What now?

How to successfully handle Alzheimer's

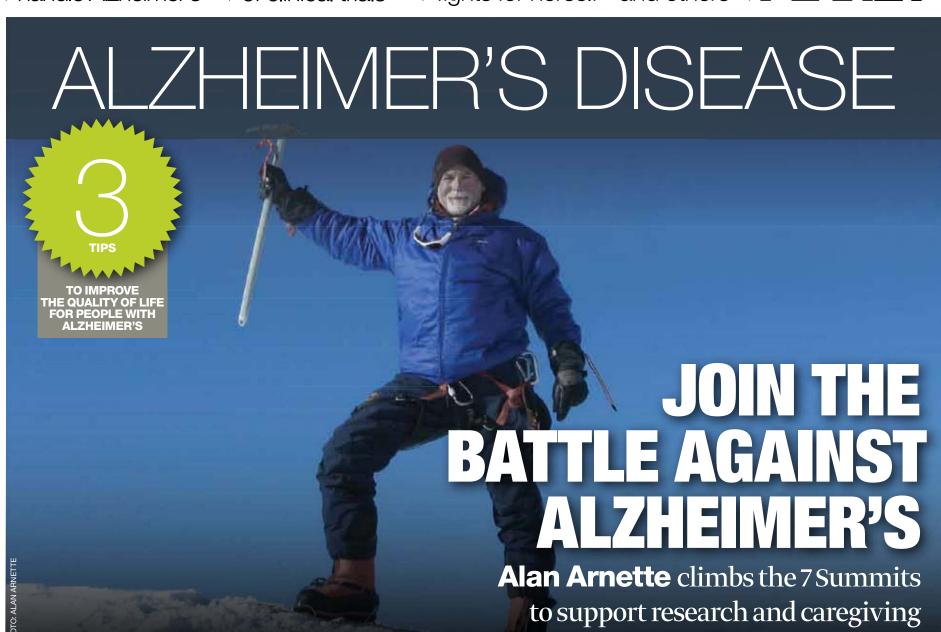
#### Volunteer

The importance of clinical trials

#### Active advocacy

A woman with Alzheimer's fights for herself—and others





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#### MENA

## CHALLENGES

# Talk to your friends and family about Alzheimer's. Talk to your doctor as soon as you have concerns.

# We need to act now

lzheimer's disease is a thief and a killer. It steals e v e r y t h i n g about an individual—everything that he or she has ever been, ever done or ever known. It takes all bodily functions and then, after years, it kills.

This heartbreaking disease is the nation's sixth-leading cause of death, killing more Americans annually than diabetes, and more than breast cancer and prostate cancer combined. Yet, many Americans remain unaware that Alzheimer's disease is fatal. That it is growing rapidly. And, that without action, it has the potential to destroy our country's financial and emotional security.

Alzheimer's is the only cause of death among the top 10 without a method to prevent it, cure it or even slow its progress. In fact, death rates from Alzheimer's are skyrocketing while death rates from other diseases, such as heart disease, HIV/AIDS and certain cancers, thankfully continue to drop.

And, unlike these other diseases, there are currently no survivors of Alzheimer's. The vast majority of Alzheimer's cases occur in individuals over the age of 65. Yet, last year, as federal investments increased for most other major chronic diseases and as the first of the baby boomers began turning 65, federal investments to find the answers to Alzheimer's actually decreased.

But the discussion is changing, just as it did years ago about cancer. Today we have champions. People affected by Alzheimer are using their voices to raise awareness and pave a better path for those who will

"Alzheimer's disease doesn't just affect those with it. It invades families and the lives of everyone around them."



**Harry Johns**President and CEO,
Alzheimer's Association

follow. You will read some of their stories in this publication.

## What can you do about the Alzheimer's epidemic?

Talk to your friends and family about Alzheimer's. Talk to your doctor as soon as you have concerns. Talk to your legislators about increasing federal funding for Alzheimer's care and research. Participate in a Walk to End Alzheimer's in your community. Use your voice to change the course of Alzheimer's disease.

And if someone you know needs help, resources are available.

The Alzheimer's Association offers care, support and education in communities nationwide. Call our 24/7 toll-free Helpline at 1-800-272-3900—it's the only one in the United States dedicated to round-the-clock Alzheimer's support. Or, visit our website at alz.org to learn more and get involved.



ALZHEIMER'S DISEASE 1ST EDITION, APRIL 2011

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Is Your Memory Normal?

**As we age, many of us worry** about a declining ability to recall words and names.

Some forget why we entered the next room, and wonder if we have a problem with our brain.

With a brief test called the MCI Screen, your primary care physician can identify healthy memory patterns and reassure you about the health of your brain. If your memory pattern is not normal for your age, the MCI Screen will prompt your physician to perform a diagnostic work-up and determine the underlying problem.

**Remember, many common conditions can impair memory,** including anxiety, depression, and thyroid disorders. Memory loss can also be caused by more serious conditions such as Alzheimer's disease and vascular disease. For all causes, early detection and treatment yield optimal treatment results.

If you have a concern about your memory, ask your physician about the MCI Screen





## NEWS

In recent years, we have gained a better understanding of **Alzheimer's Disease**, such that we can now detect its earliest stages in patients with very mild symptoms.

# Alzheimer's: Early detection allows for proper treatment

During the early "pre-dementia" stage of Alzheimer's, patients' brains still function at a fairly high level.

We use the term "dementia" to describe more severe symptoms, and we use the term "mild cognitive impairment" (MCI) to describe these subtle symptoms in "predementia" Alzheimer's.

Importantly, all memory loss is not due to Alzheimer's disease. In fact, Alzheimer's is the cause in 60 to 80 percent of people with MCI. Patients with MCI have a memory complaint and, on specific testing, show memory problems that are more serious than would be expected as part of normal aging. Only

about half of people with MCI progress to dementia within five years, while the other half does not progress to more serious symptoms.

With a proper review of the patient's medical history and neurological exam, and some additional testing, such as blood tests and volumetric brain imaging, physicians can make an accurate diagnosis of "predementia" Alzheimer's. This means that they can reliably identify those MCI patients who are more likely to progress to the dementia stage of Alzheimer's, and initiate a robust treatment regi-

men. Such early intervention is our best hope for effectively keeping symptoms under optimal control for as long as possible.

The other group of MCI patients are experiencing memory impair-"Importantly, ment due to myriad causes, including all memory sleep problems, loss is not due thyroid disease, depression, and to Alzheimer's medication side efdisease.' fects, among others. The same diagnostic

> testing described above can help physicians determine whether or not the cognitive impairment is likely to be caused by the earliest stages of Alzheimer's. This also allows for timely, proper

treatment of the true underlying cause of the problem.

With new discoveries in the biology of Alzheimer's, and clinical trials being conducted using our latest understanding, we are on the brink of detecting this devastating disease at its earliest stage, where we will have the greatest chance of slowing its progression – when new, better treatments become available. Perhaps we are approaching the day when physicians can help their patients to avoid the dementia stage altogether.

#### MICHAEL RAFII, MD, PHD

Director, Memory Disorders Clinic University of California, San Diego Associate Medical Director Alzheimer's Disease Cooperative Study



Arnold and Laura Goldfoot were caring for Arnold's mother, Ola, in Florida for 10 years. In the last three years, Ola's Alzheimer's was progressing so fast that they found it necessary to move into her home to care for her full time.

Eventually, a hospice nurse told them their health was suffering as a result of their stubbornly loving caregiving efforts. Ola had become increasingly depressed and angry. She would argue with them and say that she "just wanted to die," which was heartbreaking for them. They needed help.

When the Goldfoots found a senior living community for Ola, they shared her amazing life story with staff to customize her environment and activities specifically based on her past history, roles, routines and preferences.

The Goldfoots have expressed much gratitude for this dynamic programming. They marvel at the stories that the staff is able to get her to tell them each week. They can't believe that she is taking part and enjoying activities they never thought possible for her.

editorial@mediaplanet.com



# It's time to turn Can't into Can.

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## INSPIRATION

**Question:** What effect do you think you would have by raising your goal of one million dollars for Alzheimer's research? **Answer:** My dream is that it would make a difference, so that one day we won't consider Alzheimer's an insurmountable peak.

# Mountain of memories

lan Arnette never gets tired of mountain themed quotes and analogies. This is a man who truly is moving mountains (as in, moving up one and moving on to another) to make a difference in the lives of those affected by Alzheimer's disease. Over the course of this year, Arnette will climb the 7 Summits—the highest points on each of the seven continents, to raise one million dollars for Alzheimer's research. The seasoned mountain climber launched his "Memories are

lan Arnette never Everything" campaign to honor the gets tired of moun-lives of his mother and his two aunts.

"My Mom was the rock, the memory keeper of our family," Arnette says. "It was heartbreaking to watch this disease rob her of her precious memories, and ultimately her life."

#### An uphill battle

The struggle that the Arnette family endured during his mother's descent into Alzheimer's is at the heart of the "Memories are Everything" campaign. As Alan Arnette scales each summit, he keeps a pic-

"Alzheimer's is not a symptom of 'old age.' It's a disease, like cancer or diabetes."

Alan Arnette

ture of his mom tucked close. She is a reminder that however mentally and physically taxing his climbs are, they can't compare to the exhausting and often debilitating daily routine for Alzheimer's patients and their caregivers.

#### Not a symptom of 'old age'

"Alzheimer's is not a symptom of 'old age.' It's a disease, like cancer or diabetes," he emphasizes. "We must educate people on the warning signs and make resources readily available to them. This disease places an enormous emotional and

financial burden on families."

For a man who will make history as the ninth person in the world to reach all 7 Summits, his legacy may ultimately be his ability to make a difference in how people perceive this insidious disease. Perhaps the next mountain themed quote most appropriate for the campaign is, "Great things are done when men and mountains meet." Or put simply in Alan Arnette's words, "Climb on!"

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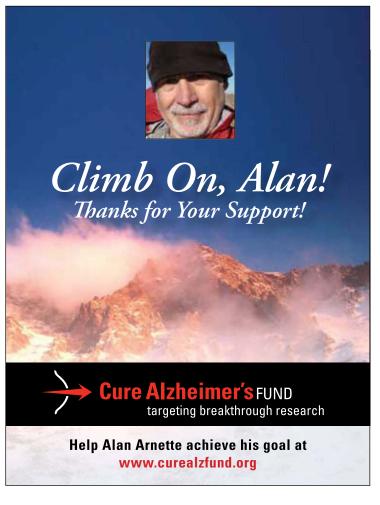


## **Brain Today**

Is it important science or commercial hype?

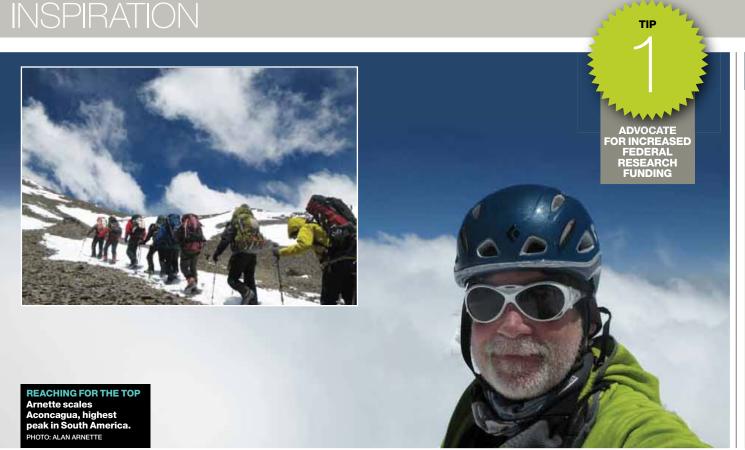
The Brain Today blog clarifies the daily news about brain health.

BrainToday.com









## GUESTION & ANSWER WITH LISA WENDT

# How would you characterize your caregiving efforts for your father?

If you called me an idealist, overprotective, or if you said I was biting off more than I could chew, I would have argued vehemently—but you would have been right! Without a single bit of information, I insisted on having my Dad, age 83, move in with my husband and me.

I told my husband it wouldn't be a problem: Dad's cool. No Alzheimer's. It will be fine. My Dad lived to be 90 years old, and was near the end of his retirement savings when he passed away. Today, complete with the battle scars from learn-as-you-go frustrations, I am more convinced than ever that planning for my own future is a must for me and my family.

editorial@mediaplanet.com

# The state of *California* is home to several

# Alzheimer's Disease Centers

To learn more about the research at these Centers, including clinical trials, call or visit:

UCLA (310) 794-6039 www.EastonAD.ucla.edu

USC (323 ) 442-7600 www.usc.edu/adrc UC San Diego (858) 622-5800 www.adrc.ucsd.edu UC Irvine (949) 824-2382 (949) 824-5733 www.mind.uci.edu

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# Protecting it is Step 2.





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# PLANNING FOR A FULL

AND SUCCESSFUL LIFE

As a social worker who occasionally counseled people with Alzheimer's and their families. Martha Watkins could draw on her experience when her father was diagnosed with the disease. But that didn't make it easier on her emotionally.

"I was devastated when Dad's physician told us (that Dad had Alzheimer's)," said Watkins, 59, now retired and living in Luray, Va. "Still, I knew essentially what Dad and I would be facing, and we could begin to plan together for the future."

penses, assets and income after an Alzheimer's diagnosis can help caregivers identify any necessary actions to take and/or documents to execute such as wills, powers of attorney, and insurance policies—to ensure they're in order.

Fortunately, Watkins and her fami-



Watkins Social Worker

helped reduce the financial stress caregivers often face. "My parents had all their legal documents in place," she said. "I already had copies of (Dad's) power of attorney and medical power of attorney, and the ability to sign

Though financial issues weren't a concern for Watkins, for a time she was raising a family as well as caring for her father in her home. The challenges of Getting a handle on a loved one's exbeing a "sandwich generation" caregiver meant that Watkins had to rely on others for help and support. She also worked closely with her father's physician to put together the best possible medical team for her father's care as his Alzheimer's progressed.

"I depended on family members and friends to visit, and sometimes to proly had a head start on planning, which vide supervision for Dad," she said. "I

recommend that caregivers develop a network of people who can help with different roles, such as shopping, preparing meals, taking care of the living space, and transportation to medical and other appointments. Doing that provided me with some confidence in my decisions, reduced my anxiety and, I believe, improved my ability to cope."

AN INDEPENDENT SUPPLEMENT BY MEDIAPLANET TO USA TODAY

Eventually, Watkins' father's Alzheimer's progressed to the point where she chose to place him in an assisted-living facility; he passed away in 1999. But Watkins never second-guesses how well she cared for him.

"I acted in a way I thought he would want," she says. "I do wish he could have lived in my home longer, but that decision was made for me by Alzheim-

Important services for caregivers to seek out include: professional financial advisers, eldercare attorneys, and voluntary health

MATTHEW HICKEY

editorial@mediaplanet.com



THE GREEN HOUSE PROJECT

# Clinical studies look for answers to Alzheimer's, and need more volunteers

**Every 69 seconds someone in America develops Alzheimer's** disease, according to the Alzheimer's Association 2011 **Alzheimer's Disease Facts and** Figures Report.

"Alzheimer's is clearly the country's #1 public health challenge and research is the only way to solve this problem," said William Thies, Ph.D., Chief Medical and Scientific Officer at the Alzheimer's Asso-

Thies says recruiting volunteers for clinical studies is one of the greatest obstacles to developing new Alzheimer's treatments.

A clinical trial is a health-related research study that follows a pre-defined and approved set of instructions. They typically investigate:

- New treatments.
- Methods to prevent diseases.
- New diagnostic tests.
- Ways to improve quality of life for patients and caregivers.

More than 140 Alzheimer's clinical studies are now recruiting participants. According to experts, some 50,000 more volunteers are needed.

To help solve this important problem, the Alzheimer's Association launched TrialMatch, a free and confidential tool that provides comprehensive clinical trial information and an individualized clinical trial matching service.

"I want to understand exactly what's going on with me, what my options are, and what I can do about it." said Russ Belleville of Boca Raton, Florida, who was diagnosed with mild cognitive impairment in 2009 and Alzheimer's disease in 2010.

"I tried Googling 'Alzheimer's trials,' but that was not very helpful," Belleville said. "So then I went to the Trial Match website. It was pretty straight forward and easy to use."

In addition, the US Government, through the National Institutes of Health, hosts a comprehensive online database of clinical trials and medical research on all diseases at clinicaltrials.gov.

Belleville remains optimistic, "Given time, research and funding, we will find an effective treatment for Alzheimer's."

NILES FRANTZ

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#### STEPS TO TAKE AFTER DIAGNOSIS

#### Find support

Local organizations and associations can answer your questions and provide information, referrals and care consultation whenever you need it. It's helpful to create a network of family and friends who can help care for your loved one as well. There are also many online communities where you can share your experiences and learn coping tips from others who know what you're going through.

#### Look into treatments

Treatments are available that may help relieve some Alzheimer's symptoms. The U.S. FDA has approved two types of medications to treat memory loss, confusion, and problems with thinking and reasoning. Talk with your doctor. The importance of loving and effective caregiving cannot be understated as well.

#### Plan for the future

Advance planning allows a person with Alzheimer's to express their wishes about finances, medical care and living arrangements. Knowing what the individual wants can ease the minds of everyone involved.

MATTHEW HICKEY

editorial@mediaplanet.com



#### MAKE YOUR WISHES KNOWN

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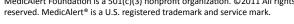
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#### GOOD CAREGIVING ALSO MEANS CARING FOR YOURSELF

As a caregiver for someone with Alzheimer's or another dementia, you may find yourself with so many responsibilities that you neglect your own well-being. But maintaining your health is important to your success as a caregiver for vour loved one.

Common signs of caregiver stress include denial, anger, sleeplessness, irritability and problems with physical health. To keep your stress levels as low as possible, follow these tips:

- Know what resources are available. Adult day care. in-home assistance, visiting nurses and Meals-on-Wheels can help.
- Become an educated caregiver. Organizations in your community can provide information, training and resources on all aspects of the dis-
- Get help and support. You are not failing as a caregiver by asking others for assistance.
- Take care of yourself. Watch your diet, exercise and get plenty of rest.
- Make legal and financial plans. Consult an attorney to discuss legal, financial and care issues.
- **Be realistic.** Many of the behaviors that occur are beyond your control.
- Give yourself credit. Don't feel guilty because you can't do more. The person with Alzheimer's needs you, and you are there.
- Learn all that you can. And take good care of yourself, too.

**BRETT ARMSTRONG** 

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# n early-stage Alzheimer's advocate Its a face to the disease

**Question:** What can people with Alzheimer's do to advocate for themselves?

■ **Answer:** Build awareness by speaking to the public. This humanizes Alzheimer's and advances the social dialogue.

In the early stages of Alzheimer's disease, symptoms are usually mild enough to allow people to participate in daily activities and in planning their own care and future. Nancy Fearon of Troy, Mich., is a prime example-and she's taking things one step further. She isn't taking her Alzheimer's sitting down-rather, she's standing up to it.

#### **Moving forward**

Fearon was 73 when she was diagnosed in 2009. She now speaks publicly about living with Alzheimer's as a member of the Alzheimer's Association Early-Stage Advisory Group. The Group helps the Association develop and provide services for people in the



early stages of the disease, raises awareness about early-stage issues, and meets with legislators to increase funding for research and support programs.

WARNING SIGNS OF ALZHEIMER'S

"Talking about Alzheimer's has helped me to accept it, and to not be ashamed

Nancy Fearon Substitute Teacher, Alzheimer's Advocate

Alzheimer's to local church groups, Alzheimer's disease support groups, and to nursing, pharmacology, social work and

Recently. Fearon talked about

#### **Memory loss that disrupts** daily life is not normal aging: it may be Alzheimer's disease.

- Other warning signs include: Challenges in planning or
- Difficulty completing familiar tasks.

solving problems.

- New problems with words.
- Withdrawal from work or social activities.
- If you or a loved one is experiencing these things, please see a doctor. For more information, visit www.alz.org/10signs.

technical college students.

Being an Alzheimer's advocate is more than just a way for Fearon to put a spotlight on the disease-it helps her survive and thrive.

"I like to talk in front of people," the former substitute teacher admits. "I feel like I have a unique experience and ability to educate people. In my own small way, I'm helping people understand not to be afraid of Alzheimer's disease and not to make jokes about it. Talking about Alzheimer's has helped me to accept it, and to not be ashamed of it."

Putting a face on Alzheimer's disease reduces the stigma attached to it, Nancy says. "(People) see I'm a normal person and I live a good life. I think that's healthy because it takes a lot of fear and misunderstanding out of it."

#### **MATTHEW HICKEY**

editorial@mediaplanet.com

**Question:** What is the least recognized facet of Alzheimer's? **Answer:** People often lose sight of the significant emotional and financial cost of caregiving.

# New report shows enormity of burden on alzheimer's caregive

According to 2011 Alzheimer's Disease Facts and Figures, just released by the Alzheimer's Association, there are nearly 15 million Alzheimer's and dementia caregivers in the United States.

This new report shows that there are far more Alzheimer's and dementia caregivers than previously believed—37 percent more than reported last year. These individuals provided 17 billion hours of unpaid care valued at \$202.6 billion.

If Alzheimer's and dementia caregivers were the only residents of a single state it would be the 5th largest state in the country.

Studies indicate that people 65 and older survive an average of

New England Journal of Medicine, 2003; 348:2508-2516

four to eight years after a diagnosis of Alzheimer's disease, yet some live as long as 20 years. The prolonged duration of this disease often places increasingly intense demands on the millions of family members and friends who provide care to those with Alzheimer's. The 2011 Facts and Figures report reveals that Alzheimer's and dementia caregivers have an increased potential to develop their own serious health issues. Those complications represent a financial burden of nearly \$8 billion in increased healthcare costs.

The Alzheimer's Association estimates that total payments for health and long-term care services for people with Alzheimer's and other dementias will amount to \$183 billion in 2011, which is \$11 billion more than in 2010.

Medicare and Medicaid costs will make up the majority of this increase. By 2050, Medicare costs for people with Alzheimer's and other dementias will increase nearly 600 percent and Medicaid costs will soar almost 400 percent.

"The projected rise in Alzheimer's incidence will become an enormous balloon payment for the nation—a payment that will exceed \$1 trillion dollars by 2050," said Robert Egge, Vice President for Public Policy for the Alzheimer's Association. "It is clear our government must make a smart commitment in order make these costs unnecessary."

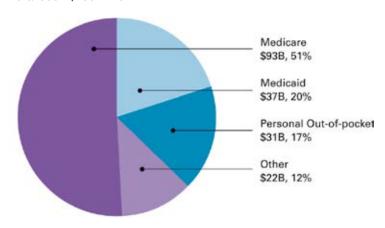
**TONI WILLIAMS** 

editorial@mediaplanet.com

#### THE RISING COSTS OF ALZHEIMER'S

Aggregate costs of care by payer for americans aged 65 and older with alzheimer's disease and other dimentias, 2011\*

Total cost: \$183 Billion



\*Data are in 2011 dollars.

Source: Alzheimer's Association 2011 Alzheimer's Disease Facts and Figures.

# Give your parents the mental stimulation they need.

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The risk for dementia begins around age 65—and by 85, half the population is afflicted. But more than two decades of medical research has shown that people who perform rigorous cognitive exercise have as much as a 63% reduced risk of dementia!1 Brain health is a matter of use it or lose it.

Clinically tested Dakim BrainFitness software cross-trains the brain in six essential cognitive domains, to improve memory and strengthen

focus and attention. With over 300 hours of rich, interactive exercises, vivid graphics, film clips, music, and humor—it's stimulating and fun.

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## INSIGHT



Kelly Scott VP of Program Development and Innovation



Robert Jenkens
Director, The Green
House Project, NCB
Capital Impact



Jeffrey Cummings, MD Director, Cleveland Clinic Lou Ruvo Center for Brain Health



Sam J.W. Romeo, MD, MBA Medical Director for MedicAlert Foundation



#### **Question 1:**

How are you helping to improve the lives of people with Alzheimer's disease? Caring for a resident with Alzheimer's disease begins with a strong partnership with the family to gain a deep understanding of who their loved one is, what they've experienced in their life, and what events and activities have brought them a sense of purpose and success. We work to bring those interests, experiences and hobbies to life for them, which allows us to enter their world and create days full of meaning and happiness for each individual.

Very good people live and work in nursing homes every day. Unfortunately, the prevalent model of nursing home care—impersonal environments, rigid schedules, and segregated staffing—interferes with their ability to support meaningful lives and jobs. We partner with organizations to implement innovative alternatives. Together with The Robert Wood Johnson Foundation, we are working to spread The Green House model across the U.S.

We have a "patients first" philosophy that places the patient in the center of all decisions. We offer state-of-the-art care to all patients and empower them to help rid the world of Alzheimer's disease by participating in clinical trials. Further, we recognize the critical role of the caregiver in families struck by Alzheimer's disease and offer innovative programs to support caregivers through this journey.

**Unfortunately,** more than 60 percent of persons with dementia will wander, get confused, and become lost doing tasks as simple as getting the mail. If the person is not found within 24 hours, there is a 50 percent likelihood that they will suffer serious injury or death. The nonprofit MedicAlert Foundation, in partnership with the Alzheimer's Association, developed a live 24-hour nationwide identification service to assist those who become lost.

#### **Question 2:**

What are common misperceptions about Alzheimer's disease?

Many believe that people with Alzheimer's are entirely dependent on others and lose their ability to experience joy. In reality, individuals often continue to enjoy many of the same things they have enjoyed their entire life. In fact, when these individuals are given the opportunity to continue to participate in lifelong interests, they are often most themselves.

Two persistent myths about people living with advanced dementia are that they will not benefit from non-institutional environments designed to foster deep relationships with caregivers. People living with dementia thrive when staff know them well and understand their "behaviors" as communication. This reduces agitation and allows them to live a more comfortable life.

loften hear cognitive decline is part of normal aging; there are no treatments of Alzheimer's; that Alzheimer's cannot be diagnosed until autopsy. Not only are these statements inaccurate, but they are also harmful to patients and caregivers because they create a sense of helplessness and hopelessness. Alzheimer's patients need to seek out expert medical advice as early as possible.

**People often think** that memory loss is a natural part of getting older and is a natural progression. On the contrary, significant memory loss should be taken seriously and may be a symptom of a serious illness such as Alzheimer's or a related dementia

#### **Question 3:**

A family member has just been diagnosed with Alzheimer's disease. What is the first step I should take? Begin to develop a support system of family and friends who will be able to help with the demands of caring for a loved one with Alzheimer's disease. Developing a strong support system will help ensure you have the time you need to take care of yourself, spend time with family and friends, and also get the rest you need.

The first step is to breathe deeply. New insights and models of community, residential, and skilled nursing home support can support a rich life for the person with dementia. While significant challenges and losses will confront you, changing your relationship and roles over the progression of the disease, opportunities for new and rich experiences also exist—allowing you to continue to create new and positive memories together.

Start preparing yourself and your loved ones for a long process and approach each day as one that can have meaning and joy. Seek out medical and supportive care from a team of experts you trust, and be sure to find resources in your community for caregivers. We know that the well-being of the caregiver directly impacts the health of the patient, and being positive starts with a support network you create in the beginning of the journey.

The first thing to remember is that caring for your loved one with Alzheimer's often is a long journey and not a sprint. Despite your immediate worries about your family member and arranging their medical care, a key part of the overall plan must be to take care of yourself, too.



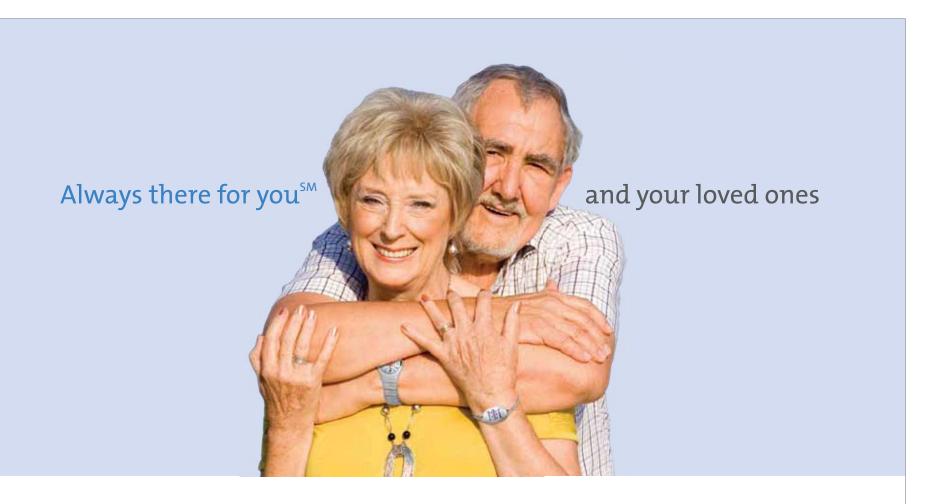
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- Live 24-hour Caregiver Notification Service
- Personalized Emergency Wallet Card
- Personalized MedicAlert medical ID
- Live 24-hour Care Consultation Services



For more information, visit www.medicalert.org/safereturn or call 1.888.572.8566.

#### **Location management services include:**

Alzheimer's Association Comfort Zone®, powered by Omnlink Comprehensive web-based GPS location service that includes MedicAlert + Safe Return membership

Alzheimer's Association Comfort Zone Check-In™ Self-service webbased location service





For more information, visit www.alz.org/comfortzone or call 1.877.ALZ.4850.



# Join Their Journey®

We understand that each family's experience in caring for someone with memory loss or Alzheimer's is unique. Our goal is to foster a relationship where we get to know your loved one and your family, allowing us to provide support and solutions for each individual situation.

Our innovative memory care approach, "Join Their Journey" provides us the ability to meet each resident's and family's needs at each stage of memory loss.

Our goal is to help each resident be purposeful and successful every day!

## www.MemoryCareEmeritus.com

Call or visit us today!

(888) 527-5135

Learn more about our Join Their Journey program

Locate a community nearest you





