



Wisconsin Alzheimer's Institute

UNIVERSITY OF WISCONSIN
SCHOOL OF MEDICINE AND PUBLIC HEALTH



Home Health Caregiver Education Training Guide

**A comprehensive guide for implementing effective education
to caregivers on the medical complications of dementia.**

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**Implementing Effective Education to Caregivers on the
Medical Complications of Dementia**

TABLE OF CONTENTS

| | |
|---|----|
| 1. About the Training | 3 |
| a. Background and Development of Clinician Training | |
| b. Home Health Partners | |
| c. Educating Caregivers on the Medical Complications of Dementia | |
| d. How to Use the Educational Topics | |
| 2. Caregiver Program Implementation at a Glance | 7 |
| a. Determining Your Organization’s Need, Capacity, and Readiness | |
| b. Implementation Logistics | |
| c. Benefits to Patients | |
| d. Benefits to Caregivers | |
| e. Benefits to Your Organization | |
| 3. Caregiver Education: Training Your Staff | 11 |
| a. Medical topics - Presentation Pages and Talking Points | |
| b. Teach Backs | |
| 4. Case Examples | 35 |
| 5. Education Resources | 37 |
| a. Frequently Asked Questions (FAQ) | |
| b. Dissemination of Materials | |
| c. Forms and Flyers | |
| 6. About Wisconsin Alzheimer’s Institute | 64 |
| a. Alzheimer’s Disease Initiative-Specialized Supportive Services Grant | |
| b. Acknowledgements | |
| 8. References | 67 |

Implementing Effective Education to Caregivers on the Medical Complications of Dementia

Chapter 1

About the Training

Background and Development of the Clinician Training

The home health caregiver education program was designed to address the needs of informal family caregivers caring for people with moderate to severe dementia. The goal of addressing the increasing rates of Alzheimer's disease and supporting caregivers for people with dementia has become a vital goal for the US Department of Health and Human Services. The 2014 update to the National Plan to Address Alzheimer's Disease states that, "providers need accurate information ... how to address the physical, cognitive, emotional and behavioral symptoms of the disease, and how to assist caregivers as they cope with the physical and emotional aspects of their caregiving responsibilities." Our education program was created to meet the relevant need of caregivers to learn more about the medical complications of people with moderate to severe dementia.

Currently in the United States there are 5.1 million people living with Alzheimer's disease: 43% severe, 30% moderate and 27% mild. As dementia progresses from the early, to middle, to late stages, the medical conditions that can co-exist during these phases can also become more complex and require more attention. Some of these can include can include physical changes such as increased falls, incontinence, pain and swallowing issue. Others can include behavioral and psychological symptoms of dementia (BPSD) such as mood changes, increased mood changes and personality changes. Managing the complexities of dementia along with other comorbid conditions would generally require a knowledgeable and skilled individual, however studies show that 51% of caregivers of persons with dementia do not have nursing or other medical training.

By developing and implementing the home health caregiver education program, we can bridge this gap in knowledge and skills-based care by training clinicians to educate caregivers on how to identify, prevent and manage the common medical complications of dementia. As home health services generally exist, services are brought into the home when a person is

Implementing Effective Education to Caregivers on the Medical Complications of Dementia

homebound and often times after a hospitalization, and they require medical care to bring them back to their baseline status. This involves having a nurse or other skilled clinician in the home to provide the necessary cares or therapy the patient needs to recover. However, the caregiver or other members in the home may be left out of the equation to observing or learning how this treatment is delivered. Once home health services are discontinued, the patient and caregiver(s) are left to their own devices. If the patient starts declining medically or exhibits new symptoms, caregivers are often unequipped to know how to handle the issue, which may result in their condition worsening to the point of an emergency room visit or another hospitalization. This can be costly, time intensive, stressful for caregivers, and detrimental to the patient. Our goal of piloting this home health program is that by educating informal caregivers it will increase their self-efficacy to manage the co-occurring dementia and other medical issues, improve patient outcomes to help them remain in their homes longer, increase the knowledge capacity of home health clinicians about dementia, and reduce the unnecessary use of emergency medical services.

Home Health Partners

Home health clinicians caring for patients that qualify for services under Medicare have a unique opportunity that goes beyond providing direct medical care to the individual that is homebound. Dementia is naturally complex, but to additionally understand the other medical complications that often co-exist can be daunting to the untrained family caregiver. This can be stressful and overwhelming to caregivers and can lead to missed opportunities to address an emerging medical issue early before it turns into an emergency situation. WAI's response to this was to partner with two home health agencies that would be trained on the common medical issues that affect people with moderate to severe stage dementia, and in turn have those clinicians educate caregivers on those person-centered concerns and how to manage them. These pertinent areas that are discussed with the caregivers include, dementia basics, caregiver role strain, constipation, dehydration, falls, incontinence, infection, pain, pneumonia, pressure injury, swallowing problems, weight loss, behavior changes, communication changes, hospice and palliative care, and other resources.

Implementing Effective Education to Caregivers on the Medical Complications of Dementia

Educating Caregivers on the Medical Complications of Dementia

The overarching goal of the caregiver education program is to help people with dementia remain in their homes as long as possible by engaging home health agencies to treat and support the individual with moderate to severe dementia, by educating caregivers on how to identify, prevent, and manage the common medical conditions associated with dementia. The idea is not to expect caregivers to be educated on the same level as nurses or therapists, but rather to have adequate knowledge to see early on when a medical issue is emerging, how to treat or manage it at home as much as possible, and to have the skills to prevent it from occurring in the future through proper precautions and addressing warning signs proactively. Furthermore, the education involves helping caregivers know who to call for when help is needed (eg, when to make an appointment with the primary provider) versus seeing a specialist for a different specific medical need.

How to Use the Educational Topics

To effectively educate caregivers in the medical complications of dementia, we designed two educational manuals to be used as primary tools for sharing the information. These include the *Clinician Manual* and the *Caregiver Manual*, which parallel each other in terms of the topics covering fourteen different medical complications of dementia. A key difference is that the clinician manual includes a user guide, more evidence-based data, and is intended to be used only by clinicians for teaching and care plan goals. The caregiver manual is written in more simple, easy to understand language for the untrained caregiver and it includes teach back sections for each corresponding section.

Each topic in the *Clinician Manual* corresponds to a topic in the *Caregiver Manual*. The *Clinician Manual* provides a brief evidence-informed synopsis of medical problems associated with moderate to severe dementia, as well as care plan goals related to providing education on that topic for the caregiver. It is recommended that the home health clinician review the *Clinician Manual* sections before providing education to the caregiver on each topic.

Implementing Effective Education to Caregivers on the Medical Complications of Dementia

The *Caregiver Manual* is a teaching tool and resource for caregivers. Each section includes information for caregivers, as well as teach back questions for the nurse to assess the learner's understanding of the material.

Both manuals include a table of contents that also serves as a checklist. The goal is to review each topic with the caregiver over the course of the home health episode. Each caregiver will have different needs. Some topics will be more pressing than others. For example, if the individual with dementia was discharged from the hospital with an aspiration pneumonia diagnosis, the section on swallowing problems and pneumonia may be more important to the caregiver than the section addressing constipation. The sections on Dementia Basics, Caregiver Role Strain, and Resources—Getting Help should be completed at the start of the caregiver education. Afterwards, the sections can be taught in any order. The topics were chosen because they are all common medical complications for persons with moderate to severe dementia. Even if the health condition is not a problem now, it could become one in the future, especially as the disease progresses. It is important to inform caregivers that there is a risk to develop this problem, and that there are tools to prevent it – or identify and manage the problem should it occur. In the first caregiver education visit, clinicians should go through the table of contents with the caregiver to identify those problems that are currently a concern. Clinicians should touch on all the topics over the course of the home health encounter, but it is appropriate to prioritize those problems that are of biggest concern to the caregiver. The education is appropriate for any caregiver. If there are alternate or paid caregivers in the home, it is important to involve them in the education as well. When involving paid caregivers, you may choose to prioritize the sections that have to do with direct caregiving. For example, it would be important for a paid caregiver who assists with bathing to hear information about preventing and identifying pressure injuries and falls. As the clinician works through each section, they check off on the teach back forms when they have been completed and who received the education.

Chapter 2

Caregiver Program Implementation at a Glance

Determining Your Organization's Need, Capacity, and Readiness

The caregiver education program can be an invaluable way to support caregivers in their journey and help patients remain safe at home longer. However, when considering whether to incorporate the caregiver education program into your organization, it is vital to examine your organizations current staffing levels, current case load demands, and ability to schedule additional time in the home educating caregivers. Some things to explore and discuss with your teams before taking on this endeavor includes:

Organizations should anticipate trainings to take 2.5 to 3 hours to thoroughly cover dementia basics and desired outcomes of the program, the entire content of topics covered in the PowerPoint, and time for questions and answers. Organizations may consider breaking the training into two 1.5 hour sessions. Materials that should be used in the training include: the training PowerPoint, training notes, clinician and caregiver manuals for trainees to refer to during the training, and local dementia resources for caregivers.

The caregiver education was designed to be delivered by any trained home health clinician, however the sections involve different medication complications that fall under various medical and therapeutic disciplines, so it is preferable to take an interdisciplinary approach to the care delivery. During the pilot period of the program, home health nurses, physical therapy, occupational therapy, speech language pathology and a social worker were all trained in implementing the caregiver education. Depending on the specialties qualified to be in the home for skilled services, those clinicians delivered the education and covered the topics most pertinent to their scope of practice. When considering which of your staff to train in the program, we recommend you use the specialists listed above and to refer to the comparative scope of practice diagrams when determining who the best experts are for teaching particular

Implementing Effective Education to Caregivers on the Medical Complications of Dementia

section to caregivers. Additionally, the diagrams are a beneficial tool when identifying which practices are best for cross referencing for additional support or education.

Determine your staff's ability and motivation to deliver the educational topics to caregivers. Consider whether this will fit into current work schedules in respect to the clinician's caseloads. If clinicians utilize the educational materials, have a plan for how it will be used, allowing enough time in visits to teach the medical complication topics. For example, determine if it is best to provide the education following the skilled services, or if it will be embedded within the nursing and therapy services (eg, educating the caregiver while you are providing wound cares). Furthermore, make a plan for examining the effectiveness of using the tool, including positive and negative impacts based on qualitative feedback and the teach-back sections.

Implementation Logistics

Implementing the caregiver education program involves two key tools: the *Clinician Manual* and the *Caregiver Manual*. These resources include all the pertinent topics about the various medical issues, as well as resources for caregivers to have at their disposal. The clinician manual includes a "user guide" on how to teach the materials to the caregivers and discusses the medical complications, signs, symptoms and prevalence with evidence-based research to support it. Whereas the caregiver manual includes the same sections, but is written in lay terms for caregivers who do not have a medical background. The sections in the caregivers' manual covers the same content but also includes some examples and is in a simplified format for ease of understanding.

Benefits to Patients

This educational program is geared towards caregivers, but the larger indirect goal is for it to have an impact on the person (patient) with dementia. Patients can certainly benefit from skilled home health services to address more acute needs, but having an added layer of support from educated caregivers about the medical complications will help increase the likelihood that the patient's health, safety and well-being will be maintained ongoing. This educational material for caregivers will help their loved ones:

Implementing Effective Education to Caregivers on the Medical Complications of Dementia

Stay in their homes longer. Having the knowledge and tools to manage medical conditions before they turn into a crisis will result in patients being able to stay in their homes longer.

Reduce illness and injury. Having the knowledge of how to prevent or manage common medical complications will help avoid injuries to the patient from infections, falls or other common medical concerns.

Reduce hospitalizations, emergency room visits, and additional home health services. By educating caregivers to have a more proactive approach to their loved one's medical issues, it will reduce the likelihood of conditions worsening and leading to a crisis response.

Benefits to Caregivers

This program is designed to educate caregivers in order to increase their knowledge about dementia and co-occurring medical complications. In addition, caregivers will benefit from:

Increased awareness and skills. As the adage says, when you know better you do better. For caregivers who know more about dementia, what to anticipate, and how to respond, they will be better equipped to respond to the ever-changing needs of their loved one. By having a better understanding of the type of dementia their care recipient has, how it will affect cognition and daily function, as well as how it will manifest over time, caregivers can learn to have more patience, compassion, and to appropriately respond to changes over time.

Caregivers who are better educated on the medical complications of dementia will be better equipped to proactively take action to address those complications before it becomes a crisis.

Decreased stress and burden. Caregiving is challenging and can create high levels of stress and health consequences. When a loved one gets ill, injured, or admitted to the hospital, it can be very physically, emotionally, mentally and financially draining on the caregiver. Particularly when caregivers don't have the resources or support to safely continue caregiving. This education delivered by clinicians to caregivers will help reduce stress, as caregivers will understand how to prevent illness and injuries, or how to manage them if they do occur.

Improved self-confidence. Having the right skills or "tools in the toolbox" can help anyone feel more capable of handling any situation thrown their way. Having the right preparedness will also caregivers to feel more confident in their ability to identify, prevent and manage the

Implementing Effective Education to Caregivers on the Medical Complications of Dementia

issues that may inflict their loved ones, so that it does not revolve into a crisis situation.

Without the proper education about the medical complications of dementia, caregivers can feel lost or unsure of how to avoid a potentially serious or fatal situation.

Increased understanding of who and when to call for help. Often times, caregivers can feel alone when caring for a loved one with dementia. It can often be isolating and disorienting when trying to figure out who and when to ask for help. This educational program will assist caregivers in establishing a way to understand how to find help. In collaboration with the home health clinician, caregivers will develop a patient-tailored plan of action to take if their loved one is sick, falls, shows signs of pain, etc.

Potential improvements to their own health. Caregiving is stressful, but caregivers of people with dementia are more likely to experience negative health consequences and early mortality than compared to caregivers of people with other health ailments. By receiving the program's knowledge and strategies that help them take better care of their loved ones, resulting in better patient outcomes and improved self-efficacy of caregivers, they will have reduced stress, isolation, and health consequences of their own.

Benefits to your Organization

If you are a clinician reading this guide, it is likely you have witnessed patients and their family members who are "frequent fliers" of the healthcare system. These are individuals who, despite receiving adequate care in the hospital or when transitioning back home, seem to decline to a state that results in an emergency response. Caregivers who know how to prevent a medical situation and how to manage the medical complexities of their loved ones, will reduce the likelihood of calling on emergency services or clinicians to come back into the home. For the clinician, this equates to fewer visits with patients, potential reduction in caseload size, and decreased stress from high demands and increasing workloads.

Implementing Effective Education to Caregivers on the Medical Complications of Dementia

Chapter 3

Caregiver Education: Training Your Staff

Medical Topics: Presentation Pages and Talking Points

In the following sections, the reader should reference the presentation pages (available in pdf) to accompany the training module slides and talking points. Also, readers should refer to the Frequently Asked Questions below to familiarize themselves with the most common questions participants asked during the training. This will prepare the presenters to answer these questions or elaborate on the training content.

[Training PDF: Medical Complications of Moderate to Severe Dementia](#)

Presentation Page 2 - Home Health Education

The main objective of the home health education to deliver effective care and support services to caregivers of people living with moderate to severe dementia. The goal is to train home health clinicians on how to train caregivers on ways to identify, prevent and manage the common medical issues associated with dementia.

Target outcomes include: Improve health and wellbeing of person with dementia, help them remain in their homes as long as possible, reduce caregiver stress and burden, and decrease the use of emergency medical services.

Page 3 - Outline

This is the outline of the training. Reviewing: **Interdisciplinary scope of practice**- How the various home health clinicians can coordinate the delivery of the education to caregivers, focusing on their areas of expertise and **Education Program and Modules**- These are the sections in the caregiver and clinician manuals about the medical complications.

Implementing Effective Education to Caregivers on the Medical Complications of Dementia

Page 4 - Referral Flow Guidelines

The following slides will cover the clinician flowcharts.

Some general guidelines:

- For all cases, always involve the social worker to cover 'Dementia Basics' and 'Caregiver Role Strain' first during the visit.
- Caregivers will various supports and services along the way; always refer to other services outside your scope of practice.
- Communicate with clinical colleagues on the modules you'd like them to cover.

Page 5 - Comparison of Scope of Practice

This chart shows the different medical topics that the different providers can cover. Bolded topics are the sections that fall within that clinician's scope of practice (eg, a nurse can educate on all the medical sections, whereas the social worker will have expertise in caregiver topics, BPSD, hospice, etc). Areas that are circled indicate the topics that 2 or more clinicians have the expertise to cover (eg, OT and SLP can both educate the caregiver on swallowing and weight loss). The division of topics helps ensure that all content is discussed with the caregiver.

Page 6 - Clinical Referral Flows: PT + OT + SW Referrals

This image shows the collaboration between the PT, OT and SW for covering the topics listed. For example, the SW or OT could educate on dementia basics and caregiver role strain, but the PT would take the lead on educating on the falls and pain modules.

Page 7 - Clinical Referral Flows: PT + SLP + SW Referrals

This image shows the division of medical topics discussed if the PT, SLP and SW are referred to the case.

Implementing Effective Education to Caregivers on the Medical Complications of Dementia

Page 8 - Clinical Referral Flows: PT + SW Referrals

This image shows the division of medical topics discussed if the PT and SW are referred to the case. In this situation, the PT and SW are advised to consult with the SLP, OT, and/or nurse regarding education on topics listed in the light blue square: swallowing, incontinence, constipation and dehydration.

Page 9 - Clinical Referral Flows: Nursing-led + SW referrals

This chart displays how the medical topics could be covered in a nurse-led home health case. The sw would cover dementia basics and caregiver role strain, but consultation or referrals to PT, OT and SLP could be made to cover the topics on the right (falls and swallowing).

Page 10 - Dementia and DSM-5 Terminology

Dementia, now called Major Neurocognitive Disorder, refers to a cluster of three categories of observable symptoms that yield a “suspected” diagnosis. These are: deficits in 2 or more cognitive areas, significant decline from previous abilities, interference with independence in everyday activities (e.g. Cooking, laundry, grocery shopping, finances, medications, driving); and are not better explained by another condition. The final diagnosis is given after death through autopsy. Currently scientists are also developing ways to meaningfully diagnose dementia using PET imaging, lumbar puncture for cerebrospinal fluid draw, and blood draw.

Page 11 - Neurocognitive Domains

Many people understand dementia to mean memory loss. Loss of memories of familiar people, faces, and routines are visible and distressing to caregivers, so it is natural they focus on this. In fact, loss of memories are only one piece of this picture. Memory, in addition to being a personal record of experiences, is also vital to new learning, which becomes difficult to impossible as dementia progresses. The full scope of cognitive function impacted by dementia includes complex attention, executive function, learning and memory, language, perceptual-motor, and social cognition.

Implementing Effective Education to Caregivers on the Medical Complications of Dementia

Page 12 - Causes of Dementia

These are estimates of the causes of dementia; evolving evidence has suggested that mixed dementia causes may be more common

Page 13 - Dementia Stages

The Quick Dementia Rating Scale (QDRS) is a tool for determining the stage of dementia. It should be completed with the help of a caregiver who can give reliable information about the extent and severity of change from prior abilities. Emphasize to the caregiver they should rate the changes based on *cognitive* changes. If the person living with dementia has physical limitations, you can ask the caregiver if they could complete the task if the physical limitation was not present, and score based on this judgement.

Page 14 - Moderate Stage

No clear cut-off to indicate the transition from early to moderate stage. Signs and symptoms that the person has moved into this stage include increased problems with cognition, executive function, and functional ability; significant decline in memory overall. BPSD can occur in any stage but is more common in the moderate stage, particularly mood disorders, sleep disorders, psychotic symptoms, and agitation. Overt personality changes such as more irritable, less humorous, increasing problems or total dependence in IADLs (cooking, driving, managing finances). Begin to need assistance with ADLs (Bathing, toileting, and dressing)

Page 15 - Severe Stage

This includes inability to recognize family members. BPSD increases- Delusions, anxiety, agitation. Decline in long term memory- Remembering few if any details of childhood or early life. Inability to walk or speak. Also more changes in eating and increased swallowing issues. Incontinence of bowel and bladder

Page 16 - Complications of Dementia

These are the common medical complications of dementia covered in this caregiver education program

Implementing Effective Education to Caregivers on the Medical Complications of Dementia

Page 17 - 2021 Alzheimer's Disease Facts and Figures

This graphic is available from the Alzheimer's Association website. Some of the facts you will encounter as clinicians are:

- 82% of seniors believe it's important to have their cognitive function checked, but only 16% do
- From 2000 to 2017, deaths from heart disease decreased 9%, while deaths from Alzheimer's disease increased 145%
- Alzheimer's disease is the 6th leading cause of death in the United States
 - One in three seniors over 80 dies with dementia
- For perspective on your work with caregivers, consider that over 16 million Americans provide unpaid care for a person with dementia
 - Nearly half of all caregivers who provide help to older adults do so for someone living with Alzheimer's or another dementia

Page 18 - Caregiving for Someone with Alzheimer's disease

The 16 million unpaid caregivers in the U.S. provide 18.5 billion hours of care or \$234 billion dollars' worth of care. The total lifetime cost of health care for a person with dementia is about \$350,174. 70% of the total lifetime cost of care is borne by families. This total does not count the financial cost to these families

Page 19 - Caregiver Statistics

Alzheimer's takes a significant toll on caregivers. Eighty-three percent of the help provided to older adults in the United States comes from family members, friends or other unpaid caregivers. *Who are the caregivers?* About one in three caregivers (34 percent) is age 65 or older. About two in three caregivers are women, and over one-third are daughters. Most caregivers (66 percent) live with the person with dementia in the community. About one quarter of dementia caregivers are "sandwich generation" caregivers — meaning that they care not only for an aging parent, but also for children under age 18. Compared with caregivers of

Implementing Effective Education to Caregivers on the Medical Complications of Dementia

people without dementia, twice as many caregivers of those with dementia indicate substantial emotional, financial and physical difficulties.

Page 20 - Caregiving in WI

Page 21 - Caregiver Role Strain

This table describes some of the threats to well-being that caregivers often experience.

Page 22 - Resources for Caregivers

We recommend that this section of the program should be introduced early, in the first visit if possible. This expands their awareness to their own well-being, which they may have been unable to attend to because of the intense demands of caring for their loved one.

This section of the program can be delivered by any discipline; if one is available on your team, a social work practitioner would be well-equipped to deliver this education.

Any team member may revisit this section later if the caregiver expresses changes in their well-being and/or caregiving burden.

Page 23 - Behavioral and Psychological Symptoms of Dementia (BPSD)

Behavioral and psychological symptoms become more common as dementia progresses, especially in the moderate and severe stages. BPSD have an adverse impact on caregivers and are strongly linked to hospital admission, institutional placement, and increased morbidity and mortality.

Page 24 - BPSD Contributing Factors

There are several factors that need to be considered when caring for a person with BPSD. Factors that might be contributing to BPSD include: Medical conditions (e.g. constipation, dehydration, and sleep disturbance); medication side effects, especially from benzodiazepines, opiates, and anticholinergics; infections (e.g. UTI and pneumonia); pain; unmet needs (e.g. boredom, loneliness, inactivity); environmental changes (e.g. noise and temperature); routine

Implementing Effective Education to Caregivers on the Medical Complications of Dementia

changes; caregiver factors (e.g. stress, depression, communication techniques, and cultural factors); and psychiatric conditions (e.g. major depression, anxiety, bipolar, and schizophrenia).

Page 25 - BPSD Assessment

There are multiple theories one can use to guide the assessment of BPSD. The ABC method focuses on the antecedent, behavior, and consequence. It is important to analyze what leads up to the behavior as well as what occurred after the behavior. Here is an example. A person is residing in an assisted living facility and has started yelling. There is a conversation in another room and he thinks they are talking to him. This is the antecedent. He begins to yell in response to the conversation. This is the behavior. The individuals talking in the other room begin to talk louder, causing the individual to continue to yell. The unmet-needs perspective holds that BPSD are an expression of an underlying need, such as the need for stimulation, pain reduction, or socialization. The learning and behavior perspective considers behavioral symptoms to be the result of inadvertently reinforced behaviors, such as patients receiving attention when they scream. The environmental vulnerability and reduced stress threshold perspective emphasizes a mismatch between a person's environment and his or her ability to cope, such as when too much noise in the environment causes patients to overreact and become agitated.

Page 26 - BPSD Management

First line treatment for BPSD includes non-pharmacological methods: DICE Method, communication adjustments, and person-centered environment-based interventions.

There are situations in which pharmacological treatment should be considered, such as:

- If BPSD are significant enough to put the person with dementia or others at risk for harm.
- When BPSD are so significant that the person with dementia cannot participate or benefit from non-pharmacologic interventions.
- When BPSD fail to respond to non-pharmacologic interventions.

Implementing Effective Education to Caregivers on the Medical Complications of Dementia

Page 27 - Communication Changes

Communication changes occur throughout the disease process. The changes will vary by the type of dementia as well as by the individual. In general, these are the changes associated with the dementia stage.

Page 28 - Communication Strategies

There are several communication strategies one can use to enhance the communication experience with a person with dementia. This includes making environmental adjustments, such as having conversations in a well-lit space, reducing or eliminating background noise, and facing the person with dementia when speaking to them so they can see facial expressions. Practice effective listening, which allows the person with dementia time to respond without interruptions and shows the person with dementia that you are paying attention to them. Use simple language and/or familiar language when talking to the person with dementia. Simplify choices so that the person with dementia is still able to make their own decision without being overwhelmed. For example, instead of asking, "What would you like to drink?" ask, "Would you like water or juice to drink?"

Provide the person with dementia with step by step instructions. For example, when brushing teeth, tell the person one step (i.e. unscrew the cap on the tube of toothpaste or place) and let them complete the step. If a person has difficulty following instruction, modeling the task might help. For example, brush your teeth next to the person with dementia and they might follow along. If a person is expressing confusion, you can approach the situation using re-orientation, compassionate fibbing, or acknowledgement techniques. The technique you chose will depend on the person and the situation.

Page 29 - Falls

Falls are the result of a mis-match between a person's ability and their environment's characteristics. Falls are a big threat to the independence and functional status of people with dementia. They are twice as prevalent in this population. People over 65 without dementia have about a 33% chance of falling in a given year; doubling this brings the change of falling to

Implementing Effective Education to Caregivers on the Medical Complications of Dementia

about 66% for people with dementia. Their falls are more consequential and damaging, increasing the likelihood of permanent transfer to medical residential care. Risk factors are personal (motor changes decreasing balance, cognitive changes affecting visuospatial processing, memory, and judgement/safety), or environmental (dim or absent lighting, surface irregularities, slippery bathroom surfaces, stairs and curbs). Fall treatment needs to be individually tailored to each person and caregiver dyad, and should be recalibrated as the person living with dementia progresses through their disease course – there's no one-size-fits-all approach.

Page 30 - Fall Prevention

Most fall prevention studies that we have are for older adults with normal cognition where they exclude people with a diagnosis of dementia or a skill below a certain cut score on the MMSE, for example. Interventions that are likely to help:

A **home safety eval and intervention** by an OT, and it has to be by an OT. A gold standard meta-analysis of lots of studies suggests this is the most effective way from the home health perspective of reducing the odds ratio of falling.

A **vitamin D supplement** if they are deficient. Nursing or OT look at a medication reconciliation list, talk to the caregiver and maybe connect to the PCP.

Pacemakers if needed...advised to avoid that in the later moderate to severe stages of dementia because it requires an inpatient admission they may not return to baseline from.

Cataract surgery or discontinue bifocals. As dementia progresses, the patient is not going to be able to participate and benefit from a regular eye exam or remember they have bifocal lenses to look through; it will distort their image and lead to falls. To work around this: advise caregivers to call the optometrist and request they split the prescription to have a reading set that the caregiver hold onto (to use for certain activities such as looking at photo albums, special books). Far vision correction is still beneficial. It can give them a better sense of the environment, but again if the prescription is out of date and they can't participate, sometimes

Implementing Effective Education to Caregivers on the Medical Complications of Dementia

the best solution is just to leave the glasses and not wear them. Talk to the caregiver about the options and what appears most beneficial.

Progressive strength and balance training: Excellent evidence for the effective progressive, strength and balance training, working on balance, gait coordination, and strength. A PT will need to be the one who prescribes that program. Do teach backs with caregivers; have them demonstrate and confirm they know how to do it. Involved PT colleagues for a consult.

Medication management: look at the med reconciliation list- Large relationship between medications and falls in non-neurocognitive disorder older adults. Four or more prescription medications exponentially increases fall risks.

Page 31 - High Risk Medications Related to Falls

High risk meds are the benzodiazepines, tricyclic antidepressants, antipsychotics and anticholinergic medications, which a lot of people with dementia take because there is some evidence that it has a small effect on memory function.

For antipsychotics (neuroleptics), a really good medication review is beneficial. Home health clinicians are not the prescribers and not at liberty to discontinue the medications, but you can see problems that the doctor's office can't see. Patients may be making their own decisions about what to take without any consultation, so do not underestimate your impact if you're concerned about medication. Diuretics- if they are dehydrated, they are more likely to fall.

Page 32 - When there is a Fall

Different organizations have different reporting protocols on what to do if there is a fall during your visit. But if the caregiver says, 'I don't know, something's maybe off, he almost fell this morning, he fell into a chair and I don't know if I'd call it a fall.' If you start getting those "if's, but maybe," as a clinician you would categorize it as a fall and go ahead and assess orthostatic vital signs, monitor cardiovascular health while there while they're walking and moving with you. Put your pulse ox on while they're moving, while they're sitting. See how long it takes

Implementing Effective Education to Caregivers on the Medical Complications of Dementia

them to recover musculoskeletal system. Do a quick check of range of motion, grip strength. If you feel comfortable doing a cranial nerve exam, that's good. If not, an eye tracking, stick your tongue out, simple other systems as indicated. If there's issues with kidney function, you could ask about when did they urinate? Or are they due for dialysis? Did anything change? Did they miss a dialysis? Look at the diuretics, are they dehydrated?

Page 33 – Infection

Older adults are at greater risk for becoming sick as a result of infection and dying from infection. Infections can present differently in older adults, which can lead to a delay in treatment. Having dementia can increase the risk of infection presenting differently.

Page 34 – Infection

The most common types of infection vary by setting. In the ambulatory or home setting, respiratory infections, UTI, and intra-abdominal infection (e.g. cholecystitis and diverticulitis). In long term care settings, aspiration pneumonia, UTI, skin and soft tissue infections, and GI infections are most common. In the acute care setting, nosocomial infections and IV catheter associated bacteremia and sepsis are most common.

Page 35 - Infection - Non-classical Presentation

Examples of infections with that present differently in older adults include meningitis, where there can be a lack of a stiff neck or the presence of severe cervical spine osteoarthritis can mask neck pain or stiffness associated with meningitis. Or pneumonia, which can be present without cough, dyspnea, or fever. Intra-abdominal infection, which can be masked by a normal abdominal physical exam; or upper and lower urinary tract infections can be present without symptoms. In older adults, there can be a mismatch of the severity of illness and severity of symptoms. In other words, an older adult could have a severe infection; however present with mild symptoms. Older adults also tend to have lower fevers. There is a saying, "the older the colder." This is a saying that can help us remember there is a lower fever threshold for older adults.

Implementing Effective Education to Caregivers on the Medical Complications of Dementia

Page 36 - Infection – Fever

A fever in older adults is indicated by the following: temperature greater than 2 degrees above baseline. An oral temperature greater than 99 degrees F; or a rectal temperature greater than 99.5 degrees F on repeated measures. A single oral temperature greater than 100 degrees F.

Page 37 - Infection – Signs

One should suspect an infection is present if the following are noticed: An acute change in mental status, decline in function, new or worsened anorexia, an onset or increase in falls, new or increase urinary or fecal incontinence, new or worsened tachypnea.

Page 38 - Infection – Management

When deciding how to manage an infection, one needs to consider the wishes of the patient and family. Do they want to treat the infection? Do they want to be admitted to the hospital? Evidence to suggest there's little benefit to antibiotics for UTI and pneumonia in people with severe dementia. If admitting a patient to the hospital, one needs to consider the risk for nosocomial infections and delirium.

Page 39 – Pneumonia

There are several factors that increase the risk for pneumonia in a person with dementia. Those factors include use of antipsychotics, benzodiazepines or anticholinergic medications – especially in the first 30 days of use. Another factor can be use of a Proton Pump Inhibitor (PPI), which can result in a reduction in pH of stomach contents and changes in bacteria content within the stomach. With an increase in bacteria in the stomach contents, there is potentially a greater risk for pneumonia when these contents are aspirated. Smoking, male gender, cerebrovascular disease, chronic pulmonary disease, congestive heart failure (CHF), diabetes, or being sedentary.

Implementing Effective Education to Caregivers on the Medical Complications of Dementia

Page 40 - Pneumonia – Prevention

Prevention of pneumonia is key, and can be done through the following interventions: immunizations, upright positioning during mealtimes, improve or sustain mobility, smoking cessation, reduce exposure to second-hand smoke, avoid hospitalization.

Page 41 - Pneumonia – Assessment

Pneumonia is the most commonly missed diagnosis. In one study, only 31% of older adults presented with the classic symptoms of pneumonia - cough, dyspnea and fever. Total WBC may be normal or marginally elevated despite a left shift. Altered mental status, confusion, falls, sudden decline in functional status may be the only indications of pneumonia. Tachypnea with or without SOB may be the most reliable sign of an acute respiratory condition in an older adult.

Page 42 - Pneumonia – Management

Health care providers will attempt to treat pneumonia in the outpatient/home setting unless the following are present, which would indicate a need for hospital admission: poor oral intake, rapid functional decline, respiratory rate >30, systolic blood pressure <90 mmHg or diastolic BP < 60mmHg, decline in renal function, hypothermia, bilateral or multi-lobe infiltrates.

Page 43 - Dysphagia

Dysphagia is common in dementia: between 84-93% people living with dementia experience this symptom. In the later stages, there is more swallowing dysfunction. This makes it more difficult to participate in a family meal if you can't swallow. Also, the caregiver may be concerned about their loved one choking so this can lead to a lot of isolation. Challenges with swallowing can lead to functional declines such as weight loss, malnutrition, aspiration pneumonia, and death. If you have a speech therapist in your wheelhouse, and you're hearing things from the caregiver, *"You hear that gurgly sound when he takes a deep breath? I just don't know, that doesn't seem right."* It's important to look at and discuss this module with the

Implementing Effective Education to Caregivers on the Medical Complications of Dementia

caregiver so they are aware this can happen. If you need a skilled assessment, call in your speech therapy team.

Page 44 - Dysphagia

In the **moderate stage**, there might be more coughing with food and fluids, and just forgetting to chew, difficulty remembering that they're eating, difficulty attending. In the **severe stage**, this is so severe you're going to have a high risk for a lot of dehydration and malnutrition, aspiration that precipitates pneumonia and even aspirating their own secretions.

Page 45- Dysphagia Signs and Symptoms

Signs to look for and share with the caregiver: Not being able to swallow, or repeatedly trying to swallow but there is still food in their mouth; Appears to be pain with swallowing; they wince or grimace. The patient complains of something stuck in their throat, or they sense discomfort or pressure when eating (that's something preserved through the moderate stage of dementia, so they'll be able to tell you if something doesn't feel right. Such as, "I have a frog in my throat" even though they're eating.) Coughing with liquids or solids, drooling, vomiting during meals, or gagging. Gurgling sounds after swallowing. (This is really, really common especially with liquids). Complaining of heartburn, and then weight loss. Relay this information to the speech therapist if you have on your team, to get involved with providing additional education and management strategies with the caregiver.

Page 46 - Stages of Swallowing

This is a quick check list of the potential deficits that will be seen in the different stages of swallowing and what a speech therapist will be able to expand in more detail. **Pre-oral** changes is something you may hear about from caregivers. Forgetting when they last ate and needing to be cued to eat. Once they forget when they last ate, they are already at risk for not being able to attend to that sense of hunger and the attention to eat and chew. This can contribute to dysphasia as well.

Implementing Effective Education to Caregivers on the Medical Complications of Dementia

Having a hard time recognizing that somethings a food, or somethings a utensil, and then having difficulties lifting the spoon to the mouth. They may contort their body and have their head forward, or put their body in other positions to try to get food to the mouth. This can predispose them to getting food in their airway. Socially inappropriate mealtime behaviors, such as eating too quickly or slowly. Poor posture and inability to sit. A swallowing specialist may prefer someone be in a perfect upright 90° x 90° in the chair, and that's not always possible or realistic people who are older with dementia. Over age 80 when someone may start getting a lot of kyphosis, your body is kind of breaking down in your neuromuscular control. It can be hard to maintain an upright posture so what you want is that you're not tilted too far back, so eating in a recliner or a sofa, and that the forward head posture is accounted for. The **oral pharyngeal and esophageal** phases were discussed in the previous slides (eg, forgetting to chew, spitting out food, coughing choking).

Page 47 – Dysphagia Education for Caregivers

Educating caregivers early, whether you're a speech therapist or not is the best thing can do for the caregivers. Some of these tips on education around dysphagia are in the curriculum modules: allow plenty of time for the meal try not to rush them, meals should happen in places with few distractions as possible and a pleasant environment. Make it a nice place to be so they're not agitated and sort of wanting to move away or around. Encourage the person to sit up with feet supported too, that is important to the person's drinking or swallowing. If in bed reclining, the neck is not tucked so it can open the airway. Have simple place settings and table. Avoiding cluttered, overly colored or patterned place settings. Make is a simple, visually clear environment (one plate, one bowl, one piece of silverware) so the patient can span for what is important. Serve foods that are appealing and easier to chew and swallow if possible. Allow the person to feed him or herself. If it looks like they can but may be struggling, the caregiver can model bringing the food to the mouth. This covers that social aspect of eating together as well and having the caregiver do that with their loved one is really helpful. Caregivers can remind them to chew and swallow, alternate solids with liquids so they do not get too much time built up, and then educate the caregivers to be alert to the signs of choking.

Implementing Effective Education to Caregivers on the Medical Complications of Dementia

Page 48 - Weight Loss

Due to dysphagia, people with dementia are at a really high risk for weight loss. The risk for malnutrition among people living with dementia is 15 - 42% and it's higher in more severe stages. And unintentional weight loss, caregivers are really worried about this and it tends to happen when other things are getting more difficult about managing the disease.

Page 49- Weight Loss Risk Factors

Risk factors for weight loss include medical risks, social and psychosocial risk or psychological risks. Especially social risk factors, consider issues with the caregiver because they are the ones to prepare and procure the meals. Can the caregiver get the food? Do they know how to cook it? For example, if the wife has dementia and her husband was never really the cook in the house (as follows in traditional gender roles, but in reality it's not always the case), is he able to learn to cook? Some caregivers might not admit they don't know how to cook. Consider the caregiver's possible physical issues like loss of smell and are they able to smell that food is spoiled. Consider mobility issues and can they safely move around in the kitchen and cook?

Page 50- Weight Loss Management Strategies

For weight loss management, talk to caregivers about dentation if they are missing dentures or have dentures that need repair. Just like with eyeglasses, it can be hard for older adults to remember and participate in wearing dentures. If you suspect dysphagia, involve a speech and language pathologist (SLP). Discuss nutrition supplements with the primary provider and discuss lab testing with the provider. They might want to order CBC, B12 and folate levels. If the issues if the feeding part, bring your OT colleagues in and ask them to look at strategies for help with some feeding skills, or coaching the caregiver on how to feed their less one safely. Consider medications they are on that can suppress appetite.

Implementing Effective Education to Caregivers on the Medical Complications of Dementia

Page 51 - PEG Tubes

PEG (percutaneous endoscopic gastrostomy) tubes (or even an NG) is a conversation that will come up a lot between caregivers and providers. Caregivers may call the Dr. because they are concerned their loved one is losing weight. If the Dr. is not looking at this from a dementia continuum perspective or even sort of a palliative perspective, and they may recommend a PEG tube.

With dementia, it's important to know that weight loss is part of the gradual physical death that is occurring in dementia. It's expected, it's actually very natural, but does it causes stress and undue harm. The American Geriatric Society recommends **against** the use of PEG tubes in people living with advanced or even moderate to advance dementia. PEG tubes do not increase survival or increase quality-of-life, they don't resist reduce the incidence of aspiration pneumonia, so you can still regurgitate and aspirate the regurgitation. PEG tubes are associated with complications and infection, pain. This is good information to share with caregivers. The decision is up to them, but you can help them be better advocates and make an informed decision if they know complications can occur.

Page 52 – Dehydration

Dehydration is costly to the health care system. It is estimated that the cost of preventable hospitalizations for older adults with a primary diagnosis of dehydration in the United States ranges from \$1.1 to 1.4 billion. In addition to the financial cost, there is significant burden on older adults. The mortality from dehydration in older adults may exceed 50-percent.

Page 53 - Dehydration Contributing Factors

Please see the page for a table that includes the contributing factors to dehydration for older adults, as well as additional risk factors for people with dementia.

Implementing Effective Education to Caregivers on the Medical Complications of Dementia

Page 54 - Dehydration Consequences

Dehydration can have severe consequences if not caught early, including delirium, falls, thromboembolic complications, kidney stones, renal failure, pressure injuries, infection, drug toxicity, or death.

Page 55 - Dehydration Types

The three types of dehydration include: Isotonic dehydration, which occurs when loss of sodium and water. This is common in GI illness. Hypertonic dehydration, which occurs when water loss exceeds sodium loss. This is common in fever or limited fluid intake. Hypotonic dehydration, which occurs when sodium loss is higher than water loss. This is common in diuretic use.

Page 56 - Dehydration Assessment

The following are unreliable signs and symptoms of dehydration in older adults: absent axillary moisture, orthostasis, hypotension, low urine output, reduced fluid intake, urine color, urine specific gravity, heart rate, dry mouth, or thirst.

Page 57 and 58 - Dehydration Assessment

When assessing for dehydration, one needs to consider a patient's baseline oral intake, mental status, mobility, and function. A change in baseline, together with caregiver history and physical signs of dehydration are key to identifying those at risk or experiencing dehydration. When assessing for dehydration, one needs to consider the medications a patient is taking.

Medications that increase the risk for dehydration include: diuretics, antidepressants, antipsychotics, anticonvulsants, anticholinergic medications, ACEs and ARBs, benzodiazepines

Page 59 - Dehydration - Management

Implementing Effective Education to Caregivers on the Medical Complications of Dementia

Management of dehydration includes oral rehydration, subcutaneous rehydration, and intravenous rehydration. Suggestions for oral rehydration, which is the most common type of rehydration done in the home, include: serve beverages at appropriate temperature, offering flavored or favorite drinks, serve drinks in brightly colored containers that do not blend with the surrounding. Any fluid is helpful, including broth. Provide cues.

Page 60 and 61 – Incontinence

Incontinence is the "involuntary loss of urine which is objectively demonstrable and a social or hygienic problem" (Abrams et. al, 1988). It is not a disease in itself, but rather a symptom. It is not a normal part of aging. It is often treatable, not just containable. Its prevalence among older adults ranges from 53 to 90-percent. In order for a person to be continent of urine, one must have: functioning lower urinary tract, adequate cognition, physical mobility, motivation, supportive environment. Experiencing incontinence can lead to LTC placement, depression, anxiety, falls, fractures, sleep disturbance, pressure injury, or UTI.

Page 62 - Incontinence Types

There are several types of incontinence, which are described in the table on this page.

Page 63 - Incontinence Prevention

Suggestions for preventing incontinence include keeping a clear path to the toilet, keeping toilet in line of sight, keep the bathroom door open, utilized raised toilets, grab bars, bedside commodes, prompted and scheduled toileting, remove planters, waste-paper baskets, buckets or anything else that might resemble a toilet in the immediate vicinity, prevent constipation, eliminate caffeinated beverages.

Page 64 - Drugs Associated with Incontinence

Drugs that are associated with incontinence include alcohol, alpha adrenergic agonists (midodrine or pseudoephedrine), alpha blockers (doxazosin or tamsulosin), ACE inhibitors,

Implementing Effective Education to Caregivers on the Medical Complications of Dementia

caffeine, cholinesterase inhibitors (donepezil or rivastigmine), diuretics, anticholinergic medications, opioids, sedatives or hypnotics.

Page 65 - Incontinence Management

Using a multi-disciplinary approach is beneficial when managing incontinence. One will need to involve the caregiver, as they will need to assist with changes in the environment and routine to manage incontinence. PT and OT can address functional components (mobility, caregiver's transferring skill and capacity, lower body hygiene and dressing, bathroom environment and access, cues and modifications to the routine). Collaborating with health care providers is also necessary to ensure a thorough work-up and in some cases, the use of medications. A key perspective in managing incontinence is that benefits of any improvement in incontinence in someone living with dementia should not be underestimated.

Page 66 and 67 - Constipation

Chronic constipation is defined as two or more of the following symptoms present for at least 12 weeks in the previous six months: constipation that includes straining at defecation at least 25% of the time, emptying stools that are in lump or hard at least 25% of the time, experienced sensation of incomplete evacuation at least 25% of the time, three or fewer bowel movements a week. Constipation affects about 30% of adults for over the age of 65. It affects 50% of adults who are over 65 in nursing homes and hospitals. Risk factors include underlying medical conditions, medication side effects, lack of appropriate toileting facilities, or assistance with toileting, reduced mobility, inadequate oral intake of food and fluids.

Page 68- Constipation Consequences

Consequences of constipation include hemorrhoids, anal fissures, fecal impaction, rectal prolapse, bowel obstruction, pain, discomfort and distress that can lead to BPSD. There are significant and concerning consequences to constipation which again is why we're going to want to try to prevent and manage it as possible.

Implementing Effective Education to Caregivers on the Medical Complications of Dementia

Page 69 – Constipation Assessment

Assessment for constipation includes understanding the baseline pattern of bowel movements, knowing if the patient is able to sit on the toilet with or without support, knowing if the patient has the cognitive ability to find the toilet, and are they in a suitable environment

Page 70 - Medical and Medication Causes for Constipation

Medical causes that can contribute to constipation are listed in this table: IBS is a common one. Medications that can contribute to constipation are listed. Reviewing the patient's medication list is important; be in tune to what medications they are on that could be contributing to the constipation.

Page 71 - Constipation Management

Constipation management includes identifying and treating an underlying cause. Reasons could be a medical diagnosis, medication side effects, or an environmental issue. It's important to get to the root of the problem and prevent or treat it. Ways to manage constipation include increasing fluid intake to 1500 mL a day can be helpful; getting appropriate amount of dietary fiber anywhere from 6 to 25 g of dietary fiber a day can be helpful. Increasing physical activity as possible. Considering medication after consulting with a provider. They may suggest a bulking agent, osmotic laxative, stimulant laxative, take medication two to three times a week and power pudding is another one that may get used or recommended.

Page 72 - Constipation Medication Management

This page shows a list of those agents and their onset of action. Bulk Laxatives- fairly quick response anywhere from 12 to 72 hours. These medications include Citrucel, Metamucil and Fibercon. Osmotic laxatives are anywhere from 24 to 96 hours and that can include things like MiraLAX. Stimulant laxative anywhere from 15 minutes to 10 hours, that includes medications

Implementing Effective Education to Caregivers on the Medical Complications of Dementia

like Dulcolax and Senokot, Colonic secretagogues are anywhere from 48 to 96 hours. We see these used less often; we're more likely to see these other over-the-counter agents.

Page 73 - Pressure Injury

Pressure injuries in dementia, the prevalence is anywhere from 39 to 47%. Motor neuron pathology which impairs mobility, which is one of the main reasons that puts them at risk for pressure injury. They also are experiencing sensory deficits, diminished pain response, blood pressure dysregulation causing hypotension, and poor peripheral perfusion, higher risk of fecal and urinary incontinence as well.

Page 74 - Prevention and Management for the Interdisciplinary Team

Prevention management from an interdisciplinary standpoint is important for pressure injury. Have PT and OT involved for mobility, transfers, and hygiene self-care. Include dietary consults for malnutrition and Speech therapy if there's concerns for dysphasia, incontinence management, specialty bed, seat, cushions or mattresses (therapists can make recommendations for these devices). Pain management, wound care specialist, caregiver education are also part of the interdisciplinary management. An individual may not require all of those services but just recognize they may need a robust team for someone who is experiencing pressure injury or is at risk for pressure injury.

Page 75 – Pain

Chronic pain experienced by 20 to 50% of adults over age 65 years. It is estimated to be double that among people living with dementia. Untreated pain can be an underlying cause of BSPD. Pain is often under-detected and under-treated in people living with dementia.

Implementing Effective Education to Caregivers on the Medical Complications of Dementia

Page 76 - Pain Consequences

Pain that is untreated or under-treated in people living with dementia can lead to the following consequences: BPSD, depression, anxiety, increased hospitalizations, premature death, loss of functional ability, decreased socialization, or impaired sleep.

Page 77 – Pain Assessment

The following pain scales are recommended to use in people living with dementia: assessment of Pain in Advanced Dementia Scale (PAINAD), Visual Analog Scale (VAS), Faces Pain Scale (FPS)

Page 78 - AGS Panel on Persistent Pain in Older Adults

The Page contains the content of the AGS Panel on Persistent Pain in Older Persons.

Page 79 – Pain Management

There is evidence that people with dementia receive less pain medication than those without dementia. When they receive opioids, the dose is 30% of the dose prescribed to individuals without cognitive impairment. When managing pain in a person with dementia, consider Acetaminophen as an appropriate and safe first-line treatment (up to 3,000 mg in 24 hours). Adequate pain management can reduce BPSD.

Slides 80 - Palliative and Hospice Care

Dementia is progressive and there is no cure. The average life expectancy after diagnosis is 4.5 years. The last year of life is characterized by the inability to walk, recognize family members, or perform activities of daily living in addition to urine and fecal incontinence and minimal speech. There is a high risk for pain, shortness of breath, and medical complications. Only recently, has the health care community begun to see dementia as a terminal diagnosis. In 2015, only 16.5% of people who died in hospice had a diagnosis of dementia. Given the discrepancy in people on service with hospice and those who qualify, it is important to educate family and caregivers on palliative care and hospice care programs.

Implementing Effective Education to Caregivers on the Medical Complications of Dementia

Page 81 Teach-Back

The teach-back method is a way of checking understanding by asking caregivers to state in their own words what they need to know or do to care for the person with dementia. There are a few teach-back prompts after each topic for the caregiver to answer to check their understanding of the material. If the caregiver is unable to or has difficulty responding to the prompt, clinicians can go back and provide additional teaching on that topic.

Page 82 - Resources

Pages 83-84 - References

Implementing Effective Education to Caregivers on the Medical Complications of Dementia

Chapter 4

Case Examples

Behavior Change Related to Environmental Changes

A woman residing in an assisted living facility, where she suddenly started to refuse shower assistance from staff. More specifically, caregivers were struggling to get the patient to accept help transferring into the shower. After some brainstorming with the patient's care team and reflecting on when this change occurred (since the patient previously had been receptive to assistance with showers), they determined this behavior change occurred around the time a floor shower mat had been removed. During a recent safety and falls assessment the patient received, it was advised that caregivers removed the floor mat to reduce the risk for potential falls. However, this change in the patient's environment inadvertently caused confusion for the patient and how she should respond; the floor mat seemed to be a cue for her to shower. The facility caregivers tested this by replacing the floor mat, which resulted in the patient accepting help to transfer again. Although the shower mat was a potential fall risk or safety hazard, it was determined to be more beneficial to keep in place because it was a "visual cue" to the patient dementia that it was time to shower.

Patient with Hallucinations and Sleep Disturbances

A male patient was seen by home health, who had no formal dementia diagnosis, although he scored on the lower end of moderate on the QDRS. The patient's caregiver was his wife, who expressed concerns about husband's increased hallucinations and confusion on a daily basis. Although they were increasing in frequency, the caregiver denied that they were distressing to her, the patient or cause of concern over safety. In the caregiver education program, the PT taught the caregiver some communication responses (eg, validation) to the hallucinations and modifying the environment to reduce any misperceptions of what he is seeing. WAI advised the PT working with this case to assist with getting lab work done to explore other potential causes,

Implementing Effective Education to Caregivers on the Medical Complications of Dementia

such as an electrolyte imbalance (sodium, glucose), endocrine imbalance (thyroid), or another nutritional imbalance (he was already on vitamin B12 supplement). Also advised they help advocate to the primary care provider for further visual workup to assess for any vision changes, and discuss the patient's medications and potential side effects could be contributing. Caregiver education: In addition to covering the other medical complications of dementia in the education program, the PT focused on the dementia basics section, behavior changes and touched base on hallucinations. The PT also reviewed the basic dementia basics section of the caregiver manual and hallucinations. The PT educated the caregiver on communication tips with the caregiver around validation and redirection. The caregiver expressed that she didn't realized she needs to "meet him where he's at" in his reality, and she agreed to try validation, rather than correcting him when he was confused or hallucinating.

Furthermore, the PT discussed awareness and modification of the home environment, being mindful of lights and shadows that could lead to hallucinations. This led the caregiver to understand that her husband may be misperceiving regular objects in the home as something else. More specifically, she discussed that her husband talked about seeing a snake on the chair. The caregiver realized that there was a blanket on the chair that had threading on the trim, in a rope-like pattern, that her husband may have perceived as a snake. This resulted in the caregiver removing the blanket so it did not cause confusion for her husband.

**Implementing Effective Education to Caregivers on the
Medical Complications of Dementia**

Chapter 5

Education Resources

Frequently Asked Questions (FAQ)

Over the course of our home health education training sessions, clinicians asked a number of questions that helped clarify or expand upon points made during the presentation. Here we present some of these questions, with proposed responses. Users should be prepared to answer the following questions or similar ones that may arise.

Q: *The patient does not have a formal diagnosis of dementia; can I still use this education on the medical complications of dementia to the caregiver?*

A: Yes, the patient does not have to have a formal diagnosis of dementia to for the caregiver to receive this education. If you, the caregiver or primary medical provider suspects the person has a memory impairment, it would be beneficial to teach that topic to the caregiver. A valuable screening tool to utilize if there is not a diagnosis of dementia but suspected impairment, is the Quick Dementia Rating System (QDRS). This screen is able to detect early cognitive changes and can reveal if there is a problem occurring or how severe it is. The QDRS is scored in a range from 0-30 to indicate if the patient's cognition falls into the range of normal, mild cognitive impairment, mild dementia, moderate dementia, or severe dementia. It is recommended that a clinician complete this tool with the caregiver, and assisted with answering questions based on the patient's "worst day" or how they would manage without any assistance from another person; this will help curtail any caregiver bias.

Q: *How much time should be spent on teaching the educational sections versus providing regular home health skilled services?*

A: In general, clinicians have spent approximately 45 minutes in addition to their regular skilled medical services to cover 2-3 sections. With that said, the time spent will be dependent on the caregiver's current level of understanding of dementia and the medical issues at hand, the level of stress and burden the caregiver may be experiencing at the time, and other potential distractions that could be taking place in the home. The additional time allotted to the education may be at the discretion of your agency and what is feasible for clinicians' schedules. Our general guideline is not to undertake more than 3 topics per visit, and to go at the caregiver's pace. Some caregivers may exhibit better comprehension, while other caregivers may need the clinician(s) to go over the sections more than once. Clinicians may choose to do complete their nursing/therapy services first followed the caregiver education, while others may choose to merge the two and do them simultaneously.

Implementing Effective Education to Caregivers on the Medical Complications of Dementia

Q: *Can I give the caregiver education manual to the caregiver to read on their own?*

A: It is not advised to give the manual to the caregiver for any self-instruction. The program was designed solely for home health clinicians to be trained on the caregiver education, and subsequently educate the caregivers on the medical topics. The content in each section requires someone with medical knowledge and expertise to guide the education. This program will be more effectively received when taught by a home health expert and to be available to address questions from the caregiver and assess for thorough understanding through the teach back forms.

Dissemination of Materials

The Home Health Caregiver Curriculum training materials, guides and other resource links will be disseminated through the [Wisconsin Alzheimer's Institute website](#). To access and download the guides, users will need to complete a form on the webpage providing their name, organization and email address.

Forms and flyers

[QDRS Form](#)

[Caregiver evaluation](#)

[Home health clinician evaluation](#)

[Chartwell Home Health flyer for caregivers](#)

[Heartland Home Health flyer for caregivers](#)

Dementia Capable WI: Creating New Partnerships in Dementia Care

Demographic Information

We are asking you to provide this information to help us comply with federal reporting requirements. Completing this form is voluntary, but we hope that you will choose to fill it out. We also need it to help us analyze and evaluate programs that facilitate care and support for people with dementia. This information will be stored in a secure electronic database. We will not share your information with another agency without your permission. We will not sell this information to anyone.

If you have questions regarding this questionnaire, please contact:

Dr. Art Walaszek, Principal Investigator
Wisconsin Alzheimer's Institute
610 Walnut St, Suite 957
Madison, WI 53726
Phone: 608-263-6106

1. What is your professional role? _____

2. How many years have you worked in this role? _____

3. Are you Hispanic, Latino, or Spanish origin?

- Yes
- No

4. What is your race? (Check all that apply.)

- American Indian or Alaska Native
- Asian or Asian-American
- Black or African-American
- Hawaiian Native or Pacific Islander
- Hispanic
- White or Caucasian
- Other: _____

5. What is your gender? _____

6. Please circle the highest year of school you have completed:

- | | | | |
|-----------|----------------------|----------------|-----------------------|
| 1 2 3 4 5 | 6 7 8 9 10 11 12 | 13 14 15 16 | 17 18 19 20 21 22 23+ |
| (primary) | (middle/high school) | (tech/college) | (graduate school) |

Information about Medical Conditions and Treatment

Instructions: We are interested in your confidence level to effectively train caregivers to identify and carry out prevention and management strategies for types of medical conditions that your clients may develop as a result of dementia.

Carrying out prevention strategies

How confident are you that you can effectively train caregivers to prevent the following:

| | Not at all | Low | Moderate | High |
|--|-------------------|------------|-----------------|-------------|
| Pressure ulcers / Bedsores? | 0 | 1 | 2 | 3 |
| Falls? | 0 | 1 | 2 | 3 |
| Aspiration? | 0 | 1 | 2 | 3 |
| Weight loss and related complications? | 0 | 1 | 2 | 3 |
| Pneumonia and related symptoms? | 0 | 1 | 2 | 3 |
| Incontinence and risk-factors? | 0 | 1 | 2 | 3 |
| Dehydration? | 0 | 1 | 2 | 3 |
| Behavior changes (BPSD)? | 0 | 1 | 2 | 3 |
| Infections? | 0 | 1 | 2 | 3 |
| Constipation? | 0 | 1 | 2 | 3 |
| Pain? | 0 | 1 | 2 | 3 |
| Communication changes? | 0 | 1 | 2 | 3 |

Identification of complications

How confident are you that you can effectively train caregivers to identify the following:

| | Not at all | Low | Moderate | High |
|--|-------------------|------------|-----------------|-------------|
| Pressure injury (e.g. pressure ulcers, bed sores)? | 0 | 1 | 2 | 3 |
| Aspiration (e.g. swallowing problems, dysphagia)? | 0 | 1 | 2 | 3 |
| Weight loss? | 0 | 1 | 2 | 3 |
| Pneumonia? | 0 | 1 | 2 | 3 |
| Bladder infection? | 0 | 1 | 2 | 3 |
| Dehydration? | 0 | 1 | 2 | 3 |
| Condition changes related to medication? | 0 | 1 | 2 | 3 |
| Other Infections (ex. UTI)? | 0 | 1 | 2 | 3 |
| Constipation? | 0 | 1 | 2 | 3 |
| Cognitive or thinking changes? | 0 | 1 | 2 | 3 |
| Pain? | 0 | 1 | 2 | 3 |

| | Not at all | Low | Moderate | High |
|---|-------------------|------------|-----------------|-------------|
| Stages of dementia and related complications? | 0 | 1 | 2 | 3 |
| End-of-life stages? | 0 | 1 | 2 | 3 |
| Communication changes? | 0 | 1 | 2 | 3 |

Management strategies

How confident are you that you can effectively train caregivers to manage the following:

| | Not at all | Low | Moderate | High |
|--|-------------------|------------|-----------------|-------------|
| Pressure injury (e.g. pressure ulcers, bed sores)? | 0 | 1 | 2 | 3 |
| Aspiration (e.g. swallowing problems, dysphagia)? | 0 | 1 | 2 | 3 |
| Weight loss? | 0 | 1 | 2 | 3 |
| Pneumonia? | 0 | 1 | 2 | 3 |
| Incontinence of bladder? | 0 | 1 | 2 | 3 |
| Incontinence of bowels? | 0 | 1 | 2 | 3 |
| Dehydration? | 0 | 1 | 2 | 3 |
| Condition changes related to medication? | 0 | 1 | 2 | 3 |
| Other Infections (ex. UTI)? | 0 | 1 | 2 | 3 |
| Constipation? | 0 | 1 | 2 | 3 |
| Cognitive or thinking changes? | 0 | 1 | 2 | 3 |
| Pain? | 0 | 1 | 2 | 3 |
| End-of-life stages (including palliative care, hospice)? | 0 | 1 | 2 | 3 |
| Communication changes? | 0 | 1 | 2 | 3 |

Other strategies

How confident are you that you can effectively train caregivers to:

| | Not at all | Low | Moderate | High |
|---|-------------------|------------|-----------------|-------------|
| Calling the doctor if their loved one is sick with acute illnesses? | 0 | 1 | 2 | 3 |
| Asking to speak directly with a nurse about the specific health concerns of the person they are caring for? | 0 | 1 | 2 | 3 |
| Understanding which doctor/specialist to call, for the person they are caring for? | 0 | 1 | 2 | 3 |
| Identifying resources to help them take care of their loved one? | 0 | 1 | 2 | 3 |

Knowledge of Memory Loss and Care (KAML-C)

Which of the following is the most common cause of memory loss in persons over age 65?

- 1. Alzheimer's disease
- 2. Senility
- 3. Normal aging
- 4. Hardening of the arteries
- 5. Benign senescent forgetfulness

Which of the following conditions may resemble Alzheimer's disease?

- 1. Major depression
- 2. Pernicious anemia
- 3. Thyroid disorder
- 4. Parkinson's disease
- 5. All of the above

A symptom of Alzheimer's disease usually NOT seen in the early stage is

- 1. Disorientation to time and place
- 2. Word finding difficulty
- 3. Aggressive behavior
- 4. Recent memory loss
- 5. Difficulty with calculations

The BEST way to enable someone with memory loss to understand you is to

- 1. Logically explain your reasoning
- 2. Write out a detailed note
- 3. Repeat yourself until the point is made
- 4. Give brief and simple instructions
- 5. Speak in a quiet tone

Which of the following is NOT likely to be a problem for a person in the early stage of memory loss who is living alone?

- 1. Forgetting to turn off the stove
- 2. Making travel plans
- 3. Managing money
- 4. Remembering to take medications
- 5. Getting dressed in the morning

Which of the following approaches is NOT HELPFUL for persons with memory loss in completing tasks?

- 1. Breaking tasks down into small steps
- 2. Encouragement to try harder
- 3. Repeating old, familiar skills
- 4. Having others assist them as needed
- 5. Companionship

Most persons with Alzheimer's disease live

- _____ 1. In nursing homes
- _____ 2. In retirement communities
- _____ 3. In their own homes
- _____ 4. With their adult children
- _____ 5. In assisted living facilities

Primary caregivers of persons with Alzheimer's disease suffer from major depression

- _____ 1. At about the same rate as the general population
- _____ 2. At a lower rate than the general population
- _____ 3. At a much higher rate than the general population
- _____ 4. At a slightly higher rate than the general population
- _____ 5. At a much lower rate than the general population

Those LEAST likely to be primary caregivers of persons with Alzheimer's disease are

- _____ 1. Their sons
- _____ 2. Their daughters
- _____ 3. Their daughters-in law
- _____ 4. Their husbands
- _____ 5. Their wives

Dementia Attitudes Scale (Connor & McFadden)

Please rate each statement according to how much you agree or disagree with it. Circle 1, 2, 3, 4, 5, 6, or 7 according to how you feel in each case. Please be honest. There are no right or wrong answers.

The acronym “ADRD” in each question stands for “Alzheimer’s disease and related dementias.”

| | Strongly disagree | Disagree | Slightly disagree | Neutral | Slightly agree | Agree | Strongly agree |
|--|----------------------|----------|----------------------|---------|-------------------|-------|-------------------|
| It is rewarding to work with persons who have ADRD. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| I am afraid of persons with ADRD. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Persons with ADRD can be creative. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| I feel confident around persons with ADRD. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| I am comfortable touching persons with ADRD. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| I feel uncomfortable being around persons with ADRD. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Every person with ADRD has different needs. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| I am not very familiar with ADRD. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

| | Strongly disagree | Disagree | Slightly disagree | Neutral | Slightly agree | Agree | Strongly agree |
|---|-------------------|----------|-------------------|---------|----------------|-------|----------------|
| I would avoid an agitated person with ADRD. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Persons with ADRD like having familiar things nearby. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| It is important to know the past history of persons with ADRD. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| It is possible to enjoy interacting with persons with ADRD. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| I feel relaxed around persons with ADRD. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Persons with ADRD can enjoy life. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Persons with ADRD can feel when others are kind to them. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| I feel frustrated because I do not know how to help persons with ADRD. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| I cannot imagine taking care of someone with ADRD. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| I admire the coping skills of persons with ADRD. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| We can do a lot now to improve the lives of persons with ADRD. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Difficult behaviors may be a form of communication for persons with ADRD. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

Thank you!

THE QUICK DEMENTIA RATING SYSTEM (QDRS)

Purpose of Use

The detection of mild cognitive impairment (MCI), Alzheimer's disease (AD) and related dementias in community samples of older adults may be limited in part due to the lack of brief tests that capture and characterize the earliest signs of impairment and monitor response to therapies and interventions. The average busy clinician does not have 90-120 minutes to examine each patient, yet this is the time required to generally collect the detailed information needed to make a diagnosis of Alzheimer's disease. This may affect eligibility determination for care and services, impede case ascertainment in epidemiologic studies, and inhibit the ability to identify eligible individuals for clinical trial recruitment. We developed the Quick Dementia Rating System (QDRS)—a rapid dementia staging tool to meet these needs. The QDRS provides a brief but valid and reliable assessment of whether a problem is present, and if present how severe it is. The QDRS was tested and validated in 267 patient-caregiver dyads compared with Clinical Dementia Ratings (CDR), neuropsychological testing, and gold standard measures of function, mood, and behavior. Like all brief tests, a positive result should be followed up with a more comprehensive evaluation or a referral to a specialist. However in places where specialist are limited, use of the QDRS could help to more appropriately triage patients for appropriate use of services. It could also be used to follow patients in a succinct way to see how they are responding to therapy or if they have progressed and need more services. In a broader sense, a brief test such as the QDRS can be used to enrol people in research projects, and help determining prevalence of disease in communities in a very quick fashion

Administration and Scoring Guidelines

The questions are given to the respondent on a clipboard or computer screen for self-administration or can be read aloud to the respondent either in person or over the phone. The QDRS was designed as an informant rating, preferably someone who has frequent long-term contact with the patient, such as a spouse or adult child, in order to provide a rating of the extent and severity of change from prior abilities.

When administered to an informant, specifically ask the respondent to rate change in the patient with emphasis placed on changes due to cognitive problems (not physical problems). If the patient has a physical limitation, ask the informant to rate whether the patient could perform the tasks if the physical limitation were not present.

The QDRS has 10 categories, each with 5 options that characterize changes in the patient's cognitive and functional abilities. The informant is asked to compare the patient now to how they used to be – the key feature is **change** – no specific timeframe for change is required. Have the informant choose **one answer** for each category that best fits the patient – **NOTE**, not all descriptions need to be present to choose an answer

Interpretation of the QDRS

A screening test in itself is insufficient to diagnose a dementing disorder. The QDRS is, however, quite sensitive to detecting early cognitive changes associated many common dementing illness including Alzheimer disease, vascular dementia, Lewy body dementia and frontotemporal dementia. The QDRS may also capture change in cognitive abilities due to other conditions, including depression, traumatic brain injury, and medication-induced cognitive dysfunction.

The QDRS is scored on a continuous scale with a range of 0-30. Higher scores suggest more impairment. Based on receiver operator characteristic curves from 267 individuals included in the development and validation samples, QDRS scores differentiate with the following cut-points:

| | |
|---------------------------|-------|
| Normal | 0-1 |
| Mild cognitive impairment | 2-5 |
| Mild dementia | 6-12 |
| Moderate dementia | 13-20 |
| Severe dementia | 20-30 |

Scores in the impaired range indicate a need for further assessment to establish a formal diagnosis. Scores in the "normal" range suggest that a dementing disorder is unlikely, but a very early disease process cannot be ruled out. More advanced assessment may be warranted in cases where other objective evidence of impairment exists.

The QDRS contains two subscales were designed to see whether cognitive (questions 1, 2, 3, and 8) or behavioral (questions 4, 5, 6, 7, 9, 10) symptoms are the predominant features.

The QDRS can also be used to calculate a Clinical Dementia Rating (CDR score) using the first six categories. Note: for the Toileting and Personal Hygiene category the 0 and 0.5 category would be counted as 0 in computing the CDR.

QDRS Permission Policy

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QUICK DEMENTIA RATING SYSTEM (QDRS)

The following descriptions characterize changes in the patient's cognitive and functional abilities. You are asked to compare the patient now to how they used to be – the key feature is **change**. Choose **one answer** for each category that best fits the patient – **NOTE**, not all descriptions need to be present to choose an answer

| 1. MEMORY AND RECALL | |
|---|--|
| 0 | No obvious memory loss or inconsistent forgetfulness that does not interfere with function in everyday activities |
| 0.5 | Consistent mild forgetfulness or partial recollection of events that may interfere with performing everyday activities; repeats questions/statements, misplaces items, forgets appointments |
| 1 | Mild to moderate memory loss; more noticeable for recent events; interferes with performing everyday activities |
| 2 | Moderate to severe memory loss; only highly learned information remembered; new information rapidly forgotten |
| 3 | Severe memory loss, almost impossible to recall new information; long-term memory may be affected |
| 2. ORIENTATION | |
| 0 | Fully oriented to person, place, and time nearly all the time |
| 0.5 | Slight difficulty keeping track of time; may forget day or date more frequently than in the past |
| 1 | Mild to moderate difficulty keeping track of time and sequence of events; forgets month or year; oriented to familiar places but gets confused outside of familiar areas; gets lost or wanders |
| 2 | Moderate to severe difficulty, usually disoriented to time and place (familiar and unfamiliar); frequently dwells in past |
| 3 | Only oriented to their name, although may recognize family members |
| 3. DECISION MAKING AND PROBLEM SOLVING ABILITIES | |
| 0 | Solves everyday problems without difficulty; handles personal business and financial matters well; decision-making abilities consistent with past performance |
| 0.5 | Slight impairment or takes longer to solve problems; trouble with abstract concepts; decisions still sound |
| 1 | Moderate difficulty with handling problems and making decisions; defers many decisions to others; social judgment and behavior may be slightly impaired; loss of insight |
| 2 | Severely impaired in handling problems, making only simple personal decisions; social judgment and behavior often impaired; lacks insight |
| 3 | Unable to make decisions or solve problems; others make nearly all decisions for patient |
| 4. ACTIVITIES OUTSIDE THE HOME | |
| 0 | Independent in function at usual level of performance in profession, shopping, community and religious activities, volunteering, or social groups |
| 0.5 | Slight impairment in these activities compared to previous performance; slight change in driving skills; still able to handle emergency situations |
| 1 | Unable to function independently but still may attend and be engaged; appears "normal" to others; notable changes in driving skills; concern about ability to handle emergency situations |
| 2 | No pretense of independent function outside the home; appears well enough to be taken to activities outside the family home but generally needs to be accompanied |
| 3 | No independent function or activities; appear too ill to be taken to activities outside the home |
| 5. FUNCTION AT HOME AND HOBBY ACTIVITIES | |
| 0 | Chores at home, hobbies and personal interests are well maintained compared to past performance |
| 0.5 | Slight impairment or less interest in these activities; trouble operating appliances (particularly new purchases) |
| 1 | Mild but definite impairment in home and hobby function; more difficult chores or tasks abandoned; more complicated hobbies and interests given up |
| 2 | Only simple chores preserved, very restricted interest in hobbies which are poorly maintained |
| 3 | No meaningful function in household chores or with prior hobbies |

| 6. TOILETING AND PERSONAL HYGEINE | |
|--|--|
| 0 | Fully capable of self-care (dressing, grooming, washing, bathing, toileting) |
| 0.5 | Slight changes in abilities and attention to these activities |
| 1 | Needs prompting to complete these activities but may still complete independently |
| 2 | Requires some assistance in dressing, hygiene, keeping of personal items; occasionally incontinent |
| 3 | Requires significant help with personal care and hygiene; frequent incontinence |
| 7. BEHAVIOR AND PERSONALITY CHANGES | |
| 0 | Socially appropriate behavior in public and private; no changes in personality |
| 0.5 | Questionable or very mild changes in behavior, personality, emotional control, appropriateness of choices |
| 1 | Mild changes in behavior or personality |
| 2 | Moderate behavior or personality changes, affects interactions with others; may be avoided by friends, neighbors, or distant relatives |
| 3 | Severe behavior or personality changes; making interactions with others often unpleasant or avoided |
| 8. LANGUAGE AND COMMUNICATION ABILITIES | |
| 0 | No language difficulty or occasional word searching; reads and writes as well as in past |
| 0.5 | Consistent mild word finding difficulties, using descriptive terms or takes longer to get point across, mild problems with comprehension, decreased conversation; may affect reading and writing |
| 1 | Moderate word finding difficulty in speech, cannot name objects, marked reduction in word production; reduced comprehension, conversation, writing and/or reading |
| 2 | Moderate to severe impairments in speech production or comprehension; has difficulty communicating thoughts to others; limited ability to read or write |
| 3 | Severe deficits in language and communication; little to no understandable speech is produced |
| 9. MOOD | |
| 0 | No changes in mood, interest or motivation level |
| 0.5 | Occasional sadness, depression, anxiety, nervousness or loss of interest/motivation |
| 1 | Daily mild issues with sadness, depression, anxiety, nervousness or loss of interest/motivation |
| 2 | Moderate issues with sadness, depression, anxiety, nervousness or loss of interest/motivation |
| 3 | Severe issues with sadness, depression, anxiety, nervousness or loss of interest/motivation |
| 10. ATTENTION AND CONCENTRATION | |
| 0 | Normal attention, concentration and interaction with his/her environment and surroundings |
| 0.5 | Mild problems with attention, concentration, and interaction with environment and surroundings, may appear drowsy during day |
| 1 | Moderate problems with attention and concentration, may have staring spells or spend time with eyes closed, increased daytime sleepiness |
| 2 | Significant portion of the day is spent sleeping, not paying attention to environment, when having a conversation may say things that are illogical or not consistent with topic |
| 3 | Limited to no ability to pay attention to external environment or surroundings |
| COGNITIVE SUBTOTAL (QUESTIONS 1, 2, 3, 8) | |
| BEHAVIORAL SUBTOTAL (QUESTIONS 4, 5, 6, 7, 9, 10) | |
| TOTAL QDRS SCORE | |

Dementia Capable WI: Creating New Partnerships in Dementia Care

We are asking you to provide this information to help us comply with federal reporting requirements. Completing this form is voluntary, but we hope that you will choose to fill it out. We also need it to help us analyze and evaluate programs that facilitate care and support for people with dementia. This information will be stored in a secure electronic database. We will not share your information with another agency without your permission. We will not sell this information to anyone.

If you have questions regarding this questionnaire, please contact:

Dr. Art Walaszek, Principal Investigator
Wisconsin Alzheimer's Institute
610 Walnut St, Suite 957
Madison, WI 53726
Phone: 608-263-6106

HH Main Interventionist ID _____

HH 2nd Interventionist ID _____

HH 3rd Interventionist ID _____

Information about Medical Conditions and Treatment

We are also interested in your confidence level to identify and carry out prevention and management strategies for types of medical conditions that your family member may develop because of dementia. In this section, please circle one option for each item. There are no right or wrong answers; we just want to know how you feel based on your interpretation on the questions.

Carrying out prevention strategies

Confidence Level

How confident are you that you can prevent the following in your family member with dementia:

| | Not at all | Low | Moderate | High |
|--|-------------------|------------|-----------------|-------------|
| 1. Pressure injury (also known as pressure ulcers or bed sores)? | 0 | 1 | 2 | 3 |
| 2. Falls? | 0 | 1 | 2 | 3 |
| 3. Swallowing problems? | 0 | 1 | 2 | 3 |
| 4. Weight loss and related complications? | 0 | 1 | 2 | 3 |
| 5. Pneumonia and related symptoms? | 0 | 1 | 2 | 3 |
| 6. Incontinence (including leakage or “accidents”) & risk-factors? | 0 | 1 | 2 | 3 |
| 7. Dehydration? | 0 | 1 | 2 | 3 |
| 8. Behavior changes? | 0 | 1 | 2 | 3 |
| 9. Infections? | 0 | 1 | 2 | 3 |
| 10. Constipation? | 0 | 1 | 2 | 3 |
| 11. Pain? | 0 | 1 | 2 | 3 |
| 12. Communication changes? | 0 | 1 | 2 | 3 |

Identification of complications

Confidence Level

| How confident are you that you can <u>identify</u> the following in your family member with dementia: | Not at all | Low | Moderate | High |
|---|-------------------|------------|-----------------|-------------|
| 1. Pressure injury (also known as pressure ulcers or bed sores)? | 0 | 1 | 2 | 3 |
| 2. Swallowing problems? | 0 | 1 | 2 | 3 |
| 3. Weight loss? | 0 | 1 | 2 | 3 |
| 4. Pneumonia? | 0 | 1 | 2 | 3 |
| 5. Bladder infection? | 0 | 1 | 2 | 3 |
| 6. Dehydration? | 0 | 1 | 2 | 3 |
| 7. Condition changes related to medication? | 0 | 1 | 2 | 3 |
| 8. Other Infections? | 0 | 1 | 2 | 3 |
| 9. Constipation? | 0 | 1 | 2 | 3 |
| 10. Cognitive or thinking changes? | 0 | 1 | 2 | 3 |
| 11. Pain? | 0 | 1 | 2 | 3 |
| 12. Stages of dementia and related complications? | 0 | 1 | 2 | 3 |
| 13. End-of-life stages? | 0 | 1 | 2 | 3 |
| 14. Communication changes? | 0 | 1 | 2 | 3 |

Management strategies

Confidence Level

| How confident are you that you can <u>manage</u> the following in your family member with dementia: | Not at all | Low | Moderate | High |
|---|-------------------|------------|-----------------|-------------|
| 1. Pressure injury (also known as pressure ulcers or bed sores)? | 0 | 1 | 2 | 3 |
| 2. Swallowing problems? | 0 | 1 | 2 | 3 |
| 3. Weight loss? | 0 | 1 | 2 | 3 |
| 4. Pneumonia? | 0 | 1 | 2 | 3 |
| 5. Incontinence of bladder? | 0 | 1 | 2 | 3 |
| 6. Incontinence of bowels? | 0 | 1 | 2 | 3 |

| How confident are you that you can <u>manage</u> the following in your family member with dementia: | Not at all | Low | Moderate | High |
|---|-------------------|------------|-----------------|-------------|
| 7. Dehydration? | 0 | 1 | 2 | 3 |
| 8. Condition changes related to medication? | 0 | 1 | 2 | 3 |
| 9. Other Infections? | 0 | 1 | 2 | 3 |
| 10. Constipation? | 0 | 1 | 2 | 3 |
| 11. Cognitive or thinking changes? | 0 | 1 | 2 | 3 |
| 12. Pain? | 0 | 1 | 2 | 3 |
| 13. End-of-life stages? | 0 | 1 | 2 | 3 |
| 14. Communication changes? | 0 | 1 | 2 | 3 |

Other management strategies

Likelihood Level

| | Not at all | Low | Moderate | High |
|--|-------------------|------------|-----------------|-------------|
| 1. How likely are you to call the clinic if the person that you are caring for is more confused? | 0 | 1 | 2 | 3 |
| 2. How likely are you to call the clinic if the person who you are caring for is much more tired? | 0 | 1 | 2 | 3 |
| 3. How likely are you to call the clinic if the person who you are caring for is suddenly having trouble getting out of the chair or getting out of bed? | 0 | 1 | 2 | 3 |
| 4. If you think the person you are caring for is sick, how likely are you to ask to speak to a nurse when you call the clinic? | 0 | 1 | 2 | 3 |
| 5. How confident are you in identifying resources to help you to take care of your loved one? | 0 | 1 | 2 | 3 |

6. What would you would do if there was a change in condition for the person you are caring for? Please give an example of the change in condition and what you would do.

Feelings about Caregiving

The following is a list of statements that reflect how people sometimes feel when taking care of another person. After reading each statement, circle one option of how often over the past month you have each of these feelings toward the person you are caring for. There are no right or wrong answers; we just want to know how you feel based on your interpretation on the questions.

| | Never | Rarely | Sometimes | Frequently | Nearly Always |
|--|-------|--------|-----------|------------|------------------|
| 1. Do you feel that because of the time you spend with your relative that you do not have enough time for yourself? | 0 | 1 | 2 | 3 | 4 |
| 2. Do you feel stressed due to caring for your relative and trying to meet other responsibilities for your family or work? | 0 | 1 | 2 | 3 | 4 |
| 3. Do you feel angry when you are with your relative? | 0 | 1 | 2 | 3 | 4 |
| 4. Do you feel that your relative currently affects your relationship with family members or friends in a negative way? | 0 | 1 | 2 | 3 | 4 |
| 5. Do you feel strained when you are around your relative? | 0 | 1 | 2 | 3 | 4 |
| 6. Do you feel that your health has suffered because of your involvement with your relative? | 0 | 1 | 2 | 3 | 4 |

| | Never | Rarely | Sometimes | Frequently | Nearly Always |
|---|--------------|---------------|------------------|-------------------|----------------------|
| 7. Do you feel that you do not have much privacy as you would like because of your relative? | 0 | 1 | 2 | 3 | 4 |
| 8. Do you feel that your social life has suffered because you are caring for your relative? | 0 | 1 | 2 | 3 | 4 |
| 9. Do you feel that you have lost control of your life since your relative's illness? | 0 | 1 | 2 | 3 | 4 |
| 10. Are you not sure of what to do about your relative? | 0 | 1 | 2 | 3 | 4 |
| 11. Do you feel that you should be doing more for your relative? | 0 | 1 | 2 | 3 | 4 |
| 12. Do you feel that you could do a better job in caring for your relative? | 0 | 1 | 2 | 3 | 4 |
| 13. Please share other thoughts or feelings that you have about caregiving for your person with dementia: | | | | | |

Revised Scale for Caregiving Self-Efficacy (Steffen et al, 2002)

Instructions: We are interested in how confident you are that you can keep up your own activities and also respond to caregiving situations. Please think about the questions carefully, and be as frank and honest as you can about what you really think you can do. I will read items which cover activities and thoughts that could come up for you as a caregiver. Please think about each one and tell me how confident you are that you could do each item. Rate your degree of confidence from 0 to 100 using the scale given below:

| | | | | | | | | | | |
|------------------|----|----|----|----|------------------------------|----|----|----|----|-------------------|
| 0 | 10 | 20 | 30 | 40 | 50 | 60 | 70 | 80 | 90 | 100 |
| Cannot do at all | | | | | Moderately certain can do | | | | | Certain can do |

For example, a rating of 20% confidence means that it is unlikely, but not totally out of the question for you to be able to perform the activity. A rating of 100% means that you are absolutely certain that you could perform the activity whenever you wished. A 50% confidence rating would mean that if you gave it your best effort, chances are about 50-50 that you could perform the activity. You can use any score between 0 and 100 (10, 20, 30, etc.) to express your confidence.

******Please make all your ratings based on what you could do TODAY as the person you are NOW rather than on the person you used to be or the person you would like to be. Just rate how you think you would do as you are TODAY.**

Questions: How confident are you that you can do the following activities? The ____ stands for the name of your family member with dementia. (If a question is not applicable to your situation, put N/A.)

- ____ 1. When ____ forgets your daily routine and asks when lunch is right after you've eaten, how confident are you that you can answer him/her without raising your voice? (For interviewer: clarify that "answer" can be direct or a distraction.)
- ____ 2. When you get angry because ____ repeats the same question over and over, how confident are you that you can say things to yourself that calm you down?
- ____ 3. When ____ complains to you about how you're treating him/her, how confident are you that you can respond without arguing back?
- ____ 4. When ____ asks you 4 times in the first one hour after lunch when lunch is, how confident are you that you can answer him/her without raising your voice?

_____ 5. When _____ interrupts you for the fourth time while you're making dinner, how confident are you that you can respond without raising your voice?

All caregivers sometimes have negative thoughts about their situation. Some thoughts may be brief and easy to get rid of. Other times, thoughts may be hard to put out of your mind, just like a silly tune is sometimes hard to get out of your mind. We would like to know how well you can turn off any of the following thoughts. Don't be concerned about how often the thoughts come up. We want you to rank your confidence that you can turn off or get rid of each type of thought when it does come up. Use the same confidence rating. Rate your degree of confidence from 0 to 100 using the scale given below:

| | | | | | | | | | | |
|------------------|----|----|----|----|------------------------------|----|----|----|----|-------------------|
| 0 | 10 | 20 | 30 | 40 | 50 | 60 | 70 | 80 | 90 | 100 |
| Cannot do at all | | | | | Moderately certain can do | | | | | Certain can do |

The _____ stands for the name of your family member with dementia. (If a question is not applicable to your situation, put N/A.)

- _____ 6. How confident are you that you can control thinking about unpleasant aspects of taking care of _____?
- _____ 7. How confident are you that you can control thinking how unfair it is that you have to put up with this situation (taking care of _____)?
- _____ 8. How confident are you that you can control thinking about what a good life you had before _____'s illness and how much you've lost?
- _____ 9. How confident are you that you can control thinking about what you are missing or giving up because of _____?
- _____ 10. How confident are you that you can control worrying about future problems that might come up with _____?

In this section, please circle one option of how often you felt or thought about each item in the last 6 months. The _____ stands for the name of your family member with dementia.

| | Never | Rarely | Sometimes | Frequently | Nearly Always |
|--|-------|--------|-----------|------------|---------------|
| 1. How often do you wish you had more help from community services in caring for _____? | 0 | 1 | 2 | 3 | 4 |
| 2. How often have you felt that _____ might be better off in a nursing home or assisted living facility? | 0 | 1 | 2 | 3 | 4 |
| 3. In the last 6 months, how often have you and other family members discussed moving _____ to a nursing home or assisted living facility? | 0 | 1 | 2 | 3 | 4 |

Medical and Community Service Use

Medical services

Please provide the following information about your family member with dementia.

| | | |
|--|----------|---------------------------|
| 1. Did your family member go to the emergency room within the past 6 months? | NO / YES | If Yes, # of times? _____ |
| 2. Was your family member hospitalized within the past 6 months? | NO / YES | If Yes, # of times? _____ |
| 3. Did your family member go to urgent care within the past 6 months? | NO / YES | If Yes, # of times? _____ |

Community services

Did you and/or your family member with dementia use the following caregiver services within the past 6 months?

| | | |
|--|----------|---|
| 1. Memory Care Connections (MCC)? | NO / YES | |
| 2. Services from the Alzheimer's Association? | NO / YES | |
| 3. Services from the Alzheimer's and Dementia Alliance of Wisconsin? | NO / YES | |
| 4. Adult Day Center services? | NO / YES | |
| 5. Respite? | NO / YES | If Yes, # of times? _____ |
| 6. Powerful Tools for Caregivers (PTC)? | NO / YES | If Yes, when did you begin? Give approximate date: _____ How many sessions did you complete? _____ |

7. Please share thoughts or feelings that you have about your needs for additional support in caring for your family member:

Caregiver Demographic Information

1. What is your age?
 - Under 60 years old
 - 60 years old or over

2. What is your gender? _____

3. Are you Hispanic, Latino, or Spanish origin?
 - Yes
 - No

4. What is your race? (**Check ✓ all that apply.**)
 - American Indian or Alaska Native
 - Asian or Asian-American
 - Black or African-American
 - Hawaiian Native or Pacific Islander
 - White or Caucasian
 - Other: _____

5. What type of geographic area do you live in?
 - Urban (place with a minimum population of 50,000 residents or more)
 - Rural

6. Have you ever served in the military?
 - Yes
 - No

7. What is the relationship with the person with dementia that you are caring for?
 - Spouse / Partner
 - Parent
 - Other: _____

8. Please circle the highest year of school you have completed:
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23+
(primary) (middle/high school) (tech/college) (graduate school)

Demographic Information of Family Member with Dementia

1. What is the age of the family member with dementia?
 - Under 60 years old
 - 60 years old or over

2. What is the gender of your family member with dementia? _____

3. Is the family member with dementia Hispanic, Latino, or Spanish origin?
 - Yes
 - No

4. What is the race of your family member with dementia? (**Check ✓ all that apply.**)
 - American Indian or Alaska Native
 - Asian or Asian-American
 - Black or African-American
 - Hawaiian Native or Pacific Islander
 - White or Caucasian
 - Other: _____

5. What type of geographic area does the family member with dementia live in?
 - Urban (place with a minimum population of 50,000 residents or more)
 - Rural

6. What is the living arrangement for the family member with dementia?
 - Lives alone, has an identified caregiver
 - Does not live alone, has an identified caregiver

7. Have the family member with dementia ever served in the military?
 - Yes
 - No

8. Please circle the highest year of school that your family member with dementia completed:
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23+
(primary) (middle/high school) (tech/college) (graduate school)

Survey is complete. Thank you!

HEARTLAND HOME HEALTH CAREGIVER EDUCATION PROJECT



As dementia progresses, medical issues can become more complex. To address this, Heartland Home Health has partnered with the Wisconsin Alzheimer's Institute to develop the Home Health Caregiver Education Project. Funding support for this project is provided by the Administration for Community Living, US Department of Health and Human Services.

PARTICIPATION INCLUDES:

- Home health nurses help participants complete an initial survey and another 6 months later, in their home.
- Services will take place during regularly scheduled home health visit times and include specialized teaching on how to prevent, identify and manage medical complications of dementia.

WHO CAN PARTICIPATE:

- Family caregivers for individuals with dementia who are enrolled in home care.
 - Participation is completely voluntary and information will be kept confidential.
- **Declining participation will not negatively impact their regular home health care.

THE BENEFITS TO PARTICIPATING IN THIS PROGRAM MAY INCLUDE:

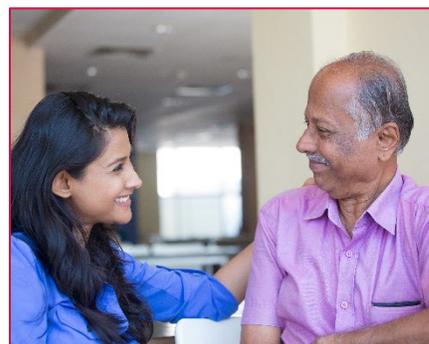
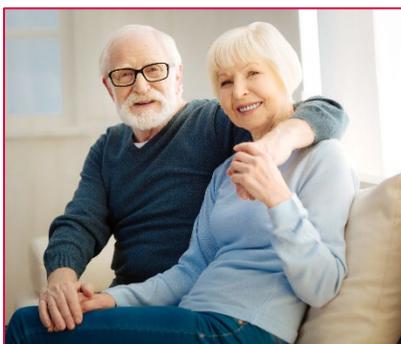
- Reduced use of emergency medical services and hospitalizations
- Decreased caregiver stress and burden

**For more information or to participate,
please speak with your Heartland Home Health clinician.**



Wisconsin Alzheimer's Institute
UNIVERSITY OF WISCONSIN
SCHOOL OF MEDICINE AND PUBLIC HEALTH

CHARTWELL HOME HEALTH CAREGIVER EDUCATION PROJECT



As dementia progresses, medical issues can become more complex. To address this, Chartwell Midwest WI Home Health has partnered with the Wisconsin Alzheimer's Institute to develop the Chartwell Home Health Caregiver Education Project. Funding support for this project is provided by the Administration for Community Living, US Department of Health and Human Services.

PARTICIPATION INCLUDES:

- Home health nurses and therapists help participants complete an initial survey and another 6 months later, in their home.
- Services will take place during regularly scheduled home health visit times and include specialized teaching on how to prevent, identify and manage medical complications of dementia.

WHO CAN PARTICIPATE:

- Family caregivers for individuals with dementia who are enrolled in home care.
 - Participation is completely voluntary and information will be kept confidential.
- **Declining participation will not negatively impact their regular home health care.

THE BENEFITS TO PARTICIPATING IN THIS PROGRAM MAY INCLUDE:

- Reduced use of emergency medical services and hospitalizations
- Decreased caregiver stress and burden

**For more information or to participate,
please speak with your Chartwell Home Health clinician.**

Implementing Effective Education to Caregivers on the Medical Complications of Dementia

Chapter 6

About Wisconsin Alzheimer's Institute

The Wisconsin Alzheimer's Institute (WAI), an academic center of the School of Medicine and Public Health at the University of Wisconsin-Madison, was founded in 1998 by a coalition of service providers, community-based organizations, educational institutions, and advocates organized by the Wisconsin Bureau on Aging and Long-Term Care Resources and Bader Philanthropies.

The hallmarks of the Public Health Pillar of WAI are community outreach and the development of culturally-tailored, innovative programs to improve the quality of care for people with Alzheimer's disease and other causes of dementias. It is through generous grants from agencies such as the U.S. Administration for Community Living (ACL) that we are able to create and share this guide. WAI's mission is to promote the health equity and improve the quality of life of people living with Alzheimer's disease and other dementias and their families through research and community engagement. We are committed to helping in improving the lives of people with Alzheimer's disease and dementia, their caregivers, and other professionals who support them. Their purpose is to increase dementia awareness, provide education on Alzheimer's disease and related disorders, identify and disseminate strategies to reduce dementia risk, convene stakeholders across the state, improve access to quality dementia care services, and to develop and support culturally tailored, effective clinical and community-based models of care.

The Wisconsin Alzheimer's Institute receives funding from the state of Wisconsin, the National Institutes of Health (NIH), and Bader Philanthropies. The development of this Clinician Training guide was made possible under federal funding from the Administration for Community Living.

Implementing Effective Education to Caregivers on the Medical Complications of Dementia

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This guide is part of the Alzheimer's Disease Initiative-Specialized Supportive Services (ADI-SSS) grant through ACL. This three-year grant titled, *Dementia Capable Wisconsin-Creating New Partnerships in Dementia Care* was awarded to WAI in 2016. The project goals in the ADI-SSS grant are to enable people with dementia to live at home for as long as possible, reduce caregiver stress and burden, and decrease any unnecessary use of emergency medical services by addressing dementia care system gaps through person-centered, evidence-informed approaches. The trainings on how to implement the Home Health Caregiver Education by home health clinicians, were developed to help increase the knowledge and capacity of clinicians working with patients with dementia as well as their caregivers.

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**Implementing Effective Education to Caregivers on the
Medical Complications of Dementia**

Chapter 9

References

Alzheimer's Association. (2016). 2016 Alzheimer's disease facts and figures. Retrieved June 20, 2016, from https://www.alz.org/documents_custom/2016-facts-and-figures.pdf.

Alzheimer's Association. (2014). The 2014 Alzheimer's Association women and Alzheimer's poll. Retrieved June 20, 2016, from <http://m.alz.org/facts-and-figures.asp>.

U. S Department of Health & Human Services. (2014). National plan to address Alzheimer's disease: 2014 update. ASPE Publication retrieved June 21, 2016 from <https://aspe.hhs.gov/sites/default/files/pdf/102496/NatIPlan2014.pdf>.

National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S. Retrieved June 20, 2016, from <http://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-reportrevised.pdf>.