

Advance Care Planning and dementia

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This lecture, through the presentation of doctoral studies will examine the existing evidence base for advance care planning in dementia and early findings as to how well carers can predict the choices that the person with dementia would make.

This will all be set in the context of the practitioner role of Admiral Nursing, specialist dementia nurses for families affected by dementia.

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What is an Admiral Nurse?

Admiral Nurses are mental health nurses who have specialist knowledge of dementia care based within mainstream services: working with and supporting families who are affected by dementia.

Admiral Nurses provide education, leadership, development and support to other colleagues and service providers.

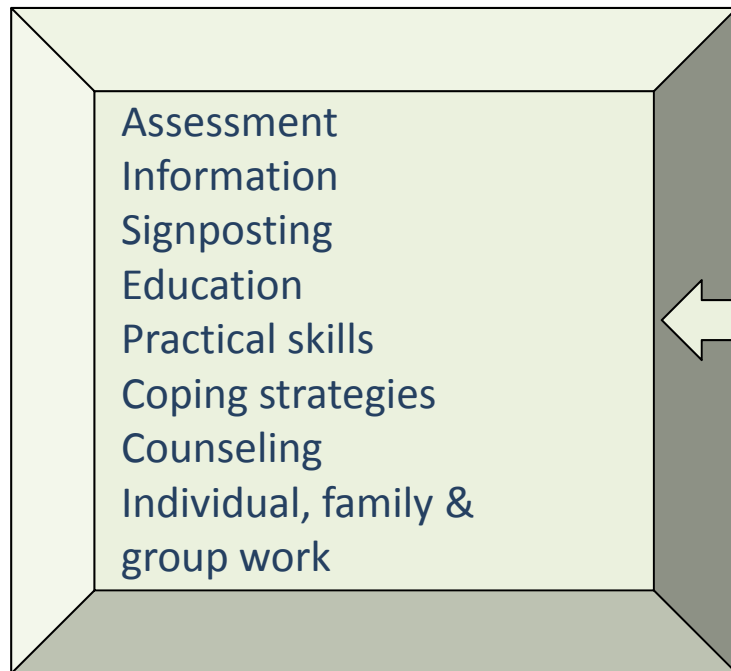
Admiral Nurses aim to make a positive difference to the lives and experiences of all those affected by dementia.

Need?

- Growing numbers of people with dementia
- Majority of people with dementia live in their own homes
- Growing number of family members providing care
- High multiple health and social care needs
- Patchy services

Integrated nursing role

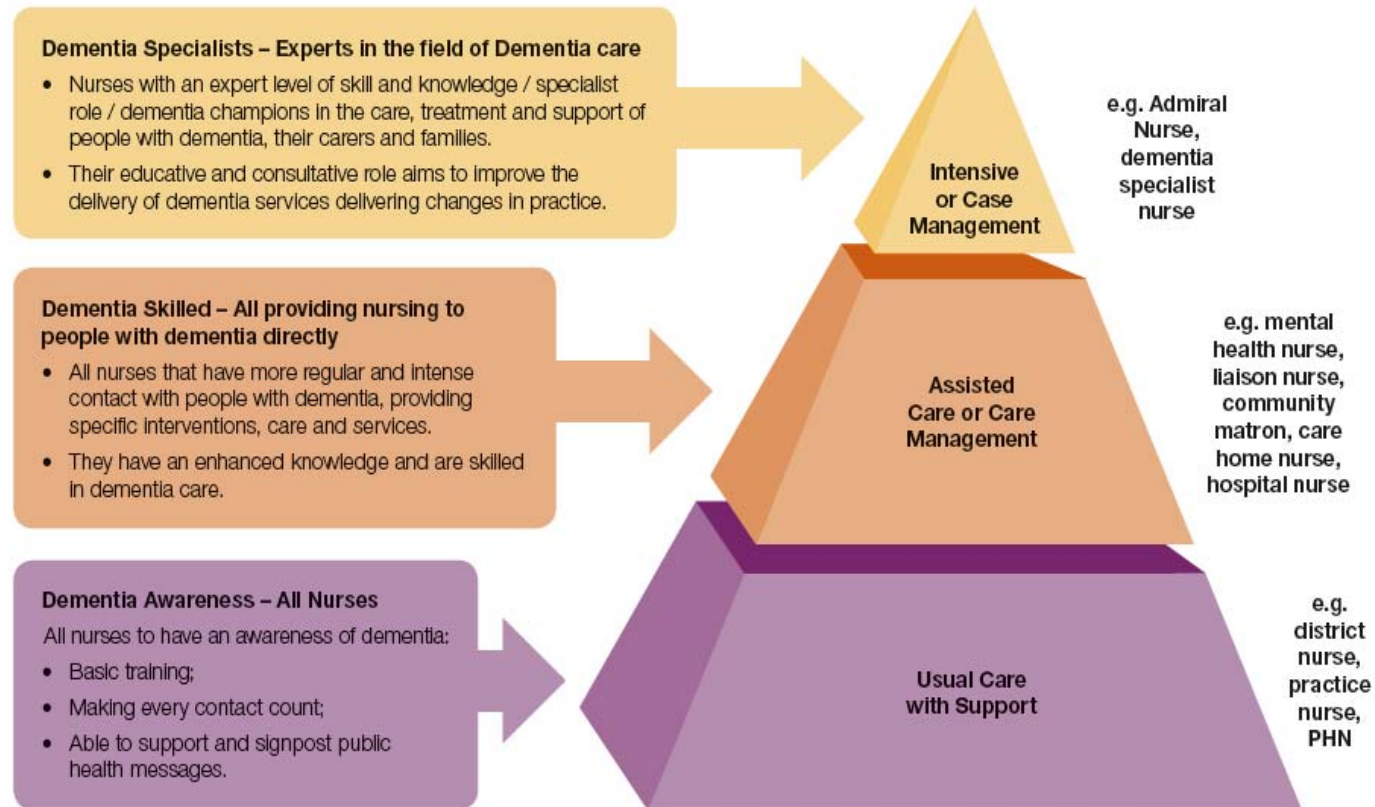
Working with families



Supporting best practice



Making a Difference in Dementia: Nursing Vision and Strategy



https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/147956/Making_a_Difference_in_Dementia_Nursing_Vision_and_Strategy.pdf

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Advance Care Planning in Dementia

Why this subject and why now?

- First case as a Community Psychiatric Nurse
- Consultant Admiral Nurse
- Memory assessment and post diagnostic support
- Growing interest in palliative and end of life care in dementia
- Planning ahead

What is advance care planning?

ACP is a voluntary process of discussion and review to help an individual to anticipate their preferences for future care in the event they lose capacity.

NICE Guidance recommends that people with dementia should have the opportunity to discuss and make decisions about their future care while they have capacity.



- Advance Care Plan (ACP)
- Advance Statements (AS)
- Advance Decisions to Refuse Treatment (ADRT)
- Living Will
- Lasting Power of Attorney (LPA) x 2
- And now.....Anticipatory Care Plan (AnCP)

Advance care planning

- Growing numbers of people living *and* dying with dementia
- Multi morbidity
- Life limiting condition
- Palliative care
- Policy
- Personhood and identity
- Decision making
- Family decision making
- Agreement
- Advance care planning

Themes in the literature

- Cognitive impairment and mental capacity
- Advance care planning and decisions about life sustaining treatment
- Advance care planning in dementia compared to other groups
- Prevalence of ACPs in dementia
- Family carers and decision making
- Professional attitudes
- Education of professionals and relatives



Harrison Denning K *et al* (2011) Advance care planning in dementia: A review. *International Psychogeriatrics*. **23**:10, 1535-51

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Phase one

Explore whether people with dementia and their carers were able to generate ideas about the choices they may wish to make for their future care.

Method

Modified Nominal Group process (Delbecq 1971)



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Nominal Group: Ranking

- Carer group
 - No unnecessary prolonging of life
- People with dementia group
 - Maintaining family links
- Dyad group
 - No unnecessary prolonging of life



Nominal Group: **Discussions**

- Recorded and transcribed
- NVIVO 8: data storage and thematic content analysis
- Manual coding and themeing

Themes

- Control at the end of life
- Family contact towards the end of life
- Dignity and respect
- No prolonging of life unnecessarily

Nominal Group: Conclusions

- Already a divergence of views
- When present, carers influenced the person with dementia
- People with dementia did not consider end of life care issues

Implications for practice?

- Direct approach
- Guidance for practice
- Agreement in views

Harrison Denning K *et al* (2013) Preferences for end-of-life care: A nominal group study of people with dementia and their family carers. *Palliative Medicine*. 27(5) 409-17

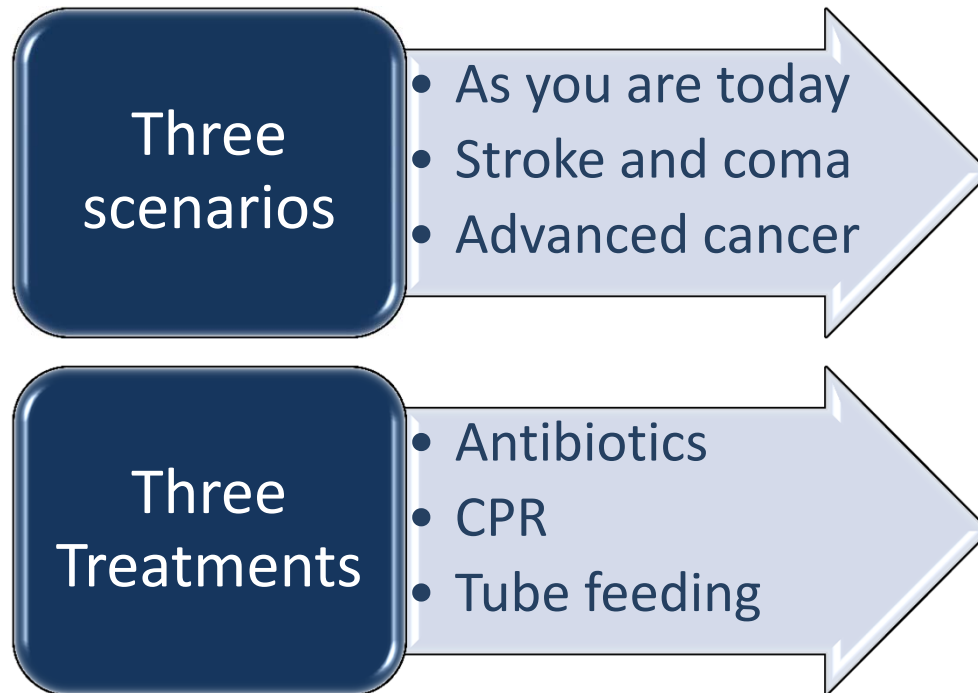
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Phase two

- Cross sectional study
- 60 dyads
- Semi Structured Interviews:
 - Caring context
 - Life Support Preferences
- Nested qualitative semi structured interviews

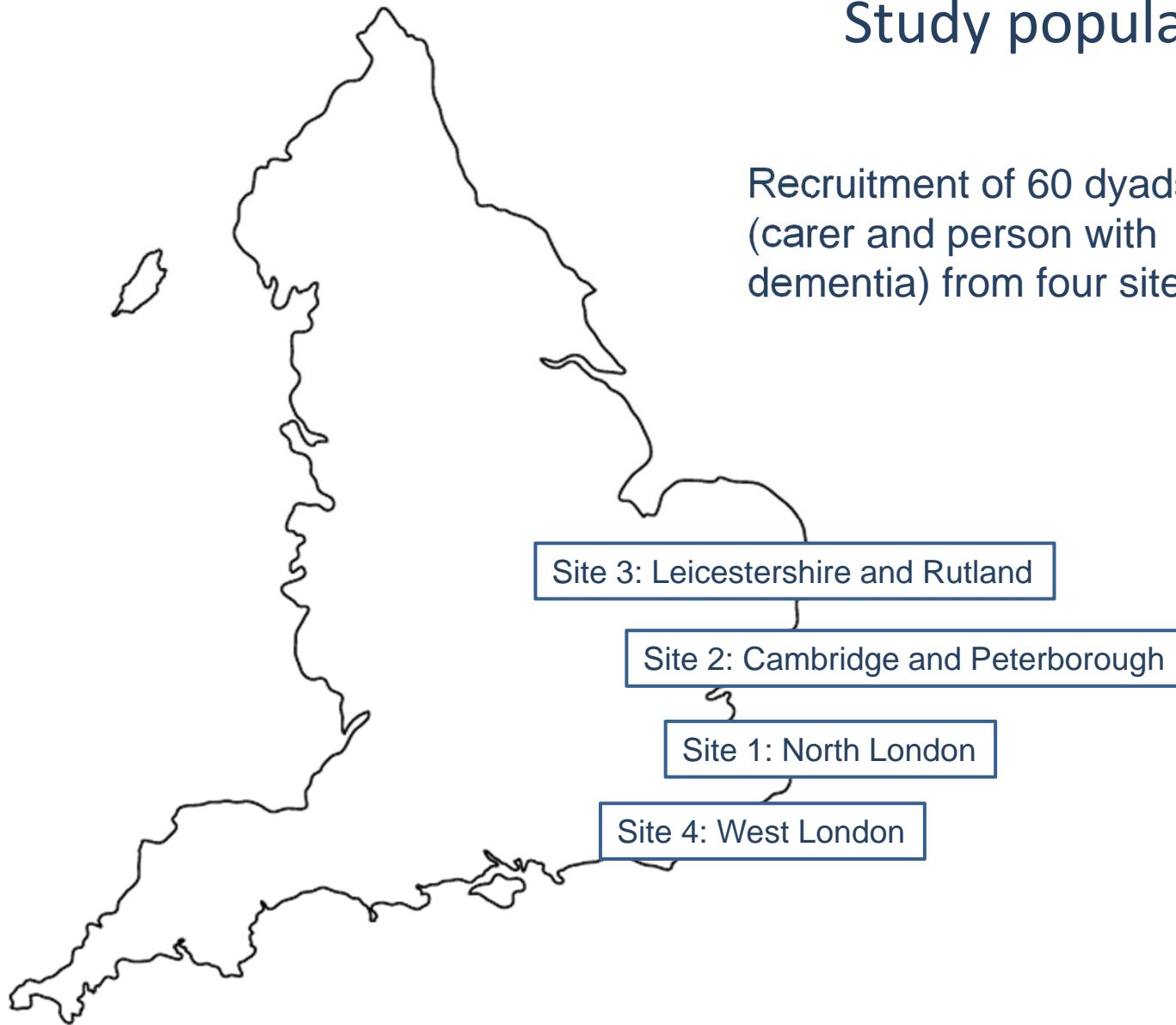
Life Support Preferences Questionnaire



No participants have been distressed by discussing these issues.

Study population and sites

Recruitment of 60 dyads
(carer and person with
dementia) from four sites



Results at 25 dyads....

- Twenty five dyads (25 PWD/25 carers)
 - The mean age of PWD = 80.6
 - The mean age of Carer = 66.2
 - MMSE of PWD (Mean 25.2; range 20-29)
 - Gender PWD (M=12 F=13)
 - Gender Carer (M=5 F=20)
 - A wide range of ethnic backgrounds were represented as were levels of education.
-
- Most agreement was found on rating *current health state* on LSPQ.
 - In all health scenarios lowest agreement was found for resuscitation and tube feeding which had the lowest levels of agreement in treatment choices.
 - Scenario 2 (stroke and coma) showed low agreement (κ .332; $P=0.052$).
 - Scenario3 (advanced cancer) showed moderate agreement (κ .478; $p= 0.005$) treatment issues.

What next?

Agreement on Life Sustaining Treatments

kappa co-efficient

Multivariate analysis

Quality of care-giving relationship

Carer burden and distress

Early analysis suggests that carers may not be able to consistently predict the treatment preferences for the person with dementia and this has implications for the reliability of proxy influence on end of life care of a person with dementia.

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Nested qualitative interviews

Ethical approval gained in December 2013 for nested qualitative semi structured interviews of 6 dyads; now completed, transcribed and coding has commenced.

1. *How have you make decisions about healthcare and/or treatment wishes in the past?*
2. *What changes to this decision making process (if any) do you see the diagnosis of dementia has made?*
3. *What healthcare and/or treatment decisions may you need to make in the future now that there is a diagnosis of dementia made (for you/your family member)?*

So, five years on.....

Would I do it again?

Yes!

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Rolling boulder.....

- **Advance Care Planning**
 - MCPCIL – Anticipatory Care Planning Programme
 - ALCOVE – (WP4) ADRT European Consensus
 - Developing an Advance Care Planning Tool for families affected by dementia
- **GEMSS (Steering Group)**
- **DeNDRoN – Nursing in Dementia**
- **DeNDRoN – Distress in Dementia**
- **DeNDRoN – Primary Care Clinical Studies Group**
 - Co applicant SEED project
- **Developing the evidence base for Admiral Nursing**
 - The role of the Admiral Nurse in end of life care in dementia (University of Worcester)
 - Admiral Nurse DIRECT: discourse analysis on intervention (University of Loughborough)
 - Literature review in support of Admiral Nursing (University of Hertfordshire)



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Thank you for listening!

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