STOP, LOOK AND LISTEN:
Supporting people with dementia and their families at the end of life

www.ncpc.org.uk  #DementiaEoLC  www.dyingmatters.org
Today

10.00 - Chair’s welcome: Anita Hayes
10.10 - Setting the scene: Anita Hayes and Dr Jackie Morris
10.40 - Our work regarding dementia and what we have learnt regarding communicating to those with dementia and their families: Martina Kane
11.10 - Discussion: All
11.30 - Refreshments
11.50 - Practical group work session: A carers perspective – the importance of communicating effectively with people with dementia: Barbara Pointon MBE, Dr Jackie Morris
12.50 - Lunch
1.30 - Chair’s welcome back: Anita Hayes
1.40 - Group work activity – putting yourself in the shoes of someone with dementia or their next of kin: Anita Hayes & Dr Jackie Morris
2.40 - Refreshments
2.50 - Sharing our work and learning: Debbie Pegram
3.20 - Interactive session: Using Dying Matters materials and resources to help: Joe Levenson
3.40 - Discussion: Debbie Pegram & Joe Levenson
4.00 - Chair’s closing remarks: Anita Hayes

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Event Objectives

- Explore the principles of good communication and its importance in providing good care
- Learn how to encourage people with dementia to communicate in the easiest way for them
- Develop techniques for listening to and understanding people with dementia at the end of life
- Take part in practical exercises to help you understand the person and carers perspectives
- Leave feeling more confident about communicating with people with dementia at the end of life, and those close to them
Dementia

Definition:

Dementia is a syndrome – usually of a chronic or progressive nature – in which there is deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from normal ageing. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not affected. The impairment in cognitive function is commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation.

World Health Organisation
Dementia

Definition:

The term 'dementia' is used to describe the symptoms that occur when the brain is affected by specific diseases and conditions. Symptoms of dementia include loss of memory, confusion and problems with speech and understanding.

Alzheimer’s Society

www.ncpc.org.uk

www.dyingmatters.org
Palliative care
Definition

• The holistic care of people with advanced, progressive, incurable illness, based on the management of a person’s pain and other distressing symptoms; and the provision of psychological, social and spiritual support to them and their family.

Palliative care is not dependent on diagnosis or prognosis and can be provided at any stage of a person’s illness and decline – not only in the last few weeks and days of life. The aim is to support people to live as well as possible until they die with dignity.
End of Life Care
Definition

Patients are approaching the end of life when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with:
(a) advanced, progressive, incurable conditions
(b) general frailty and co-existing conditions that mean they are expected to die within 12 months
(c) existing conditions if they are at risk of dying from sudden acute crisis in their condition
(d) life threatening acute conditions caused by sudden catastrophic events.

GMC Treatment and Care towards the end of life July 2010
Priorities for Care of the Dying Person

Duties and Responsibilities of Health and Care Staff

Published June 2014 by the Leadership Alliance for the Care of Dying People

RECOGNISE
The possibility that a person may die within the next few days or hours is recognised and communicated clearly, decisions made and actions taken in accordance with the person’s needs and wishes, and these are regularly reviewed and decisions revised accordingly.
Always consider reversible causes, e.g. infection, dehydration, hypercalcaemia, etc.

COMMUNICATE
Sensitive communication takes place between staff and the dying person, and those identified as important to them.

INVOLVE
The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.

SUPPORT
The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.

PLAN & DO
An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

If unsure, or the dying person or those important to them raise concerns, a senior clinician must review the person and the goals and plan of care. The titles above are intended as memory prompts and attention should be paid to the whole description for each section. Expanded explanations are included overleaf.

Local palliative care contact:
Priorities for Care of the Dying Person

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Local palliative care contact:

For further guidance www.nhsiq.nhs.uk/endoflifecare

scan on a smartphone to access to website guidance
Outcomes for people with dementia

By 2014, all people living with dementia in England should be able to say:

- I was diagnosed in a timely way
- I understand, so I make good decisions and provide for future decision making
- I get the treatment and support which are best for my dementia, and my life
- Those around me and looking after me are well supported
- I am treated with dignity and respect
- I know what I can do to help myself and who else can help me
- I can enjoy life
- I feel part of a community and I’m inspired to give something back
- I am confident my end of life wishes will be respected. I can expect a good death
Dementia

National Dementia Strategy: 17 objectives (February 2009)
Anti-psychotic Report - 11 recommendations (November 2009)
Public Accounts Committee – 10 conclusions (January 2010)
Prime Minister’s challenge on dementia 2020 - End of life Care

By 2020 we would wish to see:

• All people with a diagnosis of dementia being given the opportunity for advanced care planning early in the course of their illness, including plans for end of life.

• All people with dementia and their carers receiving co-ordinated, compassionate and person-centred care towards and at the end of life, including access to high quality palliative care from health and social care staff trained in dementia and end of life, as well as bereavement support for carers.

• A right to stay for relatives when a person with dementia is nearing the end of their life, either in hospital or in the care home.

• Dementia education, training and workforce
Dementia in the General Hospital

Acute awareness
Improving hospital care for people with dementia

Report of the National Audit of Dementia Care in General Hospitals 2011

Economic evaluation of a liaison psychiatry service
Types of dementia

- Alzheimer’s Disease (60-80%)
- Vascular dementia (20-30%)
- Dementia with Lewy Bodies (10-25%)
- Frontotemporal dementia (rare)

Plus others
Symptoms

- memory loss, especially short-term memory
- difficulty with tasks and activities that require concentration and planning (dypraxia/apraxia)
- depression
- changes in personality and mood
- periods of mental confusion
- difficulty finding the right words (dysphasia)
Cognitive Assessment Tests
(initial assessment in primary care)

- General Practitioner Assessment of Cognition (GPCOG)*
- Memory Impairment Screen (MIS)
- 6 item cognitive impairment test (6CIT)
- Mini cognitive assessment screen (Mini-Cog)*
- Informant questionnaire on cognitive decline in the elderly (IQCODE)
- Mini mental state examination (MMSE)*

* Copyright restrictions apply
Treatment

• There is currently no cure for dementia

However …

evidence based early interventions effective in improving:
• Cognitive function
• Treating depression
• Improving care giver mood
• Supporting independent living
Life Story Work

What is Life Story Work?

• Life Story Work is an activity which involves reviewing and evaluating an individuals past life events, in developing an individual biography of that person.

• It is used to help develop an understanding of a persons’ past experiences and how they have coped with changes in their life.

• Life story work is a shared activity between the person, their family carer(s) and staff as appropriate.

Life Story Work
Continued...

How to use Life Story Work

• A template for putting together Life Story books has been developed by Dementia UK and the Central and North West London NHS Foundation Trust.

• The chapter headlines include: Introduction to my life (date and place of birth, parents, siblings etc), My childhood, My working life, Significant life events, Significant places, Significant events, Social activities & interests, Later life and retirement, My life now (What I Like to Eat and Drink, Things I Enjoy, My likes and dislikes) and My wishes for the future.

• This framework is used by staff to collect information about the people they are working with in order to help them understand more about them and to provide information, which can help them to deliver person centred care. This is a collaborative process with family members and friends and emphasis is placed on using images and photographs to bring the life story book ‘to life’.

• A recent project supported by the Foundation of Nursing Studies and Dementia UK involved the facilitation of life story work within 7 NHS Older Adult Mental Health in-patient areas. The results of this project indicated that the experience of doing Life Story Work was overwhelmingly positive and there was evidence that the delivery of care had become more person centred as result.

How would I know?
What can I do?

How to help someone with dementia who is in pain or distress