

**No Red Lights:  
Moving  
Forward with  
Alan Patricof**

**PATRICOF**

caringkind

**Let's  
end Alzheimer's**

**I AM  
88**



*Also inside:*

A New Approach to  
Support Groups  
Celebrating our Walkers  
and Marathoners  
Our 2022 Achievements



## No Red Lights: Moving Forward with Alan Patricof



"My wife, Susan, was diagnosed with Alzheimer's in 2009 and passed away from Alzheimer's in 2021. When she was first diagnosed, we had no idea about the nature of the illness and how long the journey would be or what it would require of us. I did my best to keep my wife involved in social activities inside and outside the home. In the last few years of her life, she wasn't able to speak, and we worked hard to ensure that she was comfortable. Fortunately, there are organizations that exist to help families deal with the unique challenges of dementia caregiving, and CaringKind is the leading source of this kind of support.

I participated in a support group for several years which meant meeting with a professional facilitator and a group of like-minded people who are going through the caregiving journey. It was very helpful to talk with other people who were facing similar issues. Overall, the support group was of great value and something I would recommend to anyone going through this. CaringKind also trained our professional caregivers and gave advice on different services for my wife.

I am so grateful to everyone who provided support to my family that I've spent the past few years doing my best to give back. My family has supported the CaringKind Alzheimer's Walk for the past two years and we're proud that we've raised over \$250,000 for CaringKind and raised a lot of awareness in the process.

My experience as a caregiver really underscored for me an essential belief: staying active and engaged no matter your age. I believe I will live until I am 114 years old and I want to stay busy the entire time! To that end, I've been doing things I've always wanted to do. For example, I recently attended Burning Man and completed the NYC Marathon.

I've run the NYC Marathon before, but the last time I did it was 43 years ago! I did it for two reasons: 1) to inspire older people to try and overcome their fears of challenges. When something seems too difficult, do it anyway! It's worth trying - whether you fail or succeed - than not trying at all. And 2) to help raise even more funds and awareness for CaringKind. I am incredibly grateful to all my donors who helped me cross the finish line - we raised almost \$600,000 for Alzheimer's

and dementia caregiving. At 88 years old, I am the oldest person on record to complete the NYC Marathon, and I did it for a great cause.

Because I'm 88, I have a lifetime of hard-won experience that might help others. So, I've put all the lessons I learned into a new book, "No Red Lights." I hope that when people read my book - especially older people - they are inspired to say yes to every new opportunity. When you say yes to opportunities, it opens your future to unexpected possibilities, and before you know it, you're doing things that you didn't think were possible!

If I had advice to give someone facing an Alzheimer's or dementia diagnosis, I would say to call CaringKind. The sooner you accept the disease, the better able you'll be to navigate the journey alongside the person living with dementia. In other words, say yes to that opportunity!"



Photo: Zeptepi Creative



# Team CaringKind Runs the 2022 NYC Marathon



**Congratulations to our 2022 NYC Marathon team! Our 40-runner team ran 26.2 miles in support of CaringKind! For more photos of this extraordinary team, please scan the QR code on this page.**

*Photos: Zeptepi Creative*



If you'd like to run the NYC Marathon, NYC Half Marathon, or TD Five Boro Bike Tour with us in 2023, visit [caringkindnyc.org/athletes](https://caringkindnyc.org/athletes) for all the details. Apply soon – entries go fast!

**Wow.  
What an incredible  
day we had!**

Hundreds of our walkers – caregivers, persons living with dementia, partners, volunteers, friends, and families – all came together for a day of remembrance, reflection, reunion, and celebration!

## Our CaringKind Community at Walk 2022



SAVE THE DATES  
Brooklyn Walk:  
September 10, 2023

Manhattan Walk:  
October 22, 2023



We've written a special message of gratitude that can be viewed by scanning the QR code below. To our sponsors, walkers, speakers, and partners: Thank you!

If you missed the Walk, don't worry. We took plenty of photos. View them by scanning the QR code.



SCAN FOR  
MORE  
MARATHON  
PHOTOS



Or click: <https://flic.kr/s/aHBqjAef16>

SCAN FOR  
OUR WALK  
THANK YOU  
MESSAGE



Or click: <https://tinyurl.com/4jfvhtcd>

SCAN FOR  
MORE  
WALK  
PHOTOS



Or click: <https://flic.kr/s/aHBqjAcGBV>

Join our 2023 Walk leadership committee for Brooklyn or Manhattan! Limited availability.

Please contact Chris at [cdoucette@cknyc.org](mailto:cdoucette@cknyc.org)



The Heart of Alzheimer's Caregiving



A Message from  
Eleonora Tornatore-Mikesh

## 2022 Year End Appeal

Dear Friends,

I hope you and your family have been well and safe. As we close the year, I wish to thank you for being a partner in our work. It has been a difficult two years of Covid, and families affected by dementia, already at high risk, have relied on us more than ever. Because of you, we met the immediate challenge. Thank you!

But our life-changing work, which is more important than ever, is just beginning. We are expanding our roster of programs and services – in the year ahead. – while continuing to provide support to all who turned to us in 2022. We hope we can count on you, once again, to lend support to ensuring that everyone who needs our help has access to the information, support and compassionate care, free of charge, that CaringKind is known for, making us New York's trusted partner in dementia care.

With pride, I share that we have re-launched our Early-Stage Services with a suite of evidence-based programs for those with early memory loss and Mild Cognitive Impairment, filling a much-needed gap in service for this population. One of these programs is called Cognitive Stimulation Therapy. I would like to share a note from a caregiver wife whose husband is in the program.

***"You've touched his heart and mine as well. It's more than I can ask for. It's a connection he won't forget."***

Social isolation remains one of the critical health issues for our clients. And many individuals with early memory loss live alone. Over the next year we will reach these individuals with home visits and connect them to CaringKind and community resources. No one should have to experience the journey of dementia alone.

CaringKind has been a lifeline for thousands of families, and I am delighted to share progress over the year:

- Our **Helpline** staff of trained dementia care specialists fielded 5,400 calls from caregivers, persons with dementia, and the worried well, seeking information, referral, and guidance.
- The network of **90 Support Groups** is busier than ever, with groups held via telephone, conferencing, or in-person.
- Our licensed **Social Workers** provided one-on-one and family consultations with more than **1,285 counseling sessions**, helping caregivers better navigate the complex road ahead.





- Our **Connect2Culture** program has broadened its reach and extends across the country, virtually, while continuing to serve local communities with culturally sensitive programming, helping to reduce social isolation through engagement with the arts.
- Our **MedicAlert® NYC Wanderer's Safety Program** is busier than ever, providing a vital safety net to persons with dementia who wander and go missing.
- Our **Education Seminars** are back to a pre-Covid schedule and over **670 caregivers** have attended, virtually, learning about Legal and Financial Planning, Medicaid Home Care, Introduction to Dementia, and a host of other topics.
- Our relaunched **Early-Stage Services** is providing a suite of evidence-based programs to persons with early memory loss and Mild Cognitive Impairment.

CaringKind relies on donations, from people like you, to keep our programs free of charge, and to be able to respond to new challenges as they arise. Your tax-deductible contribution directly supports our community.

We recognize that we are living in challenging times. Please know that a gift of any amount would be greatly appreciated and have a healing impact on the caregiver families we serve. However, gifts of \$250, \$500 or \$1000 are especially needed. **CaringKind would not be here without you!**

On behalf of CaringKind, I wish you a healthy, peaceful, and productive 2023, and thank you for supporting our work today and into the future.

Sincerely,

Eleonora Tornatore-Mikesh, President and CEO

P.S. Donations can be made on our secure website  
[www.caringkindnyc.org/yearend](http://www.caringkindnyc.org/yearend)

For additional ways to donate, including stock,  
please contact **646-744-2900**.

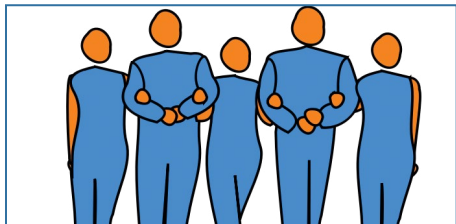


Or Scan and Donate here.



# NEW! Introducing Support Groups for People in the Early Stage of Dementia *And support groups for their care partners!*

Support groups are a critical means of support for people managing a dementia diagnosis in their family. For 40 years, our support groups have historically served the needs of caregivers only, caring for someone in any stage of dementia – from early to late stage.



CaringKind is launching a pilot program to serve an unmet need: offering support groups to people living in the early stage of Alzheimer's or dementia. We're also piloting a corresponding support group for their care partners. The care partner support group will run concurrently with the early stage support group, so that both people in the care partnership get the support they

need for the unique position they're in.

Here's what's interesting: We've learned that when people join a support group, they come to the group at all levels of experience – some have a little, some have a lot. The difference in experience can sometimes be a point of frustration for group members. To prevent this distracting dynamic, we are offering a 10-session workshop for potential support group members. The workshop will occur prior to the support group. The aim is to create a base level of understanding on the most common elements of dementia caregiving. This way, support group members come to their first meeting with a shared experience and a shared set of basic knowledge. The onboarding workshop should facilitate a discussion that 1) has fewer distractions, 2) covers more ground, and 3) has a more meaningful impact.

The program for people with dementia

is called Journeying Together and the corresponding program for care partners is called Partnering Together.

“Fear creates stigma, and stigma creates loneliness,” says Pamela Atwood, Dementia Specialist for Early Stage Services at CaringKind. “When people are first diagnosed, they feel like no one can understand what they're going through. This program creates a safe space for both the person with the disease and their care partner to express themselves and learn from their peers.”

The pilot program begins in December. This program is supported (in part) by a grant from AARP. We'll share our findings with you in early 2023. For more information on Early Stage Services, visit: [caringkindnyc.org/earlystage/](http://caringkindnyc.org/earlystage/)

## Resources We Love

*CaringKind wants you to know about other organizations doing great work for Alzheimer's caregiving!*

**Voices of Alzheimer's** is a new advocacy organization created to advance the policy priorities of those living with cognitive illnesses and those most closely affected. We are uniquely led by those living with Alzheimer's and care providers. We feel passionately that it is time that people living with Alzheimer's and everyone affected by the condition have a voice. Our primary focus is to draw attention to the unmet medical needs of people with Alzheimer's – especially to ensuring the FDA and CMS get meritorious products approved quickly and into the hands of patients without delay.

More information about becoming a member can be found at <http://www.voicesofad.com>

Or scan here →



**FAIR Health** helps you understand and plan for your healthcare costs and health coverage. It is an independent, national nonprofit trusted for providing fair and neutral information to all, including consumers like you. You can use FAIR Health's helpful tools and resources for older adults, including Shared Decision-Making tools, total treatment cost estimates for Alzheimer's Disease, checklists and more.

Find these tools at <https://www.fairhealthconsumer.org/for-older-adults>

Or scan here →



## Free Live Webinars in December, January, and February

*Webinars are at Eastern Time, and in English unless otherwise specified.*

### December 2022

Understanding Dementia  
Dec. 9 10 am – 12 pm  
*In Spanish:*  
Dec. 16 10 am – 12 pm

Legal and Financial  
Dec. 19 5:30 – 7 pm

Medicaid Home Care  
Dec. 1 5:30 – 7:00 pm

Family Caregiver Workshop  
*In Spanish*  
Dec. 12 10 am- 1:00 pm

Monthly  
Education Meeting  
*Caring and Anger*  
Dec. 12 6:00 – 8:00 pm

### January 2023

Understanding Dementia  
Jan. 13 10 am – Noon  
*In Spanish:*  
Jan. 20 10 am – Noon

Understanding Dementia for  
Professional Caregivers  
Jan. 17 2:00 – 4:00 pm

Legal and Financial  
Jan. 9 12:00 -1:30 pm

Medicaid Home Care  
Jan. 5 5:30 – 7:00 pm

Family Caregiver Workshop  
Jan. 10, 17, 24, 31  
10:00 am -1:00 pm  
*In Spanish: Monthly  
Education Meeting  
Research Opportunities*  
Jan. 9 6:00 – 8:00 pm

### February 2023

Understanding Dementia  
Feb. 10 10 am – 12 pm

Legal and Financial  
Feb. 6 5:30 – 7 pm

Medicaid Home Care  
Feb. 2 5:30 – 7:00 pm

Monthly  
Education Meeting  
*Online*  
Intimacy and Sexuality  
Feb. 13 6:00 – 8:00 pm

### Ways to Give

#### Giving by Check

Please make checks payable to CaringKind and mail to:

360 Lexington Avenue, 3<sup>rd</sup> Floor  
New York, NY 10017

Online/Credit Card

Visit [www.caringkindnyc.org](http://www.caringkindnyc.org) and click on Donate or call 646-744-2908. We accept MasterCard, Visa, and American Express.

#### Appreciated Securities

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

#### Bequests

By remembering CaringKind in your will, you can have a significant impact on improving the quality of care for those affected by Alzheimer's disease. Your bequest may have estate tax planning benefits as well. The following is sample bequest language for discussion with your attorney:

I, \_\_\_\_\_ (first and last name, city, state, zip), give, devise and bequeath to CaringKind (or Alzheimer's Disease and Related Disorders, New York City, Inc.) with offices located at 360 Lexington Avenue, 3<sup>rd</sup> Floor, New York, New York 10017, (insert written amount of gift, percentage of the estate, or residuary of estate, or description of property) to be used for (insert "its unrestricted use" or name of CaringKind program).

#### Life Insurance and Retirement Plans

CaringKind can be named a beneficiary of your retirement plan or insurance policy.

#### Donor Advised Funds

If you have established a donor advised fund through another organization (e.g., community foundation, investment firm) 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.

Please contact Christian Doucette at 646-744-2979 or [cdoucette@cknyc.org](mailto:cdoucette@cknyc.org) if you would like additional information.

### OUR MISSION

The mission of CaringKind is to create, deliver, and promote comprehensive and compassionate care and support services for individuals and families affected by Alzheimer's disease and related dementias, and to eliminate Alzheimer's disease through the advancement of research. We achieve our mission by providing programs and services for individuals with dementia, their family and professional caregivers; increasing public awareness; collaborating with research centers; and informing public policy through advocacy.

Register by calling the CaringKind Helpline: 646-744-2900  
or visit: [www.caringkindnyc.org/caregivereducation](http://www.caringkindnyc.org/caregivereducation)

Professional Caregivers register here:  
[www.caringkindnyc.org/unde-professional-rsvp](http://www.caringkindnyc.org/unde-professional-rsvp)

## How FAIR Health's Tools and Resources Can Benefit Older Adults with Alzheimer's Disease and Related Dementias, and Their Care Partners

Managing Alzheimer's disease and related dementias involves making many decisions about care and related costs. Cost information is not easy to find or understand. With patients increasingly bearing more of these costs, it can be challenging to make informed decisions. FAIR Health, a national independent nonprofit, provides resources to help patients and their care partners address these issues.

With a generous grant from The John A. Hartford Foundation, FAIR Health has launched [tools, educational content and resources](#) that can help older adults with Alzheimer's disease and related dementias and their care partners. The tools are offered on a [dedicated section](#) of FAIR Health's free, award-winning national consumer website, [fairhealthconsumer.org](http://fairhealthconsumer.org), which is available in English and Spanish.

The FAIR Health Consumer [Older Adults section](#) offers several types of tools, articles and resources that can help you use the healthcare system and manage related healthcare costs. A cost estimator tool called **FH® Total Treatment Cost** shows the range of costs of care for a year for several chronic conditions, including one for Alzheimer's disease and related dementias, and procedures like knee arthroscopy. How do you use this tool? Simply click on the total treatment cost scenario for Alzheimer's (or another condition or procedure of interest), click view, select the option for insurance or no insurance, and enter your provider's zip code. Based on the location of your provider, the tool will generate two types of costs: the out-of-network (or uninsured) prices and the in-network price related to the suite of services for Alzheimer's care. These prices are based on data from FAIR Health's expansive database of private healthcare and Medicare Advantage claims.

Use the cost information to plan for and manage the cost of care for Alzheimer's. If you choose, you can negotiate the costs of care (more tips on that are offered [here](#)).

The website also offers **decision aids** for a set of conditions that are common among older adults (like hip osteoarthritis) and for which there is no "right" treatment option. They are useful when you would like to make decisions about care together with your care partner and healthcare provider based on your preferences and values, potential risks and benefits, and clinical evidence. This process is called shared decision making. Research has highlighted its effectiveness in engaging patients and care partners in healthcare decision making and reducing unnecessary healthcare spending and costs. FAIR Health's decision aids combine clinical and cost information—the latter of which is rarely included in these types of tools—for the following: hip replacement, spinal stenosis (spinal narrowing), early-stage breast cancer, fast-growing prostate cancer, nutrition options, dialysis and ventilation.

Under the **FH® Healthcare Toolkit** section, you can access printable checklists with questions to ask as you use the healthcare

system or engage in shared decision making. Be sure to download and print them before appointments. The [Financial Health Literacy](#) section offers information and helpful tips on how to manage and prepare for healthcare costs and links to resources that can help. Educational **FH® Insurance Basics** articles delve into topics such as Medicare, understanding medical bills, dental coverage in retirement and help for older adults and care partners, among many others.

The [Resources](#) section offers links to organizations and agencies that provide education and services related to the care and management of Alzheimer's disease and other dementias, among other conditions. You can print various sections of the site and educational materials, making it easier to use the tools and resources at home or at the doctor's office. Care partners who need assistance with Alzheimer's care can also find information on services and support groups.

Visit FAIR Health Consumer's [Older Adults](#) section for helpful tools, articles and resources that can help you use the healthcare system and make better decisions with greater ease.





## Thank You To Our Sponsors

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