

Geriatric Mental Health Training Series: Revised

When You Forget That You Forgot:

Recognizing and Managing
Alzheimer's Type Dementia, Part I

Revised by Marianne Smith, A.R.N.P., C.S., M.S.

From original content by

Kathleen Buckwalter, R.N., Ph.D., F.A.A.N

Marianne Smith, R.N., M.S.

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

INTRODUCTION AND OVERVIEW

>>Title slide: When you forget that you forgot

//Trainer: Explain that this is a two part series about dementia. Please give credit to the source of the training materials.

Today we're going to talk about dementia, which is the permanent loss of ability to remember and to use one's thinking abilities. This is part one of a two-part program about dementia.

>>Goals for Today

The topics that we will discuss and review today include:

- What dementia is, what the essential features of dementia are;
- Common types of dementia;
- Conditions that cause confusion and are often MISTAKEN for dementia, but may be reversible;
- Stages of Alzheimer's disease (AD), a specific type of dementia, including how AD affects people and what you might expect to see over time. And finally,
- A model, called the Progressively Lowered Stress Threshold or PLST model of care, which explains some of the problem behaviors that result from dementia.

In the second program, we'll review interventions that many be used to support and assist the person with dementia, including how we can change our approach and routines to better accommodate lost abilities.

>>More than "confusion"

Many people complain about their memories. And as we age, we become increasingly aware of and concerned about how well we are able to recall things. Any number of things can interfere with how our memory works – and with that interference, we can become "confused."

Many of those things have nothing to do with a permanent loss of ability. Some of the things that can interfere with our memory and ability to think clearly include:

- ✓ being overloaded; having too much going on at one time;
- ✓ medications; even those taken according to directions;

- ✓ illness and disease that are unrelated to brain disease; such as infections or depression; and
- ✓ unfamiliar surroundings such as relocation & hospitalization.

These kinds of problems cause something that is commonly called REVERSIBLE DEMENTIA. These “reversible dementias” are better called DELIRIUM, which is a temporary state of confusion. The point is that the *problems you see in patients, residents, or family members may be caused by something other than permanent brain cell loss.*

Because the person appears “confused” does not mean that they have dementia.

OVERVIEW OF DEMENTIA

>>Dementia: Permanent loss of mental abilities caused by damage to brain cells

The words dementia and Alzheimer’s disease are commonly used today. Most people know that both of these terms refer to what used to be called “senility.” *But what is dementia, really? How does it affect people? What does it do to their ability to function and get along in life?*

Dementia is defined as a LOSS OF MENTAL ABILITIES CAUSED BY DAMAGE TO BRAIN CELLS that is not a normal part of the aging process. People with dementia appear confused and may have problems with their thinking and that interferes with their social relationships in work, home, and community life.

It is important to remember that there are many types of dementia, and that dementia is caused by a variety of health problems. As a result, *each person will have slightly different symptoms and behaviors!*

>>Dementia: Essential features → Memory, Language

Dementia includes a progressive loss of abilities.

The most common lost ability is MEMORY.

Loss of short-term memory usually comes first, and long-term memory is lost later in the disease. That means that *the person may be able to tell you about their past history in great detail, but can’t remember what they had for breakfast!*

Over a period of time, the person will also lose their ability to use LANGUAGE. This is called “aphasia” which is also common among people with strokes. Early in the dementia, the person may have trouble finding words, but over the course of the disease will become less and less able to understand what is said to them, or express their needs and thoughts. Most people eventually become mute in the advanced stages.

>>Dementia: Essential features → Purposeful movement, interpret sensory information

Another loss that is commonly caused by dementia is the loss of purposeful movement, which is called APRAXIA. Even though the person is mobile, and has no physical problems to explain their inabilities, they can't do even "simple" tasks. Commonly performed movements like dressing, grooming or even buttoning a button are "lost."

Some people also lose their ability to accurately interpret what is going on around them – called AGNOSIA. Even though their sight and hearing and other senses all work reasonably well, they are not able to "use" this sensory information. They don't seem to understand what they appear to see or hear.

AGNOSIA causes similar, and yet different, types of problems as sensory impairment. In sensory impairment, the person can't hear or see well enough to understand what is said or done – they MIS-interpret information. In agnosia, the person's ability to recognize common objects can't be explained by sensory impairment. They see or hear what is said or done – but cannot accurately interpret it. And often, the person with dementia has both problems, agnosia AND sensory impairment!

As you can well imagine, these lost abilities show up in some pretty interesting behaviors that are hard for caregivers to understand

But what is dementia, really? How does it affect people? What does it do to their abilities?

>>Dementia: Essential Features → Impairments in thinking, ability to reason . . .

The person with progressive dementia has difficulty THINKING ABSTRACTLY, which is the ability to "think about thinking."

They aren't able to REASON, which requires the ability to think about several things at once. Their ability to problem-solve, which requires making a choice after considering different options, is lost.

JUDGMENT, which is the ability to make a choice based on values and beliefs, is also lost. The person may say or do things that they would NOT do otherwise. Cursing and name calling are common problems associated with impaired judgment.

Loss of ability to CONTROL IMPULSES also deteriorates in dementia. The person is unable to "wait a minute." If their instinct (impulse) is to say or do something, they likely will.

>>Dementia: Essential Features → Changes: personality, behavior, emotions

These symptoms combine and overlap to create changes in personality, behavior and emotion. In many ways, the person is "not him or herself" anymore. This causes lots of pain and sadness to family, who may say things like "My mother would never say or do such a thing. This isn't her."

>>Who has dementia?

Dementia is a "generic" kind of term that is used to mean "loss of mental abilities." As we will see in a minute, there are lots of different types of dementia. Many people continue to believe that Alzheimer's disease is the most common type of dementia. However, others now say that "mixed types" are actually more common. We will discuss each in a few minutes.

Getting older puts people more at risk for developing Alzheimer's disease and other dementias. As listed here, nearly half of the people over the age of 90 years have functionally limiting dementia.

This is what the slide says.

Risk of functionally limiting dementia increases with advancing age

- 25% of 80 year olds
- 33% of 85 year olds
- 50% of 90 year olds

The words "functionally limiting" are important. Over a period of time, the loss of ability caused by dementia interferes with the person's ability to do even simple day-to-day tasks. While many people are able to be cared for at home, many more will be moved to a supervised setting to assure their health and well-being.

>>Who has dementia? Common problems among nursing home residents

We have long known that most nursing home residents have some type of dementia.

Of equal importance, many of the people who reside in assisted living (AL) facilities also have dementia. Recent studies suggest that as many as 50% to 67% of residents in AL have dementia. And some researchers have found that people with dementia in assisted living are in the later stages.

And of course, a large number of individuals with dementia are still living at home and being cared for by family members. The Alzheimer's Association reports that 7 out of 10 people with Alzheimer's disease live at home. In many cases, supportive services, like adult day health care, community nursing services, home health assistance, respite care and other services are needed to help support family caregivers.

TYPES OF DEMENTIA

>>Dementia: Types -- Alzheimer's Disease

**** Refer to handout: Types of dementia**

ALZHEIMER'S DISEASE (AD) is often considered the most common type of dementia. As the slide suggests, a large number of people are currently affected by AD. And as the group of older

Revised by M. Smith (2003) from K.C. Buckwalter & M. Smith (1993), "When You Forget that You Forgot: Recognizing and Managing Alzheimer's Type Dementia," *The Geriatric Mental Health Training Series*, for the Hartford Center of Geriatric Nursing Excellence, College of Nursing, University of Iowa.

people gets larger in the future (as the Baby Boom generation ages), so will the number of people with AD.

The onset of Alzheimer's is often steady and gradual. The symptoms get worse over time, which is why we call it a "progressive" dementia. The person with AD gradually becomes more and more disabled; *that means they'll be less and less able to get along on their own, and will need assistance with even simple, day-to-day tasks.*

The loss of abilities in AD occurs over a period of months to years – from 2 to 20 years with an average of 10 years from the early stages until death. Losses in AD are often grouped into STAGES to help us think about “where the person is” in the disease process. However, *the course of dementia, both in terms of the symptoms and the length of the illness, is varied and unpredictable.*

>>Dementia: Types → Vascular, Mixed

VASCULAR DEMENTIA, which used to be called Multi-Infarct dementia, is caused by damage to the blood vessels in the brain. Vascular dementia is typically the result of multiple small strokes that occur at different times. Compared to Alzheimer's disease, the onset of vascular dementia tends to be more sudden and the course is slower and highly variable. Loss of abilities tends to be “patchy” – meaning that loss of function depends on what part of the brain was destroyed. Also, loss of abilities tends to be step-wise, meaning that the person has a sudden decline in ability, followed by a period in which there is little change, followed by another rapid change. The person may also be *more likely to have episodes of acute confusion*, or delirium, which follow these small strokes.

People with vascular dementia often have other vascular problems, such as a history of stroke or transient ischemic attacks (TIAs). Risk factors for vascular dementia are similar to those for other vascular disease, including high blood pressure, smoking, angina and diabetes. Early treatment of hypertension (high blood pressure) and vascular disease may prevent further progression of vascular dementia.

MIXED DEMENTIA means that the person has AD plus another type of dementia. In most cases, the term “mixed dementia” is applied to people who have characteristics of both AD and vascular dementia.

>>Dementia: Types → Frontotemporal dementia (FTD)

In recent years, two additional types of dementia are increasingly recognized by clinicians and researchers. They are of particular interest because the signs and symptoms may be quite a bit different from AD.

FRONTOTEMPORAL dementia or FTD is the label now used for “frontal lobe dementia” and “Pick's disease.” Pick's disease, which involves a clinical syndrome of progressive personality change, atrophy of the frontal lobes of the brain, and presence of “Pick bodies,” was first

described by Arnold Pick in 1906. In 2000, researcher developed criteria for a broader group of FTDs that have shared characteristics. Today, Pick’s disease is considered just one type of FTD.

Of most importance here, FTD tends to

- ✓ affect a younger age group than AD or Vascular dementia,
- ✓ is more common in women than in men,
- ✓ has an insidious onset, like AD, and
- ✓ involves PERSONALITY CHANGES and LANGUAGE DIFFICULTIES, *not memory loss*, early in the disease course.

Although memory problems do occur, they tend to be a problem late in the disease instead of early. At the same time, communication problems (related to language loss) can make the person LOOK memory impaired.

>>Dementia: Types → Lewy Body Dementia (LBD)

LEWY BODY DEMENTIA, which is also called LBD and Dementia with Lewy Bodies, is another “new” dementia. Lewy bodies are insoluble proteins found inside some cells, and have long been associated with Parkinson’s disease. Some researchers believe that LBD is a separate type of dementia; others think it is a subtype of Alzheimer’s disease, and still others think LBD and AD may be “mixed,” just like AD and vascular disease may be “mixed.”

Of importance here, the main features of LBD are different from AD, and involve:

- ✓ more fluctuation in impairment,
- ✓ visual hallucinations which are usually very vivid, and may include other types of hallucinations (e.g., auditory, olfactory) and delusions,
- ✓ Parkinson-like features,
- ✓ repeated falls,
- ✓ particular sensitivity to antipsychotic drugs.

>>Dementia: Types → Other causes

As noted on this slide, dementia may be “due to”

- ✓ medical illness like HIV disease,
- ✓ neurological diseases like Parkinson’s or Huntington’s diseases, and

- ✓ general medical conditions, like lack of oxygen or vitamin deficiency.

Dementia may also be caused by head trauma. In this situation the dementia is stable and does not progressively get worse.

Dementia can also be caused by substance abuse, and impairments persist even when the substance use stops.

>>Dementia: Types → All AD is dementia but not all dementia is AD!

In summary, dementia is a general term that applies to a wide variety of health problems that share common characteristics.

Alzheimer's disease is commonly believed to be the most common type, but is just ONE TYPE. There are many others.

As the slide says, *all Alzheimer's is dementia, but not all dementia is the Alzheimer's type!*

>>Dementia: Types → Lost of variability in presentation

The important thing to remember when working with people who have dementia is that there is no “one way” to do things. There are LOTS OF DIFFERENCES:

- ✓ Within certain types of dementia (e.g., Alzheimer's disease, FTD)
- ✓ Between types of dementia (e.g., FTD compared to AD)

Overlapping syndromes are also common. A person can have

- ✓ Dementia and various other mental and physical health problems, and
- ✓ Two types of dementia at once!

In summary, VARIABILITY – or differences between people – is far more common than most people expect. As a result, *care must be individualized and person-centered!*

“REVERSIBLE DEMENTIA” (i.e., delirium)

>>“REVERSIBLE DEMENTIA” (i.e., delirium)

As noted earlier (on page 2), medical and health conditions can cause confusion and other behaviors that “look like” dementia – but are NOT.

If left untreated, some of these will eventually cause permanent brain damage, which is then considered “dementia.”

Of most importance, the person with dementia can have an overlapping health problem that causes their confusion to be WORSE. Many medical problems cause acute confusion, called DELIRIUM, which can overlap on dementia. Even when you know the person has AD or some other related disorder, *always be alert to RAPID loss of ability, increased confusion, or change in function.*

Many times this signals another health problem that can be treated. Although the person never recovers the abilities lost DUE TO DEMENTIA, they may get “better” because the health problem, which caused the overlapping acute confusion (delirium), was treated.

>>D-E-M-E-N-T-I-A

****Refer to handout: Types of dementia: “Reversible dementia” (i.e., delirium)**

A number of health problems are known to *cause symptoms that may look like dementia and are often mistaken for Alzheimer's Disease.* This memory aid, which spells “dementia,” can help you remember some of the more common causes.

- D -- **Drugs**
antipsychotics, antihypertensives, anticholinergic, diuretics, sedatives, hypnotics
- E -- **Emotional disorders**
depression, paranoid schizophrenia
- M -- **Metabolic disorders**
hypoxemia, myxedema, hypoglycemia, electrolyte disturbance
- E -- **Eyes and ears**
impaired vision and hearing
- N -- **Nutritional deficiencies**
B12, folate, thiamine, anemia due to iron deficiency
- T -- **Tumors and traumas**
brain cancer, accidental injuries
- I -- **Infections**
urinary tract, respiratory, pneumonia
- A -- **Alcoholism**
strokes, transient ischemia attacks (TIAs), congestive heart failure (CHF)

STAGES OF DEMENTIA

>>Stages of Dementia

**** Refer to handout: Stages of Alzheimer's Disease**

Alzheimer's disease occurs in stages – and early in the disease the person and their family might blame other causes for changes in ability.

The number of stages outlined for Alzheimer's disease varies from three to seven or more. Many experts agree that there are four main stages, which include:

- 1) Early dementia, in which the person is FORGETFUL
- 2) Early middle dementia, in which the person is increasingly CONFUSED
- 3) Late middle dementia, in which the person is still AMBULATORY, but is very disabled and confused, and
- 4) Late or ENDSTAGE dementia, in which the person is basically terminal.

>>Early: Forgetful

In the very EARLY STAGES the person is more forgetful and begins to lose things. They may express awareness of the problem and try to compensate for their lost ability by using lists and other memory aids.

They often blame their problems on stress, illness, or fatigue.

Depression is a common problem at this point. As the person gradually becomes aware of their memory problems, they may develop depression. As many as 30% of people who have Alzheimer's disease and related disorders develop depression.

Remember: depression is highly treatable and is one of the factors that can make the person look more impaired than he/she really is!

>>Later: Confused

MEMORY LOSS is the first sign of Alzheimer's disease the CAUSE of many other problems. Over time, the person has more and more difficulty managing even simple daily activities. He/she may withdraw from social or work roles because increased discomfort. They KNOW that they are forgetting more than is "normal." Again, depression is common – and many *fear "losing their minds."*

Gradually, the person becomes disoriented, or confused; that is, they have difficulty keeping track of

- ✓ time (hours, days, month, date, year),
- ✓ place (where they are),
- ✓ person (who they are, who you are, who their children are)
- ✓ and things (what objects really are).

These losses usually occur in that order: time, then place, then person, then things.

The person may ask the same questions over and over again because they can't remember the answer. And even though they can't remember *what has just happened*, they may still remember certain people or skills, especially things that were "overlearned" – meaning that they did it so often it became almost "automatic."

>>Confused: Example → Helen

Examples on the slide:

- ❖ “Helen” crochets using a single simple stitch but doesn’t remember that she is retired – and sometimes puts her bra on over her blouse.
- ❖ “Harold” greets everyone like his oldest friend (“Nice to see you! So good of you to drop by! I’m great! How are you?”), but doesn’t know his own wife.

In spite of memory loss that can truly interfere with activities of daily living, many people retain certain social skills. They “look good” but when pressed for more information, or to do more for themselves without help, are truly unable. They are more impaired than they appear at first glance.

They can remember some things but not others – *which may leave caregivers and family members feeling that they “could remember if only they wanted to!”*

>>Confused: Example → Mildred

Examples on the slide:

- ❖ “Mildred” avoids the question “How old are you? With “Jack Benny and I are both 29.” When asked what she had for lunch, she replied “I went to the Riviera and had pink champagne and caviar.”
- ❖ “George” got lost walking in his neighborhood of 30 years – as soon as he could no longer see his house.

Another problem comes up because the memory loss is gradual and often the person finds ways to “cover up” what they don’t really know. They “make up” answers – called confabulation – to avoid being embarrassed. Many people, including family members, are “bluffed” by these

answers. As a result, the person is given credit for having abilities that they do not – which may create safety hazards.

Later in the CONFUSED stage, the person becomes less and less able to function independently. Their abilities to cook, drive, and manage their affairs declines. They are more likely to become disoriented, and may even get lost when they're close to home.

And over time, they have more and more difficulties managing stress – even simple stress that most people take for granted. Later in the CONFUSED stage, supervision and assistance are often needed – either by family members, or by formal caregivers. Day care, in-home assistance, and even residential placement in either assisted living or nursing home care, may be needed to assure their safety and well-being.

>>Later Still: Ambulatory dementia → Progressive loss of ability interferes with function

Eventually the person's ABILITY TO FUNCTION is lost.

Over time, the person becomes more withdrawn and self absorbed. Depression tends to resolve as the person's awareness of their memory loss and disability decreases. That is, the person is less aware of their impairments. They lose their ability to reason, to plan for safety, and to use language. Overall, they are less "accessible" to us -- unable to retain information or use past experiences to guide their behavior. They don't recognize family members, or even their own image when they look in a mirror.

>>Ambulatory: Functional losses

- | |
|---|
| <p>This is what the slide says.</p> <ul style="list-style-type: none">-- Willingness & ability to bathe-- Grooming-- Choosing among clothing-- Dressing-- Gait and mobility-- Toileting-- Communication, reading, and writing skills |
|---|

The ability to conduct normal activities of daily living, and to participate and interact with others, is lost over time.

The loss of function listed on this slide occurs in about the order noted. That is, first persons with dementia become unwilling to bathe; then they resist grooming; later they have difficulty choosing among clothes, and so forth.

>>Ambulatory dementia: Behaviors

Behavioral symptoms become increasingly common as the person responds to their “internal reality.” They may have false beliefs, including simple delusions and/or time confusion, that affect their behavior.

Their tolerance for stress continues to go down -- and they may become irritable, agitated, combative, or anxious without clear reasons. They may pace, or wander, and are often easily frustrated. Loss of ability to use language may result in use of repetitive words or phrases in loud tones (e.g., yelling or screaming) to signal their discomfort.

As functional abilities decline, and the person becomes increasingly dependent on others to cue or guide them through daily routines, the risk of “resistiveness” to care increases.

If the person does not understand what is being done, or why, he/she may RESIST by pulling back, withdrawing, or physically pushing the caregivers away, and may even strikeout if sufficiently threatened.

To understand how frightening the world becomes to a person with dementia, *try to imagine what it would be like to NOT REMEMBER from minute to minute what has just happened.* Each and every time things happen, they happen for the first time. Every time the person sees you, they see you for the first time. Every time they go to the dining room, they see it for the first time. When they look at their son or daughter's picture, they don't know who they are. There are no “comforting memories” to draw on.

>>Endstage Dementia

This is what the slide says.

All abilities are lost

- Mute
- No longer walks
- Little purposeful activity
- Forgets to eat, chew, swallow
- Complications are common

In the ENDSTAGE of the disease, the person no longer walks and has little purposeful activity. They forget how to eat, swallow, and chew, and are at increased risk for choking.

They lose weight and are “at risk” for all the problems associated with immobility:

- ✓ Pneumonia
- ✓ Pressure ulcers
- ✓ Urinary tract infections

✓ Contractures

Incontinence of both bowel and bladder is common and seizures may even occur. In short, the person is “terminal” and will likely die from the complications of the dementia, not directly from the disease itself. Comfort measures, and palliative care (e.g. hospice approach) is often the best care that can be provided during the endstage.

>>Symptoms: Not in distinct stages

This is what the slide says:

Losses and symptoms vary from person to person, depending on

-- Extent of brain cell death and loss

-- Location of brain cell death and loss-- Speed with which losses occur

Although it is very common to describe dementia in stages, and most experts do use this approach, the symptoms VARY from person to person, depending on the EXTENT and TYPE of brain cell loss. Each person’s disease trajectory will be different.

COMMON BEHAVIORAL PROBLEMS

>>Common behavioral problems → Concealed memory losses

****Refer to handout: Common behavioral problems**

//Trainer: Review this handout so you are able to give examples of the behaviors listed.

A number of problematic behaviors result from the loss of ability caused by Alzheimer’s disease and related disorders.

The loss of memory, judgment, impulse control, language, ability to reason, abstract thought and use of language can cause the person to do some pretty distressing things. As a result, a wide variety of behaviors may be observed. The following are some of the more common types of behavioral disturbance:

- ✓ *Concealed memory losses*: “covers up” what they don't know; seems to be better off than they really are
- ✓ *Wandering*: goes into other resident’s room, causing anger and 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 and concern

- ✓ *Inappropriate sexual behavior*: upsetting to staff and residents

>>Common behavioral problems → Repeating questions

- ✓ *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 (e.g. hears water dripping and thinks someone is knocking on the door)

>>Catastrophic Behaviors → Agitation . . .

****Refer to previous handout: Common behavioral problems**

This is what is on the slide:

- | | |
|-------------------|--------------------------------------|
| -- Agitation | -- Noisy behavior |
| -- Combativeness | -- Purposeful wandering |
| -- Confusion | -- Sudden withdrawal from activities |
| -- Fearfulness | -- “Sundowning” |
| -- Night wakening | |

Another group of problem behaviors are called CATASTROPHIC REACTIONS or catastrophic behaviors. CATASTROPHIC is taken from the word CATASTROPHE, which is a great or sudden disaster or calamity.

So catastrophic behaviors are *unexpected, intense, seemingly "out of nowhere" and out of proportion reactions to a situation*. They may include anger, aggression, tearfulness, withdrawal, and other behaviors and emotions listed on this slide.

>PLST: Progressively Lowered Stress Threshold model

One model for better understanding and explaining catastrophic behaviors in dementia was developed by Dr. ’s Geri Hall and Kathleen Buckwalter, experts in geriatric and psychiatric nursing care from the University of Iowa College of Nursing.

Their model emerged out of clinical practice – from watching the behaviors of older adults with dementia and trying to understand WHY some people became so upset and uncomfortable.

These “over-reactions” seemed to be the result of STRESS that the person with dementia could no longer manage.

Their model is called the **P**rogressively **L**owered **S**tress **T**hreshold, or PLST model of dementia care.

The PLST model is based on theory about “person-environment fit.” In very simple terms, this theory says that people’s ability to function and be comfortable is the result of a “good fit” between them (and their abilities) and the environment. If the demands in the environment are greater than their abilities, they are more likely to have difficulties.

>>PLST

This is what is on the slide:

Basic Principles

- Some behaviors result from losses associated with dementia
- Other behaviors result from environmental stress
- Stress takes many forms in dementia
- Stress threshold is lower in dementia

Although we know that some behaviors in dementia are directly related to the person’s loss of ability, many more are caused by stress in the environment.

Two principles are important when thinking about the relationship between stress and behaviors in dementia.

First, stress takes many forms for people with dementia. Even simple, day-to-day problems that wouldn’t be expected to cause anxiety, frustration and stress DO JUST THAT.

Second, we believe that the person with dementia gradually loses their ability to handle stress. That is, their “stress threshold” becomes lower and lower as the disease progresses.

>>PLST → Goals

This is what is on the slide:

Goals:

- Redefine “stress” for person with dementia
- Recognize lowered stress threshold
- Interpret behavior as anxiety that increases to cause dysfunctional behavior
- Manage stress for person with dementia
 - Modify routines, approaches
 - Monitor internal, social, environmental stress

The PLST model can help caregivers “reframe” problems behaviors. As outlined on the slide:

- ✓ Stress takes many forms in dementia.

- ✓ The person with dementia can't handle stress like they used to.
- ✓ They are vulnerable to becoming anxious as the result of stress – and if we don't help them handle their stress and discomfort – their behavior will likely become dysfunctional.
- ✓ Caregivers can manage stress FOR the person with dementia. By adjusting routines, approaches and demands placed on the person, caregivers can help the person with dementia be as successful as possible.

//Trainer: Examine the graphs and be prepared to give examples of how this works.

The horizontal axis is time. The vertical axis is amount of stress. "Normal behavior" is associated with low stress, and anxious and eventually dysfunctional behavior is associated with increasingly higher levels of stress. The dotted line at the top of the graph represents the "normal" stress threshold, or breaking point.

The first slide shows how any person can have a series of stressful events throughout the day and eventually reach their breaking point. The accumulation of stress, which moves the person from "normal" to "dysfunctional" behavior, is represented by the jagged line marked "stressors."

Think of an example to use with the group, something that you are comfortable relating and that they will understand and find meaningful. As always, humor is appreciated. Point to the line on the graph as you relate your story. For example, you have a sick child at home (stressor) are already late for work (stressor) when you realize that you are out of gas (stressor). You go to the station, put gas in the car (stress reduced). Then realize that you left your purse at home (stressor). You go back home to get the money, return to the station and pay your bill (stress reduced). You call work to let them know that you are running late, and apologize. They tell you that you'd better come soon since 5 out of 8 people scheduled to work have called in sick with the flu (stressor). You arrive at work. The physician is there to do rounds even though this isn't the usual day (stressor) and a family member is angrily waiting to speak with you about the care of their parent (stressor). You feel nearly overwhelmed -- stressed, anxious, and unable to figure out what to take care of first. The "straw that breaks the camel's back" is when the State Department of Inspections and Appeals walks in the door to conduct an unannounced inspection. You are now over your stress threshold!

The second slide represents the loss of ability to handle stress which is experienced by a person with Alzheimer's disease. The line that runs diagonally across the graph represents the gradual lowering of the person's stress threshold, as described in the text.

The third graph, labeled "Lowered Stress Thresholds: Catastrophic Behaviors," is intended to help the learner SEE the relationship between stress and catastrophic behaviors that are associated with being "stressed out." Note that this graph has two stress threshold lines. The top line (dots) represents the person's "normal" stress threshold. The line below it (dashes) is their current stress threshold. Note out how much LESS stress it takes to push the person into dysfunctional behavior. Also note that the left side of the slide is pink, representing morning, and the right side is blue, representing afternoon and evening. The point is that stress accumulates throughout the day, with most dysfunctional behavior (sundowning, wandering, night awakenings) occurring later in the day.

The last slide, "Care Planning for Lowered Stress Threshold," is intended to represent the GOAL of interventions used with the demented person. The idea is to keep stress at a manageable level by recognizing factors that are now stressful to the person, and by reducing stress periodically throughout the day.

>>PLST: Normal Stress Threshold

**Refer to handout: Stress thresholds

To understand the PLST model, let's first consider "normal stress" and how any person can be pushed over their "stress threshold."

Every person has a "breaking point" – which is called a "stress threshold." The dotted white line on this slide represents a "normal" stress threshold.

Stress can become so great that we break down and can't function effectively.

And show on this slide, stress can accumulate across time. Notice that TIME runs horizontally, or "across" the graph from left to right.

STRESS runs vertically, or "up and down" on the graph. The jagged white line shows how stress builds up over time.

We can all handle some stress, as shown by NORMAL behavior being at the bottom where stress is low.

But as stress gets higher, we become more and more ANXIOUS, and may even panic.

And if stress continues, we may even become DYSFUNCTIONAL – which means we can't cope or function any more. We can't "handle it."

>>PLST: Lowered Stress Threshold

This slide shows the stress threshold for a person with dementia.

The dotted white line represents the person's PREVIOUS stress threshold.

The dashed white line is the person's CURRENT stress threshold. As the disease progresses, their ability to tolerate stress becomes lower and lower.

As a result, they will become ANXIOUS and DYSFUNCTIONAL sooner. It takes less STRESS to push them over their threshold.

In summary, people with dementia have a lower stress threshold than the "typical" person AND they have a lower level than they had earlier in their own lives. That means the person will be overwhelmed by stress more quickly than the "typical" person. They won't be able to handle things that you, or others around them, may easily manage.

>>PLST Behaviors (Dementia - 26)**This is what is on the slide:**

- | | |
|---------------------------|-------------------------|
| -- Increased anxiety | -- Purposeful wandering |
| -- Night awakening | -- Confusion, agitation |
| -- Catastrophic behaviors | -- Combative behavior |
| -- “Sundowning” syndrome | -- Diminished reserve |

More likely to increase as stress increases

Many of the "problem" behaviors seen in dementia are the result of increased stress that the person can't manage.

Some people call this “excess disability” – meaning it is disability that exceeds the type of behavior we would EXPECT to see given the stage of dementia the person has.

As noted before, some behaviors are more “predictable.” They are closely related to the loss of ability in dementia.

Others, like those in the PLST cluster, are believed to be caused by factors in the environment.

>>PLST: Catastrophic Behaviors

The PLST model suggests that CATASTROPHIC behaviors, like *anger, aggression, fear, or withdrawal*, are the result of STRESS. You might even think of the person as being "*stressed out*." That is, they have passed over the point where they can cope, and their anxiety becomes unmanageable.

In this slide, the pink area is early in the day (12 midnight to 12 noon) and the blue area is later in the day (12 noon to 12 midnight).

The white dashed line represents the stress threshold of a person with dementia. Note how much lower it is than the dotted white line – which is the person's previous stress threshold (before dementia).

The white jagged line represents STRESS. Note how it starts out low and builds up over the course of the day. Because the person isn't able to problem-solve, they can't regulate how much stress they experience.

- ✓ STRESS continues to build.
- ✓ ANXIETY becomes unmanageable.
- ✓ They pass over their stress threshold and become DYSFUNCTIONAL.

Dysfunctional behavior may include sundowning, wandering, night awakenings, or catastrophic behaviors. It depends on the person and the situation.

ASSESSMENT

>>PLST Sources of Stress → Fatigue, competing stimuli

****Refer to previous handout: Common behavioral problems**

This is what is on the slide:

- Fatigue
- Multiple competing stimuli
 - Noise, confusion
 - Television, radio, public address
 - Too many people
 - Too many things going on at once
 - * Eating dinner
 - * Taking medications
 - * Meal-time entertainment

It is important to realize that "stress" can take many forms for the person with Alzheimer's disease.

Remember. Simple things that caregivers may take for granted may be very confusing and upsetting to the person with dementia.

For example, noise or lots of things going on at once may be part of a “normal day” for lots of people. But those same things are STRESS-FULL to a person who can't figure out “where those voices are coming from” or “who all those people are!”

Any of the things listed here, or on the next slide, can be stressful to the person with dementia and push them toward dysfunctional behavior.

>>PLST: Sources of Stress → Physical stress, Changes

This is what is on the slide:

- Physical stress
 - Illness, medication side-effects
 - Hunger, thirst, discomfort
- Changes
 - Caregiver
 - Routine
 - Environment

The “environment” isn't just “outside” the person either – it includes the person's “internal environment” including fatigue, pain, hunger or thirst, and other physical sensations.

Changes can also create stress for the person with Alzheimer’s and related disorders. As the person becomes more disabled, consistency in caregivers, routines, and surroundings provide comfort and security.

>>PLST: Sources of Stress → Demands, Negative feedback

This is what is on the slide:

- Demands that exceed abilities
 - Decisions that are too complex
 - Tasks that are outside abilities
- Negative and restrictive feedback
 - “Don’t do that!”
 - “Your parents are dead”
 - “But this IS your house”
 - “No, you’re not going to work”

Giving the person too many choices, or pushing them to do things that are now too complicated, also is stressful.

Another type of stress that caregiver must think about is called “negative and restrictive feedback.” These are repeated messages that YOU ARE WRONG.

Being told “you are wrong” is hard for nearly anyone to handle. And it is easy for caregivers and others to forget how OFTEN they tell the person with dementia “you are wrong.”

For example, the person with dementia wanders into another resident’s room at the care facility. She picks up a colorful strand of beads and admires them. Without thinking, the caregiver says “Don’t touch those! This isn’t your room! Those aren’t your things!” and then tells the person to go somewhere else. The caregiver’s tone of voice, facial expression and other nonverbal messages are as important as the spoken word. Both are powerful messages that the person is “wrong.”

The person with dementia is just as likely to have a negative reaction to these “corrections” as anyone else!

Knowing that these factors put the person with dementia “at risk” for problem behaviors is important. It allows caregivers to better monitor what is going on with the person and in their environment. *Caregivers can keep stress in a manageable range by manipulating their routines, their approach and the environment.*

//Trainer: Ask participants to think about their LTC environment. How many of these factors are present? Could they be altered?

>>PLST: Care Planning Goal → Act like a prosthetic device

This is what is on the slide:

- Goal: To act like a “prosthetic device” that supports the person to do what he/she is able to do
 - Interventions serve like a memory “crutch” that fills in for lost abilities
 - Supports person to be autonomous in spite of lost abilities
 - Keeps stress at a manageable level throughout the day

The GOAL of the PLST model is for caregivers to act like a “prosthetic devise” to support the person to be as independent and functional as possible.

Just like an artificial limb can support a person with a leg amputation to walk, caregivers can act like a “crutch” for the person’s failed memory.

Interventions can be developed to cue the person, assist them as needed, and fill in what they don’t remember. By acting as a MEMORY CRUTCH, caregivers can help the person with dementia maintain their independence. This type of support and assistance helps to keep stress at a manageable level and reduces the risk of problematic behaviors.

>>PLST: Care Planning Goal

As shown on this last graph, the goal is to keep stress down, below the person’s stress threshold, throughout the day. By using rest periods in the mid-morning and afternoon, along with other interventions that will be reviewed in Part II of this program, caregivers can help reduce the amount of stress that the person with Alzheimer's experiences.

Instead of letting the stress accumulate, as the earlier slide showed, caregivers can work to keep bringing stress back down to baseline. That way, the person with dementia is less likely to have problems like sundowning, nighttime episodes, and other problematic behaviors that are caused by stress.

>>PLST: Summary

This is what is on the slide:

- Safety needs of both the client and other residents
- Disruptive behaviors
- Inability to participate in care & treatment
- Disturbances to other residents
- Family needs
- Increased care time and need for staff

To summarize, there are numerous challenges in providing care to the person with dementia. We need to be sensitive to the problems created for the resident, for the other non-demented residents, for the family, and certainly for the staff who are caring for the person.

Attention to these factors in planning care will help everyone cope as well as possible!

>>Alzheimer's Disease: Incurable -- Not Untreatable

This ends of Part I of the training program about dementia. In closing, try to remember that at present Alzheimer's Disease is incurable, but doesn't mean that it's untreatable! There are many things caregivers can do to help the person be "the best that they can be." By careful assessment of their abilities and the environment, caregivers can

- ✓ Preserve and enhance their remaining abilities;
- ✓ Avoid unnecessary stress and overstimulation;
- ✓ Treat illness or other complications (that make them worse);
- ✓ Provide education and guidance for families and other caregivers.

Part II of this program discusses interventions that may be used to promote function by reducing stress and keeping stress at a manageable level.