Geriatric Mental Health Training Series: Revised

When You Forget That You Forgot:

Recognizing and Managing Alzheimer's Type Dementia, Part I

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When You Forget That You Forgot:
Recognizing and Managing Alzheimer's Type Dementia: Part I

CONTENTS

The revised version of this training module includes the following components. To facilitate use, some components are combined in a file, others are located in independent files, and all are provided in at least two formats – the electronic processing format in which they were created (Microsoft Word or PowerPoint) and a PDF version. A brief description of each is provided to enhance overall use of these training materials.

- Statement of Intended Use: Contained in this file. Provides guidelines for use of the training materials.

- Statement of Purpose, Learning Objectives, Content Outline: Contained in this file. Provides guidance about both content discussed in the module and provides the basis for applying for continuing education credits for teaching the module to a group of people. The program is about an hour long.

- Notes for the Instructor: Contained in this file. Provides an overview of the goals of the module, along with suggestions to personalized the content and make the training more individualized to the audience.

- Handouts, Bibliography: Contained in this file. Handouts that address program content are provided. These may be used independently, or in conjunction with handouts made from PowerPoint. The bibliography is provided for your reference and consideration. As before, these materials are provided in two formats to best accommodate all users.

- PowerPoint Program: Separate file(s), provided in both PowerPoint format and in PDF (slides only). The module contains 46 slides. If opened using PowerPoint, they may be viewed and used in a variety of ways: 1) slides may be shown in Presentation View using a projector,
  2) lecture content is provided in Notes View, and may printed for use to lecture, 3) slide content may be printed as handouts. Because some users may not have PowerPoint, the slides have also been converted into a PDF file which allows you to print a hard copy and make overheads or 35mm slides if desired to accompany the training program.

- Lecturer's Script: Separate file(s), provided in Microsoft Word and PDF format. This content provides the narrative to accompany and explain the slides and is also found in Notes View in the PowerPoint program.

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Statement of Intended Use

This training module is provided by the Hartford Center of Geriatric Nursing Excellence (HCGNE), College of Nursing, University of Iowa, as a free service. The training program, "When You Forget that You Forgot: Recognizing and Managing Alzheimer's Type Dementia, Part I" is revised and updated from a module by the same title that was first published in *The Geriatric Mental Health Training Series (GMHTS).* The GMHTS was developed and evaluated during a five year grant from The Division of Nursing, Bureau of Health Professions, Department of Health and Human Services, Grant # D10NU2711801, between 1989 and 1994. Other titles in the GMHTS include:

- Whose Problem Is It? An Introduction to Mental Health and Illness in Long-term Care Centers
- Getting the Facts: Effective Communication with the Elderly
- Help, Hope, and Power: Issues of Control and Power in Long-term Care
- When You Are More Than Just Down in the Dumps: Depression in the Elderly
- When You Forget that You Forgot: Recognizing and Managing Alzheimer's Type Dementia, Part II (Interventions)
- Acting Up and Acting Out: Assessment and Management of Aggressive and Acting Out Behaviors

 Revisions and updates to program materials (2003) are undertaken under the leadership of the HCGNE as part of their Best Practice initiative.

To facilitate widest dissemination and use of the training modules in the GMHTS, the original paper and slide format has been modified so that materials may be accessed as electronic versions. Updated copies n Microsoft Word and Powerpoint, as well as materials converted to PDF format, are provided.

Questions regarding copyright or use of materials may be directed to:
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When You Forget That You Forgot:
Recognizing and Managing Alzheimer's Type Dementia: Part I

Purpose:

Alzheimer's Disease and other dementias are commonly encountered in the long-term care setting. However, staff frequently misinterpret or misjudge behaviors and abilities due to lack of knowledge about the extent and nature of lost abilities. This program provides an overview of various types of dementia, but focuses on Alzheimer's' Disease (A.D.). The stages of A.D. are reviewed, including common behavioral problems associated with each. The Progressively Lowered Stress Threshold model of care is introduced as a model to help caregivers reduce stress and promote more functional behavior in dementia.

Objectives:

1. Define dementia and list 3 common types.
2. List 3 possible causes of "reversible dementia" (i.e., delirium).
3. Describe the type of problems that are typical in each of the 4 stages of Alzheimer's Disease.
4. Describe (in simple terms) the Progressively Lowered Stress Threshold model of care.
5. Discuss the relationship between stress and problem behaviors.
6. List 3 very common causes of stress for demented residents.

Content Outline

Introduction and overview

- Reversible vs. irreversible causes
- Dementia defined
- Essential features, losses in dementia
- Age and incidence of dementia

Types of dementia

- Alzheimer's Disease (A.D. or SDAT)
- Vascular dementia (also known a Multi-infarct Dementia or MID)
- Mixed dementia
- Frontotemporal dementia (FTD)
- Lewy Body Dementia (LBD)
- Other causes:
- "Reversible dementias"

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Stages of dementia

- Forgetful
- Confused
- Ambulatory
- Endstage

Common behavioral problems

- Problems resulting from lost abilities
- Catastrophic reactions
- Progressively Lowered Stress Threshold (PLST) model

Assessment

- Loss due to disease
- Stress: fatigue, change, stimuli, demands, physical
- Careplanning with the PLST model
- Common care problems

Summary

- Alzheimer's is incurable, not untreatable

Dementia, Part I: Notes for the Instructor

In this program, we introduce the topic of dementia by providing a mix of conceptual and practical information, focusing on dementia of the Alzheimer's type. We begin by providing a brief overview of the various losses that occur in dementia, noting the stage-wise progression that is characteristic of Alzheimer's Disease. Various other types of dementia are briefly reviewed, including some of the "reversible dementias" (i.e., delirium). Although we don't dwell on the reversible types, it's important for your staff to at least be introduced to *other factors that can mimic dementia.* Even a person who has Alzheimer's Disease can be more disabled because of the overlay of delirium caused by a urinary tract infection, medications, and other medical problems that cause acute confusion (a.k.a. delirium). That means that any abrupt change in mental status should be thoroughly assessed.

We then review some of the more common behavioral problems that tend to occur in the ambulatory stage of dementia and introduce a model for understanding catastrophic reactions. The model is called the Progressively Lowered Stress Threshold (PLST) model of care and was developed and refined by Iowa's own Geri Hall, RN, PhD, and Kathleen C. Buckwalter, RN, PhD, both faculty at the College of Nursing and members of the Hartford Center for Geriatric Nursing Excellence.

This revised version of the dementia module divides the original content into two training modules. Evaluation feedback from the original evaluation of the training modules suggested that the program was difficult to teach in an hour, the length of time often provided for inservice education. To better address important points made throughout the module, the content has now been divided in two. Although trainers/users may elect to use only one of the two modules, they are designed to be used in conjunction with one another. The second module, which focuses on interventions to promote function among people with Alzheimer's disease and related disorders, builds on the content provided in this first module.

We recognize that there is a lot of VARIATION from facility to facility, in terms of the amount of information needed to effectively manage their demented residents. For example, assisted living and residential facilities often transfer residents with dementia before they reach the more advanced stages of the disease. And although most intermediate and skilled facilities will be confronted with managing demented residents, there are tremendous differences BETWEEN facilities. Some facilities focus on rehabilitation and discharge (e.g. those linked to hospitals). Others provide longer term care and a few will have special care units for their demented residents, which creates special staff training needs. *No matter what the environment, successful training depends on the skills of the trainer and level of personalization of content to real-life needs of staff.*

Even when taught in two segments, this program provides a substantial amount of information in a short period of time. This requires that you, as the trainer, are familiar and comfortable with the content. We urge you to thoroughly read and review the lecturer's manuscript and other supportive materials.

Throughout the lecturer's script you will find instructions (e.g. **//Trainer:**) asking you to "personalize" the content. In some cases, that means selecting information from the content on the slide to mention and discuss. In another case, you may just want to allow time for the staff to read the slide. The instructions may direct you to select an example from the handout to discuss

(e.g. management of delusions and validation therapy). In another case, you will need to prepare an illustration of how stress can accumulate till a person reaches their "breaking point" or stress threshold. (An example is given but your own experiences are always better!)

We have used this format because so many of the slides have lists of information (stages of illness, problems of behavior, interventions) that don't necessarily need to be read verbatim. The handouts supplement the slides as well, and often provide more in-depth information than is found in the lecturer's script. This provides you with an opportunity to *focus on the aspects that are most relevant to your group*. Again, these decisions rely on the type of resident population that live in your facility and the expertise of the staff that you are training (e.g. nurses vs. nursing assistants vs. other ancillary personnel).

We urge you to go throughout the script and underline or "highlight" the points that you want to discuss, that you believe may not be easily understood by your staff. Examine the handouts for examples and illustrations. And then apply the concepts to any and all residents that are familiar to your staff.

We highly recommend that you "try out" the concepts and interventions in advance of teaching the program so that you can relate, from you own personal experience, how they may work out in a real life setting with a real, live resident. After reviewing the program materials, think about the following questions and suggestions and make some notes to yourself in the margin of the lecturer's script, handouts, or Notes View.

1. Who in your facility has some type of dementia diagnosis? Do some residents continue to have “organic brain disease” or other obsolete diagnoses? Offer them as illustrations during the program to reinforce that staff may not actually see a diagnosis of dementia, or Alzheimer's Disease.

2. Think about the "average age" of the folks living in your facility. Can you offer any interpretation of that information in light of the increased risk of dementia with advancing age. (e.g. "Think about this in terms of our resident!! Over half of the folks who live in our facility are over ___ years old.")

3. Do you have a resident who has vascular, frontotemporal or lewy body dementia? Can you compare and contrast this person's behavior with someone who has Alzheimer's?

4. Is there anyone in your facility with one of the more rare types of dementia? Perhaps related to Parkinson's Disease? How does that person's ability compare to a resident with Alzheimer's type?

5. Think back over the last 6 months. Who in your facility had an episode of acute confusion? What happened? How did staff respond to the person? What was the source of the confusion? Medication? Infection? Relocation? Depression? How was the problem resolved? Can you remind staff of that experience and relate it to the "reversible dementias” (i.e., delirium)?

6. Think about residents in your facility and about the examples offered for the "confused" stage of dementia? Can you compare and contrast the acute confusion (#5, above) with the confused stage of dementia?

7. Review the losses in the ambulatory stage. Who in your facility is exhibiting these behaviors? What happens?

8. What kind of real life examples can you give as you review the list of common behavioral problems? Who rocks, or paces? Wanders? Who calls out over and over again? (E.g. "Over here! Over here!" or "Help me! Help me!" or "Is it alright? Is it alright? or "Where am I? Where am I?") Who has claps, or taps, or stamps their feet repetitively? Who believes their parent are alive? Or that they're going to work? Or that you're their daughter? or mother? Who "sundowns?" Or gets up in the middle of the night? Examples of real residents are always useful.

9. Read and review the slides for the PLST model and try to think of a personal example of how YOU have gotten pushed to your stress threshold.

10. As you look at factors that increase stress for the demented person, remember that those same things can affect a cognitively intact person! How tolerant and patient are YOU when you are really tired? (Remember Scarlett O'Hara in "Gone With The Wind?" She said, "I can't possibly think about it today! I'll just have to think about it tomorrow!!" when she was too weary to deal with her problems.) Do you have any stories (funny ones in particular) that you can tell on yourself?

11. Provide information about when, specifically, you will teach the second part of the program that focuses on interventions. Provide support and encouragement that many care strategies may help support function among people with ADRD.

As always, HUMOR is appreciated!! Can you think of a story, joke, or anecdotal story to tell about dementia? One of my personal favorites is the story of the three sisters, which I tell about my "aunts" (M.S.).

One day I was visiting my three aunts. They're my mother's sisters and really a lot of fun. Two of them, Aunt Jean and Aunt Zella, are widow women and the oldest, Ada, is a maiden lady. She taught school and really took over Grandmother's role in the family after she died. They all live together in Ada's house now. Anyway, we were all sitting around the table visiting when Aunt Jean began to quiz me about memory losses in old age. Now, they know that's my line of work, so I figured she was just getting some "free professional advice!!" Well, she kind of hedged around the subject for a while and then finally said that she was beginning to *really worry about her memory*. She finally confessed, "You know, it seems that I get to the top of the stairs and forget what I've gone after! And it's happening nearly every trip!!" Then Aunt Zella popped up, "Well, that's nothing to worry about! I have to stop and catch breath just *halfway up the stairs*. And by the time I catch my wind, I've forgotten what I was going after!!" Then my Aunt Ada, who always did think she was just a little bit better than the rest, if you ask me, said, "Well! *Thank goodness, I never have any problems like that!!* **Knock on wood**!!" (I knock on wood to imitate Aunt Ada.) A few seconds later she wrinkled her forehead and started for the back door, saying, "Say, did you hear someone there at the door?" (Knocking?! Ha! Ha! Get it?)

Types of Dementia

Dementia -- the permanent loss of mental abilities caused by damage to brain cells; not a normal part of the aging process; the common end result of many entities (e.g. diseases, traumas, infections, drugs)

Alzheimer's Disease (A.D) Also known as Senile Dementia of the Alzheimer's Type (S.D.A.T.)

- ✓ 4 million American afflicted
- ✓ 4th leading cause of death among older adults
- ✓ 14 million predicted to be afflicted by the year 2050 as Baby Boom generation ages
- ✓ the cause is unknown
- ✓ characterized by a progressive loss of memory, judgment, impulse control, language, abstract thought
- ✓ losses result in changes in personality, behavior, emotions
- ✓ often described in terms of stages of lost ability
- ✓ very individualized in terms of length of illness and type of lost abilities

Vascular Dementia

- ✓ previously known as Multi-Infarct Dementia or MID
- ✓ caused by multiple small strokes (infarcts) which leads to decreased blood supply to the brain
- ✓ onset tends to be sudden compared to AD
- ✓ course is irreversible and progressive, but tends to be slower than AD
- ✓ loss of abilities tends to be step-wise, with sudden loss of ability followed by period of relative stability, then another sudden loss
- ✓ loss of ability tends to be "patchy," meaning that signs and symptoms depend on what area of the brain was injured and the extent of injury
- ✓ mental abilities tends to fluctuate (go up and down) as short episodes of confusion follow the small strokes; acute confusion is more common than in AD
- ✓ tends to occur in people with other vascular problems like stroke or transient ischemic attacks (TIAs)

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- ✓ risk factors for vascular disease, including history of hypertension (high blood pressure), are common
- ✓ treatment of risk for hypertension (high blood pressure)

Frontotemporal Dementia (FTD)

- ✓ frontotemporal is the label now commonly used for "frontal lobe dementia" and "Pick's disease"
- ✓ a clinical syndrome that involves progressive atrophy of the frontal lobes of the brain
- ✓ widely recognized by researchers and clinicians
- ✓ research now indicates several types of FTD, not just when "Pick bodies" are present as in Pick's disease
- ✓ tends to affect a younger age group than AD
- ✓ is more common among women than men
- ✓ has an insidious onset and is progressive like AD
- ✓ involves personality changes and language difficulties early in the disease
- ✓ memory often is intact early and deteriorates later in the disease

Lewy Body Dementia (LBD)

- ✓ like FTC, is increasingly recognized by researchers and clinicians
- ✓ is characterized by presence of lewy bodies, insoluble proteins found inside some cells (and which are commonly associated with Parkinson's disease)
- ✓ may co-occur with AD
- ✓ involves more fluctuations in impairment than AD
- ✓ visual hallucinations (seeing things that are not there) are common and usually vivid; other types of hallucinations/delusions may be present
- ✓ Parkinson-like features are common, including problems with gait; falls are common
- ✓ individuals with LBD have a particular sensitivity to antipsychotic medications

Other Common Causes

- ✓ Medical illness: HIV,
- ✓ Neurological diseases: Parkinson's disease, Huntingtons' disease
- ✓ General medical conditions: anoxia (lack of oxygen), vitamin deficiencies, *many* others

"Reversible Dementias" (i.e., delirium)

D -- **D**rugs
antipsychotics, antihypertensives, anticholinergic, diuretics, sedatives, hypnotics

E -- **E**motional disorders
depression, paranoid schizophrenia

M -- **M**etabolic disorders
hypoxemia, myxedema, hypoglycemia, electrolyte disturbance

E -- **E**yes and ears
impaired vision and hearing

N -- **N**utritional deficiencies
B12, folate, thiamine, anemia due to iron deficiency

T -- **T**umors and traumas
brain cancer, accidental injuries

I -- **I**nfections
urinary tract, respiratory, pneumonia

A -- **A**lcoholism

Note: Two additional factors that should always be considered when the person seems "confused" are:

- *being overloaded, having too much going on at one time:* noise, stress, distractions, trying to remember too much at once;
- *unfamiliar surroundings:* relocation, hospitalization, even a new room.

Stages of Alzheimer's Disease

Forgetful --> Confused --> Ambulatory Dementia --> Endstage

Early Symptoms: Forgetful

1. Short-term memory losses; misplace, forget, lose things
2. Compensate with memory aides; use lists, routine, organization
3. Express awareness of problem; feel concern about abilities
4. May become depressed which complicates symptoms & makes worse
5. Not diagnosable at this stage

Later: Confusion

1. Progressive memory decline interferes with all abilities; short-term most impaired, long-term follows later
2. Disorientation; time, place, person, thing
3. Problems with instrumental activities of daily living (IADL's); money management, legal affairs, transportation difficulties, housekeeping, cooking
4. Denial is common but give clues that fear "losing their mind"
5. Depression more common; aware of deficits and frightened
6. Confabulation and stereotyped word usage; covering up for memory losses
7. More problems when stressed, fatigued, out of own environment, ill
8. Day care and in-home assistance commonly needed

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Ambulatory Dementia

1. Functional losses in ADL's (in approximate order of loss): willingness & ability to bathe, grooming, choosing among clothing, dressing, gait and mobility, toileting, communication, reading, and writing skills

2. Loss of ability to reason, to plan for safety, and communicate verbally

3. Frustration is common

4. Become more withdrawn and self absorbed

5. Depression resolves, as the person's awareness of their memory loss and disability decreases

6. Become less "accessible" to us; unable to retain information or use past experiences to guide their behavior

7. Communication becomes more and more difficult with loss of language

8. Behavioral evidence of reduced stress threshold; up at night, wandering, pacing, confused, agitated, belligerent, combative, withdrawn

Endstage

1. Don't recognize family members, or even their own image in a mirror

2. No longer walk; little purposeful activity

3. Are often mute and may yell or scream spontaneously

4. Forget how to eat, to swallow, and chew; weight loss is common and they become emaciated

5. Develop problems associated with immobility: pneumonia, decubitus ulcers, urinary tract infections, and contractures

6. Incontinence is common; may have seizures

The stages of dementia described here were developed by Geri Richards Hall, R.N., Ph.D., F.A.A.N. and Kathleen Coen Buckwalter, R.N., Ph.D., F.A.A.N.

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Common Behavioral Problems

Problems Resulting From Lost Abilities

Concealed memory losses: skill at covering up what they don't know; seem to be better off than they really are

Wandering: causes anger & resentment; risk of injury or getting lost if go outside

Sleep Disturbance: wake others

Losing and hiding things: accuse others of stealing; families express frustration & concern

Inappropriate sexual behavior: upsetting to staff and residents

Repeating questions: monotonous repetition due to memory loss

Repetitious actions: clapping, rocking, pulling hair, rubbing

Territoriality: protective of own space; e.g. push others away at their dining table

Hallucinations: seeing, hearing, smelling, tasting, or feeling things that are not really there; hearing most common type

Delusions: false beliefs that are maintained (fixed) in spite of clear and obvious proof

Illusions: misinterpretation of something real in the environment

Catastrophic Reactions/Behaviors

Agitation: increased physical movements, restless, "worked up"; may be accompanied by calling out; can lead to combativeness

Combativeness: strikes out at others

Confusion: mixed up about time, place, person, thing; says things that indicate they don't know "who, what, where"

Fearfulness: becomes frightened without clear cause; seen in facial expression, body posture, words & phrases

Night waking: episodes of confusion, wandering, and sleeplessness that are linked to daytime stresses

Noisy behavior: calling or yelling out words, phrases

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Purposeful wandering: wandering results from some unmet need, drive, or internal tension; agitated purposeful wandering often results from a desire to leave and "go home"

Sudden withdrawal: pulls back from activity or action (walking out of their room) suddenly and without apparent cause

"Sundown Syndrome": confusion and behavioral problems tend to increase in late afternoon, as the "sun goes down"

Factors That Increase Risk For Catastrophic Behavior

Fatigue: become tired more easily and have a diminished (lower) reserve of energy than in the past

Multiple competing stimuli: too much going on at once; may include television, radio, noise or voices outside the room, public address system announcements, etc.

Physical stress: illness, medications, discomfort, hunger, full bowel or bladder

Changes: in caregivers, the routine, or the physical environment (even holiday decorations or new furnishing, paint, etc.)

Demands: to achieve beyond their abilities; e.g. being asked to make decisions that are too complicated for them

Note: Also remember the stressful effects of "negative and restrictive feedback":

"No, this isn't your room."

"No, you're not going to work today"

"No, this is your home now."

"Your parents are dead. They have been for years."

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