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Signs Your
Loved One
Needs Care

**The One Thing
Alzheimer's
Can't Steal**

**MONEY
MATTERS**

**10 TIPS TO KEEP
TABS ON YOUR
PARENTS' FINANCES**

*Miraculous
Mediterranean
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THE SCIENCE-BACKED
HEALTH BENEFITS,
plus A RECIPE FOR
A SAVORY SOUP THAT
WILL WARM YOUR SOUL

Summitt-ing Alzheimer's

PAT AND TYLER SUMMITT'S
CHAMPIONSHIP MINDSET
FUELS THEIR FIGHT AGAINST
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Who are the Caregivers?



“Caregiver” is a term thrown around by many, yet understood by few. It is used to describe a variety of groups—from

new mothers to those caring for an aging loved one. Indeed, caregivers come in so many forms, the only truly accurate way to categorize them is as fellow human beings. They are men and women who happen to be looking after the wellbeing of a loved one—or multiple loved ones—and must also be acknowledged for who they are outside of their caregiving role.

“I believe that we are more than just the sum of what we do. Otherwise, we are set up for a major identity crisis. For some people, their situation becomes their entire identity,” says Diane on the AgingCare.com Caregiver Support Forum.

As you’ll read in our featured story, much of Pat Summitt’s enviable identity lay in her legacy as the all-time winningest coach in NCAA basketball history. For nearly four decades, she steered the storied University of Tennessee Lady Volunteers basketball team to a whopping 1,098 victories. But in 2011, at the height of her career, Pat and her son, Tyler, were confronted by an opponent unlike any they’d encountered on court: early-onset Alzheimer’s disease.

The mother-son duo’s journey from inspirational sports anecdote to fierce fighters for Alzheimer’s awareness is featured in this

issue, alongside several other tales of everyday caregivers and patients who refuse to be defined by their circumstances. These vibrant individuals look beyond their challenges and see the opportunity for growth and love, even when facing the specters of aging.

I invite you to explore the many faces behind the word “caregiver,” and discover why some terms truly do defy definition.

Keep caring and sharing,

Anne-Marie Botek
Editor In Chief, AgingCare.com

INSIDE OUR FALL ISSUE 2014



COVER IMAGE: University of Tennessee Athletic Department

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20 Signs Your Loved One Needs Help at Home

BY ANNE-MARIE BOTEK

Family caregivers begin their journey in one of two ways: the sudden sprint or the gradual march. The sudden sprint towards caring for a loved one is often set off by an unexpected event—a fall, a stroke, complications from surgery—which acts as a catalyst, escalating your family member's care needs practically overnight. The gradual march towards caregiving is less dramatic. You can't say exactly when it began, but you've started noticing little changes in how your family member interacts with the world around them. Perhaps they get lost while driving to the grocery store, or they can't seem to keep track of their medications. Maybe balancing their checkbook has become too difficult, even though they've been doing it for decades.

Whether the change is sudden or gradual, there are certain signs you can look for that signal an older adult may need extra help:

PHYSICAL

- *Fluctuating weight*
- *Balance problems*
- *Poor hygiene*
- *Sleeping too much or too little*
- *Unexplained bruises or burns*

COGNITIVE

- *Confusion*
- *Memory loss*
- *Repetition*
- *Hallucinations*

EMOTIONAL

- *Mood swings*
- *Abusive behavior and outbursts*
- *Lack of motivation*
- *Anti-social behavior*

ENVIRONMENTAL

- *Unusual odors (urine, garbage)*
- *Unfilled or untaken prescriptions*
- *Not enough food in the house*
- *Unkempt yard*
- *Unusual carpet stains*
- *Dents or scratches on the car*
- *Unpaid bills*



Caregiver to Caregiver

AgingCare.com/Caregiver-Forum

WHEN TO INTERVENE

Determining when (and how much) to help a loved one can be a complex decision. Caregivers offer their insights on this tricky situation on AgingCare.com:

“Just know that there will never be an easy time for this; it is arguably the most difficult decision family members have to make. However, it often has a positive impact on everyone's lives.”

“I am very blessed that my dad and I had this conversation early on. He realized on his own that he could not handle the house any longer.”

“For the longest time I think mom needed and wanted help, but wouldn't ask. Now that she is receiving care, she feels much better.”

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The One Thing Alzheimer's Can't Steal

BY MICHELE DESOCIO

Many times I hear the question: "Are our loved ones there? Do they know what is going on?"



My mom was 58 years old when she was diagnosed with bi-polar disease and moved in with my family and I. Five years later, after spending 19 days in a psych ward following a mental breakdown, mom was formally diagnosed with dementia. To this day, the doctors aren't sure what's causing her cognitive issues—whether it is FTD (frontotemporal dementia), Pick's disease or Alzheimer's. It doesn't matter; they just don't know.

Mom chose nursing home placement after her rehab stay. It broke my heart. Looking back on it, I didn't understand how sick mom was. But she knew it, and she did the right thing.

We've had many good years together, since she was placed. Her disease progression was slow, yet consistent. She is now in the advanced stages of the disease; confined to a wheelchair, has difficulty swallowing, etc.

Mom mostly stares and sleeps, but she can put some words together and knows who I am. I visit often, and she lights up when she sees me. Sometimes she gets confused, but I just look her in the eye and tell her my name. Her response is, "I'm so happy, I love you, and you are beautiful." She can, to my amazement, still recite the Lord's Prayer and remembers many songs from way back when.

One day, when I went in to visit mom, there was a live banjo show. She was sleeping, so

Caregiver to Caregiver

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Sometimes our loved ones can surprise us with statements that warm our hearts. Caregivers share their touching anecdotes on AgingCare.com:

“Dad and I walk around the mall every day. He always tells me, ‘If you keep doing this, you’re never going to get rid of me!’ My standard reply is, ‘Thanks for the warning.’”

“I took Mom to a restaurant during happy hour. When we walked in, she looked a bit startled and said, ‘Is this a bar?’ When I told her it was, she asked ‘Is it alright for a lady to go in, uncortected?’ The bartender overheard and said dryly, ‘It happens from time to time, ma’am.’”

I gently woke her and brought her to a quiet family room they have in her facility. She likes it when we sit together, either in the quiet room or in the garden. I had brought her favorite cookies—Fig Newtons—and a Coke. I wasn’t feeling too well, but I played her favorite tunes and we sang together.

Out of nowhere, mom said, “I am worried about you.” I hugged her and reassured her I was okay. Mom has not been able to ask me questions for a long time now. I did not tell her I was not feeling well.

This is not the first time she has surprised me by saying something that mothers often say to their children, out of the blue. It’s something I needed to hear. I had my mom back that day; just for a moment.

“Love is not a memory; it’s a feeling in the heart and soul.”

I held back the tears until I got in the car. I miss my mom, but I know that she is there and that she knows what’s going on. I believe this is love.

Love is not a memory; it’s a feeling in the heart and soul, never to be forgotten. This disease can take away almost everything, but not the love.

Always a mom. I love you mom.



About the author: Michele takes care of her mother, Jean, who was diagnosed with dementia 15 years ago. Since then, Michele has made it her mission to advocate and raise awareness for dementia caregivers and their loved ones.

Follow her at: AgingCare.com/Blogger/Michele-DeSocio

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Pat and Tyler Summitt

TEAM UP

TO BLOCK OUT ALZHEIMER'S

Winningest coach and former Olympian faces her toughest opponent yet: early-onset Alzheimer's

BY ANNE-MARIE BOTEK

She's baled hay and driven tractors as a Tennessee farm girl. She's played six games in two days, sleeping on gym floors and subsisting on a diet of bologna-and-cheese sandwiches, as a member the women's varsity basketball team at the University of Tennessee-Martin. She's represented the United States in the Olympic Games on two separate occasions—once as a player and once as a coach. And, over the course of a 38-year-career as head coach of the University of Tennessee Lady Vols basketball team, Patricia Sue (aka "Pat") Summitt has won 1,098 games, 32 Southeastern Conference titles and eight NCAA Championships, earning her the title of winningest coach in the history of sport, bar none.

Despite the struggles and triumphs of her past, Pat is the first to admit that her current situation is "by far, the biggest challenge I've ever faced. There is no comparison." She is one of the estimated 250,000 Americans living with early-onset dementia, Alz-

heimer's type. Thought to be strongly influenced by genetics, this disease can strike people as young as 30.

Pat was 59 when she was diagnosed, in the spring of 2011. "There was a rush of emotions...and then denial," she says. "I realized I had to face and fight the toughest opponent I had ever faced."

Fighting this formidable foe alongside Pat is her son, Tyler. As a child, he helped her cut down basketball nets after the Lady Vols' victories; now he is, in many ways, her "rock."

"Since my mother's diagnosis, our relationship has only grown closer," Tyler says. "My mom has had a profound impact on the person that I have become."

It was Pat who encouraged her son to pursue his own dream of becoming a collegiate basketball coach, a goal he achieved this past spring, when he was appointed head coach of Louisiana Tech University's Lady Techster basketball team. Today, Pat's undaunted attitude towards her Alzheimer's diagnosis further inspires her son. "My mom continues to men-



tor me, more than she realizes."

Honesty, diligence and teamwork—the trio of traits that created Pat's inimitable athletic legacy—have also guided her approach to Alzheimer's.

As is often the case, Pat's symptoms progressed slowly. Tyler remembers growing up with a mom who could easily juggle 10 tasks simultaneously. But, when Pat could no longer manage three or four things at once, she knew she needed answers.

Mother and son made the trek to the world-renowned Mayo Clinic in Rochester, Minnesota, where they received the life-altering diagnosis. The action-oriented duo quickly recovered from their shock and moved forward, coming up with a plan for how to tell, not just friends and family, but the entire sports world the shocking news.

"I have always encouraged my son and my players to be open and honest, so, while it was difficult, it was



Clockwise from left: Pat and her championship trophies; Pat and Tyler cut down the net after a win; Mother and son celebrate Pat's Sportswoman of the Year Award.



the right thing to do," Pat says about the decision to go public with her diagnosis, mere months after receiving it. Tyler remained unfazed by his mother's candor; she's always been an authentic, open individual.

Pat continued to serve as head coach of the Lady Vols for one more season, before handing over the reins to her long-time assistant, Holly Warlick. Stepping down from the post she'd held for nearly four decades was a devastating move. However, in her current role as head coach emeritus, Pat continues to mentor the Lady Vol players.

Family, fellow coaches and fans responded to Pat's revelation with an overwhelming wave of support. Standing ovations of people in shirts bearing the slogan "We Back Pat" are common sights whenever the storied coach takes to the court.

Pat's frankness in confronting her diagnosis has led to a flood of much-needed funds and attention for the Alzheimer's cause.

In 2011, she and Tyler founded the Pat Summitt Foundation, a non-profit dedicated to winning the fight against Alzheimer's disease by awarding grants to Alzheimer's research initiatives and support organizations for patients and caregivers. "I think one of the biggest challenges is the lack

of research dollars going to finding a cure for the disease," Pat laments.

Indeed, the federal funding allotted for Alzheimer's research (\$500 million) is a mere fraction of the money that goes to cancer (\$5.6 billion) and heart disease (\$1.2 billion). Thin financial support and the persistent stigma that surrounds Alzheimer's disease helped compel Pat to share her experiences with others. "The first step is having the courage to get out of our comfort zone and understand the disease," says Tyler. "This requires people not to be embarrassed about themselves or their loved ones. It's nobody's fault that they have Alzheimer's—we need to have fierce courage together to battle this disease."

As a younger caregiver—just 23 years old—Tyler has had to shoulder heavy responsibility and learn to cope with the emotional ups and downs that inevitably accompany a loved one's journey with Alzheimer's. But the grit and determination he learned at his mother's side have served him well. To other caregivers, he offers two main pieces of guidance: "Join a support group. Know that you're not on an island; you are not alone," and, "Enjoy the priceless moments and make new memories every day. Focus on what you do have."

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Caregiver to Caregiver

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NEW CHALLENGES

People who are new to the world of elder care get tips and information from veteran caregivers on AgingCare.com:

Should I agree to be a live-in caregiver for my grandmother?

“If I were you, I would not move her in with me—the toll of live-in caretaking is enormous. But I would be her caretaker. Keep her at a residence where experienced staffers can take care of her needs. Then you can spend loving, quality time with her at her residence.”

“Leave grandma where she is, as long as she is safe and being taken care of properly. Go and visit her as much as you can. Bring her home for a day, bring her ice cream, do her laundry.”

“It may be something you wish to do, but you need to have your ducks in a row first, or it will be overwhelming. Caring for an older adult is unlike caring for a child. The child, over time, becomes more independent—needing less care. The elder will become more dependent—needing more care.”

Should I quit my job to care for my parents?

“It is difficult to still ‘have a life’ while being a responsible caregiver. I have found that maintaining my career helps give me balance and is good for me emotionally.”

“All situations are different and it all depends on the situation. My suggestion is to think of how you would feel if you were them.”

“If they are truly unable to care for themselves, then it’s time for them to go somewhere they can still live together while getting the care they need. Do not give up your job. You can’t afford it; mentally, physically or emotionally.”

I’m new to caregiving for my dad; any tips?

“Listen carefully to his concerns. He’s becoming more dependent and the smallest things may seem like mountains to him. Don’t hover and run his life, just keep your ears open and make sure he’s not battling with something.”

“Make sure all legal papers are prepared while he’s still competent. Power of attorney documents and HIPAA forms for doctors are essential.”

“Take time for you, or you’ll get burned out. Don’t make him your number one priority all the time. Make sure to keep up with your friends.”

Do things ever settle down when you’re a caregiver?

“In my experience we have ups and downs, and it seems like the downs are never going to stop! When things do level-off, we tend to take it for granted. Then, before you know it, a ‘down’ will hit and we are riding the roller-coaster again.”

“Elder care is just complicated. It’s one of the most difficult periods of our lives and it doesn’t get any easier. My mom has been gone for four months and I’m still cycling through emotions that defy explanation.”

Where can I get training to help me care for Dad?

“Check with your local hospital or the Red Cross; they typically offer CPR and first aid courses that can be helpful.”

“Your nearest nursing home will have support groups. You can also learn a lot online by going to YouTube and elder care websites like AgingCare.com.”

How do I deal with my parents’ hurt feelings (and my guilt) when I can’t be there 24/7?

“If at all possible, drop the guilt. If you can’t fully let go of it, push it way to the background and make decisions without consulting the guilt. Know that you are a good child—believe it. Whether your parents acknowledge it or not, you are a good child.”

“I suggest a couple of sessions with a good therapist. Your mental health is vital and you need coping skills. You cannot allow guilt and manipulation to do this to you. You are worth more than that.”

“One of the first things I did when my mother started to fail was to get her some outside help. I knew I wouldn’t be able to do everything. You’re doing great. Do what you can and don’t let it get you down.”

“You need to have an honest conversation with your parents. Boundaries are important with caregiving. You have to just set them and stick to them.”

“All of you will need to work out a way to compromise. No one is going to be completely ‘happy’ at first, but with communication, patience and open-mindedness, you can find a solution that will enable everyone to be content.”

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Life as an Alzheimer’s Caregiver

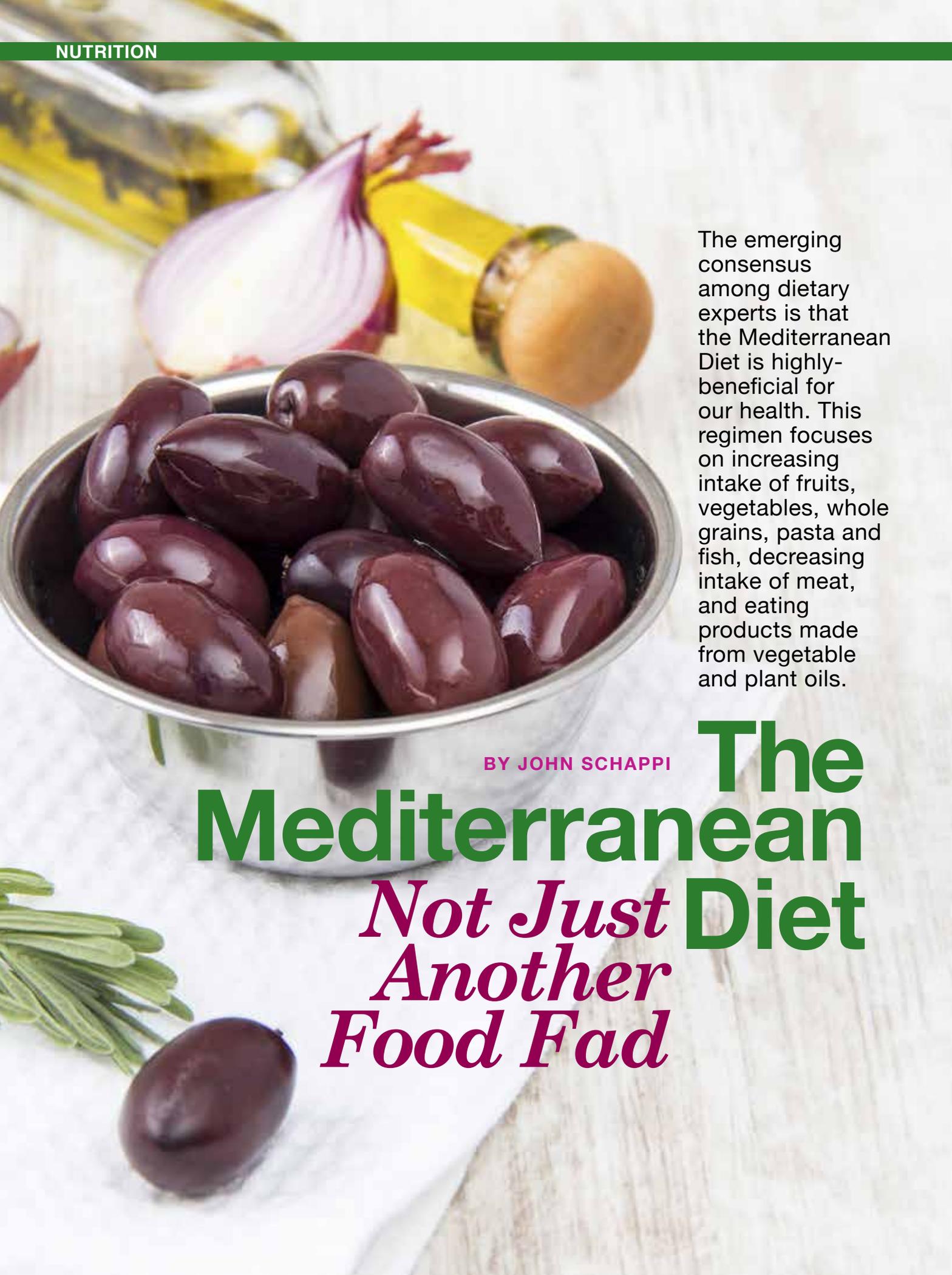
The most thorough guide on caring for someone with Alzheimer’s. Learn from experts, caregivers and patients.

The emerging consensus among dietary experts is that the Mediterranean Diet is highly-beneficial for our health. This regimen focuses on increasing intake of fruits, vegetables, whole grains, pasta and fish, decreasing intake of meat, and eating products made from vegetable and plant oils.

BY JOHN SCHAPPI

The Mediterranean Diet

Not Just Another Food Fad



Here are some benefits of the diet:

- It reduces the risk of heart attack, stroke and cardiac death by about 30 percent in high-risk individuals, according to a study published in the New England Journal of Medicine.
- It may reduce the risk of stroke, depression, cognitive impairment and Parkinson's, particularly for males, a group of Greek researchers concluded after reviewing 22 different studies.
- The battle against dementia should focus on the benefits of a Mediterranean diet, rather than "dubious" benefits of drugs, says an open letter sent to the British Health Secretary by a group of leading researchers. Their stance is based on a 34-year study, the longest of its kind. The doctors argue that the diet—unlike drugs—has no side effects.

“It reduces the risk of heart attack, stroke and cardiac death by 30 percent in high-risk individuals.”

- People who adopt a Mediterranean diet have a lower risk of heart attack and cardiovascular-related death than those who follow low-fat or low-cholesterol diets, according to a new study, which notes that the American Heart Association recommends keeping fat intake below 30 percent of daily calories, saturated fat below 10 percent, and cholesterol under 300 mg daily.

These endorsements fit in with my favorite life slogans: easy does it, less is more, and K.I.S.S.

DIY GUIDE TO The Mediterranean Diet

A short shopping list

- **Fish:** salmon, shrimp, tuna, tilapia
- **Herbs:** basil, garlic, oregano, cumin, parsley
- **Produce:** tomato, avocado, olives, onions, spinach, kale, squash, red and green peppers, apples, pomegranate, grapes
- **Whole grains:** bulgur, brown rice, couscous, barley
- **Dairy:** feta cheese, Greek yogurt
- **Beans:** pinto, black, lentils, garbanzo beans (hummus)
- **Oils:** extra-virgin olive oil, canola oil



About the author: John blogs about aging, exercise, diet, pills, supplements, and his life with Parkinson's disease and prostate cancer. Follow his blog on AgingCare.com/Blogger/John-Schappi

SAVORY FALL SOUP

FAKES SOUPA (GREEK LENTIL SOUP)

INGREDIENTS (serves 4)

- 2 tablespoons vinegar
- 5 tablespoons extra-virgin olive oil
- 2 bay leaves
- 2 garlic cloves (chopped)
- 1 onion (chopped)
- 1 large carrot (chopped)
- 1 celery stalk (chopped)
- 2 tomatoes (peeled and grated)
- 1 cup dried lentils (green or brown)
- 2 ½ cups water

DIRECTIONS

- 1 Rinse dried lentils.
- 2 Put lentils in a sauce pan with just enough water to cover them.
- 3 Bring to a boil, then let simmer for 5 minutes. Strain lentils.
- 4 In a separate saucepan, sauté onions until translucent, then add garlic and sauté for an additional minute.
- 5 Add carrot, celery, tomatoes, bay leaves, garlic, vinegar and water to saucepan. Bring to a boil, then reduce heat to medium. Cover and simmer for 30 minutes; stirring occasionally to prevent vegetables from sticking.
- 6 Add lentils. Cover and simmer for 30 minutes (or until soup is of desired thickness).



- 7 Season with salt and pepper to taste. Garnish with parsley.

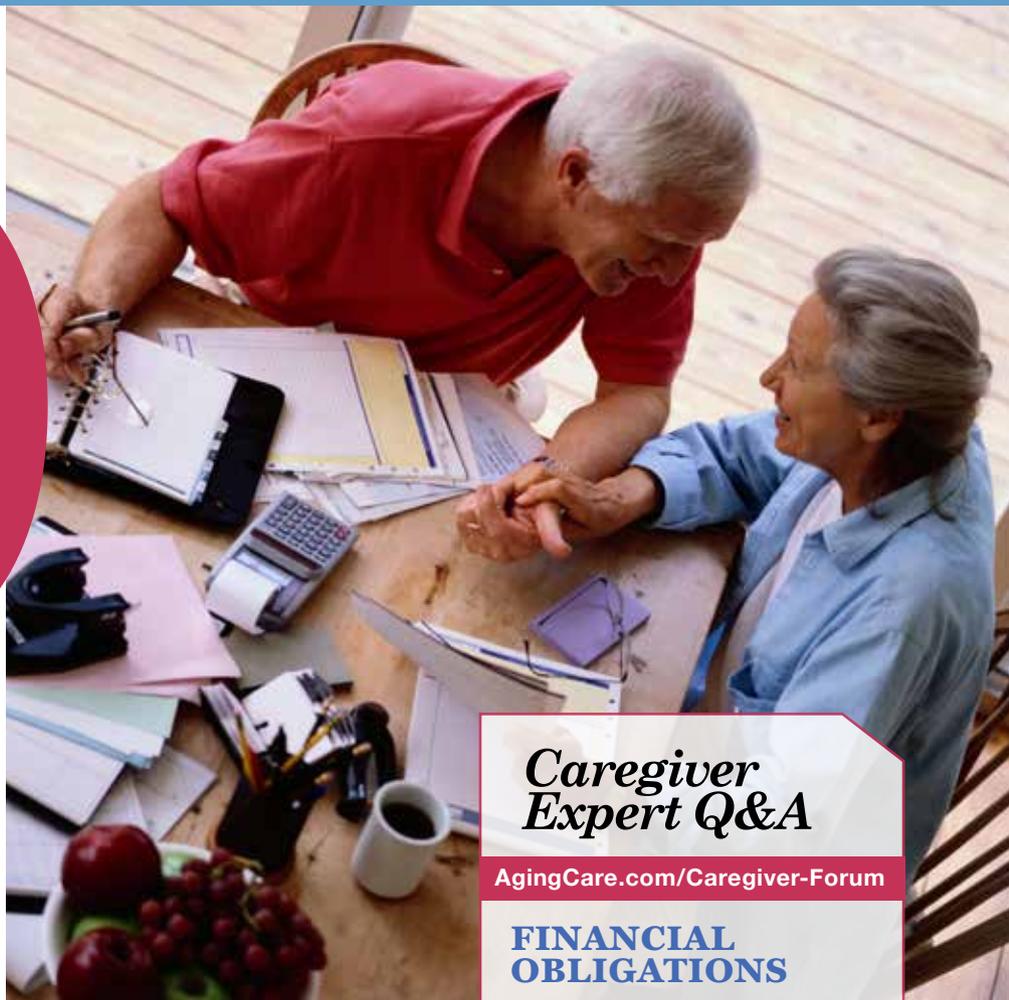
10

Things to Know About Your Parents' Finances

BY ANNE-MARIE BOTEK

In case you ever have to take over an older family member's finances in a hurry, here's a list of 10 things to know that will help make the transition as smooth as possible:

- 1 Where their money comes from: Pension, investments, etc.
- 2 Which government programs they're on: Social Security, Medicare, Medicaid, disability.
- 3 If they have health insurance besides Medicare: Health benefits as part of a pension.
- 4 What they're spending money on each month: Car payment, mortgage, utilities, etc.
- 5 How they pay their bills: Automatic deductions, online banking and bill pay, paper checks.



Caregiver Expert Q&A

AgingCare.com/Caregiver-Forum

FINANCIAL OBLIGATIONS

AgingCare.com Expert, John Roberts, J.D., is an elder law attorney who is also a caregiver to his father with dementia. He offers insight on legal and financial questions on AgingCare.com, including:

If I have financial POA, am I responsible for their future expenses?

“On one level, the answer to this question is clear: no, you do not become jointly liable with your parents for their expenses when you take on the responsibility of managing their funds and financial affairs. But the question brings up some important things to remember once you do start acting for your parents. Under the power of attorney, you are acting as a fiduciary: a person responsible for other peoples' money. So, with that in mind, you have to carefully fulfill your responsibilities. Like the trustee at the bank who manages funds for the bank customer, you can be held liable for your parents' expenses if you transfer their funds to yourself or use their money in a way that goes against their interests.”

—John Roberts, J.D.

Over 60% of family caregivers manage their loved ones' finances.

- 6 Important banking information: Which banks they use, their account numbers, etc.
- 7 Where their financial records are kept: Under the bed, in a lock-box or safe, etc.
- 8 If they have a financial planner or accountant: What kind of estate planning have they done?
- 9 Who has financial power of attorney (POA): Only a POA can access the accounts of someone who's incapacitated.
- 10 If they have long-term care insurance: How do they plan to pay for their long-term care needs?

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