Royal College of Nursing

Dementia Care Principles for People in Prison

CLINICAL PROFESSIONAL RESOURCE

Acknowledgements

This project was led by:

- Jo James, Chair of the Older People's Forum
- Jessica Davidson, Chair of the Nursing in Justice and Forensic Health Care Forum
- Ann Norman, Professional Lead for Justice
- Dawne Garrett, Professional Lead for Older People and Dementia Care
- Nikki Mills, Project Co-ordinator.

Thanks to all steering committee members for the Older People's and Nursing in Justice and Forensic Health Care forums, the expert reference group and key stakeholders who kindly reviewed and amended this document.

Particular thanks to those in prison, and their families, who shaped this document.

This document has been designed in collaboration with our members to ensure it meets most accessibility standards. However, if this does not fit your requirements, please contact corporate.communications@rcn.org.uk

RCN Legal Disclaimer

This publication contains information, advice and guidance to help members of the RCN. It is intended for use within the UK but readers are advised that practices may vary in each country and outside the UK. The information in this booklet has been compiled from professional sources, but its accuracy is not guaranteed. Whilst every effort has been made to ensure the RCN provides accurate and expert information and guidance, it is impossible to predict all the circumstances in which it may be used. Accordingly, the RCN shall not be liable to any person or entity with respect to any loss or damage caused or alleged to be caused directly or indirectly by what is contained in or left out of this website information and guidance.

Published by the Royal College of Nursing, 20 Cavendish Square, London, W1G 0RN

© 2021 Royal College of Nursing. All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means electronic, mechanical, photocopying, recording or otherwise, without prior permission of the Publishers. This publication may not be lent, resold, hired out or otherwise disposed of by ways of trade in any form of binding or cover other than that in which it is published, without the prior consent of the Publishers.

Contents

Introduction **4**

Principles **5**

Dementia **6**

Depression 7

Delirium 8

Symptoms of dementia 8

The person living with dementia 9

The role of family carers and the wider prison community 9

SPACE principles **11**

Principle 1: Staff who are skilled and have time to care 11

Principle 2: Partnership working 12

Principle 3: Assessment, early identification of dementia and post diagnostic support 13

Principle 4: Care and support plans which are person-centred and individual 16

Principle 5: Environments that are dementia friendly 17

Finally 18

Resources **19**

References **20**

Introduction

A diagnosis of dementia is profound. It affects the person, their circle of support, and the wider community - particularly if that community is a prison. In order to support the person and the wider prison community, the Royal College of Nursing has adapted its long-established SPACE principles in order to promote dementia care in prisons.

This document sets out the five principles that form a shared commitment to improving dementia care in prisons. The principles are based on evidence gathered from people living with dementia, carers and practitioners. Each principle is considered essential to ensure the appropriate delivery of care. Whilst intended for use in dementia care, many of the principles have applicability to other conditions that affect cognition.

Principles

This guide will be helpful for nurses, staff and volunteers working in prisons. The principles can influence service provision, commissioning and audit.

SPACE stands for:

Staff who are skilled and have time to care

Partnership working within the prison community

Assessment, early identification of dementia and post diagnostic support

Care and support plans which are person-centred and individual

Environments that are dementia friendly

The RCN SPACE Principles video offers further explanation: https://youtu.be/1fJslbFGl4g

SPACE principles can be used along with other initiatives that support innovation and improvement. It is recommended that staff and the wider prison community use them to inform the development of practice in a systematic way that demonstrates real benefits for the individual, circle of support and the prison community.

The approach requires dedicated leadership, development of shared action plans and evaluation of outcomes, particularly the individual and family experience.

Thoughout this document the term “carer “is used. This is intended to encompass family, friends and all those who have regular interactions with the person living with dementia. We also use the term “circle of support”, which might include family, friends, listeners, chaplains and peer supporters.

Dementia

The term dementia is used to describe a range of conditions which affect the brain and result in an impairment of the person's function. The person may experience memory loss, problems with communication, impaired reasoning and difficulties with daily living skills.

This can result in changes in behaviour, which can disrupt their ability to live independently and may affect social relationships. There are many types of dementia. The most common cause is Alzheimer's disease, where there tends to be a progressive and gradual decline over time. The second most diagnosed type is vascular dementia, where small blood vessels in the brain become damaged and the circulation is affected. Other types include dementia with Lewy bodies, fronto-temporal lobe dementias, Posterior-Cortical Atrophy and alcohol-related dementia.

Each type of dementia has different features and people may experience elements of more than one type of dementia, usually Alzheimer's disease and vascular dementia, in which case a "mixed dementia" may be diagnosed. Although dementia is more prevalent with increasing age, it is not a normal aspect of ageing.

Dementia can also affect younger people and it is estimated that more than 42,000 people in the UK under the age of 65 have young onset dementia. The prison population is more likely to have the risk factors associated with the development of dementia and to experience health inequalities.

Risk factors for dementia include:

Age: people diagnosed with dementia tend to be over the age of 65. Above this age, a person's risk of developing Alzheimer's disease or vascular dementia doubles roughly every five years. Over the age of 80, there is a one in six chance of developing dementia. It is recognised that the health-related needs of prisoners are advanced by around 10 years, relative to people in the general population.

Ethnicity: certain ethnic communities appear to be at higher risk of dementia than others. For example, South Asian and African or African-Caribbean people seem to develop dementia more often than white Europeans. Specific risk factors associated with these communities such as stroke, diabetes, hypertension and cardiovascular disease, as well as differences in diet, smoking, exercise and genes, are thought to explain this.

Gender: more women are affected by dementia than men. Worldwide, women with dementia outnumber men two to one. Twice as many women over the age of 65 are diagnosed with Alzheimer's than men, whereas vascular dementia is diagnosed in slightly more men than women.

Genetics: in rare cases, Alzheimer's disease can be passed from one generation to another. This type of dementia usually affects people under the age of 65.

Although getting older is undeniably the biggest risk factor for dementia, research suggests up to one in three cases of dementia are preventable. Modifiable risk factors include:

- diabetes
- high alcohol intake

- high blood pressure
- lack of exercise
- low educational attainment
- obesity
- poor physical health
- smoking
- deafness
- head injury
- depression.

Dementia UK: dementiauk.org/understanding-dementia/prevention-and-risk-factors

For people living in prison, lifestyle factors such as access to health care, long term condition management, access to positive lifestyle choices, and previous drug and alcohol use can all increase their risks.

Dementia is a progressive and terminal condition, which will in most cases lead to increasing cognitive difficulties and dependence on others. How long the person will live depends upon the type of dementia, their age and their general health, but many will live with the condition for several years and can have a good quality of life. We know managing dementia alongside other health conditions can be challenging.

Depression

Low mood that usually develops over weeks or months but can result in significant problems with concentration, sleep patterns and impaired functioning. Identification of depression is very important, as treatment can be offered. Symptoms of depression can mimic symptoms of dementia, such as poor concentration, agitation or restlessness, disturbed sleep, and changes in functioning, but depression in all ages can be treated with psychological therapies and/or medication. People living in prison are more likely to experience depression, and separation from family and friends can exacerbate this. People in prison also tell us that the environment is frequently seen as a place for young people and this increases their vulnerability.

> "I am not afraid of death, I wish for death every single day, I am under tremendous stress"
>
> **Elderly man living in prison over a long time, with both physical and mental health issues**

Further details can be found online: england.nhs.uk/publication/a-practice-primer-on-mental-health-in-older-people

Delirium

Delirium is a disturbance of consciousness and a change in cognitive functioning that develops over a short period of time and which can fluctuate during the course of the day. It is often associated with trauma or infection or as the result of drug and alcohol misuse. People with dementia have a fivefold risk of developing delirium and, in someone with dementia, risk factors include medications, lack of mobility, malnutrition and infection. The environment or psychosocial influences can also contribute to a worsening delirium. Delirium may be prevented through effective interdisciplinary prevention, diagnosis, treatment of the underlying cause, environmental changes and supportive care. Research indicates that many older people who have delirium will also have either an underlying dementia or an increased chance of developing dementia.

One of the clearest ways to ascertain if the use of recreational drugs has caused a behaviour change is by making sure of the difference between active intoxication and perpetuating symptoms of behavioural change once the expected effects of any recreational drug would have worn off, such as a high, mood change or aggression. Assessment regarding drug-induced psychosis helps to create an expected timeframe in which recreational drugs and any triggered psychosis can abate.

Distinguishing between delirium, depression and dementia is an important aspect of assessment and all people who present as ‘confused’ should be assessed carefully. Staff should have awareness training for all three conditions and be able to make appropriate referrals.

For further information about delirium, the RCN website hosts a number of useful links and learning resources: rcn.org.uk/clinical-topics/older-people/delirium

Symptoms of dementia

While there are common symptoms associated with dementia, not all of them may be present and each person will be affected in a different way. This depends on the type of dementia, the stage of the illness, the individual’s personality and life experiences, and, importantly, the way others interact with them. Some people have limited awareness of their difficulties and as the condition progresses, insight tends to decline along with other cognitive abilities. As previously stated, people living with dementia may also experience depression and older people who are ill commonly experience delirium.

Common symptoms of dementia include more than one from the list below:

- **Memory loss (anterograde amnesia)**
  Short-term memory loss is the most common feature of dementia. It becomes worse as the disease progresses and eventually may affect long-term memory.
- **Communication (dysphasia/aphasia)**
  Difficulty with finding the right words or understanding what is being said.
- **Carrying out tasks (dyspraxia/apraxia)**
  Difficulty with sequencing and doing everyday tasks such as getting dressed.
- **Concentration**
  Difficulty with attention for periods of time.

- **Recognition (agnosia)**
  Difficulty with recognising familiar objects, people, sights, places or sounds.
- **Orientation**
  Difficulty with finding your way around, knowing the time, date etc.
- **Perception**
  Difficulty with understanding and interpreting information, for example thinking people have taken things.
- **Misinterpreting or misjudging things**
  (Visual-spatial difficulties) or seeing things that are not there (hallucinations).
- **Psychological changes**
  People may behave in unusual or uncharacteristic ways, such as being disinhibited or irritable, withdrawn or depressed.

The person living with dementia

It is vital to understand that while some general statements can be made about dementia, each individual will be affected differently. Also, while dementia fundamentally changes the way in which a person functions, it is only one aspect of their life. Rather than seeing 'someone with a dementia', it is essential to seek to understand the individual. Knowing and respecting each person remains central to the relationship and includes:

- valuing people with dementia, and those who care for them, and recognising their rights
- treating people as individuals; appreciating that all people have a unique history and personality
- looking at the world from the perspective of the person and listening to their voice
- recognising that all human life is grounded in relationships and that people need to live with social interaction which supports their wellbeing. Simple changes can have a great impact
- understanding changes related to behaviour and mood
- affording opportunities for meaningful activity.

The role of family carers and the wider prison community

Family carers often have a crucial role in the care of people with dementia. When a person with dementia develops a physical health problem and/or their behaviour changes, the family is often the first to be aware of this. As capacity declines, family carers can provide vital information about the person's needs and preferences so that the right care and treatment is provided. They may also be an individual's lasting power of attorney for health and welfare. Where appropriate, circles of support should be kept involved and informed throughout any assessment and treatment of the person they care for. Family carers also have their own needs, which should be assessed and taken into account, particularly when planning release from prison.

It is important to maintain the role of family carers. They should be offered an assessment in their own right and be supported in their caring role through education and skills training. Where possible, links should be maintained with the person's circle of support, underpinned by consent and appropriate risk assessment.

Within the prison community the person with dementia should have their human rights supported and upheld. There may be the need for increased education and training for prison staff, trusted prisoners, peer supporters, volunteers, chaplaincy, and other people engaged in the life of the prison. Dementia training should be part of the induction programme and regular refreshers should be available. Staff should be aware that people of all ages can develop dementia and that people in prison have higher risk factors.

> "Dementia is close to my heart, I did a dementia awareness day which was held in the chapel. I raised money for the Alzheimer's Society."
>
> **Someone living in prison who has spent time in education and fundraising for charity for those with Alzheimer's**

SPACE principles

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

Supporting staff need to be informed, skilled and have enough time to care in the most appropriate setting.

This will be supported by:

1. High quality training and education in dementia for all staff that is easy to access, practical and focuses on attitudes/approach and communication, and is based on recognised guidelines. The level of training should be based on an analysis of training needs and incorporate perspectives of people with dementia and carers. Staff should be released by employers to participate in training. There should be a baseline level of understanding of dementia held by all staff.

2. Availability of identified clinical leads for dementia, for example, dementia specialists, for advice and support.

3. Careful consideration of staffing levels which ensures that skill mix, ratio and numbers of staff are adequate to support the complex needs and numbers of people with dementia being cared for.

4. Good quality training and education in dementia involves listening to the way people with dementia want to be cared for and hearing the views of family and the wider prison community. It needs to be relevant to the setting and include some face-to-face learning, provide opportunities for interaction and discussion, and be facilitated by expert trainers. Surveys reveal that lack of staff understanding and time were the major barriers to achieving good care.

It is recommended that:

- all staff and peer supporters have training in dementia awareness and are informed about the needs of those affected by dementia
- staff who have regular responsibilities for providing care or interacting have an enhanced knowledge and are skilled in dementia care
- each facility has a dementia leader and/or access to support from a specialist with an expert level of skill and knowledge
- a culture is developed within the prison community where men and women living with dementia are valued, using person-centred care and behaviours. It is important they have opportunity to debrief and discuss the impact on themselves
- there is a focus on values, attitudes, and approach of staff, which supports good communication and a relationship-centred approach
- a team approach to training is taken and supported in practice by dementia champions, specialists and leaders who have further training
- training includes opportunities to hear about the experience of people with dementia and their families/carers
- learning culture that uses outcomes and data to support the improvement of dementia care is encouraged, rather than apportioning individual blame

- there is development of understanding and skills to enhance the quality of life for people with dementia, with a specific focus on communication, assessment, life story work and meaningful activity
- information on pain, nutrition and hydration, continence, activity, rehabilitation, environment, and end of life care is available
- staff are able to discuss lifestyle factors that reduce the risk of dementia throughout life.

Clinical staff need to understand the latest evidence and the way in which messages are best shared. The opportunities to educate people on how to reduce their risk should be grasped early. Advice given to people should be tailored to their individual circumstances and based on thorough assessment of lifestyle and risks of dementia. **nhs.uk/conditions/dementia/dementia-prevention**

> "All prison staff, not just officers, should receive training by an organisation that understands dementia and the prison system key workers should be selected with enhanced understanding and empathy."
>
> **A 61-year-old male prisoner serving a 22 year sentence**

Principle 2: Partnership working

Effective care requires a relationship-centred approach, with careful risk assessment which acknowledges the needs of families, prison staff and the wider prison community, as well as the person with dementia. It is important to learn from carers about the person with dementia and how they function best. It is also important to recognise that carers and those who share cells may themselves feel in need of support. Carers can experience stress in relation to changes in role, practical demands, emotional and physical needs. For example, they may have physical and mental health problems, emotional difficulties due to changes in their relationship and be experiencing feelings of loss. Some carers or members of the wider prison community may be worried about their own risks of developing dementia and they should have access to high quality information.

Carers who are supported and can derive something positive out of caregiving have better wellbeing.

It is essential for staff to work in partnership with people with dementia, social care, the wider prison team and their family carers so that needs are understood and recognised.

This is supported by:

1. Involvement of family carers in assessment, care planning and decision making. Working in partnership with family carers, the wider prison community and people with dementia is not only important for delivering the right care but can also be helpful for staff. Families often hold valuable information that can help staff get an accurate assessment and provide care which meets the needs of the individual. Relationship-centred care identifies the people or agencies involved in the care of people with dementia: the person with dementia, family or friends, and practitioners. Quality of care is dependent on the relationships between each of these agencies.

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 consistently express their needs, they should have access to advocates that have the necessary skills and understanding to ensure the person's voice is heard.
3. Signposting people to appropriate community in reach support can improve people's experiences of living with dementia. This may include peer support groups, charities, and meaningful activity.
4. Where appropriate there should clear referral mechanisms to other health care professionals to ensure current/additional needs are addressed. This includes end of life care. Where people are transferred between prisons, it is important the care record accompanies them and comparable services are available. The use of the *This is Me* document may be helpful: alzheimers.org.uk/get-support/publications-factsheets/this-is-me

"Slow moving semi dementia sufferers missing their wives and children are looked on with suspicion by others many decades younger than them."

45-year-old man in prison

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

It is essential that people in prisons have parity of service with those living in the general population. Assessment is fundamental to good care and vital in order to achieve the services and support that a person with dementia will need on an ongoing basis. People with some dementias may be at increased risk of imprisonment due to disinhibited behaviour, for example those with Frontotemporal behavioural variant dementia. Screening, prompt identification and accurate, timely diagnosis is essential and should follow the best available evidence. The reasons for assessment should be explained to the individual and their circle of support. Prior to any assessment it is important to create a conducive environment for communication and ensure that the person with dementia can see and hear to the best of their ability, with aids as necessary. Attendance at a health care setting can ensure proper diagnostic assessment but reasonable adjustments must be made to the person's care to take account of their dementia.

Systematic identification of people with cognitive impairment is also likely to improve the detection of delirium and depression and give opportunities to support them better. As dementia progresses, or if the individual has complex health needs, further assessment may best take place in the person's own setting.

Examples of the types of assessment which may be required include swallow or speech and language assessment, continence assessment, rehabilitation needs, mental health, advance care planning and decisions about end of life care. Assessment should also include a focus on physical comorbidities and complexity and the impact that dementia may have on other long-term conditions and their management. There is evidence that older people in prison access health services less than the general population.

Access to assessment may be problematic in prison settings, as signs of dementia may be attributed to a person choosing distressed behaviours due to a lack of liberty. Consideration of dementia should be encouraged as part of routine consultation and person-centred assessment. It is important to remember that people with long prison sentences may require reassessment during their stay. Diagnosis may also impact an individual's sentence and have implications for compassionate release.

This will be supported by:

1. use of agreed screening and assessment tools, ideally in conjunction with local memory services
2. access to skilled, knowledgeable practitioners
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. Ensuring that the person has access to their medication in a safe and person-centred manner
5. post diagnostic support designed to help the person living with dementia and their circles of support once a diagnosis of dementia has been given
6. all prison staff should undertake dementia awareness training at induction with regular updates and training events. Prison staff should also have access to more in-depth training, particularly if they are regularly working with people with dementia.

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 present with symptoms. All clinical staff who work with adults should be familiar with dementia screening tools. As the diagnosis of dementia is complex, most screening tools are used to identify the presence of cognitive impairment. The term cognitive impairment is an overarching term for someone who may be experiencing problems with memory, perception, judgment and reasoning. It is recommended that there are agreed approaches and processes for screening and assessment so that those with a possible cognitive impairment receive the right treatment and care, depending on whether they have dementia, delirium and/or depression.

Assessment should include:

- a full clinical history of the person, including any previous physical or mental health problems
- a physical examination and blood testing to rule out any treatable causes
- an initial test or screen of the person's cognitive abilities
- gathering collateral history from a relative or member of the wider prison community who knows the person well
- checking for possible depression (particularly in people with a past history of depression or a chronic physical health problem with associated functional impairment).

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?"

All assessment should be informed by NICE guidance: nice.org.uk/guidance/conditions-and-diseases/mental-health-and-behavioural-conditions/dementia

2. Having skilled and knowledgeable practitioners

(as identified in Principle one)

Where staff members and other people living in prisons have regular engagement 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

In most cases, people with dementia are in health care facilities for clinical reasons other than their diagnosis of dementia. 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, both for the dementia and the primary reason for which they have been admitted. As dementia and delirium share commonalities, having an agreed pathway in place for people with dementia and delirium can help ensure the right treatment and care. 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 be pushed beyond their limit of coping, become distressed, agitated or even aggressive. Understanding the individual through personal profiles and discussions with those closest to them can help to predict and prevent distress. It is important to understand that distressed behaviours are not always due to dementia. Factors such as pain, discomfort, disorientation or misinterpreting information may cause distress. Addressing these factors may resolve issues. Reducing distress experienced by people with dementia and carers should be a priority. Reaching for medication to suppress symptoms may seem like an easy fix – and medication has its place in treatment – but there can be dangers associated with antipsychotics which can include:

- sedation (drowsiness)
- parkinsonism (shaking and unsteadiness)
- 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
- misuse and death.

Good fundamental care can prevent the need for medication for distress in most situations, and a broad range of interventions that do not use drugs has now been identified. Audit of the use of antipsychotic medication should be carried out. Additionally, some medications, particularly anticholinergics, can have an adverse effect on cognition and a regular review of medication is recommended. It is important that someone with dementia has a medicines management assessment to ensure they are able to safely access any regular medications they are prescribed.

A prisoner in a category B prison told us that there needs to be:

"Continued assessment of those with dementia rather than a one-off diagnosis where people are told they have it but nothing happens subsequent to that."

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

All people with a diagnosis of dementia should be offered a care and support plan by a nominated individual who will co-ordinate their care. Ensuring that care is based on the individual, their biography, preferences and an understanding of their abilities is particularly important for people with dementia in achieving person-centred care. This requires an understanding of the way dementia affects that person and how care can be adapted to compensate for and meet individual needs. Issues relating to mental capacity should be clearly documented and communicated to those involved in supporting the person, and those involved should have access to mental capacity training and refreshers. Care plans should be developed collaboratively and communicated clearly with the circle of support and those providing care. Care plans will be person-centred, responsive to individual needs and will support nutrition, oral health, dignity, comfort, continence, wellbeing, rehabilitation, activity, meaningful occupation, sleep, advance care wishes, safeguarding needs and end of life care. Care plans should be held by the person, where possible, with appropriate safeguards in place. There should be strategies in place for communication of care and support plans, particularly during transitions across health and social care settings and prison facilities, and detailed plans leading up to release and resettlement from prison including aftercare.

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
4. the inclusion of advance care planning, nutritional tools, pain assessments and safety assessment tools
5. plans and any prior consent about engagement in research in plans
6. provision of appropriate activity to encourage social engagement, peer support, maintenance of function and wellness, including recognition of spiritual needs
7. access to dementia specialists

8. access to, and availability of, palliative care specialists
9. a named member of staff responsible for coordinating care planning activity and sharing.

Safeguarding

The safeguarding needs and responses to both the person and others they come into contact with, both within prison and on release, should be carefully planned. Risk assessments should be undertaken and the importance of communication with other agencies recognised. All staff must have safeguarding training on induction and the opportunity of regular refreshers. Health care staff should have training in line with the intercollegiate documents for both adults and children and young people.

> "Some prisoners take prisoners from one wing to another or to healthcare for medication and this can result in medication being missed and the prisoners confused about what is happening."
>
> **A 61-year-old man serving a 22 year sentence**

Principle 5: Environments that are dementia friendly

Unfamiliar environments can be very difficult for people living with dementia; prison environments in particular can be confusing, noisy, and difficult to navigate. The pace and noise of prisons can be challenging for people living with dementia. Environments should be dementia friendly and support independence and wellbeing. A risk assessment should inform where people are situated in prison. Their sensory and mobility needs and ability to navigate must be taken into consideration. Where accommodation is shared, the person with dementia should be protected from abuse or manipulation and their human rights upheld. Some older people in prison are worried about assault or bullying. Health care staff should be involved in the environmental planning of the prison estate to ensure clinical needs are taken into consideration, drawing on the best available evidence.

This will be supported by:

1. Minimal moves to avoid unnecessary distress

Moving between environments can cause unnecessary distress to people living with dementia and such moves should only be undertaken when absolutely necessary. This should not prevent the opportunity for people to attend appointments, engage in meaningful activities and environments that are familiar.

2. Dementia friendly design features such as signage, lighting and noise minimisation

Evidence based design features should be included in all new builds and refurbishments of prison health care facilities and older people's wings such as appropriate flooring, lighting, signage, contrast and technology. In older units, retrofitting should be considered.

> "I forget names, events, my stomach churns at noises, loud voices, bad attitudes"
>
> **Elderly man living in prison over a long time, with both physical and mental health issues**

3. Personalised space – (cell or shared cell)

Regardless of facility, individuals should have access to items they recognise as their own. This can include personal possessions, photographs, or colours that are recognisable to the person. The principles of dementia friendly environments should be adopted. Risk assessment should be undertaken to ensure the appropriateness of those sharing accommodation.

> "I have seen an elderly man with dementia being allocated a cell with a much younger man who assaulted him badly"
>
> **A 45-year-old man living in an open prison**

4. Adequate space and resources to support activity and stimulation

Settings should ensure people have access to rehabilitative opportunities and activities to maintain functional independence and social interaction. The person should have access to social interaction with people who understand the nature of dementia, such as a peer system or buddy arrangement.

> "I have a memory diary to remind me what I have to do daily. I have been trying to phone my Mam. I cannot remember doing that, I know my Mam passed away some time back."
>
> **A 60-year-old person living in prison with Korsakoff's Syndrome**

5. Sensitive use of technology to support independence

There is an increasing opportunity for the sensitive use of technology to support independence, such as reminder alarms, prompts, tracking and visual surveillance. This should be undertaken with the permission of the person, family/legal representatives and in accordance with the law. Ideally people with dementia should participate in the development of new technologies to ensure they are fit for purpose.

Finally

The dementia SPACE principles are designed to assist services and staff to assess the quality of dementia care delivered within the prison. From this baseline assessment, prison communities can work together on improving specific aspects of care. The principles can be used with a wide range of training packages, quality improvement methodologies and practice development activities. Whilst the evidence base drawn upon is for the care of people with dementia, there are potential benefits to people with other cognitive difficulties. We hope you find that the principles inspire you and your service to improve care for people with dementia in prison, and their families.

Resources

BGS www.bgs.org.uk/resources/end-of-life-care-in-frailty-delirium

DEMENTIA UK www.dementiauk.org
www.dementiauk.org/for-professionals/how-to-become-an-admiral-nurse/hedn

Dementia Friends www.dementiafriends.org.uk

Dementia Action www.dementiaaction.org.uk/assets/0000/4336/dementia_friendly_environments_checklist.pdf

Health Education England www.e-lfh.org.uk/programmes/dementia
www.hee.nhs.uk/our-work/dementia-awareness/core-skills

Health and Social Care Northern Ireland www.hscboard.hscni.net/dementia

IDEAL PROJECT www.idealproject.org.uk

King's Fund www.kingsfund.org.uk/publications/developing-supportive-design-people-dementia

Mental capacity www.gov.uk/government/publications/mental-capacity-act
www.health-ni.gov.uk/mca
www.gov.scot/publications/adults-incapacity-scotland-act-2000

NHS Scotland www.knowledge.scot.nhs.uk

NICE www.nice.org.uk/guidance/conditions-and-diseases/mental-health-and-behavioural-conditions/dementia
www.nice.org.uk/guidance/ng97/resources/antipsychotic-medicines-for-treating-agitation-aggression-and-distress-in-people-living-with-dementia-patient-decision-aid-pdf

SCIE www.scie.org.uk/dementia

SIGN www.sign.ac.uk/our-guidelines/risk-reduction-and-management-of-delirium

Skills for health skillsforhealth.org.uk/info-hub/dementia-2015-updated-2018

Social Care Wales socialcare.wales/cms_assets/file-uploads/Good-Work-Dementia-Learning-And-Development-Framework.pdf

Royal College of General Practitioners bulger.co.uk/prison/RCGPsaferprescribinginprisons2019..pdf

RCN www.rcn.org.uk/clinical-topics/older-people/delirium/delirium-champion

Royal College of Psychiatrists www.rcpsych.ac.uk

4AT Rapid clinical test for delirium www.the4at.com

References

Age UK (2020) *Written evidence from Age UK (AGE0025). (Evidence to the House of Commons Justice Committee's inquiry into the ageing prison population).* Available at: **http://data.parliament.uk/writtenevidence/committeeevidence.svc/evidencedocument/justice-committee/ageing-prison-population/written/105992.html** (Accessed 22 September 2021).

Age UK (2016) Diversity in older age – Older Offenders. London: CPA. Available at: **www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/equality-and-human-rights/rb_may16_cpa_rapid_review_diversity_in_older_age_older_offenders.pdf** (accessed 23 August 2021).

Association of Directors of Adult Social Services (2020) *Written evidence from the Association of Directors of Adult Social Services (ADASS) (AGE0024). (Evidence to the House of Commons Justice Committee's inquiry into the ageing prison population).* Available at: **http://data.parliament.uk/writtenevidence/committeeevidence.svc/evidencedocument/justice-committee/ageing-prison-population/written/105988.html** (Accessed 22 September 2021).

Care Quality Commission (2020) *Written evidence from Care Quality Commission (CQC) (AGE0038). (Evidence to the House of Commons Justice Committee's inquiry into the ageing prison population).* Available at: **http://data.parliament.uk/writtenevidence/committeeevidence.svc/evidencedocument/justice-committee/ageing-prison-population/written/106342.html** (Accessed 22 September 2021).

Ministry of Justice, Department of Health and Social Care, Public Health England, NHS England and Improvement (2020) *Written submission from the Ministry of Justice, Department of Health and Social Care, Public Health England, NHS England and Improvement for the Justice Select Committee's inquiry into the ageing prison population (AGE0036).* Available at: **http://data.parliament.uk/writtenevidence/committeeevidence.svc/evidencedocument/justice-committee/ageing-prison-population/written/106110.html** (Accessed 22 September 2021).

NICE (2017) *Mental health of adults in contact with the criminal justice system.* London: NICE guidance no. 66. Available at: **www.nice.org.uk/guidance/ng66** (accessed 23 August 2021).

Nuffield Trust (2020) Locked out? Prisoners' use of hospital care. London: Nuffield Trust. Available at: **www.nuffieldtrust.org.uk/research/locked-out-prisoners-use-of-hospital-care** (accessed 23 August 2021).

RCN (2018) Adult Safeguarding: *Roles and Competencies for Health Care Staff.* London: RCN. Available at: **www.rcn.org.uk/professional-development/publications/pub-007069** (accessed 23 August 2021).

RCN (2019) *Safeguarding Children and Young People: Roles and Competencies for Healthcare Staff.* London: RCN. Available at: **www.rcn.org.uk/professional-development/publications/pub-007366** (accessed 23 August 2021).

RCN quality assurance

Publication

This is an RCN practice guidance. Practice guidance are evidence-based consensus documents, used to guide decisions about appropriate care of an individual, family or population in a specific context.

Description

This guidance is aimed at nursing colleagues, prison staff and the prison community working to support people with dementia. It sets out the five principles that form a shared commitment to improving dementia care in prisons.

Publication date: November 2021 Review date: November 2024

The Nine Quality Standards

This publication has met the nine quality standards of the quality framework for RCN professional publications. For more information, or to request further details on how the nine quality standards have been met in relation to this particular professional publication, please contact **publications.feedback@rcn.org.uk**

Evaluation

The authors would value any feedback you have about this publication. Please contact **publications.feedback@rcn.org.uk** clearly stating which publication you are commenting on.

The RCN represents nurses and nursing, promotes excellence in practice and shapes health policies

RCN Direct
www.rcn.org.uk/direct
0345 772 6100

Published by the Royal College of Nursing
20 Cavendish Square
London
W1G 0RN

020 7409 3333
www.rcn.org.uk

November 2021
Review date: November 2024
Publication code: 009 751