# Identifying and Meeting the Needs of Individuals with Dementia Living Alone

Kate Gordon, MSW
Splaine Consulting

| Comparing adults with cognitive impairment by living arrangement[1] | | |
|---|---|---|
| | Living alone | Living w/ others |
| Women | 66% | 49% |
| Average age | 76 | 72 |
| Own home | 55% | 73% |
| Total liquid wealth (2014) | $88,466 | $122,499 |
| **MARITAL STATUS** | | |
| Widowed | 61% | 17% |
| Divorced | 27% | 7% |
| Never married | 11% | 3% |
| Married | 2% | 73% |
| **RACE/ETHNICITY** | | |
| White | 62% | 68% |
| Black | 20% | 18% |
| Latinos/Hispanics | 10% | 16% |
| Other | 3% | 4% |

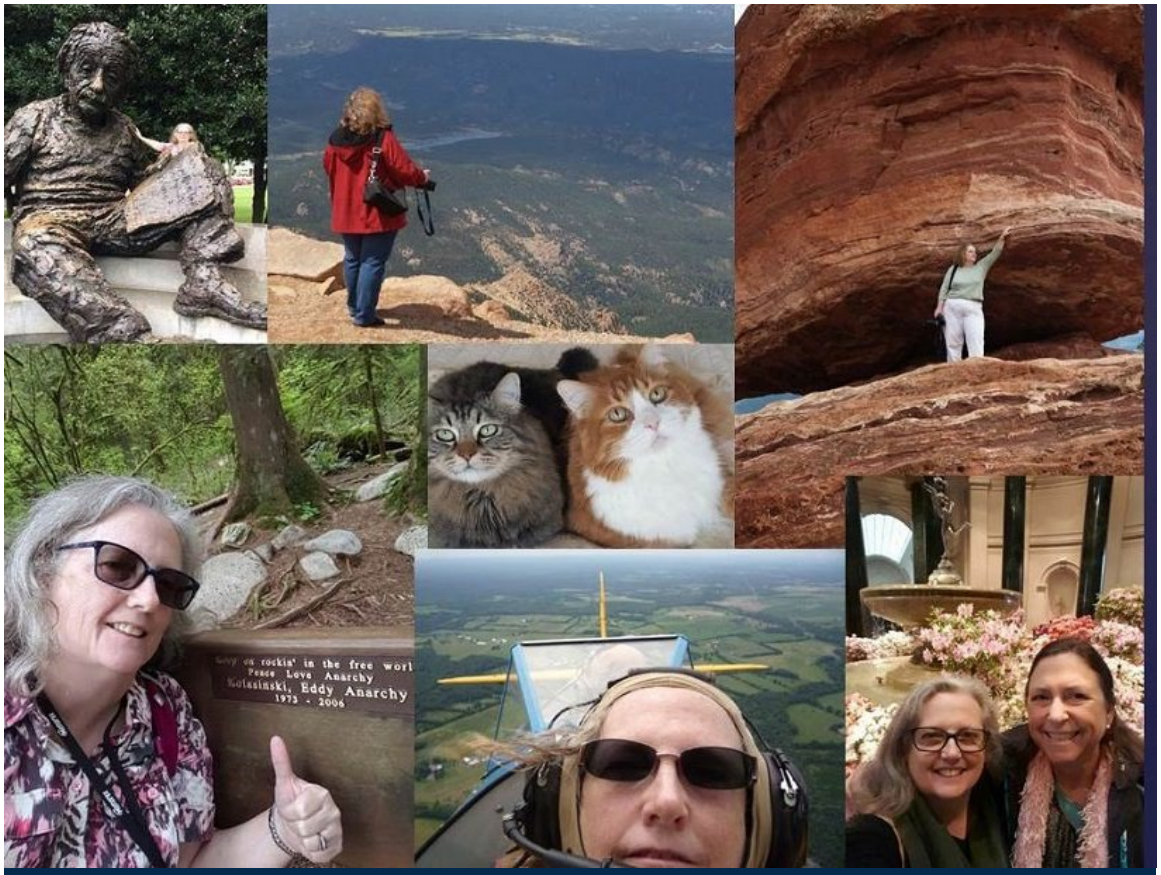
Source: “Living alone with cognitive impairment: a common challenge in the United States,” Living Alone with Cognitive Impairment Policy Brief, n.1, Spring 2023.


20% of older adults living alone with cognitive impairment report being covered by Medicaid.

Source: “Living alone with cognitive impairment: a common challenge in the United States,” Living Alone with Cognitive Impairment Policy Brief, n.1, Spring 2023.


- 27% of individuals 65+ live alone in the community
  - 15.2 million people
- Living alone as an older adult is a risk factor for dementia
- ~25% of older Americans with cognitive impairment live alone

Communities need to identify ways to support **all** people living alone with dementia to remain safely in their homes and community as long as possible.




Diana Blackwelder

# With remembrance and deep respect: Patricia “Pat” Etienne passed away peacefully at the age of 90 on February 20, 2024.

COLUMBIA MISSOURIAN



## PAT ETIENNE: Living a bold, determined life with Alzheimer's

NAOMI KLINGE Mar 22, 2018

1 of 2

Pat Etienne stands outside the Alzheimer's Association in Columbia. Etienne works with the association to advocate and raise funds for research about the disease. She also volunteers

# Why Are People Living Alone?

PERSONAL CHOICE

OUTLIVING ALL FAMILY AND FRIENDS

OTHERS CHOOSING TO DISCONTINUE CONTACT

TEMPORARY SITUATION (E.G. CAREGIVER HOSPITALIZED)

UNEXPECTED SITUATION (E.G. NURSING HOME PLACEMENT OF THE CAREGIVER)

# Identifying People who Live Alone with Dementia

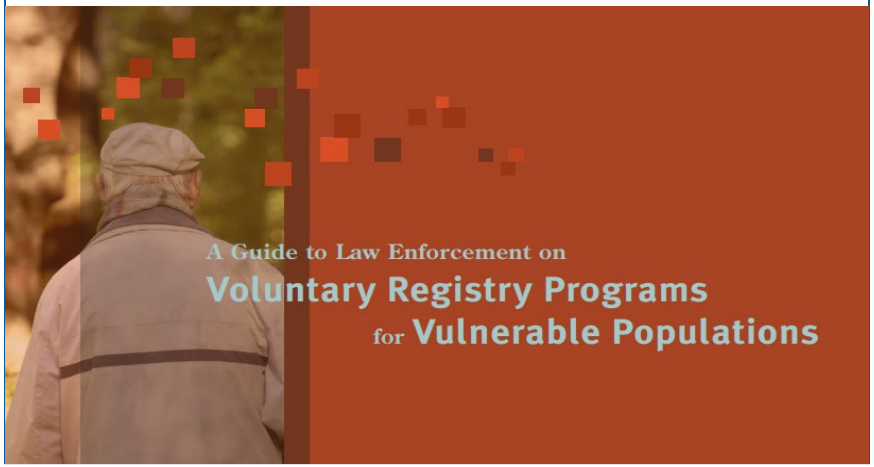
# First Responder Programs

## Senior Watch Program

- Person must register/provide some personal details (age, medical conditions, neighbor or nearby contact)
- Daily telephone contact with follow up as needed


## Voluntary Registry Programs

- Assists law enforcement in locating missing persons who may have wandered
- Voluntarily submit information to be used to bolster search efforts



# Gatekeeper Model

***"Those who most need help are the least likely to ask for it."***

***- Ray Raschko***

- Proactive, systematic approach of identifying at risk older adults
- Non-traditional system of referral
- Gatekeepers provide "discreet surveillance," monitoring for any unsafe behaviors without being invasive
- Trains individuals likely to come in contact with at risk older adults (Traditional and Non-Traditional Gatekeepers)

# Gatekeeper Model continued

**Training**
Teaches signs to watch for: unkempt appearance, disorientation /confusion, no mention of family or friends, financial problems, alcohol use, poor condition of home, accumulated mail, un-shoveled walkways.

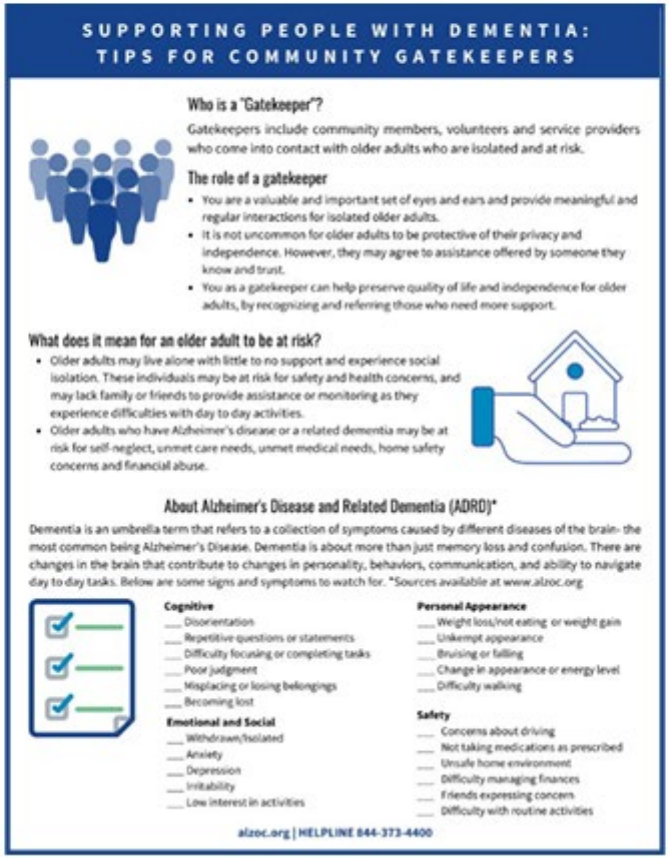
**Referrals**
Occur via telephone screening or Information and Assistance to gather basic information.

**Treatment**
Includes in-home assessment to identify needs: care management, family support, mental health services, crisis intervention.

# Gatekeeper Model continued

Alzheimer's ORANGE COUNTY

*Supporting People with Dementia: Tips for Community Gatekeepers*



SUPPORTING PEOPLE WITH DEMENTIA:
TIPS FOR COMMUNITY GATEKEEPERS

### Who is a "Gatekeeper"?

Gatekeepers include community members, volunteers and service providers who come into contact with older adults who are isolated and at risk.

### The role of a gatekeeper

- You are a valuable and important set of eyes and ears and provide meaningful and regular interactions for isolated older adults.
- It is not uncommon for older adults to be protective of their privacy and independence. However, they may agree to assistance offered by someone they know and trust.
- You as a gatekeeper can help preserve quality of life and independence for older adults, by recognizing and referring those who need more support.

### What does it mean for an older adult to be at risk?

- Older adults may live alone with little to no support and experience social isolation. These individuals may be at risk for safety and health concerns, and may lack family or friends to provide assistance or monitoring as they experience difficulties with day to day activities.
- Older adults who have Alzheimer's disease or a related dementia may be at risk for self-neglect, unmet care needs, unmet medical needs, home safety concerns and financial abuse.

### About Alzheimer's Disease and Related Dementia (ADRD)*

Dementia is an umbrella term that refers to a collection of symptoms caused by different diseases of the brain- the most common being Alzheimer's Disease. Dementia is about more than just memory loss and confusion. There are changes in the brain that contribute to changes in personality, behaviors, communication, and ability to navigate day to day tasks. Below are some signs and symptoms to watch for. *Sources available at www.alzoc.org

**Cognitive**
- ___ Disorientation
- ___ Repetitive questions or statements
- ___ Difficulty focusing or completing tasks
- ___ Poor judgment
- ___ Misplacing or losing belongings
- ___ Becoming lost

**Emotional and Social**
- ___ Withdrawn/Isolated
- ___ Anxiety
- ___ Depression
- ___ Irritability
- ___ Low interest in activities

**Personal Appearance**
- ___ Weight loss/not eating or weight gain
- ___ Unkempt appearance
- ___ Bruising or falling
- ___ Change in appearance or energy level
- ___ Difficulty walking

**Safety**
- ___ Concerns about driving
- ___ Not taking medications as prescribed
- ___ Unsafe home environment
- ___ Difficulty managing finances
- ___ Friends expressing concern
- ___ Difficulty with routine activities

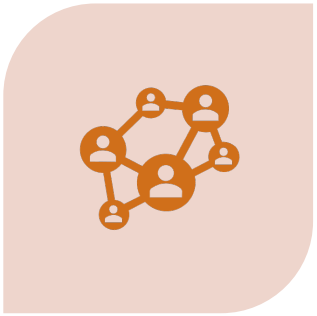
alzoc.org | HELPLINE 844-373-4400

# Identifying the NEEDS of People who Live Alone with Dementia

| Unmet Need | Service Provided |
|---|---|
| **Home safety** | Arranged for home repairs and home modifications and completed fall risk screenings (Alzheimer's Greater Los Angeles, 2017a; Eddy Alzheimer's Services, 2020; Latino Alzheimer's and Memory Disorders Alliance [LAMDA], 2022). |
| **Poor health conditions / medication management** | Coordinated appointments with health care providers and administered memory and depression screens (Alzheimer's Greater Los Angeles, 2017a; Eddy Alzheimer's Services, 2020). |
| **Nutrition** | Arranged for grocery shopping assistance to deliver food to the home or provide home-delivered meals from MOW (Eddy Alzheimer's Services, 2020; LAMDA, 2022; ONEgeneration, 2021). |
| **Self-care** | Coordinated personal care assistance services (Eddy Alzheimer's Services, 2020; ONEgeneration, 2021). |
| **Transportation** | Connected individuals with transportation options in their community (LAMDA, 2022; ONEgeneration, 2021). |
| **Accessing government-funded programs** | Provided assistance in completing paperwork for fuel assistance, health insurance, etc. (MaineHealth, 2019; Rector and Visitors of the University of Virginia, 2021). |
| **Advance planning** | Provided guidance on how to complete an advance directive (Alzheimer's Greater Los Angeles, 2017a). |

| Unmet Need |
| --- |
| Home safety |
| Poor health conditions / medication management |
| Nutrition |
| Self-care |
| Transportation |
| Accessing government-funded programs |
| Advance planning |

# Varying Degrees of Support



FREQUENT SUPPORT, VISITS, MONITORING

CHECK IN CALLS FROM LONG DISTANCE RELATIVES

NO SUPPORT/NO KNOWN SUPPORT

# Determining Whether There is a Support System

Start by making the person comfortable and asking about family, friends, and neighbors.

Gradually ask about who they rely on for different tasks, who they trust or don't and why.

Take the time necessary to develop trust and listen to the person's stated concerns.

# Determining Whether There is a Support System

- **“In case of emergency” card or identification bracelet**
- **Cell phone contacts**
- **Personal address books, photographs of the person and others, holiday or special event cards, or old mail**
- **Legal, financial, or insurance documents**
- **Health care providers, service providers and local faith and community organizations**
- **Landlord or management office**
- **Current or previous employers**

# WISCONSIN FAMILY CAREGIVER PROGRAM NEEDS ASSESSMENT

| Caregiver Name | Caregiver ID Number | Date |
|---|---|---|
| | | Enter Date |

Care Recipient Name

**SECTION I:** Unmet Care Recipient Needs (Check all of the items needs help with)

| | | | |
|---|---|---|---|
| Adaptive Equipment | ☐Yes ☐No | Managing Health Care | ☐Yes ☐No |
| Bathing | ☐Yes ☐No | Mentally Stimulating Activities | ☐Yes ☐No |
| Dressing | ☐Yes ☐No | Money Management | ☐Yes ☐No |
| Companionship | ☐Yes ☐No | Nutritional Counseling | ☐Yes ☐No |
| Cooking | ☐Yes ☐No | Overnight Care | ☐Yes ☐No |
| Dementia Care Specialist Referral | ☐Yes ☐No | Personal Emergency Response System | ☐Yes ☐No |
| Eating | ☐Yes ☐No | Shopping | ☐Yes ☐No |
| Elder Benefits Counseling | ☐Yes ☐No | Supplemental Nutrition Assistance Program (FoodShare) | ☐Yes ☐No |
| Grooming | ☐Yes ☐No | Toileting | ☐Yes ☐No |
| Home Delivered/Congregate Meals | ☐Yes ☐No | Transferring | ☐Yes ☐No |
| Home Modifications | ☐Yes ☐No | Transportation | ☐Yes ☐No |
| In Home Safety/Security | ☐Yes ☐No | Other: | ☐Yes ☐No |
| Incontinence Strategies | ☐Yes ☐No | Does not apply | ☐Yes ☐No |
| Interaction with Others | ☐Yes ☐No | | ☐Yes ☐No |

**Top needs identified by caregiver:**

**Note**: Sections II through V Refer to the Caregiver's Needs, not the care recipient

**Note**: Sections II through V Refer to the Caregiver's Needs, not the care recipient

**SECTION II:** Unmet Caregiver Respite Needs (Check all that you need more time for or help with)

| | | | |
|---|---|---|---|
| Free Time to Oneself | ☐Yes ☐No | Outside Chores | ☐Yes ☐No |
| Housecleaning | ☐Yes ☐No | Overnight Respite | ☐Yes ☐No |
| Laundry | ☐Yes ☐No | Preparing Meals | ☐Yes ☐No |
| Making/Keeping Appointments | ☐Yes ☐No | Shopping | ☐Yes ☐No |
| Managing Your Own Medications | ☐Yes ☐No | Transportation | ☐Yes ☐No |
| Meeting Employment Obligations | ☐Yes ☐No | Other: | ☐Yes ☐No |
| Money Management | ☐Yes ☐No | Does not apply | ☐Yes ☐No |

**Top needs identified by caregiver:**

**SECTION III:** Unmet Caregiver Physical Health Needs (Check all that you need or would you benefit from)

| | | | |
|---|---|---|---|
| Access to Affordable Health/Dental | ☐Yes ☐No | Nutritional Counseling | ☐Yes ☐No |
| Exercise | ☐Yes ☐No | Powerful Tools for Caregivers | ☐Yes ☐No |
| Food Pantries | ☐Yes ☐No | Shopping Access/Transportation | ☐Yes ☐No |
| Free Time to Oneself | ☐Yes ☐No | Supplemental Nutrition Assistance Program (FoodShare) | ☐Yes ☐No |
| Help Preparing Balanced Meals | ☐Yes ☐No | Other: | ☐Yes ☐No |
| Home Delivered Meals | ☐Yes ☐No | Does not apply | ☐Yes ☐No |
| More Sleep | ☐Yes ☐No | | ☐Yes ☐No |

**Top needs identified by caregiver:**

**SECTION IV:** Unmet Caregiver Emotional Health Needs (Check all that apply)

How have you been handling the emotional stress of caring for _____? Has it been difficult emotionally?
Are you able to handle the added stress from caring for _____?
Are you aware of support groups/memory cafés and that counseling and support groups are available?

| | | | |
|---|---|---|---|
| Family Meeting | ☐Yes ☐No | People Willing to Help | ☐Yes ☐No |
| Free Time to Oneself | ☐Yes ☐No | Social Time with Family/Friends | ☐Yes ☐No |
| Memory Café | ☐Yes ☐No | Stress Relief/Relaxation Techniques | ☐Yes ☐No |
| Mental Health Counseling | ☐Yes ☐No | Support Group | ☐Yes ☐No |
| Options Counseling/Resources | ☐Yes ☐No | Other: | ☐Yes ☐No |
| Paid Respite | ☐Yes ☐No | Does not apply | ☐Yes ☐No |
| Participate Activities Outside Caregiving | ☐Yes ☐No | | ☐Yes ☐No |

**Top needs identified by caregiver:**

**SECTION V:** Education and Resource Needs (Check all that apply)

Are advance directives in place for your loved one? For yourself? Would more information or education about handling behavior challenges or the person's condition, caregiving stress or community resources be helpful?

| | | | |
|---|---|---|---|
| Advanced Directive/Power of Attorney | ☐Yes ☐No | Options Counseling/Resources | ☐Yes ☐No |
| Alzheimer's 24/7 Helpline | ☐Yes ☐No | Powerful Tools Workshop | ☐Yes ☐No |
| Clarify End-of-Life Wishes | ☐Yes ☐No | Share the Care Program | ☐Yes ☐No |
| De-escalation Techniques | ☐Yes ☐No | Support Group | ☐Yes ☐No |
| Health Care Literacy | ☐Yes ☐No | Trualta Online Caregiver Training | ☐Yes ☐No |
| | | Other: ☐Yes ☐No | |
| Information about Disease Progression | ☐Yes ☐No | Does not apply | ☐Yes ☐No |
| Long-Term Planning | ☐Yes ☐No | | |

The questions/prompts below will help you identify the member's authorized representative and/or the person(s) assisting with the most hands-on care. Questions/prompts are not all-inclusive, but serve to facilitate conversation.

(1) Identify the authorized representative

Name: _____ Relationship: _____

Contact Information: _____

(2) Does someone live with the member? _____

If so, name and relationship: _____

(3) If the member lives alone, how often does someone visit the home [if at all]? _____

Who is most likely to visit the member? Name and relationship: _____

If questions below are asked directly to the member, consider saying, ***"If you needed help with any of the following, who would you ask?"***

| Type of assistance provided | Name and relationship of person who provides assistance | No assistance provided |
|---|---|---|
| (4a) ADL assistance (e.g., bathing, dressing, toileting, eating/feeding) | | |
| (4b) IADL assistance (e.g., meals, housekeeping, laundry, telephone, shopping, finances) | | |
| (4c) Medication administration (e.g., oral, inhaled, or injectable) | | |
| (4d) Medical procedures/treatments (e.g., changing wound dressing) | | |
| (4e) Supervision and safety | | |
| (4f) Coordination of medical care (e.g., scheduling medical appointments, transportation) | | |

[*Adapted from Centers for Medicare and Medicaid Services "Care Tool; Acute Care," 2008* and prepared by Alzheimer's Greater Los Angeles]

**Based on your conversation, identify the person who provides the most hands-on care:**

Name: _____

Relationship to member: _____

Contact information: _____

**Part 3: Social Support Profile**

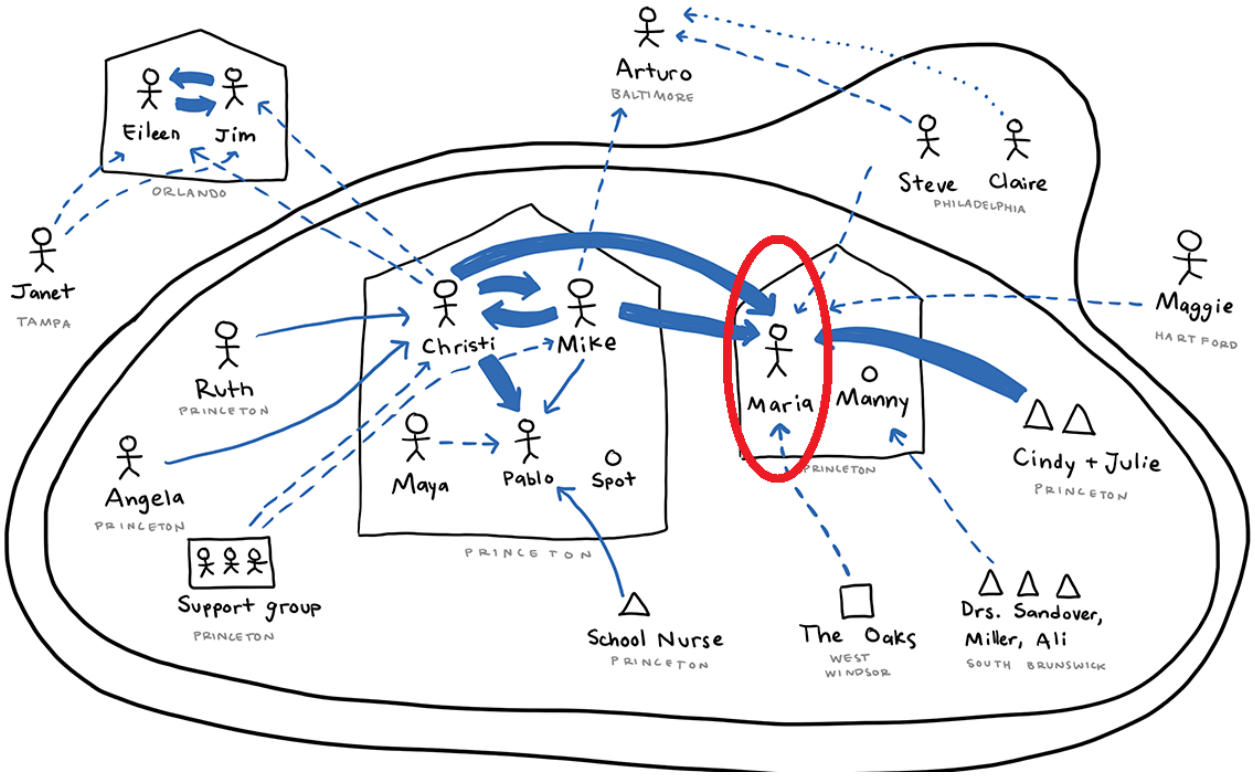
Assess who *currently provides* or who *could provide* certain types of social support by listing people in the table below under the appropriate category. (You can list the same person more than once.) Circle those who currently provide you with support. Put a star next to anyone who also comes to you for support. If you left some boxes blank, think about ways you might work on finding a support person to fill that role.

| **Type of Support Person** | **Emotional:** People you can trust with intimate thoughts and feelings, fears | **Social:** People with whom you can hang out, share experiences | **Informational:** People you can ask for advice about decisions, get mentoring help | **Practical:** People who can help you when you need assistance with day-to-day problems (e.g., rides, money, place to stay) |
|---|---|---|---|---|
| Partner/Significant Other | | | | |
| Relative | | | | |
| Friend | | | | |
| Neighbor/Classmate | | | | |
| Roommate/Housemate | | | | |

# Atlas Care Map

Illustrates:

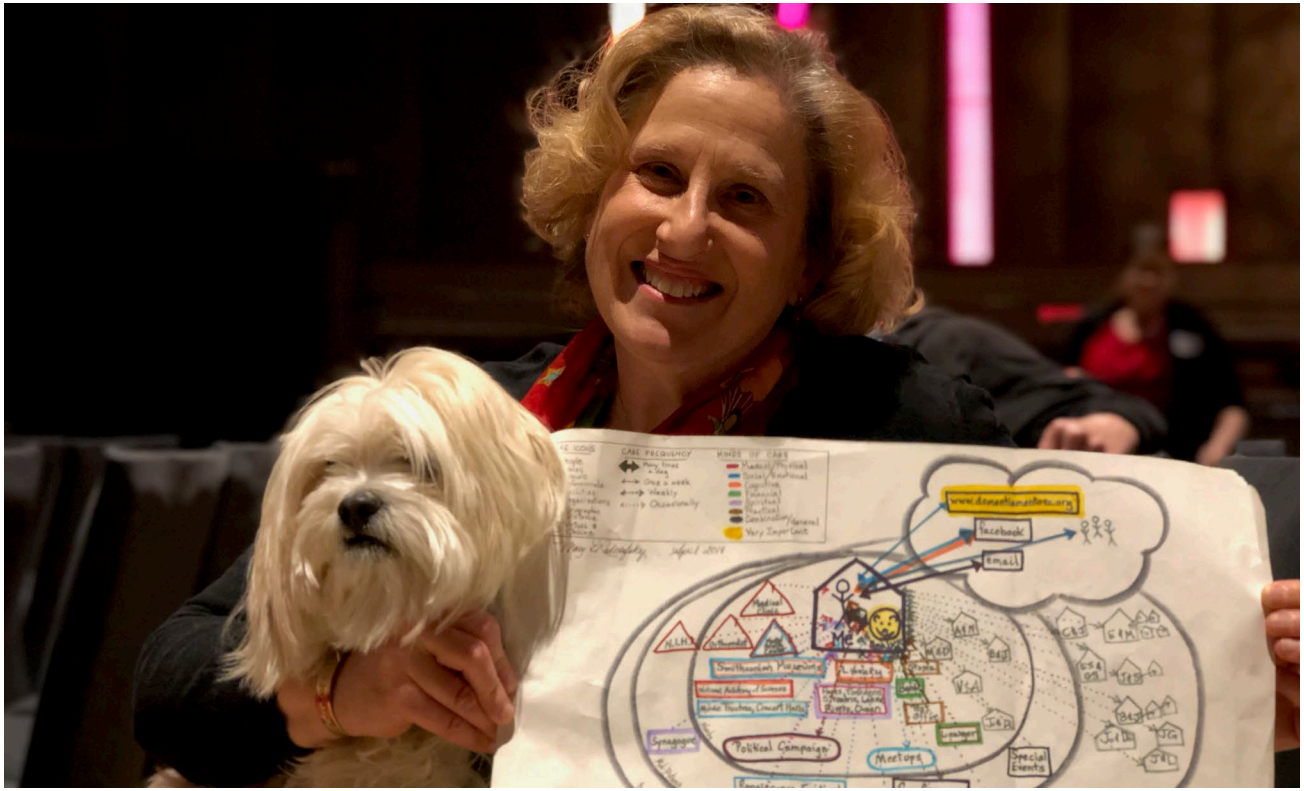
- Any sort of relationship you have with another person
- Where you give or receive help, support, or advice




ATLAS OF CARE

https://atlasofcaregiving.com/

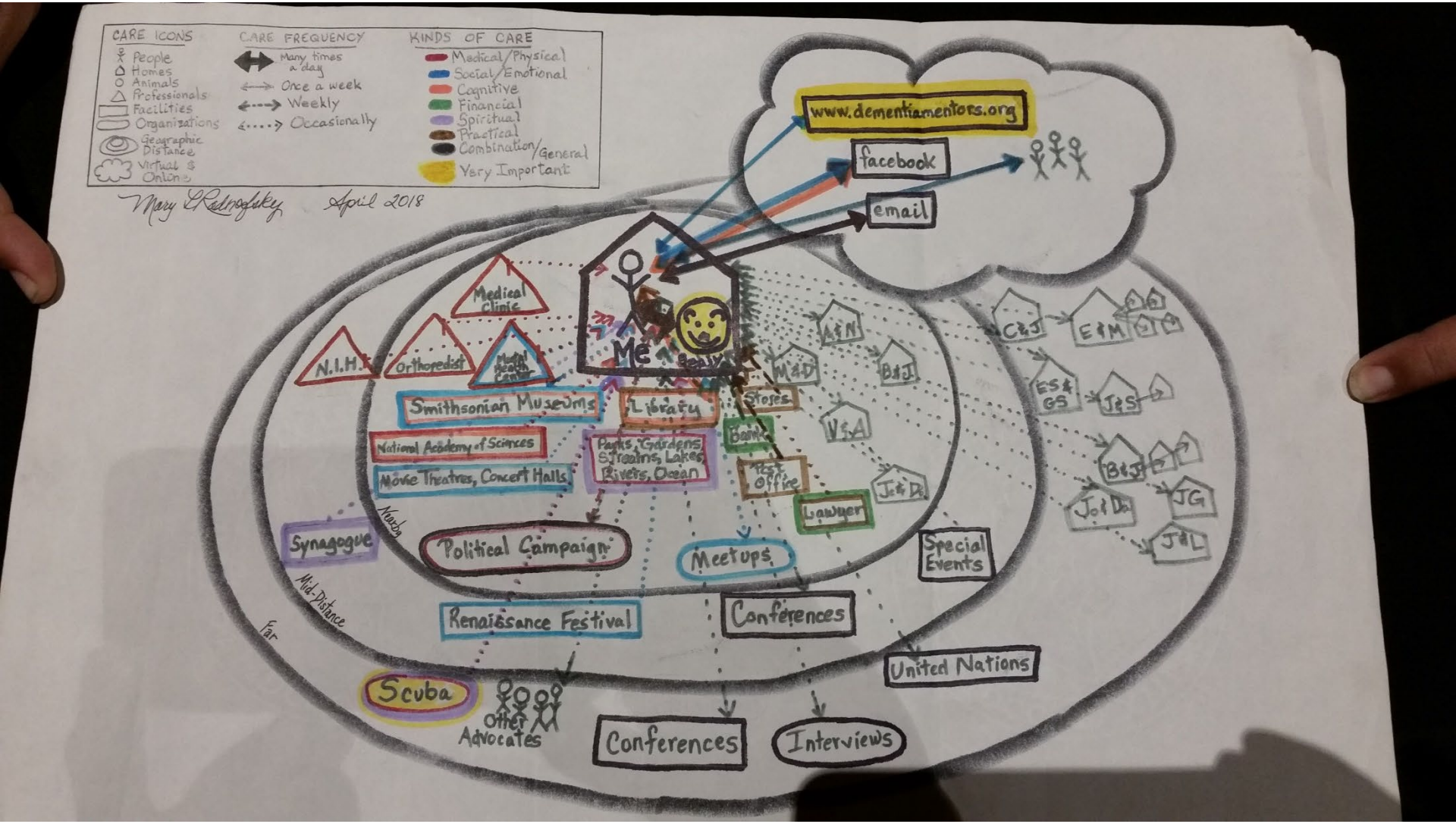
# Mary & Benji




The Human Need for Equilibrium: Qualitative Study on the Ingenuity, Technical Competency, and Changing Strategies of People With Dementia Seeking Health Information

Emma Dixon, BS, PhD; Jesse Anderson, BS; Diana C Blackwelder, BS, MS; Mary L Radnofsky, BA, MA, PhD; Amanda Lazar, BS, PhD

J Med Internet Res 2022;24(8):e35072) doi: 10.2196/35072


CARE ICONS
People
Homes
Animals
Professionals
Facilities
Organizations
Geographic Distance
Virtual & Online
CARE FREQUENCY
Many times a day
Once a week
Weekly
Occasionally
KINDS OF CARE
Medical/Physical
Social/Emotional
Cognitive
Financial
Spiritual
Practical
Combination/General
Very Important
Mary L Radzykewycz
April 2018
www.dementiamentors.org
facebook
email
Medical Clinic
N.I.H.
Orthopedist
Mental Health Center
Me
Family
Smithsonian Museums
Library
National Academy of Sciences
Parks, Gardens, Streams, Lakes, Rivers, Ocean
Movie Theatres, Concert Halls
Stores
Bank
Post Office
Lawyer
A&N
M&D
B&J
V&A
J&D
C&J
E&M
ES&GS
J&S
B&J
JG
J&L
Jo&Di
Synagogue
Political Campaign
Meetups
Special Events
Renaissance Festival
Conferences
United Nations
Scuba
Other Advocates
Conferences
Interviews
Near
Mid-Distance
Far

***I am never sure when to step in. I don't want to rob her of her independence.***

***— Caregiving daughter***

# University of Iowa Risk Assessment

## PEOPLE WITH DEMENTIA LIVING ALONE ASSESSMENT

The following conditions may indicate when a person with dementia is no longer safe to live alone or will require more services, assistance or placement. Place a check by each statement that is known or observed. Calculate scores in each section and utilize recommendations from Boxes A–C.

**GRADE**

| **A = Emergent** | **A / B Emergent/ Semi-Emergent** | **B = Semi-Emergent** | **C = Non-Emergent** |
|---|---|---|---|
| Only one condition needs to be present. ***Immediate*** help or placement is required. | Can be either A or B depending on the cause, severity, and the person's response to the situation. | > 2 conditions indicate that there are safety concerns that must be addressed and remediated. | > 3 conditions are present. Additional help will be beneficial. Re-evaluate monthly. |

**OBSERVED OR REPORTED CONDITIONS**

| | | | |
|---|---|---|---|
| __ Weight loss of > 6 pounds or 10% body weight in 6 months, evidence of protruding bones | __ Malfunctioning plumbing | __ Not able to manage bowel/bladder care | __ Phone calls from community members advising help is needed |
| __ Presence of paranoia, hallucinations, delusions, aggression or thoughts of suicide | __ Thermostats not set appropriately for weather conditions | __ Repeated calls to family/others asking what to do next | __ Vegetative or socially isolated behavior (sitting all day with TV on or off) |
| __ Threatens violence with/without weapons | __ Chronic anxiety, panic attacks, worry or depression is present | __ Dirty/infested household | __ Missing belongings, hiding things |
| __ Evidence of caregiver injury/domestic violence | __ Unsafe driving or refuses to stop driving | __ Garbage accumulation | __ Poor grooming, wearing the same clothing all the time, soiled appearance |
| __ Repeated ER visits, hospitalizations | __ Neighbors calling police | __ Food stored inappropriately | |
| | | __ Taken advantage of by family, friends, neighbors | |
| | | __ Refuses personal care for prolonged period of time | |

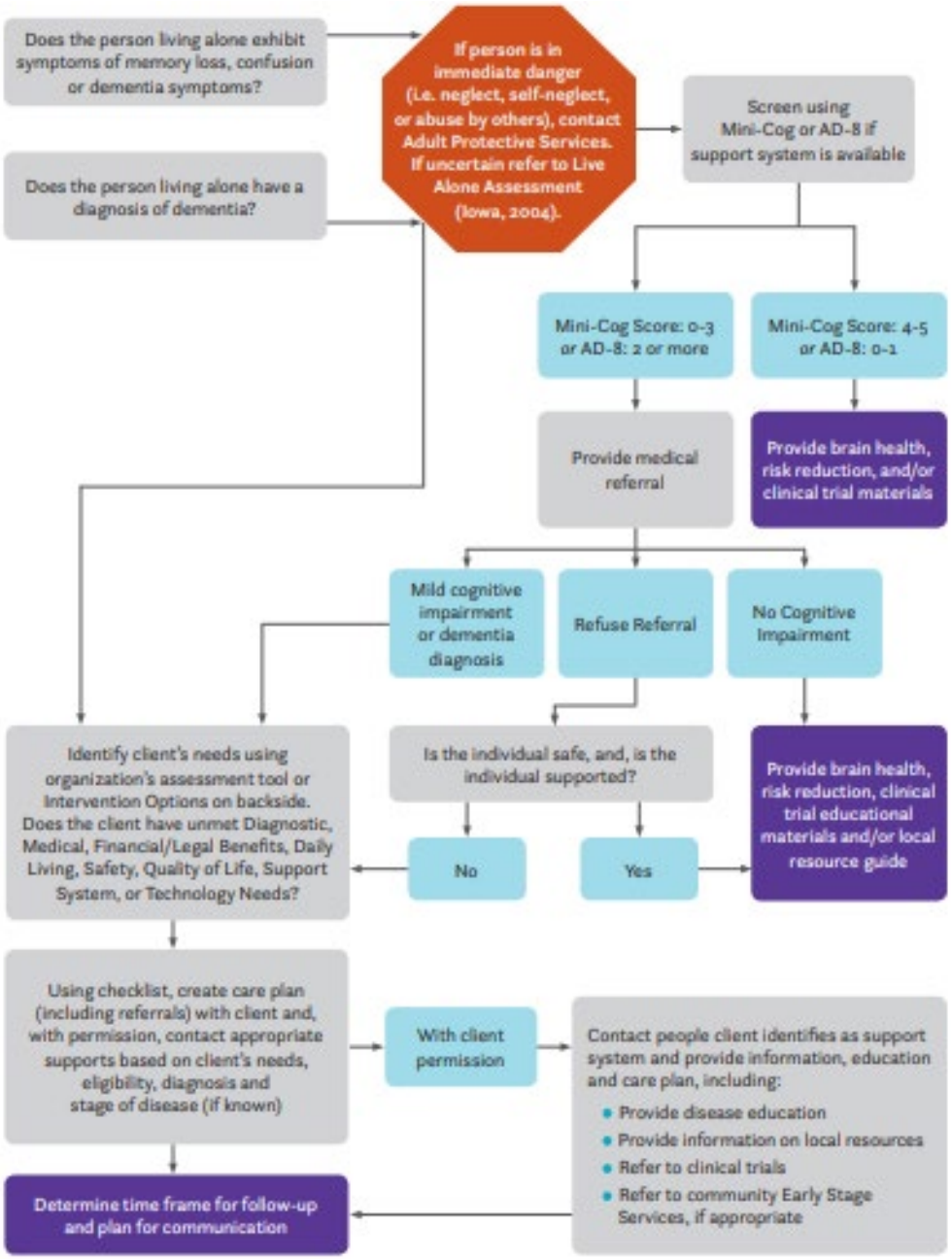
# Dementia Crisis to Thriving Scale

Southern Maine AGENCY On AGING
Creating Better Days

## Community Support Program
## Dementia Crisis to Thriving Scale

| CRISIS | VULNERABLE | SAFE | STABLE | THRIVING | UNABLE TO ASSESS |
|---|---|---|---|---|---|
| **Nutrition Status** | | | | | |
| 1-2 Unable to cook/prepare food. Does not initiate eating without prompting. | 3-4 Able to use the microwave to cook/prepare food. Does not have help. Does not eat a sufficient diet. | 5-6 Receives some help preparing meals. Uses only the microwave to cook/prepare food when alone. Diet is suboptimal. | 7-8 Receives reliable support with meals. Uses only the microwave to cook/prepare food when alone. Diet is sufficient. | 9-10 Can safely use the stove to prepare some meals, and uses the microwave for others. May occasionally eat out. Diet is sufficient. | |
| **Food Security** | | | | | |
| 1-2 No means to access food. Has less than a day of food on hand. | 3-4 Help with shopping is unreliable or inconsistent. Food is in short supply 1-2x/week. | 5-6 All food is obtained from food assistance resources. Has adequate food supply when receives shopping help. | 7-8 Partially relies on food assistance resources. Has reliable help with food shopping and stable supply. | 9-10 Can afford to buy desired foods. Can shop without help. No unmet food needs. | |
| **Health Care** | | | | | |
| 1-2 Has immediate unmet health needs and no provider. | 3-4 Has unstable health needs with inconsistent follow-up and/or inconsistent adherence to recommended regimen. | 5-6 Major health needs are generally well managed with consistent follow-up; inconsistent adherence to recommended plan. | 7-8 Most health needs are generally met with consistent follow-up; generally adheres to prescribed regimen. | 9-10 Health needs met, well connected to healthcare resources, and solid adherence. | |
| **Medications** | | | | | |
| 1-2 Unsure of medications, has no supervision & no list, evidence of missed doses and/or poor access. | 3-4 Unable to manage meds independently, only sporadic supervision, takes more than 5 meds, has no med list. | 5-6 Has list of meds from PCP and tries to follow it with weekly supervision, no back-up plan. | 7-8 Medications taken match list, inclusive of OTC, does not know reason for taking meds but takes as prescribed. | 9-10 Has list of meds from PCP and tries to follow it, able to manage medications independently. | |
| **Falls Risk** | | | | | |
| 1-2 Falls 2 or more times in past month, with injury, home is unsafe. | 3-4 Home unsafe. Fall without injury, or no fall in past 3 months. | 5-6 Home is safe. Fall within three to five months, no injury. Fall risk factors exist. | 7-8 No falls in past 6 months, home is safe, no fall risk factors. | 9-10 No falls in past 12 months, gait stable, active, safe home. | |
| **In-Home Care** | | | | | |
| 1-2 Needs paid assistance but no service in area or poor staffing; OR care available but cannot afford. | 3-4 Needs paid assistance, care available, but client declines help. | 5-6 In-home health care is available but staffing inconsistent and no backup; OR could use more help. | 7-8 In-home health care is available, fully staffed, and reliable; client is satisfied with services. | 9-10 No in-home care is needed at this time. | |

# Live Alone Dementia Safety Net Algorithm



## Diagnostic Referrals
for positive screen or diagnostic uncertainty

**Refer to Primary Care Provider** (or specialist as needed)
- Neurologist
- Neuropsychologist
- Geriatric Psychiatrist
- Geriatrician
- Memory Disorders Clinic

## Additional Medical Needs
- Mental Health Services
- Prescription Insurance and/or Assistance programs
- Vision, Hearing, Dental, Podiatry
- Holistic/Complimentary Medicine
- Trialmatch/clinical trials
- Home Health
- Durable Medical Equipment
- Adult Day Health
- Patient Advocacy and/or translation services

## Legal, Financial & Benefits
**Legal**
- Encourage client to assign durable power of attorney and complete healthcare directives and POLST. Refer to legal assistance programs, elder law attorney, public guardian/conservator as needed.

**Financial**
- Day to day money management
- Refer to fiduciary program
- Refer to Representative Payee Program through Social Security

**Benefits**
- Social Security/SSDI/SSI
- Veterans Administration (VA)
- Health Insurance – Medicare, Medi-Cal (Medicaid)
- PACE
- IHSS – In-home Supportive Services (Medi-Cal)
- Case Management – MSSP, Linkages, VA, Alzheimer's Greater Los Angeles, private
- SNAP – Senior Nutrition Assistance Program

## Daily Living & Functions
- **Personal Care:** In-home care assistance (VA, long-term care insurance, In-home Supportive Services, or private pay)
- **Shopping:** grocery delivery
- **Meals:** Meals on Wheels, congregate meals, private meal delivery
- **Assistive Technology:** Telephone Assistance Programs, Independent Living Centers
- **Chores:** In-home Support Services, private pay, volunteer programs

## Safety
*In situations where client is in immediate danger by self-neglect or by neglect or abuse from others, contact Adult Protective Services.*

**Driving**
- Counsel on risks
- Refer for driving evaluation
- DMV Unsafe Driver Form
- Transportation resources: paratransit services, private hire, volunteer transportation programs
- Taxi vouchers/scrip

**Medication Management**
- Oversight by a health care professional
- Automated/electronic Medi-set
- Pharmacy blister or bubble pack

**Wandering**
- MedicAlert Found California, or Project Lifesaver
- GPS tracking systems

**Home Safety**
- Home safety evaluation
- Home modification program
- Equipment loan programs
- Stove safety
- Personal Emergency Response Systems
- Activity monitoring systems

## Quality of Life & Activities
- Community Early Stage Programs & education
- Senior Centers (including virtual programs)
- Adult day services
- Friendly visitor, companion, telephone reassurance programs
- Culturally appropriate resources
- LGBT resources

## Care Circle & Support System
Identify support (family, friends, neighbors, religious & spiritual organizations, community groups, social service agencies, cultural & LGBT organizations)
- Obtain consent to contact on behalf of client
- Contact identified individuals
- Convene care circle/support system meeting
- Provide education and referrals

## Technology (also see Care Circle Resource Guide)
- Activity tracking & home automation
- Wandering
- Medication management
- Activities of daily living support

***Often the needs of my patients with dementia who live alone are less about their medical condition and more about being connected to others as a way to avoid further decline in physical and cognitive health.***

***—Geriatric nurse***

# Services for Persons Living Alone with Dementia

**Serving people with dementia who are living alone requires time and patience to build trust, understand their needs, and develop a support system. Helpers must be willing to do things differently, rather than trying to hustle the person along or shortcut the process.**

***–AAA social worker***

# Care Coordination

- Conduct dementia care planning, coordination of services, and communication with appropriate parties, with participant's (or surrogate decision maker's) consent

- Contingency planning for future decline

ID unmet assessment process

In-person home visits to assess safety, health, functionality, and dementia care needs

Collaborative development of a comprehensive dementia care plan

Regular, weekly contact, to evaluate the level and types of support or assistance needed

# BEHIND CLOSED DOORS: DEMENTIA CARE COORDINATION TO AT-RISK INDIVIDUALS WHO LIVE ALONE

Vickie Avila, MSW Intern; Lynne Conger, LCSW; Adria Navarro, PhD, LCSW

## Introduction

- Alzheimer's Orange County (AlzOC), a 501(c)(3) non-profit providing education, resources, referrals, and support to people living with Alzheimer's Disease and Related Disorders
- Alzheimer's Disease Project Initiative (2018-2021) to provide dementia care coordination to persons who live alone and are impacted by dementia
- Intervention designed to reduce social isolation, safety risk factors, and improve quality of life through frequent service coordination contacts, in-person or by phone
- Aim: To reduce risk factors and improve quality of life for persons living alone with dementia by providing dementia care coordination utilizing MSW interns

## Background

- One in four persons with dementia (26 percent) live alone, putting them at significant risk for isolation and self-neglect
- Low interpersonal social support increases rates of depression, anxiety, and poor health outcomes
- Living alone with dementia is a serious public health issue, causing increased risks for harm, malnutrition and wandering

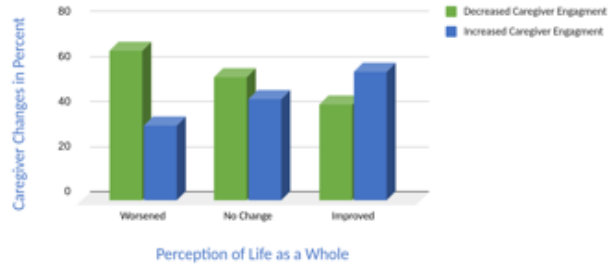
## Methods

- Geriatric Social Work Education Consortium MSW interns and an MSW were embedded into senior serving agencies - Meals on Wheels Orange County and Laguna Woods Village
- Dementia care coordination training and service delivery provided with frequent check-in regarding support, safety, health, and referral linkages
- COVID-19 pivot to remote services (Phone, Zoom), with introductory personal letter and photo and warm hand-offs from partner agencies
- Two standardized, quantitative tools (13 domain Dementia Crisis to Thriving Scale, 13 domain Quality of Life-Alzheimer's Disease) used to measure client progress, completed at enrollment and at six-months post program enrollment

## Results

Figure 1. Dementia Care Coordination: Changes in Perceived Life as a Whole


Figure 2. Caregiver Engagement Changes and Perceived Life as a Whole at 6-Month Post Survey




- Over 100 individuals have been enrolled in this program
- Outcomes from two standardized measures, (Dementia Crisis to Thriving Scale, Quality of Life in Alzheimer's Disease (QOL-AD) collected pre and post (3 or 6 months) in-person and telephonic (COVID-19 pandemic (n=34)
- Participants who rated their QOL-AD *Perceived Life as a Whole* as "Excellent" doubled after six months. No participants rated their *Perceived Life as a Whole* as "Poor" (Figure 1)
- Participants with decreased *Caregiver Engagement* were more likely to report lower *Perceived Life as a Whole*. QOL-AD *Perceived Life as a Whole* improved with increased Caregiver Engagement levels after six months (Figure 2)
- Participants who reported less *Socialization* did not indicate a change in their *Perceived Life as a Whole*, following program participation, which may indicate stability as a result of dementia care coordination.

## Discussion

- This model supports improved *Perceptions of Life as a Whole* by persons living alone with dementia receiving dementia care coordination services
- Results suggest a positive role for socialization and caregiver engagement in maintaining quality of life. Referrals helped stabilize the social network for persons living alone with dementia during the COVID-19 pandemic
- During the COVID-19 pandemic, persons living alone with dementia have become increasingly isolated, with deteriorating social networks, making it difficult to measure the full extent of the benefit of dementia care coordination services
- Partnering graduate level MSW Interns within a community-based partnership to provide dementia care coordination may be a cost-effective way to meet the needs of a growing, at-risk older population
- Future studies are recommended on the use of technology services to impact the quality of life for persons living alone with dementia.

## References

An, S., & Jang, Y. (2018). The role of social capital in the relationship between physical constraint and distress in older adults: A latent interaction model. *Aging & Mental Health, 22*(2), 245–249.

George, L.K. (2006). *Handbook of aging and the social sciences* (6th ed.). Academic Press.

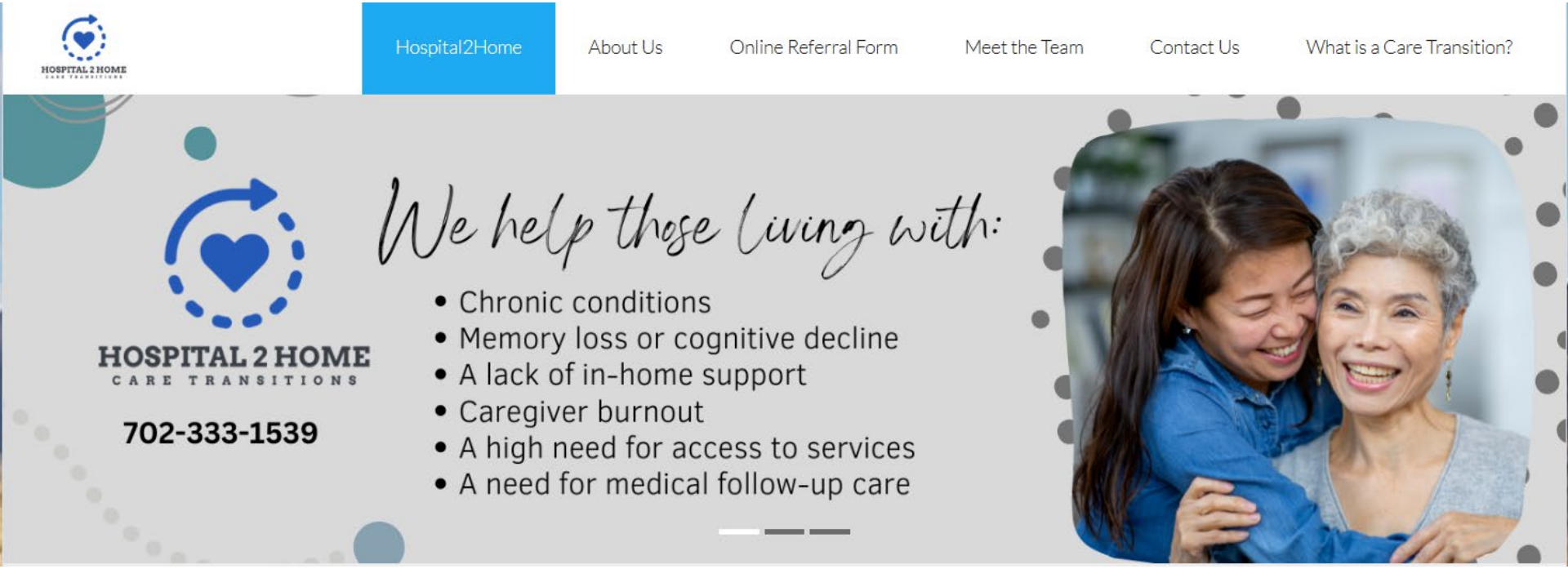
Hanson, H. M., Hoppmann, C. A., Condon, K., Davis, J., Feldman, F., Friesen, M., Leung, P. M., White, A. D., Sims-Gould, J., & Ashe, M. C. (2014). Characterizing social and recreational programming in assisted living. *Canadian Journal on Aging, 33*(3), 285–295.

King, D. B., Cappeliez, P., Canham, S. L., & O'Rourke, N. (2019). Functions of reminiscence in later life: Predicting change in the physical and mental health of older adults over time. *Aging & Mental Health, 23*(2), 246–254.

Moak, Z. B., & Agrawal, A. (2010). The association between perceived interpersonal social support and physical and mental health: Results from the National Epidemiological Survey on Alcohol and Related Conditions. *Journal of Public Health, 32*(2), 191–201.

Alzheimer's Orange County received a multi-year federal grant from the Administration on Community Living's Alzheimer's Disease Programs Initiative to support Special Populations Impacted by Alzheimer's Disease, including those with ADRD who live alone (Grant number 90ADPI0002-01-00). Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.

# Hospital2Home




15% Living Alone w/ Dementia

150 Nevadans

# Home Delivered Meals

- Up to five meals each week to each participant in the program. Meals are delivered frozen.
- "Warming Crew" goes to the home and heat the meal if needed.
- Daily wellness check is available through Phone Pals daily check-in calls.
- Volunteers and staff are trained to make sure that clients are safe when they deliver.

HEALTHY AGING
Southern Maine Agency on Aging

# Home Care Services and Case Management

- Target isolated clients living in the same building
- Provide services to multiple clients on the same day
- Nonmedical home-care services
- Home care aide visits 2-3 times per week
- Initial assessment conducted by case manager
- Case manager oversees home care aide services and coordinates other services

Home Care Partners, Washington, DC
"Cluster Care"

# Friendly Visitors

## THE CHALLENGE

Older LGBT adults quite often become isolated from friends and loved ones as they age and face considerable challenges as compared with the general population:

- They are two times more likely to live alone.
- They are two times more likely to be single.
- They are four times less likely to have children.
- They are much more likely to be estranged from their families.

## THE SOLUTION

**SAGE's Friendly Visitor Program helps alleviate isolation and reconnect LGBT elders to their communities across generations.**

*"It's one of the best things that has happened to me since I joined SAGE. He's always there for me, every week."*

—ED, FRIEND AT HOME

## The Friendly Visitor Program

### How It Works

When clients (Friends at Home) come to the Program, they are assigned to a SAGE care manager who makes a home visit to assess the need for SAGE's services, including the Friendly Visitor Program. If interested and appropriate, they are then assigned a Friendly Visitor volunteer.

Friendly Visitor volunteers are carefully screened and fully trained. They commit to spending at least one year with their assigned Friend at Home, visiting once a week and following up between visits via phone or email.

In addition, volunteers receive one-on-one supervision and are required to attend bimonthly support meetings.

*"Applying for the Friendly Visitor Program was one of the better decisions I've ever made. I see Greta more regularly than I see most of my friends and family. In our time together, she has become both."*

– ALLISON, FRIENDLY VISITOR VOLUNTEER

# Tech-based Direct Services

**Alzheimer's Community Care**
**High Risk Intervention Project (HRIP) – Live Alones**
**Care Buddy Volunteer Position Description**

| | |
|---|---|
| **Title:** | HRIP Care Buddy Volunteer |
| **Department:** | Community Care Services |
| **Supervisor:** | High Risk Intervention Project Manager |
| **Location:** | Palm Beach, Martin and St. Lucie County |
| **Hours:** | 2-6 Hours per Week |
| **Purpose:** | To provide emotional support and connectivity to patients affected by Alzheimer's and related disorders that are participants in the HRIP – Live Alone Project. |

**Summary of Position:** The volunteer maintains phone contact with the patients affected by Alzheimer's disease and related disorders (ADRD) that are living alone in the community. This service will provide additional one-to-one attention and support. Referrals to a Care Buddy will originate from a Family Nurse Consultant (FNC) or the HRIP Manager.

https://www.alzcare.org/our-services/live-alone-program

# Tech-based Direct Services

## Telehealth Therapy and Counseling

- Determining if telehealth is an option
- Technology has access/usage challenges, but is increasingly easy
- Person-centered and individualized (e.g., video/audio preferences)
- Assessing the person and the environment
- Ensuring environments are quiet and private

LiveWell INSTITUTE

www.livewell.org

# Tech-based Direct Services

caringkind *The Heart of Alzheimer's Caregiving*

*CaringKind Early-Stage Services*

## *Join Us!*

**Small group program for people with early-stage Alzheimer's or dementia.**

## Cognitive Stimulation Therapy Program (CST)

**Improve thinking abilities, communicate, and interact with others in a relaxed, fun, and social setting.**

*CST Sessions include:*

- Discussions around current events.
- A main activity with a theme.
- Validation of thoughts and opinions.
- Stimulating conversation.
- Enjoyable connections.

CST, an evidence-based program, creates a positive, accepting atmosphere where opinions rather than facts are shared and new ideas, thoughts, and associations are generated. CST activates various aspects of peoples' minds and its research shows improvements in cognitive function, mood, and quality of life.

# Tech-based Direct Services


Group by Living Alone and Connected

**Living Alone and Connected!**

Private group · 65 members

Join group | Share

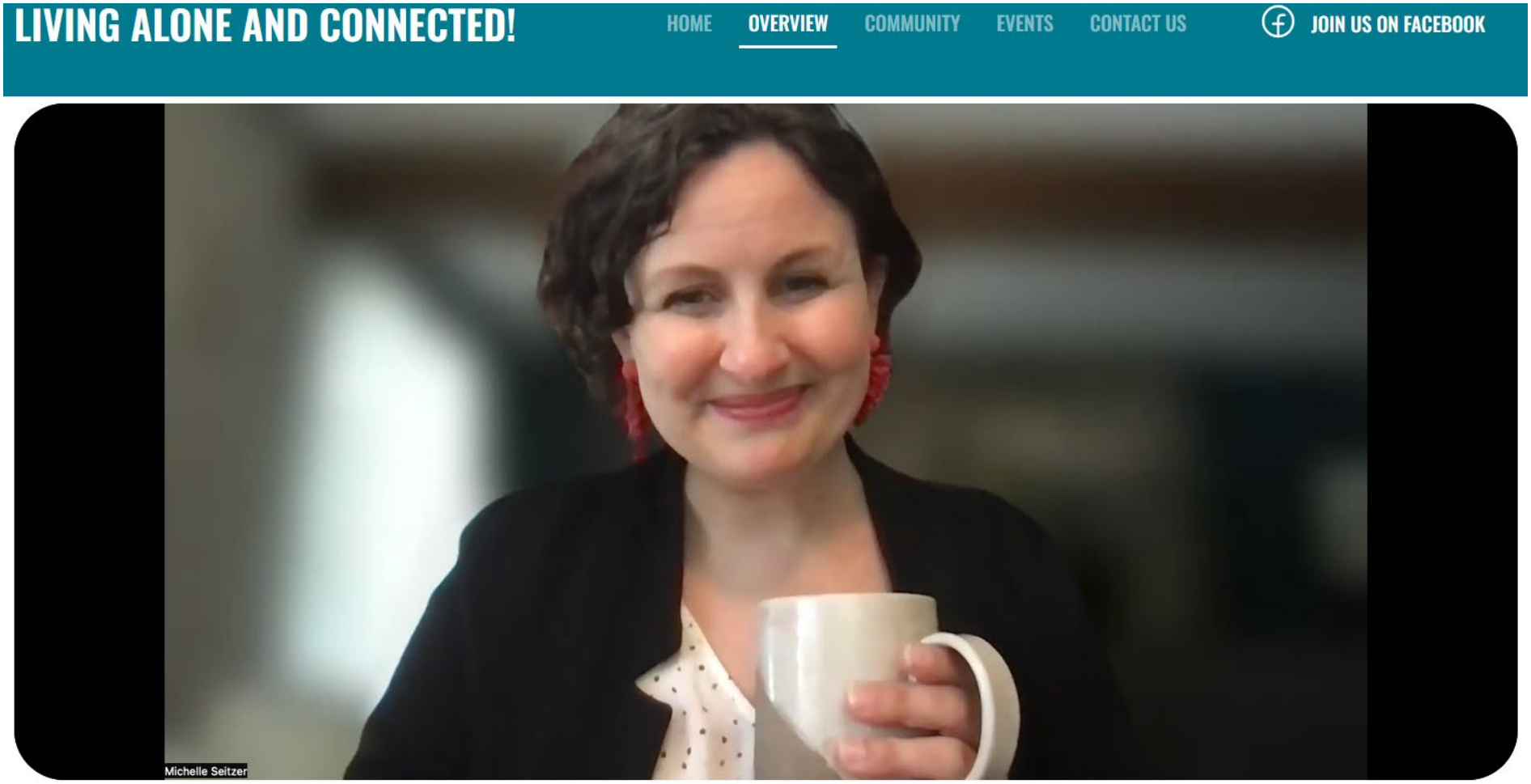
About | Discussion

**About this group**

This online community is a place where people can come together to share questions, ideas, find curated information to provide emotional and mat... **See more**

**Private**

Only members can see who's in the group and what they post.




https://www.youtube.com/watch?v=BpwE0mFVQkc

# Tech-based Direct Services


Group by Living Alone and Cor

**Living Alone ar**

Private group · 65 member

roup Share

About Discussion

## About this group

This online community is a place where people can come together to share questions, ideas, find curated information to provide emotional and material support to those living with Alzheimer's disease or another dementia who live in a single person household. We want this to be a place where they can find and offer support, tailored as much as possible to their unique living situation. (Though it's hard to think it is unique when it may be upwards of one million persons living alone with dementia just in the U.S.).

Living Alone and Connected! is hosted and moderated by Splaine Consulting.

Living Alone and Connected! is supported in part by a cooperative agreement #90ADPI0067-01-00 from the Administration on Aging (AoA), Alzheimer's Disease Program Initiative (ADPI) and cooperative agreement NVADPI0082 from the Neighbor Network of Northern Nevada and Nevada Senior Services. **See less**

**Private**

Only members can see who's in the group and what they post.

LIVING ALONE AND CONNECTED

# EVENTS

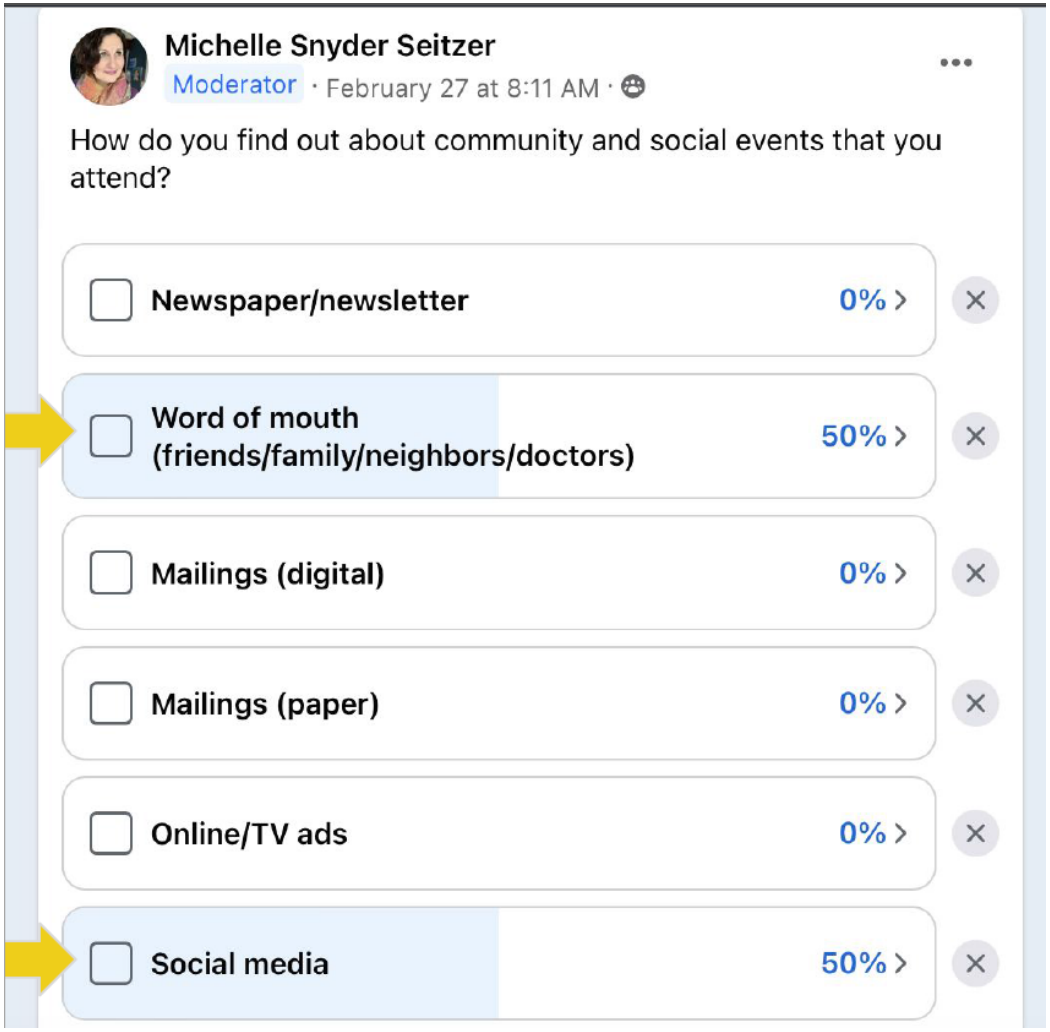
**Thursdays at 10am HST/ 1pm PST/ 4pm EST**

### Relationships – September 26th

We'll discuss the kinds of meaningful connections in our lives, what we've learned from our loved ones and what those relationships mean to us.

RSVP HERE

# LIVING ALONE AND CONNECTED



# Tech-based Direct Services

SUPPORT PLAWD

**Support PLAWD**

43 likes • 76 followers

Message Like Search

Posts About Mentions Reviews Followers Photos More

# Tech-based Direct Services

## Support PLAWD

43 likes • 76 followers

Message | Like | Sear

Posts | About | Mentions | Reviews | Followers | Photos | More

### Intro

Support PLAWD (People Living Alone with Dementia) is a community for friends and allies of people living alone with dementia. Here you'll find ideas and inspiration to best support PLAWD. PLAWD make up as many as 20% of all persons in US.

Page · Social Service

Not yet rated (0 Reviews)

### Photos

See all photos


### Featured

**Support PLAWD**
October 14 at 1:47 PM

Do you know someone who has dementia & lives alone?
...

**Support PLAWD**
September 16

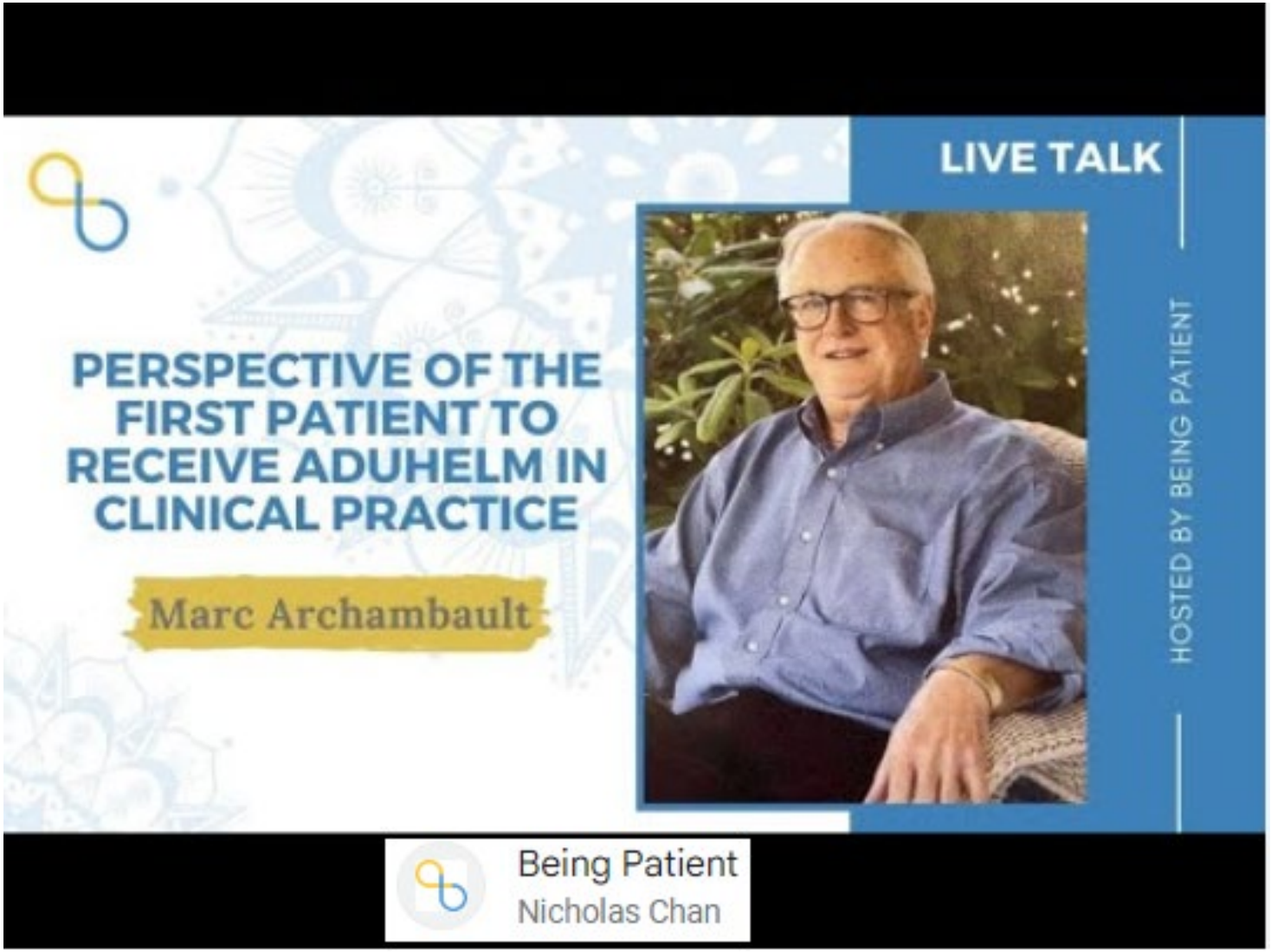
Support PLAWD (People Living Alone with Dementia) is for people who are friends and allies to people with dementia who...

LIVINGALONEANDCONNECTED.COM
**Living Alone And Connected!**

# SUPPORT PLAWD

## SUPPORT PEOPLE LIVING ALONE WITH DEMENTIA

# Marc




Source: https://www.beingpatient.com/marc-archambault-livetalk/

# Summary

- Few evidence-based interventions
- Some promising programs and practices
- Test and share innovative practices