

NATIONAL INTELLECTUAL DISABILITY MEMORY SERVICE



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THE LANGUAGE OF BEHAVIOUR: UNDERSTANDING AND ALLEVIATING EMOTIONAL DISTRESS IN PERSONS WITH DEMENTIA DURING LOCKDOWN

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Understanding Emotional Distress

- People with dementia are..... *“trying to survive in a world full of uncertainty and insecurity”*.
- Their world is different than our own but it is a world we can understand if we pay attention to it.



Origins of the behaviour

- Loss of neurotransmitters occurs normally with the ageing brain
- **BUT**, if you have dementia this loss may become much more significant and result in certain changes in behaviour.
- For example, the area of the brain that controls the sleep/wake cycle may be affected and consequently the sleep pattern will become very erratic.
- If the frontal lobes are effected there will be marked changes in personality and behaviour.



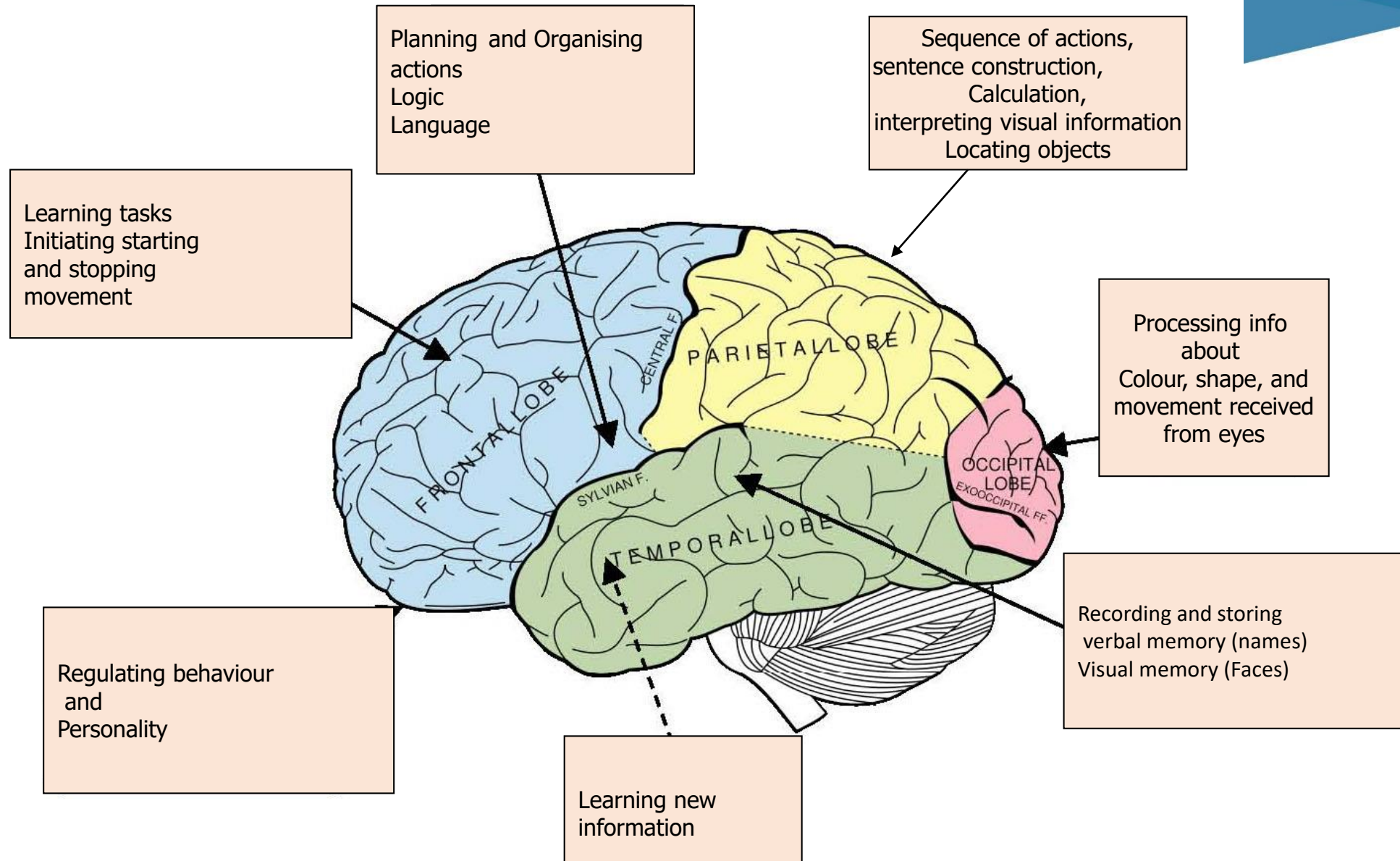
Origins of Behaviour

- The area responsible for spatial perception may be affected making it difficult for the person to recognise objects or to identify their surroundings.
- The lateral frontal lobes of the brain may be affected causing the person to get '**stuck in the moment**' causing them to repeat themselves over and over and causing distress.
- **HOWEVER**, only some behaviours can be attributed to neuropathology.
- Many other variables which impact on behaviour i.e. physical, psychological and social factors must be considered.

We must take on a bio-psychosocial approach to care.



The brain is divided into different regions - known as lobes – each control different functions



Responsive Behaviours

- Dementia is characterised by changes in behaviour that are often viewed as responsive
- ‘Responsive Behaviours’ are behaviours that challenge **US** as carers – family or professionals.
- They are behaviours that **WE** find “tough” ; “testing”; “emotionally draining” to deal with.
- However these behaviours may not always pose a problem for the person!



Some Common Responsive Behaviours

- Personality changes
- Agitation – distress
- Shouting
- Verbal aggression
- Throwing objects
- Stripping
- Physical aggression
- Sleep disturbance
- Repetitive talking
- Paranoia/accusations
- Resistance to care
- Food refusal
- Wandering
- Socially inappropriate behaviours
- Sun-downing
- Hyperacusis



Delirium also occurs frequently in older adults, especially in those who are cognitively and medically compromised

Communication and Behaviour

- Behaviour is a form of communication.
- As Alzheimer's disease progresses and language skills deteriorate, individuals who previously were very expressive may respond behaviourally rather than struggling with verbally expressing his or her basic needs and wants.
- In this scenario, one's behaviour may become the key form of communication, as vocabulary becomes smaller or abilities to find words and make sentences gets more difficult.
- *To say someone is aggressive or agitated only describes the behaviour NOT the need they are trying to communicate.*

Dementia and Behaviour

- It is widely recognised that the Behavioural and psychological symptoms of dementia (BPSD) are more often the persons attempts to communicate
- In many respects, learning to effectively communicate with people with Alzheimer’s disease can feel like learning a new language.
- As caregivers we need to *“learn the language of dementia”* so that we can anticipate certain barriers and achieve the ultimate shared goal of being heard and understood.



Why is emotional distress seen in Persons with Dementia?

1. **Dementia related causes** include pain, concurrent physical problems-constipation, sensory impairments, infections, side effects to medications etc.
2. **Dementia Specific causes** often relate to a misfit between the client and the physical and social environment.



Physical Factors

- Pain / discomfort
- Infection
- Trauma
- Hunger/thirst
- Medications
- Constipation
- Dehydration
- Fatigue
- Sensory impairment
- Delirium
- *Pain Assessment*



Psychological Factors

- History of psychiatric illness (depression; anxiety)
- Response to recent losses (independence; mobility; coping skills; home; friends/family)
- Pre-morbid personality

Social & Environmental Causes

- *Over stimulation*; too much noise; too much activity; too many people
- *Under stimulation* ; boredom
- *Loneliness* ; missing family; friends
- *Social isolation*; from community; from staff; from peers
- *Environment* ; poor lighting, colour; cues; misfit between the client and the physical and social environment.
- Inconsistent *routine*
- Regular changes in staff
- Provocation by others
- *Negative attitudes* ; labelling, ageism, malignant social psychology



A Word About Pain

- Pain can frequently be an overlooked key contributor to negative behaviour, poor sleep, or agitation.
- Because pain is subjective and thus dependent on the individual's personal experience and perception of discomfort, recognition of pain symptoms can be missed by caregivers and healthcare providers.
- <https://www.stoswaldsuk.org/how-we-help/we-educate/education/resources/disability-distress-assessment-tool-disdat/>



Down syndrome & Pain

- It is so important to stay mindful of the possibility of pain as a contributing factor when behaviour, mobility, or overall demeanour changes.
- Recall the common conditions that occur with age in adults with Down syndrome: such as osteoporosis, and osteoarthritis.
- These conditions, coupled with increased immobility or risk of skin breakdown or irritation, all raise risk for discomfort or pain.



Goals of Care

- **GOAL** - To act like a “**prosthetic device**” that supports the person do what he/she is able to do
- Interventions serve like “**memory crutch**” that fills in for lost abilities
- Support person to be autonomous in spite of lost abilities
- Keeps stress at manageable level throughout the day

What can we do?

- PREVENTION is truly “the best medicine” in dementia care!!
- Keep stress at a manageable level
- Learn to recognize signals that the person is becoming uncomfortable or threatened
- Intervening early to identify & meet the need, keeping the person calm and comfortable



Interventions

Person-Centered care:

- Think about **the person** “behind the illness”
- Personal strengths, retained abilities, longstanding personality traits
- Rule out physical causes – pain, infection etc.
- Establish what is going on within & around the person that has led to the behaviour – are they upset, uncomfortable, lonely?
- Is the care giver familiar with the person, and know their life story?

The Personhood Paradigm

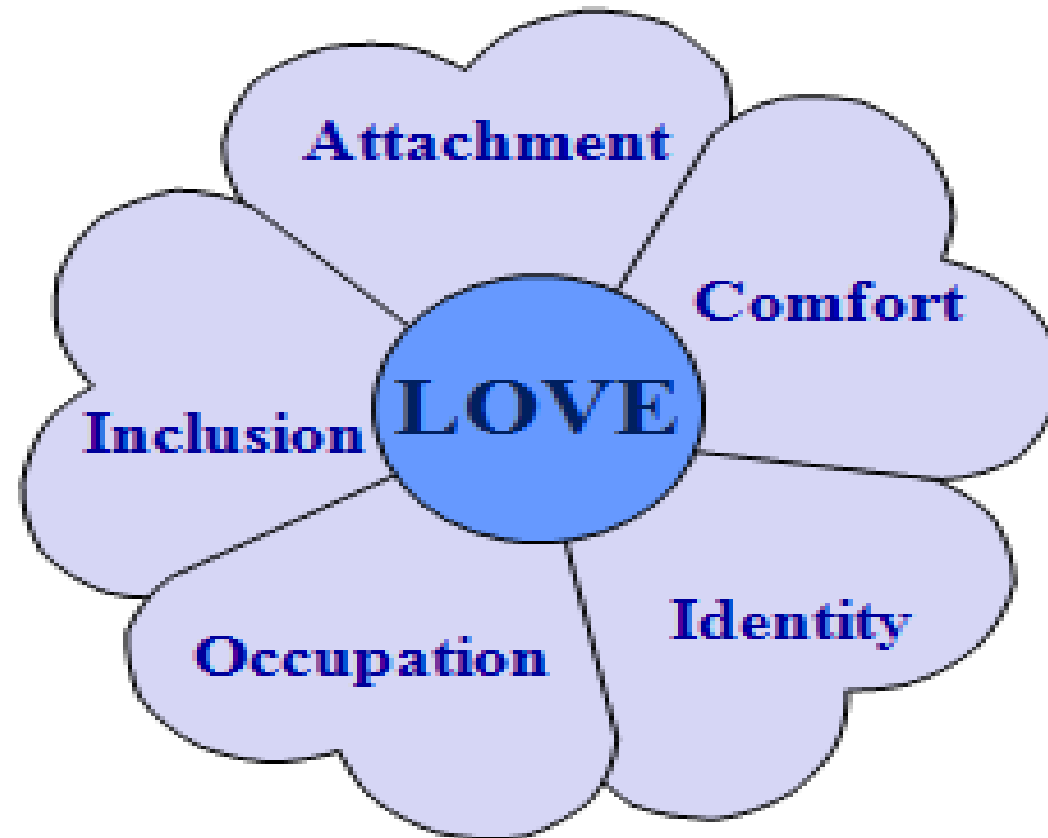
Experience of dementia is unique to the individual and depends upon the interaction of five key factors

- P= The persons Personality
- B= Their Biography
- H= Physical Health
- NI= Neurological Impairment
- SP= Social Psychology of the environment

Kitwood (1996)



What do people with dementia need?



The main psychological needs of people with dementia

Tom Kitwood (1997) *Dementia Reconsidered: The person comes first.*

Strategies for Success

- Maximize safe function by supporting losses in a prosthetic manner
- Provide unconditional positive regard
- “Listen” to the person with dementia (what does the behavior “tell you”?)
- Modify the environment to support losses and enhance safety
- Encourage caregivers to participate in ongoing education, support, self-care, and problem-solving

Strategies for Success

- **Validate feelings, empathize.** Remember that actions are often borne out of fear, so reinforce reassuring statements such as *“I’m here to help you”, “You’re safe”*.
- **Stay in the present moment** when interacting with individuals with Alzheimer’s disease. The present moment is all you have.
- **Anticipate** certain stressful events or times of day and planning accordingly to **minimize anxiety**.

Strategies for Success

- Try to **tie a pleasurable activity to a stressful activity** to make it more manageable. For example: put on headphones and play favourite music when cutting toenails, sing songs while giving a bath
- **Do not attempt to reason or rationalize.** You will not win an argument with someone with Alzheimer's disease.

Strategies for Success

Stay engaged in pleasurable activities. Individuals will depend more on the guidance and supervision of caregivers to keep busy.

- Get familiar with the “art” of **positive redirection**. Practice shifting focus and redirecting at times of stress or escalating behaviour.

Meaningful Life enhancing Pursuits

- Life Story
- Music – individualised to person's taste
- Hand massage
- Therapeutic touch
- Social interactions
- Video of significant others (family/friends)
- Memory box
- Reminiscence
- Validation
- Doll therapy
- Pet therapy
- Previously enjoyed activities

Under Stimulation/ Boredom

- If devoid of occupation & stimulation the person may repeat themselves to alleviate boredom or may act out (may be aggressive) or may disengage.
- Redirect to and engage in meaningful activities.
- **NB** – Know the Persons life story



Human Contact

- The person may repeat things as a means of holding the presence of another, the question is unimportant – **human contact is.**
- Meet the person in their space, gentle physical contact- holding hands



Compensate for lost abilities by adjusting

APPROACHES

- Use calm consistent approach & routine
- Do not try to reason
- Do not ask to “try harder”
- Do not try to teach new routines
- Do not encourage to recover lost skills



Compensate for lost abilities by adjusting

ROUTINES

- Limit choices to ones person can make
- Monitor changes in environment
- Reduce, eliminate changes in pace
 - Routine = Familiarity and comfort
 - Repetition does not become “boring” to person with dementia

ADAPTIVE STRATEGY: IT'S NOT ANYONE'S FAULT.

- When accidents happen or frustration arises, caregivers may often revert to communication techniques that feel familiar to parenting – raising his/her voice, expressing disappointment, or repeating a list of certain set rules or expectations.
- This approach commonly yields the exact opposite of the desired outcome from the individual with Alzheimer's disease, and may increase agitation, irritability, or combativeness.

Remember to avoid correction, use positive body language, and listen and observe closely and respond to the feelings or emotion behind the message.

Positive Redirection

- To help alleviate the mounting stress or anxiety that the individual may be experiencing, **positive redirection** can be a very powerful strategy to help address and defuse negative feelings and emotions.
- This technique involves trying to gently distract or redirect an individual towards a more calming, or pleasurable activity, as a way of changing focus towards a new positive present moment.

ADAPTIVE STRATEGY: Make simple requests

- Bargaining and incentives are common strategies used by many people throughout their lifetime to encourage or reward positive behaviour, many times with good success. However, when supporting persons with dementia this strategy is no longer useful or practical.
- Behaviour strategies that are designed around future rewards based on current behaviour are destined to be a struggle, since this plan requires a working memory.



What can we do?

- *Instead, behaviour approaches should be adapted to meet the needs of the individual in the present moment. Effective strategies are those that primarily reinforce a sense of calm, reassurance, safety, and security.*
- Stay in the present moment, attempt to positively redirect any negative behaviour, and listen and respond to the emotion that the individual is expressing.

Summary

Dementia is
INCURABLE
but not
UNTREATABLE!

Preserve
remaining
abilities

Avoid
unnecessary
stress

Treat overlapping
illness that makes
symptoms worse

Provide education
& guidance to
families

Summary



Staff need to:

Understand
and know the
person

Understand
dementia

Think ahead
and predict
'stressors'

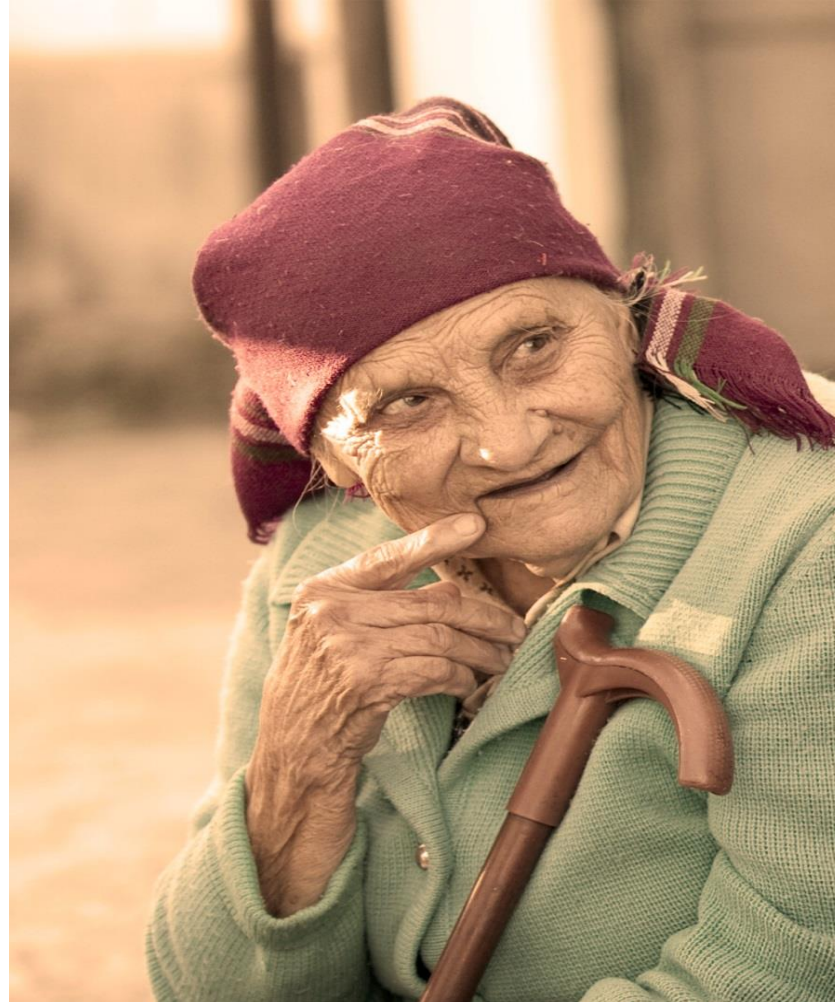
Keep the Person at the centre

- The most important consideration in caring for a person with ID and dementia is that the needs of the person are paramount:
- People with dementia need to have/be
 - Stress Free
 - Failure Free
 - Individualised care
 - Consistency but without time pressure.



Finally

Each Person's
experience of
Dementia is
as unique as
their finger
print!



The National Intellectual Disability Memory Service is a partnership between the Trinity Centre for Ageing and Intellectual Disability, Trinity College Dublin, Tallaght University Hospital and the Daughters of Charity Disability Support Service.



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Thank You