Identification, Diagnosis, and Unmet Needs

Studies indicate 28%-34% of people with dementia live alone.

Identification/Diagnosis
- Less likely to be diagnosed
- Do not receive the same level of care

Unmet Needs
- Daily activities
- Health conditions
- Safety
  - Home safety/Falls
  - Unattended wandering
  - Emergencies/Getting Help
- Abuse/Self-Neglect
- Social Isolation/Loneliness

Studies indicate 28%-34% of people with dementia live alone.
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)
Varying Degrees of Support

- **FREQUENT SUPPORT, VISITS, MONITORING**
- **CHECK IN CALLS FROM LONG DISTANCE RELATIVES**
- **NO SUPPORT/NO KNOWN SUPPORT**
Caregiver Roles

Proportion of Caregivers Who Reported Helping the Person with Specific Activities, 2009

- Bathing: 22% PwD Living Alone, 57% PwD Living with Caregiver
- Dressing: 27% PwD Living Alone, 63% PwD Living with Caregiver
- Managing incontinence and diapers: 17% PwD Living Alone, 51% PwD Living with Caregiver
- Managing medications: 59% PwD Living Alone, 90% PwD Living with Caregiver
- Managing money: 79% PwD Living Alone, 89% PwD Living with Caregiver
- Providing transportation: 91% PwD Living Alone, 93% PwD Living with Caregiver

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
What about HIPAA?
I am never sure when to step in. I don’t want to rob her of her independence.

— Caregiving daughter
# 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

<table>
<thead>
<tr>
<th>Grade</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>A = Emergent</td>
<td>Only one condition needs to be present. <strong>Immediate</strong> help or placement is required.</td>
</tr>
<tr>
<td>A / B</td>
<td>Emergent/Semi-Emergent. Can be either A or B depending on the cause, severity, and the person’s response to the situation.</td>
</tr>
<tr>
<td>B = Semi-Emergent</td>
<td>&gt; 2 conditions indicate that there are safety concerns that must be addressed and remediated.</td>
</tr>
<tr>
<td>C = Non-Emergent</td>
<td>&gt; 3 conditions are present. Additional help will be beneficial. Re-evaluate monthly.</td>
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</tbody>
</table>

## Observed or Reported Conditions

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

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

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

- Does the person living alone exhibit symptoms of memory loss, confusion or dementia symptoms?
- Does the person living alone have a diagnosis of dementia?

If person is in immediate danger (i.e. neglect, self-neglect, or abuse by others), contact Adult Protective Services. If uncertain refer to Live Alone Assessment (Iowa, 2004).

- Screen using Mini-Cog or AD-8 if support system is available
  - Mini-Cog Score: 0-3 or AD-8: 2 or more
    - Provide medical referral
  - Mini-Cog Score: 4-5 or AD-8: 0-1
    - Provide brain health, risk reduction, and/or clinical trial materials
- Identify client’s needs using organization’s assessment tool or Intervention Options on backside. Does the client have unmet Diagnostic, Medical, Financial/Legal Benefits, Daily Living, Safety, Quality of Life, Support System, or Technology Needs?
- Using checklist, create care plan (including referrals) with client and, with permission, contact appropriate supports based on client’s needs, eligibility, diagnosis and stage of disease (if known)
- Determine time frame for follow-up and plan for communication
- Contact people client identifies as support system and provide information, education and care plan, including:
  - Provide disease education
  - Provide information on local resources
  - Refer to clinical trials
  - Refer to community Early Stage Services, if appropriate
- Is the individual safe, and is the individual supported?
  - No
    - Mild cognitive impairment or dementia diagnosis
  - Yes
    - Refuse Referral
    - No Cognitive Impairment
      - Provide brain health, risk reduction, clinical trial educational materials and/or local resource guide
### Diagnostic Referrals
- Neurologist
- Neuropsychologist
- Geriatric Psychiatrist
- Geriatrician
- Memory Disorders Clinic

### 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/script

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

### Wandering
- MedAlert 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

### 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

### 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

### 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

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

“\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.

THE SOLUTION
SAGE’s Friendly Visitor Program helps alleviate isolation and reconnect LGBT elders to their communities across generations.

“\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
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
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.
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”
Life Hacks for Living Alone - Is Assistive Technology the Answer?
Summary

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

- Identifying and Meeting the Needs of Individuals with Dementia Who Live Alone (2015)

Audio Learning


On Video

- YouTube: "Leave Me Alone,” 1 Million Americans with Dementia Live Alone (CA-specific information)


Lampley-Dallas, V.T. (2002). Research issues for minority dementia patients and their caregivers: What are the gaps in our knowledge base? Alzheimer's Disease and Associated Disorders, 16(Supplement 2), S46–S9.


