



Maintaining the Person

Optimising Communication
when Dementia gets in the way

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Presentation assumes an understanding of

- Definition of dementia
- Understanding of all the major subtypes of dementia
- The type of communicative breakdowns characteristic of these different types
- An overview of the current literature, including Person Centred Care

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Overview

- Importance of human communication & Person Centred Care (PCC)
- Obstacles to communication with the Person with Dementia (PWD)
 - Patient factors
 - Environmental factors
 - Communication partners
- What can we do to improve communication?
 - Generic strategies
 - Specific ideas

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Communication

- ‘impart’ ‘confer’ ‘interrelate’ ‘make contact’
- At the heart of all human connections
 - Sharing meaning
 - Fostering of social connections
 - Basic human need
 - Basic human right
 - Enables us to project our identity
 - Communication is an ‘act’ and a ‘process’
(Young et al 2011)



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Communication: Losses

- Dementia profoundly affects a person’s ability to communicate effectively
 - Loss of self; purpose & identity
 - Loss of emotional and social connections
 - Loss of meaning
 - Confusion and bewilderment
 - “I have lost myself” Auguste D,
(The first person to be diagnosed with Alzheimer’s disease)
- Affects all aspects of a person’s life and their
 - ‘Emotional Need’ (Kitwood)
 - ‘Personhood’ (Kitwood)

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Model of Emotional Need (Kitwood)

ATTACHMENT	Feelings of security associated with strong bonds with others
INCLUSION	Need to belong to a group and have social interaction with others
OCCUPATION	To be involved in meaningful activity
IDENTITY	Sense of self – knowing who we are and where we fit, connecting with their past
COMFORT	Closeness, calming, soothing, feeling of security, empathy and support from others

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Communication: Kitwood's Personhood

- A unique interplay
 - Dementia
 - Neurological impairment
 - Personality
 - Biography
 - Physical health
 - Physical environment
 - Social environment



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Communication: Person Centred Care

- More than individualised care
- Kitwood brought together ideas and ways of working with dementia patients emphasising communication and relationships and exploration of their lived experiences
- Social model which emphasises well-being, social inclusion, and self-management and hope
- Promotion of personhood, despite deteriorating cognition, where the rights and respect for the person as an individual is paramount

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Obstacles to communication: Patient factors

- Hearing and/or Visual deficits
- Language barrier/ESL
- Personal Characteristics
 - Limited education
 - Personality/Transference
 - Cultural background
- Physical discomfort
 - Pain
 - Constipation
 - Hunger/thirst

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Patient factors: Cognitive

- Memory deficits (STM, LTM, WM, Procedural)
- Executive Dysfunction
- Attention
- Concept formation (comprehension) & Association between objects/ideas
- Reasoning (problem solving),
- Symbolisation

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Patient factors: Cognitive and medical

- Confusion
- Delirium
- Perception
- Agnosia (5 senses)
 - Associative
 - Recognition (faces, objects)
- Poor mental imagery



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Patient factors: Cognitive-linguistic

- Word finding difficulty (poor retrieval and reduced vocabulary)
- Difficulty inferencing (relating language meaning to situations)
- Difficulty reasoning and following logical argument and complex ideas
- Difficulty considering hypothetical situations
- Difficulty with humour and sarcasm

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Patient factors: Speech & Language

- Speech deficit (articulation, prosody)
- Voice deficits (volume, quality)
- Abnormal vocalisation (tics, screaming, grunting, tardive dyskinesia)
- Expressive Dysphasia (semantic, phonemic, syntactic)
- Receptive Dysphasia (semantic, phonemic, syntactic)

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Patient factors: Behavioural & Mental Health

- Depressed Mood
- Apathetic
- Irritable Mood
- Angry Mood
- Elevated Mood
- Disinhibited
- Suspicious



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Patient factors: Behavioural & Mental Health

- Anxious
- Agitated
- Hallucinations
- Delusions
- Confabulation
- Tangential/Over-inclusive
- Thought disorder

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Environmental factors

- **Setting**
 - Garden, sitting room, bedroom, ADLs
 - Seating & furniture arrangement, accessible
- **Visual**
 - Lighting, visual contrast between walls, items and floor, etc. Pictures
- **Auditory**
 - Noise, alarms, acoustics, quiet, music, etc
- **Tactile/olfactory**
- **Odours, appropriate items, textures**

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Environmental factors

- **Look for environmental clues to help understand the patient's communication**
- **Is the patient**
 - Requesting, denying
 - Wants attention, privacy
 - Is the setting uncomfortable
 - Is the activity difficult
- **Problem solve if there are adverse communication behaviours, shouting, etc**

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Personal environmental factors

- **Mindfulness and empathy**
- **Understand behaviour**
- **Understand 'unmet need'**
- **Get to know their life history, significant others, preferences, etc. and anticipate how they might see things, their culture**
- **Prompt and cue PWD to help their understanding**
- **Help them retain a 'sense of self'**



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Environmental factors



- Many of our patients have very little verbal expression. Clavel (1999) looked at simple vocalisations by demented elders, and analysed the possible message, in order for us to anticipate their needs:
 - “I’m tired, I hurt, I need, I’m lonely, I’m stressed (sensory overload), I’m bored (lack of sensory stimulation) What are you doing to me?(personal boundaries invaded) . I don’t feel well, I’m frustrated (loss of autonomy) . I’m lost (memory impairment) . I feel strange (medication side effects) I need attention/affection”

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Acknowledge yourself as a communication partner

- Attitude
- Assumptions
- Countertransference
- Cultural background
- Style of dress
- Lack of patience
- Rushing
- Lack of empathy
- Language/accents



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Our responsibility as care providers

- Take on the communicative responsibility to optimise communication for PWD
- ***
- Based on principle of maximising ‘quality of life’ (QOL)
 - Focusing on ‘Functional Communication’ in ‘Activities of Daily Living’ (ADLs)
 - ‘Person-centred Approach’ (Kitwood, Brooker 2007)

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What can we do ?
Role of the Speech Pathologist

- Assist differential diagnosis of dementia
- Identify communication strengths and weaknesses
 - Cognitive linguistic assessment
 - Compensation strategies – what works/doesn't
 - Communication partners
 - Environment & social setting



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Goals of Speech Pathology

- Design individualised interventions to improve communication abilities – for earlier stages
- Train compensatory strategies to facilitate communication in everyday interactions and activities
- Educate PWD and family/carers about the impact of the type of dementia on communication
- Modify the environment to help communication
- Troubleshoot individual communication issues causing barrier to meaningful relationships, activity and participation

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Speech Pathology strategies

1. Enhance depleted cognitive and memory skills

- Orientation - to time/place/person - using clock/calendar/photos
- Attention - eg. picture 'what's missing?'
- Associations – repeatedly bring into consciousness, concepts, events, and words, that are associated, eg. completing common phrases
- Memory aids – using cues, labelling (verbal & written) schedules, pictures

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Speech Pathology strategies

2. Reduce demands on cognitive systems and memory

- Reduce sentence length and complexity
- emphasise important information
- use cues for next step
- chunk information
- Simplify syntax with slow multi-modal approach
- Talk about 'here & now'
- use nouns not pronouns
- ask 'choice questions' to help semantics
- 'Revise and restate' to help pragmatics



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Speech Pathology strategies

3. Increase reliance on less impaired cognitive systems

- Use Procedural memory for *cortical dementias*, eg. *Alzheimers*
 - use familiar, habitual procedures and context to prompt names and function in ADLs
- Use Factual memory for *subcortical dementias*
 - use names and function to prompt procedure in ADLs



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Tools: Dementia Toolkit for Effective Communication (DEMTEC). Young & Manthorp, 2009, 2011

- 3 Level strategy framework, where PCC informs and guides the 8 components of good communication practice – What/why/how
 - Conversation
 - Non-verbal communication
 - Environmental considerations
 - Anxiety reduction
 - Mindfulness & empathy
 - Understanding behaviours
 - Retaining sense of self
 - Checking understanding

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Tools: Support memory to help communication
 – RECAPS. Liddle et al 2012

R – REMINDERS	Spoken prompts Word & picture reminders
E – ENVIRONMENT	Permanent place for objects Don't change environment
C – CONSISTENT ROUTINES	Keep up familiar routines Make routines
A – ATTENTION	Avoid distractions Focus attention
P – PRACTICE	Maintain skills through use Practice new skills
S – SIMPLE STEPS	Break into simple steps Allow extra time

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Tools: Communication Strategies – MESSAGE
 Liddle et al, 2012

M – MAXIMISE ATTENTION	Attract attention Avoid distractions One at a time
E – Watch your EXPRESSION & BODY LANGUAGE	Relaxed and calm Show interest
S – Keep it SIMPLE	Short simple and familiar Clear choices
S – SUPPORT THEIR CONVERSATION	Give them time Find the word Repeat then rephrase Reminders of the topic
A – ASSIST WITH VISUAL AIDS	Gesture and actions Objects and pictures
G – GET their message	Listen watch and work out Note behaviour and nonverbal messages
E – ENCOURAGE & ENGAGE in communication	Interesting and familiar topics Family and friends

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Tools: Specific Communication Interventions

- Non-verbal communication supports PWD ability to understand, and encouraging them to use it helps them to convey meaning
 - Eye contact & eye movement
 - Gaze (direction & intensity)
 - Facial expressions
 - Hand gestures and touch
 - Body posture and orientation
 - Voice volume, tone, pitch, intonation, speed & vocalisations, (um, ah)
 - Dress and adornment



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Tools: Non-Verbal Communication

- 80% of our communication is via NVC and only 20% via verbal communication
- The ability to understand NVC lasts longer than the ability to understand speech
- Using NVC encourages the PWD to use it to respond
- NVC can provide an essential 'addit' to verbal communication; enabling the PWD to 'fill in the gaps' of understand what is being asked of them, or said to them – where only verbal communication would be insufficient
- Be very mindful of your NVC to the PWD

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Tools: Conversation



- Conversation fosters connections; the 'act' of conversation for the PWD can be as rewarding or more, than the exchange of ideas
- Conversation acknowledges someone as a person. It is not 'just chatting'
- The PWD is considered 'hard' to converse with, as they contribute less to the 'give and take', of the conversation, and then they get less practice too, and become more isolated.
- Make time to converse with the PWD. Routine, or: "I'll be back in a minute and we'll have a chat"

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Tools: Conversational Tips


- When speaking:
 - Touch the PWD to reassure, gain attention, signal a change in question/topic
 - Use simple language, not long/complex sentences/words
 - Use nouns, not pronouns
 - Revise and re-state
 - Say it another way – do not repeat
 - One idea at a time
 - Key words at the end
 - Use conventional greeting and finishing phrases eg. "Lovely to see you." " See you later"
 - Keep all instructions 'short and simple'

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Tools: Conversational Tips

- When listening
 - Give the PWD your full attention
 - 'listen 'actively' ; use body language
 - Focus on the positives
 - Make the PWD feel valued
 - Validate their comments by empathy and understanding
 - Ignore meaningless expression
 - 'bring back to topic' if PWD is tangential/confabulates
 - Reassure, redirect and distract, if PWD escalates in distress about a topic
 - Do not reinforce incorrect information they provide, but do not lie either
 - Thank the PWD for their comments and company



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Tools: Conversational Tips

- Concentrate on 'conversational rules' & the environment
 - Always introduce yourself to remind and reassure
 - The setting
 - The seating and comfort, lighting, environment
 - The topic
 - May use a focus, especially as the PWD has little expressive language, eg Cup of tea/cake, items, magazines
 - Talk about the 'here an now'/whatever they are doing
 - Reminisce

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Tools: Conversation Tips

- Keep the 'turntaking' going, even if the PWD says little
 - Can do this by conversational 'tone of voice' and use 'filler phrases eg. "oh do you see this?" "Oh that's interesting – look"
 - Allow time to respond, pauses
 - Use lots of supportive and reassuring NVC
- Fels & Astell (2011) studied storytelling in PWD. They found 4 basic concepts of storytelling was retained, even in the later stages of dementia:
 1. The story text (gist)
 2. The context and socio-cultural setting
 3. The audience or listener contribution
 4. Performance ownership and control over the story



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Tools: Concept checking

- Always check the PWD understands, particularly if you are trying to convey a specific message, idea, instruction, etc
 - PWD may distract self with 'off topic' talking
 - PWD may be distracted by the environment, unmet need, physical preoccupation, repetition of ideas or behaviour
 - PWD may be exhibiting BPSD
- Use patience and positive reinforcement
- Revise and re-state, etc

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Tools: Other ideas

- Life Story/Chat Books
 - Captures a person's life; memories, stories, etc
 - Enjoyable and empowering activity for PWD
 - Promotes sense of self
 - Opens up communication between PWD and others
 - A good tool for reminiscence, and draws on better LTM
 - Enriches relationships and carer's understanding as disease progresses, and PWD may have BPSD
 - PCC

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Tools: Life Story/Chat books

- Work with the PWD and their significant others to compile photos, pictures, objects:
 - Memories
 - Family & people
 - Places
 - Work
 - Hobbies & interests
 - Holidays
 - Significant achievements/milestones



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Tools: Groups



- Fosters social connection, and 'normality' of social gatherings
- Draws on 'non-verbal' and LT 'learned skills'
 - Turntaking and conversational rules
 - Provides role modelling
 - Provides cues and prompts
 - Selected topics for reminiscence
 - Objects to touch/smell/see and elicit communication
 - Information sharing on similar past experiences
 - Reinforces self and value as a communicative partner

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Tools: iPads and Dementia

- Apps for 'meaningful activities'
 - 'Life Story/Chat Books'
 - Past experiences, hobbies, interests, etc
 - Work on memory recall or word-finding
 - Interactive – eg You Tube
 - Support Independent Living
 - Social connection, eg SKYPE



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Case Studies

- I hope you feel confident now to optimise communication with the :
 - Mild community client at home
 - The hospitalised client in an acute older age psychiatric assessment unit
 - The moderate to severe nursing home client
- Use the content of this presentation to test yourself on how you would maximise communication

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Case Studies

- By considering the:
 - Patient factors
 - Environmental factors
 - Communication partners



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