

Care of People living with Dementia - SPACE principles

We have five ways to improve care for people with dementia. We would like to tell you about them. They are

Staff who are skilled and have time to care.

Partnership working

Assessment, spotting dementia early and support when you have dementia

Care and support plans which meet your needs

Environments that are dementia friendly.

Dementia



Dementia is an illness caused by damage to a person's brain. You cannot catch dementia from another person. Part of the person's brain dies. Changes to the person's brain can lead to memory difficulties and problems with thinking. A person may forget names or where they have put things.

Dementia can affect how people feel and behave. They may be sad or angry or get confused. They will still enjoy things, laugh and have fun.

Younger people (under 65) can also get dementia. People with learning disabilities are more likely to get dementia when they are younger.

Dementia cannot be completely prevented. But there are things people can do that may make it less likely they will get dementia.

- Staying active and getting lots of exercise can help prevent dementia.
- Eating healthy food and not drinking too much alcohol can help prevent dementia.
- Not smoking means people are less likely to get dementia.
- Being a healthy weight
- Learning new things and doing puzzles and activities may help prevent dementia.¹



Finding out if you have dementia

The prison staff may ask you to the hospital or memory clinic for more tests. You may be asked to go for a scan. This helps the doctors to see how the brain is working.

Dementia cannot be cured. It gradually gets worse over time. There are medicines that can help with some of the effects of dementia. The doctor/nurse will explain these. Scientists are working to find a cure and new treatments.



Depression



Having dementia and living in prison may increase your chance of depression. You may find you are tearful or sleep poorly. You may want to eat more or less than usual. You may not be able to concentrate on things or feel worried. Being away from your friends and family may make this worse.

There is treatment for this such as talking therapy or medication.

Living in Prison with Dementia

The way dementia effects each person is different, it depends on the type of dementia, how long you have had it and the way people treat you.

You may need help with

- Remembering things
- Finding the right words
- Understanding what is being said
- Concentrating
- Recognising people and things
- Finding your way around
- Dressing and undressing
- You may see things that aren't there
- You may find it difficult to control your moods



Looking after people with dementia

Dementia can change the way you behave. It is only one part of your life

It is important that

- You are valued and your rights are recognised
- You are treated as an individual and your history and personality is unique
- That people listen to you and see the world from your point of view
- That your wellbeing is supported
- You are given new opportunities and have meaningful activities



The role of family, friends and supporters (buddies, listeners, trusted members of the prison community)

- Any family, friends or supporters have an important role in the care of people with dementia.
- Families can provide information about your needs and the things you like so the right care can be given.
- Families also have their own needs which staff should know about so they can be helped.
- They should be offered information and education about dementia.
- It is important to help families stay involved.
- Where possible links should be maintained with families, underpinned by consent and appropriate risk assessment.

SPACE Principles

Principle 1: Staff who are skilled and have time to care

This will be supported by

1. Training and education in dementia for all staff. The training should be easy to access and practical. It should focus on attitudes and communication. It should be based on high quality guidance. Training should be based on what is needed for the job people are doing. Training should include the views of people who have dementia. Staff should be given the time to attend training.
2. People should be able to speak to Specialist dementia staff
3. There should be enough staff to support people living with dementia.
4. Training and education should involve listening to the way people with dementia want to be cared for and hearing the views of family and the wider prison community. Trainers need to be expert in dementia care.



It is important that:ⁱⁱ

- all staff have training in dementia awareness and know the needs of people with dementia.
- staff who regularly give care have an extra knowledge and are skilled in dementia care
- each area has a dementia leader and/or support from a specialist who are experts
- there is a culture within the prison community where men and women living with dementia are valued
- there is a focus on values, attitudes and approach of staff, which supports good communication
- there is a team approach to training
- there is a learning culture to improve dementia care
- staff are able to improve life for people with dementia with communication, assessment, reducing risk of developing dementia/health promotion, life story information, pain, eating and drinking continence, activity, rehabilitation, environment and end of life care.
- it is important staff are able to discuss how healthy living
- can reduce the risk of dementia for an individual.



Principle 2: Partnership working

People living or working in the prison community should work with the person with dementia. This may be family or friends or other people who matter to you. It can be helpful to learn from carers about the person with dementia. Carers may be in need of support because of changes in role, practical demands, travel, emotional and physical needs. It is important for staff to work in partnership with people with dementia, social care and their families so that needs are understood and recognised.

This is supported by

1. Involving families and supporters in assessment, care planning and decision making particularly when people are released. Families often have important information to help staff provide care. Good care involves good relationships the person with dementia, family and staff. Quality of care is dependent on the relationships between all these people.

2. An identified member of staff who is responsible for supporting and liaising with the individual's family and carers. Where people living with dementia are unable to explain what they need. There should be somebody to speak to who understands dementia.

3. Signposting people to appropriate community support can improve people's experiences of living with dementia. This may include local peer support groups, charities and events. Active engagement with local community resources can enhance the experience of health care, for example, volunteers, chaplains.



Principle 3: Assessment, early identification of dementia and post diagnostic support

Assessment is important to good care so that a person with dementia gets the care they need every day. It is important the environment is good for communication and ensure that the person with dementia can see and hear, with aids as necessary. Health care settings should make changes to help get the best from the person with dementia. As dementia gets worse or if the person has a lot of health needs, assessment may be best in the person's own setting. Assessment should include other physical conditions that can make life with dementia difficult.

Examples of the types of assessment which may be required include swallow or speech and language assessment, continence assessment, rehabilitation needs, advance care planning and decisions about end of life care.

Spotting people with dementia may be more difficult in prison because staff may think a person's difficulties are because their lives are restricted. Routine healthcare should always consider if a person has dementia.

This will be supported by

1. Using the same screening and assessment tools as local memory services.
2. Skilled knowledgeable staff.
3. Clear delirium protocols, dementia/ depression pathways and referral to post diagnostic support.
4. Clinical review of medication and ensuring any use of antipsychotic medication is only as a last resort and on a short term basis.
5. Post diagnostic support designed to help the person living with dementia and their families once a diagnosis of dementia has been given.
6. All prison staff should undertake dementia awareness training when they start their jobs

1. Use of agreed screening and assessment tools

It can be difficult when a person does not have a diagnosis of dementia but seems to have the symptoms. All clinical staff should be familiar with screening tools to use if someone is having problems with memory, perception, judgment and reasoning. There must be processes for screening and assessment so people can receive the right care

Assessment should include:

- a full medical history of the person, including any previous physical or mental health problems
- a physical examination, to rule out any treatable causes
- an initial test or screen of the person's cognitive abilities
- Information from a relative or member of the wider prison community who knows the person well

It is important to assess for possible depression and consider asking:

“During the last month, have you often been bothered by:

- feeling down, depressed or hopeless?
- having little interest or pleasure in doing things?”



2. Having skilled and knowledgeable practitioners

(as identified in *Principle one*)

Where staff members and other people living in prisons have regular interaction with people living with dementia, their training should exceed dementia awareness and they should have access to a higher level of training and skill in order to appropriately support the person living with dementia

3. Clear delirium protocols and dementia and depression pathways

It is therefore important that dementia is taken into account throughout a person's stay and that a care pathway is in place to ensure the needs of the person are met. This should be supported by a clinical lead with responsibility for dementia care in the organisation.

4. Clinical review of medication including use of antipsychotics

Due to illness, people with dementia can become distressed, agitated or even aggressive. To help understand the person those closest to them can help to predict and prevent distress. Distressed behaviours are not always due to dementia. Factors such as pain, disorientation or not understanding information may cause distress. Reducing the distress that people feel should be a priority.

Medication can improve distress but can cause side effects such as

- parkinsonism (shaking and unsteadiness)
- Drowsiness
- increased risk of infections.
- increased risk of falls.
- increased risk of blood clots.
- increased risk of ankle swelling.
- increased risk of stroke.
- worsening of other symptoms of dementia.



Principle 4: Care and support plans which are person centred and individual



All people with dementia should be offered a care and support plan by someone who will co-ordinate their care focussing on their life and understanding their abilities. Understanding the way dementia affects the person and how care can get the best from them is important.

Care plans should be made with the person and families and those providing care must know about them. Care plans should respond to individual needs and support nutrition, oral health, dignity, comfort, continence, well-being, rehabilitation, activity, meaningful occupation, sleep, advance care wishes, safeguarding needs and end of life care.

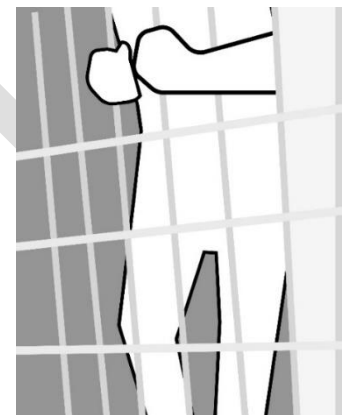
This will be supported by

1. Routine gathering of personal life story information.
2. Involvement of family and friends in care planning and review.
3. Use of mental capacity assessments. Plans must include advance care planning, nutritional tools, pain assessments and safety assessment tools.
4. Plans and any prior consent about engagement in research.
5. Provision of appropriate activity to encourage social engagement, peer support, maintenance of function and wellness including recognition of spiritual needs.
6. Access to dementia specialists
7. Access to and availability of palliative care specialists
8. A named member of staff should be responsible for coordinating care planning activity and sharing.



Principle 5: Environments that are dementia friendly

Prison environments in particular can be confusing, noisy and difficult to navigate. The pace and noise of prisons can be difficult for people living with dementia. Environments should be dementia friendly and support independence and wellbeing.



This will be supported by

1. Minimal moves to avoid unnecessary distress

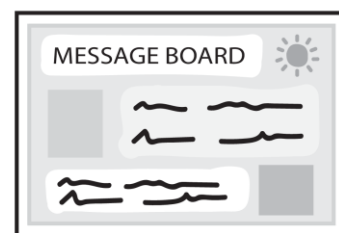
Moving between environments can upset people and should be limited. This should not stop people going to appointments, or doing things that are familiar such as recreational activities.

2. Dementia-friendly design, such as signage, lighting, minimising noise

Good design features should be included in all new builds and refurbishments of prisons health care facilities and older people's wings such as appropriate flooring, lighting, signage, contrast and technology.

3. Personalised space- this may be a cell or shared cell

Regardless of where they are people in prison should have some way of recognising their own space, this can include personal possessions.



4. Adequate space and resources to support activity and stimulation

Settings should ensure people have a chance to do meaningful things and see people.

5. Sensitive use of technology to support independence

Technology can be used to support independence, to help people with dementia getting around, helping people to find their way or to stop falling over. Ideally people with dementia should help develop new technologies.



Thank you so much for taking the time to read this. Your help will mean we are able to start improving the care for people with dementia in prison.

With grateful thanks to Ruby Morton for providing the illustrations throughout the document.

ⁱ <https://www.alzheimers.org.uk/get-support/publications-and-factsheets/easy-read-factsheet-what-dementia>

ⁱⁱ <https://www.nhs.uk/conditions/dementia/dementia-prevention/>