



The Heart of Alzheimer's Caregiving

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

Presented by Adina Segal, LCSW

Defining Dementia

- A group of symptoms resulting from an underlying medical condition.
- Affects 4 areas of functioning:
 - ✓ Memory - short-term and later long-term
 - ✓ Cognition - thinking, planning, reasoning, language, judgement, processing, etc.
 - ✓ Behavior - mood and personality, apathy
 - ✓ Physical functioning – motor skills, gait, visual spatial function

Dementia



Alzheimer's disease

Vascular dementia

Lewy-Body dementia

Frontotemporal dementia

Mixed

Reversible dementias

Normal Aging vs. Dementia

- Occasionally misplacing keys
- Forgetting the right word
- Temporarily forgetting the day
- Forgetting how to use a key
- Having difficulty with conversation
- Losing track of the date and season

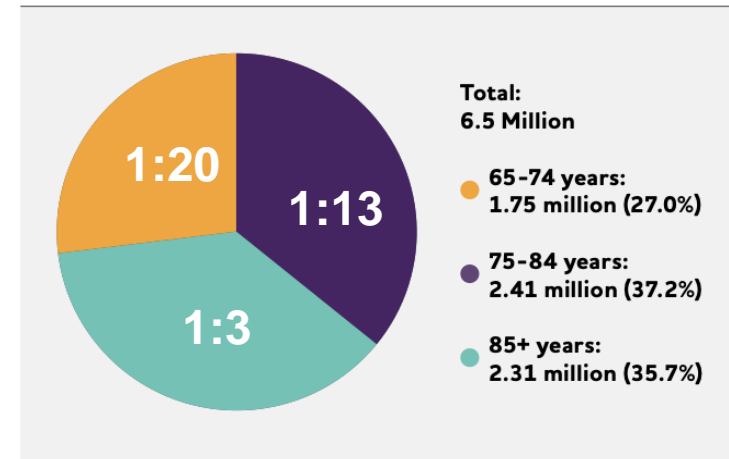
Diagnosing the Cause

- Differential diagnosis
 - Family history
 - Physical exam & blood tests
 - Neuropsychological testing - memory, cognition and personality
 - Brain Imaging - PET/MRI scans
- 90-95 percent accuracy

Alzheimer's Disease in US

- Most common cause: 60-80% of dementia
- In 2022, over ~6.5 million
- By 2050, over ~14 million
- 1 in 9 adults 65+ with AD
- Risk increases with age
- 1 in 3 older adults dies with AD
- 5th leading cause of death age 65+

Number and Ages of People 65 or Older with Alzheimer's Dementia, 2022*



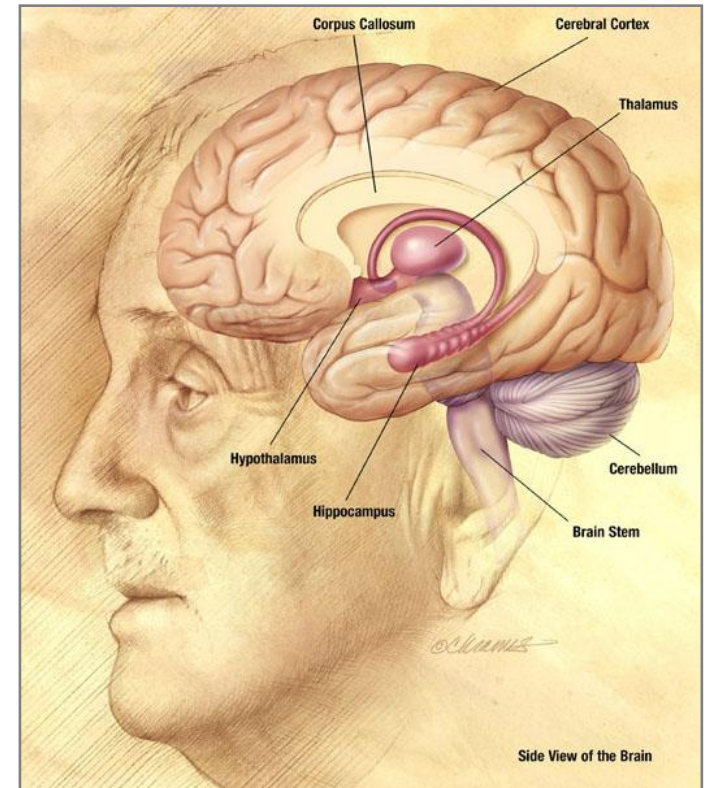
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19

Alzheimer's Association. 2022 Alzheimer's Disease Facts and Figures.
Alzheimers Dement 2022;18.

Understanding Alzheimer's

To understand Alzheimer's disease, it is important to know some facts about the brain:

Number of neurons or nerve cells:
100,000,000,000 (100 billion)



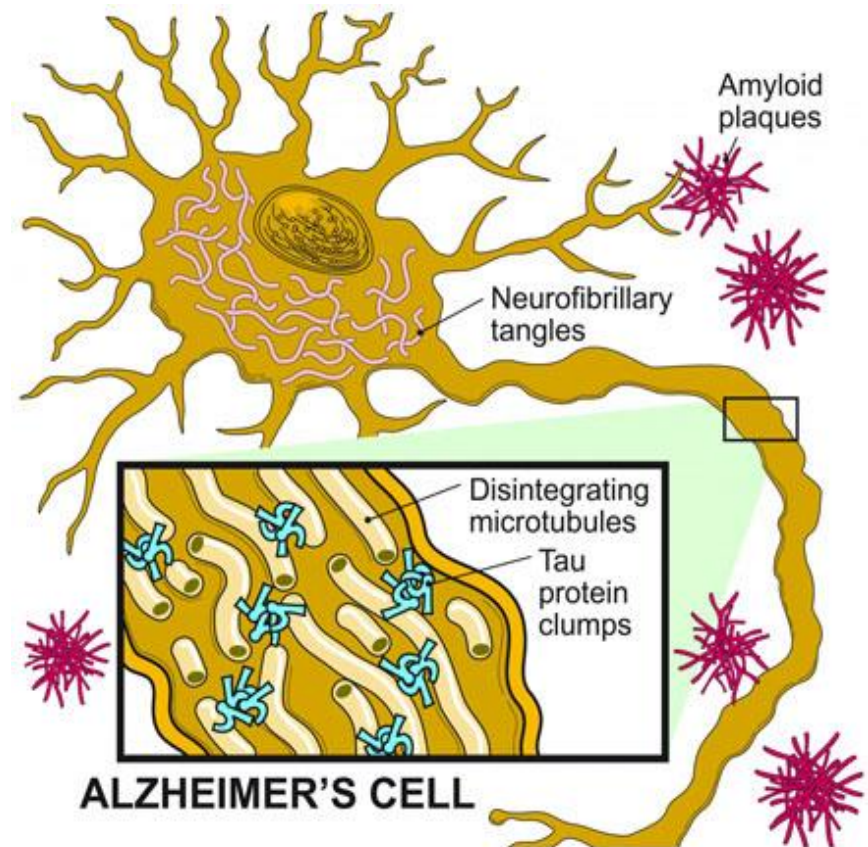
Alzheimer's Pathology

Plaques:

Abnormal clusters of the protein **beta amyloid** build up between nerve cells and lead to cell death.

Tangles:

Strands of protein called **tau**, essential for maintaining cell structure, collapse leading to cell destruction.



Brain Comparison



Normal

Alzheimer

Risk Factors

- Age
- Race
- Gender
- Family history
- Genetics
- Head injury
- Heart-brain connection
- Substance abuse
- Down syndrome

How Long? Staging Estimates

Early Alzheimer's – 2-7 years

Moderate Alzheimer's – 2-7 years

Late Alzheimer's – 1-3 years

(Based on FAST/GDS Scales)

*Many years to live well
with purpose*



Mild Cognitive Impairment

- Causes problems with memory and thinking serious enough to be noticeable by self and others.
- Not severe enough to interfere with independence
- Increases the risk of developing AD (MCI due to AD)

Early-Stage Symptoms

- Short-term memory loss
- Confusion in orientation to place and time
- Inability to follow complex instructions
- Problems with money
- Loss of initiative and motivation
- Difficulty performing regular tasks
- Difficulty learning new things – routines, people, etc.
- Poor judgment

Early-Stage Considerations

Abilities

- Understanding implications of illness
- Participating in decision making
- Identifying and articulation of feelings
- Often living independently

Concerns/Goals

- Preserve Autonomy
- Self-esteem
- Dignity
- “I am not my disease”

Middle Stage Symptoms

- Increased memory loss/confusion
- Difficulty thinking logically/organizing thoughts
- Confabulation
- Problems with recognition
- Increased communication difficulties
- Mood swings/changes
- Disinhibition
- Hallucinations/delusions
- Sundowning - agitated/restless in afternoon/evening
- Motor problems
- Incontinence or “Accidents”
- Wandering

Middle Stage Considerations

Abilities

- Participating in modified activities
- Making choices

Concerns/Goals

- Loss of control
- Frustration
- Abandonment
- Safety - no longer able to live alone
- Support individual – give choices, initiate activity, maintain routine and familiarity

Late-Stage Symptoms

- Limited verbal communication
- Minimal recognition of family or self
- More sedentary; eventually bedbound
- Contractures, stiffness of arms and legs
- Eating and swallowing difficulties
- Total incontinence
- No capacity for self-care

Late-Stage Considerations

Abilities

- Some awareness of surroundings
- Benefits from sensory stimulation - talk, music, touch

Concerns/Goals

- Comfort
- Dignity
- Positioning regularly
- Smaller meals, finger foods, hand feeding if needed
- Monitor weight
- Palliative Approach to Care

Medications

1993 - 2021

- Most manage symptoms, but DO NOT modify disease
 - 1. Cholinesterase inhibitors**
 - ✓ Aricept/donepezil
 - ✓ Exelon/rivastigmine
 - ✓ Razadyne/galantamine
 - 2. Glutamate pathway modifier**
 - ✓ Namenda/memantine
 - 3. Combination therapy**
 - ✓ Namzaric/donepezil & memantine
- Side effects - gastrointestinal, vivid dreams

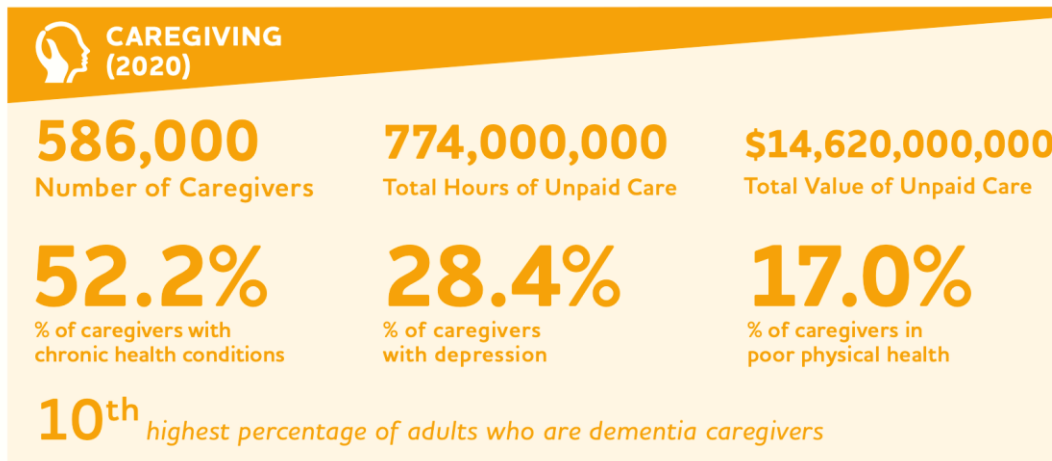
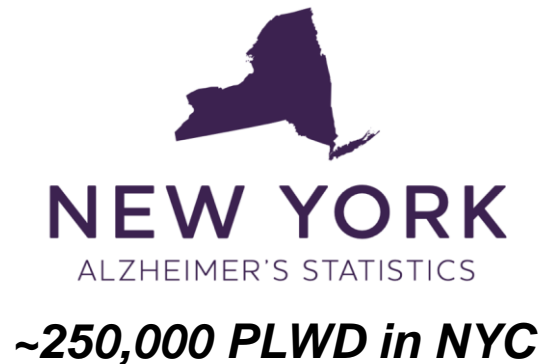
Lecanamab approved 1/6/23

- FDA approved under “accelerated” approval, i.e. biological affect. Reduction of amyloid
- Approved for “traditional” approval July 6, 2023
- Slowed rate of cognitive decline by 27%
- Slowed rate of functional decline by 37%
- Projected to delay progression to next stage by 2.5 – 3 years.

Donanemab

- Risk of side effects similar to other MAB's against AD.
- Symptoms mild
- 1.6% of brain swelling was serious
- Requires thoughtful discussion with health care provider
- Monthly infusion vs. biweekly (Leqembi)

Caregiver Stats



1321 hrs/CG
(25 hrs/week)

Alzheimer's Association. 2022 Alzheimer's Disease Facts and Figures.
Alzheimers Dement 2022;18.

Caregiver Concerns

- Most dementia caregivers perform key tasks such as managing finances (65%) and communicating (79%) and advocating (63%) on behalf of the care recipient
- 51% of dementia caregivers provide medical or nursing tasks without prior preparation
- Health care providers ask Alzheimer's caregivers about their needs in 25% of cases and the needs of the care recipient in 46% of cases

*Source: National Alliance for Caregiving and AARP Public Policy Institute. (2015).
Caregiving in the US, 2015. Bethesda, MD: NAC, and Washington, DC: AARP.*

Caregiver Burnout

- Isolation and withdrawal
- Loss of interest
- Symptoms of depression and irritability
- Exhaustion
- Getting sick often
- Changes in eating and sleeping patterns
- Suicidal ideation

<https://my.clevelandclinic.org/health/diseases/9225-caregiver-burnout>



- Caregiver Burnout Self- Assessment:
- <https://www.healthinaging.org/sites/default/files/media/pdf/Caregiver-Self-Assessment-Questionnaire.pdf>

Caregiver Self-Assessment Questionnaire

How are YOU?

Caregivers are often so concerned with caring for the relative's needs that they lose sight of their own well-being. Please take just a moment to answer the following questions. Once you have answered the questions, turn the page to do a self-evaluation.

During the past week or so, I have ...

1. Had trouble keeping my mind on what I was doing....	<input type="checkbox"/> Yes <input type="checkbox"/> No	13. Had back pain.....	<input type="checkbox"/> Yes <input type="checkbox"/> No
2. Felt that I couldn't leave my relative alone.....	<input type="checkbox"/> Yes <input type="checkbox"/> No	14. Felt ill (headaches, stomach problems or common cold).....	<input type="checkbox"/> Yes <input type="checkbox"/> No
3. Had difficulty making decisions.....	<input type="checkbox"/> Yes <input type="checkbox"/> No	15. Been satisfied with the support my family has given me.....	<input type="checkbox"/> Yes <input type="checkbox"/> No
4. Felt completely overwhelmed.....	<input type="checkbox"/> Yes <input type="checkbox"/> No	16. Found my relative's living situation to be inconvenient or a barrier to care.....	<input type="checkbox"/> Yes <input type="checkbox"/> No
5. Felt useful and needed	<input type="checkbox"/> Yes <input type="checkbox"/> No	17. On a scale of 1 to 10, with 1 being "not stressful" to 10 being "extremely stressful," please rate your current level of stress.	_____
6. Felt lonely.....	<input type="checkbox"/> Yes <input type="checkbox"/> No	18. On a scale of 1 to 10, with 1 being "very healthy" to 10 being "very ill," please rate your current health compared to what it was this time last year.	_____
7. Been upset that my relative has changed so much from his/her former self.....	<input type="checkbox"/> Yes <input type="checkbox"/> No		
8. Felt a loss of privacy and/or personal time.....	<input type="checkbox"/> Yes <input type="checkbox"/> No		
9. Been edgy or irritable.....	<input type="checkbox"/> Yes <input type="checkbox"/> No		
10. Had sleep disturbed because of caring for my relative.....	<input type="checkbox"/> Yes <input type="checkbox"/> No		
11. Had a crying spell(s).....	<input type="checkbox"/> Yes <input type="checkbox"/> No		
12. Felt strained between work and family responsibilities...	<input type="checkbox"/> Yes <input type="checkbox"/> No		

Comments:
(Please feel free to comment or provide feedback.)

AGS

Geriatrics
Healthcare
Professionals

Leading Change. Improving Care for Older Adults.

Healthinaging.org
Trusted Information. Better Care.

Impact of Caregiving on Caregivers

- Family conflict
- Role Reversal
- Worried about finances
- Over 11 million Americans provide unpaid care for people with Alzheimer's and other dementias at an estimated value of \$340 Billion”

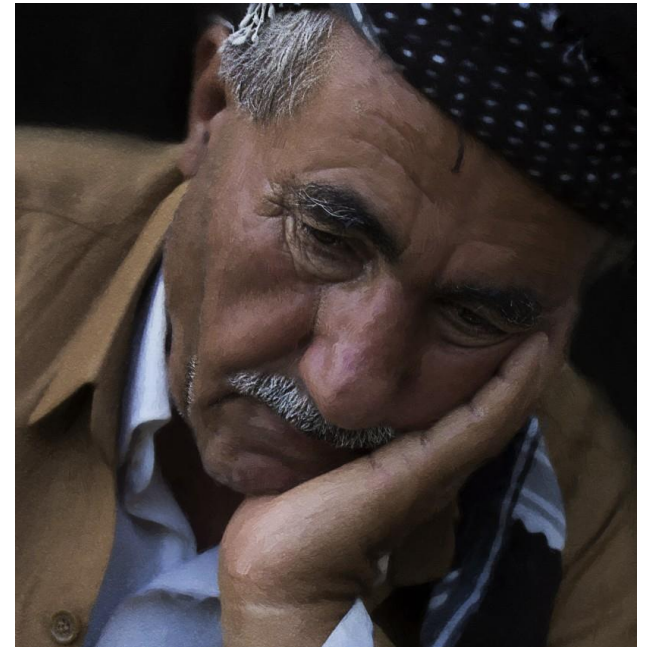
Family Concerns

- Keep in mind the relationship to the care recipient
- Spousal issues:
 - Common for well spouse and/or spouse with dementia to pull away (Barr et al 2016 pp 44-45)
 - Well spouse- stigma, anticipatory loss, role change
 - Spouse with dementia- apathy as a result of the disease
 - Intimacy issues (Rolland 2017)
- How to Help:
 - Important to have a clear understanding of the illness and its trajectory
 - Intimacy issues (Rolland 2017)
 - Communication is critical (Kim et al 2017)
 - Well spouse should be encouraged to accept help and reevaluate identity using “both and” approach (Boss 2006)



Ambiguous Loss

- Ambiguous Loss describes grief that occur when there is no closure. It is a common experience with dementia where a person is "there but not there."
-
- Source: Pauline Boss, "Ambiguous Loss" (2006)



Ambiguous Loss- Pauline Boss (2006)

- Identifies the need to understand the ambiguity as a challenge
- Live with the ambiguity
- Use both/and as part of your thinking
 - She is both gone and still here
 - I take care of both him and myself
 - I am both a caregiver and a person with my own needs

Helping Caregivers Cope

- Validate, Validate, Validate
 - Emotions change- it is normal to feel a sense of accomplishment around caregiving at some point only to then feel resentful
- Anger management techniques- Deep breathing, pausing
- Identify what is behind the anger and assist in problem solving
- Support Groups
- Assist Caregiver in experiencing the "both/and"
- Respite



Working with PWD's

- Stage dependent
- Adult communication – they're not children- no baby talk
- Use preferred name or title – Pastor Jones, not Bob
- Speak in shorter sentences.
- Give time and cues if needed
- Use limited choices, or yes/no questions
- Be aware of your tone and body language
- Reflect their emotional state – be sensitive to outbursts or anger
- Reassure, re-direct, reminisce

Until there's a cure.... We'll be... caringkind

Programs, Services and Education for:

- People with dementia OR a chronic cognitive disability
- Family members, Partners, Friends providing care or support
- Care staff, healthcare/aging/dementia service professionals
- Community, Residential, Cultural organizations

Delivered Virtually and In-Person through:

- 1:1 Sessions
- Small group programs
- Education seminars & webinars
- Trainings
- Special events

**Services provided
FREE of CHARGE
Available in English,
Spanish, Chinese**

**For more information, call our
Helpline: 646-744-2900**

www.caringkindnyc.org

Family/Partner, Friend Caregiver Services

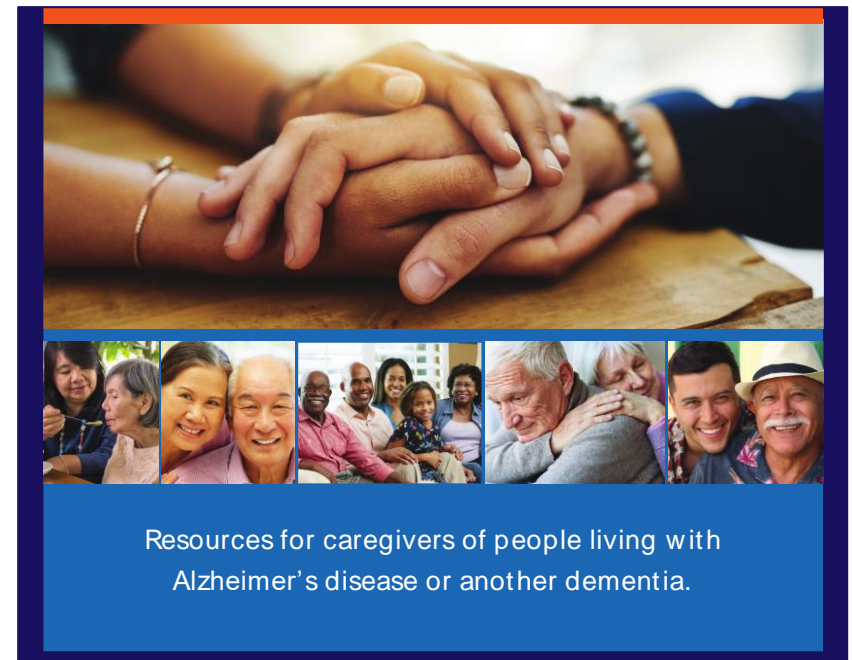
Helpline – Information, Referrals, Resources and
Dementia Consultations

1:1 Coaching Services – Social work led services
including evidence-based programs

Partnering Together – Support Workshop for New and
or Early-Stage Family/Friend Caregivers

Support Groups – Spouses/Partner, Adult Children,
Young Onset, LBD, FTD, LGBTQ+

Topical Monthly Webinars



Services available in English, Spanish, Chinese

For more information,
call our Helpline: 646-744-2900

Early-Stage Programs

Cognitive Stimulation Therapy – Evidence-based small group therapy – 16 sessions

Journey Together - Early-Stage Support Workshop and Early-Stage Support Groups

To Whom I May Concern® - Writer's Workshop



caringkind
connect 2 culture®



Engagement Programs

- *Connect2Culture*
- *Connect2Baseball*
- *360 Meet-Ups*

360° Meet Up! Join Us!



caringkind

MEDICALERT® NYC WANDERER'S SAFETY PROGRAM

- 24-hour nationwide emergency response service
- Provides assistance for finding persons diagnosed with Alzheimer's disease or related dementia who wander locally or far from home or have a medical emergency.
- Bracelets available for the Person living with dementia, AND for their caregivers
- Annual service fee
- Scholarships for bracelet purchase and first annual fee made possible through a generous grant from the Charles and Mildred Schnurmacher Foundation, Inc. and NYC Council

 MedicAlert® NYC



To enroll online, visit
www.caringkindnyc.org/WanderSafety

For more information,
call our Helpline: 646-744-2900

REFERRALS

CaringKind Connection Form

➤ <https://www.caringkindnyc.org/ckconnection/>

Send via Email:

➤ helpline@cknyc.org

Send via Fax: 212-697-6158

Call Helpline: 646-744-2900



CaringKind Connection
No cover sheet necessary

FAX: 212-697-6158 EMAIL: Helpline@CaringKindNYC.org

HELPLINE: (646) 744-2900

Date: _____

PERSON WITH MCI/DEMENTIA: _____

(Please **PRINT** first and last name)

Gender: ☐ F ☐ M Prefer to self-describe: _____ Pronouns: ☐ She/Her ☐ He/Him ☐ They/Them DOB: _____

Cognitive Status: MOCA: _____ MMSE: _____ SLUMS: _____ Other Testing: _____

Diagnosis: ☐ Mild Cognitive Impairment ☐ Alzheimer's Disease ☐ Lewy Body dementia ☐ Vascular dementia

☐ Mixed dementia ☐ Frontotemporal Degeneration ☐ Other: _____ Date of Diagnosis: _____

Preferred Language: ☐ English ☐ Spanish ☐ Chinese ☐ Other: _____ Second Language: _____

Living Situation: ☐ Lives alone ☐ Lives w/caregiving partner/spouse ☐ Lives w/other caregiver ☐ Lives w/other non-caregiver

Phone: _____ Email Address: _____

Street: _____ Borough/Town: _____ Zip: _____

CARE/SUPPORT PARTNER: _____

(Please **PRINT** first and last name)

Preferred Language: ☐ English ☐ Spanish ☐ Chinese ☐ Other: _____ Second Language: _____

Relationship: ☐ Spouse/Partner ☐ Daughter/Son ☐ Sister/Brother ☐ Grandchild ☐ Other: _____

Phone: _____ Email Address: _____

Street: _____ Borough/Town: _____ Zip: _____

Best Person to Contact: ☐ Person w/MCI/Dementia ☐ Care/Support Partner. Preferred Method of Contact: ☐ Phone ☐ Email

I give permission to CaringKind and the service provider below to exchange contact and health information for the person with MCI/dementia and/or care/support partner named above in order to provide dementia education, information and support related to the coordination of care. I understand that a CaringKind Specialist will contact me about services and programs that are available. I understand the contact and health information provided will not be disclosed or shared with any other entity unless authorization from the listed parties is obtained. I understand this permission can be revoked at any time by contacting CaringKind and/or the referring provider named below. Person referred provided verbal consent instead of a signature ☐ Yes

Signature (To be signed by the person to be contacted): _____

TO BE COMPLETED BY REFERRING PROVIDER:

Referring Person/Agency: _____

Phone: _____ Email Address: _____

Specific Needs/Concerns: _____

Recommended Programs and Services (check category and/or specific service/program):

<input type="checkbox"/> MCI/Dementia Client Services & Programs	<input type="checkbox"/> Family Care/Support Partner Education	<input type="checkbox"/> Support Groups, Social Work, Counseling
<input type="checkbox"/> Early-Stage Programs <input type="checkbox"/> Cognitive Stimulation Therapy Class <input type="checkbox"/> SHARE – Self-Directed Care Planning <input type="checkbox"/> Connect2Culture <input type="checkbox"/> Wanderer Safety Program <input type="checkbox"/> MAP Volunteer Matching Program*	<input type="checkbox"/> Understanding Dementia <input type="checkbox"/> Family/Support Partner Education Workshops <input type="checkbox"/> Legal & Financial Seminars <input type="checkbox"/> MAP Volunteer Matching Program*	<input type="checkbox"/> General Information & Referral <input type="checkbox"/> REACH-II, (Evidence-Based Family Caregiver Intervention) <input type="checkbox"/> CK Connects Meeting - Care Consultation

January 2022

To Register:

<https://give.caringkindnyc.org/event/2024-caringkind-new-york-city-alzheimers-walk/e568780>



The poster features a blue skyline at the top. Below it, an orange banner reads "Celebrating CaringKind's 36th Walk Year!". The main title "caringkind New York City Alzheimer's Walk" is in blue and orange. A blue box contains the date and time: "Saturday, October 19th, 2024 • 10 am Central Park Naumburg Bandshell". A circular orange callout says "Join Us at New York City's Longest-Standing Alzheimer's Awareness Walk and Brain Health Day in Central Park!". A photo of a crowd is shown with the text "REGISTER VOLUNTEER CKWALK.ORG". At the bottom, it says "SERVING: BROOKLYN, BRONX, MANHATTAN, QUEENS, STATEN ISLAND...AND BEYOND!". Two orange boxes at the bottom contain contact information and a mission statement. A grey box on the right says "QR CODE Print version".

Celebrating CaringKind's 36th Walk Year!

caringkind New York City
Alzheimer's Walk

Join Us at
New York City's
Longest-Standing
Alzheimer's
Awareness Walk
and Brain Health Day
in Central Park!

Saturday, October 19th, 2024 • 10 am
Central Park Naumburg Bandshell

REGISTER
VOLUNTEER
CKWALK.ORG

SERVING: BROOKLYN, BRONX, MANHATTAN, QUEENS, STATEN ISLAND...AND BEYOND!

For over 45 years CaringKind has been your Trusted Partner in Alzheimer's and related dementia care. Our mission is to be a compassionate ally for everyone, ensuring no one faces this journey alone.

For more information, contact Samantha Vaccaro at svaccaro@cknyc.org or 646-744-2979

360 Lexington Avenue, 3rd Floor
New York, NY 10017
Helpline: 646-744-2900 • helpline@cknyc.org

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THANK
YOU!

