that love has no boundaries when it comes to taking care of your mom. Yes, it was worth every second to be there ... and ... yes, I'd do it again. I'd sit by my momma's side, hold her hand again, whisper to her I love her, and be there as this beautiful woman ascended to heaven."

—DS

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Keeley: “There were phone calls at all hours requiring one of two responses: ‘I’ll take care of it,’ or ‘I’m on my way.’ There were multiple, usually late-night, trips to the emergency room. I had to coordinate the care given by doctors, caregivers, nursing homes, and hospice. I had to deal with attorneys, bankers, contractors, real estate agents and estate appraisers.

“I planned and prepaid for their funerals, and I had to keep my half-siblings and their mother updated on what was going on. My husband wanted my attention, and I was too tired, wired and stressed to give it to him. People kept telling me to ‘have fun’ when I barely had time to brush my teeth. Caring for my parents, who were difficult to deal with under the best of circumstances, was the hardest thing I’ve ever done.”

All areas of Keeley’s life were affected, she says, but “I just kept going. I knew they wouldn’t be around forever.”

She sacrificed “free time, peace of mind, and the ability to plan anything. ... Eventually it cost me my marriage. I couldn’t deal with the issues that came up between me and my husband as they occurred, and by the time my parents died and their estates were settled, so many issues had accumulated between us that we couldn’t overcome them.”

She was grateful for the help she got from her husband and her brother. “My husband did whatever he could to help. My brother never second-guessed or criticized my decisions. Unlike many siblings in such situations, we worked together well and got closer through the pro-

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cess. My mother's sister was supportive, but her brother and his wife stayed as far away from the situation as they could get. That was painful.

"My childhood was difficult, and my adult relationships with my parents were strained," she says.

"I cared for my parents because I knew if I didn't, I wouldn't be able to live with myself once they were gone. ... If I had chosen not to take care of them out of anger or vengeance, I'd have been no better than they had been to me."

Would she do it again? "I don't know."

Ultimately, there is this: "The family I have left—however little of it there is—is more important than ever now."

*A sweet closing*

Brucie Boggs, a 63-year-old hu-

man resources executive and her sister, Sara Boggs Bemiller, a 68-year-old writer and retired public relations professional, took care of their widowed mother, Kathleen Boggs, for nearly 15 years. It was the kind of loving, fulfilling end-of-life closure many people dream of.

"This began as our mother reached her 80s and required assistance with activities of daily living but wanted to stay in her own apartment," says Boggs. "Between the two of us, we checked on her and provided some level of care weekly to daily, depending on her health status." She was often hospitalized and finally moved into an elder-care facility. She died in September of 2015.

Their mother had aging afflictions, but says Boggs, "she was mobile, mentally sharp, had a ter-

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rific sense of humor and was socially engaged until the last few months of her life ...”

“It was important that she be able to count on us and that it was purely and simply the right thing to do,” says Boggs. “We wanted to be attentive; we never wanted her to feel abandoned or alone. When someone lives to be 100, she inevitably experiences so much loss, and my mother had lost her husband, siblings and friends.”

Says Sara Bemiller: “It was a natural reaction to seeing our mother age and seeing that she needed us during those later years of her life. There’s something almost magical about the bond my mother formed with my sister and with me, and we were such a part of her that caring for her was second nature.”

“I honestly believe we gave up very little—at least, very little of anything that truly matters. Yes, her care required emotional and physical energy and considerable time. ... I didn’t give up much at all, especially compared to what I gained. I gained one of the most cherished and inspiring relationships of my life, and a relationship with my mother that was different than the mother-child relationship of decades earlier.”

Bemiller “gained so many precious moments and memories of a woman who loved poetry and Bloody Marys, who couldn’t carry a tune in a bucket yet loved to sing, and who delighted in reminiscing about her own dear mother and growing up in the deep South.”

The stress of care was what most experience, says Boggs, but

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“watching someone so strong and vibrant become so reliant on others is a difficult emotional ordeal. ... Family and friends were the greatest coping resources. The love, understanding, time and support that my sister and our spouses provided were indescribably important.”

Sara Bemiller echoes that: There was a “frustration at seeing such a force of nature start to grow discouraged by increasingly serious illnesses and setbacks.”

There is much to learn from the experience, says Boggs. “I learned that even the healthiest person with the healthiest lifestyle will have challenges as he or she ages; I mention this because it’s important to avoid being judgmental or assuming that we’re entirely in control of our health. ... I learned that there will come a

time when doctors, nurses and therapists will not be able to tell you what’s wrong with your parent, nor will they be able to tell you what you or they can do to fix it. ... I learned that, trite as it may sound, one’s frame of mind ... can truly be the greatest asset in coping with the unpredictable, unavoidable and cruelest aspects of illness and aging.

“I do believe,” says Boggs, “that the commitment my sister and I made to spend such considerable time with my mother and to be with her so extensively before she died brought us closer together. It’s hard to explain, but as we cared for my mother, we also took great care of each other, I think.”

Says Bemiller: “My sister [and our husbands] collaborated on so many decisions when it came to my mother. We each brought

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our own resources, strengths and perspectives to bear when deciding what was best for her. ... I learned that the best support team is one that has a full understanding and appreciation of the kind of commitment a son or daughter makes to an aging parent. ... We never simply assumed [family support] would be the case. Conversations need to take place and assumptions should never be made. I would do it all again just to be with my funny, sweet, pretty mother one more time.”

### **Bitterness lingers**

“Because she was my mother, I gave up my life to help extend hers,” says Belinda Ayers, a 42-year-old disabled Roanoker who cared for her ailing mother for seven years until her death in 2010.

Ayers’ mom, Janet Ayers, had conditions that required oxygen,

and that posed a problem. Ayers “made sure she didn’t light a cigarette while wearing her oxygen, which she had done a half a dozen times, even though the hospice nurse was outside” her room. Ayers laughs at the thought.

Stress was constant. “I was already an anxiety and panic-disorder sufferer,” says Ayers. “I had my medication dose increased to help me. My life was at a complete halt. I used my intuition, along with her doctor’s assistance, in making decisions. My sibling, a registered nurse, attempted to hinder me in every way.” She says siblings “can be your worst enemy” in end-of-life situations.

Ayers’ relationship with her mother had not been perfect, but she visited daily before her mom became ill and “even lived in her house in an upstairs apartment.

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She was my mother, so regardless of our prior relationship I would have been there to help.”

It is the relationship with her sister, says Ayers, that has suffered most. “I do not have any relationship with [her] any more. My mother’s death made me realize that it’s best to not have family as part of my care, simply to prevent any problems between them. People go through what I’m going through all the time and they shouldn’t have to.

“My routine has yet to return to normal because of her death and legal issues I’m now having to deal with ...”

### It’s about family

There was never any question about commitment for Concetta Yuhasz and her family. “My mom [Sally Persinger] came from a big family,” she says. “Family is what

we knew how to be. Mom, stubborn as she was, knew what it meant to be family. She was there for her brothers—Neil and Walter—just before they died of cancer. She taught us that no matter what, you must be there for your family. It’s what holds us together, even when we’re miles apart.”

Yuhasz is a 50-year-old yarn-machine operator, divorced with five kids. There are eight extended family members living in her home. Her sisters, Denise Altice, who lives in Vinton, and Anita Fendrock Janiki, who lives in Maryland, were strong supporters during their mother’s cancer. She died in 2013.

The cancer changed Yuhasz’s mother. She was “almost childlike, sometimes incomprehensible, and always, always, in so much pain.” Yuhasz took family medical leave

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and helped Denise and a friend of their mother's with the care.

Sally Persinger ultimately opted for an elder care facility because "she loved us [and] she didn't want us to watch her suffer." Persinger died, "surrounded by my sister, her friend Becky [Rebecca Nimmo] and myself, holding her hands, crying, but also letting her know that it was OK to go."

It was especially difficult watching "mother rapidly age at least a good 20 years before her passing," says Yuhasz. "She had gotten to the point where she sometimes became confused, like forgetting things. She had great difficulty going to the bathroom and bathing on her own." Much of her normal functioning was lost.

There was considerable stress, mostly revolving around the fact that they knew their moth-

er would die soon, says Yuhasz. "I'm not gonna say money, or lack of it, was a stress in itself because you can't put a price on the value of your mom."

Watching her mother suffer was difficult. "I would get behind my mom, let her rest against me, rub her head and her back, in attempts to eliminate as much pain that she had to endure. It tore me up inside, but I didn't let her see that."

She and Denise "talked about everything. What mom wanted, what we thought would be good for her to ease her daily struggles."

The future? "I know I need to make plans for myself as I get older, but I haven't yet. I'm going to make sure that my wishes are respected, just as my mom's wishes were honored and respected."

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### Discovering a new Mom

Between 1988 and 1999, Sandra McCown, who is now 66, nursed her mother and father before their deaths. Her dad had Alzheimer's and her mother bowel cancer, among other debilitating conditions. Sandra moved into her parents' home—with her two sons—to care for her mother, who died after six months, and stayed because of her father's condition.

“Soon after mom died, I sent dad for neurological testing and my greatest fears for him were true,” she says.

The result was that she met a mother she hadn't known (one no longer dependent upon alcohol) and “I cared for dad because he was an amazing and wonderful person and deserved the best that life could offer. ... It was a long haul for sure. During the time I

cared for dad, my sons grew into young adults. Being part of the sandwich generation was a true reality for me.”

While taking care of her father, McCown returned to school at Radford University to get her bachelor's degree and wanted to continue toward a master's and PhD, but time and “that kind of freedom had run out” for her. A nursing assistant helped and the boys did what they could.

“I came back after being ... estranged from mom when she got sick,” says Sandra McCown. “Dad called me and told me what was happening with her. I was an oncology nurse and knew what mom and dad were in for, and my thoughts were that they should not have to walk that path alone. There had been only myself and my brother, and now he

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was gone. Mom and Dad had no one else.”

Being there allowed her to get to know a sober mother: “I had never known her like this before. She was a truly beautiful soul. ... I will always be grateful for the opportunity of getting to know her. It was a healing for both of us. ... The last thing she heard from me was that I loved her.” McCown’s mother died in her arms.

The young sons benefitted, as well, getting close to their grandparents in their final years. McCown and her kids lived with her parents, easing the financial strain. They ultimately put her father in a hospice and the fact that she was a nurse “made it easier for both dad and me.

“My experience of caring for mom at the end of her life made

me see in a profound way to not ever leave relationships hanging,” says McCown. “Mom and I ... got mad at each other and we could not make any progress toward resolution. When people know that they are at the end of their life they get a new clarity and perspective. ... Old hurts melt away and the clarity of needing to make it right comes through. Mom and I made it right. We are at peace.”

### *An appropriate closing*

Ray Cox’s relationship with his mother had always been close, loving, nurturing and, well, something of a model. Their relationship in her death followed true to form.

Cox, who is 58 and married with two grown children, is a teacher and a freelance sportswriter, whose mother, Leila Albrecht,

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was a veteran journalist. She died in 2004 at 81 of “a number of debilitating illnesses,” set off by a serious heart attack, he says.

She was “a tough” woman, says Cox, one “able to do a lot for herself,” even under difficult circumstances. “She didn’t complain, even though she was in constant pain.” She was “remarkably independent and didn’t want to ask for help.”

Albrecht finally developed a form of dementia and “needed help ... for the most part, we kept her at home,” which was a major goal. Cox says his family—Sarah and the children—helped as they could, and Albrecht’s friends “were wonderful,” but the care of his mother was primarily up to him.

Cox says that even though the care was often time-consuming, “my job with the newspaper (*The Roanoke Times*) allowed my schedule to be my own. I came and went as I pleased.” Still, the stress was

obvious. “I was constantly worried she might fall,” says Cox. “The heart attack set off a chain reaction of bad health.” At one point, Albrecht spent several months in a nursing home, says Cox.

Cox was his mother’s only child and she was also an only child. “Mom and I were very close,” he says. That made caring for her “that much easier. I’d do it again in a heartbeat. We went through hardship, but I treasure those days. I spent more time with her in the last five years than in the 20 years leading up to it.”

Still, he says, “I can understand” how families are torn apart by late-in-life care. “There is stress on the marriage” because of the time commitment, but his strong marriage did not suffer, he says.

(\*A wide range of home care statistics from AARP, among others, is available at <https://caregiver.org/selected-caregiver-statistics>) ☆