

DementiA Education Programme Incorporating ReminiscenceE for Staff (DARES)

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*“A DementiA Education Programme
Incorporating REminiscence for Staff -
Designing the trial*



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Background

- 38,000 people with dementia in Ireland, 40% of these are in residential care
- Residential care staff sometimes find caring for people with dementia challenging
- Calls from nurses for increased training & education
- Increasing recognition that psychosocial interventions may be important
- Reminiscence now accepted as a therapeutic approach to working with people with dementia but evidence evaluating effectiveness limited



Effectiveness of reminiscence with people with dementia

- Weak body of evidence on effects of reminiscence
- Cochrane review included only five RCTs –(Small trials with total of 174 people with dementia) and some of poor quality (Woods 2005).
- Each examined different types of reminiscence
- Some impact on mood and cognition; reduced care-giver stress in some circumstances
- ‘In view of limitations of studies reviewed.....urgent need for more quality research’



WHAT IS DARES

- Cluster randomised trial, with an embedded qualitative component
- Draft protocol will be published soon
- Sample Size
 - 20 long-stay units
 - 15 residents with dementia per unit
 - 10 staff per unit
 - Total 300 residents and 200 staff



Public units

(n=11, 37% of beds)



Private units

(n = 34, 63% of beds)



Key questions

- Can a structured education reminiscence-based programme make an ongoing difference to day-to-day care?
- Will using reminiscence make a difference to residents with dementia?



Understanding Reminiscence in DARES

- Conducted a literature review & a concept analysis of reminiscence
- Prompting people to remember and if possible, discuss, past events and activities
- Help staff to get to know the person, their present needs and wishes
- Seeks to use the past to work for people in the present – to stimulate conversation and improve communication
- We have differentiated reminiscence from life review work
- We are focusing on individual reminiscence



What are we doing in DARES?

- Inviting public and private long-stay residential units along Western seaboard to participate
- Clustered trial at the level of a unit.
- Dividing units randomly into control group (care continues as usual) and intervention group
- Delivering an education programme to care staff working with residents with dementia and supporting the ongoing use of reminiscence
- Measuring if the programme makes a difference to residents and staff



Phase 1: Designing the structured education programme

Structured Education Programmes

- NICE (2003) defines structured education as:
- “a planned and graded programme that is comprehensive in scope, flexible in content, responsive to an individuals clinical and psychological needs and adaptable to his or her educational and cultural background”

aim to: empower, inform and support development



Developing the structured Education Programme

- Structured education programmes are formally developed, have a philosophy and specify all that will happen in the programme-consistency
- Developed through: Literature review work, dementia, reminiscence, concept analysis
- Qualitative interviews with experts and staff



NICE 2003

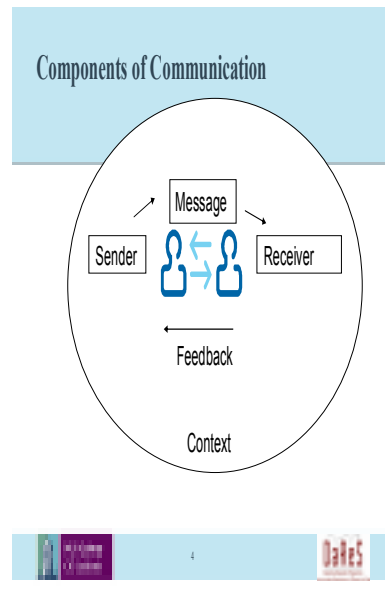
- The educational intervention should reflect established principles of adult learning
- The education should be provided by appropriately **trained** multidisciplinary team with groups.
- The education should be **accessible** to all regardless of literacy level or cultural background.
- A variety of techniques which promote **active** learning adapted to meet individual needs should be used.
- Programmes should be integrated into the routine care given over the long term.
- Empowerment philosophy



Structured Programme contains all that you need to run the programme, content, slides, activities

Day 1, Session 5: Communicating with persons with dementia

Slide



Getting started

Duration of session 90 minutes
Room layout Arrange chairs in a semi-circle
Resources A flip chart and pens
Computer with sound, projector and extension lead
Power Point Session 5
DVD with video clips

Handouts

- Hartford Institute communication assessment tool (Frazier Rios & Zembeuski 2007)
- Pain Assessment for Older adults (NRS & VDS) (Flaherty 2007)
- Pain assessment in advanced dementia (PAINAD)
- How best practice environmental design principles might be applied in practice
- Handout on 'Communication and dementia' (Ex Memoria video)
- Handout on communication tips
- Handout on how to respond to difficult statements "What would you say"

Slide



Activity 5.1

Click on the following link and show Evon Ryan, administrator for the dementia care unit at Cherry Hill Haven USA discuss the importance of responding to the person with dementia's perception of events and their reality.

Care Giver 5 Of 6 start to 1.22

<http://www.youtube.com/watch?v=d-sHmlKgXpY&feature=related>



Where we will start: baseline assessments

- For each resident participant, we measure:
 - Quality of life
 - Levels of agitation
 - Levels of depression (if any)
- For each staff participant, we establish current perceptions on burden of caring for residents with dementia



What we are looking at: Outcome measures

- **Primary:** QOL-AD for quality of life
- **Secondary:**
 - Cohen Mansfield Agitation Inventory (CMAI)
 - Cornell Scale for Depression in Dementia
 - The Modified-Nursing Assessment Care Scale (M-NCAS) for carer burden





DaReS

Dementia Education Programme
Incorporating Reminiscence Therapy for Staff

Building the Programme

Qualitative Data

Analysis of

Expert/resident interviews



DaReS

Dementia Education Programme
Incorporating Reminiscence Therapy for Staff

Qualitative interviews with staff, experts and residents: exploring content and issues

- Aim to inform the development of the structured staff education programme:
 - Gather contextual data.
 - Understand what staff consider important in relation to the content, design and delivery of the programme.
 - Gather experts' advice and recommendations.
 - Understand context.
- Semi-structured interviews were carried out with experts (n = 9), staff (n = 20) people with dementia (3) and relatives (n = 5).
- Preliminary analysis



Expert Interviews

- Nine experts interviewed:
 - Dementia educationalists
 - Psychiatrists
 - Occupational therapist
 - Reminiscence trainers/practitioners
 - Psychologist
- Face-to-face and telephone interviews



Themes: The Experts told us that context is key to effective use of reminiscence:

- **Carer attitudes**
 - Staff attitude key.
 - Tied to their understanding of dementia.
- **Care environment and culture**
 - Need to be cognisant of the organisational structure of long-stay facilities if focus of care is to change.
 - Person centred care/ Relationship centred care.
 - Challenge staff to look at new ways of working.
 - On-going support.



Experts suggest reminiscence is important but we also needed to include:

- **Knowing the person**
 - Essential.
 - Usefulness of life story emphasised.
- **Reminiscence**
 - Differentiated between life review and life story.
 - Individual/group reminiscence.
 - Using all senses.
- **Understanding dementia**
 - Implications for programme delivery.
- **Challenging behaviours**
 - Understanding behaviours.
 - Massage, music, smell potentially useful.



What staff told us

- Eight facilities subdivided into four public and four private facilities
- Ten different units/wards subdivided into:
 - 5 general/ 4 dementia-specific units,
 - 1 day-care
- One CNM, one staff nurse or one healthcare assistant from each unit/ward (n=20)
- 3 telephone, 17 face-to-face interviews.



Themes from staff interviews

3 main themes

- Being Positive (overview)
- In the real world (overview)
- What we need (more detail)



Theme: Being Positive

- **Positive Attitude**
 - Wanting to work with people with dementia.
 - Attitude
 - Confidence + accepting
 - Recognising the person (as opposed to the disease)
- **Positive Environment**
 - Clear function
 - Home-like
 - Use of colour
- **Positive Approach**
 - Calm
 - Continuity
 - Person centred
 - Team approach
 - Family involvement
- **Positive Ethos**
 - Knowing the person
 - Person centred
 - Responsive and fluid
- **Positive Plan**
 - Planned interventions
 - Planned strategies



Theme: In the real world

■ Challenges

- ❖ Shifting moods.
- ❖ Physical aggression.
- ❖ Caring for the person who is in 'a bubble'
- ❖ Wandering
- ❖ Not eating

Lacking knowledge
Being afraid
Mixed groups
Constrained space

Strategies

Open
communication
De-escalation
Distraction
Deception



Theme: What we need

- **Understanding Dementia**

- What is it? What happens ‘in’ the brain? What happens ‘to’ the person? Linked to changing attitudes

“Like we have one particular person, and if you go near him at all to do anything kind of physical work at all, like to change his trousers or whatever, he’ll go to hit you out, sure of course he would, like he’s not used to anybody doing that for him - he was used to doing it himself ... it’s to get that across to people initially, that it’s not personal to them, it’s just the person themselves are dealing with a situation that they think is foreign to them. That’s all. And it’s to get people to understand that I think.” (1-DPU-E)

- **Person Centeredness**

- What? How?

“We used to have a kind of structured activity thing that kind of on a Monday, on a Tuesday, on a Wednesday, on a Thursday, you’d do that. But then kind of we began to realise that like it’s not us laying the pace here, it’s the people we’re looking after are, then we kind of stood back, and we said ‘no, what we’ll do is, we’ll take it on a daily basis, we’ll see what the form is like, who wants to do what, and work it from there’. (1-DPU-E)



Contd.

- **Effective Communication**

“I think one of the main problems is communication. The staff find it hard to... as the illness progresses, they find it hard to sometimes communicate with the patient we’d have one lady now... I suppose they find it frustrating - she’s walking, and walking, and walking constantly, and I suppose due to the structure of the environment, you know there’s a lot of supervision required. They’d find it difficult like that, and I suppose it’s the skills - they feel they lack the skills in able to cope with those sorts of situations with her, in relation to communication, you know, distracting her, and trying to settle her more than anything.”(I-GPU-A)

- **Understanding the Impact of the Environment**

Our physical environment is very different ... we stripped it basically down to giving each area a function, so you ... our bedrooms - we don’t have bed tables, we don’t have chairs, right? ... our bedrooms will offer a bed and a locker. Each bed then has pictures, has things that people can identify as theirs, and they may not always identify them, but they are a keystone... you know they’re something there that we can use, to start off and say ‘this is your bed, this is your photograph when you were in the army’ or ‘this is your cat’, or whatever it will be. But we’re not confusing that space with any other function other than the bedroom. There’s no tables to sit and eat your meals ... Whereas on the long-stay wards, maybe somebody can really upset... at dinner-time for lots of people because of their efforts to try and conform in a situation that really isn’t very conducive to them. So each area has its own specific design to function.”



Contd.

- **Managing situations effectively**

“Well one thing that I could suggest is I don’t think we’re trained properly how to deal with them. You know like we’ll deal with patients with dementia, Alzheimer’s as the best we can, but I don’t know... you think that... if we knew a little bit more, you know.... Like we’re taught for dinner-time, not to put loads of things in front of them, and stuff like that, but I think for patients with dementia who... who get angry, that side of it.” (3-GPU.G)

- **Interventions**

- **What? How? When?**

“We wouldn’t have a set group of reminiscing, it’s very... how would you say - informal. But like you could have... you could be doing say some crafts or whatever in the afternoon, and a topic comes out of that, of what you’re doing.” (1-DPU-E)



Interviews with people with dementia: What mattered to them

- Three interviews with people with dementia



For people for dementia: attitude was so important

- PWD 2: I think it's very important for the nurses to be kind. They know what's wrong with you. In all fairness now, I think they're fair enough. They work hard. There's no getting away from it. ... I know our girls, there's two of them now. One of them came home from work one time and cried because of a baby that died. That sort of thing. I always tell them whatever about younger people, the older people need the care. Kindness is everything.



For people for dementia: attitude was so important

- PWD 2: Don't cut anyone short.... I do think it gives them great courage to be nice to them, so that's it.
- PWD3: Treat them as an individual. Go over to them and say, “How are you?” It's very important. You're saying their state of mind. Some of them might not even know, mightn't remember in two minutes. It's very important that people are nice”.



Where are we now

- Structured education programme developed and in process of piloting
- Following piloting will run the programme in intervention sites and examine outcomes



What did we learn so far

- The diagnosis of dementia remains an issue
- You can not focus exclusively on reminiscence, without addressing contextual issues
- Need to address understanding of dementia as empathy key to attitudes
- Knowing the person is central to reminiscence



References

- Woods B, Spector AE, Jones CA, Orrell M, Davies SP. Reminiscence therapy for dementia. Cochrane Database of Systematic Reviews 2005, Issue 2.'

