

RETROGENESIS

Dr. Barry Reisberg, Professor of Psychiatry at New York University School of Medicine, and his colleagues have studied Alzheimer disease for many years and have developed a system to identify stages of the disease called the **Global Deterioration Scale (GDS)**. Reisberg (1999) believes that persons with Alzheimers proceed through the disease in a somewhat predictable manner, though there will always be unique variations. The **Retrogenesis** theory refers to **“the process by which degenerative mechanisms in dementia reverse those of normal human development”** (Reisberg, et.al, 1999). In other words, the person regresses backwards as a child’s brain progresses forward, e.g. a person in the early stages of dementia will have the skill level of a 5 to 7 year old. This leads us to alter our expectations of the cognitive and motor abilities to those of a 5 to 7 year old child, e.g. they cannot live alone. This does not mean, however, that we can treat people as children: they have history and life-long skills still available. By determining the developmental age of the person with Alzheimers, we can better understand their behaviour and adapt their environment so we can be realistic in our expectations and they can be successful in daily tasks and activities. The following table, developed by Reisberg and his colleagues (1999), gives clarity to this Retrogenesis theory.

CORRESPONDENCE OF FUNCTIONAL ASSESSMENT STAGES IN ALZHEIMER DISEASE TO NORMAL HUMAN DEVELOPMENT				
GDS Stage	Characteristics	Age of Skill Acquisition	Stage Appropriate Activities	Alzheimer’s Regressed Behaviour
1	No cognitive decline evident			
2 Very mild	Complaints of memory loss (word finding)			
3 Mild	Lose or misplace articles Can’t retain reading Decline in social performance Denial Difficulty with multitasking Difficulty with complex tasks	13-19 years	<ul style="list-style-type: none"> • Reduce stimulation • Adjust expectations of the person • Consider reducing work time, make plans for future needs. • Maintain active participation in decision making. 	<ul style="list-style-type: none"> • Frustration or withdrawal if expectations too high • May experience anxiety, worry or attempt to cover up deficits
4 Late confusional	Decline in ability to handle finances Anxiety Can’t travel Cannot perform familiar tasks, e.g. meal preparation, shopping without supervision	8 years to adolescence	<ul style="list-style-type: none"> • Reduce stimulation, adjust expectations, • Simplify tasks; continue to make plans for future care needs. • Provide meaningful activities that highlight sense of self-worth and contribution. • Involve person in decision making. 	<ul style="list-style-type: none"> • Maintains deliberate activity • Insists on carrying out daily tasks • No emotional outbursts, however may experience anxiety and frustration • May express “morbid commentary” (“I’m useless, I wish I were dead”) – this is not suicidal intent.

GDS Stage	Characteristics	Age of Skill Acquisition	Stage Appropriate Activities	Alzheimer's Regressed Behaviour
5 Early Dementia	Difficulty concentrating Cannot recall significant information Some disorientation Needs assistance with choosing clothing for occasion, season and weather conditions. Needs assistance with cooking.	5 to 7 years	<ul style="list-style-type: none"> Adult Day Care setting. Persons with Stage 5 AD (just as children 5-7 years of age) need to be able to demonstrate their competence, intelligence & independence. The person with AD may still struggle to continue to work in some capacity as a means to maintain dignity (e.g. wants to pay bills). Activities must be meaningful & achievable to enhance a feeling of being participating members of society. Adjust expectations & simplify tasks realistically Preserve dignity. 	<ul style="list-style-type: none"> Cannot live alone Fear of being alone (40%) May believe that their dead parents are still alive and they are living with them May see caregiver as helper or assistant, may see spouse as a parent or a stranger. May be embarrassed cannot do own ADL's Delusional ideas help make sense of their world, e.g. accusing people of stealing when they have lost an item. May not be able to manage appliances or telephone.
6 Moderate dementia	Requires assistance dressing Requires assistance for proper bathing Requires assistance with mechanics of toileting (flushing) Urinary incontinence Fecal incontinence Repetitious questions and behaviours Early-learned tasks (e.g. playing music, looking at pictures, some chores) can provide an 'access point' for relating to those with more advanced disease.	5 years 4 years 48 months 36 to 54 mos. 24 to 36 mos.	<ul style="list-style-type: none"> Walks, colouring books, having stories read out loud, stringing beads, helping with simple household tasks such as sweeping floors, folding towels & laundry, playing with musical instruments, singing songs & dancing. Songs should be simple & repetitive. Holding a doll or stuffed animal may soothe. A controlled environment to avoid distraction overload. 	<ul style="list-style-type: none"> Require same care as 2-5 year old. Can't be left alone. Catastrophic reaction to fear (similar to tantrum of child) Aggression as in 2 year old Wandering, purposelessness Inappropriate behaviour Likes to receive instructions May be soothed by holding a doll which is perceived as their baby
7 Severe dementia	Speech limited to about six intelligible words Intelligible speech limited to 1 word Ambulation lost Ability to sit-up lost Ability to smile lost Ability to hold up head lost	15 months 12 months 12 months 24 to 40 wks 8 to 16 wks 4 to 12 wks	<ul style="list-style-type: none"> Music can often reduce agitated behaviour, as can "empathic verbal dialogue" from caregivers such as cooing, gentle talking & positive exaggerated facial expression. Pacifying activities such as sucking are often observed. There is an increase in fascination with children and infants. 	<ul style="list-style-type: none"> Requires same emotional & physical care as infant. Screaming behaviour may occur. Withdrawal syndrome will occur if deprived of human contact. "If we neglect a healthy infant, they cry out; if we continue to ignore, they withdraw."

Adapted by Sandie Somers CNS Caregiver Video Series June 2018

Produced by: Reisberg, Ferris, Leon, et. al., (1982); Adapted from Reisberg, B., 1986In Geriatrics; Reisberg lecture, Victoria BC, 1999; Reisberg lecture, Victoria, BC, 2000



RESPONSIVE AND/OR PROTECTIVE BEHAVIOURS

APPROACHES	APPROACHES
<p>Client Centered Strategies: Try to determine if client is in discomfort, pain, needing bathroom, dehydrated, bored, frustrated, fearful and disoriented. Prevent problems where possible and address unmet needs.</p> <p>Have vision and hearing assessed.</p> <p>Seek medical evaluation to assess for medical cause and review of medications.</p> <p>Ensure the person is taking their prescribed medications appropriately. Ask physician or pharmacist if any drugs could be contributing to symptoms or behaviours such as anxiety or restlessness.</p> <p>Assess for malnutrition and dehydration and attempt to have person eat a balanced diet.</p> <p>Assess alcohol use and reduce intake if possible.</p> <p>Caregiver Centered Strategies: Be consistent.</p> <p>Recognize impact of personality traits and work history (eg: working nights, leadership roles)</p> <p>Remain calm and patient; try to make eye contact and speak with a gentle voice.</p> <p>Reassure the person that they are safe.</p>	<p>Environmental Centered Strategies: Change environment as little as possible.</p> <p>Create a routine that works and stick to it.</p> <p>Increase lighting in the environment.</p> <p>Establish a calm and soothing environment.</p> <p>Simplify the environment and remove clutter and organize so less chance of things going missing.</p> <p>Have duplicates of favorite items and photocopies of favourite photographs (laminated if indicated.)</p> <p>Monitor over-stimulation in the environment; consider television program and volume.</p> <p>Ensure person is receiving appropriate level of sensory stimulation as boredom can cause agitation.</p> <p>Let go of expectations that don't work anymore; take your lead from the person; leave your agenda at the door.</p> <p>Never rush the person or expect them to be able to multi-task.</p>

Reinforce and support positive behaviours.

When the person thinks things have been stolen: remind him/her of where valuables are stored - assist the person to look for lost items – never scold for losing items - learn his/her favorite “hiding spots” and let others know.

Assist person to look for lost items.

Do not scold person for losing items.

Learn person’s favorite “hiding spots” and let others know.

Distract rather than confront.

Do not argue with the person as this may only make them more paranoid or agitated.

Respond to the person’s feelings rather than argue or correct; example “I see that you are feeling upset about losing your jewelry, tell me more about when you received this ring.”

Redirect the person’s attention to a familiar distraction such as music, exercise, going for a walk, playing cards, conversation, reviewing photo albums, playing with their pet, making a cup of tea, washing dishes.

Use physical touch as reassurance; example, “I know you are upset, would it help if I held your hand?”

Explains sounds or events that may cause alarm or confusion; example, “that noise is the truck picking up the garbage”.

Use a diary to help you monitor when challenging behaviours occur.

Revise and adapt tasks so they are more manageable for the person to prevent them from becoming upset.



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Orientation	Everyday Activities That <i>May Be</i> Affected	Possible Recommendations
<ul style="list-style-type: none"> • Person • Place • Time 	<ul style="list-style-type: none"> • Recognizing Caregiver • Getting lost in or community apartment/condo building • Missing appointments; meals • Missing medications • Wearing inappropriate clothes for season 	<ul style="list-style-type: none"> - Use names, repeat - Lost person registry - Large calendars; large clock; special alarm - Docettes

Attention	Everyday Activities That <i>May Be</i> Affected	Possible Recommendations
<p>Auditory</p> <ul style="list-style-type: none"> • Speed of processing • Mental manipulation of information • Capacity (span of attention) <p>** (ensure hearing has been assessed recently)</p> <p>Visual</p> <ul style="list-style-type: none"> • Visual scanning • Speed of processing • Sustained attention <p>** (ensure vision has been assessed recently).</p>	<p>Communication</p> <ul style="list-style-type: none"> • Following lengthy directions, fast-paced conversation, especially with several speakers <p>Leisure Activities</p> <ul style="list-style-type: none"> • Enjoying TV, radio, group activities <p>Communication</p> <ul style="list-style-type: none"> • Reading, copying information (eg., phone numbers) due to poor visual scanning or neglect (lack of awareness) of information on one side of visual space 	<p>Communication</p> <ul style="list-style-type: none"> - Use touch and eye contact to gain attention - Use shorter instructions (eg., one instruction per sentence) - Make use of visual cues facial expression, gestures, pointing to objects) to enhance meaning <p>Leisure Activities</p> <ul style="list-style-type: none"> - Simplify activity; use demonstration / visual cues modify environment: eg., reduce noise; smaller groups <p>Communication</p> <ul style="list-style-type: none"> - Use touch, eye contact, and voice to gain attention - Use a phone with big buttons, emergency numbers programmed into

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	<p>Household Management</p> <ul style="list-style-type: none"> • Misperceive similar-looking items; not notice food is spoiled • Difficulty selecting specific items from a group (eg., cupboard, closet, fridge) • Operating buttons, dials on appliances may be difficult • May not attend to potential environment hazards (eg., papers near stove may be fire risk) • Mobility - eg., carpet edges, obstacles. <p>Dressing / Self-Care</p> <ul style="list-style-type: none"> • May skip buttons, not notice zippers, shoelaces are undone, may miss a spot when shaving or applying make-up <p>Driving Ability Driving may be a problem, may also affect use of scooter, wheelchair</p>	<p>phone or posted in large numbers by phone</p> <p>Household Management</p> <ul style="list-style-type: none"> - Modify environment eg., adequate light, no clutter, clear walking areas, remove appliances no longer in use, wires/electrical cords from walkways; sticker on sliding glass doors - Reduce fire risk, eg., mark burners for touch control - May need household supervision <p>Dressing / Self-Care</p> <ul style="list-style-type: none"> - Pullover tops, velcro fasteners, elastic shoelaces - Monitoring of self-care by family, home support worker <p>Driving Ability</p> <ul style="list-style-type: none"> - May need further assessment, eg., road test if unsafe, provide transportation alternatives, eg., bus, volunteer driver, taxi saver coupons.
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Language	Everyday Activities That <i>May</i> Be Affected	Possible Recommendations
<p>Expression (verbal and written)</p> <ul style="list-style-type: none"> • Word retrieval • Use of language (grammar, syntax) • Spelling 	<p>Communication</p> <ul style="list-style-type: none"> • Expressing thoughts, conveying needs • Making conversation • Writing letters 	<p>Expression: Communication</p> <ul style="list-style-type: none"> - Ask permission to assist with word-finding; avoid "teaching" - Watch for nonverbal cues, identify underlying message

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<p>Comprehension (verbal and written)</p> <ul style="list-style-type: none"> • Understanding vocabulary • Understanding grammatical constructions • Following directions of increasing length and complexity 	<p>Leisure Activities</p> <ul style="list-style-type: none"> • Makes socialization difficult; Makes socialization difficult; may cause embarrassment and lead to social isolation <p>IADLs (eg., Shopping, Finances, Appointments)</p> <ul style="list-style-type: none"> • Difficulty writing lists, cheques, reminders for self <p>Communication</p> <ul style="list-style-type: none"> • Understanding instructions • Understanding conversation • Reading letters, newspapers, books <p>IADLs (eg., Meal Preparation, Finances)</p> <ul style="list-style-type: none"> • Difficulty following recipes, understanding documents, bills, requests for money <p>Leisure Activities</p> <ul style="list-style-type: none"> • Affects ability to socialize 	<ul style="list-style-type: none"> - Give time to speak and process information; validate feelings and concerns; monitor for depression <p>Leisure Activities</p> <ul style="list-style-type: none"> - Offer supportive environment, - Offer activities that do not rely on language, eg., sensory stimulation involving other senses; puzzles, handicrafts, listening to music, etc. <p>IADLs</p> <ul style="list-style-type: none"> - May need assistance with writing cheques, shopping lists, sending of birthday, sympathy cards, etc. - Ensure there is Power of Attorney <p>Comprehension:</p> <p>Communication</p> <ul style="list-style-type: none"> - Simplify - one-step commands; avoid ambiguity, abstractions, questions; offer limited choices - Use visual cues/demonstration, physical prompting/guidance - If can't read, use pictures or objects to cue <p>IADLs</p> <ul style="list-style-type: none"> - Avoid written lists; assistance with reading mail, finances; may need assistance with meal prep because no longer able to read recipes <p>Leisure Activities</p> <ul style="list-style-type: none"> - May need structured supportive day program, volunteer to continue participation in groups, activities; taped books
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Visuoperception	Everyday Activities That May be Affected	Possible Recommendations
<ul style="list-style-type: none"> Perceptual organization (eg., recognizing fragmented drawings) Visual-motor coordination (eg., copying drawings) Hemispatial neglect Figure-ground 	<p>Mobility</p> <ul style="list-style-type: none"> May be at risk for falls; difficulty with steps, getting in and out of tubs, up and down curbs, etc. May become disoriented in environment May bump into objects <p>Leisure Activities</p> <ul style="list-style-type: none"> No longer able to do handicrafts, woodworking, etc. - eg., cannot copy patterns, problems with eye-hand coordination May have difficulty recognizing faces, watching TV. <p>Household Management</p> <ul style="list-style-type: none"> May misperceive similar-looking items May have difficulty identifying objects, locations May have difficulty with clocks, stove knobs 	<p>Mobility</p> <ul style="list-style-type: none"> - Reduce safety risks in environment - Install tub guards - Paint nosings on steps - Install railings on stairs - Mark sliding glass doors <p>Leisure Activities</p> <ul style="list-style-type: none"> - Explain things verbally or use touch cuing rather than using only visual demonstration - Provide assistance; switch to activities less reliant on visuoperceptual skills, eg., music, talking books, walks with volunteer; simple games <p>Household Management</p> <ul style="list-style-type: none"> - Use contrast colours for table setting - Label stove knobs - Use digital or "talking" clocks - Label cupboards - Put away items not in use

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Memory	Everyday Activities That <i>May</i> Be Affected	Possible Recommendations
<p>Short Term (new learning)</p> <ul style="list-style-type: none"> Recall of new information (eg., paragraphs; visual designs; lists of words) both immediately after presentation and following a delay <p>Long Term</p> <ul style="list-style-type: none"> Retrieving old information learned previously (eg., personal/autobiographical information, factual knowledge) <p>Procedural</p> <ul style="list-style-type: none"> Habits/routines (not formally assessed but obtained from observation/collateral information) <p>Prospective</p> <ul style="list-style-type: none"> Remembering to do something in future (not formally assessed but obtained from observation / collateral information) 	<p>Communication</p> <ul style="list-style-type: none"> Repetitive comments, questions Difficulty recalling names, faces <p>IADLs / ADLs</p> <ul style="list-style-type: none"> May forget to take pills; forget that pill has already been taken and take another one May miss appointments; forget to look at calendar forget to write appointments down May become lost; may forget where items are in cupboards Forget to pay bills; forget that bill has already been paid and pay again May order multiple copies of magazines; may purchase multiple items of same food item May leave pots on stove; forget to take items out of freezer May forget how to use appliances, familiar recipes May forget routines, such as dressing, bathing <p>Leisure Activities</p> <ul style="list-style-type: none"> Decreased knowledge of current events Difficulty reminiscing (recalling milestones in life, places, people); may lose sense of self <p>Difficult to engage in previously learned activities ("nothing to do")</p>	<p>Communication</p> <ul style="list-style-type: none"> Obtain collateral information to verify history; introduce yourself; supply orienting information; gently remind / assist; repeat information as needed and respond to repetitive questions as though person has not asked before; divert if too repetitive Do not forewarn about activities to reduce concern / perseverative questions; provide reassurance; validate feelings <p>IADLs / ADLs</p> <ul style="list-style-type: none"> Post-written instructions or reminders; emergency numbers Signs for hot/cold water, direction of tap turning Use calendar label cupboard contents, etc Provide gentle reminders re bath, grooming; remove clothing items not in season; make appointment and escort to hairdresser, dentist, physician, etc.; ensure regular medical/dental appointments Reduce safety risks in environment eg., kettle with automatic shut-off; 2 or 3 button microwave, cool-touch toaster, smoke detectors Home support worker may be needed for assistance for IADLs/ADLs Keep routines as familiar as possible

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		<p>Leisure Activities</p> <ul style="list-style-type: none"> - Ensure groups appropriate for current ability, eg., structured dementia day program may be needed - Ensure person has familiar objects, pictures, books that reflect past interests/life - Evoke past memories using props to stimulate, eg., pictures of flowers, pet, baby, etc, collection of hats; target special life experiences, eg., marriage, career, activities that will tap fund of general knowledge
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Reasoning / Problem Solving	Everyday Activities That <i>May</i> Be Affected	Possible Recommendations
<p>Verbal</p> <ul style="list-style-type: none"> • Concrete and abstract reasoning abilities • Logical thinking • Ability to separate essential from nonessential details eg. Consistent introduction of extraneous information <p>Visual</p>	<p>Communication</p> <ul style="list-style-type: none"> • Black and white thinking, literal, concrete • May not appreciate verbal humour, sarcasm • May not be able to imply/infer meaning <p>Leisure Activities</p> <ul style="list-style-type: none"> • Difficulty socializing due to literal, concrete thinking and difficulty recognizing humour <p>IADLs</p> <ul style="list-style-type: none"> • Susceptible to scam artists 	<p>Communication</p> <ul style="list-style-type: none"> - Be careful of choice of words; avoid ambiguity - Provide concrete clues (verbal and/or visual) - Instructions, simple sentences; offer no more than 2 choices <p>Leisure Activities</p> <ul style="list-style-type: none"> - Provide structured program; use above suggestions when communicating <p>IADLs</p> <ul style="list-style-type: none"> - Assist with IADLs, eg., meal preparation, shopping, finances, etc - Be aware of level at which person is functioning

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<ul style="list-style-type: none"> • Visuospatial skills • Analysis and synthesis • Nonverbal reasoning 	<ul style="list-style-type: none"> • Difficulty recognizing similarities and differences and generalizing from one task to another <p>Household Management</p> <ul style="list-style-type: none"> • Difficult making repairs, eg., installing new vacuum bag, fixing a faucet • Difficulty judging amounts and measuring quantities • Difficulty following a recipe; planning a meal <p>Leisure Activities</p> <ul style="list-style-type: none"> • Problems with following a pattern for sewing, woodworking, etc. • Problems doing jigsaw puzzles, playing checkers 	<p>Household Management</p> <ul style="list-style-type: none"> - Provide assistance; break down all activity into component parts - If no longer able to manage stove/oven, may need meals delivered - Adapt kitchen; eg., labels on cupboards, cup/plates - Visible on counter tops, eliminate clutter <p>Leisure Activities</p> <ul style="list-style-type: none"> - Provide friendly visitor, volunteer, home support worker or day program for socialization <p>Adapt activities, based on previous interests eg., woodworking to sanding, difficult crossword puzzles to ones with fewer words or word-search puzzles, knitting sweaters to squares for afghan, artwork to adult colouring books</p>
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Executive Functions	Everyday Activities That <i>May</i> Be Affected	Possible Recommendations
<p>Involves:</p> <ul style="list-style-type: none"> • Planning, organizing, sequencing • Impulse control • Regulation of attention • Deciding from feedback whether a trial solution is right or wrong • Judgement 	<p>Finances</p> <ul style="list-style-type: none"> • Papers may be disorganized; decreased judgment regarding investments, budgeting, priority of bill payment; may be susceptible to scam artists. 	<p>Finances</p> <ul style="list-style-type: none"> - Ensure there is Power of Attorney - Assist with finances eg., trust officers, family members automatic bill payment and deposit of cheques may need to involve Public Trustee if financially incompetent and no family to help protect from scams (redirect mail)

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<ul style="list-style-type: none"> • Mental flexibility • Initiation • Self-perception 	<p>IADLs / ADLs</p> <ul style="list-style-type: none"> • Wearing indoor clothes outside and vice-versa • Disrobing in public • Underclothes over outer clothes • May have difficulty with planning, initiating, sequencing, completing tasks • Fire safety issues - eg., storage of papers near stove. • Difficulty in making any decisions • Perseverate on one task <p>Leisure Activities</p> <ul style="list-style-type: none"> • May dress inappropriately for season/situation • May no longer behave appropriately in social situations 	<p>IADLs / ADLs</p> <ul style="list-style-type: none"> - Increase supervision, assistance - Simplify environment, eg., remove excess stimulation, eg., from kitchen table remove ketchup, salt/pepper, etc. - Ensure environment is safe <p>Leisure Activities</p> <ul style="list-style-type: none"> - Provide supported environment (eg., day program), one-to-one assistance, eg., volunteer, friendly visitor, paid companion; arrange transportation to activity
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Psychoemotional / Personality	Everyday Activities That <i>May</i> Be Affected	Possible Recommendations
<ul style="list-style-type: none"> • Symptoms of depression or anxiety • Behavioural / personality changes (eg., disinhibition, impulsivity, apathy) 	<p>Communication</p> <ul style="list-style-type: none"> • May talk too much or too little • Content may be tangential, circumstantial <p>Leisure Activities</p> <ul style="list-style-type: none"> • May not use appropriate social skills for situation; may make inappropriate remarks 	<p>Strategies for Managing Depression/Anxiety</p> <ul style="list-style-type: none"> - Arrange for referral to determine whether pharmacological treatment (eg., antidepressant, anxiolytic, neuroleptic), psychotherapy (individual or group) is appropriate - Assist with social re-integration <p>Strategies for Managing Challenging</p>

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	<ul style="list-style-type: none"> • May avoid social settings (social isolation) • May be sexually inappropriate in public <p>IADLs</p> <ul style="list-style-type: none"> • May no longer perform due to apathy, lack of interest, decreased energy <p>ADLs</p> <ul style="list-style-type: none"> • May not bathe, dress due to apathy, lack of interest, decreased energy 	<p>Behaviours</p> <ul style="list-style-type: none"> - Alternate quiet times with active periods - Ensure person is rested - Reduce sensory overload - One family member/friend visit at a time - Ensure everyone aware that behaviours not purposeful but in response to brain injury - If sexually inappropriate arrange privacy - Adapt clothing to make behaviours more difficult - Remove firearms from premises (eg., if disinhibited, impulsive, aggressive) - Arrange for referral to determine whether pharmacological treatment is appropriate for managing behaviours that cannot be controlled by environmental changes and are distressing to client/others, eg., aggression, paranoia, apathy
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Praxis -Movement	Everyday Activities That <i>May</i> Be Affected	Possible Recommendations
<p>Praxis - inability to carry out purposeful movement even when physical ability is present.</p>	<ul style="list-style-type: none"> • Backing up to sit down on chair, toilet • Using an eating utensil etc • Inside out, upside down clothing 	<ul style="list-style-type: none"> - Break down into simple components - Use touch to direct physical movement - Compensate - eg., move chair to client; repetitive practice - Assist with initiation of movement or the parts person is having difficulty with.



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		eg. assist with spoon to mouth - once process begun, person may be able to carry on.
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*Sandie Somers Clinical Nurse Specialist, Seniors Strategy
May 2018*



Responsive and/or Protective Behaviour Strategies: Ways to Maximize Success When Providing Care and Support to a Family Member with Dementia

A person with dementia still expresses what their basic needs and feelings are, but in new and different ways (verbal, non-verbal and behavioral).

Responsive and/or Protective behaviours are the best response to their environment that a person with dementia can display, at any given time. Unexpected or difficult to understand behaviour in a person with dementia is most often a response to a cue or trigger experienced by the person with dementia.

Can be an expression of:

- Un-met physical needs (pain, hunger, thirst, constipation, infection, dental problems, arthritis.
- Response to a stimulus in the environment (over/under stimulation, overcrowding, change in routine, change in environment, not understanding the intentions of others, noise, light activity).
- Psychosocial needs (stress, apathy, loneliness, lack of purpose, embarrassment, fear, loneliness, sadness)
- Disturbances in usual sleep patterns
- Responses to the approach of an unfamiliar care provider
- Changes in medications; new medication, medication side effects.
- Not being able to understand what someone wants them to do
- Feeling that they are being rushed, minimised or ignored

The term *responsive behaviour* is intended to focus attention on the reason behind the behaviour and on discovering the care approach that addresses the reason for the behaviour.

Behaviour is a means of communication. ***“When words are lost, communication becomes behavioural.”*** Sometimes, *“responsive and/or protective behaviours”* occur as a result of communication difficulties. ***“They won’t resist if you don’t insist.”***

Responsive Behaviours may include:

- *Restlessness*
- *Suspicion*
- *Verbal outbursts*
- *Physical outbursts*
- *Repetition*
- *Wandering*
- *Shadowing*
- *Hoarding, Rummaging, Hiding*

A PERSON-CENTRED CARE APPROACH TO BEHAVIOUR:

Person-centred care values people with dementia as individuals with unique histories, values, likes, beliefs and strengths. Care includes a person’s abilities, preferences, and choices. Providing person-centred care moves beyond the physical act of providing care and involves the whole person and their social, cultural and individual identity.

Attitudes of Personhood

Every person has contributions to offer and the right to make choices

It’s easier to change the environment than to expect the person with dementia to adapt

We must acknowledge persons with dementia as the experts of their own lived experience

“Blame the Disease, Not the Person”

OUTCOMES OF A PERSONHOOD APPROACH

Emotional well-being

Quality of life

Safety

PERSON CENTRED STRATEGIES

RESTLESSNESS, AGITATION, SUSPICION, VERBAL OUTBURST, PHYSICAL OUTBURSTS

- Focus on the feelings of the person with dementia, rather than the behaviour.
- Try not to take the behaviour personally. ***The person with dementia usually won't remember the event, and therefore will not be able to learn from it.*** Try to stay positive
- Look for patterns in the behaviour, and try to identify any triggers; things that cause the person to react in a certain way. Certain behaviours may only be displayed at certain times, or during particular activities. Consider the effect of the environment, such as bright lights and noise from the television or radio, as these may add to confusion, or restlessness
- Establish a routine. Familiar surroundings are important for the person with dementia, and help promote orientation and feelings of safety. The person with dementia may become upset if they find themselves in a strange situation or among unfamiliar people, and may become confused, anxious, or restless.
- Clear and simple communication is important. The person with dementia may become upset if they do not understand what is expected of them. They may also feel frustrated with their inability to make themselves understood. It is important to face the person, speak slowly in a calm and reassuring voice and use simple sentences. Be patient and allow extra time.
- Calm the person with dementia by playing relaxing music, or give them reassurance with the touch of the hand, a warm smile, and gentle tone of voice.
- Keep furniture and objects in the same place to avoid confusion or suspicion that someone has taken their belongings.
- Introduce new clothing one at a time, while keeping older familiar articles of clothing available. New items that are not familiar can be confusing and can evoke fear.
- Ensure the person with dementia participates as much as possible in daily activities. Make sure the task isn't too complicated or the person with dementia may become overwhelmed. Simplify the components of a task.
- Regular exercise is important. Simple exercise, like a walk outside or a game, can reduce anxiety and depression and can minimise other behaviours such as wandering and restlessness.
- Distraction often helps. If possible, direct the person with dementia away from a particular task or environment that seems to be triggering the behaviour. Suggest a different activity that the person with dementia may like, such as listening to a favourite song, having something to eat or going outside.
- Be consistent. If there are strategies for addressing behaviours that work, try to ensure other people who also care for the person with dementia use the same strategies.
- Don't force an activity. If the person with dementia starts to get tense, stressed and/or angry-walk away for the time being to let them regain control. You can always try later
- Don't rush the person. Allow them to do as much as possible for themselves with cues from you-but complete the task in their own time, and if reasonable, in their own way.
- Be aware that the "invisible bubble" or their personal space may be bigger and that standing close may make them feel uncomfortable stressed or threatened. Get their permission first to stand close to them. Determine their personal space by greeting the person with an outstretched hand to shake. The person will let you know how close to stand as he/she shakes your hand.

It may be necessary to experiment with different strategies at different times to meet the changing needs of the person with dementia. What works one day may not work the next. Have a plan for the day but be ready to change it. Concentrate on handling the situation as calmly and effectively as possible. Try to be realistic about the person's abilities and plan activities that the person can succeed at.

Deescalating and Defusing

Do not argue or try to reason-Remain calm

Use short, simple sentences-repeat if necessary

Approach from the front

Validate feelings ***"You can't find your dog, what is the dog's name, tell me about him"***

Watch for fear and anxiety

Align with the person rather than take control ***"Your wallet is missing, I lost my purse, let's look together", "Your paper is missing, no wonder you are upset, I'll help you look"***

Try to ***"Take the one down position" "I'm so sorry, how I can help?"*** rather than argue or defend your case.

Avoid overwhelming

Leave the room and then come back in a few minutes as if you just arrived, ***"Hi Bill so nice to see you. What lovely day. Would you like to go for a walk?"***

REPETITION

Repetitive behaviours can include repeating a sound, a word, a question or an action (for example, tapping fingers or feet, continually crossing legs). ***Always look for the trigger to the behaviour.***

Repetition may be caused by:

- Possible side effects of medications (particularly when the person is repeating a physical movement).
- Pain
- Inability to express a need such as hunger.
- Trying to express an emotion, such as fear or anger.
- Separation from a loved one (***may ask repeatedly, "where is my mother, brother?", "I want to go home"***). ***Because person's with dementia rely on their long term memory to make sense of the present the person may be looking for people in their past or a home they lived in when they were growing up.***
- An unfamiliar environment or over-stimulation.

The person with dementia is not aware that they are repeating themselves because of the memory loss associated with the disease.

- Use memory aids (write notes, make signs, use large clocks and calendars) to help orient the person.
- Keep routines consistent.
- Distract or redirect the person with another activity.
- Give reassurance that they are safe and you are there for them.
- Look for patterns in the behaviour (take note of the time of day, event, or people who trigger the behaviour). Identify the pattern, then remove the trigger.
- Modify the environment based on the trigger (once you know what causes the behaviour, for example a barking dog, a stranger at the door).
- Introduce activities that require repetitive movements (walking, dusting, sanding, folding, raking).
- Playing music may have a calming effect.

WANDERING

Wandering may be due to the person searching for a person, place or object from the past.

- Reminiscing about things from the past may be comforting. Photo albums, travel books and magazines are ways of introducing a reminiscence activity and validating the person's feelings.

For some people with dementia, wandering is a coping mechanism to release energy or reduce stress and tension. Trying to stop the wandering may increase agitation and cause anger and frustration.

- Plan daily activities during the time a person tends to wander. This could include an exercise regime, participation in household activities, participation in gardening activities, walks to the store, etc.
- Remove items from view that may trigger a desire to wander such as shoes, boots, purse, coat rack.
- Anticipating an event such as a visit to or from a relative may contribute to wandering. Consider if the person needs to be advised of plans ahead of time and what amount of advanced notice is necessary without causing undue anxiety or restlessness.

Wandering may occur when the person is in an unfamiliar environment.

- Bring something familiar that they can carry, provide an explanation that helps them make sense of their surroundings.

A person who wanders at the same time every day may be returning to a former schedule or routine.

For example, a person may be trying to get back to work after lunch or fixing a snack for children coming home after school.

- Think of ways to accommodate this by going for a walk or a drive or provide other distractions during this time of day.
- Install locks that are difficult to operate and higher up on doorframe, out of field of vision or the person's reach.

HOARDING, RUMMAGING, HIDING

Rummaging, hiding, and hoarding are all things a person with dementia may do to gain control in their lives and a sense of security. Persons with dementia may hoard items out of fear that they may "need" the items someday. They may begin to hide items when they are not able to recognize the people around them any longer. They may rummage through items because seeing and touching the items reminds them that they are there and gives them comfort.

People with dementia may be driven to search or rummage for something that they believe is missing, something familiar to make sense of their world. ***If the person always had change in their pocket they may pick up items such as rocks, spoons etc. to fill their pockets. They know something is missing.***

Hiding or hoarding items may be an attempt to keep items safe or the inability to distinguish between items that should be kept or thrown away. This behaviour may also be triggered by a lack of stimulation, loss of sense of purpose, boredom, or difficulty initiating new activities.

Sometimes removing clutter or taking items from pockets or purses can cause severe emotional upset, and it is usually not beneficial to remove everything that a person hoards. This is because the items that the person collects give them a sense of security and safety.

Only remove what is needed to eliminate safety and health hazards.

- Give the person with dementia a good reason to part with their items. They may be more willing to let go of something if they are told that the item will be given to a charity, church, family member, etc.
- Negotiate. Trade a year's worth of newspapers for a month's worth. Trade expired food for fresh food.
- Remove discarded items immediately because the person may rummage through the garbage and bring items back into their home.
- Have activities planned and ready to divert the person's attention from the removal of their items.
- Reduce the amount of clutter coming into the home by reducing spending money and monitoring purchases. Consider blocking home shopping channels. Stop junk mail and catalog mailings and consider getting bills sent to another address.

What can appear cluttered and disorganized may help the person with dementia function and cope. Some individuals keep belongings out in the open or in unusual places because they may forget where they are if they cannot see them. If the clutter is not posing a safety or health hazard, then leave it as is.

Make Rummaging an Activity

Restricting access to all drawers and cabinets can be distressing for a person with dementia. Many individuals will rummage or constantly reorganize items because they feel a need to be productive.

- Provide the person with dementia an opportunity to rummage and make rummaging a stimulating activity. This can be done by providing easy access to some closets, drawers, or portable boxes that contain safe items that the individual can rummage in. Boxes can contain random items or be themed: sewing drawer, sports closet, jewelry box, etc.
- If the person enjoys sorting and organizing items make this an activity. Ask the person to help you fold and sort items like socks, napkins, and scarves. This may help the person fulfill their desire to be productive.

TIPS FOR FAMILY CARE GIVERS DEALING WITH RESPONSIVE AND/OR PROTECTIVE BEHAVIOURS

STOP!! Think about what you are about to do and consider the best way to do it.

PLAN AND EXPLAIN!! – Who you are; What you want to do; Why you want to do it etc.

SMILE!! The person who takes their cue from you will mirror your relaxed and positive body language and tone of voice.

GO SLOW!! You have a lot to do and you are in a hurry but the person you are caring for isn't. How would you feel if someone came into your bedroom, pulled back your blankets and started pulling you out of bed without even giving you time to wake up properly?

GO AWAY!! If the person is resistive or angry but is **NOT** causing harm to themselves or others, leave them alone. Give them time to settle down and approach them later.

GIVE THEM SPACE!! Any activity that involves invasion of personal space **INCREASES THE RISK OF ASSAULT AND/OR AGGRESSION**. Every time you provide care for a person you are invading their space.

STAND ASIDE!! Always provide care from the side not the front of the person, where you may be a target to hit, kick etc.

DISTRACT THEM!! Talk to the person about things they enjoyed in the past. Whilst you are providing care, allow them to hold a towel or something that will distract them.

KEEP IT QUIET!! Check noise level and reduce it when and where possible. Turn off the radio and TV etc.

***Lori Amdam RN. MSN. and Sandie Somers Clinical Nurse Specialist, Seniors Strategy
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