

for dementia admiral nurses

# Admiral Nursing : A Palliative Care Model



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**NCPC, February 2009, Regent's College, London**

**for dementia**  
training ■ development ■ admiral nurses

# A palliative care approach in dementia care

## WHAT IS PALLIATIVE CARE ?

### Definition

- “Palliative care is an approach that improves the quality of life of the patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”

World Health Organisation, 2002

# Principles of Palliative Care (PC)

- PC is an approach to care which shifts away from cure towards Quality of Life
- PC is about flexible, fluid care for people with a life threatening / non-curable illness
- PC relies on effective teamwork and skill sharing and honest communication
- PC has at its heart, respect for autonomy

# Principles of PC

- PC aims to reduce distress and improve comfort for the patient AND the family
- PC aims to prevent or reduce suffering
- PC has a whole person approach
- PC sustains the family and its health during the course of the illness and afterwards

# Palliative care is NOT just about end of life care

..... It is about the person's whole journey



DIAGNOIS

Living with  
dementia

End of life  
& after  
death

# **POLICY and STRATEGY (Dementia)**

- ▶ **End Of Life Initiative 2004**  
(£12m, 3 year programme)
- ▶ **A New Ambition For Older Age 2006**  
( 3 programmes, end of life care within Dignity in Care)
- ▶ **NICE Dementia Guidelines 2006**
- ▶ **End of life strategy 2008**
- ▶ **National Dementia Strategy 2009**

# **POLICY - NICE Dementia Guidelines 2006**

(NICE Clinical Guidance 42)

## ***Key principles for palliative care and dementia :***

- 1) Palliative approach in dementia is from **diagnosis to death**
- 2) People with dementia should die with dignity
- 3) People with dementia should be able to die in a place of their choice
- 4) Continued focus around QoL issues at end of life
- 5) Carers should be supported during illness and into bereavement.

# **POLICY - NICE Dementia Guidelines 2006**

(NICE Clinical Guidance 42)

## ***Specific issues identified :***

- **Pain relief**
- **Withdrawal or withholding nutrition**
- **Eating and Drinking**
- **Treatment of fever**
- **Advance decision making**

# **POLICY - National Dementia Strategy 2009**

## *Objective 12 of 17*

### *Improved end of life care for people with dementia*

**Demonstrator sites, piloting models of service**

**Providing end of life care that reflects personal wishes**

**Developing local end of life care pathways consistent with GSF**

**Improving pain relief for people with dementia at end of life.**

# Admiral Nursing and palliative care

**Working together - an example of good practice**



# What is an Admiral Nurse ?

- **Admiral Nurses are specialist mental health nurses based within mainstream services, working with and supporting families of people with dementia, and people with dementia.**
- **Admiral Nurses provide education, leadership, development and support to other colleagues and service providers.**
- **Admiral Nurses make a positive difference to the lives and experiences of all those affected by dementia.**

# **Aims of Admiral Nursing**

- **Improve family carer's well-being and quality of life.**
- **Enhance family carer's adjustment and coping with their caring role and changing relationships.**
- **Improve the well-being and quality of life of the person with dementia.**
- **Enhance the person with dementia's ability to adjust and cope with dementia.**
- **Enhance colleague's knowledge and experience of working with family carers and people with dementia.**

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# Admiral Nursing and palliative care

## Diagnosis

- Pre -diagnosis Support
- Diagnosis support
- Understanding the impact of diagnosis
- Adjustment and adaptation
- Understanding diagnosis
- Fostering a positive outlook
- Signposting
- Coming to terms with diagnosis

# Admiral Nursing and palliative care

## Living with Dementia

- Coming to terms with diagnosis
- Family centred holistic care
- Education
- Navigation through services
- Skill enhancement
- Support with changing dementia symptoms
- Advance planning
- Support with prognosis
- Practical, emotional & psychological support
- Maximising quality of life and keeping things normal
- Supporting changing family relationships and dynamics
- Supporting anticipatory grief, working with loss and change

# Admiral Nursing and palliative care

## End of life and after death care

- Recognising end of life
- Collaborative working
- Preparing the family as end of life approaches
- Supporting family and person with dementia's wishes at end of life
- Ongoing emotional support
- Supporting to grieve and adapt to loss
- Supporting family to cope and move forward

# Admiral Nursing and palliative care

## CASE STUDY - Jenny, Paul and Tom

### Following a palliative care pathway



# **CASE STUDY - Jenny, Paul and Tom**

## **INTRODUCTION**

- Paul diagnosed with young onset Alzheimer's Disease aged 59
- Paul experienced severe anxiety , fear and distress due to awareness of his symptoms of dementia and his inability to understand these
- Jenny struggled to cope with understanding and accepting of the diagnosis and symptoms – referred herself for support.
- Tom took dad's illness in his stride until he approached the end of his life.

# Case study - JENNY AND PAUL - Diagnosis

A family centred approach was adopted and partnerships were built between Jenny, Paul, their son Tom and the A/N.

The main focus for Admiral Nursing was with Jenny.

Support focussed on early strategies such as maximising life and health and adjustment to diagnosis .

Support was given to help enhance Jenny's understanding of the diagnosis; this led to better coping and reduced conflict between Jenny and Paul.

Paul was supported to understand certain symptoms and was helped to express the range of emotions he experienced.

Jenny was helped to understand Paul's personal experience and his sense of fear which contributed to problems, she was able to adapt her approaches to meet his needs.

# Case study - JENNY AND PAUL - Living with dementia

Jenny and Paul were encouraged to maximise opportunities in life - to live with dementia and not die from dementia. They were encouraged to follow their retirement plan of holidays in the sun.

Advice given to help cope with symptoms during travel and in the unfamiliar setting of a holiday resort. Encouraged to make new memories.

Jenny passed on her increasing understanding of dementia to family and friends, this had a positive impact on Paul as family and friends became more able to support Jenny and Paul, leading to a better quality of life.

Tom worried about his mother's ability to cope. He was given time to talk about his concerns for his mum. He was listened to, reassured that his concerns would be addressed; and was given feedback about the positive approaches he used.

# Case study - JENNY AND PAUL - Living with dementia

As Paul's symptoms progressed interventions began to focus on preparation for the future. He was unable to plan for the future himself.

Jenny was supported to explore the prognosis of Alzheimer's disease. She was encouraged to set the pace and determine the depth of information discussed.

Jenny was supported to begin to consider what her future fears were, what she felt she may be unable to cope with. She was helped to plan for the future by mapping out what the important aspects of care would be for Paul from her own thoughts and those of Paul's past ideas.

A life story was started by the family, which Paul enjoyed getting involved in. It made him feel worthwhile and useful. A record of important aspects of care was written in case Paul ever went into full time care.

# JENNY AND PAUL - End of life and after death care

At home Paul's symptoms began to change quickly and he became harder to care for. He needed more intensive help with physical and mental health care. A further rapid decline in health led to hospital admission .

Interventions with Jenny now focussed upon preparing her for Paul's death. She was made aware that he was dying, and was supported to consider some of the difficult decisions such as resuscitation and active treatment before they were asked. This allowed Jenny the opportunity to explore how she felt about these decisions as no advanced decisions had been made by Paul.

At this point, Tom began to struggle and stay away as he didn't want to face the situation. The A/N supported him to talk and he became prepared for his father's death. The uncertainty and unknown had frightened him.

Jenny was helped to understand the process of dying and what may happen to Paul as his death became imminent. Support became more intensive . Jenny was supported to make the environment a calm relaxed one with elements that Paul enjoyed such as music and massage as he entered his final few days of life.

## Case study -

# JENNY AND PAUL - End of life and after death care

### Post bereavement support.

For the 4 months following Paul's death, Jenny was supported by the Admiral Nurse to help her reflect upon the experiences leading up to and during Paul's death.

Immediate comfort was provided at the time of death. Latter support was focussed upon helping Jenny to understand the bereavement process and to accept the feelings she experienced.

She was then helped to begin to adapt to a new life without Paul and without the caring role she had experienced for 4 years. She was helped to rebuild her confidence as the caring role and its isolation had diminished her confidence, Jenny began to re-build her life.

Tom coped well once he had been given information about his fathers prognosis,

At discharge, Jenny had got a part time job which improved her confidence and reduced her social isolation, she was setting a routine in her life with her extended family and was considering whether to return to full time work.

**Problems in delivering effective  
Palliative Care to people with  
Dementia .....**

# Professional attitudes within dementia care

- Understandings and misconceptions that PC is only about end of life care.
- Concerns that terminology will frighten people with dementia and families.
- New concept ,whose job is it ????

# Prognostication

- The end of life component of PC is fraught with difficulty around prognosis. It can be hard to pinpoint exactly when someone is at the end of their life.
- People with Dementia can live for many years in a frail condition including those who have the recognised prognostic indicators.
- Prognostic indicators for eligibility for the LCP are that a team agrees the person is thought to be dying, all reversible causes of the condition have been considered and that they meet at least 2 of the following :
  1. *Unable to take tablets*
  2. *The person is semi-comatose*
  3. *The person is bed bound*
  4. *The person is only able to take sips of fluids*
- GSF have more detailed prognostic indicators but research in this area is felt to be lacking

## Honest , Open Communication ???

- Is post diagnostic support for people with Dementia common place ? Do we give people with Dementia an opportunity to discuss and come to terms with their diagnosis ?
- Do we routinely discuss and encourage people with Dementia to write an advance plan or advance directive ?

## Societal attitudes to death and dying

- Reports submitted to the Darzi review around end of life care , commonly detailed that societal attitudes prevent open discussion around death and dying, it has become a taboo subject.
- This makes it hard for us as professionals to have open discussions at the end of someone's life and also prior to reaching this point , it prevents us from advance planning.

## Ethical issues

- The ethical approaches to withdrawal and withholding of treatments , nutrition and hydration are issues less commonly understood by practitioners and personal beliefs and relationships can make this course of action hard to follow.

- Mental capacity is another poorly understood issue which hampers decisions making when advance directives, or statements have not be made.

The MCA applies to every decision made by anyone over 16 with impaired capacity to make that particular decision.

MCA : where life sustaining treatment is an issue you **MUST NOT** be motivated by a desire to bring about death..... You **MUST NOT** make assumptions about QoL issues.

MCA introduced a legal recognition and status for family carers and friends to be consulted and involved in decision making.

**Discussion .....**

## **DEMENTIA AND PALLIATIVE CARE**

**What are the issues for you as  
practitioners ?**

# Thankyou for listening .....

## Guidance

- NICE Dementia Guidelines
- Liverpool Care Pathway for the Dying Patient (LCP)
- Gold Standards Framework (GSF - Macmillan)
- Preferred priorities for care (PPC)
- Withdrawing / withholding nutrition (GMC)

## Useful contacts

**For dementia and Admiral Nurses** [www.fordementia.org.uk](http://www.fordementia.org.uk)

**National Council for Palliative Care** [www.ncpc.org.uk](http://www.ncpc.org.uk)

**End Of Life Care Programme** [www.endoflifecare.nhs.uk](http://www.endoflifecare.nhs.uk)