



Evidenced Based Approaches to Dementia Care in Persons with Intellectual Disability

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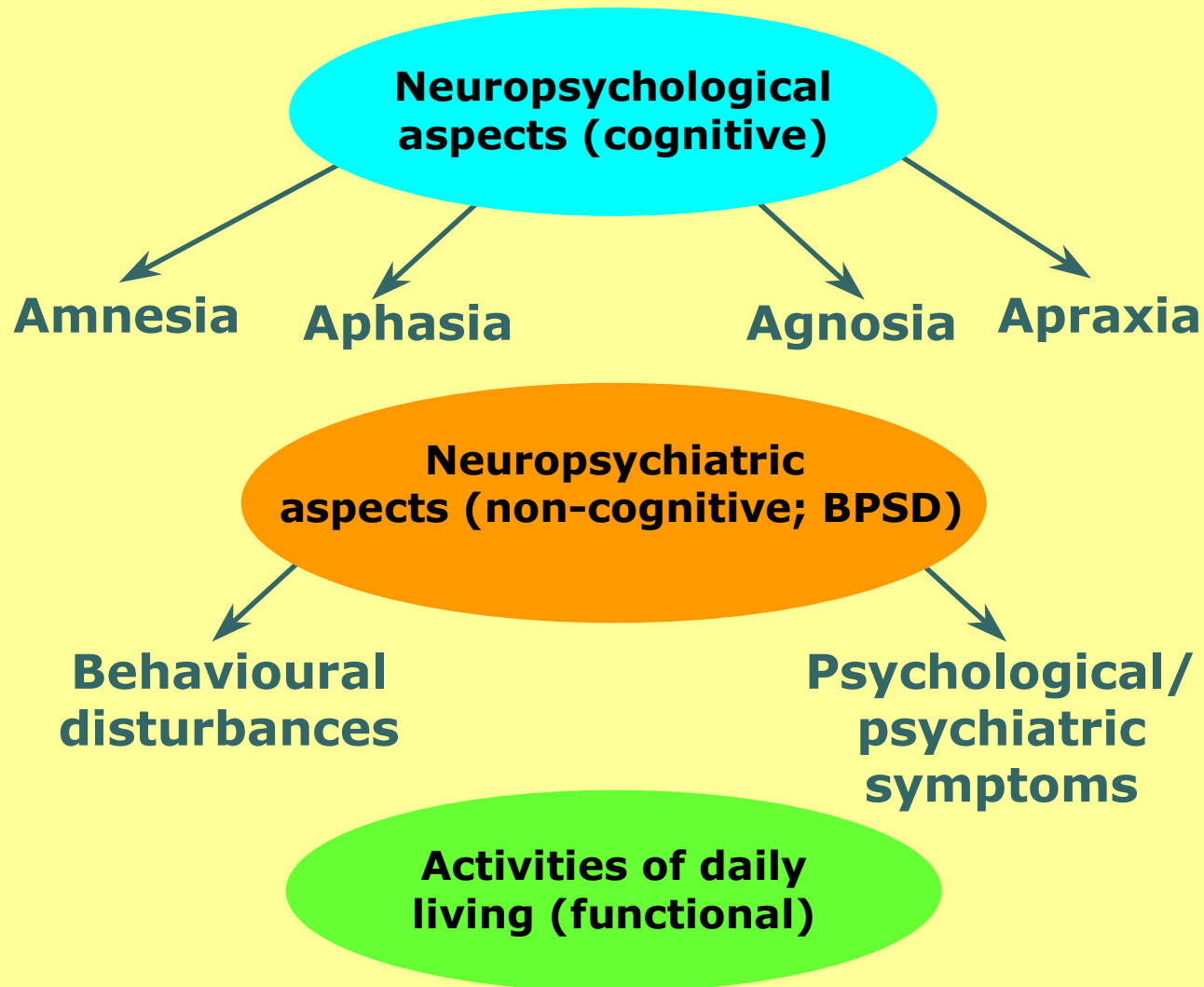
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Dementia Dimensions



Alzheimer's Dementia: Some Commons Behaviors that Challenge

- Screaming/crying
- Verbal aggression
- Physical aggression
- Wandering
- Outbursts of temper
- Non-compliance/resistance to care
- Over-activity
- Eating inedible objects





Context of Behaviors in Dementia

Most disruptive behaviours exhibited by people with dementia are understandable in the context of the cognitive difficulties experienced by the person.

- Disorientation in time and place
- Dis-inhibition –particularly common if frontal lobes are affected and results in inappropriate behaviour
- Agnosia-failure to recognise



Context of Behaviors in Dementia

- Pacing and wandering behaviours in dementia are not all bad, and in fact most may be adaptive in that they provide exercise and physical stimulation.
- The aim is to try and accommodate these behaviors rather than limit them.
- The goal should be the provision of a safe level of wandering without putting people at risk of injury

Cohen-Mansfield et al 1997



Agitation and Dementia

- 'Agitation describes excessive motor activity with a feeling of inner tension and is characterized by a cluster of related symptoms including anxiety and irritability, motor restlessness and abnormal vocalizations.
- Behaviors are often associated with pacing, wandering, aggression, shouting and night time disturbance'

(Howard et al 2001)



Some Causes of Agitation or Restlessness in Dementia

- Boredom
- Frustration
- Isolation
- Over-stimulation
- Depression
- Physical discomfort or pain
- Side-effects to medication
- Delirium



First Steps in Effective Intervention



Know the Person

- Previous personality
- Previous lifestyle
- Previous social role
- Life experiences
- Likes and dislikes



...View behavior as an
attempt to communicate,...



Find the Memory

- As people with dementia review the past more and more, they may also revisit past conflicts and problems that can cause agitation
- Listen for familiar names and events, ask simple questions that encourage and assist the person with dementia to explain what is upsetting



Inventory Favorite Things

Music

Walking

Going to church

Having time alone

Massage

Trips/Outings



Principles of Good Care



Principles of Good Care

- Recognize the individuality of the person
- Respect privacy, independence, confidentiality and dignity
- Find ways to empower individuals to discuss concerns about their care
- Involve the person in life and activity at whatever level they are capable, even if only through eye contact, smiling and touch



Principles of Good Care

Realize that *You* do the adapting

Accept that *You* must enter the person's reality
and not drag them into yours

Respect that each person is unique and
individual

Understand there is *no* simple recipe book,
problem solve step by step-*be flexible*



Principles of Good Care

- Success in care giving is measured in terms of *confrontations avoided* as opposed to the number of tasks accomplished
- *Happiness* and optimal participation by the person in activities *they* value are the important outcomes of care



-First Steps in Effective
Intervention

- Principles of Good Care

Challenges and Opportunities in Your Own
Agency

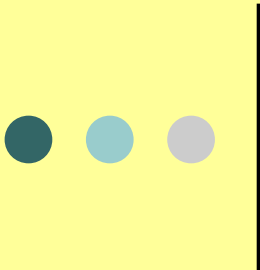
Who to engage?

How to engage?

Barriers to engagement?



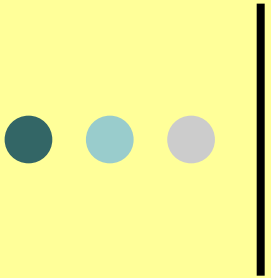
Failure-Free Approaches to
Day to Day Care



Highly Rated Approaches to Day-to-Day Care

Bathing

- EXPLAIN
- VISUAL CLUES, such as hand motions to show the person what you would like them to do.
- TOUCHING the person in a forceful way may result in more resistive, agitated behavior
- Facilitate the person doing as much of the bathing him/herself as possible, even if this only means using a cloth to wash their face.



Highly Rated Approaches to Day-to-Day Care

Dressing

- OFFER limited range of choices
- Use TOUCH cautiously – feeling forced will increase resistance
- Use PRAISE, in an adult tone of voice

Toileting

- Adaptive devices.... Easy Access
- Avoid negative or tense responses to toileting accidents as they will increase the person's frustration.

Highly Rated Approaches to Day-to-Day Care

Eating

- Keep mealtimes pleasant, relaxed, not rushed
- Remove unsafe objects such as sharp knives from open and accessible areas
- Simplify the table

Losing or hiding things

- Use praise and smiling to reinforce positive behaviors

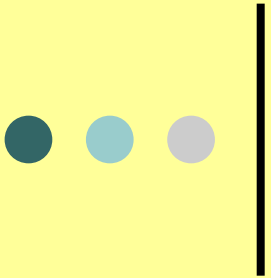




Relaxing Music and Agitation During Meals

- **Relaxing music:** music with a slow tempo; slow, irregular and unpredictable rhythm; no sound impulses; linear melody; with a certain degree of homogeneous monotony and no variation in intensity (New Age).
- 30 nursing home subjects, moderate to severe dementia, quasi-experimental design
- Reductions in wandering, pacing, restlessness, repetition, complaining and requests for attention. No impact on aggressive behaviors.

(Goddaer & Abraham, 1994)



Highly Rated Approaches to Day-to-Day Care

Repeated Action or Behaviors

- If the person needs to manipulate objects with his/her hands, find a useful activity using the same motion - folding clothes.

Loss of interest in activities

- Simplify activities that the person has done previously to maintain interest and offer opportunities for success

(Burgener et al., 1999)



Wandering/Screaming/Sleep



Wandering

The term wandering is used to describe patterns of behaviour including pacing, leaving the building, trying doorknobs, entering into other people's rooms.



Wandering Behavior

- Exit-seeking wandering: characteristic of mid-stage dementia; wandering is a highly motivated, goal directed behavior
 - elopers: perceive themselves as visitors and leave to accomplish responsibilities (go to work) and will often tell staff they are leaving
 - runaways: worriers (someone needs me), feel prevented from leaving and will sneak out or bolt.
- Self-stimulatory and restless pacers: do not have a desire to leave and only exit home accidentally.

(Lucerno, 2002)



Exit Seeking Wandering

- Residential life routinely provides 4-5 opportunities for exiting:
 - after each meal: end of meal is a prompt to begin a new activity including leaving the building
 - at shift change: staff putting on coats and leaving is a prompt for the person to leave
- Strategies
 - Purposeful activities for the person after each meal
 - Distracting change of shift activities



Masking Doors





Dementia – Home Design

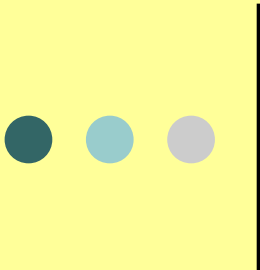


Wandering

- Backyard enclosed
- Wandering paths defined by brickwork
- Benches conveniently placed for resting or sitting
- Courtesy: Helping Our Mobile Elderly, Venice, CA

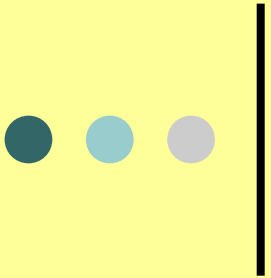
Creating Pleasant Places – Accessible Gardens





A Walking Program for Persons who Wander

- The Walking Program: Lay volunteer-led; occurring after main meal; in and outside depending upon weather; 1 1/2 Hours duration including rest stops; Singing, talking and holding hands strong components
- 11 subjects with dementia and disruptive wandering behaviors in quasi-experimental design
- 30% reduction in aggressive incidents
(Holmberg, 1997).



Screaming

- **When and where does it occur?**

- More likely in the evening and on the weekend
- More likely during ADL activities
- More likely when the person is alone
- More often in the bathroom and in the person's own room
- Generally not directed at any person

Based upon a systematic study of 408 nursing home residents with dementia of whom 25% screamed at least 4 times per week. (Cohen-Mansfield et al., 1990)



Screaming - Intervention

○ **Potential Issues**

- depression
- physical discomfort/pain
- Response to stimuli
- Limited access to valued activities/people

○ **Responses**

- Assessment of physical condition
- Music
- Differential reinforcement
- Touch/massage/aromatherapy
- Space to wander



Sleep Disturbance

o **Issues**

- Normal aging related change
- Decreased day time activity
- Depression
- Restless leg syndrome
- Sleep apnea
- Changed patterns and sense of time associated with dementia (Sundowning)



Sleep Disturbance - Intervention

- Physical assessment
- Increased day time activities
- Overnight activities/places to go
- Monitoring of caffeine, eating, drinking patterns
- Addressing toileting/incontinence concerns
- Light therapy
- Day and night clues
- Massage
- Decreased night time interruptions



Challenging Behaviours That Disrupt Quality of Life and/or Pose Safety and Health Risks

Physical aggression

Injury to self or others

Refusal of needed care/treatment

Behaviors that Challenge in Dementia: Possible Functions

I'm confused-What is happening?

I need help, I don't understand

Ask me nicely

I am frightened

I'm tired

I'm hungry

I want to go to my work

Its very noisy in here

I cant explain what I want

I want to be alone

I'm unwell

I am in pain

No!

Don't say wait

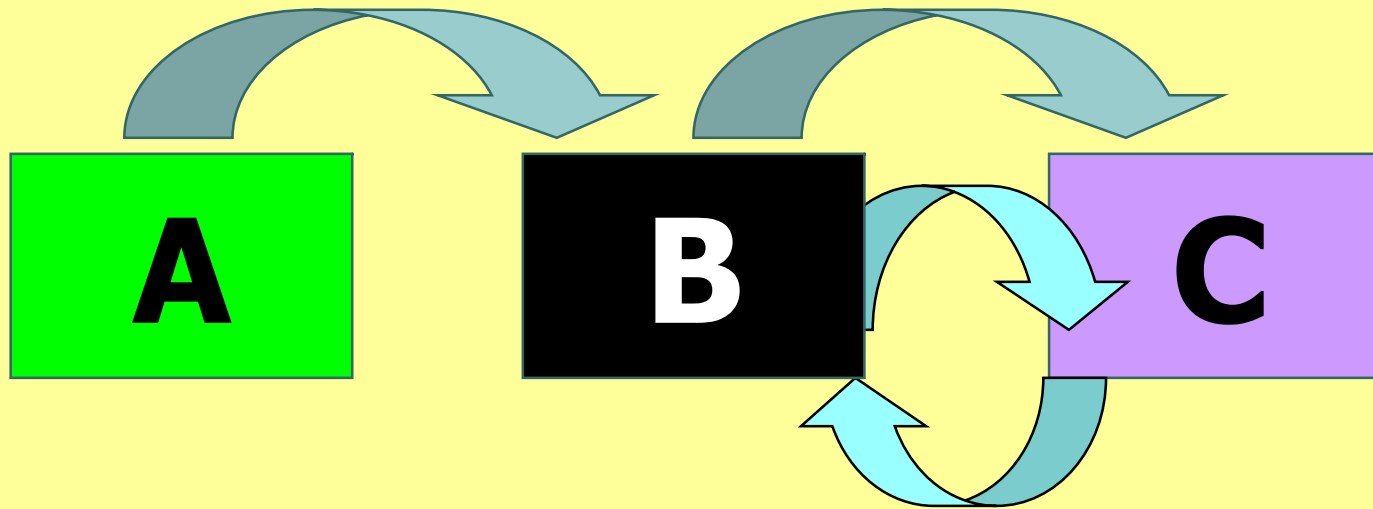
I want to go home

I am looking for something?

● ● ● | A-B-C Approach to Problem Solving

Problem Behaviours Occur in Three Parts

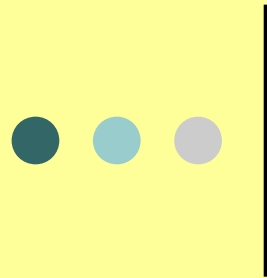
- Antecedent = A triggering event.
- Behavior = The behavior itself.
- Consequence = The response to the behavior.





A-B-Cs: Simple but Tricky

- Behaviors are part of a web, not a linear chain
- The function of the behaviour can be more important than the form
- Focus on specific, observable, measurable
- Observation is critical and challenging
- Creative brainstorming is not easy
- The caregiver is always right
- In dementia will a focus on consequences work?



Antecedent Analysis

Purpose of the antecedent analysis

- Internal antecedents

- General health?
- Sleeping pattern?
- Seizure activity?
- Medication?



Antecedent Analysis (cont)

- External antecedents
 - WHERE is the behavior MORE or LESS likely to occur?
 - With WHOM is the behavior MORE or LESS likely to occur?
 - WHEN is the behavior MORE or LESS likely to occur?
 - What occurs immediately before the behavior?



Antecedent Control

- Remove triggers
- Reduce conditions in which behavior is more likely
- Increase conditions in which behavior is less likely
- Remove seductive or dangerous objects
- Remove unnecessary demands
- Eliminate provocative statements (“no”, “wait”)
- Interrupt the behavior in response to precursors
- Environmental considerations



Interventions with an
Evidence Base



Evidence-based Interventions to Improve Quality of Life

Communication Approaches

Validation

Reminiscence

Leisure

Music

Aromatherapy

Snoezelen

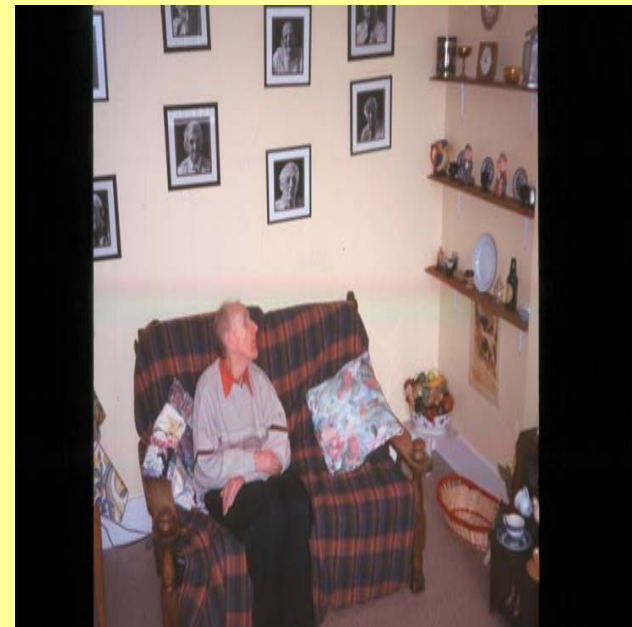


Principles Underlying Communication with Persons with Dementia

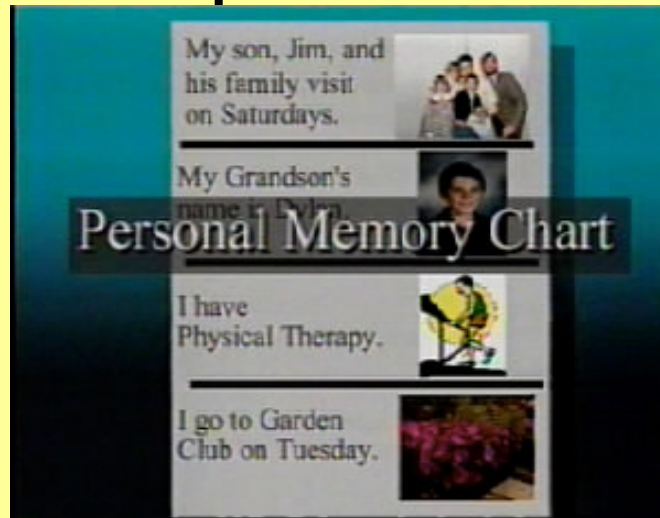
- Each individual experiences dementia differently
- There are reasons for behavior
- Compensate by using remaining abilities
- Understanding and empathy are key
- Understand communication styles
- Tailored to meet needs and preferences
- Effected by sensory changes

Preserving and Building on Memories

- Types of Memory AID
 - 1. Strategic labeling
 - 2. Personal Memory Albums
 - 3. Memory Charts
 - 4. Memory Audiotapes
 - 5. Memory Rooms



Memory Aids





Research Evidence

- In controlled studies,
 - reduction in symptoms of depression, physically and verbally aggressive behaviors, wandering/pacing, and irritability for persons with AD
 - reduced staff turnover

(McCallion, et al., 1999a&b)

Manual: Toseland, R. & McCallion, P. (1997).
Maintaining Communication. NY: Springer



Leisure: Personalizing Care

- People with dementia retain the capacity to enjoy life
- Allocate short time periods each day for leisure and recreation
- Recognise and agree as a care team that this is an essential component for holistic client care and well-being.
- Try to ensure that there are minimal disruptions during this period
- Devise a 'menu' of leisure and entertainment options for your client
- Allow the person to set their own pace and style of participation
- Record the range of life enhancing activities clients engaged in and or/were exposed to and what works and doesn't work as an activity.



Research Evidence

- Anecdotal and single subject evidence for reduction in sleep disturbance and increase in interactions.

- Website

<http://www.hort.vt.edu/human/ther-res.html>



● ● ● | Snoozelen

Snoezelen Therapy- **‘sniffing and doozing’**

AIM: Pleasurable sensory experiences arranged to stimulate the primary senses without the need for intellectual activity in an atmosphere of trust and relaxation. It is also a failure free approach-with no pressure to achieve (Hutchinson & Kewin 1994).





Snoozelen

- Snoezelen environments aim to maximise the senses
- Snoezelen increases the amount of sensory stimulation by using lava and fibre optic lamps to provide changing visual stimulation, pleasant aromas, gentle music, and various materials of interesting textures to touch and feel.





Research Evidence

- Controlled study evidence for reductions in socially disturbed behaviors and increase in communication.

(Baker et al., 1997)

- Website

<http://www.codi-com.com/>

<http://www.activitytherapy.com>

Other Psychosocial Interventions

- -Pet Therapy
- -Rocking Chair Therapy
- -Behavior Modification
- -Complementary Medicine/Therapy Approaches

<http://www.dementiasolutions.com/EDGE.htm>

- The Electronic Dementia Guide for Excellence

www.albany.edu/aging

