



Navigating A Network Of Support

How to Avoid Confusion as Local Groups Split From the Alzheimer's Association

By **KAREN BARTOMIOLI**

It was a plan to bring laser focus to doing battle against a disease growing at an alarming rate. But a consolidation of all chapters affiliated with the Alzheimer's Association fell apart when some of the largest chapters decided to go it alone.

Three years later, what that means in terms of direct support for the five million diagnosed with the disease, their families and caregivers is still gelling, but both the association and the new incarnations of its former affiliates are mounting intense initiatives and long-term strategic plans.

In the fall of 2015, 27 chapters had already merged with the national association. At the Alzheimer's Association's Chicago headquarters, Mission Forward, as the initiative that brought the groups together was called, was no doubt feeling like a

much-needed redirection in the face of the health crisis that dementia has become.

Across the country, affiliates came to see it from a different perspective, and they were not happy with a plan that they saw as having no major changes. Their lack of input into the plan itself fueled fear that they would lose the power to initiate services fine-tuned to meet the needs of their specific communities.

Prior to the merger, affiliates sent 40 percent of what they raised to the association — essentially the extent of their legal connection. (Some of that made its way back in the form of programs and research funding). The merger, came with the requirement that 100 percent of donations be sent to the national group and that local boards of directors be dissolved, effectively taking all local control away.

A vote of the remaining 54 chapters was

split. Soon after, the national board of directors unanimously voted to consolidate.

Within weeks of the merger approval, affiliates began splintering off, starting with New York, Greater New Jersey and Orange and San Diego/Imperial counties in Southern California.

What's been happening in communities since is somewhat fluid as the new structure of agencies address both the split and a tidal wave of need.

There really isn't a coordinated effort between the Alzheimer's Association and its former affiliates. Both sides have set up shop and their leaders say there is plenty for all to do. Duplicating efforts is a good thing in that respect.

But it isn't so helpful when it comes to public persona. The merger/split is not

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LEGAL TOOLS

Health Directives Are So Important

By **ANDREA VAN LEESTEN**

I wanted to spend some time discussing why it's so necessary to have health directives, and why you should take the time now while you have the mental capacity to decide who can make decisions with the authority over your physical health.

I want to help you understand that there are anticipated changes along the way and challenges for us all. With the right advice you can designate people to resolve your health care issues confidentially and provide cost-efficient paths to solutions. In this article, I am discussing the value of having a durable power of attorney for health care and a living will as an alternative to a court supervised conservatorship in California.

When you are healthy and you have mental capacity, you can consent to medical decisions. You are in charge of your body and your mind. But if you are unable to understand what is occurring to your physical health, due to your mental or physical incapacity, you need an agent to speak and advocate on your behalf. An agent is someone you have selected to give authority for your medical treatment and the course of care when you cannot speak.

The durable power of attorney for health care is also referred to as the "living will" which gives your wishes in the event you are in a persistent vegetative state. An individual can express their wish to be kept on life support as long as possible or to consent to feeding by tubes. Or in the alternative, an individual can

express that no extraordinary measures be taken, for instance "a do not resuscitate" order. One can express a preference for no blood transfusions.

The health directives are essential. Each one is a personal choice, that you should express for yourself. These documents allow an individual to plan for their choices by naming a person(s) commonly called an "agent" who can speak on your behalf when you are unable to speak for yourself.

Having an advance health directive or the power of attorney for health care has numerous benefits for the individual and the family. The documents help you avoid the need for filing for a costly court supervised conservatorship of the person. A properly drafted document will allow the nominated agent(s) to speak for you when you cannot speak for yourself regarding your health care. If you need to seek medical treatment and something happens to you during the procedure, your nominated agent can speak for you. The medical staff will look to your agent for direction.

If your family members do not have a health care directive, now is the time to urge them to get one. Your loved one must have mental capacity to execute a health directive which would authorize an agent to make those decisions. Even if a loved one knows you, but has a diagnosis of dementia or Alzheimer, it's usually too late.

It's difficult for me to decline to assist someone who needs a health care document, but if someone does

not have capacity, it cannot and should not be done. The alternative is usually a court conservatorship.

Who is an agent? An agent can be a relative, a parent, sibling, a spouse or just a great friend. That agent should be over 18 and informed about the duties he or she will undertake by becoming your health care agent — the duty to not only

know what your desires are for treatment and your last wishes, but how to enforce them. The agent must be able to advocate for your health care with your doctor. An agent may have to support your choices against your family's wishes. Your agent may have to authorize that no extraordinary measures be taken when your doctor says there are no more options. An agent needs your best interests at heart and courage when the hard decisions must be made.

If you authorize an agent for your health care, the agent should be informed of your medical conditions, medical preferences and the names and locations of your doctors. Please keep a list of your current medicines so your agent can locate them in an emergency. All of this is important to assure that your doctors are getting the right information for your treatment.

If you are not a family member, make sure that you have the contact information for a family member.



Andrea Van Leesten

There is potential for abuse because the health care directive gives the agent authority without any supervision. An agent could abuse his authority for his or her own benefit. That is, an agent could choose to withhold feeding or medications which could impact your life, or the agent could overlook their responsibility, ignore their duties and fail to

perform. The duties of an agent are important. Decide who will speak for you and make sure that your agent understands and accepts the responsibilities.

There is another difference with the durable power of attorney for health care, in that it does not die when you do. It is the document that allows the agent to make decisions for your burial or cremation. The only way family members can object to funeral decisions is to file an action in court against the agent. Now that I have informed you that this is the most important document that you need and you understand some of the powers, make sure you go and talk to your loved ones about it today. Don't wait!

Stay tuned and look for my next important article: "Durable Power of Attorney for Assets."

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REAL ESTATE TIPS

A Return to Multigenerational Living

By **HUGH WILLIAMS**

What some see as a new housing trend is actually a resurrection of the pre-1945 normal. In the United States, extended family members tended to live close together until after World War II, when young people began to leave their hometowns to move to bigger cities. The G.I. bill gave returning veterans access to low interest mortgages which fueled a housing boom. That generated tens of thousands of jobs, made banks more money and created a new industry: home building. Hundreds of companies sprang up throughout the country to build planned communities and kick-start the new American dream of home ownership. This led to more people choosing to move to single generational dwelling homes, seen as a measure of prosperity.

Now many families are redrawing that picture of success. Today, accomplishment means choosing a way of living that best utilizes the resources of the family, so all can triumph while fostering closeness. Multigenerational living is not only a way to live, but a way to thrive.

Traditionally, as people age and become empty nesters, they have downsized their home to something smaller or chosen to age in place. But this is no longer the case. Millennials typically face more obstacles when buying homes than other generations, due to factors like unemployment and personal debt. In fact, 67 percent of millennials claimed to have encountered obstacles that delayed home-buying plans, according to Department of Housing and Urban Development. Furthermore, an increasing amount of millennials are foregoing family expansion and remaining renters.

Although student loan debt threatens mortgage payment capacity, the promotion of higher education and improved job skills could also position millennials for homeownership. The connection between homeownership and improved job skills and education has nearly doubled in the past 10 years. As aging baby boomers exit the housing market, millennials will need to find ways they can take over homeownership.

Having children is no longer a strong indicator that a young family will move on to become homeowners. Across the country, homeownership among young families is decreasing. For families dealing with day to day expenses, being able to set aside the additional savings that are needed for home ownership is becoming a bit more difficult. Hence the move to multigenerational living.

With multigenerational living, one or more generations live together on the same property. This means

seniors living with children and grandchildren. This is common in other cultures but not nearly as common in the United States. The latest reports show one in five Americans live in such a household.

Family members see benefits from the arrangement. With living expenses, child care and senior care, family members chip in to help each other. This can help families mentally, physically, spiritually and financially. Based on current trends I can foresee multigenerational senior living will grow between 15 and 20 percent over the next 10 years.

If you're asked to picture a typical American home, you'll probably imagine a single-family dwelling with a dad, mom, kids and maybe a pet. That isn't as typical as it once was. Today's home may also house grandparents or a young adult or two. Multigenerational housing is a growing trend that makes sense to many. It's one way of reducing expenses, building savings and growing family ties. Those who have experienced it say it has multiple advantages, but also some challenges.

The two types of multigenerational households are two-generation and three-generation. The first is created when adult children continue to live with their parents after finishing college, or return at an age when they would typically be on their own. The three-generation type consists of grandparents, parents, and kids living together.

When it comes to two-generation households, low starting salaries and student debt have fed the growth. Many parents are encouraging their newly graduated children to come back home for a few years to acclimate to adulthood, pay off debt and grow their nest egg. Children that have left home and are finding it difficult on their own are coming back to cut expenses in order to save to buy a home or help aging parents with health issues. The three-generation trend is due to an aging population and rising housing costs.

Multigenerational housing is very common in cultures outside of the United States. I have family members in Jamaica, where several generations will live on family land for years until they can purchase their own. And often the land that is purchased is used for farming or rented out to other farmers to generate income that is shared among family members. Multigenerational housing is just a way of life for them. They look at single family housing as a Shine eye/Yankee way to live. Throughout the world for centuries, culturally diverse populations tend to have the highest levels of interest in co-housing/multigenerational living.

Of course, family members

should care for each other if they are going to live together, but they also need to like each other. Having shared interests, compatible habits and common goals will contribute to a harmonious household, especially when times get hard or major issues arise.

Sharing expenses in a multigenerational home isn't always simple. Should expenses be split down the middle, or shared on a per-person basis? Will food expenses be shared, or will each branch of the family supply its own meals? Who pays for home repairs? It's important to have a financial agreement in place before the move takes place, and the agreement should probably be in writing. Every penny shouldn't have to be accounted for, however. Everyone should be prepared for some inequity from time to time.

But in some cases, family members shouldn't even try to live together. Certain individuals may be good-hearted but may have character traits that do not work well in this environment. Those who are very confrontational about their possessions, overly meticulous about finances or too particular about their surroundings may not be a good fit. Remember, this is a lot more important than having that college roommate, so choose wisely. A meet-in-the-middle approach can work.

Boundary issues, both physical and verbal, can also create problems. It's best if everyone has some private space, and that others stay out of it. Another boundary issue is control of the children. Grandparents who are in charge of the children during working hours should let the parents handle the children at other times.

Parents reap multiple benefits when grandparents are healthy enough to help out with childcare. Parents save money, and those with early working hours don't have to struggle to get children out of the house and deposited at daycare. When children have minor illnesses, they can stay at home with the grandparents, and the parents won't have to miss work. Since most grandparents enjoy being with their grandchildren, this arrangement has dual benefits, as long as the parents are careful not to regard the grandparents as full-time babysitters.

When family members begin to age and are having health issues, moving in with their adult children can make sense. Well-being issues can be more easily managed and loneliness — an issue that is widespread among the elderly — can be



Hugh Williams

reduced. However, elder care typically gets more difficult with time. Sometimes young families find themselves dealing with accessibility issues, or having to find space for an additional part-time caregiver. Still, many families find that keeping their loved ones in a home setting is worth the trouble — mentally,

physically and financially. This way most caregiving can be provided by family members, avoiding the rising cost of paid caregivers.

In many of the new multigenerational living environments, family members are not relegated to the spare back bedroom. The new designs are actually far different. Families, cities and now builders have seen the shift and have embraced it.

In response to financial, cultural forces and housing trends, builders have begun to offer floor plans that are more accessible and more family share-friendly. These include plans with two downstairs master suites. Other plans call for The Home Within a Home. These typically offer a private suite within the home, with a kitchenette and sitting area as well as a private bedroom and bathroom.

Several major builders have begun building multigeneration dwellings into some communities. These Next Gen homes were introduced around 2010, when urban planners began to address the need for more affordable housing in large, dense cities. Some designs provide privacy and separation, yet both generations reside under a single roof. Families in these homes have separate entrances and their own living space, allowing for as much or as little interaction as individuals want.

Multiple generational living can be accommodated by addressing single family property lots. Regulations and fees are being eased in booming cities like Los Angeles, Seattle and Portland, where city officials see Accessory Dwelling Unit (ADUs) — sometimes called granny flats or casitas — as a method of infill development. Now they are allowing the building of ADUs on lots that for years were strictly designated for single-family homes only. Senior living is impacting the way many families construct, remodel, or use the space on their property in levels not seen since the 1950s.

Today many families are rethinking what success is. For them, success is choosing a way of living that best utilizes the resources of their extended family. To them, multigenerational living is not just a way to live, but a way to thrive.

ON ELDER CARE

Planning for the Journey Ahead

By **DR. BRYAN F. GAINES**

Regardless of where you are in the process of being a caregiver, the struggle is devastating for all involved in caring for someone living with Alzheimer's disease (AD) or a related type of dementia.

Knowing firsthand after caring for my father, I understand the struggle. I witnessed my father lose the ability to care for himself. By the end, he could not chew or swallow food, and he eventually forgot how to even breathe as his brain slowly shut down. Caring for my father explains why I continue to wake up every day to work on how we, as a community, can change the direction of this horrible disease that impacts the African-American community at a higher rate than any other.

Now is the time to move away from the scientific jargon to tell real stories with depth, and hope for everyone to embrace the caregiver journey. The number of lives impacted by this disease is a clear indication of the need for the journey ahead to find a cure for AD.

But in the meantime, we have a responsibility to educate communities about the risk factors associated with AD; to lead brain healthy lifestyles; to explain how to live with and manage AD; to ensure resources and services are available; to shape policies to inform elected officials; and to fight AD through community research and clinical trials.

Advocates for African American Elders (AAAE), founded by Dr. Karen D. Lincoln, an associate professor and my colleague at the University of Southern California Suzanne Dworak-Peck School of Social Work-Edward R. Roybal Institute on Aging, with myself as co-founder/chair — is a university based program that has been conducting Community Partnered Participatory Research (CPPR) and successfully providing culturally competent

outreach and health education for African-Americans throughout Los Angeles County since 2014.

AAAE research activities have included a community survey of 550 African-Americans; a healthcare experience survey of 200 African-Americans; the Wisdom Project, a study to explore African-Americans' knowledge about AD and attitudes toward clinical research; and most recently, BrainWorks, a randomized, comparative effectiveness trial to increase knowledge about AD and to examine the effects of cultural mistrust and racial discrimination upon research attitudes.

The BrainWorks pilot engaged patient advocates, caregivers, former AAAE research participants and service providers in recruitment,

protocol design, survey design, development of the AD curriculum, data collection and dissemination. After completion of the pilot, two focus groups were conducted with 20 study participants to share findings, assess their experience, get feedback and identify potential research informants for future

studies. Currently, AAAE is conducting BrainWorks 2.0: Assessing the Need for Alzheimer's Disease Education among African Americans, Providers and Payers.

AAAE's Brain Health Initiative was created to address the higher risk and greater burden of AD among African-Americans compared to other groups. Research activities have been guided by an active and empowered Senior Advisory Council (SAC) Research Team: Dr. Lincoln, myself, Sikizi Allen, Maxine Toler and Mardell Reed (AAAE SAC Members). The SAC Research Team helps identify priority topics to support education and research activities; assist with study design and data collection; and provide guidance in translating study findings for presentations to research participants and community stakeholders. In

addition to community research being conducted by AAAE, we must consider the level of need and access to various types of resources to appropriately address the health gaps in program and service delivery for African-American seniors impacted by AD or a related dementia and the families that care for the afflicted.

Through creative collaborative efforts and partnerships, we can increase education, outreach and engagement activities and create innovative program and service delivery models that are culturally sensitive and relevant to African-American seniors and caregiving families.

Having greater access to programs and services and knowledge of the difference between AD, dementia and the normal or typical process of aging will change the current trajectory of AD and related dementias for African-American seniors and their caregiving families.

As a community, we must also promote brain health initiatives that can potentially reduce risk factors associated with AD and related dementias in ethnically diverse communities. A BrainWorks 2.0 study participant in a recent focus group mentioned being a firm believer in Each One, Teach One, sharing the information learned in the study with family, friends, neighbors, co-workers and church family.

Through the process of sharing information, we must also encourage people in our communities to seek cognitive assessments during their annual wellness visits with primary care physicians, thereby promoting early detection and proper diagnosis for AD and other dementias at the onset of noticeable changes that are NOT a normal process of aging. It is recommended that an interdisciplinary team approach be used for the most effective and thorough diagnosis and treatment of AD or a related dementia — more than the routine



Bryan F. Gaines

remembering three names and drawing a clock.

Additionally, we must encourage our elected officials throughout Los Angeles County to support reinstating data collection activities that have been eliminated as a result of budget cuts—ensuring data is being collected on

the most vulnerable populations and used to drive service development and delivery in communities of the greatest need. And, collectively as a community concerned for our well-being, we should convene to develop clear, coordinated, community-based strategies to ensure robust African-American participation in forthcoming programs and services.

In the coming decades, the impact of AD among African-Americans is expected to increase, and the economic implications for the United States and public health officials is daunting. The challenge of achieving health equity is huge and we must move in a direction that addresses eradicating health inequities for future generations.

Lastly, the implementation of clear goals and objectives; support from followers and stakeholders; strategies to address AD; and funding to sustain efforts are vital to addressing AD in the African-American community and supporting caregivers through the journey. If you or someone you know has special training or expertise in caregiving, nursing, social work, AD education, senior care, public health or policy, or feels the urge to volunteer, please contact: WHO'S GONNA TAKE CARE OF ME at 8467 S. Van Ness Ave., Inglewood Ca 90305; (Office) 310-693-4681; (e-mail) info@whosgonnatakecareofme.com.

Dr. Bryan F. Gaines serves as assistant director of the USC Hartford Academic Center of Excellence in Geriatric Social Work at the University of Southern California.

CRISIS HOTLINES & HOSPITALS

If you are experiencing a current emergency, call 911.

Crisis Team Hotlines

Crisis Hotline, ALWAYS OPEN, 800-854-7771
S.M.A.R.T. Team, Monday – Friday only, 213-996-1300
Police Officer responds with Mental Health Worker, 310-966-6500
PMRT (Pet Team) Psychiatric Mobile Response Team, 310-482-3260
MEU – Mental Health Evaluation Unit – LAPD, 213-996-1300
MET – Mental Health & Sheriff for LA County, 800-854-7771

Santa Monica Police, 310-458-8491
Local Police West L.A. Captain, 310-575-8400
TTY-hearing impaired, 562-651-2549
Suicide Prevention Hotline, 310-391-1253
West L.A. Mental Health Center – Ed Edelman, 310-966-6500
San Fernando Valley Mental Health Center, 818-832-2586
Exodus Recovery, Inc. (no insurance), 310-253-9494
Suicide Prevention Hotline, 310-391-1253

Source: <https://namila.org/crisis-hotlines-hospitals/>

A Play From the Perspective of an Alzheimer's Victim

"I'm Still Yo Mama," starring Donna Carroll Crockett, is a heartfelt one-woman show, written through the eyes of an Alzheimer's victim. Take the journey and experience the highs and lows. The gospel music will take you back.

Alzheimer's destroys families. It slowly destroys memory as well as physical and thinking skills. Verbal or not, "I'm Still Yo Mama." This play carries you through a life of turmoil, struggle, happiness, determination and the ultimate.

For show information, contact Donna Carroll Crockett by email at imstillyourmama@gmail.com.



Donna Carroll Crockett

Alzheimer's, a Disease That Targets You by Race

By **KAREN BARTOMIOLI**

Alzheimer's disease discriminates. As if there wasn't already enough to dislike about it. Your race, ethnic background and gender can be grounds for being targeted by this incurable killer, making it the relentless bully on the playground.

Those who are hit hardest by the disease — minorities — are also the least likely to be connected to support resources, to be diagnosed or even to be aware of the disease and their heightened risk. Combined, African-Americans, Latinos and Asian/Pacific Islanders make up about 70 percent of the Los Angeles County population, seriously compounding the challenge of outreach.

The county's two major support organizations — the local Alzheimer's Los Angeles and the national Alzheimer's Association — both have long-term, strategic plans that recognize the need to find ways to make inroads into communities that are isolated to various degrees by language and culture. When it comes to diversity outreach, the issues are more complicated than most might imagine. They go beyond awareness.

"There is a stigma attached to Alzheimer's for some cultures," said Marie Mayen-Cho, director of Education and Latino Services at Alzheimer's LA. "It's still something to be ashamed of. It can prevent them from seeking a diagnosis or support services. They may be hidden away by their family."

Mayen-Cho's focus extends to all minority groups, despite her job title. Her staff of five, like the 35 or so other Alzheimer's LA employees, reflect the community's diversity, representing a broad spectrum of ethnic backgrounds and languages. This is helpful, she said, because the biggest barrier is trust.

Mayen-Cho said: "It's what keeps people from reaching out. But when we have people who understand their perspective, we are able to reach deeper through more culturally-appropriate ways."

Outreach is a two-way street. Recipients need to be willing to meet supporters partway. For supporters, that means looking for approaches that are relevant for each culture.

Susan Howard, the program director for the Alzheimer's Association's California Southland, said the diversity of need is met by diversity in all aspects of support as her group seeks to reach all 16 million people in the greater Los Angeles area. This starts with a myriad of ways to connect, recognizing that not everyone is on the internet.

Their most effective tool continues to be their 800-number, a 24/7 hotline with help available in more than 200 languages. They, too, run into issues of embarrassment and keep all calls as anonymous as callers desire.

Out in the diverse neighborhoods

To be heard in all of the diverse neighborhoods of Los Angeles, it is important for outreach organizations to embrace diversity in their staffing and messaging.

that make up Los Angeles, California Southland is augmenting its ranks with community stakeholders.

"One of our major goals right now, which fits within our mission statement and strategic plan, is to greatly increase the number of volunteers and community partners," Howard said. "We look for volunteers who are from and mirror the communities they serve."

They work as community educators; support group and early stage engagement facilitators; and in faith-based programs. Most importantly, they bring more of a peer-to-peer approach that helps breach the trust barrier.

"We train them to know the warning signs of Alzheimer's and to have very accurate information to share," Howard said. "Outside of programs, they find innovative ways to reach out. They might hold a meeting in the home of someone they know. Some have even held meetings on buses."

Both Alzheimer's LA and the Alzheimer's Association are grasping

onto real grass-roots solutions.

Factors like lifestyle, longer life expectancy and a huge number of baby boomers hitting retirement age are contributing to the Alzheimer's epidemic. Genetics and cultural habits, like diet, also clearly play a role. Compared to Caucasians, African-Americans are twice as likely to get the disease, and Hispanics and Asian/Pacific Islanders are about 1.5 times more likely.

Here's a shocking reality: Hispanics make up more than 47 percent of the population in Los Angeles, and African-Americans and Asians are each about 10 percent. Pacific Islanders are at less than a percentage point, but have a much larger presence in the city than most places in the country. Alzheimer's also happens to be the third leading cause of death for

women in Los Angeles. Right now, there are more than 147,000 Angelinos living with the disease. Without a cure, that number is expected to nearly double by 2030.

In order to improve awareness and education, the groups are taking a close look at how people interact with the rest of the world. They are also reworking training and support materials such as "Savvy Caregiver," an evidence-based program developed by a group of psychologists that is proven to make a difference for families.

Culturally-focused videos used in community programs follow real caregivers and are shown at community centers. A Japanese-American family, for instance, would be featured in a video shown at a Japanese Community Center. The videos spark a lot of discussion and are requested more and more, Mayen-Cho said.

Other approaches taken by Alzheimer's LA include trying to raise awareness of the disease at opportune times, like Black History Month, and

inviting a black doctor involved in Alzheimer's research to speak at a community event.

Then there is the novella. Yes, the diverse staff has written four chapters following a family in East LA who are caring for their grandmother. The compelling, award-winning narrative covers symptoms, diagnosis and the family's musings about the journey.

Hitting on the broadest possible spectrum of communication is key, Howard said. In addition to different communities based on ethnicity and geography, she listed the LGBTQ community.

Familiarity — the more you talk about the disease, the easier it is — plays an important role in awareness. The Alzheimer's Association has a class on dementia conversation, how to bring it up and other practical tools.

Advocating for better diagnosis is another approach.

"Medicare offers an annual wellness screening of cognitive abilities, but most doctors are not routinely doing it during a regular visit," Howard said, "and the patient expects the doctor to bring it up. Both sides need to be more aware of the need."

Community volunteers hope to be able to convince individuals or their families to seek a diagnosis, which can open up many avenues of support.

Further emphasizing the importance of diversity, research funding for professionals from underrepresented groups will be awarded this summer.

The Alzheimer's Association Research Grant to Promote Diversity program is aimed at increasing the number of dementia researchers from backgrounds that are underrepresented in biomedical research. Factors being considered are race; ethnicity; economic or geographical disadvantage; physical and mental disabilities; and having completed a degree or residency within the last 10 years.

Karen Bartomioli is an artist, photographer and journalist specializing in freelance investigative reporting. She lives in Connecticut, and on the Web.

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PUBLISHER'S NOTE

Everyone's Not Ready For Primetime Caregiving Time to Step Up

By **BUTCH GRIMES**

Every day I hear a story about a family member who has disconnected, doesn't have the capacity or won't play any part as a caregiver for their loved one. There are several reasons for this. Some people are just plain selfish and others are scared.

This kind of misunderstanding occurs very often with family members dealing with a loved one suffering from Alzheimer's/dementia.

Sometimes just hearing the words Alzheimer's or dementia drives family members away. They become afraid of the caregiving responsibilities that accompany the disease. Some are just ashamed to be identify with the disease and others disappear as a result of ignorance, fear, busy schedules or a deliberate attempt not to be involved.

However, what most people fail to understand, is that

we do not have the luxury to choose who our family members are.

We can choose who we want to be friends with; those we want to bring into our sphere of contact. We can even choose our colleagues. We can choose our pets, clothes, the wife or husband we want to marry.

After marriage, your wife is your wife; your husband is your husband; your children are your children; your parents are your parents; and your in-laws are your in-laws. So not to be there for them in times of need or critical condition would amount to denial.

When I write about this, I get the heebie-jeebies. I just don't understand how someone wouldn't care for their MOM or DAD as they were cared for when they were young or in need.

My brother Tony is 1,500 miles away and has never run from a request to be by my side or support me with

OUR mom, who is suffering from Alzheimer's /dementia.

We communicate regularly, make decisions together and are never too busy to make that daily call to each other making sure we are eating right, getting enough sleep or exercising regularly.

A broke down caregiver is no good to anyone. I know, I am a very lucky older brother to have that support from my younger brother, Tony. I shouldn't be surprised, that's just how we were raised.

I'm sharing my experience because so many families are being emotionally broken apart and financially strained by caring for their loved ones.

Of course, it might not be possible to be there 100 percent, or 24/7, for anyone — more so when a loved one is dealing with Alzheimer's/dementia, and is sick and incapacitated.

Every little bit of time counts. Do you grumble,



Butch Grimes

Butch Grimes says that even though his brother Tony, right, lives far away, he knows he can count on him.

complain, nag or curse when you are asked to participate in caregiving activities?

Trust me, we all need a break and you just might be the one to provide rejuvenation for the lead caregiver. Every family member **MUST** step up to the plate and do their part. Alzheimer's/dementia is a team sport. All hands must be on deck.

If you feel like you don't know enough about the disease, read the Alzheimer's Digest, its free. Talk to people online. Talk to colleagues, friends or other family members. Trust me, there is no shortage of Alzheimer's cases and stories to reference, especially in the minority community.

Also, encourage other family members to be sup-

portive in any way they can. You must not be judgmental, be a good listener — even when your siblings complain or don't make sense. Don't add to the confusion! Be the facilitator, not the agitator. Participate in decision making, don't be in a rush, carefully listen and participate in the all discussions.

Don't forget my earlier example, distance doesn't matter. If you really want to be there, you will, like my brother Tony. If I need him, he always has my back. That plane ride from Texas is no big deal. He is always right at my side.

Let this be an example of how your family can work through the rough spots and make things run smoothly for your loved ones suffering with Alzheimer's/dementia.

DO YOU KNOW A MISSING PERSON WITH ALZHEIMER'S?
PLEASE CONTACT US TO POST AN ALERT: 310-693-4681 or info@alzheimersdigest.info



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'What's That, Boss?' A Son Questions His Mom's Care

By MARIE Y. LEMELLE

Los Angeles resident Eddie Rochester Anderson Jr. is the son of the legendary actor and comedian Eddie "Rochester" Anderson, known for a nearly 30-year run on the Jack Benny Program and starring in more than 60 classic feature films, including "Cab-in in the Sky."

The elder Anderson was known for the line "What's that, Boss?," a catch phrase that was designed to expose Benny as a self-absorbed cheapskate. Rochester in real life was the opposite of his employer on the show: He was generous to a fault and lived life to the fullest. He died in 1977, when Eddie Jr. was 19. Before his death, he passed the baton to Eddie, his youngest son, to preserve the family legacy and help others by establishing a nonprofit to provide humanitarian services.

As a result, the younger Anderson became a champion for the homeless with a dream of serving his community. "It didn't come in a flash or some type of epitome, instead it grew from many seeds my father had planted in me at a very young age," Anderson said. "One of my fondest memories was the surprise gift of an authentic Superman suit from my father. His grand gesture exceeded all celebratory expectations by proclaiming me as his hero."

Anderson's father told him, "I'm not a religious man but I'm a righteous man". This philosophy instilled in him the desire to be of service and to lead by example.

Today, Anderson is his mother's hero. "About seven years ago, I noticed many alarming changes in my mom's appearance; from 145 pounds to 90 pounds; her angry moods and lack of interest in eating, and inability to swallow solid foods," he said. "Her doctor announced that

my mother was suffering from severe Alzheimer's and Dementia."

Anderson, like many people, knew very little about the disease. Alzheimer's is a type of degenerative brain disease and the most common form of dementia. Some symptoms of dementia are declines in memory, thinking, behavior and the ability to perform everyday activities. There are many different forms of dementia.

"My lack of knowledge pushed me to enlist God to form my Mission Possible team," Anderson said. "My mother's failing health only supported the doctor's diagnosis that she was in the stages of her last days on Earth."

He soon learned that Alzheimer's affects more than 5.5 million Americans and is currently the sixth leading cause of death. According to the World Health Organization, there are an estimated 47 million people living with dementia worldwide, a number projected to increase to 75 million by 2030.

Currently, there is no cure for Alzheimer's or dementia. Anderson refused to accept the doctor's diagnosis as a death sentence for his mother. "I immediately empowered myself and began the research to find a better solution and not give up or give in to the doctor's course of action or lack of a solution," he said.

"I had a 'What's that, Boss?' moment of skepticism and insisted on meeting with my mom's doctor," Anderson said. "The doctor and his team were ill prepared for my barrage of probing questions about the treatment method and medication that was prescribed as her daily regimen."

After reviewing all available information, Anderson believed that the medications prescribed to his mother were not designed for her recovery. (Note: Every case is unique, just as



Anderson Estate

Eddie Rochester Anderson Jr., the son of a Hollywood legend, was unhappy with a doctor's suggestions after his mom, Eva, was diagnosed with Alzheimer's disease and dementia.

our brains are not the same.) Anderson came to the conclusion that the medication was having an adverse effect on his mother. "I asked the doctor if there isn't a cure, what is the reason for all the drugs?" he said.

Anderson said that the doctor took offense to the question. "He spoke to me in a condescending manner and had asked, 'What am I a doctor now?'," he said. "Of course, I replied no, I'm not, but I do possess this small meaningless thing called a brain and this tells me that all of the medicine you're prescribing to her is not helping. The side effects are killing my mother."

Anderson was unhappy with his mother's diet, and sought one that might provide a nutritional advantage in her battle for life. "I chose a more natural approach in a holistic manner with herbs and eliminating any type of meat in her diet, no alcohol, no laxatives, and no heavy metal substances," he said. "To be honest, making such a decision was very uncomfortable and very fearful. Instinctively and factually knowing the doctor's order of submitting to a generic dream wouldn't make her life healthier."

Today, Anderson is proud and excited that his mother is thriving. "My mother has gained all of her weight back and her memory has not continued to decline," he said. "She still has short term memory but there are

times that she recalls certain things from the past, which was not the case several years ago."

Anderson said that his mother also walks faster than him, can touch her toes and playfully throws a mean left and right punch.

"My mother will soon be 87 years old and she's had this disease for countless years," he said. "Parents of many of my friends have suffered from the same disease and their condition accelerated and ultimately resulted in death."

His father's words, "Defeat could not be an option" and "What's that, Boss?," were the catalyst to push Anderson to be the hero for his mom. He continues to champion the Anderson legacy and honor his father as a trailblazer and humanitarian in his community.

On June 19, Eddie "Rochester" Anderson Sr. was honored in Los Angeles with a ceremony on Rochester Circle. The street's name was changed to Eddie "Rochester" Anderson Street.

Marie Y. Lemelle, MBA, is a public relations consultant and the owner of Platinum Star PR and can be reached on Twitter @PlatinumStar or Instagram @PlatinumStarPR. Send questions or stories related Alzheimer's, dementia or any other form of memory loss to info@platinumstarpr.com.



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DOCTOR'S CORNER

Knowing the Stages of Alzheimer's

By **SHERRIL RIEUX, M.D.**

Alzheimer's is one subcategory of dementia accounting for 60 to 80 percent of all dementia in the United States. Symptoms of memory loss, problems thinking and behavior changes develop slowly and progressively worsen over time.

The disease can take four to 20 years to run its course. Stages don't progress neatly from one into the other. There will be some overlap, some better days that follow bad ones. But it is always a relentless march, and once a symptom appears, you can bet you'll see it again soon.

Knowing the stages of Alzheimer's is important for the patient as well as the caregiver. It allows both sides to plan, delegate and reduce some of the stress associated with this devastating disease. Some things to consider:

- Financial planning such as wills, trust and banking.
- Choosing which family member to control finances vs. make medical decisions.
- Home vs. facilities?
- Remain in California or move to be closer to more family members.

These are decisions that are much easier to make when the patient is able to have input.

Caring for someone with Alzheimer's is as much about their state of mind, and yours, as it is about the physical. As changes happen, you can be prepared for them; with resources, a revised care plan and the strength that results from taking

charge.

Physical symptoms, like incontinence, can be tough to deal with. Others require vigilance because they can put the patient in danger: things like hallucinations, depression, aggression and wandering.

Avoiding the surprise of an unexpected issue can help you maintain control over whatever circumstances arise, and help you bring dignity to your loved one's last years.

Stage One goes undiagnosed because mom or dad is likely experiencing only the forgetfulness that comes with age. People in this stage may continue to work, drive and live independently, and can go years without experiencing real cognitive and functional decline, mood and behavioral changes.

Stage Two is marked by more noticeable forgetfulness, but the disease remains pretty much undetectable.

In **Stage Three**, family and a physician may begin to notice a slight decline in your loved one's ability to focus on ordinary tasks, or the occasional struggle to find the right word or remember a familiar route. This stage typically lasts for about seven years.

Stage Four or **Early Stage** is when dementia is most often diagnosed. Cognitive decline may be only slightly more apparent than in Stage Three, but there will be further loss of memory and focus.

Mom or dad may forget recent events, find it difficult to solve problems, manage finances and put their

thoughts into words.

As they begin to worry about their symptoms, they may revert to denial and avoid family and friends, making antisocial behavior a telltale sign.

This stage usually lasts for two years and is when a doctor can most easily diagnose by interviewing the patient.

Mid-Stage can last for years — through stages five and six — and is marked by continued decline and the start of psychological symptoms that may include mood swings, anxiety, depression, paranoia, agitation and hostility.

Most of these are the result of the disease's impact on various parts of the brain, but may also have to do with the patient remaining aware of their situation. They may experience a pervading sense of loss or insecurity as their memories and focus fade away.

This is often the most challenging time; when caregiving becomes essential and families begin to consider a move to a care facility.

In **Stage Five**, people need help with daily activities, such as dressing and meals. Memory loss can be severe and they forget things like their home address. They lose orientation to time and place. This stage lasts about one and a half years.

Stage Six lasts an average of two and a half years and is often marked



Sherril Rieux

by the inability to recall names of close family and friends, both long-term and recent memories and the simplest cognitive skills. Speech difficulties and personality changes may be evident and incontinence is likely to be an issue, along with decline in the ability to walk.

Seventh- or Late-Stage is when speech and psychomotor capabilities decline significantly and 24-hour care is needed as the patient becomes unable to do anything for themselves. This stage lasts an average of two and a half years.

It's easy to see how the disease can be overlooked for years, and how important it is to be on the lookout for symptoms. The end will usually come four to eight years after diagnosis.

It may not feel like a good thing to know as early as possible, but the silver lining is that, while there is no cure, medications and lifestyle changes can slow Alzheimer's progression. Quality of care has been shown to have very significant effects, such as extending the patient's ability to walk, show emotions like laughing or being able to give a hug.

The added time also allows the opportunity to talk with your loved one, in a less emotional way, about a plan for care, bringing some comfort to both the patient and the caregiver.

SPLIT, From Page 1

on the radar of the general public, which may be confused, instead, about a deluge of new marketing and websites with similar names and logos, and wondering why there are more fundraisers.

Is this fostering distrust and lower donations? Hard to say. Organizations all claim they haven't seen any downward trends in program participation and donations, and if that can be attributed to growing need, it would not be surprising.

In the greater Los Angeles area, national calls it's new chapter California Southland. Free support services are provided to Los Angeles, Riverside, San Bernardino, Kern, Tulare, Kings and Inyo counties.

The independent affiliate has gone through several name changes, and now calls itself Alzheimer's Los Angeles. It serves Los Angeles County and the Inland Empire. The latter, encompassing cities in parts of Riverside and San Bernardino counties, has one of the largest Latino

populations in the nation.

It follows that this area is at great risk when it comes to Alzheimer's, both in terms of developing the disease and in a lack of access to, or awareness of, support services.

Recent research is revealing alarming statistics for minorities, including that in the United States, Latinos are 1.5 times as likely as Caucasians to develop Alzheimer's, and African-Americans are twice as

Alzheimer's Los Angeles hasn't seen much disruption since breaking off from the Alzheimer's Association.

likely. A report from the University of Southern California projects an 832 percent increase in Latinos living with Alzheimer's over the next 40 years. Add to the issues a higher rate of non-diagnosis, said Susan Howard, programs director for California Southland.

"Diversity and inclusion are extraordinarily important, especially considering the increasing need among minorities, and that they are

less likely to reach out for help," Howard said. "We just created a new pillar and appointed a chief officer to address that. In L.A., especially, we need to identify and prioritize services. That goes back to our original mission."

A pillar that remains steadfast is research funding, with more than \$15 million pumped into the Los Angeles area annually. In concert with that, local offices work to match

participants with clinical studies.

At Alzheimer's LA, Heather Cooper Ortner, the chief executive and president, said they have been working on building a broad base of support from within communities; partnering with city and county agencies. The split has been not caused much disruption. Only two people from their staff did not stay with them.

Cooper Ortner said: "It's been

good in many respects. The drama of the change is behind us. Our departure from the national organization gave us the opportunity to re-evaluate, and we have appointed a Director of Latino Outreach and Services. The biggest challenge is the people who don't know they need us."

She said not being bound by national priorities is liberating. "We can really work locally, and pull state and federal focus toward what they need to be doing in our three counties," Cooper Ortner said. "We collaborate with three state agencies and 10 health plans in six counties."

Research for a cure, or at least an effective treatment is too important for any Alzheimer's organization to overlook. Alzheimer's LA recognizes the wealth of young, innovative researches at places like UCLA and Loma Linda University, and is devoted to supporting them.

About to make its debut is a new strategic plan that factors in socio-economics, addresses ways to expand, in particular, into under-served areas.

ANOTHER PERSPECTIVE

Toughing it Out, or Not

By VICTOR JACKSON

In an ad campaign sponsored by AARP, movie tough guy Danny Trejo talks candidly about male caregivers and how everyone has “a toughness that’s unbelievable” that allows them to do one of the hardest jobs ever.

He also talks about love, suggesting that, while putting your head down and going for it may work, there is no avoiding the emotions involved. You can’t just man up or get in the zone and expect a clean result. There no scoreboard in caregiving. Just a lot of coping.

As many as 16 million men in the U.S. help with or are the primary caregivers for their parents or spouses with long-term illnesses; a large percentage with Alzheimer’s disease or other dementias. The gender ratio has been on the rise with men now at 40 percent.

In that respect, we are getting past macho stereotypes. But men are still far less likely to look for emotional support, and anyone who thinks they don’t need it is kidding themselves. Caregiving is heart-breaking, especially when it’s for a loved one with a disease that robs them — maybe your mom or wife — of their very personality. Knowing that others are going through the same thing may not make it easier for you, but a support group can have an impact like nothing else:

- Only they can truly understand and laugh at what you experience.
- Only they know you would never act on the desperate feelings you sometimes have.
- Only they will know the answers to questions you haven’t even thought to ask.
- You will not be the only person in the room dealing with family issues or experiencing profound loneliness.

■ Reassurances can be as energizing as the full night’s sleep you never get.

Here are some common misconceptions about support groups:

- They are for the weak.
- They are for those who are comfortable expressing their feelings or require you to talk about personal things that make you uncomfortable.
- They don’t offer practical tips for caregiving and talking with doctors.
- They don’t offer one-on-one counseling and are always a group of people sitting in a circle.

Support groups these days can be found online in chat forums and groups that meet via video. They can mimic what women have always been more inclined to do: develop



Victor Jackson

their own support network. They can rotate through caregivers’ homes, or meet in the home of a caregiver who cannot get away. An in-person group can be a resource for developing a new social circle of friends who understand that sometimes what you really need is a break without introspection.

The bottom line here is that trying to be a hero is not a good game plan. Start by searching online for support groups in your area, or for a one-time event. Talk to your town social worker, clergy person or community center director. If they can’t point you to resources, consider asking them to help you start a group. Helping others could be just the therapeutic support you need.

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ALZHEIMER/DEMENTIA

with Butch Grimes

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SUPPORT GROUP DIRECTORY

For caregivers, finding support and meeting others who understand their struggles is important. This information comes from Alzheimer's Los Angeles, an organization dedicated to supporting families and caregivers. According to the group's website, www.alzheimersla.org, "Our Support Groups are free, led by trained group facilitators, completely confidential and are held throughout Los Angeles County in multiple languages."

TELEPHONE SUPPORT GROUPS

All service areas YO, FT
Facilitator: Dr. Linda Ercoli
Facilitator: Yael Wyte
310-794-3914

SANTA CLARITA VALLEY Newhall

■ Santa Clarita Senior Center **CG, ***
Facilitator: Etta Martin
661-259-9444
Facilitator: Monique Castillo
818-830-4835
■ Oakmont of Santa Clarita **CG, ***
Facilitator and contact:
Mary Dembkowski
661-993-3240
Facilitator: Deborah Dicorradro
661-993-2004

SAN FERNANDO VALLEY Agoura Hills

■ Meadowbrook Senior Living **CG, ***
Tami Podell
818-357-1123
Burbank
■ Burbank Joslyn Senior Center **CG, Spanish, ***
Francisca Reynoso
818-398-1475
■ Leeza's Care Connection **AC, EP, ***
Contact: Wendy Saltzburg
818-847-3686

Calabasas

■ Silverado Senior Living Calabasas Memory Care Community **CG, ***
Jennifer Watson
818-317-3421

Canoga Park

■ Canyon Trails Assisted Living and Memory Care **CG**
Dinora Toj
323-930-6247

Encino

■ Hope Connection **B**
Jo Christner
818-788-4673

Glendale

■ Glen Park Healthy Living **CG, ***
Facilitator: Annie Cardillo
818-242-9000
Facilitator: Paula O'Sullivan
818-296-4097

Granada Hills

■ Aegis Living of Granada Hills **CG**
Facilitator: Brittany Kramer
Contact: Ron Borzcon
818-776-1183

North Hollywood

■ Private Home **CG, Spanish, ***
Nadia Cantuña
818-720-4482

Northridge

■ Brookdale Northridge **CG**
Gabriel Diaz
818-886-1616
■ Somerford Place of Northridge **CG, ***
Jennifer Watson
818-317-3421

Pacoima

■ Little Tokyo Service Center – Japanese-American Community Center **CG, English, ***
Facilitator: Isabelle Miyata

CAREGIVERS SPOTLIGHT



Donald Candys is a real estate investor in Los Angeles. He is also the sole caregiver for his mother, who was diagnosed with dementia five years ago.

Donald Candys

Contact: Lois Okui
818-899-1989

Panorama City

■ Kaiser Permanente **CG**
Lisa Luna
818-788-5862

Reseda

■ Jewish Home for the Aging – Eisenberg Village **EP, ***
Jennifer Watson
818-317-3421

■ Jewish Home for the Aging – Fountainview **CG, AC, S, ***
Facilitator: Jennifer Watson
Contact: Susan Leitch
818-757-4490

Sylmar

■ LA Caregiver Resource Center Lake View Terrace Library **CG**
Lucila Torres
855-872-6060

Tujunga

■ Verdugo Hills Family YMCA **CG, ***
Facilitator: Bernice Sanders
Contact: Gaby Najera
818-583-4744

Van Nuys

■ ONEgeneration Adult Day Care **CG, ***
Denise Kee-White
818-708-6376

West Hills

■ Meridian Senior Living **CG**
Vana Pensuriya
818-264-0970
■ Sunrise Senior Living **CG**
Stephanie Bien
818-701-9550
818-991-8282

Woodland Hills

■ Woodland Hills Caregiver Group **CG, EC***
Karin Marin
818-734-9991
■ The Commons at Woodland Hills **CG, AC, ***
Jennifer Watson 818-317-3421

SAN GABRIEL VALLEY

Glendora

■ La Fetra Senior Center **CG, ***
Jill Bakker
626-774-1419

Pasadena

■ Alzheimer's Los Angeles Memory Club at Huntington Hospital **EP, EC, Early Stage, ***
Kristen Tachiki
626-397-8145
■ Alzheimer's Café / Pasadena Senior Center **CG**
Facilitator: Jenny Delgado
Facilitator: Renee Concialdi
Facilitator: Amber Bolanos
626-584-8130
■ CAPS Adult Day Care Center **CG, ***
Mimi Brown
626-351-5427
■ Pasadena Senior Center **CG**

Mei-chi Kuo
213-821-6920

■ Terrace at Park Marino **CG, ***
Carolyn Wong
626-798-6753 x303

Rosemead

■ California Mission Inn **CG**
Yvonne Kuo
213-821-6919

METRO LOS ANGELES

Beverly Hills

■ Nessah Synagogue **CG, Farsi, ***
Nancy (Nahid) Rafii
310-874-5110

■ Sunrise Senior Living Beverly Hills **CG**

Ann White
310-247-4479

Los Angeles

■ Silverado Senior Living Beverly Place **CG, ***
Facilitator: Thomas Baird
323-825-4304
■ Male Caregiver's Support Group – Alzheimer's Los Angeles **CG, M, ***
Dave Sitzer
213-293-9408

■ Adult Children Support Group – Alzheimer's Los Angeles **AC, YA, ***
Zina Paris
323-930-6212

■ Alzheimer's Los Angeles Memory/ Grad Club/Alumni Club **EC, EP, EO, ***
Alicia Villegas
323-930-6289

■ APHCV – Los Feliz Health Care Center **CG, Tagalog**

Perla Santos
323-644-3880 x341

■ Little Tokyo Service Center – St. Francis Xavier Chapel **CG, Japanese & English, ***
Kiyoko Kaneda
213-473-3035

WEST LOS ANGELES

Culver City

■ Culver City Senior Center **CG, ***
Zina Paris
323-930-6212
■ Kaiser Permanente Culver Marina Medical Office **AC, ***
Ed Holly
310-915-4567
■ Meridian Culver City **CG, ***
Reggie Rodriguez
559-349-3466
■ Kaiser Permanente – West LA Medical Center **CG, ***
JB Saunders
323-857-3784
■ OPICA Adult Day Health Center **CG, S, AC, \$**
Facilitator: Anne Galbraith
Facilitator: Elizabeth Lira
310-478-0226
■ St. Sebastian Catholic Church

CG, Spanish

Facilitator: Dr. Xavier Cagigas
Facilitator: Enrique Gracian
310-825-4304
■ West LA VA Medical Center – for Veterans or Caregivers of Veterans **CG**
Jessica Alva
310-478-3711 x41652

Santa Monica

■ UCLA Medical Center Santa Monica **CG, LB**
Facilitator: Dr. Kathleen Tingus
Facilitator: Catherine Jones
Contact: Monica Moore
310-794-3914

■ Sunrise of Santa Monica **CG, ***
Facilitator: Julie Liker

Contact: Denese Taylor
310-922-5659

■ WISE & Healthy Aging **CG**

Facilitator: Nick Eisner (a.m.)
Facilitator: Blaine McFadden (p.m.)
Contact: Phyllis Amaral
310-394-9871

West Los Angeles

■ Hope Connection **B**
Jo Christner
818-788-4673

Westchester

■ Westchester Senior Center **CG, ***
Loli Ramezani
310-649-3317

Westwood

■ Belmont Village of Westwood **CG**
Dena Schwimmer
323-451-9313
■ UCLA – Mary S. Easton Center / Alzheimer's and Dementia Care Program Support Group **CG, ***
Facilitator: Barbara Hament
Facilitator: Monica Moore
310-794-3914

SOUTH LOS ANGELES

Los Angeles

■ National Council of Negro Women Building **CG, FB**
Facilitator & Contact: Jeanie Harris
Facilitator: Sharon Melancon
323-296-2975

■ St. Paul's Presbyterian Church **CG, FB, ***

Facilitator: Lois Hines
Facilitator: Andrea Michelle Bracken
323-295-2062
323-637-3170

■ USC Davis School of Gerontology **CG**

Jenny Peterson Grace
855-872-6060

■ First AME Church **CG**

Mrs. Bobbe Akalona
855-872-6060

EAST LOS ANGELES

Cerritos

■ Cerritos Senior Center **CG**
Lisa Miyahata
562-916-8550

Downey

■ Remita Health **CG**
Elisa Gaytan
562-904-6777

Huntington Park

■ Alzheimer's Los Angeles – Huntington Park Public Library **CG, Spanish, ***
Angie Moran
323-859-8810
CG, Spanish, *

■ Alzheimer's Los Angeles **CG, Spanish, ***

Dinora Toj
323-881-0586

Montebello

■ Beverly Hospital Women's Care Center **CG, ***
Facilitator: Sandy Acosta
Contact: Alice Baldwin
800-618-6664

SUPPORT GROUP DIRECTORY

323-725-5032

Santa Fe Springs

- Gus Velasco Neighborhood **CG, ***
Lucila Torres
855-872-6060

Whittier

- Oakmont of Whittier **CG**
Vickie Pearson
562-693-8222
- Whittier Place Senior Living **CG**
Tina Hernandez
714-856-3909

SOUTH BAY**Gardena**

- Southbay Caregiver Support Group **CG, Japanese & English, ***
Akiko Takeda
310-819-8659

Inglewood

- Rogers Park **CG, ***
Linda Peterson
310-412-4368

Long Beach

- Brittany House **CG**
Colleen Rozatti
562-421-4717
- Faith Presbyterian Church **CG, ***
Terri Furlow
562-427-8048
- Long Beach Memorial Medical Center **CG, ***

Facilitator: Jim Kelly
Contact: Dinora Toj
323-930-6247

- Namaste Center for Spiritual Living Paty Piar **CG, ***
562-795-5762

- Skills4Care **CG, ***

Facilitator: Paty Piar
Contact: Robert Skidmore
562-413-1061

- Grace First Presbyterian Church **CG**
Yvonne Kuo
855-872-6060

Manhattan Beach

- American Martyrs Church & Homewatch Caregivers **CG**
Facilitator: Dick Williams
310-292-0996

Palos Verdes Peninsula

- Palos Verdes Peninsula Center Library **CG, ***
Lauren Spiglanin
310-383-1877
- Mary and Joseph Retreat Center **CG**
Lucila Torres
855-872-6060

Redondo Beach

- Beach Cities Health District **CG, ***
Facilitator: Rosalie Rapas
Contact: Officer of the day
310-374-3426 x138
- Beach Cities Health District – Memory Club **CG, EP, EC, ***
Facilitator & Contact: David Hart
Facilitator: Tara Guden

310-792-8666

- The Neurobehavioral Healthcare Center **CG, ***
Dr. Lauren Keats
310-855-3288

San Pedro

- Harbor Terraces Assisted Living **CG, ***
Lauren Spiglanin
310-383-1877

- The Salvation Army Sage House Adult Day Care Center **CG**
Sherrie Similton
310-832-6031

Torrance

- Always Best Care **CG, ***
David Hart
310-792-8666
- Family Connect Memory Care **CG, ***
Lauren Spiglanin
310-383-1877

INLAND EMPIRE**Apple Valley**

- Valley Crest Memory Care **CG**
Renee Savage
760-242-3188

Big Bear Lake

- Senior Citizen Center of Big Bear Valley **CG**
Sokura Solario
909-584-0323

Chino

- Pacifica Senior Living Hillsborough **CG**
Facilitator: Ahley Goodley
Facilitator: Jennifer Helboorn
909-386-6068, 909-548-2100

Chino Hills

- Pacifica Senior Living Chino Hills **CG, ***
Lloyd Mustin
909-270-0866

- Chino Valley Community Church **CG, ***
Facilitator & Contact: Lloyd Mustin
Facilitator: Lisa Laufer
909-270-0866

- Oakmont Senior Living **CG, ***
Lloyd Mustin
909-270-0866

Claremont

- Claremont Joslyn Senior Center **CG, ***
Facilitator: Angelika Pittet
Facilitator & Contact: Lydia Bouroumand
909-621-9900 x238 or 909-399-5488

- Claremont Place **CG, ***
Facilitator: Angelika Pittet
Facilitator: Lydia Bouroumand
Contact: Tricia Elliker
909-447-5259 or 909-399-5488

- Claremont Club **CG, ***

- Laura Van Dran
909-921-1033
- Pilgrim Place Health Services **CG, ***
Laura Van Dran

909-921-1033

- Sunrise of Claremont **CG, ***
Lloyd Mustin
909-270-0866

Corona

- Brookdale Corona **CG**
Joy Rivera
951-898-6991

Loma Linda

- Linda Valley Senior Living **CG**
Antonia Lopez
909-799-3117

Mentone

- Rose Garden **CG**
Justina Cardenas
909-794-1040
- Welbrook Senior Living **CG**
Michelle Thompson
951-200-3110

Rancho Cucamonga

- Alzheimer's Los Angeles & Home Instead Senior Care **CG, ***
Sharon Jones
909-476-9030
- Sunlit Gardens **CG**
Kelli Garfield
909-215-2142

Redlands

- Blossom Grove **CG**
Mechelle Alona
909-335-6660
- Plymouth Village Retirement Community **CG, ***
Connie Garrett
909-793-1233 x1620
- Somerford Place Assisted Living **CG**
Debra Walls
909-793-9500

Riverside

- Care Pathways **CG**
Karen Armijo
951-867-3800
- Care Connexus Adult Day Services **CG**

- James Slater
951-509-2500
- Pacifica Senior Living **CG**
Jill Johnson-Young
951-360-1616

- Sunrise Senior Living – Canyon Crest **CG, ***

Facilitator: Paul Velen
Contact: Mary-Ellen Taber
951-686-6075

San Dimas

- Brookdale Senior Living **CG, English & Spanish, ***
Maria Monedero
909-394-0304 x233

Upland

- Oakmont of San Antonio Heights **CG, EO, AC, S**
Anthony Villegas
909-981-4002
- St. Anthony's Catholic Church **CG, ***
Laura Van Dran
909-921-1033

KEY TO ABBREVIATIONS

AC Adult Children
B Bereavement
BS Bereavement Spanish
CG Caregivers (General)
DS Caregivers of Down Syndrome Persons with Dementia
EC Early Stage Caregivers
EP Early Stage Persons
EO Early Onset Persons
FB Faith-Based
FT Frontal Temporal Caregivers
H Huntington's Disease
LB Lewy Body Dementia Caregivers
LGBTQ Lesbian, Gay, Bisexual, Transgender, Questioning
M Male Caregivers
P Parkinson's Caregivers
PWD Persons with Dementia
S Spouse
VD Stroke Survivors
YA Young Adults of PWD
YO Young On-Set (EO) Caregivers
\$ Inquire about fee/donation
***** Trained by Alzheimer's Los Angeles

Victorville

- Home Instead Senior Care **CG**
Sharon Jones
760-843-5655 or 909-476-9030
- Sterling Commons **CG**
Debra Newlin
760-245-3300

SOUTHWEST RIVERSIDE COUNTY**Beaumont**

- Beaumont Senior Center (Albert Chatigny) **CG**
Veronica Ramos
909-799-3117, 909-266-2672

Hemet

- Desert Hills Memory Care Center **CG, ***
Facilitator: Jane Farmer
Contact: Chantelle Hudson
951-652-1837

Sun City/Canyon Lake

- Canyon Lake Community Church **CG**
Facilitator: JoAnn Wickerath
Contact: Beverly Haney
Facilitator: 951-679-7736
951-244-1877 x200 (church)

Sun City/ Menifee

- Care Connexus Adult Day Care **CG**
Jim Slater
951-509-2500

Temecula

- Rancho Community Church **CG**
Facilitator: Sylvia Garcia
Facilitator: Lyn Euzenas
951-303-3986



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Long-Term Care Considerations

Staff Report

Getting old, getting sick, no matter what, it's going to be expensive. But getting an idea of costs now can reduce sticker shock later, and motivate those who need to mount a preemptive strike.

Costs for assisted living facilities vary widely from state to state, and even within states. Nationally, the average monthly bill, per the latest compiled data (2016), is \$3,600. That's for standard nursing home care. Add on specialized Alzheimer's/dementia care, and the bill goes up another \$1,150. Look for alternatives, such as independent apartment living with options for various levels of skilled care, dining services and other amenities, and that \$3,600 is a starting point.

Throwing money at the situation only works for the one-percent. The rest of us worry about what Medicare will pay for. Remember that it is no longer one-plan-fits-all. You need to know exactly what your benefits cover.

The same goes for in-home care. You may or may not be covered, or only partially, depending on where you live. Nationally, in-home caregivers — homemakers, healthcare workers or a combination — are paid \$20 per hour on average. Plan on paying at least \$125 per day for a contracted week, usually 44 hours. You're prob-

ably thinking, "what about the other 124 hours in the week?"

That's where the 16 million Americans who provide unpaid home care come in. Not everyone needs round-the-clock care, but with 55 million people living with the disease, the hours add up across the board, to 18.5 billion. That's \$234 billion worth of care, provided by spouses, other family members and friends.

Whaddaya gonna do?

We also worry about becoming a burden to our children and family. Planning is the best solution. If there is an upside to an Alzheimer's diagnosis, it's that there is time to do things that will ease the burdens later on:

- Find a health care advocate to guide you through the process of signing up for Medicare, Medicaid or other coverage, to work toward enrolling in a plan that better suits your needs or to simply be clear about your benefits.
- Buy supplemental insurance for specifics like medications and long-term care.
- Buy life insurance you can tap into later on.
- Explore programs such as Program of All-Inclusive Care for the Elderly (PACE).
- Consider assets, such as property equity, and look into transferring ownership.
- Reduce family stress by putting your house in order,

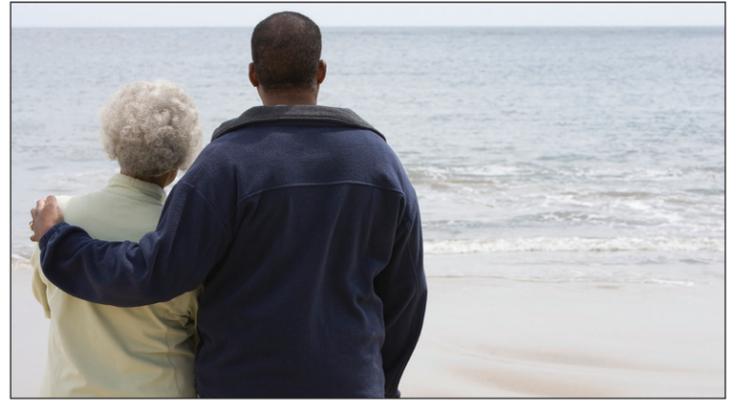
literally. Declutter, organize, hire someone to clear out the basement or garage, donate unneeded furniture, make a list of who will get specific items.

■ Do the legal stuff; advanced directives that include at least a living will (medical proxy), DNR and other directions for advanced life support, as well as funeral arrangements. Consider organ/tissue donation so your loved ones aren't left with the decision.

■ Buy an insurance policy to pay for your funeral.

Allow for flexibility. Remember that, in the end, it is about those who love you. Use that as motivation for the things that are difficult to face, or when encouraging a loved one to do them.

What are you gonna leave in your wake? A great example of considering family is a favorite great-aunt, who not only spelled out everything, legally and otherwise, but who made sure her funeral attendees remembered her joy for life by arranging for masses of balloons and "holiday" goodies from a popular local bakery to be sent to the reception. During the service, her children (grateful for not having to write eulogies) each read a letter from mom telling them how much they meant to her. There was never anything morbid about her comprehensive planning, and she left this world on a positive note for everyone



Ingimage.com

who knew her.

Be Prepared

With in-home care, the cost of incidentals can mount up. Again, look carefully into coverage, but expect to be out-of-pocket for things like over-the-counter medications and incontinence supplies. Medicare is not going to pay for adult diapers, which average about a dollar each. Complete incontinence can cost up to \$240 per month. Keep in mind, that depending on your state, Medicaid should cover at least some incontinent expenses for assisted living residents, but proper care will likely require supplementing supplies.

Add in the cost of fuel for errands and doctor's appointments, plus travel for those who don't live with the patient. Maybe you're buying food and preparing special meals, or making extra for your family meals.

The list goes on, and the reality is, despite all of the information out there, in-home care may be just as expensive as a facility. But based on what's covered, it's not, so the goal for insurers and states providing subsidized programs is to keep people in their homes longer. Check websites such as payforseniorcare.com to find out

about help, as well as with the Veterans' Administration, if applicable.

The true cost of Alzheimer's is not revealed until you look beyond that number of unpaid caregiver hours, as mind-blowing as that is.

It's impossible to calculate how much those caregivers have given up. How many have quit jobs or taken a leave of absence? Caregivers take on an enormous amount of stress, which can rob them of their own health, costing them money and quality of life. There is also the emotional toll. Those in the trenches will feel the weight of watching a loved one slip away. Yet, it can be just as bad for those who are prevented by circumstances — distance, other commitments, financial restraints — from pitching in, especially if others pile on guilt.

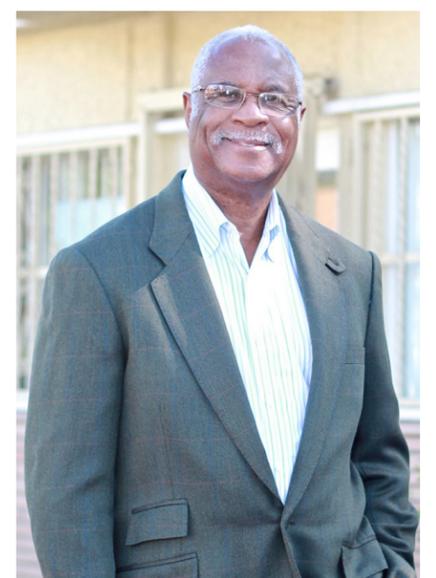
The way a family deals with a long-term illness can cost them more than can ever be calculated. Alzheimer's can be so cruel; causing spouses to forget their devotion and mothers to not recognize their children. Aim to get through it in one piece, and maybe become stronger for it. Offset a balance sheet of necessities and challenges by digging deep to be understanding and forgiving.



• Long Term Care Insurance

• Guaranteed Issue Life Insurance

Protect your Family and Finances with **INSURANCE.**



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