



Medication Management for People with Dementia

Helping a family member with dementia to take medication safely can be challenging for both the care recipient and the family caregiver.

This article is the fourth in a series, *Supporting Family Caregivers: No Longer Home Alone*, published in collaboration with the AARP Public Policy Institute. Results of focus groups conducted as part of the AARP Public Policy Institute's No Longer Home Alone video project supported evidence that family caregivers aren't being given the information they need to manage the complex care regimens of their family members. This series of articles and accompanying videos aims to help nurses provide caregivers with the tools they need to manage their family member's medications. Each article explains the principles nurses should consider and reinforce with caregivers and is accompanied by a video for the caregiver to watch. The fourth video can be accessed at <http://links.lww.com/AJN/A78>.

Alzheimer's disease and related dementias are estimated to affect one in nine U.S. adults older than 65 years of age.^{1,2} The number of older adults with dementia is expected to rise substantially during the next several decades, as the post-World War II population ages. Dementia causes impairment in memory and judgment; in the later stages, it can lead to physical impairment and death.¹ Most of the estimated 5.4 million people with dementia in the United States receive help and care from a family member.^{1,2} Family caregiver involvement is central to helping patients successfully navigate the disease process. In the early stages, family caregivers provide emotional support and practical guidance. In the later stages, they take on more complex tasks, such as medication management.

In this article, we offer recommendations for nurses as they teach family caregivers how to manage medications for a family member with dementia. The recommendations were developed based on the "just culture" movement in health care, which is supported by the American Nurses Association.³ (For a description of the just culture concept, see the first article in this series, "Managing Complex Medication Regimens," November 2016.) Using the recommendations included in this article, nurses can teach family caregivers strategies to minimize medication errors. For example, recurrent medication errors may indicate that the family caregiver is overburdened and needs respite services. The below recommendations also provide nurses

with information about which tactics family caregivers can use when errors inevitably occur.

BACKGROUND AND EVIDENCE

Dementia is an umbrella term for neurodegenerative disorders that affect memory, judgment, communication, personality, and daily functioning. Alzheimer's disease is the most common type of dementia. For many people who have dementia, the disease trajectory is often long, lasting years from diagnosis to death. Those with mild dementia can often function independently, but eventually most need assistance with activities of daily living.^{1,4}

More than 15 million Americans provide assistance to people with dementia, and women make up approximately two-thirds of this group.¹ In 2015 alone, caregivers provided more than 18 billion hours of (unpaid) care, valued at more than \$221.3 billion.

How to Use This Series

- Read the article, so you understand how best to help family caregivers manage medications.
- Encourage the family caregiver to watch the video at <http://links.lww.com/AJN/A78>.
- Ask the family caregiver if she or he has any questions.

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A family caregiver attempts to give medication to her reluctant mother. Photo courtesy of the AARP Public Policy Institute.

This care has major psychological costs: more than 50% of people caring for someone with Alzheimer's disease report high levels of emotional stress owing to caregiving, which can result in depression, anxiety, and feelings of being overburdened.¹

Despite the high prevalence of dementia in the United States, and the well-established health risks of caregiving, family caregivers describe feeling a lack of support from health care professionals.⁵ A study commissioned by AARP found that many family caregivers in the sample (N = 1,677) described medication management as time intensive and anxiety provoking.⁶ Family caregivers felt ill prepared, with 47% reporting they did not receive any training. Of the 373 family caregivers who found medication management "hard to do," almost 24% found it difficult because the care recipient resisted taking medications or had cognitive and behavioral problems.⁶

Helping a family member with dementia to take medication safely can be challenging for both the person with dementia and the family caregiver. The person with dementia may feel apprehensive about turning over control of medications to family members. This increased dependence on others can result in anxiety, negative thoughts, and lowered self-esteem.⁷ The family caregiver may feel challenged by this

change in roles. As dementia progresses, families may be uncertain about when and how to take over medication management. The desire to maintain safety, while at the same time protecting dignity, can be difficult for all family members and has the potential to lead to conflict.⁸

Along with coping with the psychological and practical challenges, family caregivers often have to grapple with how to give medications to care recipients who may be inconsistent in their willingness to take the medications. Frustratingly, it can be unclear why care recipients refuse medications. Ishii and colleagues found that people living in nursing homes who had cognitive impairment, severe visual impairment, delusions, depression, or severe pain were more resistant to care, including medication administration.⁹ These behavioral symptoms may lead them to misinterpret caregivers' intentions, leading to medication refusal.

A controversial approach to managing medication resistance is to give the medications covertly (for example, to hide them in food or drinks). Much of the literature on covert medication administration addresses professional nursing practice and maintains that giving medication covertly should only be done when people lack the cognitive capacity to make

decisions about their care.¹⁰ One exception can be found in an article by Treloar and colleagues, in which the authors report that the majority of the 50 family caregivers they surveyed approved of the covert practice if the medication was helpful and was used to manage mental distress.¹¹ Notably, more than half of the caregivers believed that the care recipient's physician should decide whether to give the medications covertly.

The use of covert strategies could be considered within the framework of a person-, family-, and culture-centered care model.¹² This model incorporates the needs of both the family and the person with dementia into the decision-making process. Using this approach, a family may decide it is more beneficial for the care recipient, as well as the family, to have a medication used covertly to prevent distress or hospitalization. For example, covert administration of a diuretic to a person with congestive heart failure and dementia would prevent shortness of breath, anxiety, and possibly a visit to the ED. This would stave off the emotional and physical stress of an acute event for the entire family.

teach family caregivers about medication management in the context of dementia care.

Preparation and education. Taking on the task of medication management for a family member with dementia can be anxiety provoking for both the family caregiver and the person with dementia. The family caregiver may be taking on a new role that she or he feels ambivalent about, and the person with dementia may feel a sense of loss of independence.¹⁵ Nurses can lessen apprehension by establishing rapport with the family member, acknowledging complex feelings, and teaching the necessary skills in a self-confident manner. If appropriate, include care recipients in the teaching sessions to communicate respect for their knowledge and experience. Encourage family caregivers to discuss their feelings about taking on this task and remind them that they have developed coping and management skills throughout adulthood that can help them to learn these new strategies.¹⁶

Throughout the teaching sessions, provide written information to reinforce the lessons, as well as phone numbers for health care professionals who

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Whether medications are administered covertly or not, family caregivers often have to use their judgment as to when to give a medication and when to withhold it, particularly when the medication has been prescribed "as needed." It's especially important that family caregivers know which clinician prescribed which medication, so that they know whom to talk to when making these decisions and if the medication is not effective, affordable, or otherwise practical.^{8,13}

RECOMMENDATIONS FOR TEACHING MEDICATION MANAGEMENT STRATEGIES

A recent study by George and Steffen found that family caregivers who felt more prepared to take on the role of medication management for a family member with dementia felt less hassled.¹⁴ Nurses can play a vital role in helping family caregivers to prepare for and manage the provision of medication to those living with dementia. Yet, as the evidence indicates, family caregivers often lack the support of health care professionals.⁶ We address this gap in family care by providing recommendations that nurses can use to

can provide the family caregiver with assistance. Finally, take the time, if appropriate, to recognize the contribution the family caregiver makes to the well-being of the care recipient—and acknowledge the care recipient's wisdom in accepting help.

As discussed above, remind family caregivers that everyone makes mistakes. Describe what a mistake is (for example, giving the wrong dose of a medication), and when and how to notify a health care professional if this occurs. Reassure family caregivers that mistakes happen, and knowing about these errors helps the health care team provide safe care.³

Administration recommendations. The following recommendations can be used when teaching family caregivers about medication management.

Identify goals of care. Because goals of care vary, depending on the stage of dementia, family caregivers should work closely with the care recipient's health care provider, discussing goals and plans for management across the dementia trajectory, from diagnosis to death. Nurses can help family caregivers clarify the goals of care and help them understand



that what may be appropriate when someone is in the early stages of dementia may not be necessary in the late stages. For example, a lipid-lowering agent may not be needed in a person with end-stage dementia.

Alternatively, some medications may be needed to improve quality of life. For example, a person with dementia may not have the cognitive function to request “as needed” medications. Thus, medications for chronic pain, such as acetaminophen, may need to be given on a routine basis. Goals of care should be assessed every six months and documented clearly. They should also be communicated to all team members and easily accessible.

Medication safety and efficacy. Carefully review all medications and provide guidance on how to simplify the medication regime. A pharmacist can be very helpful in this process. Family caregivers need to understand that prescribed medications can interact with herbal therapies and over-the-counter medications. They will also need instruction on how to know when medications are effective. A person with dementia may not be able to articulate if she or he is in pain, for instance, but may be observed to be calmer and more engaged after receiving pain medicine.¹⁷

Family caregivers should know to call the health care provider if the care recipient consistently resists taking medications.

Care-recipient resistance. Teach family caregivers that people with dementia may at times resist medications and that this is not unusual. Also, it will not always be clear why the person is resisting the medication. Nurses can help family caregivers to identify priority medications as well as those that can be safely skipped now and then. Family caregivers should know to call the health care provider if the care recipient consistently resists taking medications. Illness, pain, or depression may be affecting the care recipient’s ability to engage in her or his care.

It can be frustrating for caregivers when a family member with dementia resists taking medications. To minimize resistance, help family caregivers to establish a comfortable routine that is in concert with the daily routine. For example, give medications with meals (if allowed). Advise family caregivers to administer the

most important medications first, and, if possible, in the morning, when people with dementia less frequently experience agitation.^{18,19} To minimize confusion, family caregivers need to make sure the care recipient is wearing glasses and hearing aids, if needed. A simple amplifier, such as a Pocketalker, can improve communication²⁰ and facilitate ease of medication administration.

Encourage family caregivers to use a calm approach and employ stress reduction techniques (for example, deep breathing) when medication administration becomes challenging. Teach them not to argue or try to convince the care recipient to take medicine, as this is often futile and can exacerbate tension. Family caregivers need to know that it is acceptable to stop and try again at a later time or have another person (for example, a friend or neighbor) give the medication. Help these caregivers to recognize that the family member’s resistance to taking medication may vary each day, and support is often necessary.

Family caregivers can also try using distraction (for example, listening to music or reminiscing), so that medication administration is more of a pleasant event and less about ingesting a pill. Help the family caregiver draw up a list of pleasant activities that she or he can refer to as needed.²¹

When resistance is commonplace, encourage family caregivers to discuss medication options with the health care provider and pharmacist. Ask if some medications can be discontinued or given in an alternative form, such as a liquid or disintegrating tablet for people who have difficulty swallowing pills. Some medications, such as rivastigmine (Exelon), a common dementia medication, come in a patch form.

For some caregivers, providing medications covertly (in food or drink) is an option that can be used to cope with resistance. Nurses can review the goals of care to identify if covert use is needed. For example, if a goal of care is to minimize pain, it may be more compassionate to manage the pain by giving a pill covertly.

Emphasize that family caregivers can and should call their support team (the pharmacist, nurse, or a peer) when medication strategies aren’t working. Family caregivers should have a low threshold for calling for support. Help them to identify other information sources as well. For example, the Alzheimer’s Association has a help line—(800) 272-3900—that is staffed by counselors 24 hours a day. The AARP Web site (www.aarp.org/home-family/caregiving) includes several resources for family caregivers.

Managing mistakes. Importantly, teach family caregivers to recognize that mistakes will happen. Develop a plan for handling errors, with an emphasis on problem-solving instead of blame.

VIDEO CASE EXAMPLE

Go to <http://links.lww.com/AJN/A78> to watch how Linda copes with her mother's resistance to taking medications. Rosa has dementia and is dependent on Linda's help with day-to-day care. Linda has learned that a daily routine helps keep Rosa oriented and their day running smoothly. She gives Rosa her medications at the same time every day, for example, and typically Rosa does not resist taking them.

In the video, however, Rosa does refuse to take her medication. Linda becomes more and more frustrated, but then she remembers advice given to her by her mother's nurse, who told her to stop and take a break when this occurs. Linda doesn't know what to do next, however, so she calls a caregiver hotline and talks to a nurse, Terri, about her concerns. Together they identify several options that may enable Linda to successfully provide Rosa with the medications she needs. One of Terri's suggestions is for Linda to find a pleasant activity to do with Rosa, so she is focused on the activity, not the medication. She also suggests that giving the medication along with a favorite food might be helpful. After ending the call, Linda opens the family photo album and reminisces with Rosa about a trip to London. During this time together, Linda gives Rosa her medication along with a spoonful of yogurt and encounters no resistance.

This video demonstrates techniques family caregivers can use when care recipients resist medications. Nurses need to remind family caregivers that what works one day may not work another day—and that they need to seek support when they feel frustrated. Nurses, pharmacists, and peers should be available and willing to help family caregivers in their important work. ▼

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