

Developing a Dementia Toolkit for Effective Communication

DSIDC
St James Hospital, Dublin
November, 2011

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Overview

1. Motivation for the project
 - *The challenge of dementia*
 - *Supporting 'Personhood' through communication*
2. A toolkit for effective communication
 - *Development*
 - *Finalising*
 - *Testing and disseminating*
 - *Outcomes*
3. Your comments, questions...

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The Challenge of dementia for societies

- 820,000 people living with dementia (PLWD) in the UK
- 1.7 million with a care need by 2025
- 1/4 of people over 82
- 1/3 of people over 95
- High cost of care as populations age
- A global problem – currently c. 3, 000,000 – 100,000,000 by 2050

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The challenge of dementia for individuals

- Loss of cognitive functionality:
 - Memory
 - Reasoning
 - Selfhood
- Impairment of communicative ability
- Need for effective communicative greater than ever - importance of effective communication with social partners, especially carers (formal and/or informal)
- Positive effects of experience of empowerment

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Acknowledging Personhood in Communication

- Strictly biomedical approach prevails but is problematic
- Communicative Predicament of Aging (CPA) model (Ryan, Giles, Bartolucci, & Kenwood, K., 1986)
- Need for a recognition of Personhood (e.g. Kitwood, 1997) - life history, beliefs, values, individual wants, resistance to socially-constructed 'otherisation' of sufferers
- Communication Enhance Model (CEM) (Ryan, Meredith, MacLean & Orange, 1995)



Mutual empowerment of PLWD and their social partners ⁵

Current situation for carers

- Little explicit communications guidance for formal or informal carers
- What exists in UK (e.g. Alzheimer's Society, 2005) tends to be:
 - minimal
 - and/or not clearly indexed
 - and/or not linked to underlying principles/theory/research

A way forward...?

- A three-level *Dementia Toolkit for Effective Communication (DEMTEC)* modelling agreed best practice in optimising communication:
- 1st author (Manthorp) – Nurse, Bradford Dementia Group, residential care manager, writer, advisor to Barchester Healthcare and the Joseph Rowntree Foundation (actual guidance)
- 2nd author (Young) - Communications researcher (theoretical and empirical background, overall framework)
- 3rd author (Howells) - Psychiatrist and old age care specialist (contributing at all stages)

Project partners

With the Alzheimer's Society UK, Manthorp, Young and Howells organised a consultative process and wider participation:

- People living with early to mid-stage dementia (via self help groups)
- family members of people living with dementia
- psychiatrists, speech and language therapists
- care home managers and workers
- sheltered housing wardens, managers

Methodology

- A series of consultations (groups and individuals), 100 people
- All stakeholder groups (PLWD, carers, professionals...)
- Input on:
 - Need for a communications intervention
 - Shape and content of level 1
 - Components of level 2
 - Real-life scenarios for level 3

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Findings

- A pressing need for an intervention – many examples of bad practice, centrality of good communication in people's lives, even more pressing when living with dementia....

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Agreed structure of DEMTEC

Level 3	Actual communication, training, care plans
↑	↑
Level 2	Components of good communicative practice (each with a <i>what</i> , <i>why</i> and a <i>how</i>)
↑	↑
Level 1	Beliefs about effects of dementia on communication and about approaches to optimising effective, empowering communication

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Level 1

- Statement of the nature of the communicative impairments and their consequences
- Resultant downward communicative spiral (inappropriate communication to stereotype reinforces impairment) – CPA model
- Instead- reinforce agency, support a sense of self, help to retain and regain competencies (CEM)
 - Stress personhood
 - Stress the need for evolving an individual approach
 - Guidance rather than iron rules in an evolutionary framework

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Level Two Components

- Conversation
- Non-verbal communication (NVC)
- Environmental considerations
- Anxiety reduction
- Mindfulness and empathy
- Understanding behaviours
- Retaining a sense of self
- Checking understanding

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Audience-specific versions

- We developed different versions of the core *DEMTEC*
 - Same template and basic structure
 - Advice tailored to different audiences
 - PLWD, family members, health care assistants, **health care professionals** (today's focus...)

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Level 2 example: Mindfulness and empathy (1)

- **What are they?**
- *Mindfulness and empathy represent a commitment to finding meaning in confused speech or behaviour through your understanding of the individual, their motives and their circumstances. They constitute having an openness to 'clues' to meaning in speech, behaviour and their linkage. This might involve being open to gestures that suggest distress or need, or repetitions that suggest that something is important, or fractured or unusual language that might be hinting at a particular target, rather like a cryptic crossword clue.*

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Level 2 example: Mindfulness and empathy (2)

- **Why are they important?**
- *Although it is often difficult (and sometimes impossible) to find meaning in confused speech, the alternative of assuming that all speech from people living with dementia or advanced dementia is meaningless isolates and alienates the individual, undermining their self-confidence and has a self-fulfilling quality. A mutually agreed consensus on meaning can often be arrived at – even if the main focus of concern may shift for the individual living with dementia. A sense of communication is a validating and comforting experience for both parties. As with everyone, people living with dementia have the right to have reasonable desires satisfied where possible.*

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Level 2 example: Mindfulness and empathy (3)

Key implications (extracts)

- Try to relax! Allow yourself to go for instinctive 'feelings' for what a person might mean.
- Bring an understanding of the individual to this process – for example, someone who is frequently hungry may often be referring to meals; someone who hates being confined may often be trying to find ways to express a desire to leave; a car mechanic might be given to lying under tables, etc.
- Bring an awareness of environmental and physical circumstances to exchanges – on hot days people will often want to ask for a drink!
- Time of day may also be an issue – some of us aren't 'morning people', and many people living with dementia have unusual waking and sleeping patterns.
- Those with living with dementia may not adhere to familiar cultural norms in many aspects of behaviour and their needs may best be met through a flexible approach and respecting their individual wishes...

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Level 3

Actual communication, training and care plans

- Use of scenarios to illustrate reflective practice in reality

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Now...

- We have a finalised toolkits for testing in the UK and beyond (adapted versions for different user groups, also for different language/culture groups (e.g. non English L1 carers and PLWD in the UK and in Hong Kong)
- Undertaking wider consultation and dissemination
- Establishing web-sites
- Seeking funding for testing (evaluation)...

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Evaluating a finalised DEMTEC

On a pre and post intervention basis:

- *DEMQOL* and *DEMQOL-proxy* (Smith et al, 2007):
 - daily activities and self-care,
 - general health and well-being,
 - cognitive functioning,
 - social relationships, and self-concept)
- Semi-structured group interviews with PLWD and formal and informal carers (anything missing, extraneous, etc)

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Outcomes (1)

- Many different 'DEMTECs', free to all users, adapted for different users, contexts, settings and languages
- A cost-effective enhancement of the quality of life for people living with dementia. Greater agency, empowerment and reinforcement of identity for individual sufferers, and enhanced and better relationships with carers
- The establishment of a comprehensive national and international benchmark for effective communication with people living with dementia
- The use of this in carer and health care professional training and in informal carer guidance, in the UK and internationally

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Outcomes (2)

- The first testing of an inclusive process approach to innovation in communicative practice in health care environments
- Empirical testing of the efficacy of interventions based on a person-centred approach to communication involving people living with dementing illnesses, and of specific strategies based on work relating to the CPA model and the CEM

Testing the efficacy of DEMTEC should help to advance the research agenda, and broaden our understanding of the processes involved in operationalising personhood and empowerment in the health communication context.

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*Developing a Dementia Toolkit for
Effective Communication*

Thank You!

Your questions, comments...?

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References and further information

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