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The Heart of Alzheimer's Caregiving

SUPPORT GROUPS



FALL 2018

- Please support our 2018 Year-End Campaign on page 14.

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Visit www.caringkindnyc.org and click on Donate or call 646-744-2908 or 2927.

We accept MasterCard, Visa, and American Express.

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Gifts such as stocks or bonds may offer substantial tax advantages. Please speak to your tax advisor.

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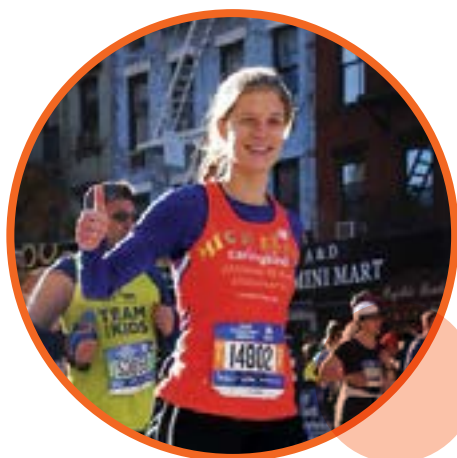
If you have established a donor advised fund through another organization you may recommend the award of a grant to CaringKind. Please check the guidelines pertaining to your donor advised fund.

Corporate Giving

Payroll deductions, matching gifts, and event sponsorships are ways to support CaringKind. 100% of your donation supports New York City individuals and families affected by an Alzheimer's or dementia diagnosis.

Monthly Gifts: By giving to CaringKind each month, you'll join a community committed to providing the gold standard of dementia care for all New Yorkers.

Please contact Carol Berne at 646-744-2905 or cberne@caringkindnyc.org for additional information.



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Dear Readers,

"I don't need a caregiver support group. I've never been a joiner. I can handle this by myself."

"I have no interest in listening to other people's problems. I have enough of my own."

"Who has the time for a support group?"

In my almost 30 years at CaringKind, I have heard every possible excuse from caregivers who are reluctant – for whatever reason – to join a support group.

But, just as often, I hear the flip side:

"This CaringKind support group has changed my life."

"There's nowhere else I feel as safe. Here in this circle, no one is judging me. These people understand what I'm going through because they've been here too."

"The friends I have made in this group are friends for life."

Being a dementia caregiver can be isolating, frustrating, and scary. Even the strongest, most independent person needs a little help. Such was the case with Susan.

Susan was caring for her husband who had early onset Alzheimer's. A take-charge person of the highest order, she was going to manage this alone. But, soon, she realized that she was in over her head.

Fast-forward seven years, and Susan is now one of our most loyal and committed support group members. She freely tells the story of her transformation. Susan says that the sense of community and belonging she's found in her support group has become one of the most important cornerstones of her life. All she needed was to take the first step.

Support groups are the foundation of CaringKind's services. Their roots trace back to the mid-1970s when a group of family caregivers came together to try to

help each other and to find information about this, then, little known disease. Out of that very humble beginning came what is now CaringKind.

Support groups are important for so many reasons. They help caregivers stay connected with professional help and resources during a time when the overwhelming responsibilities of caring for a person with dementia can easily lead to further isolation.

Support groups are invaluable sources of information. And what better experts are there than other caregivers? These caregivers have been there and can cite chapter and verse on innovative tips they use to prevent wandering, simplify mealtime, make bathing or bedtime easier, or calm agitation. They also share resources about professionals they have worked with, research centers, home care, day care programs and the like. Group members don't just share valuable information, they share their stories, their conflicts, their frustrations, guilt and grief. Ultimately, it is the emotional sharing that gives group members the strength and encouragement not just to care for the person with dementia but to begin to care for themselves.

But two other things set CaringKind support groups apart from others.

First, our support group leaders go through rigorous training provided by experts in the field. Our training acknowledges that caring for someone



JED A. LEVINE
President & CEO
jlevine@caringkindnyc.org

with Alzheimer's or dementia has very profound psychological and emotional consequences. Leaders are well versed in the technique and theory of group process.

Even after the training is complete, they receive ongoing support and supervision. This ensures that the people who lead our groups create a nonjudgmental environment where every group member feels safe, supported and accepted. Even though these are not therapy groups, they are, in a very real sense, therapeutic.

Something else distinguishes our support groups from many others. These are not "drop in" sessions. Many groups meet weekly – some meet twice a month. We ask our caregivers to make a firm commitment to participate. This is a commitment not just to themselves but to their fellow group members. Every participant understands the "contract" with their other caregivers as well as the rules of the group. Respect for one another is paramount.

I get it. Support groups are not for everyone. But, I encourage any caregiver who is feeling isolated and alone, to please call our 24-hour Helpline to learn more at 646-744-2900.

I promise you. It can change your life.

P.S. Please support our 2018 Year-End Campaign on page 14. Your help is very much appreciated!

Eat, Sleep and Be Merry: What We Know About Brain Health

by James Campbell

Few would disagree that a delicious, wholesome meal and a good night's sleep are some of life's great pleasures. But what other benefits, aside from a full belly and an energized morning might they provide? *Eat, Sleep and Be Merry: What We Know About Brain Health*, CaringKind's 31st annual research meeting hosted at TheTimesCenter in New York on October 22, provided a rare look into the ways that sleep and diet affect brain health.

CaringKind Founding Director Lou- Ellen Barkan kicked off the evening by underscoring the importance of investing in research for care and imploring the audience to seek out good science when considering lifestyle choices. "Ask yourself," she said, "is the research coming from a legitimate source and from qualified research scientists?" If you aren't sure the therapies you're reading meet this distinction, CaringKind is there to direct you to the best sources of real information.



Next Jed A. Levine, in his role as CaringKind's new President and CEO, elaborated on some of the services CaringKind provides, including the connect2culture® program, which makes New York City's cultural institutions accessible to people with dementia. He went on to introduce the evening's moderator: award-winning WCBS-TV medical reporter, Dr. Max Gomez.

The panelists themselves addressed how their respective areas of expertise relate to brain health. Dr. Lisa Mosconi, Associate Director of the Alzheimer's Prevention Clinic at Weill Cornell Medical College New York-Presbyterian Hospital and author of *Brain Food: The Surprising Science of Eating for Cognitive Power* discussed the role of diet in Alzheimer's prevention while Dr. Andrew Varga, Assistant Professor in the Mount Sinai Integrative Sleep Center at the Icahn School of Medicine brought to the conversation his knowledge of the effects of sleep disorders on cognitive function.

Dr. Mosconi showed how diet is relevant to Alzheimer's by presenting two brain scans: one belonging to a person who followed a Mediterranean-style diet consisting of fresh vegetables and fish and one of a person with a Western-style diet of highly-processed foods. The brain of the person who followed the Mediterranean-style diet was visibly more full with tight ventricles, while the person who followed the Western-style diet had a brain that showed signs of atrophy and shrinking, a risk factor for Alzheimer's.

Dr. Varga explained the connections between sleep and Alzheimer's through the metaphor of a tide. When you sleep, cells shrink in size, allowing fluid to enter the brain and flush beta amyloid,



an important protein in the pathology of Alzheimer's" out of the brain like waves pulling rubbish from the seashore.

The two specialists concluded the event by providing the audience with some key points to take home. Dr. Mosconi urged the audience to refocus their understanding of food to "something that has a function both inside your body and inside your brain." Dr. Varga told the audience to prioritize sleep by viewing it as "a pillar that should be up there with diet and exercise." In his closing remarks, Jed A. Levine managed to tie together the various threads of the wide-ranging discussion into a single, cohesive statement: "Good care is the best treatment."

James Campbell is a freelance writer based in New York City. He holds an MA in International Affairs from The New School and has written for various academic, non-profit and human rights organizations.

Support Group Basics

Being a caregiver for someone with dementia can be a daily challenge. The uncertainties of the disease, coupled with the emotional and logistical tasks of taking care of someone with dementia, can be exhausting.

It's common to feel alone or overwhelmed when you're a caregiver. Friends and family can be invaluable supports during the often difficult experience of caregiving. But, they may not always be available or understand what you're going through. Sometimes it helps to talk to someone who gets it.

Support groups provide an opportunity to give and receive support from people who understand what it's like to be a caregiver.

What is a Support Group?

You'll find many different kinds of support groups out there, but here at CaringKind, it's a group of dementia caregivers who commit to coming to the same group of people to share their own experiences

Our Support Groups:

- Are emotionally-focused
- Have regular, committed membership
- Are facilitated by trained volunteers
- Meet 2-4 times per month, ongoing, for around an hour-and-a-half
- Are always 100% free of charge
- Are confidential meetings held in all NYC boroughs



The support group is a welcome refuge.

It's a safe place where I can share concerns, worries, anger, and anxieties with people who are experiencing the same feelings and issues.

I am no longer facing my mother's decline on my own but am now facing it with the support and understanding of others. ”

Maureen,
CaringKind support group member for over 6 years

and connect with others who get what they're going through. They find relief in the relationships and connections that are built over time, and comfort in having people to turn to when things get rough.

Kinds of Groups

In every support group, you'll probably find a range of ages, experiences and situations – people who are caring for someone in their home and who are caring for someone in a facility; people who are caring for someone nearby and people who are caring for someone far away; people at the beginning of caregiving and people towards the end.

Though some of our groups are for specific types of caregivers, you will find a variety of backgrounds and situations in every group. Available groups vary by the month, as membership fills, but generally we offer groups for:

- Adult children
- Spouses/partners

- LGBTQ community
- Daughters
- Siblings
- Frontotemporal dementia caregivers
- Lewy body dementia caregivers
- Creutzfeldt-Jakob dementia caregivers
- Veterans
- African-American community
- Long-distance caregivers
- Spanish, Russian, Mandarin, Cantonese, Korean-speaking caregivers
- General illness caregivers (not all dementia-specific, though mostly)
- Bereavement (these meetings are time-limited)

What Happens When I Join a Group?

When you call, our Helpline Specialists and Social Workers will conduct a brief screening to see which of our services are most appropriate for your situation. Sometimes, support groups are most helpful and, sometimes, we find that individual support with our social workers is a better option.

If you are referred for a support group, you and the leader will connect, and make arrangements to meet in person to see if a group can meet your needs. If it can't, we'll work with you to find the right support for you.

If you join the group, the leader will review some important guidelines about how our groups run and what's expected, including regular attendance and sharing your experience. Groups usually sit in a circle of chairs, and the leader will open the meeting by letting members know when someone is absent, and share any important news from CaringKind.

When you come to your first meeting, you'll have an opportunity to introduce yourself to the group, share a little about your caregiving situation and get to know the other members.

People will share their present experiences with each other. Other group members will offer support and, if requested, advice or feedback.

The leader will make sure everyone has a chance to speak, although some people will talk more in some meetings than in others, depending on what they're going through. People will be encouraged to explore the emotional experience of caregiving, and to connect with each other on this level.

The leader will close the meeting, and confirm the next group date.



Benefits of Sharing

We find that while caregivers can usually get the information and skills they need through our other programs and referrals, the support groups are often the best place to connect emotionally with other caregivers.

It's not always a normal practice in every culture to openly share your feelings with others. Many people are taught that sharing negative feelings makes them worse, is a burden to others or will make them seem weak. Some people are so used to "thinking" about everything, they don't always know how they feel - and that's ok!

Learning to express your feelings to others can feel unnatural at first if you're not used to it but, like any skill, it gets better with practice.

As humans, we have a deep-seated need for social support. The benefits of sharing your feelings in a safe environment are enormous:

- **Learn healthier ways to manage difficult emotions.**
- **Sharing feelings can help you feel less isolated and alone.**
- **Actively holding back your feelings is hard work, and exhausts your body's defenses.**
- **Gain insight into life experiences.**



Our Support Group Leaders

Our Support Group Leaders are trained, screened and supervised volunteers and community partners all over the five boroughs. They run groups in six different languages and volunteer nearly 5,000 hours each year to this program. We would not have a program without their dedication and commitment.

Our Support Groups all follow the same model, whether the leaders are social workers, counselors psychologists, or former caregivers themselves. Leaders who are former caregivers may be drawn by their past experience to want to help others. However, in our model, they keep the focus of the group on the members and their experiences now.

Each leader has their own personality, experience and style, and while they all follow a similar model, each group has its own unique energy and culture.



After Caregiving: Bereavement at CaringKind

With all of the demands of caregiving and the ever increasing needs throughout the disease progression, there hasn't always been time to cope with all of the losses that come with dementia.

Support groups provide relief during the journey of caregiving, and following the death of the person you've been caring for, our free After Caregiving Bereavement Groups can be a helpful next step. They run weekly for 10 weeks in a series, several times a year. There are groups for both adult children and partners/spouses, and they're designed to help former caregivers understand more about the unique nature of grief following a death from dementia, and to make conscious choices about how to reconnect with others and with yourself, and to build your own future.

With our bereavement groups, you'll have a chance to connect with other people who get what you're going through and can help you process what you've been dealing with for the past several years.

Whether it's been a month or two, or a year or two since the death, our dementia caregiver bereavement groups may be helpful for you.

For more information, please call our 24-hour Helpline at 646-744-2900, and you can be added to the list for the next bereavement group. The leaders of the group will contact you before the next series starts.

**If you
or someone
you know
is interested in
becoming a
Support Group
Leader,
please call
646-744-2900.**



**The 24-hour
Helpline is available
around the clock,
365 days a year
at 646-744-2900.**



When I call about support groups, the Helpline Specialist asked me personal questions. Why can't they just send me to a group?

Answer: Since our groups are ongoing and relationship-based, we invest a little more in making sure they're going to be helpful for the people who attend. We want to make sure we get each client the services they need, and we ask about your situation and experience to make the best match possible. Also, the more we know about your situation, the better we can connect you with our other free services, too!



Can I just show up to meetings as needed?

Answer: Most of our groups are not "drop-in" groups – they have regular members who commit, meeting after meeting, to show up and support each other. This structure encourages relationships, connection and trust. When new members show up regularly, or regular people show up sporadically, a lot of group time is spent introducing yourselves, getting to know people or catching up. When you have the same group of people, you can really build on your relationships to support each other. A small number of our community partners do run successful drop-in

groups, which accept anyone at any time. For more information, please call our 24-hour Helpline at 646-744-2900.



Who benefits from being in your groups?

Answer: Caregivers who want to connect emotionally with others who get what they're going through, are able to share their feelings and experiences, and listen and support the experiences of others.



What if I want advice about how to manage challenging behaviors, or information about financial issues?

Answer: While this sometimes comes up in CaringKind support groups, we encourage you to attend our education and training programs. The Legal & Financial Seminar or the Family Caregiver Workshop are geared to answer these kinds of questions. All our services are free of charge. They are held on a regular basis in all boroughs to accommodate caregivers. Please call our Helpline to learn more and to register for our programs.



What does the support group leader do?

Answer: The leader facilitates the group process – that is, they help the members

of the group connect with and talk to each other, share their experiences and maintain the group culture of trust, respect and connection. They don't focus on providing factual information or setting agendas.



How is a support group different from therapy?

Answer: In both, there is a safe space provided to process feelings and experiences. In a support group, caregivers who are going through what you're going through provide support and feedback to you, and the focus is on what's happening right now with the person you're caring for. It's not about treating what's "wrong" with you; it's about building you up so you can cope better with the demands of caregiving. In therapy, modalities vary widely, but the therapist may share their expertise with you, go more deeply into your emotional/behavioral patterns, and the focus is on management and improvement of a disorder, situation or issue from your past or present. Many people, especially those with long-standing histories of emotional distress, may find being in both helpful.

**Still have more questions?
Call our 24-hour Helpline
at 646-744-2900.**



TCS New York Marathon



JESSICA GONZALEZ
Manager of Constituent Events
jgonzalez@caringkindnyc.org

On November 4, 2018, over 50,000 people gathered in Staten Island to run 26.2 miles. Forty of those runners were members of CaringKind's Team Athletes to End Alzheimer's®. Some came from as far as Texas, Florida, and Washington State to run with us and raise awareness and funds for Alzheimer's disease and CaringKind.

Every member of the team had a personal connection to dementia. Our youngest team member was a 19-year-old whose

parent is living with Alzheimer's Disease. And, Katie Boer, one of our runners from Seattle, is a news anchor at Q13 Fox who uses her voice to raise awareness about the reality of caring for her mom with Alzheimer's through her #Dementiadiaries series.

In 2018, Team Athletes To End Alzheimer's has raised over \$200,000! These critical funds help ensure we can continue to provide our life-saving caregiver programs free of charge. We are grateful to have had the support of such a wonderful and dedicated group of people.



Above:
Team Photo



Right:
Michelle Florin,
completing the
Marathon with
a stress fracture

What Supports Groups Mean to Me by Elizabeth Mainiero

My dad was diagnosed with Early Onset Alzheimer's one year ago. He had recently turned 62 and I had just celebrated my first month of marriage. It rocked our world.

I was left with an overwhelming range of emotions, questions, uncertainties and responsibilities. I felt sad, angry, lost, lonely, confused, uneducated, and powerless. A few months after the official diagnosis, a friend of mine mentioned CaringKind and that it was a resource based right here in NYC that focused on dementia and Alzheimer's. I called the Helpline to ask for literature I could read, and information about seminars and support groups. The relief I felt when I was told there was a "Young Adult" support group that met once a month was palpable. I didn't feel so alone.

Attending the first session proved to be easier than expected. CaringKind provided all the information I needed: time, date,

location. The group leader called me a few weeks prior to ask me some questions, get a better understanding of my current situation and ask what I was looking for from the support group. She also told me a bit about the other attendees and what to expect. This included both the easy and the hard aspects and I really appreciated that. I was able to prepare myself a bit. Although I was very nervous attending my first session, once we began, I felt these nerves dissipate a bit and even more as I listened and found myself nodding.

This monthly support group has meant a great deal to me. In this first year of processing, living with and trying to understand this disease and diagnosis, the group has brought me comfort, advice, support and knowledge. There has been something very powerful about knowing there are other people out there, dealing with similar issues, who understand your emotions without you having to explain

them and who can provide advice based on their own experiences. Attending a support group at CaringKind has allowed me to express my feelings, process them with different input, ask really hard questions and share experiences I didn't know how to discuss with others. The group is judgment free, supportive, caring, honest and not afraid to acknowledge similar feelings, experiences or fears. I have come to look forward to our monthly meetings. The group has provided a safe outlet, a network of people to lean on and a place to feel a bit better about the most difficult thing in my life.

Joining the support group has also introduced additional CaringKind resources. I've heard about upcoming seminars, discussed recent articles, received references for therapists and used the Helpline to ask questions related to estate planning. All of it combined is invaluable.

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caringkind Alzheimer's Walk



The CaringKind Alzheimer's Walks

The CaringKind Alzheimer's Walks brought nearly two thousand New Yorkers together in Brooklyn, Manhattan, Queens and Staten Island, all with the mission to support care, advocacy and research. Throughout the city, walkers raised their ribbons and their voices to give care.

Sporting our bright orange color, our walkers joined together to honor and remember those affected by Alzheimer's or dementia diagnosis, while also highlighting and celebrating the sacrifices and efforts of caregivers throughout New York City.

At the Manhattan CaringKind Alzheimer's Walk, the "Good Samaritan Award" was given to **NYPD Officer Wilhem Thomas** and two everyday New Yorkers -- **Aiyesha Ubiles** and **Natalie Arthur Campbell** -- who got involved and helped return to safety two men -- one with dementia

and one with Alzheimer's -- who had wandered and become lost. And in a surprise moment, we also took time to honor our loyal supporter, **WABC-TV's Bill Ritter** with this year's "Community Partner Award". Bill has been dedicated to CaringKind and the cause, emceeding our Manhattan Walk for almost 20 years. CaringKind's other staunch supporter, Tony award winning actor and tireless advocate for the Alzheimer's community, **David Hyde Pierce**, presented the award. It was a lovely day for all!

Thank you to our 2018 sponsors, Walk Team Captains, Walkers, and their families, co-workers and friends who supported our Walks. Because of you, we raised over \$600,000! **Thank you for supporting us, donations will continue to be accepted until November 30.**



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Dear Friends of CaringKind,

Technology has made life easier and more efficient for New Yorkers in many ways. As CaringKind's new President and CEO, with more than thirty years of experience providing dementia care, **I know that there is one job that requires the human touch: dementia caregiving.**

While we are proud of our investments in technology, we know that every individual and family affected by a dementia diagnosis has unique challenges that require personal attention. My team is committed to providing world class programs and services delivered by caring professionals. Professionals who listen to your concerns, meet with you in person, and help you develop a care plan that addresses your individual needs. CaringKind is the only organization in New York City providing comprehensive, personalized systems of support.

Our expert counselors connect you to social work services, support groups, training and education programs, MedicAlert® NYC Wanderers' Safety Program and our community partners. All our caregiver services are free of charge and delivered by trained professionals who have the experience, knowledge, patience, empathy and resources to solve your short-term problem and develop a long-term plan.

CaringKind clients confirm the impact of your support through the human touch they receive on their first call. "Thank you for listening. I'm so glad I made this call. I only wish I had made it sooner." Many of our clients have been calling for more than a decade, getting personal counseling at every stage of the disease. Our clients tell us, "I no longer feel isolated and frightened by what's ahead. I know I'm not alone."

This year, as you think about your charitable commitments, I ask you to consider a gift to CaringKind and help us reach our one-million-dollar goal.

By reaching and surpassing our one-million-dollar goal we will grow our programs and ensure that every New Yorker has access to the care they need. I am proud to take this moment to share the highlights from 2018:

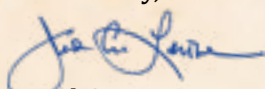
- We responded to **10,000** calls on our 24-hour Helpline, the gateway to our services.
- Our social workers had more than **3,000** counseling sessions advising clients on dealing with the challenges of today while ensuring that they have a plan for tomorrow.
- We welcomed over **1,200** clients to our Education Seminars, on topics ranging from legal and financial planning to the selection of long-term care resources.
- We trained **500** family and professional caregivers, whose difficult jobs were made easier with their new skills and resources.
- We registered an additional **1,400** people with dementia to the **29,000** already in our CaringKind MedicAlert® NYC Wanderers' Safety Program, saving lives every day.
- We have **80** support groups, each facilitated by a trained leader, and meeting in person; many meet weekly.
- We trained docents and staff at **18** of NYC's top cultural institutions, making their outstanding resources accessible for our clients and their families.

As 2019 begins, I acknowledge the many public officials and private supporters who, while hoping for rapid development of effective therapies, now recognize that these are far off in the future. **We can no longer put off funding programs and services for care.**

Whether you have been personally helped by CaringKind or know someone who has, today we need you more than ever. Approximately 95 percent of CaringKind's support is privately funded. With your tax-deductible contribution, we can ensure that you and your family will have the benefit of our human touch when you need it most.

On behalf of the clients we serve, I wish you a peaceful and productive new year.
Thank you.

Sincerely,



Jed A. Levine
President and CEO

PS: Please call us at **646-744-2900** for information on making a stock donation, monthly contribution or including us in your estate plans, or for any reason.

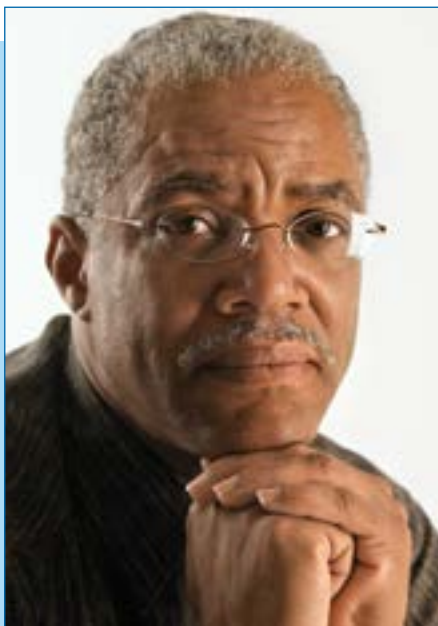


Caregiver Self-Care Tips

As actress and singer Lena Horne once said, **“It’s not the load that breaks you down, it’s the way you carry it.”** While we can’t change the nature of the “load,” or the stresses of dementia caregiving, we can help caregivers learn to carry it more easily. The tools, tips, information, and food for thought that follow are intended to keep you flexible, strong, and capable of carrying your load without being too weighed down by the burden.

Research confirms that caregivers of persons with dementia (PWDs) are at a much higher risk for depression than non-caregivers. Caregivers also often report high levels of stress and psychological strain. Some factors that may contribute to the emotional roller coaster so many caregivers experience are:

- **The innate unpredictability of the disease.** Never knowing what symptom or behavior will surface from one day to the next along with the inability to control the situation.



- **Fear.** Wondering whether you will have the energy or strength to face the progressive decline of the PWD.
- **The constant shifting** of your relationship with the PWD, of daily responsibilities and roles, or of your own emotions.
- **Complicated feelings.** The future is not what you anticipated; family members you thought would help shoulder some responsibilities are not as helpful or are not helpful at all. Perhaps you miss the relationship you used to have with the PWD – the intellectual stimulation, the companionship, the security.
- **Loneliness/depression.** As the PWD’s condition deteriorates, friends and family often withdraw. People are sometimes scared to see the PWD, unsure of how to communicate, and often retreat, leaving the caregivers to fend for themselves.

Know Yourself

Step back for a moment and think about your personality. What kind of caregiver are you and what effect might this have on the way you provide care? Examine who you are: how your personality impacts your caregiving, your sense of burden, your ability to solve problems, and your own health. Do you feel comfortable asking for help? Or do you feel like you have to do everything yourself? Have you chosen this caregiving role or have you been thrust into it? Do you feel like you have to be eternally cheerful? Can you get in touch with your own emotions, even the not-so-pretty ones? **It’s normal to feel grief, anger, sadness, frustration, resentment, guilt, and many other feelings. You are not alone.**

Consider Your Relationship With The PWD

Has it historically been a loving relationship or has it been contentious? Does she push your buttons? Do you have a strong attachment to her? All relationships are complicated and dementia further complicates things in the way it affects not only the person with the disease, but everyone involved.



Know Your Boundaries

It is not only okay to draw lines – what you will and will not do, can and cannot do – but having appropriate boundaries is essential to ensuring your own well-being throughout your caregiving journey.

Know Your Triggers

Understand what sets you off. Caring for someone with dementia can be very frustrating. Being able to catch yourself before you reach the end of your rope should improve both your quality of life and that of the PWD for whom you care.

Try not to immediately react to a stressful situation with anger. Take a breath, observe what is going on, and then respond in a thoughtful manner. Try to slow your words and actions

down. Keep in mind your desired outcome, and evaluate whether your actions and words are likely to achieve that outcome. If you lose your temper, forgive yourself for being human and try again next time. This can be very difficult, and as with any new skill it will require time and practice.

Give Yourself Permission To Care For Yourself

Caregivers often put their needs last on the daily list of things to do. Here are some small things that can make a big difference in the quality of your day and in the way you are able to handle stressful situations:

- **Nourishment** – Make sure you eat and drink enough to maintain your blood sugar levels and energy. Breakfast is truly the most important meal of the day. If your response to stress is to eat too much, try to keep healthy snacks on hand to replace less healthy food items.
- **Sleep** – Try to get at least seven hours of sleep per night. When you're fatigued in the afternoon, try to take a nap.
- **Exercise** – Even if the exercise is as simple as taking a walk around the block, or dancing in your living room, get your blood flowing so your brain and body can get the benefits of movement.
- **Spiritual practice** – Including prayer, meditation, or just sitting and being aware of the breath.
- **Social connection** – Reach out and call a friend, or attend a support group.
- **Physical health** – When was the

last time you went to the doctor for yourself? It's important to take care of your own health conditions because stress tends to make these conditions worse.

- **Mental health** – Who can you turn to for emotional support? Putting a lid on unpleasant feelings of anger and guilt will only make them bubble up and boil over at another time. Look for healthy ways of acknowledging and expressing your emotions that are not directed at the PWD.

Educate Yourself And Others

Read books and newsletters, do research online, and talk to other people. Learn new techniques and strategies to help improve your quality of life and help sustain your relationship with the PWD throughout the course of the disease. There are some excellent books that have been written by authors who have dementia. Reading about the first-hand experience of dementia may give you valuable insight into what the PWD may be experiencing and feeling.



Develop Creative Problem Solving Skills

When caring for a PWD it is essential to consider what is truly important and let the other things go. Avoid arguing with the PWD – you probably will not win. Develop the art of being wrong. Saying you are sorry often ends an argument.



Begin to try and accept the disease process and the changes it creates. Step into the PWD's reality, understand her underlying emotional needs, and provide validation. Think outside the box and avoid reverting to reality and facts.

Join A Support Group

Explore your feelings and form connections with others caring for a PWD. CaringKind has nearly 100 groups with trained and experienced group leaders, which meet during the day as well as in the evening. We offer groups throughout the NYC metropolitan area for many different types of caregiving situations including groups for spouses, adult children, long-distance caregivers, and LGBT caregivers.



Meet With A CaringKind Social Worker, Or Seek Individual Counseling

Not everyone is a “group person.” Some issues are best dealt with individually or as a family. Our social workers are licensed and, like all of CaringKind’s programs and services, consultations with them are available free of charge.

Understand There Are No Perfect Solutions

Caregivers are human beings, and can never be perfect all the time. The care systems with which we interact (doctors, hospitals, home care agencies, day programs, and residential facilities) are often far from perfect. Your best efforts toward keeping the PWD safe and getting her needs met may not always have the expected result, but your best is all you can do.

Be Three Steps Ahead Of A Crisis Instead Of Continually Responding To One

While it is not always possible to avoid crises, taking certain steps can help keep them at bay.

- **Take care of legal and financial matters.** Complete a living will, health care proxy and power of attorney. Attend one of our Legal and Financial Seminars to learn more about transferring assets,

supplemental needs trusts, Medicaid, and Medicare. Call the 24-hour Helpline to register for upcoming dates.

- **Remove environmental hazards from the home that could result in harm to the PWD (falls, burns, etc.).** Visit www.thiscaringhome.org for a list of tools and tips for safety, or contact our 24-hour Helpline for guidance.
- **Keep a current list of the PWD's medications with you** for doctor's appointments and in case of an emergency.
- **Prepare for wandering. Keep a current photo of the PWD with you at all times.** Enroll the PWD in the MedicAlert® NYC Wanderer's Safety Program. Register yourself in the program, too, as a caregiver, so that if something happens to you, emergency responders will know that you are caring for someone who relies on your help.
- **Remove important papers such as birth certificates from the home or keep them somewhere safe.** Give the PWD a laminated copy of her ID card, insurance card, etc. in case she loses or misplaces her wallet or purse. Consider securing valuable jewelry or family heirlooms as well.
- If the PWD is at risk for spending large sums of money by responding to telephone calls requesting money or donations to charities, **remove the credit card and checkbooks from the home or stop telemarketers from calling** by registering with the National Do Not Call Registry at 1-888-382-1222 or www.DoNotCall.gov. Consider having mail sent to a forwarding address or P.O. Box.

Give Yourself Permission To Enjoy Life

You deserve it! Take care of yourself first and you will be able to better care for the PWD. If you are happier and more relaxed, the PWD will also surely benefit. What makes you feel good? When was the last time you had a good hearty laugh?

Take time to:

- **Take your dog for a walk.**
- **Meet a friend for lunch.**
- **Sing songs (at the top of your lungs!).**
- **Go to a movie.**
- **Get a hair cut.**
- **Watch your favorite sporting event.**
- **Read a magazine.**
- **Take a class.**
- **Visit a museum.**
- **Take a vacation** (If a vacation isn't possible, try a “staycation” – take a weekend at home when you don't have anything scheduled).
- **Garden.**
- **Cook.**
- **Listen to music.**
- **Play.**
- **Make art.**
- **Keep a journal.**
- **Read a book.**
- **Sit quietly by yourself.**
- **Meditate.**
- **Pray.**
- **Exercise.**

The 24-hour Helpline
is available
around the clock,
365 days a year.
646-744-2900

Connect With The PWD

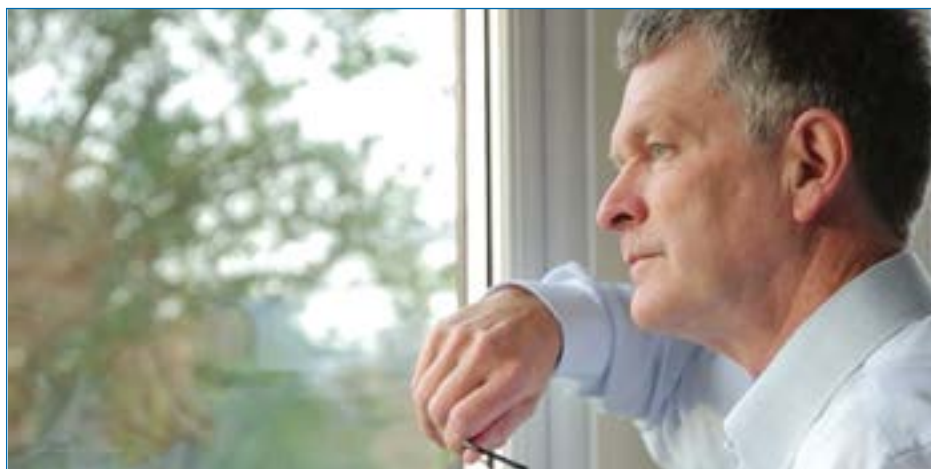
The relationship that you share with your mother, father, spouse, sister, brother, or grandparent with dementia is now different than before, but it is still a relationship. Look for ways to honor and enhance that relationship. Try to find enjoyable activities, separate from day-to-day medications, meals, bills, and medical appointments, that you can do together. The goal is to have fun! Here are some ideas:

- **Take a walk.**
- **Window shop.**
- **Look at family photos and reminisce.**
- **Create a scrapbook** from images in magazines or printed off the Internet.
- **Storytelling** – check out Anne Basting's TimeSlips program for ideas at www.timeslips.org.
- **Movies** – the PWD may not be able to follow the plot of an entire movie, but she may like short clips of famous scenes, or classic TV programs that rely on physical comedy such as *The Three Stooges* or *I Love Lucy*.
- **Read out loud** – jokes, poetry, or religious verses.



- **Sing or dance together.**
- **Make art or look at art.**
- **Visit a museum** – visit the connect2culture® page on our website for more information about local museum programs for people with dementia and their caregivers (www.caringkindnyc.org/connect2culture).
- **Share a treat** – ice cream, chocolate, or other favorite food.

Try to think of activities that the PWD historically enjoyed. The activities may need to be adapted for attention span, ability, and safety, but they can be an excellent way to reconnect with each other. **Positive emotional and relationship benefits can be retained long after the PWD has forgotten about the details of the activity or outing.**



Strike A Healthy Balance

Olivia Ames Hoblitzelle, author of *Ten Thousand Joys & Ten Thousand Sorrows: A Couple's Journey Through Alzheimer's* (2010), quotes a Tibetan Nun who is discussing balance:

"In Buddhism we talk about the principle of the two benefits. The idea is very simple. For anything to be of benefit to another person, it must also be balanced with benefit to oneself. We can get all trapped into giving too much of ourselves and lose the balance in relationships. That's where this idea of two benefits can be a helpful reminder."

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 know that we are here.*



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Although you'll often find Jed A. Levine highlighting the importance of caregivers in the media, this summer he became a bit of a newsmaker himself. News of Jed becoming President and CEO of CaringKind was reported on in The Chronicle of Philanthropy and New York Nonprofit Media.

This October, Jed and Jessica Gonzalez, CaringKind's Manager of Constituent Events and a caregiver herself, were guests on the hour-long radio show, "Community Connections" with veteran reporter Bill Ayers, on 95.5 WPLJ. Throughout the show, Jed and Jessica discussed CaringKind's mission, important programs and events such as the Annual Research Meeting and the CaringKind Alzheimer's Walk in Manhattan.

Speaking of the Manhattan Walk, it was featured on WABC-TV, Channel 7. Their anchor – and longtime CaringKind supporter – Bill Ritter, emceed the event and was awarded CaringKind's Community Leadership Award.

Jed's written comments were published by The New York Times in response to a story that relayed the struggles facing family caregivers. He wrote, in part, "Caregivers do not need to navigate the journey of Alzheimer's or dementia alone. CaringKind, NYC's leading expert in Alzheimer's and dementia care for more than three decades, offers help for family caregivers."

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The TimesLeder newspaper put a bright spotlight on Chris Doucette, CaringKind's Director of Administration, and a new podcast he created that has become an important educational resource for dementia caregivers. The podcast, "Caregiver/Storyteller" features poignant and compelling interviews with Alzheimer's caregivers and has quickly found its way to the top as the most popular caregiving podcast on iTunes. Congratulations, Chris!

In October's "Care Chronicle" column, featured in five borough papers, Jed emphasized how important it is for caregivers to care for themselves. And, as the school year kicked off in September, Jed focused his first column on education as an "important weapon" in the fight against Alzheimer's. Jed highlighted CaringKind's numerous resources including the website, the 24-hour Helpline and CaringKind's various support and education meetings that educate and guide all through a difficult time.

For her last "Care Chronicle" column, Lou-Ellen Barkan, Founding Director of CaringKind, reflected on the effect music, arts and cultural experiences can have on a person with Alzheimer's or dementia. Recalling a memory with her mother, who had Alzheimer's, Lou-Ellen described the happiness and peace her mother found when hearing her favorite song. Lou-Ellen encouraged caregivers to take advantage of CaringKind's connect2culture® program as a way



to recreate moments like the one she described with her mother.

This summer, CityLimits, an online publication that provides in-depth reporting on NYC, featured connect2culture® in a piece about City institutions which use art in their Alzheimer's programming. Jed, Jessica and Meredith Wong, CaringKind's Manager of the connect2culture® program, are quoted in the article.

CaringKind's Annual Research Meeting, "Eat, Sleep and Be Merry: What We Know About Brain Health," that took place in October, was promoted in over 30 community calendars throughout the New York City area.

Photos from our fantastic "Forget-Me-Not" Gala were included in Social Life magazine, New York Social Diary, 25A Magazine, and Black Tie magazine.

Back in June, CaringKind's overnight softball tournament, Play to Remember, was featured in the NYC Patch, Rivertowns Patch and The Rivertowns Enterprise.

Newspapers and news sites, which play an important role in helping us raise awareness and educate the community, continue to include our wide range of education meetings in their calendars, making New Yorkers aware of where and when they can get the help they need from CaringKind.



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**"I always
think
about
Steel
Magnolias**

**when Shelby said, 'I just
need to simplify.' That's
what you have to do."**

- Rob Zukowski, ep 4

Caregiver
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Caregiver Storyteller

**A storytelling podcast
about Alzheimer's and
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of what caregiving is actually like.
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a sense of loss, there is
also a surprising amount
of fortitude, loyalty,
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These are their stories.

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www.caringkindnyc.org/podcast/

Understanding Dementia Seminar: What You Need to Know and Where to Go

Sessions provide family members and friends with information about Alzheimer's, other types of dementia, resources, and services available.

Upcoming Dates in English:

November 9	12:00 - 2:00 p.m.	Manhattan
November 20	2:00 - 4:00 p.m.	Brooklyn
November 28	5:30 - 7:30 p.m.	Manhattan
December 14	12:00 - 2:00 p.m.	Manhattan
December 18	5:00 - 7:00 p.m.	Brooklyn
December 19	5:30 - 7:30 p.m.	Manhattan
January 11	12:00 - 2:00 p.m.	Manhattan
January 15	2:00 - 4:00 p.m.	Brooklyn
January 16	5:30 - 7:30 p.m.	Manhattan

Upcoming Date in Chinese - Mandarin

November 4	1:00 p.m. - 3:00 p.m.	Queens
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Contact our 24-hour Helpline at 646-744-2900 for more information.

Legal & Financial Seminar

An attorney specializing in elder law discusses important topics Alzheimer's and dementia caregivers should understand before meeting with a personal attorney. Topics include power of attorney, guardianship, Medicaid eligibility, long-term care insurance, healthcare proxy, and more.

It is recommended that you attend an Understanding Dementia: What You Need to Know and Where to Go Seminar prior to attending.

Upcoming Dates in English:

Manhattan	
November 5	12:00 - 1:30 p.m.
November 19	5:30 - 7:00 p.m.
December 3	12:00 - 1:30 p.m.
December 14	5:30 - 7:00 p.m.
January 7	12:00 - 1:30 p.m.
January 28	5:30 - 7:00 p.m.

Seminars for Professionals

Understanding Dementia for Professionals:

December 12	3:00 - 5:00 p.m.	Manhattan
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The Seminars are free of charge.
Two (2) Social Work Continuing Education units are available for a fee.

Medicaid Home Care Seminar: A Practical Guide to the System

Caregivers are guided through the application process for Medicaid home care service. Prior attendance at a Legal & Financial Seminar is required.

Upcoming Dates in English:

November 1	5:30 - 7:00 p.m.	Manhattan
December 6	5:30 - 7:00 p.m.	Manhattan
January 3	5:30 - 7:00 p.m.	Manhattan

Placing Your Relative in a Nursing Home

Sessions educate caregivers about the steps involved in nursing home placement, paying for care, easing the transition, and being a successful advocate for the resident.

Upcoming Date in English:

Manhattan	
November 13	5:30 - 7:00 p.m.

**Our 24-hour Helpline
is available around the clock,
365 days a year.
646-744-2900**

Monthly Education Meetings

Meeting topics change monthly.
All meetings from 6:00 – 8:00 p.m.

Monday, November 12th

Creating a sense of purpose: Meaningful Activities for a person with dementia

- Discover how to create meaningful activities to enhance connection
- Learn about the different needs of a person with dementia in every stage
- Review resources and tools that can facilitate activity planning

Speaker:

Toni Musto, MPH, CDP, CALA, CDAL, Executive
Director Brightview Senior Living, Tenafly NJ

Monday, December 10

Behavior has Meaning

- Recognize how dementia impacts behavior.
- Understand root causes of behavioral changes.
- Formulate strategies to adapt and adjust responses to behaviors

Speaker:

Amy Torres, Director of Training, CaringKind

Monday, January 14

Dementia and Nutrition: Improving Meal Time

- Uncover nutritional strategies to enhance a person with dementia's well-being
- Learn how to support challenging dietary issues caused by dementia
- Find out how adaptive equipment or changes in meals can facilitate mealtime

Speakers:

Lisa Zullig, MS, RDN, CSG, CDN, Director of
Nutrition Services at God's Love We Deliver

Family Caregiver Workshops

During this 10-hour workshop series, caregivers learn to view the world from the perspective of the person with dementia. They also learn how to communicate more effectively with the person for whom they are caring and receive new insights on how to manage the challenging behaviors often associated with Alzheimer's disease, as well as the importance of self-care. Attendance is required at all workshops in a series.

Upcoming Dates in English – In Manhattan:

January 4, 11, 18, 25

Afternoons

To register, please call our
**24-hour Helpline at
646-744-2900**
or visit **www.caringkindnyc.org**.

Registration is required.
Space is limited.

All meetings are free of charge
and subject to change.

You may notice that specific locations of
upcoming meetings are not listed.
You will receive location information
during your registration call.

**We wish to thank the following community
partners for providing meeting space:**

Atria Senior Living, Kew Gardens
Carter Burden/Leonard Covello
Senior Program
Heights & Hills
Selfhelp Alzheimer's Resource Program
Queens Library
Avis – South Shore JCC
The Brielle at Seaview
Hand in Hand Together Homecare

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Technology



LOU-ELLEN BARKAN

Founding Director

lbarkan@caringkindnyc.org

We take it for granted that technology makes life easier and better. We order goods and groceries, pay our bills, read our books and watch our movies online. And most of the time, everything works just fine. Until it doesn't. And that's when we look for help from a real live human.

Problem is, most of the time, organizations don't have enough staff

with enough knowledge to solve our problems. So, they parse it out. You talk to one person for an introduction and then end up on one or more queues to get just the right expert you need.

I don't know about you, but if I had all the hours that I've waited on the phone for a person to help me solve a problem, I could write the great American novel or a symphony. So, I've come to value organizations that provide quick access to human experts who listen, advise and are accessible for follow up, however many times I need them. How many of these organizations do you have in your life? I have very few, so as CaringKind's Founding Director, I am proud that we remain committed to the human touch,

the gold standard in personalized service for individuals and families affected by a dementia diagnosis.

Our 24-hour Helpline and social work services, available free of charge, are provided by experienced professionals who listen and guide you with expertise and kindness at what may be the hardest time of your life.

In my opinion, more than a few other organizations could learn a few things from CaringKind, but while they are learning, you or anyone you know can take advantage of CaringKind's human touch. And save your time for doing the things you love!

JUSTICE IN AGING

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Beware! Phone Scam

There's a new phone scam targeting Social Security beneficiaries that advocates for older adults should be aware of. The Federal Trade Commission is warning that scammers are engaging in a caller ID trick called "spoofing" to make it appear that they are calling from the Social Security Administration (SSA).



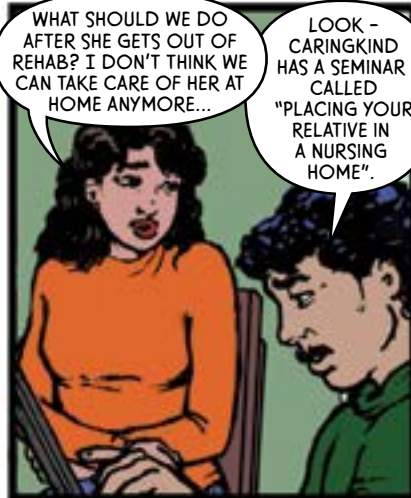
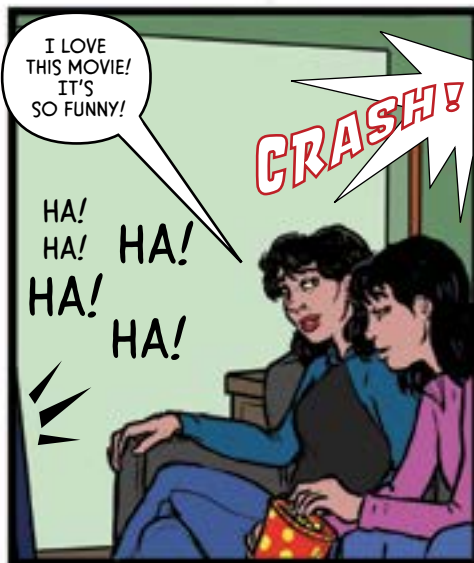
These phony callers claim to work for SSA and ask for personal information—such as the individual's Social Security Number—supposedly in order to process a benefit increase. These scam artists have also tried to get this information by claiming that the person's benefits will be cut off if the personal information isn't provided. **To learn more, including where to report such calls, and what people should do if they get one of these calls, read the FTC's warning at www.consumer.ftc.gov and click on "Scams".**

If you or your organization directly serve older adults, please make this information available widely in your community.

caringkind chronicles

Writer: Jennifer Camper Artist: Ivan Velez

Episode 8 Previous episodes: caringkindnyc.org/comic



NEXT EPISODE:
A NEW STORY
BEGINS

CaringKind's seminar, *Placing Your Relative in a Nursing Home*, covers moving a person into a nursing home, paying and more. For more information, call the 24-hour Helpline at 646-744-2900 or go to <https://caringkindnyc.org/nursinghome>.

caringkindnyc.org

Programs and Services

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The Heart of Alzheimer's Caregiving

Education and Training

Understanding Dementia for
Caregivers & Professionals

Dementia Care Training for
Professional Caregivers

Monthly Education Meeting

Legal & Financial Seminar

Medicaid Home Care Seminar

Placing Your Relative in a
Nursing Home Seminar

Family Caregiver Workshop