



ASSESSING and PLANNING for CARE and COMPANIONSHIP

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Goal of Highest Quality Home Care (what clients expect of you)

- To enable the person (1) to continue to live for as long as possible (2) in his/her preferred home (3) with as high a level of quality of life as is possible
- (4) by creating an environment that provides:
 - Personal and/or home care
 - Enjoyment/pleasure/companionship
 - Safety

How can you accomplish this goal?

- By having...
 - the needed **FACTS**
 - the most effective **SKILLS**
 - the best **ATTITUDES**

What every in-home care provider needs:

- **Facts:** Assessment of mental status is key to good care –
 - Dementia, Delirium, Depression, Behaviors
 - Client's life story – baseline
- **Skills:** Assessment techniques and tools
- **Attitudes** for caring and effective interaction:
 - Communicating with compassion
 - Handling difficult behavior
 - Creating FUN and functionally appropriate activities

WHY do you need these facts, skills and attitudes?

- Statistics show – a majority of persons receiving in-home care have some form of dementia (and associated depression, delirium, and psycho-behavioral problems).
- Dementia creates an unpredictable distortion of reality for the client and those trying to help. Without the right knowledge, attitude, and skills, most are not prepared to enter and manage this reality.

Why...

- You need to avoid **surprises**:
 - Families often don't realize the extent of disability the elder has due to dementia OR they minimize because they want to avoid institutionalization—or they think you won't take the case. The client is often unaware of or in denial of cognitive and functional disabilities. Also....
 - There is a huge difference between caring for a frail elder and a cognitively impaired person.

Why...

- Planning for **effective care** and **communication** requires knowledge of:
 - quality of health and physical functioning
 - quality of mental functioning and presence of dementia, delirium, and/or depression
 - client's baseline – life history and interests

(Similar to Minimum Data Set in nursing homes.)

Why...

- With this knowledge a caregiver is better equipped to develop more meaningful and appropriate **activities** – to create an interesting, stimulating day!
- Good care leads to **positive relationships** with client, client's family and support system.

MY STORY:

Risks of Naivete and Ignorance

- First work with older adults – case manager – Southwest Boston Senior Services
- First clients: Mrs. and Miss Whyllie
- Outcome: Close call – jail????
- Lesson Learned: Know your clients and what you're getting into!
- After 32 years of experience with elders and their caregivers...

Definitions

- Here are terms and definitions you need to know to assess, plan, and care for elders.

DEMENTIA

Dementia is a non-curable, progressive loss of brain function due to disease which affects:

- Long- and short-term memory
- Thinking, reasoning, problem-solving
- Ability to use and understand language
- Ability to plan and organize
- Ability to carry out motor activities despite intact motor functioning
- Emotions
- Personality
- Behavior

Types of Dementia

- Approximately 137 diseases can cause dementia! Most common are:
 - Alzheimer's Disease
 - Vascular Dementia
 - Lewy Body Disease
 - Pick's Disease
 - Frontal Lobe Dementia
 - Dementia of Parkinson's Disease
 - Also: dementia due to HIV, Creutzfeldt-Jakob Disease, Huntington's, Head trauma, substance use

Demographics

47.9% of persons 85+ are affected by dementia.

Each dementia has a particular pattern of presentation.

Over 1/2 of patients with dementia may have a behavioral problem.

AD can last from 2 to 20 years. 10-12 is average duration.

Assessment of Dementia

- **Informal:** Observation of ability to remember, think, and perform daily functions.
- **Simple questions:** e.g. breakfast
- **Formal (demonstration)**
 - Activities of Daily Living: Unique, IADL, ADL
 - CAPE – Caregivers' Assessment (handout)
 - Folstein Mini Mental Status Examination
 - Clock Drawing
 - Mini-Cog:
 - 3-Word Recall
 - Clock Drawing

DELIRIUM

Disturbance of mental status not caused by dementia
occurs over a short period of time – hours to days.

Due to: change in a medical condition (e.g. infection, constipation) substance or medication use or withdrawal, toxin exposure, alcohol.

Characteristics: agitation, inability to focus or sustain attention, OR drowsiness, lethargy; impairment of memory, reasoning and thinking, change in sleep-wakefulness pattern

CAN occur in presence or absence of dementia.

ANY infection can cause delirium: e.g. colds, flu, urinary tract infection.

ALWAYS a medical emergency – can be fatal in a short time!

CURABLE!!!!

Assessment of Delirium

- **OFTEN** overlooked, ignored.
- Observation is key:
 - Is the person less active or responsive than usual?
 - Is the person more 'hyper' and unable to focus attention than usual?
 - Is there any abrupt difference from usual mental state – mood, behavior, thinking/memory?
 - Has this change occurred within the past few days or hours?
 - Have there been any changes – i.e. medications, appetite, urinary incontinence, health (colds, pain, etc.)?

What to do...**REPORT ASAP!**

- Delirium is a medical emergency – medical care is needed as soon as possible.
- Notify contact person and agency.

DEPRESSION

25% of patients with dementia have depression

Not all with depression have dementia

Common symptoms: self-neglect, refusal to eat, lack of motivation, apathy

DSM-IV-TR:

Five (5) or more of following symptoms, lasting two or more weeks, change from previous functioning. At least one of symptom is:
depressed mood
loss of interest or pleasure

Symptoms of Depression

5 or more—every day or nearly every day

- Depressed mood most of day
- Diminished interest and pleasure in all or almost all activities
- Decreased OR increased appetite/ weight loss or gain
- Insomnia or hypersomnia
- Motor agitation or retardation
- Fatigue, loss of energy
- Diminished ability to think, concentrate, indecisiveness
- Feelings of worthlessness or guilt
- Recurrent thoughts of death, suicide thoughts or plan

Causes of Depression

- Chronic stress over long time
- Unexplained change in brain chemistry/heredity
- Dementia
- General medical illnesses
- Pain
- Medication
- Loss of any kind
- Hopelessness
- Helplessness
- Boredom/lack of stimulation

WARNING!!!!

- Depression can occur all by itself.
- Sometimes, the symptoms of depression look like the person has DEMENTIA.
- When this happens the person may be treated inappropriately for dementia instead of for depression!

Assessment of Depression

- **Formal:** Geriatric Depression Scale (handout)
- **Informal:**
 - Observation – low mood, other symptoms for two or more weeks
 - Test: Draw a line, number from 1 to 10.
 - Ask: Think about the time when you were most unhappy—this is #1. Think about when you were happiest—this is #10. Where are you on this scale right now?

1 2 3 4 5 6 7 8 9 10

Other Related Mental Status Problems

- **Anxiety:** worry, restlessness, irritability, phobias (irrational fears)
- **Delusions:** untrue beliefs about someone or thing
- **Hallucinations:** visual, auditory, sensory
- **Paranoia:** general distrust and suspiciousness of others—belief that others will harm, exploit, deceive them

Dementia, Depression, Delirium, Paranoia Often Cause **Behavior Problems**

- Diseases of the brain can cause both chemical and biological changes in the brain.
- Whenever the brain is damaged, both short and long term memory, the ability to think and reason, emotions, functional ability and movement may be disturbed.
- The result is often maladaptive or inappropriate behaviors which cause problems for BOTH the patient and caregiver.

BEHAVIORAL PROBLEMS

Behavioral problems are one of the major barriers to successful home care!

Effective caregivers develop skills to manage them.

Types of Behavioral Problems

- Agitation – restlessness, rummaging, ‘sundowning’ and “catastrophic” behavior
- Wandering, pacing
- Resisting personal care, including refusal to bathe, dress, eat, walk, etc.
- Verbal behavior – insults, anger, arguing, cursing, moaning/crying, screaming, yelling, ‘firing’ the caregiver

Behavioral Problems (cont'd)

- Physical aggression – hitting, grabbing, fighting, biting
- Inappropriate sexual behavior – undressing/exposing, masturbation, grabbing breasts or buttocks of caregiver
- Sleep disturbances – wakefulness, sleepiness
- Emotional changes – depression/sadness, withdrawal of interest, crying, hopelessness
- Hallucinations, delusions, paranoia

Effect on Caregivers and Clients

- Caregivers – informal and professional:
 - Fear – impulse to protect self or withdraw, neglect
 - Feelings of being overwhelmed, personally attacked, insulted
 - Frustration – burnout, quitting
 - Anger – increased incidence of abuse: psychological and physical
- Patients
 - Increased falls and injuries
 - Social isolation
 - Increased use of chemical and physical restraints

Caution!

- The #1 mistake inexperienced caregivers make when responding to problem behaviors is to take the behavior personally.
- The first lesson to learn is to **NOT** interpret behavior as an affront to self!!!!

What to do????

Effective COMMUNICATION SKILLS are the KEY to managing problem behaviors.

Management of Problem Behaviors – Communication

- Humans have two basic ways of knowing reality and communicating about reality:
 1. Objective knowing/communicating
 2. Relational knowing/communicating

Objective Communication

- Most common way
- Begins after language develops
- Use decreases as dementia progresses until lost – person cannot understand words
- Highly dependent on words, facts
- May ignore, dis-value feelings
- Rational, logical, linear, left-brained
- Concerned with cause + effect
- Necessary for life in everyday society
- Can cause behavioral problems for persons with dementia – cuts off relationship

Example

- **Client:** I want to go home, take me home, take me home!!!!
- **Caregiver:** This is your home. You have lived here for 55 years. Your husband built this home. You brought up your children here. See...this letter has your name and this address where you live. ('reality orientation')
- **Common Response:** no! No! NO! Take me home. This isn't my home. I've got to go home! (escalation of distress)

Relational Communication

- Begins before language
- Use increases as dementia progresses – person understands non-verbal messages longer
- Basis of one's sense of 'self'
- Connectional
- Right-brained
- Direct, wordless
- Draws on feeling, intuition
- Not concerned with facts
- Uses symbols
- Uses non-verbal ways to communicate –
 - Tone of voice and body language very important
 - Communication continues

KINDNESS IS KEY

People with dementia are particularly sensitive to caregivers' tone of voice and nonverbal indicators of stress and tension.

Practice calming yourself and learning to create a 'kind voice' – slower, lower, smiling

Example

- **Client:** I want to go home. Take me home. Take me home!!!
- **Caregiver:** You want to go home? Tell me about your home. What is it like? Is it pretty? Is it big? Who else lives at home with you? (validation method)
- **Common Response:** I love my home. It is pretty. It is yellow and has a big garden. My mother has roses in the front. We all live there.



Communication – Client

- In dementia, language and reasoning are limited.
- **Any** behavior may represent an attempt to express feelings or needs.
- Nonverbal behavior may ultimately become the primary means of communication for both.



Helpful responses
to problem behaviors...

Wandering

- Redirect focus – “Come with me—let’s go see what the birds are doing!”
- Reduce external stimulation.
- Provide meaningful objects that client is able to recognize or take comfort in.
- Give tasks suitable to the client’s mental capacity.

Agitation

- Look for pain
- Check for any infection
- Decrease overstimulation
- Simplify tasks – one step at a time
- Caregiver creates inner calm so that the client may mirror that (nonverbal communication)

Agitation (cont'd)

- Toilet at regular intervals
- Check all medications, especially side effects of antipsychotics
- Respond quickly to avoid catastrophic reaction – extreme agitation

Verbal/Physical Aggression

- Is the person a danger to himself, caregiver, or others?
- Do not take personally
- Refocus, redirect
- Be consistent
- Be slow to make any changes
- Do not argue with any misinterpretation
- Give familiar objects

Difficulty With Personal Care Tasks

- Divide task into single, separate steps
- Be patient, allow ample time
- Demonstrate the action or the task needed
- Be aware of pain
- Ask the person to help with task

Inappropriate Sexual Behavior

- Distract while performing personal tasks
- Do not overreact to behavior – respond calmly and firmly
- Do not give a mixed message
- Make sure the client is toileted
- Check for perineal problems
- Offer appropriate touch – stuffed animals
- If nothing else prevails, (re: self-stimulation) offer privacy

Sleep Disturbances

- Evaluate medically
- Check for new meds
- Schedule later bedtime
- Increase daytime exercise
- Decrease caffeine
- Decrease or stop daytime naps
- Toilet prior to bedtime
- Create bedtime rituals – calming activity one hour prior to bedtime

CREATING SUPPORTIVE, FUN ACTIVITIES

One of the best ways to create a happy caregiving situation and avoid behavioral problems is to plan activities that are interesting, meaningful, and appropriate to the client's mental status.

As the person becomes increasingly frail, activities will have to change to accommodate decreasing ability.

Activities must be consistent with person's background.

- Mrs. T – “Honey, I wear REAL pearls!”
- Ongoing assessment of functional ability is essential.
- Plan activities that the caregiver does with client. Socialization is essential.

Types of Activities

- Motor
- Sensory
- Interactive
- Cognitive

Alone or in combination

Motor Activities

- Anything that enables the body to move.
 - Walking (indoors or outside)
 - Chair exercises
 - Stretching (in bed, if necessary)
 - Hand dancing

Sensory Activities

- Listening to favorite music (client's, not caregiver's) – clapping, foot tapping, player piano
- Listening to books on tape
- Television/movie
- Looking at picture books, especially of nature, without words
- Hand, foot gentle massage, nail polishing
- Consider a pet, if client likes animals – even two goldfish or a bird
- Sniffing perfume, soap, spices, etc.

Interactive Activities

- 'Tea parties' with friends, relatives
- Reminiscence – scrapbooks, old photos, asking “Who is this? Tell me about ...”
- Games – cards, jigsaw puzzles, board games – checkers
- Visits to malls, museums, friends
- Singing (story of Frankie)
- Animal visits
- Planting and tending indoor garden

Cognitive Activities

- Computerized memory exercises
- Crossword or any other puzzle
- Memory games – e.g. 'Concentration', 'Simon'
“Let's name all the words we know beginning with 'A'”
- “I Spy” children's game
- Name that tune

Guidelines for Planning Activities

- Involve both client and caregiver
- Reflect the ability of client – never push beyond capability
- Do for short, frequent intervals
- KEY: Caregiver should set up activity, then draw in the client; not ask, “Do you want to listen to music now?”

Goal of Homecare

- To enable the client to have the highest quality of life possible considering her abilities.
- When the caregiver is enjoying the client and the caregiving process, the atmosphere of pleasure and enjoyment is contagious—the client will feel it!
- When the client is happy the family will be happy!



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