[redacted]

Dementia and Cognitive Impairment in the Older Prison Population in England and Wales (DeCIsion: Session 2)

Name of presenters, *organisation*
Venue/audience, date

*This presentation contains content adapted from Health Education England with permissions from Health Education England (reference)

[redacted]

Session 1 recap

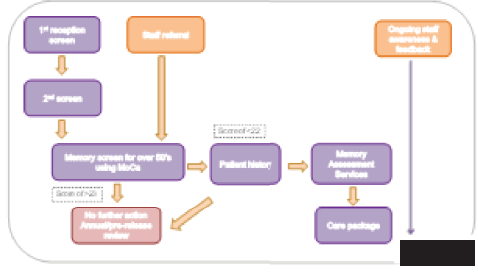
- Dementia in prison
- Importance of early diagnosis
- Communication
- Diversity and stigma
- Mental Capacity

[redacted]

Pathways to assessment

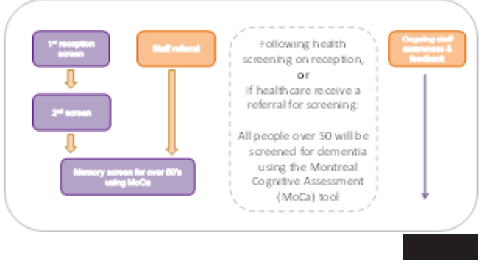
[redacted]

DeCIsion care pathway



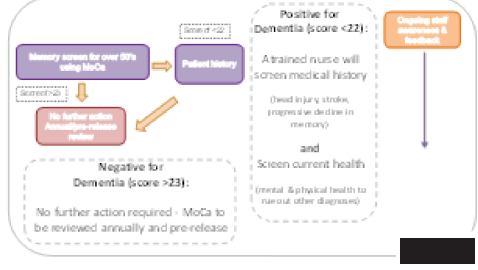
[redacted]

Screening / referral



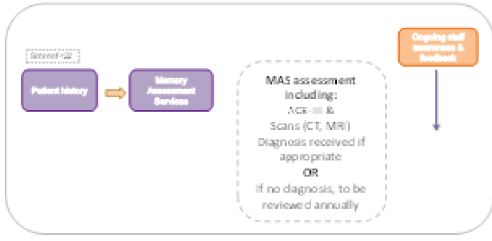
[redacted]

Memory screen



[redacted]

Memory Assessment Service



Care package

DeCIsion care pathway

- **Group discussion**
- Please think about your work environment and how the DeCIsion care pathway could be implemented
  - How might the pathway be adopted?
  - What might need to change for the pathway to be implemented

Care of a person with dementia

Underlying philosophy

Person centered care

- Understanding...
  - The human value of people with dementia, regardless of age or cognitive impairment, and those who care for them
  - The individuality of people with dementia, with their unique personality and life experiences among the influences on their response to the dementia
  - The importance of the perspective of the person with dementia
  - The importance of relationships and interactions with others to the person with dementia, and their potential for promoting well-being

Person centred approaches

Collecting stories

- How?
- This is Me (or alternative document)
- Complete with prisoner
- Documentation
- On-going process with contributions from all those involved in that persons care

Source: Alzheimer's Society, 2013

Prison case study 1

Fred

- Dementia with learning difficulty
- Discusses deceased family members
- Older prisoner wing
- Violence with other prisoners
- Distraction - sewing
- 4.5 years over his tariff

<insert audio>

'We became quite stuck really because he wasn't in the community, and there were no other agencies involved with him, so I had a really difficult time getting them to actually take that application seriously and actually allocate him a social worker, because obviously he's not in the community. He's not a priority for them, so that then, we became stuck'

Probation worker

Prison case study 2

Peter

- Dementia and Parkinson's
- Health care wing
- Frightened
- Peer carer
- Care plan
- Eating on view
- End of life

<insert audio>

'Keeping an eye on them, make sure that they're healthy because we can spot signs, because we're with them 24/7, sort of thing. We can see when they're deteriorating a little bit. If somebody is not well or just under the weather, we'll point towards the nurses and say, look have a check of Thomas or have a check of whoever it is and say, look he's not right, he's hasn't been well for a couple of days, he's not him self, can you just have a look. And a lot of the time they'll respond to that and say, he's all right, he's just a little bit down or we just need to keep an eye on him again'.

Peer carer

Prison case study 3

John

- Vascular dementia
- Reports LT memory is good, problems with ST
- Diagnosis prior to prison
- located on induction wing for seven months
- lock down majority of the time on due to his VP status.
- Moved to health care due to his social care needs
- Reports feeling more settled on healthcare.
- Frail, physical health problems present.
- 10 year sentence, will most likely die in prison
- Majority of time sat in his cell, watching T.V with lights dimmed

<insert audio>

'You had to do a lot of things in an hour, you had to go and fetch your meal one, which was right down the far end there, and there'll you'll be standing in the queue for about 20 minutes. Come back, get your meal, go to the stores if you want to go to, go the toilet if you want to go to it…store, oh, and then if you wanted a meal you had to go to this thing and put your card in and put your ring er print and I've got no fingerprints, you see, because I used this stuff for my…look at my feet, swollen… And so I have difficulty there, because I've never even touched a flipping computer, let alone used one, you know'.

Probation worker

Health and well-being

Health and well-being promotion

- Strategies
  - Nutrition
  - Fluids
  - Oral health
  - Social engagement – board games, crafts, life stories
  - Stress
  - Exercise – encourage walking outside and use of the gym if safe for the person
  - Physical environment – reduce risk of falls

Noticing deteriorating health

- It is essential to know what is normal or usual functioning and behaviour for the person in order to detect changes in their health. Once we know what is usual, we can use all our senses to notice change in the usual.
- Keep an eye out for signs of deterioration e.g. worsening of memory, change in behaviour.
- Also important to monitor the person for signs of other illness e.g. depression, dehydration
- Once signs of health conditions have been noticed, it is important to communicate these changes to others.

Refer to healthcare / GP

Promoting independence

- People living with dementia benefit from retaining independence and being able to do what they choose to for as long as possible.
- Being independent can meet our psychological needs in a number of different ways:
  - Increased contact with others
  - Sense of continuity with the past
  - Sense of usefulness and accomplishment
  - Feelings of belonging
  - Skills are maintained for longer
  - Self-esteem and confidence are raised
  - Help with memory and recall
  - Reduce the level of ongoing care needed

Identifying solutions

- How to involve and enhance the independence of the person living with dementia in specific activities:
  - Mobility
  - Washing and hygiene
  - Dressing
  - Using the toilet
  - Eating
  - Sexual behaviour
  - Going out

- Activity – work in pairs to discuss how you could help a person in prison with the above activities

Impact of losses

- People living with dementia typically experience many losses.
- Examples of such losses include:
  - The loss of their own abilities
  - The loss of their sense of place in life
  - The loss of their friends
  - The loss of their home (if they move to a care home)
  - The death of a spouse, relatives or friends

Group exercise

- How can you support the health and well-being of a person with dementia in your prison?
- How can prison and healthcare staff work together to promote this?

Interventions

Medication and dementia

- 40 - 70% of people with Alzheimer's disease benefit from taking cognitive enhancers
- Improve symptoms such as:
  - Reduced anxiety
  - Improvements in motivation, memory and concentration
  - Improved ability to continue daily activities
  - Reduce behavioural disturbance

Medication and dementia

- Two main types of medication:
  - Acetylcholinesterase (AChE) inhibitors
    (donepezil, galantamine and rivastigmine) - used for mild-to-moderate Alzheimer's disease
  - Memantine
    moderate Alzheimer's disease who are intolerant of, or have a contraindication to, AChE inhibitors or severe Alzheimer's disease

Psychiatric medications

- **Antipsychotics** are used for behavioural / psychological symptoms. May be useful for targeted symptoms such as hallucinations.
- Depression is very common in people with Alzheimer's disease, and **antidepressants** (e.g. sertraline, citalopram, mirtazapine, trazodone) are prescribed for severe depression but the benefits in people with dementia are limited
- Anxiolytic medication (**benzodiazepines**) can be helpful in acute management of anxiety in cases of high distress or risk but the evidence base is poor and they can increase agitation

Polypharmacy

- Polypharmacy defined as having five or more medications.
  - Many people living with dementia are on more than five medications for co-occurring conditions
  - May be more prone to side –effects and impact on appetite and nutrition, mood and cognitive difficulties
  - Regular reviews of treatment are recommended with the prescriber to determine the appropriateness of use of all medications.
  - People in prison at risk of negative effects from polypharmacy need regular discussions with prison staff around side-effects

The person living with dementia should be seen at least every 6 months by their prescriber.

Psychosocial interventions

- Day care/day centres
- Support groups
- Personalised care plan
- Cognitive stimulation therapy
- Offender management: adapted sex offender treatment programme

Psychosocial interventions

- **Group discussion**
  - What is already in place in your prison regarding psychological intervention?
  - What could you implement?

End of life care

End of life care - ACP

- Advance care planning (ACP):
  - Ensures that the individual's wishes and preferences are known
  - Is consistent with providing person-centred care, in line with the preferences and wishes of an individual
  - Allows for a record of the individual's preferences which can guide care at end of life when the person may have lost capacity and families are faced with difficult decisions
  - Ensures people have enhanced choice and control over decisions about their care

Example advance decision

Advance decision

To my family, my GP, my Health and Welfare Attorney (where applicable) and all other persons concerned, this advance decision has been made by me, entirely without influence from any other person whether they might stand to gain from my death or otherwise.

Full name in capitals: _____

Of (address): _____

_____

_____

Date of birth: _____

I declare that if at any time:

- I am unable to participate effectively in decisions about my medical care **and**
- two independent doctors (one a consultant) are of the opinion that I am unlikely to recover from illness or impairment **and**
- the gravity of my condition/suffering is such that treatment seems to be causing distress beyond any possible benefit,

then in those circumstances my directions are as follows:

Approaching end of life

- The Gold Standards Framework provides guidance on knowing when a person is in the actively dying phase. Indicators that a person is entering the dying phase (can last days or weeks) of end of life include:
  - Stopping eating and drinking
  - Loss of consciousness
  - Difficulty swallowing
  - Restlessness
  - Change in breathing pattern
  - Cold hands or feet
  - Fever
  - Sleeping more
  - Decreased urine output
- When these impairments combine with frailty, recurrent infections (chest or urinary) and skin breakdown it is likely that the person is nearing the end of their life.

Physical and medical needs

- People approaching end of life will need special attention paid to pain assessment and treatment, difficulties with eating and drinking, and recurrent infections.
  - Personal care
  - Pain assessment
  - Pain treatment
  - Treating infections

Physical and medical needs

- Best practice in caring for people with dementia who are dying also means caring for their family members. Care providers can support family members by:
  - Providing appropriate information
  - Acknowledging and supporting those experiencing feelings of loss and grief
  - Discussing appropriate local support groups and online sources of help

Summary

- People living with dementia and their family members require coordinated, compassionate and person-centred care towards, and at, end of life
- People can live for many years with advanced dementia with impairments similar to those approaching end of life
- It is not always easy to know when a person living with dementia is entering the active dying phase
- People should be given the opportunity for advance care planning early in the course of living with dementia and opportunities for regular review of their advance care plan

Summary

- There is lots of guidance available to support care providers to feel comfortable about raising the topic of end of life care with people living with dementia and their families
- Best practice in end of life care must consider the needs of the person living with dementia and how to support family members and care staff
- A number of groups (e.g. the Alzheimer's Society) are able to provide information and support about planning for and ensuring quality end of life care

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