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# **A Guide to Supporting Family Caregivers Through the Alzheimer's Disease Trajectory: Grief and Personal Growth**

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**An Education and Resource Manual**

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Graphic design: Susan McKay, UW–Milwaukee, Visual Design Services

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### **Acknowledgements**

We gratefully acknowledge the Helen Bader Foundation and the Extencicare Foundation for funding this work. Thank you also to the UW–Milwaukee Center on Age and Community, the UW–Milwaukee Center on Addiction and Behavioral Health Research, and the UW–Milwaukee College of Nursing for supporting this research.

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# INTRODUCTION

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Caregivers of persons with Alzheimer's disease and related dementias (ADRD) experience many losses as their family member progresses through the long trajectory of this chronic disease. As a health care provider, you may encounter these caregivers at any point during the patient's illness.

This manual is based on results of a study entitled "Grief and Personal Growth in Spouses and Adult Children of Persons with Alzheimer's Disease." The 201 participants generously shared their experiences of being a long-term care provider, in the hope that their suggestions would assist other families who are going through similar experiences. They also expressed the hope that their insights would result in improvements in health care for persons with ADRD and their families. We dedicate this manual to the many participants who shared their most intimate thoughts and feelings about the impact of dementia on their lives.

The purpose of this manual is to assist healthcare professionals in providing more sensitive care to patients with ADRD and their families. To achieve that goal, these are the topics discussed in the following chapters:

- A summary of current research on the grieving process in family members of persons with ADRD
- Specific findings from the study, "Grief and Personal Growth in Spouses and Adult Children of Persons with Alzheimer's Disease"
- Methods to assess caregiver grief
- Discussion of the needs of patients and caregivers in relation to the stages of dementia of their family member
- Examples of what services and type of support caregivers found helpful from health care providers and suggestions for improvement
- Resources that may be helpful to both health care providers and caregivers



## FORWARD

### What is Grief for Alzheimer's Caregivers?

*Sara Sanders, PhD, LSW*

Grief is the expression of emotional reactions associated with the losses in the relationship with a person with Alzheimer's disease, which can take on physical, psychological, cognitive, and affective forms.<sup>1,2</sup> The grieving process involves symptoms such as changes in sleep patterns, crying, sadness and longing, weight changes, problems concentrating and focusing, as well as anger and frustration.<sup>1</sup> Attachment theory has commonly been used to examine the reasons for strong grief reactions following a loss. Adults, like children, seek out bonded or attached relationships with others in an attempt to promote safety and security.<sup>3</sup> When safety and security of the attachment in the relationship is threatened, the person has an emotional reaction and suffers from feelings of loss and grief. Situations that threaten affectional bonds, such as prolonged caregiving, may trigger a variety of feelings including grief.<sup>2</sup>

Nancy Mace and Peter Rabins<sup>4</sup> in the *36 Hour Day* inferred that the grief of caregivers does not subside as it does with other losses, but instead, it continues throughout the duration of the disease. The losses associated with Alzheimer's disease have been characterized in research as similar to those associated with a death. Researchers have identified that grief reactions in caregivers are affected by the social stigma that comes from the disease process and the societal view that grieving the loss of a loved one prior to the actual death impedes the continuation of the relationship and, therefore, is inappropriate.<sup>5,6</sup>

Specific attention to grief did not develop until the early to mid-1990s. The research that has been conducted, however, has determined that grief in caregivers typically develops as a result of changes in the caregiving situation, such as placement in a long-term care facility, or mental, cognitive, or physical declines in the caregiver and/or care recipient.<sup>7,8,5</sup> "The emotional responses of spouses caring for dementia patients are very similar to those experienced by people who have lost their loved ones through death, in that they experience the psychological reactions normally associated with grief."<sup>8</sup>

The grief experienced by caregivers of people with Alzheimer's disease has often been classified by the overwhelming sense of loss that the caregivers experience on a daily basis, commonly called the "long goodbye." Caregivers experience a variety of losses including the loss of relationship between themselves and the care recipient, the loss of social interaction, the loss of closure on a variety of relationship issues, the losses associated with the caregivers' physical and mental health, and finally the losses that accompany institutionalization.

**Grief responses.** A range of emotional reactions are expressed in the grief response of caregivers of individuals with Alzheimer's disease. Many caregivers feel intense sadness throughout the duration of the caregiving period. These feelings have been associated with events such as the loss of recognition experienced by their loved one. Grief is often misdiagnosed as clinical depression in caregivers of individuals with Alzheimer's disease. Other emotions have also been found to co-exist with caregiver grief. Sadness, guilt, and anger have been identified as prevalent in the grief of caregivers.

The post-death grief of caregivers has been shown to be directly related to the amount of stress or burden they felt during the caregiving period. Caregiver

#### Comment from an adult child:

"I think when you lose somebody through death, you have that grief right there. And then after a while time kind of takes the sting away. But when you're dealing with somebody with Alzheimer's, you're reminded of what you have lost all the time. Sometimes mom doesn't know who I am and sometimes she's very angry and that's just typical of the disease. And even though rationally I know that it's the disease, it's like you wonder well why, you know why is that happening, you don't like it but you have to deal with it."

stress and burden is a significant predictor of grief or bereavement strain. Perceived support prior to the death of the care recipient has a strong impact on the caregivers grief reactions post death. Professional intervention has a strong impact on bereavement outcomes.<sup>9</sup> Unaddressed emotional aspects of grief can often lead to a state of chronic sorrow. “The realization of the pervasiveness of the caregiving responsibilities and the recognition that there was no end in sight was identified repeatedly by caregivers as triggering grief-related feelings.”<sup>10</sup>

Grief is complicated by a sense of ambivalence felt by the caregivers. A sense of ambivalence has been found in the grief of the caregivers, which was demonstrated by the caregivers wanting the actual death to occur, while at the same time striving to maintain a close relationship with their loved one for as long as possible. The grief of caregivers of people with Alzheimer’s can be complicated by the inability to determine if the person with the dementia is “absent or present, dead or alive.”<sup>11</sup>

**Length of time caregiving and grief.** Length of time caregiving has briefly been identified as a factor that impacts the grief of caregivers. Caregivers experience a grief reaction, as well as other emotions, immediately following the diagnosis; however, over time they develop an increased level of patience and understanding about the changes in the care recipient. Grief has been characterized as fluctuating depending on the symptoms of the disease that the care recipient exhibited or the degree of intimacy that was felt between the caregiver and care recipient. Grief intensifies as the duration of caregiving progressed; however, the grief declined as the death of the person with Alzheimer’s disease approached. The grief experienced by caregivers has been shown to be directly related to location of care. While caregivers of individuals in the nursing home experienced more sadness and guilt, individuals who were providing care at home felt more anger.<sup>8</sup> Caregivers of individuals in nursing homes reported more grief symptoms because they had “more time to dwell on the loss” as a result of the overall stress and burden of caregiving being eliminated.<sup>8</sup> Other researchers found that levels of caregiver grief remained constant throughout the disease process.<sup>12</sup>

**Grief reactions based on gender and relationship status.** Differences in the ways that grief is expressed by caregivers have also received some empirical attention. Grief in women has been characterized by greater despair, anger, loss of control, somatization and death anxiety; while men’s grief has been more associated with denial.<sup>13</sup> Wives expressed more anxiety, sadness and guilt in their grief than did husbands.<sup>8</sup> Much of the anxiety that the wives felt was associated with the variety of losses in the relationship and social roles that they experienced as a result of their husbands’ dementia. Adult children and spousal caregivers differed in grief reactions at each stage of the disease.<sup>14</sup> In the first stage of the disease, adult children expressed more denial and avoidance, while spousal caregivers were more reality based in their grief. During the second stage of Alzheimer’s disease, adult children experienced raw emotions characterized by frustration, guilt, anger and wishing the parent would die; whereas spousal caregivers felt more sadness, empathy and focused on maintaining relational ties with their significant other. Finally, in stage three of Alzheimer’s disease, adult children expressed their grief as loss of relationship with their parent and as a loss of opportunities as a result of their care giving role; while spouses expressed grief at the loss of couple identity, uncertainty, and aloneness.

**Comment from an adult child:**

“There was a huge anger phase. You go back and forth a lot. But there is no particular point at which to grieve. It is just a series of a lot of small deaths. With each big decline you have to go through the whole process again. It becomes very debilitating and that’s the distinction. It just goes on for such a long time.”

Adapted and used with permission.

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# CHAPTER 1

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## Results of the Study “Grief and Personal Growth in Spouses and Adult Children of Persons with Alzheimer’s Disease” with Implications for Health Care Providers

*Carol H. Ott, PhD, RN, LPC*

### About the Study

This study was designed to understand the grief and personal growth experience of spouses and adult children of persons diagnosed with Alzheimer’s disease and related dementias (ADRD). Specifically, we wanted to know about:

- the intensity of grief experienced by caregiving spouses and adult children.
- links between the level of grief and other factors including severity of the disease, social support, ways that people cope, mental health, life satisfaction, and place of residence.
- factors that contribute to higher levels of personal growth in spouses and adult children.
- what family members need from health care providers.

Caregivers (adult children and spouses) completed a survey that included questions about: their grief and depression, how they coped with their situation, whether people were available to provide social support, and how they had grown personally from the care giving experience. Once the survey was completed, caregivers were interviewed. The surveys and interviews were analyzed to answer the research questions.

The participants in the study included 201 volunteers (90 spouses and 111 adult children). Participants learned about the study from support groups, caregiver groups, extended care facilities and community agencies. The table at the end of the chapter further describes the participants.

### Results

- The average age of the participants was 64 (spouse average age was 76; adult child average age was 55).
- Over half of the caregivers developed a new physical illness since their spouse or parent was diagnosed with ADRD.
- About half of the caregivers had attended an ADRD support group and 82% of those attending found it helpful.
- Grief increased for both spouses and adult children as the severity of the disease increased.



**Comment from a spouse:**

"I am thinking about all I have lost and how she can't be part of anything much in my life any more. I think to myself, 'this is so unreal'. This is not the way that I could have imagined how my life would have gone."

**One spouse stated:**

"It's a very difficult disease because of all of the losses that have happened with him. However, I feel my husband was always there for me through the tough times in life. I guess I look at what I am doing for him now (caregiving) and feel this is the one last thing I can do for him. I am a different person since this has happened. I am more sensitive to other people and what is going on with them."

- Participants with high grief scores had more physical and mental health problems than those with lower scores.
- Spouses experienced more heartfelt sadness and longing and generally had higher levels of grief than the adult children.
- For both spouses and adult children, venting of emotions contributed to increased grief.
- For both spouses and adult children, acceptance of the disease, trying to see the situation in a more positive light (reframing) and having a positive state of mind led to decreased grief and more personal growth.
- For spouses, grief increased when planning was used as a coping strategy. The types of plans and decisions that spouses have to make (e.g. placement in adult daycare, assisted living, or nursing home) in the ADRD experience resulted in further losses leading to more grief.
- For adult children, grief increased as the hours of care increased.
- For adult children, burden decreased when the parent with ADRD lived in assisted living, a nursing home or a group home. For spouses, heartfelt sadness and longing and worry and isolation increased when the spouse with ADRD lived in a nursing home or group home.
- The majority of participants experienced personal growth from the caregiving experience with adult children experiencing more personal growth than spouses.
- For adult children, increased social support led to more personal growth. Being disengaged from the situation led to less personal growth.

**Implications and Applications for Health Care Providers**

1. Grief increased as the severity of the disease increased and high levels of grief were associated with more physical and mental health problems.

**Use of Grief Inventory**

- Grief can be assessed intermittently in family members caring for spouses and parents with ADRD from diagnosis to the end of life. The Marwit and Meuser Caregiver Grief Inventory-Short Form (MM-CGISF)<sup>1</sup> is an inventory that provides a total score and scores on three subscales: Heartfelt Sadness and Longing, Worry and Isolation, and Personal Sacrifice Burden (*see Chapter 2 for directions on administration and scoring*).

**Support Groups**

- The MM-CGISF<sup>1</sup> instrument could be administered in a support group setting under the direction of a professional group leader. The group leader would have participants fill out and score the inventory (*see Chapter 2*) followed by a discussion of results in small groups. The items that relate to Personal Sacrifice Burden (e.g. "I will be tied up with this for

who knows how long”) and Worry and Isolation (e.g. “I have nobody to communicate with,” “I spend a lot of time worrying about the bad things to come”) are areas of grief that may be most amenable to change. The group leader could discuss respite and daycare options, thus decreasing feelings of being burdened. To decrease feelings of worry and isolation, the group leader could discuss ways of connecting with others such as continued attendance at a support group and by making connections with others who are in a similar life circumstances. The Heartfelt Sadness and Longing subscale (e.g. “I feel very sad about what this disease has done”) may be more difficult to change because this aspect of grief is a unique process for each person. Group leader’s acknowledgement of the diverse feelings expressed by group members would be recommended.

### Implications of High Grief Scores on the MM-CGISF<sup>1</sup>

- Caregivers with scores above the cutoff points on the MM-CGISF<sup>1</sup> may benefit from supportive counseling and/or referral for professional counseling. Cognitive behavior therapy has been shown to decrease complicated grief in bereaved samples (*see Shear et al.*).<sup>2</sup> Future research needs to determine if these interventions also apply to complications in grief identified prior to the death.
2. For spouses, grief (i.e. sadness and longing and/or worry and isolation) increased when the spouse with ADRD lived in a nursing home or group home and burden did not decrease. Health care professionals such as nurses and social workers need to be aware that spouses may experience increased grief (i.e. sadness and heart-felt longing and/or worry and isolation) when the spouse with ADRD is in a nursing home, group home, or assisted living. In contrast, adult children may feel a sense of relief when the parent lives in an extended care facility.
- Nurses and social workers need to be aware of the possibility of strained family dynamics about placement into an extended care facility. Interventions targeted to the special needs of spouses and adult children should be implemented.
  - Assessment of grief in spouses after placement in an extended care facility is recommended. The MM-CGISF<sup>1</sup> grief inventory provides a way for professionals to assess the family member’s grief after placement (*see Chapter 2*).
  - After nursing home placement, spouses experience additional losses including a loss of control over the care giving situation and loss of the partner’s physical presence in the home. In this study spouses experienced increased sadness and longing and/or worry and isolation when the person with ADRD lived outside of the home. To address these emotional needs, spouses should be invited to continue participation in the care giving role to the extent possible and desired. Extended care staff need to demonstrate, to the spouse that the person with ADRD is receiving competent, compassionate care which may allay some of their worry and isolation.

### One participant commented:

“The staff was so helpful. They helped me realize that there’s really nothing that I could do to make this disease better but then they gave me a list of all these nice little things that I could do with mom such as: don’t overstay your welcome, do smaller things like play a simple card game, play a little board game, play her favorite music, and go for walks. These ideas seem like pretty basic suggestions, however, when you’re upset with the person’s behavior, you don’t think of some of these simple ways to be with a person with Alzheimer’s. You are trying to think of the big thing you can do to make mom better right now.

**Quote from a participant:**

"Humor, it's a release. And we don't want to be sad. Yes it is sad, but we're not and we want to be more optimistic. And we don't want to lose that. This is a very bad situation, but life is not over."

**Comments from a spouse about how she coped with the situation:**

"Yes. I go to Bible study. I write and compose things. I play music. I read excessively. And then, there's a quiet time that I have, sometimes when he's asleep or something like that. And I have a chance to think, and to analyze and to evaluate, and see what can be done that is positive. And try to forget the negative aspect of it."

3. Although emotional disclosure is often regarded as helpful, findings from this study indicate that venting of emotions contributed to higher levels of grief and depression.

- Some participants stated that they did not return to support groups because the leader was unable to move other members beyond the point of introductions and sharing of negative emotions. Continuing education should be provided to group leaders about how to balance the need for self-disclosure in participants tempered with positive reframing.
- Professional health care providers including support group leaders need to consider providing interventions that balance emotional disclosure about unchangeable situations tempered with helping participants identify a positive perspective (e.g. reframing the importance of their care-giving efforts).
- Suppression of grief-related distress may be maladaptive but increasing evidence suggests that rumination over distress is also maladaptive.<sup>2</sup>
- Focusing on the distressing situation distracts a person from active coping efforts. Reframing a stressful situation into more positive terms may lead the person to continue or resume more active, problem-focused coping actions.<sup>4</sup>
- A number of grief intervention studies have demonstrated that cognitive behavioral interventions can be helpful for individuals who ruminate (i.e. engaging in thoughts and behaviors that maintain one's focus on negative emotions and on the possible causes and consequences of those emotions).<sup>2</sup> Rumination impairs a person's motivation to engage in everyday activities that can provide an increase in their sense of control and lift their mood. Encouraging the use of a social support network may be effective in providing support, as well as in solving practical problems which may distract the person from rumination.

4. For both spouses and adult children, a positive state of mind (i.e. being able to focus attention, be productive, be a responsible caretaker, and experience pleasure) contributed to decreased grief and to increased personal growth. Other researchers have found that positive emotions within the context of stress sustains coping efforts, counteracts the negative physiological consequences of stress, elicits social support, and restores depleted social and psychological resources.<sup>3</sup> Moskowitz et.al.<sup>3</sup> found that finding positive meaning in caregiving was associated with less depression over the first 7 months of bereavement.

- Health care providers may help promote positives states of mind by:
  - o having a spouse or adult child describe something that happened in the past week to make the person feel good, that was meaningful, or that helped get them through the day.
  - o aiding the caregiver in solving some of the concrete problems they face as a result of their life situation. By making use of resources within the community for solving problems, such as a loss of finances, caregivers can begin to elicit positive emotions. As one woman in the study stated, "I didn't realize that I could put my home in my own name."

5. For spouses and adult children, acceptance contributed to decreased grief.
- Professionals should work with family members to help them come to an acceptance about the progressive nature of ADRD while providing pertinent information and anticipatory guidance (see Chapters 3, 4, 5, and 7). Acceptance implies a restructuring of one's experience to come to grips with the reality of the situation while integrating the experience into an evolving world view. Acceptance does not imply passive resignation and disengagement from the caregiving role.
6. A recurring theme from the caregiver interviews was the value of receiving information and anticipatory guidance from health care providers. As one spouse stated, "I spent a lot of time in waiting rooms while my wife was ill. I wish someone would have given me information on what the dying process would be like and what would follow."

The information contained in Chapters 3 through 7 is based on what caregivers told us they wanted from health care providers.

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### Comment by an adult child:

"I think it's just hard to cope with the role reversal. That you know your parent is somebody that you always looked to for support and guidance and comfort and now its, you're the one that they depend on you. And you know, it's just hard to sometimes accept that. But I think that that's what you need to get a hold of, is your acceptance of the situation."

**TABLE**  
**Individual Characteristics of Spouse & Adult Children**  
**In Grief Study (N = 201)**

	<b>Total</b> (N=201)	<b>Spouse</b> (n=90)	<b>Adult Child</b> (n=111)
<b>Gender</b>			
Female	80.6%	73.3%	87%
<b>Age</b>	<i>M</i> =64.07 ( <i>SD</i> =13.88)	<i>M</i> =75.54 ( <i>SD</i> =8.75)	<i>M</i> =54.87 ( <i>SD</i> =9.86)
<b>Religious Affiliation</b>			
Protestant	51.3%	59.1%	45.0%
Catholic	35.5%	31.8%	38.5%
Other	13.2%	9.1%	16.5%
<b>Religion a Source of Comfort &amp; Strength</b>	74.6%	82.4%	70.2%
<b>Education</b>			
College Graduate	54.8%	42.9%	62.3%
<b>Other Stressful Life Events</b>	74%	67.8%	79.1%
<b>Health Change Since Diagnosis of Memory Loss</b>	57.7%	65.6%	51.4%
<b>Received Counseling</b>	17.0%	17.8%	16.4%
<b>Attended a Support Group</b>	51.7%	62.2%	43.2%
<b>Support Group Helpful</b>	82%	80%	84.8%

## CHAPTER 2

### Grief Assessment Using the Marwit-Meuser Caregiver Grief Inventory

*Thomas M. Meuser, PhD Washington University*  
*Samuel J. Marwit, PhD University of Missouri-St. Louis*



The Marwit-Meuser Caregiver Grief Inventory Short Form (MM-CGISF) was developed with funding support from the Alzheimer's Association and the authors consider it to be part of the public domain for clinical and supportive care purposes.

The MM-CGISF is based on the authors' Caregiver Grief Model (*see* <sup>1,2,3</sup>) and measures common grief reactions experienced by family caregivers of persons with Alzheimer's disease and other forms of progressive dementia. The MM-CGI has two purposes: (1) to raise awareness about grief reactions that may be overlooked or misattributed to depression; and (2) to provide an individualized grief profile to focus supportive discussion and promote personal healing.

The MM-CGISF is composed of three sub-scales (factors) and a total grief (TG) score:

- |             |   |
|-------------|---|
| Factor 1    | <b>Personal Sacrifice Burden</b><br>(What "I" as the caregiver have had to give up in my life)      |
| Factor 2    | <b>Heartfelt Sadness &amp; Longing</b><br>(True grief factor including sadness and longing)         |
| Factor 3    | <b>Worry &amp; Felt Isolation</b><br>(Uncertainty of how things will turn out and social isolation) |
| Total Grief | Factor 1 + Factor 2 + Factor 3  |

#### General Instructions for Use

The MM-CGISF is appropriate for use in any clinical or supportive care setting where individual attention is available. Although the inventory can be self-scored, we believe it is important for caregivers to discuss and understand their scores in the context of their larger life situation. Personal attention (either 1:1 or in a group format) from a lay or professional counselor is essential for such discussion and understanding.

Until further research data becomes available, interpretation of the MM-CGISF total and sub-scale scores will remain somewhat subjective. As noted in self-scoring instructions on the MM-CGISF form, "high scores may indicate a need for formal intervention or support assistance to enhance coping." Low scores may be indicative of adaptive coping or denial of grief-related issues. Denial can often be adaptive early in a grief process or just after a new loss is recognized. It is when denial continues for months/years that problems can occur.

For example, a caregiver who denies aspects of grief may become depressed over time. An important part of the healing process is awareness of loss-grief concerns by taking the MM-CGISF and plotting individual scores. Talking through the underlying grief issues may help to reduce or even resolve the mood disturbance. It is up to the lay or professional counselor to sort this out on an individual level. The assignment of scores to high, average and low ranges is based on statistics and the meaning of these ranges will differ from person to person.

### **Gender, Caregiver Type & Dementia Stage**

When interpreting MM-CGISF scores, it is important to be aware of how gender and other factors may influence an individual's grief profile. First, women tend to report greater emotional distress on questionnaires than do men. This was true for four scales used in the MM-CGISF validation study<sup>1</sup>: Beck Depression Inventory, Anticipatory Grief Scale, Caregiver Strain Index, and the MM-CGISF Factor 2 – Heartfelt Sadness & Longing. When working with men, it is important to recognize that their internal reactions may be somewhat greater than they initially report. Men in older age cohorts were socialized to keep their emotional needs in the background. It is up to the counselor to gradually tease these out and offer an appropriate level of support. Forcing someone to express feelings is never a good idea, however.

In the validation study for the MM-CGISF<sup>4</sup>, adult-child caregivers reported greater strain from the caregiving role in comparison to their spousal counterparts. This is due, in part, to the fact that children of demented persons often must meet two or more sets of competing demands: maintaining home life while also caring for their parent. Although the physical burdens of care may be greater for adult-children, the emotional burdens (e.g. Heartfelt Sadness & Longing – Factor 2) may be somewhat greater for spousal caregivers.

Grief may be driven by losses that are individual (what I have lost), other-oriented (what my loved one has lost), or conjoint (what is lost in our shared relationship). Our research to date suggests that adult-children and spouse caregivers may be concerned with different types of losses over the course of dementia progression. There appears to be a shift in focus of loss that occurs over time, such that adult-children focus on their own personal losses first then shift to grieving for what the parent has lost and other conjoint issues later. The pattern may be the opposite for spouse caregivers, with other-oriented and conjoint losses carrying more weight early on, only to be followed by grief due to individual losses later.

Grief is also different across stages of dementia progression (mild, moderate, or severe). Validation data showed a steady rise in total grief (TG) across dementia stages for spouse caregivers, but not for adult-children. Nursing Home placement brings high levels of heartfelt sadness and felt isolation for spouse caregivers (MM-CGISF Factors 2 and 3). Adult-Child caregivers reach their peaks in personal sacrifice burden and felt isolation at the moderate stage, months or years prior to placement. Adult-child caregivers appear to demonstrate an overall decline in grief by the severe stage and after nursing home placement. Whereas the adult-child can return to his or her formal life at this point, the spouse caregiver enters a new stage fraught with new fears and challenges.

When working with a grieving caregiver, it is important to consider caregiver type and dementia stage in your assessment process. Adult-children are likely to

experience pronounced distress earlier in dementia progression, especially when care demands are increasing. Spouse caregivers, in contrast, may experience their greatest challenges after nursing home placement, when loss of the marriage is most evident.

### **How to respond?**

Each person recognizes loss and expresses grief differently. An individual approach to provide grief-related support often works better than a less focused group intervention. The MM-CGISF and grief profile are tools to get this process underway. As noted already, it is important to consider the individual characteristics of the caregiver when assessing the qualities of their grief and coping resources. Men may express less raw emotion, yet need the same level of support as women. Adult-children have a very different grief pattern than do spouse caregivers. What is high or low for one person may not translate well to another.

“Good” grief-related support usually involves more listening than talking, an honest dialogue about emotional and life-death issues (especially anger and guilt) and a comfortable pace set to match the caregiver’s openness and coping capabilities.

The authors of this chapter would appreciate hearing your comments on use of the MM-CGISF. Please e-mail them to Dr. Meuser at [meusert@wustl.edu](mailto:meusert@wustl.edu).

## Marwit and Meuser Caregiver Grief Inventory – Short Form

**Instructions:** This inventory is designed to measure the grief experience of current family caregivers of persons living with progressive dementia (e.g., Alzheimer's disease). Read each statement carefully, then decide how much you agree or disagree with what is said. Circle a number 1-5 to the right using the answer key below (For example 1 = Strongly Disagree and 5 = Strongly Agree). It is important that you respond to all items so that the scores are accurate. Scoring rules are listed below.

	<i>Strongly Disagree</i>	<i>Strongly Agree</i>	
I've had to give up a great deal to be a caregiver.	1	2 3 4 5	A
I feel I am losing my freedom.	1	2 3 4 5	A
I have nobody to communicate with.	1	2 3 4 5	C
I have this empty, sick feeling knowing that my loved one is "gone".	1	2 3 4 5	B
I spend a lot of time worrying about the bad things to come.	1	2 3 4 5	C
Dementia is like a double loss...I've lost the closeness with my loved one and connectedness with my family.	1	2 3 4 5	C
My friends simply don't understand what I'm going through.	1	2 3 4 5	C
I long for what was, what we had and shared in the past.	1	2 3 4 5	B
I could deal with other serious disabilities better than with this.	1	2 3 4 5	B
I will be tied up with this for who knows how long.	1	2 3 4 5	A
It hurts to put her/him to bed at night and realize that she/he is "gone".	1	2 3 4 5	B
I feel very sad about what this disease has done.	1	2 3 4 5	B
I lay awake most nights worrying about what's happening and how I'll manage tomorrow.	1	2 3 4 5	C
The people closest to me do not understand what I'm going through.	1	2 3 4 5	C
I've lost other people close to me, but the losses I'm experiencing now are much more troubling.	1	2 3 4 5	B
Independence is what I've lost...I don't have the freedom to go and do what I want.	1	2 3 4 5	A
I wish I had an hour or two to myself each day to pursue personal interests.	1	2 3 4 5	A
I'm stuck in this caregiving world and there's nothing I can do about it.	1	2 3 4 5	A

**Self-Scoring Procedure:** Add the numbers you circled to derive the following sub-scale and total grief scores.  
Use the letters to the right of each score to guide you.

**Personal Sacrifice Burden (A Items)** = \_\_\_\_\_  
(6 Items, M = 20.2, SD = 5.3, Alpha = .83, n = 292)

**Heartfelt Sadness & Longing (B Items)** = \_\_\_\_\_  
(6 Items, M = 20.2, SD = 5.0, Alpha = .80, n = 292)

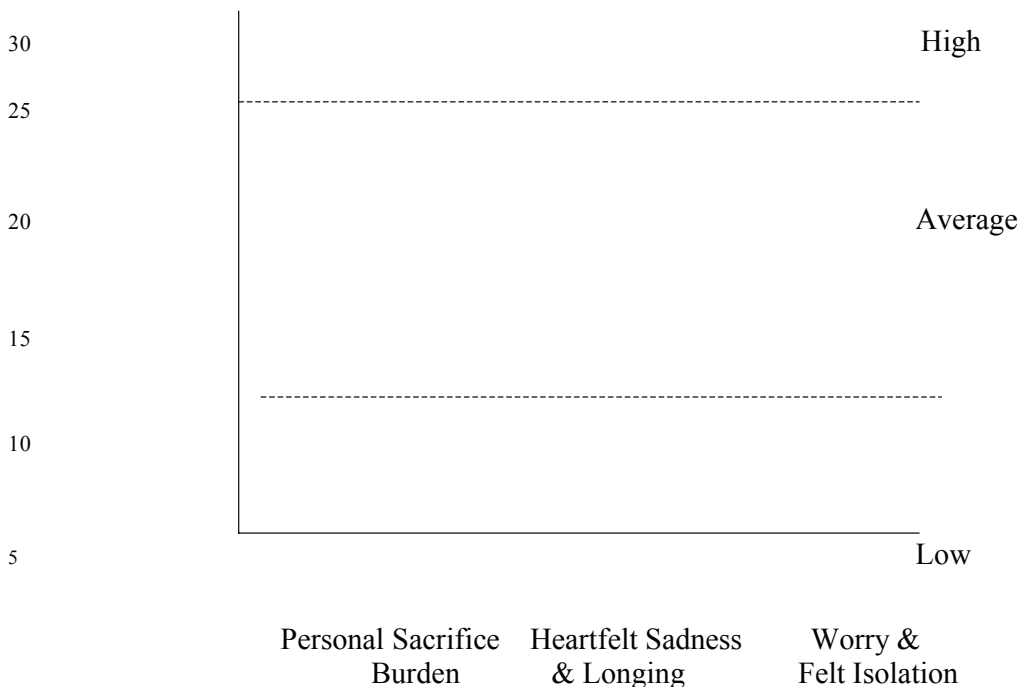
**Worry & Felt Isolation (C Items)** = \_\_\_\_\_  
(6 Items, M = 16.6, SD = 5.2, Alpha = .80, n = 292)

**Total Grief Level (Sum A + B + C)** = \_\_\_\_\_  
(18 Items, M = 57, SD = 12.9, Alpha = .90, n = 292)

**Plot your scores** using the grid below. Make an “X” nearest to your numeric score for each sub-scale heading. Connect the X’s. This is your grief profile. Discuss this with your support group leader or counselor.

**Author Note:** This scale may be copied and freely used for clinical or supportive purposes. Those wishing to use the scale for research are asked to e-mail for permission: [meusert@abraxas.wustl.edu](mailto:meusert@abraxas.wustl.edu) (5/04)

### MM-CGI-SF Personal Grief Profile



#### What do these scores mean?

Scores in the top area are one standard deviation (SD) higher than average based on responses of other family caregivers (n = 292). High scores may indicate a need for formal intervention or support assistance to enhance coping. Low scores (one SD below the mean) may indicate denial or a downplaying of distress. Low scores may also indicate positive adaptation if the individual is not showing other signs of suppressed grief or psychological disturbance. Average scores in the center indicate common reactions. These are general guides for discussion and support only— more research is needed on specific interpretation issues.

## References

<sup>1</sup>Marwit, S.J., & Meuser, T.M. (2002). Development and Initial Validation of an Inventory to Assess Grief in Caregivers of Persons with Alzheimer's Disease. *The Gerontologist, 42*(6), 751-765.

<sup>2</sup>Meuser, T.M., & Marwit, S.J. (2001). A comprehensive, stage-sensitive model of grief in dementia caregiving. *The Gerontologist, 41*(5), 658-770.

<sup>3</sup>Meuser, T.M., Marwit, S.J., & Sanders, S. (2004). Assessing Grief in Family Caregivers. In *Living with Grief: Alzheimer's Disease*. Kenneth Doka (Ed.). Hospice Foundation of America: Washington, DC. 169-195.

<sup>4</sup>Marwit, S.J., & Meuser, T.M. (2005). Development of a short form inventory to assess grief in dementia caregiving. *Gerontologist, 41*, 658-670.

# CHAPTER 3

## Alzheimer's Disease Stage and Caregiver Needs

Sheila A. Reynolds MS, APRN, BC

Health care professionals should be mindful of caregiver type and care recipient's dementia stage. Marwit and Meuser<sup>1</sup> found that a caregiver's grief experience varied depending on whether the caregiver is a spouse or adult child and by the loved one's stage of dementia. Why is this important? Focused interventions for the caregiver type at each stage of dementia should be incorporated in the overall plan. With caregiver well being, comes better outcomes for all involved.


Persons with Alzheimer's disease are unique and many may not experience extremes in behaviors as listed at each stage below.

In **EARLY STAGE** dementia, the person with dementia may experience:<sup>2</sup>

- Memory loss
- Poor judgment
- Personality changes
- Withdrawal and/or depression
- Partial disorientation to time
- Visual/spatial difficulties

### Early Stage: Areas of Concern<sup>3</sup>

- Relationship changes, especially intimacy issues
- Getting lost
- Unable to remember things, (i.e. appointments, dates, medication management, bill paying, etc.)
- Driving safety issues
- Trouble with ADLs
- Repeat questions
- Losing "stuff"
- Accusations of stealing



Manageable  
in their home

### Early Stage: General Interventions for Care of Person with AD<sup>3,6</sup>

- Provide as much routine as possible.
- Try to help the person with Alzheimer's disease preserve as much function as possible by encouraging independence as long as safety is maintained.
- Provide specific instructions, one at a time, and when appropriate provide verbal cues and prompts.
- Be flexible when approaching the loved one. What works well one day may not work at all the next day.
- Provide positive encouragement to the person.



"If you have met one person with Alzheimer's disease, you have met ONE person with Alzheimer's disease."

Author unknown

**One participant states:**

"What happens as this disease progresses? The nurse says they get worse. And I said "but how do they get worse"? Is she going to fall down on the floor, or is she going to rant and rave again. You know I don't know what to expect."

**What Caregivers in the Study Found Helpful from Health Care Providers during the Early Stage**

- Provide timely but not overwhelming information on the disease; progression and programs available (money for medications, in home care, respite care).
- Support groups that focus on problem identification and solutions, not just venting of emotions.
- Someone to talk with, listen to their problems/issues, and specific individualized help to resolve their unique problems.
- To be included in the care, be present during their loved one's evaluation/ family care meeting, to actually see and hear responses to better understand the gravity of the situation.
- Personal attention / time for self [adult child caregiver].
- Be available by phone to discuss problems or issues that arise.

**Early Stage: Professional Interventions for Caregivers**

Guidance during the early stage for both caregiver types (spouse and adult child) is similar. However, differences may occur in the grief reactions of spouses and adult children (*see boxed interventions below*).

**Professional Interventions: Spouse Caregiver: Early Stage**

"Focus of loss is on the spouse-losses, changes in their shared activities and relationship, causing sadness"<sup>1</sup>

- Assess for grief (i.e. Marwit-Meuser Caregiver Grief Inventory; *see Chapter 2*).
- Assess relationship change, ask, "In what ways has the diagnosis of Alzheimer's disease affected your relationship?"
- Listen and provide information on voiced concerns, usual issues, and what to expect (easy to read books/handouts for the older spouse, internet sites).
- Discuss management of day-to-day activities, (i.e. care issues, bill paying, shopping, driving, role changes).
- Facilitate new ways for the spouse to relate and maintain the changed relationship (refer to a professional counselor, if necessary).
- Plan for the future and refer as necessary (*see end of chapter & Chapter 5*).
  - o Refer to legal resource for Guardianship, Durable Power of Attorney, Advance Directives
  - o Financial planning
  - o Driving evaluation
- Discuss and give a list of community resources (*see Chapter 5 – Family Resources*).
  - o Provide a list of support groups/organizations in the area
  - o Alzheimer's Association 24 Hour help line (1-800-272-3900)
  - o Give information on Geriatric Care Manager/Consultant
  - o Adult day care centers
- Introduce what to expect in the next 3-6 months.

### Professional Interventions: Adult-Child Caregiver: Early Stage

“Focus of loss is on self-personal sacrifices of caregiving”<sup>1</sup>

The adult child may not be as accepting of the AD diagnosis, may be emotionally avoidant focusing on tasks and care needs and most troubled by the personal sacrifices of the caregiving role<sup>1</sup> (i.e. demands on time and other family obligations leaves little time for themselves).

- Assess for grief (i.e. Marwit-Meuser Caregiver Grief Inventory; *see Chapter 2*).
- Provide a list of Web Sites on the disease and management (*see end of this chapter and Chapter 5*).
- Introduce use of adult day cares, respite centers, home care help, to allow for breaks from the caregiving role.
- Encourage to plan time for self (explore the possibilities with caregiver).
- Connect with community resources.
  - Give list of support groups/organizations in the area
  - Alzheimer’s Association 24 Hour help line (1-800-272-3900)
- Plan for the future (*see end of this chapter and Chapter 5*).
  - Refer to legal resource for issues related to: Guardianship, Durable Power of Attorney, Advance Directives
  - Driving evaluation
  - Financial planning
- Introduce what to expect in the next 3-6 months.

## Useful Resources

### Alzheimer’s Disease Information (Internet)

- Alzheimer’s Association (provides educational information about the disease, sections specifically for caregivers and health professionals, links to information about support groups and safety as well as a message board and chat room where you can get ideas from other caregivers from their experiences).
  - Web Address: [www.alz.org](http://www.alz.org) Helpline: 1-800-272-3900  
Business: 414-479-8800
- National Council on Aging (dedicated to improving the health and independence of older persons).
  - Web Address: <http://www.ncoa.org>
- Alzheimer’s Disease Education and Referral Center (ADEAR) (contains information about the disease from the National Institute on Aging).
  - Web Address: <http://www.nia.nih.gov/alzheimers>
- National Institute on Aging (contains useful, up to date information about Alzheimer’s disease, links to current articles with the latest news, and links to related topics).
  - Web Address: <http://nihseniorhealth.gov/alzheimersdisease/toc.html>  
and <http://www.nlm.nih.gov/medlineplus/alzheimersdisease.html>

### Caregiving Information (Internet)

- Family Caregiver Alliance (is a public voice for caregivers, illuminating the daily challenges they face, offering them the assistance they so desperately need and deserve, and championing their cause through education, services, research and advocacy).
  - o Web Address: [www.caregiver.org](http://www.caregiver.org)
- National Alliance for Caregiving (is dedicated to providing support to family caregivers and the professionals who help them and to increasing public awareness of issues facing family caregivers).
  - o Web Address: [www.caregiving.org](http://www.caregiving.org)
- National Family Caregivers Association (supports, empowers, educates, and speaks up for the more than 50 million Americans who care for a chronically ill, aged, or disabled loved one).
  - o Web Address: [www.nfcacares.org](http://www.nfcacares.org) Phone : 1-800-896-3650
- Children of Aging Parents (gives caregivers reliable information and sound advice and will extend its outreach through new support groups, workshops, and presentations for churches, schools, employers, service clubs, and television audiences).
  - o Web Address: [www.caps4caregivers.org](http://www.caps4caregivers.org)
- Caregiver Survival Resources (resources and a wealth of information, both general and specific. There are links to other health-related web sites, information on books, and disease-specific resources).
  - o Web Address: <http://www.caregiver911.com>
- AARP (various caregiving information).
  - o Web Address: <http://www.aarp.org/families/caregiving>

### Temporary Respite (Respite and Adult Day Care)

- See Chapter 5

### Financial Planning Information

- MetLife (has a wide range of planning tools and protection and investment solutions to address the planning and financial issues of caregivers and their families, especially those affected by Alzheimer's disease and related illnesses).
  - o Web Address: <http://proleads.metlife.com/proleads/letter/AFA.do>
- The National Council on the Aging (free, easy-to-use service that identifies federal and state assistance programs for older Americans).
  - o Web Address: <http://www.benefitscheckup.org>

### Nursing Home Information (Internet)

- ElderLaw Answers (supports seniors, their families and their attorneys).
  - o Web Address: <http://www.elderlawanswers.com>

- Federal Centers for Medicare and Medicaid Services (CMS) Nursing Home Compare
  - Web Address: <http://www.medicare.gov/NHCompare>
- Wisconsin Nursing Homes
  - Web Address: <http://www.dhfs.state.wi.us/bqaconsumer/NursingHomes/NHindex.htm>

### Drug Assistance Program

- Partnership for Prescription Assistance (program that connects qualified, low-income people with discount prescription drugs, direct from the pharmaceutical manufacturer.).
  - Web Address: <http://www.pparxwi.org/who>

In **MIDDLE STAGE** dementia, the person with dementia may experience the above plus<sup>2</sup>:

- Short term memory loss with some loss of long term memory
- Slowed speech and understanding
- Complete disorientation to time
- Restlessness and/or pacing
- Irritability
- Urinary incontinence
- Increased rigidity of muscles
- Decreased ability to perform self care
- Perseveration (repeating words or phrases over and over)
- Personality changes and/or develop suspiciousness, delusions, hallucinations

### Middle Stage: Areas of Concern<sup>3</sup>

- Unable to structure the day
- Not safe to be left alone
- Needs cueing & prompting for eating & ADLs
- Unable to cook, shop, pay bills, or drive
- May mix up day & night (i.e. sundowning)
- Impaired walking for some
- Requires toileting
- Speaks less, may curse, & have difficulty expressing self
- Wanders, does not remember phone number or address
- May not recognize family & friends
- May kick, scream, hit, bite, or grab

Requires 24 hour supervision, manageable in home with help or assisted living

### Middle Stage: General Interventions for Care of Person with AD<sup>2,3</sup>

- Modify the person's environment to keep it safe. (i.e. special locks on doors and windows).
- Accommodate wandering as much as possible. (i.e. wander program, bracelet; *see Chapter 5 – Wandering*)
- Minimize agitation using various approaches, not arguing or being confrontational with the person.

**One female spouse stated:**

"I wish there was a night care place where you could take your loved one for just a couple hours so that you can go out with the girls."

"...going to the hospital is a very, very stressful thing for the caregiver because they are going to have to stay there with him. You cannot leave the person because they are in unfamiliar surroundings and they would drive the nurses batty."

- Try to maintain the person in his or her current residence as long as possible.
- Assess the need for future placement and plan for it.
- Address issues of advanced directives and guardianship if that has not yet been done.

**What Caregivers in the Study Found Helpful from Health Care Providers during the Middle Stage**

- Providing information on what's ahead:
  - o Wanted to be told loved one's stage of the disease
  - o How the disease progresses and what to expect
  - o How the disease may affect family dynamics
  - o Wanted to know if there is a genetic component for themselves
  - o How much activity is OK for their loved one
  - o Information on and use of in home care (especially for night time), use of respite care, support groups, how to manage vacations and care arrangements
  - o Programs available for those who can not afford services
  - o If person with dementia is in a nursing home, wanted frequent updates and information on how to visit
- Showing concern and support as well as being compassionate.
  - o Listen to concerns
  - o Talk 1:1 to the caregiver to discuss their losses and simply spend time to listen to what's on their mind
  - o Inquire about their needs and ask how things are going
- Providing positive feedback, optimism, and reassurance about their caregiving abilities.
- Exploring ways to incorporate caregiving breaks.
- Interacting with healthcare providers who were knowledgeable about Alzheimer's disease and their understanding about individual's unique situations.
- During an acute care hospital stay, asking caregivers about care needs of person with dementia. Most caregivers expressed fear for their loved ones safety during acute care stays.

**Middle Stage: Professional Interventions for Caregivers**

Caregiver guidance during the middle stage, the longest stage, includes:

- Good listening
- Provide information and resources based upon the unique family needs and circumstances
- Place more emphasis on day-to-day care issues, behavior management, and caregiver burnout
- Communication, safety, and behavioral issues are major stressors for the caregivers<sup>1,3</sup>

### Professional Interventions: Spouse Caregiver: Middle Stage

“Focus of loss is on spouse — continues to grieve the losses in shared activities, start to note the caregiving burden and personal sacrifices”<sup>1</sup>

- Assess for depression (i.e. Geriatric Depression Scale;<sup>8</sup> see <http://www.geronurse.online.org>).
- Assess for grief (i.e. Marwit-Meuser Caregiver Grief Inventory; see *Chapter 2*).
- Based on assessment, provide supportive interventions acknowledging grief/loss issues.
- Assist spouse to accept the progressive nature of Alzheimer’s disease.
- Suggest time away from caregiving (i.e. respite, adult day care; see *Chapter 5 – Family Resource section*).
- Re-assess needs and provide necessary resource information (see *resource list from early stage*).
- Suggest resources for household support (i.e. meals on wheels, grocery shopping, lawn/shoveling services, handyman).
- Suggest assisted living/nursing home arrangements as indicated.<sup>1</sup>
- Introduce what to expect in the next 3-6 months (e.g. assisted living, nursing home placement).

### Professional Interventions: Adult Child Caregiver: Middle Stage

“Focus of loss is on self — personal sacrifices of 24-hour caregiving may now be expressed as anger, guilt, and resentment”<sup>1</sup>

- Assess depression (i.e. CES-D Depression Scale).<sup>8</sup>
- Assess for grief (i.e. Marwit-Meuser Caregiver Grief Inventory; see *Chapter 2*).
- Based on assessment, provide supportive interventions acknowledging areas that are high on the assessment (e.g. personal sacrifice burden issues).
- Encourage expression of feelings coupled with reframing.
- Encourage support from friends, clergy and other family members.
- Refer for supportive counseling &/or professional help, if necessary (i.e. anger management).
- Explore with the person enjoyable activities and suggest ways to make that happen.
- Listen to fears and assist with problem solving.
- Suggest assisted living/nursing home arrangements as indicated.<sup>1</sup>
- Introduce what to expect in the next 3-6 months (e.g. nursing home placement).

#### One spouse commented:

The support group. I can’t emphasize it enough... And I went there for about three years and I heard things that helped me. I also bought the book that the facilitator recommended and then I ordered seven copies; one for me and one for each of our children. You always wonder what stage your loved one is at, and you don’t know what is to come next. The book lays out the different stages of Alzheimer’s and even death. It is always helpful to know just what’s to come.

## Useful Resources

(In addition to the list provided for the early stage)

### Caregiving Services (Internet)

- [Eldercare Locator](#) (offers referrals to information on services for seniors).
  - o Web Address: [www.eldercare.gov](http://www.eldercare.gov) Toll-free: 1-800-677-1116

- [Interfaith Older Adult Programs](#) (Links older adults to community services in Milwaukee, WI).
  - o Web Address: <http://www.interfaithmilw.org/programs/caregiver.html>
- [Family Care America](#) (helps caregivers identify and locate the agencies, institutions, professionals, associations, manufacturers, and vendors that can help them with their specific needs).
  - o Web Address: [www.familycareamerica.com](http://www.familycareamerica.com)

**Assisted Living Information**

- [Medline Plus](#) (Varied information on assisted living).
  - o Web Address: <http://www.nlm.nih.gov/medlineplus/assistedliving.html>
- [National Center for Assisted Living](#) (Read, '2006 State Regulatory Review').
  - o Web Address: [http://www.ncal.org/about/2006\\_reg\\_review.pdf](http://www.ncal.org/about/2006_reg_review.pdf)
- [American Health Care Association/National Center for Assisted Living](#) (Find a facility by clicking on 'Find a Facility' in the furthest left column).
  - o Web Address: <http://longtermcareliving.com/assess>

**Study participant:**  
 "...she was admitted to the ER. It turned out that the physical symptoms we were seeing were due to the effects of the pneumonia which resolved. They dealt with the pneumonia but nothing else. I specifically told them that I would stay with her but they restrained her. They did not ask me how she took her medications. They automatically assumed that she would take them in pudding. She swallows perfectly fine. It was that they didn't make a good assessment."

In **LATE STAGE** dementia, the person with AD may experience the above plus,<sup>2</sup>

- Fecal incontinence
- Inability to walk
- Decreased appetite and weight loss
- Inability to recognize family members
- Inability to recognize self in mirror
- Loss of ability to care for self
- Severe memory loss
- Vocabulary limited to 1-5 words or all vocabulary lost

**Late Stage: Areas of Concern<sup>3</sup>**

- Requires assistance to walk & use of a wheelchair
- Requires a toileting schedule
- Communication barrier exists with incoherent speech
- Swallowing problems, weight loss
- Experiences repeated infections

Requires 24-hour nursing care, manageable in the home with a health care provider or nursing home

**Late Stage: General Interventions for Care of Person with AD<sup>3</sup>**

- Provide increased assistance as person's ability to follow even simple commands diminishes
- Provide constant direction and supervision
- Provide comfort care
- Build on any retained skills
- Use touch and nonverbal communication

### What Caregivers in the Study Found Helpful during the Late Stage from Health Care Providers

- Listening, especially listening to concerns and taking them seriously.
- Including caregiver in care planning, in acute care, assisted living, and nursing home settings.
- Being supportive and understanding. Asking family members how they are doing. Providing a follow-up phone call.
- Support groups.
- Good communication regarding future issues, explanation of medical problems, nursing home placement.
- Knowing their loved ones was taken care of properly.

### Late Stage: Professional Interventions for Caregivers

Caregiver guidance during the late stage, or final stage, has similarities, but is different for the spouse and the adult child. Although both find care relief from nursing home placement, grief intensity for the spouse is at its peak. The adult child's grief is at an apex, it remains high, but lessens with passing of time.<sup>1</sup>

Each feels guilty and defeated over nursing home placement.

Am I a failure for giving into institutionalization?

Will the care be good enough? Is this the right decision?

#### Professional Interventions: Spouse: Late Stage

“Focus of loss is on self, end of married life, emptiness, sadness, aloneness, and worry”<sup>1</sup>

Grief comes from the realization that married life, as it was, has ended and the spouse begins to worry about the future as a single person. Sadness and longing; worry and felt isolation increased for spouses with nursing home placement, exacerbating the feeling of aloneness. Many spouses voiced a disconnection from family and friends.<sup>1</sup>

- Administer the Marwit-Meuser Caregiver Grief Inventory (*see Chapter 2*).
- Provide supportive counseling for high grief especially heartfelt sadness and longing and worry and felt isolation.
- Provide anticipatory guidance related to the dying process and bereavement.
- Provide information on hospice (*see Chapter 7*).
- Encourage spousal caregiving role in the nursing home, if desired.
- Encourage a support network for sources of strength (e.g. religious community, AD support group, family).
- Introduce what to expect in the next 3-6 months (i.e. possibility of death and the dying process).

#### One participant quote:

“As I was walking out, a C.N.A. was sitting next to my mother said ‘yea she wants me to sit here with you and make sure you eat’ ...and to see that made me feel good because then I knew that even though my mom might not eat they were concerned and they told it to her as well. That helps a lot, knowing that they’re taking care of her.”

### Professional Interventions: Adult Child Caregiver: Late Stage

“Focus of loss is on loss of the parent and child relationship once known, sadness and regret ensues.”<sup>1</sup>

Nursing home placement brings a sense of relief from the caregiving burden, but grief comes from the realization and regrets over lost time and opportunities with the parent when they had the chance.<sup>1</sup> Previous stage feelings of anger and frustration are replaced with sadness about the finality of what will never be.<sup>1</sup>

- Administer the Marwit-Meuser Caregiver Grief Inventory (*see Chapter 2*).
- Help by listening and acknowledging their grief, and reframing the positives of their caregiving experience.
- Provide supportive interventions for high levels of grief, especially heartfelt sadness and longing and personal sacrifice burden.
- Discuss creative ways to reconnect with the parent (i.e. how to visit, how to communicate, share a moment).
- Provide information on hospice (*see Chapter 7*).
- Provide anticipatory guidance related to the dying process and bereavement.
- Introduce what to expect in the next 3-6 months (i.e. possibility of death and the dying process).

## References

<sup>1</sup>Marwit, S.J., & Meuser, T. (2001). A comprehensive, stage sensitive model of grief in dementia caregiving. *The Gerontologist, 41*, 658-670.

<sup>2</sup>Kovach, C., Noonan, P., Reynolds, S.A., & Schlidt, A. (2005). *The Serial Trial Intervention (STI) Teaching Manual: An innovative approach to pain and unmet need management in people with late stage dementia*. Milwaukee, WI.

<sup>3</sup>Parrent, J. (2001). *Courage to care. A caregiver's guide through each stage of Alzheimer's*.

<sup>4</sup>Administration on Aging. AOA fact sheet on Alzheimer's disease. Retrieved June 29, 2006, from [http://www.aoa.gov/ALZ/Public/alzcarefam/disease\\_info/facts\\_alz/aoa\\_factsheet.asp](http://www.aoa.gov/ALZ/Public/alzcarefam/disease_info/facts_alz/aoa_factsheet.asp).

<sup>6</sup>Hall, K. (2006, May). *Alzheimer's disease syndrome and developmental disabilities: Weaving a tapestry of understanding*. Presentation at the 20th Annual State Conference on Alzheimer's Disease and Related Disorders, hosted by the Alzheimer's Association. Green Bay, WI

<sup>7</sup>Loos, C.H., & Boyd, A.D. (1997). Caregivers of persons with Alzheimer's disease: Some neglected implications of the experience of personal loss and grief. *Death Studies, 21*, 501-514.

<sup>8</sup>Radloff, L. (1977). The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement, 1*, 385-410.

# CHAPTER 4

## Learning Needs of the Family

Sheila A. Reynolds MS, APRN, BC

### Anticipatory Guidance

Implement anticipatory guidance from the initial diagnosis through to post-death. Caregivers of people with dementia want more information, including what to expect with the disease.<sup>1</sup> One study found that at the time of a dementia diagnosis less than 50% of the caregivers were advised by their general practitioner of usual issues.<sup>2</sup>

- Provide timely information on what the family can expect at each stage and guidance about new caregiving skills to manage likely symptoms or behaviors.
- When selecting types of information and educational strategies, be sensitive to the caregivers:
  - Learning style,
  - Educational background, and
  - Age.

The majority of the dementia caregiving is provided by elderly spouses.<sup>3</sup> Males account for approximately 41 percent of all caregivers of people with Alzheimer's disease.<sup>4</sup>

Before giving information, educate yourself about the material and most importantly find out what the caregiver already knows about dementia and caregiving and build upon that knowledge. There are several excellent internet sources that provide a wealth of educational material on dementia and a variety of common care issues that can be printed for handout for those without Internet access (*see Chapter 4 – Useful resources*).

In their national survey of caregivers of persons with Alzheimer's disease, Belden, Russonello & Stewart<sup>4</sup>, found that caregiving information was sought from the following sources:

- Internet (31%),
- Doctor (26%),
- Health care professionals (12%),
- Family and friends (9%),
- Books, magazines, or the library (7%),
- Government agency (7%),
- Senior citizen's center (7%), and
- Aging association, group, or organization (6%).



#### As one participant stated:

"I don't feel that the doctor fully explained what we could have been looking for, what we should be looking for as far as the progression of the disease and what we are looking for down the road, what the prognosis will be."

### Strategies to Use for the Older Learner

- Older adults learn best if information is presented in an organized and concise manner.
- Divide teaching into small units/stages, no more than 3-5 points at one session, avoid too much content to minimize anxiety.
- Connect new information to their past knowledge and try to make the information as relevant to them as possible.
- Schedule immediate hands-on-practice (return demonstration) allowing ample time to perform and master a task following new learning to instill confidence.
- Use visual material along with auditory material to augment learning.
- Give verbal & non-verbal feedback (reinforcement) regarding performance of tasks (smile, touch shoulder, good, etc.).

From: Reynolds, S.A. (2003). Learning Capabilities in the Elderly: Education Considerations" by Faculty Development in Geriatric Nursing Program, Mather LifeWays Institute on Aging. Reprinted with permission.

## Alzheimer's Disease and Caregiver Guidance

The caregiver's journey is long and arduous, imposed with ongoing changes and losses. One of the most difficult aspects for the caregiver of persons with Alzheimer's disease is the progressive deterioration, especially the gradual loss of the person and relationship they once knew.<sup>5</sup> Everyday is new and what was yesterday may all change today. The loss of the person psychologically, while physically present, coupled with uncertainty has been labeled "ambiguous loss."<sup>6</sup>

The lack of clarity about the family member's status is very stressful and debilitating for the caregiver. This can result in the caregiver being stuck in a state where they are unable to effectively cope and grieve.

Boss<sup>7</sup> suggests that health care professionals help caregivers by:

- Informing them that their source of distress has a label (ambiguous loss),
- Listening to their stories to get a better understanding of what they are experiencing,
- Initiate a discussion on past ways of coping, and
- Dealing with ambiguity.

By looking at the situation differently, the caregiver can begin the process of coping and grieving the losses to eventually come to an acceptance of the situation and the progressive nature of the disease.

Caregiver guidance should be individualized and flexible to target both the person with dementia and the caregiver. Keep in mind that male caregivers may grieve differently than females. Results of a study of grief and loss experienced by male caregivers found that while not all caregivers perceived themselves to be grieving, expressions of loss were present in all statements.<sup>8</sup> The males, who experienced intense grief and were in a state of crisis, did not accept help even though social supports were available. Some did this because they felt embarrassed or perceived others would not understand their situation. It is important to note, these male caregivers went on to express thoughts of harming themselves and/or the care recipient.<sup>8</sup>

## Principles of Care for Family Caregivers: Position Statement

The American Association for Geriatric Psychiatry (AAGP) developed a position statement on principles of care for patients with Alzheimer's disease and their family caregivers.<sup>9</sup> In that statement, they suggest that health care professionals develop a checklist that addresses at a minimum, the identified critical areas of supportive care for patients and their family caregivers.

The **4 critical areas** of supportive care to **patients** with Alzheimer's disease according to the AAGP position statement are:

- Safety matters should be addressed, especially with regard to driving, living alone, medication administration, environmental hazards, wandering, and falls.
- The day-to-day living of patients should be structured to maximize their remaining abilities and function.

- General medical health should be closely monitored  
(i.e. routine medical and dental check-ups, immunizations up to date, maintain regular exercise, and later stages nutrition, hydration, and skin care).
- Advanced care planning and advanced directives.

The **6 critical areas** of supportive care to **family caregivers** according to the AAGP position statement are:

- Educating caregivers  
(i.e. dementia, Alzheimer's disease, cognitive impairment, noncognitive functional, and noncognitive neuropsychiatric symptoms, how diagnosis is made, prognosis, treatment options, supportive care, role changes, communication techniques such as avoidance of arguing and how to involve the patient only in decisions appropriate to their current level of cognitive ability.).
- Teaching problem-solving skills  
(i.e. identify the problem, gather information about the problem (time of day, circumstance, etc.), find the probable cause or causes, devise possible solutions, select most workable solutions, implement, & follow-up evaluation). Teaching caregivers how to problem-solve by role-playing or detailed face-to-face instruction is a critical and very effective aspect of providing care to caregivers.
- Accessing resources  
(i.e. finding alternative caregivers within the family, referral to local Alzheimer's Association chapter, support groups, and access to primary care clinician on a 24-hour basis for crisis intervention. Elder care attorneys, social workers, physical therapists, home care nurses, elder "care managers", Interfaith organization, non-medical in home services for the elderly, like Home Instead can be another important resource).
- Long-range planning  
(i.e. financial matters, planning for future living arrangements such as assisted living or nursing home, advanced directives).
- Emotional support  
(i.e. providing assistance in resolving family conflicts, referrals for counseling and mental health or physical health assessment and emotional support to express frustrations and problem solve).
- Respite  
(i.e. accessing informal caregivers, adult day care, professional caregivers, weekend admission to assisted living and others. Set the stage early after diagnosis for the potential need of respite in the future.). (see Chapter 5 Family Resource Section).

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### **Advance Directives**

(Living Will & Durable Power of Attorney for Health Care)

(Forms Available Free)

<http://www.dhfs.state.wi.us/forms/AdvDirectives/ADFormsPOA.htm>

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## References

- <sup>1</sup>Ott, C., Sanders, S., & Kelber, S. (in review). Grief and Personal Growth in Spouses and Adult Children of Person's with Alzheimer 's Disease and Related Dementias.
- <sup>2</sup>Van Hout, H.P, Vernooij-Dassen, M.J., Jansen, D.A., & Stalman, W.A. (2006). Do general practitioners disclose correct information to their patients suspected of dementia and their caregivers? A prospective observational study. *Aging & Mental Health, 10*(2), 151-155.
- <sup>3</sup>Family Caregiver Alliance (2005). Selected Caregiver Statistics (fact sheet). Retrieved from [http://www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=439](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=439) on August 3, 2006.
- <sup>4</sup>Belden, Russonello & Stewart (2004). Caring for persons with Alzheimer's 2004 national survey. *Alzheimer's Association and National Alliance for Caregiving*. September 2004.
- <sup>5</sup>Sifton, C.B. (2004) *Navigating the Alzheimer's Journey: A compass for caregivers*. Baltimore: Health Professions Press, Inc.
- <sup>6</sup>Boss, P, & Couden, B.A. (2002). Ambiguous loss from chronic physical illness: Clinical interventions with individuals, couples, and families. *Journal Clinical Psychology, 58*, 1351-1360.
- <sup>7</sup>Boss, P. (1999). Ambiguous loss: Living with frozen grief. *Harvard Mental Health Letter*, Nov., 16, (5), p.4.
- <sup>8</sup>Sanders, S., Morano, C., & Corley, C.S. (2003). The expression of loss and grief among male caregivers of individuals with Alzheimer's Disease. *Journal of Gerontological Social Work, 39*(4), 3-18.
- <sup>9</sup>Lyketsos, C.G., Colenda, C.C., Beck, C., Blank, K., Doraiswamy, M. P, Kalunian, D.A., & Yaffe, K. (2006). Position statement of the American Association for Geriatric Psychiatry regarding principles of care for patients with dementia resulting from Alzheimer disease. *American Journal of Geriatric Psychiatry, 14*:7, 561-572.

# CHAPTER 5

## Family Resources

Sheila A. Reynolds MS, APRN, BC

## Support Groups



### Study participants had this to say about support groups:

“I would definitely recommend a support group. Sometimes you can find people that you may not know that well but when they learn of your situation they may be able to help you in very valuable ways.”

“By going to support groups, I saw people in different stages and I learned things. As we went along, I was pretty prepared and was able to handle the situation reasonably well.”

“The support groups are great but it’s tough because you’ve got talkers in there. And they’ll just take off and go with something which is fine. Everybody needs to talk, but I don’t really get a lot out of that. You need a leader who can direct that talk.”

“Actually I didn’t go to that many because I always had to have someone to take care of my wife. Most of them were in the afternoon.”

### How are Support Groups Helpful?

Alzheimer’s support groups are places for caregivers and family members with the disease. Participants in the study<sup>1</sup> identified what they received from attending a support group as follows:

- Learning about Alzheimer’s disease,
- Learning how to handle different problems,
- Support from others who are going through the same thing,
- Anticipation about the future,
- Acquiring new ways of managing the situation and coping,
- Sharing ideas and making new friends,
- Talking about feelings, and
- Socializing

Some participants (17.8%) in the study<sup>1</sup> indicated that they discontinued group attendance because the group facilitator failed to redirect emotional venting by participants or to move beyond introductions.

### What Should a Support Group Leader Know?

Findings from this study indicated:

- Venting of emotions contributed to increased grief.
- Reframing the experience and acceptance of the disease led to decreased grief.
- Group leaders should allow for expression of feelings tempered with reframing and more active problem solving strategies.

## How can you Locate a Support Group in Your Area?

Contact the local Alzheimer's association to get up to date information on current support groups in the area. In southeast Wisconsin, contact the following:

- **Alzheimer's Association: Southeastern Wisconsin Chapter**  
6130 W. National Avenue Suite 200, Milwaukee, WI 53214  
1-800-922-2413  
<http://www.alzheimers-sewi.org/services.htm>
- **Eldercare Locator**  
Phone: 1-800-677-1116  
Monday through Friday 9:00 AM to 8:00 PM (ET)  
<http://www.eldercare.gov>
- **Children of Aging Parents**  
Phone: 1-800-227-7294  
<http://www.caps4caregivers.org/index.htm>

## Internet Support Services Available

### Informal Internet Support

- Caregiver Support Network by ElderCare (provides links to caregiver and online support services, i.e. chat sessions, support groups with experienced instructors, discussion groups).
  - o <http://www.ec-online.net/Community/Activists/can.htm>
- Alzheimer's Caregiver Support Online by AlzOnline (provides education, information, and support).
  - o <http://alzonline.phhp.ufl.edu>
- Family Caregiver Support Network by Interfaith Older Adult Programs, Inc. (provides information on living accommodations).
  - o <http://www.living-options.org/index.html>
- The Caregiver's Home Companion for caregivers to learn information and meet and share experiences with other caregivers.
  - o <http://www.caregivershome.com/index.cfm>
- Community Care helps the elderly live independently in the community.
  - o <http://www.communitycareinc.org>

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See copy of Family/Caregiver Support Group listings with locations and contact information from the Alzheimer's Association Southeastern WI Chapter. Hard copy of listing is located in Appendix, or check for updated version via the web [http://www.alzheimers-sewi.org/support\\_group\\_listing.pdf](http://www.alzheimers-sewi.org/support_group_listing.pdf).

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## References

<sup>1</sup>Ott, C., Sanders, S., & Kelber, S. (in review). Grief and Personal Growth in Spouses and Adult Children of Person's with Alzheimer's Disease and Related Dementias.

## Geriatric Consultants

Geriatric Consultants [Geriatric Care Managers, Care Manager] are professionals, generally nurses, social workers, or psychologists, who have geriatric experience that assess needs and coordinate care for the elderly.<sup>1</sup>

### When to use the service of a Geriatric Consultant

There are no set rules as to when or whether to use a geriatric consultant. However a helpful guideline is to use a geriatric consultant when:

- the family caregiver has determined they are at the point of needing the assistance from a geriatric consultant.<sup>2</sup>
- the family caregiver is encountering complex problems, time constraints due to other responsibilities and commitments, or long distance management.
- the person with dementia is placed in a facility and it is not working out.

However, those family caregivers on a limited budget may not be able to afford this type of service. The service is private pay only. The initial assessment fee ranges from \$150-\$250, with subsequent hourly sessions costing \$50 to \$150 depending on geographical location.<sup>1</sup> In addition to the usual charges, other incidental charges, such as mileage, long distance telephone calls, caregiving supplies, and such, may be added to regular fees.

### How do you Locate a Geriatric Consultant in Your Area?

To find a care manager in your area, log on to [www.caremanager.org](http://www.caremanager.org), the Web Site of the National Association of Professional Geriatric Care Managers and click on the link called "Find a Care Manager". You will find up to date information.

#### A spouse participant stated:

"...The geriatric consultant started me on the path of knowing where to go...she had me itemize everything I needed to do. This is what you need to do, contact a geriatric lawyer. I didn't know I could put my house in my name..."

### Dealing with Difficult Behaviors

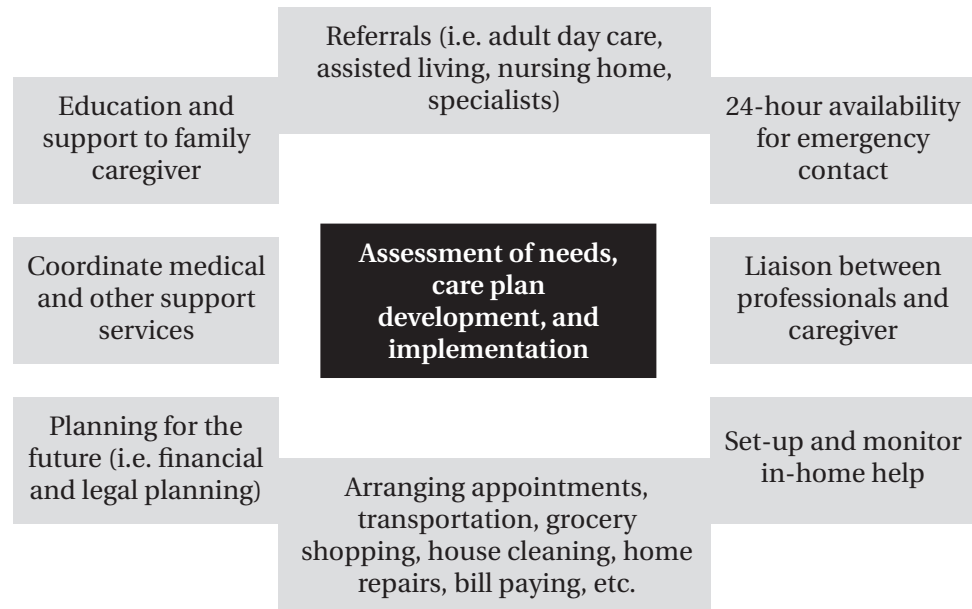
Find a **Geriatric Psychiatrist** in your area:

<http://www.gmhfonline.org/gmhf/find.asp>

## What services do Geriatric Consultant's provide?

Geriatric consultants provide variety of services. Check with the agency.

Common services<sup>1</sup> are:



## References

<sup>1</sup>Alzheimer's Association, (nd). What is Alzheimer's disease? Retrieved July 5, 2006, from <http://www.alz.org/AboutAD/WhatIsAD.asp>.

<sup>2</sup>National Association of Professional Geriatric Care Managers. Do I really need a geriatric care manager? Retrieved from <http://www.caremanager.org/displaycommon.cfm?an=1&subarticlenbr=39> on August 15, 2006.

## Temporary Respite

### Study participant's comments regarding needing caregiver breaks:

"Putting him in daycare will help. Last week, I put him in on Wednesday and I went right from there to Mayfair. I just spent all five hours in Mayfair and I just did what I wanted to do. I shopped, and then I sat down and ate something, and for five hours just sat there and looked at people and relaxed. And you know, it just was different. It was sorta nice you know to do something like that, and it felt good. And then when I picked him up, I felt good".

"Yeah, (it) would really be a big blessing... if they had a program where these people could get away, a 2 or 3 day weekend, wherever and then, do what they wanted to do."

"a place to take my mother if we want to go on vacation and if my siblings can't take her."

### What is Temporary Respite?

Temporary respite is a service that allows caregivers time away from the responsibility of providing care. Examples of types of respite care include:

- Adult Day Care Centers (where people reside during the day),
- In Home Care Services (provide care in the home).

Fees vary and can range from approximately \$30 to \$50 per day (some have reduced fees for those who are low income) in the Milwaukee area.

### How do you locate an Adult Day Care or In-Home Care in Your Area?

#### National Organizations

##### Locate an Adult Day Care Center in your State

National Adult Day Services Association

Phone: 1-800-558-5301

<http://www.nadsa.org>

New Lifestyles; The Source for Seniors

Phone: 1-800-820-3013

<http://www.newlifestyles.com/>

##### Locate a Caregiver

Phone: 1-800-677-1116

Monday through Friday 9:00 AM to 8:00 PM (ET)

<http://www.eldercare.gov>

#### Wisconsin Adult Day Care Programs

- Adult Day Care Directory, from the Wisconsin Department of Health and Family Services (alphabetical by county, last updated 6/29/06)
  - o Web Address: <http://dhfs.wisconsin.gov/bqaconsumer/AssistedLiving/adcdir.pdf>

### **Wisconsin In-Home Care**

- Home Instead Senior Care provides companionship and home care services for seniors
  - o Web Address: [www.homeinstead.com](http://www.homeinstead.com)
  
- Interfaith Older Adult Programs, Living Options Program
  - o Web Address: <http://www.living-options.org/index.html>
  - o 414-291-7500

### **Respite Care**

- Senior Companion Program provides respite care to relieve live-in caretakers for short periods of time
  - o Social Development Commission, Milwaukee
  - o Contact: Mattie Payne, SCP Director 414-906-2779

## Safety Matters

### One study participant's comment:

"One of the things that we've been fighting with is driving. And I understand that a doctor can force him to take a driving test and we've spoken to the doctor several times about it and he's talked to my dad and told him to stop driving but it doesn't always work. But I wish the health care professionals could step in more if they had more ability to help us to get him to stop driving."

Persons with Alzheimer's disease lose their sense of danger early in the disease. Key to successful home management of persons with Alzheimer's disease is ensuring their safety.

### What Are Some Common Safety Concerns?

- Driving
- Environmental Issues
- Wandering

### Helpful Safety Resources

#### Driving

##### Laws in Wisconsin for the Older Driver

- No special provisions for the older driver, 8 year renewal cycle  
[http://www.iihs.org/laws/state\\_laws/older\\_drivers.html](http://www.iihs.org/laws/state_laws/older_drivers.html).
- Restrictions can be recommended by a physician or vision specialist or determined by the road test.
- Physicians are encouraged though not required to report. They can report by submitting form MV3141 ("Driver Condition or Behavior Report") or a letter on letterhead stationary. Form MV3141 is available [www.dot.wisconsin.gov](http://www.dot.wisconsin.gov) or a hard copy can be found in the appendix section.
- Resource booklet from the American Medical Association, *Physician's Guide to Assessing and Counseling Older Drivers* can be useful in evaluating the older adults driving abilities. This guide can be obtained from the AMA's web site <http://www.ama-assn.org/ama/pub/category/8925.html>.

##### Driving Evaluation Specialist in Southeastern Wisconsin

- Find a driving rehab specialist in your area who can complete a driver safety assessment:
  - o American Occupational Therapy Association  
<http://www.aota.org/olderdriver/>

- o Association for Driver Rehabilitation Specialists (ADED)  
[www.driver-ed.org](http://www.driver-ed.org) or [www.aded.net](http://www.aded.net) (1-800-290-2344 )

### **Helpful Web Sites with Background Information on Driving**

- The American Occupational Therapy Association web site (<http://www.aota.org>) has a wealth of information for the professional and the consumer on driving.
- A Practical Guide to Alzheimer's, Dementia and Driving  
<http://www.thehartford.com/alzheimers>
- Driver Safety Information by AARP  
[http://www.aarp.org/families/driver\\_safety](http://www.aarp.org/families/driver_safety)

### **Alternate Transportation**

Below are some organizations that can help you find transportation for the elderly.

- Eldercare Locator: 1-800-677-1116  
o <http://www.eldercare.gov/Eldercare/Public/Home.asp>
- Milwaukee County Department on Aging  
Area Agency on Aging: 414-289-6874  
o [www.milwaukeecounty.com](http://www.milwaukeecounty.com)

### **Environment Modifications**

- Ageless Design <http://www.agelessdesign.com>  
o Solutions for living with Alzheimer's: The caregiver's guide to home modification.
  - This article describes techniques for "Alzheimer's-proofing" the home. Full text available online at [www.thefamilycaregiver.com/pdf/magazine-summer06-simcoe.pdf](http://www.thefamilycaregiver.com/pdf/magazine-summer06-simcoe.pdf)
- National Resource Center on Supportive Housing & Home Modification  
<http://www.homemods.org>
- Comprehensive Assessment and Solution Process for Aging Residents (health care professionals can use in assessing homes and specifying modifications) [www.ecaspar.com/ec/caspar.pdf](http://www.ecaspar.com/ec/caspar.pdf) or by calling 847-215-9490
- National Association of Home Builders  
[http://www.nahb.org/reference\\_list.aspx?sectionID=112](http://www.nahb.org/reference_list.aspx?sectionID=112)

## Wandering

- Alzheimer's Association Safe Return is a program of the National Alzheimer's Association to enable the safe return of persons with dementia who have become lost in the community. Cost: Enrollment fee \$40, annual rate \$20. (<http://www.alz.org/safereturn>)
  - o Contact: Southeastern Wisconsin Chapter for more information and registration.
    - Phone 1-800-922-2413
    - <http://www.alzheimers-sewi.org/services.htm>
- Medical Bracelet is a bracelet that is worn by the person with Alzheimer's disease to indicate they have a brain disorder and to contact the 24 hour emergency response number for further information. Contact to get membership fee charge.
  - o Contact: MedicAlert
    - Phone: 1-800-763-3420
    - <http://www.medicalert.org/AFA>
- Door Alarms to alert caregiver to an unsafe home exit.
  - o Some Contacts:
    - The Alzheimer's Store <http://alzstore.com>
    - Radio Shack (portable alarm for door/door knob)
    - Wander Guard, Inc. Call 1-800-235-8085 (door alarms, wander prevention systems)
    - Guardian Electronics 414-241-4850 (wander prevention systems)
    - The Safety Zone 1-800-999-3030 (door alarms)
    - Wander Watch Alert 24 1-800-526-0162 (wander prevention systems)
    - Secure Care 1-800-451-7917, 603-796-6404 (door alarms)

## Other Resources for Care Providers and Caregivers

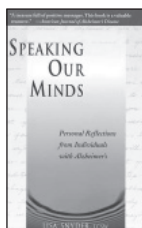
### Newsletters

Caregivers Home Companion [www.caregivershome.com](http://www.caregivershome.com)  
 Eldercare Quarterly [www.caregiver.on.ca](http://www.caregiver.on.ca)  
 Caregiving Newsletter [www.caregiving.com](http://www.caregiving.com)  
 Today's Caregiver [www.caregiver.com](http://www.caregiver.com)

### Books

#### **Speaking Our Minds**

Personal Reflections from Individuals with Alzheimer's  
*Lisa Snyder, LCSW*



Trade Paperback, 176 pages  
 Size: 5 1/2 x 8 1/4  
 List Price: \$15.00  
 Henry Holt and Co.  
 W. H. Freeman  
 Pub Year: 2000  
 ISBN: 0-7167-4010-9

**Elder Rage or, Take My Father... Please! How to Survive Caring For Aging Parents**

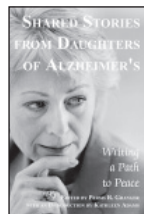
*Marcell, Jacqueline / Marcell, Jacqueline*



Trade Paperback  
368 Pages  
02 Edition  
Impressive Press  
April-2001  
List Price: \$19.95  
ISBN: 0967970318

**Shared Stories from Daughters of Alzheimer's: Writing a Path to Peace**

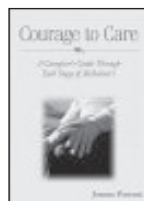
*Persis Granger*



Paperback  
Pages: 163  
Size: 6 x 9  
Jan-2004  
List price: \$15.95  
ISBN: 0-595-29726-9  
<http://www.iuniverse.com/bookstore/index.asp>

**Courage to Care: A Caregiver's Guide Through Each Stage of Alzheimer's**

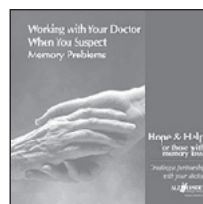
*Joanne Parrent / Joanne Parrent*



Paperback  
Pages: 343  
Size: 6 x 9  
Jan-2005  
List price: \$15.00  
ISBN: 0756785626

**Working with Your Doctor When You Suspect Memory Problems**

*Alzheimer's Association*

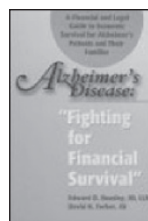


Gives information about health care standards and offers suggestions for partnering with the doctor.

Download at: [www.alzla.org/education/ahei.html](http://www.alzla.org/education/ahei.html)

**Alzheimer's Disease: Fighting for Financial Survival**

*Edward Beasley & David Ferber*



Paperback  
Pages: 135  
Oct-2000  
List price: \$24.95  
ISBN: 1889902152

**Internet Sites**

AgeNet ElderCare Network <http://www.agenet.com>

Caregiver Regional Resource-WI <http://www.caregiver.com/regionalresources/states/WI/index.htm>

MedlinePlus <http://www.nlm.nih.gov/medlineplus/alzheimersdisease.html>

National Electronic Library for Health (NeLH) [www.nelh.nhs.uk](http://www.nelh.nhs.uk)



# CHAPTER 6

## Managing Patients with Dementia in an Acute Care Hospital

*Sheila A. Reynolds MS, APRN, BC*



### Hospital Stay / HIPAA

Hospitalization of a person with dementia is a difficult and stressful time for all involved. Health care providers need to be sensitive to the special needs of both the person with dementia and the caregiver.

#### Quoted from a study participant:

“When my mother went to the hospital...it was eye-opening to me as how incompetent the medical staff was dealing with somebody with Alzheimer’s, from the nurses aids right up through the doctors. And, it was very frustrating dealing with that. You had to be an advocate for that person; you had to be there almost constantly to respond to the physicians. They would be asking her questions regarding her health that there was no way she was capable of answering. But she would give them an answer but the validity of the answer was not there. And it was like every single doctor that came in, it was the same thing, they direct the questions to her and they would be taking the answer as if these were valid answers.”

Key to managing needs in an acute care hospital are:

- a good understanding of Alzheimer’s dementia,
- information sharing, and
- coordination.

Remember to include the patient, if he/she is capable of understanding, and the patient’s caregiver/family in the care planning process. The caregiver has a wealth of information to share.

The caregiver’s knowledge comes from years of experience, caring for the person with dementia and knows what works best and what to avoid. Health Insurance Portability and Accountability Act of 1996<sup>1</sup> (**HIPAA**) **does not require an authorization to solicit information from caregivers, family members, or others**, so always accept and document this information.

### Sharing Information

Disclosure of health and medical information is protected by Federal law. The HIPAA Privacy Rule became effective on April 14, 2003. The aim of the regulation is to protect patient privacy, while continuing the exchange of necessary information to promote quality of care. A health care provider must obtain an authorization either from the patient or the patient’s legal representative, before sharing protected health information. There are a few exceptions when it is OK to share health information.

For instance, a health care provider can share information that is:

- Directly relevant to the involvement of a spouse, family members, friend, or others, in the patient's care or payment for health care, without consent. For example, a family member (the caregiver), who is not a legal representative needs to be informed about medication management in order to properly care for this person.

Or

- Directly relevant to the condition of the incapacitated patient with a family member without consent. In addition, a health care provider can in an emergency situation, in their professional judgment and the patient's best interest in mind can share medical information about the patient's condition with a spouse or family member.<sup>2</sup>

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**Another participant in this study said:**

"Well they took my mom to the hospital and the ambulance wouldn't tell me where they took her. I'm the only one who knew what medication she was on. She's dying, nobody knows, I know. It took me an hour to call around to get the hospital. The ambulance said the HIPPA thing. And all I hear from HIPPA is erroneous knowledge, erroneous assumptions of what it's supposed to be. I have power of attorney; do you think anybody would tell me? No. I wanted to be called when something happened, I have power of attorney. They say 'well give me the paper.' I say the paper is on file in the hospital, I'm in the hospital. I have to carry around papers with me to prove to everybody whether they got it on file or not. So it's just not, it's not user friendly."

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**Wisconsin regulations**

(parallel with the Federal laws)

Sharing of Information is permitted with family and friends when there is an authorization either by the patient or if incompetent, the legal health care decision maker, unless it is an emergency then the health provider uses their clinical judgment of what is in the best interest of the patient.<sup>3</sup>

It is important to note here that it can be difficult to determine if a person with dementia, is competent to give consent. Research has shown that cognitively impaired individuals can make some decisions, but that ability can vary from day to day and time of day.<sup>4</sup>

To protect the decision-making right of the person with dementia, an evaluation for decision-making capacity should be completed.

**Activation of the Power of Attorney for Health Care** occurs when:

- Two physicians or one physician and one psychologist have examined the person and have signed a statement deeming the person with dementia incapacitated.<sup>5</sup> At this point the Power of Attorney for Health Care (POA-HC) is activated.

A person is competent, unless a court finds him/her incompetent. Competency is a legal decision.

## Meeting the Needs of a Hospitalized Alzheimer's Patient

The person with Alzheimer's disease requires special care. Confusion and behavior disturbances can increase while hospitalized. Delirium exacerbates confusion and difficult behaviors and should be assessed routinely because it is commonly seen with acute illnesses or surgery in elderly patients.

Dementia patients have perpetual distortions and diminished ability to interpret environmental cues. In addition, some can not speak. They are often bewildered by the sights, sounds, and physical stimulation.

### Changes in behavior can be caused by four major problems:

#### 1. Physical & Medical Problems<sup>6</sup>

- Delirium (from illness)
- Impaired vision or hearing
- Toxic reaction to medication
- Physical discomfort (pain)
  - o Examples: pain, fatigue, constipation, dehydration, sitting/lying in one place too long, use of restraints, hunger, too cold, too hot, need to urinate

#### 2. Environmental Stresses<sup>6</sup>

- Unfamiliar surroundings and people
  - o Impaired person may feel abandoned, lost, insecure, when a familiar person is out of sight.
- Over stimulation
  - o Too much going on in the environment, such as alarms, equipment noises, voices, intercom usage, too many people and interruptions throughout the day and night.
- Complicated tasks
  - o Giving instructions that have too many steps all at once. For example, when describing how to complete ADL's
- Frustrating interactions
  - o Task not modified for increasing impairments
  - o Task unfamiliar
  - o Inability to communicate effectively
  - o Lack of privacy
  - o Intrusion into their personal space
  - o Being misinterpreted
  - o Being rushed through tasks
- Physically uncomfortable environment
  - o Too cold/hot, inadequate lighting, too cluttered, too noisy

### Definition and Clinical Features of Delirium

The essential features of delirium include disturbances of consciousness, attention, cognition, and perception. The disturbance develops over a short period of time (usually hours to days) and tends to fluctuate during the course of the day. Following are the DSM-IV criteria for delirium:

- A. Disturbance of consciousness (i.e. reduced clarity of awareness of the environment) with reduced ability to focus, sustain, or shift attention.
- B. A change in cognition (such as memory deficit, disorientation, language disturbance) or the development of a perceptual disturbance that is not better accounted for by a preexisting, established, or evolving dementia.
- C. The disturbance develops over a short period of time (usually hours to days) and tends to fluctuate during the course of the day.

From the American Psychiatric Association: Diagnostic and Statistical Manual of Mental Disorders, 4th ed (DSM-IV). Washington, DC, APA, 1994 Retrieved from [http://www.psych.org/psych\\_pract/treatg/pg/pg\\_delirium.cfm](http://www.psych.org/psych_pract/treatg/pg/pg_delirium.cfm) on August 8, 2006.

**Sundowning** is a dementia-related symptom that consists of increased agitation, confusion, and hyperactivity that often occurs in the late afternoon and becomes especially severe at night. Some causes, include fatigue, loss of visual cues in the dark, and instability in circadian rhythm.

From Alzheimer's Foundation of American, Coping with ... sundowning. Retrieved from <http://www.alzfdn.org/education-care/sundowning.html>, on August 8, 2006.

### 3. Sleep Problems

- Insomnia
  - o Physically uncomfortable environment
  - o Pain
  - o Needs not met
  - o Interruptions
- “Sundowning”

### 4. Psychiatric Syndromes

- Psychosis
- Aggression or Anger
- Depression
- Anxiety

It is important to remember that the person is not acting this way on purpose.

## **Tips for Managing the Patient**

### **1) How to Manage Physical & Medical Problems**

Implement the **Serial Trail Intervention** (STI). The STI is an innovative clinical protocol for assessment and management of unmet needs in people with middle to late-stage dementia.<sup>7</sup> There are five steps to the STI<sup>8</sup> that start after there is an identified change in behavior.

#### **Step 1: Physical Assessment**

Assess for health, illness, functional, and other physiological needs. If a problem is identified, appropriate treatment(s) are initiated. If behavior continues, proceed to Step 2.

#### **Step 2: Affective Assessment**

Assess psychosocial and environment needs, such as visual, auditory, olfactory, tactile, and thermal stress, too much or too little activity, and amount of meaningful human interaction. If a problem is identified, appropriate treatment(s) are initiated. If behavior continues, proceed to Step 3.

#### **Step 3: Non-pharmacological Treatments**

Try a series of non-pharmacological comfort treatments. Examples, massage, ambulating with a staff member, pet therapy, hugging, exercise, providing quiet time, watching TV, 1:1 visit. If these steps are ineffective, proceed to Step 4.

#### **Step 4: Trial of Analgesics**

Start a trial of a PRN analgesic. If the person is already on a scheduled analgesic, contact the medical professional for an escalation of the dose of analgesic. If ineffective, proceed to Step 5.

### Step 5: Consultation with Physician or Advanced Practice Nurse Prescriber and/or Trial of Psychotropics

If consultation is ineffective, repeat the consult or trial of a PRN psychotropic. If the behavior still continues, repeat the STI. For more information see the manual.<sup>8</sup>

## 2) Communicate Effectively<sup>9</sup>

### a. Use the ABC approach

#### A

- APPROACH
- Use a calm, gentle, patient-centered approach
  - Have a positive, friendly facial expression (Smile)
  - Approach slowly from the front and get the person's attention first (use his/her name)
  - Identify yourself by name and title
  - Initiate small talk prior to starting a task
  - Use touch to convey 'care'
  - Be flexible
  - Give choices

#### B

- BODY LANGUAGE
- Be aware of how you are presenting yourself, the person with dementia often acts like a mirror in reflecting back the emotion of the interaction.

#### C

- COMMUNICATION SKILLS
- Look at the person and make sure you have his/her attention before you begin to speak.
  - Be at eye level
  - Maintain eye contact
  - Speak slowly & clearly
  - Use short, simple sentences
    - If possible, use yes/no type of questions
  - Use concrete terms and familiar words
  - Talk in a calm, easy going manner
  - Keep your tone of voice low
  - Listen actively
  - Respond to the emotional tone of the statement (feelings, not facts)
  - Break tasks (care process) into clear, step-by-step instructions
  - Ask one question at a time
  - Allow enough time for a response or to complete a task
  - Repeat instructions exactly the same way, don't get angry
  - Use nonverbal communication, such as gestures, visual cues, demonstrating

**Tip:** Modeling calm, friendly, relaxed behaviors often results in calmer and positive behaviors in the patient.

#### Don't:

- Argue or get angry with the person
- Boss them around
- Talk down to them
- Ask questions that require a good memory
- Talk in front of them as if they were not there

## 3) Reduce Environmental Stressors

### a. Structure daily routine

- i. Schedule consistent staff to care for patient
- ii. Toilet at usual times

- iii. Arrange rest times
- iv. Include special information on the plan of care

b. Minimize distracting noises

- i. Turn the radio or TV off during rest times
- ii. Prompt response to all alarms (IV pumps, bed alarms)
- iii. Close door to room when hallway noise is too loud
- iv. Don't use in-room intercom
- v. Keep voices down in the hallways

c. Use memory aids in room, such as labeling objects (i.e. closet, bathroom, name of nurse on a board)

d. Ensure wearing of glasses/hearing aid when awake

e. Make sure room temperature is set for comfort

f. Well lighted room helps reduce disorientation and confusion, so use night lights

#### 4) Safety

- a. Use a low bed, to avoid climbing over rails
- b. Avoid using restraints
- c. Initiate hospital elopement precautions
- d. Disguise tubes (i.e. IV tubes, foley catheter) by covering

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The article below describes best practices in nursing care for wandering behaviors

#### **“Wandering in the Hospitalized Older Adult”**

Available at: <http://www.hartfordign.org/publications/trythis/wandering.pdf>

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### **Tips for Managing Family/Caregiver Needs**

Typically, we tend to think about the hospitalized person with dementia as the sole patient, but in dementia care the family/caregiver is really an important part of the equation and should be included in the care planning process.

Equally important, the healthcare provider should recognize the caregiver as:

- An individual who also has needs and concerns to be addressed.

The hospitalization brings added stress for the caregiver, from dealing with the health care system, the uncertainty of the acute illness, to the after affects of the hospitalization.

A recent study sponsored by National Institute on Aging (NIA) found spouses of persons with dementia had an increased risk of illness and death when compared to other caregiver types.<sup>10</sup>

If the caregiver becomes overwhelmed, ill, or can no longer cope with caregiving tasks, ultimately the person with dementia suffers.

Nichols and Heller's<sup>11</sup> found from their focus group sessions of family caregivers of persons with dementia that families had several concerns regarding the acute care experience. They described what families said:

People [family caregivers] were saying that the hospital experience itself was not a good experience for the person that they loved, nor for themselves. They [family caregivers] told us that they felt ignored when they came to the hospital, and that they knew crucial things about what the patient needed, but there was not anyone to give that information to. They [family caregivers] told us that we were relatively insensitive to the emotional stress that they were undergoing (p. 182).

Similarly, Levine (2001)<sup>12</sup> director of the Families and Health Care Projects at the United Hospital Fund in New York City who has been involved in hospital based family caregiver programs had this to say regarding family caregivers of people with dementia acute care concerns:

They [caregivers] indignantly reported the difficulties they encountered in getting information from hospital staff about the patient's condition and the results of tests or procedures. They reported that they felt invisible—or worse, unwelcome—in hospitals until the patient was ready to go home. They described the lack of training in complex medical equipment that they were responsible for operating at home. What training was provided was perfunctory and dismissive of their fears (The Impact of the Care Recipient's Hospitalization on the Caregiver section<sup>12</sup>).

Understanding and addressing the needs of the caregiver is advantageous for all involved and time well spent. Here are some suggested tips for the health care provider.

### **Tips for Managing Patient and Family Caregivers in the Emergency Room (ER) Setting<sup>9</sup>**

- With consent, encourage the family/caregiver to accompany the person with dementia to provide emotional support and information.
- Give support and positive encouragement to the caregiver (i.e. “You made the right decision in bringing him/her in for an evaluation,” or “We will help”).
- Introduce self, state your title, and your role.
- Gather information from both the person with dementia, if capable, and the family caregiver regarding reason for visit.
- Share the gathered information with other health care providers before they enter the room to avoid repeat questions.
- Check-in routinely and give updates:

Majority of patients spend less than 4 hours in the ER, with the average patient care time of 2.5 hours.<sup>13</sup>

- o Explain what and why certain tests, procedures are being done. Use easy to understand terms or write information on paper.
- o Give an estimation of how much time they can expect to be in the ER, before the decision to admit or discharge home.
- o Share results with family.
- Show warmth and compassion:
  - o Eye contact,
  - o Listen,
  - o Respond to questions and concerns,
  - o Inform location of restrooms, phone, food, drink;
  - o Offer reading material to pass the time (magazines).
- Encourage questions.

### **Tips for Managing Family Caregivers in the Acute Care (Inpatient) Setting<sup>9</sup>**

- Treat Family as Partners in Care
  - o Listen and allow enough time for the family caregiver to share information about the person with dementia's special needs, usual routine, known solutions for difficult behaviors, and document in patient care record.
  - o Include family caregiver in day-to-day care with consent
    - Explain equipment, medications, and treatments.
    - Encourage involvement 'hands on' care with instruction/supervision.
    - Ongoing education regarding management of medical condition.
    - Discuss identified patient issues and work on solutions together.
    - Hold family conference, if necessary.
- Provide Information to Caregivers:
  - o Hospital rules; visiting hours, overnight stay, cafeteria.
  - o Daily discussions regarding the patient's condition, behaviors, changes, medications, and the results of tests or procedures and what it means, in easy to understand language, with the consent.
    - If handouts available, print a copy for caregiver to review at a later time.
  - o Likely, length of stay and if needs rehabilitation following the acute care stay, discussed reasons for and give information on suggestions of rehabilitation facilities.

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A **Toolkit** to Help Practitioners Assess the Needs of Family Caregivers

**"Caregivers Count Too"** (Available at web address below)

[http://www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=1695](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1695)

- 
- Build Relationship and Show Respect to Caregivers:
    - o Be friendly, give enough time to needs, answer questions and concerns.
    - o Give the names and credentials of the healthcare providers caring for their loved one that shift.

- o Call family caregiver with changes in condition.
- o Give hospital phone number, if questions arise.
- Monitor for Caregiver Burnout
  - o Inquire about the caregiver health status.
  - o Assess for anxiety and depression.
    - If elderly: Geriatric Depression Scale (Available at <http://www.hartfordign.org/publications/trythis/issue04.pdf>)
- Reassess the Caregiving Situation – Tools are available from <http://www.geronurseonline.org>
  - o Use assessment/screening tools to assist with assessment.
    - Mutuality Scale (a 15 question likert scale tool that identifies relationship issues).
    - Preparedness Scale (a 9 question likert scale tool that measures how well the caregiver thinks they are prepared for caregiving).
    - Caregiver Strain Index (a tool that identifies families with potential caregiving concerns/strain related to the caregiver role).
  - o Give referrals and resources to help them in the community:
    - Options for placement, respite, alternate back up help.
    - Consider referral to Social Services
  - o Assist them make whatever adjustments that will be necessary for the home.

### Tips for the Health Care Provider for the Discharge:

- Give specific instructions, verbal and in written format regarding medications, treatments, limits on physical activity, diet, lifestyle changes, and date/s for follow-up appointments.
  - o Have the adult child/spouse without dementia present when you go over the discharge information.
- Make sure the family caregiver knows how to use equipment properly. Demonstrate proper operation, ask for return demonstration, answer questions and give praise.
- Give a name/s and phone number of whom they should call, if they run into problems or have questions once at home.

## References

<sup>1</sup>Health Insurance Portability and Accountability Act of 1996 (HIPAA). Public Law 104-191 (104th Congress). AUG. 21, 1996.

<sup>2</sup>HIPAA Privacy Rule. (54 C.F.R. §164.510(b)).

<sup>3</sup>HIPAA Collaborative Of Wisconsin (COW). *Wisconsin Consumer's Guide to Health Information Privacy*. Retrieved on July 30, 2006 from <http://www.dhfs.state.wi.us/hipaa/consumerguide/consguide.htm#seven>.

<sup>4</sup>Family Caregiver Alliance. (nd). Helping families make everyday care choices (for providers). Retrieved from [http://caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=405](http://caregiver.org/caregiver/jsp/content_node.jsp?nodeid=405) on August 10, 2006.

<sup>5</sup>Elder Law Center of the Coalition of Wisconsin Aging Groups (April 2005). *Powers of attorney for health care: An overview*. Retrieved on July 31, 2006 from <http://www.cwag.org>.

<sup>6</sup>Alexopoulos G.S., Silver J.M., Kahn D.A., Frances A., & Carpenter D. (1998). *The Expert Consensus Guideline Series: Agitation in Older Persons with Dementia*. A Postgraduate Medicine Special Report. The McGraw-Hill Companies, Inc.

<sup>7</sup>Kovach, C., Noonan, P., Schlidt, A., Reynolds, S., & Wells, T., (2006). The serial trial intervention: An innovative approach to meeting needs of individuals with dementia. *Gerontological Nursing*, 32,18-27.

<sup>8</sup>Kovach, C., Noonan, P., Reynolds, S., & Schlidt, A. (2005). The Serial Trial Intervention (STI) Teaching Manual: An innovative approach to pain and unmet need management in people with late stage dementia. (To obtain a copy, contact Christine Kovach PhD, UWM College of Nursing, Milwaukee, WI. Email: [ckovach@uwm.edu](mailto:ckovach@uwm.edu)).

<sup>9</sup>National Institute on Aging, Alzheimer's Disease Education & Referral Center. *Acute hospitalization and Alzheimer's disease: A special kind of care*. Mar 02, 2006 retrieved from <http://www.nia.nih.gov/Alzheimers/Publications/acute.htm>.

<sup>10</sup>Christakis, N.A., & Allison, P. D. (2006). Mortality after hospitalization of a spouse. *New England Journal of Medicine*, 354, 719-730.

<sup>11</sup>Nichols, J.N. & Heller, K.S. (2002). Windows to the heart: Creating an acute care dementia unit. *Journal of Palliative Medicine*, 5, 181-193.

<sup>12</sup>Levine, C. Hospital-based family caregiver programs: Building institutional resources and community ties. *Innovations in End-of-Life Care*, 2001;3(2), <http://www2.edc.org/lastacts/archives/archivesMarch01/default.asp>.

<sup>13</sup>McCaig L.F., & Nawar, E.W. National Hospital Ambulatory Medical Care Survey: 2004 emergency department summary. Advance data from vital and health statistics; no 372. Hyattsville, MD: National Center for Health Statistics. June 23, 2006.

# CHAPTER 7

## When to Seek Hospice Care

Sheila A. Reynolds MS, APRN, BC

Hospice means a *'special kind of caring'* for the terminally ill. The goal of hospice is on care, rather than a cure. Hospice attends to the management of physical, psychological, spiritual, and social distress in the dying process for patients and their families.<sup>1</sup>

Hospice programs are 24 hours a day, seven days a week that can be carried out in various settings, such as:

- in the home,
- a nursing home facility,
- a hospice unit,
- a hospital,
- free-standing hospice, or
- a residential care setting.

Many people do not realize that hospice care can be provided *in addition* to care provided in an extended care facility.

More people can be helped through hospice services, however, roughly 80% of Americans do not think of hospice as a choice for end of life care.<sup>2</sup> In fact, only 8.9% of admissions to hospice facilities are dementia related.<sup>2</sup> This suggests more education about timely hospice care is needed.

Hospice care should be sought for any person who has:

- A terminal illness (*six months or less to live*), and
- No longer seeking active treatment to cure.

The attending physician and the hospice medical director must certify in writing that the illness is terminal. The difficulty with Alzheimer's disease is predicting end of life. There is no typical end of life timeframe for a person with Alzheimer's disease. Each person progresses differently and often a person can go on for years before being overcome by an acute condition, such as pneumonia.<sup>3</sup>

The guideline "Medical Guidelines for Determining Prognosis in Selected Non-Cancer Diseases" published by the National Hospice Organization<sup>3</sup> has been



### Quote from a study participant:

"I didn't know my husband, diagnosed with Alzheimer's disease, could get hospice coverage in a nursing home!"

### Hospice Requirements

- You have Medicare Part A, health insurance with a hospice benefit, or other provisions are made for payment.
- Your doctor and the hospice medical director certify that you are terminally ill and have 6 months or less to live if your illness runs its normal course.
- You sign a statement choosing hospice care instead of other Medicare-covered benefits to treat your terminal illness.
- You get care from a Medicare-approved hospice program.

(From U.S. Department of Health and Human Services. Centers for Medicare & Medicaid Services, 2005, p. 3)

### Scenario An Example of a Hospice Candidate

An 84-year old female with late stage dementia, living in a nursing home, is not eating and losing weight. Staff has tried to get her to eat, but have been unsuccessful because she does not swallow the food, allowing the food to collect in her mouth and drool out. Over the past year, the staff has witnessed a progressive decline. She's had bouts of UTI's and decubitus ulcers due to her incontinence of urine and stool. She does not talk, relies on staff to complete ADL's, and spends her day sitting in a geri-chair for support.

used by physicians in determining when a person with dementia is appropriate for hospice care. However, more recently, additional criteria are also being assessed; advanced age, impaired nutritional status, and greater functional impairment.<sup>4</sup> The guideline can help health care providers, including social workers and nurses, decide the appropriate time to initiate discussion about hospice with the attending physician and the caregiver. These recommendations are just guidelines and not part of the hospice regulation. The hospice regulation says that physicians are to use their clinical judgment when determining prognosis.<sup>5</sup>

The **three key areas** necessary to meet the **criteria for hospice care** for a person with dementia include:<sup>3,4</sup>

1. **Meeting criteria 7 of the Functional Assessment Staging Tool (FAST) for dementia.**<sup>6</sup> FAST criteria items for stage 7 include any of the following:

- Ability to speak is limited to six words or fewer
- Single word vocabulary
- Ambulatory ability is lost
- Cannot sit up without assistance
- Loss of ability to smile
- Cannot hold up head

2. **Must have all of the following present:**

- Inability to ambulate independently
- Unable to dress without assistance
- Unable to bathe properly
- Incontinence of urine and stool
- Unable to speak or communicate meaningfully

3. **Plus, one of the following within the past 12 months:**

- Aspiration pneumonia
- Pyelonephritis or other upper UTI Septicemia
- Multiple stage 3 or 4 decubitus ulcers
- Fever that recurs after antibiotic therapy
- Inability to maintain sufficient fluid and calorie intake, with 10 percent weight loss during the previous six months or serum albumin level less than 2.5 g per dL (25 g per L).<sup>4</sup>

## Hospice Programs in Southeastern Wisconsin

There are many hospice programs in southeastern Wisconsin. As of 2004, there were 10 licensed hospice programs in Milwaukee County, two in Sheboygan County, and one in Washington, Waukesha, and Kenosha counties, respectively.<sup>7</sup> Hospice programs are regulated by the Federal government and, therefore, all must follow the same standard set of rules. However, differences in programs can be found with the interpretation of the rules and typical clients (i.e. some are more familiar with cancer, dementia, adults vs. children, etc.). Before recommending a hospice, inquire about key characteristics (listed below) that should be part of every hospice program<sup>8</sup> and their familiarity with caring for patients with dementia.

- **Patient and the family are viewed as a single integrated unit.** Care is centered on the dying person and his or her family. The patient and the family are part of the interdisciplinary team and care planning process. Their beliefs and values are acknowledged and respected. The patient and family are the authorities on what matters most and direct the care. Family needs are addressed equally as are the patient's needs.
- **Care is provided in several settings.** The aim is to allow the dying person to choose the setting where they want to die (i.e. home, nursing facility, hospice unit, free-standing hospice, hospital, or residential care setting).
- **Manage symptoms and reduce unneeded and unwanted medical interventions.** Hospice recognizes death is the final stage of life and as such the aim is to facilitate '*living at the end of life*' through relief of symptoms and pain, not curing the disease.
- **Provide comprehensive care that addresses all dimensions of the patient (i.e. "treat the whole person").** Suffering not only encompasses physical pain, but it can also be psychological, spiritual, or social distress. Hospice addresses the physical, social, psychological, and spiritual needs of the patient and family.
- **Accessibility to services 24 hours a day, 7 days a week.** Caregivers in the home need a lot of support in order to maintain that role and when problems occur. Day or night, families need to know they have a hospice team member available.
- **Care is Interdisciplinary.** The core team consists of physicians, nurses, social workers, clergy, volunteers, and others involved in the care of the patient and family. The team not only provides comprehensive care, but also provides support for one another. The team is responsible for developing and ensuring that all services are provided in accordance with the patient care plan.
- **Volunteers are a program requirement.** Volunteers supplement hospice services though being supportive, performing various tasks, active listening, and other services for both the patient and family. Some patients and families find it easier to talk to and relate to volunteers than to professional staff.
- **Bereavement support.** Hospice provides bereavement counseling and services to the bereaved both *before* and for *one year following* patient death.

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National Hospice and Palliative Care Organization

### Find a Hospice Program

<http://www.nhpco.org/custom/directory/index.cfm>  
(Enter state, program, or zip code).

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American Board of Hospice & Palliative Medicine

### Find a Hospice Physician

<http://www.abhpm.org/Locator.aspx>  
(Enter state, city, or name).

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## Hospice Web Sites

- **Hospice Foundation of America**  
2001 S Street, NW, #300, Washington, DC 20009  
Phone: 202-638-5419  
Email: [hfa@hospicefoundation.org](mailto:hfa@hospicefoundation.org)  
Web: [www.hospicefoundation.org](http://www.hospicefoundation.org)

- **Hospice**  
401 Bowling Avenue, Suite 51  
Nashville, TN 37205-5124  
Email: [info@hospicenet.org](mailto:info@hospicenet.org)  
Web: <http://www.hospicenet.org/>
  
- **National Hospice and Palliative Care Organization**  
1700 Diagonal Road, Suite 625  
Alexandria, Virginia 22314  
Phone: 703-837-1500 (Helpline: 800-658-8898)  
Email: [nhpco\\_info@nhpco.org](mailto:nhpco_info@nhpco.org)  
Web: <http://www.nhpco.org/templates/1/homepage.cfm>
  
- **Caring Connections (program from NHPKO)**  
Web: <http://www.caringinfo.org/i4a/pages/index.cfm?pageid=1>
  
- **Hospice and Palliative Nurses Association**  
One Penn Center West, Suite 229  
Pittsburgh, PA 15276-0100  
Phone: 412-787-9301  
Web: <http://www.hpna.org/>
  
- **Hospice Association of America**  
Web: [www.hospice-america.org](http://www.hospice-america.org)

### Useful Additional Hospice Resources

- On Your Own Terms (inventories and information for dying patients and their families).
  - o Web Address: <http://www.pbs.org/wnet/onourown/terms/tools/index.html>
  
- EPERC End of Life/Palliative Education Resource Center (share educational resource material among the community of health professional educators involved in palliative care education).
  - o Web Address: <http://www.eperc.mcw.edu/>
  
- Health Care Financing Administration (Federal laws governing hospice can be found at the US government printing offices).
  - o Web Address: [http://www.access.gpo.gov/nara/cfr/waisidx\\_00/42cfr418\\_00.html](http://www.access.gpo.gov/nara/cfr/waisidx_00/42cfr418_00.html)
  
- American Board of Hospice & Palliative Medicine (search for a certified hospice or palliative physician).
  - o Web Address: <http://www.abhpm.org/Locator.aspx>

<b>Myths &amp; Facts About Hospice</b>	
<u>MYTH</u>	<u>FACT</u>
Patients must have a Do-Not-Resuscitate order to be eligible for hospice	No Medicare provider can deny service based upon DNR status.
If the patient lives beyond the 6 months, they are no longer eligible for hospice care.	Hospice coverage is <i>available for extended periods of time</i> beyond six months provided that proper certification is made at the start of each coverage period ( <i>Two 90-day periods of care are followed by an unlimited number of 60-day periods</i> ).
If the patient revokes the Hospice Medicare Benefit, he/she cannot receive hospice care again.	The patient <i>can</i> re-enroll in a hospice program again without losing hospice care days for hospice election periods for which he/she is eligible regardless of past terminations of enrollment.
If a patient is enrolled in a home-based hospice program they cannot switch to an inpatient hospice program later on.	A person may <i>change once in each election period</i> where he/she chooses to receive hospice care, but the person must file and complete a signed statement indicating intent with both hospice providers.
Once you have enrolled in a hospice program, you can not be admitted to the hospital	Medicare covers inpatient hospital care for the following: <i>respite care</i> for relief of the patient's caregivers and for <i>pain control and symptom management</i> .
Medicare coverage is forfeited if hospice care is chosen	<i>Full Medicare coverage is retained</i> for health care needs not related to the terminal diagnosis.
Hospice means giving up	Hospice is not a 'giving up'. Rather, hospice provides specialized treatment and supportive care to both the terminal patient and family when cure is no longer possible. This enables the patient to live as fully and comfortably as possible, which affords the family and friends quality time with the patient.
Hospice only accepts patients dying of cancer	Hospice accepts patients with diagnoses other than cancer, i.e.: <i>HIV, or AIDS, end stage cardiac, renal disease, or diabetes, advanced neurological decline</i> (e.g., Alzheimer's, Parkinson's, severe stroke patients), severe Chronic Obstructive Pulmonary Disease ( <i>COPD</i> ), severe <i>debilitating rheumatoid arthritis</i> , and <i>other disorders</i> deemed terminal with 6 months or less to live.
Hospice care is really like assisted suicide	Hospice does not participate nor condone any action that either prolongs life or hastens death.
There are costs incurred to the patient for hospice care	Hospice care can be fully covered by Medicare Part A to Medicare beneficiaries, must be specified in the plan of care. ( <i>Drugs used for management of pain &amp; symptom control are covered, all others are subject to a fee at 5% of what it cost the hospice and not to exceed \$5</i> ).
Reprint with Permission from: Reynolds, SA. Learning Capabilities in the Elderly: Education Considerations" by Faculty Development in Geriatric	

## References

<sup>1</sup>U.S. Department of Health and Human Services. Centers for Medicare & Medicaid Services. Medicare hospice benefits. *A special way of caring for people with a terminal illness*. CMS Pub. No. 02154 Revised July 2005.

<sup>2</sup>National Hospice and Palliative Care Organization. (2004). *NHPCO's 2004 facts and figures*. Retrieved on July 24, 2006 from [http://www.nhpc.org/files/public/Facts\\_Figures\\_for2004data.pdf](http://www.nhpc.org/files/public/Facts_Figures_for2004data.pdf).

<sup>3</sup>Stuart, B., Alexander, C., Arenella, C., Connor, S., Herbst, L., Jones, D., Kinzbrunner, B., Rousseau, P., Ryndes, T., Wohlfeiler, M., Cody, C., & Buckley, S. (1996). *Medical guidelines for determining prognosis in selected non-cancer diseases*. Second edition. The National Hospice Organization, Arlington, VA.

<sup>4</sup>Schonwetter R.S., Han, B., Small B. J., Martin B., Tope K., & Haley W. E. (2003). Predictors of six-month survival among patients with dementia: An evaluation of hospice Medicare guidelines. *American Journal of Hospital Palliative Care*, 20,105-13.

<sup>5</sup>Federal Register. Department of Health and Human Services. Centers for Medicare & Medicaid Services. 42 CFR Part 418. *Medicare program; Hospice care amendments*. Vol. 70, No. 224 / Tuesday, November 22, 2005.

<sup>6</sup>Reisberg, B. (1986). A systematic approach to identifying reversible causes. *Geriatrics*, 41, 430-446.

<sup>7</sup>Wisconsin Department of Health and Family Services, Division of Public Health, Bureau of Health Information and Policy, Wisconsin Hospice Directory, 2004 (PPH 5362-04). July 2005.

<sup>8</sup>Connor, S. (1998). So what is hospice, anyway? In *Hospice: practice, pitfalls, and promise* by Stephen R. Connor. Washington, D.C.: Taylor & Francis, c1998.

# APPENDIX I



Southeastern Wisconsin Chapter				
FAMILY/CAREGIVER SUPPORT GROUPS				
Serving the counties of Dodge, Fond du Lac, Jefferson, Kenosha, Milwaukee, Ozaukee, Racine, Sheboygan, Walworth, Washington, Waukesha				
TO INSURE AVAILABILITY, PLEASE CALL FACILITATOR BEFORE FIRST ATTENDANCE 1-800-272-3900				
LOCATION	DAY	TIME	ADDRESS	FACILITATORS
<b>KENOSHA COUNTY</b>				
Kenosha	4th Thursday	6:30 - 7:30pm	Aurora Hospital 10400 75th Street Rooms J Kenosha, WI 53142	Steven Lauer Gail Tefts Candace Brown (262) 697-7778
Bristol Respite care available. week advance notice for respite.	3rd Monday	7:00pm	Westpsha Community Center 19200 93rd Street Bristol, WI 53104	Kathy Hinks Elaine Engel (262) 605-6667
Kenosha	2nd Tuesday	10:00am	St Joseph's Adult Day Center 9244 29th Avenue Kenosha, WI 53143	Mike Callaghan Robin Whiteside (262) 654-5410
Kenosha	2nd Monday	7:00pm	Kenosha Area Family & Aging Service 7730 Sheridan Avenue Kenosha, WI 53143	Jennifer Swartz (262) 658-0237 Becky Banks (262) 658-4125
<b>MILWAUKEE COUNTY - SPECIALTY GROUPS</b>				
All Women's Group	3rd Monday	6:00pm	Meadowmere 2330 S. 54 <sup>th</sup> Street West Allis, WI 53210	Carolyn Holzman Val Holzman 1-800-272-3900
All Male Group	4th Thursday	1:00pm	Alzheimer's Association Office 6130 W. National Avenue Suite 200 Milwaukee, WI 53214	Ken Graf Joseph Amrlein 1-800-272-3900
<b>MILWAUKEE COUNTY - CAREGIVER SUPPORT GROUPS</b>				
Bay View	2nd Tuesday	3:30pm	Bay View Community Center 1320 E. Oklahoma Avenue Bay View, WI 53207	Charlene Busse (414) 483-2061 Janet Krahn (414) 228-8700
Brown Deer Respite care available with advance notice.	3rd Monday	2:00pm	Alexian Village 7979 W. Glenbrook Road Brown Deer, WI 53223	Diana Joy (414) 355-9300
Greendale	3rd Monday	7:00pm	St. Alphonsus Parish Enrichment Center 5960 W. Loomis Road Greendale, WI 53220	Ann Roeder (414) 464-3880 x353 Kerri Livermore (414) 258-6170 x235
Greenfield	4th Wednesday	2:00pm	Clement Manor Rainbow Room 9405 W. Howard Avenue Greenfield, WI 53207	Ruth Hovland (414) 325-4002

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Greenfield	Last Thursday	6:30 - 8:00pm	Layton Terrace 9200 W. Layton Avenue Greenfield, WI 53228	Rev. Keith L. Johnson Donna Walker (414) 425-5600
Hales Corners	2 <sup>nd</sup> Thursday	7:00 - 8:30pm	Hales Corners Lutheran School 5425 S. 111th Street Hales Corners, WI 53214	Rev. Keith L. Johnson Joan Richter (414) 529-6700
Milwaukee Respite care available. 24hr. advance notice requested.	1st Tuesday	1:30pm	Luther Manor Faith & Education Building 4545 N. 92nd Street Milwaukee, WI 53228	Jennifer Harders Irene McGoldrick (414) 464-3888
Franklin	1st Tuesday	7:00pm- 8:30pm	Lake Terrace - West 6771 S. 68th Street Franklin, WI 53132	Judith Gunkel (414) 258-1030

**MILWAUKEE COUNTY - CAREGIVER SUPPORT GROUPS**

Milwaukee	4th Monday	6:00pm	Milwaukee Catholic Home 2462 N. Prospect Milwaukee, WI 53211	Linda Bruss (414) 220-4610 Ext 131
Milwaukee	1st Tuesday	10:00am	Luther Haven 8949 N. 97th Street Milwaukee, WI 53224	Marlene Miller Sue Schneider (414) 354-4600
Milwaukee	3rd Monday	10:00 - 11:30am	St John's on the Lake 1840 N. Prospect Avenue Milwaukee, WI 53202	Julia Kaczmarek (414) 831-6915
Milwaukee	2nd Wednesday	1:30 - 2:30pm	MCFI Older Adult Day Center 2020 W. Wells Street Milwaukee, WI 53233	Jennifer Degeneffe Renee Kirsch (414) 937-2035
Milwaukee	3rd Tuesday	6:00pm	Villa St Francis 1910 West Ohio Milwaukee, WI 53215	Sister Barbara Marie (414) 649-2888
Milwaukee	3rd Wednesday	4:00pm	Plymouth Apartments 826 W. Galena Street Milwaukee, WI 53205	Renelle Nelson (414) 263-3154 Connie Chestnut 1-800-272-3900
Milwaukee	3rd Thursday	6:00pm	Beverly Health Care - Bradley 6735 W. Bradley Road Milwaukee, WI 53223	Joni Barrie Pat Noble (414) 354-3300
Wauwatosa	3rd Thursday	1:00pm	Harwood Place 8220 W. Harwood Avenue Wauwatosa, WI 53213	Ken Graf (414) 256-6908

Wauwatosa Respite care available. Advance notice requested.	3rd Tuesday	6:30pm	The Lutheran Home 7500 W. North Avenue Wauwatosa, WI 53216	Kerri Livermore (414) 258-6170 Pat Preis (414) 258-6170
Wauwatosa	1st Wednesday	7:00pm	Froedtert Hospital 9200 W. Wisconsin Avenue Wauwatosa, WI 53226	Sue Moser (414) 805-3056 Jan Beyer (414) 805-5250
Wauwatosa	4th Tuesday	10:00am	San Camillo Atrium Dining Room 10200 W. Bluemound Road Wauwatosa, WI 53226	Sally Redmond (414) 258-1814
<b>OZAUKEE COUNTY</b>				
Grafton Respite care available with 24 hr. advance notice.	1st Wednesday	2:00 - 3:30pm	Lakefield Adult Day Center 1193 Lakefield Road Grafton, WI 53025	Karen Helland (262) 377-9780
Mequon	4th Tuesday	10:00 - 11:30am	Highlands @ New Castle Place 12600 N. Port Washington Road Mequon, WI 53092	Riki Nedbeck Nancy Alpren, RN (262) 387-8884
<b>RACINE COUNTY</b>				
Racine	4th Monday	6:30pm	Becker Shoop Center 6101 16th Street Racine, WI 53406	Diana Shekhinah Tracey Reimers (262) 637-7486
Racine	1st Friday	10:00am	C.A.R.E. Center 3801 Spring Street WI 53405	Marilyn Joyce (262) 687-1810
<b>SHEBOYGAN COUNTY</b>				
Sheboygan	4th Tuesday	6:30 - 8:30pm	Human Service Annex - Office On Aging Conference Room 1011 N. 8th Street Sheboygan, WI 53081	Christine Jeske (920) 459-3095
<b>WASHINGTON COUNTY</b>				
Germantown	2nd Tuesday	6:30 - 8:00pm	Virginia Highlands W173 N 10915 Bernie's Way Germantown, WI 53022	Lorraine Henrickson 1-800-272-3900
Hartford	1st Wednesday	6:30 - 8:00pm	Club 1022 69 Sell Drive Hartford, WI 53027	Sharon Feucht (262) 670-7733
West Bend	2nd Wednesday	1:00pm	Cedar Bay West 5555 Cedar Bay Drive West Bend, WI 53095	Melissa Gerkin (262) 306-4267
<b>WAUKESHA COUNTY</b>				
Brookfield	2nd Tuesday	1:30pm	Elmbrook Memorial Hospital 19333 W. North Avenue Brookfield, WI 53005	Veronica Naumann Bugel 1-800-272-3900 Debby Judkins (262) 548-1457

Caregiver's Guidelines

Brookfield	3rd Tuesday	10:00am	Congregational Home 3150 Lilly Road Brookfield, WI 53005	Meredith Turner (262) 781-0550 Cindy Schultz
Brookfield Respite care available. Advance notice requested.	3rd Tuesday	12:45 - 2:00pm	St. John Vianney Parish 1755 N. Calhoun Road Brookfield, WI 53005	Debbie Wakefield (262) 782-0740
Menomonee Falls	2nd Wednesday	6:00pm- 7:30pm	Heritage Court Memory Care Community 14250 W. Hampton Avenue Menomonee Falls, WI 53051	Jane Leuzinger (262) 781-6930
Menomonee Falls	4th Friday	2:00pm	The Arboretum Multi Purpose Room W180 N7890 Town Hall Road Menomonee Falls, WI 53051	Joe Amrhein 1-800-272-3900
Mukwonago	2nd Wednesday	6:30pm	Linden Ridge 841 County Hwy. NN Mukwonago, WI 53149	Meg Gleason (262) 363-6830 Holly Wise
New Berlin	3rd Thursday	6:00pm	Heritage @ Deer Creek 3585 S. 147th Street New Berlin, WI 53151	Elizabeth Steinhoff (262) 789-6600
Oconomowoc	3rd Thursday	7:00pm	Oconomowoc Library Spaulding Conference Room 200 W South Street Oconomowoc, WI 53066	Sharon Munro (262) 567-3111 Judy Tremaine (262) 567-4532
Oconomowoc	2nd Tuesday	10:00am	Oconomowoc Senior Center 1306 West Wisconsin Avenue Oconomowoc, WI 53066	Pamela Thomas (262) 560-6915 Geri Heppe (262) 928-4337
Sussex	3rd Thursday	6:30 - 8:00pm	Sussex Community Center W240 N5765 Maple Avenue Sussex, WI 53089	Lorraine Henrickson 1-800-272-3900
Waukesha	4th Monday	4:00 - 5:00pm	Heartland Health Care N26W23977 Watertown Road Waukesha, WI 53188	Tina Vandenneunel (262) 523-0933
Waukesha	2nd Thursday	4:00 - 5:00pm	Linden Grove-Waukesha 425 N. University Drive Waukesha, WI 53188	Jane Taylor (262) 524-6400

**THIS LISTING IS NOT TO BE USED FOR ANY FORM OF SOLICITATION.**

Throughout Southeastern Wisconsin, the Alzheimer's Association sponsors numerous support groups. They are open to all adults. FREE OF CHARGE. We urge you to attend regularly. You may benefit from attending more than 1 group per month.







