

## Dementia and Cognitive Impairment in the Older Prison Population in England and Wales (DeCision: Session 1)

Name of presenter, organisation  
Venue/audience, date

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## Aims of the training

- To introduce the most common types of dementia in the UK and their underlying causes
- To present why early diagnosis of dementia is important and the likely outcomes if assessment and treatment is delayed



## What is dementia?

- Is it any of these?
  - Psychiatric disorder?
  - Neurological condition?
  - Chronic long term condition?
  - Normal part of ageing?



## Types of dementia

- |                            |     |
|----------------------------|-----|
| 1. Alzheimer's Disease     | 62% |
| 2. Vascular Dementia       | 17% |
| 3. Mixed type              | 10% |
| 4. Lewy Body Dementia      | 4%  |
| 5. Frontal Lobe Dementias  | 2%  |
| 6. Rarer forms of Dementia | 5%  |
- a) Alcohol Related Dementia, e.g. Korsakoffs Syndrome  
b) Creutzfeldt-Jakob Disease (CJD)  
c) HIV & Aids Related Dementia



(Alzheimer's Disease Society, 2014)

### Slide 4 notes: Types of dementia.

There are 5 main types of dementia and several much rarer subtypes. Alzheimer's Disease is by far the most common

#### Alzheimer's disease

Alzheimer's disease is the most common cause of dementia.

It develops slowly over several years and tends to start with difficulties involving short-term memory, orientation and word-finding.

The exact cause of Alzheimer's disease is not fully understood.

However, we know that it can run in families (rarely) and that people with Down syndrome are more likely to develop early-onset Alzheimer's.

**Slide 4 notes continued:**

**Vascular dementia**

Vascular dementia is characterised by a sudden onset and stepped episodes of decline in functioning. It is caused by disruptions to the blood supply to the brain, whether due to narrowing of the arteries supplying blood to the brain (usually as a result of atherosclerosis) or a haemorrhage in the brain (usually as a result of hypertension).

The risk factors for vascular dementia are the same as those for stroke or ischaemic heart disease. Early impairments depend on which part of the brain has been damaged.

**Mixed dementia**

People with elements of more than one type of dementia may receive a diagnosis of mixed dementia. Alzheimer's disease and vascular dementia is the most common type of mixed dementia.

**Dementia with Lewy bodies**

Dementia with Lewy bodies shares similarities with Parkinson's disease (and hence Parkinson's dementia).

It is commonly associated with fluctuating memory impairment, visual hallucinations and the symptoms of parkinsonism (tremor, stiffness and gait abnormalities).

It occurs as the result of abnormal protein aggregates in the brain.

**Frontotemporal dementia**

Frontotemporal dementia is the second most common form of dementia in those under 65 years.

It is caused by damage to the front of the brain and leads to behavioural changes as well as memory issues.

These changes may affect social cognition (i.e. the ability to adopt another person's perspective and empathise with others).

Hence, a person may become unusually rude due to the loss of inhibitions and damage to his or her social skills.

There are growing concerns about heavy alcohol use and its effect on the brain, although Korsakoff's Syndrome results from heavy and chronic alcohol misuse.

**Teaching points:**

For more statistics, please see Alzheimer's Society Infographic – <https://www.alzheimers.org.uk/infographic>

## Dementia in prison

### Group discussion

- Please think about your professional and/or personal experience of dementia.
  - How might dementia present in prison?
  - Have you cared for an individual with dementia in a prison setting?



## Video presentation

### Living with dementia in prison

>insert video<



## Importance of early diagnosis

- An early diagnosis can:
  - Help the person to understand the changes they are experiencing and why things have become difficult
  - Allow the person to make appropriate choices for the future (e.g. to engage in advance care planning)
  - Be used to generate a care plan



## Importance of early diagnosis

- An early diagnosis can:
  - Enable the person to live well with dementia
  - Rule out other treatable causes of memory problems (e.g. depression and delirium)
  - Facilitate access to support services, advice and information (emotional and practical)



## Group exercise

- What are the barriers for presentation to healthcare for people with dementia?
  - Personal barriers
  - Stigma
  - Lack of insight
  - Cultural insight
  - Apprehension
  - Prior experiences
  - Denial
  - Professional barriers
- How might the prison environment impact on early diagnosis of dementia?



## Communication



## Communication difficulties

- May involve problems with:
  - Pronouncing words due to impairment of the muscles used to produce speech, e.g. tongue and lips
  - Finding the right words to use, resulting in difficulties expressing wants and needs
  - Understanding what is said by others
  - Participating in conversation, e.g. starting a conversation, maintaining a topic, taking turns
  - Using reading and writing as a means of communication



*These can manifest as distress/difficult behaviour*

## Supporting communication

- **Repetition** – be patient and try and understand why they might repeat what they are saying
- **Not understanding what they are saying** – ask them what they mean, use non verbal communication
- **Person doesn't start conversations** – take the lead in starting
- **The person forgets what they are saying** – gentle reminder of the topic



## Supporting communication

- **Seeking people who have died** – think what is right for that person
- **Forgetting the names of things** – find out if they would like reminders, prompts or would prefer time to think
- **Forgetting why they are in prison** – think about potential distress and how their offence should be explained



## Communication tips

- Gain a person's attention before asking a question or beginning a task with them
- Understand the importance of speaking clearly, calmly and with patience
- Demonstrate active listening skills
- Get to know the person, their past, present, experiences and concerns



## Communication tips

- Build a sense of trust
- Ask family/use life story information to enable or support more effective communication – find out what you can do to help them communicate
- Pay attention non-verbal communication e.g. body language, visual images and the appropriate use of touch



## Diversity and stigma

## Attitudes and prejudice

- Diversity:
  - Influences the experience of dementia (support, services and care people need and receive, discrimination)
  - Care and services need to be tailored to suit diverse people, including those who do not speak English.
- Stigma:
  - Myths and assumptions often lead to stigma –which can arise when we think that the person is of less value, we hold negative attitudes about their life and what they are capable of and we talk about them in negative terms



## Discrimination

- Discrimination:
  - We need to recognise assumptions we make that may discriminate against a person with dementia who differs from ourselves
  - The Equality Act 2010 makes it illegal for public services to treat people less favourably on account of any of these characteristics.
- People living with dementia are entitled to the same human rights as anybody else



## Human rights

- That includes **the right to;**
  - Privacy
  - Dignity
  - Family life
  - Liberty, and
  - To not be treated in an inhuman or degrading way.
- Dementia is now recognised as a disability by the United Nations Convention on the Rights of Persons with Disabilities
- Yet too often people living with dementia experience stigma, discrimination and poor care and support which contravene their human rights



## Advanced care planning

- People living with dementia and those involved in their care should be offered ongoing opportunities to engage in advance care planning
- This could be a series of conversations between the person living with dementia, whoever is closest to them, and professionals responsible for their care to discuss:
  - The benefits of planning ahead
  - Lasting power of attorney
  - Advance statements about wishes and preferences
  - Advance decisions to refuse treatment
  - Preferences for place of care and place of death



## Mental Capacity Act

- **The Mental Capacity Act** protects and empowers individuals who may lack the mental capacity to make their own decisions about their care and treatment.



Mental Capacity Act 2005

## Mental Capacity Act

- To **have capacity** a person must be able to:
  - Understand the information that is relevant to the decision they want to make
  - Retain the information long enough to be able to make the decision
  - Weigh up the information available to make the decision
  - Communicate their decision by any possible means, including talking, using sign language, or through simple muscle movements such as blinking an eye or squeezing a hand



## 5 key principles of the MCA



1. Every adult... must be assumed to have capacity
2. A person must be given all practical help...
3. ... an unwise decision does not mean they lack capacity
4. Anything done... must be done in their best interests
5. Anything done... should be the least restrictive

## Defining best interests



- The decision maker should consider:
  - The person's past and present wishes and feelings - these may have been expressed verbally, in writing or through behaviour or habits
  - The beliefs and values that the person would be likely to have if they had capacity
  - Factors the person would consider if they were making the decision for themselves

## Defining best interests



- The decision maker should consider:
  - The views of others should also be consulted, if appropriate, namely: Anyone named by the person as someone to be consulted
  - Anyone caring for the person or interested in their welfare
  - Anyone appointed under a Power of Attorney
  - Any deputy appointed by the court
  - The Mental Capacity Act does not define best interests, but does give a checklist which should always be used

## Abuse, neglect & exploitation



- People living with dementia are some of the most vulnerable people in our society.
- Neglect, abuse and exploitation can take a variety of forms:
  - Financial
  - Physical
  - Emotional
  - Psychological
  - Sexual
- You have a responsibility to report any signs of neglect, abuse or exploitation by using Safeguarding Vulnerable Adults resources and prison safeguarding protocols

## MCA Summary



- All adults should be assumed to have capacity
- People living with dementia often need extra help to make difficult decisions
- If capacity is questioned, it should be assessed for the decision in question with the 'capacity test'
- Key legislation relevant to people living with dementia includes the Mental Capacity Act, Deprivation of Liberty Safeguards (DoLS), equality and human rights

## MCA Summary



- A human rights based approach to dementia care strives to ensure people living with dementia are included in their communities, involved in their care and empowered to make decisions, and that services and systems are held accountable
- Someone may wish to plan for the future by preparing Lasting Powers of Attorney or advance statements
- The person may be vulnerable to abuse and neglect and, when relevant, professionals should consider this and use Safeguarding Vulnerable Adults resources to make a plan to protect them

## Sources of support

- Organisations such as Age UK, Alzheimer's Society, Carers UK, Dementia UK (Admiral nurses), TIDE and NHS Choices are often a good place to find out what is available.
- Look at this YouTube video to see what the Alzheimer's Society have to offer.
- There are also charities that support particular groups of carers, including young carers. These include: [Young Carers Hub](#) or [Action for Children](#).

## Further reading

- <https://www.mentalhealth.org.uk/publications/what-truth-inquiry-about-truth-and-lying-dementia-care> - guidance on what to do when a person is living with different realities and beliefs - something that increases as the dementia accelerates. Should they agree or contradict? What should they say?
- The document 'Dying Well in Custody Charter' is a useful resource for supporting those on an end of life pathway in custody.*  
<http://endoflifecareambitions.org.uk/wp-content/uploads/2018/06/Dying-Well-in-Custody-Self-Assessment-Tool-June-2018.pdf>

## Further reading

- <https://www.alzheimers.org.uk/get-support/daily-living/eating-drinking?documentID=149> - leaflet about supporting eating and drinking