Dementia Care: Challenges and Solutions

Presenter: Kim Warchol, OTR/L
President, DCS

dementia care specialists
a CPI specialized offering
Course Objectives

1. Describe Alzheimer’s disease and related dementias (ADRD) and the statistics, prevalence, and trends.

2. Define Dementia Capable Care and the key components of this model in long-term care.

3. Using a Dementia Capable Care model approach, identify solutions to common problems and challenges that impact residents with dementia and the staff and businesses that serve them.
What Is Dementia?

- Dementia is not a disease itself, but a group of symptoms that may accompany certain diseases or conditions.

- The loss of intellectual functions of a severity that interferes with a person’s daily functioning.
  - IADL decline
  - BADL decline

- Often classified as chronic and progressive or acute and reversible.
Alzheimer’s Disease and Related Dementias (ADRD) are chronic and progressive and include:

- Alzheimer’s Disease (AD)
- Lewy Body Dementia
- Vascular Dementia
- Frontotemporal Dementia
- Mixed Dementias

✓ AD is the most common form of dementia.
✓ ADRDs move through predictable stages of decline.
Alzheimer’s Disease Stats and Trends

• Currently over five million people in the US have Alzheimer’s disease.

• This number is expected to grow to 14–16 million by the middle of the century.

• Risk increases with age: one in eight aged 65 and almost half of those aged 85 have AD.

• Every 69 seconds someone in the US develops AD.

Source: 2011 Alzheimer’s Disease Facts and Figures
Alzheimer’s Disease Stats and Trends

• **AD is the sixth leading cause of death**, and it is the only one of the six that did not decline—it went up 66%.

• People live an average of four to eight years with AD, but can live as many as 20 years. During this time, **most of their years are spent in the severe stages, and most of their time is spent in nursing homes.**

Source: 2011 Alzheimer’s Disease Facts and Figures
Prevalence in LTC

- **Skilled Nursing Facilities (SNFs):**
  Studies show 50–80% of the residents in a SNF have dementia.

- **Assisted Living Facilities (ALFs):**
  A study found two-thirds of persons living in ALFs had dementia. *(The Maryland Assisted Living Study, 2004)*

- **Underdiagnosed:**
  Research has shown that only 12–35% of those with dementia/AD/cognitive impairment actually have diagnoses.
Dementia is a chronic condition that poses a major and growing threat to the public’s health.

Improving the effectiveness of care and optimizing patient outcomes will become increasingly important as the population of the US ages.

—Sept 2010 AMA report
Dementia Care Challenges

Impact on the person

Impact on the family

Impact on the staff

Impact on the organization
Dementia Care Problems: A Devastating Negative Cycle

- Staff turnover
- Increased direct and indirect costs
- Low therapy
- Early discharge
- QI; Survey
- Liability

- Dressing total dep. 23.67%
- Eating total dep. 15%
- Transfer dependence 23%

Facility Challenges: Loss of Revenue, etc
- Contractures 28%
- Weight loss
- Falls
- Ulcers

Mental Health Complications
- Depression 51%
- Behaviors 28%
- Psychoactive meds 65%

- ADRD hospitalized three times as often

- Hospitalizations

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Dementia Underlies Dependence and Problems

FUNCTIONAL ABILITY

Potential

MEDICAL & PSYCHOSOCIAL STATUS

Cognition

Physical

Sensory

Mood and Behavior

Cognition is the primary determinant of the highest ability to function. *Functional Cognitive Assessment is essential or “excess disability”*
What Is the Solution?

*Dementia Capable Care (DCC)*
What Is Dementia Capable Care?

Interdisciplinary care designed for those with ADRD to:

- Attain and maintain the highest practicable level of function, safety, and emotional well-being.
- Minimize or prevent deterioration caused by the disease.
- Successfully engage in meaningful activity.

Interventions delivered by Dementia Capable Care partners:

- Heart, passion, patience.
- Specialized skills.
- DCC staff with proactive dementia-trained therapists.

Care delivered within a framework of:

- Aligned philosophy, goals, and frames of reference.
- Infrastructure support.
DCC: Frames of Reference

Cognitive Disabilities Model—Claudia Allen, OT

Person-Centered Care—Thomas Kitwood

Theory of Retrogenesis—Dr. Barry Reisberg
Cognitive Disabilities Model

- **Cognitive Functional Assessment** to identify dementia stage and highest functional potential (BATF).

- Administered and scored by trained therapists.

- Describes *preserved abilities* at each stage.

- Framework to simplify and create “task equivalence.”
Person-Centered Care

Life Story

• Places the person with dementia at the focal point of caring.

• Discover and use individuality.

• Care is driven by choices, needs, and interests.
Theory of Retrogenesis

Used to Educate and Connect to What We Know

• Literally means “back to birth.”

• Hypothesizes that people reverse-develop from Alzheimer’s disease.

• Stages of dementia correlate to developmental age.

• Helps understand functional and behavioral expectations at each stage and approaches to create task equivalence or the “just-right challenge.”
DCC: Process to Discover and Facilitate Potential

1. Comprehensive assessment to identify stage of dementia and corresponding “highest level of function”.

2. Simplify meaningful activities to “just right challenge” level.

3. Use stage specific approaches to encourage participation and use of remaining abilities.
Dementia Stages: A Road Map to Success

- Identifies the person’s highest possible level of function.
- Identifies what approaches to use to facilitate BATF.
- Identifies risks and prevention strategies.
Dementia Stages as Defined in Allen Cognitive Levels (CDM)

- Allen Level 1: End Stage
- Allen Level 2: Late Stage
- Allen Level 3: Middle Stage
- Allen Level 4: Early Stage
- Allen Levels 5 and 6: MCI and “Normal”
Defining Allen Levels and Dementia Stages

Allen Level 1—Automatic Actions (End Stage)
Approximate Dev. Age Comparison = Infant
BATF = Total Cognitive Assist
• Can respond to stimulation with vocalizations, tracking, and partial range of motion.

Allen Level 2—Postural Actions (Late Stage)
Approximate Dev. Age Comparison = 12 to 18 months
BATF = Max Cognitive Assist
• Can sit/stand/walk; make gross motor actions; has a few-word vocabulary.
Defining Allen Levels and Dementia Stages

Allen Level 3—Manual Actions (Middle Stage)
Approx. Dev. Age Comparison = 18 months to 3 years
BATF = Moderate cognitive assist
- Can use hands to manipulate objects; can follow simple directions to be sequenced through activities; can speak in sentences and short phrases.

Allen Level 4—Goal-Directed Activity (Early Stage)
Approx. Dev. Age Comparison = 4 to 10-/12-year-old
BATF = Min cognitive assist to supervision/Independent
- Can sequence self through the steps of a familiar activity; can achieve partial learning/problem solving; verbal skills are good.
Keys to Achieve and Maintain Potential

✓ **Establish task equivalence**: Adapt/simplify the activity to the just-right challenge level.

✓ **Use the appropriate approaches** to match the level.

✓ **Use personal history** information to tap long-term memory and capture interest and attention.

✓ **Modify the environment** to enhance function and safety.
How to Implement?
DCC Key Components

- Let your passion drive you!
- Believe and change our perspective.
- Define your program.
- Proactive therapy.
- Gain buy-in.
- IDT team training.
Key 1 = Perspective

What we see is dependent on the lens we look through.

Things end as they begin.
Key 2 = Define Your Program

✓ Goals and Objectives
  Example: To optimize function, emotional well-being, and safety at every stage of dementia.

✓ Philosophy/ Frames of Reference
  Example: Stage-specific care; focused on the use of remaining abilities and life story; using the CDM and PCC principles.

✓ Role definition—Who will do what, when?

✓ Ongoing training/ support → ROI

✓ Outcomes measurement
Key 3: Proactive Therapy

CMS Program Memorandum Sept 2001
Reference: AB-01-135

A memorandum is a direct communication, correction, or instruction to the Medicare Contractors, who manage the benefits.

• “A Medicare beneficiary cannot be denied therapy services based solely on a diagnosis of dementia.”

• This went out to all A & B contractors. A definite directive that they “may not” edit or deny based on ADRD dx.
Key 3: Proactive Therapy

Medicare Benefit Policy Manual
The manual is a description of the benefits included in the Medicare Policy. CMS Manuals address all Medicare beneficiaries, both A & B.

- Development of a maintenance program is a right of the beneficiary and the manual explains how it can be a covered service.
Key 3: Proactive Therapy

Maintenance programs designed to:

• Prevent or minimize decline or deterioration related to the disease.
• Maximize function.
• Decrease a functional limitation.

OBRA, Nursing Home Reform Act of 1987—

All policy manuals and MDS refinements relate back to OBRA (Public Law 100-203).

“Each facility must provide the necessary care and services to help residents attain the highest practicable physical, mental, and psychosocial well-being.”
Key 3: Proactive Therapy

- **IDT (Implement):**
  - Communicate changes in function or health.
  - Implements Maintenance Program using special approaches.

- **Therapy:**
  - Discovers and facilitates potential.
  - Develops Maintenance Program and educates IDT.

Since 2001: Medicare reimbursed service

Key for sustained outcomes
Key 4: Gain Buy-In

Techniques to Gain Commitment

**Family**
- Offer hope for QOL.

**Staff**
- Demonstrate what’s possible.
- Empower and support with knowledge and skills training.
- Reward learning and commitment.

**Leadership**
- Revenue management (raises census and therapy, and drives costs down).
- Solve problems such as survey issues, staff turnover, QI problems, and hospitalizations.
Key 5: IDT Specialized Training

Set Training up for Success With Discussion:

• **Why?** Benefits for client, facility and **WIIFM.**
• **What?** Describe specific goals, objectives, etc

**How?**

All team trained in basic philosophy and principles:

- Stages—abilities and best ability to function
- Approaches to establish task equivalence
- Communication
- Behavior management and prevention
- Family support

**Tips for Successful ROI:**

- Recognize and reward via clinical laddering
- Learn together = collaborate together
Key 6: Let Your Passion Drive You Through Barriers!

All elders who are Medicare beneficiaries have the right to receive services to:

• Unlock their potential to achieve their highest practicable levels of function and emotional well-being.

• Prevent or minimize deterioration of function and health complications.

Quality of Life Is Possible at Every Dementia Stage!
Key 6: Let Your Passion Drive You Through Barriers!

A young man was seen walking on a beach throwing starfish in the ocean when another man came along and asked,

“What are you doing”?
“Throwing starfish in the ocean”, the boy said.
“Why?” the man asked.
“If I don’t they will die”, said the boy.
“But don’t you realize there are thousands of starfish on the beach. You can’t possibly help them all”, the man said.
The boy replied, “Yes, but I helped that one.”
Dementia Capable Care

Application of DCC to Address Common Challenges
Challenge: “Excess Disability”

EVIDENCE:
“When CNAs allow residents to control more of the eating process, they consume a higher portion of food. . . .”

CNAs trained to tailor their care to the capabilities of the individual resident, resulted in improvements in residents’ dressing independence.

OT has been demonstrated as effective in managing the occupational performances of people with AD.
(Gitlin, Hauck, Dennis, and Winter, 2005; Graff, et al, 2006)
Facility Challenges and Example Outcomes

125-Bed, All-ADRD SNF = Year-One Outcomes

- **Weight loss and supplement use** 3–5%.
- **Activities** = Average of 8–10 per day per resident.
- **Therapy** = 85%+ of all new admits.
- **Staff turnover** = 25–30% with industry average of 100%.
- **Census** full with industry average in area of 75%.
Challenge: Maximize Revenue

Company #1 with same number of patients

Five facilities were tracked over five months after DCS training.

The average number of patients in each facility remained the same. The number of visits increased (LOS) and minutes (units) of each visit increased.

Part B revenue/month increased by 25.5% and continues.
Challenge: Maximize Revenue

Company #2 ROI with increase in number of patients and billable units

This company tracked ten facilities over three months for number of patients, number of billable units and revenue with ADRD before and after DCS training.

The result was a 170% increase in Part B revenue overall, an average of $10,000/bldg. in a three-month period.
Thank you for helping to make life better for those with Alzheimer’s and related dementias.

Questions?

Call: 877-816-4524
“After the initial evaluation of the extent of the disorder, illness, or injury, if the treating qualified professional determines the potential for rehabilitation is insignificant, an appropriate maintenance program may be established prior to discharge.

“Example. The skills of a qualified speech-pathologist may be covered to develop a maintenance program for a patient with multiple sclerosis, for services intended to prevent or minimize deterioration in communication ability caused by the medical condition.”
“Skilled therapy may be needed, and improvement in a patient’s condition may occur, even where a chronic or terminal condition exists. . . .

“In the case of a progressive degenerative disease, for example, services may be intermittently necessary to determine the need for assistive equipment and to establish a program to maximize function.”
“Rehabilitative therapy occurs when the skills of a therapist . . . are necessary to safely and effectively furnish a recognized therapy service whose goal is improvement of an impairment or functional limitation.”

“During the last visits for rehabilitation treatment, the clinician may develop a maintenance program. The goals would be, for example, to maintain functional status or to prevent decline in function.”
ADRD Impact on Business—Loss of Revenue

Hospitalizations
due to falls (often facilitated by weakness, psychotropic drugs, unsupervised walking or wandering, etc.), weight loss, pneumonia, and other infections.

Study:
“Residents with dementia remained in a facility 209 fewer days at the median than residents without dementia. After adjustment for other variables, lack of treatment for dementia was the primary reason.”
Source: Journal of the American Geriatric Society, 2007

People with Alzheimer’s disease and other dementias have more than three times as many hospital stays as other older people.
Source: 2009 Alzheimer’s Disease Facts and Figures
ADRD Impact on Business—Loss of Revenue

Premature discharge to a SNF from an ALF

**Study:**
Primarily due to increasing care needs, most residents in the specialized AL relocated to a nursing home after a median stay of 10.9 months. Depression, falling, and wandering were significant predictors to the transition.


**Experiential:**
Care is often very reactive, as we often rely on a person’s self-report of abilities before providing care.
Both functional impairment and patient dependence are associated with higher costs of care and caregiving time.

A one-point increase in Dependent Scale was associated with a:
- $1,832 increase in total cost.
- $1,690 increase in informal cost.
- 5.7% increase in medical cost, a 10.5% increase in nonmedical cost, and a 4.1% increase in caregiving time.

A one-point increase in Blessed Dementia Rating Scale was associated with a:
- $3,333 increase in total cost.
- $1,406 increase in direct medical cost.
- 7.6% increase in medical cost, a 3.9% increase in nonmedical cost, and an 8.7% increase in caregiving time.
Challenges and Problems—Study Shows:

“Residents with dementia remained in a facility 209 fewer days at the median than residents without dementia.

“After adjustment for other variables, lack of treatment for dementia was the primary reason.”

Source: *Journal of the American Geriatrics Society*, 2007
Premature discharge from an ALF to a SNF

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“Depression, falling, and wandering were significant predictors to the transition.”