Strategies for Caregivers with Loved Ones Living with Dementia

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Prelude: Our Expectations.

What is the Norm?
Here we all are.

Ask Yourself:

How did that happen?

What implications does it have?
Complex Abilities

To show up in this room, at this time:

✓ Judgment
✓ Reason
✓ Planning
✓ Organization
✓ decision-making
✓ Memory
✓ abstract thought (time)

To take part in the session:

✓ Reasoning
✓ Language
✓ Attention
✓ judgment
✓ Sophisticated social/behavioral skills
Our unimpaired brain provides the deep structures for:

- our functioning in the world
- our social contract and
- our social interactions

- And we seldom, if ever, think about this;
- it’s a given in our lives
Alzheimer’s Changes Everything

Someone caring for a person with Alzheimer’s or another dementia cannot rely on those deep structures

A Dis-Integration is Taking Place
Objectives

- Appreciate differences between normal aging and dementing disorders
- Acknowledge that caregiving is a role for which few have received training; it affects the caregiver
- Understand the impact of dementing disorders on thinking, emotions and behaviors, and everyday performance
- Recognize ways in which a “clinical outlook” can produce Savvy strategies for providing care for persons with dementia
A Few Facts
Normal Aging and Dementia

- Losing keys; misplacing glasses; forgetting names
- Serious errors in familiar tasks
- Unusual behavior in unfamiliar situations
- Serious misjudgments
- Persistent short-term memory problems
- Not recognizing familiar people
Definition of Dementia

Dementia is a condition of global deterioration of memory and cognition that impairs thought and social functioning.

Problem with memory and one or more cognitive domains
5.2 Million Americans with Dementing Diseases

All Are Disease Conditions that Affect the Brain and What it Does

- Alzheimer’s Disease
- Vascular Dementia/Multi-Infarct Dementia
- Frontal Lobe Dementias

Key Points:
- Progressive and Irreversible
- Not Personality Disorders (i.e., on purpose)
- Dementia a syndrome, not a specific disease
Facts about Dementing Diseases

- Age-associated
- Generally of long duration
- Generally community-living until end stages

- Not Equally Distributed
  - More women than men (survival)
  - Higher rates among African Americans and Hispanics
The Course of Dementing Disease

Early Stages

Community-based Care

Late Stage -- Institutional Care

Years

0  3  6  9  12

Years
Caregiving

- Most care provided by families, usually by one caregiver; almost always a woman
- Family caregiving lasts a long time
- Caregivers pay a toll for what they do:
  - Physical and Emotional Health
  - Immune Function
  - Sleep Disruption and Deprivation
  - Social and Economic Impact
The Feeling Quadrants

- Powerful
- Negative
- Powerless
- Positive
Typical Caregiver Emotional Profile

Powerful

Powerless

Negative

Positive

angry

successful

frustrated

sad

overwhelmed

devastated

hopeless
What Kinds of Things Do You Do?
Caregiving: The Unacknowledged Role

✓ Nurse
✓ Social Worker
✓ Activity Planner and Coordinator
✓ Financial and Legal Affairs Manager
✓ Personal Care Attendant
✓ Security Specialist
✓ Driver
✓ Cook
✓ Launderer
✓ Etc.
The Savvy Caregiver Program: A Training Program for Caregivers

- The relationship provides the motive

  BUT

- This is a role – a clinical “job” – for which few are likely to have had relevant prior training
The Savvy Caregiver: Street-Smart

A Sleuth
A Scientist
A Clinician
The Savvy Caregiver Model

Acquire Knowledge about impact of the disease

Develop and Use a “clinical perspective”

Apply to Behavior

Something Happens → Step Back

What am I seeing of the disease at work?

Form a Strategy: how use skills & knowledge to make The situation better?

Implement; Succeed/Fail Evaluate; Redesign/Repeat
Recognizing and Compensating for Disease-Produced Losses

- Thinking
- Emotion
- Behavior
- Performance
The Impact of Dementia on Thinking

Consider Some Key Attributes of Thinking:

- ✓ Reasoning
- ✓ Memory
- ✓ Judgment
- ✓ Organization
- ✓ Language
- ✓ Perception
- ✓ Abstraction
- ✓ Attention
# Dementia Erodes Thinking Powers

<table>
<thead>
<tr>
<th>Reasoning</th>
<th>Memory</th>
</tr>
</thead>
<tbody>
<tr>
<td>✓ Can’t negotiate</td>
<td>✓ Retrograde amnesia</td>
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<table>
<thead>
<tr>
<th>Language</th>
<th>Judgment</th>
</tr>
</thead>
<tbody>
<tr>
<td>✓ Can’t find words</td>
<td>✓ can’t see consequences</td>
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</table>
Dementia Erodes Thinking Powers

Abstraction
- Concrete thought

Attention
- Distractible

Organization
- Can’t self-direct

Perception
- Easily Confused
# Caregiving Strategies: Anticipation and Puzzle-Solving

<table>
<thead>
<tr>
<th>Memory</th>
<th>Judgment</th>
</tr>
</thead>
<tbody>
<tr>
<td>✓ Don’t test – don’t try to cure</td>
<td>✓ Don’t count on it</td>
</tr>
<tr>
<td>✓ Use long-term memory</td>
<td>✓ Be pre-emptive (driving)</td>
</tr>
<tr>
<td>✓ Expect Disinhibition – forgets manners</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Reasoning</th>
<th>Attention</th>
</tr>
</thead>
<tbody>
<tr>
<td>✓ Don’t argue: Direct</td>
<td>✓ Redirect</td>
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</table>
Caregiving Strategies: Anticipation and Puzzle-Solving

Perception
- Look for clues

Abstraction
- Don’t deal in time: next week is NOW
- Fathers and sons are the same

Language
- Supply words
- Simplify speech

Organization
- Progressively provide structure
Practical Examples of Strategies to Deal with Disease-Produced Losses in Thinking
Consider the Following Sentences

- “We’re going to your brother’s for dinner on Thursday.”
  [Abstraction]

- “If we can have hamburger tonight, I won’t have to go to the store till the weekend.”
  [Reason, Abstraction and Language]

- “I’ll leave your lunch in the tupperware in the frig; eat at noon.”
  [Memory and Organization]

- “Take the medicine 3 times a day for the next 10 days.”
  [Memory, Organization, Judgment, Attention]
Make the Savvy Caregiver Shift

- Wait till Thursday pm to talk about dinner at the brother’s house.
  ➔ [Concrete]

- “We’re having hamburger tonight.”
  ➔ [Directive -- not Reasoned]

- Leave written note about lunch (plus reminder call)
  ➔ [Reminders by YOU]

- Set up the meds and remind -- or administer them
  ➔ [no expectation -- Take Control]
Conversations with Dementia

- “No one’s ever won an argument with Alzheimer’s”
- Deal with the emotional truth of the situation
A Simple Model of Normal Behavior

- Person
- Others
- Surroundings
- Behavior
How Progressive Decline in Dementia Affects Behavior

- Person
  - Others
  - Surroundings
  - Behavior

- Others ↔ Surroundings
- Behavior

- Person
  - Others
  - Surroundings
  - Behavior

- Others ↔ Surroundings
- Behavior
Progressively Lowered Stress Threshold in Dementia

- Potential Catastrophic Reactions From Overstimulation
- Potential for Withdrawal from Understimulation

Ability to Handle Multiple Tasks and Various Stresses

- High
- Med.
- Low

Stage of Dementia

- Normal
- Early
- Early-Middle
- Late-Middle
- Late

Comfort Zone
The Impact of Dementia on Emotions and Behavior

☐ All Behavior Has Meaning
   ✓ Look for what went before what you saw

☐ The Universe is Closing in

☐ Progressively Lowered Stress Threshold
Caregiving Strategies: Taking Control and Promoting Calm and Security

- If you’re in a blizzard, it’s often best to get off the freeway.

- The Caregiver is “It”
  - S/he provides the safety net
  - Control = Kindness
A Modest Goal for Caregiving: Contented Involvement

Contented Involvement

Under-stimulation

Distress

Withdrawal

Distress

Catastrophic Reaction

Over-stimulation
Performance

A Puzzle
The Impact of Dementia on Performance – Doing Things Every Day

- Key Elements of Performance:
  - Purpose
  - Order
  - Use

The Key Elements are lost in overlapping progressive order in dementia.
Caregiving Strategies: Fit, Promoting Pleasant Involvement, and Settling for Less

- **Fit: Link Activity to Ability**

- **Three Anchors of Pleasant Involvement:**
  - Person
  - Structure
  - Support

- **Create a Routine and Forgive Yourself, in Advance, for not Sticking to it.**
Summary

- You weren’t born knowing how to be a dementia family caregiver
- Mantra: Don’t just do something; stand there.
- Caregiving strategies: intentional responses to disease-produced losses
- Caregiving goal: pleasant days
- Care for the instrument!