

CSS Shared Resources , Ontario East.



Geriatric Psychiatry Community
Services of Ottawa

Person-Centered Dementia Care: Enhancing Communication and Focusing on Spared Abilities

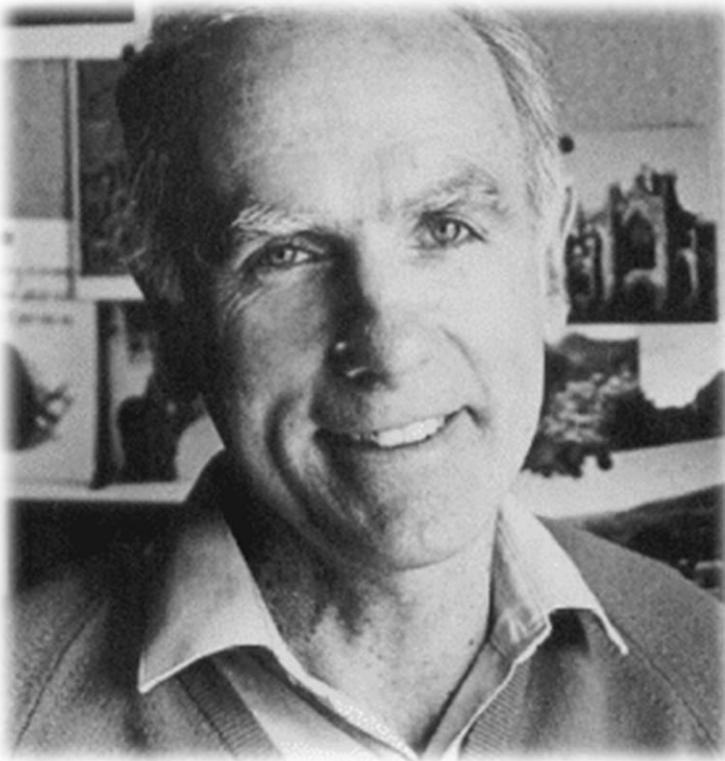
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Learning Objectives

1. Explore the foundations of person-centered dementia care
2. Understand the role of personhood
3. Paradigm shift: focusing on remaining skills, needs, abilities
4. Tailoring activities in response to cognitive and physical function decline
5. Implementation barriers



Person-Centered Dementia Care



Thomas Kitwood (1937-1998)

(Bolby Sifton et al., 2011)

Core Principles:

- Valuing all human life regardless of age and mental abilities
- Rooted in respect for the other and knowledge of their personhood
- Paying attention to the person as a whole - not their symptoms
- Understanding the world from the perspective of the person living with dementia



Personhood



- The qualities that make up a person's unique identity, values, beliefs, and sense of self
- Rooted in dignity, respect, trust
- Supporting older adults while respecting their desire for autonomy and independence.
- Acknowledging personhood involves our dedication to knowing who the person is, past and present, and incorporating this into their care plan as they journey through dementia.

Person-Centered Language

- Historically, language used to describe dementias has largely focused on losses experienced
- While these losses are real, negative wording can promote stigma against dementia through perceptions, interpretations and approaches to care that focus on weakness rather than strength, illness rather than wellness, and victims rather than whole persons
- By being more conscious of the language we use, we can avoid reducing people living with dementia to a series of labels, symptoms or medical terms



People living with dementia are still people first & must be treated as such

Person-Centered Language

Language to be avoided	Reasoning	Person-centered language
Adult Day Care	More appropriate for children's services than adults	Adult Day Program
Bib	Terms are reflective of products used in the care of children	Apron Clothing protector
Caregiver Burden	Implies that caregiving is always a burden. The term can validate the burden some caregivers experience, but should not be assumed and avoided when speaking in generalities	Caregiver Stress Caregiver Challenges Effects of Caregiving
Demented person	Implies person is completely incapable	Person with dementia Person living with dementia (PLWD)
Diapers	Terms are reflective of products used in the care of children	Incontinence product Adult brief



Person-Centered Language

Language to be avoided	Reasoning	Person-centered language
Feeder	Labels person & depersonalizes	A person who needs support to eat
Placement or Placement Planning	One places or puts objects, not people	Moving to a new home Future care planning
Hoarder / Screamer / Wanderer / etc..	These terms are not specific, suggesting that the behaviour is a result of a problem with the person. They do not support a person-centered response.	Describe the behaviour with specific examples Ex. PLWD collecting tissues Ex. Person is pacing and appears restless + frustrated



Person-Centered Language and Behavioural Expressions

Vague Language	Specific Language
“person is agitated and upset”	“person is pacing the halls with their fists in balls”

Key point: Describe the behaviour using specific details

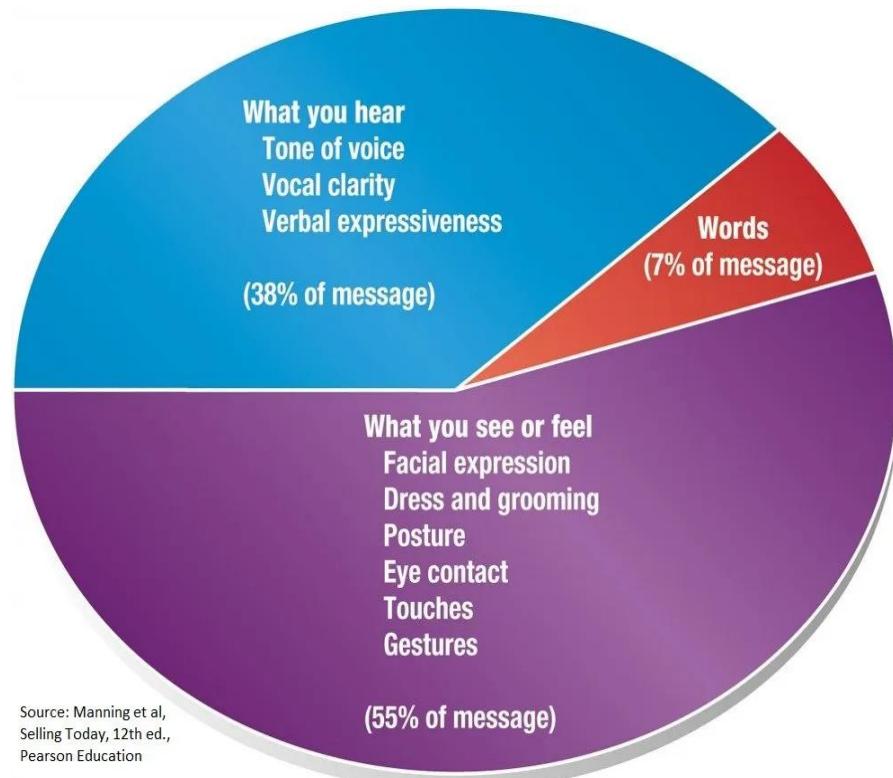
Biased Language	Objective Language
“sexually inappropriate”	“person took off their clothing and walked out of the dining area”

Key Point: Describing behaviours objectively minimizes bias.

Labelling Language	Respectful Language
“was aggressive during the activity”	“while attempting to assist to a standing position, person pulled program coordinator’s hair and screamed”

Key point: There are social and clinical consequences to labelling a person’s behaviours.

Components of Person-Centered Communication



Verbal vs. Non-Verbal

- What you say
- The way you say it (pace)
- How you sound (tone)
- How you look (demeanor, facial expression)

Components of Person-Centered Communication

- Emphasize recognition, not recall
 - Avoid beginning or ending a conversation by saying: “Do you know who I am?”
 - Introduce yourself and your relationship to the person (or your role)
- Speak slowly and clearly
- Allow plenty of time for response, pausing between statements
- Eliminate distractions (radio, TV, other conversations)
- Face the person when speaking to them – ensuring they can see you and hear you (wearing glasses and hearing aids if needed) & have only one person speaking
- Alert the person to your presence by touching their hand and saying their name





A BY US FOR US GUIDE

Enhancing Communication

An inspirational guide
for people living with dementia

SERIES 1

Please don't correct me. I know better;
the information just isn't available to me at the moment.

Remember my feelings are intact and I get hurt easily.

Try to ignore my off-hand remarks that I wouldn't have made in
the past. If you focus on it, it won't prevent it from happening
again. It just makes me feel worse.

I may say something that is real to me but may not be factual. I
am not lying, even if the information is not correct. Don't argue.
It won't solve anything.

I don't mean to frustrate you. I know you get impatient and
tired of telling me things three times in a row. Please be patient.

Ask me what I think or want. Don't assume you know.

https://the-ria.ca/wp-content/uploads/2018/11/BUFU_Enhancing_Communication_eversion_A.pdf



Person-Centered Dementia Care

Six psychological needs that are essential to all people:

- ❖ **Love**: unconditional acceptance and empathy
- ❖ **Comfort**: security, warmth and proximity
- ❖ **Identity**: connection to oneself (past and present)
- ❖ **Attachment**: our connections in life
- ❖ **Inclusion**: being part of a social community; acceptance
- ❖ **Meaningful occupation**: the ability to participate in your own life in such a way that you use your abilities, strength, and experience. That you are needed & have something to do





NEEDS

People - love +
belonging

Purpose + leisure

Success

Compassion



INTERESTS

**What would I
like to do?**



SKILLS

What have I always done
well?

Reading
Writing
Music



Art

Gardening
Cooking
Repairs



ABILITIES

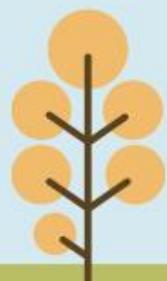
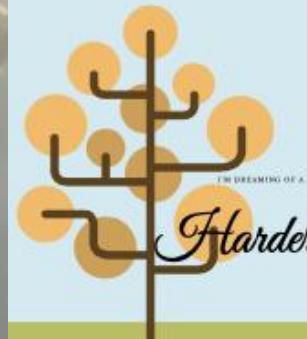
**What am I able
to do now?**



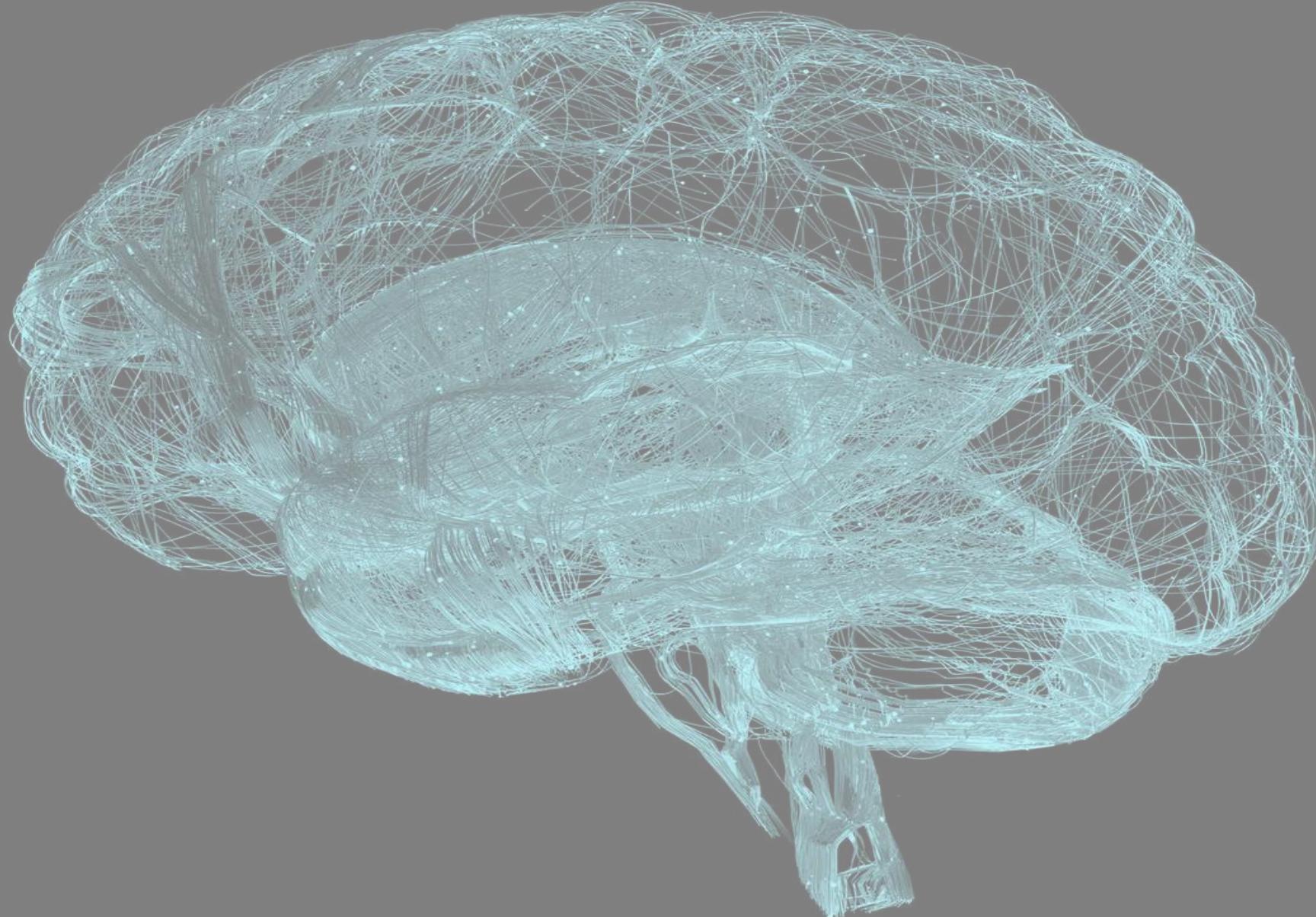
Adapt

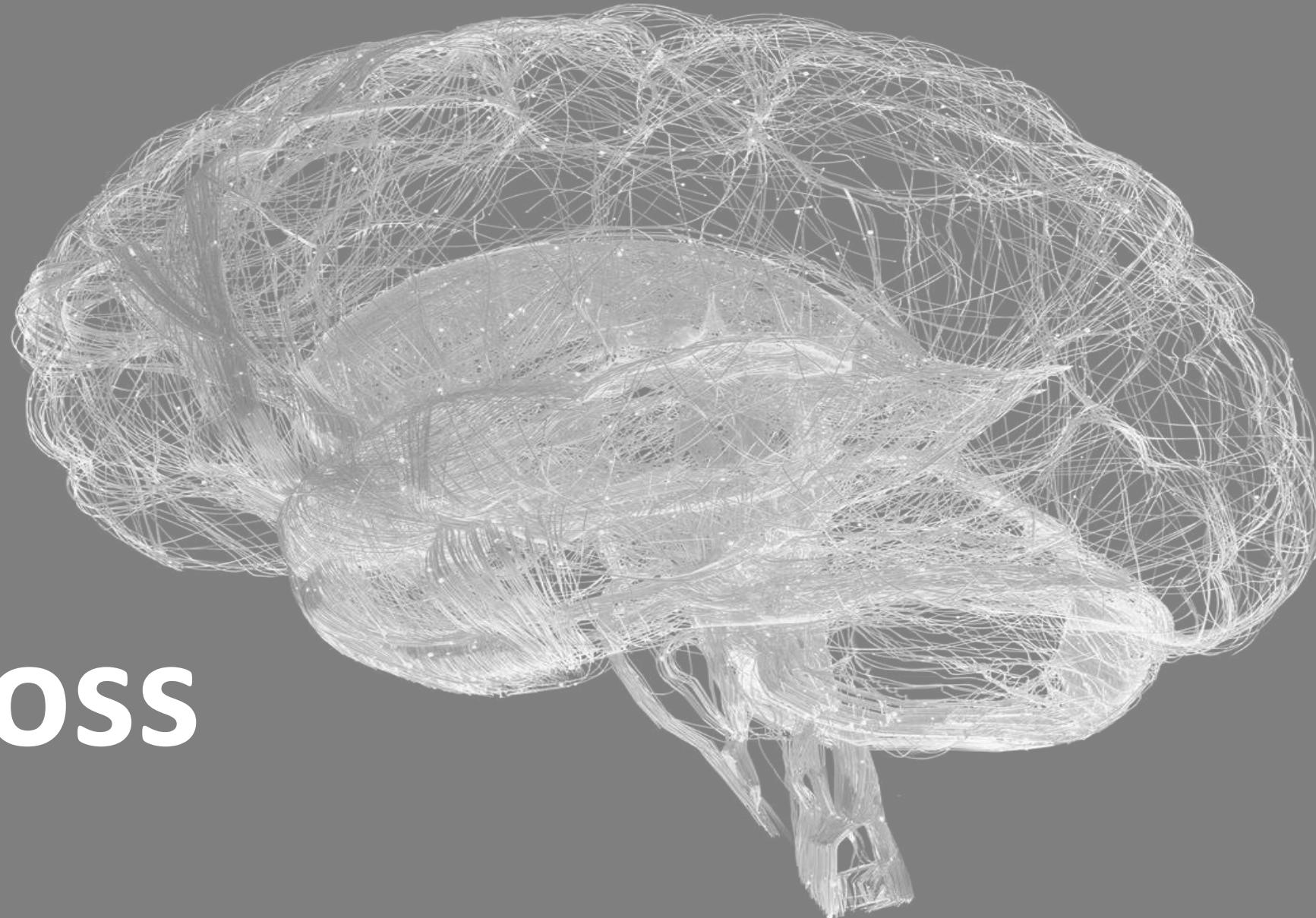
TO MATCH ABILITIES

EASY!



What do you think of when you hear the word Dementia?



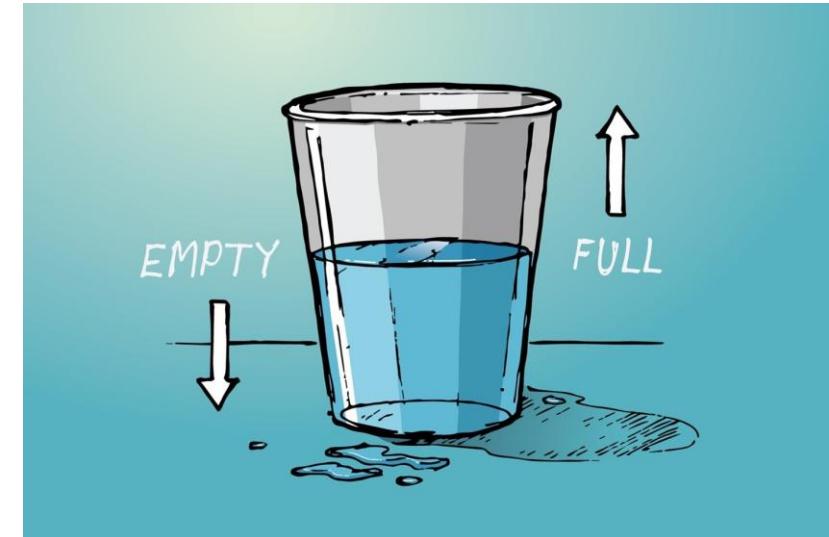


LOSS

Paradigm Shift: Spared Abilities

Shifting the focus from *deficits* to spared *abilities*

1. Habitual skills / procedural memory
2. Humour
3. Emotional memory / emotional awareness
4. Sociability / social skills
5. Sensory appreciation / sensory awareness
6. Motor function
7. Musical responsiveness
8. Long-term memory



1. Habitual Skills



AKA 'Procedural memory' – HOW we do things

Triggered by familiar cues associated with the action

- Ex. Sweeping the floor when handed a broom
- Ex. Brushing teeth when handed a toothbrush

2. Humour

- Sense of humour persists, in spite of increasing difficulties with communication.
- Considering laughter as 'medicine' or a therapeutic intervention.
- Appreciation for limitations relating to reduced language and understanding.



3. Emotional Awareness



Retained capacity for:

- Expressing and giving love / affection
- Experience a full range of emotion
- Sharing warm interpersonal relationships
- Participating in meaningful activity.

Enhanced emotional sensitivity

Many activities encourage non-verbal emotional expression:

- Caring for plants & pets
- Listening to favourite music or singing



4. Sociability



AKA overlearned social skills

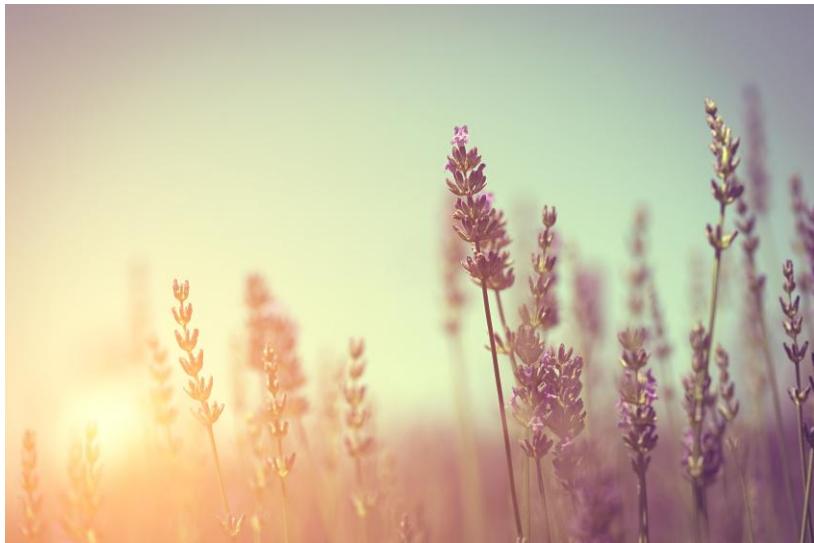
People living with dementia retain the ability to socialize and engage in social activities

Special considerations:

- Social activity requires a great deal of energy and concentration, which may leave the person feeling fatigued afterwards. Balance is key!
- Be mindful of overstimulation



5. Sensory Awareness



Experiencing touches, smells, movement, sights, sounds and tastes of everyday life can serve as an ongoing source of pleasure, stimulation, and method of communication.

Special considerations:

- Dementia can impair their ability to understand or recognize what the senses are telling them, and to decide what action to take (e.g., misperceptions, illusions)
- Be mindful of overstimulation.



6. Primary Motor Function

Strength and muscle control persist until the late stages

Movement brings enjoyment and improved health outcomes:

- ↑ range of motion
- ↑ circulation
- ↑ bowel / bladder function
- Improved breathing and heart function
- Appetite
- Energy

Special considerations:

- The ability to move continues but the person may need help getting started as the disease progresses



7. Music



Areas of the brain involved in appreciating, responding to, and becoming involved in music are typically well-preserved.

It can bypass communication deficits.

Provides an important avenue for emotional expression.

Special Considerations

- Tailor music choice to individual preferences
- Choose music from the era of their mid-teens to mid-20's for best recall



8. Long-term Memory

Intact in the early / middle stages

Less impaired with progression of disease

Events of personal significance are most memorable

- E.g. Wedding day, Graduation, Birth of children

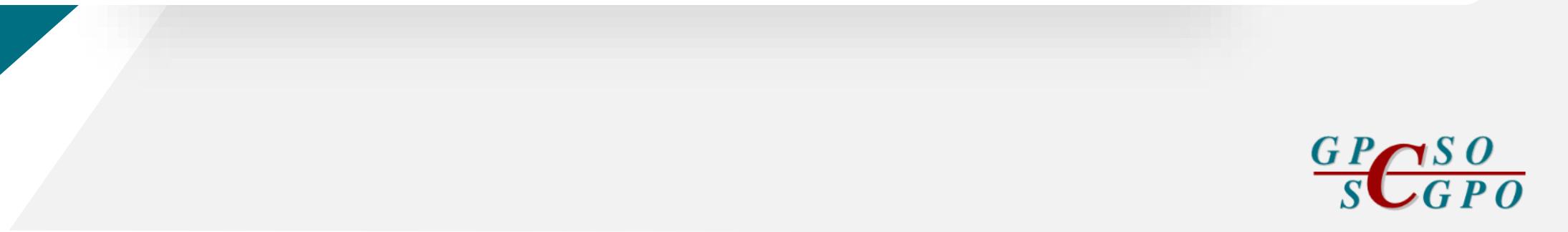
Memories of childhood and young adulthood are better preserved than more recent memories

- E.g. Will not remember something that happened 5 minutes ago vs will remember an event that occurred 50 years ago



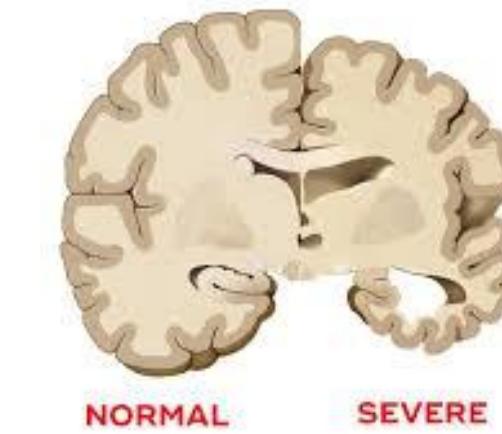
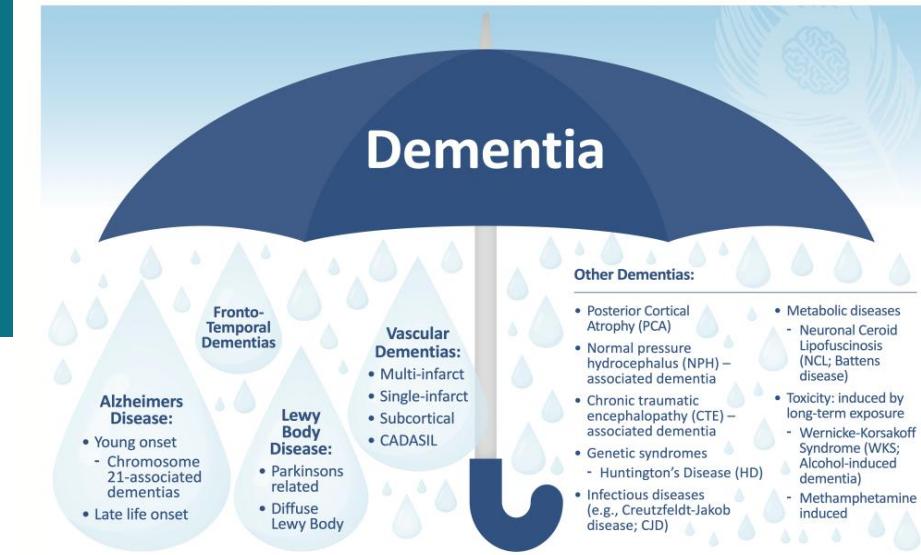


Tailoring Care and Activities to Support Changing Needs in Dementia

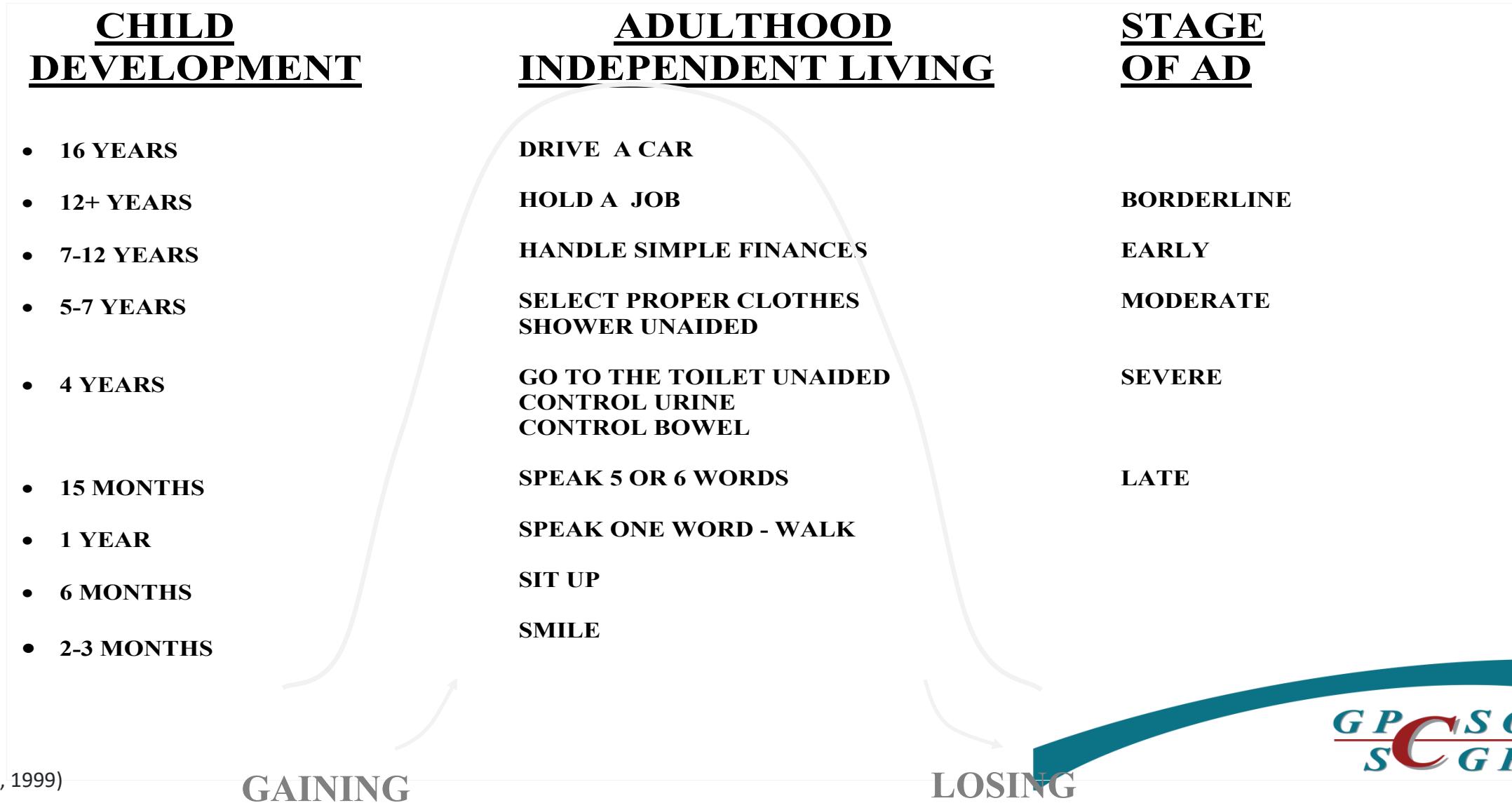


What is Dementia?

- Major Neurocognitive Disorder
 - Various types of dementias
- ❖ At least 2 parts of the brain are actively dying
- ❖ It is progressive & always changing
- ❖ It is chronic (there is no cure)
- ❖ It is terminal (but so is life!)
- Changes in memory & thinking. These changes affect a person's **ability to function** in their day-to-day lives (ADLs + IADLs)



REGRESSION-DEVELOPMENT ANALOGY (Reisberg)



Functional Assessment Staging Test (FAST)

(Reisberg, 1988)

Stage		Brief description	Developmental Age	Average duration of stage
1	Normal	No deficits	Adult	N/A
2	Possible MCI	Subjective deficits	Adult	Unknown
3	MCI	Difficulty with complex IADLs	12+	7 years
4	Mild	IADLs affected (cooking, bills)	8-12 years	2 years
5	Moderate	Needs help selecting proper attire	5 - 7 years	1.5 years
6a	Moderately Severe	Needs help putting on clothes	4-5 years 2- 4 years	3.5 – 9.5 months
6b		Needs help bathing		
6c		Needs help toileting		
6d		Urinary incontinence		
6e		Fecal incontinence		
7a	Severe/ Advanced	Language: 5- 6 words	12- 15 months 1- 8 months	1 – 1.5 years
7b		Language: 1 word		
7c		Walking		
7d		Sitting		
7e		Smiling		
7f		Holding one's head up		

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Tailoring Activities: Early Stage

Attention Span	~20 minutes, requiring 1-2 verbal or visual cues
Set up within environment	Supplies need to be within reach: 2ft in front and/or to each side Can attend to group leader from various locations of the room
Awareness of activity purpose	Aware of object of game, goal, item to be made May benefit from use of a sample project
Communication abilities	Can speak in phrases, share stories, conversational style may be self-centered. Able to read out loud; may have reduced comprehension.
Physical attributes	Gross and fine motor movements are functional (if no physical condition)
Problem solving	Situations presented need to be familiar, concrete thinking (\neq abstract)
Sequencing	Assistance required to sequence through new activity (step by step)

Tailoring Activities: Early Stage

Ability to attend to or initiate activity	Aware that activities are going on; can express interest or desire to attend. May need assistance or cueing to choose an activity. May need assistance with getting to the activity on time and to locate where it is being held if unfamiliar.
New learning	Difficulty learning new information but may learn with repetition Most successful when tied to the person's interests and skills
Ability to follow directions	Can follow simple verbal directions
Social abilities	Able to take turns, may interrupt conversations of others, make blunt or frank remarks.

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Tailoring Activities: Middle Stage

Attention Span	5-20 minutes, requiring intermittent cues
Set up within environment	Supplies need to be within reach: ~1ft in front of the person Should be within 3-6ft of group leader (in front or to the side)
Awareness of activity purpose	Unaware of object of game, goal, item to be made however is aware of the action to be performed. Unlikely to benefit from use of a sample project
Communication abilities	Less likely to ask for assistance when needed as unable to recognize the need for assistance. Speaks slowly / short phrases. Can share stories from the past
Physical attributes	Gross motor movements of arms and legs are present / functional (if no physical condition exists). Fine motor movements might be clumsy and slow however will be able to grasp, manipulate, move, explore objects with hands
Problem solving	Markedly reduced; requires assistance

Tailoring Activities: Middle Stage

Sequencing	Assistance required to sequence through activity (step by step)
Ability to attend to or initiate activity	Not aware that activities are going on; may express limited interest or desire to participate in a highly valued and familiar activity (due to apathy). May need assistance or cueing to choose an activity. Will require assistance with getting to the activity on time and to locate where it is being held (familiar and unfamiliar).
New learning	Difficulty learning new information, even with repetition. Activity should be presented as though new each time and broken down into one step. Most successful when tied to the person's interests and skills
Ability to follow directions	Able to follow simple, one step verbal directions
Social abilities	Needs cues to take turns during activity. May need assistance to interact with others or engage in conversation. May interrupt conversations of others to report own needs and concerns.

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Tailoring Activities: Late Stage

Attention Span	Requires constant cueing; limited attention span (1-2 mins)
Set up within environment	Supplies need to be within 1ft in front of the person Should be as close as possible to group leader (1-2 ft in front) *Requires 1:1 support throughout the activity
Awareness of activity purpose	Unaware of object of game, goal, item to be made May respond to actions (e.g. demonstrating gross motor movements such as throwing).
Communication abilities	Limited reading and writing ability. Will not ask for assistance (unaware of need). Can speak a few words / short statements.
Physical attributes	Can hold objects placed directly into their hands. May get lost in familiar surroundings. Gross motor movements of arms and legs are present but may need ++cueing to perform (if no physical condition exists).
Problem solving	Unable to solve problems; dependent on others.

Tailoring Activities: Late Stage

Sequencing	Needs total assistance to perform a one step action.
Ability to attend to or initiate activity	Not aware that activities are going on; not likely to express interest or desire to participate in any activity (apathy). Will need others to choose activities based on past interests / abilities. Requires 1:1 assistance with getting to the activity on time and to locate where it is being held.
New learning	
Ability to follow directions	Able to follow simple, one step directions with hand over hand assistance and / or demonstration.
Social abilities	Will need 1:1 assistance to interact with others or engage in conversation. Will demonstrated minimal verbalization and awareness of others.

Application

Card Game

Goal:

- Offer cognitive stimulation to promote and maintain cognitive abilities
- Promote and maintain self-expression and sense of self
- Offer opportunity for socialization
- Offer upper extremity exercise to promote and maintain range of motion, strength and dexterity

Warchol et al. (2002)

Early Stage:

- ✓ May assist with planning, set-up, choosing the game, helping a neighbour
- ✓ Can participate actively for a minimum of 20 mins with 1-2 verbal cues
- ✓ May be able to use cards appropriately to form hands, suits, etc.
- ✓ May need occasional cues to make decisions about what to play
- ✓ If highly familiar activity, may need less support

Middle Stage:

- ✓ Will need 1:1 sequencing to assist with game broken into single steps
- ✓ Cannot follow goal of game
- ✓ Can be expected to participate for 5-20 mins requiring occasional cues
- ✓ Will enjoy using hands to turn over the cards, shuffling them
- ✓ Can sort the cards according to colour (red in one pile, black in the other)

Late Stage:

- ✓ 1:1 sensory stimulation opportunities can be provided (e.g., manipulating the cards in the person's hands, rolling dice, watching others)

Cards Example



Application in Group Setting

Arts and Crafts: Creation of a Birdhouse

Goal:

- Offer cognitive stimulation to promote and maintain cognitive abilities
- Promote and maintain creativity, self-expression, and sense of self
- Offer opportunity for socialization
- Use of fine motor skills, range of motion, strength and dexterity

Warchol et al. (2002)

Early Stage:

- ✓ May assist with planning, set-up, clean-up, helping a neighbour
- ✓ Can participate actively for a minimum of 20 mins with 1-2 verbal cues
- ✓ Can sequence self through the steps if familiar
- ✓ Quality of work may have minor errors. Praise involvement without offering critique on end-product.

Middle Stage:

- ✓ Will need 1:1 sequencing to assist with tasks broken into single steps
- ✓ Limit choices to 1 of 2
- ✓ Can be expected to participate for 5-20 mins requiring occasional cues
- ✓ Will enjoy repetitive motions such as sanding wood, painting, etc.
- ✓ May only complete one step of the project due to short attention span

Late Stage:

- ✓ 1:1 sensory stimulation opportunities can be provided around the theme (e.g., recording of birds singing, photographs of birds)

How do we Measure Success?

- What are the person's expectations?
 - To feel less alone
 - To move
 - To have fun
 - To feel connection with others
- Even if they didn't get it 'right', offer **PRAISE**
 - "Good job!"
 - "Your help really means a lot to me"
 - ↑self-esteem, sense of purpose, belonging



How do we Measure Success?

Consider our own / caregiver's expectations regarding the success of the activity

- E.g., if we expect them to complete it exactly as we laid it out, we may never feel that it was a 'success'
 - Managing expectations about the end result

If the person is consistently struggling with completing the activity, perhaps we need to look at adapting the activity to suit changing needs

- Increasing or reducing the degree of difficulty



Keys to Presenting an Activity: The Montessori Way



While each activity comes with specific instructions, these "Keys to Presenting" offer suggestions and techniques to make activities more meaningful and effective.

Before Getting Started

- Make sure that the area is free of distractions and has good lighting.
- Have a work surface that contrasts with the activity materials to make them more visible (a dark mat when using white cards, for example).
- Read the instructions for the activity and follow the recommended steps. They are designed to follow a logical progression with one step building on the previous.
- Review and familiarize yourself with the materials.
- Identify areas of particular interest to the person so that you can focus on those.
- Set up as much of the activity as possible before inviting the person to join you.
- Have a plan in case the person doesn't want to do the activity:
 - » Be prepared to start doing it on your own in the hope that they will join in.
 - » Have another activity ready to go as an alternative.

The Concept of Correctness

- There is no such thing as "correct" when doing an activity - "correct" is relative.
- If the flow goes in ways you didn't expect, encourage it and follow the lead of the person. It is not our definition of success that is important, it is the participant's version.

10 Keys to Presenting

- **Invite the person to join you**
- **Offer a choice**
- **Demonstrate, don't explain**
- **Start simple**
- **Let the person do it**
- **Give them time**
- **Watch for frustration**
- **Success is relative**
- **Don't correct "mistakes"**
- **Follow their lead**

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that one?" - this may help them find the answer.

» Move the piece to the correct position and ask if they think it goes better there - if they say yes, leave it, if not, move it back.

• Remember that engaging the person in meaningful activity is the goal, not completing the activity in a pre-defined manner.

More tips and ideas on the reverse...

© Keeping Busy Inc.

Visit keepingbusy.com for articles and information about presenting activities effectively

Keys to Presenting an Activity: The Montessori Way

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10 Keys to Presenting



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Offer a choice



Demonstrate, don't explain



Start simple



Let the person do it



Give them time



Watch for frustration



Success is relative



Don't correct "mistakes"



Follow their lead

Barriers to Implementation at Home

- The caregiver's ability to be the "starter button"
 - Exhaustion, burden
 - Lack of respite / informal support
 - Expectations are incongruent with the client's cognitive and functional abilities
 - E.g., "It doesn't work, he won't sit for more than 5 minutes!"
- Assumptions about the person's skills and abilities
 - If the focus is primarily on loss, it can be difficult to imagine what is still possible



Barriers to Implementation in Community Groups

- Staff to participant ratio and available resources
- Large heterogeneity within the group
 - I.e., Differing needs, level of cognitive and physical abilities, behavioural and mood concerns
- Ensuring the participants are well-matched can help



Promoting Opportunities for Meaningful Engagement

- Being able to actively participate by:
 - ✓ Contributing ideas
 - ✓ Making choices
(e.g., choosing between one activity or the other)
- Benefits of this type of approach:
 - ✓ Feeling heard and treated as an equal
 - ✓ A growing sense of purpose and accomplishment
 - ✓ Increased self-esteem





Thank you!

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