

PARTICIPANT HANDBOOK

Understanding and Responding to Behavioral Symptoms of Dementia: A Guide for Direct Care Workers

This teaching package was developed through a grant from the SCAN Foundation. The content was developed by Linda Redford, R.N., Ph.D. in collaboration with Aging Services of California and the Institute for the Future of Aging Services of the American Association of Homes and Services for Aging. The staff of three nursing facilities in California graciously offered their time for focus groups to assist in shaping the content of these modules. These groups also participated in pilot tests of the curriculum and offered insights to make the curriculum most relevant to their needs.

INTRODUCTION

This Handbook contains information to supplement the presentations on Dementia. It contains notes pages for the presentation slides and additional readings and videos that you can access on the Internet. The Modules to be presented will provide you information on behavioral symptoms of dementia. These modules will help you to understand how dementia affects the brain, the behaviors that result from the damage to the brain, and how you can best care for residents who display various behavioral symptoms of dementia.

Module 1 provides you with an overview of normal memory changes with aging and the memory and behavior changes that are found in dementia. You will learn what dementia means, the types of dementia, and how the different types of dementia may result in unique behavioral symptoms.

Module 2 discusses the common behavioral symptoms of dementia and the factors that should be examined as potential triggers for various behaviors. You will learn about behavioral assessment and have the opportunity to work in teams to conduct a behavioral assessment on a resident and report your finding to the group for discussion.

Module 3 introduces strategies for addressing various behaviors. The approaches to effective interventions generally depend on the factor(s) that triggered or exacerbate the behavior. This module highlights the causes/triggers most commonly associated with particular behaviors and the strategies for addressing them.

You are encouraged to utilize the readings and watch the videos suggested before each slide presentation in this manual. These materials will reinforce the information from the presentations and further your knowledge and skills in caring for residents with dementia.

Power Point Module 3

Responding to Behavioral Symptoms of Dementia

Learning Outcomes:

By the end of this Module, you will be able to:

- Discuss three factors that will influence your response to residents with behavioral symptoms of dementia.
- Demonstrate five strategies for communicating with a resident with advanced dementia.
- Demonstrate effective ways to divert and redirect residents who are manifesting behaviors associated with dementia.
- Discuss the Do's and Don'ts of interactions with residents displaying aggressive behaviors.
- Demonstrate effective and safe approaches to responding to physical aggression.
- Discuss strategies for addressing inappropriate touching by a resident.

Key Content:

- I) Why are there behavioral changes associated with dementia?
 - a. Changes in the brain
 - b. Common behaviors in residents with dementia
- II) Basics of Communicating with a resident with dementia
 - I) Wandering (and its variants) and fidgeting
 - a. Common triggers
 - b. Safety issues
 - c. Strategies to try
 - II) Sundowning
 - a. Definition
 - b. Strategies to try
 - III) Visiting, Rummaging, Hoarding
 - a. What these behaviors are
 - b. Strategies to manage
 - IV) Responding to “Elopers”
 - a. Safety precautions
 - b. What to do if resident exits facility
 - V) Verbal Behaviors
 - a. Nonaggressive and aggressive
 - b. Common triggers
 - c. Modifying triggers
 - d. Validate, divert, redirect
 - e. Changing our patterns of interaction

- VI) Physical aggression
 - a. Common triggers
 - b. Strategies to try
 - c. Protecting yourself and the resident
- VII) Inappropriate behaviors
 - a. Types of behaviors
 - b. Possible causes
 - c. Strategies for addressing
- VIII) Prevention
 - a. General Rules
 - b. Documentation

Online Resources for Additional Information:

Readings

Family Caregiver Alliance. Caregiver's Guide to Understanding Dementia Behaviors.

http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=391

Udesky, Laurie. What to Do When Someone Shows Signs of Sundown Syndrome,

<http://www.caring.com/articles/sundown-syndrome>

WI Department of Health and Family Services Bureau of Aging and Disability Resources (2006). Guide for the Use of Disguised Doors and Other Preventive Exiting Strategies for People with Dementia.

http://www.dhs.wisconsin.gov/aging/genage/Pubs/Guide_exitingstrategies.pdf

Videos

Video #1- "Bathing a Patient with dementia/Alzheimer's" illustrates strategies for approaching a resident and getting their cooperation for undressing and bathing.

<http://www.youtube.com/watch?v=lxwJgDg3bYU&feature=related>

Video #2- demonstrates how to divert and redirect a resident who is displaying repetitive verbal comments that indicate a particular want or need.

http://www.youtube.com/watch_popup?v=YT_fcnQdJr0&vq=medium

Video #3- “*Safe Self Defense Techniques*” demonstrates defensive moves to protect oneself and the resident if the resident displays physical aggression.

<http://www.youtube.com/watch?v=HtP79JZT5mc&feature=related>

Power Points

Module 3

Responding to Behavioral Symptoms of Dementia

Slide 1

**Understanding and Responding to Behavioral Symptoms of Dementia:
A Guide for Direct Care Workers**

*Developed by
Linda J. Redford, R.N., Ph.D.
University of Kansas Medical Center
In collaboration with Aging Services
of California, Sacramento, CA and the
Leading Age Center for Applied
Research, Washington, D.C.
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Slide 2

**RESPONDING TO BEHAVIORAL
SYMPTOMS OF DEMENTIA**

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- Behavioral symptoms of dementia-
 - are the result of damage to the brain.
 - are often triggered by feelings or needs of the individual or something in the environment.
 - are often an attempt to communicate needs or feelings.

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- Changes in the brain may cause people to—
 - act in ways they would not have done before developing dementia;
 - make bad decisions;
 - have problems understanding what they are feeling; and
 - have problems telling others how they feel.

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- There are no *cookbook* responses to addressing behaviors of dementia**
- **The Person**- usual traits, disease stage, past experiences.
 - **Physical Environment**
 - **You**- understanding of behaviors, knowledge of effective ways to respond

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How Common are Behavioral Symptoms of Dementia?

- Every person with dementia will display some of the common behavioral symptoms.
 - The common behaviors are ones like forgetfulness, repetition (repeating words, questions or actions over and over), wandering, and sundowning.
 - More challenging behaviors can also occur, such as screaming, cursing, paranoid accusations, and name-calling.
 - About 45% of people with dementia may display harmful behaviors (hitting, pushing, biting, etc.) at some point in the

Slide 7

REMEMBER!!

Behavior has a purpose

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Look at each behavior individually.

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Communicating with the Resident with Dementia

- Get at eye level with resident- maintain personal space.
- Speak in a low, calm, friendly voice.
- Get their attention by stating their name.
 - DO **NOT** USE "ELDERSPEAK"- terms such as "Sweetie", "Honey" or "Girly"- maintain respect of person's dignity.
- Remain patience and give the resident time to respond.

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Communicating with the Resident with Dementia

- Never interrupt when the resident is trying to communicate.
- Break all tasks into clear and simple steps based on abilities and stage of the disease.
- Use words from the person's native language, if possible.
- Show nonverbal indications of caring and affection (smile, pat the resident on the shoulder, hug them by the shoulder).

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SECTION 1

Slide 12

Wandering
Pacing
Fidgeting

Slide 13

Common Triggers of Wandering,
Pacing, and Fidgeting

- Time of day (Sundowning)
- Discomfort
- Confusion/fear
- Boredom

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Wandering, pacing, and fidgeting are not necessarily **bad** behaviors. They provide physical exercise and possible social interaction, but may also be annoying to staff and other residents.

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Safety

- Ensure resident uses needed assistive devices for ambulation—walkers, canes, etc.
- Provide a safe space for wandering, if possible.
- Protect the skin.

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Safety

- Ensure adequate food and fluids.
 - Make nutritious finger food and drinks easily accessible to residents in the common areas.
- Take steps to protect other resident's safety and privacy

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REDUCING WANDERING

- Use behavioral assessment findings
 - What appears to have triggered the wandering?
 - Is wandering similar to past behavior—time of day, type of wandering (is it aimless or appear to be an attempt to leave the nursing home)?
 - If this episode is new or different do a complete reassessment of the behavior.
 - What has worked to reduce wandering in the past?

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STRATEGIES TO TRY

- Address hunger, thirst, need to use bathroom, and other possible sources of discomfort.
 - Make food and drink visible and easily accessible.
 - Clearly mark bathrooms and introduce a toileting schedule, if needed.
 - Assist with activities when needed.



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STRATEGIES TO TRY

- Provide exercise & prevent boredom–
 - Provide daily activities to meet the need for physical exercise.
 - Provide structured activities and a variety of activities throughout the day- particularly at times residents tend to wander.




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STRATEGIES TO TRY

- Prevent boredom–
 - Give simple tasks (for example- folding towels, watering plants, planting flowers)



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“Sundowning”

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STRATEGIES TO TRY

- Prevent or reduce “Sundowning”-
 - Reduce the intake of drinks or foods with stimulants (caffeine) during the day and do not give in the evening or at night.
 - Coffee, colas, tea, chocolate
 - Provide sufficient exercise and stimulating activities during the day.

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STRATEGIES TO TRY

- Prevent or reduce “Sundowning”-
 - Discourage long naps and keep active during the day so more likely to sleep at night.
 - A short nap after lunch will prevent resident from becoming too tired.

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Strategies to Try

- Prevent or reduce “Sundowning” -
 - Provide structured activities at times resident typically starts to wander.
 - Reduce noise in the evening (loud activities, TVs, etc.)- try playing soft music and adjusting lighting to reduce shadows.

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Strategies to try

- Use VALIDATION and REDIRECTION with the anxious and increasingly agitated individual.



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**Visiting
Rummaging
Hoarding**

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Strategies to Try

- Visiting other's rooms
 - Place pictures or a familiar items outside rooms to help residents find rooms they are looking for.




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Strategies to Try

- Visiting other's rooms *(continued)*
 - Monitor individuals to keep them out of other's rooms.
 - Validate any concerns they express, distract them from their current behavior and redirect them, if necessary.
 - Interest them in another activity
 - Give them easy tasks

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Strategies to Try

- Rummaging and Hoarding
 - Provide a safe rummaging room or area.
 - Keep valuable items away from individuals who tend to rummage.
 - Check resident's room (when resident is not present) for hoarded items.
 - Always check wastebaskets before emptying them.

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ELOPEMENT



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Strategies to Ensure Safety

- Make certain--
 - All safety devices are working,
 - Visitors and staff know not to allow residents to exit doors with them.
 - Residents are wearing identifying apparel or bracelet and possibly a tracking device.
 - Register residents with MedicAlert and the **Safe Return Program** through the local Alzheimer's Association Chapter.

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Strategies to Try

- Put Stop Signs or Do Not Enter signs on doors.
- Paint a dark area on the floor in front of exit doors. Dementia residents may perceive these as holes and not cross them.

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Know what to do if resident elopes

- HAVE A PLAN IN PLACE.
- REMEMBER--
 - Most residents are found within a half-mile from the nursing home or community.
 - They tend not to respond if called to.
 - They may head for roads or public transportation.
 - They often “hide” in any available spot- bushes, storm drains, empty buildings, and even within the nursing home.

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Know what to do if resident elopes

- REMEMBER—
 - Persons with dementia tend to move in the direction of their dominant hand. Search in that direction first, unless there are greater dangers in another direction (busy roads, bodies of water, etc.).

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Verbal Behaviors

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Repeated questions
SCREAMING
CHANTING,
MOANING
Inappropriate comments

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Causes and Triggers

- Memory Loss
 - Individual is not able to remember what was just done or said.
- Boredom- lack of engagement and stimulation.
- Pain- need for relief.
- Anxiety- an need for reassurance.
- Frustration- a need for validation.

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Triggers may be internal needs/feelings-

- Personal discomfort.
 - Soiled underwear.
 - Uncomfortable positioning.
 - Hunger.
- Pain.
- Illness.
- Fear- delusions or hallucinations.

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Triggers may be in the environment

- Changes in the environment or routines.
- Noise.
- Large number of people.
- Rushing or appearances of stress among the staff.
- Distressed behaviors by another resident- a need to possibly isolate behaviors.



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Strategies to Try

- If a trigger is identified, try to modify the triggering event.
- Validate, divert and redirect.
 - Maintain eye contact.
 - Speak in a clear, gentle tone of voice.
 - Use a gentle touch on the hand or cheek with residents who enjoys physical contact.

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Giving a person significant attention only when they are displaying undesirable behaviors may reinforce the behavior you don't want.

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To disrupt and change behaviors,
we have to disrupt the patterns we
create.

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If an underlying cause is not found-

- Ignore inappropriate behavior or walk away from the resident.
- Watch for times the resident is behaving appropriately and immediately give them some time and attention.
- Be tolerant of behavior if it is not posing any safety risks.


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Aggressive behaviors

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Verbal Aggression

- **Examples of verbal aggression**
 - Obscenities
 - Threats
 - Name-calling
 - Using sexual or racial slurs



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Physical Aggression



- **Examples of physical aggression**
 - Hitting
 - Kicking
 - Pushing
 - Spitting
 - Pacing
 - Scratching
 - Biting

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Causes and Triggers

- Aggressive behavior occurs due to changes in certain areas of the brain.
 - May be totally out of character for the individual.
 - Never take the behavior.

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Causes and Triggers

- Typical triggers are frustration/fear, confusion, and pain/discomfort.
- Watch for escalation.
- Must consider your safety and that of the resident.

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Strategies to Try

- Prevention is the best strategy
 - Always explain what you are planning to do when caring for the resident.
 - Be creative when communicating-- use pictures, gestures and demonstrations with objects.
 - Avoid appearing rushed or impatient.
- Try to relate to what the resident is experiencing and address his/her concern.

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Strategies to Try

- Reducing likelihood of agitation and aggressive behaviors during personal care activities.
 - Go SLOW!!
 - Always explain what you are planning to do when caring for the resident.
 - Communicate what you will be doing -- use pictures, gestures and demonstrations with objects.
 - Avoid appearing rushed or impatient.

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Strategies to Try

- Reducing likelihood of agitation and aggressive behaviors during personal care activities *(continued)*
 - Have everything gathered and ready before starting activity.
 - Keep the resident warm and as covered as possible when bathing.
 - Use clothes that are easy to put on.
 - If resident becomes agitated, stop the activity and speak to resident in a calm, reassuring voice. Back off and give the resident time to calm down (if necessary).

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Strategies to Try

- Try to divert and redirect the resident.
- Speak in a calm, low voice.
- Reassure the resident with words and nonverbal actions.
- Call the resident by name– DO NOT use endearing terms like “honey”, “sweetie”, “girly”.

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Physical Aggression


- Do NOT stand within striking distance- respect resident’s personal space.
- Do NOT try to touch a physically aggressive individual when he/she is upset and agitated.
- Do NOT argue with the individual.



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**Strategies to Try with Residents
Displaying Verbal or Physical Behaviors**

- Music



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Inappropriate Behaviors

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What is inappropriate behavior?

- Sexually explicit language
- Inappropriate touching of another person
- Disrobing in public
- Handling genitals or masturbating in public
- Getting in bed with another resident (uninvited)

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**Understanding Inappropriate/
Suggestive Behaviors**

- Residents with dementia often-
 - do not comprehend what they are saying
 - do not comprehend how their behavior is being interpreted by others
 - have problems that are not related to sexual intentions which are causing the behavior

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Strategies to Try

- If disrobes in public-
 - Try adaptive clothing that makes disrobing more difficult.
- If handles genitals-
 - Check for infections or clothing that is binding or causing discomfort.
- Getting in bed with another resident-
 - Quietly remove resident and return to their own bed.
 - Remind of boundaries (early stage resident) but do not scold or berate the resident.

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Strategies to Try

- If urinates in public
 - Schedule more frequent toileting.
- If fondles self or masturbates in public
 - Consider possible sexual needs and provide privacy.
 - Distract and redirect.
 - Provide more activities to keep resident occupied.
 - Be mindful of residents personal rights.

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Strategies to Try

- Inappropriate touching of a health care worker
 - Firmly and quietly remind the resident that the behavior is inappropriate.
 - Calmly state the behavioral boundaries
 - Have someone of the same sex (if heterosexual) do personal care.
 - Divert and redirect the person's attention.

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Strategies to Try

- Inappropriate touch or advances on another resident.
 - Physically separate, if necessary.
 - Gently and firmly indicate the behavior is inappropriate and remind of the boundaries.
 - Divert resident and redirect them to another activity.
 - Keep resident in view and immediately intervene if it appears he/she is approaching another resident.
 - Medication may be considered (as a last defense) if the behavior is not easily managed.

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**REMEMBER—
Prevention is the best medicine for
behavioral symptoms in dementia!**

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General Rules for Preventing Behavioral Symptoms

- Develop and maintain a simple daily routine. Be aware there can be changes and inconsistencies in the resident's wants and abilities.
- Keep the environment calm, comfortable, and homelike with familiar possessions.
- Correct sensory deficits-use hearing aids, eyeglasses, and dentures.
- Use distraction to divert the resident from precipitating events.

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General Rules for Preventing Behavioral Symptoms

- Consider the resident's personal preferences in routines, activities of daily living and food choices.
- Be flexible with bathing, dressing, mealtimes and sleep.
- Install safety measures to prevent accidents.
- Simplify bathing and dressing with adaptive clothing and assistive devices.
- Provide regular daily activities and structure.

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Your Responsibilities in Documentation of Behavioral Symptoms of Dementia

- Document
 - Behavior-- specific description of behavior, time, frequency, duration
 - Events preceding behavior
 - Signs of physical distress in the resident
 - Characteristics of the physical and social environment
 - What was done to address the behavior
 - **DID IT WORK**

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ALWAYS REMEMBER!!

The **person** is not the problem—
the **problem** is the need or
feeling that the person is trying
to communicate with the
behavior.

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QUESTIONS?