

caringkind

360 Lexington Ave, New York, NY
CARINGKINDNYC.ORG
646-744-2900



Understanding Dementia 101:

*Adjusting to the Diagnosis and
Life Changes*

*Susanne Bengtsson, LMSW
VP Family Supports*

OUR PRIORITIES

Celebrating
45 years!

- *Being a trusted partner for resources and compassionate support throughout the journey*
- *Creating and delivering meaningful, best practice programs and quality education*
- *Equipping dementia care staff, healthcare and service professionals*
- *Advancing awareness, research, policy*

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Helpline: 646-744-2900

CARINGKINDNYC.ORG



Who Do We Serve?



PEOPLE WITH
ALZHEIMER'S OR ANY
FORM OF DEMENTIA



FAMILY MEMBERS,
PARTNERS, FRIENDS
PROVIDING CARE OR
SUPPORT



HEALTHCARE
PROFESSIONALS,
AIDES, SERVICE
PROVIDERS



RESIDENTIAL,
COMMUNITY, &
CULTURAL
ORGANIZATIONS

Individual & Family Services



Helpline



Navigation
& Care
Consultations



Family
Education
Workshops



Coaching
Caregiving Skills



Support Groups



Early-Stage
Programs



Social & Peer
Engagement



Palliative
Approaches

OUR WORK

*In Person &
Virtual Services*

*Free of charge for
individuals & families*

Workforce, Community, Research



Workforce
Training



Professional
Development



Dementia
Friendly
Community
Training



Research
Initiatives

Services provided
in multiple languages

*(Spanish, Mandarin,
Cantonese, Korean)*

Family Education Seminars

Legal & Financial Considerations

Check calendar for dates



Understanding Medicaid

Check calendar for dates



caringkindnyc.org/education/

Understanding Dementia 101:

*Caregiving through the dementia stages
and changing abilities*

REGISTER NOW

TUESDAY – Dec. 17th, 2024
6:00-7:15 pm

TUESDAY – Jan. 14th, 2025
12:00-1:15pm



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@caringkindnyc

EDUCATION SEMINAR

*A free learning event for
individuals, families and professionals*

LIVE WEBINAR

Tuesday, December 17th, 2024
6-7:15 pm EST

Understanding Dementia 101:

*Caregiving Through Dementia Stages and
Changing Abilities*



Becoming a 'caregiver' or 'carepartner' to someone experiencing the cognitive and physical changes from dementia requires new knowledge and skills. Any new role or job requires training and practice and caregiving is no different - especially since the 'job' of caregiving changes as a person's dementia progresses. Learning more about the stages of dementia, how abilities change, and what strengths a person retains can provide a solid foundation for partnering in care and quality living. Join us for this foundational talk designed for caring spouses, partners, adult children and friends to learn more about:

- **Dementia Tests and Their Meanings:** *What are the common dementia tests - and what do they mean for today or the future?*
- **Dementia Stages:** *How do a person's functional and cognitive abilities change as dementia progresses?*
- **Adaptive Strategies for Activities of Daily Living:** *What are some tips to support a person's independence and autonomy?*
- **Finding Strengths as Abilities Fade:** *What strengths remain to support ongoing connection and engagement in meaningful activities?*

Speakers: Stephani Shivers, MEd, OTR/L and Anne Kenny, MD

Stephani Shivers is the Chief Innovation Officer at CaringKind where she leads the development of new programs and services for individuals and families impacted by dementia. She has over 30 years leadership experience in community based organizations including a second career as an occupational therapist specializing in cognitive function.

Anne Kenny is a Geriatrician and Palliative Care Physician, Professor Emeritus, caregiving daughter and author of 3 books on dementia. She is a clinical consultant with CaringKind and currently serves as their Interim Director of Family and Professional Education.



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Baseball Memories

In Person
Third Wednesdays
11-12pm

Virtual
Third Tuesdays
4-5pm

Registration is required and space is limited.

In-person



<https://bit.ly/45ih8WF>

Zoom



<https://bit.ly/3Oo17YF>

Or call our Helpline: 646-744-2900

caringkind The Heart of
Alzheimer's Caregiving

CaringKind Helpline: 646-744-2900

Connect2Sports

In Person and Online Social Engagement

Presented by CaringKind and Cleveland SABR Jack Graney Chapter

Baseball Memories

Reminiscence and discuss baseball



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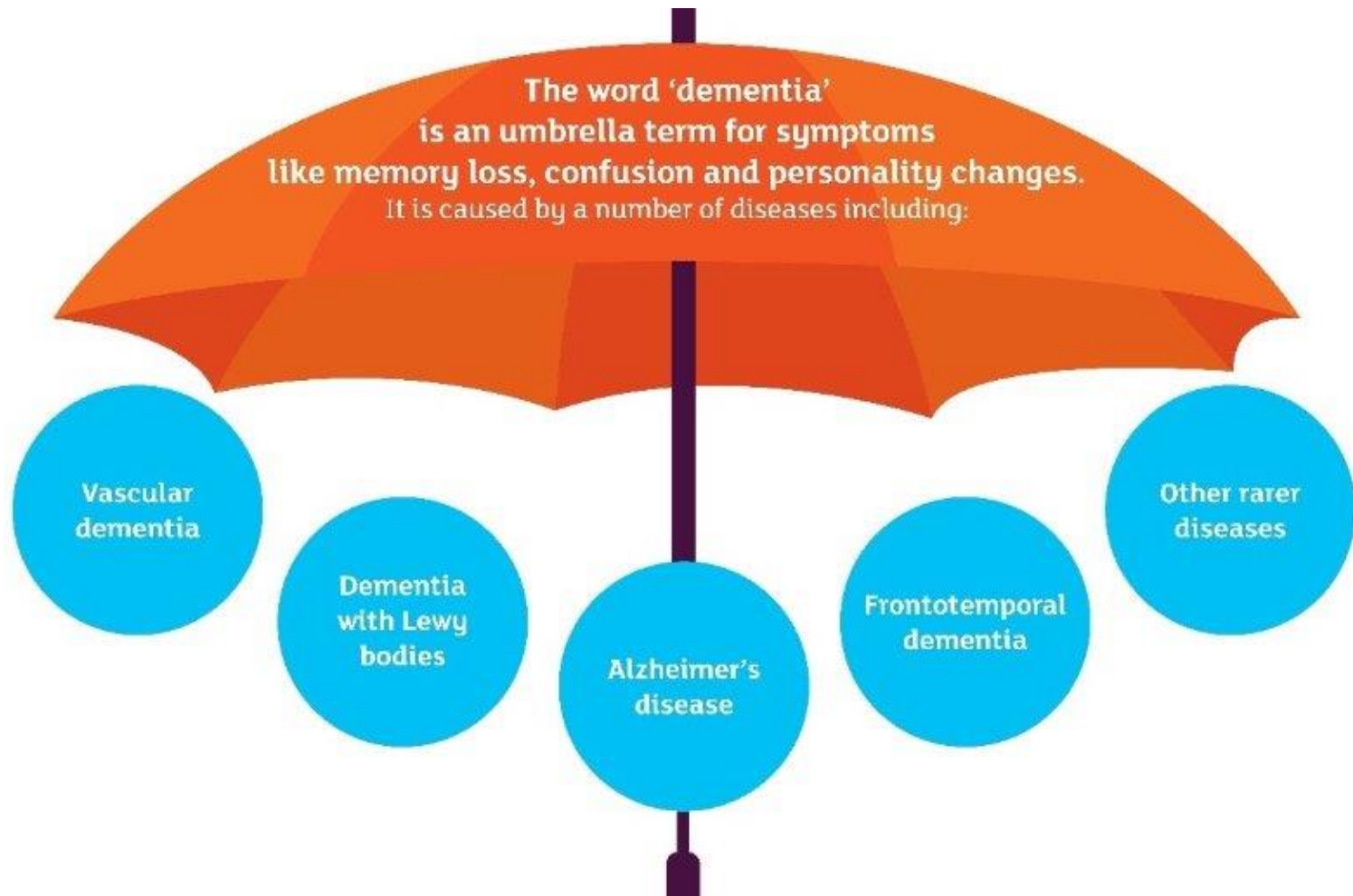
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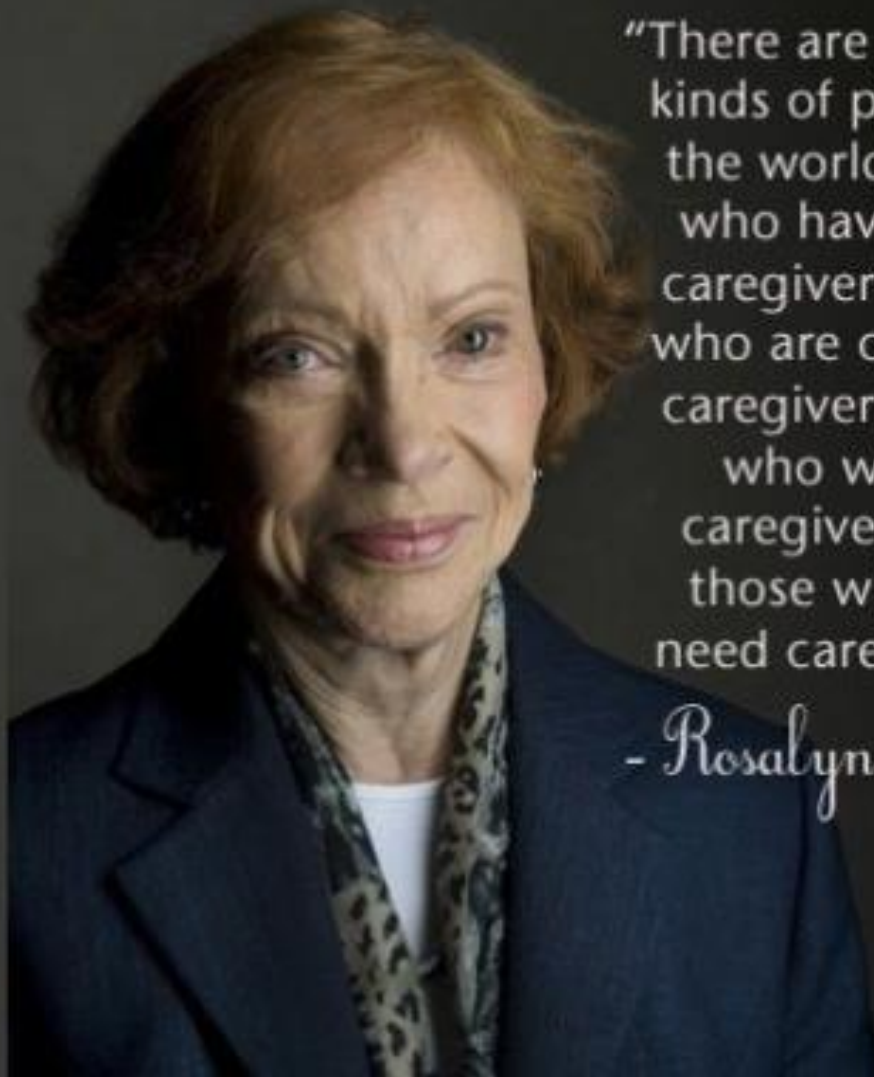
Susanne Bengtsson, LMSW

Susanne is Vice President of Family Supports at CaringKind. She oversees the programs and services available to family members and friends caring for those living with Alzheimer's Disease or related dementias. Susanne has over 20 years of experience working in aging and dementia services including working as a Memory Care Director and Executive Director in residential services and a Medical Social Worker in community home healthcare and hospice.



What is Dementia?





“There are only four kinds of people in the world: those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers.”

- Rosalynn Carter

Care Partners - Getting the Diagnosis:

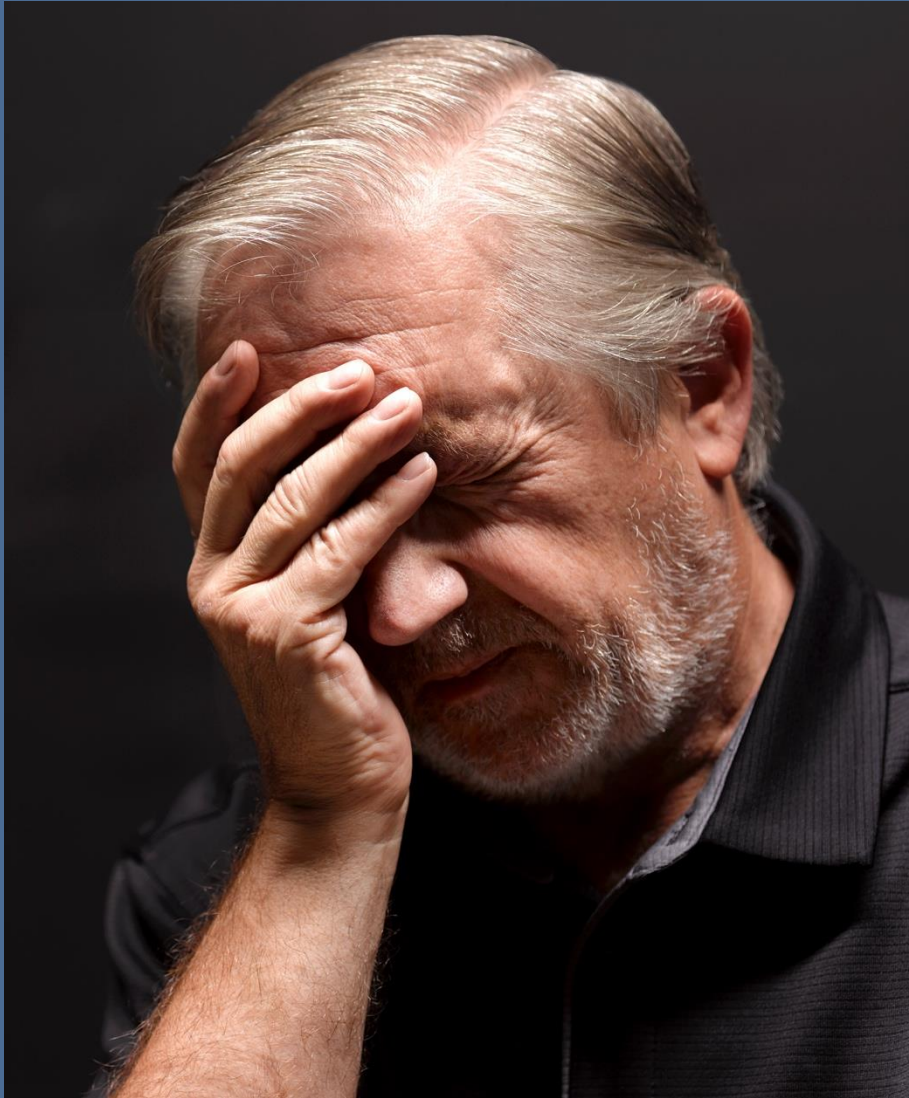
- Receiving a dementia diagnosis can be very challenging.
- Information and knowledge is key.
- Gaining a better understanding of the disease can help you adjust.



Stigma Associated with Getting the Diagnosis:

- Today, more than 6 million Americans have Alzheimer's and related dementias, and that number is projected to skyrocket in coming years.
- According to the Milken Institute, stigma associated with Alzheimer's disease often prevent people from seeking a cognitive assessment when symptoms arise





Care Partners – Learning About the Diagnosis:

- When you first learn about the dementia diagnosis, it may be difficult for you to think beyond the day to day.
- Chances are that you are afraid, not only for the person you are caring for, but for yourself as well.
- According to the Milken Institute, adults in the US fear Alzheimer's disease more than cancer, stroke, and heart disease combined.

You Will Feel a Variety of Emotions:

Anger, denial, embarrassment, frustration, fear, sadness and/or guilt

These emotions are normal and common among caregivers.

If your feelings are overwhelming and won't go away, talk to your doctor.

Challenges:



- Adapting to change:
 - *Change of Role*
 - *Change of Relationship*
 - *Change of Environment*
 - *Change of Family and Social Dynamics*

Challenges:

- Grief and Loss:
 - *Losing the Person*
 - *Loss of Peace of Mind*
 - *Grief (inward experience)*
 - *Mourning (outward expression)*



Prepare for Ongoing Changes:

Caring for a person with dementia can be a rewarding experience.

Caring for a person with dementia can be very challenging.

As the dementia progresses, the person may show changes that you weren't expecting.

Caring for a person with dementia can have high physical, emotional, and financial costs.

Day to day care needs and decisions about residential placement can be difficult.



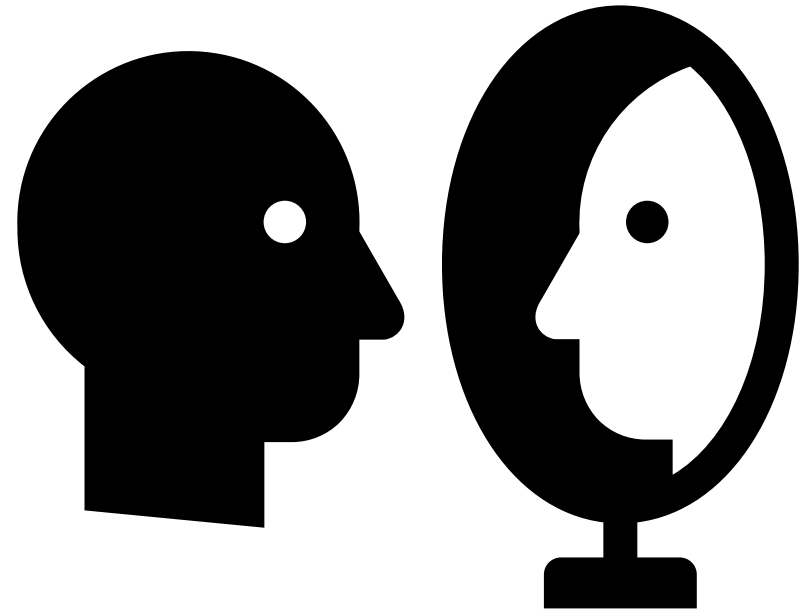
Information and Knowledge:

Care partners often don't...

- understand or believe they are dealing with a disease that will not improve.
- have a clear understanding about the course of the disease.
- realize that the disease progresses in stages and that different stages has a great impact on caregiving strategies.
- have enough information on the impact of caregiving on caregivers.

Take Care of Me:

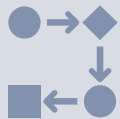
- Important self-care skills (especially skills related to managing and understanding one's own feelings)
- Skills for making decisions as the caregiving journey evolves.
- Skills for navigating family issues that come up while providing care.



Adopting a New Outlook:



Become less emotionally involved, at least when you are trying to solve a caregiving problem.



Believe you can do the work you have chosen to do.



Learn how to value and appreciate your own work.

The 8 Central Needs of Care Partners:



Tell Your Story



Educate yourself
and others



Adapt to changing
relationships



Grieve your losses



Take care of
yourself



Ask for and accept
help from others



Prepare for what's
ahead



Explore existential
and spiritual
questions

Learn More & Share Your Knowledge:

- Learn as much as you can about dementia and providing care.
- Find out how dementia can affect a person, what changes you can expect, and how you can help to maintain their independence, dignity and quality of life.
- Share your knowledge with the people closest to them, such as other family members, friends and co-workers, to help them understand.





Relationship Changes

The most typical relationship change is an increase in the emotional distance between you as a care partner and the person with dementia.

Adapt to the Changing Relationship and Learn Skills:



Dementia progresses over time and will affect a person's daily functions. Learn about the changes dementia can cause so that you have realistic expectations of the person's abilities.



Ask the person how you can help them stay independent and maintain a sense of autonomy. One tip often heard from care partners is that, though it isn't always easy, it helps to be patient.



Patience is one of the most important skills you can have as a dementia care partner.

Adapt to the Changing Relationship – Skills:

Avoid
Confrontation

AAR – Affirm,
Acknowledge
and Redirect

KISS – Keep it
Short, Simple,
and Safe

Therapeutic
Fibbing

Unmet physical needs

Hunger and thirst
Tired and/or overstimulated
Bowel or urinary distress
Discomfort
Pain

Unmet emotional needs

Anger
Sadness
Loneliness
Fear
Boredom

Unmet psycho-social needs

Comfort
Compassion
Occupational
Attachment
Identity
Inclusion

Uncovering Unmet Needs or Wants:




Stages and What to Expect Next:

Mild Cognitive Impairment (MCI)

Early-Stage (Mild) Dementia

Middle-Stage (Moderate) Dementia

Late-Stage (Severe) Dementia



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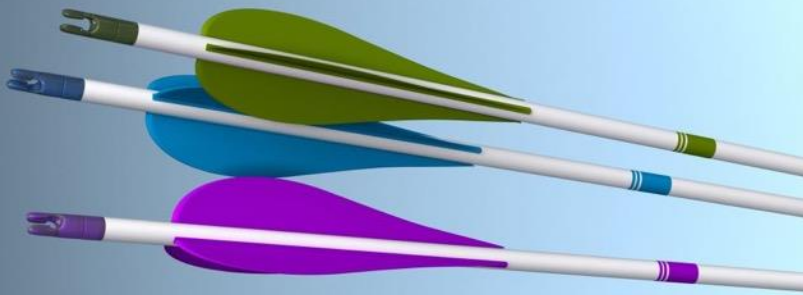
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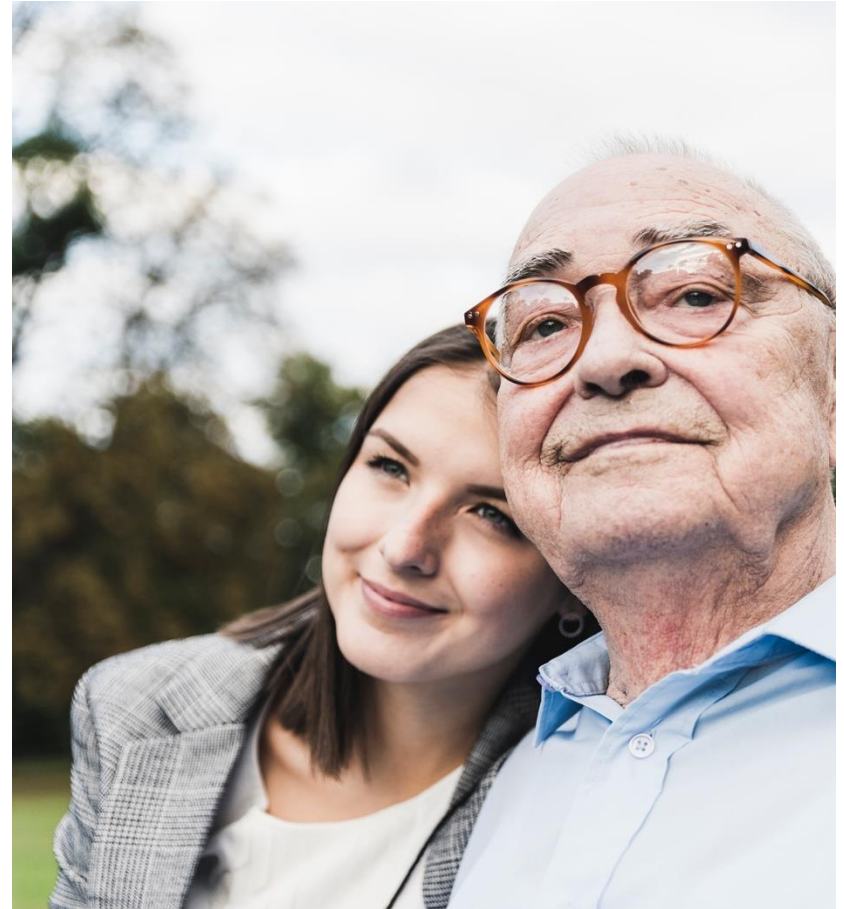
Think About Your Approach:

- Adjust your approach and demands to match the person's abilities.
- Take the person's disease stage into account.
- Help the person become and remain involved in daily tasks and activities.
- Promote autonomy and sense of purpose.



Treat the Person with Dignity and Respect:

- No matter how dementia affects an individual, it is essential to treat them with dignity and respect. Although certain abilities may change, their emotions and feelings will remain, as will the need for companionship and a sense of belonging.



Grieve Your Losses:

- Being a dementia care partner might be one of the loneliest and most isolating experiences of your life:
 - Feeling desolate – no one else can (or wants to) understand what you are going through.
 - Your world is shrinking – care partners often become bound by the walls of their home.
 - Friendships may become more distant or fade away.



Personal Losses:



- Time and Freedom
- Personal Health
- Occupation
- Social activities and Recreation

Common Emotions:

Grief

Guilt

Anger

Embarrassment

Loneliness

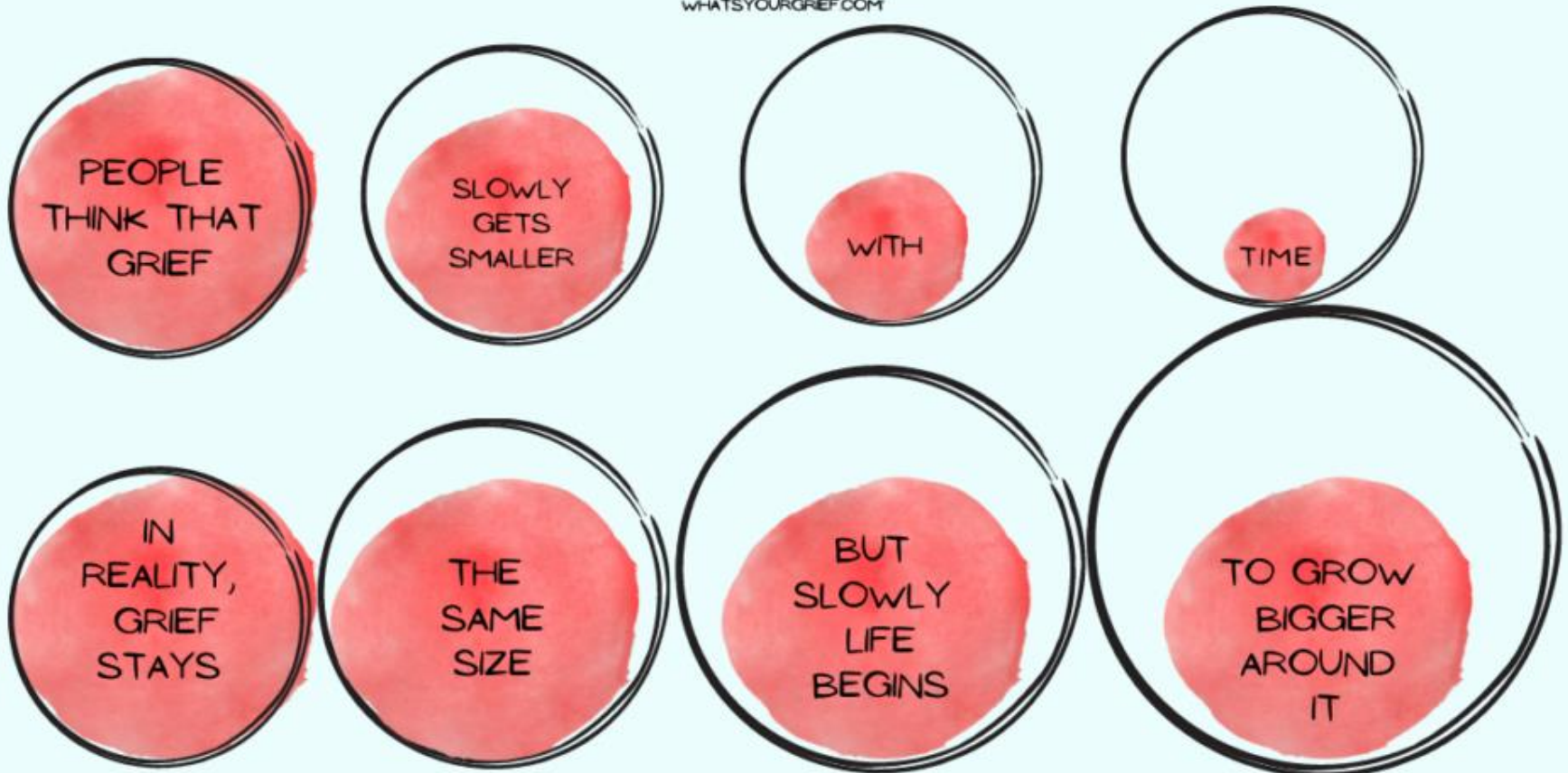


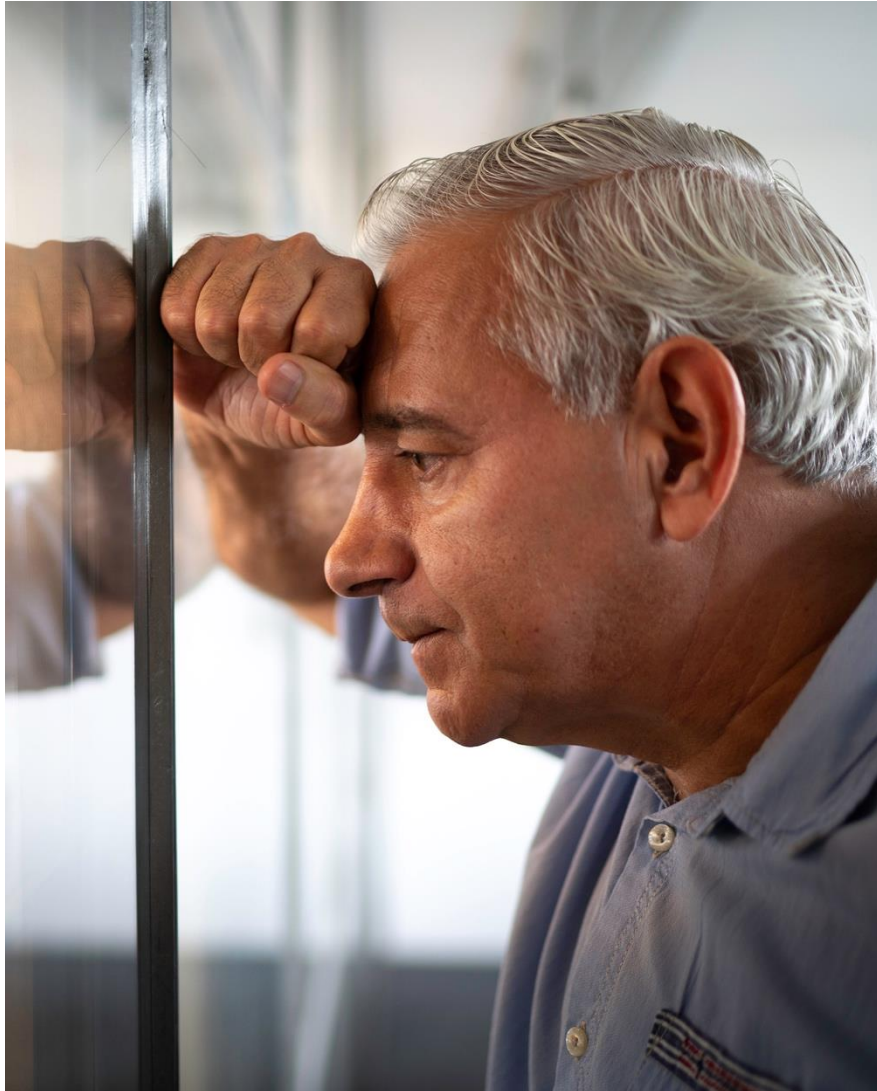


'GROWING AROUND GRIEF'

(LOIS TONKIN, 1996)

WHATSYOURGRIEF.COM





Stress and Self-Care:

Compared to non-caregivers, dementia care partners are more likely to experience:

- Fatigue
- Frustration
- Despair
- Depression
- Anxiety
- Insomnia
- Medical problems
- Marital strain

The Need for Self-Care and Wellness:



PHYSICAL HEALTH



MENTAL HEALTH



SOCIAL
RELATIONSHIPS



SPIRITUAL HEALTH



COMMUNITY
ENGAGEMENT



INTELLECTUAL
CURIOSITY AND
CREATIVE THINKING



OCCUPATIONAL
CONTENTMENT AND
CONTRIBUTION



FINANCIAL
STABILITY

Assembling a Caregiving Team:



- Dementia caregiving is a team sport.
- You will need to recruit members to your team.
- You will need to be intentional and proactive about recruiting members.

CaringKind Programs & Services

- **Helpline** – Information, Referrals, Resources and Dementia Consultations
- **MedicAlert NYC** – Wanderer's Safety Program
- **Support Groups** – Spouses/Partner, Adult Children, Young Onset, LBD, FTD, LGBTQ+
- **Partnering Together** – Support Workshop for New and/or Early-Mid Stage Family/Friend Caregivers
- **Education Workshops** – for Supporting Family Members and Friends
- **1:1 Coaching Services** – Social work led services including evidence-based programs

**Need Support or
Direction?**



**Talk to a Navigator
646-744-2900**





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Thank you!

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