Royal College of Nursing

Commitment to Care of People living with Dementia

SPACE principles

CLINICAL PROFESSIONAL RESOURCE

Royal College
of Nursing

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Publication

This is an RCN professional resource, designed to help guide decisions about appropriate care of an individual, family or population in a specific context.

Description

This guidance sets out the five principles that form a shared commitment to improving care for people with dementia and their families. The document is designed to be used in a wide range of health and social care settings and has included the most recent evidence and best practice.

It is aimed at staff and managers working in a range of health and social care settings.

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The Nine Quality Standards

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Evaluation

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Introduction

This document sets out the five principles that form a shared commitment to improving care for people with dementia and their families. They 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.

This updated document is designed to be used in a wide range of health and social care settings and has included the most recent evidence and best practice.

The NHS Long Term Plan

The NHS Long Term Plan, published on 7 January 2019, commits the NHS to continuing to improve the care provided to people with dementia and their carers, whether in hospital, at home or in care homes. This document sets out the five principles that nurses and other health and social care staff, as well as senior managers, can use to fulfil that commitment.

Principles

This guide is for nurses and other staff working in health and social care settings, as well as senior managers and directors. The aim is to support the implementation of the SPACE principles.

SPACE

Staff who are skilled and have time to care.

Partnership working with carers.

Assessment, early identification of dementia and post diagnostic support.

Care and support plans which are person-centred and individual.

Environments that are dementia friendly.

These resources can be used along with other initiatives that support innovation and improvement.

It is recommended that staff and patient/resident teams use them to support the development of practice in a systematic way that demonstrates real benefits for patients, carers and staff.

The approach requires dedicated leadership, development of shared action plans and evaluating outcomes, particularly patient and carer experience.

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 more than 100 different types of dementia. The most common cause is Alzheimer's disease, where there tends to be a progressive and gradual decline over time. Another common 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, in which case a mixed dementia may be diagnosed. Although dementia is more prevalent with increasing age, it is not a normal feature 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.

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.

Symptoms of dementia

While there are common symptoms of 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 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. 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 of the following:

- **memory loss (anterograde amnesia)**
  Short-term memory loss is the most common feature of dementia. It becomes worse as the disease progresses and eventually affects 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, laying the table, cooking etc
- **concentration**
  Difficulty with attention for periods of time
- **recognition (agnosia)**
  Difficulty with recognising familiar objects, people, sights, places, sounds
- **orientation**
  Difficulty with finding your way around, knowing the time, date etc
- **perception**
  Difficulty with understanding and interpreting information
- **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.

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 can be treated with psychological therapies and/or medication.

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.

People with dementia have a fivefold risk of developing delirium and, in someone with dementia, risk factors include medications, lack of mobility, malnutrition, infection, an indwelling catheter, environment or psychosocial influences.

Delirium may be prevented in up to one third of older patients through effective interdisciplinary prevention, diagnosis, treatment of the underlying cause and supportive nursing care.

Research indicates that many older people who have delirium will either also have an underlying dementia, or have an increased chance of developing dementia.

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: **https://www.rcn.org.uk/clinical-topics/older-people/delirium**

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 a 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 in a social environment, which supports their wellbeing
- understanding changes related to behaviour and mood. Affording opportunities for new and life affirming experiences.

The role of family carers

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 carer 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. Carers should be kept involved and informed throughout assessment and treatment of the person they care for.

Family carers also have their own needs, which should be assessed and taken into account. It is known that carers of people with dementia can experience greater strain and distress than carers of people with other conditions. In addition, many carers of people with dementia are older people themselves, with physical needs and health conditions of their own.

Family carers should be offered an assessment in their own right and be supported in their caring role through psycho-education, skills training. access to support services and psychological support such as Admiral Nurse support.

Admiral Nurses are registered nurses with experience in dementia care, more information available here: **dementiauk.org**

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. Good 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.
2. Availability of identified clinical leads for dementia, e.g. dementia specialists.
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 carers. 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 experienced trainers. Surveys reveal that lack of staff understanding and time were the major barriers to achieving good care.

It is recommended that:

- all staff have training in dementia awareness and are informed about the needs of those affected by dementia
- staff who have regular responsibilities for providing care have an enhanced knowledge and are skilled in dementia care
- each area has a dementia leader and/or support from a specialist with an expert level of skill and knowledge.

Considerations for training and education in dementia

- Focus on values, attitudes and approach of staff, which supports good communication and a relationship-centred approach.
- A team approach to training and ensure this is supported in practice by dementia champions, specialists and leaders who have further training.
- Include hearing the experience of people with dementia and families/carers within training.
- A learning culture that uses outcomes and data to support the improvement of dementia care rather than apportioning individual blame.
- Develop understanding and skills to enhance the quality of life for people with dementia with a specific focus on communication, assessment, reducing risk of developing dementia/health promotion, life story information, pain, nutrition and hydration, continence, activity, rehabilitation, environment and end of life care.
- It is important staff are able to discuss lifestyle factors that reduce the risk of dementia throughout life. Staff need to understand the latest evidence and the way in which messages are best shared. The opportunities to educate people how to reduce their risk should be grasped early. Advice given to people should be tailored to their individual circumstances and based thorough assessment of lifestyle and risks of dementia. https://www.nhs.uk/conditions/dementia/dementia-prevention/

Principle 2:
Partnership working

Effective care requires a relationship-centred approach, which acknowledges the needs of families and carers as well as the person with dementia. It is important to learn from carers about the person with dementia and how they function best in everyday life. It is also important to recognise that carers may themselves feel in need of support. Family carers can experience stress in relation to finances, changes in role, practical demands, emotional and physical needs. For example they may have physical health problems, emotional difficulties due to changes in their relationship and be experiencing feelings of loss. However 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 and their family carers so that needs are understood and recognised.

This will be supported by

1. Recognition and assessment of both the person and family carers' needs following diagnosis.
2. Involvement in assessment, care planning and decision-making, including family carers/supporters where appropriate.
3. Flexible visiting and flexible approaches so that family carers/supporters can be involved directly in care where desired.
4. An identified member of staff who is responsible for supporting and liaising with the individual's family and carers. In the event that an individual does not have access to family/carers advocacy should be arranged.
5. Engagement with and signposting to local community resources.

This is supported by

1. Recognition and assessment of carers needs as well as the person with dementia.

   Carers of people with dementia can experience high levels of anxiety, depression and stress as a result of caring and their needs often go unrecognised. It is essential that carers are identified and assessed as having their own needs and are offered support. Assessing the needs of a person living with dementia may provide an ideal opportunity to identify potential concerns. Admiral Nurses where available, can provide a key role in supporting the needs of the whole family.

2. Involvement of families/friends in assessment, care planning and decision making.

   Working in partnership with family carers, friends 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 three 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.

3. Flexible approaches to routines so that family carers/supporters can be involved directly in care where desired

4. An identified staff member should ensure that family and carers are supported to work in partnership. People living with dementia often benefit by having someone who knows them well to advocate on their behalf. For those people without an identified person it is important that advocacy arrangements are put in place to provide independent and informed support.

5. 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, schools.

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

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 on-going basis. The reasons for assessment should be explained to the individual and their families. Prior to any assessment it is important to create a good 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 home. 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. Assessment should also include a focus on physical co-morbidities and complexity and the impact that dementia may have on other long term conditions and their management.

This will be supported by

1. Use of agreed screening and assessment tools.
2. 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.
5. Post diagnostic support designed to help the person living with dementia and their families once a diagnosis of dementia has been given.

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 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 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
- gathering collateral history from a relative or friend who knows the person well
- it is important to assess for possible depression (particularly in people with a past history of depression or a chronic physical health problem with associated functional impairment) 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?”

Assessment should be informed by NICE Guidance.

2. Having skilled and knowledgeable practitioners

(as identified in *Principle one*)

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 the person has been admitted. As dementia and delirium share commonalities, having an agreed pathway in place for people with dementia and delirium can help ensure that people receive 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.

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. Good fundamental care can prevent the need for medication in most situations, and a broad range of interventions that do not use drugs has now been identified. Additionally, some medications particularly anti-cholinergics, can have an adverse effect on cognition and a regular review of medication is recommended.

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 professional 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. Care plans should be developed collaboratively and be communicated clearly with families and those providing care. Care plans will be person-centred, responsive 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. Care plans should be held by the person. There should be strategies in place for communication of care and support plans particularly during transitions across health and social care settings.

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 and identification of those with legal authorities, i.e. power of attorney, court of protection. 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 and sexual health needs.
6. Access to dementia specialists/leads.
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

Unfamiliar environments such as in a hospital, care home or hospice can be very difficult for people living with dementia; hospital environments in particular can be confusing, noisy and difficult to navigate. The pace and noise of many places can be challenging for people living with dementia and their carers. 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 cause unnecessary distress to people living with dementia and such moves should only be undertaken when it is in the best interests of the person. This should not prevent the opportunity for people to attend appointments, enjoy activities and environments that are familiar and enjoyable e.g. visits to well-remembered places, outside spaces and undertaking hobbies.

2. **Dementia-friendly design features such as signage, lighting, minimising noise**
   Evidence based design features should be included in all new builds and refurbishments of health care facilities such as appropriate flooring, lighting, signage and technology.

3. **Personalised space**
   Regardless of facility, individuals should have access to items they recognise as their own, this can include personal possessions.

4. **Adequate space and resources to support activity and stimulation**
   Settings should ensure people have access to rehabilitative opportunities and opportunities to maintain functional independence, this might include cooking, gardening, pet care etc.

5. **Sensitive use of technology to support independence**
   There is an increasing opportunity for the sensitive use of technology to support independence, this might include alarms, prompts, tracking and visual surveillance. This should be undertaken with the permission of the person, family/legal representatives. Ideally people with dementia should participate in the development of new technologies.

Resources

Admiral Nurses (Dementia UK)
www.dementiauk.org/

Alzheimers Society
www.alzheimers.org.uk/

Alzheimers Scotland
www.alzscot.org/

Alzheimers Northern Ireland
www.alzheimers.org.uk/about-us/northern-ireland

Alzheimers Wales
www.alzheimers.org.uk/about-us/wales

Carers Trust
carers.org

Johns Campaign
johnscampaign.org.uk

NICE Dementia Topic
www.nice.org.uk/guidance/conditions-and-diseases/mental-health-and-behavioural-conditions/dementia

NHS About Dementia
www.nhs.uk/conditions/dementia/about/

RCN Clinical Topics dementia
www.rcn.org.uk/clinical-topics/dementia

SCIE Dementia
www.scie.org.uk/dementia/

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