DEMENTIA: BARRIERS TO ACCESSING QUALITY END OF LIFE CARE AND ROLE OF ADMIRAL NURSES

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Putting people first
Delivering excellent, accessible healthcare
What is an Admiral Nurse?

Registered nurses who have specialist knowledge of dementia care

Provide support to family carers and people living with dementia, particularly during complex periods of transition

Provide education, leadership, development and support to other colleagues and service providers
Admiral Nurse

https://www.youtube.com/watch?v=3wSPH6o8znk
Admiral Joe

Why ‘Admiral’ Nursing?

• Named by the family of Joseph Levy CBE BEM, who founded the charity.

• Joseph had vascular dementia and was known affectionately as “Admiral Joe” because of his love of sailing.

• The charity was founded in 1994.
Aims of Admiral Nursing

• Improve family carers’ well-being and quality of life
• Enhance family carers’ adjustment and coping with their caring role
• Improve the well-being and quality of life of the person with dementia
• Enhance the person with dementias’ ability to adjust and cope with dementia
• Enhance colleagues’ knowledge and experience of working with family carers and people with dementia
Admiral Nursing - areas of practice

- Community
- Care home
- Admiral Nurse Dementia Helpline
- Acute Hospital
- Home care
- Hospice
- Admiral Nurse Clinics
What do Admiral Nurses do?

- Family & relationship centred approach
- Offer specialist holistic assessment & evidence based intervention
- Provide psychosocial support for the carer(s) and person living with dementia
- Work in partnership with other services
- Intensive case management/ care coordination
- Liaison with other professionals and organisations
- Promote and implement best practice
- Provide supportive education
Dementia in Numbers

850,000
People are estimated to be living with dementia in the UK

24.6 million
People in the UK – 38% of the population – know a family member or close friend living with dementia

One in 14
People over 65 have dementia in the UK and one in 79 of the whole population

Increased life expectancy since 1948 has increased by 13 years (68-81)
NHS ENGLAND TRANSFORMATION FRAMEWORK – THE WELL PATHWAY FOR DEMENTIA

PREVENTING WELL
Risk of people developing dementia is minimised

I was given information about reducing my personal risk of getting dementia

DIAGNOSING WELL
Timely accurate diagnosis, care plan, and review within first year

I was diagnosed in a timely way
I am able to make decisions and know what to do to help myself and who else can help

SUPPORTING WELL
Access to safe high quality health & social care for people with dementia and carers

I am treated with dignity & respect
I get treatment and support, which are best for my dementia and my life

LIVING WELL
People with dementia can live normally in safe and accepting communities

I know that those around me and looking after me are supported
I feel included as part of society

DYING WELL
People living with dementia die with dignity in the place of their choosing

I am confident my end of life wishes will be respected
I can expect a good death

STANDARDS:
Prevention(1)
Risk Reduction(5)
Health Information(4)
Supporting research(5)

STANDARDS:
Diagnosis(1)(5)
Memory Assessment(1)(2)
Concerns Discussed(3)
Investigation(4)
Provide Information(4)
Integrated & Advanced Care Planning (1)(2)(3)(5)

STANDARDS:
Choice(2)(3)(4)
BPSD(6)
Liaison(2)
Advocates(3)
Housing (3)
Hospital Treatments(4)
Technology(5)
Health & Social Services (5)
Hard to Reach Groups(3)(6)

STANDARDS:
Integrated Services(1)(3)(5)
Supporting Carers(2)(4)(5)
Carers Respite(2)
Co-ordinated Care(1)(5)
Promote independence(1)(4)
Relationships(3)
Leisure(3)
Safe Communities(5)(5)

STANDARDS:
Palliative care and pain(1)(2)
End of Life(4)
Preferred Place of Death(5)

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Public Awareness of Dementia

52% of UK population know a family member or close friend living with dementia
Public Awareness of Dementia

One in five UK adults (22%) incorrectly agree with the statement ‘Dementia is an inevitable part of getting older’. Three in five people (60%) correctly disagree and a further 17% are unsure either way.
Public Awareness of Dementia

Just half (51%) of the public recognise that dementia can cause death, despite Alzheimer’s disease and other dementias now being the leading cause of death in the UK, accounting for more than 12% of all deaths.
• By 2040, annual deaths in England and Wales are projected to rise by 25.4% (Etkind et al. *BMC Medicine* May 2017)
Preferred place of care for end of life
Supporting families and managing their expectations

• 70% of people would prefer to die at home” - Dying Matters March 2017.
• But only 45% die in their usual place of residence.
Numbers of patients with dementia in a year (East Surrey Hospital)

- **80,500** adult admissions
- **1/3** of our admissions are people over 75 years old
- **13%** had a confirmed dementia diagnosis
- **85%** of people over 75 living with a dementia were admitted via our emergency department
- **450** under 75 (0.6% of all 18-75 admissions)
- Average age of admission **64 years** old increase from **58** over last 4 years
Deaths in Hospital and receiving EOLC

- 12% with a dementia diagnosis died during the admission
- 10% where on an end of life care plan.
- Note not all the patients that died in hospital were on an end of life care plan

Taken from a recent sample of 50 notes
Case Study, Mary
Case Study  Mary

- Admitted with dehydration and not eating. 8 year history of dementia

- Lived at home with her husband (Main carer) children not local and provided limited support weekend visits. Paid carers, once a day.

- Dementia had progressed rapidly in previous 6 months since admission to hospital following a chest infection. Now not walking, skin breaking down, eating small amounts with lots of encouragement small amounts of fluid.

- Prior to admission seen by ambulance staff asked if he wanted his wife to die at home or in hospital.

- Husband was keen to get fluids in and get her home. Limited understanding of progression of dementia
Team approach

- Discussions did not centre on decisions to withhold specific treatments. Instead, talk about the Mary’s illness and what will make them comfortable.
- Discharge plan to home with a package of care and support from community Hospice team
- Carers support to the husband through local carers support
Team approach

• The whole team recognised that Mary was at advanced stage of dementia and reaching end of life.
• Establish families understanding of dementia and offered support and information
• Staff worked together with a clear plan of action.
• We were consistent when responding to families and being able to refer up
• Discussions about EoLC demonstrated at a senior level.
• Discussions do not centre on decisions to withhold specific treatments. Instead, talk about the individual’s illness and what will make them comfortable.
Barriers to accessing quality End of Life Care

- **Identification and Planning**

  - Lack of appropriate/timely diagnosis and care planning

  - Poor recognition of dementia as a terminal illness and a cause of death
Empowering the person  Advanced Care Planning

- Advance care planning involves discussion of future care preferences to develop an understanding of an individual’s wishes in the event that they are unable to make decisions for themselves
- Adults with dementia have the opportunity to discuss advance care planning at diagnosis and at each health and social care review
- NICE Quality standard for dementia DRAFT (January 2019)
Planning for the future

- Advance statements (written statement of preferences, wishes, beliefs and values regarding future care)
- Advance decisions (decision to refuse treatments in future)
- Lasting power of attorney – patients appoints someone to make decisions on their behalf should they lose capacity (health and welfare, property and affairs)
What are the barriers to involving people with dementia in identifying their wishes and preferences for future care?
Barriers to accessing quality End of Life Care

• Inequality of Access

- Poor access to palliative care,
- hospice care and funding
Barriers to accessing quality End of Life Care

• **Quality of Care experienced by the person living with dementia**

  - Inconsistency in care standards and inappropriate hospital admissions

  - Poor pain management
Future Challenges

DYING WELL
People living with dementia die with dignity in the place of their choosing

"I am confident my end of life wishes will be respected"
"I can expect a good death"

STANDARDS:
Palliative care and pain\(^{(1)(2)}\)
End of Life\(^{(4)}\)
Preferred Place of Death\(^{(5)}\)
61% increase in the number of over 65s in the UK by 2032

Britain’s over 65s already outnumber its under 16s
Comments/Questions?

Admiral Nursing