Advances in Caregiver Support for Alzheimer’s Disease: Reducing Caregiver Burden

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Gray Matters
Neuropsychological Healthcare Services
"WILL THIS BE ALL FOR TONIGHT DAD?"
Pre/Post Questions

1. What are three (3) types of burden experienced by caregivers of patients with Alzheimer’s disease?

2. Identify three (3) individual risk factors for increased caregiver distress and worse patient outcome.

3. What are three (3) specific empirically-supported intervention strategies for reducing distress among caregivers of people with Alzheimer’s disease?
General Caregiver Statistics

- 51% of care recipients live in their own home
  - 29% live with their family caregiver
  - 4% live in nursing homes & assisted living

- > 65 million unpaid caregivers in the US
  - 29% of the US population

- Average 20 hours of care per week

- Estimated value = $375 billion annually

National Alliance for Caregiving in collaboration with AARP. 2009
Alzheimer’s Disease Caregiver Facts

- In 2007, approximately 10 million individuals were caring for an individual with dementia (Alzheimer’s Association, 2007)

- Informal caregivers provide support for 75% of individuals with dementia (Shuolz & Martire, 2004)

- The majority of caregivers are spouses, second to children (mostly female)

- AD caregivers provide care for a longer period of time than other caregivers (National Alliance for Caregiving and AARP, 2009)

- Women, spouses, and those in a lower SES group appear to be more vulnerable to burden.
Motivations to provide care

- Sense of love or reciprocity
- Spiritual fulfilment
- Cultural factors
- Modeling for younger generations
- A sense of duty
- Guilt
- Social pressures
- Incentives/ greed (rarely)
Benefits of Caregiving

• Feel good about making care recipient feel good
• Keep care recipient out of a facility
• Feel closer to care recipient
• Learn new information and coping strategies
• Feel better about self
• Will be blessed
• Praise / admiration
• Satisfaction in “doing the right thing”

Picot, 1997
Caregiver Responsibilities

- Assist with ADLs
- Assist with IADLs
- Financial responsibility
- Behavior management
- Provide emotional support
Caregiving for People with Different Problems

- Broken bone
- Terminal Cancer
- Schizophrenia
- Developmentally Disabled Child

- Why is caring for a person with Alzheimer’s Disease different?
## Dementia Caregiving Tasks

<table>
<thead>
<tr>
<th>Task</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Help with IADLs</td>
<td>Household chores, shopping, meal preparation, transportation, scheduling, financial management, medical &amp; legal decision making</td>
</tr>
<tr>
<td>Medication management</td>
<td>Reminders, administration, convincing to take medications</td>
</tr>
<tr>
<td>Adherence to other treatment recommendations for dementia or other conditions</td>
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</tr>
<tr>
<td>Help with ADLs</td>
<td>Bathing, dressing, grooming, feeding, ambulation, transfers, toileting, managing incontinence</td>
</tr>
<tr>
<td>Management of behavioral symptoms</td>
<td>Aggression, wandering, depressed mood, agitation, anxiety, repetitive activity, nighttime/sleep disturbances</td>
</tr>
<tr>
<td>Finding &amp; using support services</td>
<td>Support groups, adult day service programs</td>
</tr>
<tr>
<td>Arranging paid in-home care</td>
<td>Nursing home, or assisted living care</td>
</tr>
<tr>
<td>Hiring &amp; supervising other care providers</td>
<td></td>
</tr>
<tr>
<td>Other non task-specific responsibilities</td>
<td></td>
</tr>
<tr>
<td>• Overall management of care recipient throughout the day</td>
<td></td>
</tr>
<tr>
<td>• Manage family dynamics related to providing care</td>
<td>Communication, decision-making, arranging respite for caregiver</td>
</tr>
</tbody>
</table>

*2014 Alzheimer’s Disease Facts and Figures, pg.31, 2014*
Prevalence of AD

Projected Number of People Age 65 and Older (Total and by Age Group) in the U.S. Population With Alzheimer’s Disease, 2010 to 2050

 Millions of people with Alzheimer’s

<table>
<thead>
<tr>
<th>Year</th>
<th>Ages 65-74</th>
<th>Ages 75-84</th>
<th>Ages 85+</th>
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</thead>
<tbody>
<tr>
<td>2010</td>
<td>4.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2020</td>
<td>5.8</td>
<td>2.1</td>
<td></td>
</tr>
<tr>
<td>2030</td>
<td>8.4</td>
<td>3.8</td>
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<tr>
<td>2040</td>
<td>11.6</td>
<td>5.0</td>
<td></td>
</tr>
<tr>
<td>2050</td>
<td>13.8</td>
<td>6.2</td>
<td></td>
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</tbody>
</table>

Created from data from Hebert et al.

Definitions of Caregiver Burden

• “A multidimensional response to the negative appraisal and perceived stress resulting from taking care of an ill individual”  (Kim, 2011)

• “High level of stress that may be experienced by people who are caring for another person (usually a family member) with some kind of illness.”  (Tull, 2008)

• The negative reaction to the impact of providing care on the caregiver’s social, occupational, and personal roles  (Given, et. al., 2001)
Sample Zarit Burden Interview Questions

1. Do you feel like your relative asks for more help than he/she needs?
2. Do you feel that because of the time you spend with your relative that you don’t have enough time for yourself?
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?
4. Do you feel embarrassed over your relatives behavior?
5. Do you feel angry when you are around your relative?
6. Do you feel that your relative affects your relationships with other family members or friends in a negative way?
7. Are you afraid what the future holds for your relative?
8. Do you feel your relative is dependent on you?
9. Do you feel strained when you are around your relative?
10. Do you feel your health has suffered because of your involvement with your relative?
Risk Factors for Caregiver Burden

• Social isolation
• Financial stress
• “Sandwich generation”

Adelman, Tmanova, Delgado, Dion, & Lachs (2014)
Risk Factors for Caregiver Burden

- Female sex
- Low educational attainment
- Residence with the care recipient
- High number of hours spent caregiving
- Depression
- Lack of choice in becoming a caregiver
- Care recipient factors

Costs of Caregiving

Research suggests caregiving for individuals with dementia have higher levels of burden than other caregivers

Alzheimer’s Association, 2014
Dimensions of Burden

Dimensions of burden:
1. Physical
2. Psychological
3. Emotional
4. Social
5. Financial

Alzheimer’s Association, 2014
Physical

• 43% of caregivers report physical impact is “high” to “very high”

• Poor health outcomes
  – High levels of stress hormones
  – Compromised immune response
  – Greater medication use
  – Increased risk of developing chronic conditions
  – 7% report greatest difficulty of caregiving is the aggravation of own health problems

• Greater cognitive decline

• Sleep disturbances

(Bouldin & Andresen, 2010; Peng & Chang, 2012; Vitaliano, Young, & Zhang, 2004; Vitaliano, et al., 2005)
Psychological

• Negative beliefs about ability to cope

• Feeling trapped

• Few perceived benefits/ uplifts

• Dysfunctional coping styles
  – Avoidance/ denial
  – Wishful thinking
Emotional

- 59% of caregivers rate the emotional stress as “high” to “very high” (Alzheimer’s Association, 2014)

- High levels of depression and anxiety

- Lower levels of subjective well-being

- Poorer self-efficacy
Social

• Reduction in social network

• Reduction in social contact

• Arranging assistance from friends and family

• Dysfunctional family interaction patterns
Financial

- Significant economic disadvantage
  - Direct: Medical consultations, pharmaceuticals, personal and nursing care, residential care
  - Indirect: loss of earnings, hours of informal care, mortality burden

- In 2013, unpaid caregivers provided an estimated 17.7 billion hours of care (estimated value=$220.2 billion)
  - 21.9 hours of care/week or 1,139 hours/year
Predictors of Caregiver Burden

Adapted from Sorensen et al., Lancet Neurology

**Background & Contextual Factors**
- SES
- Ethnicity/Culture
- Gender
- Age
- Geography/Rural-Urban
- Health Systems

**Primary Stressors**

**Patient Characteristics:**
- Cognitive Impairments
- Functional Disability
- Problem Behavior

**Care Situation:**
- Duration of Caregiving
- Hours of Caregiving
- # of Caretaking Tasks

**Caregiver:**
- Unmet needs

**Secondary Stressors**

**Work Interference**
- Financial Strain
- Family Conflict
- Social Isolation
- Reduced Relationship Quality
- Decreased Leisure
- Other Opportunity Costs

**Appraisal**

- Perceived Situational Control
- Perceived Role Conflict
- Role Captivity
- Perceived Adequacy of Resources
- Positive Appraisal
- Finding Meaning
- Short- vs. Long-Term

**Exacerbating/Ameliorating Factors (Moderators)**

Lack of Knowledge/Information About Dementia
- Self-efficacy/Perceived Competency/Mastery
- Personality
- Coping Resources
- Social, Emotional, & Financial Support Resources
- Formal Service Use
- Availability of Informal Assistance
- Quality of Relationships
- Uplifts of Caregiving

**Outcomes**

- Psychological
- Physiological
- Health Behaviors
- General Health
Evidence-based interventions:

• Individual interventions > group interventions for caregiver well-being

• Group interventions > Individual interventions for care-recipient symptoms
  \[(\text{Sorenson, et al., 2002})\]\n
• Combination of multiple approaches work better than single approaches
  \[(\text{in Ostwald 1999})\]\n
• Programs tailored to the specific needs of the caregiver work better than general programs
  \[(\text{in Ostwald 1999})\]\n
Evidence-based interventions: Psychoeducation

• Provides disease-related information
  – Physiology
  – Disease progression

• Let’s caregiver’s know what to expect
  – Behavioral, functional, emotional changes
  – Reasonable expectations

• Train caregiver in specific skills
  – Strategies for assisting with (I)ADLs
  – Problem-solving strategies
  – Behavior management strategies
Evidence-based interventions: Psychoeducation

- Improves caregiver knowledge
- Reduces burden
- Reduces depression symptoms
- Increases subjective well-being and caregiver satisfaction
- Treatment effects only occur if intervention includes active participation and behavioral management skills-building
- May improve symptoms of the patient

(Pinquart & Sorensen, 2006; Brodaty, Green, & Koschera, 2003)
Evidence-based interventions: Environmental Skill-Building Program

• Home-based
• Provide caregivers with tools to reduce specific environmental stressors
• Focus on 4 layers
  – Physical dimension (objects)
  – Task dimension (daily routines)
  – Social dimension (household composition, social resources)
  – Cultural dimension (shared values and beliefs)

(Wisniewski, et al., 2003)
Evidence-based interventions: Environmental Skill-Building Program

• Identify & prioritize problem areas encountered in the environment

• Brainstorm environmental strategies
  – Assistive devices
  – Home alterations
  – Simplifying tasks
  – Enlisting family support

• Variable cost strategies
  – rearrange furniture
  – Install grab bars

(Wisniewski, et al., 2003)
Evidence-based interventions: Supportive Interventions

• Professional or peer lead (groups)
• Focus on;
  – Rapport building
  – Creating a space to discuss problems, success, feelings
• Not group therapy
• Normalize
• Exchange ideas & strategies
• Rarely standardized/manualized
Evidence-based interventions: Supportive Interventions

- Reduced caregiver burden
- Increased caregiver knowledge/ability

Sorensen, Pinquart, Habil, & Duberstein, 2002
Evidence-based interventions: Respite Care

• Give caregiver time off
• In-home or out of home
• Assistance with ADL or skilled nursing care
• May include activities or programming for care recipient
• Adult day care
  – Respite & programming for care recipient
  – Out of home
Evidence-based interventions: Respite Care

- Reduced overall burden
- Improved caregiver depression
- Improved caregiver overall wellbeing
Evidence-based interventions: Relaxation Training

• Breathing Retraining
• Progressive Muscle Relaxation
• Mindful Meditation
• Guided Imagery

• Outcome
  – Improved caregiver self-efficacy

Fisher & Laschinger, 2001
Evidence-based interventions: CBT

- Structured, often manualized
- Teach self-monitoring
- Challenge negative thoughts, assumptions
- Teach problem-solving skills
- Time management
- Identify & manage emotional reactivity
- Re-engagement in pleasant activities
  - With and without care recipient

Sorensen, Pinquart, Habil, & Duberstein, 2002
Evidence-based interventions: CBT

- Improves caregiver burden, depression, and anxiety
- Does not necessarily improve knowledge about dementia
- May reduce secondary stressors
  - social isolation
- Alter appraisals of caregiving
  - perceived pressure and burden
  - Perceived role conflict

*Broday, Green, Koschera, 2003; Akkerman & Ostwald, 2004; Roth et al., 2005*
Evidence-based interventions: Training for Care Recipient

- Memory Clinic for care recipient
- Activity therapy/programs
- Reminiscence Therapy

• Outcome
  – Improvements in caregiver wellbeing

Sorensen, Pinquart, Habil, & Duberstein, 2002
Evidence-based interventions: Communication Skills Training

- Monitor non-verbal cues (care recipient and giver)
- Simple commands
- Reduce environmental distractions
- Give choices rather than open-ended questions
- Avoid long explanations
- Avoid arguing
- Agree with some made-up stories
- Use distraction when care recipient is repeating questions

- Outcome
  - Reduced care recipient’s agitation and behavioral disturbances

_Sorensen, Pinquart, Habil, & Duberstein, 2002_
### Evidence-based interventions

<table>
<thead>
<tr>
<th></th>
<th>Caregiver Burden</th>
<th>Caregiver Depression</th>
<th>Caregiver Well-being</th>
<th>Caregiver Knowledge/Ability</th>
<th>Care Recipient Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychoeducation</td>
<td>Minimal</td>
<td>Small*</td>
<td>Medium</td>
<td>Medium</td>
<td>Small</td>
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<td>Supportive Interventions</td>
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<td>Multi-component</td>
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<td>Medium</td>
<td>Large</td>
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</table>

*(Sorensen, Pinquart, Habil, & Duberstein, 2002)*
Evidence-based interventions

<table>
<thead>
<tr>
<th>Factors Affecting Intervention Effectiveness</th>
<th>Caregiver Burden</th>
<th>Caregiver Depression</th>
<th>Caregiver Well-being</th>
<th>Caregiver Knowledge/Ability</th>
<th>Care Recipient Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Format</td>
<td>Individual</td>
<td>n/a</td>
<td>Individual</td>
<td>n/a</td>
<td>Group</td>
</tr>
<tr>
<td># of Sessions</td>
<td>Reduced</td>
<td>Improved</td>
<td>None</td>
<td>None</td>
<td>Improved</td>
</tr>
<tr>
<td>Caregiver Age</td>
<td>Improved</td>
<td>None</td>
<td>Improved</td>
<td>Improved</td>
<td>Improved</td>
</tr>
<tr>
<td>Care Receiver Age</td>
<td>Improved</td>
<td>Improved</td>
<td>Improved</td>
<td>None</td>
<td>None</td>
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<tr>
<td>Care Receiver Diagnosis of Dementia</td>
<td>Reduced</td>
<td>Reduced</td>
<td>Reduced</td>
<td>Reduced</td>
<td>None</td>
</tr>
<tr>
<td>Caregiving Hours</td>
<td>Reduced</td>
<td>Reduced</td>
<td>Reduced</td>
<td>Improved</td>
<td>None</td>
</tr>
<tr>
<td>Caregiver = Child</td>
<td>Improved</td>
<td>Improved</td>
<td>Improved</td>
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<tr>
<td>Caregiver = Spouse</td>
<td>Reduced</td>
<td>Reduced</td>
<td>Reduced</td>
<td>Reduced</td>
<td>Reduced</td>
</tr>
</tbody>
</table>

(Sorensen, Pinquart, Habil, & Duberstein, 2002)
Skills Training: Managing Behavioral Disturbances

- Physical Discomfort
- Frantic Environment
- Loud Noises
- Communication Difficulties
- Task Difficulties
- Unfamiliar Surroundings
Skills Training: Managing Behavioral Disturbances

• Create a calm environment
  – Good lighting, minimal mirrors, minimize loud noises
  – Caregiver should remain calm
  – General stress management for care-recipient
    • Exercise
    • Reconnecting activities
    • Reminiscence
    • Calming music/music therapy
    • Social interaction
    • Pets
Skills Training: Managing Behavioral Disturbances

• Manage Wandering
  – Due to restlessness or disorientation
    • Physical exercise
    • Redirect restless behavior
    • Predict wandering behavior and redirect (e.g., at specific times of day)
    • Reduce loud noise and high contrast (can be disorienting)
    • Install child safety devices
    • Hide items the care-recipient would always take with them
    • Plan for when it happens
Skills Training: Managing Behavioral Disturbances

• Managing Belligerence, Anger, Aggression
  – Do not confront the person or try to discuss the behavior in the moment
  – Avoid physical contact during the outburst
  – Let the aggression play out
  – Distract with more pleasurable activities
  – Look for patterns & try to predict/avoid episodes
  – Don’t take it personally
Skills Training: Managing Behavioral Disturbances

• Rule out medical conditions/problems
  – Care recipient may have difficulty communicating

• Try to establish and not to change routines
  – Be prepared if the routine changes

• Try to understand the underlying cause of the behavioral disturbance
  – misinterpretation of a situation or miscommunication
  – Physical pain
  – Difficulty expressing emotions
Skills Training: Managing Behavioral Disturbances

• Try to understand the underlying cause of the behavioral disturbance (cont.)
  – May have to “play into a delusion” to reduce distress about it
  – Use problem-solving and creativity

• Identify triggers that have caused past disturbances

• Identify strategies that have historically worked
Web Links

• Alzheimer’s Association Caregiver Training Resources

• Alzheimer’s Association Tips for Early Stage Caregivers

• National Association of Professional Geriatric Care Managers – Can find a person to help
  – http://www.caremanager.org/
Web Links

• AlzOnline Positive Caregiving classes

• Strategies for Managing Behavior from Helpguide.org

• Caregiver education and resources
Web Links

• Department of Health Care Services: Caregiver Resource Centers
  - http://www.dhcs.ca.gov/services/MH/Pages/AdultsCaregiverResourceCenters.aspx

• Los Angeles Regional California Caregiver Resource Center (at USC)
  - http://fcscgero.org/

• Rosalynn Carter Website (Caregiver Resources)
  - http://www.rosalynncarter.org/
Thank You.
living with alzheimer’s
for caregivers

tips for early-stage caregivers
tip 1: report early signs and changes

Families may notice a variety of symptoms in the early stage. The hallmark of Alzheimer’s disease is memory loss, but not every symptom will affect each person with the disease at the same time or in the same way. Even after the diagnosis has been made, make note of any changes you see in the following areas, and discuss those changes with the doctor. Sometimes those issues may be treatable, and sometimes they can indicate an issue that must be addressed immediately.

Mark any of the early signs of a problem that you notice now by checking the boxes below. These may indicate a shift that could signal a problem in another area.

- Memory changes
- Changes in executive functioning
- Concentration changes
- Difficulty with reasoning and abstract thinking
- Difficulty with language and ability to communicate
- Impaired judgment
- Confusion with time or place
- Difficulty with visual-spatial relations
- Withdrawal from work or social activities
- Personality changes

Other changes to discuss:

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tip 2: stay organized

Symptoms in early-stage Alzheimer’s are often more manageable when family members provide some degree of help and encourage the person with the disease to continue living as independently as possible. Notes and shared calendars can be used as a reminder system as well as a way to stay organized. We encourage you to find other creative ways to help the person you care for stay organized by tapping into his or her strengths and abilities. This will allow the person with Alzheimer’s disease to cultivate independence as much as possible.

Check the tips below that you are already doing and that work for you now, and add any of your own. Remember that these will change over time, so stay flexible!

- Notes for the person with Alzheimer’s
- Shared calendars
- Medication schedules
- Written “to do” lists
- Planned times for exercise
- Written meal plans

Other suggestions include:
tip 3: stay active

Staying active can help the person with dementia maintain a consistent “sense of self” that continues with them throughout the course of the disease. Consider the person’s everyday routines, hobbies and interests, previous employment, level of education, and activities most enjoyed – these will tell you what the person considers important and interesting. Focus on the person’s strengths as well as creating a sense of purpose as you partner with the person to stay engaged.

Check the tips below that you are already doing and that work for you now, and add any of your own. Remember that these will change over time, so stay flexible!

- Continue everyday tasks and routines to maintain sense of self
- Focus on unique strengths and interests
- Modify activities to match abilities
- Adapt activities over time
- Plan for rest periods

Other suggestions include:

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tip 4: nurture your relationship

Nurturing your connection with the person with Alzheimer’s disease can sometimes seem to take a back seat to the business of daily life. But keeping your connection foremost in your mind can help everyone enjoy themselves together.

Check the tips below that you currently use to nurture your relationship with the person with Alzheimer’s.

- Stay flexible with plans. If it’s not a good day, it’s ok to modify or cancel plans.
- Trust that these ups and downs are normal.
- Live in and enjoy the present moment together.
- Gently share your feelings in non-threatening ways.
- Listen without judging.
- Reassure the person that you are there as source of support and care.
- Think of ways to complete tasks as a team,
- Solve problems together.
- Experience moments together that help you relate in new ways.
- Go with the flow.
- If there is something that you have always wanted to do together, do it now!

Other suggestions include:
tip 5: partner with your medical team

Your care team is made up of those in the health care professions. The physician who made the diagnosis and those in that office – nurses, social workers, nurse practitioners, etc. – are crucial members of your health care team. Building a relationship with the physician takes time and effort, but it can significantly improve the care received by the person with the disease.

Check the tips below that you currently use to partner with the medical team.

- Make a list of questions for the doctor as they arise and bring it with you to the next appointment.
- Be sure you also have a notepad on which to record the doctor’s responses.
- Bring a list of everything the person with dementia is taking, including prescription medications, over-the-counter products, and vitamins and supplements.
- Be open and honest with the doctor, especially if you do not understand something the doctor is saying. Ask for clarification until you understand.
- Clarify the purpose and results of any tests performed.
- Determine under what circumstances you can contact the doctor between appointments and what the regular appointment schedule will be.

Other suggestions include:

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tip 6: disclose the diagnosis directly

Disclosing a diagnosis of Alzheimer’s disease is a difficult thing to do, as Alzheimer’s is a disease that currently has no cure. Many people think of it as a disease that immediately leaves the person with Alzheimer’s bedbound and unable to do much for him or herself. This stigma is significantly reduced when the disease is brought into the open in the early stages, and this openness allows families to get the support that they need from others.

Most people find that telling people in a matter-of-fact way works best. It allows you and the person with dementia to get the support you need and to serve as advocates for yourselves and others with the disease.

Check the tips below that you are already doing and that work for you now, and add any of your own.

- Alzheimer’s is not a normal part of aging but a disease of the brain that results in impaired memory, thinking, and behavior.
- The disease is a medical condition and not a psychological or emotional disorder.
- The disease does not immediately take all the strengths and abilities away from the person.
- You and the person with dementia value friendship and want to continue enjoying the company of family and friends throughout the course of the disease.

Other suggestions include:

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tip 7: plan now for future care

A diagnosis of Alzheimer’s disease presents a factor to include when making future plans. This begins with thinking and talking about what the person with dementia’s wishes are for how he or she would prefer care to be provided. The answers to the questions below will dictate what kinds of plans will need to be made in advance, which avoids putting undue demands on friends and family later.

Check the questions below that have already answered or are in the process of being discussed, and add any of your own that you feel are important.

- Who would the person want to make decisions when he or she no longer can?
- Where would the person want to live if he or she could no longer be cared for at home?
- What kinds of medical care does the person want or not want?
- What transportation is available for when driving is no longer an option?
- What are his or her preferences about end-of-life decisions?

Other questions might include:

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Living with Alzheimer’s: For Caregivers
tip 8: take care of financial matters

In the early stage of the disease, it is important for both of you to consider all of the financial situations you will face. You may choose to involve family, friends, or professionals in your research and planning. Plan early so the person with dementia can participate and make choices whenever possible.

Check the tips below that you have already done or are in the process of doing, and add any of your own.

- Don’t put off talking about finances and future care wishes
- Organize and review important documents
- Get help from well qualified financial and legal advisers
- Estimate possible costs for the entire disease process
- Look at all of your insurance options
- Find out for which government programs you are eligible
- Learn about income tax breaks for which you may qualify
- Explore financial assistance you can personally provide
- Take advantage of low-cost and free community services

Other suggestions include:

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Living with Alzheimer’s: For Caregivers
tip 9: make legal plans

Legal plans can ensure that the wishes of the person with dementia are carried out regarding health care, long-term care, finances, and decision making. If you and the person with the disease feel that there are legal issues that need attention, you might want to consider obtaining advice from an elder law attorney.

Check the tips below that you have already done or are in the process of doing now, and add any of your own.

- Ensure that all those named in the power of attorney document have a copy of and access to the original document.
- Name a successor (back-up) agent for power of attorney; your agent may one day be unable to act.
- Consider a neutral third person as an agent to have power of attorney if family members don’t get along.
- If a power of attorney for healthcare document and/or a signed living will is in place, give a copy to the physicians and other health care providers.
- See if the agent for the power of attorney for healthcare has authority to consent to a brain autopsy.
- Consider choosing an attorney or a bank to manage the estate if you lack a family member with the time or expertise.

Other suggestions include:
tip 10: pay attention to home safety

Safety at home begins with adapting the environment to support the person with Alzheimer’s as his or her abilities change over time. Now is the time to get those adaptations started. Be sure to re-evaluate home safety measures regularly as new issues may arise. It is a good idea to evaluate the person’s home environment by going from room to room and assessing what could pose a danger to person. You can use the list below to help make that assessment. Check the items below that you currently have in place, and consider using the ideas to help keep the person with Alzheimer’s and the family safe.

Assess fire and carbon monoxide risks

☐ Be sure to always have working fire extinguishers, smoke detectors and carbon monoxide detectors in the house and check batteries regularly.

☐ Make the use of fireplaces unavailable without supervision.

Beware of dangerous objects and substances

☐ Use appliances that have an auto shut-off feature.

☐ Install a hidden gas valve or circuit breaker on the stove.

☐ Monitor the use of power tools and outdoor grills.

Avoid injury during daily activities

☐ Install walk-in showers and grab bars in the shower or tub and at the edge of the vanity to allow for independent, safe movement.

☐ Add textured stickers to slippery surfaces. Apply adhesives to keep throw rugs and carpeting in place - or remove rugs completely.

Adapt to vision limitations

☐ Remove throw rugs altogether to reduce the likelihood of tripping if the person has difficulty walking, or uses a cane or walker.

☐ Create an even level of lighting by adding extra lights to entries, outside landings, areas between rooms, stairways and bathrooms.

☐ Use night lights in hallways, bedrooms and bathrooms.
Firearm safety

- Keep firearms in a locked cabinet, firearm vault, safe or storage case.
- Lock ammunition in a place separate from firearms.
- Exercise full control and supervision over firearms at all times.
- Ask for help from local law enforcement if you are unfamiliar with firearm safety or if you choose to discard the weapon.
- Unload firearms when not in use.
- Remove the firearm from the living space.

Other suggestions include:

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tip 11: pay attention to driving safety

Driving demands good judgment, quick reaction times and split-second decision making. A diagnosis of Alzheimer’s disease alone is not a reason to take away driving privileges. But due to the progressive nature of Alzheimer’s, a person with the disease will eventually be unable to drive.

It’s often difficult to decide when to stop or limit driving. To help make this decision, get a driving evaluation from a certified professional. Contact the Alzheimer’s Association (800.272.3900) for referrals to organizations in your community that can perform these evaluations.

Ideally, families should talk openly about driving soon after a diagnosis. They should make plans for how the person will get around when he or she can no longer drive.

Signs of unsafe driving
The following behaviors may be signs that it is time to stop driving. Check those that you notice:

- Forgetting how to locate familiar places
- Failing to observe traffic signals
- Making slow or poor decisions
- Driving at inappropriate speeds
- Becoming angry and confused while driving
- Hitting curbs
- Using poor lane control
- Making errors at intersections
- Confusing the brake and gas pedals
- Returning from a routine drive later than usual. The person may be wandering and getting lost in the car. Consider enrolling the person in MedicAlert + Safe Return.
tip 12: take care of yourself

Being a care partner for someone with Alzheimer’s disease is emotionally taxing in the early stages, and also becomes physically demanding as the disease progresses. It is crucial that care partners pay attention to taking care of themselves in order to be able to help meet the needs of the person with dementia.

Check any of the following that apply to you regularly. Do you:

- Feel like you have to do it all yourself, and that you should be doing more?
- Withdraw from family, friends and activities that you used to enjoy?
- Worry that the person you care for is safe?
- Feel anxious about money and healthcare decisions?
- Deny the impact of the disease and its effects on your family?
- Feel grief or sadness that your relationship with the person isn’t what it used to be?
- Get frustrated and angry when the person with dementia continually repeats things and doesn’t seem to listen?
- Have health problems that are taking a toll on you mentally and physically?

If you checked any of the above, you may be experiencing stress related to being a care partner of someone with Alzheimer’s disease.

While every situation is different, specific needs apply to all dementia care partners. Care partners notoriously put their own welfare and needs “on the back burner,” often due to time constraints, lack of respite care, or lack of energy.

In order to be a healthy care partner, it can help to do the following. Check those you are already doing, and consider adding some new components of caring for yourself as a care partner.
To help you sustain your energy and emotions, be sure to:

☐ Take care of your own needs by making healthy habits a priority.
☐ Listen to your body; it will tell you if it is tired, hungry, or run down. These feelings are like red flags indicating that you need to reassess how you are taking care of yourself.
☐ Make and keep regular appointments with your own physician.
☐ Exercise regularly, keeping in mind that exercise can take the form of short bursts of activity that you enjoy.
☐ Eat right to sustain your energy and boost your immune system.
☐ Get enough sleep.
☐ Stay connected with others
☐ Maintain those hobbies that bring you relaxation and satisfaction.
☐ Let go of perfection.
☐ Ask for or hire help from others

For more information, resources and support, see the Alzheimer’s Association’s website at www.alz.org, or call our 24/7 Helpline at 1-800-272-3900.

Other suggestions include:
Notes:

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Home Caregiver Training Manual
“There are four kinds of people in the world:
Those who have been caregivers,
Those who are currently caregivers,
Those who will be caregivers, and
Those who will need caregivers.”

~Rosalynn Carter
Helping Yourself Help Others

For an additional listing of community resources, please visit
www.bjchomecare.org
www.bjchospice.org
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1. Caring for Someone in Bed

As patients become weaker, they stay in bed or chairs longer. Moving and changing positions can ease some of their discomfort, relieve pressure and help prevent skin breakdown. Changing positions every two hours helps prevent pressure sores and stiffness.

When moving patients, explain what you are doing in order to reduce their anxiety in being moved, so they can cooperate and let you know how they would like to be turned. Provide pain medication approximately 30 minutes to an hour prior to movement, if moving is uncomfortable for the patient. Keep any tubing free from being blocked or pulled. Using two people to move someone is easier than one. (NOTE: If you have questions about any instructions or suggestions contained in this book, the nurse/home health team will be happy to explain and demonstrate for you.)

BODY MECHANICS
- Avoid twisting your back or trunk; use your legs and feet to turn in place.
- Lift with your legs, not your back.
- Bend or flex knees; use legs and stomach muscles.

BODY HYGIENE

Baths provide cleanliness and comfort, and may be given at any time.

*Items Needed for Bathing*
- Large basin of warm water
- Soap, washcloths and towels
- Lightweight sheet to cover patient during bath
- Skin care lotion

*Tips for Bathing*
- If the patient experiences pain with movement, give the prescribed pain medication about one hour before bathing.
- Provide privacy for the patient by asking others (who are not helping) to step out of the room. Also, remember to close drapes and doors.
- If you are using a hospital bed, raise the bed to reduce the strain on your back. If the patient cannot tolerate a bath everyday, focus on important areas—face, hands, back, underarms, and genitals.
- To avoid chills, wash small areas at a time while keeping other areas of the body covered with light linens.
- Begin at the patient’s face and work toward the feet. Soap the skin gently, rinse, and dry with towels.
- Turn the patient on his or her side to wash the back. Apply lotion to dry skin areas as well as the back.

- The genital area should be washed last. Washing this area daily is important to prevent bacteria growth and skin irritation. Wash area in between the legs front to back—rinse and dry well.
- Shaving, brushing, and styling hair can improve patients’ spirits and can be done around bath times.
- When giving a bath inspect the skin for redness or open areas. Notify the hospice nurse of any changes.
- Do not use powders after bathing; they cake on the skin and can cause irritation.

CHANGING BED LINENS
- Linens should be changed as needed or at least every third day. If the patient has lost control of bladder and/or bowel function, check the sheets, bedpad, and change if dirty. Cloth underpads (bedpads) can be purchased at medical supply companies or handmade.
- To change the linen, turn patient on his/her side and roll dirty linen close to patient. Place the clean linen on the bed and roll close to dirty linen, being careful not to soil the clean linen. Turn the patient over the rolls of linen and continue process until dirty linen is removed and clean linen is in place.

USE OF PULL/ROLL SHEET
- A folded sheet placed under the body can be used to move the patient around in bed.
- Always support the head if the patient is unable to do so.
- Two people can move a person up in the bed by rolling the sides of the sheet up close to the person’s hips and together moving the person up in the bed.
- One person can use the sheet to move a person onto their side.

ADJUSTING THE PATIENT’S POSITION
- When turning the patient to the near side of the bed, begin with the head, then the shoulders, trunk, legs, and feet.
- When moving from side to side, bend the patient’s knees. This helps the rotation of the hips, and the body will follow.
- When the person is in the new position, support the arms and legs with pillows or rolled-up towels.
- If the person cannot communicate, imagine yourself in that position. Check that the shoulder/arm is not pinned beneath the patient.
- Keep skin clean and dry. Keep bed linens and clothing dry and wrinkle free.
- A nurse should check any reddened areas or opened areas of skin.
- Apply lotion and massage the skin to increase circulation and general comfort.
WHEN MOVING SOMEONE FROM THE BED TO A CHAIR

• Place the bed in a low position.
• Assist the patient to the strong side, if there is one.
• Always lock/secure the bed, wheelchair or chair to prevent movement.
• Stand in front of the person being transferred with your feet apart to improve your balance and control.
• Help the person lying in the bed to a sitting position and let any dizziness subside.
• Use your legs, not your back, to lift.
• Standing in front of the person, place your arms around the body, with your hands on their ribs in back.
• Tell the patient to put their hands on your shoulders (not around your neck).
• Make sure the patient’s feet are on the ground before you begin to gently rock the person into a standing position.
• To turn, maintain your wide stance for balance, pivot on your feet, and slowly turn your whole body.
• Gently lower the person into the chair by bending your knees.

SKIN CARE

One of the most difficult problems in caring for a patient who is bed-bound is maintaining good skin condition. When a patient is bed-bound, there is a potential for pressure sores (bedsores) to develop. Pressure sores occur when a patient remains in the same position for extended periods of time.

AN OUNCE OF PREVENTION

• Encourage the patient to turn frequently and assist as needed.
• If movement is painful for the patient, then give pain medication one hour before turning the patient.
• Use pillows between the patient’s legs when the patient is laying on his/her side.
• Elevate the feet to relieve pressure on the patient’s heels by placing a towel roll or pillow under ankles.
• Turn the patient every two hours while awake.
• Your hospice nurse can provide instruction on proper turning techniques.
• Elevate the patient’s head to 30 degrees when the patient is short of breath.
• Gentle exercises can increase and stimulate circulation, improve appetite and promote a sense of well-being. The hospice nurse can instruct you on these exercises.
• Even with the best skin care, breakdowns in the patient’s skin can still occur. Your hospice nurse will offer suggestions on how to best care for skin breakdown.
• Washable or disposable bed pads can promote ease in keeping a clean, dry bed.

ORAL CARE

A clean mouth can improve the patient’s sense of well being, improve appetite, and prevent mouth sores.

Items Needed For Oral Care

• Soft toothbrush or Toothette
• Toothpaste
• Cool water
• Small basin
• Wash cloth
• Lip balm

How To Do Oral Care

• If patients can do their own mouth care, encourage them to do so. If assistance is needed, raise the patient to a sitting position and place a dry towel under his/her chin. Moisten the mouth by giving patient a sip of water. Gently brush teeth to remove food and other materials. After brushing, rinse the mouth by having the patient take a sip of water and then spit in the small basin.
• Patients with dentures should follow their normal routine. Remove and clean dentures at least once a day. After denture removal, the mouth can be rinsed and cleansed with a soft toothbrush. Rinse with cool water or mild mouth rinse.
• When a patient loses weight, dentures may fit improperly. If dentures do not fit properly, remove them to prevent mouth sores; however, continue to rinse the mouth as described above.

A FEW REMINDERS

• To avoid gagging, do not push toothbrush too far back into the mouth.
• If the patient is unable to swallow or is unconscious, do not give mouth care except as instructed by your hospice nurse.
• If you see mouth sores, (white patches in the mouth) notify the hospice nurse.
• To remove dentures, slide a gloved finger to the back edge of the top denture to release the suction; remove from the mouth. Next, remove the bottom denture plate.

2. Urine Elimination

WHAT IS BLADDER INCONTINENCE?

Incontinence is loss of bladder control causing loss of urine; the problem has varying degrees of severity. Some people have only small, minor leaks or dribbles of urine, while others lose large amounts of urine at a time. Bladder muscles, nerves, and the brain all work together to control bladder function, and a problem in any of these areas can result in incontinence. Infection, constipation and mobility problems can also cause
incontinence. Urine left on the skin can lead to irritation and odor.

WHAT CAN BE DONE TO CONTROL URINARY LEAKAGE?

• Establish with the patient a regular pattern of urinating, using the toilet every two hours during waking hours.
• Make it easier for the patient to get to the bathroom by moving closer to the toilet, or using a bedside commode, urinal or bedpan.
• Protect the patient’s privacy and dignity.
• Suggest that the patient avoid fluids or foods that contain caffeine (soft drinks, coffee, tea or chocolate) and alcohol which can over stimulate the bladder.
• Ask your nurse about exercises that can help develop more control or medications that may help improve bladder function. Sometimes a catheter is used to drain the urine from the bladder, but catheters are not right for everyone. They can increase the risk for infection.

PROBLEMS WITH URINE ELIMINATION CAN CAUSE THE PATIENT MUCH DISCOMFORT AND ANXIETY.

• Because urine is needed to dispose of body waste, it is important for the patient to attempt to drink the recommended 6-8 glasses of fluid each day or as much as they can tolerate.
• A patient who is bed-bound will need to use a bedpan or urinal. For some patients, diapers may also be helpful.
• In some patients, control over urination is lost or the passage way may become blocked. In these situations, it may be necessary for the nurse to insert a catheter (tube) into the patient’s bladder to drain the urine.
• The nurse will give instructions on how to care for and drain the catheter bag.
• Remember, it is important to keep the genital area clean and dry to prevent skin irritation.
• Notify your nurse if the urine changes color, the catheter comes out or is pulled out, or no urine or very little urine is noted over a 2-3 hour period of time.

WHAT CAN BE DONE TO PREVENT ODOR OR SKIN IRRITATION?

• Keep the skin clean and dry; products are available that can help you feel clean and eliminate odor. (Ask your hospice nurse for suggestions.)
• Use barrier creams to protect the skin and protective products to help keep clothing dry.
• The nurse can help you select which type of garment and products would be most helpful to use.
• Change garments frequently.
• Wear gloves and always wash your hands before and after care to help prevent infection.

WHAT TO DISCUSS WITH THE NURSE?

Notify the nurse of changes in bladder function including burning, pain or discomfort with urination, and changes in the amount, color or odor of urine; make the nurse aware of any skin irritation.

FOLEY CATHETER

What is a Foley catheter? A Foley catheter (also called an indwelling catheter) is a thin rubber tube, which is placed in the bladder and used to drain urine out of the body. After the catheter is inserted, its tiny tip can be filled with sterile water to make a small balloon which holds the catheter in place and keeps it from slipping out of your bladder. A Foley catheter can be used for a short or long time.

Why is it used? Sometimes, when a patient is very weak and cannot get up, a Foley catheter is inserted for comfort and convenience. It is also used when a patient is unable to urinate on his/her own, or retains urine.

DAILY CARE OF THE FOLEY CATHETER

Follow these steps every day to help prevent a bladder or kidney infection, and keep the patient comfortable. Always wash your hands with soap and warm water before and after catheter care.

• Clean the skin around the catheter at least once each day and after every bowel movement.
• Always keep the urine bag below the level of the bladder which is about waist level. Keeping the bag below this level will prevent urine from flowing back into your bladder from the tubing and urine bag. Backflow of urine can cause an infection.
• Do not tug or pull on the tubing. This can cause bleeding and hurt the urethra. Be careful to keep the tubing from being under step when the patient is walking; the tubing can be held curled in the hand with the urine bag low when walking. You may also want to clip or pin the tubing to the patient’s clothing.
• Place the catheter tubing so it does not kink or loop. When the patient is in bed, hang the urine bag beside the bed, making sure the bag is below the level of the bladder. If you use movable bed rails, do not hang the urine bag on the bed rail. Instead, hang the bag on the frame of the bed.

EMPTYING THE DRAINAGE BAG

A drainage bag or catheter bag should be emptied only when it is full enough to be necessary. Typically, empty full-sized bags every 8 hours and smaller (leg) bags every 3 to 4 hours, or sooner if they fill up. The following steps are to be used when emptying the drainage bag.

• Place a large plastic or metal container on the floor next to you, or you may empty urine into a toilet.
• Wash your hands with soap and water before emptying the bag.
• Without touching its tip, remove the drain spout from its sleeve at the bottom of the catheter bag. Open the slide valve on the spout.
• Let the urine flow out of the urine bag into the container or toilet. Do not let the drainage tube touch anything.
• When the bag is empty, clean the end of the drain spout with water and tissue. Close the slide valve and put the drain spout back into its sleeve at the bottom of the urine bag.
• Wash your hands with soap and water.
• If the catheter does not drain, or appears to be “plugged” or not draining, please call the nurse.

3. Bowel Movements

Bowel habits vary from person to person. As time progresses the patient may develop changes in bowel habits.

CONSTITUTION

What is constipation? Constipation means that bowel movements are occurring less often than the normal pattern for the individual, hard stool is produced, or there is increased difficulty moving bowels.

What should be reported to the hospice/palliative care team?
If the patient has no bowel movement in 2 days or a change in the frequency of bowel movements; pain, cramping or tenderness or a feeling of fullness or bloating; nausea and/or vomiting; blood in stools; and diarrhea or oozing of stools should all be brought to the attention of the nurse.

• Try to maintain the patient’s intake of well-balanced meals.
• Set aside time each day that the patient spends time on the bedpan/bedside commode/or toilet.
• Encourage the patient to drink 6-8 glasses of fluid a day. Allow patient to drink what they can tolerate.
• If the patient has not had a bowel movement in 2-3 days, inform your nurse. The nurse will suggest a bowel regimen.
• Pain medications sometimes cause constipation. If the patient is taking pain medications, the nurse will suggest daily bowel regimens to prevent constipation.
• Record when bowel movements have occurred.
• Notify hospice/palliative care team if constipation continues.
• Have the patient:
  • Drink as much fluid (liquids) as is comfortable. Drinking warm liquids has benefited many patients.
  • Consume more fruits and fruit juices.
  • Increase physical activity if possible. Walking even short distances can be beneficial.
  • Sit upright on toilet, commode, or bedpan.
  • Establish routine times for toileting.
  • Take laxatives/stool softeners as ordered by healthcare provider. Avoid bulk laxatives if not taking in enough fluids.

DIARRHEA

Diarrhea can also be a problem for the hospice patient. Frequent, watery stools often accompanied by stomach cramping characterize diarrhea. You should keep a record of frequency of diarrhea. Your nurse and your physician will decide if medications need to be ordered to help control diarrhea.

WHAT CAUSES BOWEL INCONTINENCE?

Not being able to control a bowel movement from the rectum is called bowel incontinence; cramping, loss of appetite and fecal leakage may be symptomatic. The condition has many causes including:

• Weakness of the anal muscle
• Not moving around, lack of exercise
• Nervous system disorders
• Long-term use of laxatives
• Not enough fluid intake
• Hemorrhoids
• Sedation
• Severe constipation may also lead to leakage from the rectum

WHAT TO DISCUSS WITH THE HOSPICE/PALLIATIVE CARE TEAM?

• Medications and diet history
• Changes in activity level
• Color, looseness and odor of the stool
• Abdominal discomfort, cramping or bloating
• Skin problems developing in the affected area
• Patient and caregiver concerns or worries

WHAT CAN BE DONE FOR BOWEL INCONTINENCE?

• Know the patient’s bowel history and usual routine regarding time of day, following a meal, etc.
• Plan a bowel-retraining program that is easy and fits into the patient’s lifestyle. Your nurse can help develop the plan.
• Ensure that the patient takes in enough fluids and fiber if possible.
• Provide ample time and privacy during toileting.
• Keep skin clean and dry to prevent odors and skin breakdown. Avoid use of baby powder and cornstarch.
• Be sure the patient wears loose fitting clothing to allow for air flow and protective garments as appropriate.
• Control odors with fresh air and room deodorizers.
• Avoid offering the patient foods that can act as laxatives such as caffeine, alcohol, diet soda or artificial sweeteners.
Use Depends or similar products or liners for ease in keeping patient and bedclothes clean.

Talk to your nurse for other ideas or for more information.

**USING BEDPANS OR BEDSIDE COMMODES**

- Keep the bedside commode near the bed if one is in use.
- Put a towel on the back of the bedpan for padding.
- Sprinkle baby powder or cornstarch around the top of the bedpan so the patient's skin will not stick to it.
- If the patient is bed-bound, it is important to try to put him/her in the sitting position for bowel movements by raising the head of the bed.
- Use rubber or latex gloves and remember to wash your hands and the patient's hands after helping him/her.
- Give the patient ample time while using a bedpan/bedside commode.

**4. Nutrition/Hydration**

Frequently, appetite and food intake decreases during the course of an illness. Your nurse can instruct you about these changes and what you can do about them as is appropriate for your individual circumstances.

In normal situations after an injury, illness, or surgery a physician can provide the patient with artificial nutrition (food) and hydration (liquids) that aid the body in recovery. Fluids are utilized by the body to keep mucous membranes moist and promote the removal of body waste, while nutrition feeds the physical needs of the body.

When a patient cannot recover from an illness, decisions about artificial nutrition and hydration must be made – difficult decisions. In order to make the best decision possible in relation to each unique situation, it is important to know the facts about artificial nutrition and hydration, and how the body processes foods and fluids:

- Use of artificial nutrition and hydration allows patients to receive nutrition and hydration when they can no longer take enough by mouth to maintain life or health. Doctors can provide this nutrition and hydration through an intravenous line (IV) or by putting a tube in the stomach.
- Artificial nutrition and hydration is different from ordinary eating and drinking. It requires professional skills and training to insert the tube, and know how much and what types of nutrition/hydration to give.
- Because it is given through an IV or tube in the stomach, artificial nutrition does not offer comforts such as taste and texture typically associated with foods and beverages.
- When a patient has a serious illness and can no longer eat or drink, he/she is usually approaching an end-of-life state where the body is beginning to stop functioning. Even with artificial nutrition and hydration, the patient will not return to a healthy state.
- Many physicians agree that artificial nutrition and hydration can prolong suffering for the patient due to bloating, swelling, cramps, diarrhea, and shortness of breath. It is important to remember that the person's body is beginning to shut down because of the disease and the dying process, and not because of the absence of food and liquid.
- The artificial feeding and hydration cannot bring back the health that was lost due to the advancement of the disease process.
- Legally, artificial nutrition and hydration is a medical treatment and can be refused at any time in the patient's treatment. It is easier for families and/or caregivers to know the patient's wishes when they have completed an advance healthcare directive that explains the patient's wishes regarding artificial nutrition and hydration.

**WHAT TO REPORT TO THE HOSPICE/PALLIATIVE CARE TEAM?**

Tell the team if the patient:

- Is unable to eat or drink
- Has trouble swallowing
- Has a dry mouth or tongue
- Loses more than five pounds in a week
- Is producing less urine
- Becomes confused or drowsy

**HOW TO ENCOURAGE PROPER NUTRITION/HYDRATION**

For patients not utilizing artificial nutrition and hydration, there are steps that can help maintain the best possible intake:

- Encourage favorite foods and drinks.
- Offer drinks or sips often - at least every two hours.
- Clean the mouth often - a pleasant tasting mouth may make food taste better.
- Help other family members and friends understand why eating and drinking may cause the patient to be uncomfortable and suffer.
- Support the patient’s decision not to eat or drink.
- If dentures do not fit well, consult a dentist.
- Make mealtime a quiet and pleasant time - candles, flowers, soft music and good conversation all help.
- If nausea is a problem, serve small portions of salty (not sweet) dry foods and clear liquids.
- Find other ways besides food and drink to show the patient you care. For example, offer the patient a massage or look through a picture album together.
6. Managing Nausea & Vomiting

WHAT IS NAUSEA AND VOMITING?

Nausea is the unpleasant feeling that may occur in the back of the throat or stomach prior to vomiting. Vomiting is the emptying of stomach contents through the mouth.

WHAT TO REPORT TO THE HOSPICE/PALLIATIVE CARE TEAM?

• Amount and frequency of nausea and vomiting.
• Description of vomited fluid.

WHAT CAN BE DONE?

The good news is that there is much that the caregiver and the hospice/palliative care team can do for nausea and vomiting. The team will always try to discover the underlying cause and discuss treatments with your healthcare provider, so it would be helpful to have a record of what seems to cause or decrease the patient’s nausea and/or vomiting. Suggestions that may improve patient comfort include:

• Provide sips of carbonated drinks (i.e. 7-Up) that have gone flat.
• Avoid acidic juices (such as cranberry, grape, apple, orange or grapefruit).
• Offer sports drinks (such as Gatorade - with children use Pedialyte).
• Provide small amounts of salty foods (such as crackers, chicken broth).
• Avoid fried foods, milk products or those with strong smells.
• Provide frequent mouth care.
• Provide foods as requested by patient in small frequent amounts as large meals may be overwhelming.
• Avoid strong odors such as perfume and deodorizers.
• Avoid eating immediately after vomiting.
• Offer sips of water or ice chips before eating again.
• Maintain a comfortable room temperature.
• Avoid constipation.
• Administrate medications as ordered by healthcare provider.
• Contact hospice/palliative care team if nausea/vomiting continues.

5. Fever

TIPS FOR DEALLING WITH FEVERS

At times, fever may become a problem for the hospice patient. If so, these options may be helpful:

• Give sponge baths with lukewarm water.
• In conjunction with your physician, your hospice nurse may provide instruction on administering medication to reduce fever.
• Lip balm, toothettes (little sponges on a stick), or ice chips may be helpful in relieving the dryness of the mouth associated with fever.

HYDRATION

Fluids are utilized by the body to keep mucous membranes moist and promote the removal of body waste.

• Do not force liquids; as the disease progresses the patient may experience difficulty swallowing.
• Encourage intake of high-calorie liquids when possible (such as milkshakes, Ensure).
• Prune and fruit juices aid in promoting bowel function.
• Give liquids in other forms such as Jell-O, puddings, ice cream, and popsicles.
• Very cold or warm liquids are more satisfying than room temperature liquids.

• Do not force the patient to eat and/or constantly remind him/her about their decreased appetite. The choice of eating is up to the patient.
• Serve meals in a relaxed and comfortable setting and eat with the patient when possible.
• Remove unpleasant odors from the room and avoid unpleasant procedures around meal times.
• Cold foods have minimal odor and are easier to swallow.
• Because of many disease processes, tastes that were once enjoyable may now be unpleasant.
• Allow for rest before and after meals.
• Small, frequent meals are better than three larger meals.
• When regular meals are less desirable, your hospice nurse can make suggestions about high-calorie nutritional supplements.
• As the disease process progresses, food becomes less desirable.
• Appetites tend to decrease throughout the day. Try to make the most of breakfast meals.

5. Fever

TIPS FOR DEALLING WITH FEVERS

At times, fever may become a problem for the hospice patient. If so, these options may be helpful:

• Give sponge baths with lukewarm water.
• In conjunction with your physician, your hospice nurse may provide instruction on administering medication to reduce fever.
• Lip balm, toothettes (little sponges on a stick), or ice chips may be helpful in relieving the dryness of the mouth associated with fever.
7. Pain Management

The fear of pain, the reality of pain and the medications to control pain can produce anxiety for the patient as well as the family. It is important to have FACTS about pain and pain management.

WHAT IS PAIN?
The hurting or discomfort a patient experiences can cause physical, emotional, and spiritual suffering. Pain cannot be measured from the outside; pain can only be felt and described by the person with the pain.

WHAT TO REPORT?
How severe or intense the pain is as a number -- using 0 as no pain and 10 as the worst possible pain imaginable. Additional ways of reporting pain are also available such as faces, thermometer scale - ask your nurse to tell you more about these options. Descriptors helpful for your health care team can be determined with these questions:

- Where is the pain?
- Does the pain keep the patient from doing his/her usual activities?
- What makes the pain worse?
- What makes the pain better?
- How well is the pain medication working?
- Is the patient experiencing side effects of the medication (such as constipation, nausea, vomiting, sleepiness, dizziness, itching).
- What words best describe the pain such as “aching, burning, gnawing, grabbing, sharp, dull, continual,” etc.
- What is the effect of the pain on the patient and family (for example, is the family anxious or unsure about how to give the medicines? Is the patient becoming irritable from lack of sleep because of the pain?)

PAIN FACTS

- The patient is the only one who knows how bad the pain is.
- The patient is the only one who knows how well the pain medication is working.
- Encourage the patient to always be honest in verbalizing how severe the pain is and how often it occurs.
- Remind the patient that pain is not a punishment and does not have to be tolerated.
- An increase in pain does not always mean that the disease is progressing.
- Patients who have had long-term pain may not show signs of pain but may still be in pain. Always ask the patient about the pain.
- Reports of pain by the patient should be believed and reported.

PAIN MEDICATION

- Everyone’s pain is different. The amount, type, and frequency of pain medication will vary from patient to patient. Do not be afraid of addiction. The patient is taking medication to relieve pain. The patient is not taking the medication for emotional or psychological reasons. Studies have shown patients with pain do NOT become addicted to medication administered within the guidelines.
- It is important to follow the pain medication schedule as instructed by the nurse. This ensures that the patient receives optimal pain control.
- Do not stop pain medication suddenly.
- A patient’s pain medication may need to be adjusted periodically. This is a normal process.
- Some long-acting pain medications require up to 24-hours to reach full effectiveness. Your nurse will instruct you on the specific actions of your pain medicine, as well as possible side effects and a dosing schedule. The nurse will visit or call within 24 hours of changing the medication to make sure the patient is comfortable.
- Record pain medications on the pain assessment sheet, as instructed by your nurse. This helps the nurse and physician to evaluate and make necessary adjustments in the pain management plan.

PAIN MEDICATION SIDE EFFECTS & HOW TO DEAL WITH THEM

- Drowsiness or confusion may occur when the patient is increasing a medication or starting a new pain medication. This can lessen in a few days after the body adjusts to the change in medication.
- Remember: the patient may sleep more because the pain is lessened and he/she is more comfortable or he/she may be catching up from a lack of sleep due to pain.
- Some medications can cause mild side effects. Some of these may include:
  - Constipation - Narcotics dry out the bowel. Your nurse can instruct you on how to establish a bowel routine.
  - Sweating - This may occur at night. Keep the room cool, have the patient wear light clothing, and cover with a sheet.
  - Dry mouth - Use of hard candy, cool washcloths, and/or ice chips will help relieve dry mouth and lip balm can be used for chapped lips. Check with your nurse prior to using any of these remedies.
  - Hallucinations - Some narcotic medications cause hallucinations. Reassure the patient that what they are seeing is not real and that the medication is causing the hallucinations. If your patient becomes anxious, contact the nurse.
  - Upset stomach - Some medications can be irritating to the stomach. Try to have the patient take the medication with food when possible.
PAIN CONTROL METHODS

Pain medications come in many forms: tablet, liquid, suppository, patch, and intravenous. Your nurse will discuss the specifics about pain medications.

There are physical methods that may relieve pain in addition to medications:

- **Heating pad** – Check with the nurse before utilizing a heating pad and apply the heating pad for a short period of time only. Always use the lowest heat setting.
- **Ice pack** – Place ice in a plastic bag, secure the opening, wrap in towel, and place on affected area for short periods of time only.
- **Local massage** – Apply massage with or without warmth-producing lotions such as icy hot or mentholated deep heating rub. Please check with your nurse before providing massage.
- **Soothing music** – Ask the patient about his/her preference of music and provide a quiet, comfortable, and soothing environment.

Other things that might make the pain better are:

- Relaxing or distracting activities such as watching TV, listening to music or playing a game
- Smells of certain plants (called aroma therapy)
- Guided imagery ( picturing relaxing scenes to take one's mind off pain)
- Soaking in a tub of warm water
- Meditation

The hospice team has specialists to help with relaxation techniques to aid in pain relief as well as psychological pain; please discuss these options with your nurse.

SLOW RHYTHMIC BREATHING FOR RELAXATION

Relaxation techniques are easy to learn and they can help to reduce anxiety. No equipment is needed. Rhythmic breathing is free, easy, and effective:

- Breathe in slowly and deeply, then breathe out slowly, feel yourself beginning to relax; feel the tension leaving your body.
- Now breathe in and out slowly and regularly, at whatever rate is comfortable to you. You may wish to try abdominal breathing. (If you are unsure how to do abdominal breathing, ask your nurse for help.)
- To keep focus on breathing slowly and rhythmically, breathe in as you silently say to yourself, “in two, three.” Breathe out as you silently say to yourself, “out, two, three.” Or you may think to yourself “peace,” “relax,” or “black velvet” each time you exhale.
- You may imagine yourself in a place that is very calming and relaxing for you, such as lying in the sun at the beach.
- End with a slow, deep breath. As you breathe out, say to yourself “I feel alert and relaxed.” Please note that if you intend to do this for more than a few seconds, find a comfortable position in a quiet place. You may want to close your eyes or focus on an object.

PAIN QUESTIONNAIRE - APPENDIX A

Your hospice nurse and physician would like to know your concerns about the pain medications. Please complete the questionnaire on page 22 (Appendix A Pain Questionnaire). Put a check mark by any worries you have and your hospice nurse will discuss these concerns with you at his/her next visit.

8. Managing Fatigue

WHAT IS FATIGUE?

Fatigue feels like tiredness, exhaustion or lack of energy. It is a condition which impacts the ability to perform any activity - and it’s seen frequently in hospice and palliative care patients. Fatigue is a complicated symptom which can have many causes and sometimes comes with depressed feelings.

WHAT ARE THE SIGNS THAT A PATIENT IS FATIGUED?

- Unable to perform the normal activities for that patient (every person is different in their normal activity level), “just too tired”
- Not participating in the normal routine
- Lack of appetite - do not have the energy to eat
- Sleepiness
- Not talking
- Depressed

WHAT SHOULD BE REPORTED TO THE HOSPICE/PALLIATIVE CARE TEAM?

- Share signs of any of the behaviors listed above
- What seems to make the fatigue better or worse?
- Any distressing symptoms that are not controlled
- Any concerns you as the caregiver have about the fatigue
- Spiritual concerns voiced by the patient
- Assist your loved one to rank their fatigue using a scale – it helps the team to be able to find what works for him/her and how severe the fatigue is:
  
  0 = no fatigue ↔ 10= in bed all day

WHAT CAN BE DONE TO HELP FATIGUE?

Because fatigue is a complex problem, it takes a group of actions to help the symptoms. The team will work with the patient, family and the primary care provider to find the causes for the fatigue and discuss treatments.
Things family can do:
• Plan, schedule and prioritize activities at optimal times of the day; help the patient keep a log of which time of the day seems to be best
• Eliminate or postpone activities that are not his/her priority
• Assist with position changes to help with physical body stress
• Use sunlight to cue his/her body to feel energized.
• Assist with daily activities such as eating, moving or bathing to conserve energy
• Plan activities ahead of time
• Accept the new energy pace of the patient
To rest and sleep better:
• Encourage him/her to rest as needed
• Establish and maintain a regular bedtime and awakening time
• Avoid sleeping later in the day, which could interrupt nighttime sleep.
• Plan rest times or naps during late morning and mid afternoon
• Ask the team if using oxygen while sleeping will help.
To increase and improve food intake:
• Try nutritious, high-protein, nutrient-dense food
• Serve small frequent meals
• Add protein supplements to foods or drinks
• Provide frequent mouth care (before and after meals)
• Ask your team about possible use of medications to stimulate appetite

9. Managing Restlessness

WHAT IS RESTLESSNESS?
Restlessness is an inability to rest, relax, or concentrate; extreme restlessness is sometimes called agitation. Many patients experience restlessness, and nearly half of all patients during the last 48 hours of life

WHAT ARE SIGNS THAT THE PATIENT IS RESTLESS?
Restlessness is generally easily identified and can include muscle twitching, fidgeting, moving around without a known reason, plucking/pulling at sheets, covers or clothing, trying to get out of bed for no apparent reason, sleeplessness, an inability to get comfortable, and grimacing.

WHAT CAN BE DONE TO MAKE THE PATIENT MORE COMFORTABLE?
The team will try to find the reason for the restlessness and talk with you about helpful treatments. There are some options you can use including:

• Give medications to the patient as ordered
• Offer frequent reassurance to the patient and remain quietly nearby as much as possible
• Offer relaxation activities if the patient is alert and oriented
• Play soothing music and keep things calm around the patient (for example, decrease number of visitors)
• Read favorite stories, poems, etc. in a calm voice
• Do gentle massage, comforting touches, or other things to calm the patient
• Keep the patient safe (do not leave the restless patient alone)
• Understand that restlessness may be a sign that the patient is close to death – let other family members know what is happening

WHAT TO REPORT TO THE HOSPICE/PALLIATIVE CARE TEAM?
• Any of the signs or behaviors of the patient listed above
• Inability of the person to swallow medications
• Things that make the restlessness worse (for example – loud music) and things that make the restlessness better (for example – soft music)
• Concerns that you may have as caregiver - what will help you cope with the restlessness
• Emotional or spiritual concerns
• Situations that might be unsafe (for example, the need for side rails to keep the patient in bed)

10. Managing Anxiety/Uneasy Feelings

WHAT IS ANXIETY?
Anxiety is the feeling or deep sense that things are not right.

WHAT ARE THE SYMPTOMS OF ANXIETY?
A person experiencing anxiety may exhibit fear, worrying, sleeplessness, confusion, rapid breathing, shaking, sweating, an inability to relax, or difficulty focusing.

WHAT CAN BE DONE?
The team will try to find the cause for the anxiety and discuss treatments with you and your primary care provider. Steps you can take to alleviate some of the patient's anxiety are to keep things calm, treat physical problems such as pain, play soothing music, speak quietly to the patient, provide medications as prescribed, or massage the patient's arms, hands, feet or back.
11. Managing Delirium

WHAT IS DELIRIUM?
Delirium is the sudden change in a person’s mental status over a period of hours to days that results in mental clouding with less awareness of one’s environment and confusion about time, place, and person.

WHAT ARE THE SIGNS AND SYMPTOMS OF DELIRIUM?
Delirium shows in various ways including the reversal of sleep and awake cycles, “Sundowning” or confusion that worsens at night, mood swings, difficulty focusing attention, hallucinations, agitation and irritability or drowsiness and sluggishness.

WHAT CAN BE DONE FOR DELIRIUM?
Delirium can be caused by many things and is common at the end-of-life. The team will try to find out what is causing the delirium and discuss treatment options with you. As a caregiver you can:

- Keep the patient safe
- Remind the patient of who you are and explain what you are going to do. For example, “I am going to help you get out of bed now.”
- Offer reassurance and support such as “I am right here with you.”
- Try to maintain a routine and structure
- Avoid asking a lot of questions
- Provide a quiet, peaceful setting, without TV and loud noises
- Play the patient’s favorite music
- Keep a nightlight on at night
- If starting a new medication, watch for improvement, worsening, or side effects and report to healthcare provider

WHAT TO REPORT?
Be sure the Hospice/Palliative Care team members are aware if any of the signs or behaviors listed above occur as well as changes in food or fluid intake, decrease in urine output, or change in frequency or type of bowel movements. Other symptoms that may be pertinent are depression, wandering, and withdrawal from people or activities formerly enjoyed. The nurse needs to know of all changes in medications.

12. Managing Depression

WHAT IS DEPRESSION?
Depression includes a range of feelings: sadness, gloom, numbness, emptiness, helplessness and hopelessness. Chronic and terminal illnesses often induce depression, and it is sometimes difficult to determine if the symptoms seen are a result of the illness or depression.

WHAT ARE THE SIGNS AND SYMPTOMS OF DEPRESSION?
- Fatigue
- Sadness, depressed mood
- Loss of appetite with weight loss
- No interest or pleasure in daily activities
- Withdrawal from family and friends
- Sleep problems
- Feelings of worthlessness, hopelessness, guilt
- Difficulty focusing and thinking
- Thoughts of death or suicide
- Agitation or slowing down

WHAT CAN BE DONE FOR DEPRESSION?
Depression is common at the end-of-life and displays a wide range of intensity. The home health team will help you sort out causes of depression and discuss treatment options with you. Some steps you can take might include:

- Help optimize the patient’s physical status with rest and nutrition
- Set small, realistic, achievable goals to help the patient’s sense of well being
- Encourage the use of relaxation techniques and consider complementary therapies such as aromatherapy, art and music therapy
- Take caution to keep the patient and area safe
- Remind the patient that you will be there to help
- Allow the patient to express feelings without discounting them
- Give the patient as much control as possible in activity and treatment decisions

WHAT TO REPORT TO THE HOSPICE/PALLIATIVE CARE TEAM?
- Tell the nurse about any of the above symptoms as well as any known history of depression
- Make a note of physical symptoms such as pain, nausea, difficulty breathing
- Report changes in medications the team may be unaware of

WHAT TO REPORT TO THE HOSPICE/PALLIATIVE CARE TEAM?
Be sure to share any fears or worries the patient voices such as fear of dying, money worries, relationship problems with family or friends, or spiritual concerns. Keep the team informed of any signs that the anxiety is getting worse.
13. Social Distress

**WHAT IS SOCIAL DISTRESS?**

Social distress is a disruption in one's social life (changes in roles, relationships, sense of belonging, sexual function, and appearance) that causes a suffering of mind or body.

**WHAT ARE THE SIGNS AND SYMPTOMS OF SOCIAL DISTRESS?**

Patients experiencing social distress may talk about feeling lonely and/or feeling alone, or being a physical or financial burden to others. It will become apparent that they are unable to carry out personal roles (spouse/partner/parent/friend, etc), and may feel shame for that failure. Those in this situation often do not want company or visitors, even close friends or relatives whom they have always treasured.

**WHAT TO SHARE WITH THE HOSPICE TEAM?**

- Any signs of behaviors listed above
- Any expressions of suicide
- Prior history of social distress
- Unusual anger or lashing out; the patient may not understand reason for anger or how to cope and may take it out on others
- Any change in relationships that concern you

**WHAT CAN BE DONE FOR SOCIAL DISTRESS?**

Social distress is common with terminal illnesses and not every patient experiences it the same way or to the same degree. Never feel that you are bothering the team with questions. Asking questions means you care.

Other ways to demonstrate your care is to provide a calm setting, be willing to be present without ‘doing’ anything, treat the patient with dignity and respect, and be willing to listen.

You may be able to help the patient cope by reminding the patient that:

- It is okay to limit talking with many people but that it is very important to have at least one person to trust – someone to share thoughts and feelings
- It is okay to be angry and to tell others about your anger
- It is important to take medications for pain and other symptoms
- It is okay to want quiet time
- It is okay to use this time to reflect, record memories, and create future messages for family and friends

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14. Spiritual Distress

**WHAT IS SPIRITUAL DISTRESS?**

Spiritual distress is a disruption in one's beliefs or value system which affects a person's entire being. It shakes the basic beliefs of one's life.

**WHAT ARE THE SIGNS AND SYMPTOMS OF SPIRITUAL DISTRESS?**

- Questions the meaning of life and own belief system
- Afraid to fall asleep at night or other fears
- Angry at God/higher power
- Experiences a sense of emptiness; loss of direction
- Seeks spiritual help
- Questions the meaning of suffering
- Pain and other physical symptoms can be expressions of spiritual distress, as well

**WHAT TO REPORT TO THE HOSPICE/PALLIATIVE CARE TEAM?**

- Any signs of behaviors listed above including behaviors that are out of character for the patient at this time, not caring about self and life in general, or the sudden rejection or neglect of previous practices or beliefs
- Side effects of medications
- Any symptoms that are getting worse
- Talking about suicide
- Known history of spiritual distress

**WHAT CAN BE DONE FOR SPIRITUAL DISTRESS?**

Spiritual distress is common with terminal illnesses although not everyone experiences it, or feels it the same way or to the same degree.

- Look for ways to keep and honor desired rituals and ways of life.
- Provide a calm, relaxing setting.
- Be willing to be present without having to “do” something.
- Treat the patient with dignity and respect.
- As much as you can, enjoy time together and look for ways to make memories.
- Do not say, “I know how you feel” because you do not. Instead, offer empathy for the continual loss of familiar meaning.
- Support any desire to maintain links with friends and family.
- Be willing to listen and reminisce.
- Be open to giving spiritual support if asked or contact your minister, rabbi, priest, etc.
Recognize that family/friends/caregivers can experience spiritual distress as well.

Encourage the patient to have at least one person to trust and talk with about fears and concerns.

Allow the patient to be angry.

Offer the opportunity to hear devotional tapes or soothing music.

Try listening to music without words.

Ask the patient if someone else can pray for them, if the patient is unable.

Encourage the patient to take prescribed medication.

15. Dementia

WHAT IS DEMENTIA?
Dementia includes multiple cognitive deficits that progress gradually over time. The most common deficit is memory impairment that can affect the ability to interact with others or function independently. Alzheimer’s Disease is one kind of dementia.

WHAT ARE THE SIGNS AND SYMPTOMS OF DEMENTIA?
People with dementia may consistently demonstrate some of these issues: forgetfulness, difficulties with familiar activities, or math and language problems. Patients may not be able to use simple words that have long been part of their vocabulary. They may lose their sense of direction, going somewhere familiar and not knowing how to get back home. They may demonstrate poor judgment by dressing inappropriately to the weather or occasion. They may put things in the wrong place, such as the milk in the bathroom. Sudden mood swings may come on, or you may see a personality change drastically over a period of time. They may lose interest in hobbies and people they love.

WHAT TO REPORT TO THE HOSPICE/PALLIATIVE CARE TEAM?
It is important for the health care team to know about any signs of behaviors listed above or any attempts by the patient to hurt him/herself or others.

WHAT CAN BE DONE FOR DEMENTIA?
To offer support to someone with dementia:

• Treat the patient with respect.

• Remember to treat an adult as an adult, not like a child which could be embarrassing. Offer an explanation before helping the patient. Try to understand the emotions and feelings of the patient, who may feel confused, frightened and threatened. Remember that you cannot understand everything; you can only do your best.

• Set limits and take control when possible. You may need to remind the patient of the day, place and time.

• Create a daily routine with small rituals. These can include prayers, washing hands, or preparing food. Try not to do too little or too much.

• Allow the patient to do as much of their own care as possible. This will help maintain their self-esteem.

• Include former habits and memories. Provide the patient with things to hold that represents a part of his/her life including pictures, clothing, or other objects with meaning to the patient.

• Provide physical closeness with touching, gestures and eye contact. Show your own feelings.

• Do not expect the patient to remember. It can bring on anxiety and feelings of failure. Your loved one may be losing memory, but the senses never “forget”. Try stimulating their senses through aromatherapy, pleasant sounds, music from their era, tactile pieces, or visually with a mobile or lava lamp.

• Talk in a calm and reassuring manner.

• You may need to be more tolerant of unusual behavior by reducing your reaction to bizarre behaviors. Resist the impulse to control the patient’s behavior because the behaviors may have meaning for the patient which makes no sense to you.

• Try to move calmly to a new activity when the patient becomes stressed.

Caring for someone with dementia is very demanding. Take care of yourself. If you begin to feel overwhelmed, realize that the sooner you accept help, the longer you can help the patient. Always be aware of safety.

16. Emotional Withdrawal

Individuals with terminal illness often withdraw from familiar activities and from their loved ones. Withdrawal is often used to conserve energy and to allow the patient time for self-reflection. Touch and silently being with the patient may become more meaningful. Talk with Hospice staff about your questions and concerns regarding your loved one’s emotional withdrawal – they can help in this life-reflection process with patients and their loved ones.

DISORIENTATION

In the weeks prior to death, the patient may begin to sleep much of the time. It may become difficult to keep their eyes open, and they may become disoriented to time and place. The patient may be confused or may talk or gesture to people who are not present or those who have already died. Patients may often speak in what is called Symbolic Language, which includes statements such as, “I have to pack for my trip” or “I have to cross the bridge now.” These activities are normal and can be reassuring and calming for the patient. If you have questions or concerns talk with the Hospice staff.
CAREGIVERS
You can offer support at this important end-of-life time. Letting go is one of the most powerful expressions of faith and the greatest parting gift you can offer your dying loved one. Saying goodbye can be painful, but it is more so if you believe the illusion that after you say goodbye your loved one will die. The act of saying goodbye will sometimes be repeated over and over in different forms. Hearing the words – having your blessing – creates a foundation of trust so that your loved one can feel secure in letting go. Helping your loved one move from your hands to the next world might include the following:

• Touch your loved one; hold hands, rub the head.
• Tell your loved one you love him/her, and if the patient is unable to respond answer yourself, “And I believe you love me, too.”
• Forgive your loved one of any past estrangement/behaviors/words. If they are unable to respond answer: “And I believe you forgive me, too.”
• Tell your loved one about your shared beliefs in spirituality.
• Share with your loved one your favorite memories with him/her, and why he/she is important to you. This is a wonderful time to express gratitude you may feel toward the patient.
• Give your loved one permission to let go.

17. Using Oxygen Safely
If the patient experiences difficulty breathing, try the following:

• Raise the patient’s head with pillows or raise the head of the bed.
• Use oxygen if ordered.
• Give pain medications or sedation as ordered.
• Stay with the patient if possible (having trouble breathing is scary).
• Turn a fan on in the room to provide better air circulation.

OXYGEN THERAPY
Using Oxygen Safely
Oxygen is a drug and must be used only as prescribed by the physician. Treat it just like any other medication, and do not change the amount unless instructed to do so. The oxygen supply company will provide the proper instructions regarding the use of oxygen. Here are a few basic tips:

• The prongs of the nasal cannula must be in the patient’s nose. If using a facemask, it must fit snugly on the face. Make sure the nasal cannula or facemask is clean to reduce potential infection and to ensure adequate oxygen delivery.
• Small pieces of cotton or pads between tubing and skin can lessen irritation.
• Be sure you understand how to use the equipment and any backup system.
• Never use petroleum products (e.g. oil or grease) if oxygen equipment is being used because of the risk of a fire. Vaseline is a petroleum-based product and should never be used for nasal irritation. Instead, use a water-based moisturizer such as K-Y Jelly.
• Oxygen tubing should be no longer than 50 feet, because longer tubing can decrease the amount of oxygen received by the patient.
• Those smoking cigarettes, cigars or pipes should not be in the same house/room as oxygen.
• Keep open flames (candle, wood stove, pilot light for stove, and fireplace) at least 10 feet away from the person using oxygen, all tubing, and the source of oxygen.

Oxygen can be provided in different ways:

• Concentrators are machines that take the air and concentrate it into oxygen. These should be kept away from curtains, heating units or open flame. Remove any frayed electrical wiring, and do not use extension cords with concentrators because they can overload circuits. Do not use aerosol sprays near the concentrator because they can clog the filter.
• Liquid Systems must be stored in a cool, well-ventilated place at least 10 feet from outlets, open flames, or heat sources. Do not touch the fill adapter (the area that frosts over) after filling the portable. When traveling with liquid oxygen, follow the special precautions. During hot weather, car temperatures may exceed 200° F, so leave windows open for ventilation. Be sure the car’s electrical system is in good working order to prevent sparks from igniting in a highly combustible atmosphere.
• Tank/Cylinder Oxygen must be stored away from heat sources, because the pressure inside the tank increases for each 5-degree increase in cylinder temperature. Because of high pressures inside the tank, damage to the tank or regulator can be dangerous. Do not store in hot, unventilated areas such as trunks of cars, closets, or storage units. Extra oxygen tanks should be stored by laying flat on floor or in a secure tank holder.

NOTE: Both liquid and cylinder oxygen must be secured with a seat belt when traveling. Your oxygen supply company will also provide you with all instructions and education needed.

Do not smoke or allow others to smoke in the presence of oxygen. It is a dangerous fire hazard. Store tanks standing upright and secured with good air circulation.

SUCTIONING
Often as patients become weaker, they are unable to cough deeply enough to bring up secretions which may collect in the throat and mouth, and suctioning may be needed. The items necessary are:
1. Suction machine
2. Suction catheters
3. Container of clean water

The nurse will teach you how to use the equipment, but these reminders may be helpful:

- Check to be sure the machine is plugged in, then turn it on.
- Place the catheter tip in the clean water and suction a small amount of water.
- Place catheter in mouth, moving from side to side within the mouth and over the tongue.
- Be careful to avoid putting the catheter too far in the back of the throat, which might cause gagging.
- Put catheter tip in water and clear tube.
- Ask the hospice nurse if the catheter can be reused.

**SHORTNESS OF BREATH**

Some patients experience a feeling of breathlessness at the end stages of life, and may experience an uncomfortable feeling of having difficulty breathing. Sometimes it is described as not getting enough air (feeling that he/she cannot get their breath), feeling like the room is closing in, or there is not enough air in the room.

**WHAT TO REPORT TO THE HOSPICE/PALLIATIVE CARE TEAM?**

Let the health care team know when the patient demonstrates fear, anxiety, nervousness or restlessness. Contact the team if there is a bluish discoloration of face, nose, fingers, toes.

**WHAT CAN BE DONE TO HELP THE PATIENT?**

- Make notes about what seems to increase shortness of breath and what decreases it.
- Increase air movement by using an open window or fan.
- Keep room cool and apply cool cloths to face, neck and/or chest; if air conditioner is not available, try sitting a bowl of ice in front of a fan.
- Keep the environment quiet to decrease feelings of anxiety.
- Elevate the patient’s head or sit the patient in chair or recliner.
- Use relaxation techniques with spiritual support, yoga, calming music, massage.
- Focus on breathing - encourage slow, deep breaths or use breathing exercises.
- Use pursed lipped breathing (breathe in through the nose and blow air out through the mouth slowly with lips pursed together)
- Use oxygen as directed by the healthcare team.
- Provide medication as directed by the physician.

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**18. The End of Life**

Talking about death is not easy for many people. Those who know that life’s end is near often reflect on their experience – and it does not have to be a lonely, difficult task. If you are comfortable, you may wish to explore some of these topics; you may find some wonderful avenues open for you to help your loved one in a deeply personal manner.

**QUESTIONS ABOUT LIVING FOR THE PATIENT**

When there is only a short time left in life, choices must be made:

- What do you still want to accomplish?
- What do you need to do to ensure your affairs are in order?
- Who are the people you want to spend time with?
- Are there issues to resolve or conversations to have?
- What will bring pleasure to this part of your life?

It is healthy to think about these questions and to talk about them with family and friends. Knowing life’s end is drawing near can allow patients to focus their energy on the people and issues important to them.

**QUESTIONS ABOUT DYING FOR THE PATIENT**

It is natural to have questions about death. It is mysterious, and we all wonder about the process and what it means.

- What do I believe about death and what happens to a person during and after death?
- What can help me with my feelings of fear and sadness?
- What can I do to make peace with the person I have been and who I am now?
- What kind of service or other remembrance do I want after my death?
- Whom do I want with me when I die?

While these questions can be painful, they can also bring inner peace. Those experiencing a terminal illness need others who will encourage them to explore these questions, and who will listen and offer support.

**WHERE TO GO FOR HELP**

There are many individuals who can help patients and their families when the end of life is near, sometimes just to talk and gain spiritual comfort, or maybe to help resolve a family conflict or other issue. Don't be afraid to ask for help from:

- Hospice staff
- Priests, ministers, rabbis, or other spiritual leaders
- Private therapists
- Support groups
- Friends and family
PREPARING FOR DEATH

When a friend or family member is dying, the patient needs to know that you are open to talking or listening when the time is right. Do not be afraid to laugh or to cry. Emotions can bring healing – for the patient and for the caregiver. Be willing to change your plans or your topic of conversation based on how your loved one is feeling. Let the patient know what you treasure about him or her and why they are important to you.

In the final stages of the dying process, the body begins to shut down, and the individual begins to release himself emotionally and spiritually. The Hospice team is here to help you through this process, so use them as a resource.

19. Final Days

WHAT ARE THE SIGNS AND SYMPTOMS THAT THE PATIENT IS CLOSE TO DEATH?

As death nears, the patient may:

• Sleep more, withdraw from people or have little to say
• Speak to people not present
• Talk about leaving or taking a trip or journey
• Eat or drink less and have trouble swallowing
• Become more confused
• Make moaning sounds
• Lose control of urination and bowel movements
• Have moist breathing or sound congested
• Have changes in the pattern of breathing such as long periods without breathing followed by several quick, deep breaths
• Have blurred vision and/or not hear as well as usual
• Have less pain
• Have cool hands and arms or feet and legs
• Turn blue around nose, mouth, fingers, and toes

WHAT SHOULD YOU REPORT TO THE HOSPICE TEAM?

Changes in the patient such as:

• Restlessness or anxiety
• Changes in breathing
• Pain or discomfort
• Need for spiritual, emotional, or social support or guidance for the patient or family. Concerns that may need help from the social worker, chaplain or other members of the hospice team.
• Religious, cultural, or ethnic traditions important to your family

WHAT CAN BE DONE FOR THE PATIENT?

• Allow the patient to sleep without guilt or chiding.
• Continue to sit with your loved one, speaking softly and naturally. Speak to your loved one directly as you normally would – never assume the person cannot hear. Do not talk about this person in his or her presence. Hearing is the last of the senses to be lost.
• Turn the patient if it makes him or her more comfortable. Elevating the head or turning the person onto the side may bring comfort.
• If congested, gently turn the head to the side, allowing gravity to drain the secretions.
• Moisten the patient's mouth with a moist washcloth or cotton ball. Ice chips or frozen juice may refresh the mouth, or you can give small amounts by dropper or straw, if the person can swallow (ask hospice nurse).
• If the patient has a fever or is hot, apply a cool rag to the forehead.
• Give medications ordered by the doctor to decrease anxiety, restlessness, agitation, or moist breathing.
• Use light massage on the forehead, read to the person, or play soothing music to relieve restlessness.
• Write down what the patient says. Such messages may comfort you later.
• Continue to talk clearly to the patient and say the things you need or want to say. Remember that the patient may be able to hear even when unable to respond.
• Keep a light on in the room. The patient cannot see well and may be frightened by darkness and shadows.
• Play the patient's favorite music softly.
• Encourage visitors to talk directly to the patient and tell the patient who they are.
• Keep things calm around the patient.
• Open a window or use a fan in the room if the patient is having trouble breathing.
• Continue to touch and stay close to reassure your loved one.

20. When Death Occurs

Everyone handles the time of death in different ways. The Hospice team can help prepare you so you know what to expect. An expected death is not an emergency, so you can spend some precious time with your loved one.
Signs of death:
• No breathing
• No heartbeat
• No response to communication
• Eyes fixed on a certain spot
• Eyelids slightly open
• Jaw relaxed and mouth slightly open

When you want support or when the patient dies:
• Call the Hospice office. A team member will speak with you and come to your home.
• It may be helpful to have a friend or family member come be with you.
• If you wish, the nurse will call the funeral home for you after the death. The funeral home usually arrives within an hour after the call. You may choose to wait to call the funeral home until other family members or friends arrive.

At the time of death, the hospice team will need to know:
• Name of the funeral home you want to use
• Whether the body will be embalmed or cremated
• Names of family members to be contacted

21. Working With A Funeral Home

When a person dies, those left behind must deal with many issues of grief and loss. At the same time, a number of practical and business decisions must be made. One pressing issue is making funeral arrangements. You should be in contact with the funeral home within 24 hours of your loved one’s death to set up an appointment with a funeral director.

Making funeral arrangements for oneself or someone else can be a difficult and emotionally painful process. It can seem overwhelmingly complicated. Where do you start? How do you find a funeral home? How do you know which funeral home is the best for your needs? When should you call and begin to make arrangements?

PLANNING AHEAD

People often avoid the subject of funeral planning until there is a death. Often, waiting increases the difficulty of making clear and consistent decisions; even with pre-planning, there will be many choices and decisions to be made. The more that can be started and completed ahead of time, the more opportunity there will be to focus on the feelings and emotions that surround a death. Talking about preferences and plans with others may seem difficult but it is the best way to know the patient’s wishes.

MAKING DECISIONS

Most funeral directors are professionally trained, providing services with compassion and integrity. They play an important and necessary role in the community, working with people at an especially vulnerable time. When someone you love has died, you need to make quick decisions on painful issues, such as burial or cremation, what kind of casket to buy, where to purchase a burial plot, and what kind of service to have. Some decisions may involve significant amounts of money as well as being emotionally charged, so they become more complicated. Here are some suggestions to help minimize the risk of making decisions that you may later regret.

• Never send one family member alone to make funeral arrangements. If possible, have two or three family representatives go together, including one who is more detached from the pain of loss than a spouse or child.
• Most funeral homes offer a basic minimum service package, beyond which additional services are charged individually. Make sure that you understand what is included in the basic service and what is extra.
• If you have questions about whether you want or need some of the services offered, go home and think about it, then call back with your answer.

SERVICES PERFORMED BY THE FUNERAL HOME

• Immediate services including staff counseling, administrative direction, preparation, and embalming of the body for burial.
• Facilities and equipment including the use of the preparation room and equipment, use of room where body lies for visitation and a funeral or memorial service.
• Assist with preparation of the obituary, and will complete necessary paperwork for the death certificate, and needed copies.
• Caskets will be available at a range of costs.
• Basic transportation including transfer of the body from place of death to funeral home, and a hearse for local service.
• Cemetery including cost of plot, cost of opening and closing the grave, cost of a vault, and headstone. Cemeteries usually do not open graves over the weekends and will charge an extra fee for Saturday burials.
• Optional/additional costs will include limousines, drivers, police escorts, service folders, and gratuities. Generally, gratuities are given to the minister, organist, soloist, custodian, and to the church group that serves refreshments after the funeral.
• Cremation services includes the cost of cremation, and if ashes are buried, additional costs.
• Bequeathal of body includes the fee the medical school charges for accepting a body and transportation of the body.
**PLANNING A FUNERAL OR MEMORIAL SERVICE**  
The funeral or memorial can be a simple or a more formal service. Either can be comforting as you share time with family and friends to laugh, cry, and remember together. See Appendix B – *Planning a Funeral or Memorial Service* on page 23.

**22. Grief & Mourning**

**WHAT IS GRIEF?**
Grief is the normal, emotional response to a loss, and each person grieves in his or her own way. There is no right way to grieve. There is no specific timetable for completing the grief process. While grief is often associated with the death of a loved one, it may also be experienced at the time of other losses such as the loss of function due to illness, loss of a pet, losses such as divorce, the loss of future dreams, role changes and many other changes in life or health. Terminally ill people experience grief as their illnesses progress and their lives are diminished.

**WHAT IS MOURNING?**
Mourning is the outward expression of grief and includes rituals and customs such as funerals, viewing of the body, cremation and other customs. Each religion, culture, ethnicity, and even different parts of the same country may have different expressions of mourning.

**WHAT MAY BE EXPECTED DURING THE GRIEF PROCESS?**
Although we all grieve differently, grief affects behavior, emotions, mental and physical well being.

*Among the physical experiences are such things as:*
- Tightness in the chest and throat, breathlessness
- Headaches and dizziness
- Exhaustion or weakness
- Dry mouth
- Muscle aches

*Among the thoughts that one has, you may find:*
- Disbelief and shock
- Confusion and difficulty concentrating
- Hallucinations
- Preoccupation with the deceased

*Some of the emotions that are most often felt include:*
- Sadness, helplessness, or yearning
- Anger, which may be directed at God, family, health care providers or the person who died
- Shock, guilt and anxiety
- Numbness or ambivalence

**WHAT CAN BE DONE TO HELP ONE HEAL?**
- Give yourself permission to grieve.
- Get plenty of rest and exercise, and eat a healthy diet.
- Try to have at least one person with whom you can share your feelings and from whom you will receive support.
- Consider keeping a journal to write down your feelings.
- Do not push yourself to make changes in your life too quickly.
- Reminisce and put together a memory book.
- Attend a community grief support group.

**HOW TO HELP CHILDREN COPE WITH GRIEF?**
- Children will experience grief in cycles. As they develop, they will understand more about their grief. Children may ask the same questions repeatedly. Giving them the same answers each time provides them with a sense of stability and trust.
- Adults must be careful when talking with children about death. Using words that are “softer” to describe death may actually cause more confusion. To describe someone who has died as being “lost” or “sleeping” may cause the child to think that the loved one is coming back or to fear sleeping.
- Children need honest information about their loved one’s illness at a level they can understand. Talk to them about the person’s health condition and the signs that death is approaching. Expressing your own feelings during these discussions may help children express theirs. The Hospice team can provide information how to help children cope.

**WHEN SHOULD YOU ASK FOR HELP?**
Your hospice or palliative care team will give you support beyond the death of your loved one. Please use them as a resource if you experience:
- Persistent intense grief reactions months after the loss (not just occasional intense grief reactions)
- Thoughts of suicide or self-harm
- Social isolation
- Unplanned changes in weight
- Increase in use of alcohol or drugs
23. Other Business Matters

In addition to a funeral or memorial service, you may also need to follow-up on other tasks following your loved one's death, such as:

PERSONAL BUSINESS

• Contact your loved one’s lawyer about a will or any other legal business.

• Contact the bank, financial planner, accountant, insurance contacts, and others who may need to be notified. Many of these contacts will need copies of the death certificate in order to pay benefits or transfer them to surviving family members.

• Cancel subscriptions and club memberships, and stop or forward mail delivery.

• Address any unpaid bills; contact credit card companies.

• Sort through and dispose of your loved one’s personal belongings; this may be easier if shared with other family members.

SOCIAL SECURITY BENEFITS

You will want to contact the Social Security Administration regarding the death. If you apply for either of their benefit programs, medical and other information will be collected from you and a decision will be made as to whether or not you meet Social Security’s definition of disability.

• Social Security Disability Insurance – this pays benefits to you and certain members of your family if you are “insured,” meaning that you worked long enough and paid Social Security taxes.

• Supplemental Security Income – this pays benefits based on financial need.

SURVIVOR BENEFITS

A family member or other responsible person for the beneficiary’s affairs should do the following upon death:

• Notify Social Security of the beneficiary’s death by calling the Social Security Administration at 1-800-772-1213.

• If monthly benefits were being paid via direct deposit, notify the bank of the death. Request that any funds received for the month of death and later be returned to Social Security as soon as possible.

• If benefits were being paid by check, do not cash any checks received for the month in which the beneficiary died or thereafter. Return them to Social Security as soon as possible.

• It may take weeks or even months to handle your loved one’s affairs, and it can be tiring and emotional work. You do not need to take on everything at once. Be sure to share the responsibilities with other family members.

24. Hospice Checklist for Legal Affairs

The purpose of this section is to guide families in thinking about what is necessary for legal affairs to be concluded after a loved one’s death.

This is not to be used in lieu of legal advice and is not meant to be legal advice. As always, the advice of your attorney is of paramount importance.

ESTATE PLANNING

If estate planning is in place, it is always advisable to contact the attorney and inform him/her about the patient’s health status. That allows the attorney to check the file to be sure it is up to date, so that it reflects any changes in the law which have occurred since executing the documents. At that time, updating amendments to the documents can insure that the patient has the most current document.

If no estate planning is in place, it would be good to contact an estate-planning attorney to help implement documents that will help in transition. This would include but not be limited to:

• Health care directive, which names an agent to make medical, decisions if necessary, and includes up to date HIPPA provisions.

• Durable Power of Attorney(s), which name an agent for financial matters.

• A will.

• Living Trust to avoid probate and provide for secrecy of trust provisions.

• Documents titling assets in the name of the Living Trust if one is created.

DOCUMENTS NEEDED IN THE EVENT OF DEATH

Gathering documents needed with the help of the patient will simplify the tasks of the family after death. This is a suggested list of what might be needed.

• Original Will. The latest Will that has been executed will be needed. Usually only one original Will is executed.

• Living Trust and Amendments. There are normally several trusts executed. An executed Trust and any subsequent amendments to that trust are needed.

• Account Statements. The latest monthly statements of assets are needed. They might include:
  - Brokerage statements
  - Bank statements
  - Annuity statements
  - Mutual fund statements

• Security Certificates for stocks and/or bonds
• Certificates of deposit
• Deeds to real estate
• Vehicle titles including autos, boats, trailers, boat motors, RVs
• Life insurance policies
• Income tax returns for the last three years if possible
• Prenuptial agreement if any
• Military discharge papers if any
• Personal effects letter detailing items to be distributed to people after death; it must be signed and dated by the patient to be binding.
• Death certificate of a deceased joint owner on an asset. If no certificate can be found, a new one can be obtained from the Bureau of Vital Statistics of the county of the deceased person’s residence.

TITLING OF ASSETS
• If stocks and bonds are held in safekeeping at a brokerage, it simplifies dealing with the securities.
• Any assets titled in a deceased person’s name alone will need to be processed through the Probate Court.
• Consider titling all assets in a Living Trust, which will ease the transfer of assets after death and avoid Probate Court.
• Sometimes joint ownership is appropriate and sometimes it is not. Please consult your attorney for advice on this point.
• On vehicles, if the title is issued in Missouri, consider using a “TOD” (Transfer on Death) registration, naming a beneficiary of the vehicle. This can be accomplished at a Department of Revenue office. The patient’s signature will be required.
• Check all beneficiary designations to be sure they are consistent with your estate planning. Consult with your attorney about what the designation should be.

INFORMATION NEEDED
There is information needed which would be helpful to gather with the help of the patient which will ease the transition after death. The following is a suggestion of the type of information that may be needed.

1. Patient Information:
• Social Security Number
• Date of birth
• Year patient moved to Missouri or Illinois
• Occupation (even if retired)
• Father’s name
• Mother’s maiden name

2. Deceased Spouse Information:
• Date of death
• Social Security number (can be found on past joint income tax returns)
• Beneficiary information: beneficiaries of Will or Trust Name
• Address
• Social Security number
• Relationship to patient

3. Heirs’ information
If probate is necessary, the Court requires the following for each heir at law; ask your attorney who heirs at law are.
• Name and address
• Relationship to patient
• Birth date if under age 18
• Last four digits of the social security number

4. Employment benefits
Check with the patient’s employer (or former employer if retired) to see if benefits are available. These might be: life insurance, extended health benefits for survivors, and qualified plans (Profit Sharing Plan, Pension Plan, Thrift Plan, 401 (k) plans, TIAA/ CREF, V ALIC, Savings Investment Plan, and ESOP).

5. Social Security Benefits
Visit a Social Security office to inquire about what post-death benefits are available to family members, including the surviving spouse and children under the age of 18 (age 19 if still attending high school).

6. Safe Deposit Box
• Location of box
• Location of key
• Name(s) of co-owner(s) (If the patient is sole owner, the box can only be entered with a Probate Court order after death.)
• Contents of the safe deposit box (Consider reviewing the contents and discarding outdated documents such as life insurance policies no longer in force or deeds to real estate already sold.)

7. Passwords and combinations
• Computer
• Bank accounts
• Bill paying
• Credit cards
• Social security
• Safes

8. Bills to be paid on a monthly or quarterly basis
• Mortgage payments
• Car loans
• Estimated income tax payments
• Other
9. Cost Basis of Gifted Assets
When an asset is gifted, it retains the donor’s (person who gifts) original cost basis. If the patient has gifted assets, ascertain the cost basis of the donor. The donee (person who receives the gift) will need the cost basis at the future sale of the asset.

10. Death Certificates usually required
Generally, the family orders five death certificates, keeping in mind the following:
• One is needed for each life insurance company (i.e., if there are multiple policies with one company, only one death certificate needed for that company)
• One is needed for filing Federal Estate Tax Return if necessary. (Check with your attorney about whether a Federal Estate Tax Return will need to be filed.)
• Additional death certificates can be ordered at a later date from the Bureau of Vital Statistics of the county of residence of the patient.

11. Funeral Benefits
• Social Security Death Benefit may be available to a surviving spouse; often the funeral home will collect/apply to the funeral bill.
• Veteran’s Death Benefit. If the patient is a veteran, call 800-827-1000 to determine if there are benefits available, or check online at www.va.gov for information.

RESOURCE
An excellent aid in gathering information is a book entitled *When I Leave and You Are Left* by Mary M. Drakesmith and Jane R. Moerschel who live in St. Charles, Missouri. The cost is $14.95 and the ISBN# is 0-9655020-7-4. It is a guide to be filled out with information that survivors will need after a death. A portion of the proceeds of the book will be donated to cancer research.

25. Personal Record File
It is helpful to keep all of your records in one place, where family members know where to find it. You may want to put important documents and records in a large envelope or file folder with the contents marked on the outside. Here is a checklist of documents you may want to include. You can also note where to find them on the line to the right of each item.
• Will (with your attorney’s name and address)
• Insurance policies
• Records about your home (purchase information, real estate deeds, title, closing statements, mortgages, record of mortgage payments, tax information, details about improvements made, etc.)
• Investment information (broker’s name and address, stock certificates and bonds, account reports)
• Bank information (bank name, account numbers, savings bank books, names of officers with whom you have worked)
• Other assets (loans, accounts receivable, land or property ownership, etc.)
• Safe deposit box key (with name of bank and box number)
• Income tax returns (from past three years) and information to prepare current year’s return
• Birth certificates (for you and family members)
• Marriage certificates (and/or proof of divorce)
• Car/other vehicle title and registration
• Social Security card (or record of Social Security number)
• Veteran’s discharge papers and/or military records
• Burial instructions (location, plot, funeral home)
• Other instructions to surviving family members

26. Questions?
Please list any questions you may have for your hospice team members as you think of them.
27. Caregiver Resources

TAKE CARE OF YOURSELF
As a caregiver, you also need care. Being a caregiver is physically and emotionally draining, but in this labor of love you have the opportunity to strengthen and grow your relationship with the one receiving care. You are building memories and giving a gift that cannot be matched by any other and you become an expert on the person who needs care. Work with the Hospice Team, ask questions, let us know what you need, and most importantly of all, take care of yourself so that you will be able to care for your loved one. Your emotional and physical well-being are important and both may be difficult to maintain.

STRATEGIES FOR STAYING HEALTHY
• Accept help - let friends, family, hospice volunteers and others support you in doing tasks such as running errands, yard work or sitting with the patient while you take a walk or a nap.
• Take time for you - even a few quiet moments to yourself can be refreshing. You need to take part in activities you enjoy as part of the caregiving routine. Try to set a goal of one outing per week.
• Pay attention to your physical needs - eating, sleeping and exercising are important. Do not become so busy being a caregiver that you forget about your own needs.
• Practice relaxation – pause now and then for five minutes and breathe deeply. Focus on pleasant images while sitting in a relaxed state.
• Laughter and keeping your sense of humor are important, too; seek out amusement.

SUPPORT AGENCIES & SITES
• Administration on Aging
  www.aoa.gov
• National Center on Caregiving
  www.caregiver.org
• National Hospice & Palliative Care Organization
  www.nhpco.org
• Johnson & Johnson – The Caregiver Initiative
  www.strengthforcaring.com
• Caregiving Today Magazine
  www.cargivingtodaymagazine.com
• National Alliance for Caregiving
  www.caregiving.org

APPENDIX A
PAIN QUESTIONNAIRE
Your hospice nurse and physician would like to know your concerns about the pain medications. Put a check mark by any worries you have and your hospice nurse will discuss these concerns with you at his/her next visit.

☐ I worry that I should save stronger medicines for later.
☐ I am worried about constipation.
☐ I am worried about increased drowsiness.
☐ I worry about stomach upset.
☐ I do not like to complain about pain.
☐ I am worried about addiction.

What other worries or questions do you have concerning pain and pain medications?

__________________________________________________
__________________________________________________
__________________________________________________
__________________________________________________
__________________________________________________
__________________________________________________
__________________________________________________
__________________________________________________
__________________________________________________
__________________________________________________
__________________________________________________
**APPENDIX B**

**PLANNING A FUNERAL OR MEMORIAL SERVICE**

Use the following checklist to aid in the planning of the funeral or memorial service of your loved one.

<table>
<thead>
<tr>
<th>Name of Deceased</th>
</tr>
</thead>
</table>

**Type of Service (check all that apply):**

- [ ] Funeral - open casket
- [ ] Funeral - closed casket
- [ ] Memorial Service
- [ ] Religious
- [ ] Non-religious
- [ ] Family Only
- [ ] Open
- [ ] Other

<table>
<thead>
<tr>
<th>Location of Service</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Date of Service</th>
<th>Time of Service</th>
</tr>
</thead>
</table>

**Will there be visiting hours before the service?**  
[ ] Yes  [ ] No

If yes, where will visitation be held?

**When?**

**Will there be a reception after the service?**  
[ ] Yes  [ ] No

If yes, where?

**When?**

**SERVICE ARRANGEMENTS (check all that apply)**

- [ ] Organ or other instrumental music

- [ ] Soloist
☐ Choir

☐ Hymns for congregation to sing

☐ Musical selections

☐ Scripture or other readings

☐ Eulogies

OTHER DETAILS

Participants

Officiant (priest, rabbi, pastor, other)

Musicians

Speaker(s)

Pallbearers/honorary pallbearers

Ushers

Other notes
## ST. LOUIS AREA

**Home Care**
4353 Clayton Ave., Suite 128
St. Louis, MO 63110
314-362-0200
888-BJC-HOME (888-252-4663)

**Home Infusion Therapy**
1935 Beltway Drive
St. Louis, MO 63114
314-953-2000

**Home Medical Equipment**
1935 Beltway Drive
St. Louis, MO 63114
314-953-2000

**Hospice and Palliative Home Care**
8300 Eager Road, Suite 500A
St. Louis, MO 63144
314-872-5050

## ILLINOIS AREA

**Home Care**
3535 College Avenue, Suite B
Alton, IL 62002
618-463-7541
800-916-7541

**Hospice and Palliative Home Care**
One Professional Drive, Suite 180
Alton, IL 62002
618-463-7100

## SULLIVAN AREA

**Home Care**
153 East Springfield Road
Sullivan, MO 63080
573-468-5167
800-367-8402

**Hospice and Palliative Home Care**
153 East Springfield Road
Sullivan, MO 63080
573-468-3630

**Home Medical Equipment**
See Farmington address
573-747-1075
877-289-8422

## PARKLAND AREA

**Home Care**
757 Weber Road
Farmington, MO 63640
573-760-8575
888-633-9395

**Hospice and Palliative Home Care**
757 Weber Road
Farmington, MO 63640
573-760-8550
888-633-9395

**In-Home Services**
757 Weber Road
Farmington, MO 63640
573-760-8552
888-213-8552

**Home Medical Equipment**
301 N. Washington
Farmington, MO 63640
573-747-1075
877-289-8422
This booklet made possible through donations from the families of BJC hospice patients.
Caregiver Guide
Tips for Caregivers of People with Alzheimer's Disease
...from the National Institute on Aging
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Tips for Caregivers

Caring for a person with Alzheimer’s disease at home is a difficult task and can become overwhelming at times. Each day brings new challenges as the caregiver copes with changing levels of ability and new patterns of behavior. Research has shown that caregivers themselves often are at increased risk for depression and illness, especially if they do not receive adequate support from family, friends, and the community.

One of the biggest struggles caregivers face is dealing with the difficult behaviors of the person they are caring for. Dressing, bathing, eating—basic activities of daily living—often become difficult to manage for both the person with Alzheimer’s and the caregiver. Having a plan for getting through the day can help caregivers cope. Many caregivers have found it helpful to use strategies for dealing with difficult behaviors and stressful situations. Through trial and error you will find that some of the following tips work, while others do not. Each person with Alzheimer’s is unique and will respond differently, and each person changes over the course of the disease. Do the best you can, and remind yourself to take breaks.

Dealing with the Diagnosis

Finding out that a loved one has Alzheimer’s disease can be stressful, frightening, and overwhelming. As you begin to take stock of the situation, here are some tips that may help:
Ask the doctor any questions you have about Alzheimer’s disease. Find out what treatments might work best to alleviate symptoms or address behavior problems.

Contact organizations such as the Alzheimer’s Association and the Alzheimer’s Disease Education and Referral (ADEAR) Center for more information about the disease, treatment options, and caregiving resources. Some community groups may offer classes to teach caregiving, problem-solving, and management skills. See page 20 for information on contacting the ADEAR Center and a variety of other helpful organizations.

Find a support group where you can share your feelings and concerns. Members of support groups often have helpful ideas or know of useful resources based on their own experiences. Online support groups make it possible for caregivers to receive support without having to leave home. The Alzheimer’s Association and other organizations sponsor support groups.

Study your day to see if you can develop a routine that makes things go more smoothly. If there are times of day when the person with Alzheimer’s is less confused or more cooperative, plan your routine to make the most of those moments. Keep in mind that the way the person functions may change from day to day, so try to be flexible and adapt your routine as needed.

Consider using adult day care or respite services to ease the day-to-day demands of caregiving. These services allow you to have a break while knowing that the person with Alzheimer’s is being well cared for.
Begin to plan for the future. This may include getting financial and legal documents in order, investigating long-term care options, and determining what services are covered by health insurance and Medicare.

**Communication**

Trying to communicate with a person who has Alzheimer’s disease can be a challenge. Both understanding and being understood may be difficult.

- Choose simple words and short sentences and use a gentle, calm tone of voice.
- Avoid talking to the person with Alzheimer’s like a baby or talking about the person as if he or she weren’t there.
- Minimize distractions and noise—such as the television or radio—to help the person focus on what you are saying.
- Make eye contact and call the person by name, making sure you have his or her attention before speaking.
- Allow enough time for a response. Be careful not to interrupt.
- If the person with Alzheimer’s is struggling to find a word or communicate a thought, gently try to provide the word he or she is looking for.
- Try to frame questions and instructions in a positive way.
- Be open to the person’s concerns, even if he or she is hard to understand.
Bathing

While some people with Alzheimer’s disease don’t mind bathing, for others it is a frightening, confusing experience. Advance planning can help make bath time better for both of you.

- Plan the bath or shower for the time of day when the person is most calm and agreeable. Be consistent. Try to develop a routine.

- Respect the fact that bathing is scary and uncomfortable for some people with Alzheimer’s. Be gentle and respectful. Be patient and calm.

- Tell the person what you are going to do, step by step, and allow him or her to do as much as possible.

- Prepare in advance. Make sure you have everything you need ready and in the bathroom before beginning. Draw the bath ahead of time.

- Be sensitive to the temperature. Warm up the room beforehand if necessary and keep extra towels and a robe nearby. Test the water temperature before beginning the bath or shower.

- Minimize safety risks by using a handheld showerhead, shower bench, grab bars, and nonskid bath mats. Never leave the person alone in the bath or shower.

- Try a sponge bath. Bathing may not be necessary every day. A sponge bath can be effective between showers or baths.
**Tips for Caregivers of People with Alzheimer’s Disease**

### Dressing

For someone who has Alzheimer’s, getting dressed presents a series of challenges: choosing what to wear, getting some clothes off and other clothes on, and struggling with buttons and zippers. Minimizing the challenges may make a difference.

- Try to have the person get dressed at the same time each day so he or she will come to expect it as part of the daily routine.

- Encourage the person to dress himself or herself to whatever degree possible. Plan to allow extra time so there is no pressure or rush.

- Allow the person to choose from a limited selection of outfits. If he or she has a favorite outfit, consider buying several identical sets.

- Store some clothes in another room to reduce the number of choices. Keep only one or two outfits in the closet or dresser.

- Arrange the clothes in the order they are to be put on to help the person move through the process.

- Hand the person one item at a time or give clear, step-by-step instructions if the person needs prompting.

- Choose clothing that is comfortable, easy to get on and off, and easy to care for. Elastic waists and Velcro® enclosures minimize struggles with buttons and zippers.
Eating can be a challenge. Some people with Alzheimer’s disease want to eat all the time, while others have to be encouraged to maintain a good diet.

- View mealtimes as opportunities for social interaction and success for the person with Alzheimer’s. Try to be patient and avoid rushing, and be sensitive to confusion and anxiety.

- Aim for a quiet, calm, reassuring mealtime atmosphere by limiting noise and other distractions.

- Maintain familiar mealtime routines, but adapt to the person’s changing needs.

- Give the person food choices, but limit the number of choices. Try to offer appealing foods that have familiar flavors, varied textures, and different colors.

- Serve small portions or several small meals throughout the day. Make healthy snacks, finger foods, and shakes available. In the earlier stages of dementia, be aware of the possibility of overeating.

- Choose dishes and eating tools that promote independence. If the person has trouble using utensils, use a bowl instead of a plate, or offer utensils with large or built-up handles. Use straws or cups with lids to make drinking easier.

- Encourage the person to drink plenty of fluids throughout the day to avoid dehydration.
As the disease progresses, be aware of the increased risk of choking because of chewing and swallowing problems.

Maintain routine dental checkups and daily oral health care to keep the mouth and teeth healthy.

**Activities**

What to do all day? Finding activities that the person with Alzheimer’s disease can do and is interested in can be a challenge. Building on current skills generally works better than trying to teach something new.

- Don’t expect too much. Simple activities often are best, especially when they use current abilities.
- Help the person get started on an activity. Break the activity down into small steps and praise the person for each step he or she completes.
- Watch for signs of agitation or frustration with an activity. Gently help or distract the person to something else.
- Incorporate activities the person seems to enjoy into your daily routine and try to do them at a similar time each day.
- Try to include the person with Alzheimer’s in the entire activity process. For instance, at mealtimes, encourage the person to help prepare the food, set the table, pull out the chairs, or put away the dishes. This can help maintain functional skills, enhance feelings of personal control, and make good use of time.
Take advantage of adult day services, which provide various activities for the person with Alzheimer’s, as well as an opportunity for caregivers to gain temporary relief from tasks associated with caregiving. Transportation and meals often are provided.

**Exercise**

Incorporating exercise into the daily routine has benefits for both the person with Alzheimer’s disease and the caregiver. Not only can it improve health, but it also can provide a meaningful activity for both of you to share.

- Think about what kind of physical activities you both enjoy, perhaps walking, swimming, tennis, dancing, or gardening. Determine the time of day and place where this type of activity would work best.
- Be realistic in your expectations. Build slowly, perhaps just starting with a short walk around the yard, for example, before progressing to a walk around the block.
- Be aware of any discomfort or signs of overexertion. Talk to the person’s doctor if this happens.
- Allow as much independence as possible, even if it means a less-than-perfect garden or a scoreless tennis match.
- See what kinds of exercise programs are available in your area. Senior centers may have group programs for people who enjoy exercising with others. Local malls often have walking clubs and provide a place to exercise when the weather is bad.
Encourage physical activities. Spend time outside when the weather permits. Exercise often helps everyone sleep better.

**Incontinence**

As the disease progresses, many people with Alzheimer’s begin to experience incontinence, or the inability to control their bladder and/or bowels. Incontinence can be upsetting to the person and difficult for the caregiver. Sometimes incontinence is due to physical illness, so be sure to discuss it with the person’s doctor.

- Have a routine for taking the person to the bathroom and stick to it as closely as possible. For example, take the person to the bathroom every 3 hours or so during the day. Don’t wait for the person to ask.

- Watch for signs that the person may have to go to the bathroom, such as restlessness or pulling at clothes. Respond quickly.

- Be understanding when accidents occur. Stay calm and reassure the person if he or she is upset. Try to keep track of when accidents happen to help plan ways to avoid them.

- To help prevent nighttime accidents, limit certain types of fluids—such as those with caffeine—in the evening.

- If you are going to be out with the person, plan ahead. Know where restrooms are located, and have the person wear simple, easy-to-remove clothing. Take an extra set of clothing along in case of an accident.
Sleep Problems

For the exhausted caregiver, sleep can’t come too soon. For many people with Alzheimer’s disease, however, the approach of nighttime may be a difficult time. Many people with Alzheimer’s become restless, agitated, and irritable around dinnertime, often referred to as “sundowning” syndrome. Getting the person to go to bed and stay there may require some advance planning.

- Encourage exercise during the day and limit daytime napping, but make sure that the person gets adequate rest during the day because fatigue can increase the likelihood of late afternoon restlessness.

- Try to schedule physically demanding activities earlier in the day. For example, bathing could be done in the morning, or the largest family meal could be served at midday.

- Set a quiet, peaceful tone in the evening to encourage sleep. Keep the lights dim, eliminate loud noises, even play soothing music if the person seems to enjoy it.

- Try to keep bedtime at a similar time each evening. Developing a bedtime routine may help.

- Limit caffeine.

- Use night-lights in the bedroom, hall, and bathroom if the darkness is frightening or disorienting.
Hallucinations and Delusions

As the disease progresses, a person with Alzheimer’s disease may experience hallucinations and/or delusions. Hallucinations are when the person sees, hears, smells, tastes, or feels something that is not there. Delusions are false beliefs that the person thinks are real.

- Sometimes hallucinations and delusions are signs of physical illness. Keep track of what the person is experiencing and discuss it with the doctor.

- Avoid arguing with the person about what he or she sees or hears. Try to respond to the feelings he or she is expressing. Comfort the person if he or she is afraid.

- Try to distract the person to another topic or activity. Sometimes moving to another room or going outside for a walk may help.

- Turn off the television set when violent or disturbing programs are on. The person with Alzheimer’s may not be able to distinguish television programming from reality.

- Make sure the person is safe and does not have access to anything he or she could use to harm anyone.

- Discuss with the doctor any illness the person has had or medicines he or she is taking. Sometimes an illness or medicine may cause hallucinations or delusions.
**Wandering**

Keeping the person safe is one of the most important aspects of caregiving. Some people with Alzheimer’s disease have a tendency to wander away from their home or their caregiver. Knowing how to limit wandering can protect a person from getting lost.

- Make sure that the person carries some kind of identification or wears a medical bracelet.

- Consider enrolling the person in the Alzheimer’s Association Safe Return program if the program is available in your area (see page 21 for more information on contacting the Association). If the person gets lost and is unable to communicate adequately, identification will alert others to the person’s medical condition.

- Notify neighbors and local authorities in advance that the person has a tendency to wander.

- Keep a recent photograph or videotape of the person with Alzheimer’s to assist police if the person becomes lost.

- Keep doors locked. Consider a keyed deadbolt or an additional lock up high or down low on the door. If the person can open a lock because it is familiar, a new latch or lock may help.

- Install an “announcing system” that chimes when the door opens.
Home Safety

Caregivers of people with Alzheimer’s disease often have to look at their homes through new eyes to identify and correct safety risks. Creating a safe environment can prevent many stressful and dangerous situations. The ADEAR Center offers the booklet, *Home Safety for People with Alzheimer’s Disease*, which lists many helpful tips. See page 20 for information on how to contact the ADEAR Center.

- Install secure locks on all outside windows and doors, especially if the person is prone to wandering. Remove the locks on bathroom doors to prevent the person from accidentally locking himself or herself in.

- Use childproof latches on kitchen cabinets and anyplace where cleaning supplies or other chemicals are kept.

- Label medications and keep them locked up. Also make sure knives, lighters and matches, and guns are secured and out of reach.

- Keep the house free from clutter. Remove scatter rugs and anything else that might contribute to a fall.

- Make sure lighting is good both inside and outside the home.

- Be alert to and address kitchen-safety issues, such as the person forgetting to turn off the stove after cooking. Consider installing an automatic shut-off switch on the stove to prevent burns or fire.

- Be sure to secure or put away anything that could cause danger, both inside and outside the house.
Driving

Making the decision that a person with Alzheimer’s is no longer safe to drive is difficult, and it needs to be communicated carefully and sensitively. Even though the person may be upset by the loss of independence, safety must be the priority.

- Look for clues that safe driving is no longer possible, including getting lost in familiar places, driving too fast or too slow, disregarding traffic signs, or getting angry or confused.

- Be sensitive to the person’s feelings about losing the ability to drive, but be firm in your request that he or she no longer do so. Be consistent—don’t allow the person to drive on “good days” but forbid it on “bad days.”

- Ask the doctor to help. The person may view the doctor as an authority and be willing to stop driving. The doctor also can contact the Department of Motor Vehicles and request that the person be reevaluated.

- If necessary, take the car keys. If just having keys is important to the person, substitute a different set of keys.

- If all else fails, disable the car or move it to a location where the person cannot see it or gain access to it.

- Ask family or friends to drive the person or find out about services that help people with disabilities get around their community.
Visiting the Doctor

It is important that the person with Alzheimer’s disease receive regular medical care. Advance planning can help the trip to the doctor’s office go more smoothly.

- Try to schedule the appointment for the person’s best time of day. Also, ask the office staff what time of day the office is least crowded.

- Let the office staff know in advance that this person may be confused because of Alzheimer’s disease. Ask them for help to make the visit go smoothly.

- Don’t tell the person about the appointment until the day of the visit or even shortly before it is time to go. Be positive and matter-of-fact.

- Bring along something for the person to eat and drink and any materials or activities that he or she enjoys.

- Have a friend or another family member go with you on the trip, so that one of you can be with the person while the other speaks with the doctor.

- Take a brief summary listing the person’s medical history, primary care doctor, and current medications.
Coping with Holidays

Holidays are bittersweet for many Alzheimer’s disease caregivers. The happy memories of the past contrast with the difficulties of the present, and extra demands on time and energy can seem overwhelming. Finding a balance between rest and activity can help.

- Keep or adapt family traditions that are important to you. Include the person with Alzheimer’s as much as possible.
- Recognize that things will be different, and be realistic about what you can do.
- Encourage friends and family to visit. Limit the number of visitors at one time, and try to schedule visits during the time of day when the person is at his or her best.
- Avoid crowds, changes in routine, and strange places that may cause confusion or agitation.
- Do your best to enjoy yourself. Try to find time for the holiday things you like to do.
- Ask a friend or family member to spend time with the person while you are out.
- At larger gatherings such as weddings or family reunions, try to have a space available where the person can rest, be alone, or spend some time with a smaller number of people, if needed.
Visiting a Person with Alzheimer’s Disease

Visitors are important to people with Alzheimer’s. They may not always remember who the visitors are, but the human connection has value. Here are some ideas to share with someone who is planning to visit a person with the disease.

- Plan the visit for the time of day when the person with Alzheimer’s is at his or her best.
- Consider bringing along an activity, such as something familiar to read or photo albums to look at, but be prepared to skip it if necessary.
- Be calm and quiet. Avoid using a loud tone of voice or talking to the person as if he or she were a child.
- Respect the person’s personal space and don’t get too close.
- Try to establish eye contact and call the person by name to get his or her attention.
- Remind the person who you are if he or she doesn’t seem to recognize you.
- Don’t argue if the person is confused. Respond to the feelings you hear being communicated, and distract the person to a different topic if necessary.
- Remember not to take it personally if the person doesn’t recognize you, is unkind, or responds angrily. He or she is reacting out of confusion.
Choosing a Nursing Home

For many caregivers, there comes a point when they are no longer able to take care of their loved one at home. Choosing a residential care facility—a group home, assisted living facility, or nursing home—is a big decision, and it can be hard to know where to start.

- It’s helpful to gather information about services and options before the need actually arises. This gives you time to explore fully all the possibilities before making a decision.

- Determine what facilities are in your area. Doctors, friends and relatives, hospital social workers, and religious organizations may be able to help you identify specific facilities.

- Make a list of questions you would like to ask the staff. Think about what is important to you, such as activity programs, transportation, or special units for people with Alzheimer’s disease.

- Contact the places that interest you and make an appointment to visit. Talk to the administration, nursing staff, and residents.

- Observe the way the facility runs and how residents are treated. You may want to drop by again unannounced to see if your impressions are the same.
Tips for Caregivers of People with Alzheimer’s Disease

- Find out what kinds of programs and services are offered for people with Alzheimer’s and their families. Ask about staff training in dementia care, and check to see what the policy is about family participation in planning patient care.

- Check on room availability, cost and method of payment, and participation in Medicare or Medicaid. You may want to place your name on a waiting list even if you are not ready to make an immediate decision about long-term care.

- Once you have made a decision, be sure you understand the terms of the contract and financial agreement. You may want to have a lawyer review the documents with you before signing.

- Moving is a big change for both the person with Alzheimer’s disease and the caregiver. A social worker may be able to help you plan for and adjust to the move. It is important to have support during this difficult transition.
For More Information

Many organizations offer information for caregivers. To learn more about support groups, services, research, and additional publications, you may wish to contact the following:

Alzheimer’s Disease Education and Referral (ADEAR) Center
P.O. Box 8250
Silver Spring, MD 20907-8250
1-800-438-4380 (toll-free)
www.nia.nih.gov/Alzheimers

The National Institute on Aging’s ADEAR Center offers information and publications for families, caregivers, and professionals on diagnosis, treatment, patient care, caregiver needs, long-term care, education and training, and research related to Alzheimer’s disease. Staff members answer telephone, email, and written requests and make referrals to local and national resources. The ADEAR website offers free, online publications in English and Spanish; email alert and online Connections newsletter subscriptions; an Alzheimer’s disease clinical trials database; the Alzheimer’s Disease Library database; and more.
Tips for Caregivers of People with Alzheimer’s Disease

Alzheimer’s Association
225 North Michigan Avenue, Floor 17
Chicago, IL 60601-7633
1-800-272-3900 (toll-free)
1-866-403-3073 (TDD/toll-free)
www.alz.org

The Alzheimer’s Association is a national, nonprofit association with a network of local chapters that provide education and support for people diagnosed with Alzheimer’s disease, their families, and caregivers. The Association also supports research on Alzheimer’s.

Alzheimer’s Foundation of America
322 Eighth Avenue, 7th Floor
New York, NY 10001
1-866-232-8484 (toll-free)
www.alzfdn.org

The Alzheimer’s Foundation of America provides care and services to individuals confronting dementia and to their caregivers and families through member organizations dedicated to improving quality of life. Services include a toll-free hotline, consumer publications and other educational materials, and conferences and workshops.
Children of Aging Parents
P.O. Box 167
Richboro, PA 18954-0167
1-800-227-7294 (toll-free)
www.caps4caregivers.org

This nonprofit group provides information and materials for adult children caring for their older parents. Caregivers of people with Alzheimer’s disease also may find this information helpful.

Eldercare Locator
1-800-677-1116 (toll-free)
www.eldercare.gov

Eldercare Locator is a nationwide directory-assistance service helping older people and their caregivers locate local support and resources. It is funded by the U.S. Administration on Aging (AoA). AoA’s website at www.aoa.gov offers information about caregiving, working with and providing services to people with Alzheimer’s, and where to look for support and assistance.

Family Caregiver Alliance
180 Montgomery Street, Suite 1100
San Francisco, CA 94104
1-800-445-8106 (toll-free)
www.caregiver.org

Family Caregiver Alliance is a nonprofit organization that offers support services and information for people caring for adults with Alzheimer’s, stroke, traumatic brain injuries, and other cognitive disorders. Programs and services include an information clearinghouse for FCA’s publications.
The NIA Information Center offers a variety of information about health and aging. To order publications in English or Spanish or to sign up for regular email alerts, visit www.nia.nih.gov/HealthInformation. Visit NIHSeniorHealth (www.nihseniorhealth.gov), a senior-friendly website from NIA and the National Library of Medicine. This website has health information for older adults. Special features make it simple to use. For example, you can click on a button to have the text read out loud or to make the type larger.

The National Family Caregivers Association helps educate and support people who care for loved ones with chronic illness, disability, or the frailties of old age. The Association offers an online library of information and educational materials, workshops, and other resources.
National Hospice and Palliative Care Organization
1731 King Street, Suite 100
Alexandria, VA 22314
1-800-658-8898 (toll-free)
www.nhpco.org

This nonprofit organization works to enhance the quality of life for people who are terminally ill. It provides information, resources, and referrals to local hospice services and offers publications and online resources.

Simon Foundation for Continence
P.O. Box 815
Wilmette, IL 60091
1-800-237-4666 (toll-free)
www.simonfoundation.org

The Simon Foundation for Continence helps individuals with incontinence, their families, and the health professionals who provide their care. The Foundation provides books, pamphlets, tapes, self-help groups, and other resources.

Well Spouse Association
63 West Main Street, Suite H
Freehold, NJ 07728
1-800-838-0879 (toll-free)
www.wellspouse.org

This nonprofit membership organization gives support to spouses and partners of the chronically ill and/or disabled. It offers support groups and a newsletter.
The National Institute on Aging gratefully acknowledges the following Alzheimer’s Disease Centers for their valuable contributions of information in preparation of this Caregiver Guide:

Duke University Joseph and Kathleen Bryan Alzheimer’s Disease Research Center

The Johns Hopkins University Alzheimer’s Disease Center

Contact the ADEAR Center for additional Alzheimer’s disease information, including the free publication Caring for a Person With Alzheimer’s Disease: Your Easy-to-Use Guide from the National Institute on Aging.

Alzheimer’s Disease Education and Referral (ADEAR) Center
1-800-438-4380
www.nia.nih.gov/Alzheimers

The ADEAR Center is a service of the National Institute on Aging National Institutes of Health
## Support Group Directory

**KEY:**  
- **AC** - Adult Children  
- **B** - Bereavement  
- **BS** - Bereavement Spanish  
- **C** - Contact Person  
- **CG** - Caregivers  
- **DS** - Caregivers of Down Syndrome  
- **PWD** - Persons with Dementia  
- **EC** - Early Stage Caregivers  
- **EP** - Early Stage Persons  
- **EO** - Early On-Set Persons  
- **FB** - Faith Based  
- **FT** - Frontal Temporal Caregivers  
- **GL** - Gay & Lesbian  
- **L** - Group Leader  
- **M** - Male Caregivers  
- **P** - Parkinson’s Caregivers  
- **YO** - Young On-Set Caregivers  
- **$** - Inquire about Fee/Donation

*Affiliated - Support Groups that choose to affiliate with the Alzheimer’s Association have facilitators who are trained by the Association, cleared the Association’s criminal background checks, and agree to our quality assurance specifications. These facilitators receive continuing education in Alzheimer’s/dementia related topics and have access to clinical guidance and support. Although the Alzheimer’s Association, California Southland Chapter, lists all available groups in our Resource Directory (in an effort to provide consumers with a range of choices), we do not endorse non-affiliated support groups.

<table>
<thead>
<tr>
<th>City</th>
<th>Group Location/Name</th>
<th>Leader and/or Contact</th>
<th>Phone Number</th>
<th>Group Type</th>
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<tbody>
<tr>
<td>Antelope Valley</td>
<td>Lancaster Adult Day Care</td>
<td>Sheila Wright</td>
<td>661-948-1228</td>
<td>CG</td>
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<tr>
<td>Santa Clarita</td>
<td>Santa Clarita Senior Center</td>
<td>Judith Harris</td>
<td>661-259-9444</td>
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<td></td>
<td>Summerhill Villa</td>
<td>Mary Dembkowski</td>
<td>661-254-9933</td>
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<tr>
<td>San Fernando Valley</td>
<td>Agoura Hills Hope Connection</td>
<td>General Number</td>
<td>818-788-4673</td>
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<td></td>
<td>Burbank Joslyn Adult Center</td>
<td>Sami Lomax</td>
<td>818-238-5353</td>
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<td></td>
<td>Burbank Leeza’s Care Connection</td>
<td>Stefanie Elkins</td>
<td>818-847-3686</td>
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<td>Calabasas Silverado Senior Living</td>
<td>Etta Martin</td>
<td>818-222-1000</td>
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<td></td>
<td>Chatsworth Private Home - Recreation Room</td>
<td>Ronena Summers</td>
<td>310-927-5579</td>
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<td>Granada Hills Aegis Living</td>
<td>Jeri Lynn Posner</td>
<td>818-776-1183</td>
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<td>Northridge Emeritus</td>
<td>Carol Sue Selinger</td>
<td>818-499-1194</td>
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<td>Northridge Pacifica Senior Living</td>
<td>Jennifer Watson</td>
<td>818-317-3421</td>
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<td></td>
<td>Northridge Memory Club/ Grad Club/ Alumni</td>
<td>Gabriella Ruiz</td>
<td>818-830-4834</td>
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<td></td>
<td>Northridge Alzheimer’s Assn. Greater San</td>
<td>Francisca Reynoso</td>
<td>818-398-1475</td>
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<td></td>
<td>Northridge Alzheimer’s Assn. Greater San</td>
<td>Sharon Trocki-Miller</td>
<td>818-842-9602</td>
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<td>Northridge Northridge Hospital</td>
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<td>Pacoima</td>
<td>Pacioma Alicia Broadous-Duncan MPSC</td>
<td>Kenn Hicks</td>
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<td>Reseda Fountainview</td>
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<td>Reseda Jewish Home for the Aging</td>
<td>L: Carol Sue Selinger</td>
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<td>C: Susan Leitch</td>
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<td></td>
<td>L: Elissa Brown</td>
<td>818-891-7711 x7320</td>
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<td>Studio City Sunrise Senior Living</td>
<td>Jennifer Watson</td>
<td>818-317-3421</td>
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*List current as of 2/18/2014*  
*For changes to the listings or to become affiliated with the Alzheimer’s Association contact Nicole Feingold at (323) 930-6256*  
*Affiliated Support Groups*
### San Fernando Valley (continued)

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<td>Sylmar</td>
<td>LA Caregiver Resource Center (LACRC)</td>
<td>Lake View Terrace Library</td>
<td>L: Alayna Tillman</td>
<td>800-540-4442</td>
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<td>C: General # LACRC</td>
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<td>Van Nuys</td>
<td>Private Home</td>
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<td>Nancy Kunin</td>
<td>818-344-7070</td>
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<tr>
<td>West Hills</td>
<td>The Gardens at Park Balboa</td>
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<td>Susan Menkes</td>
<td>818-787-0462</td>
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<td>West Hills</td>
<td>Onegeneration Adult Day Care</td>
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<td>Denise Kee-White</td>
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<tr>
<td>West Hills</td>
<td>Calvery Church</td>
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<td>Frances Malcom</td>
<td>818-883-1532</td>
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<tr>
<td>Woodland Hills</td>
<td>Woodland Hills Office</td>
<td></td>
<td>Karin Marin</td>
<td>818-734-9991</td>
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### San Gabriel Valley

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<tr>
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<tbody>
<tr>
<td>Azusa</td>
<td>Silverado Sierra Vista</td>
<td>Linda Thyberg</td>
<td>626-812-9777</td>
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<td>Glendora</td>
<td>La Fetra Senior Center</td>
<td>Patti Schaub</td>
<td>626-963-6000</td>
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<td>Glendora</td>
<td>La Fetra Senior Center - After Stroke</td>
<td>Toni Levysohn</td>
<td>909-843-5239</td>
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<tr>
<td>Monterey Park</td>
<td>Chinatown Service Center</td>
<td>Mary Hsieh</td>
<td>626-293-8733</td>
<td>CG, Cantonese, *</td>
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<tr>
<td>Pasadena</td>
<td>Alzheimer's Assoc.'s Memory Club at Huntington Hospital</td>
<td>Kristen Tachiki</td>
<td>626-397-3110 x4428</td>
<td>EP, EC, *</td>
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<td>Pasadena</td>
<td>Brookside Golf Club</td>
<td>Diane Fortner</td>
<td>626-460-3413</td>
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<td>Pasadena</td>
<td>CAPS Adult Day Care Center</td>
<td>Mimi Brown</td>
<td>626-351-5427</td>
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<tr>
<td>Pasadena</td>
<td>Terrace at Park Marino</td>
<td>Carol Sue Selinger</td>
<td>818-499-1194</td>
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<td>San Gabriel</td>
<td>Vista Cove</td>
<td>Brenda Nicolas</td>
<td>626-289-8889</td>
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<tr>
<td>San Gabriel</td>
<td>Mission Lodge</td>
<td>Lawrence Schulte</td>
<td>626-795-8681</td>
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<tr>
<td>San Gabriel</td>
<td>Sunrise Senior Living - San Marino</td>
<td>Carol Sue Selinger</td>
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<tr>
<td>South Pasadena</td>
<td>Persona Neurobehavior Group</td>
<td>Mona Mikael</td>
<td>626-449-2484</td>
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<tr>
<td>West Covina</td>
<td>CAPS Adult Day Service Center</td>
<td>L: Janine Drulay</td>
<td>626-917-4484</td>
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<tr>
<td>West Covina</td>
<td>West Covina Senior Center</td>
<td>Patti Schaub</td>
<td>626-963-6000</td>
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### Metro Los Angeles

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<tr>
<td>Beverly Hills</td>
<td>Sunrise Senior Living</td>
<td>Gayla Scoll</td>
<td>310-387-0269</td>
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<tr>
<td>Hollywood</td>
<td>Triangle Square</td>
<td>Blossom Vernon</td>
<td>323-957-3900 x116</td>
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<tr>
<td>Los Angeles</td>
<td>Chinatown Service Center</td>
<td>L: Sina Ma</td>
<td>626-293-8733</td>
<td>CG, Chinese</td>
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<td></td>
<td></td>
<td>C: Fung-Lan Wong</td>
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<tr>
<td>Los Angeles</td>
<td>Kaiser Culver Marina Medical Office</td>
<td>Ed Holly</td>
<td>310-915-4567</td>
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<td>Los Angeles</td>
<td>Kaiser West LA Medical Center</td>
<td>JB Saunders</td>
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<td>Los Angeles</td>
<td>Leeza's Place at Olympia Medical Center</td>
<td>Stefanie Elkins</td>
<td>323-932-5414</td>
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<tr>
<td>Los Angeles</td>
<td>Little Tokyo Service Center - St. Francis Xavier Chapel</td>
<td>Kiyoko Kaneda</td>
<td>213-473-3035</td>
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<td>Los Angeles</td>
<td>Alzheimer's Association Male Caregiver Support Group</td>
<td>Dan Field</td>
<td>213-359-7722</td>
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<tr>
<td>Los Angeles</td>
<td>Memory/ Grad Club/ Alumni at the Alzheimer's Assn.</td>
<td>Amy Landers</td>
<td>323-930-6289</td>
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<tr>
<td>Los Angeles</td>
<td>Silverado Senior Living - Beverly Place</td>
<td>L &amp; C: Arpine Vardumy</td>
<td>323-582-9200</td>
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<tr>
<td>Los Angeles</td>
<td>Solheim Lutheran Home</td>
<td>L &amp; C: Sherry Wait &amp; Kari Stenberg</td>
<td>323-257-7518</td>
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List current as of 2/18/2014

*Affiliated Support Groups
### West Los Angeles

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<tr>
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<th>Contact Person(s)</th>
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<tr>
<td>Culver City</td>
<td>Culver City Senior Center</td>
<td>L: Tanya Kaplan, C: Darren Uhl</td>
<td>310-253-6729</td>
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<tr>
<td>Culver City</td>
<td>Grandview Palms</td>
<td>Judith Delaney</td>
<td>310-459-9053</td>
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<tr>
<td>Los Angeles</td>
<td>OPICA Adult Day Center</td>
<td>Anne Galbraith</td>
<td>310-478-0226</td>
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<tr>
<td>Pacific Palisades</td>
<td>Sunrise Senior Living</td>
<td>Judith Delaney</td>
<td>310-459-9053</td>
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<tr>
<td>Santa Monica</td>
<td>Beyond Alzheimer's - UCLA Medical Center, Santa Monica</td>
<td>C: Katherine Serrano</td>
<td>310-319-3222</td>
<td>CG</td>
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<tr>
<td>Santa Monica</td>
<td>WISE &amp; Healthy Aging</td>
<td>C: Heidi Yates</td>
<td>310-394-9871</td>
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<tr>
<td>Westwood</td>
<td>Belmont Village</td>
<td>L &amp; C: Gayla Scoll, C: Chris Schroeder</td>
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<td>310-475-7501</td>
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<tr>
<td>Westwood</td>
<td>Beyond Alzheimer's - Ronald Reagan UCLA Medical Center</td>
<td>C: Katherine Serrano</td>
<td>310-319-3222</td>
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<tr>
<td>Westwood</td>
<td>UCLA - Mary S. Easton Center</td>
<td>L: Barbara Hament, C: Doug Hawkins</td>
<td>310-794-6039</td>
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### South Los Angeles

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<td>USC - Tingstad Counseling Center</td>
<td>Anne Katz</td>
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### East Los Angeles

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<tr>
<td>Bell Gardens</td>
<td>Human Services Assoc. Day Care</td>
<td>Terry Terriqez</td>
<td>562-806-5400 x154</td>
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<tr>
<td>Huntington Park</td>
<td>Huntington Park Public Library</td>
<td>Joseph Herrera</td>
<td>323-881-0574</td>
<td>CG, Spanish, *</td>
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<tr>
<td>Los Angeles</td>
<td>Alzheimer’s Association</td>
<td>Joseph Herrera</td>
<td>323-859-8808</td>
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<tr>
<td>Montebello</td>
<td>Beverly Hospital</td>
<td>Alice Baldwin</td>
<td>323-725-5033</td>
<td>CG, B</td>
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<tr>
<td>Whittier</td>
<td>Presbyterian Intercommunity Medical Center</td>
<td>Debbie Gasmen</td>
<td>562-698-0811 x12453</td>
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<tr>
<td>Whittier</td>
<td>Whittier Place Senior Living</td>
<td>Tina Hernandez</td>
<td>714-856-3909</td>
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### South Bay

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<tr>
<td>Harbor City</td>
<td>Kaiser S. Bay Medical Center</td>
<td>Mahogany Joseph</td>
<td>310-832-6031 x115</td>
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<tr>
<td>Inglewood</td>
<td>Inglewood Senior Center</td>
<td>Linda Peterson</td>
<td>310-412-5338</td>
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<tr>
<td>Long Beach</td>
<td>Brittany House</td>
<td>Anita Cirifalco</td>
<td>562-421-4717</td>
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<tr>
<td>Los Alamitos</td>
<td>St. Hedwig’s Church</td>
<td>Paty Piar</td>
<td>562-795-5762</td>
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<tr>
<td>Rancho Palos Verdes</td>
<td>Belmont Village</td>
<td>David Hart</td>
<td>562-315-8582</td>
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<tr>
<td>Rancho Palos Verdes</td>
<td>Peninsula Seniors</td>
<td>Pamela Maury</td>
<td>310-562-6450</td>
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<td>Rolling Hills Estate</td>
<td>Palos Verdes Penninsula Center Library</td>
<td>Krista Emery</td>
<td>310-376-3205</td>
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<td>Redondo Beach</td>
<td>Beach Cities Health District</td>
<td>Officer of the Day</td>
<td>310-374-3426 x155</td>
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<td>San Pedro</td>
<td>The Salvation Army Sage House Adult Day Care Center</td>
<td>Mahogany Joseph</td>
<td>310-832-6031 x115</td>
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<tr>
<td>Signal Hill</td>
<td>Willow Wellness Center</td>
<td>L &amp; C: Stephanie Ford &amp; Mike Skullr</td>
<td>562-506-0000</td>
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<tr>
<td>Torrance</td>
<td>Always Best Care Senior Services</td>
<td>David Hart</td>
<td>562-315-8582</td>
<td>CG, *</td>
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<tr>
<td>Torrance</td>
<td>Torrance Memorial - Parkinson's Discussion Group</td>
<td>Jackie LaBouff</td>
<td>310-346-6252</td>
<td>P &amp; PWD</td>
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<td>Torrance</td>
<td>Little Tokyo Service Center - Victory Fellowship</td>
<td>Akiko Takeda</td>
<td>213-473-3035</td>
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List current as of 2/18/2014

*Affiliated Support Groups
## Coachella Valley

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<td>Blythe</td>
<td>Blythe Senior Center</td>
<td>Donna Sam</td>
<td>661-331-4880</td>
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<td>Cathedral City</td>
<td>The Cathedral Center</td>
<td>Kay Perryman</td>
<td>760-820-1430</td>
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<tr>
<td>Coachella</td>
<td>Coachella Senior Center</td>
<td>Teresa Segovia</td>
<td>760-328-6767</td>
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<tr>
<td>Desert Hot Springs</td>
<td>&quot;The Space&quot; Desert Hot Springs</td>
<td>Kay Perryman</td>
<td>760-820-1430</td>
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<td>Indio</td>
<td>Indio Senior Center</td>
<td>L: Toni Renoos C: Nancy Vance</td>
<td>760-391-4170</td>
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<tr>
<td>Joshua Tree</td>
<td>High Desert Medical Center - Hospice of Morongo Basin</td>
<td>L &amp; C: Gloria Beetle &amp; Peggy Kennedy</td>
<td>760-366-6424</td>
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<td>La Quinta</td>
<td>Caleo Bay Alzheimer's Special Care Center</td>
<td>L: Linda Carmi &amp; Diane Kelly C: Dee Wieringa</td>
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<td>La Quinta</td>
<td>La Quinta Senior Center</td>
<td>Diane Kelly</td>
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<tr>
<td>Mecca</td>
<td>Mecca Family Resource Center</td>
<td>Teresa Segovia</td>
<td>760-328-6767</td>
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<td>Atria Hacienda</td>
<td>Joanne Demers</td>
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<td>Center for Spiritual Living</td>
<td>Kae Hammond</td>
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<td>Eisenhower Five Star Club</td>
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<td>Mizell Senior Center</td>
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<td>Roswitha Smale</td>
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<td>Anne Gimble</td>
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<td>Rancho Mirage</td>
<td>Mission Hills Senior Living</td>
<td>L &amp; C: Jennifer Morton &amp; Heidi Nielsen</td>
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<tr>
<td>Rancho Mirage</td>
<td>Vista Cove</td>
<td>Pat Kaplan</td>
<td>760-568-9221</td>
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<td>Sun City/Palm Desert</td>
<td>Lakeview Clubhouse - Gated Property</td>
<td>Beverly Yahr</td>
<td>760-200-4410</td>
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## Inland Empire

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<tr>
<td>Apple Valley</td>
<td>Valley Crest Residential Care</td>
<td>L: Renee Lesley C: Veronica Fuentes</td>
<td>760-242-3188</td>
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<td>Big Bear Lake</td>
<td>Senior Center of Big Bear Valley</td>
<td>Mary Andresen</td>
<td>909-585-7958</td>
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</tr>
<tr>
<td>Canyon Crest</td>
<td>Sunrise Senior Living</td>
<td>L: Paul Velen L: Viola Kaake C: Mary Taber</td>
<td>951-686-6075</td>
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<tr>
<td>Chino</td>
<td>Chino Senior Center</td>
<td>Ashley Nielsen</td>
<td>909-399-5488</td>
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<tr>
<td>Chino Hills</td>
<td>Chino Valley Community Church</td>
<td>L &amp; C: Lloyd Mustin L: Lisa Laufer</td>
<td>909-270-0866</td>
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<tr>
<td>Claremont</td>
<td>Claremont Joslyn Senior Center</td>
<td>C: Ashley Nielsen</td>
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<td>Claremont</td>
<td>Claremont Place</td>
<td>Angelika Prittet</td>
<td>909-447-5259</td>
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<td>Claremont</td>
<td>Claremont Club</td>
<td>Laura Van Dran</td>
<td>909-921-1033</td>
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<tr>
<td>Corona</td>
<td>Emeritus Assisted Living</td>
<td>L &amp; C: Karen Branson &amp; Stefanie Hohenschelt</td>
<td>951-898-6991</td>
<td>CG</td>
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<tr>
<td>Grand Terrace</td>
<td>Emeritus Assisted Living</td>
<td>Paul Velen</td>
<td>951-290-0760</td>
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<tr>
<td>Norco</td>
<td>New Day Christian Church</td>
<td>L &amp; C: Heather Case L &amp; C: Sarah Sims</td>
<td>909-815-7645 714-488-6402</td>
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<tr>
<td>Ontario</td>
<td>West End Family Counseling Services</td>
<td>Denise Christensen</td>
<td>909-983-2020 x2231</td>
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<tr>
<td>Rancho Cucamonga</td>
<td>Alzheimer’s Association &amp; Home Instead Senior Care</td>
<td>L: Sergio Calderon L: &amp; C: Leticia Vazquez</td>
<td>909-476-9030</td>
<td>CG, *</td>
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*Affiliated Support Groups
### Inland Empire (continued)

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<td>Redlands</td>
<td>Somerford Place Assisted Living</td>
<td>Jennifer Castaneda</td>
<td>909-793-9500</td>
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<tr>
<td>Riverside</td>
<td>Community Care on Palm</td>
<td>Laurie Gibson</td>
<td>951-686-9001 x27</td>
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<tr>
<td>Riverside</td>
<td>Pacifica Senior Living</td>
<td>L: Jill Johnson</td>
<td>951-360-1616</td>
<td>CG, *</td>
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<tr>
<td>Riverside</td>
<td>L: Patty Roach</td>
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</tr>
<tr>
<td>Riverside</td>
<td>Raincross at Riverside</td>
<td>L: Ruthie Daniel</td>
<td>951-785-1200</td>
<td>CG, *</td>
</tr>
<tr>
<td>Riverside</td>
<td>L: Lowa Anderson</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Victorville</td>
<td>Sterling Commons</td>
<td>Debra Newlin</td>
<td>760-245-3300</td>
<td>CG</td>
</tr>
</tbody>
</table>

### SW Riverside County

<table>
<thead>
<tr>
<th>Location</th>
<th>Facility Name</th>
<th>Contact Person</th>
<th>Phone</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beaumont</td>
<td>Beaumont Senior Center</td>
<td>Kay Perryman</td>
<td>951-658-7617</td>
<td>CG</td>
</tr>
<tr>
<td>Canyon Lake</td>
<td>Canyon Lake Community Church</td>
<td>L: JoAnn Wickerath</td>
<td>951-244-1877 x200</td>
<td>CG</td>
</tr>
<tr>
<td></td>
<td>C: Church Office</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hemet</td>
<td>Desert Hills Memory Care Center</td>
<td>Jane Farmer</td>
<td>951-652-1837</td>
<td>CG, *</td>
</tr>
<tr>
<td>Hemet</td>
<td>Daybreak Senior Service Center</td>
<td>Kay Perryman</td>
<td>951-658-7617</td>
<td>CG</td>
</tr>
<tr>
<td>Murrieta</td>
<td>Lillibet’s Place Adult Day Center</td>
<td>Elizabeth Whittington</td>
<td>951-219-1739</td>
<td>CG, *</td>
</tr>
<tr>
<td>Murrieta</td>
<td>Murrieta Gardens</td>
<td>Elizabeth Whittington</td>
<td>951-219-1739</td>
<td>CG, *</td>
</tr>
<tr>
<td>Murrieta</td>
<td>The Colony Clubhouse</td>
<td>Carol Bradshaw</td>
<td>951-719-0056</td>
<td>CG, *</td>
</tr>
<tr>
<td>Sun City/Menifee</td>
<td>Kay Cisneros Senior Center</td>
<td>Tiffany Kenny</td>
<td>951-672-9536</td>
<td>CG</td>
</tr>
<tr>
<td>Temecula</td>
<td>Atria at Vintage Hills</td>
<td>Carol Bradshaw</td>
<td>951-719-0056</td>
<td>CG</td>
</tr>
<tr>
<td>Temecula</td>
<td>Rancho Community Church</td>
<td>Elizabeth Whittington</td>
<td>951-219-1739</td>
<td>CG, *</td>
</tr>
</tbody>
</table>

### Tulare County

<table>
<thead>
<tr>
<th>Location</th>
<th>Facility Name</th>
<th>Contact Person</th>
<th>Phone</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Porterville</td>
<td>Porterville Adult Day Services</td>
<td>L: Gail Nelson</td>
<td>559-783-9815</td>
<td>B, CG, Spanish</td>
</tr>
<tr>
<td></td>
<td>C: Cheri Taylor</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visalia</td>
<td>Prestige Assisted Living</td>
<td>Helen Hurley</td>
<td>559-735-0828</td>
<td>CG</td>
</tr>
<tr>
<td>Visalia</td>
<td>Quail Park Retirement Village</td>
<td>L: Linda Hewett</td>
<td>559-624-3500</td>
<td>CG</td>
</tr>
<tr>
<td></td>
<td>L: Kate McCorkle</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>C: Main # of Facility</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Telephone Support Groups

<table>
<thead>
<tr>
<th>Location</th>
<th>Support Group</th>
<th>Contact Person</th>
<th>Phone</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Entire Chapter</td>
<td>Caregiver Telephone Support Group</td>
<td>Ronena Summers</td>
<td>310-927-5579</td>
<td>CG, *</td>
</tr>
</tbody>
</table>

To find a Support Group in Orange County call 949-955-9000 or visit: www.alz.org/oc
To find a Support Group in Ventura County call 805-892-4259 or visit: www.alz.org/cacentralcoast

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### TrialMatch

**Calling All Heroes!**

Don’t just hope for a cure. Help us find one. Participate in a clinical trials.

Alzheimer’s Association TrialMatch is a free service which matches persons with dementia, healthy volunteers and caregiver to ongoing clinical trials based on personal criteria such as diagnosis, stage of disease, and location.

For more information visit: alz.org/trialmatch | (800) 272-3900

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For changes to the listings or to become affiliated with the Alzheimer’s Association contact Nicole Feingold at (323) 930-6256

List current as of 2/18/2014

*Affiliated Support Groups*
<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Quite Frequently</th>
<th>Nearly Always</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Do you feel that your relative asks for more help than he/she needs?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>4. Do you feel embarrassed over your relative's behaviour?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>5. Do you feel angry when you are around your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>6. Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>7. Are you afraid what the future holds for your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>8. Do you feel your relative is dependent on you?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>9. Do you feel strained when you are around your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>10. Do you feel your health has suffered because of your involvement with your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>11. Do you feel that you don't have as much privacy as you would like because of your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>12. Do you feel that your social life has suffered because you are caring for your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>13. Do you feel uncomfortable about having friends over because of your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
</tbody>
</table>
14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on? | 0 | 1 | 2 | 3 | 4

15. Do you feel that you don’t have enough money to take care of your relative in addition to the rest of your expenses? | 0 | 1 | 2 | 3 | 4

16. Do you feel that you will be unable to take care of your relative much longer? | 0 | 1 | 2 | 3 | 4

17. Do you feel you have lost control of your life since your relative's illness? | 0 | 1 | 2 | 3 | 4

18. Do you wish you could leave the care of your relative to someone else? | 0 | 1 | 2 | 3 | 4

19. Do you feel uncertain about what to do about your relative? | 0 | 1 | 2 | 3 | 4

20. Do you feel you should be doing more for your relative? | 0 | 1 | 2 | 3 | 4

21. Do you feel you could do a better job in caring for your relative? | 0 | 1 | 2 | 3 | 4

22. Overall, how burdened do you feel in caring for your relative? | 0 | 1 | 2 | 3 | 4

Total Score (out of 88)

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Interpretation of Score:
0 – 21 little or no burden
21 – 40 mild to moderate burden
41 – 60 moderate to severe burden
61 – 88 severe burden

Score values and interpretation are guidelines only, as discussed in: