



Care Transitions:

Resources for Caregivers of Individuals
with Dementia



December 8, 2021 | Danielle Dodson, MSW, LCSW



Objectives

1. Recognize the key transitions in care that arise for patients with dementia and their care partners.
2. Identify appropriate resources for each care transition.
3. Understand strategies to introduce these resources in ways to facilitate acceptance by patients and families.

Disclosures

I have no financial disclosures.

Background

Prevalence

- 6.2 million Americans currently living with Alzheimer's disease
- Over 11% of Americans age 65+ have Alzheimer's disease
- Over one-third of Americans age 85+ have Alzheimer's disease
- One-third of older adults dies with Alzheimer's disease or another dementia

Alzheimer's Association. 2021 Alzheimer's Disease Facts and Figures. Alzheimer's Dementia 2021;17(3).

Impact on the Family

"Any major illness transforms a patient's - really, an entire family's - life. But brain diseases have the additional strangeness of the esoteric."

Paul Kalinithi, [When Breath Becomes Air](#), 2016, p. 90



Why are Resources Needed?

- On average, primary caregivers of individuals with dementia devote 9 hours daily to caregiving tasks
- About one-third of those providing care to individuals with dementia are over age 65
- Due to caregiving responsibilities, many individuals cut back or terminate their employment; as a result, their income drops, on average, greater than \$15,000 per year

www.caregiver.org

Alzheimer's Association 2016 Facts & Figures

Why are Resources Needed?

- In survey results shared in the 2012 World Alzheimer's Report, 28% of caregivers report being "avoided or treated differently"
- 20% of caregivers decrease physician visits for themselves due to their caregiving role
- "Nearly 60 percent of Alzheimer's and dementia caregivers rate the emotional stress of caregiving as high or very high"
- Approximately 4 out of 10 caregivers of individuals with dementia experience depression

Nicole L. Batsch & Mary S. Mittelman, World Alzheimer's Report 2012
Alzheimer's Association 2016 Facts & Figures
www.caregiver.org

Care Transitions

- Recognition of symptoms
- Diagnosis
- Retirement from work
- Driving cessation
- Loss of social connections
- Need for 24/7 supervision
- Behavioral challenges
- Employing outside help
- Incontinence
- Hospitalization
- Move to residential care
- Physical symptoms (e.g. falls, difficulty swallowing, infections)
- Palliative / Hospice care
- Death
- Loss of caregiving role

Dan Kuhn, "The Normative Crises of Families Confronting Dementia," Families in Society, 1990.
Alzheimer's Society of Canada, "Ambiguous Loss and Grief," 2013.

Common Myths

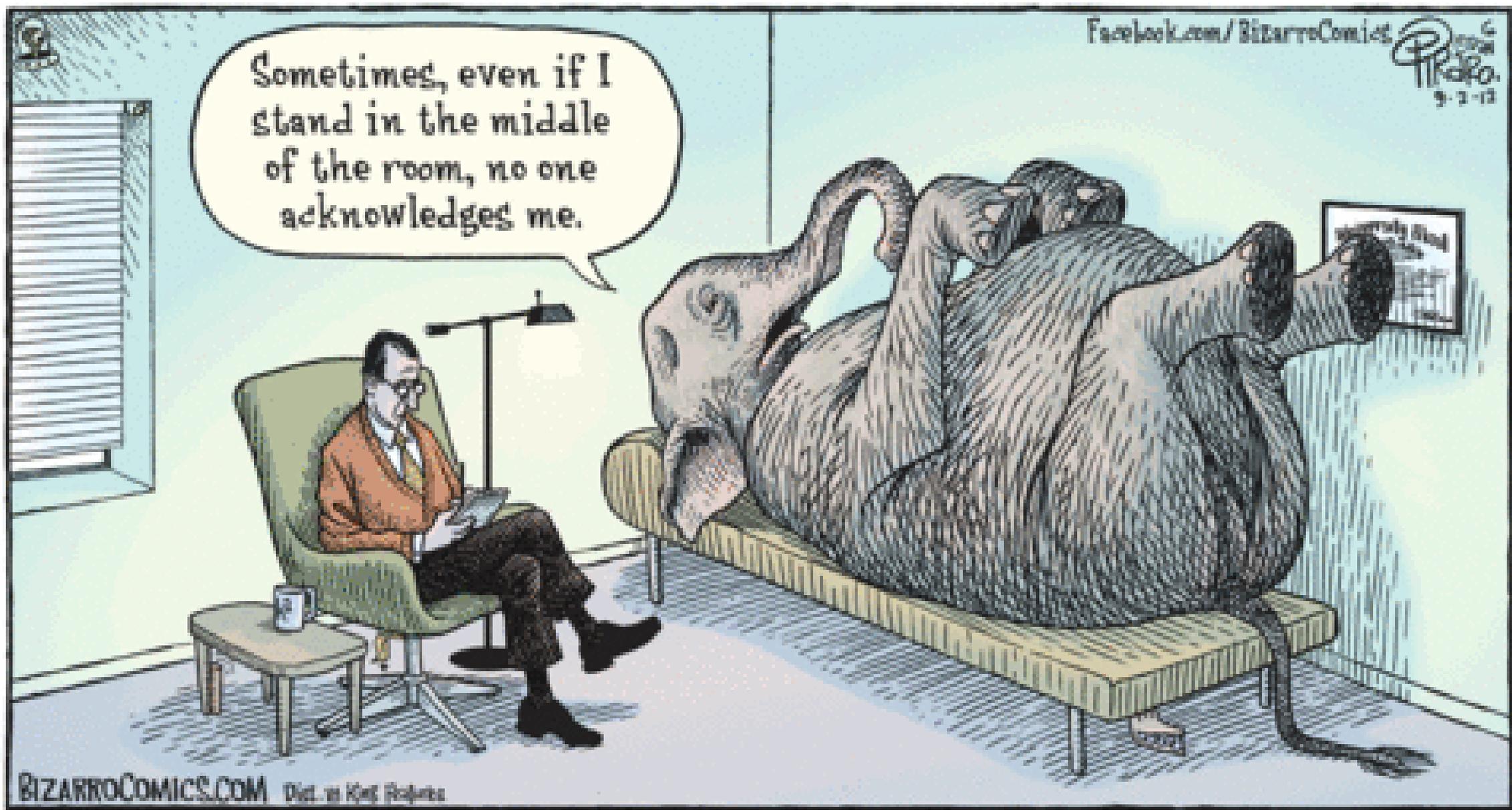
- Nothing can be done for individuals diagnosed with Alzheimer's disease.
- I don't need a Power of Attorney appointed to make health care decisions because: I'm married/have children/can make my own decisions.
- It is my responsibility (as a spouse / adult child / agent under POA) to provide all the care my loved one needs.
- When "care" is needed, the only option is a nursing home.
- Medicare pays for home care for older adults.

Common Myths

- Medicare pays for nursing home care for older adults.
- I worked my whole adult life; I should not have to spend my earnings on long-term care.
- “Memory Care” is a level of care, separate from assisted living or nursing home care.
- Accepting: assisted living/nursing home care/hospice care will “kill” my loved one.
- Hospice will provide 24/7 in-home care for my loved one.



Recognition & Diagnosis





PRINCIPLES FOR A DIGNIFIED DIAGNOSIS

The first statement of its kind written by people living with dementia on the subject of the Alzheimer's disease diagnosis experience.

Talk to me, the person living with dementia, directly.

I am the person living with the disease, and though those close to me will also be affected, I am the person who needs to know first.

Tell the truth.

Even if you don't have all of the answers, be honest about what you do know and why you believe it to be so.

Test early.

Helping me get an accurate diagnosis as soon as possible gives me more time to cope, live to my fullest potential and access information and resources.

Take my memory concerns seriously, regardless of my age.

Age may be the biggest risk factor for Alzheimer's, but Alzheimer's is not a normal part of aging. Don't discount my concerns because of my age. At the same time, don't forget that the disease can also affect people in their 40s, 50s and 60s.

Deliver the diagnosis in plain but sensitive language.

My diagnosis may be one of the most important things I ever hear. Please use language that I can understand and be sensitive to how this may make me feel.

Coordinate with other care providers.

I may be seeing more than one doctor. It's important that you talk to my other care providers to ensure everyone has the information so that changes can be identified early and I won't have to repeat tests unnecessarily.

Explain the purpose of different tests and what you hope to learn.

Testing can be very physically and emotionally challenging. It would help me to know the purpose of the test, how long it will take and what you expect to learn from the process. I would also appreciate the option of breaks during longer tests and an opportunity to ask questions.

Give me tools for living with this disease.

Please don't give me my diagnosis and then leave me alone to confront it. I need to know what will happen to me, what medical treatments are available, and what support and resources are offered through the Alzheimer's Association® and my community.

Work with me on a plan for living a quality life.

Medication may help modify some of my neurological symptoms, but I am also interested in recommendations for keeping myself as healthy as possible through diet, exercise and social engagement.

Recognize that I am an individual and the way I experience this disease is unique.

This disease affects each person in different ways and at a different pace. Please be sure to couch your explanation of how this disease may change my life with this in mind.

Alzheimer's is a journey, not a destination.

Treatment doesn't end with the writing of a prescription. Please continue to be an advocate — not just for my medical care but for my quality of life as I continue to live with Alzheimer's disease.

YOU are a key resource in the transition to recognition and diagnosis.

Evaluating Symptoms

Medicare Annual Wellness Visit

- A benefit of the Affordable Care Act, which entitles Medicare beneficiaries to a yearly preventive exam
- Brief cognitive assessment *should* be included
- In 2016, only 19% of eligible beneficiaries took advantage of the MAWV
- 50% of older patients have had a cognitive assessment by their physician
- Only 16% receive regular cognitive assessments

Alzheimer's Association. 2019 Alzheimer's Disease Facts and Figures. Alzheimer's Dementia 2019;15(3):321-87.

By Kenneth Brummel-Smith and Alexander “Sandy” Halperin

Patient-Centered Care for People with Cognitive Impairment Is Possible in Primary Care

“An activated, participating patient will be more likely to accept advice, adhere to treatments, and openly discuss disagreements.”

The authors suggest that providers ask the following questions:

- Can you tell me what you know of the course of Alzheimer’s Disease?
- What is most important for you as this condition progresses?
- How would you like to be treated as your condition progresses?

Brummel-Smith, K., & Halperin, A. “Sandy.” (2013). Patient-Centered Care for People with Cognitive Impairment Is Possible in Primary Care. *Generations*, 37(3), 87–91.

Introducing Memory Clinic Referral

- Decrease the threat
 - Explain that many health conditions can contribute to memory changes
 - Stress the benefits of early diagnosis
 - De-emphasize memory changes; focus instead on general well-being
- Be the “bad guy” so the family does not have to

Advocate Memory Center

Visit advocatehealth.com/memorycenter to learn more.

Locations

<p><u>Advocate Lutheran General Hospital: Parkside Center</u> 1875 Dempster St, Ste. 520 Park Ridge, IL 60068</p> <p>Phone: 847-720-6464 Fax: 847-720-6463</p> <p>Office Hours: Mon.– Fri.: 8 a.m. – 5 p.m.</p>	<p><u>Advocate Care Center</u> 2210 W 95th St. Chicago, IL 60643</p> <p>Phone: 773-341-3500 Fax: 773-341-3501</p> <p>Office Hours: 1st Friday of the month, 9 a.m. – 5 p.m.</p>	<p><u>Advocate Good Samaritan Hospital</u> 3825 Highland Ave, Tower 1, Suite 5b Downers Grove, IL 60515</p> <p>Phone: 847-720-6464 Fax: 847-720-6463</p> <p>Office Hours: Mon. & Wed.: 8 a.m. - 5 p.m.</p>
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Providers



Darren Gitelman, MD
Behavioral Neurology
Sr. Medical Director



Viet Le, DO, MS
Behavioral Neurology



Anthony McCormack, MD
Dementia focused
Geriatrics (not a PCP)



William Rhoades, DO
Dementia focused
Geriatrics (not a PCP)



Margaret Konieczny,
APRN
Adult-Gerontology



Elizabeth Hartman,
PhD, ABPP
Neuropsychology



Danielle Dodson, MSW,
LCSW, Social Worker

Services

- High-quality, patient-centered care to diagnose the cause of memory loss and dementia, develop a plan of care and offer support to our patients and their carepartners. All of our physicians are focused on specialty care and not providing primary care. We work with you to care for your patients.
- Advanced diagnosis and comprehensive care for all forms of dementia including; Mild cognitive impairment, Alzheimer's Disease, Frontotemporal Dementia, Lewy Body Dementia, Progressive Aphasia, Vascular Dementia and others.
- Clinical research trials related to dementia prevention and Alzheimer's disease.

To make a referral:

- **Via EPIC:** Select a Service to Neurology Order and choose Dementia / Memory Disorder as the Program.
- **Via Fax:** Send the referral order to (847) 720-6463 (for all sites)
- **Via Phone:** Call (847) 720-6464 (for all sites)

1) **Aurora Sinai Medical Center** in Milwaukee
Center for Senior Health
and Longevity clinic
414-219-7300

2) **Aurora Medical Center Summit**
414-219-7300

3) **Geriatric Medicine Clinic** at Village at Manor
Park in West Allis, WI
414-607-4291



Wisconsin Alzheimer's Institute

ABOUT ▾

WAI
MILWAUKEE ▾

CLINIC
NETWORK ▾

EDUCATION ▾

COMMUNITY
HEALTH ▾

RESEARCH

RESOURCES ▾

[HOME](#) / [MEMORY CLINIC FINDER](#)

Memory Clinic Finder

In 1998, WAI established a Network for memory clinics that follow WAI's best practice guidelines. Network clinics use a team of dementia care experts to do high-quality, thorough, interdisciplinary evaluations. The specially trained professionals recognize the importance of the early diagnosis of Alzheimer's disease and other dementias. In addition, they know the treatments and services that can help an individual and their family. [Some clinics also have staff who have experience working with individuals living with an intellectual developmental disability.](#)

For more information about the clinic network or how to develop your own clinic, please contact Dementia Diagnostic Clinic Network Manager, Jody Krainer: Phone (608) 263-6449 or [email](#).

FIND OUT MORE

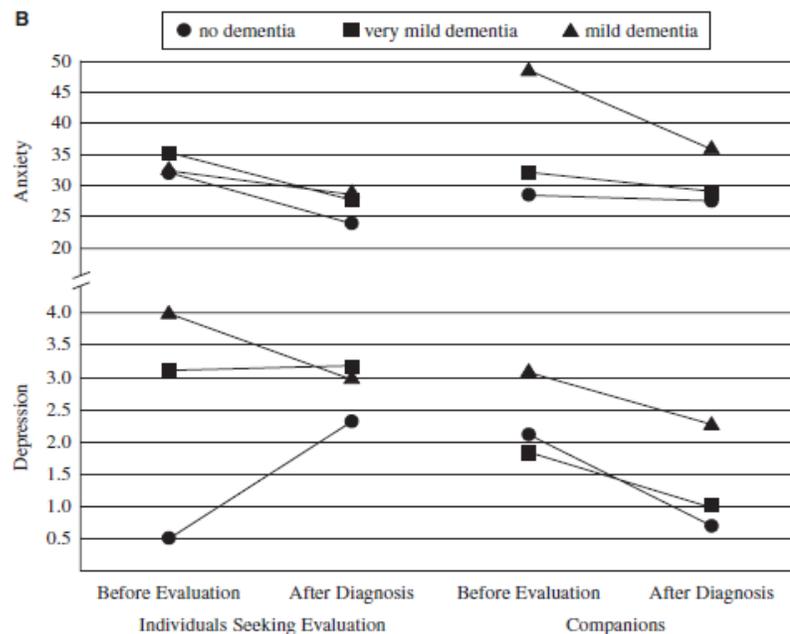
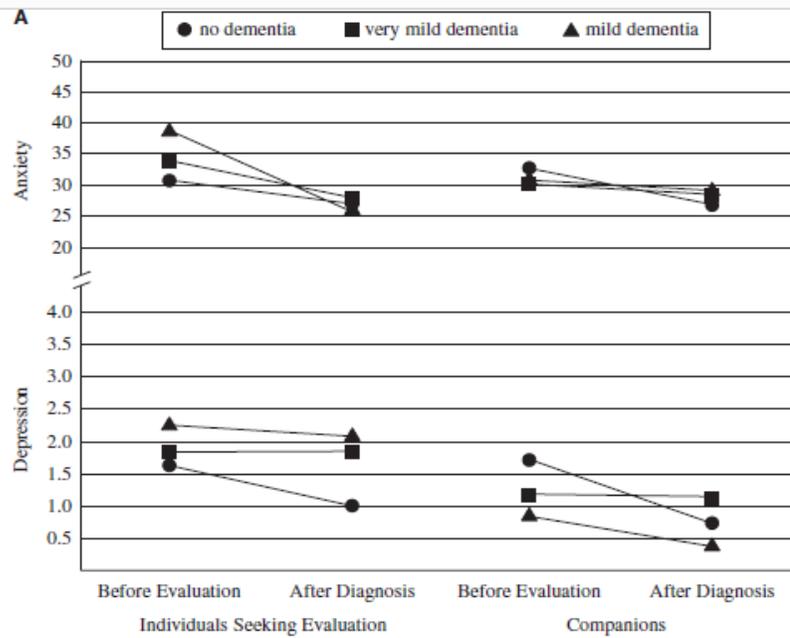
[About the Clinic Network»](#)

[Why Diagnose Dementia?»](#)

[When to Seek Help»](#)

[Clinic Development»](#)

[Memory Clinic Finder»](#)



Reaction to a Dementia Diagnosis in Individuals with Alzheimer's Disease and Mild Cognitive Impairment

Brian D. Carpenter, PhD,* Chengjie Xiong, PhD,[†] Emily K. Porensky, MA,* Monica M. Lee, MA,* Patrick J. Brown, MA,* Mary Coats, RN,[‡] David Johnson, PhD,[‡] and John C. Morris, MD[‡]

Carpenter, B. D., Xiong, C., Porensky, E. K., Lee, M. M., Brown, P. J., Coats, M., Johnson, D., & Morris, J. C. (2008). Reaction to a dementia diagnosis in individuals with alzheimer's disease and mild cognitive impairment: REACTION TO A DEMENTIA DIAGNOSIS. *Journal of the American Geriatrics Society (JAGS)*, 56(3), 405-412. <https://doi.org/10.1111/j.1532-5415.2007.01600.x>

Figure 1. (A) Mean changes in anxiety and depression after diagnostic feedback in people with no prior suggestion of dementia from another healthcare professional. (B) Mean changes in anxiety and depression after diagnostic feedback in people who had a prior suggestion of dementia from another healthcare professional. Range on the anxiety measure is 20 to 80; range on the depression measure is 0 to 15.

After a Diagnosis: First Steps

Social Work Services

- **Counseling / Psychotherapy** – to help patient and family cope with emotional reactions, changing roles / relationships, conflict, stress; appropriate for patient if she has some insight into her diagnosis
- **Disease Education** – regarding symptoms, anticipated trajectory, available interventions
- **Caregiver Education & Support** – to teach effective caregiving / communication strategies, manage stress, maintain caregiver well-being
- **Information & Referral** – assistance understanding and accessing health care services, social services, government benefits, care options
- **Care Planning** – identifying and addressing unmet care needs, education regarding anticipated future care needs, facilitated discussion regarding care preferences, advance care planning regarding end-of-life

Interventions informed by the works of: Mary Mittelman, DrPH; Darby Morhardt, MSW, LCSW, PhD; and Robyn Yale, MSW, LCSW

AAH Resources

Advocate
Older Adult
Services

Senior
Advocate

Aurora Senior
Services

Care
Management

NowPow

NICHE

ACE Units

Dementia Care Coordination

1. **The Alzheimer's Association has partnered with Advocate Aurora Health** to improve care coordination for people living with dementia and their care partners.
2. Health Care Providers (MD / DO / APN / PA / SW) at AAH **refer** people living with dementia and their care partners to the Alzheimer's Association.
3. The Alzheimer's Association **reaches out** to caregivers to:
 - **Develop** customized care plans
 - **Provide access** to disease education programs and community resources
 - **Support** caregivers to effectively manage their loved ones' symptoms
4. The Alzheimer's Association will **share** the care plan with the referring provider

Dementia Care Coordination

- **Identify a patient / caregiver** who could benefit from dementia care consultation (e.g., new dementia diagnosis, caregiver stress, change in caregiver)
 - **Please refer the caregiver.** If a caregiver is not available, refer the patient.
- **Obtain consent:** If verbal consent, indicate this on the referral form or have the patient sign the form.
- **Complete** the Referral Letter. It is available in EPIC as the Alzheimer Knight Family Grant.
- **Inform** the care partner or patient that the Alzheimer's Association will call them to schedule a care consultation
- **Send in** the completed Referral Form

Retirement

- **Social Security Disability**

- Income source for those under age 65
- Young Onset Alzheimer's disease (and other Young Onset dementia diagnoses) falls under Compassionate Allowances, allowing applications to be fast-tracked
- Disability attorney may be needed if diagnosis does not fall under Compassionate Allowances

- **Medicare**

- For those age 65+
- Younger adults can be enrolled *after 2 years* on Social Security Disability
- Senior Health Insurance Provider (SHIP) counselors can assist with choosing a Medicare Advantage plan

Driving Concerns

- **Advocate Aurora Outpatient Therapy** – Driving evaluations provided at Sinai Hospital, West Allis, and Des Plaines Outpatient Therapy locations
- **Alzheimer’s Association** – Dementia and Driving page, including a sample driving contract and videos of family conversations about driving concerns; www.alz.org/help-support/caregiving/safety/dementia-driving
- **American Occupational Therapy Association** – To search for an OT providing driving evaluations; www.aota.org/Practice/Productive-Aging/Driving/driving-specialists-directory-search
- **The Hartford** – Includes link to *At the Crossroads: Family Conversations about Alzheimer’s Disease, Dementia, & Driving*; www.thehartford.com/resources/mature-market-excellence/dementia-driving
- **Physician Report Form** – through IL Secretary of State at https://www.ilsos.gov/publications/pdf_publications/dsd_dc163.pdf or WI Department of Transportation at <https://wisconsindot.gov/Pages/dmv/license-drvs/mdcl-cncrns/medicalmedprofessionals.aspx>

Advance Care Planning

- **Advance Directive for Dementia** - <https://dementia-directive.org/>
- **Get Palliative Care** – A consumer-facing website from the Center to Advance Palliative Care; <https://getpalliativecare.org/>
- **National Academy of Elder Law Attorneys** – Information about the field of elder law and search tool to find a local elder law attorney; www.naela.org
- **Non-Profit Legal Services** – Legal Action of WI or contact IL Dept on Aging
- **POLST** – Information about POLST and a link to the form; www.polstil.org
- **The Conversation Project** – Conversation “starter kits,” including one for those with a dementia diagnosis; <https://theconversationproject.org/>

Supportive Services for Patients and Caregivers

Caregiver Support Groups

Caregiver Support Group – Meets monthly in-person in Des Plaines, IL. Contact: Mindy Haglund, MSW at mindy.haglund@aah.org or 847.296.0737.

Dementia Care Partner Support Group – Meets monthly via Zoom. Contact: Danielle Dodson, MSW, LCSW at danielle.dodson@aah.org or 847.720.6458.

Lewy Body Dementia Care Partner Support Group – Meets monthly via Zoom. Contact: Danielle Dodson, MSW, LCSW at danielle.dodson@aah.org or 847.720.6458.

Younger Onset Dementia Care Partner Support Group – Meets monthly in hybrid format (in-person and Zoom options). Contact: Danielle Dodson, MSW, LCSW at danielle.dodson@aah.org or 847.720.6458.

Dementia Grief Support Group – Meets periodically for 8-week sessions via Zoom. Contact: Shane Villanueva, MA, CGCS at 630.571.8603 or Danielle Dodson, MSW, LCSW at danielle.dodson@aah.org or 847.720.6458.

The Alzheimer's Association, Area Agency on Aging, and other disease-specific organizations have additional support group referrals.

For Diagnosed Individuals

- **Alzheimer's Association, Early Stage Services:** may include social engagement programs, classes, and early stage support groups
- **Alzheimer's Society of Canada, BrainBooster Activities:** (including crosswords, Sudoku, and wordsearch): <https://alzheimer.ca/en/Home/Living-with-dementia/BrainBooster>
- **Lotsa Helping Hands:** to coordinate assistance from friends and family; <https://lotsahelpinghands.com/>
- **Memory Café Directory:** Informal gatherings for individuals with early stage dementia and their care partners; www.memorycafedirectory.com
- **Senior Planet:** Offers a range of online programs covering technology, fitness, and wellness - <https://seniorplanet.org/>
- **TimeSlips Creativity Center:** Ideas and prompts for creative engagement at home - <https://timeslips.org/resources/creativity-center>

Disease-Specific Organizations

- **Alzheimer's Association** – www.alz.org; 24/7 Helpline: 800.272.3900
- **Alzheimer's & Dementia Alliance of Wisconsin** - www.alzwisc.org/
- **Alzheimer's Foundation** – www.alzfdn.org; 866.232.8484
- **Association for Frontotemporal Dementia** – www.theaftd.org; 866.507.7222
- **Cruetzfeldt-Jakob Disease Foundation** – www.cjdfoundation.org; 800.659.1991
- **Cure PSP** – www.curepsp.org; 800.457.4777
- **Lewy Body Dementia Association** – www.lbda.org; 800.539.9767
- **National Stroke Association** – www.stroke.org; 800.787.6537
- **Parkinson's Foundation** – www.parkinson.org; 800.473.4636
- **Wisconsin Alzheimer's Institute** - <https://wai.wisc.edu/>

Literature

- *Alzheimer's Early Stages: First Steps for Family, Friends, and Caregivers*; Dan Kuhn
- *By Us For Us Guides*, by individuals with dementia and / or care partners;
<https://the-ria.ca/resources/by-us-for-us-guides/>
- *Coping With Behavior Change in Dementia*; Laurie White & Beth Spencer
- *Creating Moments of Joy*; Jolene Brackey
- *Learning to Speak Alzheimer's*; Joanne Koenig Coste
- *Loving Someone Who Has Dementia*; Pauline Boss
- *Moving a Relative with Memory Loss: A Family Caregiver's Guide*; Laurie White & Beth Spencer
- *The 36-Hour Day*; Nancy L. Mace & Peter V. Rabins

Home & Community-Based Services

Signs of Increased Need

- Poor nutrition / hydration
- Inconsistent administration of medications
- Decline in management of personal hygiene
- Memory lapses impacting home safety (e.g. burning items / leaving gas on stove, flooding sink or toilet)
- Impaired judgement impacting security (e.g. giving away money to scams, letting solicitors into the home)
- Episodes of disorientation / getting lost
- Behavioral / psychiatric symptoms that put patient / family in danger (e.g. aggression, delusions, hallucinations)

Safety Resources

- OT home safety evaluation (available through limited AAH Outpatient Therapy locations)
- Medical ID
- Location tracking device
- Emergency Home Response System (e.g. Lifeline)
- Automated pill dispenser

Government Resources

- **Alzheimer's Disease Education and Referral Center** – A service of the National Institute on Aging, which includes publications regarding Alzheimer's, dementia, and caregiving; www.nia.nih.gov/alzheimers
- **Illinois Department on Aging, Senior Helpline** – Information and referral for senior services (especially subsidized services) in IL; 800.252.8966
- **U.S. Administration on Aging, Eldercare Locator** – National searchable database of senior services; www.eldercare.acl.gov
- **Veteran's Administration** – Veteran service officers, caregiver support coordinators
- **Wisconsin Aging & Disability Resource Centers** – Options counseling, senior centers, home-delivered meals, information and assistance

Definitions

- **Non-Medical Home Care**
 - also called custodial care, personal care, homemaker, or companion
 - can include light housekeeping, laundry, meal prep, companionship, driving, and assistance with personal hygiene
- **Home Health Care**
 - Skilled care (e.g. nursing, PT, OT, Speech therapy)
 - Home health aide (e.g. bath aide) may be provided *while there is a skilled care need*
 - Short-term coverage by Medicare / health insurance
 - Physician's order needed; *Physician must certify that patient is homebound*
- **Adult Day Services**
 - daytime group program providing activity, supervision, socialization, and structure
 - can be a "medical model" or "social model" program
 - may or may not be exclusively for patients with dementia

<https://www.medicare.gov/coverage/home-health-services>

All you need is one hook!



Adult Protective Services

- Individuals with dementia are at higher risk for elder abuse and neglect than their counterparts who do not have dementia
- Types: physical, psychological, verbal, sexual, financial, neglect, self-neglect
- Risk factors for family members perpetrating abuse include:
 - Caregiver stress (and possibly caregiver isolation)
 - Prior mental health issues of caregiver
 - Poor prior relationships between caregiver and diagnosed individual
- **We are ALL mandated reporters**
- Reports should be made to:
 - Illinois Department on Aging at 1.866.800.1409
 - Wisconsin – Aging & Disability Resource Centers

Downes et al., Abuse of Older People with Dementia: A Review, 2013

Residential Care

Signs Residential Care May Be Needed

- Individual is lonely, bored, depressed, or under-stimulated
- Management of home itself is overwhelming or not feasible
- Home environment poses safety concerns (e.g. stairs or other fall risks, unsafe neighborhood, becoming lost)
- Individual is unable to access help in an emergency (e.g. cannot dial out on phone)
- Home care has not worked for the diagnosed individual (e.g. due to cost, turnover, refusal of services)
- Family cannot help due to distance or other responsibilities
- Primary caregiver's health, mental health, employment, or family life are significantly negatively impacted by caregiving

Definitions

- **Independent Living** (also called Senior Living or Retirement Homes)

- Usually private pay, though there are some federally and state-subsidized senior apartment buildings
- Have minimum age requirements, often 55+ or 60+
- Not licensed to provide personal care or skilled care
- May include basic services such as meals, housekeeping, activities, transportation
- Additional services can be purchased

- **Continuing Care Retirement Community** (CCRC; also called Life Care Plan Communities)

- Communities offering multiple levels of care in the same building or campus (e.g. independent, assisted, memory care assisted, skilled)
- Some require an up-front investment, guaranteeing space in higher levels of care as needed

Definitions

• **Assisted Living (ALF)**

- Licensed by the state, but not federally
- Private pay
- Provide meals, housekeeping, activities
- Able to provide assistance with other activities of daily living (e.g. administering medications, bathing), often for an additional fee

• **Supportive Living (SLF)**

- Licensed by the state
- Similar level of care to ALF
- Can accept Medicaid and fees on a sliding scale
- Very few in Illinois are licensed to provide dementia care

• **Adult Family Homes / Community-Based Residential Facilities (CBRFs)**

- Available in Wisconsin only, not Illinois
- Private pay or Medicaid waiver

Definitions

- **Memory Care** (MCU; Also called Special Care Unit or SCU)

- Unit, within an ALF, CBRF, or SNF, licensed to provide care to individuals with dementia
- Only a few SLFs in Illinois have a licensed special care unit
- Secured unit
- Licensing varies by state

- **Skilled Nursing Facility** (SNF; Also called Nursing Home)

- Licensed and regulated by state and federal government
- Residential care providing 24/7 nurses and aides to assist with all daily living activities and medical needs

Exploring Residential Care Options

- It is never too soon for a family to begin exploring residential care options
- Advise caregivers to be sure they are comparing apples to apples (or are aware if they are comparing apples to oranges)
- Families should ask up front what symptoms or conditions would require a move to a higher level of care
- Advise caregivers to visit several communities without the diagnosed individual so they can narrow down the options to the top 2-3 choices
- If possible to do so without overly distressing the diagnosed individual, family may wish to bring the patient to visit a select few communities for a program or meal

Introducing Residential Care

- As with other care transitions, decrease the threat by focusing on physical, social, or practical needs
- Again, be the “bad guy” so the family does not have to! Explain the move as a physician’s order or recommendation
- Depending on the individual’s degree of understanding about the need for a move, and degree of anxiety about moving, family may want to wait until close to the date of the move to inform her
- It is not necessary to use the terminology of “memory care” or “nursing home”

Making the Transition

- Family should bring items from home, including furniture if allowed by the facility, so the environment can feel familiar and comfortable
- Family can educate staff about their loved one's personality, life story, routines, likes/dislikes, and effective approaches to care
- Caregivers should be prepared for emotional reactions (both theirs and the diagnosed individual's) and the potential for increased confusion / disorientation
- Families can bring in additional services, such as private caregiver or hospice, to supplement care in an ALF or MCU

Resources: Residential Care

- **Illinois Department of Public Health** – Takes reports of abuse or neglect in SNFs and ALFs; 1.800.252.4343 (ADRC in WI)
- **Illinois Citizens for Better Care** – Advocacy organization providing guidance on choosing a nursing home; www.illinoiscares.org
- **Long-Term Care Ombudsman** – Experts on nursing home regulations and advocates on behalf of the rights of long-term care residents; www2.illinois.gov/aging/ProtectionAdvocacy/LTCOmbudsman
- **Medicare** – Nursing Home Compare tool – Ratings of nursing homes on a 5-star scale, based upon inspection results; www.medicare.gov/nursinghomecompare

"...the physician's duty is not to stave off death or return patients to their old lives, but to take into our arms a patient and family whose lives have disintegrated and work until they can stand back up and face, and make sense of, their own existence."

Paul Kalinithi, When Breath Becomes Air, 2016, p. 166